



Supporting people who have Down's syndrome to overcome communication difficulties

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information

Supporting people who have Down syndrome to overcome communication difficulties:

information for schools and colleges, community groups and services, employers, care staff, professionals, and families about what we can all do to tackle the challenges that people who have Down syndrome face when communicating.

People who have Down syndrome face particular challenges when communicating, which affect just about every aspect of life- relationships, learning, participation, independence. In spite of these difficulties, many people who have Down Syndrome are strongly motivated to interact with others, and become skilled and successful communicators using whatever means is effective: actions, facial expressions, gesture and sign language, or words, phrases and sentences.

This leaflet has been written to support you to communicate successfully with people who have Down syndrome. It discusses some of the challenges faced by people who have Down syndrome, and suggests strategies we can all use to overcome communication difficulties so that we can....

- Spend time getting to know each other, and treat each other with respect,
- Listen to what people who have Down syndrome tell us about their lives, interests, concerns and joys,
- Share information about ourselves,
- Enjoy each other's company.

“People with Down syndrome live, laugh and love just like regular people, only with one extra chromosome.”

Christopher Burke, American actor who has Down syndrome, National Down Syndrome Society (USA) website

Most of us have 23 pairs of chromosomes in every cell of our body, which carry genetic information that shapes who we are: appearance, personality, skills and interests. One copy of each chromosome is inherited from our biological mother and father, so that we have 46 chromosomes in total. People with Down syndrome have an extra copy one of these chromosomes: they have three copies of chromosome 21, and 47 chromosomes altogether, in all or some of the cells of their body. Having Down syndrome makes people differently able: with the extra copies of chromosome 21, comes increased difficulty doing some things, alongside stronger skills in other areas.

“We need people to focus on our abilities and capabilities”

Mitchell Levitz, Editor-in-chief of a newsletter called the Community Advocacy Press, who has Down syndrome, in “Down Syndrome A Promising Future, Together”.

People who have disabilities are skilled at many things, but we can fail to notice this when we focus on difference and challenges, instead of recognising the personality, qualities and skills of each individual.

We notice disabilities when people are unable to take part in some activities and experiences that most of us can access with ease. It's the world around us that makes people dis-abled, when situations require someone to do things that are not possible for

that individual. Making small changes to the situation can completely remove these difficulties!

Instead of focusing on things that someone can't do, people who have disabilities encourage us to think about assets:

- Personality and interests: the qualities and motivations that each person brings,
- Abilities: what we can do, the skills we have and the areas in which we are proficient,
- Capabilities: what we could do, with adjustments to overcome our limitations, and opportunities to master new skills.

This enables us to work out what we need to do to reduce or remove experiences of disability, and to identify a role for everyone.

- Designing buildings with ramps and lifts, as well as stairs, makes them accessible to people with mobility problems.
- In museums and art galleries, exhibits and captions that can be touched make exhibitions meaningful for people who cannot see.
- An employer might consider that a Deaf person cannot do office work due to difficulties in handling phone calls. The employer can make good use of the person's skills by designing a role that includes filing, word processing, photocopying, responding to emails, with another member of staff assigned to deal with phonecalls.
- A young man who has Down syndrome and difficulties in producing clear speech expressed a wish to progress from working in the stock room to working on the shop floor of a DIY store. He was able to work as a "greeter" in the store, following support to identify key phrases such as "good morning, can I help you?", and to master how to say them clearly.

As a community, we are becoming skilled and knowledgeable about how to overcome the difficulties faced by people who have disabilities. We now need to get on with putting solutions in place. The Disability Discrimination Act provides a legal framework to compel businesses, services, and employers to make the necessary changes. It states that it is against the law for service providers to treat disabled people worse than they treat other people, and says that service providers have to make reasonable adjustments so that disabled people can use their services and buildings.

For guidance on how to do this with regard to the communication difficulties experienced by people who have Down syndrome, read on....

Changing the way we think about Down Syndrome

Most people recognise when someone has Down syndrome from their facial features and body, so the way they interact is immediately influenced by their knowledge and beliefs about Down syndrome. These are often based on outdated or incorrect information- this leaflet sets out to make sure that your knowledge is **accurate** and **up to date!**

People react in various ways to difference and disability. They may avoid contact because of embarrassment, or may be over protective, insisting on helping even when support is not needed. For each of us, it takes **time** and **experience** to feel comfortable about being with people who have disabilities, and to develop confidence in our ability to act appropriately and communicate with people who have Down syndrome.

Stereotyping and generalisations that circulate, such as “people with Down syndrome are funny and affectionate”, are not helpful. Each person who has Down syndrome is a unique individual: we need take opportunities **get to know the person**.

Understanding the challenges faced by people who have Down syndrome

“I feel sure that the majority of young people (who have Down syndrome) could be more like those we consider the most able at present, given family love and support, appropriate education and acceptance in the community.”

Professor Sue Buckley OBE, Emeritus Professor of Developmental Disability (Department of Psychology), and Director of Research and Training Services, The Down Syndrome Educational Trust, Sarah Duffen Centre at the University of Portsmouth, UK, in “Living with Down syndrome: Down Syndrome Issues and Information”

Many experts comment that other people’s attitudes have the biggest effect on the lives of people who have Down syndrome. Low expectations and lack of opportunities restrict possibilities for developing skills and having a fulfilling life.

Historically, people with Down syndrome have not had opportunities to maximise their skills and independence. Improved healthcare and advances in education during the past two centuries to have lead to better lives for much of the world, but people with learning disabilities have not fully shared the benefits.

Poor health care and living conditions shortened lives: in 1900, the average life expectancy in the United Kingdom was 47 years. For people who had Down syndrome, it was just 7 years. By the 1950’s this had increased to 69 years for the general population but only 15 years for people who had Down syndrome. Only recently has the life expectancy for babies born with Down syndrome matched the life expectancy for babies who don’t have the extra chromosome.

“When I was born in 1968, the doctors said that my life would not have much value because I was born with Down syndrome. They said that I might not talk, I would not walk before age 3, and the average life for children born with Down syndrome was only 12 years. They also said I could never attend ... school and an institution would be an appropriate place for me.

Fortunately, my parents did not listen to the doctors...”

Christi Todd, courtesy clerk, gymnast and public speaker who has Down syndrome, in “Down Syndrome A Promising Future, Together”.

From around 1850 until the 1960’s, governments made arrangements for people who had learning disabilities to be shut away in institutions that denied basic human rights. When families rejected this option, and people who had Down syndrome remained within communities, opportunities were still severely restricted. As a group of people who were recognised from their physical appearance, and believed to have limited capacity for learning, people with Down syndrome received little, if any, education. They experienced few opportunities to take part in society and were raised to expect and accept the position of second class citizens. Professionals had little knowledge of their true potential, and advised families to have very low expectations. We don’t know of any positive self images and role models for people with Down Syndrome during this period.

It’s only since the 1970’s that the right to education, to comprehensive healthcare, to make decisions and choices about life, and to be treated with as equal citizens are gradually

being established. So we don't yet know what the possibilities are for people with Down syndrome who enjoy opportunities and respect parallel to the rest of us! Estimates of the average intelligence of people with Down syndrome have steadily increased over the last 60 years, and each generation of parents, teachers and professionals have raised their expectations, reflecting the enhanced achievements of the previous generation of people who have Down syndrome.

“They have always said that people with Down syndrome would not learn very much. When I was eleven years old, my teacher wrote in my report that 'We should not expect too much of Ruth'; but I want to show people that they are wrong about me having Down syndrome: I had that feeling inside me that I can do things.”

Ruth Cromer, Australian actress and office worker who has Down syndrome, in “Living with Down syndrome: Down Syndrome Issues and Information” from the Down Syndrome Educational Trust

Having Down syndrome gives rise to distinctive talents, such as being skilled at engaging others and recognising visual patterns. It makes certain tasks more difficult than for other people, including speaking, and remembering lists. It's important to understand the physical and learning challenges that people who have Down syndrome face, so that we can take steps to minimise their impact. There is a great deal of variation in the skills and difficulties faced by individuals who have Down syndrome, reflecting the challenges that each person is born with, as well as the opportunities and support to master skills that each person has had.

Health issues and physical disabilities

There are a number of conditions that people who have Down syndrome are more likely to experience than people who don't have the syndrome. Some people with Down syndrome will experience few of these. For others, a number of different challenges will affect just about every aspect of life.

- Hearing problems: more than 1 in 2 people with Down syndrome have a significant hearing impairment that requires management by health professionals. Most people who have Down syndrome will experience hearing loss some of the time due to congestion of the middle ear. Up to 20% may have permanent hearing loss, resulting from problems with the functioning of the ear and auditory nerve.
- Impaired sight: The same eye problems which can affect all of us tend to occur more frequently, and sometimes to a more marked degree.
- Difficulty in co-ordinating movements are associated with anatomical differences, such as having short fingers and smaller mouth cavities, as well as less efficient automatic planning and execution of movements.
- Reduced energy levels, which may be associated with abnormalities in the structure of the heart and/or gut, thyroid problems, and other medical conditions that occur more frequently amongst people who have Down syndrome.
- Longer or more acute periods of ill health with the usual coughs, colds and stomach upsets that go around.

Be aware of the physical challenges each person with Down syndrome faces, and take the necessary steps to reduce the difficulties: for example, fixing a coat hook at a height that is

easily reached, finding a chair or foot block that allows the feet to rest on a stable surface when sitting down.

The impact of sensory impairments, physical disabilities and health problems are increased when people who have Down syndrome don't get the best medical care and support that is available. For example, someone who has Down syndrome might not get glasses because the optometrist doesn't know how to carry out eye tests with people who have limited language and reading skills, and can't recommend the correct prescription.

Professionals can fail to recognise the presence and impact of these conditions because they accept that people with Down syndrome have impaired skills, without looking for causative factors, like visual difficulties, that can be addressed. If you know someone with Down syndrome well and have insight into their aspirations and needs, then you're in a good position to **advocate**- that is, speak up to assist them to get the support that they need.

Learning Disability

Virtually all people who have Down syndrome have a learning disability: it takes more time to think things through, and it takes longer to learn new skills, because of difficulty in processing certain types of information. People who have learning disabilities master new skills when tasks and new learning are tackled in appropriate ways, which include:

- breaking learning down into small manageable steps,
- ensuring there is plenty of time to process information and respond,
- making sure that there are lots of opportunities to learn and practice new skills,
- taking into account the specific strengths and challenges that each person faces.

Cognitive skills or IQ- "intelligence quotient" varies between individuals who have Down syndrome, just as it varies in the rest of the population, so there will be differences in the type and level of support that are helpful each person.

Spoken language and communication skills

Language is an incredibly rich and complex code, and the human brain has developed sophisticated ways of handling language. But understanding and using spoken language presents enormous challenges when the language processing mechanism doesn't work so well. People who have Down Syndrome experience specific difficulties with using and processing spoken language.

People who have Down syndrome are usually able to understand far more than they can express, and make good use of words and/or signs to get the message across. As with other people who have learning disabilities, they have difficulties in understanding when a lot of information is presented quickly, and when more complex language is used. Over and above challenges associated with learning disability and hearing loss, there are further difficulties with language:

- Unclear speech is associated with challenges in making the complex series of movements that are required for speech production, an in learning the sound structure of words, and because of problems in hearing and reproducing the sound structure of words.

- Difficulties in putting ideas into sentences are associated with reduced short-term auditory memory span, not knowing the vocabulary needed, and difficulties with language structure.

There is wide variation in how individuals who have Down syndrome communicate: some may use full sentences containing lots of information, but may struggle to maintain speech clarity and put more complex ideas into language. Others will use words linked together to get across the general ideas, but may not be able to give an account of what happened, or talk effectively about plans and feelings. People who have great difficulty with speech production may use gesture and sign language. Some people who have Down syndrome communicate mainly through actions, facial expression, and responses to others, rather than using a form of language.

With the right sort of support, people who have Down syndrome can develop more effective communication skills and overcome some of the specific difficulties that they experience with spoken language.

Getting the setting right makes communication a whole lot easier!

Often communication becomes a much harder task than it needs to be because of when and where we choose to have our conversations. Get rid of distractions- by turning of the radio or TV for a while, waiting until you're sitting down before starting a conversation, finding a quiet place for a chat instead of trying to talk in a corridor or communal area. Make sure that you have gained each others' attention before you start the exchange, through calling by name, and touching the arm, or a child's face.

For people who have a *hearing loss*:

- It's even more important to minimise background noise and other distractions.
- Position yourselves face-to-face where there is plenty of light, to maximise visual cues.
- If you tend to use a quiet voice, raise your voice slightly.

Be aware that people who have *restricted vision* may miss information that you pick up with your eyes- like who is present in the room or toys available in the playroom. You can address this by bringing items to where they can be seen, and making sure that:

- There is good lighting
- The person with visual problems can adjust the position of the item to make it easier to see
- You point out important things, and show and talk about them.

Adapting the way that you communicate

There are three powerful changes you can make to how you communicate, to overcome communication difficulties:

- Make communication **visual** to overcome difficulties in understanding and using spoken language: use actions, mimes, gestures, signs, pictures, symbols, objects and written words, as described in the next section. Make it possible to reply using means other than spoken language, for example, choosing by taking one of the objects offered, or pointing to words or pictures, instead of just talking about it.

- **Slow the pace of conversation**, and **give plenty of time to respond**: slowing down means there's more thinking time available, and the possibility of processing and responding to each piece of information. Check to make sure that the other person has finished telling you what they want to say, before you take your next turn in the exchange.
- **Break information down into chunks**: because language is so sophisticated, it allows us to convey a lot of information in just one sentence: "What a shame, if I'd have known it was James's birthday, I would've brought a cake". Sentences like this use complex language structures and don't give much time to process the information. So giving the same message through a series of short sentences is really helpful: "It's James's birthday? I didn't know it was his birthday today. I bring cakes for people's birthdays. I didn't know about James's birthday, so I didn't bring a cake. I'm really sorry about that". If someone has difficulty in understanding what you tell them, then it's helpful to repeat the message, and break it into smaller sections.

Making communication visual

Because people who have Down syndrome are particularly skilled at dealing with visual stimuli (things that we see) and encounter difficulties with auditory processing (dealing with things that we've heard) and language processing, it's really helpful to make messages visual: that is to **show, as well as tell**.

Make good use **body language and facial expression** when you're communicating; **tone of voice** conveys extra information as well.

Use your hands to get across your message: **pointing, and demonstrating through actions, mime and gesture**, add masses of information to spoken language. Taking this one step further, using **signing** makes spoken language into a visual language that can be processed more efficiently. Organisations like Signalong and Makaton publish resources that support people to learn and use selected signs from British Sign Language- the natural language of the deaf in the UK- with people who have communication difficulties. Families of babies can also learn these through "baby signing" groups and videos. More and more people are finding that learning some signs is fun and easy, and goes a long way to overcoming the problems that occur when people have difficulty with spoken language.

Nearly everyone finds that **picture based illustrations** make it easier to understand information, and help us to grasp information more quickly (as when you look at a diagram showing how to assemble something) and remember it more easily (like when we use charts and diagrams to help us to memorise information). With illustrated information leaflets, and the internet, it's now possible to find an illustration of just about anything and cut these out or print these off to show what you're talking about. **Symbol systems** use standardised pictures to represent things, and software enables us to type in a word and call up the corresponding symbols, for example, using Rebus or Makaton or PCS symbols with Symbols for Windows or Boardmaker or Writing with Symbols software. We can use these to :

- make schedules displayed using pictures/symbols,
- illustrate options to support choice making,
- make illustrated lists of "things to remember"
- show step-by-step instructions.

Objects are very effective at conveying information. When we come home to find carrier bags that weren't there in the morning, we know that someone's been shopping. We can use objects to signal activities: getting out the baking trays and biscuit cutters to communicate that today's task is biscuit making. A "here's one I made earlier" approach helps e.g. "let's check what Joe has packed to give you some ideas about what needs to go in your suitcase". We can use objects to signal tricky aspects of tasks: using a carpet square to show a child where to sit on the classroom mat; leaving out 7 packing cases to signal that 7 items must be prepared for consignment; or making a tool board with silhouette outlines to show where each item belongs.

Does our communication do what it needs to do?

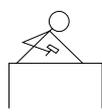
When we spend time with people who face difficulties in communicating, we have to find ways of communicating that enable us to meet each other and sustain our relationship. If you work with, meet, or know someone who has communication difficulties, you need to find and use effective ways to fulfil the fundamental functions of communication:

1. **Greet and acknowledge each other:** through touch, making eye contact, and meeting at eye level: perhaps standing up from your desk, or kneeling down if necessary, as well as more standard greetings like saying hi and good morning, shaking hands, or asking "how are you?".
2. Enable both partners in the communication to **make their wishes known and share thoughts and feeling**, perhaps through actions and sounds and laughter, facial expression and body language as well as by speaking to each other.
3. **Share information about our lives and what's happened to us**, as when children show a sore knee, adults pass round their holiday photos or family snaps, and in conversations that start with "you won't believe what happened to me today..."
4. **Communicate choices and options**, so that can make the decisions that make us who we are: little things like how strong we like our tea and who we spend our break times with, as well as the big decisions about to what we do with our time and who to spend our lives with.
5. **Share information about what's going to happen:** it's very isolating to be with a group of people who know what's happening, but you find yourself waiting and wondering what's going on. Setting up some consistent routines can be really helpful, especially if this includes starting by meeting to say hello and talking through plans. Alongside this, change and new experiences are a vital part of life so it's important to find ways to give warning and explanation about one-off events and changes to routines.

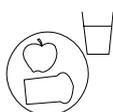
The sequence of activities, and any changes for the usual routine can be presented through picture timetables. It's best to present the steps in the order in which they will happen: "first..., next..., then....".



breakfast



work



lunch

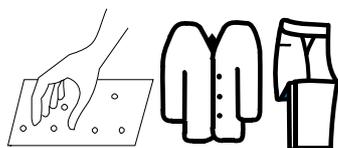


shopping

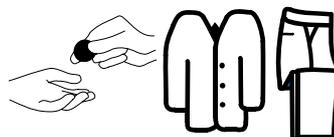


home

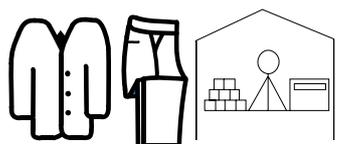
You can show pictures of what will happen in new situations: having a look at a leaflet with pictures of your destination for a trip, or explaining how hiring a suit differs from buying a suit.



choose a suit



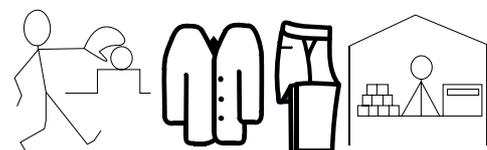
pay for the suit



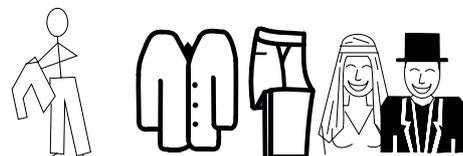
leave the suit at the shop



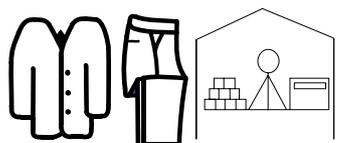
wait for the wedding



get the suit from the shop



wear the suit at the wedding



take the suit back to the shop

Conventions of communication that we don't change (but may need to approach a little differently)

“What matters most for me is that people value what I think.”

Mariana Paez, from a transcript of her speech at the Fifth International Down Syndrome Conference

There are many rules about communication that we don't need to change at all, but we may forget to apply them if we feel anxious about overcoming communication problems or simply because the person we're speaking to is someone we think of as “different”. We may need to think through how to be more effective at things we usually do automatically.

Meet and respect the individual: when we communicate with people, we encounter their personal quirks- people who take ages to make their point, or who keep telling the same jokes or stories over and over again. When our relatives and work colleagues do this, we appreciate personalities, and are polite about it or maybe have a gentle laugh- people who have learning disabilities appreciate the respect and humour too!

Be equal partners in conversation: otherwise conversations can end up like lectures, tests or interviews. Everyone should have opportunities and support to give information, to listen and ask questions. The phrases that we use in formal conversations (like job

interviews), or in family discussions, can help to make sure everyone joins in and gets a turn: “did you want to ask any questions?”; “I want to say something about that”; “listen to me”; “wait, it’s Tracey’s turn to speak”.

Value every comment: Every contribution has something to add to the exchange, even if it’s not immediately clear what the message is, or the relevance to the situation or conversation. The comment “Becky give me phone number” might be dismissed with “no she didn’t”, when in fact the meaning behind the comment is “I wanted Becky to give me her phone number” and a sensitive response would be to sympathise. Watch for actions, facial expression, pointing and gesture, and spoken language, and work out what they mean. For example, if someone repeatedly fetches their lunchbox through the morning, you need to work out what this is communicating- could be “I’d really like to eat now” or perhaps “I’m worried that someone is going to take my lunchbox”.

Act on the message: Just as you do with your friends, give importance to each message. When we’re not sure how to respond, we may pretend we haven’t heard or noticed: not helpful! Instead, we need to respond to the message behind the action or comment. If a colleague kept mentioning lunch throughout the morning, we would say things like “you’re hungry today” and “not long now”. If fetching the lunchbox conveys “I wish it was lunchtime now”, then a good response would be to talk about it and look together at the schedule of activities for the day. If it’s about making sure that no one has taken the lunchbox, then you could say, “let’s put your lunchbox here where you can see it, so that you know it’s safe”. In both cases, if you put the lunchbox in a place that is harder to access, then it’s likely that more time will be spent seeking out the lunchbox.

Pay attention when you’re listening: if someone’s speech is unclear or they have difficulty in explaining things, you’ll need to give your full attention to get the message. You may be very skilled at doing two things at once in other situations, but don’t try talking to someone who has difficulties with communication while you’re also busy doing something else. Convey that you’re interested and attentive by looking at the person that you’re listening to.

Make sure that there’s **time for the speaker to complete the message:** It can be frustrating to wait for someone to finish what they’re saying; it’s even more stressful and annoying if someone doesn’t give you time to finish your message, or finishes it off for you, especially if they get it wrong. If it takes more time to get the message, then find the time for it to happen!

Be honest if you haven’t understood: if you don’t get the message, because of difficulties in understanding unclear speech or because you can’t work out why the speaker has said certain words, then say so, apologise and ask for clarification: “I’m sorry, I didn’t get that, can you tell me again?”, or “I think you said ‘Rosie letter’, can you tell me some more?”.

Include everyone in conversation and make sure they’re respected: create opportunities to opt in to family discussions, playground talk, and workplace chats, by:

- gathering or sitting together so that no-one is left out unless they choose to be on their own,
- including each person by giving eye contact and smiling, and involving them in conversation,

- adapting the way that you communicate so that everyone can follow what's said. This might include summarising what others have contributed, for example; "Joan was saying that her mum is ill. Joan's really worried about it."

We all need mates to encourage and support us, and to stand up for us when we're treated badly. You can make sure that any disrespect is dealt with, by commenting if you feel something is out of order, or by raising it with whoever is in charge in schools, workplaces and clubs. Your friendly support will be valued.

Supporting people who have Down syndrome to develop their communication skills

It's not appropriate for everyone to work at developing communication skills: lots of relationships, particularly between adults, are about being equals and not about noticing difficulties and coaching. But if you have a teaching or supporting role, perhaps as a teaching assistant, mentor, tutor, or just as a friend who helps out with these things, there are things you can do in everyday situations and conversations that support people who have Down syndrome to build on their communication skills.

1. Learning new words: throughout life we have new experiences and learn new vocabulary to talk about them. You can support this by:

- showing pictures and/or written words to represent new things, and repeating and practising new words/signs.
- Breaking words down into syllables and clapping the syllables as you say them e.g. mix-ing-bowl.
- Facing each other and encouraging looking so your face and mouth are seen as you say the word (and hands as well, if you use signing).

2. Learning the language needed for new situations: we also learn new language scripts for new situations, for example, what to say when you pick up the phone in a new workplace, or how children negotiate having a turn at checking out their playmates' toys. You can support this by:

- Working out an all-purpose phrases or script to use, and then practising it.
- Writing down the words using written words or symbols, so they can be read back and practised.
- Acting out the situation and prompting use of the phrase: "you say,".

3. Putting ideas into sentences: It's common for people who have Down syndrome to link together some key ideas, without using sentence structure. It's helpful if you can add in the linking words, and repeat back what you have understood, as a sentence. Then move on to replying.

e.g. you hear "Sunday dinner. Roast chicken potatoes"

you say "you had Sunday dinner. You had roast chicken and potatoes." You reply, "Was that at the pub?"

4. Modelling correct sound structure of words: Similarly, when speech is not clear, it's helpful to repeat back the word with the correct sounds, and then reply.

e.g. you hear "I went to the si' pool"

You say "you went to the swimming pool." You reply, "I went swimming on Saturday too".

If you both use signing, it's also helpful to do this for signs that are made incorrectly. You can use your hands to help your partner to make the sign correctly, if they are happy for you to do this.

5. Modelling the correct words: If the wrong word is used, then seek clarification and talk about which is the correct word for the situation.

e.g. You hear “I did karate with the staff room”.

You say, “You did karate **in** the staff room?”.

You hear , “no, with a big stick like this”

You say, “you did karate with a staff, a long stick for fighting like this?”

You hear “yeah, I hold it like this”

You say “I think the staff room is where your teachers go at break time in school. And a staff is a big stick like you use in karate”.

6. Using language to talk about feelings: it gets harder for all of us to talk about our feelings when we’re upset or excited. You can support this by:

- Describing what you can see that conveys feelings, and labelling the emotion: “your face looks sad and you’re very quiet, are you upset?”
- Checking out what’s triggering the feeling and putting it into words: “are you upset about what happened with your family last night? Are you upset about what I said just now?.....oh, you’re upset because I was angry about the machine not working”
- Acknowledging emotions and talking about how to move on: “I’m sorry that I upset you. The thing is, the machine is broken, and we’ll have to do something else instead. Let’s work out what we should do next.”

7. Giving feedback about key communication skills: Positive feedback needs to be specific about what is being praised, and complimentary. With children, commonly used spoken praise includes: “good talking!”, “good looking!”, “good listening!”. With adults, it may be more appropriate to use comments “you explained that really well”, “thank you for listening”. Backing up comments with enthusiastic facial expressions, and signs and symbols, makes them even more powerful.

Most people also appreciate occasional friendly constructive criticism, when it includes suggestions and support about how to deal with the issue e.g. “I’ve noticed that when you’re talking, you look at the table or the floor. Sometimes people don’t listen to you because you look at the table. When you talk to people, you need to look at their faces. I look at people’s faces to check that they’re listening. Then I start talking. I’ll show you, like this...” You can invite, “Would you like to practise that some time?”.

If it feels appropriate to do this, then each time you mention an issue to address, it’s a good idea to balance it with a couple of compliments about communication skills e.g. “you’re such a good listener, it would be nice if other people listened to you. And you’ve always got important things to say”.

8. Providing a running commentary that models language to talk about activities:

When children are playing, or when adults are carrying out a new task with support or supervision, it’s helpful if you describe each step as you see it happen, using vocabulary relevant to the activity and the sort of sentences that are easily understood: “you’ve finished peeling the potatoes... you put the potatoes in the pan.... You fill the pan with water... you put it on the cooker.... you turn the gas on”.

9. Give suggestions about how to clarify the message when you haven’t understood: For example, “I’m really sorry, I didn’t get what you did on Saturday. Can you show me what you mean? Can you show me with your hands? Maybe you can tell me where you were?”

Putting it into practice

The purpose of this leaflet is to give you more confidence and ideas about how achieve successful communication with people that you know who have Down syndrome. It probably describes several points that you already put in practise, and others that you pick out as strategies to try out and use. If you review the leaflet every so often, it may give you for further ideas.

As more and more children who have Down syndrome and other special needs attend local schools alongside other young people from their communities, it's becoming ordinary for children to be confident and skilled at interacting with people who face additional challenges when communicating. We all need to be part of this transformation: if we're not part of the solution, then we're part of the problem.

“It is our job to say yes, we can live the dreams we have and take advantage of the opportunities before us. It is our basic human right. We should be treated with dignity and respect and we cannot let others deny us”

Mitchell Levitz, who has Down syndrome and is Editor-in-chief of a newsletter called the Community Advocacy Press, in “Down Syndrome A Promising Future, Together”.

Quotations taken from:

National Down Syndrome Society (USA) website: www.ndss.org accessed 6th Jan 2005

Down syndrome: a Promising Future Together edited by Hassold and Patterson, 1999, published by Wiley Liss

Living with Down syndrome: Down Syndrome Issues and Information module by Sue Buckley, published by Downs Ed, www.down-syndrome.info/topics/living, accessed 15th Feb 2005.

Clinical Care: Perspectives, Talk by M Paez at the Fifth International Down Syndrome Conference, Orlando USA in 1993, transcript available at www.down-syndrome.info.library/periodicals/pdst-news/03/7/001, accessed 15th Feb 2005

Resources: Signing

Makaton

Makaton is a 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

MVDP, 31 Firwood Drive, Camberley, Surrey GU15 3QD England phone 01276 61390 fax 01276 681368 website www.makaton.org

Signalong

SIGNALONG is a sign-supporting system based on British Sign Language designed to help children and adults with communication difficulties, mostly associated with learning disabilities, that is user-friendly for easy access. The Signalong Group has researched and published the widest range of signs in Britain.

The Signalong Group, Stratford House, Waterside Court, Neptune Close, Rochester, Kent ME4 4NZ, UK, phone 0870 7743752 website www.signalong.org

Resources: Symbols

Writing with Symbols

Writing with Symbols 2000 is a flexible pictorial writing tool that uses symbols, written words and speech. The program is supplied with two extensive sets of graphics images (symbols) to support the writing: PCS symbols from Mayer-Johnson, and the Widgit Rebus symbols, and includes a Talking Symbol Processor and a programme for finding symbols and arranging and printing symbols in grid formats.

Widgit Software Ltd, 124 Cambridge Science Park, Milton Rd, Cambridge, CB4 0ZS, UK 01223 425 558 website www.widgit.com

Boardmaker

BoardMaker is a graphics database containing over 3,000 Picture Communication Symbols in clip art form. You can find and paste symbols, and store, name, retrieve, resize, and paste scanned or custom-drawn pictures. The program allows you to quickly find and paste pictures to make communication display, worksheets, picture instruction sheets, reading books, journals, or posters.

The Possum Group- Possum Controls Ltd, 8 Farnbrough Close, Stocklake, Aylesbury, Bucks, HP20 1DQ, UK 44 01296 461002 website www.possum.co.uk/

Symbol for Windows Communication Software

Symbol for Windows is designed to support communication and learning using symbols. It is made up of various modules including a text processor for symbols. Various symbol sets such as PCS, Rebus, Bliss, Picture This & Pictograms are available to work with in each of the Symbol for Windows modules.

The Possum Group- Possum Controls Ltd, 8 Farnbrough Close, Stocklake, Aylesbury, Bucks, HP20 1DQ, UK 44 01296 461002 website www.possum.co.uk/