



section 6

Communication

The ability to communicate is one of the most powerful tools we possess. It allows us to ask for what we want, express our ideas and emotions and helps us form a link with other people and find connectedness. It is essential to understand that there are many ways to communicate needs or feelings including: speaking, listening, signing, writing, using voice output devices, pointing and even body language. Without this understanding, the attempts of people who can't communicate in a conventional verbal manner (ie, by talking), may be ignored or misinterpreted. For example, a child may ask for a drink by standing near the fridge door but the adult may not realise this or may interpret it as the child wanting to help cook. This type of problem occurs particularly when an individual's understanding exceeds their ability to express themselves.

People with Angelman Syndrome (AS) often have a gap between their receptive (understanding) and expressive communication skills. This means that their understanding is better than their ability to express themselves which is very limited. The majority of individuals with AS will not develop usable speech but there are many other ways to communicate. It is wise to assume the child understands more than you might think and to speak to him as though he understands every word! Robin Alvares' survey (see References) concludes that "... underlying dysfunction of sensory and motor aspects of oral motor mechanism...." results in the limited ability of AS individuals to use speech as their main form of communication.

Parents can play simple turn-taking games from very early on making sure they give the child enough time to respond. A good reference for these 'movement-type' games is the communication section of Beth Sturr's H.E.L.P. (see References). It is often necessary for different communication systems to be taught. Perhaps one system can be trialed to see if it is effective or not before another system is tried. Sometimes, children may use a combination of systems successfully.

1. Alternative & Augmentative Communication (AAC)

AAC is a term used to define methods of communication which are alternative to oral speech, or augment oral speech. There are many advantages to the use of AAC, including:

- providing a means of communication for someone who would otherwise be unable to communicate;
- reducing the frustration for the communicator;
- increasing the understanding of the listener;
- increasing the person's ability to control their environment and make choices;
- increasing socialisation skills and experiences;
- improving self-image;
- increasing eye contact and attention span. (Tammy Jones, see References)

AAC systems are often divided into aided and unaided systems.

1.1 Unaided AAC Systems

Unaided systems are those which do not require anything external (ie, you only need yourself). These include: signing, facial expression, gesture and body language.

1.1a Signing

There are a number of signing systems that are used in Australia:

AUSLAN:

this is the sign language used by the deaf community. It is a complete language with its own grammatical system. AUSLAN signs are now taught to children with communication impairments but are sequenced using English word order and grammar.

Australian Signed English:

this signing system was developed in order to help deaf/hearing impaired children learn to read English. It uses its own system of signs and follows English grammar (ie, each sign represents an English word);

Makaton:

Makaton is not a signing system. It is a suggested method of teaching people with communication impairments how to sign. Particularly, it places signs/ words into levels of acquisition.

You need to consider cognitive skills as well as fine motor skills when choosing signing as a system. Imitation may be a difficult skill for many AS children. When teaching signs, you need to list the vocabulary the person may want and then teach it using objects, pictures etc. Strategies such as modelling the sign and sign shaping (where you physically assist with the sign) can be used.

1.2 Aided AAC Systems

Aided systems are those which require something external to yourself. Aided systems may be sub-divided again into a number of categories.

1.2a Objects

For someone who has significant difficulty understanding, using objects is a good choice. The person who has difficulty may pick up a cup and this would communicate that he/she wants a drink. The objects may be:

- whole objects;
- partial objects (eg, half a cup);
- miniature objects;
- an associated object (eg, a purse may represent shopping);
- a part of an object (eg, a shoelace may be used to ask for a walk).

Sometimes, the representation is not as obvious as we think. For example, to us a miniature toilet from a doll's house may look exactly like a toilet. To a person who is unable to make the connection between a tiny toy and their own experience of being taken to the toilet, the toy means very little. What might be more meaningful for them is a sticker, for example, which is identical to a sticker near the toilet paper roll in the toilet and which she sees frequently. A video could be represented by an object relating to the subject of the video, eg a Little Ted toy could represent a Playschool video.

1.2b Photos/Symbols

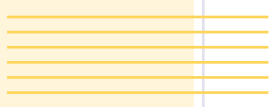
Photos and symbols may be used to communicate in a variety of ways. A number of different symbol systems have been developed, including:

- Bliss symbols: are quite difficult to interpret unless you are familiar with them;
- Rhebus: these are easier to interpret but require some familiarity;
- Compic: this is a set of black and white outline symbols. Most of these are easy to interpret although some require familiarity;
- Picture Communication Symbols (PCS). Boardmaker is the computer program which uses PCS. These symbols can be either coloured or black or white. The majority of these do not require any familiarity to interpret.

These line drawing systems have the advantage over photos and objects as they can represent abstract concepts such as 'hungry', 'same' or 'different' etc.

These symbols or photos may be used to communicate using a number of different systems including:

- Communication books/boards- As an example, photos of food choices for lunch could be placed on a board for the child to touch or indicate in some way which item he wants. Food packets or labels may be more concrete symbols to use before photos of food. You may use colour copies of video covers on a board so the child can choose which video he wants to watch. Boards may have all the vocabulary needed for a specific activity such as bath time, for instance. Books may have sections grouping words into topics such as animals, food, family etc.
- PECS (Picture Exchange Communication System). This system was initially developed for use with people with Autism Spectrum Disorder to promote their initiation of communication but is now used with many populations who don't have verbal speech. At its simplest level, it involves the person with a communication difficulty giving someone a photo to request an object/activity. However, it can also be used to make comments, ask questions and respond to questions at more advanced levels;



- Timetables - where the day's activities are ordered for the child to see and perhaps each symbol or photo can be placed in a 'completed' box when the activity is completed.

Two other useful communication aids should be mentioned here. Firstly, a Personal Communication Dictionary which is a list of behaviours that a person with a severe communication impairment uses to show likes, feelings, requests etc. This will help less familiar people respond appropriately and ensure a consistent response so the person knows their communication attempts are being recognised.

Eg;

What Mike does	What it means	What you should do
Bites at lower lip	He is hungry.	Tell him 'You're hungry, Mike'. Let him know how long it will be until the next meal or give him a snack.

Secondly, a Remnant Book is useful. It uses object symbols to help conversation with a partner. A 'remnant' from a meaningful activity such as a football ticket or birthday candle can be collected and put into a book with an accompanying comment. This can be useful in classroom activities such as news sharing or even working in pairs.

1.2c Voice Output Communication Aids (VOCAs)

These are devices which are able to 'talk'. They range from simple to very complex, including:

- single switch devices (eg BigMac) which can record and play only one message;
- devices which allow a variety of stored messages to be played, ranging from 2 to 64 or more (eg TechTalk, Macaw);
- devices which allow you to type in your own messages (eg, Lightwriter).

It is important to be able to trial these devices before buying them to determine how successful they are as they are very expensive. "Generally people are more successful at using an electronic system if they are already using a low technology or paper system" (Farrall, see References).

REFERENCES:

Tammy Jones (Teacher, Mt Evelyn Special Development School), "Education and Communication" Presentation at ASA Conference, Vic. 1999.

Jane Farrall (Speech Pathologist, Centre for Developmental Disability Health, Vic), "Augmentative and Alternative Communication (AAC) options for individuals with AS". Presentation at ASA Conference, A.C.T. 2001.

Robin L. Alvares and Leigh Brezovsky (Dept of Speech and Communication Studies, Edinboro University of Pennsylvania, USA) "Survey of Expressive Communication Skills in AS: An Update" see Presentations from 1st IASO Conference on IASO website: <http://www.international.angelmansyndrome.org>

Kim Neill (Speech Language Pathologist, Education Department, Tas.), Personal Notes, 2002.

**OTHER USEFUL REFERENCES:**

PECS website: www.pecs.com

Beth Sturr "A Few Thoughts on Communication" from H.E.L.P. (Hints and Ideas for Everyday Living for Parents of Angelman children) see Presentations from 1st IASO Conference on IASO website: (see above).

Ylana Bloom "Lets Talk Together", "The Great Ideas Manual", "Softpics Professional - Augmentative Communication Designer" CD available from Innovative Communications 9 Oaklands Avenue, Beecroft, NSW 2119. website

<http://www.innovativeprogramming.net.au> These materials were discussed at the 6th Angelman Syndrome Association National Conference, Sydney, 3 – 5 October 2003 as part of Ylana's talk on communication.

Facilitated Communication

Facilitated communication is an alternative means of expression for people who cannot speak, or whose speech is highly limited (e.g. echoed, limited to one or a few word utterances), and who cannot point reliably. The method has been used as a means to communicate for individuals with severe disabilities, including persons with labels of mental retardation, autism, Down syndrome and other developmental disabilities.

Established at Syracuse University in 1992, the Facilitated Communication Institute conducts research, public education, training and scholarly seminars. It was created as a way of bringing together the research community, people with disabilities, their families, and practicing professionals to examine, learn about, and share information on facilitated communication.

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DEAL Communication Centre

DEAL Communication Centre in Melbourne, Australia, provides services to people who are unable to talk, or to talk clearly, as a result of conditions such as cerebral palsy, strokes, acquired brain damage, autism, Down syndrome, or intellectual impairment - anyone whose speech is not clear enough, fluent enough or reliable enough to allow them to get across everything they want to say.

What does the centre do for people?

Many people with Severe Communication Impairment (SCI) know more words than they are able to say. People with SCI who know more words than they are able to say may be able to expand their expressive communication by using Alternative and Augmentative Communication (AAC) strategies.

We give people who have only a limited means of communication (a symbol board or a few manual signs, say) a chance to try out alternatives, such as speech synthesisers.

We help parents, therapists, caregivers and teachers discover the communication possibilities of people in their care, and where necessary we teach them to use non-speech communication methods (including Facilitated Communication when appropriate).

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