Foreword

This booklet has been written primarily for carers of children and adults with Complex Communication Needs (CCN). It explains what communication and Augmentative and Alternative Communication (AAC) are. The types of systems that should be used and why everyone should have access to a robust language system are also discussed. It then gives advice on the evidence-based strategy of aided language input to teach the user how to communicate with their comprehensive systems. There is a list of places to get further information and advice.

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 and Presuming Competence. I would like to apologise if I have inadvertently plagiarised 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 Ramsey Musselwhite, Maureen Nevers,

Kate Ahern, Jane Farrall, Jennifer Marden, Tina Zantke Thompson, Rosie Clark, Gayle Porter,

Linda Burkhart, Jules Whicher, Keisha Tipton, Cori Stell, Becky Burdine, Cassidy Harm and all the other wonderful people who answer questions and share their hints, tips and stories so willingly.


All errors are my own.

Notes

Any referral to device in the text refers to any robust communication system and can be a book, app or specialist system.

Aided Language Displays (ALD's) are usually topic specific single page vocabulary displays. They can be used for different areas or activities and should be set out in a similar manner and with the same symbol set as the AAC system. They should also always include a way to access further words and communication.

What is communication?

Communication is a way of telling someone else the thoughts in your head. Thank you to Kate Ahern[1] for making and sharing this great picture below demonstrating the many purposes of communication.
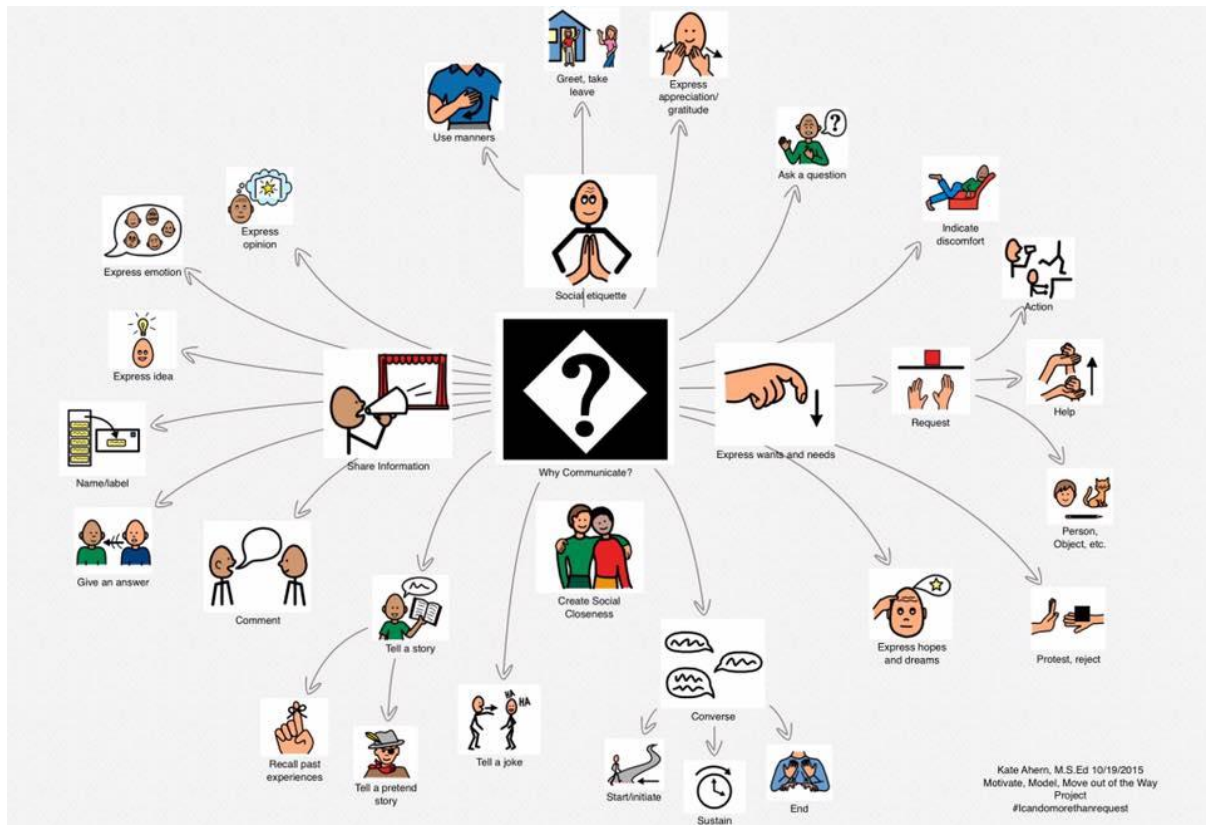
What is AAC?
Augmentative and Alternative Communication is any means of communication that is not spoken word.

If your child cannot communicate in all the above ways using their voice they should have access to a robust communication system.

Types of AAC.
There are different types of AAC but it should be a full and robust system. This means that the user has access to words to allow them to say what they want to say when they want to say it, and to whom they want to say it to.

Some examples of full language systems include PODD, Proloquo2Go, TouchChat and Avaz. As with anything there are reasons for choosing one over the other. If you are looking for advice some of the Facebook groups mentioned later on may aid your decision.

Presumed competence

First described back in 1984 by Anne Donnellan[2], 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
2. Do not teach AAC

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 2 is clearly more dangerous.

The same paper discusses that any failings in teaching are down to instructional inadequacy rather than any failings by the person being taught. In other words, it is down to the team supporting the child to problem solve difficulties, not the person themselves.

The Participation Model[3] for teaching AAC has now superceded the more old fashioned Candidacy[4] approach, which required a certain skill set before being granted access to communication. This means that no one should have to wait until they can do anything before being allowed access to a language.

Teaching AAC is essentially equivalent to learning a new language. It should run parallel to the development of typical language acquisition. There are zero prerequisites needed to introduce a comprehensive language system. If we treat learning AAC the same way as we teach babies their new language, it is clear to see that no skills are required before learning can begin. Being spoken to in that language often and for a long time before any expectation of skill development is a more natural way of language development.

Aided Language Stimulation (Modelling)

Spoken word   Aided Language Simulation

No output   Aided language
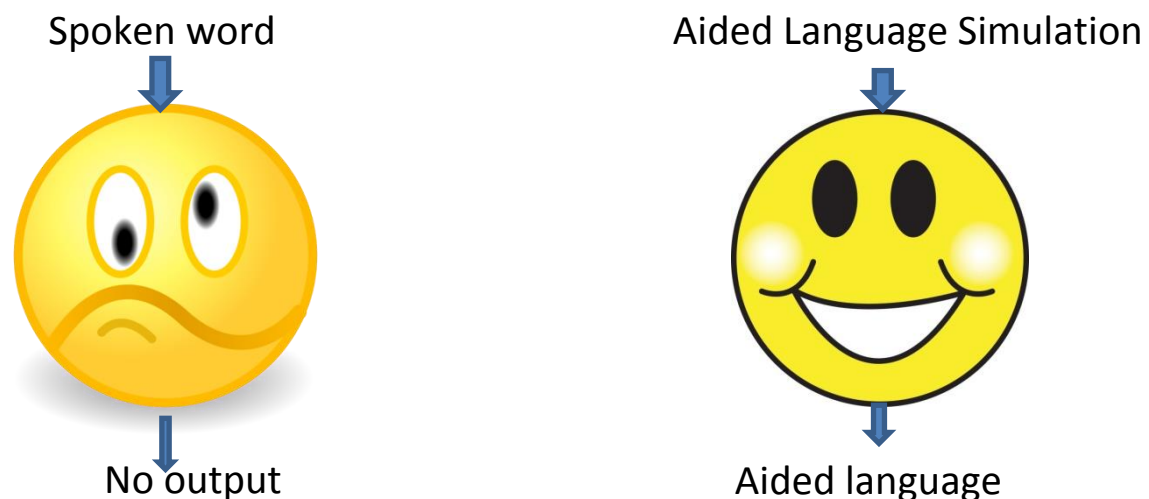
Aided language input is the act of modelling key words on an AAC device in a spoken phrase. As stated above, we should treat learning AAC like learning a new language. That means using the person's language to teach them how to respond. Using oral communication to teach an AAC user is the equivalent of speaking to a baby in English and expecting them to talk back in French. The chances of learning successful communication are not high.

We have to also consider the time it takes to fully learn a new language. A typically developing child takes 9 years to fully learn their language. They hear between 4,000 and 6,000 words per day during this time. If an AAC user only has access to language during a single Speech and Language session per week it will take them until they are over 700 years to learn the language[5].

The following table[6] was compiled by Caroline Ramsey Musselwhite and it is for users who are just beginning the journey and are not yet using their system.

| Activity	Event	Sample Language to Model
Morning meeting	Friend: shows book, toy, etc.	LIKE; LIKE THAT; GOOD
	Teacher: Uh-oh. It's raining . . .	DON'T LIKE
	Teacher: We have a visitor today	WHO? GOOD ; LIKE
Snack, Lunch or Breakfast	Para: Show 2 snacks	LIKE THAT; GOOD; EAT THAT
	Student: After first bite, reaches for food	MORE? LIKE!
	Student: Pushes food away	FINISHED; ALL FINISHED;
	Student: Holds out box of cereal	OPEN? I HELP!
Shared Reading	Something good happens in book	LIKE THAT: GOOD!
	Something bad happens	NOT GOOD! DON'T LIKE THAT
	Student wants more	TURN IT; MORE
	Student wants a turn for actions	I DO ; DO IT

Access methods

There are many different ways in which an individual can access an AAC system. This includes eye gaze, partner assisted scanning, auditory scanning, switch access and the use of a stylus. Key guards can also aid accuracy for some. Using these different methods opens communication up to all regardless of their skill set.

Where to begin?

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. Pick a language – don't procrastinate but it must be a full language system. There may be good reasons for choosing one language over another, e.g. access or support issues. However the more time choosing the language the less time using the language!

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

3. See the child, see the AAC. Problem solve taking your language everywhere, for two weeks, you have no need to open the book or device. A harness or strap of some sort is usually required. This allows the use of both hands and makes it less cumbersome. The user needs to have their voice absolutely everywhere - swimming, horse-riding, on the trampoline, climbing etc. If it is impractical then you should have the full language close by and a way for the person to indicate that they need their voice. You can use a wristband, a sign or a word to indicate that you have something to say. If using an Aided Language Display (ALD), it should have a button that says something like "I need my book" (highly recommended is a float with a laminated ALD attached for swimming). Like the one below produced by Cassidy Harm[7].
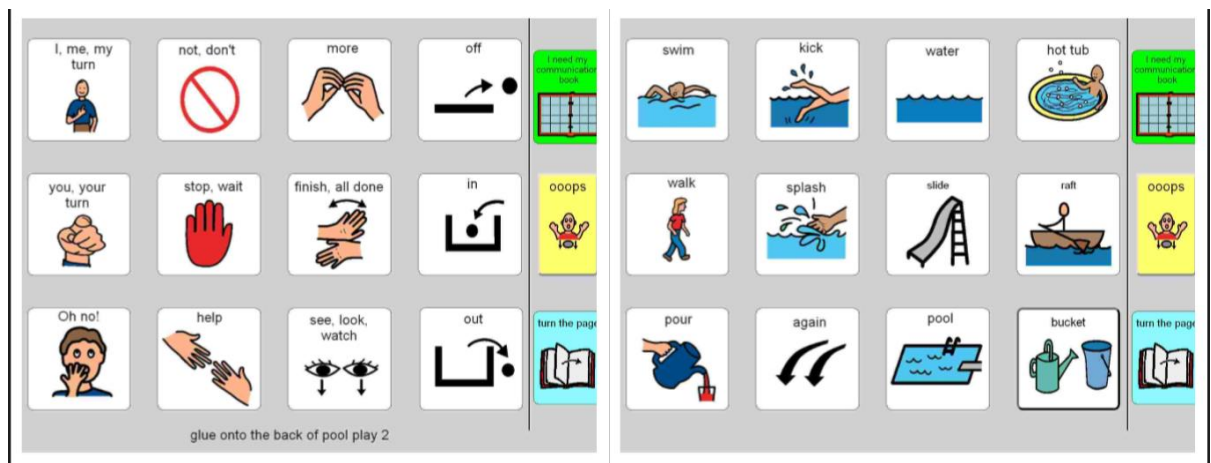
4. If possible, get a copy of the device to model on and this should be worn everywhere too. It is easier to model on a second device, it helps the AAC user take ownership of their device and it helps the AAC user to blend in.

5. It might be easier to start slowly, such as choosing four core words to model in natural contexts throughout the day, I, LIKE, NOT, MORE is the first set

recommended by the ASF communication series[8], increase over time. First locate the four words in the device and model these words throughout the day; you can use them singly or together, although be careful to model only one or two words per sentence to begin with.

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, you do not need to add an extra element of pressure at busy times. This can then be gradually built up introducing more core sets and other times when the AAC is always used.

6. Get everyone to use the system, this helps the user to see it as a valid method of communication and also decreases the burden on individuals. If only one person is doing all the modelling it is more likely to be forgotten about and the times where modelling can occur are reduced. Also, the system should never be spoken about in a negative manner in front of the person who uses it. This may be seen as insulting and it may reduce validity of the system in the eyes of the user. This can decrease motivation to use the system.

7. Don't forget to have something motivating to talk about. It is much more difficult to use AAC than the spoken word. If someone is going through the effort of using or learning AAC you should try your best to make the things they get to talk about interesting.

My list to help get everyone on board with AAC

1. We are all in this together, we need to be – never ever question it in front of the AAC user.

2. We need to model a lot, think about how many hours typical children are surrounded by their language before they speak accurately, 10 years? We need to model a LOT.

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

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

5. Always use the correct pathways to get your message across. This aids in being as clear and concise as possible. This is needed to teach how to access the full language.

6. Always model without expectations from the user.

7. Comment way more than question – it's more natural and doesn't pressure the AAC user for an answer. The ratio should be 80% comments to 20% questions.

8. Ascribe meaning to the AAC user's babbling (this is the button presses that can often be thought of as insignificant or nonsense, they are not). Babbling follows the typical progression babies go through when learning to speak.

9. If the book doesn't have the word, add it to the list.

10. The book 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. Multi-modal communication is something we all use to communicate.

How to model

1. Comment much more than question. Commenting is a much more natural method of communicating than questioning. However, it is very easy to get caught in the practice of questioning people who are nonverbal. Often the commenting that would happen with babies and other verbal people gets lost and communicating becomes an endless list of questions. When modelling AAC it is actually easier to comment than question. It means that modelling can be done with fewer words and also puts no pressure on the person learning the system to respond.

2. Use think aloud comments that reflect what the individual communicates with their body. Map that communication to their system. E.g. "I SEE you clapping your hands, I think you are saying you FEEL HAPPY." Learners with 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 compromise the system if you are wrong. They might have clapped their hands as they were retelling you a story about someone clapping their hands.
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.

3. All communication is valid, answer everything that the AAC user says/points to; this is the equivalent of babbling. When you respond, you teach that using the AAC system gets a positive response and it lets the learner know that their communication is listened to.

4. Their AAC should be thought of as a living document something that will always grow with them. Don't stop modelling even when user becomes proficient – it increases confidence if people are using the same language as you. Also, people adapt their language throughout their life and AAC users should be given this opportunity too.

5. Opportunities to model aided language are everywhere.

6. If using a paper AAC system then you must always use the correct pathways. You are teaching the AAC user how to find the vocabulary in whatever situation they need to. It also helps with motor planning which can be a challenge for many AAC users.

7. 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.

Useful apps to help with communication

Pictello – make up stories for the AAC user to read and share, mine uses this for Show and Tell

Kid in Story – similar to Pictello but you can add the AAC user's picture into the book (this can be motivating)

Explain Everything – helpful app to allow you creativity for adding to different apps, it lets you highlight words and record voices

GoTalkNow – you can buy the communication pages to go along with this but even if you don't it can be a good way to share a lot of information before the communication device is being used fluently.

You can use it for telling a story about summer holidays for example, we also have a book for Brownies. This has videos of things she has done at Brownies and also has access to frequently used phrases like what good deed has she done this week. Helpful in situations like Brownies where people are less familiar with the AAC system.

I have a book of songs. Current favourite is Let it Go. I downloaded the sing along video, cut it into different sections and added to a 9 page book. Your AAC user can now sing – they have a good voice too.

Ideas to help keep going

After the initial excitement and burst of energy it can be difficult to keep the energy going. This next section hopefully will give some ideas to help combat this. Try not to waste time feeling guilty as we all have off days. Just pick up the system and give something a shot.

Tina Zantke Thompson drafted this challenge and keeps it as the profile picture in the PODD and Angelman group. This challenge could be used with any system.

PODD book Challenge

This is intended for those of you that have a PODD book, have familiarized yourself with it and feel comfortable with how to find words, but you go through ruts where you forget to use the PODD book all day/week, or you feel overwhelmed by the idea of modeling all the time and you just need some help to change your habits.

Challenge yourself to do these five things daily and hopefully soon you will find yourself using more and more PODD and for those days when you don't do more, at least you can feel like you did something at the end of the day.

1. Pick a quick word. (Any word from pages 1a and 1b). Challenge yourself to use it at least 5 times today. Pick a different word tomorrow.
2. Pick one activity that you do daily (something simple that you usually know is about to happen before you do it, like eating, turning on the tv, or going to the car), master how to say that sentence using PODD. Model that sentence every time before you do that activity.
3. Ask another adult a question today. (Can be any question, such as how are you, where are you going, what are you doing, what's your name?)
4. Carve out a time during your daily routine (maybe at the dinner table, or before you give meds, or bedtime, or after bath), where you use the PODD book to say one thing that you did today.
5. Give an opinion about something today. (If your dinner is yummy, you can say "I like this" "yummy" or if a telemarketer calls you can say "I don't like this" "annoying").

BONUS: Come up with your own simple list of things you can do daily to model PODD and switch up your five daily. Draw them out of a hat in the morning and challenge your family members to see who gets their five first. Make it fun! (Tina Thompson)

PODD competition – Rules

This is a competition from my own house. Rather than appealing to people's better side I decided to go for competitiveness and shame!

1. Participation is compulsory for everyone who comes into the house
2. There will be prizes but there are no guarantees of when you will get one. Top prize is having Leia converse with you spontaneously, and the resulting afterglow. You may forever more bask in the glory that you have helped Leia on her road to language aquistion.
3. Points are given out for;
   a. Leia and you carrying both talkers with you the whole time you are together (1)
   b. Making sure Leia always has PODD (1)
   c. You (not Leia) manage a spontaneous use of PODD (2)
   d. You manage to use the word of the week in a short sentence 5 times (5)
   e. Play one of the PODD games from "Stuff to work on with Leia" (7)
4. Bonus points for;
   a. Original games using PODD (10)
   b. Knowing where something is when Tracey doesn't (3)
   c. Thinking of a word that needs added to the vocabulary (3)

Name	Points	Time spent with AAC user(hrs)

Games to play that use AAC

A lot of these games have been adapted or copied from the CALL Scotland booklet "Keep Talking"[9]. It is available to download here http://www.callscotland.org.uk/downloads/books/

NOTE Playing these games should never force a response from the user, but rather modelled using the device. Many of these games propose an answer to a question so it does not align with the 80-20% ratio of comments to questions[10]. However, playing these games as a fun way to model the device is okay. I would also suggest the removal of all time limits for competitive play as this will likely cause increased anxiety for many AAC users to 'perform on demand'.

Silly stories

This game is played with a few players, each one needs a pen and a bit of paper. You read out the following questions (or make up your own storyline) each person writes down their answer and then passes the paper round to the person on their left. This repeats for each question. At the end read out the silly story.

What time of day was it? (insert symbol of clock);

Where were they?

Who was there? (has to be a girl/woman/or female animal or character);

Who else was there? (has to be a boy, man, or male animal or character);

What did she say to him?;

What did he say to her?;

How did they feel?;

Then what did they decide to do?

Stories 2

Each person takes turns each to put a word into a story.

The frog jumped into the pond – plop

Players take it in turns to say the words from the above sentence in turn. On the next round each word gets said twice, then three times, etc. If you make a mistake you are out.

Where does it belong?

This game helps familiarise the players with the where vocab is on the talker

Work your way through a variety of concept categories on different occasions;

Parts of the Body –   socks/feet; hat/head; gloves/hand etc;

Parts of the Body (activities) –   thinking/head; blinking/eyes; chewing/teeth or mouth; jumping/legs; etc;

Transport –   wheels/car (or bus, bike etc.); pedals/bike; wings/plane; sail/boat etc;

Places I go –   trolley/supermarket; petrol pump/garage; ticketmachine/cinema; bench/park; table/café, etc;

Animals– scales/fish; fur/dog, cat, lion etc.; feathers/bird; collar/dog; claws/cat; beak/bird, etc;

Sports - ball/football, rugby etc.; racquet/tennis; club/golf

I went to the shops

Everyone takes turns of adding something in but before you do you need to remember what everyone before you has said. Can be done alphabetically with support.

How many things can you find that?

Can be competitive use a timer or just count number– any category that you choose

2 legs?; 4 legs?

Have wheels?

Can go in the sky? (can fly on their own?; can fly with an engine?)

You would find in/on water?

You might see on a road?

Are yellow (or any colour)

Are furry to touch?

Need electricity to be able to work

Treasure hunt

One person hides some items and the other person follows directions to find them.

Imagination game

You go to a different planet, what is that planet like? You all have to act as if you were on that planet.

You are an animal, what animal are you, act it out.

You are feeling very emotional, how do you act to when experiencing that emotion.

Any other silly games that involve overacting a choice from the AAC system! Take turns choosing but everyone acts the scenario out.

A plea for a voice

This was a letter drafted for the purpose of creating the buy-in for school teams to promote the use of comprehensive AAC systems. Please feel free to use as needed:

To all the adults who make decisions for me,

I would like to take this opportunity to ask for a really small thing. Well, let me clarify that for you. It's a really small thing, but for me it's massive.

I would really like access to a voice – a full voice that lets me say what I want to say, when I want to say it.

Ok I hear you, you don't think I can manage and it's too much for me – I might get overwhelmed, but hear me out.

I have been thinking about my baby cousin and how he got access to his voice. Here was me waiting for him to have to prove that he could use it. That's what the rest of us have to do, right?

Listen to this, they were crazy. They talked to him before he was even born, what's that about, that dude can't even breathe never mind point or nod.

Then I noticed that he didn't make a single sound for weeks, months even. But you know what, they kept talking to him using the same language. They didn't switch languages on him every few weeks.

It gets even stranger. He starts talking back to them in some weird sounding language, I have never heard anything like it, even the dog makes more sense. So here was me thinking; "that is it, he has blown his chances, new system here we come". But do you know what they did? They spoke back to him as if he was making sense! Here is an example:

Cousin: "goo, blu, coo, coo"

Aunt: "Yes you have got the best mummy ever; I love you telling me all these stories"

Really?

You know what else I noticed? If my cousin didn't answer in the way they wanted, no one ever gave 'The Look'; you know the one that says he is just never going to get this. I also noticed he didn't have to choose a lot between two random things on demand. All the stuff they talked about seemed more natural. Everyone believed in him no matter what rubbish he spoke. That side of the family have always been weird.

A much more normal approach is what my mum's friend has being doing. She is good at languages, teaches them and everything, so she decided that she would take up Mandarin. Off she goes to a class every week for an hour (I mean, it's a bit excessive but she's keen, I'll grant her that), apart from holidays and when life gets in the way she is there, primed up and ready to go. It's been about 1.5 years and she ain't exactly high functioning but hey, she can say hello and goodbye and who am I to judge.

Lately though I was wondering. Is it time to join the weird side of the family? What if I could get taught in the same way as my cousin, he has made much better progress than my mum's friend? I figure that if you just start teaching me the language, we can be working on a point or a yes or no at the same time. I mean, I know you think that I won't ever be able to do it but what if I can and you don't give me the chance? If you give me a full language, teach me how to use it, respond to my attempts in a positive way and give me time then who knows?

So I will make you a deal. If you give me this chance and you meet me in 20 years and I have a full life and a chance to contribute I will let you share in the glory. You can honestly say this started with your belief that this could work. (The rest of it is down to my hard work and everyone else's but you don't need to mention that). Hey, see even if I don't manage to get to that level, I do have a lot of good stuff going on in here, and you will be able to look me in the eye and say that you believe in me. That on its own means a lot to me.

Thanks for taking the time to listen.

Tracey Campbell,

On behalf of [insert name]

Where to get your information from

The ASF communication series – this is your number one stop. Some of the top people in the world have put this together. It is a series of lectures that are ongoing throughout the year taking you step by step throughout the process. I cannot recommend this enough, regardless of your experience.

http://www.angelman.org/understanding-as/communication-training-series/

Facebook groups –   Angelman Literacy and Education (including Alphabet Therapy)

AAC SLCN Literacy

PODD and Angelman Syndrome

PODD Europe

PODD for Angelman Syndrome and other CCN (ALL are welcome!)

AAC through Motivate, Model, Move Out of the way

The 100 Day AAC Challenge

Augmentative Communication Resources and Help

Pictello Users Group

Blogs to follow –   Jane Farrall

PrAACtical AAC

Uncommon Sense

Star in Her Eye

Understanding Lu: Blog updates and Rett Syndrome Awareness

Give the boy a chance

CALL Scotland

Communication Matters