

The Good Practice Guide

for support workers and personal assistants
working with disabled people
with communication impairments



Written by disabled people using Scope services in Essex, and in partnership with consultants from the Essex Coalition of Disabled People

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Many disabled people have communication impairments and this has particular implications for helping them to go about their daily lives. This booklet is aimed at personal assistants and support workers who are assisting people with communication impairments and it focuses on just one part of the assistance that is provided – help with communication.

Written by disabled people with communication impairments themselves, the Guide:

shows how communication is a human right

shares the experience of being a user of personal assistance who also has a communication impairment

shares the experience of being a personal assistant or support worker, working with someone with a communication impairment

offers practical advice from both the point of view of the disabled person and that of the personal assistant/support worker

lists the resources available to those working with this group of people



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Who is this booklet for?

This booklet has been written to provide advice for people who are assisting disabled people with communication impairments. If you are employed directly by the disabled person you are likely to be called a personal assistant. If you are employed by a statutory, private or voluntary organisation (in a care home or day centre, for example) your job title may be care assistant, keyworker, support worker, etc.

Many disabled people have communication impairments and this has particular implications for helping them to go about their daily lives. This booklet is aimed at personal assistants and support workers who are assisting people with communication impairments and it focuses on just one part of the assistance you will be providing – help with communication.

What do we mean by communication?

This is just a small booklet – hundreds of short and long books have been written on communication. We are looking particularly at the communication requirements of people who have language – that is they fully understand what you are saying to them – but they either do not use speech or they use it in ways which are difficult for other people to understand. There are thousands of people like this in Britain today, of all ages. Some have never been able easily to use speech. Some have had increasing difficulties. And some – like some older people – used to use speech easily, but cannot now, because, for example, they have had a stroke.

It is important to hold in mind that the group of people we are describing here – and who are writing this for you – can communicate. We are used to people saying we cannot communicate, but of course they are wrong. In fact we have powerful and effective ways of communicating and we usually have many ways to let you know what it is we have in mind.

Yes, we have communication difficulties, and some of those are linked with our impairment. But by far the greater part of our difficulty is caused by ‘speaking’ people not having the experience, time or commitment to try to understand us or to include us in everyday life. You can imagine how tough this can be. That is why we are writing this guide – and campaigning for better recognition of our rights to communicate.

What do we mean by rights?

Human rights

You may have heard of the new **Human Rights Act** which became law in 1998. There are three different parts of this Act which are relevant to our rights to communication.

Article 3. Freedom from torture, inhuman or degrading treatment. Consider how degrading and inhuman it is for year after year to go by without anyone really trying to communicate with you, except maybe just about your basic needs. If no-one takes the time to find out what you are thinking, or assists you to express your views, or just chat with others, this is treating you as if you were not a full human being.

Article 10. Freedom of expression. This means that people should not be blocked from holding and expressing their own views, or from receiving information. We can’t have proper consultation about our views unless people enable us to ‘be heard’, and we cannot access information if it is not properly available to us in formats we can use and respond to.

Article 11. Freedom of assembly and association. This means getting together with other people – whether this is for leisure, learning, work, sharing ideas and plans, or campaigning and lobbying. If our communication needs are not properly supported then this human right is blocked.

Unfortunately for many disabled people, everyday restrictions on human rights are only too common. Shortage of resources are perhaps the most common cause, but poor attitudes, both from individuals and organisations, and indeed the government, are all part of the picture. And of course, people who are not assisted to communicate are the least likely to be able to campaign for their rights. Indeed, campaigning for your rights is, under Article 11, a human right.

Civil rights

Human rights are of course worldwide. Disabled people need to be seen as full human beings. And also we need to be recognised as full and responsible citizens – that is where civil rights come in. Civil rights are the same as citizens' rights – the rights to go about your everyday life doing the same sorts of things everyone in your country does: go to school or college, get on a train, go into a shop, hold down a job... well, you can see how people with communication support needs would be having problems in all these situations. If the proper personal assistance is not available disabled people's civil rights are blocked. Unfortunately this is an everyday event for us and for many of the people you may be working with.

There is a law to protect the civil rights of disabled people: the **Disability Discrimination Act**. This has a section on goods, service and facilities, which says that disabled people must receive the same standards of service to everyone, disabled or not. Shops, business, cinemas, hospitals... by 2004 everything must be equally accessible to everyone. Some provisions are already in place.

People who need communication assistance must have their requirements properly understood and facilitated, otherwise they cannot be full citizens. It is no good living in the community if you cannot take part in that community. How much are you going to want to go out and about if no-one understands you? For years disabled people have been kept back by being in institutions. No-one ever expected us to be buzzing around working, getting into politics, going to clubs, getting into relationships, organising our own holidays. The more our human and civil rights are properly respected, the more the image of disabled people will change in the public's mind.

Entitlements

This is where you come in. Even if everyone really understood that disabled people are fully human beings and have full citizenship rights, it all means nothing if the additional requirements we have, as a result of our impairments, are not in place. If our impairment means that we cannot speak, we require other people to facilitate our communication and/or equipment in order that we can access our human and civil rights.

Our needs as disabled people with communication requirements are basically the same as yours – but we are entitled, because of the extent of our impairments – to extra support and facilitation. These entitlements are spelt out in laws like the **Community Care Act** (1990) and the **Chronically Sick and Disabled Peoples Act** (1970). These laws give us entitlements to the additional things that we need in order to access the same human and civil rights as people who do not have communication impairments.

We access these additional requirements by having our needs assessed and plans should then be put in place to meet our needs. Some disabled people handle their own budgets and employ, or take part in the employment of, their personal assistants.

Whether you are employed directly or indirectly by a disabled person, or by a charity, local authority or other agency, you are part of the disabled person's entitlement. Look at it this way. You are going to be part of the way, in some cases the main way, the disabled person you are working with gets their civil and human rights. The more skilled you are at your job, the more justly and fairly that person will be treated.

Communication is at the heart of being human. So that is how important your job is. Did you realise you were going to be a human rights worker?

We have set out this context for you because we want you to take time to think it through. It will provide you, we hope, with a firm basis to understand the importance of your work, work that should be a lot more respected (and highly paid!) than it is. There is so much more to being a personal assistant or support worker than helping with personal care – as important as that is. We know it isn't easy. But we think you will agree it can be a great learning experience.

Let's get back to communication – are you worried you won't understand us?

We usually have years of experience of our communication impairment and its effects on other people, so we know how to handle ourselves but we know that you'll be feeling anxious. We know there's something really embarrassing for you about not being able to understand someone. Try to relax and remember: we're used to people like you, it isn't embarrassing for us, and we won't be feeling irritated with you for not understanding us. It's ignoring us, patronising us, talking about us rather than to us, and generally underestimating us that gets us angry and frustrated. We welcome people trying to understand what we want to say.

It might help you if you start by thinking of us as people with a whole range of communication strengths. We just do not use speech, or we might make speech sounds but it is hard for you to get what we mean.

Having said that, we are very varied:

- some of us do not use speech at all or communication equipment¹
- some of us do not use speech, but use communication equipment
- some of us use recognisable sounds you will get used to understanding
- some of us use speech which is hard to understand if you are not tuned in to us
- some of us use sounds
- some of us use eyes or facial expressions
- some of us use our limbs
- some of us use pictures or symbols
- some of us can spell and read
- some of us cannot spell or read.

All of us have a yes, a no, a maybe and a don't know of some kind.

A few of us might use sign language, though this is rare in our group because physical impairment often means we can't make the signs. We don't need people to sign to us – unless we also have a hearing impairment – because we understand speech. But it might be necessary for you at some point to learn one of the sign languages².

It is also important to remember that many of us are affected by fatigue. It is hard work making yourself understood in a speech-dominated world. So our strengths may vary as the day goes on.

¹ There are many different sorts of communication equipment, for example, boards or books with letters and/or symbols; computers; voice output communication aids (electronic aids which produce synthesised speech).

² The RNID publishes useful leaflets for those working with people who use British Sign Language, and the Makaton Vocabulary Development Project publishes information about working with those who use Makaton (see Useful References).

How do we see our communication strengths?

Why should we always be seen as the people with the problems when we have so many strengths?

CHARMAINE: My strengths are my perseverance and patience: I will repeat things again and again for people. I use my body language, my hands and my eyes. And I am an expert in reading other people's communication – I watch other people's body and eyes, and I can help others with their communication. I also look towards the things I need done – that is a way of telling staff what I want them to do. Communicating can make me very tired – I use my Liberator³ when it is working!

SALLY: My strength is the way I have built a relationship with my keyworker. I prefer to use her to facilitate me because I do not feel vulnerable with her. I have a book of pictures, but I do not like it. It doesn't say what I really want to say. I have two machines, one I just type on, and one that does the talking too – I am good at using the machines. Another strength is my patience.

SARAH: My strength is my skill in using my yes and no. You have to look at me carefully to communicate with me. I am patient with people, I wait for them to get their questions right so I can answer yes or no. I can make excited or frustrated sounds which people can learn to interpret.

GITA: I am a confident and lively person, so I communicate using my whole body, using arm movements and touching with my feet. I have a yes and a no with expressions on my face. When I want to join in or express an interest I can make a strong sound which I can make louder or softer. I move my eyes a lot, and I can vary how intently I look at someone. I will look over at someone if I want to refer to them or get them to assist in the conversation. I know the alphabet so if you go

³ A Liberator is an electronic communication aid: it has a board from which the person selects what they want to say and the machine 'speaks' the sentence.

through it I can give you a yes or a no. I prefer all these methods to using any other kinds of aids as I find them suited to my personality.

BOB: Personally the best way to communicate between myself and my PA, Ray, is a simple wooden qwertyuiop⁴ communication pointing board which was designed by a speech therapist when I was at school. I point to letters and words on the board, and after each word Ray says the word out loud to let me know he understands what I am saying. Lots of times Ray will guess words before I spell them fully, and this saves me a lot of time.

Some PAs and my family do understand me when I trace words out, for example, on my knee. This is great when I am in the shower or in bed with my wife Sue. In my life I have tried a lot of electronic communication aids but myself and my PAs find them slower, and less personalised: it is better for me to spell out exactly the words I need.

MARIANNE: My strength is my patience. When people do not understand me I am prepared to keep on repeating it until they do. Sometimes if they really cannot understand me I would spell the word out. When giving long talks I like to use my speech synthesiser.

PRU: I am good at communicating with people I don't know, once I can get them to take my method – using my Liberator – seriously. I also use eye contact and facial expression.

MERYL: I use facial expressions to show how I feel, eye contact, and staring at things. I am good at using Bliss boards⁵. If I really know someone, I will use sounds that are actually words, although even people who know me really well can still get these wrong.

⁴ This refers to the way the letters are arranged on the alphabet board - it is similar to the arrangement of letters on the traditional keyboard.

⁵ Bliss is a symbol system. It has a very comprehensive vocabulary and is accessed through a communication board or book, or through a range of computer assisted devices. See Useful References.

What about hi-tech communication aids?

As disabled people with communication needs we welcome the development of hi-tech aids, like VOCAs (voice output communication aids) or computer-assisted systems. Sometimes, however, they can be a pain – they can be quite hard to learn and they break down and can be difficult to get repaired. Sometimes we can only use them if we have a particular wheelchair or seating arrangement. We can go for weeks waiting for someone to sort things out. It is very frustrating.

It may be part of your job to learn the basics of a machine, and about anything else we need to use it. You may also have to keep hassling to get someone to come in and fix it, and chase them up. That would all be part of our communication rights. Anything that is part of our communication strengths, including the ability and willingness to use technology, is part of our communication rights. Therefore it is likely to be part of your job as a personal assistant to facilitate us in using that strength. This may involve you in getting some extra training so you know a bit about how to use the machine and whether it is working properly or not – and who to contact if it isn't.

It will also be important that we have access to communication equipment when we need it – so you will need to make sure we have it to hand and that it is not hidden away in a cupboard!

Sometimes communication systems that non-disabled people use, like email and text messaging, will be an important way of communicating for us and it will obviously be important that we have any help we need to use these things.

What about 'low-tech' aids?

So-called 'low-tech' communication aids are anything that doesn't require a battery or electricity supply to operate it. They are often more useful to us than 'high-tech' aids because, as you can imagine, they can be used in more situations. Books with symbols, pictures and/or words are one example, alphabet boards are another. Again, you will need to become familiar with our particular communication aid and also make sure we have it to hand when we need it. You will probably also need to work with us to update it from time to time – if we have the opportunity of doing new things and meeting new people (as we should) then we will need new words/symbols/pictures in our communication aid.

Few of us will rely on only one method to communicate, however. We will all use gesture and body language, and maybe sounds and eye pointing. Some of us will use speech which might need interpreting and also communication aids. The important thing is that you give us the assistance we need to use all of our methods of communication – whether it is through interpreting our body language and speech, or helping us use a communication system.

What is our experience of good facilitation?

Someone who gets to know us well – obviously, because they will get to know our methods of communication. But remember that there are dangers here. First of all – confidentiality. If someone new can't understand us, the people who have worked with us for a while might pass on information to fill them in that we would rather keep to ourselves. Secondly, you can get stuck in a rut, and be lazy about what we are trying to communicate. You might assume things, which limits our choice and control. So although it is good to build up a long-term relationship with a personal assistant, it is also good to have a fresh approach, and always set time aside for a review of how things are going.

Otherwise however well you think you know us you will probably be missing something vital.

Another problem about relying on just one assistant who knows you well is – what happens when they are not around? And how would you like it if only one person really communicated with you, as opposed to just passing the time of day? It is not really in line with our rights if our communication has to be limited to those occasions when one or two particular people are on duty.

Someone who is respectful. Treating us as if we are equal to you in terms of our intelligence and expectations is an excellent start to communicating with us. We know you will have a few problems at first and we will in turn treat you with respect.

Someone who recognises that it is our right to communicate, and that they are responsible for facilitating that right. This means not running away from the task or just leaving it to someone else, and may mean putting a lot of effort in to chase things up, like broken equipment, or creating new communication materials with us, like boards, books, photos and so on, or helping us to research new aids and equipment.

Someone who looks at the skills they already have. You may already be a very good listener for example, and you probably have many other relevant skills you have already used in other jobs or in your everyday life, which you will find you can build on in this work. Some skills might be ones you can learn from us – ask us about our skills and strengths.

Someone who can interpret exactly what we are saying. It's one thing to understand us when we are at home, discussing our everyday needs, like what to wear, eat or drink. It gets more complicated when we go out and start participating in the community, coming across a wider range of people, most of whom won't have a clue what we are

saying or how to behave towards us. We might want you then to interpret for us (depending on the situation). Put at its most simple – although it isn't always simple for you to do – we just need you to say what we are saying (not what you think we should be saying, or would if we could, nor filling in with your own ideas, or your memories of things we have told you in the past). In other words, you would be a kind of speech machine, just like interpreters are for people who speak a foreign language. For example, in a shop where we wanted to look at a range of goods, you might have to listen to what we are communicating and then say to the shopworker: "She said, 'I want to look at some black skirts in a size 12 please.'" Another example: a meeting or a course where we were consulting with others in a group. You might not sit next to us, but, say, opposite us, to do this work. You might have to say something like, "John says, 'I don't agree with that point and I think it would be better to change the lunch arrangements so that we can get home before it is dark.'" The point is that you should tell others exactly what we have said – and not change or add to it in any way.

Someone who is flexible and sensitive to situations.

Some of us might use technology in one kind of situation, and not in others. You might facilitate someone who uses icons and signs, or pictures in one type of situation, and who relies on body language or eye pointing in another context. You will need to discuss with us what techniques we want you to use in each context.

Occasionally we can prepare something with you in advance, say for a meeting, which we might ask you to read out, especially if we are getting fatigued. Or we might ask you to assist with a particular piece of equipment.

Someone who consults with us. Most social situations are places for spontaneity and you cannot altogether predict what kind of communication context you might get into. So flexibility and consultation is important. We need you to be sensitive and creative, always thinking about what human/civil right we are trying to achieve and how you can facilitate this. If something doesn't work out, we need you to be open to discussing it, and creative in finding new solutions with us.

What are our experiences of poor communication facilitation?

CHARMAINE: They don't spend the time, and they don't let me take my time. They don't pay attention. They worry about themselves, not me. I end up having to work twice as hard at communicating because they won't spend the time. It's frustrating – I despair, and I want to cry sometimes. It's more by good luck than good practice that I meet staff who can communicate well with me. It's their attitude that's wrong. And they are always talking about people behind their backs.

SALLY: The ones who think we should be fixed or made better don't have a clue – they think we should be making all the effort. They don't see they should change themselves.

PRU: Some staff have treated me as if I am stupid and don't have views and opinions of my own. And when I go out, staff often do not have the right skills to facilitate for me. For example, they need to make it clear I can use my Liberator, and get shop workers or members of the public to concentrate on me, not talk to them.

MERYL: There are staff who do not persevere, and just assume they know what I am saying to them, or give up trying to know. Sometimes I just give up communicating when people are talking over me. People talk about me as if I wasn't there.

BOB: Sometimes PAs do guess the wrong words when I am pointing them out, but in the main when they guess they are correct and it saves me time. I found electronic equipment gave me poor facilitation especially when I dropped it or it ran out of battery power.

MARIANNE: When I was at residential college the staff did not tell me directly when something was concerning them about me. And I have had a PA who was too embarrassed to speech facilitate for me at a conference and so could not ask a question on my behalf.

Tips for facilitating communication

These are some tips that we have for personal assistants and support workers:

- Ask me how I prefer communicating and what I need you to do.
- Other people may have told you about my communication needs before you start working with me but you will still need to check things out with me. Don't just go on what other people have told you – consult with me.
- Slow down and listen.
- Pay attention to my body language and facial expression – this may tell you about what feelings I am trying to convey, whether I have something to say, whether I have finished communicating, and so on.
- Eye contact and being in the right physical position can be very important – for both of us.
- Don't be frightened by sounds or movements that I may make – they may be unusual but they may also be an important part of how I communicate.
- When first getting used to my communication we will ideally need to be somewhere quiet with no other distractions.

- Try not to get it into your head that you won't understand me – this will undermine your confidence and make it harder for you.
- Find out whether I mind you taking short cuts – for example finishing my sentences if you think you know what I'm going to say.
- Don't be embarrassed if you don't understand at first. Don't be embarrassed if you make a mistake. Accept that you will make mistakes sometimes and sometimes it will be difficult to understand. Don't try to save yourself embarrassment or time by avoiding communicating with me.
- Take the time at the beginning of our working relationship to find out how to communicate with me, or to understand my speech. This will save time later.
- Check out with me that you have got it right when interpreting my speech or using a communication system.
- When facilitating my communication, repeat exactly what I have communicated without adding your own opinion and without leaving out anything I have said.
- If it is a formal setting, such as a meeting, use the word 'I' if this is what I have said – e.g. if I have said 'I don't think that it is a good idea' you should repeat this. In a more informal setting it may be OK to say 'John says he doesn't think that's a good idea', but check this out with me.
- If you're not sure how I want you to facilitate my communication in a particular setting, ask me.
- Recognise that you may need to facilitate my communication in different ways according to the occasion and setting. For example, at home you and I may chat together, but if I am out shopping, or with friends, or attending a class or meeting, your role will be to facilitate my communication with other people.
- Tell other people to communicate directly with me, not with you (unless we have agreed this in advance).

- You may need to be assertive in a situation where other people are talking fast or across each other, so that I can join in. But you should assert my communication needs and not join in the conversation yourself.
- Recognise that sometimes a disabled person may not be used to having choices, or expressing their opinion. You can help by facilitating communication.
- Don't assume that the only things I want/need to communicate about are to do with the assistance I need ('personal care'). I am a full human being and there's all sorts of things I need to explore, share, question and argue about.
- Treat me with respect, in the same way you would want to be treated if you were in my position.
- Respect my privacy – you will probably find out more about me than anyone other than your nearest and dearest knows about you. This is only because I need assistance in order to go about my daily life. Don't share information about me without my consent.
- Be honest about what you find difficult. Together we can sort things out.

We hope you have found these notes helpful in letting you know what we need. Of course, training does help and we are campaigning to ensure more is available for you – and that some of it should be delivered by people like us, since we are the ones with the experience.

The experienced personal assistant/ support worker's view

This final section is written by non-disabled people who are employed by disabled people like us, or by charities and agencies, and who have a lot of experience in facilitating communication.

SANDY AND SHARON

Community support workers in a bungalow complex for people with high levels of support needs

We both came into this work with no previous experience and no particular training in communication issues. We didn't know any disabled people before. When you bring no experience with you, and there is no training, obviously you feel anxious. Gradually you get to know the service users, and you ask the staff who have been there longer for help. Everyone communicates in some way – it is just a matter of finding out how. Sometimes you do feel rude – staring at people's faces to work out their yes and no, for example, or asking people to repeat themselves over and over. But giving people time is the most important thing. They do not mind how many times you ask them to repeat something as long as you are listening and can catch it. You just have to be very patient.

We find people can be very rude to the disabled people we work with, especially talking over them, or to us rather than to them. It is up to us to tell the person – the doctor, or whoever – to speak directly to the service user, and if necessary, to interpret what they are saying. This means you need to be quite confident with the public.

We have found it has really helped our service users to be involved in communicating about real issues, rather than just daily care. It increases their confidence, and helps them develop all sorts of other interests. Everybody needs to chat and have a laugh, and to be able to talk about what is going

on in the news, personal relationships, feelings, family and all their interests.

We would say that the most important things are positive input from your manager and recognition that communication takes time and patience, learning to understand a range of communication methods used by residents, learning to respond to body language, and not being put off by a range of sounds which at first sound strange or disturbing. Don't be frightened, don't think it is necessarily going to be all that difficult. Always be prepared to ask for help. Sit down at people's level. Get the angle right – people might not be able to turn their heads to use their eye contact. Be flexible. Don't forget to ensure privacy and confidentiality. Let people take their time – if you rush things, you might only catch half of it, and the consequences could be very frustrating, or even serious, for the service user.

AMANDA

Previously a team leader of community support workers at a residential home for people with high levels of support needs

I came into this work first of all by working at a day centre for people with learning difficulties. It was quite disorientating. I felt embarrassed by not being able to understand people. I ended up working on an emotional level with people, trying to communicate with people through body language. Service users would make physical contact, like tugging at your clothes if they wanted something. Or you might see aggression, like throwing things, if they could not get attention in any other way. This then got seen in a very negative way – as challenging behaviour or worse. They were receiving no assistance in developing positive forms of communication. There was a lot of frustration because they felt no-one was taking any notice.

No-one ever really talked about communication as an issue. Social services never referred to it in their briefings to you: you were just told you were to work with someone who couldn't communicate. They only said to you, 'If you get stuck, ask another member of staff.'

The problem with this was that assumptions got passed down from staff who had been there a while to new staff. 'Oh, when he does this he means this', and so on. It was like folklore. Things from people's case notes – things that professionals said in the past – were passed down from staff to staff. No-one, like speech and language therapists, came in to give us any advice or work with the service users. In fact, hardly any 'outsiders' were getting involved with the service users. This was a severe restriction on the development of their communication.

By working in this setting I began to understand the crucial role communication plays in the lives of human beings. You absolutely need to convey your thoughts and feelings. All the behaviour that gets labelled challenging – in practically every case – is frustration that people do not understand what you are trying to communicate.

I have constantly been in situations where service users are surrounded by people chattering away over their heads and then saying, 'Oh sorry, I forgot about you, so let's just pretend to involve you for a few seconds, make lots of small talk and silly banter that passes for communication, basically treat you like you were five.' It's always, 'Oh, you're in a bad mood', or 'You've got bad behaviour.' It's never: 'You must be so frustrated with us that we can't understand, or that we are behaving in this excluding and patronising way.'

No-one ever sat down with me and said, 'These are the skills you are going to have to learn.' I just fell over communication aids by accident. Technology was very frightening to a lot of staff. You might have one or two who had been selected to do some training on the machines, and then they were supposed

to cascade it to the others, but that rarely happened. So the service user might get to use it for one hour a day when that person was around and then it was back to 'What do you want to drink?' So they might have technology, but it was hardly ever used effectively.

There are very important skills to be learned. Sometimes service users will give up on their communication aids and this might be for all sorts of reasons. One might be that using the aid has meant they get less one-to-one attention from staff, especially if their primary relationship is with a keyworker. They have become institutionalised into this dependency and it is very hard to give up. We need training on how to empower people out of this trap. Also what is the point of learning the technology if all people are going to converse with you about is small talk or domestic issues? There has to be a reward for making all that effort.

You have got to start from the view that the service users are going to have the same needs as everyone else even though their horizon might have been shrunk by being institutionalised or through low expectations of their rights. What might they be feeling? Try to imagine what life is like for them, and what it could be like. You need empathy, not sympathy. How would you want to be facilitated in this situation? Staff need to be supported to get beyond the charity view of disabled people. It's so much more than looking after people, caring for them. See the priorities in your own life and assume service users have the same kinds of priorities, or would if they were properly facilitated.

It may mean staff have to change, It could mean giving up that comfortable 'special relationship' keyworkers have built up with service users when it leads to too much dependency – after all, if your keyworker is the only one who understands you properly, how much good is that when he or she is just not around?

There is a key difference between communicating with a disabled person and facilitating their communication. They are both important of course, but if you have assisted the person to develop a whole range of skills and contexts in which to communicate, you will have helped expand their world, and given them the opportunity to get beyond the limits which have been imposed on them.

MARY

Community support worker working with people in a residential home who have high levels of support needs.

We are here to empower people. And unless we pay attention to communication needs, people are unable to be empowered. If they have not got the means to communicate, you will forever be putting words into their mouths. They are dependent on you asking questions, suggesting, narrowing the questions until you get to it, but obviously you cannot get inside their heads so if you do not happen to come across what they have got in their mind, they are stuck with no means of expressing it. So communication is vital.

Most people I work with have a yes and a no, and can use eye pointing, facial expressions or body language, but the more under stress they are, the more agitated they become, and the more likely it is we won't understand. And the reason they are stressed is that it is something they really need to get across, or something they are upset about, and that can be very difficult to get to the bottom of.

Sometimes it might take a couple of days to find out what someone wants to tell you about. With one of the service users, he will find a word on his board or his talker, but out of context it is hard to know exactly what he means. His grammar is restricted by his machine, or he might use the word in an unusual way you cannot at first catch on to.

I might question him for a while, but if I still cannot get it, I'll say, 'Can you give me another word?' He might just come back to the same thing, so I'll say I will keep thinking about it. It might be a couple of days later when I'll think, 'Oh that's what he means,' and go back to him and carry on from there.

Technology does give people a wider scope, but it can also be restricting – as people's skills develop, so you need to update the vocabulary and so on, on a regular basis. Staff need support and training to be able to do this. This same service user likes his board updated with jokes. As they move up the levels, increasing their skills, staff need the training to be able to move up as well.

As far as speech interpreting for a service user goes, you have to learn to sit back and just say what someone is saying without putting in any of your own stuff. This should be easy – but it isn't. I have seen it done, and I was very impressed. When you are out with someone, you have to understand the role of enabler and facilitator – it means 'stepping back', being a presence, a comfortable presence, and friendly and sociable, but it is not your occasion. You are not intruding, not taking over. If things are flagging and nothing much is happening, it is not your role to step in, however tempting that might be. And of course service users are just not used to receiving that kind of facilitation. It takes both of you a lot of practice. It is a vital skill for both of you to have if a service user is going to get out and about in the real world. If you can act as a speech facilitator you are providing a flexible communication aid which adds to the client's choice of where and how they want to communicate.

I am very interested in technology, and can see both its liberating effects and its drawbacks. That is why I try to have a range of skills. When I'm communicating with people using machines, I can see that people who are in fact able to think in complex and abstract ways can at first be reduced to a kind of pidgin English with their machines, especially at the lower levels of learning the programmes. As they move up the

levels, the language they can use is more sophisticated, but it requires a lot of practice. But once you have got the core meaning of the icons, you can move around a bit. For some people just making one selection is very time-consuming. But at a conference I went to, one young man gave a presentation using his Delta talker about the difference his communication aid has made to him. It is possible to pre-program, and then switch to speak. Then hit the pause, and directly communicate the next part, and so on. He could cover a wide range of contexts in this way. Also people can include video. The only restriction is effort and time. The technology is there for people, if only they can access it.

RAY

Personal assistant employed directly by Bob, who lives independently in the community.

I've been working for Bob now for over 10 years and Bob uses a qwertyuiop [alphabet] board which he has had since he was at school. It's the quickest form of communication he has got and he never has any trouble using it. He usually has it on his desk in front of him when he is at meetings and I sit to the left of him. When he wants to say something I read the words out on his behalf.

Sometimes it is hard as he is often overlooked in the conversation, and when he does get in, the topic has moved on. But most people at meetings try to bring Bob in as much as they can and are able to read the board themselves OK if they are sitting near enough.

When we're out and about he usually communicates by having his board on his lap. He finds this is the quickest way, better than any new machines. This is the best way for him and for me to communicate on his behalf.

SHARON

Personal Assistant employed directly by Marianne, who lives independently in the community.

I had never been involved in this kind of work before so did not really know what was expected of me. But I found having a genuine interest in other people helped. I must admit I was a little uncomfortable at first as I thought Marianne might be upset because I could not understand her. But I decided the best approach would be to say, 'I'm sorry I can't understand yet, but I am going to try.' As we got to know each other I found it helped me if we were relaxed and in a quiet place – that made it easier to really listen and watch facial gestures. I began to understand and would relate back what she had said, just to make sure I had heard correctly.

Having a sense of humour helped too. Many times I got it wrong and we would end up laughing about it. On one occasion I thought Marianne had asked for a thick sweater, when what she had actually said was, 'My throat's feeling better.' After a while it became much easier and I found I could understand without watching Marianne's face.

When I started to accompany Marianne to meetings, we were both a little unsure about how we should work together. Over a period of time I gained confidence and put into practice suggestions from others. I now usually sit opposite her and interpret a sentence at a time, or she will look my way if she wants me to speak. I think I also spoke too quietly at first, but have now learnt to throw my voice so everyone can hear.

I help Marianne communicate in all sorts of situations as she leads a very full life, so I speech facilitate for her not only at work or meetings but also in social settings or over the phone. Marianne also has a Chameleon which is a laptop computer with an electronic voice box on top. She finds this useful in preparing or giving talks. I have learnt to set this up for her by having practice sessions at home. This has been beneficial

for us both. In everyday conversation though we both find it easier and quicker if I interpret for her.

I have learnt a lot from working with Marianne. I know I don't have to be embarrassed if I don't understand what someone says immediately. There is always a way to communicate if you look hard enough for it. That may take time and patience. But it is time well spent as it enables individuals to access their rights and interact with others fully.

LETITIA

Personal assistant employed by Maresa, who lives at home with her mother and goes to college.

A personal assistant needs to be flexible. For example, at college I sometimes need to enable other people to chat to Maresa and sometimes I need to fade into the background. I have to be able to pick up on Maresa's mood – whether she's tired and just wants to listen to other people chatting or whether she's got loads of energy and wants to join in. When Maresa and I chat together in public I'm also modelling for other people how they can chat to her using her particular method of communication. How I behave with Maresa can show other people how 'normal' it is for someone like her to be there – at college or wherever – which is something that many people have to learn because most of them haven't come across someone like Maresa before.

It's important to recognise that there will be bad days and to not take it personally. Maresa shouldn't be responsible for my feelings. You have to be a good listener and be prepared to do what the young person wants you to do.

Useful references

As we said at the beginning of this booklet, there is very little advice and information available for personal assistants and support workers working with people with communication impairments. The following resources and organisations are concerned with communication impairment generally. The organisations' own words have been used, where possible, to describe what they do.

Augmentative Communication in Practice: An Introduction

Overview of alternative and augmentative communication, covering both low-tech and high-tech methods, concerning both children and adults. Available from:

The CALL Centre
Paterson's Land
Holyrood Road
Edinburgh EH8 8AQ
Tel: 0131 651 6236
call.centre@ed.ac.uk

Blissymbolics

A communication system using abstract symbols, accessed through a board or book, or computer-assisted systems. More information from:

Blissymbol Communication UK
c/o Gillian Hazell
ACE Centre
92 Windmill Road
Headington
Oxford OX3 7DR
Tel: 01608 676455
Hazell@ace-centre.org.uk
<http://home.istar.ca/~bci/>

Communication Matters 'is a UK national voluntary organisation of members concerned with the Augmentative and Alternative Communication (AAC) needs of people with severe communication difficulties. It is also the UK Chapter of the International Society for Augmentative and Alternative Communication (ISAAC) and is a core member of the Communications Forum.'

Communication Matters
c/o The ACE Centre
92 Windmill Road
Headington
Oxford OX3 7DR
Tel: 0870 606 5463
Fax: 0131 555 3279
admin@communicationmatters.org.uk
www.communicationmatters.org.uk

Communication Matters Leaflets:

Communication Matters produces a series of short leaflets, *Focus on:*
Accessing communication aids and computers

First Steps

How to be a good listener

Using symbols for communication

What can I say?

What is AAC?

See above for contact details.

Communication without speech: augmentative and alternative communication

'This ISAAC book, written by Anne Warrick, is a highly accessible but very comprehensive introduction to Augmentative and Alternative Communication.

It contains lots of questions and practical tips such as vocabulary selection, assessment, education and vocational considerations, making communication boards, and includes excellent photographs and illustrations.' £15 plus £1.50 p&p from **Communication Matters** (see above).

Don't hang up 'is based on a study which showed that the telephone is an under-used and often overlooked resource for people with communication difficulties and their carers. The package, which consists of a workbook and a video, is intended to be used as a practical tool to help people with communication difficulties use the telephone better'. £35.00 from:

AAC Research Unit
Dept. of Psychology
University of Stirling
Stirling FK9 4LA,
Tel: 01786 467645
Fax: 01786 467641
joan.murphy@stir.ac.uk

Foundation for Assistive Technology

‘The FAST database comprises a comprehensive index of assistive technology (AT) research and development, equipment manufacturers, researchers, charities, funders and other organisations. There is also a calendar of AT events. Users of AT are invited to submit an ‘I wish’ for equipment they need that is not currently available.’

FAST

Mary Marlborough Centre

Windmill Road

Headington

Oxford OX3 7LD

Tel: 01865 227599

Fax: 01865 227294

info@fastuk.org

www.fastuk.org

Improving Augmented Communication within an Organisation: A Workbook

‘This book is one of the outcomes of a research project which studied the interaction of adult AAC users in a residential setting. The findings are presented in the form of a workbook containing information from the researchers, the AAC users involved, their peers and staff. It contains information about 22 issues which emerged as being significant for

the interaction of AAC users.

Each issue is presented in three ways: firstly, from the perspective of the researchers’ observations; secondly, commented on by residents and staff during detailed interviews and finally in the form of a set of recommendations. These recommendations (154 in total) will be of value not only to AAC users but also to other people with disabilities, to the staff and carers who work with them and especially to managers. The workbook can be used in many different ways – e.g. simply for discussion in a one-to-one setting or in a group; for awareness raising; for training purposes. In its entire form it could be taken on as a standards document of an organisation.’

£10.00 from:

AAC Research Unit

Dept. of Psychology

University of Stirling

Stirling FK9 4LA

Tel: 01786 467645

Fax: 01786 467641

joan.murphy@stir.ac.uk

Makaton Vocabulary Development Project

‘Makaton is a unique language programme offering a structured, multi-modal approach for the teaching of communication, language and literacy skills. Devised for children and adults with a variety of communication and learning disabilities, Makaton is used extensively throughout the UK and has been adapted for use in over 40 other countries.’

31 Firwood Drive
Camberley
Surrey GU15 3QD
Tel: 01276 61390
Fax: 01276 681368
mvdp@makaton.org
www.makaton.org

Multimedia profiling

A multimedia profile ‘is a computer-based audiovisual diary (video, photographs, sound, graphics and text) of a person’s daily activities and personal history... It is an empowering process that builds more equal relationships – increasing awareness of non-verbal communication to open up a deeper, user-led engagement with individual experiences and personal expression.’
Information available from:

Acting Up
Unit 304
Mare Street Studios
203-213 Mare Street
London E8 3QE
Tel: 020 8533 3344
Fax: 020 8533 5511
acting-up@geo2.poptel.org.uk
www.acting-up.org.uk

Personal Communication Passports

CALL (see above) has developed and pioneered *Personal Communication Passports*, a new way of documenting and presenting information about children and adults with disabilities who are unable to speak for themselves. Passports are being developed in a number of pilot sites. The CALL Centre in Edinburgh (Communication Aids for Language and Learning) provides specialist expertise in technology for children who have speech, communication and/or writing difficulties, in schools across Scotland.
<http://callcentre.education.ed.ac.uk>.

**Royal National Institute
for the Blind (RNIB)**

105 Judd Street
London WC1H 9NE
Tel: 020 7388 1266
Textphone: 0800 515152
Fax: 020 7388 2034
helpline@rnib.org.uk
www.rnib.org.uk

**Royal National Institute for Deaf
People (RNID) Leaflets:** (available
on the website or through the post)

The RNID produces a number of useful leaflets both about deafness and hearing impairment and about the different communication requirements of people with hearing impairments. Some examples are:

Communication services for deaf people: outlines the different types of communication support that might be needed by someone who is Deaf or hearing impaired.

Basic British Sign Language:
100 illustrations of sign.

Communicating with deaf people who lipread

Working with a Sign Language Interpreter

Working with a lipspeaker

Working with a speech-to-text reporter.

Lipreading – practical information

Learning British Sign Language.

RNID

19-23 Featherstone Street
London EC1Y 8SL
Tel: 020 7296 8000
Textphone: 020 7296 8001
Fax: 020 7296 8199
informationline@rnid.org.uk
www.rnid.org.uk

Talking Mats:

A low-tech framework to help people with communication difficulties express their views.

‘Talking Mats is a framework which uses picture symbols to help people with severe communication difficulties communicate about particular issues relevant to them. It has potential for a wide range of people, both children and adults. It provides them with a means of expressing their views more easily and is an approach which may help them to think about issues in a different way. The package includes a booklet explaining how to use the mats, as well as several pages of examples to get you started. There is also a video accompanying the booklet which shows how three people used the Talking Mats.’

The package can be purchased by sending a cheque for £23.00 made payable to ‘The University of Stirling’ to:

AAC Research Unit
 Dept. of Psychology
 University of Stirling
 Stirling
 FK9 4LA
 Tel: 01786 467645
 Fax: 01786 467641
joan.murphy@stir.ac.uk
[www.stir.ac.uk/Departments/
 HumanSciences/Psychology/
 aac/TM.htm](http://www.stir.ac.uk/Departments/HumanSciences/Psychology/aac/TM.htm)

Most of the information available about personal assistants is for the disabled person who is going to be employing the personal assistant. The best guide like this is:

Everything you need to know about getting and using direct payments

free to individuals and available from:

National Centre for
 Independent Living
 250 Kennington Lane
 London SE11 5RD
 Tel: 020 7587 1663
 Fax: 020 7582 2469
 Minicom: 020 7587 1177
ncil@ncil.org.uk.

Personal Care Assistance Pack

This is aimed at people with learning difficulties and contains two guides:

Selecting Personal Care Assistance

This is a step-by-step guide to organising Personal Care Assistance. The book covers essential information, such as funding, recruitment and interview strategies. £12.50

Becoming a Personal Assistant

This guide looks at all aspects of this type of work, including the kind of personal qualities and the level of commitment needed to become a successful Personal Assistant. £10.00, or buy both for £20.

Available from:

National Development Team
 Albion Wharf
 Albion Street
 Manchester M1 5LN
 Tel: 0161 228 7055
 Fax: 0161 228 7059
office@ndt.org.uk