An introduction to AAC for people with Angelman Syndrome and other Complex Communication Needs

2nd Edition

Author Tracey Campbell on behalf of

Assert

Foreword

This booklet has been written for parents and carers of children and adults with Angelman Syndrome. It explains communication and Augmentative and Alternative Communication (AAC), the types of systems that could be used and why everyone should have access to a full language system. It will show how you can use the systems to 'model' language to support development of communication. It also includes a list of links to get further information and advice.

Over the last few years, I have been working hard to develop good AAC systems for my daughter and have learnt a lot in the process. In the course of writing this booklet I talked to others who have been involved in setting up AAC for people with Angelman Syndrome, there are some common themes that keep coming up. Many people who have started using a full AAC system, have done it on their own or as a family without professional backing or specific support to implement the system. Everyone thinks that they are not doing enough. Everyone thinks it can be hard work. Everyone is pleased they started. Everyone has been surprised by progress. No-one has looked back.

The aim of this booklet is to provide help and support for every individual with Angelman Syndrome to have access to a full AAC system and be fully immersed in an environment that will help them to learn this system. The evidence base is strong and growing that a diagnosis of Angelman Syndrome does not mean that you cannot have a voice.

The following has been written using my own words except where specifically referenced. However, these words have become mine after listening to some experts in the field of

- AAC
- Communication
- Literacy
- Education
- Presuming Competence

I would like to apologise if I have accidentally copied anyone and thank them for helping to change the world for people with Complex Communication Needs and Learning Difficulties. They are: Erin Sheldon, Mary Louise Bertram, Caroline Musselwhite, Maureen Nevers, Kate Ahern, Jane Farrall, Jennifer Marden, Tina Thompson, Gayle Porter, Linda Burkhart, Jules Whicher, Keisha Tipton, Cori Stell, Becky Burdine, Cassidy Harm, Carole Zangari and all the other wonderful people who answer questions and share their hints, tips and stories. An extra thanks to Rosie Clark and Livvy Hepburn who helped edit this second edition and Dan Hasler for his help with the graphics.

All errors are my own.

Just to say...

We would like to thank Tracey for collating and writing this incredibly useful document for us. We hope that it proves helpful in your fight to help your loved ones access language, literacy and communication whatever their age. We strongly feel that giving people with Angelman Syndrome the ability to communicate as fully as possible is the most important skill we can give them and we hope that you find this booklet useful.

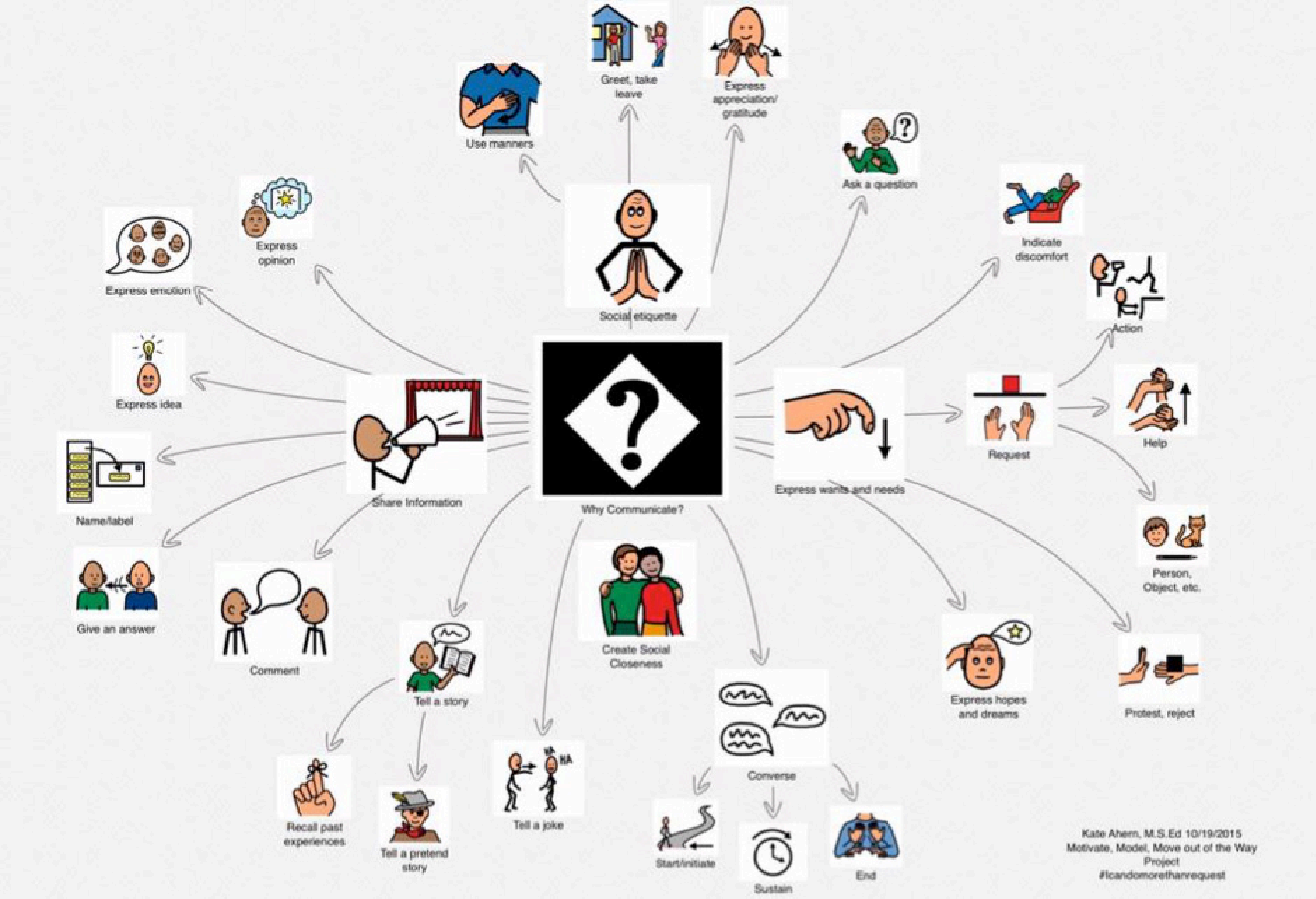
ASSERT

What is communication?

We all communicate all of the time. Communication is a way of sharing our personalities and getting our thoughts known and letting people know what we want. We use communication for many different things, for example:

- saying hello and goodbye in different ways
- giving and getting information
- being polite
- asking and answering questions
- joking
- complaining
- talking about feelings
- asking for things

When someone can't talk, we often only start by teaching them to ask for things. It will help them become better at communicating if we can teach them all the different ways to communicate. Thank you to Kate Ahern for making and sharing this great picture below showing many purposes of communication.



Kate Ahern, M.S.Ed 10/19/2015
Motivate, Model, Move out of the Way Project
#Icandomorethanrequest

> *"I know Charlie so much better now he has a communication system."*
>
> Jules, mum to Charlie

What is AAC?

Augmentative and Alternative Communication is any means of communication that is not talking. There are three main categories of AAC; no tech, low tech (also called light tech or soft tech) and high tech. Some examples of each type are in the table below. Some of these will be discussed more later on.

NO TECH	LOW TECH	HIGH TECH
Pointing	Pen and paper	Switch
Gesture	Alphabet boards	Voice output devices with static displays (e.g. 4 talk 4, Go Talk)
Body language	Communication boards (ALDs)	iPad
Signing	PECS	Eye Gaze Device
Looking	Communication books	Computer
Challenging behaviour	PODD book	Specific AAC device

All ways that people use to communicate are valid and different things will work better in different situations. It is important to think about how someone who is having difficulty talking will communicate in the future. All people with Angelman Syndrome should have access to a full communication system to help them to understand other people and to help them learn to be understood.

A full system has enough words to allow them to say:

- what they want to say
- when they want to say it
- to whoever they want to say it
- however they want to say it

This last point has been added as people may use a range of different systems for different reasons so it is important to note and accept all forms of communication.

Full language systems are also sometimes called robust systems. Examples of full systems are:

- PODD book or high tech on Compass or The Grid. There are a range of other pagesets within these, only some of which are full language systems)
- Sonoflex on Communicator
- Proloquo2Go (lots of different language sets within this)
- Speak for Yourself
- TouchChat with WordPower

These are the most common. Jane Farrall has reviewed most of the systems available on iPads and the reviews can be found on her website (janefarrall.com). All of these systems:

- have all types of words not just nouns
- allow the user to make sentences
- categorise words so you can find them easily
- can be added to easily as communication gets better

Many people find choosing the system difficult. If you have a child who is going to school, it may help to talk to your child's speech therapist and school to see what systems they already use. This may mean that people already know how to use one in particular. Another consideration may be if a person has significant motor issues they may find a soft tech communication system easier to navigate. What is most important is that you learn to use the system. Most people could use any of the systems with help to adapt it. Contact ASSERT or use Facebook groups to get advice.

> *"We were modelling for more than a year. Lefke was interested but didn't ask for or use her book often herself. Her non-verbal communication is well understood by a lot of people.*
> *Last year when I was in the hospital after brain surgery she asked my parents for her book and indicated car, hospital and mama. I guess she really needed the book then."*
>
> Esther, mum to Lefke

How do we learn our first language?

When children are learning their first language they hear it all the time. They hear it both directly and indirectly and in lots of different settings. People use the language everywhere they go, e.g. at home, at the shops, on the TV. They hear an average of 6,000 words per day. Normally children will try the language for themselves in the form of babbling. A limited number of single words then follow and are added to over time. Most toddlers have a language explosion between the ages of 2 and 3 when the range of vocabulary increases significantly. Correct grammar then follows, and by the age of 9, most children are considered to have a full grasp of their language. If your child cannot talk they do not get the same experience of people taking to them in a language that they will be able to use back (e.g. symbols or signing).

For a child who only sees their symbols being used for two lots of twenty minute sessions per week (e.g. in a Speech and Language Therapy session or at snack time, it will take them over 700 years1 to get the same level of input as a typically developing 9 year old has had with speech.

Teaching AAC is similar to teaching a new language. We should do that same as we would do with a baby learning speech. Don't wait to start using a robust language system. They don't need to be able to DO anything before we use their language around them. (We don't wait until a baby shows they can understand words before we start to speak to them)

1. Trust that being around a language that uses symbols will help understanding as well as teach someone how to use the language. Trust that being around a language using pictures helps understanding as well as teach how to use the language.
2. Keep using the language for a long time before expecting someone to start to use the language (remember it takes around 18 months of hearing spoken language before children to learn to speak).

This is a much more normal way to learn. Using a symbolised language might also be the only way some children gain an understanding of language.

> *"It took me a long time to understand why an AAC system would work for Maggie; she didn't seem to understand language and people just kept telling me to presume competence. Eventually I realised that Maggie is very visual, so we could build her receptive language by talking to her with her AAC and making spoken language visual. That's when I realised that AAC is for everyone and there are truly no prerequisite skills."*
>
> Erin, mum to Maggie

There is lots of research into why AAC is best taught in this way. Sennot, Light and McNaughton2 (2016) reviewed the research and this is a useful study to share.

Presumed competence

It can be difficult to imagine that your non-verbal child will have the ability to learn such a complex system, especially if the professionals around you are saying that your child isn't ready. This is where you have to learn to presume competence in your child and believe in their ability to learn and your ability to teach them.

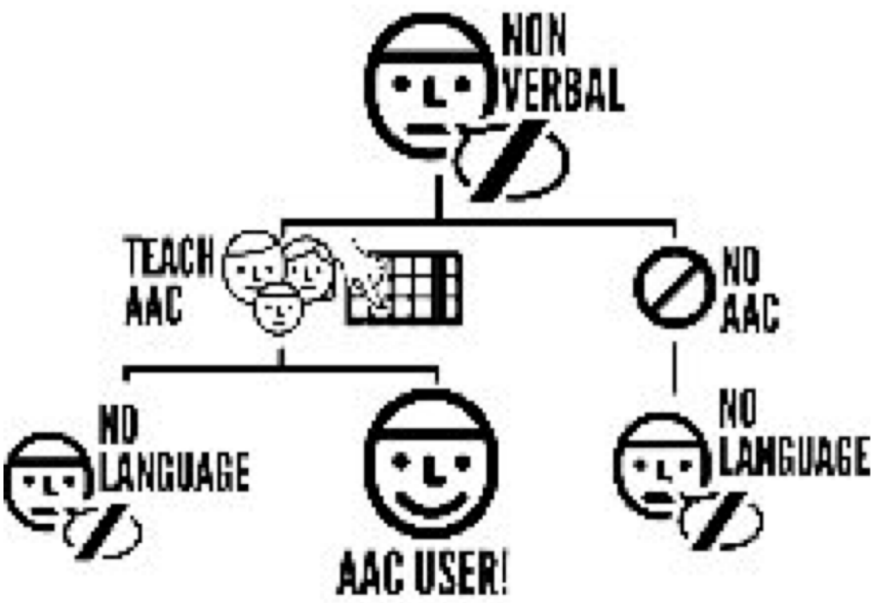
First described back in 1984 by Anne Donnellan3, presumed competence refers to making the least dangerous assumption. If you have someone who is non-verbal you have two choices:

1. Teach AAC – give the person a full language, immerse them in it, model, allow them time to learn; or
2. Do not teach AAC because you think they are not capable of learning it.

If you make the wrong choice, what is the worst thing that can happen?

1. The person does not learn and you have wasted time
2. The person had the ability to learn but was denied the opportunity and so has to live without the ability to express themselves fully.

Number 1 is clearly the least dangerous assumption to make.



> *"I was advised by professionals to use PECS with my son, while initially he had fun requesting some preferred items, it never went anywhere, we were still at the early stages years later. Dimitri really actually likes his PODD book, he likes using it, exploring it, hearing me talk with it. He often asks me to sit down with him and his PODD book and chat; we can do that for 20-30 minutes easily."*
>
> Emma, mum to Dmitri.

First steps

It can be quite daunting to look at where to begin your AAC journey. Here are some tips to get you on your way:

1. Once you have chosen the language system, you need to figure out how to take it everywhere. A strap or harness is usually required for a book or iPad. Using a bag isn't usually as effective as it is often left in the bag and isn't available when it is needed.

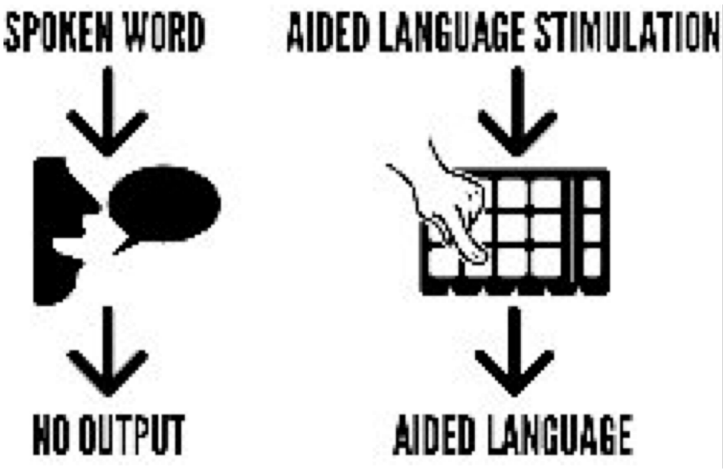
2. Personalise it – this allows the AAC user to take ownership of their new language. It is highly motivating and increases the likelihood of them being able to have access to the words they would like to use.

3. If using a device which the AAC user wears, it may be better to use a second device to model on. For some people, modelling on the second system is easier. It can help the AAC user to see their device as their own and it helps the AAC user to blend in. This is very important for teenagers in particular to help normalise their use of it. If using a book, it is better to model language in the same book as it can help focus both partners on the conversation.

> *"I introduced P2Go at home without any support; I then went on a one day PODD training day to learn about modelling. I am really pleased with the progress we have made in such a short time."*
>
> Jayne, mum to Jacob.

Aided Language Stimulation (Modelling)

Having a communication system is not the same as using a communication system. The only way to become an AAC user is by being taught how to use the system. We do this by modelling the use of the system.



Aided language input (or stimulation) is what we do when we use an AAC system to say key words from a phrase, usually by pointing to the symbol in the AAC. This is what we mean by 'modelling'. Remember, we should treat learning AAC like learning a new language. That means using the person's language to teach them how to respond to situations in everyday life using their system. Using only verbal communication to teach an AAC user rather than using their symbols as well as speech, is the equivalent of speaking to a baby in English and expecting them to talk back in French. The chances of learning successful communication are not high.

How to model

1. Start slowly. Don't try to do everything at once. There are different ways to do this and it will depend a bit on what system you are using. You could pick a few core words to start with and model them across everything you do (as described in the Angelman Syndrome Foundation training series). You could start with using the front pages or 'chat word' type pages and just practice using these as much as you can until you get more confident.

2. For example, at dinner time:
   - Whilst you are enjoying your dinner model "I LIKE" whilst saying "I like my dinner"
   - Your child finishes and touches their plate, model MORE saying "oh I wonder would you LIKE MORE?" (or simply MORE)?
   - Someone leaves something – "I do NOT LIKE that"

   During story time, comment on the content, such as:
   - "I LIKE it, this story is fun"
   - "Oh no, he is NOT nice"
   - "I have that too"

3. Do not panic! To begin with, using an AAC system feels strange and unnatural but it's not hard, it just takes practice. 18 month olds can do it! Once you can locate your first set of words or pages, with ease and know when to use them, you could then start using another communication function e.g. using opinion words or add in the next set of core words.

   Try to keep it natural. You don't need to say every word as you would in natural speech, especially at the beginning. Just look at the options that appear on the book or device and use the words you have rather than trying to look for things in English word order.

4. You might choose a time of day to incorporate use of the AAC every day. You could choose bedtime as a calm time, dinner time as everyone is all together, or any other time that suits the family. (A time when you have any time constraints will not work in the beginning whilst you are getting familiar with the system. You do not need to add in more pressure at busy times!) This can then be gradually built up by introducing other times when the AAC is always used. The ultimate aim is to use the system throughout the day to say multiple messages in a variety of settings.

5. Think of things the AAC user would want to say and not just things you want to say to them. If you only ever model… 'It's time to go to bed,' or 'you need to…' then they won't see it as being something that THEY need to use. Try to model things like… 'I think it's yucky' when there is something you don't like, or 'I need a break' as these are things they may want or need to say themselves.

6. Use "think aloud" comments that reflect what the individual communicates with their body. Then use the communication system to talk about it. E.g. "I see you clapping your hands, I wonder whether you are saying you FEEL HAPPY." People with Complex Communication Needs (CCN) often need to hear how you are interpreting their body language. That way if you are wrong, they can try to be clearer. This means that you are showing the person a different way of expressing what they might be feeling but doesn't assume you know for sure what they want to say. They might have clapped their hands as they were retelling you a story about someone clapping their hands.

   Do not say "you are doing this so you must be thinking that" – putting words into a person's mouth can belittle their meaning and can enforce that the system is still open to misinterpretation just like all their other ways of nonverbal communication.

7. Don't forget to have something exciting to talk about. It takes much more effort to use AAC than the spoken word. If someone is taking the time (which can be physically and mentally exhausting for some) to use AAC then you should try your best to make the things they get to talk about interesting or meaningful.

8. If there is a word that you are trying to model which is not on the system, add it in. If you are using a paper system, write the word on and it can be added into the next version.

"Leia had a PODD book for a year and we didn't get any training for it so she carried it about in a bag to and from school. After going to an ASSERT conference we learned that we should be modelling. I joined some Facebook groups and then watched lots of videos of other people modelling. It took us a while to figure out that modelling just meant speaking to Leia but at the same time using the PODD to say a word or two per sentence. I am so glad that we did."

Tracey, mum to Leia.

Access methods

The sensory processing difficulties that individuals with Angelman Syndrome have, can impact on how they access their language. Some are able to access the system directly with a point, a fist or a hand. A stylus or a key-guard may be used to increase accuracy for high tech devices.

Partner assisted scanning can be used when motor skills are not yet developed enough for direct access. With this method the individual is helped to navigate the system by the partner showing or pointing to the symbols and/or reading aloud the words. The individual indicates a yes or no response to convey their message. This can be time consuming and it takes more practice, but it has been used to great effect with individuals who have problems with motor skills and for individuals with Cortical Visual Impairment (CVI). CVI is not uncommon amongst people with Angelman Syndrome and using a well-spaced, high contrast symbol set may also aid here.

NOTE: Some AAC users are able to use direct access most of the time but it is very useful to model partner assisted scanning too, as if they are particularly anxious or finding it difficult to focus, this method may be much easier for them.

Here is a link to a video of Karen Owens demonstrating how to do partner assisted scanning. She is using a switch to give the 'yes' and no' responses but this could also be done with a head nod and shake, vocalisations or any other method. http://*www.youtube.com/watch?v=_g5fs-JQJvQ*

Switch access can also be used for access to high tech devices for those who find direct access difficult. It also uses a scanning technique but here the individual uses a switch/button to indicate their choice. There are technologies available that can allow this to be done without a partner. It is unlikely that using switch access would be taught before partner assisted scanning.

Eye gaze Is an access method where the user selects a symbol on a page on the computer by looking at it. Normally it is used for people with severe motor difficulties, e.g. Cerebral Palsy or Rett Syndrome but can also be useful for some people with Angelman Syndrome. Low tech communication books can be made suitable for eye gaze as well as sophisticated high tech options. Eye gaze can take lots of practice and is very tiring so individuals may find partner assisted scanning much easier.

> *Partner assisted practice has been life changing in enabling AAC access for our clients with Angelman who have the most complex bodies and processing difficulties.*
>
> Mary-Louise Bertram, expert in communication and Angelman Syndrome.

Other Communication Tools

Learning Skills: There are lots of skills involved in becoming a good AAC user and you can practice them alongside modelling the AAC system.

One of the most powerful things you can teach someone who is non-verbal is a definite 'yes' and 'no'. The concept of 'yes' and 'no' may also have to be taught too. Kate Ahern has a highly recommended six series blogspot on teaching these things. Once a definite 'yes' and 'no' is present, lots of other ways of communicating are available through partner assisted scanning.
http://teachinglearnerswithmultipleneeds.blogspot.co.uk/2012/11/the-yesno-series-part-one.html

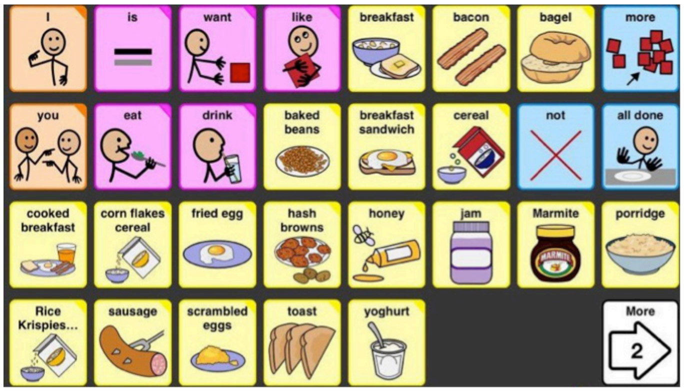
Another essential tool to teach is a way to indicate that you have something to say. Ideas include:

- 'I have something to say' rubber wristbands. Wave hand and say "I have something to say".
- Wave hand and say "I have something to say" without wristband
- Sign "talk"
- Vocalising
- Reaching towards the book or taking it to a partner

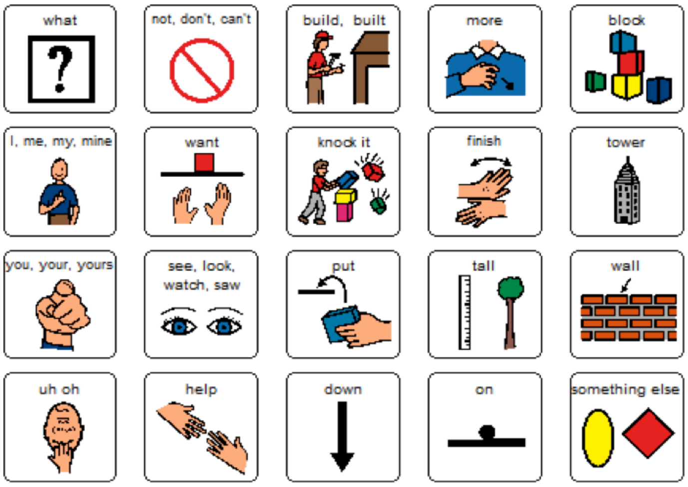
It can be whatever way is easiest for your family and there may be a few different ways for different times. The act of indicating you have something to say should be modelled along with the system and used consistently.

Aided Language Displays: Aided Language Displays (ALDs) are single sheets of topic specific words. These can be activity based such as play dough and doll play, or topic based such as days of the week or holidays. They can be very helpful when starting out with a new system and for areas that it is difficult to take the main AAC system into such as bathrooms and swimming pools. They are, by their very nature, limited and so should always contain a means to request access to the full communication system, which should be readily available. The symbol set and lay out used should be similar to the main language system.
Here is an ALD for breakfast taken from a screenshot from Proloquo 2

Here is an ALD for breakfast taken from a screenshot from Proloquo 2 Go:



PODD based ALD – Building (these are included in the final pages of the 1 page PODD books)



> *"We used objects of reference, photo cards and eye gaze with no support. As Esme became mobile we continued with PECS for snack a little lost with what to do. Then we found PODD and we have been modelling since Christmas. Esme's making progress and choices at home. We are hoping to increase the time it is used in school too."*
>
> Adele, mum to Esme.

Hints and tips to get everyone on board with AAC

It is helpful to get everyone who comes into contact with the AAC user to model the use of their system as much as possible. It helps everyone to see it as a valid method of communication and also decreases the burden on one person to do all of the modelling.
Here are some hints and tips to persuade others (also handy to remind yourself from time to time)

1. Explain about acquiring language and how often language needs to be modelled to give the AAC user the best chance to use their system.

2. It's ok to make mistakes. Communication can be messy.

3. Don't be scared of modelling AAC, it is awkward at first but you will get the hang of it.

4. Always model without expectations of a response from the user. Don't put any pressure on them at all as this will put them off.

5. Make comments more than asking questions e.g. "I like this, it's funny", instead of, "What do you think about this?" It is more natural and doesn't pressure the AAC user for an answer. The ratio should be around 80% comments to 20% questions.

6. Ascribe meaning to the AAC user's babbling. When they are learning to use the AAC system, they will explore their book or device by pressing or touching symbols and learning what they mean by the way people react to them. If they touch 'finish' but we think it was accidental and don't respond, they will not learn what 'finish' means and will think it's not worth using that again. It is much more motivating if they get a great reaction to everything they say.

7. Add words to the system as and when you need to.

8. The AAC is mainly for unmet communication needs – never ignore other methods of communication – they are valid and often easier so will not change. But, you can model the communication in the AAC system, for example the user takes yoghurt out of the fridge, you can model "want yoghurt" but do not insist that they request it on their AAC before they are allowed it. Multi-modal communication is something we all use to communicate.

> *"Anna was using her PODD only for requesting a few things; her teaching team went on a training course and then started modelling to her. She then suddenly started having many more things to say."*
>
> Violetta, mum to Anna

Access to communication systems and current guidelines

The normal route for access to communication systems is through a Speech and Language Therapist. Speech and Language Therapy (SLT) is provided for by the NHS. It is usual that individuals are referred to SLT through either a doctor or through school or nursery. In some instances self-referral may be an option. It can be extremely hard for adults with learning difficulties to get access to SLT as most adult services are tailored towards adults with an acquired communication difficulty. Access to SLT does not mean automatic access to a communication system.

Most current guidelines and policies are based on the old fashioned 'Candidacy approaches', which requires a certain skill set to be proven before being granted access to a robust AAC system. This is like requiring someone to pass a driving test before allowing them to have a car to learn to drive. In the literature, this approach has been abandoned and replaced by more progressive models in many countries. One such approach is the Participation Model4, in which people are given a language to participate in before any assessment of their ability to use it is made. These approaches are not yet evident in guidelines in the UK. These guidelines, along with attitudes, are currently the biggest hurdle to gaining access to a robust communication system. Most guidelines still state that individuals have to meet certain criteria before they get access to a communication system. These guidelines include skills such as:

- turn taking
- choice making
- eye contact
- cause and effect
- following direction
- listening and attending
- joint attention

Most individuals with Angelman Syndrome would not meet these criteria.

When an individual doesn't meet these criteria, they may be left with either no means of communication or limited methods of communication, choices or objects of reference only. If the individual is within a school environment, the term "communication environment" may be used to indicate that the individual is within an environment that accepts and validates all forms of communication.

Many parents/carers have heard the above phrases and have been continually told that the individuals are not ready or that they do not have the capacity to learn a robust language system. Indeed, a robust language can look rather large and daunting to begin with. The following section looks at why this is not the case.

1. *It is interesting to note that the Scottish Executive approved an Amendment to the Health Act 2006 which states that all individuals with Complex Communication Needs will get access to AAC in January 2016. The Amendment did, however, state that existing guidelines will still stand. The impact of the Amendment remains to be seen.*

Is AAC the right choice?

There can be many uncertainties surrounding the implementation of an AAC system, especially if you have been continually told by professionals that your child is not ready or can't do it. Here are some arguments why AAC is right for your child:

- Remember there is no evidence to support the candidacy model of communication. It is the basis for guidelines simply because that is what has always been done. There are no barriers to starting to learn a communication system. In the beginning the emphasis is all on the communication partner, not the person themselves. This approach has a large and growing evidence base for success.
- It is illogical to make someone prove that they can use a system before they have access to a system.
- There are many symbols and signs that we all learn without anyone actually teaching us; there are not too many symbols in an AAC system.
- There is no right age to introduce an AAC system. The child cannot to be too young. We start teaching children language whilst they are in the womb. Equally, there is no upper age limit. In fact, studies have shown that adults with Angelman Syndrome actually pick up AAC faster than their younger counterparts. This may be due to increased attention span.
- There are children with all genotypes of Angelman Syndrome who are now good communicators. Some of the best are deletion positive.
- Everyone has different skills and there may be a lot of problem solving needed to ensure that everyone has the best access to their communication, but it can be done.
- Someone who is a good communicator has become that way simply by a lot of time and effort, there is no getting away from it. Help is out there to teach people how to begin including:
- Someone who is a good communicator has become that way simply by a lot of time and effort, there is no getting away from it. Help is out there to teach people how to begin including:
    - Facebook groups - even if you don't generally use Facebook, it is worthwhile to have an account simply for access to these groups
    - Webinars on YouTube
    - ASSERT
    - Fellow AAC users are always willing to help
    - Charities including Communication Matters and others listed at the back of the booklet
- Start slowly and build it up at your pace, it becomes more natural. There will always be times when it slips so simply start again, don't dwell on it or blame yourself.
- Cost may be an issue if your child has no support from Speech and Language Therapy; however there are charities that can help cover funding. Libraries can often hold Boardmaker disks and you can use these to print PODD books.
- There are no guarantees that your child will become a fluent communicator but this is the best way to give them that opportunity.

"Ruth had had PECS thrust at her, then removed when she ate the food related symbols, a 4 word programmable communication device on trial for 2 weeks, then the SLT service gave up on giving her a 'voice'. We purchased proloquo2go 2 years ago when Ruth was 21; she's caught on quickly to it and can use it to comment as well as request!"

Anna, sister to Ruth

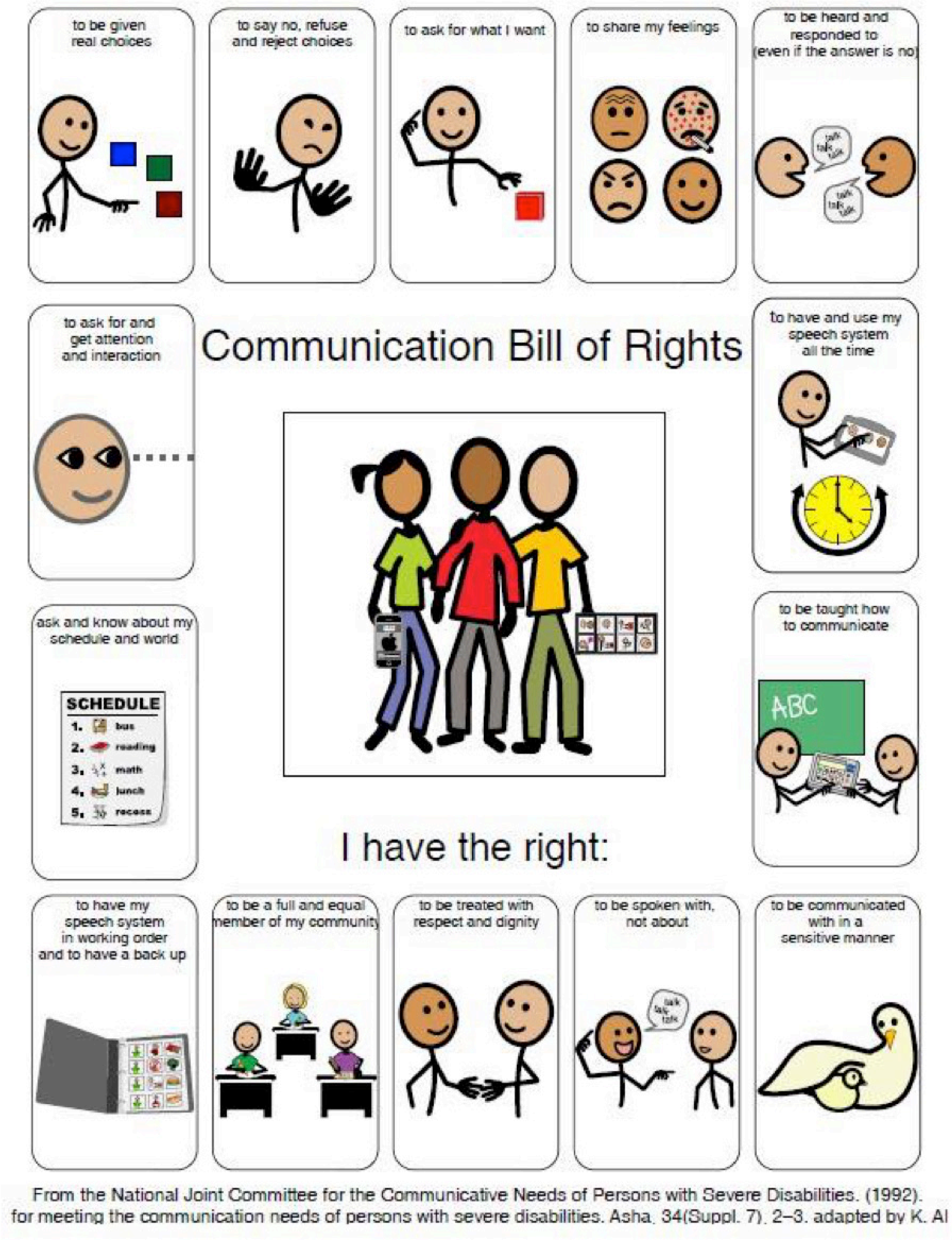
Too many words?

Many people are put off from using a robust AAC system as it seems like too many words and symbols to learn for everyone involved. We don't plan which words we are going to introduce to a baby. We use many words and see which ones they are motivated by. We need to have access to many symbols so that we can do the same with someone learning to use AAC.

Here is a lovely story from Tina and Finn at the very beginning of their AAC journey. The story demonstrates why we need to have lots of words as you are never sure what that first word may be.

> *"We were at the breakfast table and Finn had a runny nose. Since the PODD book is a full language system, I was able to use it to navigate away from the food activity page and went to the sick page, telling him "you have a runny nose." As I said that, Finn coughed. As he coughed I pointed to the symbol for "cough" on the PODD page that was now open. Finn was sitting in the middle, I was on one side of him and the PODD book was on the other. As I pointed, I both said "cough" and imitated the sound *cough**cough*. He thought this was hilarious (since he loves to imitate cough sounds) so then he imitated the cough sound *cough**cough.* Again, I pointed to cough and imitated *cough.* Same thing happened again and we went back and forth. The next time after I pointed to cough and imitated *cough* he looked at me then turned and looked at the book and pointed at "cough" then immediately looked back at me. I smiled and said, yes! Cough! **Cough, cough** Now he was very intentionally looking at me, looking at the book, looking at the book, looking at me. He pointed to the symbol a few more times and it was SO MUCH FUN!!!! And I was just sitting there thinking, yes, this is the key to communication, isn't it? This is interaction. We are having fun, and he is so into this little exchange, and if it weren't for the PODD book we wouldn't have had those symbols in front of us, we maybe would have had a food activity display (if we were lucky) or some symbols for "more" and "done" and that's it. I highly doubt that "cough" would have been one of the first symbols we would have put on a simple device. Yet, it was Finn's "first word" in his PODD book."*

Communication Bill of Rights



Communication Bill of Rights

I have the right:

- to be given real choices
- to say no, refuse and reject choices
- to ask for what I want
- to share my feelings
- to be heard and responded to (even if the answer is no)
- to ask for and get attention and interaction
- to have and use my speech system all the time
- ask and know about my schedule and world
- to be taught how to communicate
- to have my speech system in working order and to have a back up
- to be a full and equal member of my community
- to be treated with respect and dignity
- to be spoken with, not about
- to be communicated with in a sensitive manner

From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992).
for meeting the communication needs of persons with severe disabilities. Asha, 34(Suppl. 7), 2–3. adapted by K. Al

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Where to get your information from

ASF Communication Training Series

http://www.angelman.org/resources-education/communication-training-series/
This is specifically aimed towards parents and carers of people with Angelman Syndrome and professionals working with them. It provides free webinars and handouts on how to get started and implement AAC with our children and adults. It is suitable for everyone regardless of experience or type of system. There is a companion Facebook page where parents can ask questions and share information.

Aided Language Input

A link to a page by assitiveware about modelling, what it is and why we do it.
https://www.assistiveware.com/support/faq/page/353

We Speak PODD

https://www.youtube.com/channel/UCfvD20l2wn-fS2Ar4bdTXZg
A family of eight teaching four of their non-verbal children to communicate and you can follow their journey on YouTube and Facebook. Whilst the family uses PODD, following this journey is helpful to everyone for great examples on how to model.

UK Organisations

Communication Matters (CM) is a UK based charity that aims to increase knowledge, understanding and awareness of those with Complex Communication Needs
http://www.communicationmatters.org.uk/page/about-aac

ACiP is the Scottish branch of CM http://www.acipscotland.org.uk/

AAC Knowledge is maintained by CM to provide up to date evidence based information about acc.
http://www.aacknowledge.org.uk/

I CAN help is a range of information services that provide help and advice to parents and practitioners about speech, language and communication. It includes a free call back service
http://www.ican.org.uk/

ACE CENTRE is an AAC centre with two bases, the provide AAC assessments and information
http://acecentre.org.uk/

Royal College of Speech and Language Therapists
http://www.rcslt.org/asp_toolkit/csn/why_does_communication_matter__

1voice takes a family and social perspective on communication. There are local 1voice groups who meet up and use their AAC! http://www.1voice.info/

KEYCOMM Scottish AAC website, information about AAC and link to Scottish Codes framework
http://keycomm.weebly.com/

CALL Scotland resource centre for educators and families
http://www.callscotland.org.uk/home/

Now Hear Me resources and plans formulated as a result of funding from the Right to Speak Project by the Scottish Government
http://www.nowhearme.co.uk/users-of-aac/

Afasic provides communication support for families.
www.afasic.org.uk
www.afasiccymru.or.uk (Wales)
www.afasicnorthernireland.org.uk (Northern Ireland)

Facebook Groups

- ASSERT Communication and Literacy
- Angelman Literacy and Education (including Alphabet Therapy)
- AAC SLCN Literacy
- ASF communication series
- PODD and Angelman Syndrome (strictly for parents)
- PODD and Angelman Syndrome (for professionals)
- PODD Europe
- PODD for Angelman Syndrome and other CCN (ALL are welcome!)
- PODD and Alternative access
- AAC through Motivate, Model, Move Out of the way
- Augmentative Communication Resources and Help
- Pictello Users Group
- Proloquo2Go for parents
- Speak for yourself
- Tobii UK
- We speak PODD
- Little Bear sees (CVI)

Blogs:

- Jane Farrall - www.janefarrall.com/
- prAACtical aac - www.praacticalaac.org/
- aacintervention - www.aacintervention.com/default.asp?sec_id=180009852
- lburkhart - www.lburkhart.com/
- Star in her Eye - www.starinhereye.wordpress.com/
- Assistiveware blog - www.assistiveware.com/blogs
- Gail van Tatenhove - www.vantatenhove.com/
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