

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

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## Communication

This section of the Family Carer Advocacy Pack covers your relative's right to communicate, different types of communication, and the importance of ensuring your relative's communication needs are successfully met.

### Human rights and communication

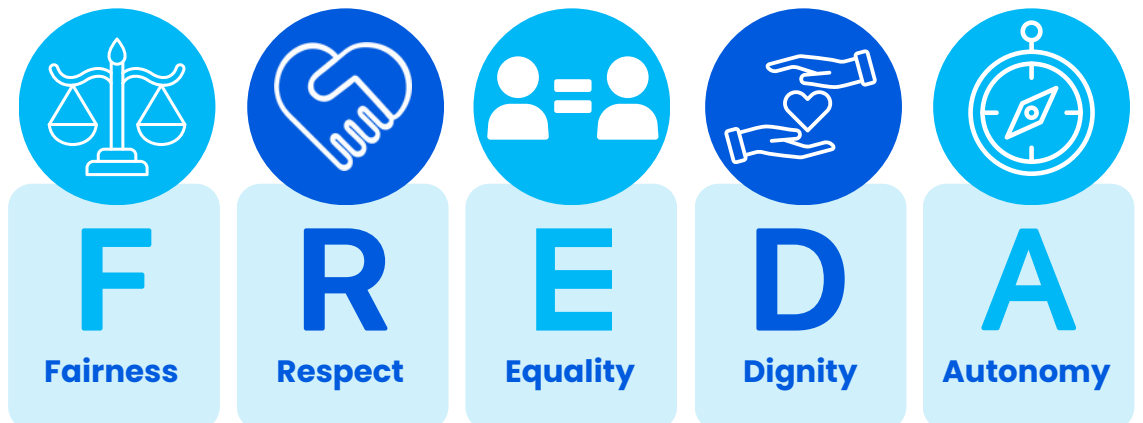
Ensuring your relative's communication needs are met is a fundamental human right. It is included in UK legislation via Article 10 of the European Convention on Human Rights and the Human Rights Act 1998. Article 21 of the 2006 UN Convention on the Rights of Persons with Disabilities confirms



“ ***the freedom to seek, receive, and impart information and ideas on an equal basis with others and through all forms of communication of their choice.*** ”

This right confirms that all forms of communication are equally important, whether it is verbal, sign, pictures/symbols, through the use of technology or a combination of more than one.

Additionally, for the FREDA principles (a human rights approach) to be followed your relative needs to be able to communicate their views about their likes, dislikes, wishes, feelings, values and beliefs.



This means that the services and staff supporting your relative should have the skills necessary to communicate with your relative. This applies to both expressive (communicating with your relative and vice versa) and receptive (understanding/ listening to your relative and vice versa). If not, it is a breach of your relative's human rights.

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***Everyone should uphold others' right to communicate as they interact with people in daily life in order to enhance equality, justice and human dignity.***

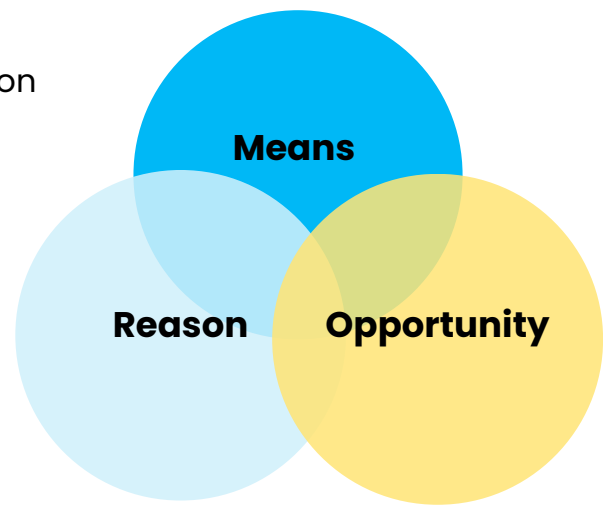
Sharynne McLeod, Professor of Speech and Language

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## What is communication

There are three key parts that make communication effective:

- Means (how)
- Reason (why) and
- Opportunity (when)



### The opportunity:

People can only communicate with others when they have frequent chances. People with a learning disability, autism or both do not always have the opportunity to communicate, e.g. if they use sign language but nobody else around them does. Limited opportunities can affect the learning and development of communication, other skills and impact on mental health.

### The reason:

Refers to why communication takes place, for example:

- expression of practical needs, e.g. asking for a drink, communicating pain
- expression of thoughts, opinions and feelings e.g. I'm feeling sad, happy, angry, bored
- sociable e.g. to ask someone their name, to make friends

### The means:

Refers to how a message is sent. This may occur via spoken or written words, sign language, body language, gesture, assistive communication devices or any other means the person uses. People need to be able to use the means of communication that best suits their needs



### Support staff think people understand more than they do.

**What does this mean for your relative** – communication is not pitched at the right level. Staff may think they have asked your relative to do something, told them what is happening but your relative has not understood this.



### Staff did not appear to see communication and spending time with people sociably as part of their role.

**What does this mean for your relative** – they may spend time feeling ignored and lonely, whilst support staff participate in administrative or household tasks.



### Adapted methods of communication were rarely seen.

**What does this mean for your relative** – if their expressive and receptive communication is not via fluent speech they will spend a lot of time not knowing what is happening or enjoying the social aspect of communication.



### Information from family carers about their relative's communication/interaction did not seem to be valued.

**What does this mean for your relative** – the expertise and knowledge you have is not being used to ensure that your relative's communication environment meets their needs.



### Communication support did not appear to be targeted at those who experience the greatest communication challenges.

**What does this mean for your relative** – the greater your relative's communication needs the less time and effort is being invested in communicating with them.

### Without the appropriate communication support people with a learning disability, autism or both may be at risk of:

- A lack of choices and involvement in everyday decisions
- Limited relationships and isolation  
More likely to be abused
- Poor mental health, including low mood, anxiety and depression
- Not joining in community life
- Less employment opportunities
- Lower standard of healthcare, risk of diagnostic overshadowing, and more inpatient admissions, e.g. assessment and treatment unit
- Support staff restricting activities because of behaviour described as challenging because this is not acknowledged as communicating an

- Support staff restricting activities because of behaviour described as challenging because this is not acknowledged as communication need. This could lead to people losing where they live and their support package.
- Increased risk of not following rules or breaking the law  
Limited access to therapies or programmes which rely on verbal communication, e.g. prison/hospital rehabilitation programmes which can contribute to delays in discharge
- The incidence of additional sensory impairments, including sight and hearing, is much greater than in the general population. Up to 40% of people with learning disabilities, autism or both have a hearing loss that is often missed.
- Autistic people have lifelong difficulties with social communication, social interaction and social imagination.
- As communication difficulties increase, behaviours described as challenging typically increase in frequency (how often), intensity (how challenging) or duration (how long).

**Without the appropriate communication support people with a learning disability, autism or both may be at risk of:**

- Up to 90% of people with learning disabilities have communication difficulties. Around half have significant difficulties with both expressing themselves and understanding what others say.
- Only 5 -10% of people with learning disabilities have recognised literacy skills (reading and writing) and most are not able to access standard written information.
- Having a communication difficulty means people with a learning disability, autism or both are misunderstood, experience failure and exclusion from events, activities and relationships.
- Physical difficulties, e.g. dyspraxia can make the production of speech challenging.
- Developing communication over a person's lifespan is not seen as a priority, e.g. increasing vocabulary in line with new experiences.

**Person-centred communication support reduces these risks. It enables:**

- **Inclusive relationships**
- **Choice and control**
- **Greater independence**
- **Improved health outcomes**
- **Improved quality of life**

## Good communication standards

The Royal College of Speech and Language Therapists has identified five recommended 'Good Communication Standards' for providers of specialist hospital and residential services. These standards provide a framework which family carers, other family members, friends, professionals and commissioners can use to judge whether a service is providing the right communication environment for your relative.

The five good communication standards:

**Standard 1:** There is a detailed description of how best to communicate with individuals.

**Standard 2:** Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

**Standard 3:** Staff value and use competently the best approaches to communication with each individual they support.

**Standard 4:** Services create opportunities, relationships and environments that make individuals want to communicate.

**Standard 5:** Individuals are supported to understand and express their needs in relation to their health and wellbeing. Everyone has the ability to communicate even if they do not have the ability to speak – communication does not just include the spoken word.

[Read the full report here](#)



## No words but lots to say

[Find out more about the CBF's Seldom Heard Project](#)

“  
*My daughter was a woman without words, but that did not mean she had nothing to say! This was true when she was very young, right throughout her life, including about her end-of-life care.*

Jean Willson, Family Carer (Seldom Heard Project)



## Total communication

**A Total Communication approach uses additional ways as an alternative or to support spoken and written communication. Some examples include:**

- Gestures (pointing)
- Facial expression (smiling)
- Body language (turning towards somebody)
- Signing (British Sign Language, [Makaton](#))
- Symbols ([Picture Exchange Communication System – PECS](#))
- Photographs
- [Objects of reference](#) (swimming costume to indicate it's time for swimming)
- Sensory objects of reference (different smells associated with different days of the week, different sounds associated with different activities)
- [Augmentative and alternative communication](#)
- Communication book (low tech book with pictures/photographs of preferred activities, topics to communicate about, important people, hobbies, favourite food)

- Chat/Talk About Book (as above but also includes things that have happened or are going to happen)
- [Music therapy](#)
- [Social stories](#)
- [Intensive Interaction](#)
- [Visual supports](#)
- [Talking mats](#)
- [Books beyond words](#)

## How to support communication for people with a learning disability, autism or both

- Abstract concepts such as negatives and time might be difficult to understand. For example instead of saying “don’t sit on the bed, say “sit on the chair”. Using visual cues can help with yesterday/today/tomorrow e.g. a calendar with photographs
- Use short sentences, simple language and avoid jargon
- Break information into smaller chunks so that one idea or concept is explained at a time.
- Allow sufficient processing time to make sure that the person has understood
- A person’s speech may sometimes give an impression of better comprehension than is actually the case, so check their understanding
- Consider a person’s sensory preferences. Watch this video clip to experience what sensory overload feels like and how difficult communication must be, e.g. you can only hear the dripping tap not the voice of somebody trying to tell you something
- It can help if you can offer a visual aid such as a photo or drawing to support understanding
- If you are trying to identify like/don’t like or explain advantages and disadvantages, the use of a tool such as talking mats can be effective
- Don’t exclude people from conversations when discussing topics such as staffing, activities. It may result in somebody misunderstanding what is being said e.g. swimming is cancelled tomorrow, but the person may have just heard the word swimming and think it is happening immediately. In both cases this could lead to behaviour described as challenging.



**Communication: speaking to people with a learning disability**  
by Mencap

[Watch Carol, Stuart and Ian – MENCAP volunteers – explain what they think makes good communication](#)

## Communication Passport

It is important to recognise and record your relative’s individual style of communication. This includes if they are bilingual, or English is their second language This can be done using a communication passport. For it to be useful it must be kept up to date and easily accessible, e.g. not put in the back of a drawer in an office. It is also helpful to have a one-page portable communication passport (sometimes referred to as an ‘All about me’ profile) that your relative can always have with them. Include your relative in the development of their communication passport as much as possible.

Even if your relative can communicate verbally and has literacy skills (reading and writing) it might still be useful to have a one-page portable communication passport. This can include information such as:

- I communicate best in small groups
- Just because I am not making eye contact it does not mean I cannot hear you
- I don't like it if people start up separate conversations. I think they are talking about me
- When I say, "Time's up", it means I have had enough. Please do not try to persuade me to stay. It will make me distressed

Make sure that your relative's communication needs are regularly assessed to ensure that any changes are addressed. For example, if your relative stops responding to their name or loses interest in listening to music, this could indicate a change in their hearing, requiring a hearing assessment. Regular assessments will also identify any gaps in skills and training for staff and for your relative e.g. vocabulary teaching for emotions, introduction of additional communication systems such as PECS or sign language. After an assessment make sure that your relative's communication passport is updated, as required.

**If your relative does not already have a communication passport here are some suggested templates:**



[Click here for a range of templates](#)



[Click here for a template from Include Me TOO](#)



[Use this template from Change which can be folded down to make it pocket size](#)



[Read about Laura's communication passport on the CBF website](#)

## Behaviour described as challenging and communication

Your relative may display behaviour described as challenging as a way of communicating an unmet need or to control their environment, particularly if experience tells them it is effective. For example, if your relative learns that every time they are left alone, if they throw something a member of staff comes and sits with them, they may continue this behaviour as a way of gaining social interaction. Over time they may generalise this behaviour as a way to get their needs met or adapt their environment.

If you think that your relative is displaying behaviour described as challenging as a form of communication, ask for a functional assessment to be carried out. A functional assessment looks at the message behind the behaviour. The findings from the assessment should be recorded in a behaviour support plan and specify any changes which need to occur, e.g. instead of waiting until your relative throws something to gain social interaction, provide this regularly and also teach your relative how to ask for some company, e.g. sign "chat", or tap somebody.



[Visit this link from the Challenging Behaviour Foundation about finding the reasons for behaviour described as challenging.](#)



[Read what the NICE guidelines say should happen as part of a functional assessment](#)

“ Imagine that you have a very limited understanding of speech, and you are unable to express your feelings. The people around you don't understand you. Imagine that you keep trying to communicate in your own way, but they just keep on speaking to you. You don't make a fuss, so they sit you in a chair in the lounge all day, every day and they think you are happy to sit there because you don't make a fuss. Imagine that you try a different way of communicating and then they say you are too challenging to take out. So now you sit in your chair in the lounge all day, every day.

Total Communication Film 2009 ”

## Advocacy and communication

If your relative has good communication skills, regardless of the method, they may be able to independently tell people involved in their life what they like, don't like, what they want, their feelings, wishes and aspirations. This is called self advocacy. On occasion though, like all of us, your relative may need additional support, e.g. to make telephone calls, attend meetings. They can access this informally through you (family carer), another family member, a friend, or contact an advocacy organisation to ask for help.

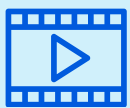
Some people with a learning disability, autism or both may use other methods to make choices, e.g. signing, pushing their plate away if they don't like a meal,



[Here are some Advonet resources to support self-advocates](#)

kicking off a particular pair of trainers. This is still communication and should be listened to carefully and recorded in a communication passport, e.g. If Ben pushes his plate away he is saying .... I don't like the meal, I am not hungry, I don't feel well. If it is a meal he usually eats consider the second two options but also does the meal look/taste like it usually does, is there something happening in the environment, e.g. noise and lighting levels.

If a more complex decision is required, your relative may need somebody to advocate on their behalf. Again this could be you (family carer), another family member, friend or a professional independent advocate. Any decision should be in your relative's best interests, and this is called non instructed advocacy.



[Watch this video clip about how a decision is made when a young man is moving home. It combines listening carefully and using background information from somebody who knows him well](#)

## The Accessible Information Standard (AIS)

The Accessible Information Standard (AIS) was introduced by the government in 2016. It is now the law for all NHS and adult social care services (e.g. doctors, dentists, hospitals, social workers) to comply with the AIS. If you have a learning disability, autism or both NHS or adult social care services need to:

- Find out your relative's communication and information needs.
- Record these communication and information needs clearly and consistently.
- Flag these needs, so when a member of staff opens your relative's record it is clear what their communication needs are.
- Share your relative's communication needs for example if they are referring to another service.
- Take action to give your relative the right support. For example, arranging for somebody who can sign, offering easy read information, providing information in a visual format, allowing somebody to accompany your relative to support their communication.



[Five things NHS and social care services MUST do by Healthwatch Suffolk](#)

[Accessible Information Standard by NHS England](#)

[Visit the National Autistic Society's website here for more information about communication](#)



We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email [info@theCBF.org.uk](mailto:info@theCBF.org.uk), or visit our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

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