COMMUNICATION
MATTERS

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Assistant University Tutor in Speech, Language and Communication

SCOTT STACK
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INTRODUCTION

My name is Scott Stack. I have cerebral palsy and I use an ECO2 device to communicate. I am currently working as an assistant lecturer for the Speech and Language Department, at the University of St Mark and St John, in Plymouth. I initially did a 12 week placement, where I was given my own office and various roles, including teaching in lectures, having one to one tutorials, and attending meetings. I really enjoyed all the responsibilities I had, as well as how fast my communication was progressing by having time in my office to really focus.

FILM

In May this year, I had a documentary film made about 'a typical day at work' for me. It demonstrated my roles and responsibilities within my job, and also had interviews from staff and students about the effect my role has had on their learning. I really enjoyed doing the film, and I love showing it to people who are intrigued about what I get up to at work, the three days that I go. I showed my film to people at the Communication Matters conference in September.

TUTORIALS

The students made appointments to come and see me, in my office, for a formal tutorial. This allowed them to get to know me better, and my good communication helped them to understand how I used my device to talk. I did not want my carers in the tutorials with me, because I wanted the time to talk to students, myself. I wanted to be in charge, and independent, in my own meetings.

MEETINGS WITH LYNSEY

My boss at the University of St Mark and St John is Lynsey Parrot, who is a senior lecturer in linguistics and communication sciences. At least once a week, we have a meeting together, in either her office or mine. I think I have good meetings with Lynsey. We work together as a team. I feel valuable because she gives me the time I need to talk in our meetings. She values my opinions and takes on board what I have to say. We discuss what we need to do, to help the students' learning.

OFFICE

I wanted my own office, because I needed quiet time to do my own personal and important work – to develop my communication. At home, it was easy for me and my carers to be distracted from doing my work. By having personal time, in my own working environment, I knew I would get more work done. I can really focus!

I have a weekly planner on the wall, so I know what I am doing each day. I also have the symbols from my device that I use to communicate with, put up all over the walls, in the correct sequences. This is so I can learn my new icons, and new sequences, much easier.

I love having my own office. It is my own space, away from home. It has given me more independence, and the ability to progress and improve a lot quicker with my communication.

My other carers, and those I live with at Cornerways, have no idea what I do at work, unless I

Lynsey and I have regular meetings

Helping with lecturing and teaching

Symbols all over my office wall to assist me learning my icon sequences

tell them. And I like that. If they want to know what I did at work on a particular day, they have to rely on me, telling them. When I am in my office, I use the time to practise my new icons and new sequences. I also spend time, writing presentations and any pre-stored paragraphs I need for lectures.

I also want to add, that when I go to work, having a good appearance is hugely important. So, each time I go to work, I wear my smart trousers, a shirt, and a tie.

VALUED

I feel like a valued member of staff at the University of Saint Mark and Saint John. The staff have welcomed me to their work place, and the students seem to like me teaching them. They take the time to listen to me. This includes, not just the speech and language department, but also the canteen staff, computer staff, reception and other departments within the university.

I went to the University of Saint Mark and Saint John's Annual Conference in July. It was organised for all the staff who work

Having a student tutorial

at the University. When I was there, quite a number of the staff members came over to talk to me. They knew who I was, and wanted to have, a conversation with me. This made me feel good. I now feel like, part of the lecturing team, the more time I spend here.

CHANGES

I have had to make really big changes to my daily routine and lifestyle to accommodate my work. I get really tired after being at work all day. All I want to do is relax. But I can't. Before I had my job, my days used to be organised around my care. Whereas I now have to organise my care around my working day.

STAFF

Also, I have had to ask my staff to become adaptable to my new work regime. I asked my key worker, Sîan, and another staff member, Coral, to be my support at my work place. Their roles have completely changed. Now, they have become more like my secretaries, because they help me with where I need to go and the work I need to do for my job. They also work with me in my office, helping me with my own personal work.

They have a system for communicating with each other. They write in my office diary, saying what I do each day and what work I need to do. They help me to arrange, my appointments and meetings. They also help me to do my weekly wall planner so I can also see my work schedule. Communication between my carers is vital. This is because it makes my working day much more structured and less stressful. I also need the rest of my staff, at Cornerways where I live, to be reliable and on time. Otherwise, it can prevent me from being at work on time or, sometimes, being at work at all.

CONTRACT

Just before my 12 week placement had finished, I was offered to return to the

University of Saint Mark and Saint John in September, to keep assisting with the teaching of speech and language therapy. I am hoping that I will be offered a more formal contract with designated hours, and more regular pay. Just like what you all have in your jobs. This would make me feel even more like an official member of the work place. I really like working there and I want to keep teaching students during the time they are in University as well as staying in Plymouth to teach, so I do not have to travel too far from my home. I like working three days a week because I can still do the things I like to do outside of my job.

INSPIRE

From this, I hope to inspire people, with or without disabilities on the use of AAC. I want to encourage them to be ambitious, and help them realise it is possible. I am proof of that. I cannot imagine my life without working. I love doing it, and I love the reaction from people – from the students I teach, the other lecturers I work with, and people like you. ✳
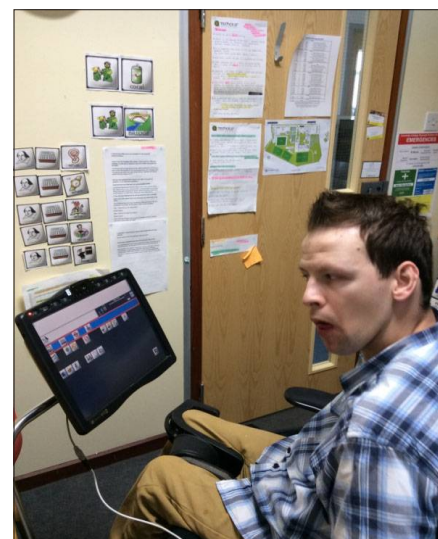
Scott Stack
Assistant University Tutor

Positive Health in a Person-Centred Way

No decision about me without me

TINA SEED[1] & LINDA NAVERAN[2]

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INTRODUCTION

Most people will have the need for health investigations and interventions during their lives. Health interventions can be scary and daunting, even if you have, and can understand, all of the information. As adults we are asked to weight up information and make decisions about what we want and how to keep well.

Health information is usually given via leaflets; many adults with learning disabilities have difficulty understanding the written word and so it is difficult to make informed choices. Consultations are frequently lengthy with a lot of verbal information given in one big chunk that makes comprehending and recalling difficult. In addition, the health world is also riddled with abbreviations, special terminology and confusing descriptions.

Everyone has a right to be included in the decisions about their life and health but if your communication or comprehension is compromised it is difficult to understand, and more likely that others will make decisions on your behalf. The government have talked about "Liberating the NHS" to make it accessible and "No decision about me without me"; both these are difficult if you find communicating or understanding challenging.

The Mental Capacity Act (2005) states that all "reasonable adjustments" must be made to support an adult to be able to understand decisions, weigh up the pros and cons, retain that information and then communicate a choice.

Health needs of adults with learning disabilities, who find communicating difficult can frequently go unrecognised and/or unmet. Changes in a person's presentation can often be overshadowed by their diagnosis and mis-labelled as "challenging behaviour" or "being difficult"

which means the people around the individual do not investigate the cause for the change. People are left in pain, and chronic longterm effects develop from untreated conditions. The MENCAP reports *Death by Indifference* (2007) and *74 Deaths and Counting* (2012) all too clearly highlight the errors that have been made in treating adults with learning disabilities.

NORTH EAST LINCOLNSHIRE

Tina is a Speech and Language Therapist and Linda is a Health & Well Being Coordinator; their roles work in harmony to develop tools with adults with learning disabilities in North East Lincolnshire to support individuals to understand their own health needs, understand their choices and be enabled to make an informed choice about what they want.

Tina and Linda support clients to communicate directly with other health professionals, to have their voices heard and their choices honoured.

Tina, Linda and their clients use imagination and creativity to support the development and use of reasonable adjustments to try and include all clients as far as practicably possible in health decisions. Fully including people in health decisions has reduced the need for sedation, covert operations, extended hospital stays and general anxiety related to the unknown.

Health services across the North East Lincolnshire region, and wider areas where access has occurred, are demonstrating an increased awareness of the needs of adults with learning disabilities, an increased willingness to work in partnership, and a realisation that inclusion is key. A greater partnership working has been established where the client remains at the centre.

FOUR CASE STUDIES

Examples of four case studies follow to demonstrate some of the many interventions that have taken place.

CASE STUDY 1
W: Cateract surgery enabled

W is a lady aged 59 with moderate learning disabilities and mental health needs. W is a fun loving and sociable lady. W's behaviour had been declining for some time and she had begun to show signs of anxiety and became angry when leaving her home. A variety of health screens were carried out to try and establish the reason for change in behaviour. A sight assessment was arranged with the local opthamologist using pictures instead of letters as W does not have any literacy skills. Testing revealed that W had bilateral cateracts developing.

Tina and Linda worked together with the eye surgeon and carers to involve W in the decision making process. Terminology was adapted, e.g. the lens was referred to as a 'window' that was 'dirty' and that was why she could not see well. We talked about the consultant needing to "clean her windows" but she needed to be asleep for this as they were at the back of her eye. Photographs and an anatomical model were used to further support W's understanding.

Linda liaised with the staff on the day unit, where the operation would take place, to ensure there was a consistent use of vocabulary that W would understand. W visited the day unit and met the staff there and saw where the operation would take place. W met the consultant that carried out her operation and called him her "special window cleaner".

With a lot of time, work and support, W was able to understand and consent to the treat-

ment five weeks later. The treatment was a success. W will tell people about her operation and is now happily re-engaging with activities and other people.

CASE STUDY 2
S: Personal bowel screening process enabled

S is a lady aged 52 with Downs Syndrome, severe learning disabilities and limited communication skills. S has a love of paperwork and being busy. S does not have any literacy skills. Historically, S had not permitted any health interventions and refused to attend any health appointments.

S began to complain of stomach pain (frequently holding her stomach and crying) and staff reported blood in her stools. Concern was further raised as it was found that there is a history of bowel cancer in S's family. Attempts were made by staff to monitor S's bowel movements but S became very distressed and angry with staff invading her privacy, resulting in significant confrontation and aggression. S had also begun to wait until she went to day services to use the toilet and as a consequence became quite constipated.

Tina made an object version of the Bristol Stool Chart (using homemade dough) so S could see and understand the different types of bowel movements. Each type was given a corresponding coloured sticker. S was tested using the object chart to check S understood; she consistently identified the right one.

Linda worked directly with S developing a record sheet and providing this and stickers in a formal pack to support S to "rate her own poo". Work was also carried out to explain re blood in the stools being worrying and could mean she was "poorly in her tummy" and S agreed to watch out for that especially.

S was able to reliably record her stools for a period of six weeks, giving a clear indicator of how her bowels were. She was supported to show her chart to the GP at the surgery every week and this enabled a relationship. After six weeks, the GP was happy that there did not need to be any further intervention as there was no further occurrence of blood in stools noted. S continues to monitor herself and sends her chart via post to the GP. Trust has been established between S and her GP. S recently had a blood test for the first time since she was a small child. S has been told about her thyroid gland and has agreed for the blood test to be checked for any problems; results were clear.

CASE STUDY 3
C: Informed decision made re. breast prosthesis or not

C is a lady aged 46 with severe learning disabilities. C is a very shy lady but has developed confidence and social skills since moving out of the family home last year into a supported living setting.

C was an only child whose family were very protective of her and they kept her at home to be safe. C had a breast removed in 2010 because of cancer; professionals from the community team were not told of this operation so C did not receive any support. The consultant and C's parents decided that C "would not understand or care" about the operation and should not be troubled to make a decision about either the operation or a prosthesis.

When C moved to supported housing, she began sharing her home with another lady who enjoyed wearing feminine clothes and C became aware of her own femininity and desire to wear similar clothing.

During a health review, C told Linda "I want two boobies". Linda liaised with the local breast clinic to request information both historical and current. C was supported to make a self referral to the clinic to explore the types of prosthesis that were available. Objects and photos were used with C to enable her to understand and make an informed choice. C was supported by Linda and paid staff to spend a month really looking and thinking about choices.

C chose not to have surgery, even though this was offered to her, and chose to have a prosthesis which could be worn inside her bra. C has bought a lot of new clothes. She now walks with her head up and is communicating more. Family have commented on the increase in confidence and say they see her as a 'woman' now.

CASE STUDY 4
S: Successful teeth extraction

S is a 50 year gentleman with Down Syndrome and moderate learning disabilities. S is a very quiet, private man who enjoys interacting on a one to one basis but declined to attend any day opportunities or group events. S refused to attend any medical appointments. There was no record of S having had any blood tests, eye tests, dentist appointments or any other appointments. S was registered with a GP practice but had never gone there.

S's support staff contacted S's GP who in turn made a referral to the community team with concerns around his general health. It was decided that S's teeth needed addressing as many were visibly rotten and S had started to refuse to eat and had lost a lot of weight. S was also in a lot of pain from his teeth and did agree to have them just "looked at".

S was introduced at his home to a dentist, Rachel, with whom both Tina and Linda have worked on many occasions and who has a positive working relationship with many clients with learning disabilities. S agreed to have a dental appointment on the understanding that Rachel would only look in his mouth. Several teeth were identified as needing to be removed.

Linda and Tina developed a pictorial social story to support S to understand the process of the procedure, including examination, x-rays and the actual extraction procedure. S was able to demonstrate that he understood and fully consented to the different parts of the treatment process.

S visited two dental units and decided which one he wanted to be in and then he visited the rooms in which he would have the procedure and recover. He chose to be asleep for the procedure and decided who he wanted in the room when he woke up. He was given a calendar to countdown to the operation and was able to talk through his social story many times in order to gain reassurance and clarify what would happen.

On return from the hospital after the extraction, S said with a smile, "I am proud of myself. I didn't need to be frightened". S then eagerly phoned his brother-in-law and sister to tell them of his achievement.

S has since attended other medical appointments and has engaged with health professionals. He has had an EEG, ECG and blood tests. His appetite has improved and, despite still being shy, he is beginning to try new social engagements.

CONCLUSION

The four cases above, and many like them, have shown that making reasonable adjustments using AAC enables people to have positive health experiences now and in the future. *

Tina Seed
Speech and Language Therapist

Linda Naveran
Health & Well Being Coordinator

REFERENCES

DoH (2005), Mental Capacity Act, London, HMSO
www.legislation.gov.uk/ukpga/2005/9/contents

Mencap (2007), Death by Indifference, London: Mencap
www.mencap.org.uk/deathbyindifference

Mencap (2012), 74 Deaths and Counting, London: Mencap
www.mencap.org.uk/74deathsandcounting
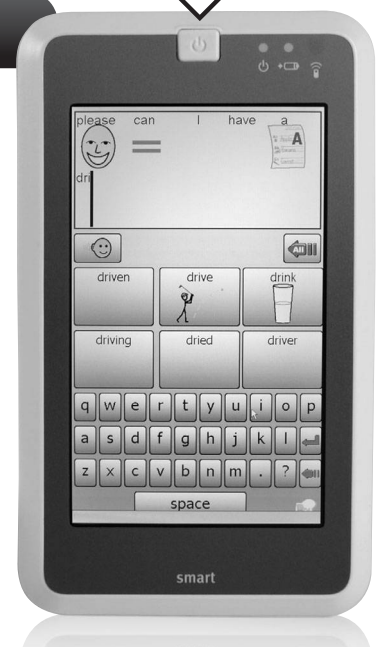
Parent Power

Training and empowering communication partners to support high tech AAC users

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BACKGROUND

An AAC assessment team for children in Cornwall has been jointly commissioned by Health and Cornwall Council since September 2009. The team consists of the County AAC Officer, Anne Williams (employed by Cornwall Council for 2 days per week) and a Speech and Language Therapist, Alison Webb (employed by Cornwall Partnership NHS Trust for one day per week).

During our AAC assessments we were struggling to engage the families and encourage functional use of the AAC devices. Intervention was taking over a year, and our waiting list was growing. We were under pressure to move children through the system quicker, but our greatest concern was that the devices were not being used to their potential.

Parents and carers had devised their own methods of communication over the years and often anticipated the child's needs and could not see the benefit of more complex communication.

Inspired by presentations at the Communication Matters Conference in 2011, we initiated parent and staff support training (which included the Community Speech and Language Therapist) prior to the introduction of a device.

We purchased the *You Matter* programme from the ACE Centre and delivered it to two cohorts of parents and educational support staff – a total of eight families.

YOU MATTER

The *You Matter* course brings together families and professionals on an equal footing in order to provide practical and positive ways forward for the children's AAC needs. It gives families the tools and the support needed to set their own goals, solve their own difficulties and become active decision-makers in supporting their own child's communication. It provides an opportunity for professionals to learn from other disciplines, and gives families the platform to share practical experiences for the benefit of all involved.

The course can be delivered with the minimum of preparation. All of the course materials and handouts are provided, including PowerPoint presentations, feedback forms and video resources. We were very positive about the ready-made resources and activities (Fig 1).

The first programme had to be adapted as it focused on one child on the Isles of Scilly. The entire team of parents, two Teaching Assistants, Special Educational needs Co-ordinator and teacher attended, but the programme had to be delivered on just one day, due to travel costs and time constraints for the presenter.

We then delivered it to a group of parents/staff over two days as recommended by *You Matter*.

It is difficult delivering information that you have not written yourself and we
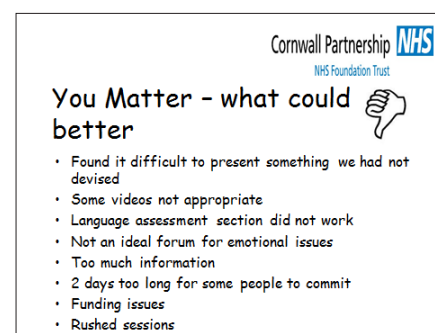

Figure 1 What went well?
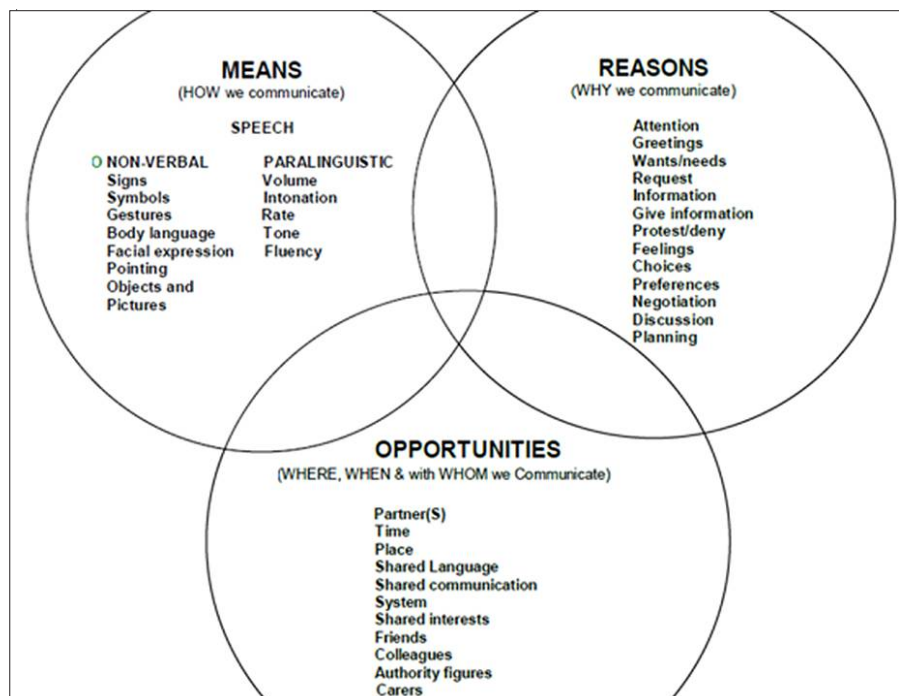

Figure 2 What could be better?

Figure 3 Means, reasons & opportunities for communication

felt sections of the course (particularly the language assessment section and some videos) were confusing to the audience and that the course was too long (Fig 2). With agreement from the authors of *You Matter,* we adapted it to become *AAC STEPS.* We really wanted to focus on means, reasons and opportunities (Fig 3) for communication.

CONTENTS OF THE COURSE

Introductions

We used an iPad and a Big Mack voice switch to introduce ourselves, which for some families was the first time they had experienced voice output.

What is AAC?

AAC Journey

We followed a child we knew (BM) through his AAC journey and used his videos to illustrate different ideas; we discussed feelings re AAC (hopes/fears/expectations).

Means

We showed a video of child BM for people to identify different means and played a game where people needed to use non-verbal means to give information

Reasons

What their child could express without and with AAC:

- Yes/No
- Getting attention
- Greetings. Social contact and connecting to people
- I want – basic needs, choice
- Protesting/complaining

- Comments – like/don't like; describing
- Requesting/Giving information – sharing experiences; talk about things I cannot see
- Questions
- Feelings
- Thoughts – preferences; reasoning
- Creative communication – stories, humour
- Independence

We used the Toby Hewson video from *You Matter.*

Opportunities

- Who (circle of Communication partners/communication passports/barriers)
- Where (community/future needs and independence)
- When (no tech/low tech/high tech - challenging)
- Choices (experience as non-verbal with yes/no, limited choice and wider choice symbol cards)
- How (core and fringe vocabulary)

Support

Support for families and staff.

RESULTS

We did the training prior to, or just after, the introduction of an AAC device. We found the parents:

- Took control in identifying vocabulary and were aware of core vocabulary
- Suggested appropriate activities to stimulate communication

- Took control in developing low-tech resources
- Used modelling effectively
- Made sure the device was available for use at all
- Researched independently for better devices
- Understood that AAC is a long journey and did not expect miracles

The children met all the set goals faster than expected, and we were able to discharge from the assessment team faster. We found we had to visit them less frequently in the early days as the parents needed less support.

Case Studies

DR – Parent did not attend. The device is not being used.

HS – Moving forward with little intervention.

GK – Mum researched new devices. Took control but this also led to some inappropriate decisions.

AT – Dad took full responsibility for programming and making decisions (appropriate); needed minimal support.

TJ – Parent did not attend. Still struggling to get her to see the purpose of low tech or offering more complex choices.

RL – Parent took eye gaze to hospital appointment and independently created low tech resources (Fig 4) for shopping.

We had expected the parents to create a support network as they had exchanged emails, but this happened only when the professionals instigated it. We also invited them to a drop-in coffee afternoon in a central location, but no-one accepted the invitation

Rachel's Experience

Rachel is the parent of a non-verbal girl who was 3.5 years old when she was first assessed. Here are her thoughts in her own words:

"Part of our introduction to AAC was a meeting held by Anne and Alison, with other parents & carers of children of all ages who also needed to use a device to help with their communication.

At the time of the meeting, I had had a quick look at the programme Chloe was going to be using, Proloquo2go, and although I am not very confident with modern technology, I was very much looking forward to her device arriving, and had it in my mind it was going to transform Chloe's life.

During the meeting I think I went full circle, from being unrealistically positive – this device was going to be the answer to all our problems – to feeling rather down about it all, realising Chloe's communi-

Figure 4 A parent created this low-tech resource for shopping

cation problems are long term and although this device would help in so many ways, it was still going to be a long road for her and us, to get her using it well, and even then it's not as simple as just "providing her with a voice" – to realising how hard it must be for Chloe, not being able to say what she is thinking, just like I do most of the time (not always a good thing, can get you into trouble!). Then back to the beginning again, where the future does look easier, and this could open up the world to her – I could see her in a few years time going into a coffee shop with her friends and being able to ask for what she wanted, even if it did take a few moments longer than the others. Just the fact that she could be independent enough for that, got me back feeling positive, but this time realistically so.

At the meeting, Ann & Alison asked us to partner up with a stranger and try and ask each other for a certain type of drink, without using words. You could almost hear the whole room groan – really, do we have to? It felt awkward and embarrassing and I felt quite stupid. Not only could I not make myself understood, but I felt guilty that I could not understand the other person. It was so frustrating, which is exactly why it was a perfect exercise for Ann & Alison to get us to do."

Some comments from other parents

"If time had permitted, more could be useful."

"Would have been good to speak to parents a little more."

"Gave opportunity to experience the frustration of a non-speaker."

"Good fun... Not too embarrassing... I don't normally like joining in but it was a very relaxing atmosphere."

"Good to meet other parents and teachers."

"Lots of food for thought & feel more confident."

CONCLUSION

Parent training is essential to helping parents take ownership of AAC methods and increases the availability and use of a device. Working in partnership with carers and educational staff maximizes the functional use of communication.

A one day course is best for Cornwall due to the large catchment area that we cover, but we plan to do a troubleshooting follow up day six months from the first course, as requested.

We have now delivered the course within a Special School. We will revise the current course to include more time for parents to speak to one another, and enable them to set up support groups.

There are clear benefits to spending a day together and building up a relationship. Parents enjoyed the social side of the day, so we are planning a fun day for AAC users and their families soon. We would also like to have an AAC newsletter with useful links and ideas but lack of funding affects these plans. We now ensure that we meet the parents at the first casework meeting and set objectives together. ✳

Alison Webb
Specialist Speech and Language Therapist

REFERENCES

ACE Centre, 'You Matter' Course
www.acecentre.org.uk/you-matter

Bousaki, A., Latham, C., Moore, R. & Buckley, K. (2011) You Matter: Training for parents and close professionals
www.communicationmatters.org.uk/symposium-session/2011-you-matter

Emerson, A. & Dearden, J. (2010) Means, Opportunities, Reasons and Expectations (MORE): Exploring ways to enhance the communication of children with autism and severe intellectual impairment
www.communicationmatters.org.uk/symposium-session/cm2010-emerson-more

Pearce, C. & Pugh, D. (2011) Involving Parents in the AAC Process in Northamptonshire
www.communicationmatters.org.uk/symposium-session/2011-involving-parents-in-aac-process

RESOURCES FOR AAC RESEARCH

Research Involvement Network

Communication Matters has set up the Research Involvement Network to encourage more people to take part in research into AAC and to help researchers find the participants they need. The Network is made up of people who use AAC, their families and carers, and professionals who work with people who use AAC.

If you are interested in participating in future AAC research projects visit the Research Involvement Network webpage (link below) for more information. We are particularly keen to recruit more people who use AAC and family members and carers.

Communication Matters welcomes applications from UK post-graduate researchers wishing to recruit participants to AAC research projects. Contact Communication Matters to discuss your project, email: rin@communicationmatters.org.uk

For more information, please visit: *www.communicationmatters.org.uk/ research*

Single Case Study Template

As part of the Communication Matters AAC Evidence Base project, one of the collaborative partners (Manchester Metropolitan University) developed a single case study template. This template was developed to support the collection of consistent and relevant case data. It is intended to support more robust data collection.

If you would like to contribute to Communication Matters' ever growing case study database of submissions from people who use AAC, please download a copy of the participants information sheet about how to contribute by following the link below. Alternatively, you may wish to download a copy of the case study template for your own use.

For more information or to download case study template/resources, visit: *www.communicationmatters.org.uk/ research*

Widgit Health

Widgit Health produce a range of materials to support communication in healthcare, from easy read sheets for patients and communication books for first responders to bespoke documents and signage.

By providing effective communication support, Widgit Health aims to improve the inclusion of patients, especially those who have a communication need.

- FREE and low-cost accessible information for patients and healthcare professionals available to download.

- Developed in partnership with community and healthcare professionals.

- 300+ Widgit symbols designed specifically for healthcare.
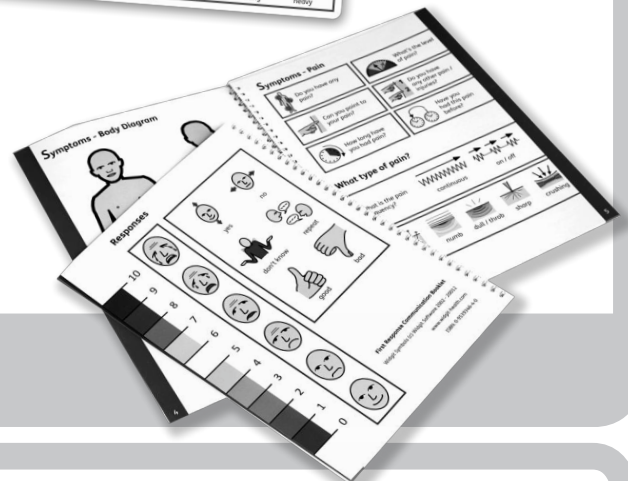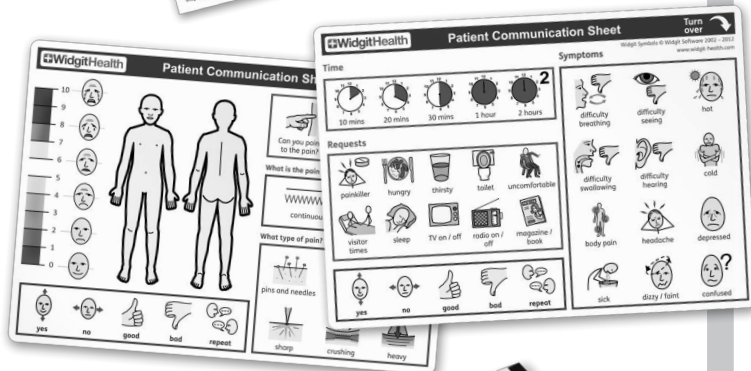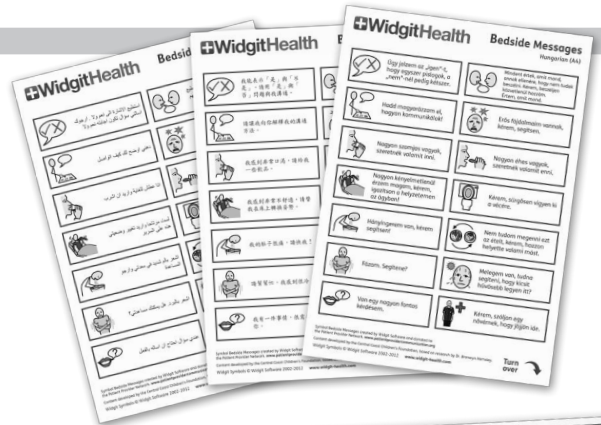
www.widgit-health.com

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The MND Association Wheelchair Project

The right chair at the right time

CHRISTINE ORR

Leeds Wheelchair Centre, Seacroft Hospital, York Rd, Leeds LS14 6UH, UK
Email: christine.orr@leedsth.nhs.uk

WHAT IS MOTOR NEURONES DISEASE?

Motor neurone disease (MND) is a rapidly progressing neurological condition which in the majority of cases is always fatal. The disease may commence at any age in adult life, the peak age of onset at 55 to 60 years, affecting twice as many men as women.

People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and the use of their limbs; the most common cause of death is respiratory failure. The individual often will remain mentally alert as they become trapped within a failing body, although some people do experience dementia or cognitive change.

There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis and at present there is no cure.

Due to the rapid progression of this condition it is imperative to provide timely, appropriate and anticipatory services for people with MND that are integrated and work together.

As a relatively rare condition health and social care professionals, often struggle to understand and respond to the needs of people with MND in a timely manner.

Current NHS prescription guidance within wheelchair services can also cause problems for people with MND as at the time of assessment they do not always meet the requirements for the provision of a more complex chair.

THE POWERED NEURO WHEELCHAIR PROJECT

Project History

The need for this project was first identified in 2007 when an Occupational Therapist, Jenny Rolfe, commenced employment with the MND Association, following the generosity of a major donor to the MND Association to provide wheelchair assessment and provision specifically for people with MND. Jenny was based within the MND Care Centre in Oxford. She set up a standalone wheelchair assessment and loan service and developed this through the funds raised via this donor to supplement the NHS wheelchair provision.

Jenny's work identified that there were delays not only in waiting times for an assessment by some NHS wheelchair services, but also delays in deliveries from wheelchair manufactures to the wheelchair services and then further delays in the handover of equipment by the wheelchair services or a third party agent.

In addition, it was identified that no one prescription available on the NHS market from manufacturers met the needs of people living with MND. Due to the rapid progressive nature of MND, the wheelchair prescribed need to meet the current and the on-going future requirements for people with MND. This meant that the chairs being prescribed were classed as 'Specials' by the manufacturers which therefore increased the costs and delivery times.

Mounting a communication aid on a power wheelchair (photo supplied by MND Association 2014)

Bluetooth pairing with and R-net joystick control and Android device (Penny & Giles Controls Ltd 2013)

This evidence-based practice supported the CIVIS report 2010, which concluded that using anticipatory prescribing of wheelchairs reduced the need for reassessment and re-provision, thus reducing overall service costs in the long term.

The Current Project

In 2013 the MND Association were given Department of Health funding to extend and develop the Powered Neuro Wheelchair concept further, through the Innovation, Excellence and Strategic Development Fund. A two year project then commenced.

Project Aims

1. To provide a responsive service in respect of assessments and provision of powered wheelchairs for people with MND at three centres across England, through the recruitment of three specialist wheelchair therapists who will only assess people with MND.

2. To work in conjunction with three leading wheelchair manufactures, to develop a specific prescription form within the NHS range of EPIOC's (Electrically Powered Indoor/Outdoor Chair), that will meet the current and on-going needs of people with MND (and other rapidly progressing neurological conditions) at an optimum cost for statutory provision and with a short lead time.

The expectation is that these two elements will enable people with MND to be seen rapidly, ensuring they receive the right wheelchair at an early stage, which in turn will meet their needs as their disease progresses.

WHEELCHAIR THERAPISTS

Three Wheelchair therapists have been appointed into the project, based in Oxford, Leeds and Surrey, working closely with the local MND care centres.

The role of the therapists

- Make links with local and regional wheelchair centres and provide support to deliver timely and appropriate assessments. Ensuring the correct wheelchair is provided at the right time for people with MND.

- Be a resource to other professionals, as and when required.

- Support inservice development and promote the use of advanced prescription.

- Work with three leading wheelchair manufacturers to develop and review the Powered Neuro Wheelchair prescription to ensure the chairs and features continue to meet the needs of people with MND.

- Make links and develop pathways to ensure people with MND get timely access to appropriate communication aids and environmental controls, which can then be integrated and mounted onto the wheelchair.

WHEELCHAIR SPECIFICATION AND DEVELOPMENT OF THE POWERED NEURO WHEELCHAIR PRESCRIPTION

The MND Association and MND wheelchair therapists have worked with three leading wheelchair manufactures (Invacare, OttoBock and Sunrise) to develop the Powered Neuro Wheelchair prescription.

Prescription Specification to Manufacturers

1. EPIOC Wheelbase – which is small and compact so it will fit around the person's home.

2. Tension Adjustable Back – with a padded back support to protect boney prominences. This helps to accommodate upper kyphosis and provide lateral support.

3. Electric Tilt in Space – to support posture; prevent sliding and improve respiratory function.

4. Padded/supportive arm rests – adjustable in positioning to support forearm and to facilitate supported driving.

5. Headrest – angle adjustable; multi positional.

6. Footplates and hangers – multi angle adjustable.

7. Seat board – to allow appropriate pressure relief cushion to be provided to meet individual needs.

8. Controls – adaptable and multi positional and functional.

9. Electronic capability to interface with AAC devices such as smart phones, tablets and environmental controls, as well as being able to control the wheelchair.

SERVICE REVIEW & ON-GOING DEVELOPMENT

Service Audit

As the Leeds therapist, I undertook an audit of wheelchair provision for people with MND. The audit reviewed time from referral to provision of the wheelchair from 2011, 2012, and 2013 prior to the appointment of the specialist MND wheelchair therapist. Data since the appointment of the Leeds therapist has been used as a comparison to pre appointment. The data shows that in the majority of cases there has been a significant decrease in time from referral to provision of the wheelchair required.

The project has a target that 80% of wheelchairs are issued to a person with
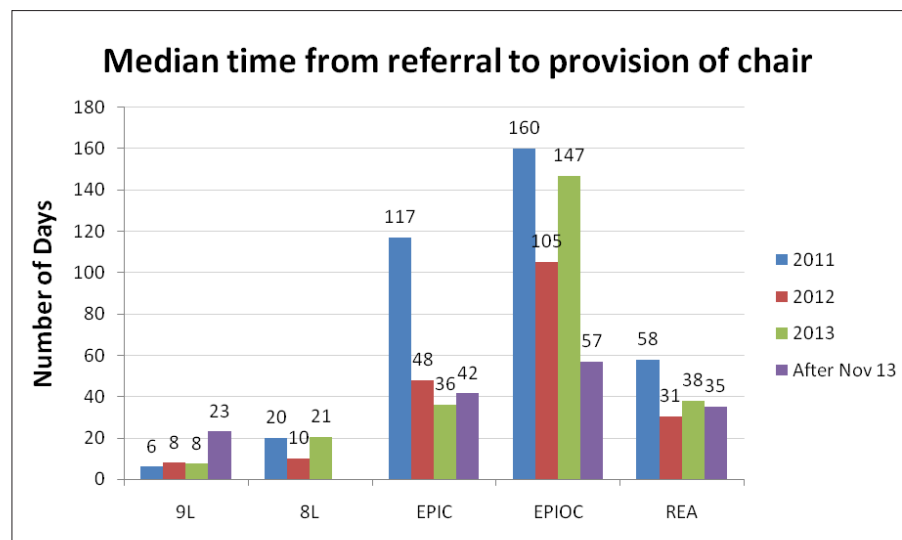
Leeds wheelchair service audit: referral to provision of wheelchair for people with MND
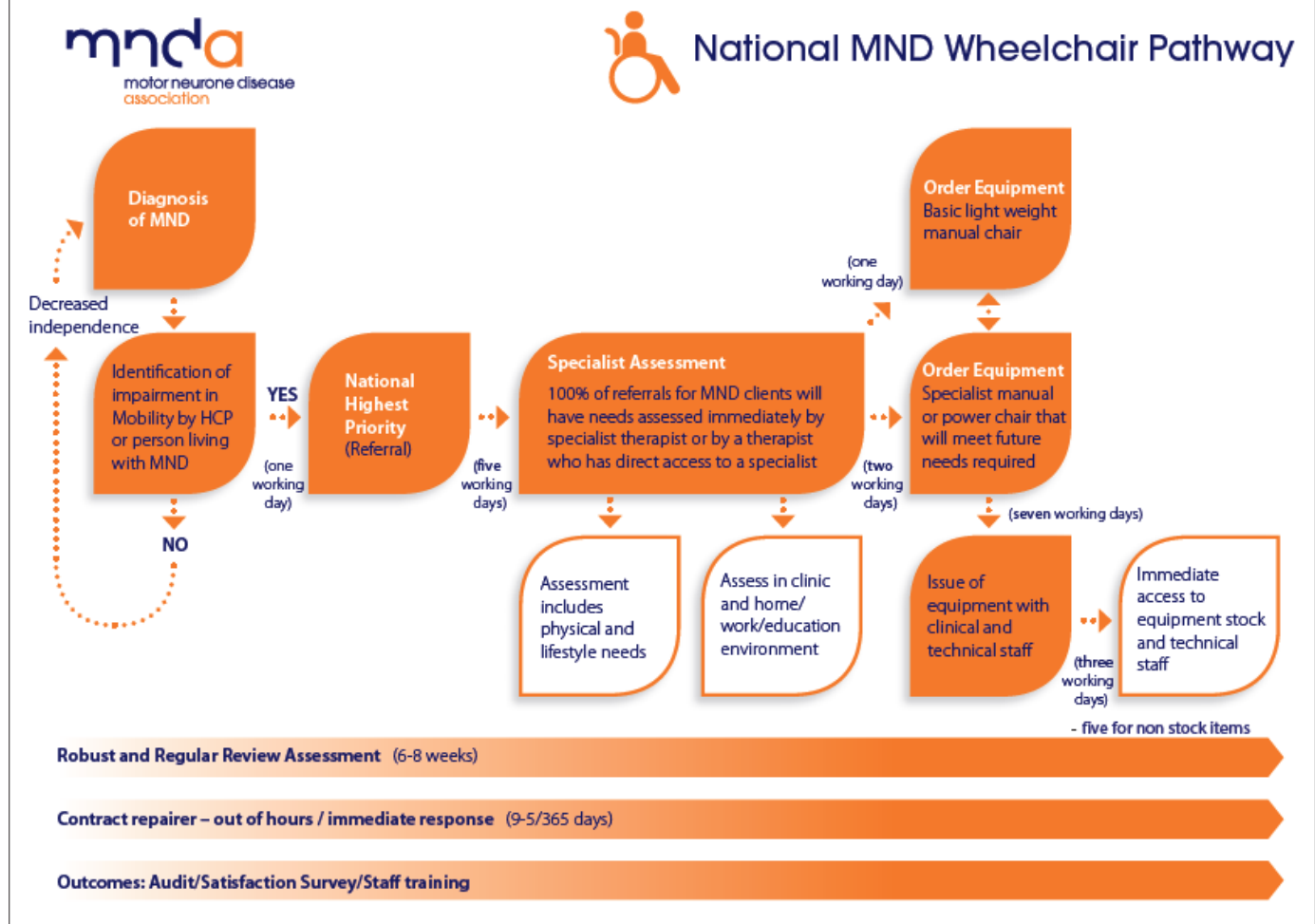
MND within four weeks of referral. Not all chairs are, or have been, delivered in the four week time frame. It has been identified that delays are due to the availability of the person with MND, clinic space, engineer availability and manufacturer delivery. The audit will be completed again in January 2015.

STEERING GROUPS

The three MND wheelchair therapists have organised local steering groups to progress the work of the Powered Neuro Wheelchair concept across statutory services. The steering groups aim to develop local and regional links with wheelchair services; local authorities, communication aid teams and environmental control teams. The group share good practice, identify challenges and develop clear pathways for people with MND to ensure they have the right provision of equipment at the right time.

The steering group identifies areas for further development and collects data for the project on wheelchair provision for people with MND who access their service.

Wheelchair Prescription Review

The prescriptions are continuously being reviewed with the three manufactures following feedback from practitioners and service users. Further areas identified for development is a standardised range of mountings and trays for ventilators, communication aids, suction machines etc. These need to be easy to fit, removable and adaptable to different products.

Person Experience Review

An outcome questionnaire has been developed for those people with MND and their carers, who access the MND wheelchair service. This will enable evaluation of the service offered by the MND wheelchair therapists and the wheelchair provision. The data will provide details of the patient and carers experience of the service, wheelchair functionality, and the impact on their independence and quality of life.

CONCLUSION

The project is currently on-going. Further work is required to ensure the interface and links to AAC and environmental controls is routine practice. Further evaluation is also required to ensure the project is meeting the aims and objectives and the key outcomes:

- Improved patient and carer experience
- Right chair first time
- Reduced cost and value for money
- Timely provision of equipment. ✳

Christine Orr
MND Wheelchair Therapist

REFERENCES

CIVIS (2010) Wheelchair Services: Costed senarios for the Motor Neurone Disease Association.

Penny & Giles Ltd (2013) R-net Rehab Control System: Bluetooth Control of Smart Devices:

www.pgdt.com/Products/R-net/Bluetooth-Mouse-Module/Bluetooth-Smart-Devices.aspx

Accessed 30 September 2014.

Rolfe, J. (2010) National MND Wheelchair Pathway: Guidelines. Motor Neurone Disease Association.

Rolfe, J. (2012) Planning wheelchair service provision in motor neurone disease: implications for service delivery and commissioning. *British Journal of Occupational Therapy* 75(5), pp217-222.

Pictorial Communication

Making it Happen

CHRISTINE FINCHAM
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INTRODUCTION

My son, Ian, is now 37 years old. From birth I knew that he might possibly have a learning disability – something I came to terms with long before any professional broached the subject. Eventually coming to the realisation that my son did have a disability, I decided that he would get the full support he needed to have an integrated and full life.

This is a step by step account of how I believe he has developed a sound communication system that has grown and changed with his own lifestyle.

THE BUILDING BLOCKS

Starting from the Premise of a Good Understanding

Believing he understood everything was essential. From the start I spoke to my son as I did to the other children: I asked him where things were, I asked him to find things for me, and I talked about what everyone had been doing that day. In short, we were a normal family. This for me was fundamental to enabling him to want to communicate and to join in conversations from a very early age. It was a contributing factor to his development of a Yes/No system early on.

Everything is Possible

Stimulation and experiences enhance communication; if you want to tell people what you have done then this motivation is the most positive starting point. We did all the normal things that families do. Ian is the middle child, with one older and one younger sister and the 'everything is possible' approach ensured that all the children enjoyed their childhood. Disability was not a word we used often even though my son uses a wheelchair – where there's a will, there's a way. Providing stimulation and fun in a normal community setting brings its rewards to all; my daughters' friends accepted him as normal and would chat away, telling him everything, without a thought to his communication abilities.

Listening

To want to talk, you need to know that someone will listen; my experience of working in a large institutional hospital taught me that stimulation and valuing played a big part in how people reacted to their surroundings.

If my son has something to say, I listen. If I'm not sure what he is saying, I will make some suggestions and he will respond to this by answering Yes and No, or going and getting objects or pictures to inform me, and eventually we get there. Everyone knows when that is, because he has a eureka moment (I always feel he's thinking "Thank God, she's got it at last"). When I can't get it, then I tell him, and if it's not too important he accepts it for now or he will carry on until I do.

This might sound obvious but I have seen people fob him off with "Yes, that's right" or "Did that really happen?" and he looks at them as if to say "I'm out of here", which usually is the case. I think his motto is "Don't waste time on people who are idiots".

Maintaining Friendships

Anyone who has a child with a learning disability knows that maintaining school friends is hard. The separation of Special Needs Education often means that friendships made at school are difficult to maintain because they are not local, and with large catchment areas sometimes as much as 30 miles away. The extra effort always pays off. Friends made at school are very special and are irreplaceable: their shared experiences of growing up together means a bond is formed that is probably stronger than any other friendships.

I have enabled him to maintain contact with the people who were his friends at school. They still regularly meet for a night out and, if we can, go away together every year. I love these occasions as you just see how much they enjoy each other's company. They are at ease with one another, and although my son was the only one of the group that did not have good verbal communication, everyone would

listen to what he had to say and most times understood him (or maybe he would allow them to think they had, because it didn't matter to him).

Now, because the schools are not local and the interaction with other parents is different, you can't always know who the friendship group is. Some three years ago my son was swimming and he saw someone he knew. They immediately greeted one another and although his friend was about eight years younger than him they had obviously formed a friendship which has now flourished. From that incident I wondered how many more friends Ian had lost because of the system and because of his communication difficulties. Just to note, the other person had communication difficulties as well.

Developing Hobbies and Interests

Sharing common interests and goals is the essential ingredient to cross over the communication barrier. Ian has many hobbies; his main one is Clowning. He has been a fan of Laurel and Hardy since he was about six years old and has been a clown since the age of thirteen, after his initial contact with a clown who visited his special school.

He is now a registered clown with Clowns International. He has visited many clowns outside the UK, and is a respected member of the clowning community. This means that at any function he's one of the gang, chatting away about the day or function, and the clowns understand him. They ask him Yes or No, or let him take them to someone or something. This has not been me making this happen, this has been my son taking an interest in and enjoying like-minded people.

He also belongs to the Laurel and Hardy appreciation society and attends their Annual Convention where they watch old films and swap memorabilia. At one of these events he was sat next to a man who happened to be a Biker – leather jacket, long hair, etc. – and first of all neither took any notice of the other until Ian started to pre-empt a scene and started to laugh and the chap turned round and said "I know this bit is really funny". My son smiled and nodded and with his own sound told the man that he liked the film. This was the start of a wonderful conversation between two like-minded people with them both laughing and anticipating the funny bits; they did not need conventional conversation to understand one another as what they had in common was enough.

REASONING BEHIND CHOOSING HIS MAIN COMMUNICATION SYSTEM

When my son was young, the professionals would want to assess and decide on what communication methods were best for him and, as a young mum wanting him to have the best, I would eagerly put all my energies into the suggested idea. Makaton, Widgit Symbols, Synthetic Speech Box, etc., but these methods were not easily transferred to enable his friends to understand him, and I felt that each therapist had a different slant on how his communication system should be organised. That is when I decided to take it upon myself to work with Ian to devise a system that he enjoyed and other people could easily understand; that is why pictures have been his main communication tool for the past 25 years.

It occurred to me that every new method professionals wanted him to try was like learning a new language, but that, as with non-disabled people, one language was enough to start with. This thought, combined with him leaving school and having to return the equipment, meant it was time to choose.

Pictures are great, everyone can understand them and they truly tell the story. My initial starting point was setting up books of people, places and things as well as lots of photo albums of special events. This worked well for a while but I did realise it was very limiting. It came to light that things needed to change when one day my son was at his computer and there was a picture of some friends he was very interested in. He has a touch screen and as he pointed to the door in the picture it got bigger and bigger until I could see their dog's head just about visible. It made me realise that maybe pictures were not always enough and we needed to put in some prompts so that when Ian was talking and showing his photos, those seemingly forgotten moments in the picture were still recorded. This discovery coincided with my son moving into his own house with a support team – so the creation of diaries began.

Developing one communication method and staying with it encourages speech. As I commented earlier, learning one language is hard enough, so once the decision is made then you should stick with it. My underlying thought was that if he could communicate more easily and be more relaxed about it, then speech might develop. He has always communicated his needs, and is encouraged to do so; by setting this up as a precedent, people know to talk to *him*, not to his carers. When he goes to the bank, for instance, he will hand over written instructions and then tell the cashier what he wants; this is then repeated back to him by the cashier who has the instructions in front of him/her and he will nod Yes. This is only one example but this happens every-

where, all the time. If he wants something, he will chat away and his support staff will help the person understand by asking Yes/No questions or suggesting an event that he is particularly excited about.

Usually when Ian enters into conversation with someone who is a total stranger, they respond very well if they know what he's talking about. The other day, he was in the chemist and decided he was going to chat to a rather jolly elderly man who was smiling at him. He started the conversation and I asked "Is it about the circus you are going to?". He nodded and smiled and once the stranger knew the subject he just chatted: "Will there be any clowns?" My son nodded. "And a ring master?" He nodded, and the man said "So nice talking to you, have a great time at the circus". Another convert!

DEVELOPMENT OF A PICTORIAL COMMUNICATION SYSTEM

My son is now 37 years old and his communication system has developed with his understanding and the development of new technology, so this is a quick run through of the steps that I have taken to get us to where we are now and the plans for the future.

My starting point was three books of People, Things and Places together with photo albums of special events. My son would point to the pictures and we would make the sentence as he went along, with him nodding Yes or No.

As Ian started to do more and more, it was obvious that this was far too limiting and he wanted to explain much more than the pictures allowed. So we moved on to daily pictorial diaries, of which he now has 15 years of records. He will still go and get one of these if he wants you to know something about past people or events.

These pictorial diaries started off as sticky labels. He would be supported to put in the monthly diary of the things he had done that day, with the support staff writing down something that he had agreed to that described the things that were not in the picture. He would take the diary out with him or use it at home to start a conversation.

I can remember when we first began to use them and he had one of his clown friends around for dinner. I left them alone whilst I went into the kitchen, and I could hear Tony saying "You went down town then and saw John playing the guitar". Whoops of delight came from my son; he was so happy having a conversation with his mate. I stayed in the kitchen for longer than necessary as I just wanted to find out how it developed. It went on and on, with my son getting more of his diaries

and Tony commenting on them. Yes, I thought to myself, this really does work.

As time went on, I started to do yearly canvas collages, which give him the story of what were important events throughout every year since he moved into his own house. He loves them and refers to them daily, as well as taking to friends to show them that they have made it into the rogues gallery.

As my IT skills improved, we began to do regular letters to friends and then a calendar every year that showed people what he had been doing. If for some reason we miss sending someone a calendar, they will phone him and ask why. Also, the clowns come up to him at events and ask if they are going to be in the calendar; that's so funny really but it shows his ability to converse with a wide range of people.

The computer has changed to a touch screen, and the diary changed from the stickers to PowerPoint, with my son choosing the pictures and printing them out. At the same time, he discovered Facebook, which is another avenue to let people know what he had been doing and also to see what his friends had been up to.

Technology is always changing; the dairy has now moved on to his iPad which is much easier to take around and show people. He also adds his weekly diaries to a yearly one, and really enjoys showing people lots more things about what he had done that year. The daily page still gets printed out to make up a paper version of the diary as he loves looking through it as a book. However, we have condensed the information so he now has a yearly diary rather than 12 separate ones.

Ian now has an iTV box, Smart TV and a hard-drive that connects to the broadband, so he can increase the pictures he can show people in different formats and places. The iPad has opened up the world of apps (which is another story).

The hardest thing is bringing everyone along with you. His staff team have to be able to understand and keep the daily diaries up to date, so we can only go as fast as they go. I find something and test it out, and then pass it over when I am sure I understand it. However, this process is not difficult and staff usually pick it up fairly quickly.

CONCLUSION

Communication is so important to all of us, not only to ask for things but to let people know what you have done, who you have seen and how you feel about things.

When I wrote this paper for the CM2014 Conference, it was a story – our story – about how, as a family, we had developed a communication tool that was inclusive and that enabled family and friends to understand Ian, and more importantly for him to be part of everyday conversation.

However, since being at the Conference and talking to people, I realise that it's more than that – it's Ian's past memories that he can access and share with people, going back to his childhood. The diaries enable him to tell his own story and share his experiences, the things we take for granted. This has always been the case for Ian but it was at the conference that I realised that there was so much emphasis put on enabling people to communicate and very little emphasis on preserving the past in an easily accessible format. ✳

Christine Fincham

COMMUNICATION *MATTERS*
National AAC Conference

13th -15th
September 2015
at
University of Leeds

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.

Following last year's very successful conference at the University of Leeds, be sure to book early for the UK's leading AAC event.

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Conference Programme

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.

- plenary sessions
- research stream
- poster session
- full seminar timetable
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- social events

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Find out more at:

www.communicationmatters.org.uk/conference

Conference Registration

- conference opens on Sunday 13th September at 4pm
- registered delegates have full access to all conference events plus plenty of networking opportunites
- registration also includes refreshments, lunch and evening meals plus breakfast for residential places
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COMMUNICATION MATTERS

FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

I am now into my third year as Chair – time marches on! It has been encouraging to see that Communication Matters continues to have a key role in many different forums and is recognised as a significant voice in consultation processes.

We have just had our first Board meeting with the newly elected Trustees, reviewing our Strategy and Budget for this coming term. This can feel like a very daunting process, but we feel excited about the future opportunities.

We are committed to our aims of increasing awareness, improving service standards, encouraging research and lobbying for change, and this is reflected in our Strategy Plan for the next three years.

ANNUAL CONFERENCE

The CM2014 National AAC Conference is now behind us and we are already well into the planning for 2015!

Although Communication Matters is so much more than the Conference, it is obviously a key part of our 'core' business. It is encouraging that the new initiatives of interactive workshops, poster presentations and research stream have been well received.

A huge thank-you to the Trustees who were involved in making this year's event so successful. We want to ensure that all CM's activities continue to maintain the high standards which people expect and deserve.

Do encourage your colleagues, work mates and friends and family to seriously consider coming to the Conference in 2015. Our keynote speakers are already booked, and we are hoping to explore the possibility of launching the exciting 'Communication Access' project in the UK. More details to follow…

STAFFING

All change for Communication Matters!

As you all now probably know, Patrick Poon who has been CM's Administrator for over 15 years has decided to take a well-earned retirement from April 2015. Peter Head, who is his assistant in the office, is also retiring in January 2015. We have consequently been tackling the huge challenge of succession planning.

Over this past year, the Trustees have been involved in reviewing the skills and competencies which are needed to underpin the work of CM. We recognise just how much knowledge and skills Patrick has acquired as the job has grown over the years. We also needed to review the location of the CM office as, historically, the office has been based in Edinburgh because that is where Patrick lives.

As a result of many hours of discussion, face-to-face meetings and hundreds of emails, we have developed a new staffing structure and produced new job de-

scriptions. We interviewed for two new posts during the autumn, and we are very pleased to announce that Hilary Gardner will be taking up the post of General Manager and Communications Officer. We have also interviewed for a full-time Administrator, and have made an appointment subject to references and Disclosure and Barring (DBS) checks. Both new members of staff will start their induction in February, so that there is adequate time to ensure as smooth a handover as possible.

Also in February 2015, the CM office will be relocating to the Leeds Innovation Centre (above), which is next to Leeds University.

This has felt like a huge task to embark on, and I am so grateful for the support of the Board (especially Ruth McMorran and Toby Hewson). Patrick too has been so typically gracious throughout the process. We remain indebted to him for his ongoing support. He will be helping us with the inductions and has also kindly agreed to be available for providing the technical website maintenance in the short to medium term as and when it might be required.

This is an exciting new stage but is also daunting and we are grateful to Patrick and Peter for giving us such a long notice period and for committing to supporting the new staff through the transition stages.

We are planning a farewell event for Patrick and Peter in March (by invitation). This will also include marking the presentation in Lisbon of the ISAAC Distinguished Service Award to Janet Larcher. We hope this will be a fitting tribute to all that Patrick and Peter have contributed to Communication Matters over so many years.

SPECIALISED HEALTHCARE ALLIANCE

A number of opportunities have arisen because of our place on the Alliance including the opportunity to attend an event at the Scottish parliament with a chance to raise the profile of AAC to MSPs who were present. This forum informs CM of upcoming debates and we therefore have an opportunity to regularly raise the awareness about AAC service delivery.

STUDY DAYS AND ROADSHOWS

The second Symbolisation towards Literacy study day in Stirling was well attended, and it was good to see

the benefits of repeating a successful study day especially after the disappointment of having to cancel two other study days on different topics earlier in the year. We will need to do some thinking about the focus and structure of future Study Days and Roadshows as there is more of a problem over getting funding and time for study leave and also many of AAC suppliers are running their own days. There does seem still to be a place for the CM events but we need to be careful to ensure we are strategic and wise in how resources are spent.

LOBBYING

The Lobbying has resulted in some significant progress with AAC now being included within Specialist Commissioning in England. The 13 Specialist Hubs have been identified and the money has been released to the Area Teams. However, there has been a considerable delay in the process which has meant there has been a reduction in the funding related to the number of months remaining. This has caused problems with the timing of advertising for new staff in the Hubs. There is still a concern as to how the CCGs will meet their commitment to funding those people who do not meet the criteria for specialised commissioning.

We have decided at present not to renew our contract with lobbying firm Whitehouse Consultancy, but we will need to review the situation at regular intervals in the light of political changes. We are working more closely with The Communication Trust and RCSLT to ensure that we do not lose our lobbying momentum and would encourage our membership to make contact with their own MPs using the resources which CM will make available during the run up to the next General Election.

ISAAC

There is still a concern about the impact of the membership fees on our own membership costs, and we are in contact with ISAAC about this. In the light of the decision by the German Speaking Chapter to withdraw from ISAAC, Communication Matters (ISAAC-UK) is now the largest Chapter. Trustees are interested in the possibility of supporting less well-resourced Chapters through ISAAC's BUILD project. It feels that our relationship with ISAAC will be a key area for discussion this coming year.

THANK YOU

Thank you to the 'old' Trustees, and welcome to the 'new' Trustees. We are looking forward to this new season, but will need all of our membership to be actively involved to ensure we serve each other and the wider AAC community as effectively as possible.

If you wish to contact a Trustee, please email via *admin@communicationmatters.org.uk* ✳

Catherine Harris, *CM Chair*

When I decided to become a self-employed consultant in the general healthcare industry rather than stay specifically in AAC, one of the first things I had to do was to purchase my own laptop. Having bought one, I had to return a few months later because of persistent problems that they couldn't seem to fix without sending it away for a period which they said could be "up to three weeks"! Explaining that I couldn't run my new business without a computer didn't seem to matter, so I just stood with my arms folded and complained and refused to shut up until a manager came who eventually sorted the problem out. But it made me wonder how someone who wasn't as forceful and strong willed as me would have coped. Fighting for your rights when something goes wrong with a purchase can be hard work, tiring and demoralising, not to mention expensive if you decide to take it down the legal route.

The same applies for anyone who is reliant on an AAC device for their communication – indeed anyone using any medical device. How do they manage if it goes wrong and the supplier either can't or won't fix it quickly – or indeed if they feel they have been sold something that wasn't really appropriate for them when the supplier insists it was? Of course, the simplest answer is to ensure that situation never arises, but is that possible? Well, probably not but at least you can take steps that will ensure you have at least some support if things go wrong, and one way is to buy from a reputable dealer that can show a good track record. Getting feedback from other clients can give you an insight into what sort of service you can expect in the future.

I would (obviously) recommend buying from a member of the British Healthcare Trades Association (BHTA). Why? Simply because if things do go wrong (and let's admit that they can), and you can't seem to get any positive response or reaction from the supplier, the BHTA will act as a mediator to try and find a reasonable compromise. The BHTA won't take sides, but will act independently and review whether the claim is justified or not – and if it is they will try and ensure that the supplier does whatever is needed to rectify the situation. If the BHTA feels a complaint is not justified then the client will be advised of this.

Ultimately, if a complaint cannot be resolved the matter will be referred to an arbitrator, who will be a totally independent Queen's Counsel (QC), and who will call on expert advice from the industry and professionals before making their decision, based on the facts and their decision will be binding on both parties. So buying any product from a BHTA registered company means that if things do go wrong there is a way of getting them put right! Of course if you prefer you can always try and fight a supplier yourself to get a complaint rectified – but I know which way I would choose! ✳

David Morgan, *BHTA AAC Chair*

21 January 2015	Webinar
Tools2Talk	
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk	
11-13 February 2015	MMU, Manchester
Evidence Based Assessment in Complex Communication Needs	
Visit www2.mmu.ac.uk/hpsc/courses/cpd/detail/?id=67	
11 February 2015	Webinar
Text-based AAC Apps and IOS8 Keyboards	
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk	
25 February 2015	Webinar
Apps for skills assessment, to support AAC choices	
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk	
4 March 2015	Webinar
Go Talk Now	
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk	
5 March 2015	Edinburgh
Using Clicker 6 in Schools	
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk	
18 March 2015	Webinar
CoWriter Universal	
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Strategies in AAC Implementation

Parents' and AAC Users' Perspectives

ELIANE MACKINTOSH

Email: eliane@kai-saskia.com

"Language most shews a man: Speak, that I may see thee." – Ben Johnson (1573-1637)

COMING OF AGE

At the dawn of a new era in AAC implementation nationwide, it is timely to highlight the chasm existing between the possibilities – as expressed in the NHS England Standard Contract for AAC (DO1/S/b) – and the realities, from the perspective of many AAC users. Without parents championing their cause with obstinacy, progress is elusive. On the basis of personal experience and that of other 'AAC Families' (for example, many *1Voice* members), a number of actions at user level seems desirable to ensure success.

This paper focuses on the case of the unassertive AAC users whose voice is by and large unheard, except through case studies, usually set in a controlled short-lived environment; those for whom GCE or above might be unattainable goals; those whose main listener is Mum.

AAC USERS

As we know, speech is vital for human and societal interaction. And yet AAC users are often silenced or unheard through carelessness, misunderstanding or ignorance because the VOCA looks and sounds alien. In an era of multimedia instant communication, most listeners to AAC users display polite impatience. And that goes for 'clever' AAC users with nifty fingers, as well as for the less able, dependent on various switches or eye-gaze for access.

And yet, all AAC users overcome significant barriers from the onset, considering that, according to Jane Korsten (2005) "The average 18 month old child has been exposed to 4,480 hours of oral language at a rate of 8 hours/day from birth. A child who uses a communication system and receives speech/language therapy two times per week for 20-30 minute sessions will reach the same amount of language exposure in 84 years".

That intrinsic 'word deprivation' naturally impacts the development of innate communicative skills from critical analysis to routine chitchat, etc. Thus, undeniably, AAC users are 'high achievers' in their pursuit of communication.

THE UK AAC ENVIRONMENT

As demonstrated, inter alia, by the unveiling of new offerings at succeeding, successful Communications Matters conferences, AAC development in the UK is vibrant, committed and realistic.

Products and Services

Technological advances have translated into a plethora of innovative products, consequently increasing public AAC awareness and user uptake. For example, *Unity*, a structured language programme and a good model for implementation of AAC applications; *Vocabulary for Life* for The Grid 2, aimed at young adults and older teens requiring symbols; Positive AACtion Information Kit for AAC Teams (Harris et al, 2010). Thus, enabling technological tools have been launched, used in selected pockets by the few, while they should be disseminated to the many.

Public Infrastructure

The cornerstone of that dissemination to the many promises to be the NHS England Standard Contract for AAC. With the roll out started in selected regions, it targets "those without or with cognitive disability, from childhood till, and into adulthood".

The hub-and-spoke model is based on existing models of good practice and recommendations by the Specialised Services National Definition Set and the Office of the Communication Champion (a result of the John Bercow Review in 2008).

Models of Good Practice

These already exist: for example, the Communication Aids Referral Team (CART) set up in Grimsby "has a structured, transparent, and sustainable process for the assessment and provision of AAC solutions for the people of Northern Lincolnshire." Tina Peck (2013) notes that the initiative was described in the Bercow Report (2008) as "a leading service of its kind" and by the Communication Champion, in 2011, as "a positive example of joined-up working".

A CAPTIVE, 'NEEDY' MARKET PLACE

These positive tidings are not echoed within the end-user population. Indeed, most parents – lone champions for these vulnerable individuals – have been/are battling with a host of separate agency representatives responsible for assessment, specifications, and funding AAC products and services. Once funded, often by any means, problems arise with mastering that AAC language, system personalisation/programming input, effective implementation, specialised polyvalent professional support, conversational practice with peer groups and others, continuity and faith! That multipronged package demands joined-up working between all components of the chain, which is currently absent. The result is uneven and limited.

SASKIA'S STORY

Born with CP and without natural language, Saskia aged 9 was introduced by her Speech and Language Therapist to a foot-switch activated scanning VOCA with 4 buttons per page. Aged 17, she got her personal 20 buttons VOCA attached to her wheelchair. Aged 20, having completed City and Guilds certificates Entry 1 & 2, the end of the device's guarantee loomed with no guidance as to the next step. The work invested risked being lost, posing a potential loss of much past achievement.

Then, at the CM2012 Conference, the inaugural presentation of Vocabulary for Life presented a Eureka moment. Funding was sourced (with much difficulty) for a new system. Meanwhile it was Transition Time: college education with its AAC pool of expertise was replaced by a post-college residence where VOCAs were largely unknown or ignored, and support was absent.

Eventually, funding was obtained for an outreach 'AAC package' for one morning per week at college. A positive progress report, begging letters, after

much uncertainty, justified continued funding for one more year by Health and Education. The NHS England AAC initiative with its goals and targets seemed unknown by the very funding agencies which should be concerned.

Saskia's story is positive overall, although riddled with uncertainty as to the future. Moreover, the relative success resulted from the fortuitous combination, at the right time, of committed specialised SLTs, suppliers of state-of-the-art products and a supportive parent championing her case. That dependence on individuals, not repeatable ad infinitum, isn't a blueprint. Hence there is a need for a long-term, fit-for-purpose, personality-independent, national AAC scenario reaching each user.

BARRIERS TO AAC USERS' PROGRESS

Today, NHS England promises a deployment fit-for-purpose, NHS Scotland is in the vanguard, and the CART model works. But as things stand, many AAC users and parents are forced now (and that could continue!) into a 'supplicant' position vis-a-vis the powers that be, including policymakers, agents in education, health and social services.

Some of the barriers impeding progress at user level are:

1. **Lack of recognition of AAC as a 'bona fide' need:** Although, communication is officially a key responsibility of both Education and Health, professionals in both public services are routinely in denial of the fact.

2. **Lack of urgency:** Precious time is wasted during the brief pre-transition 'learning' years, punctuated by various breaks. As in many disability areas, there is no urgency, no definite end goals and no built-in continuity for the future.

3. **Lack of prioritisation of AAC as a serious subject.** AAC, *a skill for life*, remains a discrete subject area among the plethora of cooking, crafts, TV watching, and shopping trips dominating the timetable in schools and colleges – and even more so in post-college care.

4. **Academic Qualifications:** City & Guilds certificates are not pursued, applied or promoted universally and many AAC users and parents are unaware of them.

5. **Lack of consideration for intrinsic difficulties linked to the user's disability:** The determination and focus required from these users is immense, often exacerbated by technical access difficulties. These difficulties should be addressed sensitively through collaborative guidelines and sustained support.

6. **Continuity.** Not enough collaborative effort is applied to the difficulties of engineering support (e.g. switches), system obsolescence and upgrades/change of program.

7. **Support Staff:** Care staff, carers and PAs who are well-placed to be key facilitators in the AAC life plan, are not trained to communicate with AAC users. One major barrier is the 'transparent wall' often separating the professional SLTs and other therapists from the care staff.

8. **Lack of SLTs and AAC specialists:** This issue needs NHS England's attention as it seems that there is a shortage of SLTs and AAC specialists to cater for demand now and in the future.

CONCLUSIONS AND RECOMMENDATIONS

In conclusion, the chasm between the possibilities – as portrayed by NHS England and suppliers' activity – and the realities, from the perspective of many AAC users and their families, is profound.

To quote Benjamin Franklin: "If you fail to plan, you are planning to fail". Indeed, without an effective AAC strategy with committed mentor/champions, and a joined-up working ethos, the plan will probably fail AAC users.

Accordingly, the following recommendations might achieve the goal of ensuring a far reaching fit-for-purpose implementation of the NHS England project for AAC end users:

1. **Nationwide publicity and promotion** of the NHS England deployment and of model implementations of AAC, throughout the regional outposts of SEN, social services and the NHS – in particular, professionals responsible for funding clients with communication difficulties. Also, visible advertising of roll out and schedule of implementation at local level.

2. **Appointment of a personal Champion/Mentor for each user,** to be the hub of his/her individual set of spokes. Each Mentor will protect his/her charge's interest. The Mentor's mandate is to "read and manage the individual's AAC Map" and to liaise with the spokes, thus facilitating the AAC user's progress.

3. **Recognition of the 24/7 learning model** as a vital need for many AAC users with cognitive/access difficulties. The right to 'AAC education' till 25 years old and beyond, by right. it is a life-time necessity, which should ultimately save NHS money.

4. **Customised AAC MAP.** Most AAC users/potential users with complex needs require a personalised communication plan, an AAC Map for Life. AAC communication should dominate their learning programme through life, with other activities becoming ancillary subjects/ practice exercises to their communication (all academic subjects, but also shopping, visual art, cooking, eating, film watching or discussion afterwards, drama, even bingo!). In short, *communication* should pervade all activities. That structured plan, tailored to the individual, should embrace all steps for the disciplined acquisition of that artificial talking mode which is AAC. AAC users need to be taught how to communicate, to convert thought into phrases, to interact – rather than just operate the tools. Many have to be convinced of other people's interest in what they have to say!

5. **AAC awareness and training, as appropriate, crossing professional boundaries,** including SLTs, AAC specialists, teachers, care staff, the home team and the rest of society.

6. **Parents' roles given official status and appropriate support and training.** Usually the mothers, those individuals embrace multiple roles of project manager, champion, personal teacher, programmer, market researcher (for new products and services), trainer of care staff, and maintenance supervisor (for intermittent faults and failing switches, for example). And since they have no clear mandate, they accumulate all these responsibilities in a fog of uncertainty, insecurity, lack of status and recognition, all imbued with a debilitating sense of pervasive futility.

SUMMARY

The AAC Mentor (who could/would manage a number of users) is at the heart of a successful deployment, dedicated to make the AAC package and device totally tailored for that user from the start and during the time required (ensuring upgrades at the right time), with the aim of making him/her 'AAC articulate'. The initial expense and commitment would result in much achievement and continuity, benefitting the individual user, his/her entourage and community, and the funding authorities responsible for his/her societal well-being. Without that personal mentor-led, hands-on, expert support, any deployment risks remaining patchy and uneven, resulting in unremarkable results. ✳

Eliane Mackintosh

REFERENCES

1Voice – Communicating Together *www.1voice.info*

Harris, E.J., Ryder, S. & Totten, L. (2010) Positive AACtion: Information Kit for AAC Teams, Perth.

Korsten, J., (2005) quoted in 'Increasing The Communicative Opportunities for VOCA Use through Staff/Parent Training' Gribble, T. et al (2014) *Communication Matters Journal,* 28(3), 9.

NHS Standard Contract for Complex Disability Equipment by NHS England: Alternative and Augmentative Communication' (DO1/S/b).

Peck, T. (2013) Establishing and Maintaining a Local AAC Service that Transcends Boundaries, *Communication Matters Journal*, 27(3), 31-32.

Talking Mats and Families Living with Dementia

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BACKGROUND

There is no denying that dementia is a dreadful illness that can cause a lot of anguish and despair for those diagnosed with it and also their families and friends. However, there is a danger in portraying dementia in an overly negative and stigmatising way by the way we use language. For example, these phrases referring to dementia with the vocabulary of war appear frequently: "The battle against dementia"; "The fight against dementia"; "Dementia is a ticking bomb"; "Win the war on dementia". Indeed, in June 2014 at the G7 Dementia Legacy event, Prime Minister David Cameron said, "The truth is that dementia now stands alongside cancer as one of the greatest enemies of humanity."

A key aspect of the work done by Talking Mats is to find ways to improve the lives of people with dementia and other communication difficulties and to find positive aspects of living with dementia. Our work in the field of dementia is based on two research projects funded by the Joseph Rowntree Foundation.

The first project examined the effectiveness of Talking Mats for people with dementia at different stages [1,2]. It found that conversations using Talking Mats were more effective for people with dementia than both unstructured (ordinary) or structured conversations. Improvements were evident in the participants' understanding, engagement, and ability to keep on track and make their views understood. Talking Mats enhanced the reliability of information provided by people with dementia, and conversations using Talking Mats lasted longer than ordinary conversations.

The second project examined how Talking Mats helped involvement in decision making for people with dementia and family carers [3,4]. It found that people with dementia reported that Talking Mats helped them to clarify their thoughts, express them to their family carers, and reach a decision in these discussions. Family carers reported that Talking Mats made them feel "listened to" by the person with dementia.

TRAINING

The Talking Mats team regularly runs training courses for staff working with people with dementia but following the positive findings from the research projects, we were keen to run free training for family members. Due to a donation from the Miss Hendry Charitable Trust and with support from Alzheimer Scotland, we offered this training in different Alzheimer Scotland Resource Centres.

We set seven conditions:

1. Training should be free.

2. Numbers at each training should be a maximum of six.
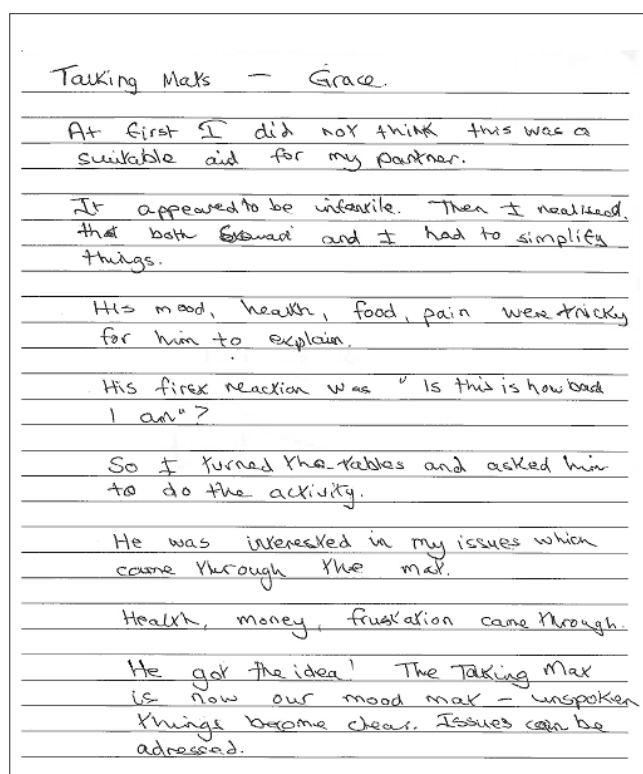

Figure 1 Group mat
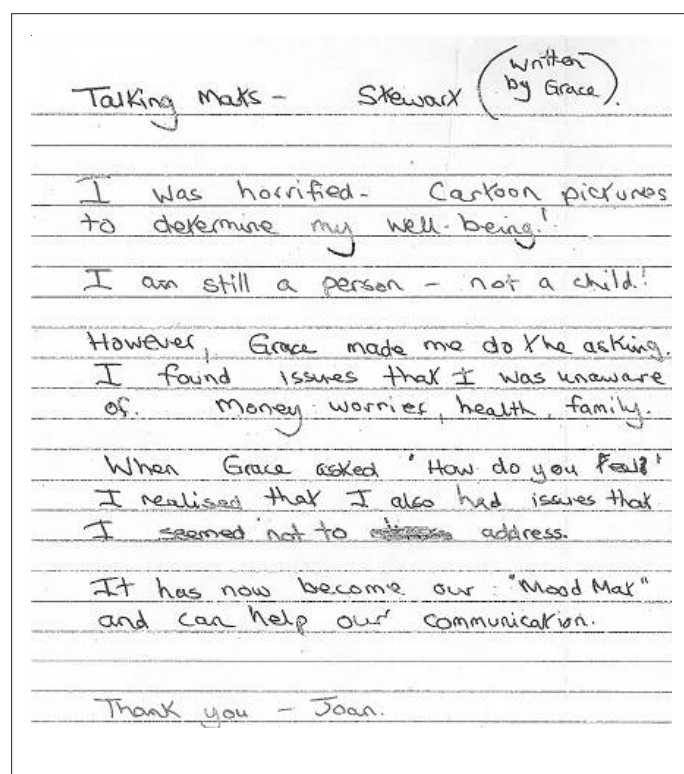
Figure 2 Grace's letter

Figure 3 Stewart's letter (written by Grace)

3. Timing of the training needed to suit the care requirements of participants.

4. There should be plenty of time to discuss sensitive issues.

5. There would be staff support from each centre.

6. The training would run over two sessions, one month apart.

7. Participants would be given their own mats and symbol sets to keep.

The format of the training was as follows:

Session 1
- Background
- Demonstration
- DVD examples
- Hands on practice
- Discussion of topics to be used at home with their relative
- Planning for next session

Session 2
- Sharing their own personal stories of using Talking Mats.

FEEDBACK

The feedback at the end of Session 1 was very optimistic:

"This was a very positive course today. It has made me feel very hopeful about establishing a time of coherent dialogue with my mother, albeit in a focused way and also in providing a tool for her to communicate in a simple way, her own thoughts. Thank you."

"Can't wait to try it with my wife. Thank you."

"I'm looking forward to trying it out and hearing how the others coped and what the outcomes will be."

"This was a very informative day and hopefully gives us a great way of communicating to find out my husband's views on subjects."

The feedback at Session 2, when people returned having tried out Talking Mats with their relatives, had some mixed views as can be seen by the group mat in Figure 1 which was used with the participants to help them reflect on their experiences of using Talking Mats. Most found the experience positive.

OTHER DISCUSSIONS FROM THE TRAINING

Giving control to the person with dementia

Overall, participants felt that using Talking Mats enabled them to keep their language simple, to ask open questions, and to use symbols, all of which helped to give control to the person:

"Reducing my language made me become invisible and the other person became centre stage."

"He grew in his understanding."

"I found out a lot in a short space of time."

"The symbols are a great gateway to understanding."

The difficulty of being so close emotionally to the relative with dementia

Some people felt it was difficult to ask their relative's views because they knew the person so well. It was suggested that in some situations it might help if a member of staff used Talking Mats with the person with dementia rather than a family member:

"There is a fine line because I know him so well."

"Maybe I'm too close to him."

Different perspectives

There was lot of discussion around the difficult issue of the person with dementia thinking things are fine when the relative thinks they are not:

"You don't want to trample on his respect but you have to be honest."

"I don't want to get on at him."

The daughter of a woman with dementia posed the thorny question: *"Whose problem is it anyway?"* By this she meant that, at times, the person with dementia is not concerned, for example, about their appearance, but that it is family members who are embarrassed.

A positive experience

Most participants agreed that using Talking Mats had been a positive experience

for their relative and for themselves as the following comments illustrate:

"Small changes made a big difference."

"It gives me time to sit down and listen to him."

"It slows you down, which is needed with someone with dementia."

"It helps me know where he is at the moment."

"It showed my husband the things he can do rather than what he can't do."

"He always feels up after he's done a Talking Mat."

"We got a load of information about how she was feeling."

A not so positive experience

However, some felt it had not been successful as either they had not found out anything they did not already know, or their spouse was unwilling to respond. We discussed the reasons for this and the groups were very supportive and suggested that the staff could help by introducing Talking Mats as a group activity at the resource centre, where these people could be included. The staff at the centres were also very positive and planned to use Talking Mats both with individual people and with groups.

Personal Stories

Relatives found out things about their partners that they did not know. For example, one person with dementia had revealed that they didn't like having the radio on all the time; another had toothache which her husband was unaware of; another said that food had become tasteless and he no longer enjoyed mealtimes. The relatives were all able to do something as a result to help the situations, e.g. reduce the background noise of the radio, make a dental appointment, add more spice to their cooking.

One couple, whose letters are printed with permission below, now use Talking Mats on a regular basis to help the husband think about issues and compare his mood from week to week. This couple have also given a demonstration of using Talking Mats to other family groups and to Norwegian visitors at the resource centre.

The letters in Figures 2 & 3 were written to the author by a wife who attended the training and her husband. They are reproduced with permission.

FUTURE PLANS

Overall it was agreed that Talking Mats is a very useful tool both for individual families and for dementia centres. We discussed future plans for individuals and also for the centres. These include:

- Planning the topics for a new Talking Mat about where to go for an outing (Fig 4).
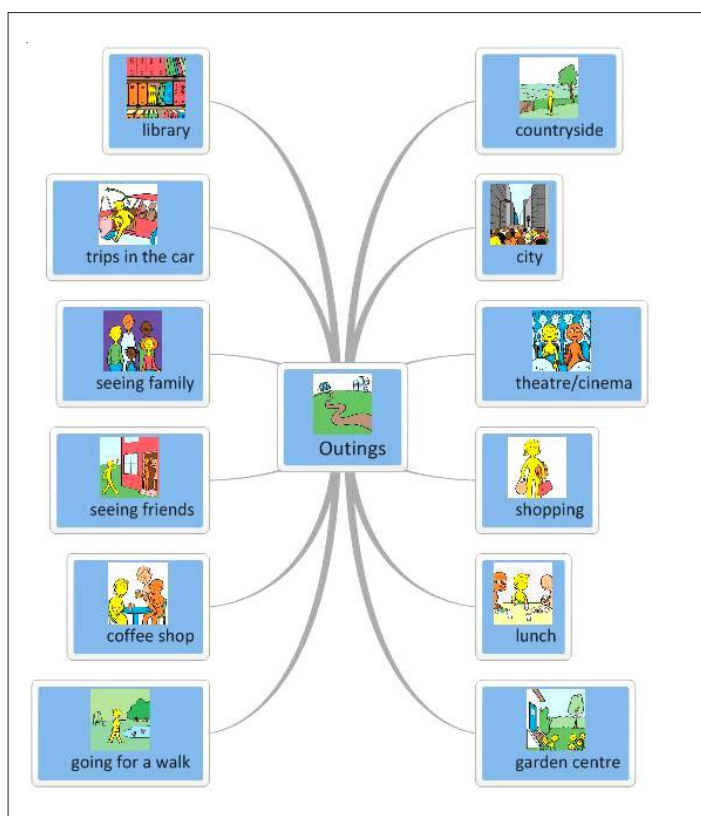- Setting up a Talking Mats group to give people more practice.

- Staff at the Alzheimer Resource Centre supporting relatives in individual use of Talking Mats.
- Using Talking Mats to show the views of the person with dementia to care home staff.
- Relatives using Talking Mats on themselves to show the person with dementia what they are feeling.
- Developing new topic sets at resource centre e.g. to discuss football.
- Using Talking Mats in group situations, e.g. planning a new allotment.
- Staff using the Talking Mats app version.
- Using Talking Mats for review meetings.

EVALUATION

Each participant was given a Post-it note at the end of the second session and was asked to write any comments, positive or negative, about the day:

"Videos of older people using the mats had a profound effect on me, for the positive effects they have."

"Keeps the person with dementia at the centre."

"Gives carers another route to engaging with loved ones."

"An efficient, non-threatening way of discovering how people with dementia feel about a range of topics."

"Good to experience and practice using the mat."

"Excellent training. Very enthusiastic about promoting the use of Talking Mats within day care as a tool to use as part of review process to enable service users to engage better and give their views."

"Well presented. Excellent resource for assisting to make sense of topics."

"Many uses from information gathering to planning, seeking opinion, feelings and fun."

"Good paced course. I enjoyed it and would love to use it more widely." ✳

<div align="right">

Dr Joan Murphy
Research Speech & Language Therapist

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REFERENCES

1. Murphy, J., Gray, C.M., Cox, S., van Achterberg, T. & Wyke, S. (2010) The effectiveness of the Talking Mats Framework with People with Dementia. *Dementia : International Journal of Social research and Practice,* 9(4), 454-472.

2. *www.talkingmats.com/wp-content/uploads/2013/09/Dementia-and-Effectiveness-of-Talking-Mats-short-Findings-1.pdf*

3. Murphy, J., & Oliver, T.M. (2013) Talking Mats and Involvement in Decision Making for People with Dementia & Family Carers. *Health & Social Care in the Community,* 21(2), 171-180.

4. *www.talkingmats.com/wp-content/uploads/2013/09/Dementia-and-Decision-Making-short-findings2.pdf*

Figure 4 Planning for Outings Mat

Arabic/English Symbol Dictionary

Early Challenges and Technological Opportunities

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INTRODUCTION

Over the last ten years there has been an expansion in the number of symbol sets available to AAC users, their therapists, teachers and carers. They have tended to be developed in USA or Europe with English or European language word lists, although some have other language options including Arabic. The problem is that few show the traits of true localisation where solutions have to be found for "the differences between cultures and the problems that are likely to occur because of these differences" (Evers et al. 2000). Researchers have shown in relation to symbol use for communication that it is important to have:

Translucency – how appropriate is a proposed symbol for a suggested meaning? (Bloomberg et al. 1990);

Guessability – can subjects guess the intended meaning of a symbol? (Hanson & Hartzema 1995, Dowse & Ehlers 2001, 2003);

Iconicity – how distinctive are the symbols? (Haupt & Alant 2003).

Simple language translations may offer word for word matching within the lexicons, but they tend to miss the issues of local colloquial vocabulary, cultural, social and environmental differences which can all impact on the speed of communication, especially when using many inappropriate icons, pictograms and other types of imagery to support dialogue and literacy skills.

BACKGROUND

The idea for the Arabic Symbol Dictionary came about with the aim of enhancing Qatari AAC users' communication and literacy skills. It was accepted as a three year research project by the Qatari National Research Fund but it soon became evident that this research project was not just going to be about an Arabic symbol dictionary.

Early on in the planning it became evident that user participation and technology would need to be at the heart of the cultural and linguistic challenges of working with the Arabic language in an environment where English was also used in the home environment, in the media, schools and workplace.

Local therapists and teachers who did not necessarily have Arabic as their first language wanted the dictionary to be bilingual but expressed their concerns about the use of westernised symbol sets. They also stated that any new developments had to work with what was already being used on AAC devices and in communication books, as well as for enhancing literacy skills. Symbols needed to match word meanings, support high contrast modes for those with visual impairments, be scalable for use in different settings and offer culturally and socially acceptable imagery.

These requirements that were gathered from several groups supported the realisation that there would be no time to make a completely new symbol set and, as has been mentioned, there were plenty available in English already. There had to be a speedy way of finding out what would be considered most suitable and adaptable so that all the requirements could be met.

METHOD

A participatory approach to the research was initiated at the outset, with the concept of degrees of involvement occurring as suggested by Fajerman and Treseder (2000).

In the case of the Arabic Symbol Dictionary, some ideas were initiated by the research team, but those using and involved with symbol communication in Qater have been asked if they would be

Entry Details Area

Language	Eng	MSA
Word Text	down 🔊	تحت 🔊
Definition	from a higher to a lower point of (something).	under
Phonemic representation	Phonemic representation d ow n Save Cancel	تحت
POS	preposition	preposition
Examples	• Go down the stairs Delete X	No sentences
Categories	Adult,Children,Core	Uncategorised
Symbols	ARASAAC symbols lie down — Male — Delete X — Stick figures — Delete X	*Double click here to add symbol here*

Figure 1 Online Symbol Management System just showing English and Modern Standard Arabic (MSA) entries - Qatari colloquial Arabic entries are also added where appropriate. With thanks to ARASAAC.

willing to participate in every way possible as the project evolves.

Action research methodologies have also been at the forefront of the project and included the setting up of an AAC forum, an advisory group of experts and ways to disseminate information such as a blog, mail list and social networking. Meetings to identify the problems, planning periods with actions for team members, data collection and analysis, reflection and a sharing of results with participants in Qatar have also been part of the process.

Quantitative and qualitative methods for gathering data have been introduced, with an online symbol management system for adding word and multiword entries, symbols with linking categories, definitions, parts of speech and phonemic segmentation. The system also has a voting area for participants to evaluate the symbols, comment on their appropriateness and ask for various changes to be made.

OUTCOMES TO DATE

During the first six months of the project, inconsistencies were found in the use of symbols for augmentative and alternative forms of communication and literacy skill development with some poor correlations of English to Arabic word meanings due to the inappropriateness of some symbols. Those working with European and USA style symbols spent a considerable amount of time making changes to the symbols and the vocabulary each time communication books or devices were developed to suit user needs. Where there have been symbols available with Arabic text, there have often been inaccurate translations of words and concepts resulting in additional barriers for Arabic symbol users and the quality of the text to speech on devices has also caused concern for those wishing to have local Qatari speech output.

There remains the need for different family groupings and other bespoke adaptations, increased colour contrast levels for those with visual impairments and improved clarity when re-sizing symbols. Symbols are used across the classroom environment as well as in books and on portable devices from the bespoke AAC device to the tablet and smartphone.

As a result of the participation of the AAC Forum, AAC users, their parents and carers, it has been possible to collect lists of Arabic and English core vocabularies used across Doha. Matching symbols have been found from two freely available symbol sets, ARASAAC and Sclera. These have been compared to those already in use in the various centres (PCS and Widgit). The voting that took place over a two month period, resulted in the agreement that the ARASAAC symbol set best suited the needs of many, despite all the additional symbols and lexical entry changes that might be required and often contradictory comments being made about a particular symbol.

Technologically it has been possible to link the English ARASAAC symbol labels to WordNet in order to speed the provision of the parts of speech and definitions. However, automatic phoneme segmentation for English words remains an issue due to the complexities of the sound structures and this may need to be completed manually unless we can develop some rules that can be applied to help the researchers.

There are insufficiently accurate WordNet definitions and parts of speech that can be used as a 'linked data' methodology for the Arabic lexical entries, but Arabic phonemic segmentation can be solved by the use of automatic diactritisation. The diacritic mark provides the equivalent of consonant plus vowel sound with resulting phoneme representation. It would seem the bilingual nature of the dictionary has thwarted a seamless use of technological strategies to populate sections of the system, but strategies to speed the process are still being explored and there is a determination to see entries supported by synthetic and/or human speech output in both languages to aid phonemic awareness and literacy skills.

DISCUSSION

This research project is in its infancy and yet it is clear that any Arabic Symbol Dictionary developed for the needs of users in Qatar should be culturally and linguistically acceptable as well as being bilingual with English as the second language, and this will require close scrutiny of the meaning of words in relation to the symbol representation so that an increase in accuracy of what are being called 'same as' word and multiword entries can be achieved. The symbols need to complement any already in use within specialist schools and organisations, in particular where there are parts of speech, tense and number systems linked to the symbols. Any newly designed symbols also need to have good 'translucency, guessability and iconicity' and to fit other requirements gathered from participants.

The online symbol management system for the design and acceptance of new symbols to fit adapted lexical entries has both Modern Standard Arabic (MSA) and, where applicable, Qatari colloquial Arabic even though MSA is used for written Arabic in Qatar. The core vocabularies in both
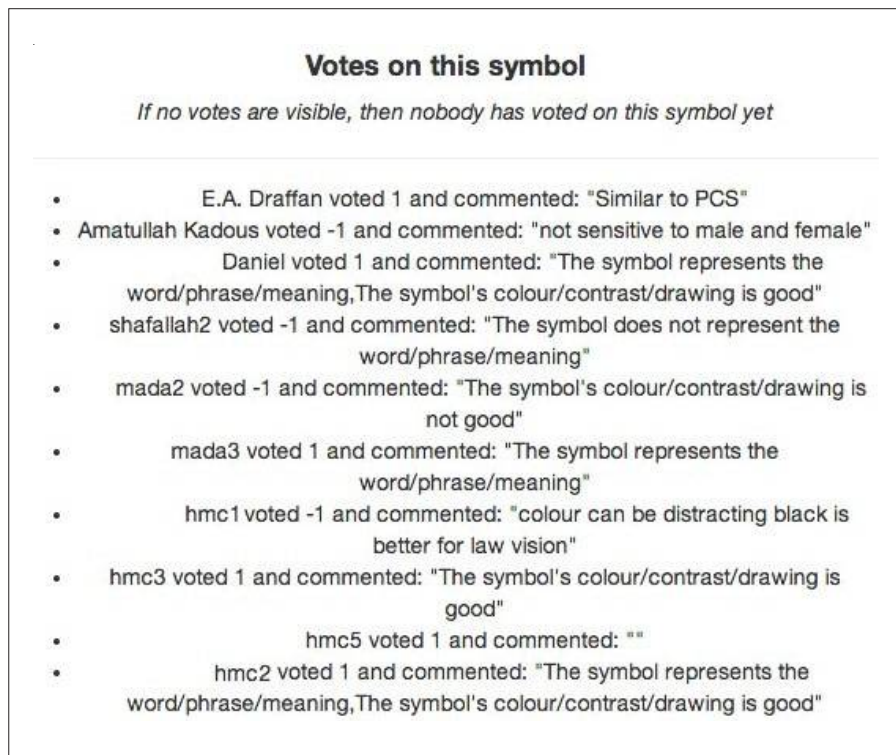
Votes on this symbol

If no votes are visible, then nobody has voted on this symbol yet

- E.A. Draffan voted 1 and commented: "Similar to PCS"
- Amatullah Kadous voted -1 and commented: "not sensitive to male and female"
- Daniel voted 1 and commented: "The symbol represents the word/phrase/meaning,The symbol's colour/contrast/drawing is good"
- shafallah2 voted -1 and commented: "The symbol does not represent the word/phrase/meaning"
- mada2 voted -1 and commented: "The symbol's colour/contrast/drawing is not good"
- mada3 voted 1 and commented: "The symbol represents the word/phrase/meaning"
- hmc1 voted -1 and commented: "colour can be distracting black is better for law vision"
- hmc3 voted 1 and commented: "The symbol's colour/contrast/drawing is good"
- hmc5 voted 1 and commented: ""
- hmc2 voted 1 and commented: "The symbol represents the word/phrase/meaning,The symbol's colour/contrast/drawing is good"

Figure 2 Voting comments about the symbols presented (anonymised other than authors)

Arabic and English are being added first as these have been built from data collected from AAC users in and around Doha. Those working with AAC individuals have estimated that around four hundred entries would be the maximum number of essential symbols needed immediately, so this collection will provide the initial core for the dictionary and will be voted on before being published during the next year.

The latest version of the online voting system allows the graphic designer to instantly see the preferences stated by the AAC Forum and users when they are making symbol choices. Decisions about the various cultural changes, parts of speech and other differences that still require more research and evaluation mean that an iterative approach can be taken to all the online systems with continual testing, refining and updating occurring throughout the duration of the project.

It is felt that in order for the Arabic Symbol Dictionary research project to be a success, the team need to continue to gather requirements from participants with regard to their linguistic, cultural, social and environmental needs alongside their personal preferences, skills and abilities. There will be a need to reflect on the adaptations and additions to all the systems as well as the final design for the online dictionary, and to provide outcomes to decisions so that participants can see and understand the results of their collaboration and other researchers can gain from the team's experiences. Finally, the team will need to disseminate all that has been learnt and achieved to a wider audience so that the localised Arabic Symbol Dictionary can be further adapted, to suit all AAC users who wish to communicate using the fifth most spoken language in the world. ✳

E A Draffan, Nawar Halabi, Mike Wald
Amal Idris, Amatullah Kadous & Aejaz Zahid

REFERENCES

Bloomberg, K., Karlan, G.R., Lloyd, L.L. (1990) The comparative translucency of initial lexical items represented by five graphic symbol systems and sets, *Journal of Speech and Hearing Research,* 33, 717-25.

Dowse, R. & Ehlers, M.S. (2001) The evaluation of pharmaceutical pictograms in a low literate South African population, *Patient Education and Counseling,* 45, 87-99.

Dowse, R. & Ehlers, M.S. (2003) The influence of education on the interpretation of pharmaceutical pictograms for communicating medicine instructions, *International Journal of Pharmacy Practice,* 11, 11-18.

Evers, V., Kukulska-Hulme, A.H. & Jones, A.C. (2000) Cross cultural understanding of graphical elements on the DirectED website. In Smith, A. (Ed) Proceedings of Annual Workshop on Cultural Issues on HCI. 5 December 2001, Putteridge Bury, University of Luton.

Fajerman, L. & Treseder, P. (2000) Children are Service Users too. Save the Children Publications, 17 Grove Lane, London, SE5 8RD.

Hanson, E.C. & Hartzema, A. (1995) Evaluating pictograms as an aid for counseling elderly and low-literate patients, *Journal of Pharmaceutical Marketing and Management,* 9(3), 41-54.

Haupt, E. & Alant, E. (2003) The iconicity of picture communication symbols for rural Zulu children, *South African Journal of Communication Disorders,* 48, 45-54.

A New Approach to Communicating Through Touch

Tactile Signing for Sensory Learners

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INTRODUCTION

Miles and Riggio (1999) suggest that communication is: "the means by which people connect with their environment and other people. Through communication, we connect in the most meaningful sense of the word. Communication IS connection" (p10).

For children and young people with profound learning difficulties and/or additional sensory impairments, making these 'connections' and becoming effective communicators can be extremely difficult, and often complex, resulting in the need for and the use of alternative ways to give and to receive information.

TaSSeLs (*Tactile Signing for Sensory Learners*) is a tactile signing system to promote the development of effective communication for children and young people with complex and profound learning disabilities, a number of whom may also have a visual impairment. It uses touch-speech cues (saying the keyword at the same time as carrying out a tactile sign) as the main route for communication, e.g. "we're going to move your chair" – the keyword 'move' is signed as the word is spoken.

The TaSSeLs system was developed from an unmet need within two Sandwell Special Schools where a number of children

functioning at very early developmental stages were making little or no progress with well established approaches to promote the development of effective communication. Many of the learners benefited from a multi-sensory approach to learning and an alternative system was required. A review of the literature indicated there was no current comprehensive system available nationally to meet the needs of our learners. Identifying this gap led to the development of a tactile signing system for this particular group.

WHY USE TOUCH?

Much has been written about touch being a vital channel of communication for learners at the earliest developmental levels, recognising that it is "humankind's earliest form of communication" (Gallace and Spence, 2010) and "our most fundamental means of contact with the outside world" (Hart, 2010). For learners with complex and profound learning disabilities, Goold & Hummell (1993) suggest that "touch offers individuals with significant multiple disabilities access to communication".

Learners with the most profound needs are "constantly being touched, turned, handled, and placed in a variety of positions" (Longhorn, 1988). Touch can help

people with complex needs to be more engaged in learning, following the thoughts of Carpenter et al (2011) who reported that "it is the right of every child/young person to be included as a learner within the curriculum, however great their degree of disability or learning difficulty" (p.6).

A key part in the development stage of the TaSSeLs system was gaining advice from the Sandwell Safeguarding Team to ensure the touch cues were appropriate whatever the age of the learner and whatever the gender of the adult supporting them. This resulted in sensitive areas of the body being avoided and ensuring that any physical support and guidance being offered did not control or restrain the learner at any time.

DEVELOPMENT OF THE TASSELS RESOURCE

Valuing and respecting the learner as an individual was central to the development of TaSSeLs from the outset. It was acknowledged that "people with high individual communication needs…rely on others to interpret their wants and needs and will generally only be able to make choices in a reactive way" (Thurman et al, 2005, p85).

Learners with additional learning difficulties also have an increased dependency upon others to organise and structure

their learning experiences (McLinden and McCall, 2002). A tactile signing system can play a key role in supporting the learner to engage and respond to these experiences as well as to the people and events in their world.

It was therefore important that we adopted a multi-agency approach to teaching and learning, involving staff working within Sandwell's Inclusion Support Service and Children's Therapies - Speech and Language Therapy service, and collaborating with education staff, other professionals, parents and carers when developing the TaSSeLs system.

The result is a system that supports life-long communication.

Alert sign

Hand-under-hand (preferred method)

Hand-under-hand (adapted method)

On-body method

THE MAIN FEATURES OF TASSELS

TaSSeLs is made up of a core vocabulary of everyday signs that are functional and part of the daily routines and experiences of the learners. This ensures that the learners have frequent opportunity to encounter the signs in meaningful ways, thereby supporting purposeful communication. It is most useful for learners who are making limited or no progress with other communication systems or who require additional sensory feedback in the communication exchange.

The TaSSeLs system helps the learner to:

- Anticipate what is going to happen next

- Interact and respond to others

- Compensate for lack of access to the visual aspects of communication

- Develop independent use of signs, so the learner can express themselves.

The system consists of an 'Alert' sign and a range of core vocabulary signs. The 'Alert' sign is always used at the beginning of an interaction, before a specific core vocabulary sign is introduced. This is the initial step used by the adult to introduce themselves to the learner and helps to prepare the learner for the interaction with the adult that is to follow. Anecdotal evidence has shown that using this approach decreases the 'startle' reflex and acts as a cue to the learner to 'listen'.

The core vocabulary contains a limited number of signs that are functional and part of the everyday routines and experiences of the learners. This ensures they have frequent opportunities to meet the signs in meaningful contexts, thereby supporting purposeful communication. Each sign uses a specific reference point on the learner's body and the signs are always accompanied with speech.

TASSELS APPROACHES

In order to meet the needs of a range of learners, the system employs three approaches:

- hand-under-hand (preferred method) this encourages the maximum amount of participation from the learner;

- hand-under-hand (adapted method) provides increasing support for the learner to participate in the sign or alternatively, allows for individual signs to be adapted to meet the specific needs of an individual learner (e.g. those with significant physical difficulties); and

- on-body method where the signs are made directly onto the learner's body.

Providing flexibility in using the signing system, particularly with those learners who have significant physical difficulties, enables them to participate as fully as possible in the signs. It also ensures that the learner's adult partners are able to "connect or mediate a given experience at a level which is appropriate to their individual needs" (McLinden and McCall 2002, p. 133).

Prior to publication of the resource, a pilot project trialling the TaSSeLs materials in seven settings across Sandwell, Coventry and Shrewsbury was carried out. This resulted in positive feedback and the addition of a separate section within the manual providing a framework to encourage consistency in using the TaSSeLs signs. This was particularly valuable to the effectiveness of the system as "consistency between interactors is vital" as it is "essential to ensure that everyone uses the same sign for the same referent" (Hurd, 2002, p140). This ensures that the learner meets the same sign (not a similar

Sample prompt card for core vocabulary sign 'Finished/stop'

one) on each occasion that the sign is used, no matter where it takes place or who is communicating with them.

The TaSSeLs resource was published in November 2012 by Pavilion Publishing and Media Limited, and includes:

- full-colour manual containing photographs demonstrating and describing in detail how to carry out each sign, with rationale of how the signs and approaches were developed;

- supporting DVD demonstrating how to carry out all of the signs using the three different approaches; and

- resource CD-ROM with guidance on how to create personalised 'Prompt cards' for each sign. The free software recommended allows each sign to be personalised for the individual learner, i.e. both the photograph and the description can be modified to reflect the personalised needs of the learner.

Once printed, the Prompt card is folded in two then laminated. This can then be attached to the learner's wheelchair so everyone engaging with the learner is aware of their individual signs.

CONCLUSION AND FUTURE DEVELOPMENTS

TaSSeLs has now been adopted in many schools across the UK. Initial feedback has been positive, but analysis of efficacy is ongoing.

Interest in TaSSeLs is far reaching and it is now being recognised internationally. The authors are currently negotiating a Swedish translation for publication.

The authors have also developed training courses for professionals to develop their competency and confidence in using the signs with a range of learners. They also offer on-site training for organised groups. The authors are also planning to develop a version of TaSSeLs for the adult population. ✳

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REFERENCES

Carpenter, B., Egerton, J., Cockbill, B. & Owen, T. (2011) Having new eyes: engaging children and young people with complex learning difficulties and disabilities in learning. *PMLD Link*, 23(2), pp4-6.

Gallace, A. & Spence, C. (2010) The science of interpersonal touch: an overview. Cited in: Hart, P. (2010) Moving Beyond the Common Touchpoint: Discovering language with congenitally deafblind people. Thesis (PhD). University of Dundee.

Goold, L. & Hummell, J. (1993) Supporting the Receptive Communication of Individuals with Significant Multiple Disabilities: Selective use of touch to enhance comprehension (Monograph series No. 4). North Rocks, Australia: North Rocks Press and Royal Institute for Deaf and Blind Children.

Hart P. (2010) Moving Beyond the Common Touchpoint: Discovering language with congenitally deafblind people. Thesis (PhD). University of Dundee.

Hurd, A. (2002) Development of pre-symbolic and pre-linguistic skills. In: Abudarham, S. and Hurd, A. (Eds) Management of Communication Needs in People with Learning Disability. London: Whurr Publications.

Longhorn, F. (1988) A Sensory Curriculum for Very Special People: A practical approach to curriculum planning. London: Souvenir Press Ltd.

McLinden, M. & McCall, S. (2002) Learning through Touch. Supporting Children with Visual Impairment and Additional Difficulties. London; David Fulton Publishers.

Miles, B. & Riggio, M. (Eds) (1999) Remarkable Conversations: A guide to developing meaningful communication with children and young adults who are deafblind. Watertown, MA: Perkins School for the Blind.

Thurman, S., Jones, J. & Tarleton, B. (2005) Without words: meaningful information for people with high individual communication needs. *British Journal of Learning Disabilities*, 33, pp83-89.

JOINING
COMMUNICATION MATTERS & ISAAC

What is Communication Matters?

Communication Matters is the UK Chapter of ISAAC (International Society for Augmentative and Alternative Communication), so members of Communication Matters are automatically members of ISAAC.

Our Vision: Communication Matters' vision is a world where speech, language and communication difficulties are not barriers to opportunity and fulfilment.

Our Mission: Communication Matters is all about enabling people to communicate. We value and promote the individual's right to participate in all aspects of life by using their most appropriate means of communication to express their thoughts, feelings, needs and desires.

What are the benefits of Membership?

Members of Communication Matters receive this Journal three times a year, reduced delegate rate at the Annual CM National Symposium, and all the benefits of ISAAC membership, including ISAAC publications at substantially reduced rates (AAC Journal, ISAAC-Israel Newsletter, AGOSCI News), and special delegate rates for the Biennial ISAAC International Conference. You can also access the member's area of the ISAAC website and, if you join early in the year, you will receive a Membership Directory.

What is ISAAC?

Formed in 1983, ISAAC is a multidisciplinary organization devoted to advancing the field of augmentative and alternative communication. ISAAC has members in more than 50 countries, including 15 national chapters in Australia, Brazil, Canada, Denmark, Finland, French speaking countries, India, Israel, Italy, Netherlands-Flanders, Norway, Sweden, Taiwan, United Kingdom and the USA. The Mission of ISAAC is to promote the best possible communication for people with complex communication needs. The vision of ISAAC is that AAC will be recognized, valued and used throughout the world.

How do I become a Member?

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How a Range of AAC Methods have Supported Participation within Sense Scotland's Service User Consultation Group

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BACKGROUND

Sense Scotland was formalised as a charity in 1985. It grew quickly from its beginnings as a small group of families pressing services for their children, who were affected by deafblindness, many because of maternal rubella. Since then the organisation has gone on to support thousands of disabled people and their families.

People who participate in our services have communication support needs due to a combination of:

- learning and physical disabilities
- sensory impairment, incl. deafblindness
- autism
- complex health care needs
- mental health needs.

The Sense Scotland Service Users Consultation Group Meeting began with a small group of people supported by Sense Scotland. In 2014 it celebrated its tenth year anniversary and launched with a new name *Our Voice*, new logo and website. Today there are several regional Our Voice meetings in Aberdeen, Dundee, and Glasgow and recently in North Ayrshire.

Our Voice asks people who use Sense Scotland services what is important to them. The group help make people's views known, not only to Sense Scotland, but to local and National Government and other organisations. It gives the opportunity for people to make their voices heard on issues that affect people in their everyday lives, for example making transport more accessible to people with disabilities or making your views known on the area where you live and the money you need to live the life you choose. Each group meets once a month and there are quarterly joint meetings where all of the regional groups come together to meet with representatives from the Leadership team at Sense Scotland.

ASSESSING COMMUNICATION SUPPORT NEEDS

As the group grew in membership size and geographical locations, we found that the formats of existing agendas and minutes were not meeting all individuals' accessibility and communication support needs. We needed to provide different alternative formats and to clarify exactly what different people's communication preferences were. A communication survey was carried out with all members with a list of new accessible formats available. Before the survey, the existing formats that were used for agendas and minutes were DVD with BSL and Text versions, sometimes with special fonts agreed with individuals. After the survey was carried out, the formats that were identified were DVD with: BSL; Text; Braille; Audio CD (using Scottish Voices); Easy Read;
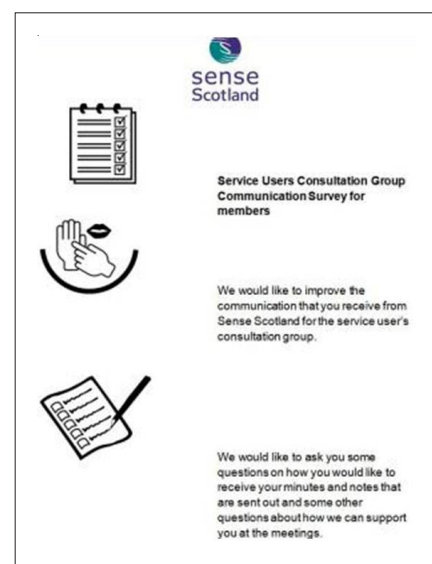

Communication Survey

individualised font (for example Comic Sans 24 which worked well for one person); and large print. Scottish Voices is a Scottish synthetic voice (male and female adult) developed by Cereproc and licenced and supplied to CALL Scotland, with funding from the Scottish Government. Together with Word Talk (used on a PC), this enabled us to save the text from a Word document into MP3 format and we were then able to create audio CDs in a short space of time. Some individuals preferred to receive more than one format. For example Braille, audio CD and a text version

sent by email so that users can access by computer with screen reading software.

AAC METHODS AND MINUTES DURING THE MEETINGS

The agenda we now use at meetings is one based on the Talk for Scotland Toolkit agenda template and uses Bonnington symbols, which are free. There is a poster with the Group rules and these are circulated with the agenda at each meeting. For meetings where there are British Sign Language (BSL) users, there are BSL interpreters, who are filmed throughout the meeting in order to make the BSL video Minutes. We use the same small group of interpreters regularly because they now adapt their signing to suit the particular language and sensory needs of individuals. The standard version of the Minutes are typed in easy read format supported by mainly Bonnington symbols. However, we also create versions in all of the formats listed previously.

Much of the work with Our Voice is responding to consultations both internally from Sense Scotland but also from external organisations. On most occasions the information has to be made into different accessible formats before it can be presented to Our Voice members. Sometimes there are Easy Read versions of the consultation document already available. This makes it more straightforward to take directly to group members. Sometimes, however, we ourselves have to make this information into Easy Read format using a variety of symbol formats.

4) Have you voted in an election before?
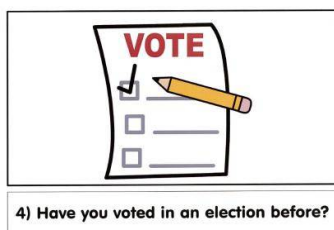
An example is the awareness-raising sessions we held to give people information about the recent Scottish Referendum and information about registering to vote. One of the consultation sessions related to finding out what accessible information was already available to disabled people about the Referendum. We prepared a survey in an Easy Read format made with Photosymbols. However, we found it was difficult for someone to understand if they had not taken part in voting before. For one of the Our Voice groups we used a ballot box, and a tactile map in order for people to understand more about the Referendum. This information was made into a storyboard.

For some of the other groups it was much easier because they had the opportunity

to take part in an information workshop and other discussions about the Referendum run by external organisations. For these discussions, video and pictures were used to help understanding.

AAC SUPPORT

A separate meeting was held for some of the support staff who accompany members to the meetings. This considered what additional support was required after the meetings. Staff identified that it was important to receive Minutes within a week after the meeting and for most people Minutes should be presented in an easy read summary format. The role of support staff and family members was very important to ensure that Our Voice members were supported to learn about matters arising from the Minutes and to prepare for any actions they had to undertake. The Leadership Team was invited, to agree involvement in organisational decisions. This all helped with communication. In addition, guidelines were put in place for members receiving Minutes a week after the meeting. This helped members prepare for the next meeting in three weeks time.

'OUR VOICE' CONFERENCE EVALUATION

One of the events that members from the service users' consultation group help to organise is their annual Conference. The Service User Consultation Group Conference is open to all people supported by Sense Scotland. We used easy read agendas and programmes using symbols and pictures together with other accessible formats such as Braille, Moon and large print. Our Voice members had different roles at the conference; some were presenting, and others were helping with registration and handing out evaluation forms.

For evaluation of the conference we used a number of methods in which participants could use. These included:

- Questionnaire made with symbols and pictures where you tick your answer with smiley faces for 'like', 'don't like' and 'not sure'.

- Talking Mats (an established consultation tool, which uses a mat with symbols attached as the basis for communication; it is designed to help people with communication difficulties to think about issues discussed with them, and provide them with an effective, visual way to effectively express themselves, that can be easily recorded).

- Evaluation Board with symbols where you can use sticky notes to write your comments.

- Video feedback.

- Filling out questionnaire using iPads (we used a trial version of QuickTapSurvey).

- Symbols with boxes and sound recordings – 'Yes' and 'No' for whether you had enjoyed attending the conference – you place the ball into the 'Yes' or 'No' box.

WHAT WE HAVE LEARNT

For inclusive communication, time has to be provided. Members have to be given the correct format with enough time for them to read the information. Staff need time and resources to learn new software or tools to make Easy Read documents. The information has to be written in plain English and adapted for different groups.

Over the last eighteen months, Our Voice members have spent a lot of time exploring the aims and objectives, rules and roles and responsibilities of the group. This included guidance on when Minutes should be sent out and guidance for external consultations. We found that we changed the way we made information from feedback from Our Voice members and that we needed to constantly check we had the correct information of the preferred method of communication.

As an individual's communication support needs change, so does their preference in how they receive agendas and Minutes. The use of technology and other methods is something we will continue to explore and develop with the group, for example Talking Mats, iPads and other symbol systems.

One final note to highlight is that "one size doesn't fit all". It is important to be flexible and to adapt to each individual's communication support needs. Of course, we can adopt general principles and prepare material using standard formats, but we have to be open to meeting the communication support needs of each individual member of a group. This might mean twenty different responses if a group has twenty different members. ✳

Tina Yu, *Sense Policy Officer*
Margaret MacKenzie, Sense

RESOURCES

Call Scotland
  www.callscotland.org.uk
Our Voice
  www.sensescotland.org.uk/community/our-voice.aspx
Partners in Communication
  www.partnersincommunication.info
QuickTapSurvey
  www.quicktapsurvey.com
Sense Scotland
  www.sensescotland.org.uk
Talk for Scotland Toolkit
  www.communicationforumscotland.org.uk
Talking Mats
  www.talkingmats.com
The Scottish Voice
  www.thescottishvoice.org.uk
Word Talk *www.wordtalk.org.uk*

Testing the Validity and Inter-rater Reliability of the Therapy Outcome Measure for AAC

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BACKGROUND

In June 2012 the Scottish Government published *A Right to Speak* (Scottish Government 2012), a document which provides guidance for people who use AAC. The guidance includes eight recommendations. The first two are relevant to this project:

1. AAC services to demonstrate the effectiveness of AAC interventions by promoting the implementation of AAC research on specific, targeted and universal AAC interventions.

2. National statistics on AAC to be gathered by relevant agencies to support future gathering of cost effectiveness data on AAC to ensure that AAC funding is sustained in the longer term.

In response to the guidance, NHS Education for Scotland (NES) commissioned research to critically appraise existing methods of measuring outcomes for use in AAC (NES 2013, Boa 2014).

The results of this project showed that currently, no standardised outcome measure exists for use with people who use AAC and it was recommended that the use of an adapted version of Professor Pam Enderby's Therapy Outcome Measure (TOM, Enderby et al 2006) should be investigated. Prior to this project, the necessary adaptation to TOM for AAC had not been finalised or tested for validity and reliability. NES commissioned Talking Mats and Pam Enderby to undertake a project to test the reliability and validity of TOM AAC.

DESCRIPTION OF TOM AAC

TOM is an outcome measure used by many rehabilitation professionals to measure the impact of their interventions. It is based on the World Health Organisation's International Classification of Functioning, Disability and Health (WHO ICF, 2001). TOM is administered following assessment/intervention of an individual by a professional.

People are rated using an 11 point ordinal scale with six defined points and in relation to four descriptors:

- Impairment
- Activity
- Participation
- Well-being

Prior to this project, Professor Enderby had, with the assistance of some AAC specialists, drafted descriptors for use with adults and children who use AAC.

METHODS

This project was conducted in two phases: (a) testing validity; (b) testing inter-rater reliability.

A. Testing validity

i. AAC professionals were recruited and trained in the use of a draft version of TOM AAC. They were then asked to rate up to ten of their own clients using it.

ii. AAC professionals were invited to participate in one of three focus groups where face validity of TOM AAC was

discussed. They were also invited to complete a questionnaire on the validity of TOM AAC.

iii. Focus group and questionnaire data were analysed using thematic analysis.

iv. Changes were made to TOM AAC in light of the focus group and questionnaire results.

B. Testing inter-rater reliability

Inter-rater reliability is important because it provides assurance that the scale can be used consistently by different professionals (i.e. the same score is given regardless of the person doing the scoring, Clark-Carter 2010). In order to do this, we devised ten composite case histories (which included children and adult AAC users). Most of the case studies were anonymised and provided in written form, but three of these were augmented with video clips of adults who consented to take part in the project and were happy to have their case history shared. AAC professionals were asked to rate each one independently. Scores were collated onto an Excel spreadsheet and then analysed by a statistician for inter-rater reliability.

RESULTS

A. Testing validity

Twenty nine AAC professionals (representing a range of AAC professionals, including speech and language therapists, teachers, social workers and rehabilitation engineers) attended an initial training

TOM domain	ICC	Range (difference between lowest and highest rating)			
		0 (complete agreement)	<=1	<=2	>2
Physical Impairment	0.887	3	5	2	0
Cognitive Impairment	0.726	0	4	4	2
Sensory Impairment	0.605	2	6	1	1
Expression	0.486	0	2	3	5
Comprehension	0.831	0	3	6	1
Activity	0.622	0	2	4	4
Participation	0.703	0	1	4	5
Wellbeing	0.816	0	5	3	2

Table 1 ICCs by domain

session in the use of the draft TOM AAC. Sixteen people attended one of three focus groups and 18 people completed the questionnaire (some participants completed the survey and also attended the focus groups, others did one or the other).

AAC professionals agreed that TOM AAC had strong face validity, but had some suggestions about how the descriptors in each domain of the TOM AAC could be reworded to make it easier to use in practice. These were predominantly related to the descriptors for communication impairment and how to score people with and without their AAC.

B. Inter-rater reliability testing

Seventeen professionals rated the ten case histories. Agreement was quantified for each of the eight domains using the intraclass correlation coefficient (ICC). The ICC is the ratio of between-case variation (the degree to which different case histories vary) as a proportion of the total variation in scores, and lies between 0 and 1; larger ICCs indicate greater agreement. ICCs were calculated as described by Shrout and Fleiss (1979) using definition two (case histories are rated by a random group of raters, drawn from a wider potential population).

Alongside the ICC, the minimum and maximum rating for each of the ten case histories is reported. For TOM, a clinically important disagreement is defined as one unit in either direction; therefore, if any pair of raters disagree by more than two units this would indicate poor agreement.

Each of ten case histories was judged by either 16 or 17 different raters: one rater did not rate three of the ten case histories. The ICCs and case history ranges are presented in Table 1. Agreement was generally acceptable, and was highest for physical impairment (0.887), comprehension (0.831) and wellbeing (0.816); the lowest was for expression (0.486).

The results showed generally good inter-rater reliability between professionals who used TOM AAC on the ten case histories. Surprisingly, the provision of DVDs did not appear to have any demonstrable effect on inter-rater reliability.

We may not have provided sufficient information in case histories five and six, as ratings for these case histories gave the largest range between individuals. The domain of 'expression' appeared to produce the most variation between raters. This may be because the indicators in this domain needed to be more clearly defined. As this domain is particularly relevant for AAC it required further investigation. It became clear that raters were not clear whether they should be rating the case with or without their AAC. This was clarified and the case histories were re-rated (on this domain alone). The ICC correlation for expression was then 0.708 which is more than satisfactory for establishing reliability.

LIMITATIONS

Case histories are known to cause difficulties in inter-rater reliability trials. However, they are resource efficient and allow presentation of data testing the full range of severities of conditions to test scoring systems. In preparing the case histories, we endeavoured to give as much information as we could without over burdening participants who were all practicing clinicians giving their time voluntarily.

Furthermore, published studies (John & Enderby 2000) with other professions and client groups using the TOM have all reported that using the TOM with their own patients in real life situations where they can explore the patient's experiences which would assist them in choosing the appropriate score, is easier than rating from case histories. Therefore, it is likely that reliability in working settings will be better than in a trial.

SUMMARY

Outcome Measures in AAC is an important topic, but no standardised reliable outcome measures currently exist for use with a range of people who use AAC. This first iteration of TOM AAC has been tested for face validity and inter-rater reliability between AAC professionals. Initial findings suggest that the scale has strong face validity and there was good inter-rater reliability for seven of the eight domains.

Further work has been done to refine the 'expression' descriptor, and retesting has been carried out with favourable results. TOM AAC will be included in the third version of TOM, which will be available for use by professionals in November 2014. ✳

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REFERENCES

Boa (2014) Outcome Measures in AAC, *Communication Matters* 28(2), 14-16.

Clark-Carter, D., Quantitative Research Methods: Gathering and Making Sense of Numbers. In: P. Roberts and H. Priest, Eds, Healthcare Research, A textbook for Students and Practitioners, Chichester Wiley-Blackwell, pp. 130-149.

Enderby, P. et al (2006) Therapy Outcome Measures for Rehabilitation Professionals (Second Edition) England: Wiley and Sons.

John, A. & Enderby, P. (2000) Reliability of Speech and Language Therapists using Therapy Outcome Measures. *International Journal of Language Disorders*, 35, 287-302

NHS Education for Scotland (2013) A critical appraisal of existing methods of measuring outcomes in relation to Augmentative and Alternative Communication: Final Report. *www.talkingmats.com/wp-content/uploads/2013/09/AAC-Outcome-Measures-Final-Report-2013.pdf*

Scottish Government (2012) A Right to Speak. *www.scotland.gov.uk/Publications/2012/06/8416*

Shrout, P.E., Fleiss, J.L. (1979) Intraclass correlations: Uses in assessing rater reliability. *Psychological Bulletin* 86(2), 420-428.

World Health Organisation (2001) WHO-ICF: International Classification of Functioning, Disability and Health. Geneva: World Health Organisation.

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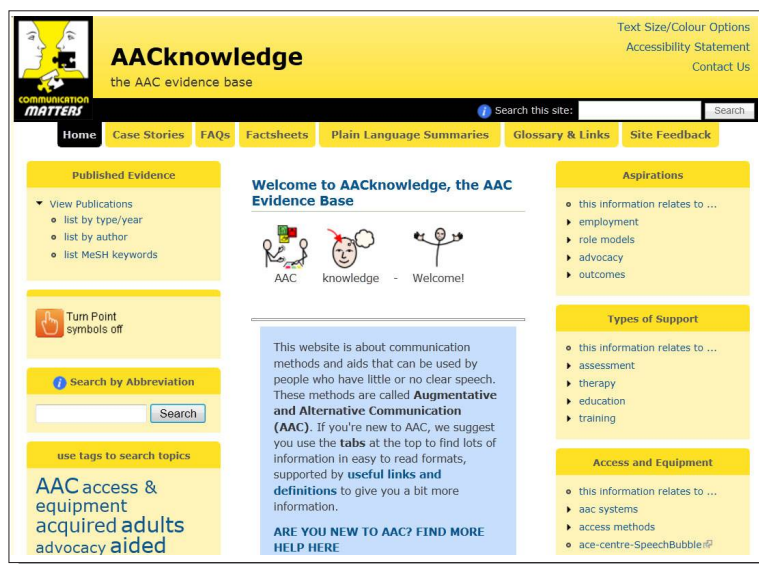
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