COMMUNICATION
MATTERS

IN THIS ISSUE

REGULAR COLUMNS

CONTENTS

Cover: Robert Holmes (see page 5)

You can do it!

Setting up a local 1Voice branch

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1Voice Committee members

WHAT IS 1VOICE?

1Voice - Communicating Together is a registered UK charity and Company limited by guarantee which aims to provide a network of support for children and young people who use augmentative and alternative communication (AAC), and their families. It takes a positive and social view of disability, aiming to create opportunities for children to build on their strengths and talents, and to develop their communication skills in a positive environment.

As a communication disability affects all members of the family and can result in a sense of isolation, 1Voice runs two annual weekend events with fun activities to promote communication and confidence for all family members.

The Vision of 1Voice is: *"A world where the voice of every child and adult, however they communicate, is listened to and heard."*

The 1Voice Mission is: *"to facilitate safe, fun and motivating opportunities for children and young people, whatever form of communication they use, to develop effective strategies to access mainstream services, participate in their wider community, and have a voice that will be listened to and acted upon."*

To be a successful user of AAC requires many skills, developed over years, including self-esteem, motivation, self determination, patience and resilience, to overcome the many challenges. 1Voice believes that bringing families together in a positive environment supports families to become strong, and gives them a sense of belonging: *"It is like being part of a big family and has given me the confidence to support my child around their AAC needs."* (Parent, personal correspondence).

Many children are isolated and rarely have the opportunity to meet others with similar needs; 1Voice provides an environment for them to develop relationships and make long-lasting friendships.

For new members who attend, it can be the first place that they come to where they are really listened to and where volunteers, role models and other families understand and respect them and their views.

Figure 1 Symbol support feedback form

Adult role models are core to 1Voice events; they are adults who successfully use AAC and who can share their experiences with children and their families, who invariably describe them as 'inspirational'. The role models raise everyone's expectations of what children who use AAC can achieve. Additionally, role models guide the direction of 1Voice from a unique personal experiential point-of-view.

1Voice was established in 1999 by Katie Clarke (parent) and Tamsin Crothers (SLT) and held its first event – a family weekend – in Blackpool in Winter 2000. As one family said, *"1Voice is a must!"*

Following the initial event, further themed Winter residential family weekends have been held annually, in the summer and winter months, (as reported by Hobson, 2004). Membership has now increased to over 800 supporters, including around 260 families.

However, as its popularity increased, the need for local branches became apparent. 1Voice members around the country felt that two events per year were not enough.

The establishment of local groups has therefore been paramount to ensure that this support is available to all those who need it, especially those who can not travel to the National events.

To this end, branches were created to (initially) cover South East, South West, West Yorkshire, and the Lakes & Bay areas of the UK.

The aims of a branch are:

- To give support and practical help to families, carers, children, young people, and adults who use AAC by providing opportunities for social contact and mutual support through holding events.

- To generate funds for branch activities and services, in accordance with statutory regulations and restrictions on the use of these funds.

- To increase public awareness by active work in the community, use of the media and by other means permitted by charity law.

- To recruit new 1Voice members using 1Voice membership literature and other information.

- To seek to co-operate with local statutory and voluntary organisations as appropriate.

SETTING UP 1VOICE WEST MIDLANDS

Julie regularly attended both the Blackpool Winter weekends and the Summer family fun days and wanted to establish a branch for people in the West Midlands; the Communication Team at Penn Hall School were keen to create a

Bat hats!

West Midlands AAC user group; therefore we joined forces!

We began by calling an open meeting of interested parties which was held at Penn Hall School, with Skype available for those unable to attend the meeting in person. We elected people to various roles on the Committee (which has to have at least six 1Voice members) and began discussing ideas for our launch event.

Our committee is currently comprised of three people who use AAC, a parent, a personal assistant, an SLT from a regional centre for Electronic Assistive Technology, an SLT from Penn Hall School, and an employee of an AAC supplier – see the photo, taken when we presented this lecture at the Communication Matters Conference 2011.

PLANNING AND ORGANISING EVENTS

Once we had the idea for a spooky Halloween theme, ideas for the activities came quickly: face painting, cake decorating, Boccia, fire hooping (!), colouring Halloween pictures, designing our West Midlands 1Voice logo, creating poisonous potions, 'Guess the weight of the pumpkin' (to raise funds for our branch), and a disco. We had a volunteer from Brum Bats (the Birmingham & Black Country Bat Group) who brought along bats for us to see and made bat hats. Volunteers from Penn Hall School joined 1Voice and helped us organise the day. In terms of practicalities, various forms had to be filled in prior to the day: a risk assessment form for the event and symbol support/feedback forms were created (Fig. 1).

Name badges, event evaluation forms, indemnity forms for parents to sign, photo consent forms, 1Voice membership forms, receipts for membership payments and certificates for attendees and volunteers were brought to the event so that all the 1Voice paperwork requirements were covered.

We had six people who use AAC and their families attend the event which ran from 10.30am to 3pm; the 3 adult role models on our committee attended, as did Gaynor Dale (National 1Voice Events & Branch Co-ordinator) to support us. Feedback included comments such as *"It was a fun day"* and *"It was FAB. I brought my three kids – they enjoyed it very much – especially the cake decorating and the bats."*

Following the first event, we had another school volunteer to host a family fun day: Wilson Stuart School in Birmingham wanted to host "I'm an AAC user... Get me out of here!" We liaised with

Treasure Hunt

Chocolate Fountain

them regarding activities and they designed a programme of activities which included: a Jungle Treasure Hunt, a sensory story, I'm a Celebrity skittles, a quiz, a chocolate fountain, and the dreaded BushTucker Trials!

One of our parents is a part-time clown, so he brought along his balloons and juggling equipment and did an impromptu circus skills session. This event was attended by eighteen families, and we raised over £100 for our branch with a raffle! Again the feedback was positive: *"Very good day!"* and *"Lots of great activities."*

FUTURE PLANS FOR 1VOICE WEST MIDLANDS

As a result of organising these events, we have realised the need for the focus of the day to be on communication and interaction, not just on fun activities; this was especially apparent when the disco at our Halloween day meant that there was difficulty actually hearing what people were saying!

Other feedback has been that families can be shy and reluctant to interact together, therefore at future events, we plan to have a 'Getting to know you' quiz so that people have to find out information about each other and thus start a conversation, using simple 'About Me' vocabulary which is found on most AAC systems.

In the future, 1Voice West Midlands also has a 'Fun and Gaming' day planned at Hereward College, with computer games and technology adapted for people with disabilities. 1Voice West Midlands aims to have three events a year but 1Voice branches have the freedom to organise as many (or few) events a year as they feel is realistic and/or appropriate.

The 1Voice branch manual clearly states that "events do not have to be expensive and often families just want to get together and share experiences in an informal way."

1Voice West Midlands is therefore also planning more low key events where families can meet up and participate in ready-made events and activities, such as going to the Birmingham Christmas Market, going bowling or having a picnic in the Summer (if we get one!) Gaynor Dale, the 1Voice Events & Branch Co-ordinator, provides support in terms of ideas and practical solutions to assist with organising events and activities.

RULES!

There are, as in all organisations, rules that branches are asked to take into consideration. A branch of 1Voice represents the charity in all that they do and say when using the logo and charity number, therefore 1Voice has to have a few rules that are insisted upon to ensure that everyone works in a safe way, and that 1Voice has the information needed to respond to funders and legislative practice.

Information on all these issues is contained within the *1Voice - Communicating Together Branch Manual*. This covers practicalities such as banking, the need for all volunteers to be 1Voice members and CRB checked, and that our membership databases meet data protection regulations. Again, Gaynor (1Voice Events & Branch Co-ordinator) supports us with all these issues and attends our meetings, when invited, in order to assist us with practicalities.

MONEY, MONEY, MONEY!

1Voice is a charity and therefore, inevitably, some fundraising is required in order for a branch to prosper. National 1Voice provided us with a start-up grant of £150 in order to put on events, or to meet the aims of the branch described earlier. Local branches are supported in terms of fundraising ideas from Gaynor and with banking from the 1Voice national Treasurer.

1Voice West Midlands has added to the original £150 fund-raising during events ('Guess the weight of the pumpkin' and a raffle.) 1Voice West Midlands has also been exceptionally lucky to have received a large donation as a result of a charity ball from Birmingham Unlimited; this will enable us to further publicise the work of 1Voice and to hold more events.

COME AND JOIN US!

We hope that this article has raised your awareness of the work of 1Voice, both nationally and also at a local branch level, and that you will help us to bring more families together, either by inspiring you to set up your own local branch, or by advertising our events to families with children who use AAC.

National Annual membership of £5 per family is payable from April 2012; membership includes a DVD and two newsletters a year and ensures the future of the charity.

For more information, please contact Julie Atkinson, visit the 1Voice website *www.1voice.info* or contact Gaynor Dale on 07932 858 363. ✳

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Overcoming Barriers to Communicating Using a Communication Aid

ROBERT HOLMES

Email (via my speech & language therapist): farah.moini@nhft.nhs.uk

My name is Robert Holmes. I am 36 years old. I use lots of different ways to communicate. I use speech, gesture, symbols and a high tech communication aid.

I have had my communication aid for nearly three years. It took a long time for me to get the aid. I had to be assessed by the speech therapist who works with me and also by a specialist from the Oxford Centre for Enablement who came to see me.

The aid I have is really good. It helps me to communicate in a way that I never could before. It can also be really difficult communicating with a high tech aid.

pendent as I can speak on my own, without anyone having to help me by getting my book out. I just need them to switch it on for me at the start of the day, and make sure that they charge it up for me at night.

The aid is also good as I can do other things on there. I can look on the internet. I can use it anywhere that I want to. Before if I wanted to use the internet I had to use it in the lounge, but I can use my aid in any room.

GOOD THINGS ABOUT USING A COMMUNI-CATION AID

The best thing about the aid is that it means that I can talk to people. I can use long sentences. When I speak I can only use one or two words. There aren't as many symbols in my book as there on my aid so there aren't as many things that I can say. I can surprise people – when I use my book they know what I am about to say as they point to the symbol first but when I use my aid, they don't know what I am going to say.

If I want to ask staff a question, I can ask them, without them having to get my book out. It makes me more inde-

DIFFICULT THINGS ABOUT USING A HIGH TECH COMMUNICATION AID

It is also really hard using my aid. It has taken me a long time to get the words on the aid that I want, and there are still not all the things on there that I want to say. If I want to have more words put on the aid, it is very hard for me to tell people what I want them to program onto it.

Not everyone knows how to use the aid. At the moment, only my speech therapist and two members of staff know how to make changes on the aid. My staff don't always want to make changes to the aid. They are afraid that they will break it.

Sometimes it breaks. It has broken twice since I have had it. If it gets sent off to be repaired, it means that I have to go back to using my book. That is hard once you have got used to using the aid.

Some staff don't know how to use it, so they don't like using it with me. They like it more when I talk or use my book.

Sometimes staff can't even find it. If people don't put it back in the same place, sometimes it gets lost.

It is very difficult when what I want to say isn't on the aid. Sometimes I want to say something but it isn't on the aid, so

I have to say something else instead, or not say anything. If I want new words putting on the aid, it is hard to tell people what I want them to put on it. I have to wait and see if they say the words that I want. If they don't say the words then I can't have them on the aid.

Sometimes I use the aid to say things and people don't hear it. That can be embarrassing and frustrating. And sometimes my head gets tired. When I was writing the presentation I had to use the aid a lot, and it was very hard work, as I wasn't used to using the aid that much. It made my head and neck ache as I use my head to press the switch.

I have to wait for my speech therapist to see me if I want to make big changes to my aid. She cannot always come very often. Sometimes I am waiting for a long time to see her. We set goals together then work for a few weeks on trying to make them happen. We have long term goals and short ones. I try and think with my staff what I want my goals to be first so I can tell her.

MY GOALS

1. I want my staff to have more training so that they get used to the aid and so that they can change things on it for me.
2. I want more people to know about aids, so if I use it in the community

people would accept it more, and listen to it more.

3. I don't know anyone else who uses an aid. I want to meet more people who use aids.
4. I want to make more changes to the aid, so I don't need to rely on other people as much.
5. I want some different games on the aid, as I sometimes get bored with the ones that I have on there.

I know my goals will take a long time to happen. I am interested to speak to other people who use aids to find out things which have made it easier for them. ✳

Robert Holmes

FOOTNOTE

I wrote this presentation with my speech and language therapist using a combination of my communication aid, Talking Mats, speech, and my communication book.

"I wish they could stay more than an hour"

A Communication Partner scheme involving people who use AAC & speech and language therapy undergraduates

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INTRODUCTION

People who use Augmentative and Alternative Communication (PWUAAC) are often aware that even speech and language therapists (SLTs) have little experience of conversations when AAC is being used. PWUAAC also want to make a difference to the lives of people with disabilities, by training and raising awareness.

Students training to be SLTs need experience of communication where there are challenges to:

- Enable them to reflect on real experience, to support their learning

- Keep them in touch with the reasons that they have come to the profession.

There is therefore a relationship between what people who use AAC can offer and what SLT students need.

The Birmingham City University SLT teaching team had been involved in offering their first year students the chance to take part in a communication partner scheme. Originally, in 2007, this was set up with volunteers who had aphasia. Then, in 2009, Julie Atkinson – an SLT at Access to Communication and Technology (ACT) – suggested that this scheme could be extended to include PWUAAC.

COMMUNICATION PARTNERS

The model that Birmingham City University (BCU) used to develop the role of communication partners was based on the ideas of Supported Conversation (Kagan et al 2001) which provides a framework for training people to support the communication of people with aphasia. These skills enable the person with communication needs to reveal his/her true competence and include:

- Providing time in a conversation

- Asking open questions

- Recognising skills and strengths

- Providing communication 'ramps and props' to conversation.

Central to the idea of Supported Conversation is the concept of the social model of disability (Hasler 1993). This model promotes concentrating, not on the presenting impairment, but rather on what someone can do, given some simple adaptations within society. In physical terms, this might mean ramps to allow access to different levels rather than kerbs and stairs. In communication terms, the term 'ramp' can extend to adaptations such as:

- Giving more time

- Using alternative means of communication which are equally valued.

For the SLT students, learning about how to engage in and maintain communication these skills and attitudes are vital and are best learned by experience.

AIMS OF THE PROJECT

Give the students opportunities to:

- Meet people who have communication needs

- Understand the importance of having a real conversation

- Reflect on communication skills: their own and those of their communication partner volunteer

- Work with another student over time and develop skills in team working

- Learn about the social model of disability.

Enable the PWUAAC volunteers to:

- Meet new people

- Have conversations where there is time

- Share their knowledge about AAC and communication

- Develop their own skills in training.

HOW THE VISITS WERE SET UP

For the first time, in 2011, five PWUAAC were involved, providing experience to ten students. The model that BCU de-

veloped was of 6-8 home-based visits of an hour or so, over the period from January to May.

To find volunteers, BCU staff circulated information to SLTs in the Birmingham area at the end of 2010 asking for referrals of people with aphasia who might be communication partner volunteers. After consultation with BCU the SLTs in ACT added PWUAAC. The BCU team provided suitable accessible letters of invitation, explanation and ways of recording consent.

The ACT SLTs contacted people known to them who might be interested in the role.

We looked for people who:

- would be able to have visitors fairly easily in their home;
- were usually well, so there would be minimum visit cancellations;
- had control over their day to day lives and could therefore book appointments;
- Would be able to deal with the nervous beginning and the potentially painful ending;
- would feel able to say "no" if they did not want to do it.

The university paired the volunteers to the students considering travel needs and resources of the students and the locations of the volunteers. The students visited in pairs.

Before the visits students were introduced to the ideas of Supported Conversation in order to provide them with the basics on which to build skills when they met the volunteers. They could also contact the SLTs at ACT for more advice and information.

BEING CAUTIOUS

As SLTs referring PWUAAC volunteers for the scheme we needed to think of people who were adults and who could give consent. We wanted to make sure they would really be able to understand the role, the time limit and that the purpose was not to get therapy input, but rather to be teachers in real conversations.

We felt there was a real risk that some people might so enjoy the rare chance to have a proper chat and make some new friends, that they might be upset by the ending of the visits. It was this sentiment that led to the comment "I wish they could stay more than an hour", when we asked a volunteer how it was going during the weeks of the project.

People who volunteered needed to be those who would understand what would happen and who, if they did feel sad, would have the resources to overcome this and people around to support them

Our concerns were borne out by events when some people were indeed sad at the end. In addition, we attended the Communication Matters National Conference in 2011 and heard about the work of the team at Dame Hannah Rogers Trust (Gribble and van Wijk 2011). Their presentation showed that people with severe disability are more likely to have:

- experienced more loss in their lives than is average;
- less chance to understand and deal with the loss through talking and processing the feelings.

So we had been right to be cautious about whom we chose to invite.

WHAT DID THE AAC USERS DO?

Esther told us about this in answer to questions as part of the presentation and in preparation for the talk:

What did you think when you first heard about the communication partner scheme?

"I was keen to take part. A student SLT should know it is important to communicate with a client."

What did you do to make it happen?

"I planned different communication for each session. One week I booked the lady from DynaVox and she came to explain my aid more."

How was the first meeting?

"They were shy at first, but it went well. We talked about ourselves and asked questions about each other. I told them my history."

How did things change over the weeks/visits?

"It went from formal to informal. We had laughs."

How was the ending?

"A bit sad. We keep in touch (by social networking). One of the students has visited and brought her child to meet me."

Since the end of the scheme, what effect do you think it's had for you?

"I want to do it more. I went to the Uni and did a lecture and made a video. I took on an extra set of students so more people had the chance to learn."

WHAT DID THE SLT STUDENTS DO?

Rachel told us about this in answer to questions as part of the presentation:

What did you think when you first heard about the communication partner scheme?

"I was quite nervous, as I didn't know what to expect, but excited to have the opportunity to learn about a different form of communication."

What did you do to make it happen?

"I contacted my conversation partner's SLT and looked at relevant websites and information to gain more information about my conversation partner's type of AAC. I contacted my conversation partner to arrange a suitable time and date to visit him."

How was the first meeting?

"I was very nervous at first and found the silence between asking my conversation partner a question and him answering quite difficult as I didn't know what to do during that time, but it didn't take long to get used to it."

How did things change over the weeks/visits?

"I became comfortable with the silence, and looked forward to seeing him every week as he taught me a lot about AAC and living with cerebral palsy. He was easy to talk to; we had things in common and laughed a lot."

How was the ending?

"Very difficult to say goodbye, as I had made a friend and enjoyed the visits. We haven't kept in touch much as we are both very busy, but I would like to keep in contact and see him again."

Since the end of the scheme, what effect do you think that it's had for you?

"I'm more aware of the different forms of communication people use and how they work, and also if someone is unable to speak they can be very intelligent. I feel more confident meeting with new people with communication difficulties. Overall, it's been a very valuable experience and I thoroughly enjoyed it."

Further answers from other students told us about the things that helped them prepare and learn:

- YouTube films of AAC being used.
- Watching the Communication Passport DVD made by one of the volunteers.
- Regular opportunities to discuss their experiences with other students and university staff.

WHAT WILL HAPPEN NEXT?

The scheme is going to run again in early 2012 and PWUAAC will be involved.

For the students in 2012

As a result of feedback from last year, there has been more teaching for all the students about AAC before the scheme

gets underway. This has been partly delivered by PWUAAC and ACT staff, and has included:

- What is AAC?
- Why AAC might be used?
- Dealing with silence in conversation.

The scheme is now a more formal part of the course and is considered a placement so students can claim travel expenses, which allows them to be more flexible in the distances they can travel. The scheme is not compulsory but the students are strongly advised to take part. The university is trying to develop ways that the students can be assessed on the placement and on what they learn so that the marks can go towards their degree, but it has been hard to plan a way to do this appropriately.

For the people who use AAC in 2012

The invitation and information sheets have been made more accessible with more pictures and calendar based materials to show how many visits and when they will be.

More information has been provided for the volunteers about what the students are doing on the scheme and what they need to achieve.

There is improved contact with BCU including by email and the offer of visits to BCU or to the volunteer's home if necessary.

Invitations can be extended to younger volunteers to take part, i.e. people aged 16-18 who can give consent alongside their parents.

HOW THIS WORK ADDS TO THE WORLDS OF AAC, ACT AND LEARNING TO BE AN SLT

The scheme allows PWUAAC to volunteer and be acknowledged experts in their own communication. It has brought them extra activities and contact to make friends and chat, and enabled them to make a difference for other people with disabilities by raising awareness. This is also a role that can be added to a CV: most people have many roles in life and this work brings in elements of being a teacher and a knowledgeable friend/mentor. For some people, the volunteer role has led on to small amounts of paid work from BCU as visiting teachers.

Future SLTs are more aware of the services ACT can offer and how ACT can help and advise students while on placement and the SLT clinical tutors with whom they will work.

Future SLTs from BCU will be more aware of AAC when they enter the profession and this gives them something extra in comparison to most other SLT courses in the UK. ✳

Christine Sherlock
Speech & Language Therapist

Rosemary Patterson
Speech & Language Therapist/Senior Lecturer

Esther Baston
Person who uses AAC

Rachel Sedgwick
Speech & Language Therapy student

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You Matter

Bringing together parents of children who use AAC and their supporting professionals

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INTRODUCTION

The provision of augmentative and alternative communication (AAC), whether as a paper-based system or electronic communication aid, has developed over the last forty years. As technology has advanced, so too has the ability to create ever more sophisticated systems to support those who find speech difficult. However, it is the ability to facilitate communication through these systems, particularly when the written word cannot be used, that remains challenging, leaving those left in the supporting role feeling isolated.

You Matter addresses this challenge. It has been written in the firm belief that those closest to the individual make a difference; they are the ones who really matter.

WHAT IS IT?

You Matter is a training course for parents, carers and professionals of children who use any form of AAC. It is an 'off the shelf' training resource that experienced AAC professionals can deliver. It consists of:

- PowerPoint presentation with video support materials embedded.
- Tutor Guide that takes the course leader step-by-step through the slides and learning activities.

- Participant's Guide containing the course information in an easily read format.
- All the handouts and activity materials that support both learning and running of the course.

The course has been written in eight sessions which can be delivered flexibly, for example as two full days or over four mornings/evenings.

THE COURSE DEVELOPMENT

The course was developed as part of the Becta 'Innovative Projects' funding in partnership with The ACE Centre, Oxford. Over a two year period, the authors completed an extensive international literature review and national parent consultation (in the form of a questionnaire and individual parental interviews) to ensure the content of the course was specifically tailored to the needs identified from these forums.

You Matter is firmly focused on the triangular relationship and dynamics between child, parent and educational professional with a view to achieving better outcomes in terms of aided communication development, service delivery and cost effectiveness. It has been developed to promote the positive role of aided communication and empower those close to the child by

increasing awareness, understanding and knowledge in the belief that they can make a difference. It has been reviewed by an experienced SLT with Hanen certified training (Pepper and Weitzman 2004) to ensure that adult learning styles are considered to maximise the impact of the content and how it is presented.

Having a common understanding of terminology and more extensive knowledge of aided communication promotes communication between speech and language therapists and parents/professionals. *You Matter* incorporates the principle belief that knowledge leads to empowerment, resulting in parents/professionals fully engaging within the therapeutic/educational process, thus reducing conflict and facilitating shared ownership of goal setting for their child.

Three pilot courses were run as part of the project to gain comprehensive feedback from participants and tutors. This feedback was then used to review and refine the content and presentation of the final publication.

THE CONTENT

Participants learn skills to help them identify their child's level of communication and employ effective strategies

to develop their child's communication. *You Matter* provides participants with knowledge and skills to enable them to become effective communication partners, to explore their feelings about their child using AAC, the practicalities of using AAC effectively within everyday family/school life and explore how to involve significant others with the child's communication system.

Participants have the opportunity to openly identify barriers and support each other to find solutions. This is very powerful in coming to terms with the benefits of AAC and taking control of what they realistically are able to achieve. In doing so, parents and support workers feel they are part of the planning process for their child and can contribute towards it; they are actively involved in their child's intervention rather than feeling they must comply with the professional's opinion.

THE STRUCTURE

- Session 1 sets the scene for the course. Tutors take time to draw out participant's hopes and concerns, in particular the demands and difficulties faced in facilitating interaction through aided communication.

- Sessions 2 & 3 give participants key information: what we mean by communication; how interaction develops through aided communication; how to select vocabulary to meet a child's needs.

- Session 4 is the essence of the course. It addresses how the participants' communication, in particular their use of aided communication, affects the child's progress. This leads to a critical aspect of the course, that of videoing participants with the child concerned in their settings. This is done to enable participants to reflect on their own communication skills.

- Session 5 reviews the videoing experiences within the group, enabling participants to support each other. It also looks at using these learnt communication skills to involve others in the child's communication.

- Sessions 6 & 7 help participants to systematically select where in a given setting the actual difficulty with communication lies, how to address this and how it fits with the long term goals they identified at the beginning of the course. It emphasises the importance of working together to gain a consistent approach.

- Session 8 is an additional half day that looks at each child's communication system, ensuring the

participants have the technical skills to adapt it to meet their and the child's needs.

PARTICIPANT FEEDBACK

The three pilot courses and several others have now been completed. This is a limited number and the gains are qualitative only at present, but the tutor and participant experiences of the course have been encouraging.

The following are sample comments from the course feedback forms:

Professionals

"This is brilliant; I am finally getting the parent's point of view and finding out what they want from us."

"A new way of communicating, understanding what's important and what's achievable."

"Enjoyed listening to parent's views and how they are affected by the challenges."

Parents

"A very useful course. Meeting people in similar situations and getting the help and information we need to move forward with our child."

"Fantastic to meet professionals who understand our problems."

"I believe communication is as fundamental as walking. ... You should get the same support to learn to talk through AAC...A very inspiring course."

"Brilliant! Showed importance of setting up activity; having everything you need nearby & time to do this; not asking to confirm too much; learned lots."

"Initially I was daunted but very glad I took part, I was able to reflect and actually see what I had achieved."

"Gaining an understanding of AAC and how I can begin to use it... Fan-

tastic to have guided sessions on actually making pages for us."

Tutors

"The teaching assistants and parents were becoming a team."

"Our parents were keen, hardworking, open to suggestions, and want the best for their children – we can all learn a lot together."

"It was really good to have parents there because they brought so much to the table and I think TAs really benefited from hearing from them."

"Videoing is such a powerful tool and really enables a person to stand back and watch what they are doing. It really facilitated reflective practice. I feel that they [parents] came up with relevant feedback without me needing to be too directive."

CONCLUSION

No one course is the answer to all communication needs, but the authors hope that this course provides knowledge, enables experiences to be shared, concerns to be aired and confidence gained in communicating in a different way.

We hope that the easy-to-use format will encourage those experienced in the field of AAC to lead the course and thereby reach out to those who are close to the children using these systems. The supporting role can be tough; they really do matter.

To obtain the *You Matter* course or for further information, please email: *info@ace-centre.org.uk* ✳

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Language Development and Literacy and the Role of Symbols

The use of symbols to support struggling readers in the comprehension of text

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Literacy is defined by Collins Dictionary as both the ability to read and write, and also the ability to use language proficiently. Access to written language is part of everyday life, be it in school, work and professional matters or for leisure. Difficulty in the successful acquisition of literacy is a barrier to learning and ultimately in achieving full participation in a wide range of daily activities. People who are at greater risk of having problems with literacy covers a wide base and includes; hearing impairment; learning disability; specific learning difficulties; developmental delays and disorders; speech and language delay or disorder (Snow, Burns & Griffin 1998); and those with complex communication needs.

This article looks at what skills are required to read successfully, particularly the language components, reading comprehension difficulties, and the potential of symbol use in literacy, alongside other strategies to support written language comprehension development at different levels.

READING AND MODELS OF READING

To read proficiently is to be able to read silently, with *comprehension* (Cunningham 1993). Learning to read involves a range of complex intellectual activities including visual perception,
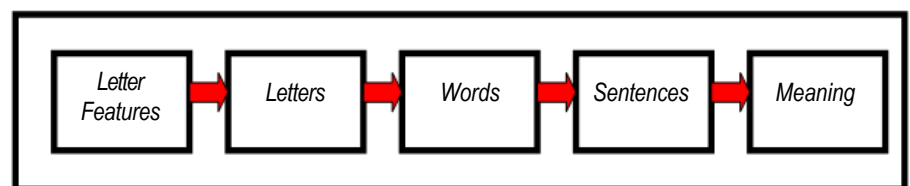

Figure 1 Bottom-Up model of reading

pattern recognition, word identification, short term memory, comprehension, language, thinking and reasoning. In order to be truly able to extract meaning from text, a reader has to read the lines, read *between* the lines, and read *beyond* the lines. In current times, this skill is applied to an ever increasing range of written materials; from information pamphlets, instruction booklets, novels, newspapers, celebrity-gossip websites, and beyond.

There is no true consensus view of the reading process, but several models are proposed. The first of these is referred to as the Bottom-Up model of reading. This is a more traditional approach to reading development, and is often the dominant approach in teaching reading. It presents of series of stages in a hierarchy, starting with letter features and working up through words, eventually to meaning. It presumes the lower level and perceptual processes (letters, their patterns, and sounds they represent)

precede the higher level (meaning), where decoding the pattern leads to understanding.

The second model of reading is the Top-Down. This takes a whole-language approach, and presumes that the reader approaches the text with a specific intention or purpose in mind, expecting to find particular things in print, and drawing on a knowledge of language and a knowledge of the world. In this model, the reader brings meaning *to* the print, rather than deriving meaning from it.

Finally, the Interactive Model of Reading proposes an interactive process where the reader is employing bottom-up and top-down processes alongside each other. In this instance, the reader has several sources of information; letters, sounds, words and clauses, and the reader *also* makes predictions and brings his own experience to the text. The *skilled* reader draws on low level basic skills comprising surface level decoding (making out what a word is) and recall
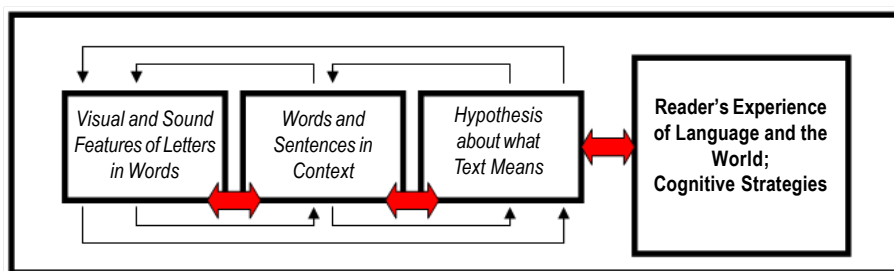
| Visual and Sound Features of Letters in Words | Words and Sentences in Context | Hypothesis about what Text Means | Reader's Experience of Language and the World; Cognitive Strategies |

Figure 2 Top-Down model of reading

of information combined with higher order critical thinking skills and the ability to personalise meanings to individual experiences.

Ultimately, reading results from the reader's use of the features of **language** and the application of the reader's own experience and expectations of text. The transition into fluent reading with comprehension depends on developing orthographic automaticity (readily recognising letters and word shapes and decoding), but also on syntactic competence and semantic strength. Knowledge of grammar and word meaning are critical to comprehension of what is being read, yet is the area in which many individuals with complex communication needs are struggling.

LANGUAGE IN READING

Grammar can be considered the building blocks of language, or how it is put together. Grammar, or syntax are the 'rules' of language, and dictate aspects such as word order (where in a sentence words go), word classes (nouns, verbs, adjectives), and morphology (changing the word to distinguish and mark for example plurals). Struggling readers are particularly challenged by morphological changes both in decoding *and* in comprehension.

Grammar can be both 'simple' and 'complex', and typically, grammar in written language is much more complex, making comprehension of the language in text even more of a challenge. Presented alongside grammar, is the content, or the ideas that are packaged within those blocks in well built, grammatically ordered sentences.

Content and structure are closely linked: the more complex the grammatical structure, the more ideas can be conveyed. Understanding the 'ideas' means having access to the range of vocabulary which is presenting those ideas, understanding their sequence and flow, but also being able to draw meaning from content not overtly stated. To understand implied content invokes the interactive reading model; having decoded the words, the reader now brings his own experience to the text to extract the ideas.

The language features required for reading comprehension are phonology, syntax, semantics at a lower level, but also higher level language skills. These include inferencing (identifying information not explicitly stated, the implied content), understanding metaphors and similes, problem solving, reasoning, the ability to refer outside of the text and relate to personal or previous experience, and the ability to understand and extract humour.

The following example requires use of all the lower and higher level skills listed in Fig. 3 to truly appreciate the meaning, which is not overtly stated:

"Since it started snowing, all my husband has done is look through the window. If it gets any worse, I might have to let him in."

DIFFICULTIES IN READING

Much school-based learning takes place through the spoken and written word. The student who experiences difficulty with language risks continuing to have difficulties throughout the whole of their education.

Students who are struggling with reading comprehension may be unable to answer factual questions based on the material read, find it difficult to identify the main idea of the passage or may not be able to follow directions in print. They are likely to have problems retelling much of what they have read, or struggle to construct an outline of the content. Even in later years, they may only be able to answer the very literal questions, and may find it challenging to from any kind of judgment on what they have read.

Being able to read out loud is *not* an indication of understanding, but merely represents good decoding skills (phonic skills). Students who have difficulty with comprehension are likely also to be struggling with context clues and cues. They may give a word that does not fit the context, and not recognise that this is an error. They may have particular difficulty in recognising words specifically related to a topic, this latter issue linking back to semantic skills also. They may be poor at predicting words which may be expected in a passage on a given topic and be unable to hazard a guess at an unknown word when its meaning is clearly indicated by the rest of the sentence.

In order to help students with poor literacy skills to engage in the whole of the curriculum and acquire other knowledge and understanding, it necessary to attempt to minimise the problems that literacy difficulties cause and assist in *comprehension*.

HOW COULD SYMBOLS HELP?

Symbols may prove a useful tool in facilitating the language component of reading comprehension. There is an advantage of pictorial symbols over more abstract symbol systems in that they can more easily be understood, whatever the age, language or reading ability of the majority of readers. Symbol-support for written language comprehension

Phonology (Sound System)	Syntax (Grammar)	Semantics (Word Knowledge)
Awareness + discrimination	Word order	Single word understanding concrete + abstract
Segmentation	Rules	Classification + categorisation
Sound blending	Irregular - rule breakers!	Concepts
Rhyming	Morphology	Pronouns and referential pronouns
Phoneme manipulation	Simple vs. complex Embedded clauses	Vocabulary + lexical diversity
Phoneme-Grapheme Correspondence	Punctuation	Text meaning

Figure 3 Lower level language features and how they translate in text

Symbol Groups	
Transparent or Guessable *These pictorial symbols are usually recognisable and need little teaching*	*House*
Translucent or Learnable *These symbols often fall into groups or schema, which can help their learnability*	*Bedroom*
Opaque *As vocabulary and ideas become more complex, so does the representational nature of the symbols used to represent them. Symbols representing abstract concepts will need explanation, but for people with learning/language difficulties, changes of recall are better with the help of the graphic image than through an unrecognisable text alternative.*	*Every*
Purely Abstract *Symbols which cannot be illustrated and are the most difficult to learn, as the user not only has to learn the meaning, but also their use in sentence construction.*	*is*

Figure 4   Different symbol groups

should be considered in the context of already living in a very symbolised world. Symbols are already widespread to communicate everyday messages swiftly and without ambiguity, whether on road-signs, menus or in logos for companies.

There remains little research, particularly beyond single-word reading, in the use of symbols to support literacy development. Current evidence is largely anecdotal rather than conclusive, and what research has been undertaken demonstrates variable results, undertaken in variable formats (Sheehy and Holliman 2009). However, Slater (2002) did find an increase in written language comprehension (which was maintained) when symbols were incorporated into reading materials, and Pamplou and Detheridge (2009) reported an increase in motivation and self-esteem in similar circumstances.

Of interest also is the observation by Morgan & Moni (2008) that adults with learning disabilities even while preferring age-appropriate reading materials, themselves sought picture support to aid comprehension. In summary, current practice suggests increased interest, attention, time on task, *comprehension of context*, and self-esteem (secondary to increased success) when symbols are included.

Symbols can be used to support some or all text. However the use of symbols should not be about employing a 'package' to be applied to all, but about tailoring materials to the individual *lan-*

guage needs of the student. The relationship between the symbol and the text will depend on the reader's cognitive, literacy and language levels, and the reason for which symbols are being used.

There are two main groups of people who may be using symbols to support their comprehension: those for whom symbols are the *main* communicative item, and those for whom the symbols are being used as a support, or a *bridge* towards traditional orthography, assisting the reader towards an exact reading of the written words. Ultimately, the text is more important than the pictures, and the pictures should be a clue, or a pointer to the content of the print.

The eventual goal, especially for the latter group of symbol users, is for the reader to learn to read the words, and extract meaning, not merely recognise symbols. Consequently, over time, focus should shift to print, particularly for higher level and more able readers, and as skills develop, symbols over the majority of the text is not required as the reader should be beginning to draw on
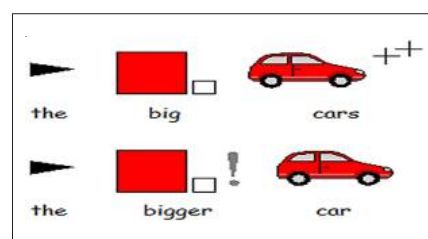
Figure 5   Example of change in meaning

context and grammar to support their comprehension.

SUPPORTING STRUCTURE

While symbols are not seen as part of an integrated linguistic structure in themselves, they *can* support comprehension of the linguistic structure of the text. Structure skills can be built upon through identifying word order (statements vs. questions); word groups for example 'doing' words and 'describing' words, and focusing on morphology including plurals, -ing endings, superlatives, possessives and so on.

In the example shown in Fig. 5, using Widgit symbols, there is a subtle change in meaning due to the morphological changes in both the adjective, and the noun. The additional markers to the symbols draw the reader's attention to this subtlety, increasing comprehension.

SUPPORTING CONTENT

Working on developing comprehension of the 'ideas' in a text is challenging, and not met with a straightforward strategy. Areas that support comprehension development and help to extract meaning include building vocabulary, in advance of reading, helping prepare the reader for what they may come across. The use of semantic networks, or creating 'maps' of words and ideas related to a single topic, develops this further. In the example shown in Fig. 6, key related vocabulary develops from a core concept.

Thinking about the sequence of events in any given story allows for discussion around the concept of a story-structure, the idea that every story has a beginning, middle and an end. This kind of awareness allows readers to think about where in a text they might find an answer. Activities that focus on reasoning, problem solving and inferencing are all significant in developing reading comprehension skills in students.

Adopting a *Five Step Framework* can be helpful (Tierney & Cunningham 1984). The following Steps 1 and 2 occur before reading, Step 3 during, and Steps 4 and 5 after.

1. Building and Activating Background Knowledge

Encouraging a reader to think of words related to the topic to be read about, and categorise words provided to them, not only helps build and strengthen these semantic networks, but also builds and activates the background knowledge that a successful reader brings to text.

Symbols and visual maps such as that illustrated (Widgit Communicate Ideas)
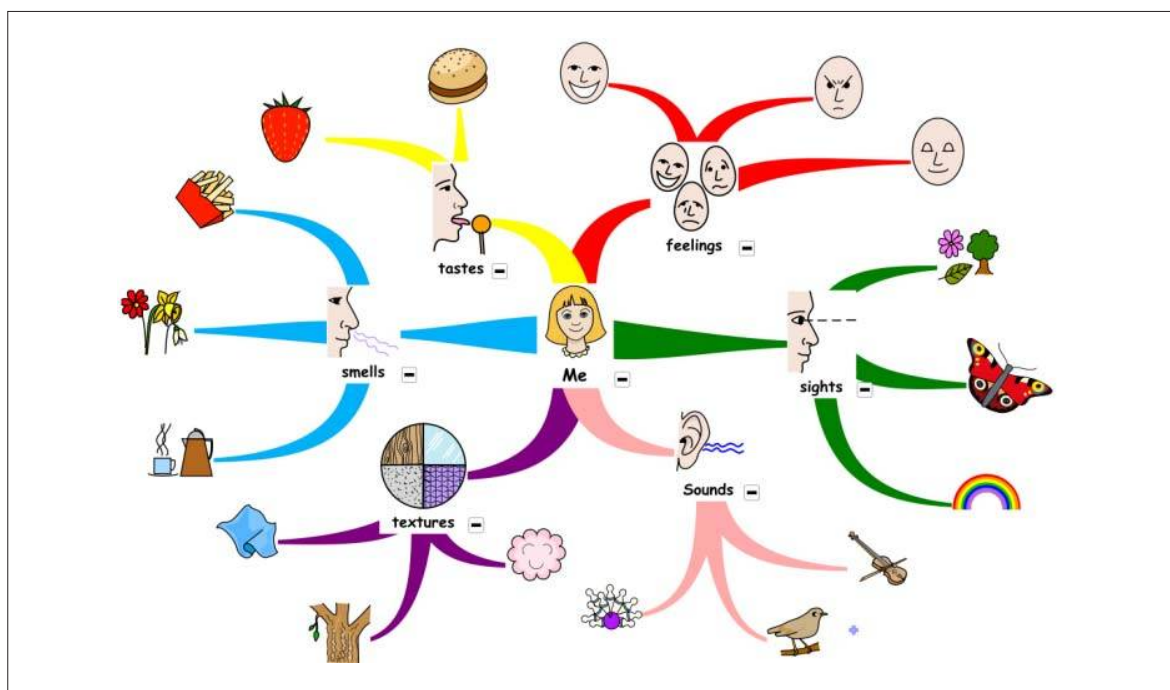
Figure 6 Key related vocabulary develops from a core concept

can also be helpful in teaching the meaning of important vocabulary, not just through definitions, but through relating new words to other *known* words. Such maps can also be useful in linking the topic of the story to other, personal experiences.

2. Setting a Purpose for Reading

There should be a purpose to what is being read *before* it is read, otherwise the student is being asked to guess what might be important, or try to remember everything. Setting a purpose focuses the reader's attention. Symbols can be used in many ways to do this, either through the elements of the text symbolised, or in the stated purpose if written down.

3. Reading

Adding symbols to the vocabulary, or grammatical aspects that are known to be challenging to the reader facilitates the actual reading activity. Time spent on actual reading is important.

4. Completing a Task

Complete a task that is related to the purpose set for reading. The same text can be read on a different occasion with a different purpose and task. For example, if the text was related to bullying, the task shown in Fig. 7 could be set.

5. Provide Informative Feedback

Finally, get the reader to explain what they did to accomplish the task of successful reading. This helps the reader understand exactly what he did to get the correct answer, or what went wrong if they did not. This last element of the framework helps develop strategy, to know what to do to get it right the next time. It may also inform regarding what supports the reader needs.

SUMMARY

Access to written language is a significant part of everyday living, and difficulties with reading comprehension is a barrier to full participation in life. A wide range of people struggle with the *language* component of learning to read proficiently. Symbols can be used with a variety of language-based strategies to support readers to successfully extract meaning from text. ✳

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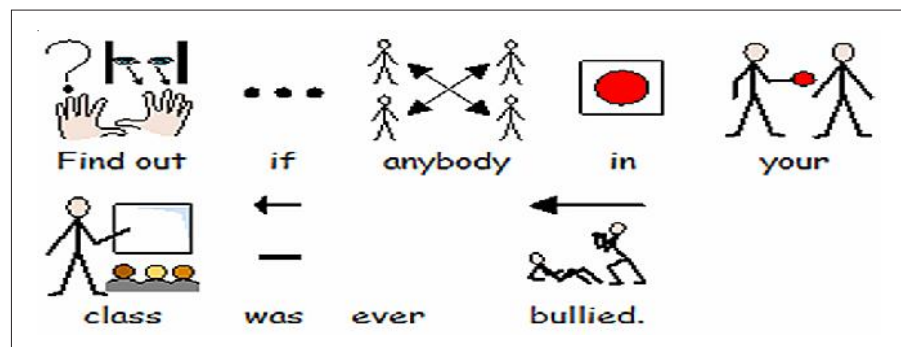
Figure 7 Task related to bullying

Using 'Tacpac' with PMLD Adults in a Social Care Setting

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INTRODUCTION

Recent research focusing on adults with profound and multiple learning disabilities (PMLD) supported in social care settings has looked at the issues involved in understanding their communicative behaviours (Bartlett and Bunning 1997, Bradshaw 2001, Healy and Walsh 2007, Porter et al 2001). These investigations have led to a greater understanding of the significant barriers and difficulties encountered by this group of people.

An individual with PMLD may communicate through speech, vocalisations, sign, symbol, gesture, facial expression or body language, and of course, a combination of these. The communicative intent may be clear as in turning the head away from unwanted food, or it may be so subtle – the flicker of an eyelid, a slight variation in vocalisation – that it is missed altogether. Accurately interpreting meaning requires empathy, good listening skills and close observation. It involves getting to know the person well, as the method of communication is typically idiosyncratic.

This paper provides an account of the introduction of Tacpac as part of a communicative development plan for three non-verbal adults with PMLD currently in residential care.

Tacpac is a commercially available activity resource designed to aid communication and sensory awareness in people with PMLD, sensory and/ or neurological impairment or developmental delay. Everyday objects such as fans, spatulas, chopsticks and sponges are patted, stroked, rolled, or flicked over the body in time to the beat of music composed for that purpose. The resource is being used in education and health care with anecdotal evidence as to its efficacy and application in the various settings.

MULTISENSORY PROCESSING & LEARNING

Many educators have long insisted on the benefits of multisensory training to enhance learning. One of the earliest was Maria Montessori who opened her first school in 1907. Sensory stimulation arouses attention, focuses concentration, develops awareness of cause-and-effect, and enables social interaction.

The provision of sensory experiences and multisensory environments has become of increasing interest among educators of children with special needs. There are a growing number of aids and approaches devised to bring multisensory experiences to those with severe disabilities including autism.

Recent neuroanatomical, neuroimaging and electrophysiological studies have provided evidence in support of a re-evaluation of our understanding of sensory processing. The traditional view is that the different sensory modalities operate "largely as separate and independent systems" (Seitz et al., 2006, p1423). However, it now appears that interaction between modalities in the processing of sensory information is the rule rather than the exception: "It is likely that the human brain has evolved to develop, learn and operate optimally in multisensory environments" (Shams and Seitz, 2008, p411).

The focus of these studies tends to be on visual/auditory processing (and, increasingly, visual/tactile processing) with little known about the brain mechanisms of audio/tactile interaction. One study that has looked at audio/tactile processing found touch to have facilitated hearing both in normal and hearing-impaired adults (Schurmann et al., 2006).

WHY TACPAC?

Tacpac was chosen as a sensory programme to complement the less structured sensory experiences already offered by the staff. (There is a clear emphasis in the home on visual stimulation, including a designated sensory room focusing on light displays, with a gradually increasing use of auditory experiences, but very little in the way of organised tactile, olfactory or novel gustatory sensations.)

A further consideration was the focus on touch and hearing, two senses considered to be unimpaired in the three adults chosen to take part in the sessions (and of particular benefit, it was hoped, for the participant with early onset blindness).

In addition, Tacpac is an approach that makes use of repetition providing numerous opportunities for the receiver to experience the same sensory stimulation. Using Tacpac may lead to a developing awareness of sound and a growing recognition and response to simple patterns. Tacpac also, uniquely, focuses on rhythm. There is a growing literature highlighting the importance of rhythm for the development of coordinated movements.

CASE STUDY EXAMPLES

The three adults in this study – Annie, Jack and Emma – share a residential home with five other PMLD adults. All eight residents have lived together for a long period of time and most attended the same special needs school. They have therefore been in close proximity for much of their lives. Two of the three adults also attend the same day care centre. Two of the three receive regular touch therapies, i.e., aromatherapy or reflexology.

ANNIE

- Female early 40s
- profound learning difficulties
- severely visually impaired
- epileptic (with complex partial seizures)
- non-verbal
- stroke in her 30s
- poor motor control (permanently clenched fists)
- non-weight bearing; wheelchair user
- dislocated hip

Communication:
- pre-intentional
- crying
- moaning
- a few stereotypic vocalisations typically accompanied by teeth grinding
- facial expression
- body language

Annie requires 24-hour care and sensitive support to make use of and develop her senses. She is totally dependant on her care providers offering her food that stimulates her taste as well as nourishes her body, sounds she can learn to anticipate and recognise and the sensation of touch brought to her for she cannot reach out and explore for herself. Annie has regular aromatherapy and neuroskeletal re alignment massage sessions.

Her language and communication skills would appear to be severely impaired. She does not respond to oral requests nor does she seem to react to any voice in particular. Her means of communicating is limited to a very restricted range of vocalisations, teeth grinding, cries and head turning. From records kept over a number of years it does not appear that her communicative skills have altered significantly for better or worse since childhood. Communication between Annie and her care providers takes the form of staff that know Annie well interpreting her communicative signals and the very limited use of scent to indicate the commencement of a particular activity.

JACK

- Male early 40s
- profound learning difficulties
- cerebral palsy
- epileptic (severe tonic clonic seizures)
- non-verbal
- poor motor control
- non-weight bearing: wheelchair user
- myopic (requires glasses)

Communication:
- screams
- facial expression
- body language
- limited self harm (hand biting)

Jack has some strength and movement in his arms and upper body with severe muscle weakness and restricted movement in the legs. His opportunity to physically explore his surroundings is almost as restricted as Annie's. Jack appears to enjoy touch on occasion and to have some musical preferences and therefore some appreciation of music. He expresses happiness and distress through loud and prolonged screams that nonetheless differ noticeably in their pitch and quality making it fairly easy to interpret and react to his expression of extreme emotion.

In addition, he uses facial expression and on occasion hand biting to express like and dislike. He appears to have some ability to concentrate for short periods, for example looking at a passing scene or images on a TV or interacting with a care provider. He is able (if given time) to focus on his communicative partner's face and to use expression to signal interest or disin-

terest. Jack receives reflexology, aromatherapy and neuroskeletal realignment massage on a regular basis.

EMMA

- Female late 30s
- profound learning difficulties
- epileptic
- non-verbal

Communication:
- pre-intentional
- crying
- a few vocalisations
- facial expression
- body language
- minor self harm (hand biting)

Emma can walk short level distances unaided though is unaware of and therefore unable to respond to any danger en route. She expresses emotion through crying, short vocalisations and minor self-harm (hand biting). Emma is not deaf, however she is unresponsive to speech and most environmental sound, i.e. doors banging, bells ringing, something falling to the ground.

She has, though, demonstrated some interest in certain genres of music notably classical and on occasion will tap her foot as the music plays. She also taps her foot in a similar manner without musical accompaniment. This is interpreted as a sign that she is content. It has been noted that she is able to focus for limited periods on another person copying the tapping sounds/ rhythm with his or her own foot. She cannot be induced to copy a variation on her tapping pattern.

ASSESSMENT

The aim of using Tacpac over a period of time with these PMLD adults is to stimulate sensory awareness, increase understanding of self and the world around and provide multisensory experiences in a safe environment. It is hoped that the approach will provide feedback on a person's likes and dislikes to complement other assessments, and increase understanding of their communicative signals.

One important consideration is that as the same programme is offered to all three adults, staff will also quickly become used to the routine and this will help ensure continuity of provision.

The same tabulated record keeping is followed in all three cases. Note is kept of physical responses (in the form of body and facial movement), and the gestures and vocalisations made during each particular section to build a pic-

ture of the type of sensory stimulation liked and disliked by each person. Additionally, it is becoming possible to interpret small changes in behaviour that attend a variation in sound or touch. Accurate recording provides an insight into whether Annie, Jack and Emma attend and respond to different sounds on a consistent basis. In this way a better understanding, and therefore a better response to, someone's communicative methods can be developed.

Differences in levels of alertness, concentration and relaxation can be observed during the sessions with all three adults, as can a reduction in tactile defensiveness. Any increase or reduction in self-harming episodes following the sessions can also be monitored. The study is intentionally longitudinal as any changes or gains may take a very long time to occur and are likely to be very small. Obviously consistency of interpretation is vital in order to facilitate the development of intentional communication.

INITIAL FINDINGS

The Tacpac resource provides structured auditory and tactile experiences. There is a growing body of work looking at the roles of music and touch therapies in a variety of settings and with people presenting with various clinical syndromes (see Aldridge 1993, 1994 and Field 2003). Touch provides emotional contact with another. It is closely linked with the proprioceptive sense. In Annie's case in particular, the regular and consistent movement of the tacpac objects over her body may be assisting her to develop or increase her awareness and knowledge of her own body – where it is and what it is doing.

Both Annie and Jack, restricted to wheelchairs for much of the day, have had numerous new haptic sensory experiences otherwise denied them (the Tacpac objects are placed in their hands before each section of music is played). Emma who can walk and grasp but shows little or no interest in physical manipulation or exploration of her surroundings has likewise been given the opportunity to experience novel sensations.

All three adults appear to be benefiting from receiving more touch. Annie, who has received more Tacpac sessions and over a longer period of time, may be starting to anticipate either a change in music or touch or both, is somewhat less tactile defensive and her small communicative signals are becoming more familiar. Jack is showing interest, focusing and using eye contact and Emma's reactions may portray a preference for vibration sensations.

As an aid to communication Tacpac, by providing uninterrupted one-to-one sessions, enables close observation of responses and reactions to a regular activity carried out over a period of time. Preferred sensory input such as warm or cold, light or firm touch, soft or bobbly, tickling or kneading can be discovered and sensory function developed. Likewise, Tacpac sessions provide data as to the type of sound, including musical sounds enjoyed or disliked. Furthermore, a growing awareness of self, others and the environment may reduced anxiety and promote increased confidence in the abilities of their caregivers to interpret Annie, Jack and Emma's communicative signals. ✳

Dr Paula Hellal

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COLLATED BY JANICE MURRAY, CHAIR

BRAVE NEW WORLD

In this brave new world of the 'public face of AAC', there appear to be many more opportunities than we are experienced and familiar with. And after years of asking for, agonising about, and wishing for things to be different, this does seem like a key moment in time for us here in the UK to strike, to be brave, to take every opportunity afforded us in the field of AAC and, in particular, for Communication Matters to play its part.

We have much to celebrate and share, but that brings with it a responsibility for all of us to keep pushing forward. I feel as though this pitch is turning into a battle cry…and yes, William Wallace was a hero of mine long before Mel Gibson discovered him.

But worry not – putting aside those 'auld' gripes, this seems to be a critical phase in achieving *our vision* for people who use AAC. (N.B. whilst William Wallace's campaign resulted in his own demise, it did eventually change the terrain of the UK for the next few hundred years at least!)

Some of our actions pushing that vision forward include…

SAFE SOCIAL NETWORKING DAYS

By popular demand, we have been able to extend the Safe Social Networking study days this year into four new colleges. The sessions will be happening over the next few months. Thanks again to the students and colleges who want to be involved, to Tom Griffiths for his enthusiasm and commitment to providing content for the programme, and Sally Chan for her liaison work.

WORKING PARTIES

We have taken the decision to fund some project work that promotes the development and knowledge of front line workers. These projects include work on Workforce Competencies in AAC and Outcome Measurement tools to inform practice and decision making. We advertised for project workers for the two projects, and were overwhelmed by the interest and applications received. We had a high calibre field to consider. Both projects reflect the diverse nature of the Communication Matters' membership through the involvement of two working parties. These working parties continue to inform and direct the work of these initiatives.

Competencies Project

The working party achieved much in terms of determining competencies across the AAC workforce. Liz Panton, with many years' experience of service delivery, has been appointed as the project worker for Competencies. We hope to have information to share with you by late summer.

Outcome Measurement Project

The working party has determined the scope of Communication Matters' focus on outcome measurement. Professor Pam Enderby, with considerable recognition in the field of outcome measurement, has been appointed as the project worker. We hope to have information to share with you by early summer.

Anyone wishing to comment/contribute to considerations within either project should contact Janice Murray at *jancommatters@mmu.ac.uk*.

ONLINE TRAINING

A working group of Trustees (Simon Judge, Dithe Fisher, Gillian Hazell and Mike Clarke) is moving towards completion of this project jointly funded by Communication Matters and a grant from the Big Lottery Fund (Awards for All). It is anticipated that this will be available in early summer and should provide information for a gap in the market, and inform aspects of the AAC Evidence Base research project's database development.

LOBBYING ACTIVITIES

We have recently been involved in a lobbying campaign (House of Lords' Reception on 6 March 2012), in collaboration with the BHTA.

Dave Morgan's report (page 23) expands on this so I will not duplicate details here. However, it is important to acknowledge the efforts of a number of people who enabled this initial lobbying event to happen. Sandra Hartley worked energetically on behalf of the Board of Trustees to ensure this event resonated with our mission and vision. Anna Reeves, in her role as the National AAC Co-ordinator (England) provided considerable time and knowledge to achieving our collective aims, and Dave Morgan, as e-CAT Chair and I (as CM Chair) orchestrated the co-ordination between CM and BHTA to make this the event we hoped for.

We anticipate that this is a beginning and that we need to maintain the lobbying momentum. Watch this space, and please make use of the Toolkit for contacting MPs (which was circulated via our E-News).

SPECIALIST AAC SERVICES

Communication Matters funded a meeting in London on 10 February to support discussion about anticipated service commissioning negotiations. This was co-ordinated by Sally Chan and Dithe Fisher. Specialist services in England are currently in negotiation regarding the proposed 'hub and spoke' provision of services. Scotland has recently been informed of health service funding proposals. Wales is reviewing service proposal documentation and Northern Ireland awaits further funding proposals.

STANDARDS DOCUMENTATION

Having successfully launched documentation directed at Commissioners of services the remaining standards documentation is imminently anticipated. This includes a poster with summary standards statements, plain English summaries and the detailed standards documentation.

Please keep an eye on our website for final release dates of these publications.

Thanks to Gillian Hazell for her work on this, supported by several Trustees.

GENERAL AWARENESS RAISING INITIATIVES

Communication Matters will be exhibiting at conferences in its aim to continue to raise awareness of AAC, including Naidex, Afasic's Voice for Life and NAPLIC (National Association of Professionals concerned with Language Impairment in Children).

The conference scene appears to be changing... Last year we found ourselves part of 'communication villages' at such events, but this year we are one of very few communication related exhibitors. Does this mean we should pull back from such events or that it is more important than ever that we attend and contribute? Comments welcome to *jancommatters@mmu.ac.uk*.

CM2012 NATIONAL CONFERENCE

Preparation for CM2012 is well underway, and we will continue to host the conference at Leicester University for 2012.

Last year was a huge success, but we have recently been informed by the university that their new plenary conference accommodation is considerably smaller than our anticipated requirements. As you might imagine, moving conference venue is a considerable undertaking. We do not feel we can do that successfully in the short window of time before September, so we will continue at Leicester with the same alternative plenary room accommodation as last year, whilst we explore other venues that offer us our valued campus venue and sufficient accessible bedrooms.

ISAAC CONFERENCE

This is an ISAAC Conference year, so for those of you fortunate enough to be able to attend the conference in Pittsburgh, enjoy…and fly the UK flag.

A number of us have the privilege of being there. I will be attending a number of committee meetings on our behalf, as will Liz Moulam as our Associate Member representative (see her report). Please let us know your feelings and comments about anything ISAAC related before these meetings over the summer (email *jancommatters@mmu.ac.uk*). We will report back to you both in the CM Journal and at our National Conference in September.

I have not forgotten our aspirations to host an ISAAC conference but I continue to attempt to get clarity on ISAAC's and CM's cut on any profits. Communication Matters is an unusual Chapter of ISAAC as we host our own annual conference. This helps us to be a financially robust organisation allowing us fund and support a range of activities. I am not aware of many Chapters that do this. It is important that we do not jeopardise the long term future of our own organisation by hosting an international ISAAC event. I will keep you informed of developments.

RESEARCH

We continue with the main activity of the Communication Matters: Research Matters project funded by the Big Lottery Fund (see article on page xx).

BOARD UPDATES

We are well into this year's Board of Trustees activities, and I trust that you can see we are aiming to ensure we enable and complete a number of activities on your behalf. We always welcome your comment and feedback (please email *jancommatters@mmu.ac.uk*).

There are some changes to the Board of Trustees. We have recently co-opted Cathy Harris as a new member of the Board. Many of you will know Cathy from her previous time on the Board. She is keen and enthusiastic to be more involved in the organisation and running of Communication Matters and we welcome her into this role.

In addition, Tom Griffiths, has been co-opted onto the Board – Tom has organised the CM Road Shows in London for several years and has been very active preparing and presenting material at the Safe Social Networking study days last year.

FINALLY

Currently, all of our activities are maintained by voluntary commitment and drive. We should be very proud. People like Jean Gross and others, e.g. Commissioners of Children's Services, have noticed and commented on the unique and awe inspiring role of an organisation like Communication Matters. That means YOU!

I guess we could describe ourselves as having been on a slow burn over the last 25 years and in that time we have accrued knowledge, experience and determined direction from the eclectic membership that makes Communication Matters strong…and just a little bit intimidating. Let's keep working together, appreciating what we all bring to the table, and continue to work towards our ultimate mission and vision. ✳

Janice Murray
Chair of Communication Matters

Outside of the home nations, Communication Matters is known as ISAAC-UK and I have the honour of representing the Associate membership on the ISAAC Council. The Council is made up of each Chapter President/Chair and a representative of their membership.

At the Council meeting in Barcelona in 2010 I offered to be involved in reviewing the ISAAC governance. For those of you who have been around a while, you may remember this was something I was involved with here in the UK back in 2007 when our own governing documents were updated; so having enjoyed the experience I threw my hat into the ring. It was agreed I would lead the committee work.

With a two year lead time to the next Council meeting the work got off to a slow start, partially down to my other commitments, floods in Australia, storms in the USA and general workloads of the committee.

'Face-to-face' meetings (using Skype) have proved unviable due to the time differences in the USA, Europe and Australia. We have communicated via email with Shelley Deegan, Chair of Council, working on behalf of the committee with the Executive Board. This has been a huge job but we now appear on track to begin to offer up documents for consultation, and hopefully approval, at Pittsburgh 2012.

Our work has been greatly helped by adopting a format similar to that used by Communication Matters, with a formal governing document and then a procedural manual to cover how the Executive Board and its committees, the Council, the Secretariat and others interface and carry out their day to day roles. The process has provided me with an unique insight and understanding of the complexities of an international voluntary organisation.

The second task I volunteered for was to develop greater family membership of ISAAC. Mary Ann Glicksman of France has worked hard to pull this together and recently a survey was sent to all people who use AAC, and their families, who attended Barcelona to find out how they benefitted from their participation. From a personal perspective I see the biggest challenge in this area is that each Chapter has its own policy on how to engage with families and people who use AAC across the world. This shows through the very variable number of members in these categories by nation.

I am to remain the Council member for a second two year term (2012-2014), which will allow me to see through the governance work.

During 2013, Communication Matters will hold an election for a new Associate member representative for the UK. ✳

Liz Moulam
ISAAC Council Member

The BHTA eCAT section wanted to support the Year of Communication in 2011 and the obvious month to do this was October, the AAC designated month. Because Lord Rennard, one of the founders of the Lib Dem party, is on our Board of Directors, we can get access to the House of Lords for events. However, our plans were put on hold due to another Year of Communication event, at the House of Commons, already booked for that month.

So we rescheduled the event for March 2012 to try and keep interest in the project and in **Jean Gross's report** alive after the Year of Communication had ended. After discussions, eCAT members joined forces with Communication Matters to run a joint event. We believed this would show MPs and Peers that the industry was working closely with the third sector and that, rather than being an event run by suppliers to try and line their own pockets, the event was really about getting assessment processes and funding in place for the benefit of people who need communication aids.

An eclectic mix of influencers, MPs and Lords were invited together with a cross section of users, carers, professionals and suppliers who were available to network with those who have the ability to make change happen. The event was opened with **Lord Rennard** welcoming all those attending, after which I was delighted to speak on behalf of the BHTA eCAT members. I emphasised how communication aids can make such a difference to individuals and how much England has fallen behind Scandinavia, Northern Europe and the USA in terms of a legal right to a speech aid and the lack of structures for assessment and funding.

Janice Murray, CM Chair, followed and spoke about how difficult it can be to get an assessment and funding – sounds like we had planned our speeches so they dovetailed together – and yes we had! We both felt it was important to make the most of this opportunity to 'influence the influencers'!

The special guest speaker, **Sarah Teather MP**, Minister of State for Children and Families at the Department of Education followed Janice on the platform, and the afternoon was concluded with a short speech from **Martin Pistorius,** who uses AAC.

It is too soon to know whether it will have any real effect but we can now use information from this event to push for more support for Jean Gross's recommendations to ensure those who have the power to make change do so.

The other major news is that at the annual BHTA dinner in December, **David Mason,** of Toby Churchill Ltd was honoured with the first ever eCAT award for services to the AAC industry. ✳

David Morgan
Chair of eCAT section, BHTA

Note: BHTA is the British Healthcare Trades Association; eCAT is one sector of the BHTA, dealing with electronic Communication and Assistive Technology

1-3 May 2012   *NEC, Birmingham*
Naidex National 2012
Register for free entry: www.naidex.co.uk/National

2 May 2012   *Bristol*
Introducing Clicker 5
Contact PCAS: 0117 3533613 www.nbt.nhs.uk/pcas

8 May 2012   *Oldham*
Communicate: in Print
Contact ACE Centre North: 0161 358 0151 www.ace-north.org.uk

11 May 2012   *Bristol*
Boardmaker Training
Contact PCAS: 0117 3533613 www.nbt.nhs.uk/pcas

11 May 2012   *Edinburgh*
Personal Communication Passports
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

15 May 2012   *Glasgow*
Communication Matters Road Show: Glasgow   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

16 May 2012   *Bristol*
Communicate: in Print 2
Contact PCAS: 0117 3533613 www.nbt.nhs.uk/pcas

22 May 2012   *Liverpool*
Communication Matters Road Show: Liverpool   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

DIARY
DATES

30 May & 11 June 2012   *Hants (May), Devon (June)*
Safe Social Networking: at Treloar & Hannahs   `COMMUNICATION MATTERS`
Contact: 0845 456 8211 www.communicationmatters.org.uk

30 May 2012   *Bristol*
Beyond Snack Time: AAC at home and school
Contact PCAS: 0117 3533613 www.nbt.nhs.uk/pcas

31 May 2012   *Oldham*
Communicate: Symwriter
Contact ACE Centre North: 0161 358 0151 www.ace-north.org.uk

13 & 14 June 2012   *Aberdeen (13th), Edinburgh (14th)*
ICT and Inclusion 2012
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

19 June 2012   *Newcastle upon Tyne*
Communication Matters Road Show: Newcastle   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

28 June 2012   *Northampton*
Communication Matters Road Show: Northampton   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

23-25 September 2012   *Leicester*
CM2012 National Conference   `COMMUNICATION MATTERS`
Contact: 0845 456 8211 www.communicationmatters.org.uk

13 November 2012   *London*
Communication Matters Road Show: London   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

COMMUNICATION MATTERS

2012
cm
NATIONAL CONFERENCE

23-25 SEPTEMBER 2012   UNIVERSITY OF LEICESTER

The Communication Matters / ISAAC (UK) National Conference is an annual event embracing a wide range of issues relating to augmentative and alternative communication. The two and a half day event provides a forum to meet and to exchange information with representatives from all disciplines associated with AAC, including people who use AAC and their family members.

SYMPOSIUM PROGRAMME

Platform Presentations
Practical Workshops
Case Studies & Research Papers
Seminars
Trade Exhibition
Guest Speakers
Social Events

REGISTRATION

All registrations allow full access to all the presentations and trade exhibition. The registration fee also includes refreshments, lunch and evening meals. Residential registration additionally covers accommodation in student halls (with breakfast). There is a substantial discount if you register and pay before 31 July. Prices from £385 for full residential registration.

There are a number of subsidised places for people who use AAC, and their family members. Book early to avoid disappointment.

BOOKING FORM & INFORMATION

For further information and a booking form, please visit **www.communicationmatters.org.uk**, or ring Communication Matters on **0845 456 8211** or email: **admin@communicationmatters.org.uk**

The Research Journey

Developing an online AAC evidence base

JANICE MURRAY[1], MICHELLE BEECH[1], ALAN MARTIN[2] & KATIE HOLMES[3]

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INTRODUCTION

Communication Matters (CM) is leading on a research project with Manchester Metropolitan University (MMU) to develop an online AAC resource. One of the aims of the project is:

"To improve accessibility to best practice evidence through an online, searchable database."

This paper will outline the research and development process that the collaborators have gone through in producing an online evidence base that will enhance awareness and knowledge across the field of AAC.

VISION

Communication Matters' aims as a charity include facilitating "the publication and exchange of information relating to research into communication disorders". We have a diverse membership representing different interests in the field of AAC, including: people who use AAC and their families and carers; professionals; academics; and companies. We are committed to making information accessible to all of these groups and to the wider public and this is a guiding principle behind the AAC Evidence Base. The AAC Evidence Base will lead to more evidence being published and made publicly available to all stakeholders.

EVIDENCE BASED PRACTICE

The AAC Evidence Base was originally conceived of as an online resource that would make best practice evidence available to a wider audience. The driving force behind this was the utilisation of an Evidenced Based Practice (EBP) approach. EBP has been described by Sackett et al (1997) as the integration of best research evidence with clinical expertise and patient values.

Dollaghan (2007) defines EBP as *"the conscientious, explicit and judicious integration of (1) the best available external evidence from systematic research, (2) the best available evidence internal to clinical practice, and (3) the best available evidence concerning the preferences of a fully informed patient"* (p. 2).

This implies that the perspectives of professionals, families and people who use AAC are likely to reflect differing needs and experiences, whilst each strive for valid sources of knowledge to inform their practice or skill development. Dollaghan (2007) summarises the intentions behind the AAC Evidence Base beautifully by suggesting that *"facts known only by practitioners need to be anchored by values known only by patients"* (p. 2), and as such it would be important to collate opinions from relevant stakeholders to inform the content and structure of the online resource.

ABOUT THE PROJECT

In October 2009 Communication Matters was awarded a £467,751 grant by the Big Lottery Fund under its research programme for a project entitled *Communication Matters - Research Matters: an AAC Evidence Base.*

Communication Matters is leading the project and working with three research partners. The University of Sheffield and Barnsley Hospital NHS Foundation Trust are researching prevalence of need and mapping service provision. Manchester Metropolitan University is developing the AAC Evidence Base and a case study template.

For more information, contact Katie Holmes, Research Manager, E: katieholmes@communicationmatters.org.uk

METHODOLOGY

A Participatory Action Research (PAR) methodology (Baum et al, 2006) was the obvious approach to adopt. This approach enables participants to be part of a reflective cycle of collecting and analysing data to determine what actions or choices best serve the community involved.

RESEARCH TEAM

The team includes a research speech and language therapist, an information and communication technologist and an adult with a lifelong experience of using AAC. The makeup of the research team was an important aspect of a PAR approach to data collection.

An initial literature review informed the procedures for data collection and the content of the initial research questions.

The starting point was:

- What type of information is required in the evidence database?
- In what formats should information be available to support wider access?

PROCEDURE

Nine focus groups were held across the UK. These involved all stakeholder groups within the current Communication Matters' membership (e.g. family members, people with lifelong AAC needs, those with acquired AAC needs, and a similar mix of health and educational professionals, researchers and product representatives), as well as some commissioners of services and other third sector organisations.

The research team attended all groups. Data was also collected through some individual interviews and questionnaires. This initial data collection phase involved 87 participants.

The key stimulus questions used in the discussions were:

- What does the term 'evidence' mean to you in relation to AAC?
- What do you do/use now to get evidence?
- What are the advantages and disadvantages about how you get that evidence now?
- Who would you envisage could make use of an accessible evidence AAC database?
- What access and navigational features would support your use of the website?
- What would you want to use the database content for?
- How should we (Communication Matters) market the database and

which stakeholders should be the priority?

These questions led to a wide and far ranging debate particularly about who might want to use the evidence base and what they might be looking for. One consequence of this was to add to the data collection phase by including the collection of word or phrase lists that we might associate with AAC. It was envisaged that this list would be useful to the process of developing an architectural structure and in organising the resources within the database. This evolution in the data collection phase fits within a true action research philosophy.

Towards the end of the data collection phase it became clear that we had reached 'data saturation' as the same key points and themes were emerging irrespective of the stakeholder perspective. This was a positive place to start more detailed analysis.

ANALYSIS

The raw data were analysed using Thematic Framework Analysis (Denzin & Lincoln, 2000). Using a PAR approach it was important at this point to include the reflections of the researcher who had personal experience of using AAC. This process added validity to the exploratory aspects of the focus group debates. Distillation of the data produced the following findings for consideration in the development of the evidence database.

KEY FINDINGS

Terminology

One clear message is that terminology is often confusing and exclusive; for example 'evidence' does not have a unitary meaning across stakeholders. It may have particular meaning to professionals and researchers but it held negative, legal and medical model connotations for many people who use AAC and their families. Acknowledgment of this will be critical in terms of what the database is called and how we use terminology within the structure of the database to help people navigate through the resources.

Content

All stakeholder groups felt it was important that this resource offered something for the uninitiated to AAC as well as those with much greater experience and familiarity with the field. One could say that the range of best evidence that people would like to see has emerged from the data.

To date the key content desired includes:

- A glossary of terms, including some definitions and condition specific information.
- User experiences in the form of case stories (this would include from the perspectives of users of AAC, professionals, family members).
- Technical specifications of AAC systems and devices, with reviews from stakeholder groups.
- Assessment studies (from peer reviewed journals to anecdotal experiences).
- Intervention studies (from peer reviewed journals to anecdotal experiences).
- Service provision, funding and policy studies (from peer reviewed journals, other publications to anecdotal experiences).
- Published case stories (assessment, intervention and training focus).
- Fact sheets.

Accessibility

The content should be made available to as wide an audience as possible.

Consideration of accessibility issues have included debate about the development of symbolised navigational features, plain language summaries, instructional videos and the use of discussion forums. The features consistently identified as critical in the first phase of development have been plain language summaries and discussion forums. Focus group members indicated that audio (e.g. screen reader) facilities would generally be available at the end users' location, if required, and should not be an initial priority. All other accessibility elements identified were met with varying enthusiasm.

DEVELOPMENT OF THE ONLINE RESOURCE

Clearly, many aspects of desired content already exist in a range of differing resources. This project is not about re-inventing the wheel: where relevant the AAC Evidence Base will offer links to other websites. A key requirement of this project is to ensure that the structure and thematic content are robust and appropriate for the on-going development and use of the resource. MMU and CM have worked together to define the technical architecture. MMU are sourcing and developing the initial content.

As the AAC Evidence Base continues to be developed there will be an iterative review process with input from

people who participated in the focus groups, as well as naïve participants who can evaluate the pilot versions from a slightly different perspective.

This research has identified what the product could look like and the action research approach has resulted in identification of a much wider range of information than may have been conceived in the original project proposal.

This is hugely positive for the longer term development of this resource; however, every research project has a financial and time budget. Given these constraints we will focus on developing the content and structure first and the key accessibility features identified. We will work towards funding at a later date some of those elements that may

not be easy to complete at present, for example, video training resources.

We anticipate launching the AAC Evidence Base in September 2012 at the Communication Matters National Conference in Leicester.

POTENTIAL FOR FURTHER DEVELOPMENT

In many respects the completion of this research project is the starting point. For this to continue to be an evolving and useful resource it will require the AAC community to use it and offer ongoing feedback on the content. We will evaluate how the AAC Evidence Base is used through monitoring usage of the website, surveys and feedback.

We look forward to sharing this innovative work with you. The content has certainly emerged from the ground up,

and as such is more likely to be of lasting benefit to Communication Matters and the community it serves. ✳

Dr Janice Murray, *Senior Lecturer*
Michelle Beech, *Research Assistant*
Alan Martin, *Dancer & disability rights trainer*
Katie Holmes, *Research Manager*

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JOINING COMMUNICATION MATTERS & ISAAC

What is Communication Matters?

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

Our Vision: *A world where all individuals have a right to a 'voice' through the provision of equipment and ongoing support services.*

Our Mission: *Communication Matters values people who use any form of communication and promotes the individual's right to participate in all aspects of life by using their most appropriate means of communication to express their thoughts, feelings, needs and desires.*

What are the benefits of Membership?

Members of Communication Matters receive:
- *The Communication Matters Journal three times a year.*
- *Reduced rate at Communication Matters Study Days.*
- *Reduced delegate rate at the CM National Symposium.*
- *Regular electronic newsletters with the latest news in AAC developments, Road Shows, study days and more.*
- *Access the members' area of the CM website.*
- *All the benefits of ISAAC membership.*

How do I become a Member?

You can become a UK or Overseas member of Communication Matters (and therefore of ISAAC) by contacting: **Tel: 0845 456 8211 E: admin@communicationmatters.org.uk www.communicationmatters.org.uk**

If you wish to become a member of ISAAC directly or subscribe to this Journal, please contact: ISAAC Tel: +1 416 385 0351 info@isaac-online.org www.isaac-online.org

What is ISAAC?

- *ISAAC stands for International Society for Augmentative and Alternative Communication.*
- *ISAAC is a big international organisation that focuses on AAC.*
- *ISAAC was formed in 1983 and has over 3,600 members.*
- *ISAAC members live in more than 50 countries around the world.*
- *There are ISAAC Chapters in Australia, Canada, Denmark, Finland, French-speaking Countries, German-speaking Countries, India, Israel, Italy, Netherlands-Flanders, Norway, Sweden, UK and USA.*

ISAAC's Vision: *AAC will be recognised, valued and used throughout the world.*

ISAAC's Mission: *To promote the best possible communication for people with complex communication needs.*

What does ISAAC do?

- *Advocates for augmented communicators & their families.*
- *Supports the use of AAC around the world. This includes countries that do not know about AAC.*
- *Has an exciting awards & scholarship program for members.*
- *Encourages the development of AAC products & services.*
- *Produces a series of books for people involved in AAC.*
- *Has an international conference every two years.*
- *Sponsors a peer-reviewed scientific journal – Augmentative and Alternative Communication (AAC). Visit the website at: www.isaac-online.org/en/publications/aac.html for more details.*

What do ISAAC members receive?

- *Full access to ISAAC Information Exchange, an international resource for sharing knowledge, experiences & perspectives on AAC.*
- *An International Directory with a list of all ISAAC members.*
- *ISAAC members can buy the AAC Journal at 54% discounted rate.*
- *ISAAC members can attend ISAAC conferences and meetings at 15% or more discounted rate.*
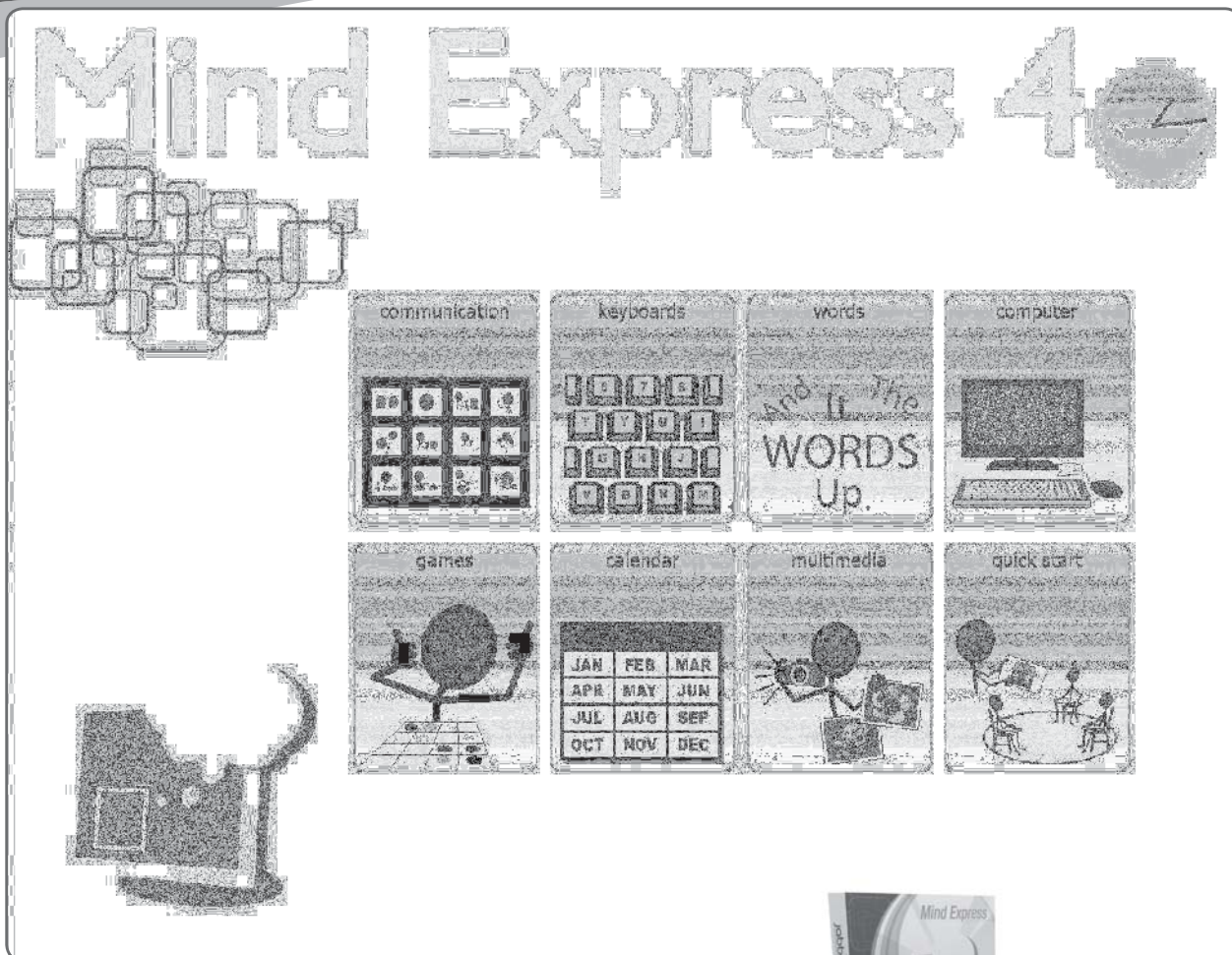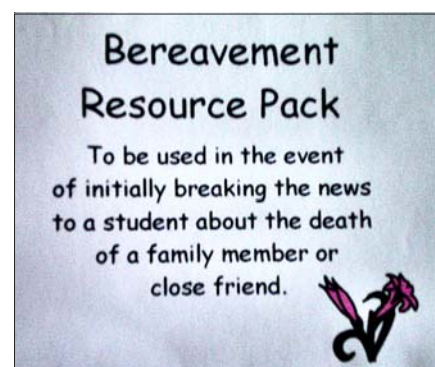
An AAC Bereavement Resource

A 'whole organisation' approach to communicating and supporting individuals with learning disabilities to deal with initial bereavement

TAMZIN GRIBBLE, LEONIE VAN WIJK, VALERIE SARDELLA & CAROLINE HODGSON

Dame Hannah Rogers Trust, Woodland Road, Ivybridge, Devon, PL21 9HQ, UK
Email: tamzingribble@damehannah.com

Bereavement is a difficult issue to talk about for even those with the most sophisticated communication skills. However for those with communication impairments, either due to comprehension difficulties or expressive difficulties, or a combination of both, talking about a death can seem insurmountable. Dark & Balandin (2006) stated that: "A successful grieving process is dependent on having access to satisfactory communication and the opportunity to explore the loss with a chosen network of supports". People with comprehension and expressive difficulties need to be supported with their communication around bereavement.

The Dame Hannah Rogers Trust (DHRT) is a school and Adult Care provision for children and young adults with physical and associated learning disabilities. Alternative and augmentative communication is used by the majority of the young people. During the Spring and Summer Term of 2009 there were a series of four deaths at DHRT. Two young people died, a parent had a heart attack and a member of staff passed away after a terminal illness.

In the current political climate, those young people with communication difficulties who were previously in special schools are now able to access inclusive, mainstream settings. Hence DHRT has continued to exist by becoming a provision for the increasingly complex in terms of physical disability, health and medical needs. We have an increasingly vulnerable caseload and a much higher risk of mortalities.

As an organisation we have been forced to face up to this reality in the past year. This has made the staff group reflect on existing practices and identify what needed improving for now and the future in terms of dealing with bereavement.

Issues that arose immediately were how ill equipped the staff felt in breaking the news of a death to the students and young adults who attend DHRT. This was often coupled with the fact that staff themselves were grieving also. There was a lack of understanding of the bereavement process by staff and insight into how much the young people attending DHRT could understand. Generally their comprehension levels were overestimated, leading to staff breaking news to them at too high a level and invariably by verbal means only.

This led on to further difficulties of prolonging the 'agony' for students and young people, who were confused, upset by the adult's emotions but not fully understanding why. This finding is supported by Clements (2004): "Many times, the person is not told about a death until well after the fact and may not be included in the funeral or other related activities. This may result in a delayed and ineffective grieving proc-

ess." Hence initial breaking the news of a death is essential to get right with people who have comprehension difficulties.

There are many resources on the market which enable effective communication about bereavement, such as life books, photos, Makaton signs & symbols. Buckman (1991) has written a six-step protocol or framework that can be used when breaking bad news and has been usefully related to people with learning disabilities by S. Read (1998). This protocol however does not include a script that could be used when breaking this news. We were unable to find a suitable ready-made resource that would support staff and students to inform the person about a death in simple, concrete language.

A multi-disciplinary bereavement working party was established to reflect on our current practice for dealing with bereavement and to think of strategies to improve the way we dealt with this sensitive issue. The working party consisted of speech and language therapists (SLTs) and assistants, a teacher, a nurse, a care manager and a quality assurance manager.

The working party identified the need for:

- purchasing and developing appropriate resources to support our staff and young people;

- a revised bereavement policy;

- rolling out staff training on bereavement and loss;
- implementing changes to the curriculum.

After the deaths within DHRT, the SLT department was flooded with questions from staff on how to talk to the students and young people. We needed clear guidelines on where our role as SLTs ended, as we are not bereavement counsellors. Therefore, a protocol for SLTs was developed by two final year SLT students (Yvonne van Essen & Leonie van Wijk, 2010) which includes:

- background information on bereavement and grief theories, related to DHRT's students and clients;
- a step-by-step plan that can be used to write communication advice on bereavement for staff and parents of the young person;
- a list of useful resources to support comprehension;
- a clinical framework to describe the role of an SLT working with AAC users on bereavement.

SLTs advise members of staff to use concrete vocabulary and provide visual support when communicating with people with learning disabilities. When talking about a death, the person with LD should be provided with the basic facts, using language that is truthful and cannot be misunderstood (Read, 2007). However, an SLT at DHRT who helped to break the news to a young person of the death of his father was struggling to find the right words in this situation. She was dealing with her own emotions and was tempted to use words that would soften the message, such as 'passed away', as words such as 'died' sounded callous. Therefore, the SLT department focussed on developing a low-tech bereavement package. This resource can be used specifically in the event of initially breaking the news to a young person with learning disabilities about the death of a loved one. It consists of a written script and appropriate list of symbols (which can be chosen accordingly), Makaton signs & symbols and photos (Appendix 1).

We have used this resource and staff have fedback on it's usefulness. It provides a concrete starting point which is reassuring for the person breaking the news. We have found that according to the comprehension levels of the person, that we then naturally adapt the script. Also difficult questions such as "where has she gone?" and "why?" have been asked. At these times, when we have been unable to answer we have said "I don't know". It would have been very useful to already have had knowledge of the beliefs of the person receiving the news and wishes of the family at this point, hence there is more work to be done in terms of making profiles for all our young people's family beliefs.

Shelagh Crossley has already highlighted the importance of supporting people who use AAC to talk about bereavement or loss at the Communication Matters conference in September 2009. She developed bereavement pages for high technology communication aids. Her presentation and article (CM, 2010) urged us to develop a low-tech resource. At Total Communication Network meetings that we then hosted, we used questionnaires to pilot the usefulness of the bereavement package resources as a peer review, with a randomized staff group. The reponses were generally positive (Appendix 2).

We acknowledge that the resources are only the first step in aiding the bereavement process. We are currently developing resources to support communication for the longer term, around loss, as it is required. For example we have developed a 'chat' page in a young person's communication book about the loss of her parent, giving her the opportunity to request to talk about her loss and vocabulary to do so.

We have developed a Social Story to enable a young person to comprehend that his Grandad was very poorly and deteriorating, relating to him in concrete terms what would change, for example: "He is feeling tired and will not be able to lift you, but you can still have cuddles", which was then followed up by a further social story when his grandad had died of what had happened and what this would mean. It provided a focal point for staff to chat to him about this very sensitive but important issue and ensured that it was talked about.

Dodd (2005) highlights that "the absence of a person who has died is the tangible manifestation of his/her death, and people with learning disabilities will recognise the absence of someone they love. They will grieve for a loss with or without comprehension of the abstract nature of death".

We are aware that people with learning disabilities who are cared for, tend to experience more loss, as staff who they have become attached to change jobs and shift roles; particularly in times of transition, such as leaving school and moving on to adult provision. Research shows that multiple losses include: saying "goodbye" to staff and friends, moving house, loss of privacy and loss of daily contact with family. Doka (1989) states "cumulative losses may result in an atypical, prolonged or complex grieving process". Hence we need to recognise the importance of key people in the lives of learning disability clients and prepare them for change. So there is a need for resources to support other types of loss which can be very stressful and upsetting for people with learning disabilities.

The bereavement working party is due to re-convene, a year after the first work was done to discuss how we can continue to improve the support process now that we have had some experience of using the resources. Suggestions so far include exploring different faiths

and making profiles on family beliefs, discussing things that have and haven't helped, building resources to explain to the young person regarding the next steps such as the funeral and life without that person, addressing some of the difficult questions that arise from the young person and building AAC resources to support understanding around other types of loss such as change of staffing. ✳

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Speech & Language Therapists

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APPENDIX 1 - CONTENTS OF RESOURCE PACK

Initial Breaking News

- *Instructions*
- *Script*
- *Makaton signs in the order of the script*

- *Makaton signs for family members*
- *Makaton signs in alphabetical order*
- *Symbols to use with the script*
- *Symbols for family members*
- *Photos of relevant people. These should be with the student/customer.*

Talk Further

- *Symbols for "I need some space/time to think", "I have a/some question(s)", "Why?", "Tell me again", etc.*
- *Signs and symbols life & death, feelings.*

A second Resource Pack is available which can be used as talking points after the initial breaking news and there may have been some time to absorb the news – could be hours later or next day or at a later date – hopefully with staff who know the student well:

- *Ideas of how to initiate conversation giving opportunity to talk*
- *Social story re. funeral (to be made)*
- *Do they want to go*
- *Ways of coping with their feelings*
- *Makaton signs re. Bereavement.*

Instructions

Take a little time to familiarize yourself with the contents of this pack before going into the situation.

These are guidelines to be used by the person /people who have the task of breaking the news of bereavement to one of Dame Hannah Rogers Trust students or customers.

It is vital to keep your language simple at this stage. The script should be followed as closely as possible. It may sound harsh to you and those around you but it is necessary at this point.

Do not use phrases such "gone to sleep" or "passed away". Use concrete language.

Before you begin to speak, extract the photograph of the person who has died from the person's family photos. Only use this photo, do not use any others at this stage as it may cause confusion as to who has died.

Have the pack of symbols and signs to hand and make yourself familiar with what is avail-

able and appropriate to use. These are all included in the pack.

Find a quiet place with no distractions.

*The words in *italics* have the description of their signs in the pack. We use Makaton signs.*

Script

I have/We have something very sad to tell you. [Do not assume it will be sad, it may not be. If appropriate, omit the words "very sad".]

Your Dad Mum sister brother has died.

He/she died yesterday/today.

He/she died at home/in hospital/(somewhere else).

You will not see him/her again.

It is very sad.

We will look after you and help you … pause ... (time to take it in).

Do you understand?

Dad Mum sister brother has died.

It is very sad ... pause ... (time to take it in)

Mum/Aunty/whoever is coming today/tomorrow.

Someone will stay with you.

We will talk with you again soon/when you want to.

Symbols to use with the script

Sad, Dead, Today, Yesterday, Tomorrow, Home, Hospital, Won't see, Help, Do you understand?, Stay with you, Do you want to talk? (Let's talk).

We used Mayer-Johnson PCS symbols.

APPENDIX 2 - FEEDBACK

Here is the feedback from our bereavement presentation at Seale Hayne in June 2011:

Comments

Make the negative concept easier to understand. Use "gone" or "not" rather than "won't".

Good guidance.

Clear, useable and reassuring for staff.

When publishing the pack, probably give the ideas and outlines for stories so people can develop their own resources based on the symbol set/signing set they use in their own establishment, e.g. We use STC (Somerset Total Communication) signs, Widgit black and white symbols, some Widgit coloured symbols, some pupils use photographs. We would buy a published copy!

The person is asked if he would like you to stay with him. I wouldn't leave someone alone if I had just given him news of a death.

Some use of capitalization in text does not help.

Encourage people to individualize – ask for relevant photos from family. Try photo stories.

Clear photos as well as symbols would be useful. Also resources for other religions.

Good, but some of my clients would find the vocabulary difficult e.g. tomorrow, yesterday

Social stories are great!

The Chailey Communication System

Twenty years on

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The Chailey Communication System was introduced in the summer of 1991 at Chailey Heritage, a centre in East Sussex providing education, assessment, medical, and therapy services for children and adults with complex physical disabilities.

THE HISTORY OF THE CCS

The Chailey Communication System (CCS) is a low tech communication book. The vocabulary is laid out in the book in a particular way: there are sixteen categories, each with a number of subcategories and potentially an unlimited number of vocabulary items. In order to locate any vocabulary item, there are always these three levels to go through, for example:

1. Category: *Places*
2. Subcategory: *School*
3. Item: *Classroom*

The system was initially developed twenty years ago at Chailey Heritage Clinical Services and Chailey Heritage School, in conjunction with Widgit. The development team consisted of a speech and language therapist, specialist teacher and the team at Widgit.

Originally the CCS was developed for children with severe visual impairment.

The systematic structure and layout meant that it was predictable and could be learnt by people who required auditory scanning: they were able to predict what came next. However, it soon became apparent that this system was suitable for people who did not have a visual impairment, but who required a structured alternative communication system. Therefore the original project team developed the CCS using Rebus symbols as well as a written word version.

Since 1991 there have been three versions of the CCS available commercially. These are A4 and A5 with black and white symbols, and an auditory scanning word list version. The symbol versions have up to fifty symbols per page.

THE CCS NOW

The CCS has developed over the last twenty years and it is now used with a much wider client group than it was originally designed for. It is used with children and young people with and without a visual impairment. The CCS is easily adaptable and personalised to include photographs, pictures, symbols or written words depending on the user's needs. This makes it an appropriate tool to use with people who have a range of physical and learning disabilities. Many people use the CCS as their permanent alternative method of communication and it has also been used successfully with people with an acquired brain injury, as a stepping stone to regaining their language skills and speech.

The CCS can be accessed in a range of ways including direct access (using a finger, eyes or a pointer), auditory scanning or visual scanning.

Despite what might at first appear to be a rigid structure, the CCS provides huge flexibility – it can be used to express single words, short phrases and complex novel phrases.

The CCS is a complete communication system enabling the user to potentially fulfil any communication function, including expressing a need, conveying a message, sharing an idea, and asking a question.

The CCS is taught alongside activities to promote normal language experiences and concept development. The system can be reduced or expanded to meet the person's developmental level and the structuring of vocabulary provides a consistent framework in which lan-

guage comprehension can evolve by repetition and rehearsal.

CASE STUDIES

Joshua

Joshua is a twenty year old man with a diagnosis of cerebral palsy. Joshua has used the CCS since he was four years old. He is able to point to the symbols using his hand when he is feeling well. When he is not feeling well enough, he relies on his communication partner to point to the items and he will indicate 'yes' when they point to the item he wants to say. Joshua is able to construct full sentences using his CCS book. Through using the 'alphabet' category he has also developed his literacy skills and is now a competent user of an alphabet chart for giving short messages; this is always on his wheelchair tray.

Joshua also has a voice output communication aid (VOCA) and he has the CCS programmed onto this. This means that his low and high tech methods of communication provide the same vocabulary and layout.

Last year Joshua used his CCS book to help him to take his entry level examinations.

George

George is an eleven year old boy with a rare genetic disorder and associated physical disability. At a young age, George's speech was severely unintelligible (dysarthric) and caused him great frustration. A CCS book with photos and symbols was introduced to him when he was two years old. He used this system alongside his speech in order to develop his language skills and to help him to be more easily understood. This also reduced his frustration.

As his speech developed, he relied on his CCS book less and less and at the age of ten he made the decision to use his speech as his main method of expression. He still has the book although it is very rarely used.

Natalie

Natalie is a 13 year old girl. She has a diagnosis of cerebral palsy, associated learning disability and is registered blind. Natalie does have some vision, but does not use it functionally especially in busy environments such as a classroom, rather she uses her hearing to understand the world around her.

Natalie was introduced to the CCS initially by learning how to make a choice of two activities. Her visual difficulties meant that using pictures or symbols was not a functional way for her to access the vocabulary in the book. She therefore began to learn the skill of auditory scanning. She worked on developing a consistent yes and no response. Natalie could quickly make a choice from a list of two activities and then three, four and then eventually up to twenty at a time.

Natalie was also able to learn basic categorisation skills, so that she knew that playing with a doll was in the *activities* category. Following this, as her vocabulary developed she learnt the skill of sub categorising and knew that playing with a doll was in the *toy* subcategory. This is not an easy task for someone with a visual impairment and a physical disability but Natalie was determined to have her say.

Natalie is still learning about her CCS book. New words and phrases are constantly taught and added to it. She is able to select a series of keywords to construct a message. She uses her CCS book to: access the curriculum; say what she wants to do and who with; tell her news; chat with her friends; and tell jokes.

THE PROJECT

During the last twenty years the client group at Chailey Heritage has changed, and as a result it has been necessary to develop the CCS. An increasing number of children require a communication book with fewer symbols on a page, or they need it in colour.

As the English language has evolved, the vocabulary in the CCS has become dated and therefore there was a need to update this vocabulary. For example 'tape recorder' needed to be replaced by 'CD player', as well as 'MP3 player', 'iPod', and so on. Additionally, CCS users regularly ask for additional commonly used phrases to be put into their CCS books.

Therefore a new project team was established in order to review the CCS. The team consists of speech and language therapists from Chailey Heritage Clinical Services, a specialist teacher from Chailey Heritage School and the team at Widgit.

The team have updated and modernised the vocabulary in all the categories; many more phrases have been added to the vocabulary lists. Widgit have developed new symbols for the CCS in order to accommodate all the additional vocabulary.

During the project, the team has consulted with teachers who use the CCS daily, physiotherapists, occupational therapists, nurses and families to ensure that all the most commonly used vocabulary is available.

In addition, people who use the CCS were consulted to help critique the current CCS and to give their ideas about improvements or additions to the vocabulary and layout of the system.

QUOTES

CCS users

"It's like the world to me."
  "Helpful."
"It would be rubbish without one."
  "Good, nice."

Parents

"It has served him well."
  "The relatively small steps through, and the fairly concise vocabulary seem to be the most efficient way of making himself understood."
"The CCS is great."
  "It's a fast way to identify keywords."

Speech and Language Therapists

"It's an invaluable tool for a child with acquired brain injury, especially in the early stages."
  "Care staff find it really quick to learn and easy to use."
"It's transportable and flexible."
  "It can be used as a temporary or permanent solution to a child's communication difficulties."

THE FUTURE OF THE CCS

As a result of the project a greater range of CCS book designs were developed. CCS books with 6, 15 or 45 vocabulary items per page were produced in order to allow for a wider range of users to access the system. Each of these versions could be produced in black and white or colour for symbol users, or in a written word list for use with auditory scanning; each of these could be made in A4 or A5.

The team continue to work together to develop the vocabulary and choice of symbols available in the CCS. The team hope that in the future the CCS can meet the needs of many more client groups and that it will be a readily available tool for people who require a low tech communication system.

It is hoped that the new versions of the Chailey Communication System will be commercially available in 2012. ✳

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Information – Need it, but can't read it

The use of Computer Aided Information

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Imagine the scene, Becky has her first baby. She is alone, save limited support from paid care staff, with no family or friends. Similar to all new mums, she is bursting with questions, keen to learn how to care for her baby and anxious make sure that she does everything right.

Her anxieties are increased by children's services placing her baby in foster care. This results in supervised weekly contact, during which her parenting skills will be assessed. There is the threat of 'adoption', whatever that means. People she does not know appear on the scene, talking to and at her using strange new terms like 'child abuse' and 'risk' and lots of long meetings are held. Becky has a learning disability.

Most information about child care is written in 'Easy Read' formats. Walmsley (2010) argued that 'easy read' information can be over simplistic and not effective. A recent review of 'easy read' materials to enable parents with learning disabilities identified that it was used inconsistently and could result in confusion (Dowds 2011). Becky is unable to read any information provided for her. This is a complex and challenging situation. How do we support Becky to access the information she requires?

This article aims to describe the work undertaken to support information access based on the principles of the 'Accessibility triangle' (Oldreive and Waight 2011). It summarises a journey that began with challenges, resulted in

clinical innovations and demonstrated the value of personalised accessible information based on individual screening.

THE ACCESSIBILITY TRIANGLE AND ITS IMPLICATIONS

This model (Figure 1 overleaf) aims to outline the three components that determine effectiveness of accessible information: (1) breaking the codes; (2) functional use of information; and (3) memory and control. Each theme will be briefly explored before reference is made to the example.

1   Code breaking

There are two codes to consider:

- The ability to understand the language including the meaning of words and grammar – the linguistic code.
- The ability to extract meaning from the code – the symbolic code.

The relevance of the material to the individual is also of importance. If Becky felt that the information reflected her story and her reality, she would consider it as more credible and relevant to her (Ward and Townsley 2005).

She was able to understand a range of everyday words but was confused by jargon or less commonly used words. She tended to use her own personal terms which she found easier to understand. She was able to understand negatives (not) but could be confused by pronouns and tenses. As she was

unable to read, she quickly became upset and agitated when asked to read a series of single words.

Assessment of her abilities suggested that she would need help to understand both the symbolic and language codes. This could be done by dispensing with the need to read any information, simplifying and clarifying the language used and explaining any complex jargon or professional terms.

2   Using information

This theme refers to the ability to use information through verbal reasoning i.e. being able to make judgements based on information, by considering all the different options. In previous work regarding mental capacity we had developed the levels of processing framework to help account for variable abilities in this area (Waight and Oldreive 2011, Oldreive and Waight 2011b). A summary is included in the accessibility triangle.

Assessment demonstrated there was a degree of rigidness to her thought resulting in some difficulty thinking creatively. She easily became confused and benefited from information being split into chunks to help her make decisions or identify the correct information for a specific situation. She found it hard to follow sequences of events or timelines. This could impact on her ability to develop an overall understanding of when events occurred.
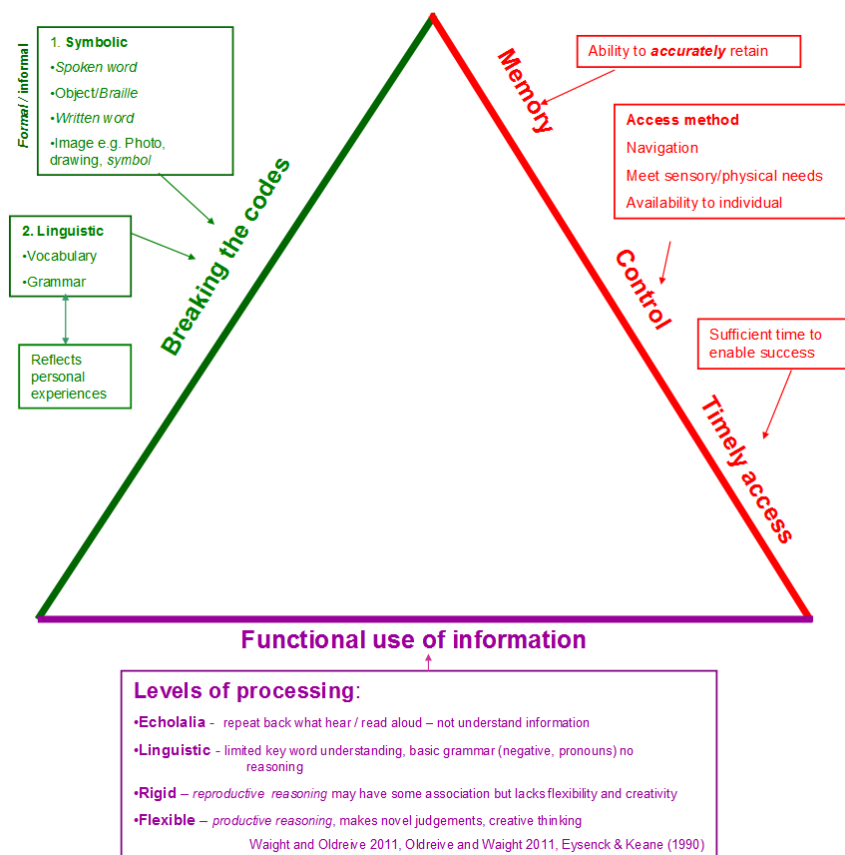
Figure 1 **The Accessibility Triangle**

3. Memory and control

Memory involves the ability to retain accurately specific details of information. Control refers to the ability to both access information independently and to control the flow of information by making selections and choices.

Becky found it hard to retain specific items or points of information. She was confused if a lot of information was provided from different sources at the same time. She tended to use prior information to fill in gaps of her knowledge. This influenced her ability make decisions with the correct information. She had her own personal lap top which she was able to access at will. She was able to access the Internet without assistance from staff.

WORK UNDERTAKEN

In order to help Becky we needed information that could:

- overcome literacy needs;
- enable individual to control process;
- use personalised language where possible;
- use images to support understanding;
- support understanding of sequences of events;
- support understanding on variety of related topics;
- support memory needs by ensuring independent access.

Computer AideD Information (CADI) was used to provide the information.

This approach has been explained in detail in Oldreive and Waight 2011 a&b and Oldreive and Waight 2010. It involves the individual accessing icons on computer screens which talk. Thus s/he is able to access pre-prepared information without the need to read it and personalised language can be used. The spoken word is supported by images including photographs, drawings or other symbols as appropriate.

Oldreive and Waight (2010) argued that efforts should be made to include individuals in the development of their materials. This principle was applied and accordingly meetings were held with the individual at her home address to agree what information was required. The accuracy of the information especially regarding the complex issues of adoption and child abuse had been checked by local agencies, e.g. the adoption advisory service.

Becky requested information on:

- Child care – including how to change nappies and use bottles
- Child health – how do you know something is wrong and what to do
- Child development – specific information on first year
- How to play with your baby including nursery rhymes and games to play.

- Key information arising from meetings. This included details of the child permanence report and the adoption process with specific details about child abuse.

Individual programs were created on each of the topics. The programs were organised into an index to help with selection of the topic. Becky was able to scan and choose between specific programs. When a program was selected it went to the introduction screen for that program. She was able to use icons to return to the index if she decided that she did not want that topic.

Generally each specific program contained a menu screen which was controlled in the same way as the index. This enabled Becky to make specific selections, e.g. age groups or skill requiring support.

Where appropriate, the menu enabled access to *timelines* to explain sequences of events (including how to complete a task or relating to adoption) and *definition screens* to explain complex jargon terms e.g. child abuse and foster care.

It was possible to include music within the programs which meant that nursery rhymes could be 'sung' to help her learn them. In order to enable access to the information, the CADI software was installed on her personal laptop.

THE PROCESS OF SUPPORT AND REVIEW

Becky was shown how to use the computer program initially on a computer owned by the Community Team for People with Learning Disabilities (CTPLD) supporting her and in due course the programs were transferred to her own computer. Sessions were held at her house to familiarise her with the information and programs gradually introduced usually on one to one sessions.

At one point, there were concerns about her ability to access the programs on her computer. After investigation it was evident that she could not use menus on her lap top to locate the software. Placing an icon on the desk top screen solved this problem. She learnt how to use the software, activate the icons and navigate through programs. She quickly demonstrated that she was able to access the right program for specific information without support from the therapists, although she probably favoured the lighter programs e.g. how to play with her baby than those about more stressful matters, e.g. foster care and adoption.

Screening effectiveness is important (Oldreive and Waight 2010) and she was asked to locate specific information contained within the programs. This helped us to evaluate her problem solving, program selection as well as navigation. We were pleased with her responses. Occasional errors in program selection were made, but she was quickly aware of them and could correct independently.

We also asked Becky questions during these sessions, aiming to evaluate her ability to both understand and use information. If there was language used that was unclear, modifications were made including: the inclusion of a definition screen or a re-wording of language used. For example she stated she preferred the term solicitor to that of lawyer (the one which had been used in the program) so that was changed.

In this way the program continued to evolve to meet her needs and to facilitate her understanding. This evolution also occurred within the index screen. Over time the specific programs included were modified to meet differing needs. The links to specific programs could be removed and new ones created.

CONCLUSIONS

By using CADI we are able to support Becky to access information to a certain degree. Her staff team observed a change in her attitude towards them, saying that she became more willing to ask questions and make comments.

On one occasion, she fed back her concerns about an observation made about her which had been written in a report that she could not read but which had been put on the computer. She herself thanked the support team and suggested that the use of the computer had helped her understand what was happening. ✳

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Service Delivery

The perspectives of a speech and language therapist and a client

BARRY SMITH & LINDA PAGE [1]

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INTRODUCTION

What is a good AAC Service?

In order to provide the best possible outcome for the person who uses AAC, it must be about more than an initial assessment and support in the early stages of using a device.

In this paper, speech and language therapist Linda Page gives a brief overview of how the AAC Service of NHS Ayrshire and Arran has developed over the years, and Barry Smith gives a personal perspective as someone who has experience of using this service over many years.

AAC RESOURCE NHS AYRSHIRE AND ARRAN – LINDA

NHS Ayrshire and Arran covers a population of nearly 370,000 across both urban and rural areas. There are three local authorities in the area covered by our Health Board – North, South and East Ayrshire.

NHS Ayrshire and Arran has developed its service to people who use AAC over the last 20 years. The AAC Resource provides assessment, loans of equipment and support to children and adults across the Health Board area. We strive to ensure provision of services are tailored to meet each individual's needs, and that the initial support and training when the individual receives their communication aid is of a high quality. Beyond that, the AAC Resource aims to ensure that people who use AAC have access to ongoing support and advice on using their device, as well as being available to help solve technical problems as they occur. There are key times when additional intervention or support is required, around transitions in life, or when a client's device needs replacing.

MY USE OF AAC – BARRY

I currently use a Lightwriter SL40 to augment my speech. I have cerebral palsy and have used a range of methods to augment my communication over the years. My early experience of AAC was as a Bliss user. I also tried some voice output devices while at school, however it wasn't until I was leaving school to go to college that I decided to look again at AAC.

I arranged to meet with Linda for an assessment and attended with my mum. During this assessment, we looked at some voice output devices. We also discussed my past experiences of using augmentative communication and why I wanted to use voice output now. We arranged a trial loan of a Lightwriter for me to see how I got on with it.

I started college using this Lightwriter. It felt good using the Lightwriter and it made a difference to me that people weren't standing over me reading what I was saying, which is what happens when you use a low tech system. Linda visited me at college to see how I was getting on with the Lightwriter. Following this, Linda applied for funding for a Lightwriter SL35 for my use.

SERVICE DEVELOPMENT – LINDA

Around this time, a bid to provide extra staffing for the service was successful, which allowed an increase in the sessions I provided – the post increased from 0.1 WTE to 0.5 WTE. Simultaneously, additional funding for AAC devices allowed the purchase of new equipment. The increased allocation of time allowed me to look at how I should move forward to develop the service. I wanted to make sure that SLTs, clients and their carers and families all knew how to access the service and what they could expect.

Protocols were developed with the agreement of the Speech and Language

Therapy Manager and these detailed the referral procedure for the case therapist. This document also clearly identified the ongoing role of the case holding SLT and detailed what they could expect of the AAC Resource SLT. A referral form, and equipment loan forms were also developed at this time.

Tracking the equipment up to this point had been done via a card index box. This was a reliable system, however it made collating an annual report on the activity of the resource cumbersome. A database to track all the voice output devices and switches was developed. The design of this was carefully considered and over the years has allowed the service to report accurately on activity relating to client (diagnosis, age, location), equipment type and referral source which was of early use when there were three NHS Trusts in Ayrshire and Arran. It has allowed us to keep track of the equipment and has ensured robust management of all the devices funded by the Health Board.

GETTING MY LIGHTWRITER - BARRY

The Lightwriter SL35 I got was funded by the National Health Service, and the good thing about this is that the NHS pays for any repairs to my Lightwriter. Over the years, this has saved me a lot of worry. I know exactly who to go to if there are any problems, and Linda has always been able to provide another Lightwriter for me to use, if mine is away for repair. This is the same for everyone in Ayrshire.

I know this is not the case in some parts of the UK. Linda had made a form which I signed, and this explained all of this. It also told me that if I did not wish to use the Lightwriter at any time, it should be returned to her department. Having my Lightwriter made such a difference to my life. I would like to see the same service available to others in my position across the United Kingdom.

Linda also organized for my Lightwriter to be mounted onto my wheelchair. I didn't want my Lightwriter mounted. I thought it would stop me getting in and out of my chair at first. However, this mount allows me to move it aside easily. I felt really happy with my new Lightwriter, and had help when I was getting used to it both at college and from Linda.

I used this SL35 Lightwriter for years, and loved it. I used it through my college course, and then to take part in a *Partners and Policy-Making* course. I got a huge amount out of that course and was able to learn new skills, make contacts, and move towards making my life

better. I think that taking part in these groups, would have been so much more difficult without a voice output device. In fact without my Lightwriter I don't think I would have been able to take part in the project. All through this time, my goal was to get my own home, which I did indeed achieve.

Once I was settled and living independently in my own home, I needed a new challenge. I decided that sharing my experiences of using a communication aid, was the next goal I wanted to achieve. So, in 2008 I submitted an abstract to Communication Matters. It was accepted. Linda and I approached Toby Churchill Limited, who agreed to support my attendance at the conference. I wrote my talk, and Linda helped program it onto my Lightwriter.

Giving a presentation about my life using my Lightwriter SL35 and attending the conference was a fantastic experience for me. It also was my first chance to see the new Lightwriter model SL40.

PROVIDING ONGOING SUPPORT – LINDA

Retaining ownership of all the systems, and providing an ongoing and supportive link for everyone who uses high-tech AAC devices in the area has benefits for clients and for our service. Any equipment no longer in use is returned to the resource for cleaning and resetting and can then go back into our loan bank of equipment. Devices in use by clients are kept in good working order either by maintaining the warranty or by paying for repairs.

In our aim of providing the most effective AAC, we must review the equipment we have provided to clients on a regular basis. With the launch of the new Lightwriter, it was clear that this would speed up Barry's communication and bring him other benefits, so I applied for funding to purchase the Lightwriter SL40 for his use.

MY NEW LIGHTWRITER - BARRY

I got my Lightwriter SL40 in January 2009 and it has really taken my independence and confidence up a level. As well as speeding up my communication, the ability to use the Lightwriter to send and receive texts is great. Once, when I was out alone in my power chair, I toppled over. I had no way of getting help, but now with my Lightwriter SL40 I could text someone to get help. Mum feels it has given her peace of mind.

More recently I swapped to a Lightwriter Connect which is great. It gives me access to making phone calls and texting from my Lightwriter. The Lightwriter

voice quality when using my hands free phone on the land line is great, but it is fantastic being able to make calls on my 'Lightwriter mobile'!

MAINTAINING AND DEVELOPING THE AAC SERVICES – LINDA

As well as my assessment, support and training role for people who use AAC, it is essential to promote the use of AAC across the Health Board and local authorities in Ayrshire, as well as Scotland wide, to secure funding and support for future developments. This is something we are both involved in. Currently we are awaiting a report on AAC services in Scotland that is due to be published by the Scottish Government.

MY DREAM FOR FUTURE AAC PROVISION – BARRY

The experience I have had of using my Lightwriters and the support I have had over the years has been good. I want to see people in Scotland and across the United Kingdom getting the same support as myself. Lack of money should not stop people communicating. ✳

Barry Smith

Linda Page
Lead Speech and Language Therapist for AAC

The Aphasia Software Finder

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In 2010, the Tavistock Trust for Aphasia commissioned a project to develop a free online resource to help those looking for aphasia therapy software.

WHY WAS IT DEEMED NECESSARY?

Unfortunately, not everyone with aphasia has access to regular speech and language therapy throughout their journey to recovery. Consequently, some look for alternatives and in doing so, very often turn to the Internet to find solutions.

Evidence has shown that computer assisted treatments are an effective way to intensify and continue the rehabilitation process.

Indeed, in its resource manual for commissioning & planning services for SLCN (speech, language and communication need), the Royal College of Speech and Language Therapists quotes in its section on aphasia that "computer based therapy directed by a speech & language therapist is beneficial, cost effective and acceptable".

A fair number of aphasia therapy programs are now available. The aim of this free website is to gather into one place, information about all those programs in the English language.

It is designed to help people with aphasia, their carers and therapists, to find objective information rather than just investigating via the distributors' websites.

HOW DOES THE SITE WORK?

There are three different ways to use the site:

- The Finder: enter the area(s) of language difficulty (e.g. talking, spelling, listening) and the finder will identify those programs which could potentially be of benefit.

- Comparison table: if you have set criteria that you'd like the program to meet, compare all the programs available in the table to find those which you'd like to know more about.

- The search box: Put the name of a program you've heard about in the search box and it will find the program summary.

Regardless of which method is used, the site will provide detailed SLT focused or

aphasia friendly summaries of each program suggested, enabling an objective, informed choice to be made.

HOW WERE APPROPRIATE PROGRAMS IDENTIFIED?

Only programs professing to specifically target aphasia and which were identified by British, American, Australian, South African and New Zealand search engines were included.

Search words likely to be used by people with aphasia, carers & therapists were used (e.g. 'computer therapy', 'aphasia', 'treatment', 'reading therapy for aphasia', 'speaking therapy for aphasia').

From these programs, only those available through known suppliers, providing some level of support were included on the site ('home-made' programs and those for research purposes weren't included at this stage).

ENSURING OBJECTIVITY

It was very important that the site remain objective and provided no qualitative judgements.

This was achieved by analysing each module of every program using the same rigorous criteria set out by the project team at the outset.

No incentives were provided by suppliers. The entire site was then 'road tested' by people with aphasia who gave invaluable feedback on the layout and language used as well as what they considered to be useful/non useful information.

Price details are not included on the site since these are subject to frequent change. At the end of each program summary is a link to the software supplier where detailed information about prices and demonstration versions of the software can be obtained.

FUTURE PLANS

The Tavistock Trust have provided ongoing funding to maintain and update the website over the coming years so it will grow and change as more software becomes available.

Funding has now also been provided to develop a similar 'Finder' for aphasia therapy apps, other useful apps and also for non-aphasia specific programs to help with functional activities of daily living.

To find out more, visit the website at *www.aphasiasoftwarefinder.org* and provide any feedback you have via the 'Feedback' buttons on the site. ✳

Sarah Woodward
Highly Specialist Speech & Language Therapist

WEBSITE

www.aphasiasoftwarefinder.org

An Audit of AAC in a Special Needs School

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BACKGROUND

Curnow School is a large special school situated in Redruth, Cornwall. Curnow School caters for children with severe learning difficulties, some of whom have additional sensory and/or medical needs. Many of the children have difficulties in managing their own behaviour as a result of their Autistic Spectrum Disorders. Curnow School covers a large geographical area from Newquay to Coverack on the Lizard to Hayle, a total of 170 square miles.

As part of Curnow School's Improvement Plan, the school became a specialist school in Communication and Interaction in September 2009. With this funding a Communication & Interaction Team was created. The Communication & Interaction Team consisted of a Lead Teacher, a Speech and Language Therapist, and two Communication Support Workers. These posts were funded for a fixed term of three years.

The Communication & Interaction Team was given the primary task of improving communication in Curnow School by coordinating communication activities within the school. Within this task there were a number of projects on which the team focused.

The first was the Communication Passport project. The school aimed to ensure that every pupil at Curnow School had a communication passport. As part of this project, 'hotspots' were identified and prioritised. The first of these hotspots was the new intake at the lower end of the school – those pupils coming from nurseries or Child Development Centres across the county. The other hotspot was the post-16 group who would soon be moving on to adult services or on to college provision.

As well as the Communication Passport project, the team also wanted to develop: the use of objects of reference in school; improve the directional signage throughout the school; and maintain the momentum of the Makaton training that was being done with a core team of staff in the school with the support of an external provider.

AIMS

With the creation of the Communication & Interaction Team and the identification of these initial projects, it was felt that there needed to be a baseline to enable progress and contribution to measured. An audit would allow for the number of Communication Passports to be recorded, and which AAC systems were being used within the school and how often.

The AAC audit had several aims. The main reason for conducting the audit was to determine the number of pupils who had communication passports and to identify the AAC systems currently being used by pupils in the school, and thus how their current communication needs were being met.

The audit also had the added benefit of identifying any areas where the staff might require further support to ensure that the classroom environment was as conducive to effective communication as possible. An additional benefit of this audit was that staff were encouraged to complete the forms as a class team thus creating an opportunity for the team to discuss each pupil's individual needs and to share strategies.

This would also mean that the communication systems being used with the pupils were consistent across staff teams and it would highlight the shared

responsibility of communication needs. The audit was intended to be conducted regularly enough to ensure any changing communication needs of the pupils continued to be met, and that any progress the pupil was making was supported effectively.

The audit form distributed to staff also contained a section where staff could request specific resources to be created or ask for support around a specific pupil's communication needs. A formal record of this was then created to ensure it was followed up, and to track to whom the task was allocated.

METHODS AND PROCEDURES

Each class team was given an audit form to fill in for each pupil (see Figure 1). Each audit form consisted of tick boxes and comments sections relating to various communication systems. This information was then transferred into a database collating all the information into a communication systems summary.

Any requests that were made on the audit form were also recorded in the database, and then shared with the Communication & Interaction Team

and the speech and language therapy colleague in the school. These requests were then allocated to members of the team to follow up.

Some examples of the requests from the first audit that was completed in the Autumn Term included updates to communication passports with new class information; guidance around developing PECS with a pupil; and support in developing the use of a visual timetable. Requests from the second audit included updates for a communication book to include vocabulary relevant to the curriculum, and advice around de-

Name of pupil: Class/Class Teacher:							Date: **Autumn Term**			
Makaton 1:1	Comm. Passport	Comm. Book	Symbols	O of Ref.	PECS	Visual timetable	Now/next Sequence Strip.	High tech Big Mac, Go Talk, etc please specify	Other	
How frequently are the systems used?				Are these systems effective? Please give reasons why.			Any other comments?			

Figure 1 Autumn Audit Table - Communication and Interaction Team audit of communication systems

Name of pupil: Class: Class Teacher:						Diagnosis of ASD: Yes No		Date of Birth:		Da**te: Spring Te**rm	
Objects of ref.	Photos	Symbols	PECS	Comm. Book	Makaton	Now/next Sequence Strip	Visual Timetable	Voice Output Communication Aids (VOCAs)	Verbal	Comm. Passport	Other
Used to aid Comp. Used to aid Exp.	Used to aid Comp. Used to aid Exp.	Used to aid Comprehension Used Expressively Please specify symbol set used:	Yes No N/A	Yes No N/A	Group 1:1 Both N/A	Yes No N/A	Class Individual N/A	Y N N/A Please Specify:	Primary Method Secondary Method N/A	Yes No N/A	Please Specify: ....
How frequently are the systems used?					Are these systems effective? Please give reasons why.			Any other comments?			
									Key Comp. = Comprehension Exp. = Expression		

Figure 2 Spring Audit Table

veloping the use of objects of reference in class.

The audit form that was distributed for the second audit in the spring term (see Figure 2) was updated in collaboration with the staff teams to gather more specific responses, particularly with regard to the use of pictures, symbols and photos and how they are used in the classroom.

For each audit a summary spreadsheet was completed, thus enabling any new systems to be noted and the change in the number of passports to be recorded.

OUTCOMES AND RESULTS

In the initial audit in the first half of the Autumn Term 2010 all 87 pupils on the school role had a form completed by their class staff teams. The second audit was conducted in the first half of the Spring Term 2011, again with completed responses from all 87 pupils.

The second audit recorded an overall increase in the use of communication systems across the whole school with the Communication & Interaction Team's support and contribution. With the results of the second audit it was found that the number of Communication Passports being used in the classrooms hadn't increased, despite numerous requests coming in and forms being sent out to parents to gather the information. However, when the team looked into this, it was confirmed that there were 30 in the process of being created that were near completion but waiting on photographs and additional information from parties involved e.g. parents and professionals (for a summary of the information gathered please see Figure 3).

The audit had the added benefit of raising staff awareness of the AAC systems they already used in school and prompted consideration of other strategies. The audit database included a formal record of the requests that were followed up by the Communication & Interaction Team and colleagues. This ensured that no requests were forgotten, as is sometimes the case with verbal requests in a busy school setting.

CONCLUSIONS AND IMPLICATIONS

The audit showed a general increase in resources used throughout the school to support communication. The audit also had the positive effect of an increase in the awareness of the

Communication System	Autumn Term 2010	Spring Term 2011	Change
Objects of Reference	24 Yes	24 comp 15 exp+comp	+15
Photos	-	29 comp 25 exp	
Symbols	44 Yes	1 exp 33 comp 16 exp+comp	+50
PECS	20	20	=
Communication Book	16 Yes	26 Yes	+10
Makaton	9 one to one 32 group 19 both 24 none	6 one to one 20 group 40 both 18 none	+6
Now/Next	24 Yes	28 Yes	+4
Visual Timetable	51 Yes	14 Individual 50 Class	+13
VOCAs	22 Yes	23 Yes	+1
Verbal	56 Yes	52 Primary 9 Secondary	Clarified
Communication Passports	25 Yes	25 Yes	= 30 near completion with C&I Team
Other	Music Smell of the day Traffic Lights Talking Photo Album Working Towards Card Pass	Music Smell of the day Traffic Lights Talking Photo Album Working Towards Card Pass	

Figure 3 Audit Summary

importance of communication systems to support language. It encouraged staff to really consider each child's individual communication needs, and prompted the staff to consider areas for further support.

The audit of AAC will now be conducted twice a year by the Communication and Interaction Team. This will be in the second half of the Autumn Term to cover the September

intake, and in the second half of the spring term to cover the January intake.

The Spring audit will also ensure that the pupils in the post -16 group have up to date communication summaries ready for transition. The regular completion of the audit will ensure that the momentum of this project is maintained. ✳

Sally Mills
Speech and Language Therapist

ESSENTIAL PUBLICATIONS

FROM COMMUNICATION MATTERS
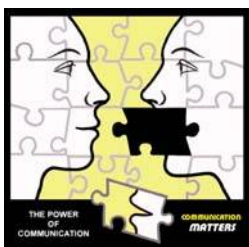
### The Power of Communication (DVD)

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

Michelle Finds a Voice

This book is a story about a young adult with disabilities who is unable to speak or communicate effectively. A number of events cause her to feel unhappy until she and her carers are helped to overcome the communication difficulties. Michelle's story is told through pictures alone to allow each reader to make his or her own interpretation. Published by Royal College of Psychiatrists.

Price: £10 plus £1.50 p&p from **Communication Matters**
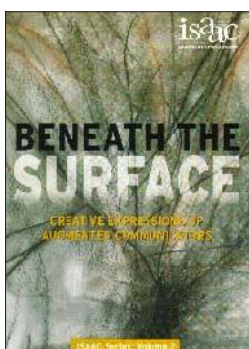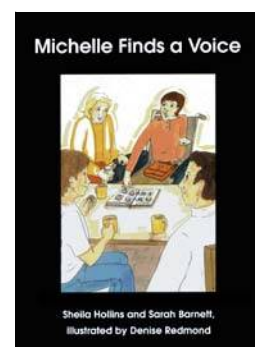
Beneath the Surface

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.

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

Waves of Words

The challenges confronting individuals with severe communication disabilities are chronicled in this ISAAC book. The focus is on the strategies that teachers, therapists and individuals who rely on augmentative communication from around the globe have used to produce ultimate success in the struggle to learn to read and write.

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

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 in-cludes excellent photographs and illustrations.

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

iPad Communication Aid with Grid Player

Available on the App Store

- ✓ iPad
- ✓ Grid Player app
- ✓ The Grid 2
- ✓ Carry case
- ✓ Amplifier
- ✓ Hardware and software support
- ✓ Basic package just £995

gp GridPlayer

iPad with SoundPod speaker system £1210

iPad with iAdaptor hard case £1105

What is Grid Player?

Grid Player is a free app for alternative communication through text and symbols. It enables users of The Grid 2 to use their grids on an iPad. Grid Player for the iPhone and iPod Touch is coming soon!

Grid Player includes 3 grid sets: Symbol Talker A, Symbol Talker B and Text Talker. Other Sensory Software grid sets that can be used with Grid Player include Grid Talk, Talkative and Chatterbox.

Keyguards are available from £50 to fit any size of grid.

Features of Grid Player:

- Widgit and SymbolStix symbols included
- High quality Acapela speech
- Word completion, word prediction and symbol prediction
- 100s of ready-made resources available from the Online Grids website (www.grids.sensorysoftware.com)
- Contact us to arrange a free product assessment

IT DOESN'T ALWAYS HAVE TO BE BLACK!

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