



The Power of Communication

Robert Steeples (Care Manager) and Amy Steeples (Speech and Language Therapist) tell us about communicating with their sister, Claire.

What would a world be like without communication? Think about this morning, how many times did you communicate before 9am? This might have

been saying good morning to the cat, sending an email, asking your son what he wants for breakfast or maybe even a rant at the driver that cuts you up on a roundabout. We communicate all the time, as human beings are programmed to seek out others to make our needs known, to share ideas and opinions, to share problems and to hopefully find solutions. It is a fundamental need in all our lives. So, what would life be like if you couldn't communicate? If you had, say, difficulties in being able to ask for things or even to tell someone you were sad? It's hard to imagine, however that this is what life is like for some of the clients we work with. Our job is to help them find their voice and a way of communicating.

So, what can happen if you are struggling with your communication?

One common outcome is a huge impact on behaviour. There was some interesting research done in the criminal justice system, when they looked at youth offenders and assessed them for difficulties with their speech and language skills. Of the 7000 young offenders assessed they found that 60% had significant language difficulties with the most common areas of

concern being their comprehension and their narrative skills¹. This means that they are struggling to understand what is being said and what is going on around them and then having difficulties in explaining what has happened. This leads us to start questioning whether communication is a factor not only in their behaviour but also their criminal convictions as this finding is too great to ignore. Perhaps the child said something they shouldn't, misinterpreted the situation, the tone or what was said to them. Then once into the system, perhaps they didn't have the vocabulary or the expressive skills to explain what happened in an interview, they couldn't accurately sequence the events or answer the questions properly when giving evidence in court. At every point of the justice system communication is involved so it is no wonder that children struggle when 60% of them have significant difficulties communicating.

Communication is not just about the words that we say. In fact, research originally done back in the 60's by Albert Mehrabian found that only 7% of the impact we have as a speaker comes from the words we say and

actually 93% comes from our non-verbal communication – our body language and the way we sound². This has then led us to explore other ways of helping people to communicate. We can use body language, sign



language, writing, drawing, pictures, facial expressions, eye gaze or even technology. These additional ways of supporting someone to communicate are termed AAC – Augmentative and Alternative Communication. This can range from low tech AAC such as drawing to high tech which involves technology such as that used by Stephen Hawking. All of these though have one thing in common, they give people a voice, a way to communicate and have their voice heard.

We are going to focus on one particular AAC strategy which has not only made a huge impact for the clients we work with but also completely changed life for our sister. This tool is known as PECS – Picture Exchange Communication System. PECS is a communication tool which uses pictures and symbols to help an individual initiate communication and conversation. It can be used with a variety of clients but needs to be implemented in a controlled and planned way to ensure its success.

PECS originated from America and was developed by Andy Bondy and Lori Frost. They started using this system of images with pre-school children who had a diagnosis of autism, helping them to begin communicating what they wanted and needed. It is now used worldwide and with a huge range of clients who struggle with their communication³. Each client using this system has a personalised folder of images that are useful and relevant to them. To communicate they select an image and hand this to the communication partner to request that item, for example they may find and exchange an image of a glass of juice to request a drink. As the client becomes confident using the system, this can be built up to create sentences, request more complicated items or even to comment and communicate thoughts and ideas about a subject such as on a walk – ‘I see a bird’.

In 1977 our sister Claire was born. Following complications and lack of oxygen at birth she was left with a brain injury and a severe learning disability. She started school aged 5 in the UK but at that point the family was faced with a huge decision. Her father worked for the FCO and was given an ultimatum: being told no other family has these complications, find your disabled daughter a residential home or resign from your post; postings cannot accommodate a child with needs. So, that’s what the family had to do. They took postings in Europe so they were never more than a few hours flight from Claire but had to find her a suitable residential school and maintain her care and needs from afar.

School progressed well and staff worked effectively with Claire, by getting to know her and drawing out the best in her. However, as Claire got older and moved into adult residential settings, the care and support changed. One-to-one support was almost non-existent and previously nurtured skills were lost and forgotten. Sadly, this was the same with her communication. Until then, Claire had a limited range of words she used to communicate her wants and needs, even speaking to her family on the phone. Once in adult services, she became isolated as support and encouragement stopped. Her anxieties increased hugely and so did her challenging behaviour. She had no control or choice over her day, had no way to communicate and no support was put in place to help her understand what was happening. Staff regularly reported that she was too old to learn new skills and was written off. This escalated over the years that she spent in adult social care and led to her pulling out half her hair. She went on to develop strong challenging behaviours that we still see at times today.

When she was 30, the family made the decision that enough was enough and they removed Claire from the residential care system. They bought her a small house and began setting up a caring environment around her that was person centred to meet all her needs, one of the biggest being her communication.

Her brother Robert set about introducing her to PECS and created a folder of symbols including all her favourite things and most treasured items. Slowly he built up her knowledge of the images and repeatedly they practised exchanging for items until Claire realised the meaning and benefits of the exchanges. This changed her life. All of a sudden, she had control and had a voice that was being listened to. Her challenging

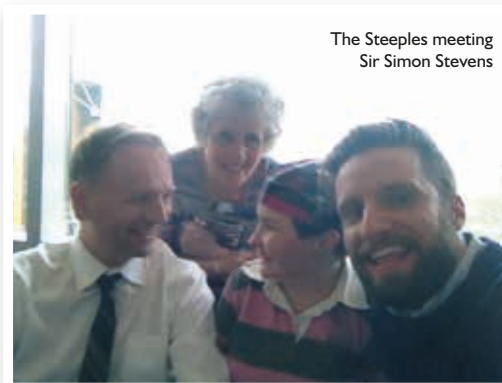
behaviour slowly reduced, her confidence grew and finally, so did her hair. In her 30s, Claire was able to learn a new way to communicate and create a new life because she had the right help and support around her. Her motivation and desire to communicate was always there, it just needed to be unlocked.

Since then, Claire and her family have spent time campaigning for personalised care and the rights of adults with learning disabilities particularly for support around their communication.

They regularly attend conferences and forums, telling their story and helping other families. They have won two accolades with Skills for Care for their efforts and designing a new model of working. In 2015 they were also invited to London to meet



with Sir Simon Stevens, head of the NHS to talk about personalisation in the adult care world. Claire communicated with him using her PECS and showed off her newly found voice.



Now, at age 43, her PECS book

is central to her life. Throughout the day she will select images of activities she would like to do, items she has lost, to request a snack or drink or even to ask for bath and bedtime. She knows that when she uses her symbols she can communicate what she needs and that this will be listened to and get a response. At times she can’t always have what she has requested such as numerous ice creams! But that begins a conversation and we can help her to understand why that can’t happen or build it into a schedule for later in the day. This has become even more prominent recently with the arrival of Covid 19. Routines stopped overnight, many of the activities Claire loves have been closed, she hasn’t been able to go horse riding or to a disco for over a year and access to the swimming pool, her physiotherapy, has been very limited. She often requests to go to the zoo or to see her friends but this is just not possible. It has been a challenge but she has been so resilient and adapted to these changes, finding new interests in crafting, baking, dog walking and a huge love of virtual sessions! Now when Claire requests friends or one of the specific people photos we have created for her, we give them a video call and say hi!

Claire’s life has changed vastly and all for the better. She now has a life not just an existence and most importantly, she has the power of communication.

You can find more details on their website: www.cpstrust.co.uk

References:

- 1 Bryan (2004) Speech and language therapy for young people in prison. Submitted to HM Prison Service and quoted in Bercow Report 2008
- 2 Mehrabian A (1971) Silent messages, Wadsworth, California: Belmont
- 3 Pyramid Communication Consultants, (Accessed 2021), <https://pecs-unitedkingdom.com/pecs>