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Alan Martin

‘Mouse on the Move’

JOAN RUDDELL

Alan was 31 when he was given his first communication aid, ‘The Liberator’. Good friends worked hard to raise the funding and it turned his whole life around, enabling him to show us all what could be achieved with determination, commitment and, above all, humour.

Alan insisted that he was just an ordinary man, with nothing special about him at all. That was certainly not the case, as those who knew him can testify! His personality shone through all the challenges that he faced in his too short life.

In the early days of using AAC, Alan was delighted that he was now able to start to make choices about his life. Just being able to say ‘Yes’ or ‘No’ meant so much to him.

Over the 18 years since getting that first communication aid, Alan struggled to master many different devices, with different software. Nothing came easily for him; just finding the words in his head before converting them to speech was very difficult. Alan told us that he thought in pictures and moving images, not in words. Preparing speeches and presentations took many long hours of hard work but he was so motivated to be successful that he persevered.

In those 18 years of having a voice, Alan was able to move from family care, to live independently in his own home, employ his own staff and make all the important choices about how he lived his life. He started earning his living by setting up his own business, ‘Mouse on the Move, Dance workshops’. He was fiercely independent and very bad at taking advice from his well-intentioned staff, who eventually learned that Alan usually knew what was best for himself.

Alan lived his life to the full and crammed into a few short years achievements that many of us never manage in a whole lifetime.

Taking courses to make up for gaps in his early education, Alan gained qualifications in disability equality training, computer studies, facilitated communication training, business management, workshop leadership skills, creative dance and a host of other subjects.

He worked for several years voluntarily, gaining experience and honing his skills until he established his own business in 2004. He was very proud of himself for earning his living from his work and had great ambitions to spread the word about inclusive creative dance. He was excited about a new development known as ‘light painting’ which used creative dance as a vehicle to produce unique and beautiful light photographs. Some of Alan’s early light paintings now adorn the walls of public buildings in Liverpool and a few lucky friends were given a light painting as a gift. Alan was not forced to come off benefits, and go into work. He chose to do so. He felt that the only way to know if people genuinely accepted and valued your work was when they had to pay for it!

A great many people from different areas of life came to pay their respects to Alan at his funeral, reflecting the number and variety of networks that had welcomed Alan into their hearts. Those friends came from creative music technology, performing arts, politics, local government, university research, community dance, charities, disability equality, motorcycling, coarse fishing, communication organisations, theatre, TV and film-making and rock music to name just a few! He was known, respected and loved by so very many people.

Alan had much to teach us. He recognised the truth that so many professional people ignore, which is that disabled people are often the real experts about their own lives or conditions. He was often asked to present his views from his own ‘lived experience’ of having a severe disability. At conferences of architects, equipment providers, doctors, town planners or politicians he did not hold back and ruffled many feathers by telling it as it is. There are
numerous photographs of Alan getting hugged by politicians. He always made sure of getting his message across before they moved on to another photo opportunity. "Communication is a basic human right. Funding for assessment, training, provision, maintenance, replacement, should be provided by statutory services not charities, for all who need it."

Alan fumed inwardly and on occasions outwardly too, about the inequalities of services. He did much to move things forward. Communication rights, and inclusion in all aspects of life were his main themes. In 1995, when the Disability Discrimination Act was in the news, Alan was very excited that at last disability equality might really be achievable. When it became obvious that the Act had no ‘teeth’, and was becoming side-lined by issues of cost, he was saddened and angered. He wrote a song about the DDA which, thankfully, was never made public. It began with "The DDA is rubbish. The DDA is shit" and got worse as it went on – the rest is unrepeatable!

There were never enough hours in the day for Alan. He worked late into the night on programming his communication aid with phrases to use at the next job or event. When not out working and earning his living, Alan enjoyed coarse fishing with the only PA who could bear it! He would tend his garden, watch football or old wrestling matches on TV. Alan was always one for a bargain when he went shopping to buy his favourite foods, or to flea markets. He was a keen eBay trader and made a fair profit on non-food ‘likes’ included Liverpool Football Club, Status Quo, black clothes, long showers with lemonade ("go easy on the lemon and no ice, thanks"), Southern Comfort with milk and one sugar, not too hot, thank you!), Southern Comfort with lemonade ("go easy on the lemon and no ice, thanks"), Newcastle Brown Ale, cheese and his own home-grown strawberries. He loved chocolate and more chocolate! Non-food ‘likes’ included Liverpool Football Club, Status Quo, black clothes, long showers with chocolate scented shower gel, cats, both large and small), motorbikes, skull and crossbones, clothing, and more), fishing, gardening, writing music and dance. Alan had a soft spot for ladies of all shapes, sizes and ages! And he really did not speak when he hit the buttons. This page was set up for situations where he couldn’t endure how dull and boring things were and he had to escape. He’d indicate to his PA that he was moving to some fresh air.” “I’m sorry. I’ve come into the wrong presentation.”

He himself could never be accused of being boring. Some of his naughty behaviour as a child was just his attempt to liven up the proceedings, in school lessons, and later on, those endless ‘day centre’ days, where Alan says that he almost died of boredom. Nobody who had been exposed to Alan’s ‘dressing up’ will ever forget the sight. At 1Voice events, he was a wizard, a circus ringmaster, the Old Man of the Sea, his own master, the Old Man of the Sea, his own master, Alito Alessi, from Oregon, a leader in inclusive creative dance, that separating people into ‘Special’, ‘Disabled’ or groups with any labels like that, was the cause of so many of society’s problems. Accepting each other’s differences, and then just getting on with life together, was what Alan believed in.

Among his long list of ‘likes’ were coffee ("with milk and one sugar, not too hot, thank you!") and "Southern Comfort with lemonade ("go easy on the lemon and no ice, thanks"), Newcastle Brown Ale, cheese and his own home-grown strawberries. He loved chocolate and more chocolate! Non-food ‘likes’ included Liverpool Football Club, Status Quo, black clothes, long showers with chocolate scented shower gel, cats, dogs (both large and small), motorbikes, skull and crossbones, clothing, and more), fishing, gardening, writing music and dance. Alan had a soft spot for ladies of all shapes, sizes and ages! And he really enjoyed seeing his beloved family. Usually quite tolerant of other people’s faults, the thing he could not tolerate was boredom. He had a ‘secret’ page on his AAC device which was silent; it did not speak when he hit the buttons. This page was set up for situations where he couldn’t endure how dull and boring things were and he had to escape. He might indicate to his PA that he was moving to some fresh air.” “I’m sorry. I’ve come into the wrong presentation.”

He himself could never be accused of being boring. Some of his naughty behaviour as a child was just his attempt to liven up the proceedings, in school lessons, and later on, those endless ‘day centre’ days, where Alan says that he almost died of boredom. Nobody who had been exposed to Alan’s ‘dressing up’ will ever forget the sight. At 1Voice events, he was a wizard, a circus ringmaster, the Old Man of the Sea, his own sister, Widow Twanky and a pirate, to name but a few. At Communication Matters he was a mime artist, Boy George, Dr Fank-n-Furter, and even HM the Queen.
Apart from boring things, Alan hated prejudice and bigotry. He couldn’t abide the celebrity culture, which applauded and rewarded people for trivial qualities, while not recognising genuine goodness. He hated the attitudes and ideas which suppressed people with disabilities.

Communication Matters conferences were one of the highlights of Alan’s busy year. His first was in 1996 where he listened to Jenny Selby give her presentation ‘Does She Take Vodka?’. That gave him the motivation to give his own speech the following year. In 1997 Alan gave the ‘Distinguished User’ presentation. It was the most embarrassing day of my life. He made his speech, which went very well, with great applause. Then he beckoned me up onto the stage. I thought he had cramp and rushed up the steps onto the stage in front of around 300 people. “Happy Birthday, Joan”, he said. The giggling from the audience erupted into laughter when he followed that with “She’s 50 today!”. I was crimson for the next two days. I should have resigned right then, as it was just a taster of the tricks he played on me over the following 15 years.

Alan never missed a Communication Matters conference, and attended sixteen in all. Often he gave presentations, which will be found in old copies of journals. CM was the springboard to so many other things in Alan’s life. At the exhibitions he would grill the suppliers and ask all the most awkward questions: “If I bought your product and it developed a fault, how soon could you get a loan device to me?”, “How much?”, “How many people use these, and how many have had problems?”, “Can I use any software I want with your device?”. He was always on the lookout for the newest and best AAC software and devices.

At his second CM conference at Lancaster University, Alan met Katie Clarke, one of the founders of the 1Voice organisation. Katie invited Alan to attend the forthcoming winter event in Blackpool. This was to be one of the first 1Voice events and was ‘The Harry Potter’ weekend. Alan went along as an adult role model for the youngsters and their families. He made dozens of firm and enduring friendships at that first meeting and supported 1Voice events as often as his work commitments allowed after that. 1Voice branches have now sprung up across the country and Alan became the joint leader of the new Cheshire and Merseyside Branch, based on Wirral.

CM conferences gave Alan opportunities to practise public speaking and giving presentations. He held one of his first dance workshops there. He made so many networking connections that it took weeks following each conference to get back in touch with people he had met. One of his most memorable contributions to CM was on the dance floor, where he demonstrated that everyone can, and should, dance. He also indulged his exhibitionist side by dressing up for the fancy dress parades. Some of his costumes were unforgettable to behold and even more memorable to the staff who had to go with him to buy the fishnet stockings, black satin basque, suspender belts, makeup, and more. These events were even more memorable for those who had to remove the black nail varnish and eye makeup at 2am, before Alan was to appear suited and smart at 9am for a formal presentation!

One real conflict in Alan’s life was whether he should use his communication aid or try to communicate with his old methods of facial expressions, body language, signing and pointing. Should he just wait for the right ‘Yes’/’No’ questions to be asked and then give the thumbs up or down sign? He was a great communicator either way but he soon saw the value of having a voice which didn’t rely on only being understood by the few people who knew him very well. It is possible to sign many things but when it comes to person and place names, quick pre-stored phrases and more difficult concepts like equality and human rights, there is no substitute for being able to say “I believe that communication is a basic human right, for ALL people”.

The life story of Alan Martin is soon to be written. Any contributions would be most welcome. The few words in this article just cannot do him justice! *

Joan Ruddell
Communication on the Move

BETH MOULAM
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This article shares the process of learning to drive, a normal experience. I have approached this in stages. From why I wanted to drive through to applying for a licence, getting finance, and the adaptations needed.

I have dreamed of driving since I was very little. I have photos of me in all sorts of cars and vans since I was a baby. At age 6, I got my first motorised toy car, a two seat battery-operated jeep that took me around our village, up to the playground and let me play with a friend. Everyone always wanted a turn. At 12, I met Meredith Allen, a fantastic Australian woman who uses a Lightwriter. We first met at ISAAC in Düsseldorf in 2006. In a presentation, she mentioned she drove a car. That was it. If Meredith could drive, so would I.

NECESSITY FOR SAFE INDEPENDENCE

Being independent has always been important to me. I live in a small village with a two-hourly bus service during the day, Monday to Saturday. From 14, I used the bus regularly to get into town, both by myself when I was meeting a friend, or with my personal assistant. I quickly decided I did not want to be stuck at home during the evenings and Sundays. However, the bus is not particularly safe; the week of my 16th birthday, the bus I was on had to make an emergency stop. My chair spun around. This broke both the arm for my joystick, and tore the ligaments in my right hand. That was it for me. Driving became not just a dream but a necessity for safe independence.

ASSESSMENT FOR PROVISIONAL LICENCE

For most people, taking a test is just a case of filling in forms and having lessons. For someone like me, with a physical disability, even getting the licence was a long and drawn out process. I had to jump through hoops, although not literally. There were so many steps. First the provisional licence. I couldn’t apply online as there are special forms to fill in when you have a disability. So on my 16th birthday I made a trip to the post office. Once I found out more, I discovered it was going to be £50 for the provisional – that was fine. Then I discovered I had to pay for the assessments. To save money I decided to get assessed first in case they said ‘No’. I didn’t want to waste £50.

Luckily, two weeks after my 16th, I won the lottery: I got five numbers. Actually five numbers is not quite as much money as you might expect. But it was more than enough to pay for the licence and assessments. To save money I decided to get assessed first in case they said ‘No’. I didn’t want to waste £50.

By this time it was August, four months since I’d got the licence forms. The website had said the assessment could take a long time, and therefore to take some food. I was so glad I did, we were there five hours. The staff there were fantastic, but having Mum along was essential. She helped me transfer on and off the reaction rig – a machine with a car seat that has flashing lights and videos to simulate driving and reaction. Whilst I answered all the questions Mum sat at the back of the room. In some tests when they didn’t understand my speech she had to repeat what I said. Most of the time this seemed quite random to her. It isn’t really possible to use a communication aid when your head is fixed in a machine to test vision or spatial awareness, so someone to help is useful.

In the afternoon I was eventually let loose on a Nissan Micra. I spent more time on the grass of the driving circuit than I did on the road. I couldn’t turn the steering wheel even with light touch controls and a special handle. Fortunately they recommended a high-tech assessment as I could do everything except steer. This included being able to manage the brake and accelerator.
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with my feet. That amazed everyone including me!

Next I went back for the high-tech assessment. It was very different from driving the Micra, but so fun. I got to do several laps of the circuit and loved every minute of it. It took another couple of weeks and finally I got a second detailed report. By now it was October 2010, the reports were ready, the forms were filled in. I had been to my GP to get him to sign something too. Copies were made and everything was posted off to the DVLA and to Motability.

This was where I made a big mistake. I had not requested on the DVLA forms for email correspondence, or for an ‘appointee’1 to talk to them. I discovered it was impossible to chase them. All they would tell Mum was that they were processing my application. We did discover from the doctor he had been asked to do a report so knew something was happening. Whilst waiting I had also seen my neurologist and he was happy for me to drive, so I didn’t have any concerns.

GETTING MY FIRST VEHICLE

One day in mid January I was sat at home: I was miserable and unwell when the post came. Yippee, Yippee, Yippee. My provisional licence had arrived. What did I need to do next? I had had an acknowledgement from Motability so I knew they had my application for financial assistance. Now was the time to take action.

I sat down and programmed what I wanted to ask Motability into my Lightwriter. Then I phoned the grants team. Reception at Motability was great. I got through and the Grants team listened carefully. They promised to start processing my application. We agreed they would phone Mum later in the week if they needed more information. I nearly fell off my chair when Motability phoned back the next day and said my application was approved. They would confirm in writing but would provide me with a suitable vehicle and driving lessons.

Next step a Motability assessment. Four weeks later off I went to Harlow. There had been some phone calls to Mum about my chair, how I would drive, what I needed to have space for in the car. Mum and I thought about the next five years: where would I be in my life? Then we wrote a list of what I needed from taking a shower chair when we went away, to having two personal assistants when I was away overnight. I was prepared when we got to Motability. I could tell and show them why I needed a car with two passenger seats plus the driving seat. And also what space was needed for all my baggage. As a charity they only pay for the driver’s needs so without this planning I would only have got a car with one passenger seat. Once again, as part of the assessment, I had to prove I needed the high-tech controls. I think it was very trusting of them to let me drive a normal car around their car park after what I had done to the grass at my first assessment. But then they didn’t know how bad I had been!

In early April, Motability came to my home. They brought two vans. One with the right adaptations and the other the van they thought suited my needs. I got a drive in one and a try out with my chair and doing transfers to the driver’s seat in the other. It felt like the plan was coming together. Especially as I got to drive up and down our road and park perfectly by the kerb. The van was ordered, I chose my colour, and in anticipation of delivery during the summer holidays began learning for the theory test.

Meanwhile we got news that the van was delayed coming off the production line. It won’t arrive until November. I started hoping that it would be a Christmas present. This did give me some worries about learning to drive in bad weather. However, I need not have worried about the weather as there were still further production delays in Germany. Suddenly I was hoping to get a van for my 18th birthday. Two years from starting the process but at least I would be learning to drive in good weather.

In February 2012 we got a call to say the van was ready for my first fitting for the adaptations. They called on Thursday, and I was so eager that we were there on the Monday morning. The list of adaptations needed was huge. As I am moving out of my chair into the driver’s seat to drive, this also included a mount for my communication aid. Motability think this is needed so I can talk to the RAC if I break down. I have slightly different ideas; I plan to try out the Lightwriter mount finally positioned, but delivery was promised for the next Monday.

THE FIRST DRIVING LESSON

Delivery day dawned. The driving instructor arrived for the first lesson and I was so excited. What a bummer. I got to sit in the van but nothing more. It took the whole lesson to show how the foot pedals were installed and removed, the space drive controls set up for my steering box and how the bleeper system worked. The instructor disappeared after agreeing lesson dates and we still had paperwork to sort. My plan of arriving outside school driving went out the window!

The bleeper is a switch at the end of the arm rest for my left hand. I drive with my right. Each time I press it in and hold until it bleeps for the function I want. So one bleep is for a headlight flash, two bleeps to indicate left, four bleeps for the horn. There are nine bleep functions in total.

Motability pay for driving lessons for under 25 year olds. They say they don’t want to pay for an expensive van and then have it sat on a drive unused. I get 13 hours before I pass my theory test and then up to 40 in total. Wish me luck! The instructor and I have talked about my hearing and how he will use signals for some instructions. He will only ask closed questions when I am driving. When we stop and park, we can have a conversation and I can ask him questions.

THE THEORY TEST

The process for booking the theory test is something else that takes longer. The Driving Standards Authority has to confirm the additional assistance I need which meant emailing all the evidence they want, provided by school, and now it takes up to ten days for them to agree. It then takes a further three to four weeks to get a separate room along with extra

1 Appointee is the DVLA term for a person nominated to act as a helper.
time, my own room, a reader and a scribe. The test for both the theory and the practical is the same as everyone else, just with extra time.

The extra time for the practical driving test is for the examiner to understand how my car works. Then to find out about what I need in terms of hearing and speech. Fingers crossed for the test when I get to that stage.

I have done some work on the day to day challenges of driving and using a communication aid. My first thought was getting petrol. Not just the physical filling up and paying but the asking for what I need. I plan to always fill the tank so it doesn’t have to be done often. My local petrol station will supply assistance if I ring ahead with my registration and then hoot my horn. If I am travelling further away from home I expect to have a personal assistant with me as I need help with personal care.

If I break down or need emergency help then Motability have fitted RAC Trackstar. This uses GPS to track stolen vehicles. It can also be fitted with a two-way switch that puts me through to a control room and we can speak. We have agreed that they will greet any contact with me by using the words “Hello, are you using your communication aid?” That way they immediately know I will use an electronic voice and hopefully will be patient. We did ask if they have a standard script so I could programme some replies but it seems not. I heard from a friend of mine who has a lot of driving adaptations that he has been stopped by the police. To prepare for this I spoke to a friend’s father who is a traffic cop. What he said is that nowadays every police car, at least in our area, is equipped with identification software and they know automatically who is the owner and who can drive the car. He also said they have access to insurance information. Really what he was saying is: don’t worry. What I have done is prepare a card to go on the driver’s seat so if I am on my own it explains I am using a communication aid and to be patient.

I’ve bought myself a Satnav. With all the switches and controls, I did not want to be getting lost because I couldn’t read a map or also hold a piece of paper. Providing the directions are good at least I can concentrate on driving.

Some of the other driving challenges include having all the different controls on lanyards or straps because if I drop anything I will not be able to pick it up. The important things are the ignition key which I have to drop into a small box by my steering unit; the lift and back door opener, for getting in and out; also a strap on my Lightwriter, essential for moving it from my chair, onto the mount in the front of the car. All these things are fiddly for me but they are possible with time and practice.

**SUMMARY**

The whole process of getting the van took well over two years, but everyone has been really supportive. They have gone out of their way to get things right for me. Nearly every step has had a communication challenge. I have to admit that having an Appointee has made it easier, especially for phone calls and chasing.

My advice is that if you want to drive, make sure you plan carefully. Once the vehicle arrives you have it for five years. Think beforehand if your life will change in this time; I know mine will, which is why I fought for the things I thought I needed. *

Beth Moulam

**WEBSITE**

The full presentation given at the Communication Matters CM2012 National Conference can be found on my website www.bethmoulam.com
Language Development Using a Multi-modality Communication Strategy for a Child with Intellectual Disabilities

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INTRODUCTION
Communicative competence is fundamental for the cognitive, social and personal development of children. For a child without oral language, alternative and augmentative communication (AAC) systems provide the conditions to promote this development, and so it is critical to use them as early as possible (von Tetzchner and Martinsen, 2001).

In this paper, we present the procedures and results of using a multi modal strategy in AAC over a period of seven years for a child, Sam, with non-specific intellectual disabilities and severe speech impairment. Through analysis of his daily experiences, we see his progress and his weaknesses.

METHOD
Multiple techniques for communication (sounds, vocalizations, words, pointing, facial expressions, manual signs, tangible symbols and graphics signs) help him understand the world and express his needs and emotions, as well as providing access to the curriculum. He naturally chooses the most suitable technique, depending on the context and his development stage.

As massive input is needed to generalise most concepts, the learning provided in speech therapy and at school is reinforced in a natural home context (Lunonen, 1996; Soro, 1998): for instance, dialling phone numbers reinforces the curricular objective of recognizing the numbers 1 to 10.

Development progresses as his understanding and communication expand. But more importantly, the ability to communicate affects his cognitive capabilities, his behaviour and his family and school relationships.

CHILD AND CONTEXT
Sam is 11 and has intellectual disabilities with severe language impairment, especially expressive communication. He is affectionate and easily establishes relationships with both adults and children around him. As he lives in a multi-lingual home he understands English, Catalan and Spanish but his level of comprehension is closer to a child aged 3 or 4.

He is in year 4 of primary education at a mainstream school, having repeated two academic years. At school, he has a classroom assistant ten hours per week and four hours of speech therapy. He follows an individual programme and communicates using a few words, sign language, a communication book and a tablet used as a speech generating device (SGD). The family provides five hours of functional activities per week to support the adapted curriculum.

He recognizes the letters of the alphabet and about 100 words but there is no prognosis for his reading or writing. He
has difficulty with fine motor skills and has problems with spatial and self-awareness. He therefore still needs some help with dressing, cutting up food and personal hygiene, and he cannot write or draw. He is able to produce some words and an increasing number of word approximations only recognizable to those close to him.

His manual signing is understandable, although not accurate. He often accompanies signing with sounds and a few words. His sentences, whether signed or using the communication book or tablet, contain three or four elements.

**AAC MODALITIES**

**Signing modality**

Sam uses signs adapted from the Bimodal (Montfort & Juárez, 2006), Schaeffer (1994) and Makaton (Walker, 1998) systems. The most functional signs were chosen and adapted to Sam’s motor ability. Currently he uses about one hundred manual signs.

**Tangible and graphic modality**

Physical objects, photographs and pictograms (including word description) were used to support communication. Currently, Sam uses a communication book and a tablet with 1,300 pictograms (PCS, ARASAAC, WLS). The pictograms are organized by grammatical category displayed on a different background colour. Nouns are further classified by themes printed on separate pages.

**Interaction strategies**

Sam started an Early Stimulation Program at age 3½. Given the slow pace of language acquisition, AAC was introduced at age 4. Twice a year since then, the school, family and the SLT have collected data about his vocalisations, spoken words, graphic symbols, manual signs, linguistic functions and comprehensive language. This article focuses on the vocabulary he acquired to build his linguistic competence and the different materials and procedures that were used during the intervention process (Basil, Soro-Camats & Rosell, 1998; Gillete, 2009; Light & Draggé, 2007).

At age 4, Sam had just 10 unclear and inconsistent vocalisations. He started learning manual signing but progress was slow as he could not mimic. The ‘modelling’ technique was used to teach the signs using the ‘back word chaining’ method (Baumgart, Johnson & Helmstetter, 1996). In parallel, photos and pictographic symbols were introduced. Eight months later he had 18 consistent and spontaneous manual signs, he could recognise around 30 photos and could use 6 or 7 pictographic symbols.

Later, monographic boards with symbols for food, school material, toys, etc. (Fig 1) were introduced and fluency was developed through educational tasks, symbolic play and natural contextual activities. A double sided triptych board with 180 symbols was created as the amount of information grew (Fig 2). At first he would only use it during guided activities or as a dictionary and its adoption as a means of communication was gradual. As he mastered the verb-object structure on the board he started to generalise and transfer it to signing. At school, the use of AAC helped with his inclusion and participation in the activities and routines of daily life.

The pictographic symbols were used both to consolidate vocabulary with exercises of grouping, relating, categorizing, discriminating, etc., and to work on cognitive abilities such as memory, attention and conceptual comprehension (e.g. big/small, here/there).

At age 7, Sam’s understanding of the world and his oral comprehension had grown significantly but his expressive capability remained limited. He often became frustrated when he could not make himself understood. AAC allowed the introduction of signposting to help him understand and remember what was going to happen (e.g. “After your bath and supper, you will have a story”). Although there was an increase in the number of pictographic symbols used, it seemed to come at the expense of signing. In parallel, Sam’s intentionality and desire to communicate was definitely increasing. Observing this, and as he started mastering the construction of two word sentences, a communication device was introduced.

Over the next years, Sam’s dependency on adults reduced, and he strengthened relationships with his classmates. At 9

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1 PCS: Mayer-Johnson
2 ARASAAC: www.arasaac.org
3 WLS: www.widgit.com
years, he could use his board or communication device to work with his adapted curriculum and to participate in some group activities and organised games.

Regarding language instruction, there was an increased focus on sentence structure to increase his ability to generalise across different environments. His oral language improved this year and he was able to repeat more sounds. Literacy continued with the support of a computer and a synthesised voice.

**The present**

With a vocabulary of around 800 multimodal words and facial expressions, pointing, gestures, etc, Sam communicates with both adults and children.

The relationship with his classmates has been consolidated and he interacts with them in a spontaneous way.

As his linguistic capacity has increased considerably, new tools were needed to hold his increased vocabulary and organise it into semantic categories. A communication book and a speech communication device with identical vocabulary and structure were introduced (Fig 3). Having the low-tech version remains useful in situations or activities where the tablet is not very functional such as in the park, on the beach or riding a bike.

**Speech communication device**

The device is used both as a learning aid and for communication. As a learning aid it supports his adapted curriculum by facilitating presentations and increasing class and group interactions (e.g. as class monitor for materials he has to ask the teachers what materials they need and fetch them; or reading out the school menu to the class). It has also been useful for vocabulary practice and sentence structure.

As a communication device, its use is still not consolidated. Message construction is slow and creating understandable sentences remains a challenge given his linguistic competence.

It is important that Sam understands that the use of the speech communication device will vary according to context: as an academic tool, the sentence elements and structure are important; as a communicator in daily life, he may use pre-built sentences to enable fast and fluid communication.

**ACQUISITION OF VOCABULARY**

**Pictographic symbols**

Sam’s progress shows that the proportion of pictographic symbols used (i.e. recognised and consistently understood) to those available has steadily increased over the last 5 years from 25% to 75%. The use of symbols has predominantly helped with his integration at school and provided the support for his adapted curriculum.

**Manual signs**

Although his initial adoption of manual signs was quite rapid, his usage reached a plateau as he found it difficult to physically make the signs and to use them to construct sentences. Furthermore, signing had a limited use in his context of a mainstream school with its periodic changes of groups and teachers. Nevertheless, with his family and friends this system is the most useful for communicating and clarifying what he wants to say.

**Vocalisations**

Sam’s use of spoken words has been consistently very low. Progress was slow until aged 9, when suddenly it increased. However his verbalisations remain comprehensible mainly only to his family and
the SLT, and are by no means sufficient to communicate with other people.

Multimodal use of vocabulary

At age 5, manual signs made up 75% of Sam’s vocabulary (34 words). However, his use of pictographic symbols increased more rapidly than his use of manual signs. At age 10, pictographic symbols made up 75% of his vocabulary and manual signs represented just 25% of the total (Fig 4).

The graph also shows that Sam’s communication remains ‘multi-modal’ as he progresses, with vocabulary increasing across the different systems. Different factors affect Sam’s choice of which system to use: the communication partner and their expertise, the context or kind of conversation, and the environment or location (school/home/beach). Most of the time, however, the different communication systems are mixed and used in combination.

Coordination between speech therapist, school and family

Concepts that have been defined in his adapted curriculum are introduced in the classroom and generalized at home. Thus his understanding of curricular activities is reinforced with practical knowledge acquired from home activities.

Each term, and with guidance from the Assessment Centre, the teacher, family and SLT meet to agree on the use of adapted materials and to coordinate learning across the three environments. At school, the speech therapist holds weekly meetings to decide on day-by-day adaptations of the curriculum.

RESULTS

The use of a pictogram board has improved Sam’s understanding of instructions and sequencing of events. As regards expressive language, he can communicate with a degree of fluency with the following people: speech therapist, helper, class teacher, family, close family friends, and with some classmates.

He communicates by using a combination of sounds, words, signs, communication book and tablet, depending where and with whom he is speaking. They are often used in combination to express a single idea.

His behaviour underwent a significant change as communication made negotiation possible, providing him a way to express his understanding or confusion, his likes or dislikes. As a result, his self-confidence and autonomy increased greatly, and seemingly his improved communication has influenced his cognitive and social abilities. The objective now is to generalise his communication skills and improve his social capabilities.

CONCLUSIONS

A multi-modal system approach provides a child with more tools to meet his different communication, cognitive and social needs. It is also a useful way to improve behaviour and social relationships.

A consistent methodology and coordination between professionals, school and family facilitates the entire learning process, the generalisation of language and a successful integration in mainstream school.

Further validation of this case study with more cases of children with similar learning difficulties would be required to investigate learning patterns and establish frameworks.

Elvira Sancho, Marc Coronas, Carme Rosell & Emili Soro-Camats

REFERENCES


Creative communication at the end of life

It’s Never Too Late to Make it Personal

KATE BURNS
C.A.N Communicate, 7 Barry Road, Bramington, Chesterfield, Derbyshire S43 1PX, UK
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INTRODUCTION
We are a multi-disciplinary group made up of:
• Kate Burns - C.A.N Communicate
• Joyce Dent and Angela Gilroy - Community Learning Disability Nurses, Barnsley Integrated Learning Disability Team, Barnsley Business Delivery Unit (BBU), South West Yorkshire Partnership NHS Foundation Trust (SWYPFT), Barnsley Metropolitan Borough Council (BMBC)
• Janet Owen - End of Life Care Clinical Lead, SWYPFT, BBU
• Sandra Montisci - Professional Head of Learning Disability Nursing/Community Matron, Barnsley Integrated Learning Disability Team, SWYPFT, BBU, BMBC
• Ann Parr - family carer

We have applied Creative Communication - a technique for including people with profound and multiple learning disabilities (PMLD) in consultation - to End of Life Care (EoLC) planning and supporting the use of the Preferred Priorities of Care (PPC) document for those with PMLD and/or learning disabilities and dementia.

In 2009, Valuing People Now acknowledged that people with PMLD were missing out and aimed to include “groups who are least often heard and most often excluded” (DH 2009:13). In its response to Valuing People Now, the PMLD Network welcomed the fact that the government had recognised people with PMLD are missing out. The response has suggestions for ways to make these ideas a reality, including: “Staff should be trained in communication skills, complex health needs, supporting people with behaviour that challenges, understanding what PMLD means, how to make best interests decisions, how to help people with PMLD show their preferences and choices” (PMLD Network, 2008: 39).

In 2009, following Equal Treatment: Closing the Gap (2006), Healthcare for All (2008) and End of Life Care Strategy (2008), contact was made with the EoLC Team with a view to exchanging staff education and building relationships. Work began on a resource that provided information for people with LD and their families/carers, mainstream health staff, social workers and frontline staff providing direct care to people with LD who required palliative care. In Barnsley we introduced the use of the PPC document in 2010 to support advanced care planning at the EoL. The PPC document is a tool used nationally to promote the discussion about, and recording of, an individual’s preferences and priorities for their end of life care and support advanced care planning. As the use of the PPC increased we found issues when trying to establish preferences for people who are assessed as lacking capacity.

The Mental Capacity Act 2005 advocates that all adults should be assumed to have capacity, unless it can be proved otherwise. The Code of Practice emphasises that “there is a duty to do whatever is possible” to empower people to be involved in decisions (Department for Constitutional Affairs, 2007). Despite this, Raising our Sights reports evidence from families of “prejudice, discrimination and low expectations” (Mansell, 2010:6). If communication is limited, those undertaking the assessment need to “ensure the person’s capacity is not incorrectly judged simply because no one could recognise their communication” (Richards & Mugha, 2005).

INVOLVE ME
In Barnsley we had developed protocols to promote discussions with carers, but it was clear that even where a person lacks full capacity they may be able to contribute in the identification of their preferences. We wished to ensure that a person’s involvement was central and ensure that once preferences are identified we work towards meeting these.
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www.techcess.co.uk  Totemic House | Springfield Business Park | Caunt Road | Grantham | Lincs. | NG31 7FZ
In 2011 Joyce Dent voiced her interest in Involving Me which was particularly relevant as we were trying to introduce the easy read version of the PPC.

Involving Me aims to increase the involvement of people with PMLD in decision making. The resource is the result of a three year project, run by Mencap in partnership with the British Institute of Learning Disabilities and evaluated by the Foundation for People with Learning Disabilities. The launch of the Easy Read PPC provided the opportunity to look at training for people working in the LD field in Barnsley to increase involvement of people with PMLD in their health decisions and EoLC, by applying the principles of Involving Me.

Of the approaches used within Involving Me, the one that best met our needs was Creative Communication (C.A.N Communicate).

CREATIVE COMMUNICATION

Creative Communication has developed over a number of years and has had previous success in enabling involvement of people with PMLD. As a personalised approach, it creates opportunities for individuals to participate as communicative partners. Working with a variety of creative methods in order to develop and understand an individual’s communication. Tools are created that an individual can share with others. These creative approaches are part of an ongoing process, thinking about how to use what you learn. “Creativity is of value in its own right... Creativity becomes communication when it is shared with others... This Creative Communication becomes consultation when it is shared by the individual with the people who can make a difference to their lives.” (K. Burns, C.A.N Communicate).

Training was staged to look at how Creative Communication could be used to support the easy read PPC and directly relate to decisions about EoLC. The days focused on interactive learning, involving exercises and stories of people with PMLD. These were inspirational and truly advocated the message “Involve me in decisions about my life”. Sessions were funded by the National End of Life Care Programme to support the promotion of PPC within Barnsley. Attendees included health and social care professionals: community nurses, speech and language therapists, physiotherapists, support workers, members from palliative care and EoL teams and local workforce development, alongside family carers. The result was a fantastic day which was extremely positively evaluated by everyone who attended.

DAVID

Creative Communication is now being applied in practice. We have produced a case study of David’s End of Life Care journey and how the learning from the workshop contributed to this. David’s case study provides an example of what happened as a result of the training and the progress made.

David’s sister, Ann, writes:

“David has PMLD and dementia. Joyce has been involved with our family, with Mum and Dad from 1988. She used to visit David when he lived with Mum and Dad at home and has recently become involved again as a community nurse. She was telling me about Kate and this course, that there were lots of things on it that would possibly help David. Before I came on the course, David had been very ill. He has had a long period in hospital and when he came out it was very much viewed that he just needed to be in bed all the time and receive very little stimulation. The day of the course I found very emotional, but it did make me realise how much more could be done to support David. In David’s first PPC it just spoke about his medical condition and his needs but his latest one involves lots of things, suggesting all the things that David likes that staff can support David to enjoy. And it tells us about how David used to be and the things he used to enjoy, to help staff to support him to recall those things.

One of the things that was brought on the course was a talking photograph album, which we brought for David. I’ve found it very comforting to know that David has got some photos of me with him if I’m not around, if I’m on holiday. He’s really responded to that. And it also helps to explain to other people who are supporting David what’s happening in the photos and again to explain about David’s life and what things he used to do.

Staff are very aware now of all the possibilities of things that can be done with David, to make sure he gets the best out of every day. They know to give him lots of multi-sensory experiences that appeal to any of his senses.

For example, David always liked the seaside as a child and we are trying to recreate the seaside here, because David is not well enough to go on a trip to the seaside. We are trying to bring things that are associated with the seaside to David. The aim is to make him a lovely seaside day; we are using sand and water, and projecting seaside pictures and sounds under a white umbrella.

Using Creative Communication has really made David more alert than he was, it’s really awoken his senses and he’s far more responsive than he was. David has a better quality of life now because of all this input and all the things that we did on the course.”

RAISING AWARENESS

End of Life Care in Barnsley is now developing and progressing. The use of Creative Communication has proved to be an inspiration. The key message about the importance of keeping the person at the centre of their end of life care planning, and using innovative ways to support communication, has been shared across services and our work has been supported by a number of providers in the field of learning disability. Our understanding of the complex challenges facing people with learning disabilities at the end of life is continually growing. We are now working
together to ensure individual needs and preferences are met.

We have presented what we have learned widely across Barnsley and South West Yorkshire, including:

- National End of Life Care Programme
- Quality at the End of Life – Working together in the regions
- Barnsley Learning Disability Partnership Boards
- Yorkshire Big Health Day
- Aspects of End of Life Training Course
- Living with Dying Conference
- Yorkshire Network for Palliative Care

and people with learning disabilities

We have broadened the awareness of being creative outside of just learning disability services. The sharing of information and ideas with others, across the medical and social care professions, and being more creative in working practice, has inspired other staff members to look at how effective communication can turn the lives of individuals around.

Individuals are dependent on the skills of the people supporting them. The problem still remains that most people with PMLD use informal communication methods, but are supported by staff not trained in alternative communication methods (PMLD Network, 2008). The staff trained in Creative Communication are now raising awareness of individual needs across all learning disability services and disciplines.

Families and carers are acknowledging the contribution individuals with a PMLD can make to their life. Our work on the PPC echoes the evaluation from Involve Me, that Creative Communication can be a “catalyst for taking action” and is now being incorporated into PPCs and influencing care across the board, not just at the end of life.

We aim to continue to develop our services and share our learning as we strive to be creative and continually improve the care we offer for people with learning disability, enabling people to both live and die well. Capturing a snippet of information from someone can lead to a whole story being formed. 

Kate Burns, AAC Consultant

REFERENCES


WEBSITES

C.A.N Communicate
www.can-communicate.co.uk

Involve Me
www.mencap.org.uk/involveMe

NHS Evidence
www.evidence.nhs.uk

CALL FOR PARTICIPATION

RAatE is the only UK conference focused on the latest innovations in Assistive Technology (AT) and will be of interest to everyone who uses, works with, develops or conducts research on AT.

Run in conjunction with Coventry University’s Health, Design & Technology Institute (HDTI), RAatE looks to provide news and updates on new technological developments, service innovations, results of formal research projects, service based research and development and a wide range of other stimulating topics.

RAatE offers you the opportunity to present to a unique multi-disciplinary audience dedicated to AT and the chance to meet and share knowledge with other people working in the field.

The conference welcomes papers, posters, case studies and workshops on subjects relating to advances in AT and engineering and would particularly welcome those that cover the following topics:

- Recreation
- Use of mainstream technology
- Factors impacting on AT control and use
- How to incorporate evidence based practice

Contributions are welcome from those working in the field of AT or AT users across the full range of products and services designed to enable independence for disabled and older people. If you have a paper or poster that you would like to present that does not fall in to any of the above topics, we would still like to hear from you.

To submit your paper, please visit http://www.raate.org.uk/content/submit-a-paper/

Closing date for submissions is 5pm, Monday 15th July 2013
This article shows how to select a word (we will use as an example the word ‘ahooga’, the cry of a wild animal) with a single switch, oriented scanning, an alphabetically ordered matrix and word prediction. Figure 1 shows an alphabetically ordered matrix that is easy to remember and can be accessed by a single switch. With the ‘oriented scanning’ technique, a short press on the switch moves the cursor down; a long press moves the cursor to the right. Long press repeats automatically: the focus first moves to ‘Sp’ (Space) but to select ‘a’ we keep the switch pressed to move the focus to ‘a’ then release the switch. After a pre-set pause, the focus character is selected and the screen image of Figure 2 appears, with the word prediction displaying words that start with ‘a’. The cursor reverts to the top left cell after every selection.

To select the next character ‘h’ we make one short press (focus moves to ‘Bs’) then a long press until the focus moves to the ‘h\i’ cell. Because the focus moves to the cell from the left, ‘h’ is selected and Figure 3 is displayed. Now, to start scanning the wordlist we make a long press to move the focus to ‘Sp’, release the switch, and then before ‘Sp’ is selected we make another long press and this starts a scan of the wordlist. We release the switch when the focus is on ‘ahooga’, then after the pre-set pause the word is selected.

Joris Verrips

REFERENCES


Software and some videos can be downloaded from: www.depratendecomputer.nl
Eye-gaze is a fundamental component of communication

This study day focuses on the importance of gaze:
- Observing “what we are looking at”
- Exploring how to use gaze for communication
- Examining facilitated looking and pointing
- Studying an eye-gaze pathway
- Considering the role of gaze for those with progressive conditions

This day is purely about eye-gaze, looking, eye pointing and the use of low-tech communication

(this study day is not about eye-gaze technology)

Thursday 20 June 2013
University College London

Download more details & booking form:
www.communicationmatters.org.uk/vision-study-day
Communication Matters is the UK wide charity which works for and brings together everybody who has an interest in AAC (Augmentative and Alternative Communication). Membership includes people who use AAC, family members, professionals who support them and suppliers who design and manufacture AAC solutions.

NEW VENUE
After a long search Communication Matters conference is moving to a bigger venue at Leeds University
- plenary and seminar rooms are close to the exhibition hall
- all areas are fully wheelchair accessible
- residential accommodation is of high standard
- dining room caters for all delegates

Conference Programme
Be prepared for a busy two and a half days covering a wide range of topics: practical solutions, personal experiences, latest research, plus clinical and technological developments in the field of AAC. There is always plenty for everybody.
- plenary sessions
- full seminar timetable
- practical workshops
- social events
- case study and research presentations
The conference is supported by our organisational members who you can meet at the exhibition. The ideal opportunity to get your hands on the latest technology.
Find out more at: www.communicationmatters.org.uk/conference

Conference Registration
- Conference opens on Sunday the 15th September at 4.00 pm
- registered delegates have full access to all conference events plus plenty of networking opportunities
- registration also includes refreshments, lunch and evening meals plus breakfast for residential places
- SUBSIDISED Places are available for people who use AAC and their PAs. These are limited and available on first come basis so book early to avoid disappointment

Don’t miss out on the only National AAC conference which brings together people who use AAC, families, professionals and suppliers of AAC solutions.

Book and Pay before 31st of July to claim your EARLY BIRD DISCOUNT
To download registration form, please visit: www.communicationmatters.org.uk/conference
FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

CM2013 NATIONAL AAC CONFERENCE
The past six months have flown by. The Trustees recently met for two days of Board meetings in Leeds. It has been a significant decision to move the National Conference from Leicester to Leeds but it really feels that it is a decision worth taking. The Trustees have been impressed by the Events Team at the University of Leeds; it promises to be a great venue. We hope that there will be a good range of abstracts submitted so that we can match the content of the conference to the outstanding facilities. The CM2013 conference is a brilliant forum to share knowledge, evidence and good practice and we especially welcome abstracts from people who have never presented before.

AAC EVIDENCE BASE RESEARCH PROJECT
The CM-RM (Communication Matters - Research Matters) AAC Evidence Base research project’s Final Report was ‘launched’ this April around the UK, in partnership with the launch of the Department of Education funded project to develop resources to inform stakeholders on AAC commissioning arrangements. These dissemination events took place in London and South East (London, 22 April); South West (Bridgwater, 23 April); North (Oldham, 24 April); Midlands and East (Leicester, 25 April). The target audience for these events were NHS Commissioners but a wide range of people from the AAC community were also invited. These two projects represent huge and potentially significant pieces of work. With the end of the funding of the CM-RM research project from the Big Lottery Fund, CM Trustees have been considering various routes for ongoing funding. There is obviously a responsibility to ensure that, in particular, the AACknowledge.org.uk website is updated regularly so that it continues to have a positive impact.

MARKETING
The main aims of the Communication Matters’ Marketing Strategy is to raise awareness, increase membership and encourage fundraising. Sandra Hartley has been working on our marketing materials and these are now available from the CM Administrator, Patrick Poon, via the Communication Matters office and at the launches, Roadshows and Study Days. We are very aware that there are many people who are not aware of Communication Matters and we want to get the message out more widely so that others can benefit from sharing experience and resources.

LOBBYING
We continue to work with the Whitehouse Consultancy and this is making a real difference to our lobbying activities. The Trustees have decided that it would be good to continue having input from Whitehouse over the next six months as it is such a key time for AAC services. Meetings have been arranged with interested MPs and Lords and we are so pleased by the recent news that Paul Maynard MP was able to table a question in the Prime Minister’s Question time resulting in a more overt commitment to funding specialised services.

ISAAC
Following the last Board meeting a letter was sent to Franklin Smith (Executive Director) and Jeff Riley (President) of ISAAC to raise the issues discussed at the ISAAC discussion session during the CM2012 conference and comments from members by email. ISAAC now have online newsletter available to members and I encourage you to explore this for updates on ISAAC activity. The ISAAC conference in 2014 is going to be in Lisbon; information about this is also available on the ISAAC website www.isaac-online.org

CONFERENCE PLANNING
Over the next few months we will be focusing on the more detailed planning for the CM2013 Conference. Please feel free to contact us if you have any ideas for the programme and think about encouraging others in your team to attend. We look forward to seeing you there!

CHAIR’S DIARY HIGHLIGHTS: JANUARY–MARCH 2013
3 Jan: Meeting in London with Carolyn Young (NHS Commissioning Board) about Service Specification for AAC
8 Jan: Specialised Healthcare Alliance Conference in London
16 Jan: Specialised Healthcare Alliance Meeting, London; Communication Trust Parliamentary Reception
23 Jan: Site visit to Leeds Univ. with CM Administrator
29 Jan: Meeting with RCSLT in London; Communication Trust meeting
15 Feb: Meeting Prime Minister at ACE Centre Oxford
5 Mar: Presentation for the Children and Families Working Group at Westminster
6 Mar: Meeting with CM Marketing Consultant
11 Mar: CM Board of Trustees Strategy and Finance Meeting in Leeds
12 Mar: CM Board of Trustees Business and Planning Meeting in Leeds
19 Mar: Communication Trust Consortium Meeting in London

If you wish to raise an issue with a specific Trustee, please contact them via this email address: admin@communicationmatters.org.uk

Catherine Harris
Chair of Communication Matters
At Prime Minister’s Questions on 13 March 2013 David Cameron responded to Paul Maynard MP by praising the work of the ACE Centre and making a commitment to ensuring communication aids are made available to more people.

Read the transcript below or watch recording (at time 26:33) www.bbc.co.uk/news/uk-politics-21767853

Paul Maynard MP (Cons, Blackpool North and Cleveleys): “I know that the Prime Minister recently visited the ACE Centre in Oxford and I am sure that he shares my view that they do a fantastic job helping young disabled people communicate more effectively using technical aids. What guarantees can the Prime Minister give that augmentative and assistive communication aids will be made available to more young people than is currently the case, enabling everyone who could benefit to do so?”

Prime Minister: “I am really grateful to my Honourable Friend for raising this issue because the ACE Centre - which has been now located in my constituency, previously in Oxford - has done incredible work for people with disabilities over many years and they are making the most of the extraordinary changes in technology. "And when I visited them recently, we looked at a whole raft of ways in which we could make sure the NHS is making these things available to more people. And I am very committed to working with him and the ACE Centre to make sure that happens."

Commenting on the response, Catherine Harris, Chair of Communication Matters, said: “Having recently represented Communication Matters at a meeting chaired by Paul Maynard MP, it is so encouraging to have this positive news about funding for AAC.

“We are delighted that Paul Maynard will be the Keynote speaker at our CM2013 National AAC Conference.”
Paul Canon Harris, writer, poet, public speaker and mentor read his poems and raised £78 for Communication Matters from an appreciative audience. Some of Paul’s poetry can be found on his interesting website www.paulcanonharris.org

Sweepstake – a number of members kindly ran the Communication Matters sweepstake and raised over £200. Grateful thanks to Tom Griffiths, Sandra Hartley, and the staff of Beaumont College, Thomas Wolsey School & Toby Churchill Ltd.

Would you like to raise awareness of AAC and Communication Matters, and at the same time raise funds to support people who use AAC to attend Communication Matters study days and National Conference? It’s easy to run a sweepstake at work, school or in your community. Download the sweepstake poster from www.communicationmatters.org.uk/sweepstake print it out and follow the instructions on the poster – have fun getting your friends and colleagues to play and donate!
During the final three months of the project we are focusing on sharing the research findings, as well as putting everything in place to ensure that the project is closed down efficiently. Although 13 June 2013 marks the end of the Big Lottery Fund grant, the project has created services, tools and knowledge that will continue to be of benefit, along with the AACknowledge website.

AACKNOWLEDGE.ORG.UK LAUNCH
The AACknowledge website went live on 10 December 2012. It was developed by Manchester Metropolitan University with the extensive involvement of people from across the AAC community in both the design and testing phases. AACknowledge brings together information and research evidence about AAC in one place. In order to meet the needs of a wide audience it provides different ways of finding out more about AAC.

The website features:
- Bibliography of published research into AAC
- Plain English summaries of research articles
- Case stories
- Factsheets
- Frequently asked questions

- Glossary
- Links to many other sources of information.

Our press release about the launch of the site received coverage in a number of specialist magazines and e-newsletters, as well as on several websites. We’ve already had some very positive comments about the website:

“Wow, it’s great! Love the information and accessibility.”
“A terrific new AAC resource.”
“A great resource for anyone interested in AAC.”

Our aim is that the AACknowledge website should be the key source of information and research evidence about AAC in the UK. We welcome feedback on the website as this will help us to plan future developments. Communication Matters will manage the website and ensure that new content is added at regular intervals. We are in the process of agreeing a contract with a third party for the development of new content.

THE RESEARCH INVOLVEMENT NETWORK
The idea for the Research Involvement Network grew out of Communication Matters’ consultation with stakeholders from the AAC community to determine its research priorities. People who use AAC and their families reported that they were often asked to participate in research projects and this could become a burden. Researchers also reported that it was hard to find people who use AAC to participate in research. The aims of the Research Involvement Network are:
- To support and encourage research into AAC in the UK by building a list of potential participants.
- To provide researchers with access to a wider range of participants.
And in the longer-term:

- To promote the involvement of people who use AAC in all aspects of research: not just as subjects but also as advisers, steering group members and co-researchers.
- To support people who use AAC, their families and carers, and other members of the AAC community in becoming participants in research.
- To build a network that reflects the broad population of people who use AAC.

The first request from a research project has been reviewed and approved, and publicised to the relevant members of the Network. Communication Matters will continue to recruit members to the Network. We envisage this will be a valuable resource for researchers in future.

THE CASE STUDY TEMPLATE

The case study template was developed by Manchester Metropolitan University. It is a tool that can be used by people who use AAC and by practitioners to contribute case study data that can be used by researchers in the field of AAC. The collection of comprehensive data in a consistent way will enable researchers to compare data across case studies and contribute to more research being published at higher evidence levels. Policy-makers and service commissioners use the higher levels of evidence to inform their decision-making.

Manchester Metropolitan University recruited the first case studies and developed a database to store them. Communication Matters will manage the database and continue to recruit case studies. It will publicise the service to researchers and review all applications to access the case study data. Our aim is that, over time, the case study database will contribute to building a more robust evidence base that can be used to commission improved AAC services.

THE INDEPENDENT RESEARCH PANEL

The Independent Research Panel provides advice to Communication Matters on its research activities. The Panel is made up of people who represent different interests, including a person who uses AAC; a family member of a person who uses AAC; a representative of a commercial company; a person working in the care field; a commissioner and researchers.

During the project, the Panel provided advice and gave feedback on the progress of the research. It also contributed to the development of the Research Involvement Network. The Panel will continue to operate after the end of the project, providing advice to Communication Matters regarding its research activities and a new Chair has been appointed to facilitate this.

KNOWLEDGE ABOUT PREVALENCE OF NEED FOR AAC AND SERVICE PROVISION

As reported in the previous edition of the Communication Matters Journal, findings from the research undertaken by the University of Sheffield (in collaboration with Barnsley Hospital NHS Foundation Trust) have already contributed to changes to service provision, through links with the consortia that received the Department for Education AAC grants and with lead organisations in Wales and Scotland. Data has been shared with policy-makers and this will be continued through our dissemination activities during and after the project.

The methodology used to survey AAC service provision in the UK has been developed into a tool that can be used to map and audit services in future.

PROJECT MANAGEMENT & DISSEMINATION

The project is on target to meet its milestones and is running within budget. We started planning the handover of research responsibilities with the trustees more than a year in advance, in order to minimise the risk of losing invaluable research knowledge and expertise. There are currently two trustees with research experience on the Board and Communication Matters is undertaking a reflective evaluation of the project to ensure that the lessons learned are recorded.

A final report on the project will be sent to the Big Lottery Fund shortly after the end of the project, along with a copy of the research report and a summary of key findings.

The Big Lottery Fund approved our dissemination plan in January and commented:

"The proposals submitted are very detailed, the plans look like they will most definitely reach targeted beneficiaries and those most in need, alongside achieving maximum output of the research findings and raising the profile of ISAAC (UK)."

We are pleased that the Senior Policy and Learning Manager from the Big Lottery Fund will attend one of our dissemination events.

In April and May we are undertaking joint dissemination events with the consortia working on the Department for Education AAC Grants, The Right to Speak project in Scotland and the National Centre for Electronic Assistive Technology in Wales. Policy-makers, commissioners and heads of specialist services have been invited to these events. We will also be giving a presentation at the Communication Matters Roadshow in Belfast on 1 May 2013.

Printed copies of the final research report will be available at these events and it will also be available online as a PDF. An article on the case study template by Manchester Metropolitan University is due to be published shortly in the Journal of Disability and Rehabilitation: Assistive Technology. The researchers at the University of Sheffield (in collaboration with Barnsley Hospital NHS Foundation Trust) plan to submit further articles to academic journals. The findings from the research will also be publicised and disseminated through our website, E-News, a press release, and at the Communication Matters National AAC Conference in September.

THANKS

Our thanks to the Big Lottery Fund for the grant that enabled this research to take place; to our research partners for their commitment to the project and for achieving and sometimes exceeding the intended outcomes; to the members of the Independent Research Panel for their advice and support; to everyone who has participated in the research; and finally, to our partner organisations for the dissemination events.

For the latest information, please visit www.communicationmatters.org.uk/research*

Katie Holmes
Research Manager
David Morgan
Research Lead

About the Project

The AAC Evidence Base research project is a three-year project funded by the National Lottery through Big Lottery Fund. Communication Matters is leading the project, working with three research partners: the University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University.

The project will provide fundamental information about the need for, and provision of, AAC which can be used to improve services across the UK. The project will also create an online AAC Evidence Base that will make current knowledge about AAC available to all.
This paper will explain the background and design of a pilot study on Intensive Interaction with four pupils in a co-educational special school in Somerset. It will also describe how the study has developed collaborative working and informed the practice of both educational and health care professionals in the school.

BACKGROUND
Following a local training day on Intensive Interaction, Laila Emms (Communication Specialist) and Natasha Lewis-Davidson (Speech and Language Therapist) decided to trial the approach with a small number of the children they worked with at Selworthy School, Taunton, before implementing whole school training to staff on how to carry out intensive interaction.

There were two reasons behind the pilot study:
1. The professionals wanted to investigate whether the approach might work for some of the most difficult-to-reach children they worked with.
2. If the results were positive and the children did make changes then the teaching staff would see at first-hand the benefits of using the approach and hopefully this would be directly reflected in their practice.

Intensive Interaction was originally developed in the 1980s by Dave Hewett and Melanie Nind and documented in their book Access to Communication: Developing the basics of communication with people with severe learning difficulties through Intensive Interaction (1994). It is claimed that the approach can increase the number of pre-verbal social responses in people with severe learning difficulties and/or autism.

The majority of the current research in the approach focuses on qualitative findings in either single case studies or small sample sizes. The studies tend to share uniform results of participants demonstrating an increase in eye contact, vocalisations and turn taking skills (Watson, J. & Fisher, A. (1997), Kellett, M. (2000), Kellett, M. (2005)). Other studies have reported a decrease in self harming behaviours (Zeedyk, S., Davies, C., Parry, S. & Caldwell, P. (2009)) and an increase in the ability to initiate communication (Barber, M. (2008)).

DESIGN
The study took the design of four single case studies. Communication competencies of each pupil were evaluated pre and post intervention. They were measured by each pupil’s class teacher participating in a structured interview with the educational psychologist, Mary Chaloner. During the interview the Behaviour Indication Assessment Scale (BIAS) was completed. The BIAS is a questionnaire that identifies and evaluates the communicative methods (both verbal and nonverbal) a person uses to communicate in everyday situations (Sigafoos, J., Arthur-Kelly, M., Butterfield, N. (2006)).

Four members of staff were trained to carry out intensive interaction and they alternated the children they worked with. This was to ensure that each child did not become too attached with one adult, in the hope that they would be able to easily transfer new communication skills across a range of partners.

During the sessions, the adults followed the central principle of intensive interaction and therefore the pupils led the session and the adults responded to, joined in, or mirrored their behaviour. Each pupil received 3 x 30 minutes of intensive interaction per week, over a four week time period. Every session was video recorded and therefore two members of staff were present for each session; one carrying out the intensive interaction and one video recording. Session forms and observation forms were completed by the adult carrying out the intensive interaction and by the adult video recording, to further document what happened in each session.
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RESULTS
As we would expect, the post intervention results were different for each child. However, as can be seen from the graphs, they all benefited from the intensive interaction sessions and there did not appear to be any negative effects. Overall the results support findings documented in previous published academic research. Pupil 1 and 3 demonstrated an increase in the use of their eyes and distinct facial expression to communicate (Kellett, M. (2000), Kellett, M. (2005)). Pupil 1 and 3 increased their use of vocalisation either through sounds/noises or through words and sentences (Zeedyk, S., Davies, C., Parry, S. & Caldwell, P. (2009)). Interestingly, Pupil 2’s use of sounds and noises decreased. Without knowing the child, this could be perceived as a negative effect. However, Pupil 2 often used distinct sounds and noises when she was carrying out problem behaviour. So a decrease in her use of sounds and noises, as shown in the Table, actually represents a reduction in problem behaviour. A decrease in problem behaviour also supports the research carried out by Zeedyk et al (2009).

Pupils 2 and 4 showed an increase in guiding and leading an adult and therefore initiating communication and responding to interactions which supports the findings of Watson, J. & Fisher, A. (1997) and Barber, M. (2008).

DISCUSSION
The children were selected because it appeared that they all presented in similar ways and therefore might be expected to have similar communication profiles. The pre-intervention BIAS results indicated that each of the children actually had very different communication profiles. Thus the BIAS proved to be a specific enough tool to pick up on all the subtle nonverbal skills the children use on a day to day basis to communicate. This highlighted that the BIAS would be a useful tool for teaching staff to complete for every child in their class who communicates non-verbally, to establish their unique communication profile. This information could then be used when setting appropriate individual communication intervention targets for each pupil.

When the study was completed, intensive interaction training was delivered to teaching and teaching assistance staff. Video evidence recorded from the study was used to demonstrate how to carry out intensive interaction but also to show how it can develop individual children’s communication. The results from the study highlighted the positive impact intensive interaction sessions can have on a child’s general communication, and showed that changes do not just take place within sessions.

The staff seemed to appreciate seeing the difference in the pupils they worked with and this had a direct impact on their practice. Some staff went on to timetable regular intensive interaction sessions for their pupils and they regarded these sessions as equally important as curriculum based activities. Although it would be preferable for intensive interaction to happen at natural parts of the day rather than at a scheduled time every week, it is accepted that for people to embed intensive interaction into their everyday practice, they have to feel confident with their new skills and this takes time.

Following the pilot study, further resources have been identified to monitor and document the child’s progress in intensive interaction sessions. The study focused on specific communication skills, e.g. eye contact, and evaluated whether their teacher perceived a change in that skill in general.

Although this is important information, we are now also looking at the child’s
progress with other aspects of their involvement in the intensive interaction sessions by using a two column table. The first column, headed 'Levels', lists the levels of attainment in intensive interaction sessions. The blank second column is headed 'Observations of child using the level and date attained' (Firth, G. (2004)). The levels are:

- **Encounter** - student is present but without any obvious awareness of interactive episodes, e.g. a willingness to tolerate a shared social atmosphere is sufficient.
- **Awareness** - student appears to notice or fleetingly focus on an event or person involved in the interactive process, e.g. briefly interrupting a pattern of self absorbed behaviour, movement or vocalisation.
- **Attention and Response** - student begins to respond (not consistently) to what is happening in interactive episodes, e.g. by showing signs of surprise, enjoyment, frustration or dissatisfaction.
- **Engagement** - student shows consistent attention to an interactive episode presented to them, e.g. by sustained looking or listening or repeatedly following events by movements of the eyes, head or other body parts.
- **Participation** - student engages in sharing, taking turns in sequence of events in interactive episode, e.g. sequencing their actions with another person by passing signals repeatedly back and forth.
- **Involvement** - student makes active efforts to reach out, consistently join in or even comment on interaction, e.g. sequencing actions and vocalising/signing/gesturing in a consistent and meaningful way.

**CONCLUSIONS**

The pilot study showed the positive benefits of intensive interaction with children previously described as “difficult to reach”. As a result of the study, in-house staff training has been delivered and it is hoped that this intervention will be fully embedded in staff practice as appropriate, across the school setting.

The video footage proved to be a very powerful tool in terms of staff training. Staff were able to observe children opening up and communicating in ways they had not seen before. The study also demonstrated the value and importance of video recording as a tool to reflect on our own practice.

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**REFERENCES**


A reflective case study

Now What? The Competent AAC User Who Doesn’t Want to Talk

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BACKGROUND INFORMATION
Quinn was referred to the Kent CAT service at the age of 4. He has a diagnosis of four limb dystonic cerebral palsy (GMFCS Level V). At the time of referral, Quinn was being educated via a split placement between a mainstream and a special school. He was using a Stage 4 eye pointing communication book, in addition to some functional gestures and vocalizations. His cognition was reported to be appropriate for a child of his age.

Following an assessment and trial period, Quinn was provided with a Tobii C12 device accessed via the CEye eye-gaze unit with the Ingfield Dynamic Vocabulary (IDV), Level B. This was delivered to him in May 2010, when he was 5:08 years. Within the first year, Quinn’s vocabulary package was upgraded to IDV Level D as it was felt that he had the potential to say more than was available in his initial package. He also showed a high level of navigational competence to access more cells on a page. Alongside his use of eye gaze for communication, Quinn continued to use Clicker 5 software (with head switches) to access the curriculum and develop his literacy skills.

In spite of Quinn’s operational competence in terms of using eye gaze and a head switch, and his reported cognitive levels, the following months did not produce the predicted progress in terms of functional communication and access to learning. Instead, within the first year Quinn had become highly resistant to the idea of using his communication system at all.

EARLY WARNING SIGNS
As the team reflected on Quinn’s use of his communication system and looked in more detail at reports and correspondence within the first year of receiving his device, it became clear that there were early warning signs of barriers to success that were not recognized at the time. For example, Quinn was described as a child who “absorbs information through observation” and even at an early stage was noted to rarely initiate appropriate communication or participate actively in class using alternative and augmentative communication (AAC).

After only a few months in a split placement, Quinn was transferred full-time to a mainstream school. He experienced some difficulty with this transition and this was reflected in an increasing amount of disruptive and oppositional behaviour. Although class staff were keen to implement the use of the Tobii during the school day, a strong association of the device with ‘doing work’ was unintentionally established. As a result Quinn’s reluctance to engage in learning was also seen in reluctance to use the device. This quickly escalated to a complete refusal to use the device as a learning tool and subsequently for any functional communication.

Another early warning sign that was noted on reflection was that due to Quinn’s complex presentation in a mainstream setting, much of the differentiation of his work fell to the teaching assistant supporting him. Due to time pressures, limited opportunities were available for the teacher to liaise with the teaching assistant to ensure that gaps in Quinn’s learning were identified and addressed.

In hindsight the team have questioned whether some of the behaviours that Quinn had adopted could be attributable to frustration with activities being delivered at a level that didn't account for the gaps in his learning. Furthermore, the nature of Quinn’s difficulties precluded the administration of standardized testing and assessment within a mainstream framework. His strong cognitive presentation may also have masked some specific issues with his literacy and language development.
THE NEED TO CHANGE FOCUS

During the process of review and support offered by the Kent CAT service, it became apparent that Quinn had the skills to use his eye gaze system with remarkable accuracy but was not using it to initiate any social interaction. Target setting until this point had focused heavily on operational and linguistic elements of Quinn’s use of his system. During the period where Quinn was refusing to use his device, he was invited to attend a family fun day at a local farm. In preparation for this trip, the CAT team visited Quinn at school to load some fun, participation-focused grids onto his device. They were interested to find that in the context of an activity purely focused on social interaction, Quinn became animated and engaged; he participated for longer than he had ever previously in this type of session. Quinn particularly enjoyed selecting videos of animals, activating sound effects and telling jokes.

Around the same time, Quinn’s mum reported that he was showing an interest in using email and SMS messaging at home. The CAT team took the opportunity to explore Quinn’s interest in accessing these facilities and decided to capitalize on his enthusiasm by using his device in a new way. At a time when Quinn was refusing to use his device for any purpose, this was seen as a way to get him to make friends with it again.

In view of this change of focus, the CAT team decided to abandon the current approach and capitalise on his enthusiasm by using his device in that setting to support him. The team felt that this reflected both Quinn’s interests and an increasing body of literature in the field of AAC research around participation-focused therapy and goal setting. Clarke et al (2012) have identified that “Advancing opportunities for children and young people to participate in society in ways that match their own motivations and aspirations is a cornerstone of intervention philosophy.”

In keeping with this change of approach, the team decided that Quinn would benefit from a change in vocabulary package. After some brief trials, a decision was made to provide Quinn with the ‘Talkative’ vocabulary package. This was adapted to contain the email and SMS pages from the ‘Vocabulary for Life’ package. The selection and adaptation of this package was made largely due to its inclusion of a wealth of descriptive vocabulary and pre-stored social phrases for email and SMS messaging.

MOVING FORWARD

The CAT team made an appointment to visit Quinn at home and set up an email account, environmental controls for the television and SMS messaging. During this visit, Windows Mouse Control functions were also activated on his device to enable Internet and desktop browsing. Some time was spent in discussion with school staff around shifting the focus for Quinn’s use of his device in that setting to conversational and social interaction, rather than as a tool for learning. Specific advice was given to all parties supporting Quinn to avoid using the term ‘work’ in relation to his use of the device.

A wireless joystick and switch were provided for use in class. This was for the specific purpose of enabling Quinn and his peers to participate in group work using the same means, with the interactive whiteboard. In addition to the support offered by the CAT team in school, a number of home visits were arranged in order to promote participation in a wider context.

QUINN AND TOBII MAKE FRIENDS

One of the immediate changes that the team saw following the change of approach was that he was less resistant to the team’s involvement and interventions. Where Quinn had previously exhibited negative behaviours in response to the CAT team’s attempts to engage him, he increasingly showed an enthusiasm for the activities presented to him during their sessions. With a couple of weeks of giving Quinn access to Windows Mouse Control, he was requesting access to his device daily and using it throughout the day at home. His parents reported that he was finding a greater independence in directing his own social time both through browsing the internet and using the environmental controls for the television.

Quinn’s parents also reported an increase in their own confidence in using the device with him for homework activities and general conversation. This was seen partly through Quinn’s spontaneous exploration of his vocabulary package (both through specific vocabulary and pre-stored phrases) in order to generate topics for conversation or email/SMS messaging. Quinn has enjoyed sending and receiving emails/SMS messages to family members and therapy staff. In and of itself this has widened his ‘social networks’ for communication (Blackstone & Berg, 2012).

In addition to email and SMS functions, Quinn has initiated social conversations with his parents around matters that interest him. On one occasion Quinn was browsing beehive paraphernalia on eBay and was unsure of what something was. With some support from his mum, he used his vocabulary package to generate a question for his dad about the item and then saved this as a document to share with him on his return from work. The wider scope of vocabulary offered by the new package (Talkative) also enabled ‘accidental’ selection of more abstract words and topics that acted as a springboard for social interaction and vocabulary development.

POINTS FOR REFLECTION

The CAT team continue to be heavily involved with Quinn with a role in supporting him in moving closer to the ultimate goal of independent, sponta-
neous and functional communication. There are many lessons which have been learnt through reflecting on Quinn’s experiences with AAC. These have continued to inform the team’s work both with him and many other students on their caseload.

Perhaps the main shift in thinking has been that it is possible to achieve operational and linguistic competence for AAC through the vehicle of participation. Moreover, by focusing on a participation philosophy for intervention, the overall outcomes for a student are inherently more meaningful, motivating and lasting. The team have found that explicit guidance and reassurance is needed for parents and education staff in promoting this approach to developing communication and accessing learning through AAC. This can sometimes be perceived as conflicting with the traditional curriculum approach of setting and measuring specific educational targets. However, in our experience the shift in focus to participation rather than activity has been hugely beneficial.

In Quinn’s case, by enabling him to engage with his device for social and motivating purposes, he has been given insight into the possibilities that the device offers for functional communication. Although initially he was not applying this insight to a desire to use the device for learning in school, over time he has started to tolerate the use of his system in the classroom in ways previously unseen. At the time of writing Quinn is not using his device to answer topic specific questions or generate written answers in class. However, he is using the vocabulary package to make comments about what’s happening in the classroom and express opinions. The CAT team feel that this is a very positive step towards using the device in a way that bridges participation and learning.

A further outcome that has arisen from our recent reflections is that Quinn’s Clicker 5 software has now been integrated with his Tobii C12 device (previously delivered on a laptop). This decision has been made with the purpose of presenting communication and learning as inseparable elements. Previously, classroom staff were needing to decide which piece of equipment (Tobii or laptop) to present an activity with, therefore preventing a natural interaction between commenting and learning.

Overall the team have been reminded of the importance of being led by the interests and motivations of our students. The key remains to view functional communication and independence as the goal, rather than communicative competence as an end in itself. Indeed, the very nature of focusing on participation means that an AAC user will become more competent as they engage more readily with the world around them.

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A Swan Song

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Thank you for the opportunity in this journal to say goodbye to Communication Matters and the AAC community. I retired at the end of March 2013, a decision influenced by a health condition. I was unable to attend the last Communication Matters National Conference and that would have been my swan song.

I have had links to Communication Matters since 1991, roughly half of my working life. The first person I worked with was assessed for a Lightwriter the size of a typewriter. I was introduced to such terms as iconicity, Minspeak, MAPs, multimodal, AAC. What? Everybody else seemed to understand these terms and the principles of AAC. I am so grateful to have found a field and support network where I could continue to learn, develop skills, hear innovative ideas with communication at the centre of everything.

I have loved attending the CM Conference at Portland College, Lancaster and Leicester University. It’s been one of the professional and personal highlights of my year where I have felt recognised, respected and have let my hair down! I have always learned something to take back to my practice and shared some of my work in peer presentations.

Many aspects are quite memorable, for instance the stand up row about static versus dynamic displays, facilitated communication, launches of new devices, companies and international speakers. I will never forget many inspirational speeches, especially by people who use AAC. They taught me so much and helped me promote role models. One of the proudest moments of my career was one of my service users presenting at conference. It’s been great hearing AAC jokes, AAC singing and, last year, a stand-up comedian.

One comment from years ago still resonates: “I never expected when I started work to be spending time with a screwdriver (Allen key/sticky stuff remover) in my hand”!

Thank you to all the AAC suppliers who have supported me, my work and attendance at the CM Conference (and at the bar). I’ve made some great colleagues and friends and am genuinely sorry that I will no longer be part of the AAC community.

I wish Communication Matters well with all the research, resource development and campaigning work. If you would like to contact me, do send me an email.

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A Literacy Based Pilot Study Using Boardmaker Studio® & Talk for Writing

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INTRODUCTION
The purpose of this study was to look at the impact of Boardmaker Studio used as an intervention tool to support literacy in a small group setting.
At the outset of the study we aimed to compare the impact results of three different intervention methods used on three groups of pupils. Lessons were planned around Talk for Writing by Pie Corbett and each group was to be taught the same lesson but would use a different intervention to access resources and record their work.
The study was led by Selworthy School in Taunton. Selworthy is a popular, over-subscribed school with more than 80 pupils grouped into 11 classes. It is a co-educational special school for children and young people with learning disabilities aged 4-19 and is a specialist centre for cognition and learning.

METHODOLOGY
Three groups of pupils were identified by the school to participate in the study. The aim was to get three Groups that were as equally matched in ability and disability as possible.
Group 1: Highest ability (P8 - level 2)
Group 2: Middle ability (P7 - level 2)
Group 3: Lowest ability (P7 - level 2)

Before teaching started, data was collected on each pupil, which included:
• Reading age: Salford Sentence Reading Test (Revised)
• Spelling age: Parallel Spelling Tests (Second edition)
• Test of Aided-Communication Symbol Performance (TASP) by Joan Bruno

At the end of the study the same data was recorded to provide a comparison.

Grouping
Although the intention was to create three groups that were as equal as possible in their ability and disability, it was realised that this was not possible and that the variation between the groups was too significant. Below is a subjective observation of each group from the member of staff overseeing the study:
Group 1: Highly motivated with good ability to learn. Independent learners with good ability to focus and concentrate. (All verbal).
Group 2: Some motivated learners, others easily distracted, not used to independent work and many with severe communication difficulties. (Two non-verbal children). This group included three children with complex behaviours, leading to being distracted and increased chance of frequent disengagement.
Group 3: Only a couple of motivated learners in this group. The majority very easily distracted and used to 1-1 support. One non-verbal child, the others very similar to Group 2.

Intervention Tool
The three different interventions studied were:
• Use of laptops as a tool for pupils to record their work on.
• Boardmaker Studio with Picture Communication Symbols as a tool to access various activities in the lesson and record work.
• AlphaSmarts as a tool to record work.
It was noted that it was not possible to compare hardware with software to effectively measure the impact of the intervention.

Teaching
Although planning was done jointly and each member of staff followed the same lesson plan for each group, there is no doubt that each teacher will have delivered the session subjectively. This variable is unavoidable unless the same teacher was to teach each lesson to each class. Because of this, the results could be skewed by the delivery of the lesson and not just by the intervention.

Ability of pupils
Although at the start of the study, the groups were selected with the intention of being as equal as possible it is likely that there were a number of variables in each group relating to ability. Variables such as behaviour and concentration span were not, and could not be, accounted for in the Grouping.

Baseline Data
The reading age tests and spelling age tests both have a maximum and minimum age range. If, at the start of the test a pupil scores below the minimum age then they receive no score. If on the second testing they score the minimum age, they will show a score but it is not possible to accurately measure the increase in score. For this reason, results will be displayed in a number of different ways in the results and analysis.

RESULTS AND ANALYSIS
What we would hope to see on the graphs (Fig 1-3) is that, in each of the Groups, the pupils’ second score for reading or spelling age was higher than the first score to show they had made progress throughout the course of the intervention.

As we can see from the data, in each Group some but not all pupils made progress and in both Group 2 and 3 not all of the progress is accurately measurable. For example, in Group 2 and 3, Child B appears to have made no progress between the first and second reading age test although in both tests they were scored 10yr 2m+ which is the maximum score for the test. It is possible that Child B did make progress but that it was not measurable by the tests used in the study.

Looking at the data in its purest form then, we can determine that in Group 1, three pupils made measurable progress on both the reading and spelling age tests. In Group 2, one pupil made measurable progress on both the reading and spelling age tests and in Group 3 two pupils made measurable progress in both the reading and spelling age tests. However, it was not necessarily the same pupils making progress in the spelling as in the reading test.

The table (Fig 4) shows the scores for each child.

If we include pupils who made measurable progress and pupils who may have made progress but it cannot be accurately measured, then we can see that in Group 1 the results stay the same, three pupils made progress in both the reading and spelling age tests. In Group 2, one pupil made measurable progress on both the reading and spelling age tests and in Group 3 two pupils made measurable progress in both the reading and spelling age tests. However, it was not necessarily the same pupils making progress in the spelling as in the reading test.

The table (Fig 4) shows the scores for each child.

Figure 1  Group 1 reading and spelling age scores before and after intervention.
Key: RA = Reading Age, SA = Spelling Age
Graph suggests that 4 out of 5 pupils (80%) in Group 1 made progress in reading and/or writing.

Figure 2  Group 2 reading and spelling age scores before and after intervention.
Graph suggests that 4 out of 6 pupils (66.6%) in Group 2 made progress in reading and/or writing.

Figure 3  Group 3 reading and spelling age scores before and after intervention.
Graph suggests that 3 out of 6 pupils (50%) in Group 3 made progress in reading and/or writing.
progress in their reading age and three on their spelling age.

If we look directly at the measurable progress, we can also see that in both Groups 1 and 3, one pupil seemed to make backwards progress whereas in Group 2 all pupils either stayed the same or made progress.

What we can see for each of the Groups however, when we look at the data, is that with each intervention some pupils successfully make progress, suggesting that the intervention is successful in each of the Groups.

Observations and video evidence would suggest that the AlphaSmarts and standard laptops did not engage and motivate in the same way. However, engagement and motivation do not necessarily correlate to actual learning.

CONCLUSION

Teaching reading and writing to pupils with special educational needs is often perceived as an inaccessible goal. Using symbol-based software as an interactive tool to engage and motivate this cohort of pupils is an effective way of teaching and recording their work. Pupils in this study produced work at a level and quantity not previously experienced.

Anecdotal evidence from Selworthy School suggests that the use of Boardmaker as an independent tool can engage, motivate and provide accessibility and communication for all. The most reluctant readers and writers benefited strongly from this intervention, as the barriers to their learning could be easily overcome. These pupils then became enthusiastic at skills which in the past they would have shied away from. It was also noted that during these sessions, known behaviours were reduced, thus the ability to focus and learn was increased.

The use of the software as a tool for the pupils, not the adults, has shown our teaching staff the wider potential of the software. Moving away from the old paper-based resources into truly interactive teaching has been motivating and appealing to our pupils.

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Boardmaker Studio © 2011, Dynavox Systems LLC.
Sex, Drugs and AAC

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THE BEGINNING OF THE PROJECT

This project began as part of Personal, Social and Health Education sessions in the 16+ Department at Chailey Heritage School. The students in the group were aged between 16 and 19, all with moderate to severe learning disabilities and all with severe physical disabilities. The majority of the students used AAC in the form of The Chailey Communication System (CCS) either in a book format or electronically.

We had come to the Sex and Relationship part of the programme and as the weeks went by it became apparent that although the CCS is a pretty comprehensive system, the students felt they lacked vocabulary that helped them to communicate about more personal issues associated with growing up.

I had asked Rachael Pennell, the speech and language therapist attached to our department, if she would support students in the session. During a particularly challenging session where the students were discussing sexual feelings and the start to a relationship, we could see that it was taking some students ages to communicate, e.g. ‘baby pill’ to talk about contraception, two words found in two different categories of the CCS.

PUTTING THE BOOK TOGETHER

Rachael and I then met to discuss how to organise the format of the book. We repeated the ‘Me’ category of the CCS with additional ‘emotion’ words and in the ‘People’ section we used the general people listed in the CCS and added people that the young adults may meet in the adult provision they go on to when they leave school.

Students had also asked us to put ‘Useful Contacts’ into a section. So we listed services and organisations such as ‘sexual health clinic’, ‘SHADA’ (Sexual Health and Disability Alliance) and ‘Outsiders’ (an organisation for adults with disabilities which aims to promote their sexual rights). We added an email address for all of these organisations.

Many words fitted quite neatly into a CCS category such as ‘People’, ‘Places’, ‘Actions’. But we also had some words that were difficult to fit in, such as ‘spike’, ‘drink’, ‘drugs’, ‘force’. Rachael and I discussed how we wanted to ensure that students had a structure that was easy and quick to use, but without too many ready-made phrases, which could be
seen as too ‘leading’. This is where I found it especially useful to work with a speech and language therapist, as Rachael suggested that we put together ‘sentence starters’ and ‘sentence endings’. We also decided to completely mix up words and phrases with a negative and positive connotation. We also wanted to ensure that we included different symbols for sexual orientation (gay, bisexual, lesbian, straight) so that students could talk about this if they wished.

We created some new sub-categories within the ‘Body’ section, such as a section on different types of contraception and a section on growing up words, and in the ‘Phrases’ category, a ‘Relationship’ section, so that students could become more familiar with the language of flirting and special language that might be used on a date. We developed symbol flowcharts for ‘Conception to Birth’ and also ‘Relationships’ (we did point out to students that we had very much depicted the ‘ideal’ of how a relationship might develop but that relationships don’t always fit to a prescribed pattern).


FURTHER CONSULTATION WITH THE STUDENTS

When we had a draft of the book, we consulted the students by going through the book with them in detail. We then asked them to ‘road test’ it by communicating messages to us of their choosing and also messages that we gave them. For example, explain to someone that they have misunderstood you.

With a few tweaks here and there, the students said they were happy with the book and each ordered a copy. Rachael and I then ran a training session about the book for students and staff in the department. We went through the book, talked briefly about how it came into being, and then gave students either a specific word or phrase or a scenario to communicate, to practise their skills in using the book.

THE POTENTIAL USES OF THE BOOK

Rachael and I both hoped that the Private Words Book would be used for a variety of communication purposes and that it would speed up the communication process. We hoped that it would enable our students to express their feelings, thoughts and desires regarding themselves, their relationships and their sexuality.

We also wanted it to be useful if a student needed to communicate about any sort of problem, including a safeguarding issue. Having checked it out ourselves and with the students in role play sessions, we felt that a student would be able to communicate about bullying, physical and sexual abuse using the book.

As I mentioned previously, we also envisaged that the book could be used as an ‘aide mémoire’ for students who needed a symbol prompt and an information resource for useful organisations. We anticipated that students would use it in conjunction with their CCS or VOCA. We have since had students join us in the 16+ Department from other schools, who have been through the whole book with a speech and language therapy assistant and chosen the vocabulary they wanted to be programmed into their VOCA and then customising it. Brilliant!

INFORMING PARENTS AND RESIDENTIAL STAFF

Due to the sensitive nature of some of the words and phrases in the book, we felt it important to provide speech and language therapy guidance on how to use the book with the student, and to suggest where it should be kept (accessible but private). Some students opted for a phrase to be put in their CCS which said “I want to use my Private Words Book”.

We also included a brief letter from the Headteacher endorsing the book and explaining that it had been put together with the full input of the students. I have since talked to parents about the book and its uses at Parents Evenings.

WHERE WE ARE AT NOW!

The Private Words Book has become an invaluable communication resource both for individual students and for me as a teacher of Personal, Social and Health Education. Last year I was joined by Nicky Ashdown, a speech and language therapy assistant with South Downs NHS, who worked with me in training students new to the department in how to use the book.

The feedback from new students has been overwhelmingly positive and most have requested their own copy. We continue to use the book and to familiarise students with it so that they can use it to maximum effect. It has speeded up communication and students say that they like using more ‘adult’ language. In the near future we hope to launch it as part of the CCS.

REFLECTIONS

Both Rachael, Nicky and I greatly valued the opportunity to work together with the students on this project, we all learnt something new, both from the students requests and responses and from each others skills, and felt that it was an excellent example of multi-disciplinary communication work.

Helen Dunman, Teacher
Language Acquisition through Motor Planning (LAMP)

A Fifteen Year Old Girl’s Journey Through LAMP Intervention

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In this paper we discuss a student’s experiences using the LAMP approach (Language Acquisition through Motor Planning). We will briefly explain the rationale behind the intervention, before describing the student’s participation in a therapy trial and how this impacted upon her communication skills. Prior to this we will provide some background information to give perspective on the student’s abilities pre and post-intervention.

Both of us work in a special school for young people aged 11-19 who have SLD, Complex needs and/or Autism. Prior to March 2011 (when the case study begins) neither of us had experience, or had indeed heard of, the LAMP approach.

BACKGROUND INFORMATION
The student discussed in this case study was introduced to the LAMP approach in July 2011. At commencement of the trial she was 15 years old and had a diagnosis of ASD. She was non-verbal and displayed extreme challenging behaviour. There were a number of trigger words which, if she heard, resulted in violent behaviour towards herself and others.

Despite the general consensus that she was an intelligent girl, who understood a significant amount of the spoken language around her, she had no communication system aside from using a handful of symbols and two signs. She had previously used some symbols within the PECS approach but had become resistant to using the system and so it had become redundant.

WHY LAMP?
There is a growing awareness that children with ASD often experience difficulties with sensory integration and many demonstrate motor planning dysfunction. This may provide some insight into the difficulties many young people with ASD experience in using speech as a tangible communication system. The LAMP approach draws upon knowledge of these dysfunctions and addresses them through the therapeutic process.

Sensory over- or under-stimulation must be addressed in order to ensure students are in an optimal state of readiness to learn. Multi-sensory input and the promotion of consistent and unique motor plans using the Unity language system enhances success, by developing automaticity of movements. By following a student’s interests, the language that is taught is functional and relative to motivating activities, enhancing meaning for the student. The approach promotes the use of ‘core’ vocabulary with gradual introduction of ‘fringe’ vocabulary, encouraging students to use words for multiple purposes. [1]

Aside from providing an effective communication system, LAMP is reported to often promote social communication skills, reduce challenging behaviours and in some cases encourage spoken language in previously non-verbal individuals. [1]

HOW WE DID IT
In March 2011, following attendance at an information session regarding the LAMP approach, we applied to take part in trials of an initial introduction of LAMP to the UK. The school we work in had a number of students who appeared to benefit from the approach and we were keen to take the opportunity to evaluate the potential for future implementation.

The student discussed in this study was selected as no other communication system was working for her. There were concerns about the success of the trial/assessment as she was extremely non-compliant with any adult-led activity and would frequently remove herself from any situation when asked to do something. We were really anxious and viewed her trial as a ‘wildcard’.
The student was seen for an initial assessment session by Lindsay Cargill, a specialist speech and language therapist from the USA. Within the initial session, Lindsay looked at issues such as the most appropriate grid size (based on motor ability) and whether a single hit or sequenced vocabulary system would be most appropriate.

The initial session was extremely encouraging: the student remained in the room, with unfamiliar people, tolerated changes in activity and progressed to sequenced vocabulary within three minutes! The recommendations following the session were to try Unity 84 sequenced, the most complex language setting.

A device was then loaned and the student accessed a number of therapy sessions with us. She showed remarkable success and a report was written recommending provision of a device. In an absence of a device, no further work could be done with her within the approach.

Cindy Halloran from The Centre for AAC and Autism [1] visited us a few months later and was able to give a ‘one-off’ session. Despite the gap in therapy sessions, the student quickly recalled vocabulary previously learned and used it appropriately. Following this, it was decided to try and loan devices to continue the therapy and this was done via a Service Level Agreement with the ACE Centre [2]. Subsequent trials allowed further work within the approach and allowed us to gain a wealth of video evidence to support the case for provision of a device.

**WHAT WE FOUND**

As of September 2012, the student had developed skills and demonstrated significant progress far exceeding the expectations we held, including:

**Spontaneous combinations of up to three core words.** The student could independently sentence-build to meet her needs, using word combinations that had not been modelled within sessions. This included “want more next” (whilst turning towards an MP3 player) to indicate she wanted more music using an MP3 player which she could scan through to find songs.

**Giving words multiple meanings.** The student creatively used her vocabulary to meet a variety of needs, including using the phrase “drink fall” to request lentils be scooped into a beaker and then poured out as part of a sensory game.

**Demonstrating reduced challenging behaviour.** Within therapy sessions, there were minimal incidences of any challenging behaviour and this began to be reported outside of sessions in the classroom.

**Sustaining shared interactions.** The student would participate in a variety of turn taking activities, shared interactions with a variety of adults and showed some emerging readiness to interact with her peers.

**Tolerating use of trigger words.** The student became more able to tolerate use of trigger words within therapy sessions and was able to use some of the words herself to meet needs (e.g. “stop”).

**Development of non-verbal communication strategies.** By beginning to combine pointing, integrated eye-gaze and vocabulary (e.g. “want”) she was able to increase the clarity and efficacy of her messages.

**Progression with p-levels.** Within therapy sessions, the student demonstrated appropriate abilities to progress to the next two p-levels for speaking and listening.

**NEXT STEPS**

Evidence gathered during the trial suggested that the LAMP approach significantly benefited the student’s communication development. The combination of multi-sensory input, consistent motor plans and a student-led approach appeared to meet her needs extremely effectively.

It is anticipated that once a device is provided, the student will continue to develop her communication skills significantly. This will likely impact upon a number of areas, including social-emotional wellbeing, family and peer relationships, educational progression and possible post-19 placement options. Alongside this it is hoped that further work can be trialled with other students across the school using the approach. If it can be established that a number of students will benefit from the approach, we hope to be able to secure funding for an assessment device to continue the approach in school.

Increased joint working with the occupational therapist has also begun, and therapy sessions are used to both promote communication and address sensory processing difficulties – including readiness to learn.

In addition to the expansion of the use of LAMP across the school, working practices around the balance between core and fringe vocabulary have been considered within the speech and language therapy team in school. Early AAC work within other approaches has also been adapted to promote core vocabulary with some fringe vocabulary as opposed to initially introducing a number of topic words.

**AND FINALLY…**

Following the presentation of the paper in September 2012, a device was funded by The Sequal Trust [3] which enabled the student to continue with the therapy.

* Emily Williams
  Speech and Language Therapist

Danielle Aubrey
  Speech and Language Therapy Assistant

**REFERENCES**

1. The Centre for AAC and Autism
   www.aacandautism.com
2. The ACE Centre
   www.acecentre.org.uk
3. The Sequal Trust
   www.thesequaltrust.org.uk

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Integrating Access to Social Media into AAC Devices

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BACKGROUND
Consider the way that you communicate with friends and colleagues on a typical day. Much business interaction is accomplished through exchanging email messages. If you need a more immediate response, you may opt for instant messaging or Skype. Texting is often used to touch base with family. We use Facebook to keep our friends and relatives up to date with our latest activities. Then there is Pinterest, Twitter and a host of other electronic communication channels.

Contrast this with our communication channels twenty years ago when most of our interactions were accomplished through voice or printed documents. Not only have the channels of interaction changed, the nature of the interactions have changed as well. We hold multiple, concurrent conversations via SMS, and IM. There are different expectations for grammar. There is also a different interaction cadence. In telephone or face-to-face conversations, pauses of more than a few seconds are awkward and uncomfortable. In SMS or IM interactions, pauses of several seconds, several minutes, or even longer are normal and expected.

In some ways, electronic communication would appear to help overcome barriers often faced by individuals who use AAC devices, particularly barriers caused by limited mobility and slower communication rates. And yet, AAC devices are still viewed primarily as face-to-face communication devices. While many AAC devices provide some type of connection to social media and electronic communication, access is limited and often tedious to use.

TECHNOLOGICAL HURDLES & APPROACHES
Social media and electronic communication is a dynamic area that moves quickly and in which preferences and loyalties change frequently. Some providers fade from view quickly, while others retain their popularity much longer. This variability and unpredictability presents challenges to developers of AAC systems. With limited resources to apply toward a complex and changing issue, AAC developers have typically used one of the following three approaches to provide access to social media and electronic communication:

1. Keyboard and mouse emulation
Rather than adding computer functionality to the AAC environment, keyboard and mouse emulation allows one to control a computer from the AAC device. This technique has been used for many years and effectively gives one access to all of the capabilities of the computer. The advantage of the technique is that since it only emulates keyboard entry, along with mouse movement and clicks, it is largely immune to changes to applications and computer functionality. The disadvantage is that it introduces a second level of user interface and is often very slow and tedious to use, e.g. one often has to send stored text strings from the AAC device to generate cursor movements on the graphical interface displayed on the computer.

2. Designing the communication protocol into the AAC environment
A few AAC devices include the communication protocol within the AAC application. This strategy tends to give more efficient and accessible control than is available through mouse-keyboard emulation. It works rather well for communication environments such as email or SMS, where communication primarily consists of the bi-directional exchange of text messages, but is less effective for graphical environments, such as Facebook.

3. Using message portals
Newer operating systems, such as Android and iOS, have provisions to send messages from apps to social media sites such as Twitter or Facebook. While this approach is fairly easy to implement, it is also limiting. Messages can only be sent to a few select sites. In addition, messages can typically be sent, but not received, from the AAC application.

APIS AND DYNAMICALLY DEFINED BUTTONS
Numerous social media providers now provide APIs (Application Programming Interfaces) that allow developers to integrate social media functionality into their applications. These APIs provide a way to access social media sites without requiring the user to leave the AAC environment. Furthermore, many APIs allow developers to define buttons dynamically, making it easier to integrate social media functionality into the AAC environment.
Interface). APIs are toolkits that allow developers of third party software to exchange information with the provider. For this project, we used APIs, along with dynamically defined buttons. Simply put, we exchanged information with social media providers and used this information to change the design and contents of the AAC device’s user interface.

The hardware platform used to implement the prototype functionality was Saltillo’s NovaChat products, based on the Android operating system. Although we interfaced with a number of social media providers, the examples shown in the accompanying figures are all from Facebook. Figure 1 shows Facebook homepage feeds. But note that rather than being displayed in the normal format, each feed is displayed on a separate button on a NovaChat page. For each feed, the Facebook API is used to obtain the name of the person who posted the message, their profile picture, the type of post and an abbreviated form of the message. This information is then displayed on a button.

One of the advantages of bringing the Facebook content into the AAC environment is that the content can then be accessed by using the AAC user interface. Since the content is brought onto the NovaChat’s buttons, the operator can access the messages with the same access technique that he/she would use to select a normal message button. To expand a message to see further content, one needs only to select the button. In this case, if the top button from Figure 1 is selected, the resulting display is shown in Figure 2. Note in Figure 2 that not only is the original post enlarged, but now the comments posted by others can also be seen. The buttons at the bottom of the page can be used to ‘like’ the photo or to post one’s own comments. To see the photo in greater detail, the top button is selected to reveal the display illustrated in Figure 3.

Similar techniques are used to visit friends’ Facebook pages, add comments and browse through their photo albums. Users can also update their status, upload photos, view videos and do most of the functions that we are used to doing in Facebook on a daily basis.

LESSONS LEARNED

Using APIs to access social media content proved to be a reasonable approach for bringing social media access to the AAC environment. We were able to provide access to almost all of the regularly used functionality of several social media providers and electronic communication formats from within the AAC environment. This had both the advantage of providing access to the medium and giving access to the operator’s vocabulary pages for generating messages. Beta testers found the interface much more accessible than other approaches that they had tried.

From a developer’s perspective, although using APIs allows one to provide much capability by linking to the existing functionality of providers like Skype, MSN, Twitter and Facebook, there are still hurdles that continue to make the task challenging. Among them:

• Each provider uses its own API. This means that a separate interface must be created to each social media option for which access is provided.
• There are an increasing number of social media sites and providers. MSN, Google Talk, Skype, Yahoo Messenger, Facebook Messenger and AIM are just a few of the providers of instant messaging. Most are incompatible with each other. The popularity of the providers comes and goes. Deciding which providers and sites to include is not an easy task.
• Providers periodically change their protocol and functionality. During this investigative project, Facebook made a major change to their user interface. This also resulted in a major change to the way we needed to interface to the site.

These challenges notwithstanding, however, integrating access to social media and electronic communication within the AAC environment is quite feasible. I would hope and expect to see this functionality integrated more extensively into AAC products in the near future. *

Dave Hershberger, President of Saltillo Corp
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