COMMUNICATION
MATTERS

IN THIS ISSUE

REGULAR COLUMNS

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Cover: Natasha Bello (page 2)

Communication in Natasha's World

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At the CM2013 Conference, Natasha and I gave a presentation about 'Communication in My World'. Its primary focus was to assess the places Natasha goes and the people she needs to communicate with.

Natasha has been 'doing' AAC for 23 years in some form, method or way. As her mother, I have often been the driving force in making sure she communicates her wants and needs. It's been a long and sometimes painfully slow journey. Twenty three years on, I do not have the same influence on her as in earlier years.

I started to think about all the people and places where Tasha interacts as she goes about her life. What goes on; who makes sure she communicates well; who does my job when I'm not there?

Natasha has multi-modal communication skills, typical of a non-verbal person. She can vocalise a little with throat noises. Once in a while you can hear a distinctive 'yea' or 'no'. Of course, there's gesturing – she's got a great "I don't know". Then there is her sign language, peculiar to her since she only has one arm/hand that functions somewhat. It is further complicated by the fact she learnt American Sign Language (ASL) because she lived in USA all her educational life. Moving back to UK hadn't been in the long term plan, so

thinking about other signing didn't come into the picture. Naturally ASL has been useless in the UK, and no-one has taught her any Makaton or BSL. Also many of her signs look the same, are contextual and only known to close family and some Personal Assistants.

Throughout her AAC journey Natasha has used symbol sets to represent words. She seems adept at using various sets without too much trouble. The written word is also present. It has been difficult to assess how much she actually reads written words.

Natasha has used high-end dynamic devices for most of her AAC years. However, as the theory and practice of AAC has changed and developed over the past twenty years, her page sets/boards have continually changed; we were always striving to find the best method for her – this is a conversation for another day, though.

She currently uses symbols/words in a 64 cell grid with most screens designed for word/sentence structuring with some word prediction. Some screens are phrase- and themed-based. Many of the frequently used screens are also printed out as manual boards. I have also used AAC apps designed for the iPad, as a backup system. One app in particular I have re-programmed to 'look like' her main AAC device. It has been a useful

backup and on occasion has saved the day when the main device needed recharging.

THE BLUE FOLDER

When she is out of the house, Natasha has the Blue Folder (it just happened to be the colour she liked at the time of purchase). The folder resides in the wheelchair bag and goes everywhere with her. It holds a great deal of information. With regard to communication support it has:

- Basic 'how-to' information on use of AAC device (button locations, charging ports), etc.
- The mount set up and how to use (dismantle, put on, attach device, etc.)
- How to text with her phone via the device
- Basic trouble-shooting of device problems if they occur
- Board print-outs from her device, to act as manual boards
- The Coaching Board to help support people, help her communicate.

THE COACHING BOARD

After all these years, I still find myself playing 'Twenty Questions', trying to guess what she is talking about and often feeling quite silly that I didn't get it the first time. So my thought process was,
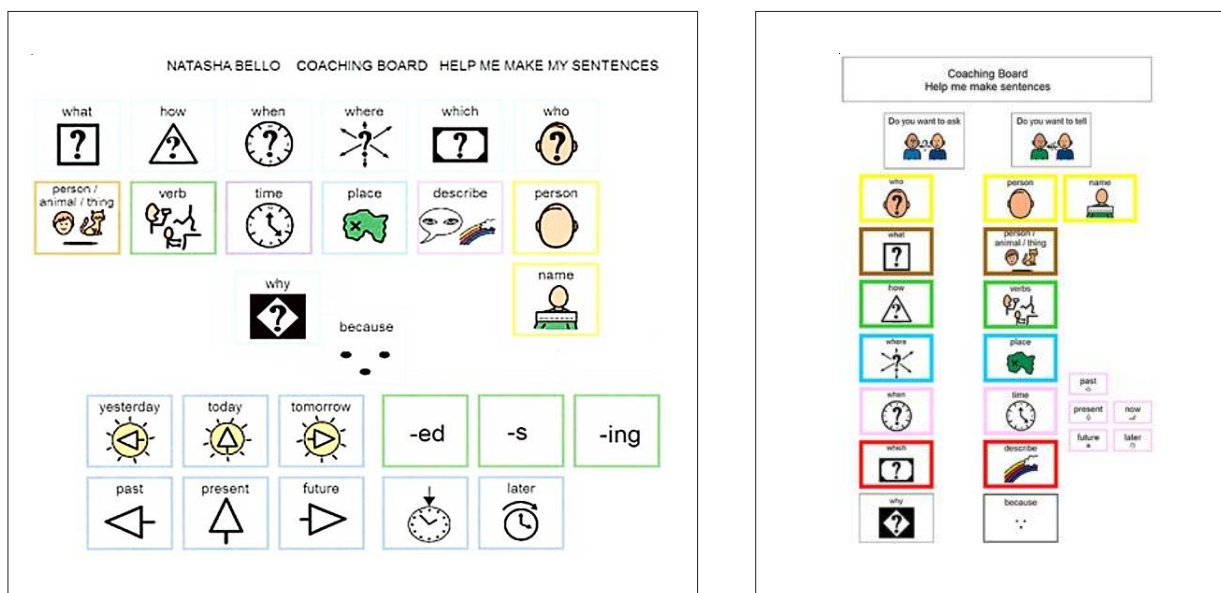
Figure 1 Coaching Boards

if I'm having trouble, then so are others around her.

I made a board to help coach her in forming more complete sentences. The symbol/words are colour coded the same as her device. The concept for the board was to help Natasha focus her mind on whether she is trying to ask a question or make a statement, and to fill in missing words to form more complete and understandable statements.

I SPEAK WITH MY FINGER

Let's take a step back for a moment. It never fails to impress me how difficult it must be to become a competent communicator with AAC. I recently had a conversation with a young child, trying to get them to appreciate how hard it is for Natasha to talk to them. I said let's pretend you are playing a game. First, you have to sit still in a chair (wheelchair), then tie one hand behind your back (hemiparesis), now pretend there is a big plaster or bandage over your mouth (non-verbal), oh and close one eye (ptosis) – while you are doing all this, tell me your name! Of course, it sounds impossible. However, with the special computer and her finger, Natasha can tell you her name.

Another sort of analogy that is often quoted in AAC presentations, is a statement from Jane Korsten, a specialist in the USA:

The typically developing child will have been exposed to oral language for approximately 4,380 waking hours by the time s/he begins speaking at about 18 months of age. At twice a week, 20-30 minutes each time, it will take the alternate symbol user 84 years to have commensurate exposure.

That statement is almost scary, but also makes one appreciate how long and hard it can be to become a competent AAC user.

AAC COMPETENCY TAKES TIME!

Another oft quoted piece of information comes from Janice Light, about the four competencies of an AAC user. In brief, there is:

- *Linguistic competence* which is about the receptive and expressive language skills.
- *Operational competence* refers to the skills required to use the AAC system or device.
- *Social competence* is about how one can use appropriate language for the situation, initiate or maintain a conversation, ask people to regard you and not your device during a conversation.
- *Strategic competence* can be skills special to doing AAC, in that an AAC user can appropriately interject in a conversation, use different styles of communication depending on the communication partner.

Referring to the four competencies mentioned above, Natasha has always been very good at operating her devices. She very quickly can access through several levels and knows where to find stuff. She has zero skills on strategy, some improving skills with social connection. The problem seems to be linguistic.

Here are some samples of her syntax:

- "Come"
- "Going Dad work"
- "Party [name] [name] [name] come don't Mum Dad Buster upstairs"

So many times, the biggest problem is that she will still revert to a single noun or verb and expect someone to fill in the blanks as though we are clairvoyant! This leads to the Twenty Questions routine – not effective at all. Other times, she will create something of a sentence but the words are out of order. So we are all confused!

How do we get Natasha to be as comprehensive and expressive as possible when out and about? Basically, I need people around her to expect more from her.

I also thought I should re-visit 'Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners', the assessment package by Sarah Blackstone and
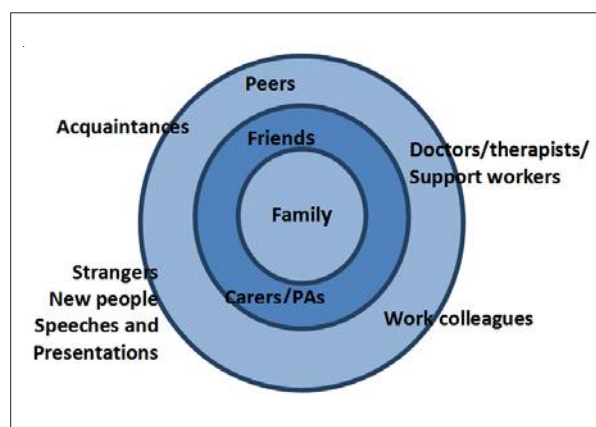

Figure 2 Communication Network

Figure 3 A print-out for her volunteer work

Mary Hunt Berg. I had gone through the workbook back in 2006/7 with the regional educational team for students with disabilities in the USA. Reviewing the people and places in Natasha's life, Figure 2 shows where I think they fit in her communication network.

The core of her communication circle is family. The closer to the core, the less a device may be needed. In the first two circles, Natasha is likely to use vocalisation and gestures/signing.

When it comes to those people in her outer circles, she may well use her device, but without creating a meaningful sentence. However, it is those people closer to the core that could encourage her more, insist or demand more meaningful communications from her, and know to use the coaching board.

OUT AND ABOUT

Natasha is someone who likes to be busy. She goes out and about several times a week to a variety of places, meeting different populations. There's Hemel Food Garden where she does volunteer work; social clubs in the evenings, yoga and sports classes, 1Voice events and respite care. Also there are relatives' homes, out walking the dog, shops, and medical appointments.

AND THE SURVEY SAID...

So what really goes on? I conducted a short survey to get an understanding of how is she really doing when away from home. I sent out a quick one page survey to the various staff at the places she goes without me.

I wanted to establish the frequency of contact, how well they understood her, and if they encouraged her to communicate better/clearer. Of twenty or so I sent out, I got nine back.

There were some encouraging results:

- Just about everyone does take the time to communicate with her
- They struggle to understand her only sometimes (at least it's not all the time!)

- It looks like the high end AAC device is used more than I thought ... and they bug her to use it
- Just about everyone doesn't use the coaching board
- Looks like I should do some in-service/training.

From that, however, I have or will:

- Make sure everyone knows about the Blue Folder and its contents.
- Change the coaching board, so that it 'flows' more easily for those coaching her
- Start a signing video dictionary – using an iPad application – there will be an information sheet in the blue folder about which words are in it and how to access that video dictionary
- Offer training/in-service
- Find ways to get her to communicate with her peers.

As for peer communication skills, I'll have to think more on that. There is much more to do to get Natasha to chat with her peers. Quoting Linda Burkhart: "*motivation for communication is driven by an inner need to connect with other people*". Natasha needs 'to want' to connect with her peers.

However, given all the places and activities she attends, many of her peers have learning disabilities and do not have knowledge or patience to wait and listen to Natasha. The only venue I have found helpful is for her to attend events such as 1Voice and Communication Matters events, where there are other AAC users who appreciate the time and effort it takes to 'do' AAC.

CONCLUSION

There is still more to be done. I think I am providing every possible tool to assist people around Natasha and her communication skills. I can only hope that, given the array of tools, a support worker will pick at least one to use, rather than none. At every opportunity, I will direct people to the Blue Folder and make sure people know how to contact me if they have questions or concerns about her communication.

The journey continues. By my calculation, we have about 60 more years to go! ✳

Julie Bello

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Figure 4 Results of Survey

Student Speech and Language Therapists using AAC in the Community

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For one week, I and four other students used AAC within the community. Our main aim was to raise awareness of AAC within the community. Secondary to this was to evaluate the public's perspective of AAC and to develop our own understanding.

Our first challenge was to choose our device. We soon realised that our device was to be an extension of who we are; and we naturally found which device suited our needs. As the week progressed we realised that like anything, our devices had their limitations; and what worked for one aspect of our lives, was unsuitable for another. However, our aim was not to evaluate the devices, they were simply the vehicle for our campaign.

Throughout the week, we used the power of social media to spread our message; and the response was astonishing. We had readers all across the world who backed our campaign; and agreed that the concept of AAC is still alien to many communities. Social media not only helped gain supporters but it also allowed us to educate people about AAC: what it means, and how it helps thousands of people across the world live a life they take for granted.

We spent the week living our normal lives: going to university, walking the dog, playing squash – everything. We wanted to see what life was like for someone who uses AAC. As students, a lot of our time is spent in lectures; our group found that using AAC devices restricted our participation. The high-tech devices took too long to navigate, and the low-tech devices did not have the capability to communicate with groups.

During our week, we used our devices to interact with the general public; library staff, shop assistants, waitresses. The reactions from the public services was quite consistent: they over-compensated and made assumptions about our abilities. Although their reactions were from good intentions, many people assumed we had other difficulties, such as impaired intellect, vision and hearing. It highlighted, that although people attempt to adapt, they can find themselves offending others.

The main event of our campaign was a stall set up in the centre of town; this provided us with an opportunity to further evaluate the perspectives of the general public. Our findings were disappointing: we were laughed at, ignored, and at times were made the focus of people's jokes. Although a negative experience, I feel that we all learnt a lot – we quickly learnt that those who did not understand were those who felt they had the right to ridicule us. Education really is the answer when it comes to such incidents.

As our week progressed, as a group we were exhausted. The effort of communication was overwhelming, we had to think about everything we wanted to say; we were constantly filtering our thoughts – What's important? What can wait? The effort of using our devices meant that by the end of the week we were opting out of conversation.

Our week highlighted the need to raise awareness of AAC within the wider community. Although there are many people who understand AAC and the important role it plays, a large majority of the community does not. As a speech and language therapy student, I feel it is vital to understand our clients; this experience has taught me more than any text book, and I believe it will enhance my practice as a therapist.

The journey of raising awareness of AAC is slowly but surely gaining momentum, and one by one, and together, we can educate the world and create a more accepting environment. ✳

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Practical Low-Tech/No Tech Approaches for Schoolchildren with Special Needs in Low-Resource Countries

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A great deal of writing about assistive technology (AT) in poor and low-resource countries focuses on the adaptations that need to be made using local materials, low-cost or no-cost solutions and cultural adaptations. That is no surprise, because we have far too often witnessed expensive failures of technology exports plunked down into environments that for various reasons simply cannot accommodate them.

Over the past several decades, economically *developed* nations have made substantial progress with assistive technology for people with disabilities, and have even met with some limited success in adapting certain kinds of AT in poor countries. Sadly, however, little or no useful information is available about effective adaptations of *low-cost, low-tech or no tech* adaptations of AAC in special needs classrooms in low-resource or very poor countries. Concrete examples of this kind of appropriate AAC in schools for children with special needs in such countries are still exceedingly difficult to find.

We *can* find lots of examples in *developed* countries of ways in which various kinds of AAC interventions have helped special needs children improve their literacy skills, communicate more effectively in their classes and build other basic academic skills, but children with special needs in schools in *developing* nations have so far benefited hardly at all from any of these new ideas or approaches.

For the past several years, the Central Coast Children's Foundation (CCCF) has been trying to make a small dent in this idea vacuum, by working with teachers of children with special needs in a number of poor countries in Africa, around issues of classroom communication, development of early literacy skills, and cognitive development.

All of these efforts have had to operate under severe constraints with respect to the existing barriers caused by under-financing (Ghana's special educators get $4.00 per child per year for classroom supplies and equipment), technology complexity, limitations in the prior preparation of local special education classroom teachers, lack of communication avenues we take for granted in developed nations (e.g., accessing e-mail at a costly cybercafé that periodically loses electric power), etc. We have benefitted greatly from a co-operative arrangement with Teachers College at Columbia University, whose bi-lingual speech therapy graduate students make an annual work and study trip to Ghana.[1]

By trying to respond directly to the specific, expressed needs of a small but increasing number of local teachers and principals in a slowly expanding number of poor countries, the CCCF has begun to accumulate a growing collection of ideas that teachers say work. They work in ways that help children with special needs in their classrooms to achieve greater success in developing communicative competence, mastering basic literacy skills, behaving more appropriately in the classroom, and developing basic academic skills.

We have even begun to facilitate the exchange of effective ideas between teachers of children with special needs in one country (e.g. Ghana) and teachers of kids with disabilities in other another (e.g. Malawi).

Examples of these ideas are already available in our newsletters [1] and through videos [2] produced by our Ghana partners at Teachers College, Columbia University. The 3-day January 2014 Professional Development retreat in Ghana demonstrated continued progress.

Many AAC approaches were reviewed from previous years, including the AAC Market Cards, Narrative Social Stories, and Communication Passports. A few new approaches were also introduced: the Five-Finger Story Retell, Community Request Cards, Talking Mats, and Joint Action Routines. Each teacher received a copy of a pamphlet [3] with specific how-to instructions.

Post-retreat teacher surveys indicated that many teachers were eager to make AAC market cards, name tags for students, communication passports, and community request cards. The special education teachers from previous AAC retreats shared how they use AAC approaches in their classroom.

Most of the ideas that work are relatively simple to learn about and implement, and are very low-tech. For example:

- **Word Walls** that help teachers develop sight vocabulary in their students.

- **Market Cards** that enable children with communication difficulties to play traditional roles by purchasing items for their families in the marketplace.

- **Talking Mats** which use specially designed picture communication symbols and mats.

- **Communication Books**

- **Visual Classroom Timetables**

- **Communication Passports** that can enable children with communication disabilities to carry around vital communication information about themselves.

We have been able on occasion to find other free instructional and tutorial resources on line that provide simply described, useful how-to information about similar kinds of ideas and techniques, useful templates and examples, helpful hints, etc. Examples include:

- **Flipbooks**

- **Community Request Cards** which were recently introduced to teachers at the 2014 AAC retreat as a follow up to market cards, or com-

munication passports for people who want to request items and services in the community.

- **Chat Books** which are small books (often a photo album) that may contain photos, pictures, symbols, words and messages about a person. Used effectively by people who understand objects, photos or pictures. Designed so people who find it hard to express themselves can relate information about activities and events they have experienced, including topics of conversation, information about the activity or event, and some interactive statements to engage other people in these conversations. (Also referred to as remnant/memento or conversation books.)

We hope to find more ways to make these ideas available to teachers of special needs children in other low-resource countries and are currently seeking to expand our network of collaboration with other groups who are working to adapt useful classroom ideas to special needs classrooms in poor countries. We are also looking for examples of effective approaches from teachers to add to the collective knowledge.

For further information about ongoing work in introducing assistive technology and augmentative communication in poor countries, please see our newsletters[1] we have been publishing online since 2009. ✳

Harvey Pressman
President, Central Coast Children's Foundation

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www.centralcoastchildrensfoundation.org/home/augmentative-communication-world-network/acwn-newsletters

2 Video
www.tc.columbia.edu/bbs/speech-language/index.asp?Id=Ghana+Program&Info=Ghana+2012

3 Pamphlet
http://leadersproject.org/media/document augmentative-and-alternative-communication-aac-approaches-pamphlet

RESOURCES

Chat Books
www.youtube.com/watch?v=JnlnKG2VRqQ

Communication Aids
www.scopevic.org.au/index.php/site/resources/communicationaids

Communication Books
How-to book for purchase:
http://acecentre.org.uk/developing-and- using-a-communication-book
Description available at:
http://praacticalaac.org/strategy/the-praactical-power-of- communication-books

Possible formats at:
http://praacticalaac.org/strategy/communication-books-making-decisions-about-format/

Communication Passports
Excellent description at:
www.communicationpassports.org.uk/About/
Freely downloadable example at:
www.widgit.com/resources/health/a_and_e/
'Personal Communication Passports: Guidelines for Good Practice', by Sally Millar with Stuart Aitken, Call Scotland:
www.callscotland.org.uk/Shop/Product-Information/?reference=3

Community Request Cards
www.spectronicsinoz.com/downloads/thirdparty/crcscope/intera-m-sample-handout.pdf

Flipbooks
http://bridgeschool.org/transition/multimodal/flipbooks.php

Market Cards
To view a video showing the use of Market Cards in Effudasi, Ghana, go to:
www.youtube.com/watch?v=uJG2K0fFBoQ&list=PL2toYybtLe6_BbIy_9Dx11gC9cxx6GJJY&index=3
And in Swahili:
www.youtube.com/watch?v=H33Xr1zKDL8
PowerPoint presentation on market cards (presented by Ghana unit school head Belinda Bukari at the East African Conference on Communication Disability in Mombasa, Kenya): 'Using Practical Tools to Support Communication and Inclusion'. Copy on request from presstoe@aol.com

Narrative Stories
Helpful ideas about implementing social stories are available at:
www.youtube.com/watch?v=WgGie_s1W40&list=PL2toYybtLe6_BbIy_9Dx11gC
www.oneplaceforspecialneeds.com/main/library_social_stories.html
www.autism.org.uk/living-with-autism/strategies-and-approaches/social-stories-and-comic-strip-conversations/how-to-write-a-social-story.aspx

Talking Mats
For descriptions and examples, go to:
www.youtube.com/watch?v=T-fFCtQ5sBA,
www.talkingmats.com/research-consultancy/free-stuff-communication- disability/
www.talkingmats.com/about-talking-mats/
http://www.spectronicsinoz.com/blog/tools-and-resources/everybodys-talking-about-talking-mats/
For a talking mat template:
www.spectronicsinoz.com/activities/talking-mats
PowerPoint presentation by Clement Ntim, Principal at the Unit School for Special Needs Children, Nkawkaw, Ghana, Equipping students with Communication Deficits to use Talking Mats. Presented at the East African Conference on Communication Disability in Mombasa, Kenya. (Copy on request from presstoe@aol.com)

Teaching techniques for special needs children:
www.youtube.com/watch?v=ocJMBbD6r0g

Visual Classroom Timetables
www.symbolsinclusionproject.org/resources/classroom/timetables/using.htm

Word Walls
Some of the best 'how-to' descriptions on word walls can be found at:
www.pedagogyideas.com/wp-content/uploads/2013/01/word-wall-unit.pdf
www.readingrockets.org/strategies/word_walls

YouTube, Facebook, Twitter: The facilitation of readiness for high-tech AAC through computer access

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INTRODUCTION

The East Kent Adult CAT Service carries out specialist assessments for adults with profound communication difficulties, and subsequently provides appropriate high-tech AAC devices that meet their needs. During our intervention with a range of clients, it has become apparent that clients who go through the assessment process to achieve their goal of obtaining AAC are then reluctant to use their communication aid once it is provided. Where appropriate, and especially when a client's condition is rapidly progressing, these clients have been additionally set up with alternative computer access, with a view to enabling them to develop those skills required for AAC.

This paper discusses, through a range of case studies, our experience of working with those clients who were not 'ready' for AAC. The focus is on the underlying reasons of why clients who would benefit from high-tech AAC may not be 'ready', and highlights the importance of providing opportunities for them to develop those skills required for high-tech AAC through other meaningful activities.

MATTHEW

Matthew was referred to the Adult CAT service in 2010 shortly after receiving his diagnosis of Motor Neurone Disease. At the time of referral, Matthew was due to become a father and was still working as a project coordinator. He presented with limited upper limb movement and slurred, but fully intelligible, speech. Matthew was noticing other frequent changes in his physical function. Matthew stated that he wanted a high-tech AAC device so that he could prepare for the possible loss of his speech and to enable him to continue to work. Following an assessment, including a successful short term trial of a device, it was decided with Matthew that, due to the rapid progression of his condition, he should be provided with eye-gaze technology.

Matthew was set up with an eye-gaze device both for speech output and computer activities for his workplace (document writing, SMS texting and email). His vocabulary was personalised where possible with pre-stored phrases and with the correct pronunciation of his new baby girl's name! However, it soon became evident that Matthew did not use the device to supplement his communication when needed; instead, he seemed to prefer to rely on other strategies such as over articulating and repeating utterances which were not understood. Upon exploring this with him, he expressed that he did not feel 'ready' to use AAC yet as he found the loss of his speech upsetting, and he was still coming to terms with his diagnosis.

Rather than persuade Matthew to use his eye-gaze for AAC, it was agreed with him that intervention should focus on developing his use of his eye-gaze device for other activities. As it was now more difficult for Matthew to get out and about, he was interested in using social media. Matthew was setup with Twitter and Facebook and he used these to keep in touch with friends and family. He spent time organising his photos, writing letters to family and watching YouTube. This change in focus enabled Matthew to become proficient in using his eye-gaze device through those activities that he found motivating and relevant.

Matthew continued to use his speech until the latter stages of his condition and he did not use the eye-gaze device to augment his speech until it had significantly deteriorated. However, being such a proficient eye-gaze user when this time came, he was able to use the device successfully to express his care needs and chat with his family. Matthew sadly passed away last year.

ANGELA

Angela (43 years old) was referred by her speech and language therapist for an assessment for a high-tech communication aid. Angela had been diagnosed with Multiple Sclerosis in her 20s. At the time of referral, Angela had no movement in either her upper or lower limbs and had limited head control. Angela was living with her mother who was also her main carer. Angela was successfully using eye-pointing, e.g. to objects in the environment, and she used an E-Tran frame for messages, but she only used this strategy with her mother, tending to mouth words for unfamiliar communication partners or relying upon her mother to interpret for her.

At the assessment, Angela expressed a wish for a voice output communication aid so that she could communicate more effectively and more quickly. Angela's mother was also keen for Angela to be able to communicate independently. Following an assessment and trial period, Angela was provided with a high-tech eye-gaze device. The appearance and layout of the communication grids and keyboard were customised to address her visual deficits. The grids were personalised with pre-stored phrases to aid quick communication.

Despite regular support visits to provide training and opportunities to practise her AAC, it was found that the eye-gaze

device was not used outside of the AAC support sessions and Angela tended to continue to rely upon her low-tech AAC strategies. As such, Angela demonstrated limited progression in terms of familiarising herself with the vocabulary, navigation and her eye-gaze skills. Upon exploring this issue with Angela and her mother, it was felt that using high-tech AAC was taking time and effort to learn and so it felt easier for them to return to their previous strategies. It was also noted that due to her physical difficulties and health complications, Angela currently had limited communicative opportunities outside of her home.

With the aim of enabling Angela to achieve her original goals, and with an awareness of the 'load' that her current low-tech strategies placed on her family, it was decided that a change of focus, to different activities of her choosing, would enable her to develop those skills needed for AAC. Angela was introduced to YouTube, which was a new concept for her as she had not been able to use a computer for many years. She has had great fun looking up videos of her favourite eye-candy! Angela also expressed an interest in using her device for games, e-books and Audible (audio books). Currently, Angela is using the eye-gaze device independently and regularly, and although this is not what the device was originally provided for, she is developing the operational skills needed for high-tech AAC. It is hoped that in this way Angela will be able have the opportunity to increase her social opportunities and be able to independently converse with a range of conversation partners.

DARREN

Darren has four limb athetoid cerebral palsy, he lives at home with his parents and his 1-1 Personal Assistant. He was referred to the ACAT service for an assessment for easier alternative computer access. At that time, Darren predominantly used low-tech strategies for AAC: auditory scanning with his father and an eye-pointing chart with others. He was using Grid2 software with single switch scanning for computer access.

Following starting a new job at a local school, Darren started to use his Grid for voice output so that he could read to children in class. Although he prepared many of his messages in advance, Darren explained that he felt aware of the time others had to wait for him to generate a response/compose his message. At this stage it was suggested that Darren might benefit from eye-gaze technology as this could enable direct access and therefore quicker text output.

Darren agreed to a trial of an eye-gaze device but he did not wish to use it for AAC; he was used to using his other strategies and expressed a fear of using eye-gaze for communication as this was unfamiliar to him. Darren's father explained that Darren is not keen on change and it takes a while for him to get used to things. Therefore the focus of intervention changed to those activities of Darren's choice, such as YouTube, Skype, Facebook and games.

After many hours practising the use of eye-gaze with Darren (watching far too many Cliff Richard videos!) we were able to build his confidence in this new access method. Darren now spends much of his time on his computer, using his eye-gaze device, to keep in contact with his friends and family. We are currently progressing to using his device for AAC, through conversation practice, so that in the not too distant future Darren can use his device at work and, more importantly, to order his own drink at the pub!

CONCLUSIONS

Learning to use high-tech AAC takes time, practice and 'readiness'. These case stories are illustrative of some underlying reasons we have found as to why some clients may not be 'ready' for high-tech AAC, despite expressing goals in relation to communication:

- The rapidity of the progression of some conditions, such as MND, allows clients little time for psychological adjustment. This can impact upon the acceptance of new strategies and equipment. They appear to want to hold on to as much natural function as they can, even if this involves much effort (e.g. many repetitions), fatigue and dependence on their family members to step in when communication breaks down.

- Learning to be a competent user of a high-tech device can take time, and places significant demands on both clients and their families/carers. These demands can be underestimated by those involved. These learning demands often come at a time when there are significant changes and other interventions in their lives.

- With adult clients and their families/carers, we need to take into account that they have already established and developed communicative strategies learnt over a long period or even a lifetime. We are often told that AAC is not needed in the home as families know the client so well.

- Individuals learning to use AAC may be reluctant to appear inexperienced and make mistakes when interacting with others in face-to-face situations.

We feel that the outcomes in these cases also highlight why it is important to persevere and work with the client to overcome, where possible, those identified barriers to 'readiness' for AAC. We need to be sensitive to our client's worries and concerns and their possible reluctance to embark on the road to AAC. It is our responsibility to show clients the potential offered by high-tech devices. By using their devices for those activities that were meaningful and motivating for them, Matthew, Angela and Darren were given insight into the possibilities that their devices offered for communication. We learned that:

- For those clients with rapidly progressing conditions it is imperative to stage intervention, to enable them to develop skills for high-tech AAC so that they can proficiently use it when needed (Beukelman et al, 2000).

- Grading activities, such as the use of virtual conversations, can improve self-confidence, and aids successful learning in AAC (Rackensperger et al., 2005).

- A client needs to acquire the skills in using a high-tech device before they can achieve automaticity in AAC (Treviranus, 1994).

- The use of computer access technology enables those physically disabled clients, who are at risk of social isolation, increased opportunities for communication (Simpson, 2013).

We have learnt that whilst communicative competence is the overall goal of AAC intervention (Light, 2003), the use of computer access has proved invaluable in facilitating the attainment of this. ✳

Jodie Rogers, *Occupational Therapist*

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Connect to Control

How we can do the 'bells and whistles'

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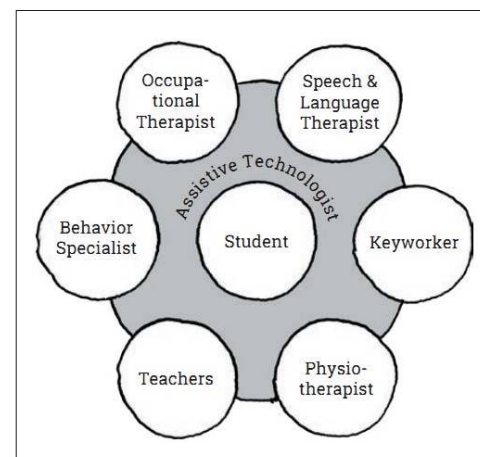Email: rohan.slaughter@scope.org.uk

Figure 1 The Assistive Technologist
(diagram by Ross Atkin after Rohan Slaughter)

INTRODUCTION

At the 2008 Communication Matters Conference, Chris Sherlock and colleagues from South Birmingham PCT gave a presentation 'Do we need the bells & whistles?' Liz Howarth and the author of this paper presented at CM2009 with the title 'Can we provide the Bells and Whistles?'.

Now that most communication aids support the type of 'connected' features that will be discussed in this paper, the justification for undertaking this work has, in the view of the College, shifted from "should we do this?" to "how do we do this?". In 2009, this work was somewhat new to Beaumont; now, five years on, the approaches have been embedded and supported by further project work.

This paper explores in more depth the presentation given by the author at the Communication Matters 2013 conference. It will explore how AAC devices can be used for functions other than talking; this includes general computing, telephone services, access to the internet, social networking and environmental control systems (ECS).

This paper will also describe the team model and the assistive technologist post as used at Beaumont College to enable students to access these features. The paper also gives an overview of the BT-funded Scope project *Connect to Control* and the original research that the author undertook, in support of this project, for an MSc by Research at Lancaster University (Slaughter, Connect to Control, 2013).

TRANS-DISCIPLINARY WORKING AT BEAUMONT COLLEGE

Beaumont College is an Independent Specialist College (ISC) operated by the national pan-disability charity Scope. The College currently has 96 students at the main Lancaster campus and an additional 15 students at two satellite provisions in Carlisle and Blackpool. Beaumont College has around 330 full time equivalent staff, making it one of the larger ISCs. The College has an Ofsted 'Outstanding' grade and was recently found to be "compliant in all areas examined" by CQC.

The curriculum at Beaumont is focused on personal development, independence and skills for life. The College has a creative arts specialism. Skills for life are often embedded into creative arts sessions. Recorded/accredited learning takes place in the 24 hour curriculum with students supported in real living contexts to develop the skills they will need for maximum independence post College.

The trans-disciplinary team at the College includes: Speech and Language Therapists, Occupational Therapists, Physiotherapists, Teachers and Assistive Technologists (AT). We are using the term trans-disciplinary to mean that we work together, sometimes in smaller teams, to achieve an outcome. An example of this would be an occupational therapist working with an AT in order to conduct a switch or other access assessment.

Professionals are also learning elements of each other's role, whilst at the same time knowing the boundaries of when to make reference to the professional as is appropriate. This trans-disciplinary team of professionals work together through an AAC COP (Community Of Practice). This fortnightly forum allows for troubleshooting individual systems that have been put in place for students at the College. We can also cover new products, technologies, ask/answer questions and deal with any other matters that impact on the AAC or AT solutions that have been put in place for our students. The purpose of this approach is to ensure that students at the College get a fast and efficient service, and that all issues are resolved as quickly as possible.

The project work described below has allowed us the capacity to develop links

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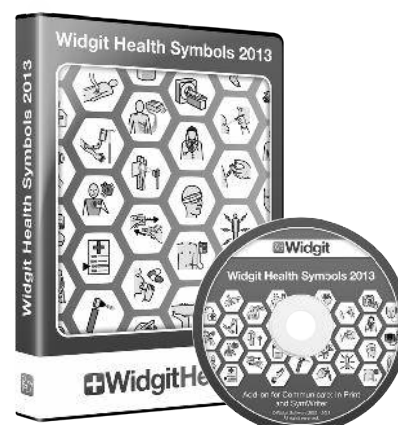
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Figure 2 Connect to Control Assessment / Choice Grid

with the rest of the trans-disciplinary team at the college, including the professionals described above alongside social care staff and teachers in order to assess for, design and implement the assistive technology/AAC system as well as training the user to use their personalised system. It should be noted that the student is consulted at the start of the process through a person centred approach, to inform the design of their system based on what they want to achieve with it.

THE ASSISTIVE TECHNOLOGIST ROLE AT BEAUMONT COLLEGE

The AT role at Beaumont College has been developed over a number of years. The role as we define it is more education focused than other roles that may have a similar title. It is not a clinical rehab engineering role, but rather a fusion of education, therapy and technical elements. One thing the College insists on is that if an individual is recruited who does not have a teaching qualification, they be supported to acquire one as part of their on-going development programme.

The College has recruited people to the role from both technology and social care backgrounds. Often we have to develop people in one area, but they may come to us with good therapy, technical or educational skills/qualifications. The key here is to have a flexible staff development programme that includes external courses such as those offered by the ACE Centre alongside work shadowing opportunities with therapists and other professionals. The goal is to re-

cruit and train people with excellent social skills, so that we develop their educational, technical and therapeutic skills in order to deliver a personalised assistive technology service.

The way this role works in collaboration with other roles is explained in Figure 1. It is important to note that the role does not replace any other existing role, but rather works with others to ensure that the total service offer is truly joined up; in this way, the AT works as the 'chief integrator' of the technology system. It's important to note that the clinical lead for seating and positioning remains with the OT, and the clinical lead for language pack selection remains with the SLT. In the case of AAC device selection, this may be dictated by one of these factors, but normally the device selection is done through collaboration within the AAC COP.

The assistive technologists all have a caseload that is mapped (where possible) to the caseloads of an OT, PT or SLT depending on which is more appropriate. The assistive technologist has an active caseload of 30 people at any one time. In this way, all students have a named assistive technologist who is their primary point of contact for all of their assistive technology requirements. The ATs are also deployed into classrooms, through consultation with the head of learning at the College, in order to support the development of staff skills, support a particular student or to achieve a session specific outcome. In this way, we have seen

observation of teaching and learning grades increase in the supported sessions. The College feels that this approach enables high quality support for students as well as providing effective training to teachers and supporting staff at the point of need.

ENABLING ACCESS TO TECHNOLOGY

The roles and teaming model described above allow the College to provide outstanding Assistive Technology services to students. In the original BT/Scope *Wheeltop* project, we developed a personalised approach: we started by asking what technology a particular student wanted to access first; a list of possible options was provided, and ranked by the student in terms of importance. A Grid Set was developed to enable this; an example is shown in Figure 2.

The services we routinely provide access to (usually, but not exclusively, from tablet computers or AAC devices) include:

- Access to the curriculum through:
  - control of standard computer software
  - access to subject specific vocabulary
  - control of subject specific equipment
- Internet access, email, SMS, voice calls, Skype, etc.
- Social networking such as Facebook, Twitter (enabled through robust e-safety processes/risk assessment)
- Control of the environment through Environmental Control Systems (ECS).

One of the ways that the College aims to keep up to date is through engaging with, and leading, sector improvement projects such as the Jisc-funded DART2 project (Beaumont College Technology, 2012) which ran from 2012-13. Jisc have recently announced additional funding for DART2.1, an ongoing project that will run from 2014-15. The DART project seeks to:

- improve AT practice in the sector
- enable the replication of the innovative Assistive Technologist role
- produce AT case studies for the sector.

The project is achieving this through:

- 'deep support' for ten providers: Further Education Colleges, both general FE and ISC
- a workshop series open to all Jisc supported Colleges
- a Natspec-sponsored research project (Maudslay, 2013).

THE CONNECT TO CONTROL PROJECT

The Connect to Control project is the second Scope/BT partnership project

Age and disability market			Smart-home / home automation
Typically high cost	☹	☺	Typically lower cost
Manufacturer lock in	☹	☺	Use standards based approaches and protocols
Out of date approaches	☹	☺	Use leading edge technology
Highly accessible design	☺	☹	Often not truly accessible

Figure 3 Two markets for ECS?

(2011-2014). It consists of a technology development project at Beaumont College as well as a policy project led by Scope's Policy team. A report 'Enabling Technology' (Jewell & Atkin, 2013) was authored by two researchers from the Helen Hamlyn Centre at the Royal College of Art.

The technology project sought to identify 'best in breed' Environmental Control Systems from the 'age and disability' market as well as evaluating equipment from the 'smart home' or 'home automation market'. BT funded time (a single AT post, plus some time from SLT and OT to contribute) as well as funding all the equipment used in the project.

Students were consulted as to what equipment they wanted to be able to control using the method described above, and this was purchased and installed in student rooms. Whatever device/interface the students normally use to speak or access a computer was 'extended' in order to access the Environmental Control Systems that were installed. In addition, students volunteered to test the prototype system described below.

MSC BY RESEARCH PROTOTYPE PROJECT

In order to effectively evaluate the potential of smart home/home automation technology, the author undertook an MSc by Research at Lancaster University in support of the project. The purpose of the prototype project was not to develop and market a system, but rather to demonstrate that it was possible to develop the software required to make a system from the smart home/home automation market accessible to students in a College environment. The project ran from 2011 to 2013 and started from the premise shown in Figure 3.

A prototype system was developed that was made accessible from a simple web interface that can run on any device with a web browser, as well as providing a method of accessing the system from The Grid2 software. The approach used was to abstract the control system (in this case, the tablet/AAC devices used by the students), from the system logic (a number of web services and a database running on a local web server), from the ECS standard (Vera2 Z-wave gateway and LightwaveRF WiFi bridge) that in turn communicate with actuators – devices that turn lights

on/off, power up appliances, etc. Figure 4 shows the prototype system.

It should be noted that this prototype system was shown to a number of ECS companies. It was also used to set the Scope/'IC Tomorrow' Technology Strategy Board 'Internet of Things' challenge prize. This was intended to allow the development of a web-based ECS system that used smart home technology. The prize was won by Therapy Box with their SmartHub system which is now being tested by students at Beaumont College.

It should be noted that the conclusions of the author's MSc work included:

- It is possible to adapt smart home type technology for the use of disabled people as evidenced by the prototype and by subsequent developments.

- The 'age and disability' and 'smart home' markets are converging, as evidenced by the use of 'smart home' technology by the companies who have traditionally used only equipment derived from the 'age and disability' market. Perhaps one of the most interesting examples of convergence is the Servus Controller from SmartboxAT which can address equipment from the smart home market (e.g. Eldat) as well as working with traditional equipment such as infra-red based Environmental Control Systems.

The author believes that such developments are positive as they lower the initial cost of systems without compromising the delivery of the assessment and installation services that users require. ✱

Rohan Slaughter
Assistant Principal / Head of Technology

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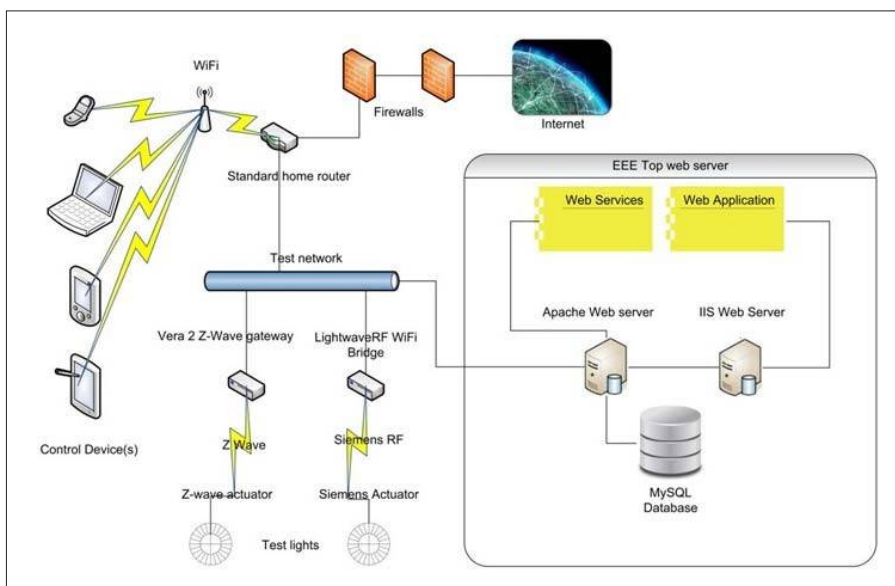www.smartboxat.com/products/servus-tablet
SmartHub http://therapy-box.co.uk/smarthub.aspx

Figure 4 Prototype System Diagram

COMMUNICATION *MATTERS*

National AAC Conference

14th -16th
September 2014
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.

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- 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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FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

It is rather humbling to find that I am now half way through the three year term as Chair. It feels as though time is racing on and yet has been encouraging to see that Communication Matters has a key role in improving AAC services.

Specialised AAC Services

The highlight this last year is the continued progress made in raising awareness at government level about the need for a robust funding structure for AAC services and equipment. The recent news of the signing off the £15 million for the Convergence Fund for England is really encouraging – see page 19 for an update on Specialised AAC Services in England.

CM National AAC Conference

The second achievement is having had such a successful Conference at the new venue at Leeds University in 2013 and planning now is well underway for the 2014 Conference. The Conference is obviously central to Communication Matters's core business, and it has been so encouraging to have so much positive feedback.

The new initiatives last year, which included the twilight session for Leeds Metropolitan University SLT students and the Interactive Art Workshop, are to be repeated and developed this year. New for this year's conference will be a 'Research Stream', poster presentations, and more interactive workshops exploring communication through creativity. We are looking forward to having presentations from the 'Seen but Seldom Heard' poetry project based in Bournemouth. We also are really pleased that our Patron, Lee Ridley, is planning to join us.

MARKETING & STUDY DAYS

We are still being challenged as to ways that we can more effectively raise awareness about AAC and increase membership. We want to more effectively get our message out especially in education settings to teachers, SENCOS and teaching assistants. It was really good to have 150 delegates for the recent study day in London on 'Symbolisation towards Literacy' delivered by Janice Murray and Martine Smith. There are also collaborations this year with 1Voice, The Stroke Assembly and the MND Association which should help to widen our impact. We are very aware that we need to make some decisions on how we invest in the marketing agenda particularly in relation to improving our external communications.

LOBBYING

Our lobbying campaign has resulted in some significant progress with AAC now being included within Specialist Commissioning. With the signing off of the £15 million Convergence Fund, we are continuing with work to ensure better joined up working between specialised and local services. It is good to have feedback from the membership on how they value the work which Communication Matters has done. We continue to work with the Whitehouse Consultancy, which makes a real difference to our lobbying activities as they provide up to date briefings and ensure that meetings are followed up so that we do not lose momentum.

CORE BUSINESS

In addition to the above we are continuing to deliver our core business activities to a high standard. Roadshows, study days and events for people who use AAC are arranged throughout the year. We have seven Roadshows already booked throughout the UK in 2014, as well as a number of study days, including 'Symbolisation towards Literacy' and 'Access Technology'. We are also delivering 'Social Networking days' for people who use AAC. Thanks must go to Patrick Poon and Peter Head for their administrative support to ensure these events are successful.

ISAAC

The ISAAC Conference in July 2014 is in Lisbon and as Chair I will be attending meetings to represent our UK Chapter. As has been previously stated, ISAAC remains an important organisation for many people. We (the Chair and Trustees) have to ensure that the UK gets the most from its membership of ISAAC. We are also looking for ways in the future as to how we might be able to better support less established Chapters and share knowledge and expertise which sometimes we sometimes may take for granted.

As a Board, it is important to remember that we need balance and perspective as we aim to fulfil the voluntary role of Trustees. We need to be realistic about what we can achieve and not afraid to outsource projects which are beyond our capacity and skills.

STAFF NEWS

We are grateful to our administrators, Patrick Poon and Peter Head, for their continued hard work. Patrick has recently decided to retire in April 2015, and Peter will also be retiring around that time. We are grateful to them both for giving us such a lot of notice for the Board to plan a smooth handover to new staff. They will be both hugely missed, and we will need an appropriate send-off for them next year!

Communication Matters is at a pivotal point. Although change is scary, we have to try to build on the success of the past as we respond to the challenges of the future.

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

Catherine Harris, *CM Chair*

BHTA AAC
NEWS

Working together rather than independently is a theme that seems to be running through the healthcare industry today, regardless of whether that is in wheelchairs, patient aids, orthotics or AAC. The days are gone when a company can isolate itself and ignore other companies and organisations in its sector and stay successful. There are clear examples where companies have tried to do this and failed even in the AAC industry.

One of the huge benefits, therefore, of being part of a trade association like the BHTA is that member companies can share information for the benefit of themselves and the industry as a whole. Now this does NOT mean that they can act as a cartel or agree anything that would be detrimental to the customer base – and that is why at least one member from the BHTA Board always attends every meeting – but it does mean that companies can share experiences and learn from each other – hopefully to the benefit of everyone involved in AAC.

But it also means that the BHTA can understand what is happening in that particular sector and try to support sector members by either making representations to government or whoever should be involved. It also means that the BHTA can feed back to member companies what they see happening on the horizon so that member companies can be prepared for any changes that are likely to happen.

Examples of how the member companies feed information to BHTA include issues surrounding what have been called 'freak orders' that can cause serious problems in stocking and supply of products and even changes in order processing and the way budgets seem to be being handled that have caused some companies difficulty in obtaining payment for goods or services provided.

On the opposite side of the coin, at the last meeting the BHTA representative was able to inform member companies of changes in the law relating to 'distance selling' that come into operation in June this year that could affect how companies deal with clients in their own homes, and also how they are monitoring the Care and Support Bill and how that might change the way GPs work with patients who need specific products or services.

There is also a strong feeling that the BHTA and CM should work closer together and it is hoped that there will be ways that we can support each other in the future for the benefit of all concerned. The BHTA AAC sector recognise CM as the leading organisation in the AAC industry for users and professionals and believes that the BHTA is the strongest advocate for commercial organisations – therefore working together makes total sense.

Hopefully we will see more instances of all aspects of the AAC industry working closer together so that everyone becomes a 'winner'. ✷

David Morgan, *BHTA AAC Chair*

HOT
NEWS

INSPIRING FILM 'A RIGHT TO COMMUNICATE'

In Dumfries and Galloway, a dynamic group of people who use AAC have created and starred in an inspiring short film 'A Right to Communicate'. The creators of the film would like your help to spread the word by sharing this film with others or linking to it if you have a website.

The film was produced by the Communication Friends Group and funded by the 'A Right to Speak' AAC project in Scotland. Watch the film on YouTube:

www.youtube.com/watch?v=fx338vnATIA

If you have any questions, please contact Megan Hughes (speech and language therapist) on Tel: 01576 205 537.

✷

APPS ON APHASIA SOFTWARE FINDER

The Tavistock Trust's Aphasia Software Finder website now has a section dedicated to apps, the small programs that run on smartphones and tablets. The new section enables you to identify apps suitable for aphasia and to learn more about them. It also offers an App Comparison Table to compare the features of different apps.

View the Aphasia Apps page here:

www.aphasiasoftwarefinder.org/aphasia-apps

✷

ISAAC LIFETIME ACHIEVEMENT AWARD

ISAAC has named **Professor Stephen Hawking** as the first ever recipient of the ISAAC Lifetime Achievement Award. The award will be officially presented at the upcoming ISAAC 2014 Conference, 21-24 July 2014 in Lisbon, Portugal.

ISAAC will be creating an endowment fund linked to the Lifetime Achievement Award.

13 May 2014   *Shrewsbury*
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20 May 2014   *Glasgow*
Communication Matters Road Show: Glasgow
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk **CM ROAD SHOW**

21 May 2014   *Newcastle*
Communication Matters Road Show: Newcastle
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3 June 2014   *Manchester*
Communication Matters Road Show: Manchester
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk **CM ROAD SHOW**

3 June 2014   *Oxford*
AAC SIG Meeting (Oxford)
More information: www.aacsig.org.uk

4 June 2014   *Middleton, Staffs*
1Voice West Midlands Summer Outing
Contact: 1voicewestmidlands@1voice.info www.1voice.info

10 / 11 June 2014   *Inverness / Edinburgh*
ICT and Inclusion
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

10 June 2014   *Oldham*
ACE Centre Network Day (Oldham)
Contact ACE Centre: 01865 759800 www.acecentre.org.uk

12 June 2014   *London*
Communication Works 2014
More information: www.charltonparkacademy.com/CW2014

24 June 2014   *Oxford*
ACE Centre Network Day (Oxford)
Contact ACE Centre: 01865 759800 www.acecentre.org.uk

24 June 2014   *Arundel, W Sussex*
Let's all Communicate
Contact: short.break.team@westsussex.gov.uk Tel: 03302 222562

19-24 July 2014   *Lisbon, Portugal*
ISAAC 2014 Conference
www.isaac-online.org/english/conference-2014

25-26 July 2014   *Lisbon, Portugal*
ISAAC Research Symposium
www.isaac-online.org/english/conference-2014

8-10 August 2014   *Cheltenham*
1Voice 2014 National Summer Residential Event
Contact: 1voice-admin@1voice.info www.1voice.info

14 September 2014   *Leeds*
1Voice-1Day
Contact: 1voice-admin@1voice.info www.1voice.info

14-16 September 2014   *Leeds*
CM2014 National AAC Conference
Email: admin@communicationmatters.org.uk to register interest **COMMUNICATION MATTERS**

16 October 2014   *South Yorkshire & Humber*
AAC SIG Meeting (South Yorkshire & Humber)
More information: nicolahayton@nhs.net

4 November 2014   *Oxford*
AAC SIG Meeting (Oxford)
More information: www.aacsig.org.uk

6 November 2014   *London (TBC)*
Access Technology: Study Day (to be confirmed)
Email: admin@communicationmatters.org.uk to register interest **COMMUNICATION MATTERS**

7 November 2014   *London (TBC)*
Access Technology: Network Day (to be confirmed)
Email: admin@communicationmatters.org.uk to register interest **COMMUNICATION MATTERS**

WANT TO HOST A COMMUNICATION MATTERS ROADSHOW?

The Communication Matters Roadshows are great opportunities to learn all about the latest communication aids and software from some of the UK's leading AAC suppliers.

CM Road Shows are held every year at various locations in the UK - and they are free!

We are always looking for new venues to hold CM Roadshows, so if you would like to host one in your area, please do let us know.

Communication Matters will handle much of the adminstration and organisation, including taking delegate bookings.

For more information, please contact Patrick Poon on Tel: 0845 456 8211 *admin@communicationmatters.org.uk*

The Development of Specialised AAC Services in England

SALLY CHAN

Email: sallychan@blueyonder.co.uk

1. SERVICE SPECIFICATIONS

The Service Specifications for Specialised AAC Services were posted on the Communication Matters website at the end of February 2014. These are currently in draft format, and will be ratified in October 2014 by NHS England. The Specialised AAC Services will be expected to be working towards these Service specs during 2014/15.

2. CONVERGENCE FUNDING

The £15 million Convergent Funding was finally signed off by the Specialised Commissioning Oversight Group on 26 February 2014. Before the middle of April 2014, the 13 identified Specialised AAC Services will be submitting a business plan to the Area Team responsible for the commissioning of Specialised Services in their regions. There was a workshop held in Birmingham on 29 January 2014 to inform the potential Specialised AAC Services of the process.

3. SPECIALISED AAC SERVICES

The following Specialised AAC Services have been derived from the *Communication Matters: Research Matters project* data collected in 2012/13. This data informed NHS England of those services which go some way to meeting the Service Specifications. The addition of Lincolnshire AAC Service was to provide a Service where a gap existed. These Services are likely to be commissioned from April 2014, if they are successful in their application to the Area Teams. This is a starting point for Specialised AAC Services, and it is likely that there will be other Services who could make an application to become a Specialised AAC Service in 2015/16 if they can prove they meet the Service Specifications. The Services are as follows:

- Access to Communication & Technology (ACT)
- ACE Centre
- Assistive Communication Service – Central London Community Healthcare NHS Trust
- Barnsley Assistive Technology Service
- Bristol Communication Aid Service
- Chailey Heritage Clinical Services
- Communication, Learning and Technology Service – Great Ormond Street Hospital for Children
- Compass Assistive Technology Service, Royal Hospital for Neurodisability
- Dame Hannah Rogers Trust, Devon
- Kent Children's & Adults Communication and Assisted Technology Service
- Lincolnshire AAC Service
- North West Assistive Technology Service
- Regional Communication Aid Service Newcastle

4. AAC SUB-GROUP

Carolyn Young is the National Lead Specialist Commissioner for Complex Disability Equipment, including AAC Services, Prosthetic Services, Wheelchair Services and Environmental Control Services. Carolyn sits on the AAC Sub-Group which feeds into the Clinical Reference Group. Other members of the Sub-Group are as follows:

- Sally Chan (Chair)
- Judith de Ste Croix
- Gary Derwent
- Alexis Egerton
- Catherine Harris (CM chair)
- Simon Judge
- Jemma Newman
- Anna Reeves

The AAC Sub-Group meet on a regular basis, either face to face or through telephone conferencing. They are a group to advise the Clinical Reference Group of the development of Specialised AAC Services, the five year strategy for such services as well as the Service Specifications.

5. CLINICAL REFERENCE GROUP

The Clinical Reference Group (CRG) is for Complex Disability Equipment, consisting of the types of services listed in the previous section. Sally Chan represents the Royal College of Speech & Language Therapists as well as the AAC Sub-Group.

The CRG meets every other month in London and Sally is responsible for feeding back on the work of the AAC Sub-Group. This is focused on the development of the Service Specifications and information to be sent out to the Specialised AAC Services, local services and the wider AAC community. Further work on feeding into the five year strategy for Complex Disability Equipment within NHS England, procurement, monitoring and quality assurance of services needs to be progressed as future work.

6. COMMUNICATION MATTERS

Communication Matters is represented on the AAC Sub-Group by Catherine Harris. ✳

Sally Chan
Chair of the AAC Subgroup & CM Trustee

Are you looking for AAC knowledge?

www.AACknowledge.org.uk brings together information and research evidence about AAC in one place. In order to meet the needs of a wide audience it provides different ways of finding out more about AAC.

Do have a look at **www.AACknowledge.org.uk** and let us know what you think using the site feedback form.

The website features:

- A bibliography of published research into AAC
- Plain English summaries of research articles
- Case stories
- Factsheets
- Frequently asked questions
- Glossary
- Links to many other sources of information

USEFUL 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 – please send an email to: 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 the case study template/resources, visit:
www.communicationmatters.org.uk/research

The Practicalities of Mapping AAC Services in England

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INTRODUCTION

The Department for Education (DfE) funded AAC Grants programme ran between April 2012 and March 2013. This programme aimed "to support organisations' transition to new commissioning arrangements, and to help move provision incrementally towards the model of regional hubs and specialist expertise" [1]. One of the objectives of the programme was to 'map' AAC services at a local level in order to better understand the nature of the services that currently exist. The mapping work carried out was the largest systematic survey of services with a remit to provide AAC at a local level in England to date.

This article describes how the mapping was carried out, and discusses the reasons for carrying it out in this way. The results of this work will be presented in another paper that is in preparation [2].

HOW WAS THE MAPPING CARRIED OUT?

The mapping work aimed to collect data about services in England which provide AAC at a local level. In order to achieve this aim, it was necessary to (i) identify the services providing AAC at a local level, (ii) find out appropriate information about each service and (iii) to collect the information in a consistent manner.

DEVELOPMENT OF THE SURVEY TOOL

The identification of the appropriate information to ask these services was informed by the experience gained during the Communication Matters - Research Matters (CM-RM) Project [3]. A survey tool had been **developed** as part of this project, with the aim of finding out details of more specialised / dedicated AAC services providing powered communication aids. The CM-RM survey aimed to elicit information such as prevalence of use of communication aids, the type and components of service provision offered, and information about resources such as equipment, service costs and funding arrangements.

The survey tool used in this study was developed from the CM-RM survey, but adapted to the different focus of this study in a number of steps:

1. The tool was further referenced against the CM AAC Services Standards [4] (which were developed as guidance as to what a service user should be able to expect from an AAC service). Where possible, the tool was designed to ensure that data returned addressed the areas covered by these standards.

2. Consultation with an expert group of professionals from the AAC Grants programme Consortia (the AAC Grants programme was delivered by consortia of organisations from four geographically defined regions).

3. Further consultation and piloting with the 'project workers' employed to carry out the surveying.

Twelve iterations of development of the tool took place over two months.

As an example: to obtain epidemiological data, respondents were asked to rank a list of conditions according to how frequently clients who use AAC with each condition are seen by the service. The list of conditions was based on work carried out in the CM-RM project, which used the literature, pilot data and consultation with AAC professionals to identify the appropriate conditions. Alternative approaches were considered (e.g. requesting exact numbers), however experience from the previous work had shown that many services did not have access to accurate data for this, and ranking the conditions would still provide useful comparative data, and be indicative of potential gaps in provision for people with certain conditions.

Definitions for all terms used in the survey were developed, again based on the CM-RM work [3], agreed and published. These can be found in Appendix 10 of the 'Beyond the Anecdote' report [5].

WHAT DID WE ASK?

The survey tool was designed to find out information about the populations served by each service, the components of provision offered by the service, and the resources the service accessed. A summary of the five sections of the tool can be seen in Table 1.

IDENTIFICATION OF SERVICES

The identification of services with an AAC remit required a systematic approach to be developed as there is no national listing of these services. Some information was known about services operating at a more specialised or dedicated level – Communication Matters manage a list of 'AAC Assessment Services' on their website [6], and many services of this type were identified during the CM-RM Project [3].

The **procedure** for identifying services was thus based on 'snowballing' from these existing known contacts – services identified in the following way were known as 'Category 1' services:

1. Permission was sought via the CM-RM project to contact the identified services.

2. The existing identified services were asked to supply lists of all the services they knew of which had an AAC component.

3. These services in turn were then contacted and asked about the services they knew with an AAC component.

4. This process was repeated until no further services could be identified.

Contact Information	Basic contact information about respondent and service
Service Information	The geographical area covered Who commissions the service Caseload data Staff (professions, level of expertise)
Access	Eligibility criteria The conditions that those accessing the service have
Care Pathway	Components of the service Transfer procedures
Skills & Resources	Staff training Access to loan banks Access to funding for long term provision of high tech devices

Table 1 A summary of the questions asked in the survey tool

A procedure was also developed for identifying services in areas where no services could be identified using the above procedure – these were known as 'Category 2' services:

1. Contact services directly across sectors, i.e.:
   a. Health, e.g. SLT services
   b. Social Care, e.g. LD services
   c. Education, e.g. Special schools; LEA SEN units
   d. Voluntary Sector, e.g. MNDA
2. Contact the commissioning bodies (PCT/LEA/Local authority) to enquire where there are services for people who use AAC in their area.
3. General call within area, e.g. on mailing lists, media.

INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria for services were defined as:

1. Services with a universal remit across a defined geographical area *(e.g. SLT service, including AAC, in York)*

OR

2. Other services with a universal remit across a defined population and area *(e.g. people with MND in Yorkshire, school pupils with SLCN in a special school in Huddersfield)*

AND

3. Provide, or are involved in the provision of AAC services, equipment or support OR have a caseload including people with speech, language and communication needs where it would be expected that there would be an AAC need.

Exclusion criteria were defined as:

1. Services without a universal remit across a defined geographical area *(i.e. tertiary services, independent practitioners, companies).*

SURVEY PROTOCOL

Data collection was carried out by 'administering' the survey to service managers, i.e. the data were collected over the phone or in person with the service managers. This method was chosen for a number of reasons. The **consistency and reliability** of the data collected was key to the effectiveness of this data. Terms and definitions used within the field of AAC are extremely variable. In addition, it is known that the models of service delivery vary significantly [7]. Also, because this was the first time a survey such as this had been carried out, there would be no familiarity with the data, terms or format of the survey that there might be for other more established surveys.

This method of obtaining the data had the advantage that the **definitions** used in the questionnaire could be explained and verified by the project worker administering the survey. For example, when asking how many people using AAC were on the caseload of each service, it was vital for everyone to be using the same definition of AAC and caseload. Equally, when asking how many AAC specialists the service had access to, it is necessary to know how an AAC specialist was defined.

Service managers were chosen as the respondents as the survey requested financial and caseload data that individual professionals may not be able to access (and thus may not provide answers to).

Another reason for administering the survey was to attempt to achieve a relatively high **return rate**. As an example, the CM-RM survey had been distributed in paper form or could be completed online and achieved a return rate of between 26% and 59% (depending on the measure [3]).

The project workers carrying out the survey were all AAC practitioners. Some of the workers had been involved in the development of the survey tool and all of the workers were trained in the use of the survey.

RESULTS

In total, 220 services across England with a remit to provide AAC at a local level across a defined geographical area were surveyed [8]. A further 44 services delivering services to a catchment population (e.g. schools) were surveyed. 377 more services were identified but it was not possible to map them during the project.

A brief summary of the initial results can be found in the report of the DfE AAC Grants Project [1]; the full anonymised data set is available online [8] and a paper providing a more detailed analysis of the results is in preparation [2].

The mapping data has provided details of the way in which AAC provision varies across the country. The amount of money spent on high tech devices, and the source of funding for the service itself are just two of the ways in which provision varies by region.

HOW WELL DID THE SURVEY APPROACH WORK?

The approach of administering the survey was resource intensive. The original rationale for this approach was around data quality (given the lack of agreement around terms, the variability in service models, and the fact this was the first time this survey was carried out). Qualitative reports from the project workers carrying out the surveying (including that of the first author) confirmed that interpretations of the questions on the survey by respondents varied significantly. During the surveying, project workers reported often having to clarify definitions, or to seek clarification on vague or inconsistent replies.

The response rate to the survey was essentially 100%, which is not surprising given the nature of the approach taken, as responses were only entered when a service manager was contacted. However, it can be seen that more services were identified than were surveyed, indicating the scale of the challenge to capture the whole population of service providers.

Due to the 'snowballing' method used to identify services, the respondents are likely to represent a high proportion of the cohort of 'active' or 'networked' services offering AAC at a local level. This is because those services with a higher profile for AAC were more likely to be known about by other services, including specialised/dedicated AAC services in their area.

The process of identifying services to survey was significantly more challenging than anticipated. A combination of the 'Category 1' approach and the 'Cat-
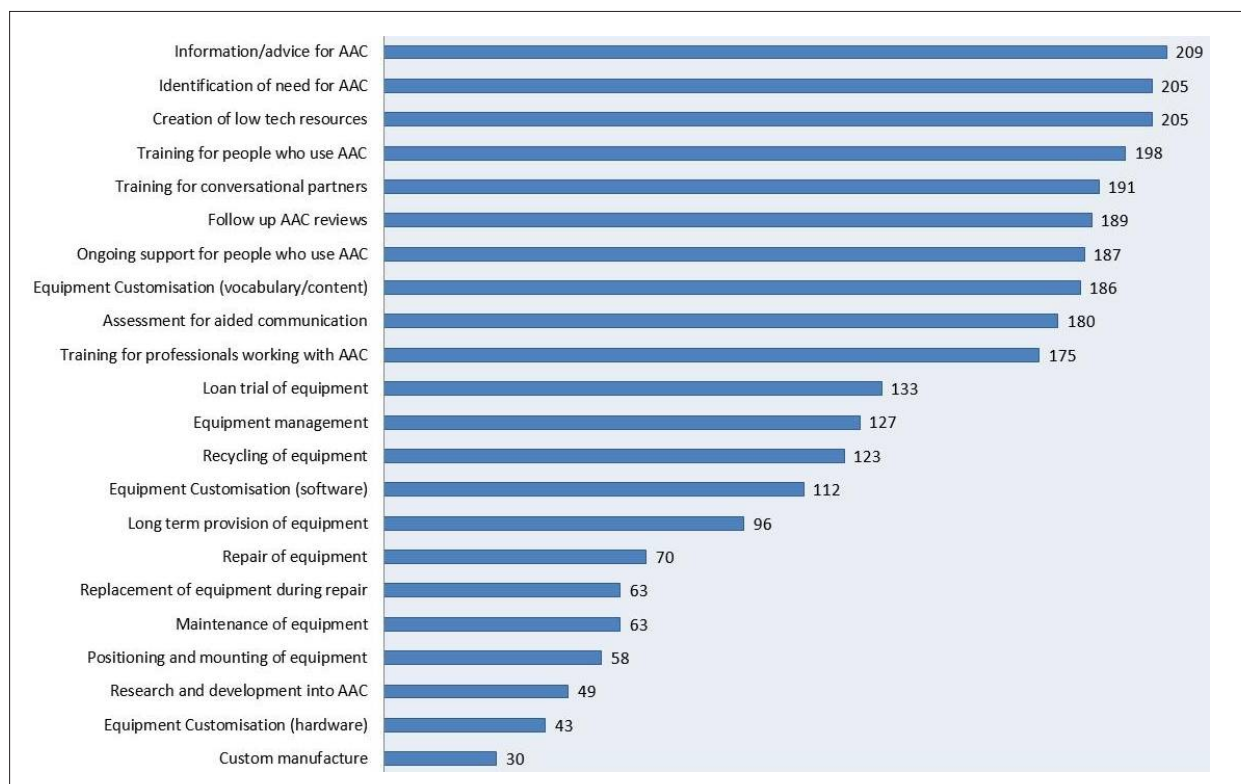
Figure 1 The numbers of services that offered each component of provision of an AAC service. The total number of services that reported offering each component is given at the end of each bar.

egory 2' approach described above were used to identify services.

EXAMPLE RESULTS

A paper providing a more detailed analysis of the results is in preparation [2]. However, as an example, Figure 1 shows the results from one of the questions asking about the components of AAC provision that each service offered. It can be seen that the majority of services surveyed offered information about AAC and were able to identify the need for AAC and offer ongoing support and advice, and many (82% – 180 of 220) services were able to offer assessment for aided communication.

However, fewer services were able to offer components of service related to equipment, such as loans of equipment (60%), long term provision (44%), or ongoing maintenance (29%).

CONCLUSIONS

This project, carried out as part of the Department for Education AAC Grants Project, was the largest systematic survey of services with a remit to provide AAC at a local level in England to date.

From a practical point of view, it was a complex task to carry out, since services had to be identified before they could be surveyed, and it was important to identify the correct questions to ask and ensure good quality data was collected.

The development of the survey tool benefited greatly from the CM-RM work and the Communication Matters AAC Service Standards. Identification of services to survey was significantly more challenging and resource intensive than predicted, which highlights the variation in models of service delivery across the country.

The approach of 'administering' the survey, although resource intensive, produced high quality data where otherwise it is likely that the quality would have been variable or poor due to varying interpretations of the questions and different approaches to service delivery.

The data obtained from the survey is likely to represent a high proportion of the more active and/or networked services delivering AAC at a local level.

It has been repeatedly reported that access to AAC services is inequitable [9,7] at a local level. The data from this project allows identification of areas in which there may be gaps in AAC provision – either where it was not possible to identify an AAC service, and/or where AAC services were only provided to people with certain conditions, or in certain age groups. Such information is important as a basis for developing equitable access to AAC services for all. ✳

Victoria Johnson, *Clinical Scientist*
Simon Judge, *Senior Clinical Scientist*

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Facilitating Participation in Children with Four-Limb Cerebral Palsy

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This paper examines themes that emerged from interviewing parents of, and professionals working with, children with four-limb cerebral palsy (CP). We were interested to find out children's needs regarding information about their diagnosis and prognosis, and to create potential resources to address them. Grounded-theory was used to analyse the data (Glaser and Strauss, 1967).

A number of themes emerged; at the forefront was that the child's condition had not been directly discussed with them, so their understanding was limited. Two main themes emerged as to what a potential resource might look like: a book concerning CP and a technological device which could facilitate asking questions. Participants clearly identified what areas should be covered in the book. This study provided the foundation for developing a resource to enhance understanding of four limb CP and to facilitate participation in this group.

INTRODUCTION

CP refers to a range of physical disorders affecting the development of posture and motor control, resulting from a non-progressive defect or lesion in the immature brain (Huang, et al., 2008). It has been recognised as one of the most common causes of childhood disability with a prevalence of 2.5 per 1000 births in Western societies (Stanley et al., 2000). Throughout childhood and adulthood, CP can affect participation in aspects of life.

In recent years, the quality of life for children with CP has improved significantly due to the development of innovative technologies and intervention programmes. Efforts have been made to allow for early diagnosis, reduce motor impairments and increase mobility. Rehabilitation programmes have begun to shift their focus from simply managing symptoms to enhancing the functional success of such children and increasing their participation in life (Majnemer et al., 2008).

There is evidence to suggest that there are significant barriers to participation for children with CP. In areas such as education, personal care and recreation, children with CP tend to participate considerably less than their non-disabled counterparts, and their activities tend to be passive in nature and limited in variety (Parkes et al., 2010). In addition, the condition can also be accompanied by the speech disorder dysarthria. The use of augmentative and alternative communication supports has allowed individuals with CP to access a 'voice' (Light et al., 2003), which has aided self-expression and has reduced passivity.

Becoming an effective self-advocate involves having knowledge of oneself. However research suggests that many children with CP have a lack of understanding concerning their disability and its impact on their lives (Abernathy & Taylor, 2009; Jones, 2006). There is evidence that some children with physical disabilities think they may outgrow their impairment (Connors & Stalker, 2007). These children can begin to develop erroneous theories to make sense of their circumstances, which can lead to self-blame and guilt (Jones, 2006), and to ongoing confusion about their disability.

Typically, for children with disabilities, parents take on the responsibility of advocating for their child, and are often the main source of explanation regarding their impairment. However, Connors and Stalker (2007) revealed that there appears to be little discussion within families. Several parents expressed dread of being asked for explanations, and tended to give relatively vague responses.

Providing children with four limb CP with information regarding their condition might give them the opportunity to manage their personal needs in adulthood and make informed decisions regarding their lifestyle and welfare.

THE CURRENT STUDY

Professionals working locally had identified situations where a child's functional performance was limited due to lack of understanding of their condition and its impact on their abilities. No appropriate resources to address this had been identified. By interviewing parents and professionals we aimed to identify the needs of these children with four limb CP regarding information about their diagnosis and prognosis; with the eventual aim of developing a resource to aid understanding. Areas examined included: the extent to which the children understand their diagnosis and prognosis; their understanding of healthcare and therapeutic interventions; barriers encountered in the process of receiving healthcare or edu-

cation; and what would help to address these issues.

Participants

Eleven people took part: four mothers of primary school aged children (three boys, one girl) with four limb CP; with limited or no functional speech using AAC supports. Five therapists and two teaching assistants working with these children also participated.

Methods

A topic guide and semi-structured interview schedule using open-ended questions were developed. Individual interviews took approximately 30 minutes and were audiotaped. Parents were interviewed first and were asked to identify members of teaching staff at their child's school and members of child's therapy to be interviewed.

Ethical considerations were observed in that participation was kept confidential and participants were notified of their right to withdraw.

Analysis

All audiotapes were transcribed and the data analysed using grounded theory (Glaser & Strauss, 1967) which groups data into themes reflecting participants' opinions, thoughts and feelings. The first five interviews were independently analysed by two separate researchers to identify initial themes in the data. These were then compared and assessed for consistency to ensure inter-rater reliability.

Following analysis of the subsequent transcripts, the identified themes were further developed, refined and discussed by three researchers to identify a thematic framework for analysis. Subsequently this framework was applied to each transcript.

SUMMARY OF RESULTS

Two overarching themes emerged from the interviews: a *lack of sureness* about what children knew about their condition and that *communication difficulties* were a barrier to understanding their condition. Participants reported having not communicated to any great extent with the children about their condition due to inherent *communication difficulties* of child, as well as some children being too young. If conversations were held, these tended to be *'ad hoc' conversations* about CP occurring as and when necessary, such as during therapy sessions to encourage compliance. Direct discussions did not happen.

Themes emerged as to *lack of sureness* of participants as how much they thought the child understood about his/her diagnosis, but also indicated they thought this area was important: "It's good to raise this sort of awareness and whether X does have an understanding because I hadn't considered it" (P7).

Several themes emerged regarding participants' thoughts about how much children understood about their condition. Participants *assumed limited understanding* on child's part due to the practicalities of having four-limb CP. Participants assumed children had a basic awareness of their condition in terms of their immediate limitations: "…he understands that there's things he can do, things he can't do, things he finds harder" (P3).

The theme emerged of children's *knowledge influenced by evident difference to others* (at school or at home): "…he can see what's around him, that he's not able to get up and walk like the other children… and he's not quite the same as his little sister" (P7).

Themes expressed that participants felt that children had a *lack of sureness about future*; a general lack of understanding of the long-term implications of CP: "Although we've never said that 'you're going to talk' or anything like that, I think he still thinks that he will one day" (P5).

Another theme identified *limited resources*: a lack of relevant literature and help available to facilitate a discussion about CP especially as children grew older.

Barriers to participation

Participants identified both the practicalities of having CP such as communication and mobility impairments as *barriers to participation* generally. Also identified were related factors such as child's anxiety about the unfamiliar, sensory issues, low motivation, pain and also frustration and upset.

Tools to facilitate communication regarding condition

Themes that emerged clearly identified that a potential resource should be available as a *book format* and/or a *technology resource*. Participants identified a *book format* as useful for its simplicity of use, portability and ready availability. Some suggested that the book should be a story book particularly for young children who are likely to be more receptive of a story rather than a fact book. Participants also identified a *technology resource* as the best approach, citing capacity for storage, flexibility of use and that it could be used in conjunction with existing communication aids as important.

What participants thought should be included in the resource

The main theme that emerged concerned *explanations of CP and the possible cause/s* of the condition. There was also some reference to identifying CP as an 'umbrella condition'. Another theme within this area was *information about need for equipment and therapy* and the reasons for these.

Prognosis and life development information was a theme identified to address expectations about puberty, secondary school, adulthood and personal relationships.

A theme emerged concerning the tone of the resource as one of *positivity and sensitivity*. The majority of participants felt it was vital that the positive aspects of living with CP be highlighted: "…real positive; this is what you can do… you can achieve a lot of things" (P8).

Themes also identified that a resource should *facilitate asking/ answering questions* and so facilitate dialogue between adult and child.

Benefits to child of a resource

Themes emerged of the resource being a *source of independent advice and information*, as well as the importance of the *objectivity of resource*. Participants identified the importance of the child being able to use the resource independently and within their own control, rather than having information filtered by an adult, or hearing about their condition indirectly. However, another theme emerged of *supported use* – identifying the importance of the child being supported to use a potential resource by an adult.

DISCUSSION

In this study we sought to discover adults' views as to the needs of children with four limb CP concerning information about their diagnosis and prognosis. We also wanted to know what they thought would be useful in terms of a future resource to address this. It was identified that children with four limb CP may have limited understanding of their condition, but this was not reported as the main factor affecting their participation. Instead, the practicalities of the condition itself and the limitations that these present were identified as major barriers.

Participants generally reported having not greatly communicated with the children about their condition. There are likely to be significant gaps in the chil-

dren's knowledge as information is delivered via means that are unplanned, unstructured and irregular. Developing a resource would help ensure that can children receive consistent and accurate information.

Findings indicate that there is a need for a resource to be developed. Participants identified that a storybook and a technology-based resource could both be useful in addressing the needs of children with CP.

The study identified potential benefits for children in having a resource of this type. Allowing children access to information regarding their disorder from a source independent from adults and peers could facilitate greater independence, and could be a step towards reducing passivity. It could also allow for greater decision making power about their immediate and future goals.

There were a few limitations in the study methodology. Primarily, the children with whom the study is concerned had no direct involvement; therefore the information gathered may not be completely accurate. In addition, the sample size was small; however, it did use well-established qualitative techniques, increasing the likely validity of findings.

This is an exploratory piece of research for an area which has not been greatly explored. Future research could seek to expand the sample to include children with CP with a range of functional abilities and presentations. This would ensure that any resource developed would be widely accessible to many individuals with CP. We have now written a prototype of the book resource based on findings of this research, which we will be taking back to parents and professionals for their comments over the next month. We hope to produce a finished book by the end of the year. ✳

Kerynne Thompson, Nicky Wood,
Marian Nairac, Friedl Jansen van Vuuren
& Rebecca Judge

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Motor Neurone Disease:
A review of local service provision

What lessons can we learn?

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INTRODUCTION

As the first dedicated Augmentative and Alternative Communication (AAC) centre in the country, the Bristol Communication Aid Service (BCAS) has been providing specialist assessments for individuals living in the South West region for over 30 years.

The adult team at BCAS assess people with a range of medical conditions that result in communication disorders. Progressive Neurological Diseases (PNDs) had always accounted for a significant proportion of the incoming referrals to BCAS, but these were evenly spread between a mixture of conditions. Historically, many of these individuals would have been provided with a Lightwriter SL35 and so their needs would have been met by the local Speech and Language Therapy teams.

In early 2013, the BCAS team noted two issues:

1. Caseloads had an unusually high proportion of people with Motor Neurone Disease (MND).

2. A high proportion of the team's non-contact clinical time was being spent addressing issues relating to this clinical group.

The team therefore looked into this issue and identified a number of trends. These were:

- BCAS were receiving an increased number of referrals for people with a medical diagnosis of MND.

- A high proportion of the MND referrals were for people in the later stages of their disease.

- The non-clinical contact work relating to these referrals was significantly increasing.

- As a result of these trends, there was increasing pressure on loan equipment and certain devices in particular, affecting the availability of equipment and how long it could be loaned to individuals for trial.

Team members reported feelings of low job satisfaction because they were putting in many hours of work to set up system for individuals but by the time they provided the equipment the patient had either reached a palliative care stage or had died. This sequence of events recurred on a number of occasions.

As a result, the current project was embarked upon with the aims of:

- Completing a literature search and reviewing the national guidelines for working with this caseload in the context of AAC interventions.

- Reviewing the incoming referral statistics to explore the trends fully.

- Gathering the thoughts of therapists who refer people with MND to the centre, regarding the care pathway.

DATA COLLECTION

Data was gathered retrospectively from client notes in conjunction with an online questionnaire sent to speech and language therapists (SLTs) who had referred clients with MND to the service. This was administered via SurveyMonkey (www.surveymonkey.com). Therapists who had referred more than one person were asked to complete a questionnaire for each client. Of the 39 SLTs were contacted, a total of 21 responses were received. Several people had moved post and could no longer be contacted.

THE FINDINGS

Between April 2010 and April 2013, 51 referrals were received by the service
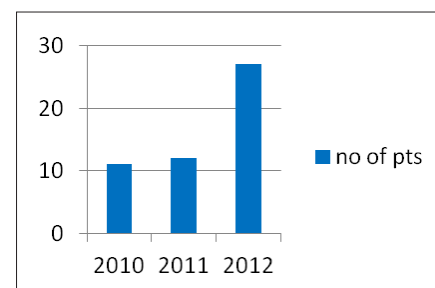

30
20
10
0
2010 2011 2012

no of pts

Figure 1 Number of referrals by year

(Fig. 1); five were discounted from the audit as they were still active in the service. (The significant increase in referrals in 2012 has continued, with 19 referrals received from April to September 2013).

Age range of referrals

National statistics report the average age of onset as 60-65 years which is reflected in the number of referrals to BCAS. However, there was also a peak of referrals of people aged 45-55 and 43% of referrals (20) were aged between 60-75 (Fig. 2).

There was an almost equal split between male and female clients (49% and 51% respectively), which is in contrast to national statistics which indicate that men are 1.5 times more likely to be affected.

Of the 46 referrals analysed, nine (20%) were not seen by the service; four because they were too unwell, two of whom died before they were seen. The following results are based on the remaining 37 referrals.

Waiting Times

Data on the length of time from referral to appointment revealed some unexpected results. People with MND are prioritised within the service due to the rapidly progressive nature of the dis-
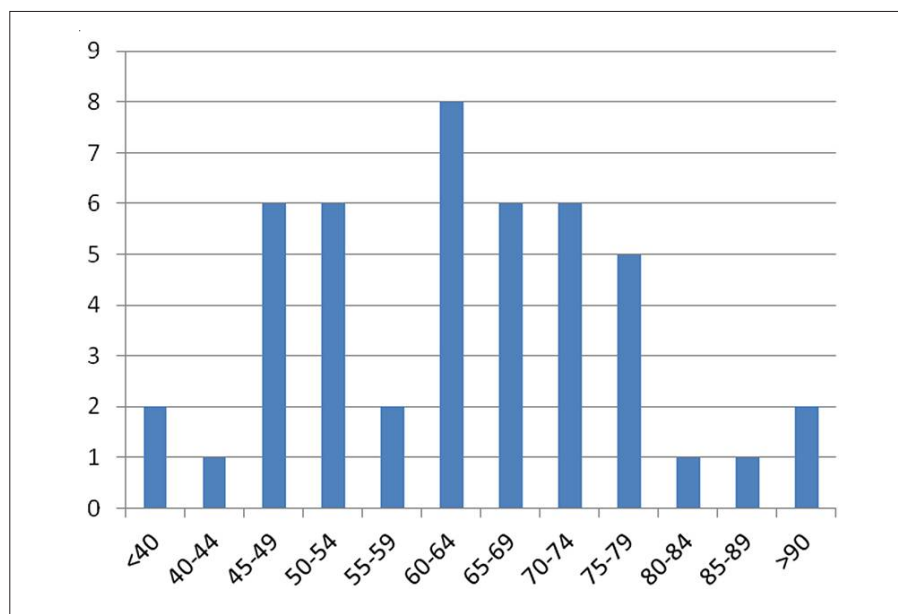
Figure 2 Number of referrals by age

Figure 3 When first referred to your service?

ease. Despite this, waiting times were lengthy (Fig. 3). Closer analysis identified several reasons for this:

- Trying to find a mutually agreeable date for the client, local SLT and BCAS staff, particularly if a home visit is required
- Staff working part-time, making liaison complicated
- Clients unwell so initial appointments had to be cancelled and re-booked. (Figures do not show when appointments were first offered, which might have been much earlier than when a convenient date was finally agreed).

The local therapist survey was designed to compare the BCAS referral process against Motor Neurone Disease Association (MNDA) guidelines presented at the CM2012 conference. These guidelines state that "during the initial assessment (by an SLT) a decision should be made as to whether the person with MND should be assessed by the local SLT service in relation to their AAC needs" (p4). "If referral to a Regional Assessment Centre is agreed... the referral should be actioned within 3 working days" (p6).

Question 1 asked of local speech therapists: *"When was the person referred to your (local SLT) service?"* (Fig. 3). MND can have different presentations and whilst the average length of life expectancy from onset of symptoms is 2-5 years, almost half of people diagnosed will die within 14 months of diagnosis (MND Association). Anecdotal evidence suggests a discrepancy in the provision of local networks and referral pathways in different areas. If people with MND are not referred to local therapists until symptoms are advanced, the clock has already been ticking for some time.
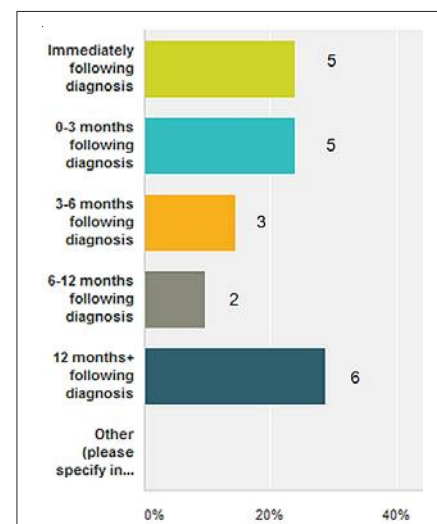
Question 2 asked: *"Once referred to your service, when did you decide to refer to BCAS?"* (Fig. 4). No doubt, these responses reflect the reality of working in the community with MND clients and illustrate that however noble the MNDA guidelines are, it can take time to build a relationship between therapist and client, and clients may not be ready to consider onward referral immediately, particularly if symptoms are mild. This was illustrated by the narrative responses given in the 'other' response option which included:

- "Depends on the rate of progression of the disease"
- "3+ years as speech easily intelligible until then"
- "Patient did not agree to referral until this point in time"
- "Depends on the patient's needs and wishes. Many do their own research on the internet and download iPad apps. Some also buy their own electronic writing tablet. Those with
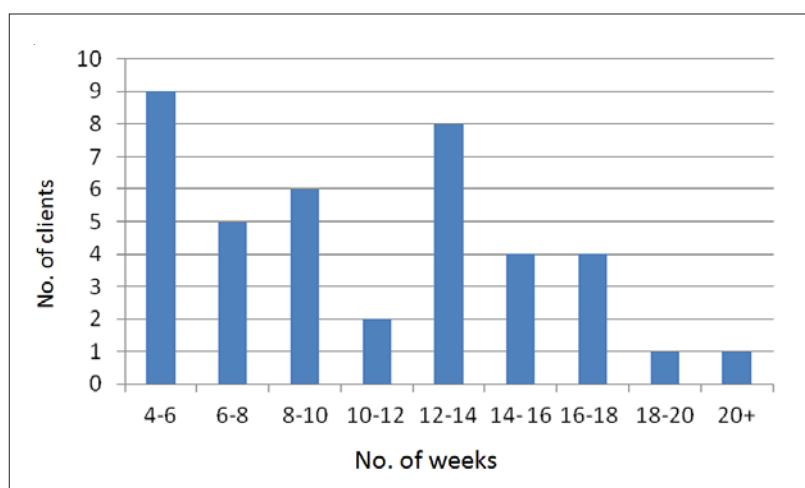

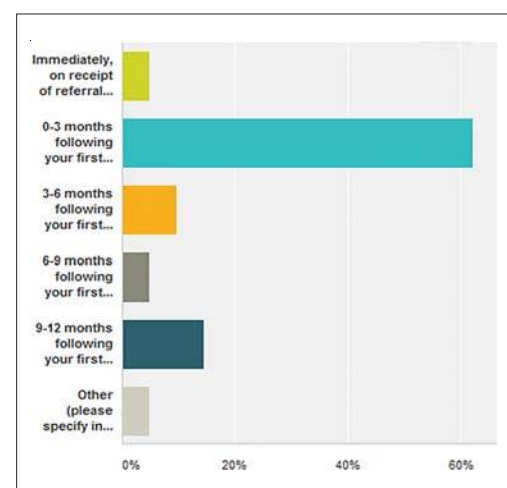*Figure 3 Length of time in weeks from date of referral to date of appointment*

Figure 4 Once referred to your service, when did you decide to refer to BCAS?

mixed involvement likely to have more complex needs."

This last comment highlights the dual nature of referrals to BCAS. Sometimes clients come via the Computer Assessment and Training Service (CATS) for initial input until support with communication becomes more of a need. This issue was explored in **Question 3**: *"What was the reason for referring the person to BCAS?"* (Fig. 5).

Reasons for onward delay

Questions 4 and 5 of the questionnaire were designed to identify other possible reasons for delays in referrals to BCAS.

Question 4 asked local therapists: *"Do you have local procedures that have to be complied with before you can make an onward referral to BCAS?"* The vast majority of respondents indicated they could refer independently. Comments suggested sometimes there was a need to consult with the GP, follow a local MND care pathway or discuss with SLT colleagues.

Question 5 considered the influence of the person being referred with MND by
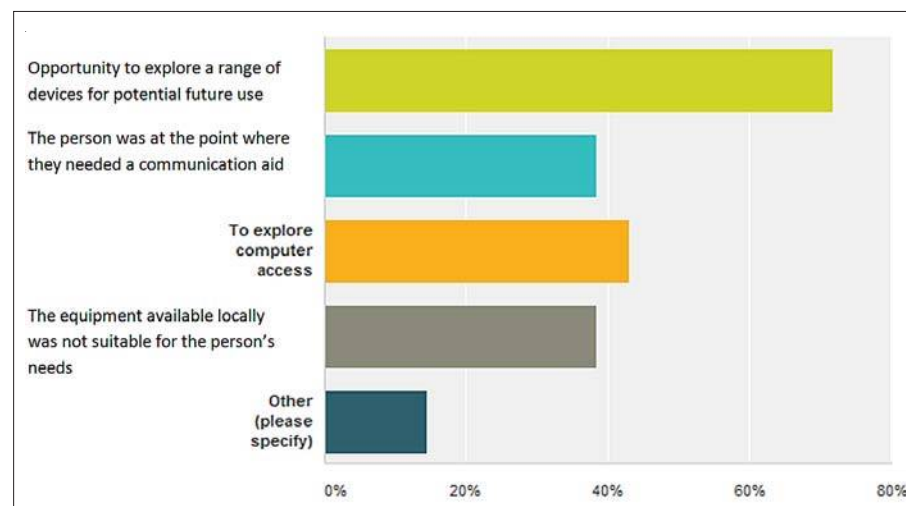

Figure 5 What was the reason for referring the person to BCAS?

asking: *"If the person with MND delayed the onward referral to BCAS, what was the reason for this?"* (Fig. 6). Answers to this question confirm discussion above but also, encouragingly, indicated the importance and use of low-tech methods of communication as an alternative to high-tech solutions.

Perceptions of local therapists in relation to waiting times for appointments
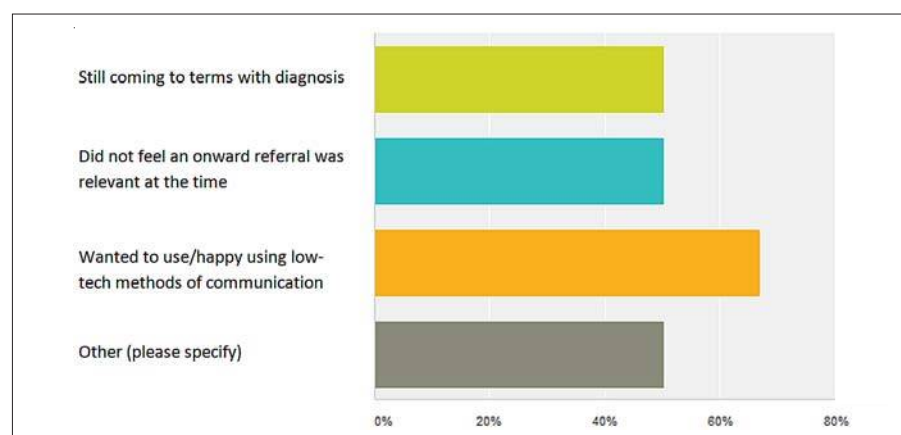

Figure 6   If the person with MND delayed the onward referral to BCAS, what was the reason for this?

Figure 7 What do you perceive to be the main causes for delays in people being seen by BCAS?

were explored in **Question 6**, which asked: *"What do you perceive to be the main causes for delays in people being seen by BCAS?"* (Fig 7). Given the logistics and waiting times discussed earlier, it is perhaps not surprising that the waiting list features highly in perceived reasons for delay. Yet, the readiness of the person to be referred is also shown to be significant. It illustrates again the idealistic nature of the MNDA guidelines as well as the practicalities of working with this client group and how this has to be taken into account in terms of service provision.

Location and length of appointments

As the number of referrals has increased so has the location and length of appointments. Not surprisingly, this is related to changes in the technology of devices being assessed for and prescribed. Figure 8 shows the changing nature of where appointments occur.

Of the 37 people with MND who had assessments, 13 clients had all their appointments in clinic, whilst 14 had all their visits at home. The remaining 10 had a combination of clinic and home visit appointments, usually being seen initially in clinic and then at home to set up equipment.

The increasing number of home visits is related to technology, as eye-gaze systems have become more available. For example, the average number of appointments for someone being assessed for an eye-gaze system is four and the majority of these are home visits. The nature of this client group is that they are often unable to travel, especially if in the later stages of the disease.

Home visits, by necessity, are longer than clinic appointments. As BCAS is a regional service, many clients live an
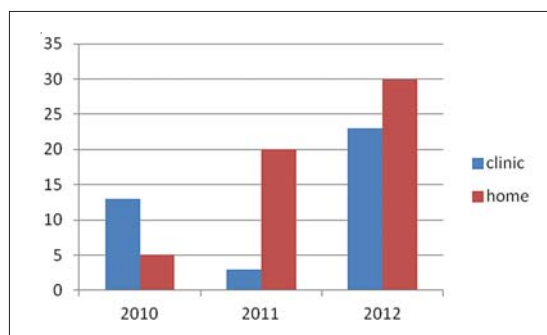
Figure 8 Location of appointments by year

hour and more away from the department. Figure 9 illustrates the number of appointments each year, whilst Figure 10 indicates the changing technology of devices provided.

Number and length of appointments

The data illustrated a direct correlation between the assessment and provision of increasingly high tech devices and the increase in number and length of appointments. For example, two eye-gaze systems were recommended in 2011, each requiring four visits and accounting for nearly half of the total contact time for all clients seen with MND. In 2012, six out of twenty referrals (30%) involved eye-gaze assessments. Of these, four people were recommended eye-gaze systems,

Figure 9 No. of appointments

Figure 10 No. of devices recommended

requiring an average of 4.25 appointments each, with a total of more than 17 hours total contact time per person (range 17-24 hours). It is important to note here that travel time can account for up to half of total contact time.

In contrast, the average individual total contact time for assessment of non eye-gaze devices was quite consistent over the three years (range 316-345mins) requiring an average of two appointments per client.

It is becoming increasingly common for people to come to appointments with their own iPads, leading to recommendations for Apps only. It is recognised that iPads will only meet a short-term need so people will need to be seen again as their needs change. Newer, Windows-based touch-screen devices now on the market (e.g. SB10) are more versatile and have the potential to be modified to meet changing needs. This reduces the need for provision of multiple devices and helps minimise the number of additional appointments.

Main delays in receiving equipment

The questionnaire to therapists was sent out against a changing backdrop

in NHS commissioning and funding of services as Specialist Commissioning of AAC services was introduced in April 2013. Prior to this, funding for devices had to be sourced locally via the referring therapist and was known by BCAS to vary across the different Primary Care Trusts (PCTs) from which clients were referred to the service. This is reflected in responses to **Question 7** which asked: *"What do you perceive the main delays to the person receiving their equipment to be?"* (Fig. 11).

Since April 2013, funding is provided via NHS England for the 10% of referrals that meet the service criteria of complex assessment. This means BCAS can order equipment for those clients and supply it on a long-term loan basis, thereby reducing the pressure on local therapists to source funding. It will also enable BCAS to build up a stock of loan equipment which will then be more readily available for clients with MND. Training needs can be included in the costings for equipment provision, reducing the commitment on BCAS therapists to do this and freeing up more time for appointments.

The length of time between equipment being recommended and actually being provided was measured in **Question 8** which asked therapists: *"What was the length of time from the person completing their assessment at BCAS and them receiving their equipment?"* The reason for asking this question was because, once recommendation reports were written, BCAS had limited further involvement with the clients (pre National Commissioning Board funding) since provision of equipment became the responsibility of the local therapist.

Encouragingly, most equipment is shown to be provided within 3 months, but when taken together with the length of time from referral to first appointment and the timescales for 2-3 further appointments, it is possible the whole process could take 6 months.

Despite the problems with waiting times and not always being able to provide a timely service, it was encouraging to see that most referring therapists were happy with the service they received, as reflected in their responses to **Question 9**: *"Overall, did you feel that BCAS offered a timely service for the person you referred?"* (Fig. 13) and **Question 10**: *"Would you refer future people with MND to the service?"* (Fig. 14).

DISCUSSION

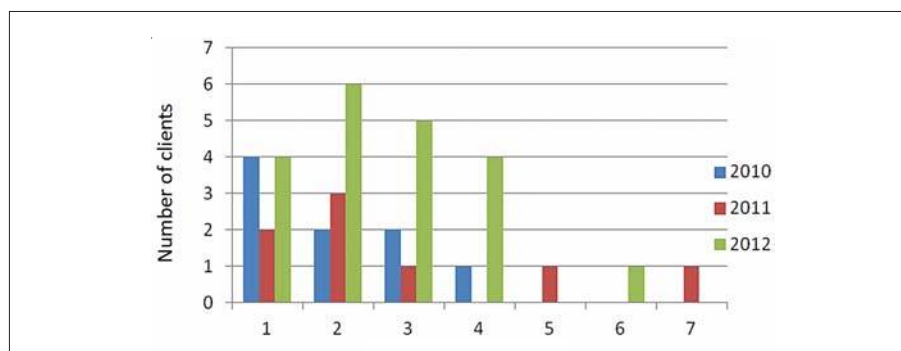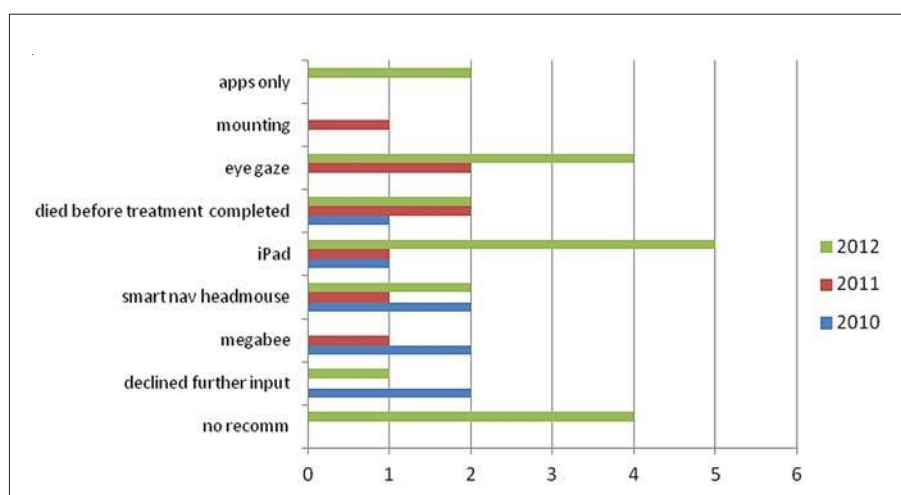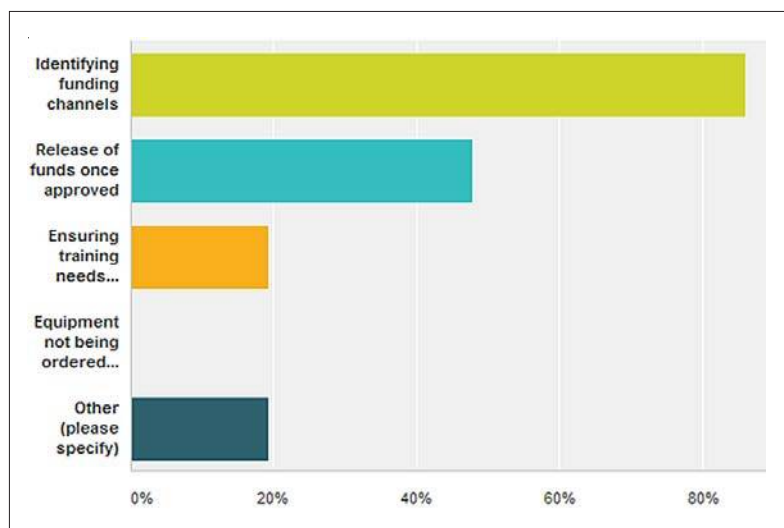It is clear that the number of referrals for people with MND is increasing de-

Figure 11 What do you perceive the main delays to the person receiving their equipment to be?
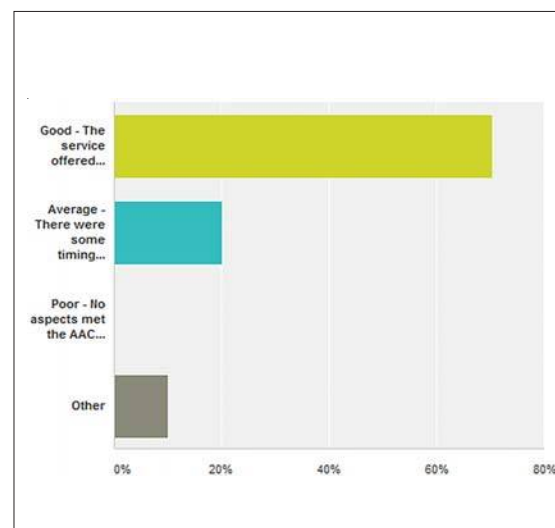

Figure 13 Did BCAS offer a timely service?

spite the incidence of MND remaining unchanged. As technology advances, so equipment becomes more high-tech and more mainstream solutions become available. However, it means more time is required for assessments and for setting up equipment.

The rapidly progressive nature of MND means that intervention needs to be timely but this is not always easily done. This audit has shown the changes in the number and length of appointments in relation to advances in technology. However, of the four eye-gaze systems actually provided in 2012, only three were ever used and two of those for less than 6 weeks, raising questions of cost-effectiveness.

As a result of this audit, local therapists are being encouraged to refer people with MND to the service as early as possible, before their symptoms are

significant, in order to offer the opportunity to introduce the service and what is available. This encourages:

• People with MND to have an opportunity to explore a range of AAC devices at the earliest opportunity.

• More timely provision of equipment.

• Identification of a single device that can be adapted to changing physical skills, reducing the need to wait to update equipment.

• Economical use of NHS resources.

This has improved job satisfaction for staff who were finding themselves in emotionally charged situations, providing equipment which people had often been waiting many weeks for and were then too ill to use, or only used for a few weeks.

CONCLUSION

This project has enabled BCAS staff to accurately review the service data for this caseload and relate the findings to the national standard guidelines produced by the MNDA. The data gathered from the case note audit, as well as the

survey monkey questionnaire, have highlighted trends that have occurred. This information has been used to identify areas in which BCAS performs well, and areas for service improvement. Within these changes, it is hoped there will be an improved service user pathway as well as increased job satisfaction for the BCAS team.

The initial transitional year of National Commissioning funding has certainly reduced the length of time from recommendation to provision of equipment, and it is hoped that in time this will be replicated nationally. ✳

Victoria Styles
Speech and Language Therapist

Polly Wingate-Saul
Occupational Therapist

REFERENCES

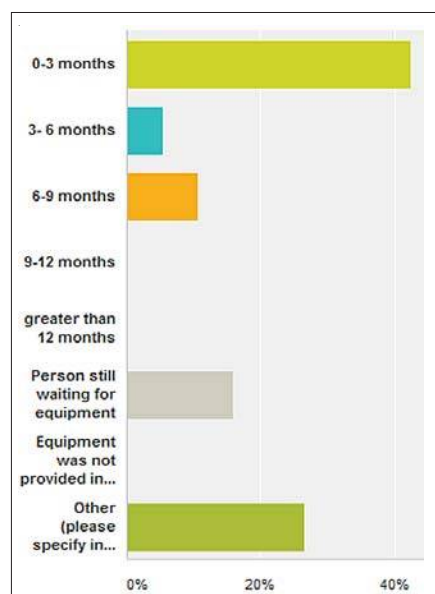Motor Neurone Disease Association (2012) MND and AAC Guidelines.

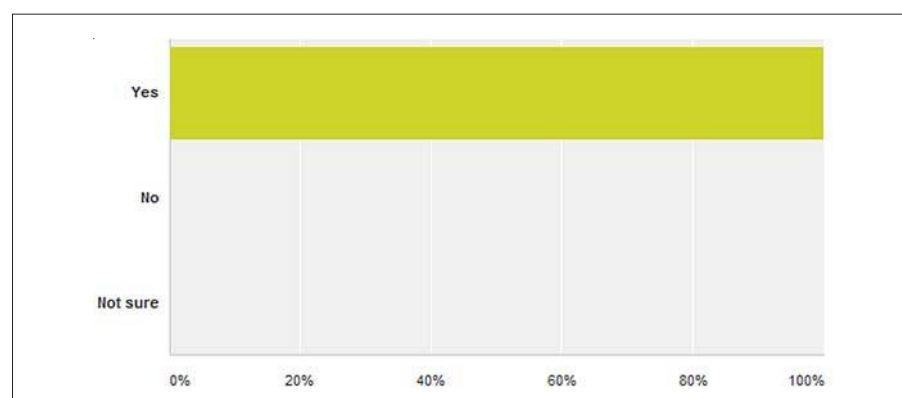*Figure 12 Time from completing assessment to receiving equipment*

Figure 14 Would you refer future people with MND to the service?

ESSENTIAL PUBLICATIONS

FROM COMMUNICATION MATTERS

Other Ways of Speaking

This short booklet provides information about children and young people who use a variety of different ways to communicate, how you can help support them and where to go for further information. You should read this booklet if you live or work with children and young people whose speech is difficult to understand or who have no speech.

Other Ways of Speaking has been produced in partnership by Communication Matters, The Communication Trust, 1Voice, ACE Centre, The Makaton Charity, Scope and Signalong.

The booklet is **free** - you can download an electronic copy or order a printed copy from Communication Matters (you only pay postage & packing).

Free Download and further information:

www.communicationmatters.org.uk/page/other-ways-of-speaking

The Power of Communication (DVD)

This DVD has been produced by Communication Matters to provide an introductory presentation on Augmentative and Alternative Communication (AAC). The film delivers a powerful message that communication really does matter. The DVD celebrates and promotes communication in all its forms - central to the values of Communication Matters, a UK charitable organisation concerned with the needs of people who use AAC.

Price: £8 each (£20 for three) including p&p
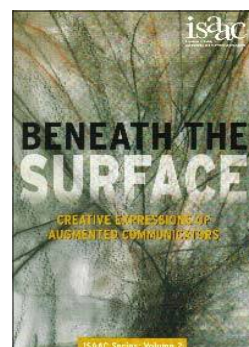

Communication Without Speech

This ISAAC book is a highly accessible introduction to AAC. It contains lots of questions and practical tips such as vocabulary selection, assessment, education and vocational considerations, making communication boards, and includes excellent photographs and illustrations.

Price: £15 plus £1.50 p&p from **Communication Matters**

Beneath the Surface

In August 2000, the creative works of 51 authors and artists from around the world were published this ISAAC book, Beneath the Surface. What these writers and artists have in common is that they are unable to speak and thus rely on assistive technology to communicate.

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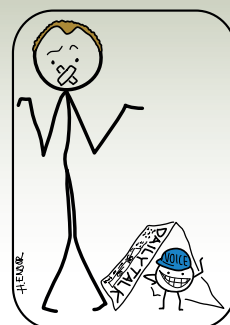
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