Total

Communication Resource Pack





Version 1

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Produced by East Sussex Adult Learning Disability Speech and Language Therapy Team (**Sussex Partnership** NHS Foundation Trust) and East Sussex County Council.

Introduction

This Total Communication Resource pack has been designed as a resource for service providers and families, and anyone involved with supporting people with learning disabilities.

This is the first version of the Resource pack. We intend to update regularly. There will also be an electronic version available where you can download templates, and an accompanying CD.

National Context

Overcoming communication barriers for people with learning disabilities is a recurring theme in all government strategies.

Valuing People Now



Valuing People Now says that more people with learning disabilities have real choice and control in their lives but we need to support many more people with learning disabilities to achieve this, particularly people with the highest support needs.

Valuing People said that communication; person-centred approaches, advocacy, service user involvement and Direct Payments are key to delivering choice and control.

The White Paper - Our Health, Our Care, Our Say



'Our Health, Our Care Our Say' endorsed these principles. It said that giving people more control means, first and foremost, listening to them. It means giving people more control of the policy setting process at a national and local level.

Putting People First



'Putting People First ' has set out a range of actions for Councils, to enable more people with social care support needs more choice and control over their support arrangements and their lives. For example, by making personal budgets available to people by 2011. Good communication with people with support needs must be the starting point, if the vision set out in Putting People First is to become reality.

Statistics

The Foundation for People with a Learning Disability estimate (2000) that:

- between 50% and 90% of people with learning disabilities have communication difficulties;
- 20% of people with a learning disability have no verbal communication skills:
- 80% of people with severe learning disabilities do not acquire effective speech; and
- 60% of people with a learning disability have skills in symbolic communication such as signs or picture symbols.

East Sussex Issues



The joint commissioning strategy 'Strong Voices, Big Ideas' (2007) is committed to improving Total Communication in East Sussex.

This Resource Pack is funded by the East Sussex Learning Disabilities Partnership Board as a sign of their commitment to Total Communication.

Aims



The aim of this pack is to:

- provide information on the different ways of communication for people with learning disabilities and their communication partners;
- explain a selection of Total Communication methods;
- give examples of communication systems; and to
- give practical ideas for you to try and details of further information.

We hope those who use this pack will become confident in supporting people with learning disabilities to communicate successfully.

Part 1: COMMUNICATING WITH PEOPLE WHO HAVE A LEARNING DISABILITY

Communication is a basic human right for EVERYONE. The government's white paper 'Valuing People Now' 2008 states that everyone should have equal access to communication.

Communication is vital to every aspect of our lives. It impacts on our relationships, choice, control, emotions, self-esteem and self- expression. Therefore it is fundamental to our wellbeing and quality of life.



"Imagine that you a 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, everyday 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, everyday."

Reference: Total Communication Film 2009

It is essential that we have a **method** of communication; an **opportunity** to communicate and a **subject** to communicate about.

In order to make communication accessible to everyone, we need to use all the ways available to us to give and receive information.

A Total Communication approach shifts the focus away from a reliance on spoken and written communication to a culture where gestures, body language, signs, symbols, photographs, objects of reference and electronic aids are used in a consistent manner to support speech or as an alternative to speech.

Using Total Communication approaches helps people with learning disabilities develop their understanding and expression in order to communicate more effectively, and live the lives they want.

Total Communication is about building relationships and self-esteem, getting to know each other and togetherness. Communication is a basic human right!



Communication Bill of Rights



The Bill of Rights was written by the American Speech and Hearing Association in 1992.

Everyone has the right to communicate.

1. The right to be able to ask for things. The right to show how I feel.



2. The right to be offered choices.



3. The right to say no to things.



4. The right to communicate and be with other people.



5. The right to information about things I want to know about.









6. The right to support with communication.



7. The right to be listened to.





The right to use my communication tools whenever I like. Tools like pictures, machines and cards.



8. The right to be in a place that supports communication between people.



9. The right to be told about things that are happening around me.



11. The right to dignity. To be included when people talk about me.



12. The right to communicate my way. The way that is right for me – that respects who I am and what I believe.



Part 2: TOTAL COMMUNICATION

Total Communication is an approach, which includes all the ways we communicate:

- Eye Contact
- Facial expression
- Body Language
- Vocalisation
- Hearing
- Touch
- Smell

- Taste
- Speech
- Symbols
- Photos
- Drawings
- Objects
- Written word

- Art
- Music
- Contextual clues
- Signs and Gestures





Everyone communicates using at least one of the ways mentioned above. We **all** communicate in different ways and each way should be equally respected and encouraged.

Non verbal communication can be just as effective as speech. For example: Turning your head away when someone puts a cup to your mouth is as clear a message as saying "I don't want a drink".

However, communication is a two-way relationship and it will only be successful if the communicator and their partner are using the same 'language'.

Sometimes an individual's way of communicating may be subtle and hard to recognise. It is very important that you spend time getting to know the person you support so they can show you and you can recognise their personal communication patterns. This information should be shared with all their communication partners and recorded in a communication passport (see page 35).



Everyone who uses non verbal communication should have a communication passport!

Who uses Total Communication?

Total Communication will help all people with learning and sensory disabilities, and should be used by everyone who spends time with them.

Type of Total Communication	Example of how it used
Body Language	J has limited communication and mobility. She will not co-operate with lifting and handling if she doesn't want to do something. J is clearly communicating to the staff supporting her that she is not happy, they know this because J is usually co-operative. Staff have spent a lot of time observing J and recording the ways she communicates in her communication passport. They can now work out what is wrong by a process of elimination.
Photos	P has autistic spectrum disorder and benefits greatly from using photos on a visual timetable to plan his day. He is much less anxious now he can see what is going to happen. This makes his life is easier.
Objects	B is non-verbal and uses objects to support her understanding. Staff show her a sponge when it is time for a bath. B can now use her objects to make choices. Staff show B a sponge and a shower cap and wait for her to choose if she would prefer a bath or shower.
Signing	T has a hearing impairment and until recently found communicating with others difficult. T had learnt to sign before he moved but noone at his new home knew how to sign. The Speech and Language Therapist recommended that the staff team attend Makaton training. T now communicates really well by signing and has grown in confidence.
Symbols	S's main method of communication is speech. However, some people find it hard to understand her. S uses symbols in a communication book when she is in a new situation, to help her get her message across. It means she doesn't have to rely on others to speak for her. It relieves the pressure and prevents communication breakdown. For example S can use it when she goes to the café.
Eye Contact, Facial expression, Touch, gesture etc	R has a daughter L with a severe learning disability. R spends time just 'being with' L. R creates an atmosphere that is comfortable, relaxing and she 'listens' to the cues from L. There is no agenda for their time together. They just enjoy being with each other.

Parents, Carers and Staff should use Total Communication approaches at all times.

For example: facial expression is a very effective way of communicating:

A smile shows we are happy



Everyone needs to support and encourage each other to use Total Communication. If used consistently, it will soon become second nature to everyone in all situations. It is up to you to ensure that the people you support can communicate in a way that is best suited to their skills and adapt your own communication to suit.

Remember: A good relationship leads to good communication!
Good communication leads to good relationships!

Part 3: COMMUNICATION SYSTEMS

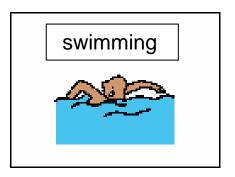
Here are some examples of communication tools and systems that use a variety of Total Communication approaches. There will be one or more that will suit each individual you support.

Make sure you choose methods that give the right level of support and that is motivating for them to use.

For example, symbols are small, easy to carry around and are great to look at but can be difficult to understand. Many people will need a clearer method such as photos. Some will find all symbolic understanding very difficult and will always need the real object in order to understand correctly.







object photo symbol

Others will rely on their communication partners* as their 'communication tool', to help them enjoy and make sense of the world around them.

*everyone who communicates with that person e.g. family, staff, friends etc

INTENSIVE INTERACTION



What is Intensive Interaction?

Intensive Interaction is an approach that can help people to connect and communicate meaningfully with people with severe and profound learning disabilities:

- An approach where interactions are lead by the person with the learning disability.
- A way of being with someone. Allowing two-way interactions that are enjoyable for the person and their supporters.
- A way that is adopted as a communication approach and used at all times in all environments.

What it isn't:

- An approach for people with mild-moderate learning disabilities or those with more 'advanced' communication skills (e.g. speech, symbols systems, signing).
- A 'teaching' approach to develop communication skills.
- 'Imitating' or 'mimicking' someone's noises or movements.
- An approach that can only be used by professionals or within allocated 'sessions' during the day e.g. to be fitted in between bowling and lunch.

Who uses Intensive Interaction?

Intensive Interaction focuses on the needs of those who are often described as having 'no' language or no effective means of communicating with others.

Intensive Interaction is based on the belief that all people are able to actively communicate at all times. People with very severe communication difficulties, (who do not recognise meaning in words, pictures, drawings or writing) often go unheard.

How does it help with communication?

The approach works by progressively developing enjoyable and relaxed interaction between the interaction partner and the person doing the learning. These interactions are repeated frequently and gradually grow in duration, complexity and sophistication. As this happens, the fundamentals of communication are gradually rehearsed and learnt in a free-flowing manner.

Research shows that this approach enables the person to develop:

- An increase in fundamental communication skills including eye contact, facial expression, turn-taking and emotional engagement.
- An increase in social skills a desire and ability to be with others, taking part in and initiating social interaction and understanding various ways in which social interaction can be enjoyed.
- A way to developing shared attention into 'activities'. To allow the person to participate in their life rather than just to comply.

An Example:

D has a severe learning disability, is very 'difficult to reach', living a socially isolated life, She has a range of self-stimulatory behaviors and shows no motivation to be with other people.

D's supporters adopted this approach and started to interact with D in a way she understood, placing no demands on her and allowing her to have control of the session. They would repeat any facial expressions, vocalisations and actions she used. Gradually D would try different things such as varying the sounds she made or changing her position to see what would happen. As supporters and D became more comfortable with the interactions they became more natural and spontaneous. Now supporters have found that D has a good sense of humour, enjoys being with others and is beginning to learn new skills such as eye contact.

There are a number of organisations, networks and individuals who offer advice and support on using Intensive Interaction.

 A Practical Guide to Intensive Interaction. Nind, M & Hewett, D. (2001) Bild Publications

Other resources:

Intensive Interaction DVD containing examples of Intensive Interaction activities taking place in schools and adult day and Further Information

- Visit the Intensive Interaction website at www.intensiveinteraction.co.uk
- Facebook intensive interaction http://www.facebook.com/group.php?gid=13657123715&ref=nf

Books:

 Residential services. It is available from www.intensiveinteraction.co.uk

Inter-Act Now is the East Sussex Intensive Interaction Network which has been set up to bring together people with profound and severe learning disabilities and their carers, families and support workers using Intensive Interaction. The Network will enable people to share experiences, build and develop skills and provide support for those wanting to promote an Intensive Interaction approach within services and the wider community.

For more information on becoming part of the Network email: Angelaangleslake@googlemail.com

OBJECTS OF REFERENCE AND SENSORY REFERENCING

What are Objects of Reference?

Objects of Reference are objects that are used to communicate a meaning in the same way as words and pictures. They can be used to represent anything we want to communicate: people, places, activities, events etc. For example a **cup** can stand for a **drink**.

You are likely to be using everyday objects with the individuals you support already. You may be saying to them "we are going out" while handing them their shoes, thereby giving them a visual clue as to what is going to happen, so they don't need understand all the words you are saying. Objects of Reference are objects that are used in a structured and consistent way, and used **every time** the activity etc is going to happen. An object becomes an Object of Reference when the person begins to associate it with the activity it represents.











The objects need to be carefully selected to suit each individual and used in situations where the need to communicate exists.

- They need to be meaningful to the individual. A simple link or a strong association between object and activity/person is best. For example, a riding hat stands for horse riding; a string of pearls stands for mum. However what might seem a clear link to you may not be for the person you support. Spend time observing them doing the activity. Each individual's set of Objects of Reference will be unique to them.
- They need to be motivating to use. For example you may wish to have an object to represent toilet but for the person you support, the toileting procedure could be a difficult and stressful experience. They will have no motivation to learn the Object of Reference for toilet. Food or favourite activities are far more motivating and rewarding!

- Start with a few objects that represent activities/events that occur frequently. Repetitions of use will make it easier for the user to understand the connection between the object and its meaning.
- It is vital that there is a consistency of approach. Everybody will need to introduce the object in the same way, using the same key words and signs. Written guidelines are essential.

Who uses objects of reference?

Objects of reference can be useful for people with communication disabilities who do not respond to other methods of communication such as speech, signs or pictures.

Objects are concrete and permanent and offer lots of sensory information. They don't rely on processing verbal information or memory.

- People with profound and multiple learning disabilities
- People with multi sensory loss
- People with sight impairment
- People with short or long term memory difficulties
- People with an Autistic Spectrum Disorder for whom the spoken word has little meaning

In order for Objects of Reference to be a successful communication tool, the user needs to be able to:

- discriminate objects by touch/smell/sound;
- appreciate that objects mean something;
- or have some capacity to remember the meaning of an object.

N.B These skills may not be present at the beginning but by introducing objects they will hopefully be promoted.

How do they help with communication?

Many people with learning disabilities have things 'happen' to them. Objects of Reference let them know what is about to happen and help understand what is being said.

Once the objects become objects of reference the person can begin to use them themselves to ask for activities and make choices. Objects can be used in the form of a timetable, so the person can begin to predict the events of the day. Objects of Reference may be the basis of an individual communication system or the stepping stone to other systems such as photographs and signing.

Objects of Reference need to be **Meaningful**, **Motivating** and **Frequently** used.

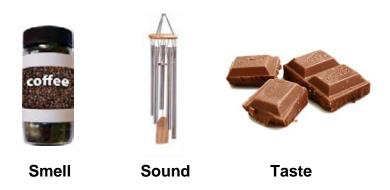
Examples of Objects of Reference

Type of Object	Type of object	How it is Used	
Swimming Costume	Real life object that is used in the activity	B likes to go swimming. She uses a swimming costume as her object of reference for 'swimming'. The swimming costume is presented to B before going swimming. This enables her to understand what is about to happen to her and to give her an opportunity to accept or refuse.	Easiest to understand
Plastic beer Glass	Real life Object that is not used in the activity	M has a plastic beer glass that he can use to indicate that he wants to go to the pub. M does not use the object of reference to drink from in the pub.	
Piece of cushion cover	Partial Object / Object with a shared feature	E enjoys sitting in the swing chair in the garden, which is covered in this material. when she wants to go into the garden, E can take the piece of material and find someone to give it to. This indicates her choice to go in the garden and sit on the swing chair.	pu
Small rubber ring	Abstract object not related to activity	B has a small rubber ring that he uses as an object of reference for going to college. The object has been used every time B has gone to college. B now recognises this object represents going to college.	Hardest to understa

References: www.oxtc,co.uk; www.lookupinfo.org

Sensory References:

Sensory References are similar to Objects of Reference but use sound, sight, smell and taste as a means of orientation rather than a specific object. It is particularly useful for those people with profound and multiple learning disabilities with a sight impairment. Tony Jones (via pri-Liberator) is the leading expert and trainer.



An example:

P's mum visits her regularly. To let P know her mum is coming to visit; her carers spray some of her mums perfume. Mum always makes sure she wears the same perfume when visiting P.

Further Information:

Tony Jones – trainer and expert: www.TalkSense.weebly.com

Ockelford, A., (2002) Objects of Reference; Promoting Early Symbolic Communication, London, RNIB. Available from RNIB, £4.50 + VAT.

'Putting objects of reference in context', an article by Marion McLarty, published in the European Journal of Special Needs Education, Vol 12, No. 1 (1997), pp12-20.

Sensory References and the work of Tony Jones www.oxtc.co.uk/soundandsmell.shtml

VOICE OUTPUT COMMUNICATION AIDS (VOCAs)

What are they?

Voice Output Communication Aids (or high tech aids / devices) are pieces of equipment that use speech that has been electronically stored. They can range from



simple devices - a button with one message or word, to very sophisticated devices such as the one Steven Hawkins uses. Those users with good reading and writing skills may use a text-based system. However, there are many people who access their vocabulary through symbols or even photos, which can be loaded onto the device.

VOCAs can be accessed in different ways depending on the skills of the user. Buttons, switches, head pointers and eye gaze are some of the ways that some users access their devices.

Who uses it?



Anyone with a communication disability, however old, may be able to use a VOCA. A person may wish to use a VOCA if they are unable to use speech to communicate with others. It is very likely that they will use other non-verbal methods of communication as well.

People with physical disabilities who are unable to access other methods of communication (such as signing) are able to use VOCAs. You do not need to use a keyboard or press a button as there are many ways to access them.

Most VOCAs require the user to understand symbols and to be able to remember where they can be found on the device.

How does it help with communication?

VOCAs are powerful tools as they give people a 'voice', which is easily understood by all listeners. Some people rely on them 100% of the time, others may use them at specific times when they need to be understood by people who are not familiar with them.

It is very motivating to be able to speak out ideas and thoughts and have control over when you speak. Those who use VOCAs speak of how empowered they feel through using them.

VOCAs can be quick and easy to use - good for those who cannot easily turn pages (of a communication Book for example).

Examples of VOCAs.

There are many different types of VOCAs on the market today and with technological developments, things change quickly!

For a database of VOCAs currently on sale in the UK go to:

www.ace-centre.org.uk



Big Mack



Pathfinder



Handheld communication aid

Examples of their Use:

There are many people without learning disabilities that use VOCAs, such as Steven Hawkins who had his larynx removed, leaving him without the power of speech. Some examples of people with learning disabilities using VOCAs are below.

A has speech but is difficult to understand. He uses signs and symbols to communicate at home, along with vocalisations. However, he likes to be independent of his carers in the community and uses a simple VOCA at the shops to request things for himself. He can press the buttons on the device himself, which access a few pre-stored sentences.

B has no intelligible speech and uses a symbol based VOCA 100% of the time. He creates his own sentences and has access to thousands of words stored in symbols on his device.

S likes to use speech but cannot be understood by those outside of his family. He accesses words and sentences on his VOCA by using a switch with his chin, which scans across the words that he wants.

Further Information:

If you are interested in a VOCA then always contact your local Speech and Language Therapist team for a full assessment.

www.ace-centre.org.uk

www.possum.co.uk

www.techcess.co.uk

www.toby-churchill.com

www.dynavox.co.uk

www.pri-liberator.com

www.communicationmatters.org.uk

www.1voice.info

MAKATON

What Is Makaton?



Happy

Makaton is an approach to teaching communication, language and literacy using combined modes of communication.

It is not a language in its own right. Speech, sign, facial expression and symbols are all key components of Makaton.

It follows spoken word order and those supporting users would always speak and sign at the same time.

It was developed by Margaret Walker, Speech and Language Therapist and colleagues in the 1970s to help people with a learning disability and deafness to communicate. However, it is now used universally with a variety of children and adults with communication difficulties.

The signs in the Makaton Vocabulary are taken from British Sign Language (BSL).

Makaton is a registered charity. There is a formal training programme for families, carers and professionals. Peer tutoring opportunities and local networks for service users are encouraged with help from the Makaton Vocabulary Development Project (MVDP).



There are also a wide range of resources to suit educational and social living needs.

Who uses Makaton?

Makaton is used by people with varying communication difficulties, including those who have:

- Hearing impairment.
- Expressive difficulties (speech and/or language).
- Autism.
- Memory and/ or comprehension (understanding) difficulties.

People with severe physical disabilities may not be able to sign but may use the symbols to support their communication.

How does it help with communication?





Book

The Makaton signs and symbols provide extra information to speech which is visual. This assists people's understanding of language and supports their expression.

It enables those people with communication difficulties and their carers to have a 'shared language' of key words around daily living.

Using the signs and symbols together with speech can prompt people to develop their verbal and literacy skills. Research has shown that signs/

gestures are easier to learn than spoken words. In using Makaton, people are able to develop important communication skills.

Signs and symbols offer 'permanence' to language that speech does not. It can therefore help people with memory difficulties to remember and process what has been said.

An Example:

J has a learning disability and dyspraxia. His speech is not easily understood by others. He also struggles to understand what others are saying to him.

He uses Makaton signs to express his ideas and choices, usually one sign at a time. Some of his signs are difficult to read and the support workers have written down a description of his signs and what they mean to assist others to communicate with him. His support workers sign when talking to him to assist his understanding of key concepts. He also benefits from using symbols to assist making choices and on a timetable which helps him to understand the structure of his week.

Further Information:

For more information you can contact the MVDP at:

The Makaton Charity Manor House 46 London Road Blackwater Camberley Surrey GU17 OAA



Main office Tel: 01276 606760 Sales Order Line: 01276 606789

Email: info@makaton.org Website: www.makaton.org

Registered charity: 1119819 Company registration: 06280108

Your local Speech and Language Therapy service will also be able to help.

SYMBOL SYSTEMS

What are they?

We are all familiar with symbols as they are used commonly in everyday life, in signs, instruction manuals, washing labels etc.

Symbols are not pictures, which may show lots of information and the focus may be unclear. Instead, symbols focus on a single concept. They can look like the concept that they are depicting or be more abstract. Examples of this in everyday life are:

No Smoking symbol – looks like what it is describing



Tumble dry symbol – abstract, its meaning needs to be learnt



Symbols can be colour or simple black and white.

There are different symbol sets that have been developed to assist communication used in the UK. Those available are:

Widgit Literacy Symbols (previously known as Rebus)

Picture Communication Symbols (PCS)

Makaton (in addition to Signs)



The software for these symbol sets can be bought so that they can be printed from a computer (for example using BoardMaker). However, it is important to be able to provide symbols for people to use at all times. You can therefore just draw them as and when necessary!

Who Uses Them?

We all do!!

However, some people use them specifically to assist them with communication and literacy. These people may:

- have memory difficulties;
- dementia;
- other brain damage;
- dyslexia;
- dyspraxia;
- spatial/time / organisational difficulties;
- be deaf or hearing impaired;
- or have Autistic Spectrum Disorders.

As there are different symbol sets, people can find it confusing and difficult to know which to use. What a person chooses to use will depend on their needs and preference. Everyone has different abilities in sight, vocabulary, spoken and written language.

How do they help with communication?

Symbols can help with:

- Communication making a symbol communication book can help people make choices. The PECs (Picture Exchange Communication System) uses symbols, so instead of words, PECS uses pictures or symbols of objects, such as someone's favourite food. The system slowly trains the person so that they can swap a picture of the thing that they want for the real thing.
- Independence and participation symbols aid understanding which can increase involvement, choice and confidence.



 Literacy and learning - symbol software encourage users to "write" by selecting symbols from a predetermined set in a grid.



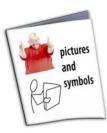




 Creativity and self expression - writing letters and stories and expressing your own opinions. The Talking Mats approach also often uses symbols to allow people to explore and communicate their feelings and opinions about certain issues.



 Access to information - all of us need accessible information and this should be presented in such a way that the reader can understand and use.



Examples of Using Symbols:

Each week, P is helped by his carer to write a shopping list in symbols. He then independently goes to the shops and is able to purchase the items from the list despite not being able to read text.

J is a carer in a home for people with learning disabilities. Whenever she is on holiday she sends a postcard to the residents, drawing symbols next to the text that support the residents to read for themselves what she is doing whilst she is away.

H is a Speech and Language Therapist in a multidisciplinary team. She uses symbol sets on the computer to support the written word in letters to those people who are unable to read.

L uses a communication book which has symbols in categories for her to point to in order to communicate with others.

J has a timetable on the wall, which uses symbols to depict her activities for the week.

Further Information: BoardMaker www.widgit.com/mayer-johnson/products/boardmaker.htm Makaton www.makaton.org **PCS** www.mayer-johnson-symbols.com **PECS** www.pecs.org.uk Rebus/ Widgit www.widgit.co.uk/widgitrebus/index.htm

TALKING MATS

Developed by The AAC (Alternative and Augmentative Communication) Research Unit at The University of Stirling, Scotland.

What is a Talking Mat?

It is a low-tech communication framework designed to assist people with communication difficulties to express feelings, choice, or arrive at a decision. A talking mat uses a three point "visual scale" (can be less or more) placed at the top of the mat, and a "topic" which is placed at the bottom. "Options" are offered one at a time to the person and they can place them on the mat, or eye point to indicate their general views.

Who uses Talking Mats?

Talking Mats have been found to be effective with children, adolescents and adults with expressive difficulties and those who have a mild to moderate learning disability.



How do they help communication?

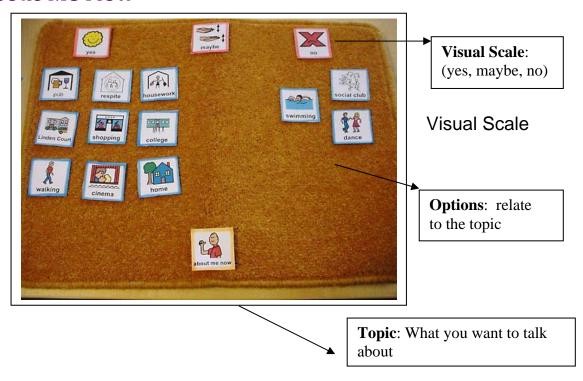
A person does not need speech to use a Talking Mat and therefore it can give a person a voice. The tool also supports comprehension, as it gives information to someone in different ways i.e. — in a visual way, in a tactile way and also through auditory channels. As Talking Mats uses a simple structure, it gives a person time to process what is being asked, organise their thoughts and then respond with what they feel in a visual way. Photographs, pictures or even objects can be used and therefore a mat can be tailored to the person's level of understanding. A permanent record of the person's opinions, choices etc can also be made by taking a photograph of what they have said. This helps the person to feel that their views are valued and will be remembered.

Example of a Talking Mat using symbols

K has her review coming up and wants to be actively involved in the meeting.

She used several Talking Mats to discuss her life now and her future wishes. Her key worker has taken a photograph of each mat for K to present at her annual review meeting.

About Me Now



Other examples of when talking mats might be used with someone with a learning disability, might be to explore feelings about moving home, likes and dislikes, future goals etc. They can be used in a person's review, to aid person centred planning or to make a complaint. Talking Mats are also used to support adults with learning disabilities understand direct payments, the "direct payment communication toolkit" now includes the use of Talking Mats alongside other low-tech communication aids.

Further Information

www.talkingmats.com

COMMUNICATION PASSPORTS

Communication Passport

Developed by Sally Millar 1991, Communication Aids for Language and Learning (CALL) Centre at the University of Edinburgh.





What is a Communication Passport?

A Communication Passport is a simple and practical guide to understanding and supporting a person's communication. It is a book using words and pictures to describe a person in a positive way. It should contain the key information the owner would want to tell when introduced to a new person, for example likes and dislikes. The reader should quickly be able to know the best ways of communicating with that person and get an idea of their personality as well as their everyday needs.

What it is not

Communication Passports are not intended to replace care plans. They do not contain all the important information about an individual, just non confidential, need to know information, in an easily accessible format.

A Communication Passport should not be confused with a Communication Book. They are not used by the individual to communicate directly but as a guide to others on how the individual communicates and how best to respond.

Who uses them?

Communication Passports are for people who are unable to tell you about themselves and need support with their communication. There are particularly useful for those people with complex needs whose communication is hard to 'read'.

Communications Passports are invaluable during transition when the individual will be meeting new people. For example when:

- Moving from one service to another.
- Moving home.
- They use more than one service.
- Where the staff turnover is high.
- Hospital admissions.

How can they help with Communication?

Communication Passports can be very useful in helping new staff/strangers to quickly understand personal needs and to ensure a consistency of approach. They can also help to avoid preventable behavioural difficulties

The passport should go everywhere with the person especially when they attend anywhere for the first time (start a new place) e.g. day centre, college. This is because they can provide a focus for attention and interaction.



Who should make one?

It can be anyone who knows the person well. But the most important thing is to involve the person, where possible, from the beginning on what they want to be included. Collect information from the person, and all their supporters (family, friends and carers), circulate a draft and agree final changes.

How do you make one?

A passport can be any colour, size or shape. It can be as simple or complex as needed. Use your imagination. Whatever the design it should be attractive, colourful, accessible and positive, not jargon-ridden or confidential.

They can be hand written. Use different coloured paper, pens, pictures of the person, their friends and family, symbols or pictures of everyday objects. Cut up old catalogues or buy a cheap picture dictionary. You don't need access to a computer to make a passport. Hand written passports are just as effective. They should be reviewed at least once a year.



An example:

G is non-verbal, uses a wheelchair and has complex health needs. He likes going out and about, and particularly enjoys travelling by train. He is due to go into hospital soon.

G has a communication passport in the shape of a train that he carries around in a bag on his wheelchair. It contains a short account of G's communication skills and needs. G will take his passport to hospital. It will give the nurses and all those people new to him, all the information they require to communicate with G and understand his needs.

Do you need more information?

Personal Passports, Information Sheet 5 has many tips and ideas. Contact Sally Millar, Call Centre, University of Edinburgh, Paterson's Land, Holyrood Road, Edinburgh EH8 8AQ. 0131 651 6236. www.callcentrescotland.org.uk

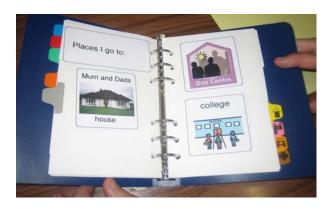
First Steps, Communication Matters c/o The Ace Centre, 92 Windmill Road, Headington, Oxford, OX3 7DR. 0870 606 5463. www.communicationmatters.org.uk

Please contact your local speech and language therapist for further advice.

COMMUNICATION BOOKS

What is a Communication Book?

A Communication Book is a low-tech communication system that can replace or support speech. It can contain photos, symbols, magazine pictures or line drawings to represent daily activities, food, places objects likes and dislikes that the owner may wish to communicate. They are many different designs from a simple sheet with a few pictures to a book full of symbols.



Who uses Communication Books?

Many people can benefit from using a Communication Book:

- People who have no speech, limited or unclear speech.
- A person who's physical disability prevents them from using other communication systems.
- People who use Voice Output Communication Aids might use a Communication Board or Book as a back-up. For example at the swimming pool.
- The additional pictorial support can help those people who generally make themselves understood but have difficulty in unfamiliar situations when they are under pressure and when communication breakdown can occur.

How can Communication Books help with communication

A person with limited speech can use their Communication Book to help tell people what they are feeling, make choices and ask for what they want. For example when asked what they want to do after lunch they can point to a picture of "walk" to indicate they'd like to go for a walk.



The pictures can help the listener key into the topics being communicated. This will decrease any frustration and promote successful interactions. Having access to an effective means of communication will encourage the user to communicate more.

A Communication Book can enable its owner to be more independent and sociable, for example using it to chat with friends at a club. People may have a book that they use to communicate a single topic or activity. Alternatively others may use a book that covers all aspects of their life with many different sections.

Tips on making a Communication Book

- Keep it simple. Start with just a few photographs and gradually add to the book. Ensure everyone can understand what the pictures represent. Write what the picture means underneath it.
- Start with pictures that represent a frequent or regular activity when the need to communicate exits but only include pictures that the owner wants to communicate. Where possible get the user to make the book with you. Remember that they have ownership!
- A small photograph album is ideal and can be carried around in a handbag or bum bag. Alternatively pictures can be put in a ring binder, business card folder or on a key ring.
- Include an index page and divide pictures into categories. It will be easier to use e.g. food, places and activities. Consider colour coding sections so they are easy to find.

- Consider physical or visual difficulties. Can the owner turn the pages independently?
- Keep a copy.
- · Keep changing and updating.
- Support the person to learn how to use the book effectively.
- Model using it.
- Aim to be consistent. Ensure <u>all</u> staff know about the book and encourage the user to use it regularly. Written guidelines may be needed.
- Don't lock it in a draw!

An example

T uses speech as his main method of communicating. He is very independent and likes to use the bus and go shopping locally. However T's speech is unclear and he has difficulty making himself understood with people who don't know him well. This makes T very frustrated and reliant on staff to communicate on his behalf, especially when he is out. None of his housemates have communication books so T is reluctant to use one and he felt it was too big to carry around.

T now has a key ring with set phrases and symbols representing activities and topics he wants and needs to communicate. The staff at his home all have key rings and use them to back up their speech and have adopted a Total Communication approach for everyone. T now takes his key ring everywhere and thinks it is cool!



Further Information

www.communicationmatters@org.uk

TALKABOUT BOOKS

What is a Talkabout Book?

A Talkabout Book is a book of photos and paper reminders to record events and achievements, activities or things that are of interest to its owner. It can include family photographs, holiday mementos, drawings, tickets, programmes etc.

Who uses Talkabout Books?

Talkabout Books are useful to all people with a communication disability. They are particularly beneficial in promoting expression. For example, a Talkabout Book can encourage a person who is verbal, but does not speak much to talk, about the people and events that are pictured in the book, as well as opening up discussion on future entries.

They can be great fun too!



How does it help with communication?

A Talkabout Book can be used as a prompt to increase opportunities for shared communication. It helps focus the person's communication and helps cue in the communication partner to what the person is talking about.

Tips for making a Talkabout Book

- The individual should be as involved in creating the Talkabout Book as their abilities allow. Whatever is entered into the book should be interesting to them. They will not be motivated to talk about events that they find tedious.
- Parents/Staff / carers should label each picture preferably with the wording the individuals have said themselves. Make sure the names of all the people in photos are included. Staff should then encourage them to chat about each picture.
- Ideally the owner should have opportunities to look through their book with others whenever the mood takes them, in an informal and unstructured way. However if this is not possible, at the very least staff should plan to have regular sessions (at least 1) per week, which will be written into the weekly timetable. The length of the session should take into account the individuals concentration span.



- It may be helpful to have photographs for events that the owner dislikes (e.g. dentist visit) so that they can talk about them. However there needs to be many more favoured activities and events pictured than non-favoured ones.
- Guidelines should be written up to ensure consistency of use.
- A Talkabout Book should be ongoing and updated regularly.
- Invest in a digital camera!

Example 1

D is very quiet and rarely initiates conversations. She spends most weekends with her parents and has regular hoildays. Staff and parents alike have no idea what D has done when she is away from them. A communication book between home and parents was introduced but this is often used to talk about practical issues and problems.

D uses a Talkabout Book to record interesting activities she has done at home and with her parents. She really enjoys making it with staff and her parents and it give her an opportunity for 1:1 time, which encourages her to talk more. D adds a sheet of paper into a clip file. These pages are laminated to make them hard wearing. She recently received a digital camera for her birthday so she can now download photos quickly and produce a sheet at the end of the day. D is very proud of her book and it has helped her have the confidence to approach people and start up a conversation.

Example 2

K is non-verbal but enjoys communicating with people. He has many interests and hobbies and is keen to share them with others. K has several Talkabout Books on topics that interest him. For example one is about steam trains. Staff have allocated regular times to look at these with K. These times are recorded on his visual timetable. K really enjoys these sessions and he particularly likes to show new /agency staff. They find this a useful way of 'breaking the ice' and getting to know K.



I went on a steam train at Bluebell Railway with Helen



This is my ticket

Both D and K have ownership of their books and keep them in their bedrooms. They have the opportunity to look through their books whenever they wish.

VISUAL TIMETABLES / PLANNERS

What is a Visual Timetable / Planner?

A Visual Timetable/ Planner uses photos, pictures, symbols or objects placed in a sequence to represent daily activities.

They show the user what is happening and can represent part of the day, a whole day, week or month.

Monday	Tuesday	Wednesday	Thursday	Friday
bowling	computer	shopping	arts & crafts	dance
lunch	lunch	lunch	lunch	lunch
bus trip	swimming	cooking	farm	music

Who are they for?

Everyone can benefit from having a visual reminder of what is happening. It is a permanent record of events and does not rely on the understanding and processing of language or memory.

People with limited understanding will find it difficult to process lots of information at once. A timetable will clearly show them what happening next one step is at a time.

The timetable can represent part of the day, a whole day or a week. You will need to use appropriate timescales for that person.

How can it help with Communication?

A Visual Timetable gives the user more control and predictability over their daily life. It can give them opportunities to make choices and encourage communication.

It can help people who do not understand the concept of time. A picture of key routines such as breakfast, lunch and bedtime can be permanent and used every day. The spaces/boxes in between can be filled daily to show activities, tasks etc. For example it can show that on Monday after breakfast they will go for a walk and after lunch they will be going swimming. On Tuesday after breakfast they go shopping and after lunch they go bowling.



A timetable can help by showing 'waiting'. Waiting for something to happen can be difficult for some people causing great frustration. A timetable can show that they have to do certain activities before they can go out.



The pictures can be used to explain things that are <u>not</u> happening .If an activity has been cancelled the corresponding picture can be removed or covered over. This is helpful when the user does not understand negatives i.e. if you say "you are not going for a walk" they will only understand "going for a walk". If a picture is <u>not there</u> or <u>covered over</u> this shows visually something is not happening.

Tips on making a Visual Timetable

- Keep it clear and simple. The timetable needs to be presented in a way the user understands. Choose simple pictures that they can recognise. Photographs of them doing the activity are very clear.
- Use appropriate timescales for the individual user. For example some people may only be able to cope with a simple time table showing what they are doing until lunch others may have one that shows their whole week.

- The timetable should be placed in a convenient place where others cannot tamper with it.
- Consider the format. This will depend on the user. Consider the size of the pictures and how many spaces you'll need.
- It is best to start with a simple daily plan with just a few spaces for activities. As the user becomes familiar with the concept you can increase the number of activities and days etc if appropriate.
- Ideally the timetable should be prepared at a set time each day, either last thing at night or early in the morning routine. It should be made part of their daily routine with staff setting aside adequate time to help the user plan their day.
- When an activity has finished the pictures can be turned over or removed (and place in a safe container so they are not mislaid).
- When offering choices make sure that only activities available are offered. For example: Going out in the car when there is a driver on duty.
- If you decide to laminate the pictures a matt finish is best, gloss interferes with the clarity of the picture.
- Use Velcro to attach the pictures. It is easy to use and reattach pictures.

Example 1:

P uses Objects of Reference to communicate. He has many objects that represent his daily activities. If P wants to go out he shows staff his object for going out. However, if it is not time and Peter's request is denied he has to wait. Peter gets very upset when he has to wait and often lashes out at staff.

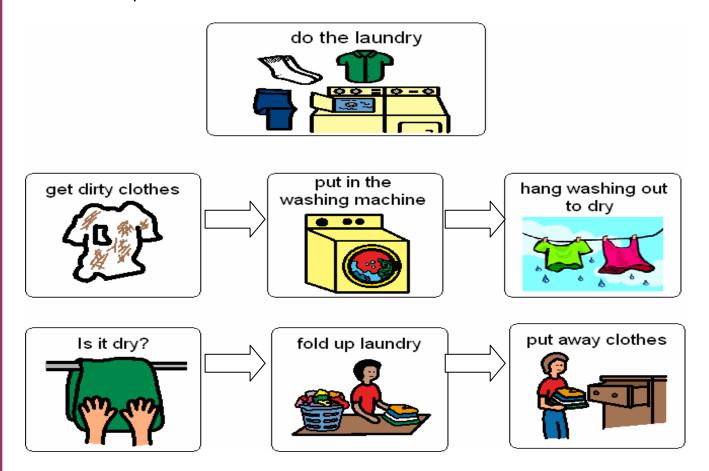
P now has a board that is divided into sections placed on a shelf in his bedroom. A bowl is placed on the first section to represent breakfast. On the next section is his object of reference for his morning activity and on the third is a plate to represent lunch and so on. P helps to plan his day by placing his objects on his board each morning. P now knows what order things are happening and is able to choose what he wants to do.

JOB AIDS

What are Job Aids?

Job Aids are visual reminders of what you are going to do. They are guides that show the user what steps they will need to take in order to complete a task. The tasks can range from simple dusting to making dinner.

Job Aids can be made using photographs, pictures, symbols or on a single laminated sheet or in the form of a booklet, showing each step on a different page. Objects can be used in the same way. The objects needed for a task can be place in order or on a tray to show what needs to be done one step at a time.



Who uses them?

Job Aids are really useful for anyone who is learning a new skill or task. People with limited understanding find it difficult to process lots of information at once.

A job Aid will break a task down into easily to manage steps and reduce the need for prompting and input from others.

They are especially useful to people who have processing or memory difficulties or who are not able to sequence events.

How do they help with communication?

A Job Aid visually communicates what needs to be done. It is a permanent record and does not rely on the understanding and processing of language or memory.

A Job Aid can increase:

- understanding;
- independence;
- participation;
- predictability;
- consistency; and
- self esteem.

Example:

S has moved into her own flat and receives staff support for a limited period each day. S has worked really hard for this to happen and wants to show people she is capable of running her own home. However she is struggling to complete some household tasks successfully and uses up her staff time on this. S would prefer staff to help her with money management and supermarket trips. Her occupational health assessment highlighted that S has some sequencing difficulties.

S has Job Aids to help support her with her household chores. Photographs show her what equipment she needs and each step that is needed to complete the task. S is really happy she can do these on her own and can now choose how to spend her staff support time.

Polishing the mirror

You will need:







Mirror

Spray polish

Duster

Polishing the mirror







Spray the polish on the mirror 1 squirt





Wipe the polish off the mirror 3 wipes







All clean!







Now put it all away!

SOCIAL STORIES

Social Stories were developed in the early 1990's by Carol Gray Consultant to Students with Autistic Spectrum Disorders in Jenison, Michigan, U.S.A

What is a Social Story?

A Social Story is a **short** story written in a **specific style** and **format.** The story describes what happens in a specific social situation, that may be obvious to us but not to people with impaired social understanding. It aims to improve their understanding of social situations and encourage appropriate responses.

Social Stories use 3 types of sentences: **descriptive**, **perspective** and **directive** that need to be balanced carefully. Gray (1994) recommends a ratio of 0-1 Directive sentence to 2-5 Descriptive or Perspective sentences.

Social Stories use a mix of writing / pictures / symbols to match the understanding / language / vocabulary levels of the person.

Who uses Social Stories?

They were originally developed for students with autism spectrum disorder, but have proved beneficial to others with learning, emotional, cognitive and communication impairments.

Social Stories are versatile and easily tailored to meet a variety of needs. However each story is unique and written for a **specific individual** about a situation **they** find difficult.

How can they help with Communication?

Social Stories provide accurate information about real and relevant situations. They present information visually and do not rely on interpersonal contact. They are a prompt about how to respond and what to expect in a specific situation. They have clear goals and give reassurance and positive feedback.

Social Stories are often used to develop appropriate behaviour:

- They describe what people do.
- Why they do it.
- What are the common responses.

Example

S has an autistic spectrum disorder and finds many social situations difficult. She refuses to go to the doctor but has ongoing health needs.

S, her key worker and the Speech and Language Therapist have worked together to produce a social story about S going to the doctor. It is a positive book with one piece of information and photograph per page. It describes what will happen at the doctors: who will be there, what they will do and why. S's feelings and what she will try to do when she is there.











Further information

A successful Social Story needs to be written and delivered using a specific formula. They need to be based on careful observation and assessment. Your local Speech and Language Therapist will be able to help.

LIFE STORY BOOKS

What is a Life Story?

"A Life Story book is an account of a person's life, including stories and memories of past events and relationships – all the kinds of experiences that make us, who we are". (Helen Hewitt 2006)

A life Story can take many forms:

- a book
- a video diary
- CD ROM
- Spoken interview

- a time line
- a family tree
- a memory box
- a poster



Who uses life Story Books?

Life Stories can benefit everyone at all levels of ability.

"Identity is what makes us unique. People with learning disabilities are often denied the opportunity to consider who they are and how life events affect their identity."

(Helen Hewitt 2006)

Many people with learning disabilities are faced with many moves over their lifetime and much of their life history has been forgotten, archived or lost.

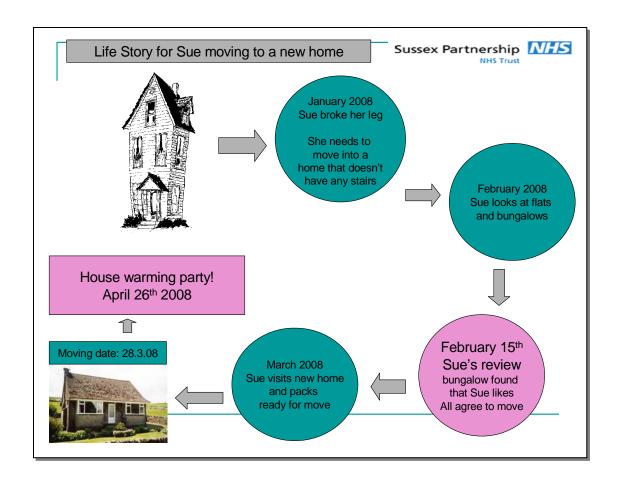
A Life Story Book can help the person with a learning disability regain their unique life story and help carers and staff appreciate them as individuals not just as person with a learning disability.

How do they help with communication?

Life Stories are a great way of getting to know someone. They provide a focus for interaction and an opportunity to promote communication.

Life Stories can be very useful:

- when preparing someone for a life change;
- for people with dementia,
- · memory difficulties;
- where staff turnover is high;
- · when meeting new people; and
- to enable the person to have an identity other than learning disabled.



How to implement them?

Before starting a Life Story for someone you support, carefully consider the following:

- Benefit to the individual.
- Ownership.
- Consent.
- Building trust with family/friends/past carers.
- Sensitive handling of personal information.
- Dealing with upsetting/traumatic past experiences.

Together, decide the best way to set out the person's life story. Collect information/pictures/photographs/interviews from the person and all other sources. Have fun putting it together!







If there aren't any contacts or written history available start a life story using the information you do have. Record life events that have happened since you met and continue to build on this. Include hopes and future wishes.

Life Stories are ongoing and should be continually updated.

Examples

1.) B has lived in many care homes since his childhood. His parents are dead and he is not in contact with his extended family. B has limited communication and little of his past history has been passed on and recorded.

Staff discussed the idea of a life story with B and got his consent to contact past carers and residential staff. They wrote to the carers outlining their aims and were able to gain some important information. A bonus result was an old key worker of B's visited him and they were able to enjoy catching up. B enjoyed hearing stories about himself.

Staff and B made a poster for his bedroom wall. It represents B's life story and shows who he is and what is, and has been important in his life.

2) M has an elderly mum who is terminally ill. She has no other family members.

M's support staff have sensitively introduced the idea of a life story book with B's mum. They made sure mum was clear of the benefits for B. Mum recorded stories of B's childhood and the family history. She gave B photographs and some personal belongings that will help B remember her in the future when she is no longer alive. B and her community support key worker made a memory box. B enjoys going through her memory box with mum and her support staff.

Further Information

Reference

Life story books for people with learning disabilities Written by Helen Hewitt, Bild publications 2006

This book is an excellent resource for all those considering starting a life story work.

www.bild.org.uk

Part 4: HOW TO CREATE A TOTAL COMMUNICATION ENVIRONMENT

It is important to create an environment that enables an individual to communicate to the best of their abilities.

A successful environment needs:



- The individual's communication partners to spend time with the individual getting to know their preferred method of communication.
- skilled communication partners who are able to adapt their communication skills to meet the needs of the individual. For example use simple speech;
- a predictable, consistent environment to live in. Many people with severe learning disabilities will derive a lot of understanding from environmental cues and routines;
- to use all the appropriate Total Communication approaches consistently and in all aspects of daily life. For example gestures, visual support, body language; access to communication aids and resources e.g. visual timetables, communication books and talkabout books.
- Different methods or a mixture may be required in different situations. For example using a social story when going to the doctors.

 to provide opportunities to engage in meaningful conversation and participate in decision making;



- to be a suitable physical environment for example, room layout; correct lighting and reduced background noise.
- hearing and visual impairment have a major impact on communication skills. You need to alter your skills accordingly and ensure the environment is suitable.
 Ensure people are formally assessed on an annual basis. Check that glasses and hearing aids are in good working order.

"1/3 people with learning disabilities are likely to have a sensory impairment – sight and/or hearing loss. "





Everyone in the household / work place will benefit from clear communication. For example, even people who can read will find that additional pictures will help focus and clarify the written and spoken word.

Total Communication is for everyone!













SEVEN THINGS TO DO RIGHT NOW!!









- 1. Respond to all attempts at communication.
- 2. Spend time getting to know the people you support / care for. Communication 'time' shouldn't be timetabled into people's days. Communication is present in everything we do!
- 3. Make a commitment to change your communication. Have time allotted to implement and discuss these changes.
- 4. Make a staff photo and residence photo board. This can show who is on duty, in or out etc.
- 5. Menu planners using photographs or symbols. This gives people better opportunities to choose their meals.
- 6. Make a communication passport for all those people who are non-verbal. See page 35.
- 7. Buy a digital camera and/or a video camera. This is useful for making communication aids and recording memories.

Make good communication your top priority!



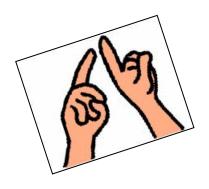




Communicating with People with a learning disability

Top Ten Tips!

- 1. Make sure you have their ATTENTION before you start.
- 2. Speak SLOWLY and CLEARLY.
- 3. STRESS the KEYWORDS.
- 4. REPEAT yourself.
- 5. Give them time to understand.
- 6. Only give ONE piece of information at a time.
- 7. Demonstrate where possible.
- 8. Use a CALM and QUIET environment.
- 9. Check their UNDERSTANDING (ask them to tell you what you've said in their own words).
- Use OTHER ways of communicating like DRAWING, GESTURES, FACIAL EXPRESSIONS, WRITING, and PICTURES.









Part 5: WHERE TO FIND OUT MORE

Further Information



Mencap www.mencap.org.uk



BILD www.bild.org.uk



PMLD www.pmldnetwork.org



Foundation for People with learning disabilities www.learningdisabilities.org.uk



information on eye care and vision for people with learning disabilities www.lookupinfo.org



Sense www.sense.org.uk

Local Organisations and groups promoting Total Communication:



Frameworks 4 change frameworks4change@ntlworld.com



Project Artworks www.projectartworks.org



Decoda www.decoda.org



Involvement Matters Team Email: ldpb@eastsussex.gov.uk



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