# COMMUNICATION MATTERS

**NOVEMBER 2015** VOLUME 29 NUMBER 3

**THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)**

**IN THIS ISSUE**

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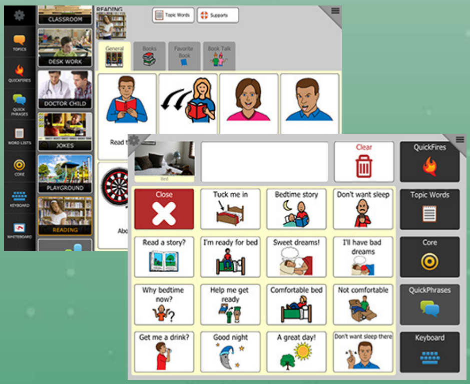

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COMMUNICATION MATTERS JOURNAL
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# Contents

*Thank you to Bob Sagoo, Rosie Clark, Conference Team Techess, Toby Hewson & Brett Reynolds for the photos*

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# Chair's report

## December 2015

In a year of change it has been something of a relief to now have the 2015 Conference safely behind us. Thank you to those who have taken the time to write to say how much you value it-we know there are always things we can do to improve but overall the feedback has been positive and encouraging. We have included more detailed feedback in this edition of the Journal for those who are interested.

The Board of Trustees is about to have the November Board meeting when we review the strategy, business and operational activity of CM. 50% of the Board changed in 2014 which has meant there has been a period of readjustment and settling as we learn to work together and maximise on our skills and expertise. It will be good to have more stability this year and we would like to welcome Janet Scott, from Scotland, who is newly elected to the Board-she brings a wealth of experience not least having been a previous Chair of CM.

The present Board of Trustees is as follows:

(Re)-elected 2015: Tom Griffiths, Catherine Harris, Toby Hewson, Janet Scott

Served for two years: Nicola Hayton, Ruth McMorran, Marion Stanton

Served for one year: Zoë Clarke, Vicky Healy, Amanda Hynan, Sergio Suchowlanski, Adam Waits

We will be looking to co-opt another user of AAC to balance the skill mix within the Board.

It is important that we regularly return to our Vision and Mission Statements and Aims as we plan our strategy for the future and work on the day to operational business of running CM so that our focus remains clear. This was revised in 2013.

**Vision:** A world where all individuals are able to communicate in all aspects of life.

**Mission:** Communication Matters promotes the awareness, understanding and use of all forms of communication so individuals can express their thoughts, feelings, needs and desires using their chosen means.

**Aims:**
- increasing awareness about AAC
- improving Service Standards
- encouraging Research
- lobbying government for change

### Activity in 2015/2016

Conference 2015: There was a good buzz around the Conference this year. Particularly inspiring were the presentations from Denise West and Brett Reynolds who were the Keynote speakers and who spoke about the Australian **Communication Access project**. The feedback from the Conference as a whole was mostly excellent/good from those who completed the feedback forms. We will endeavour to address the issues which caused any concerns and we are always trying to improve the experience for those who attend. We had 430 registered delegates plus additional visitors and students. The Network day with 1Voice, on the Sunday before the Conference, continues to strengthen our links with 1Voice and we hope this collaboration will be a regular feature. We are very pleased that we were able to to support people who use AAC with £13,000 in subsidies to enable them to attend the Conference. Katie Caryer received the Alan Martin award for creativity in 2014 and CM is working with her to facilitate a drama production as part of the 30th Anniversary 2016 Conference celebrations. This year Kate passed on the award to Sam Knapp for his excellent photography which was on display in the Exhibition Hall.

We already have 8 Roadshows booked for the coming year this year, including one in Kent piloting a new format. This follows a positive meeting with the suppliers in July 2015 to discuss how we might refresh and develop the Roadshows in the future.

Planning is underway for 3 Study Days exploring Autism and AAC, Literacy and Voice Banking.

Tom Griffiths has agreed to continue to lead our research working group and we thank him for his work in coordinating activity in this area. The Research Strategy has recently been rewritten and we will need to address how we can best move forward to ensure that research stays central to our core business. We are still reviewing the useage of and investment into the AACknowledge website.

We have a working group reviewing our involvement of people who use AAC and we hope to develop our relationships with the FE colleges this next year with a 'champion' in each college. We also have a newly established working group looking at Literacy and AAC and have set up new networks for this important area. See the article in this journal by Marion Stanton & Rosie Clarke.

There is still a demand for our publications, both hard copies and from the website and the Focus on Leaflets have been revised and reprinted. This has been funded by the money donated by the Kaha team and we are so appreciative of what they have achieved.

Our website is now a central location for updates on Specialised Commissioning and we have established good links with the AAC sub group for complex disability equipment which has a direct line to Carolyn Young. We also continue to have representation on the (NHS England) Specialised Healthcare Alliance and The Communication Trust Consortium. This is all positive in terms of our lobbying and marketing strategies.

## ISAAC

With so much happening within our UK chapter we have been aware that we have not contributed much to ISAAC this year. However, we were so pleased that the Tuesday plenary at the Conference was about looking beyond the UK. Gregor Renner who is the president elect of ISAAC presented at this session. Aldona Adamczyk presented the background to the work in Poland and Dot Frazier shared the vision for supporting less well-resourced countries through her own projects and the work of BUILD. Thanks are due to Janice Murray for her role as the Chair of Council for ISAAC and to Neil Hanson as the CM representative, with myself as the UK ISAAC council member.

There will be an opportunity in the course of this coming year for the associate membership to reflect their views on the relationship of CM with ISAAC. Next year the ISAAC conference is in Toronto. As their largest chapter, the UK needs to be more active in expressing our views and influencing the ISAAC agenda.

## What next?

2016 is 30th Anniversary of the 'conception' of CM. The world of AAC has changed dramatically during the last decade and technology is an essential part of all of our lives. There are more obvious overlaps between wheelchair services, access to technology, environmental controls and communication aids. CM needs to be leading the way to ensure that services work collaboratively and efficiently to ensure that people get the best advice, information and solutions in a timely way.

We are really committed to having more involvement of people who use AAC and are open to suggestions as to how we might do this more effectively. The Communication Access for All project could be a really exciting vehicle for this to develop and we are working on much closer relationships with other charities who are also committed to supporting people with communication challenges. We are aware too that we need to have more regional events with awareness raising about the role of AAC to ensure that we get our message out much more widely throughout the UK.

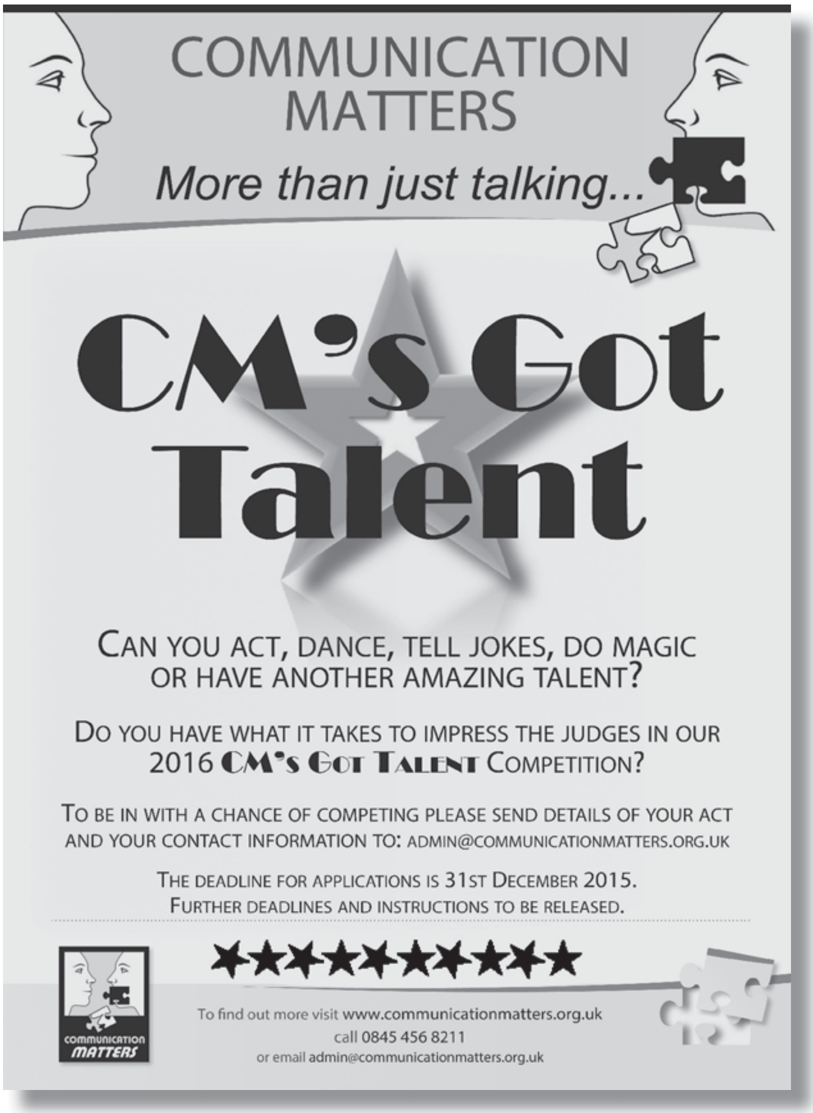
Fund raising and Bid writing is going to be central to our success in this coming year and we welcome input from anyone who has experience in this area. We are also aware that joint bids are often more successful so are looking for partners to work with so that we can apply for shared projects and areas of focus.

The CM Ball on July 2nd 2016 will be a first for CM and we are hoping to further strengthen our links with local businesses in Leeds through this event.

The Sign Out Loud has gone down a storm over the past two years and has shown us a good example of the talent we have within our membership, as did this year's Sunshine Art competition. CM's Got Talent is an initiative which was launched at the 2015 Conference. We are inviting participants (individuals, school or college groups, and adults) to submit a video. We are hoping to showcase the best acts in a fun filled performance at the 2016 30th anniversary conference.

We hope 2016 will be a bumper year to celebrate 30 years of CM.

**Catherine Harris – Chair of the Board of Trustees**



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# CM2015 National Conference: your feedback

**"This was my first CM conference and although I have always considered communication to be quite a high priority, it has really opened my eyes to what extent it can affect people's lives and to how it can be achieved in such a variety of and accessible ways".**

Well another year is over for conference and we will soon be taking bookings for 2016! We thought we would like to share the highlights of the conference feedback with you. Generally those who responded thought it was a jolly good event! Around 450 people attended this year but we only had feedback from 64 of the delegates: we have to assume the rest of you were happy enough! We hope that sharing the results with you will encourage more of you to complete evaluations next year: we really do appreciate the feedback on the organisation of the conference and the individual speakers receive theirs as well (not shown here). If you did fill in the form you may be interested to see how your views fitted with others. We have too many individual comments to share but they are always interesting and to the point!

### What was Liked Best?

***"Everybody being on the same level, barriers disappeared, being inclusive and forward thinking"***

This was one of the uplifting quotes CM received. Innovation and Inclusivity were definitely buzz words for this year. The overview of the global perspective was seen in general as a positive theme for conference. The keynote on the Australian Community Access Project (Denise West and Brett Reynolds) was seen as 'amazing' & 'inspiring' and the several sessions on the back of this project were 'thought provoking'. Local businesses who attended the special session expressed great interest in CM's potential future plans for training as it was 'much needed'. The new 'Literacy Network' was described as a fantastic idea

### Analysis of Feedback

(2014 scores shown in brackets)

| **Sessions** | | | | |
|---|---|---|---|---|
| | | | Communication Access | AAC Around the World |
| | Sessions attended | Exhibition | Mon Keynote | Tue Plenary |
| **Average %** | **86 (87)** | **83 (85)** | **88 (92)** | **60 (72)** |
| Poor (scores 0) | 0 | 0 | 0 | 0 |
| Weak (scores 1) | 0 | 0 | 0 | 1 |
| OK (scores 2) | 0 | 3 | 4 | 7 |
| Good (scores 3) | 32 | 36 | 22 | 6 |
| Excellent (scores 4) | 27 | 24 | 36 | 5 |
| *blank* | *5* | *1* | *2* | *42* |

| **Sessions attended were:** | |
|---|---|
| Too long | 0 |
| Mostly right | 54 |
| Too short | 5 |
| *blank* | *5* |

| **Parallel sessions were:** | |
|---|---|
| Too many | 11 |
| Mostly right | 45 |
| *blank* | *8* |

| **Value for money?** | |
|---|---|
| No | 1 |
| Yes | **49** |
| Yes but expensive | 11 |
| *blank* | *3* |

| **Attended CM Conference in previous 3 years** | |
|---|---|
| No | 22 |
| Yes | 39 |
| *blank* | *3* |

**Food & Drink**

| | Sunday Dinner | Lunches | Conf Dinner | Tea/Coffee |
|---|---|---|---|---|
| **Average %** | **83 (78)** | **79 (78)** | **90 (84)** | **76 (75)** |
| Awful (scores 0) | 0 | 0 | 1 | 3 |
| Poor (scores 1) | 0 | 3 | 0 | 2 |
| OK (scores 2) | 7 | 10 | 4 | 10 |
| Good (scores 3) | 25 | 23 | 10 | 22 |
| Excellent (scores 4) | 24 | 27 | 42 | 26 |
| *blank* | *8* | *1* | *7* | *1* |

**General**

| | Residential Accomm. | Socialising | Monday Night Entertainment | Joining Info | Registration at venue | Car Parking | Overall organisation |
|---|---|---|---|---|---|---|---|
| **Average %** | **89 (90)** | **88 (83)** | **84 (65)** | **83 (85)** | 89 (87) | 71 (72) | 93 (92) |
| Awful (scores 0) | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| Poor (scores 1) | 0 | 0 | 1 | 2 | 2 | 0 | 0 |
| OK (scores 2) | 3 | 2 | 7 | 4 | 2 | 12 | 2 |
| Good (scores 3) | 21 | 26 | 15 | 26 | 18 | 16 | 14 |
| Excellent (scores 4) | 35 | 35 | 31 | 30 | 42 | 7 | 48 |
| *blank* | *5* | *1* | *9* | *1* | *0* | *29* | *0* |

and the meeting to address the greater involvement of people who use AAC in the activities of CM was appreciated. Mostly the 'huge choice' of talks, the networking and opportunities to meet suppliers were also greatly appreciated. The exhibition was praised for the "variety of AAC devices on offer, opportunity to test and find out latest developments". The fact that there is time to talk, move between sessions and yet attend good quality presentations that are of an adequate length was also positively viewed. For those presenting it became a highlight, especially as they received such positive feedback from delegates.

***There is a sense of a great community atmosphere and the overriding themes 'gave the conference a flow'.***

## Entertainment

With the occasional exception views on the conference entertainment was hugely positive this year and seen very much as part of the inclusive atmosphere. Positively rapturous comments were received for Sign Out Loud, the steel band and dancing the conga, as well as the table magic (sorry but he couldn't get round to everyone!) The conference dinner was generally thought to be fab!

## Liked Least

There are always plenty of comments about the size of the rooms and the frustrations of over-popular sessions being overpopulated. It is sad when not everyone can get into the room to hear the presentation of their choice although having so many streams does hopefully mean everyone can get to something of interest. It is always a difficult compromise, even when the venue is a large campus University such as Leeds: we have to balance accessibility, distance and cost as well as try to predict who are likely to be the most popular speakers. The University conference team are very generous to us, partly because we come in just before the students return. That helps to keep costs down (believe it or not!) and we are constantly taking stock of the available rooms and the changes that occur each year. It really is a like a big game of chess! Oh and some people didn't like getting rained on: well much as we try CM doesn't get to control the weather yet! But yes the rooms do have to entail a walk sometimes.

General comments included suggestions for Future Years: do you agree?

- 'Conference was very speech/voice biased: 'please can we have more sessions on access, technology and mounting which are so important when assessing for high tech AAC. In practice I find these things are often an afterthought & it needs to be seen as an essential part of the assessment process.'
- 'Please can the titles reflect the content more accurately'
- 'Perhaps an idea to have exhibition stall holders do a short presentation in the lecture theatre? Sort of like Apple present their new products?'
- 'It would be really good to have some details which are related to people with greater needs of communication – PMLD – basic, more light tech and how to adapt a 'curriculum' in an age appropriate way'.
- Entertainment: 'more opportunities for dancing Monday night please'. 'The days of the tribute bands were good – if loud!' 'Sunday dinner: quiz'.

We look forward to making next year, our 30th Anniversary year, even better. We have some exciting ideas in store; not least the 'CM's Got Talent' Competition.

The Trustees look forward to seeing you there!

COMMUNICATION MATTERS

PRESENT THEIR 30TH ANNIVERSARY

# Midsummer's Ball

## SATURDAY 2ND JULY 2016
## 6.30PM UNTIL 1.00AM

AT THE UNIVERSITY OF LEEDS

CHAMPAGNE RECEPTION

4 COURSE DINNER

LIVE ENTERTAINMENT

GRAND RAFFLE WITH PRIZES

ALL PROCEEDS WILL GO DIRECTLY TO SUPPORT PEOPLE USING AAC
TO BOOK TICKETS PLEASE VISIT www.cmball2016.co.uk

# A Multidisciplinary approach to AAC assessment

**ANDY BANNS**
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***"Research has shown up to a 75% abandonment rate of AAC devices (SCOPE, 2007) when student's have transitioned from further education into adult services."***

This worrying statistic has prompted our Therapy team at Bridge College to take a step back and seriously address and overhaul our selection and assessment processes for high tech AAC. There are several reasons for such a high rate of abandonment of devices which we will discuss in more detail but the two main points that have come up from our research into this area have been the need to work more collaboratively and probably most importantly, ensuring that the student and their family and / or carers are involved in the AAC process as much as possible right from the start. Studies into AAC abandonment have shown user and family involvement in device procurement to be a key factor (Granlund et al., 2008, McNaughton et al., 2008, Bailey et al., 2006., Calculator and Black, 2010).

The previous assessment methodology at Bridge College was not a bad one by any means but was made a little bit piecemeal by each of our individual therapy teams running their own assessments and little collaboration between the different departments. Families were initially informed of what was happening but had little involvement in the ongoing process. Often high tech AAC was recommended based on what was deemed to be the best and most appropriate equipment without consulting the student and their family / carers. We soon realised that we needed a more cohesive process that would involve identifying an AAC team that works with the young person.

Following on from our research, a new pathway was devised in order to identify and assess for a high tech communication device. We were able to trial this with some new and existing students at Bridge College and gather some feedback from the students and their families / carers about the new assessment pathway. Initially, Bridge College has an eligibility criteria that students need to be able to meet to decide whether or not an AAC system would be suitable for them. This includes various questions including 'is there an absence of intelligible speech?,' does the individual have an understanding of 2D information?' and 'has the individual developed clear cause and effect?'. Upon meeting the criteria, lead practitioners were identified by the MDT (multidisciplinary team) to form part of the AAC team to carry out further assessment. Parents and carers were also part of the AAC team and we consulted them from the start of the process. Home visits were undertaken to observe the student at home and speak with their family to identify current cognitive, linguistic, perceptual and physical skills. We also consulted with the student's involved to find out whether they understood what a high tech AAC device was, how it would benefit them and whether or not they were interested in using AAC.

The AAC team were required to gather a range of information such as:

- The expectations of the student and their family.
- Their past AAC experience.
- Motivation to communicate or use technology.
- Current methods of expression.
- Their desire / need for assistive technology.
- Communication environments.
- Communication partner's interaction style.
- Mobility and access.

As there is not one 'standard assessment' that encompasses all of the above, we used the following assessments to ensure all the necessary information was collated:

- AAC Information and Needs Assessment (Glennon & Decoste, 1998)
- Assessing the Individual's Daily Routines (Johnson et al., 1996)
- AAC Activity Analysis (Glennon & Decoste, 1998)
- RAACS (Responsive Alternative and Augmentative Communication Style Scale) (Broberg et al. 2012)

Video evidence was collected from home visits where appropriate and also from the students within College. This helped to look at their communication skills before high tech AAC was introduced. The AAC team arranged further meetings with parents / carers to discuss assessment findings, jointly view the video evidence and discuss what device would be most appropriate based on student and family choice. This included things like portability of the device, whether it was possible to complete on screen programming and whether additional features were required such as environmental controls and Internet access.

The next stage was to trial AAC devices through a 'feature matching' process (Glennon & DeCoste, 1998). This provided our students with a good opportunity to find out if the equipment worked for them and also enabled the families / carers to see if it was something that they would be able to support their young person with. Training was provided for both staff and parents / carers, as well as step-by-step guides to support with the basic operation of the systems. This included information on setting up, mounting, turning the device on and off and some simple programming. The Means, Reasons and Opportunities Model (Money, 1994) was used in training to support communication partners in creating opportunities for the young person to expand on their reasons for communication such as making a request, expressing emotions, greeting others and commenting. An 'Anticipated Parent Support' form was completed by parents / carers which includes items such as who will take responsibility for charging the device, insurance, sources of support etc. Following a successful AAC assessment process, providing everything was to satisfaction and working correctly, equipment was then procured.

We trialled this new assessment pathway with three of our students and also a younger person (aged 8) who the speech and language therapy team complete outreach work with. A questionnaire was disseminated to parents / carers which mainly focused on their overall satisfaction and confidence in the AAC assessment process.

An accessible student questionnaire was also set up for our four students to complete. This was created within The Grid 2 software (SmartboxAT) which meant that it would be accessible via all of our student's various access methods which included Eyegaze, direct access and switch scanning (see Figure 1). The grids were set up so that when the student chose their name, it loaded a particular questionnaire up for them in Microsoft Word and all of their questionnaire responses within the Grid 2 were automatically sent to that Word document.

All students reported that they were happy with the AAC systems that had been implemented. One student stated "the iPad has changed my life". The majority of the young people knew who to talk to if they had any problems or wanted anything adding to their device. Students have expressed that they like to be involved in the decision making process and ultimately AAC acceptance has increased. Students felt that they would continue to use their device in the future.

Results from the parent / carer questionnaire were also very positive. Parents / carers reported that they felt involved and confident in the assessment process as a whole, that they knew who to talk to if there were any problems with their young person's device and that they felt that the communication aid had improved their young person's levels of confidence and self-esteem (see figure 2).

The only 'no' responses in the questionnaire were to the questions:

**Q** 'Do you feel comfortable or confident with the technology?' –

A Parents / carers stated that they can sometimes be quite worried about setting things up for themselves but are happy about the on-going support.

Q 'Have you seen a change in your young person's communication skills since they started using their device?' –

A This had some 'no' responses because many of the parents and carers already have established effective strategies to support and understand their young person's usual communication methods within the home environment.

Some of the positive feedback from parents / carers included:

Q 'Did you feel a device trial was useful?'

A *"Yes, she knew what she was getting then"*

Q 'What impact has the introduction of the device had on you?'

A *"Improved his confidence being able to show something he's proud of"*

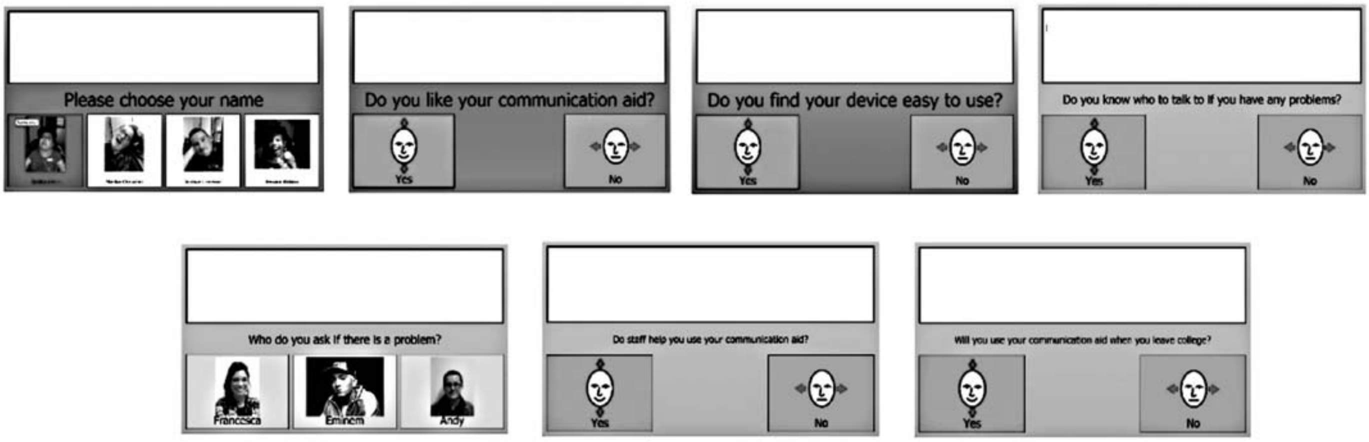
Q 'What impact has the introduction of the device had on you?'

A *"It has given each person in the family a chance to ask a question and have an answer. Communication is better"*

Q 'Has your young person had previous experience of a communication aid?'

A *"Yes, previously a Say-it-Sam. The iPad is way better!"*

Figure 1: Accessible student questionnaire



Please choose your name

Do you like your communication aid?

Do you find your device easy to use?

Do you know who to talk to if you have any problems?

Who do you ask if there is a problem?

Do staff help you use your communication aid?

Will you use your communication aid when you leave college?


tobii
Lemler
Kathrin
Can I have a cup o
Lightwriter SL40 Scan

The new AAC assessment pathway that has been implemented continues to evolve and has so far been very successful in creating better opportunities for our young people and their families to become involved in what is often quite a complex process. Future areas of development were identified by the AAC team to evolve the pathway in line with national changes to models of funding for AAC equipment. This includes further exploration of the device options through attending exhibitions and liaising with external agencies to keep up to date with current interventions and ensure that input is rooted in evidence based practice. The assessment process for AAC is a relatively new field and further research needs to be undertaken. As a college we plan to evaluate whether these changes to the assessment process increases the likelihood of sustained AAC use, promoting effective communication opportunities for users both during their time at college and on entry into adult services.

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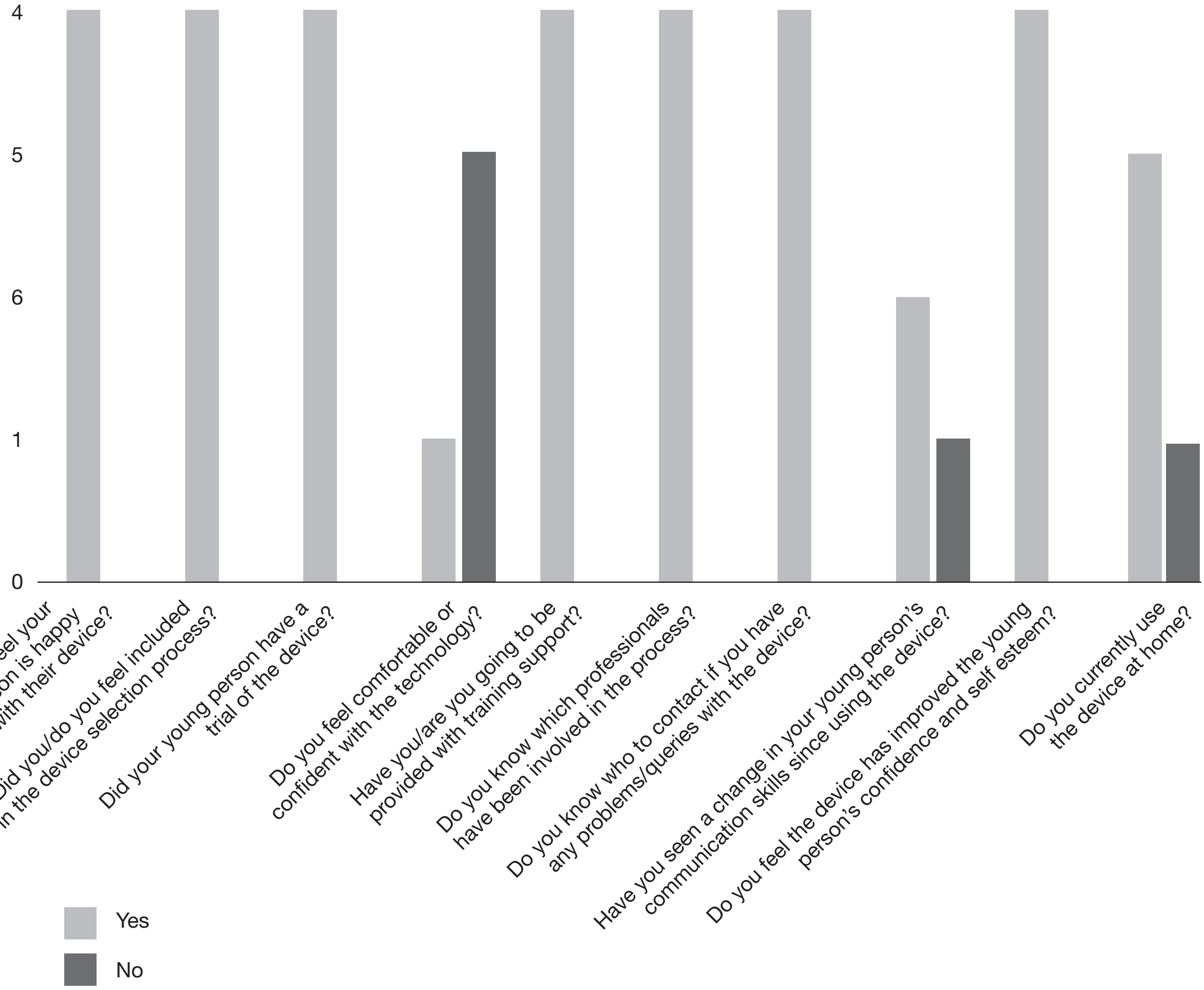
Figure 2 – Responses from parent/carer questionnaire



# Listening to different voices in families

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## Background

Parents and carers are important communication partners for children using AAC and support the generalisation of skills into more natural environments. The aim of AAC interventions is to develop participation across all environments. Yet research suggests that AAC is much more likely to be used in educational contexts rather than within the child's home environment. This paper presents the early findings from a small research study exploring the perspectives of families in using AAC in the home. The research sought the views of family members on the use of AAC and gained an understanding of the different perspectives of the 'whole' family including the parents, the young person with complex communication needs and their siblings.

The provision of an appropriate communication system not only affects an individual's ability to make choices and their health and well-being (Bush and Scott, 2009; Hamm and Miranda, 2006) but it can also affect the family's quality of life (Saito and Turnbull, 2007). This study was based on the premise that, for AAC outcomes to be successful, an understanding of parental experiences and perspectives is vital in supporting a child's use of AAC in developing everyday communication. Parents are asked by professionals to share the responsibility for the introduction and development of their child's competence in AAC (Beukelman, 1991; Light, 1989). Therefore professionals need to understand the family's individual needs as a failure to do so may result in families 'abandoning' AAC altogether. Parette, Huer and Hourcade (2003) stated that professionals need to focus on the "*voices of families*" and examine strategies that will involve families in the AAC process.

## Methodology

The study used a grounded theory methodology with a variety of data collection methods including interviewing family members, a 'draw and tell' approach for younger children (Holliday, Harrison and McLeod 2009) and Talking Mats (Murphy and Cameron, 2002) to support the children and young people with complex communication needs.

Twelve families participated with children aged 5-13 years who were using AAC in the home. The children attended a variety of schools: mainstream (1), special (7), split placement between mainstream and special (2), Designated special provision: (2).

The families used a range of low and high AAC systems from symbol communication books, Picture Exchange Communication to high tech systems including eye gaze systems and more mobile technology such as iPads and tablet computers.

## Findings

These early findings of this study were presented at Communication Matters conference (2014). Three categories 'Uncertainty and AAC', 'Evaluating and Shifting Family Priorities' and 'Managing as a Family' were revealed through the initial data analysis and capture the range of impacts of AAC on family life.

### • Uncertainty and AAC

Parents' experiences of being introduced to AAC, their responses to it and the way they gained information will be very different. Parents in this study found the added burden of introducing AAC initially caused them some anxiety particularly when they were often still coming to terms with their child's diagnosis.

*"In the beginning I was so sceptical about it because I was going through all these emotions myself and I kinda felt how frustrating you need these to communicate with your own child and I felt slightly resentful and upset"*

The introduction of AAC may be seen to undermine the abilities of mothers who have already developed their own communication with their child. Parents invest considerable energy in creating a communicative bond with their child and families may not view AAC as being able to provide anything further or they may not accept it as a suitable alternative to natural speech.

Parents, during the early stages of adopting AAC systems, ultimately want their child to talk and speech was looked upon as their preferred method of communication. Even parents of children who had used AAC for several years were often still coming to terms with their children not being able to use speech as their main mode of communication.

Parents reported that both the amount of information they obtained, or were given, and the different 'language' used in AAC was confusing and they were often not ready at that stage to manage its complexities.

*"It was so different, so much information and I only heard about using symbols and I didn't know anything about them. I was overwhelmed and I wasn't ready to deal with this"*

It is important for time to be given to families to enable them to assimilate the information before they may be ready be accepting. Many parents discussed the '*right thing at the right time*' and the importance of having the support of professionals in developing the most appropriate AAC systems with their child. For some families obtaining appropriate services was described as a 'battle' and 'fight' and many had to become 'pushy parents' as described by Goldbart and Marshall (2004).

- **Evaluating and Shifting Family Priorities**

When parents begin to implement AAC systems they often have to re-evaluate and shift their family's priorities to enable them to introduce it. The category 'time' and 'multiple roles' were strongly related to each other in the accounts given by parents. The time needed for AAC is often underestimated and children who require AAC often have additional physical, medical and behavioural needs. In this study it was found parents had to continually shift and modify their family's priorities and their daily lives to enable them to support their child in using AAC. A significant additional time commitment for many parents arises from the multiple roles which they have to take on. Some of these roles relate specifically to their child's disability but additional roles are often adopted as a result of AAC, for example applying for funding or assessment for high tech communication systems.

*"I think I need a PA or administrator to manage it all as it generates so much paperwork"*

Parents make many decisions on roles and responsibilities within the family and it was predominantly mothers in this study who had the responsibility for implementing AAC. This was also shown in studies by Angelo (2000) and McNaughton et al (2008).

Mothers considered their understanding of their child was often a hindrance in their use of AAC and they had to make a conscious effort in the early stages of using AAC to encourage their child to use their communication system.

*"That's the tricky bit because you can anticipate what she wants and I do it constantly. She goes a a a and so you tend to shortcut that and you have to be really conscious and say no! She has to tell me what she wants"*

Mothers acknowledged that as their children grew older and extended their social networks, they may not know all the things their children wanted to talk about.

*"I intuitively know what he wants to say. He's eight now and he is bound to come out with things that I don't know. Even with his eye-gaze he is quite funny as he comes out with things that are off the wall but I think great!"*

Mothers reported the initial setting up of the AAC system was the most time consuming with both low and high tech AAC.

*"It is so time consuming and really you can spend an entire weekend just making a handful of symbols because you are printing, collecting them first from the PECs CD [Picture Communication System] or the internet, finding the right ones, printing them, laminating them, velcroing the back of them"*

Mothers in the study often described themselves as "technophobic" or "not computer-minded" and programming high tech devices was often perceived as "another thing to do". They highlighted problems with continually changing software when they considered they had already invested significant time and energy in learning their child's AAC system and wanted communication devices which could 'grow' with their child. Ease of programming was also important for parents to allow them to add new vocabulary quickly to their child's system. For the majority of families this was difficult as it required considerable time and organisation and the complexity of programming high tech devices was reported as a barrier.

- **Managing as a family**

The importance of the family unit was highlighted by participants when integrating AAC into their daily routines. Parents acknowledged that implementing AAC was often '*not easy*' and a '*struggle*':

*"Communication has been like a dark tunnel but I can now see light at the end of it"*

There was often a 'defining moment(s)' which supported their belief in AAC and their child's potential to use it.

*"That particular night she had her ipad and went through and found the one she wanted. I thought yes, she is getting the hang of this"*

*"I knew he wanted to go outside but then he went to his book and found trampoline and gave it to me"*

The 'defining moments' were very different for each family and some parents had used AAC for 12-18 months before their child could use the communication system independently. Mothers commented in their need to reappraise their expectations by recognising their own child's development rather than societal 'norms' which resulted in a change in their approach to allow them to accommodate AAC.

*"In the society we live in, everyone has to do certain things by a certain age and you have to fill in the red book but you have to not worry about that and just go down to what he can do and recognise that"*

Parents in the study identified a wide range of people who provided them with help and support with their child's use of AAC. Siblings were described as being important in the development of the 'family team' and were often involved in a practical way with AAC e.g. cutting out symbols for a communication book and recording their voice on to the device.

*Figure 1: Drawing of two siblings talking (age 9 years and 5 years)*

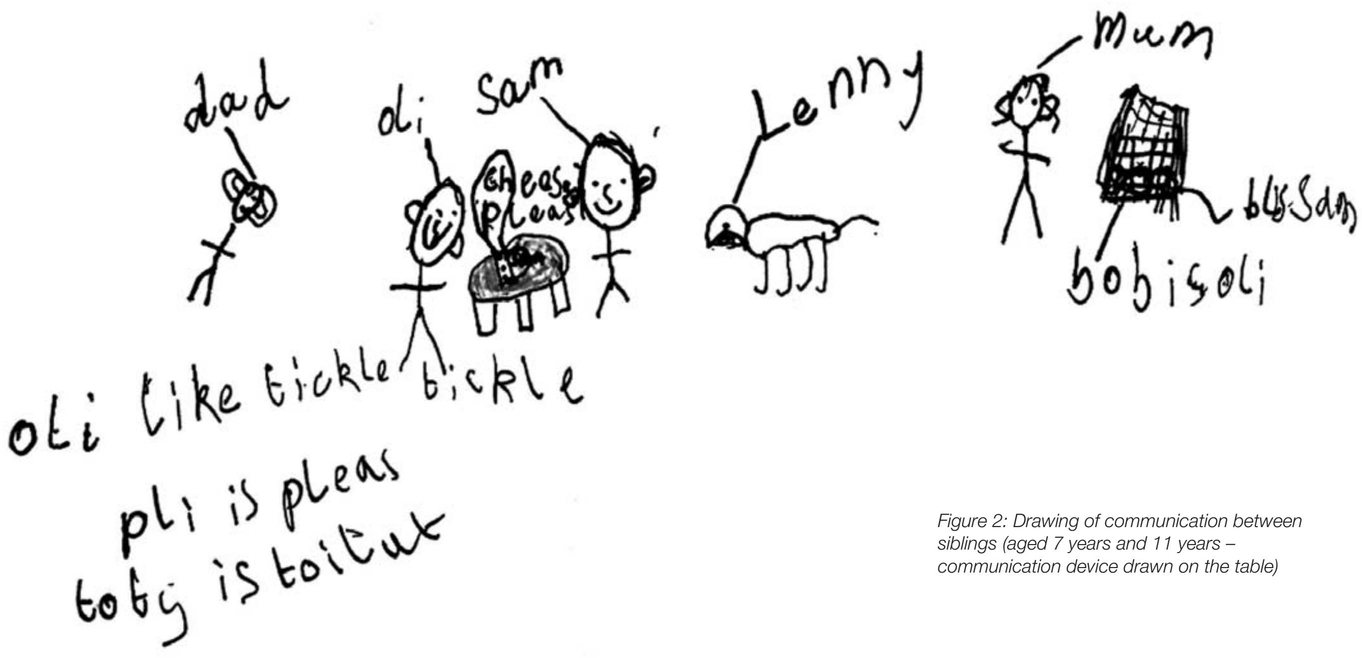

Figure 2: Drawing of communication between siblings (aged 7 years and 11 years – communication device drawn on the table)

One sibling was very involved with the technical aspect of his sister's ipad and trouble-shooting any difficulties.

*"...sorting out the ipad if something goes wrong. I help her as mum hasn't a clue so I just figure it out." ( age 7 years)*

Siblings were able to describe their sibling's communication skills in depth and gave accounts of their brother/sister's communication. Younger siblings (7-11 years) referred to talking their siblings 'language' and reported they were able to interpret and understand their sibling's vocalisations and verbal attempts.

*"I talk in his language. Totee means toilet and ple means please and tic tic means tickle tickle. I do [name of child] language" (sibling age 7 years)*

*"She goes blblblay like that and it means I am happy and she said peepe for iPad. She has her own language" (sibling age 9 years)*

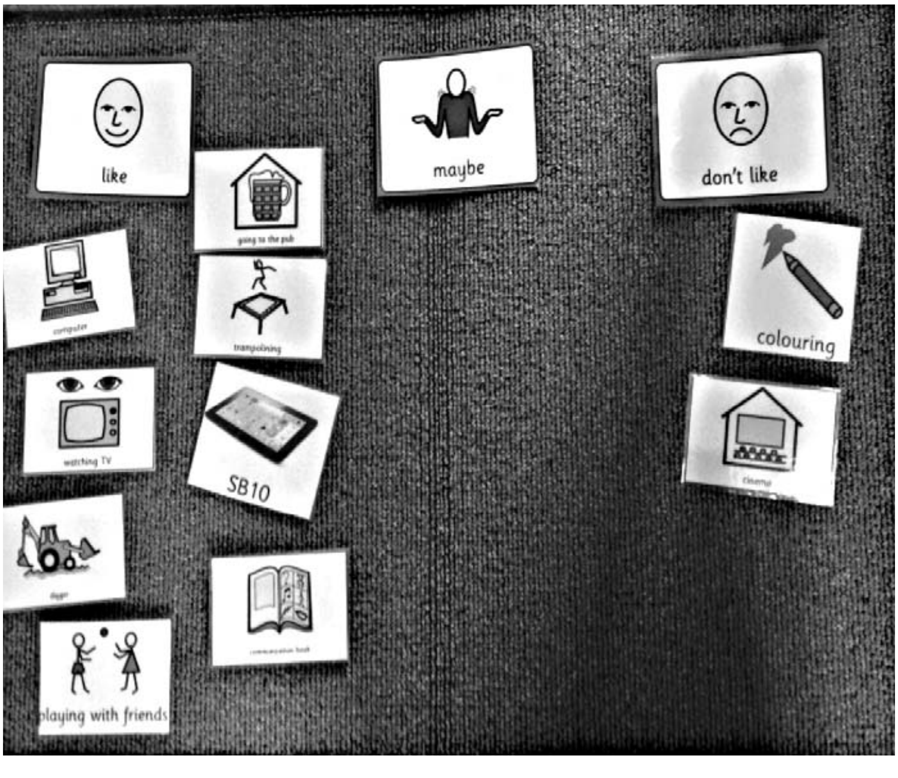

Figure 3: An initial Talking Mat on 'activities'

All the children had a good understanding of their sibling's communication difficulties and often acted as an interpreter for close family friends, particularly grandparents. Barr et al (2008) study with siblings of children with speech impairments suggest the role of 'interpreter' may only be seen in relationships between siblings and a child with communication difficulties. Grandparents were reported as preferring to use their grandchild's other forms of communication (such as vocalisations, body movements and facial expressions) rather than their AAC system.

Six children who use AAC systems were also interviewed using a Talking Mats approach (Murphy and Cameron, 2002) and the responses showed they were positive about their communication systems. A sub-mat was used to elicit further views on the child's AAC system in terms of its appearance, voice, vocabulary and use.

Examples of two Talking Mats are illustrated in Figures 3 and 4.

### You Matter (A Training course for parents, carers and professionals)

The perspectives and experiences of families in using AAC have been incorporated into the revised You Matter training course (Latham, Bousaki and Pugh, 2015). Families have the opportunity to identify challenges to using AAC in the home and support each other to find solutions. You Matter provides participants with the knowledge and skills to become effective communication partners and explores their feeling about their child's use of AAC and how it can be practically supported within their family's everyday lives. It also includes additional video support materials and is available from www.acecentre.org.uk

## Conclusion

These early findings indicate the complexities of using AAC and identified both barriers and enabling factors which support the use of AAC in the home. Further data analysis will provide more insight into families' perspectives in using different AAC systems and support the development of interventions based on their priorities and concerns.

## Acknowledgements

Thank you to the families who took part in the research and gave their valuable time to share their personal stories of using AAC systems in the home.

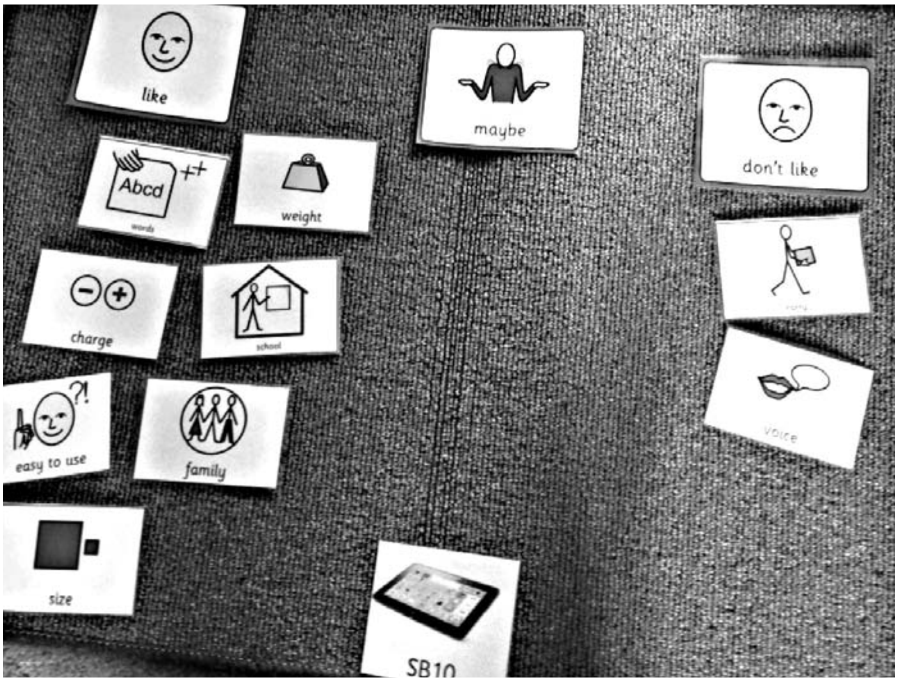

*Figure 4: A sub-mat on the communication device*

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# Mothers' views of the communication skills of Maltese children who use Augmentative and Alternative Communication

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This study forms part of a PhD research project on family interactions with individuals with severe communication difficulties. This paper focuses on the characteristics and modes of communication of Maltese children and young adults as reported by their mothers.

An estimated 0.5% of the student population in Malta has severe communication difficulties (Augmentative Communication World Network, 2009; Gatt, 2007). We know very little about parents' perceptions of the communication skills of Maltese children who use AAC and it is important that services are aware of the characteristics and needs of the client population.

## Introduction

One of the major social environmental influences on child development is parent's 'responsivity', defined as the contingent and prompt reactions that follow their child's lead and focus of attention (Warren & Brady, 2007). Parents of children with developmental disabilities may find it challenging to identify and respond to their child's prelinguistic behaviours (e.g. vocalisations, body movements and eye gaze) because they are more difficult to interpret (Brady, Steeples, & Fleming, 2005). When parents respond appropriately to their child's prelinguistic behaviours, this may help reinforce the development of communication skills (Yoder, McCathren, Warren, & Watson, 2001).

Apart from being responsive to prelinguistic communicative behaviour, parents need to be sensitive to the use of any formal forms of communication such as manual signs, symbols and medium and high tech communication aids (Stephenson & Dowrick, 2005). Families need to respond to different forms of communication which the child uses across a range of contexts and learn how to support and initiate functional interaction whenever possible.

## Method

### Participants

Participants were selected via a non-governmental organisation which provides psycho-educational support services to 300 families of individuals with intellectual and developmental disabilities. The following criteria were used to select individuals who i) present with intellectual/developmental disability ii) have severe communication difficulties and iii) attend mainstream or special schools[1]. Consent to participate was gathered from families prior to data collection.

### Methods

A 24 item structured telephone interview was designed, based on information arising from similar surveys (e.g. Blackstone, & Hunt Berg, 2002). The interview consisted of a set of closed questions which utilised a 4 point response scale as well as a few open-ended questions e.g. "What is your preferred mode of communication? Why do you prefer this mode?"

## Results

A total of 50 mothers of children and young adults, aged from 3 to 23 years, participated in the study. All mothers agreed to take part in the study thus the response rate was 100%. Forty percent of the children were infants between the ages of 3-5 years. Fifty-two percent represented children from 5-16 years and 8% from 16 years upwards. Of these, 60% were male and 40% were female. The majority of the children and young adults attended mainstream schools (84%) while a small number attended special schools (16%).

The most frequently reported disabilities revealed cerebral palsy to be the most prevalent (38%), ASD 24%, Downs' syndrome 16%, Developmental delay 8%. Other disabilities (14%) included West syndrome, Dandy Walker syndrome, Rett syndrome, hydrocephalus and macrocephaly.

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[1] The statutory age for the Young Adult Education Resource Centre is up to the age of 23 years.

**Table 1: Parent Participants' characteristics**

| | n= | % |
|---|---|---|
| Age range | | |
| 25-35 | 31 | 62 |
| 36-45 | 15 | 30 |
| 46-55 | 4 | 8 |
| Level of education | | |
| completed compulsory education | 38 | 76 |
| certificates/diploma | 8 | 16 |
| degree | 4 | 8 |
| Occupation | | |
| housewives | 31 | 62 |
| vocational | 4 | 8 |
| clerical | 5 | 10 |
| educators | 8 | 16 |
| self employed | 2 | 4 |

Table 1 represents the mothers' age ranges, level of education and occupation. Participants reported that 19 (38%) children had no other siblings, 19 (38%) had one sibling, 10 (20%) had two siblings, 1 (2%) had three and four siblings respectively.

### Means of Communication

Language Spoken at Home Mothers indicated that the main language spoken at home was Maltese (see figure 1). Children and young adults were also exposed to a variety of educational software and literacy programmes in English.

### Symbolic representation

Twenty-five individuals (50%) used pictures, 12 (24%) used orthography, 10 (20%) used objects of reference, 10 (20%) used key-word signing, 5 (10%) used photos and 2 (4 %) used other strategies. Four percent of the mothers indicated mixed representational modes mainly objects and manual signs; orthography and manual signs; objects and pictures; pictures and manual signs; photos and manual signs.

### Mode of access for aided users

There were 31 children and young adults who used some form of aided system (62%). Eighteen users of aided communication (36%) used finger pointing to access symbols for communication. Eight individuals used a combination of eye pointing (16%) and 8 used scanning with switches (16%), 18 used various modes of access; pulling symbols with Velcro using a communication exchange system, a mouse or the whole hand to access objects (36%).

### Type of symbols and keywords used

Of the AAC users in this sample, 56% didn't use any symbols, 30% used PCS symbols, 10% used more than one symbol type and 4% used photos. Nine AAC users used a mixture of Maltese and English keywords (18%) followed by Maltese (12%) and English keywords (8%) in their communication books.

### Common modes of communication

AAC users utilised a wide range of multimodal techniques and strategies as part of an AAC system in interactions with their caregivers and within the educational and community settings (see figure 2). Medium to high AAC technologies were mainly used in a school setting or in formal situations and not with their most familiar communication partners.

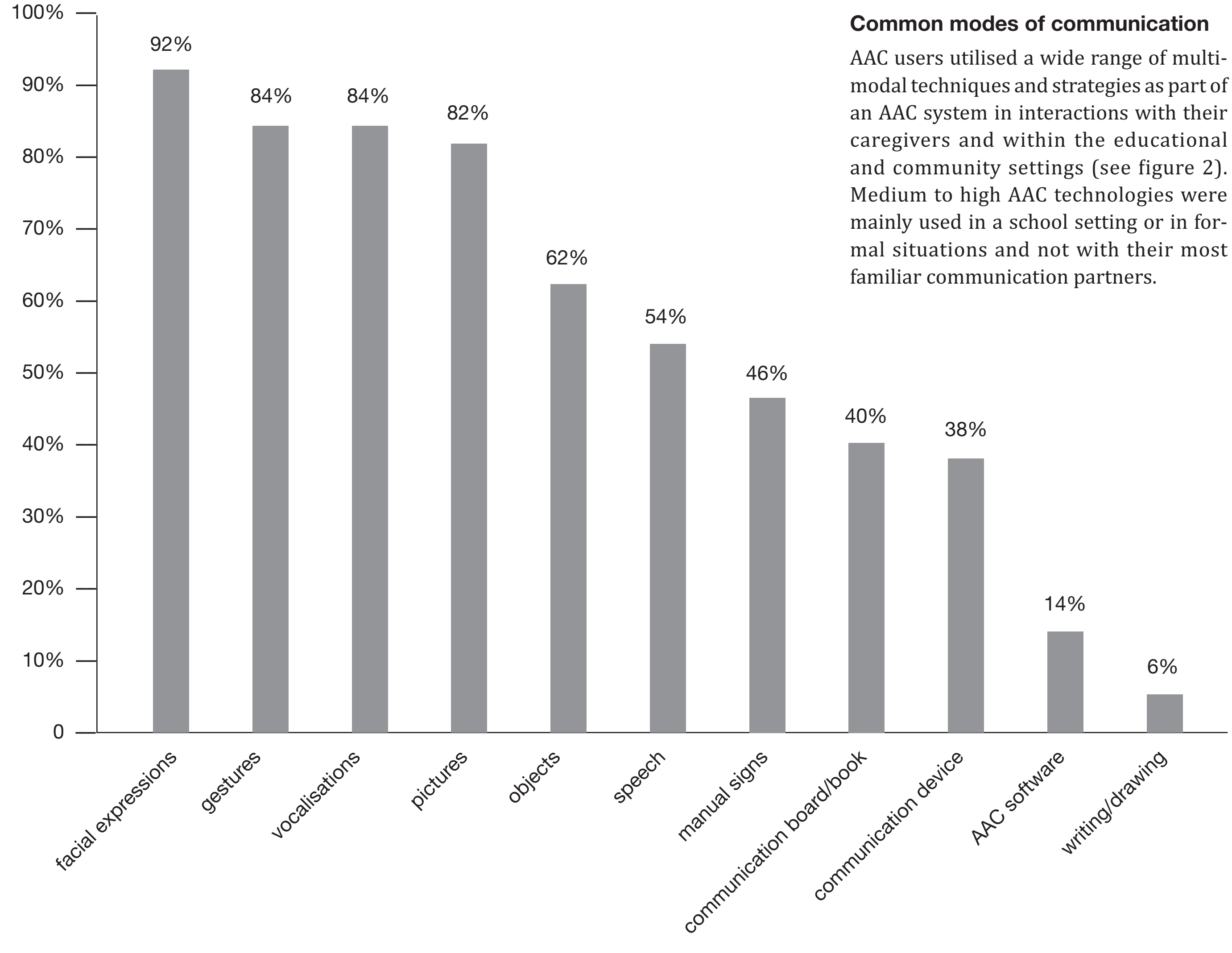


*Figure 2 – Responses from parent/carer questionnaire*

Figure 2: Common Modes of communication used by AAC users

More than 50% of the children used vocalisations and speech mostly with their primary caregivers while AAC devices were used with paid professionals and unfamiliar partners. Although many individuals used manual signs, they used very few and rarely in multi-sign utterances. Mothers admitted that AAC devices were perceived as useful in some contexts but generally they preferred unaided means of communication.

### Use of a Voice output communication aid

Forty-four percent of the AAC users in the sample had voice output devices ranging from single message communicators, multiple message communicators and high tech aids (see table 3). Some mothers added that the devices were used exclusively at school, integrated within the school system and the individual educational programme (IEP). Others commented that the device was broken and required maintenance or software updating.

**Table 3: Use of VOCAS**

| AAC users | n= | % |
|---|---|---|
| No VOCA | 28 | 56% |
| Single message communicators | 12 | 24% |
| Multiple message communicators | 2 | 4% |
| High tech aids | 7 | 14% |
| Integrated AAC software on laptop | 1 | 2% |

Figure 3 reports the preferred modes of expression used by mothers. Seventy percent (70%) of the mothers preferred to use natural speech with their child. Thirty percent (30%) of the mothers used a mixture of modalities such as speech and key-word signing used simultaneously (18%) and speech with symbols (6%). A few mothers (4%) reported that children understood them better when they used a multi-modal means of communication and in return expected that their children take up at least one of the modes. The majority of the mothers who used natural speech saw no reason why they should use other modes of communication simultaneously since they believed their children understand them when they use speech.

*Figure 1: Main language spoken at home*

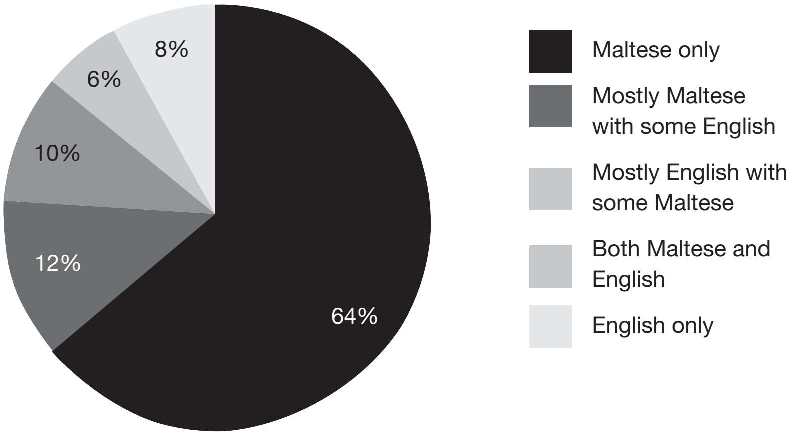
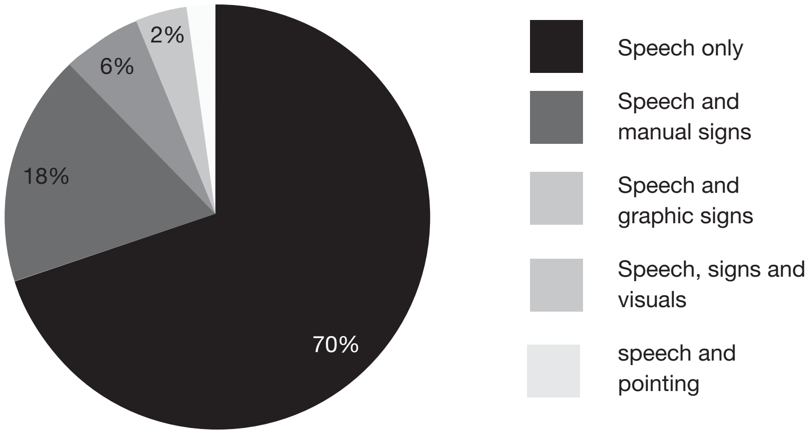


*Figure 3: Preferred modes of expression used by the mothers*



### Opportunities for training on AAC systems

Mothers reported modelling of the AAC system was given briefly by the assessor or speech language therapist during clinic based assessments or privately through home visits. Some mothers reported attendance at one day courses on a voluntary basis such as keyword signing sessions, introduction to PECS and access to literacy and AAC software.

## Discussion

Results suggest that children in Malta utilise a wide range of multimodal techniques and strategies as part of an AAC system in interactions with their caregivers and within the educational and community settings. Most users use AAC technologies in a school or other formal setting. They may also opt for a repertoire of unaided communication such as facial expressions/body language, gesture and vocalisations (though it was reported that aided communicators prefer to use VOCAs). The situation seems little changed, despite advanced technology, since Blackstone & Hunt Berg (2003) reported 50% of the children use vocalisations and speech mostly with their primary caregivers and AAC devices elsewhere. This is reported elsewhere in the literature by Baxter, Enderby, Evans and Judge, (2012); Calculator (2013); Didden et al., (2010); Stephenson & Dowrick, (2005). Whilst AAC devices are perceived as 'useful' in some contexts, they aren't used with familiar partners because the children or family prefer unaided means of communication.

Prior to the implementation of an aided means of communication, communication patterns would have already been established between family members and individuals with complex communication needs. This factor will influence the nature and quality of family interactions (Parette & Angelo, 1996). In Mexican American families Huer, Parette, & Saenz, (2001) reported that family members could understand the children without assistance and preferred to rely on physical context. Similarly, McCord and Soto (2004) reported that, although the children were able to express more complex information while using the AAC devices, family members found unaided means of communication more personal and meaningful. Reportedly whilst children revert to speech as a preferred mode of communication, this may be unintelligible. When speech modes are considered inefficient, then other means such as communication books, VOCA use and signing are used.

Parents may need support in implementing a formal AAC system, with modelling of the AAC system by professionals to ensure that generalisation occurs. It is apparent that mothers in this survey seemed reluctant to use AAC systems with their children at home. Some mothers have reportedly opposed the use of some forms of AAC, in particular, medium and high tech aids, finding it more effective and practical to communicate using natural speech modes. There could be several reasons for this, namely, (a) attitudinal barriers, (b) the limited availability of AAC systems in the family environment, (c) device abandonment, and, (d) limited training for family members. Parents may fear that with the introduction of AAC, natural speech will be hindered and children will not be motivated to speak (Romski & Sevcik, 2005) though available empirical data suggests the contrary (Cress, 2003; Romki, Sevcik, & Adamson, 1997). Unfortunately when training needs are unmet, the family is unable to implement the AAC system within everyday interactions and the system is either abandoned or hardly used (Bailey et al., 2006). Device abandonment was reported in the study due to either the device not being used or needing updating (Gatt, 2007; Parette & McMahan, 2002). It is important that family members are involved in the planning and implementation of intervention programs within the family environment.

## Conclusion

This preliminary study has analysed the use of AAC by children and young people with severe communication difficulties, according to mothers' perceptions and observations. These findings have implications for interventionists who need to work in collaboration with families and ensure that they are sensitive and responsive to all current forms of communication. It is also within their remit to design functional supports for families in order to increase positive AAC outcomes.

A full list of references is available from the author.

## Acknowledgements

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# My communication journey as an AAC user

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**My name is Helen Quiller, my paper is about my communication journey as an AAC user from a young age and the many advances in technology that have helped me. I also write about my involvement with the organisation 1Voice and representing the interests of people who use AAC.**

## Early Days

As a very young child I was diagnosed with Cerebral Palsy and my speech and communication were very slow to develop. My parents always believed that my intelligence was not affected, because of the way I responded to them talking to me. I slowly learnt to answer questions by nodding and shaking my head and indicating what I wanted eg pointing to my mouth when I wanted a drink. Aged three I started to attend my first special school, where again my intelligence was realised immediately. They had a number of children who used a system called Bliss Symbols on a board that I could point to. My first bliss board was very simple with about ten words on it, Mummy, Daddy Food, Drink and so on.

In the early 1980s communication and computer technology was just developing and I was lucky that my teachers and family realised what this technology could do to open up my world. At age seven I had my first adapted 'Possum' typewriter, I used this with a touch pad and scanning system, this system was very slow, time consuming and unreliable, compared with today. As time went on, the old BBC computer came into schools and I could play games on it. However I still hadn't developed enough hand control to access an actual keyboard and switch systems remained slow. My school catered for children with many different disabilities and although I was placed in a high ability class, all the others could talk normally, answer questions quickly and use their hands to write. I meanwhile was sat on the other side of the classroom using my computer. My parents felt that my full learning potential wasn't being realised and my access to physio and speech therapy were very hit and miss. I was also very isolated outside school and did nothing socially. It was for all these reasons that my parents and I looked into boarding schools. I started at a Spastics Society boarding school, Thomas Delarue, in September 1985. Although this was very hard at first to leave home there were a lot of benefits which helped my independence and a huge variety of social activities such as wheelchair dancing, make up club, and sailing.

It was my parents who found an expanded keyboard with much bigger keys, this was fantastic and made computer access much quicker for me. This system got me through school and all my GCSE's. As a teenager I sometimes felt very isolated in social situations because my speech was very difficult to understand for people who didn't know me very well. It would often make people presume that my disability affected my intelligence and this began to affect my confidence in group situations.

My parents and speech therapist felt that some sort of portable communication aid with technology would be very beneficial. The assessment process for this was very slow and it took two years to identify and obtain an appropriate communication aid.

The model we identified was called a Touch Talker from a company called Liberator. I was very excited when I got this first communication aid, it meant that for the first time ever, I could be understood by anyone and everyone. This meant that at school they could slowly start teaching me to go out shopping alone and to travel home by train using my aid. My Touch Talker was a system of symbols which needed a huge amount of learning and teaching for it to be used to its full potential with pre programmed words and phrases. My time was limited at school because of my GCSE work and a lack of time for speech therapy. This meant that I spelt most things out on it, which made it still quite slow to use.

## Moving on in Further Education

When I went to Hereward College at age 17, they introduced me to a new computer which worked on a system of word prediction, I found this very quick and easy to use, but it was not portable. The College was very academic and I was still lacking some basic independence skills, such as money management and learning how to direct my own care. I then spent a year at an independent training centre called Prospect Hall. However their idea was to teach me to dress and feed myself, so I took two hours to get dressed roughly and most of my food ended up down my clothes or on the floor. Was this really teaching me to lead an independent lifestyle?

I then moved into a small residential care home setting while I continued a variety of college courses. I was still using my Touch Talker for communication outside my home and always found it difficult to learn and therefore quite slow to use. I longed for a portable system of word prediction, in 1996 I heard about a company called Cambridge Adaptive who had produced one. My local Health Authority provided me a laptop with the Cambridge software called EZ-keys on it, however this system wasn't very robust and spent most of the time in repair. It had a plastic key guard which kept slipping and knocking me out of my talking programme and the repairs on it always took months. Even the battery pack became obsolete, so the whole system needed replacing. I sometimes went months without my AAC. Eventually we went to Cambridge Adaptive direct and had a private demonstration of Cameleon Two which was brilliant and exactly what I needed. It was another year's hard fight to obtain funding for this aid in February 2000.

When I reached my early 30's I really wanted my independence and the freedom of living in my own home with care support. I tried a couple of semi independent settings where staff support was still provided to a point. However there were still quite a few rules and restrictions in these settings, for example staff were often not available to go out with me at the times that I needed. Shared support was often patchy and staff call times were rigid. It was for all these reasons that in 2005 my family and I started looking into the possibility of me going onto Direct Payments and employing my own personal assistants.  We were all quite nervous about becoming an employer and the responsibility and legalities that this could involve, however we felt that this was the only way forward. This was quite difficult to set up and we didn't get much help or guidance on how to be an employer, what to look for at interview and how to safeguard both parties. My first few months as an employer were very difficult: I was financially abused. However things did settle down when I employed people who were more suited to the job. However people move on, or there can be difficulty finding backup care for when my staff are either sick or on holiday and this has become a major ongoing problem over my years on Direct Payments. Care agencies are very expensive and aren't that reliable. I haven't had any increase at all in my Direct Payments in the last nine years. It is for all these reasons that I am still very dependent on my parents to help me out when things go wrong and break down with my care. This is something that worries me for the future when my parents are no longer able to care for me, or are no longer around.

Throughout all these experiences of Residential Care and Living Independently, my lack of understandable verbal communication has been and still is a major factor in my care needs. Yes AAC is brilliant in most situations, however you can't use big high tech equipment to communicate your needs, whilst sat in a wet shower with a stranger caring for you who can hardly speak the English language, let alone my CP version of it. Sometimes I don't think there is any easy answer to this problem because, yes, I can use a simple word and alphabet board. However people need to be able to follow and read what I'm pointing to on it and this can be very slow and confusing.

## Campaigning and Getting Involved

With growing confidence I have begun to represent the needs of people who use AAC. The organisation SCOPE ran a major campaign about communication aids and how they are a human right, to enable disabled people to speak for themselves. I got involved and went to the launch at The Houses of Parliament, where I met Lord Jack Ashley and was photographed with him.

It was early in 2008 when I first heard about the organisation 1Voice. They were looking for adult role models using communication aids who could go to events and give support and encouragement to children and young people who were starting out on their communication journey.

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I am now a regular role model. We do a lot of activities that are designed to help young people develop their communication skills and to celebrate their achievements with pride. 1Voice now have a number of local branches: I am on the committee for 1Voice West Midlands, planning activities that young people with various degrees of disability can participate in.

In 2013 I was approached about whether I would become a Trustee of 1Voice and be more involved in the management of the organisation. I was voted onto the board in 2014 and I am now enjoying the challenge of this new appointment.

### My Involvement with Birmingham University

It was in 2012 when I was asked about joining the Conversation Partnership Scheme at Birmingham University through a Speech Therapist at ACT in Birmingham. This is a scheme where two first year Speech Therapy students will be partnered up with a local AAC user and visit them for a number of sessions. I think this scheme is very beneficial for the students' future practice because it gives them first-hand experience of communicating with someone who uses AAC. I have also made some good friends through the scheme who I have kept in touch with.

The University then approached me to ask if I would be willing to give a presentation and talk to their new Speech Therapy students during induction week about the experiences that I have had with my disability and communication development. I now do this annually and enjoy this experience of working with the students. I think before working with 1Voice I would not have had the confidence to do this.

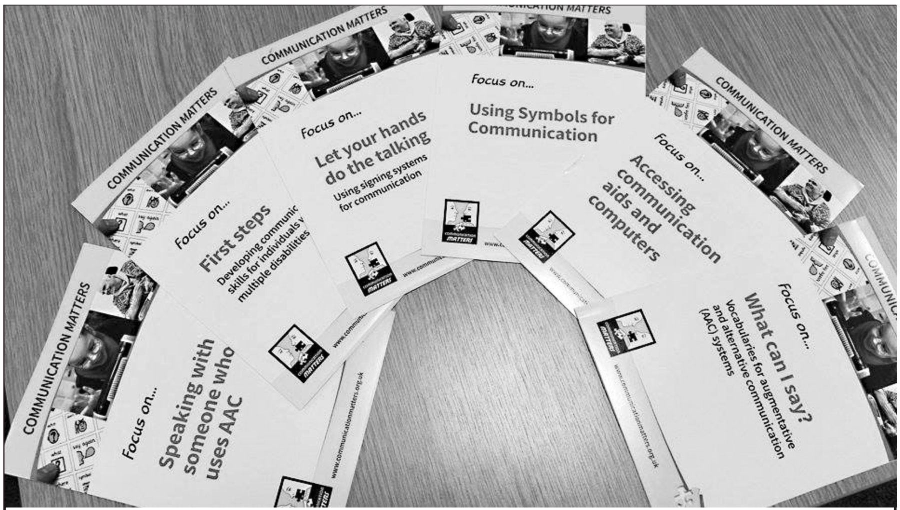
Last year I became involved in something called a 'simulation' day, going into the University and acting out a scenario appointment with the students. They are given feedback and guidance on how they approached the appointment and things that they improve. My scenario was going for an assessment for a new communication aid and the frustration I felt about how long it was taking to obtain funding through the NHS funding system. Again I enjoyed this experience and helping the students learn more about the world of AAC.

### A further fight for better AAC communication

Early in 2014 my communication aid started to fail at regular intervals and in July I was told that my device was beyond repair and would need replacing. I was given a temporary device by Birmingham ACT which had the battery life of an hour and I wasn't given much guidance on what to do next. I attended the Communication Matters Conference and identified an aid called the 'Allora' from the company Techcess. We quickly arranged for me to have the device on trial and I became certain that this was the right aid for me. However, because of all the recent changes in how AAC is funded by the NHS, this has been a very slow process. I was first told that my needs were 'not complex' and could be met by my new local Hub, only to be referred back to ACT again three months later, because my new local hub was only just setup and couldn't deal with my complex needs. The local CCG eventually agreed funding towards the end of March 2015.

I finally managed to get the Allora in May, after a prolonged fight for the funding. This has made a huge difference to my life. For instance my Grandfather has always struggled with understanding my speech, because he is very hard of hearing. This has always meant that we haven't been able to talk without help from a third person. Since I have got my new aid, we can have a proper conversation without help, and this has meant so much to us both after so many years of silence. It has also helped me talk to my little Nephew and has helped him realise that Auntie Helen can understand and talk to him. It is also helping me communicate with temporary personal assistants who don't know me very well and I have the ability to text to mobile phone. My confidence in communication keeps growing: AAC has helped me join the twenty first century. ".

I wrote a song earlier about my communication and the sense of frustration that this sometimes causes me, This song is called 'The moment has gone' available here: https://www.youtube.com/watch?v=0BVRJwNCZYM



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# AAC and curricular adaptations for a child in a mainstream school

**Case study**

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## Introduction

This article presents some AAC modalities and some examples of activities employed to adapt the primary school curriculum for a child with intellectual disability at a mainstream school. Multiple teaching strategies and supports including pictograms, a communication book and electronic devices were used according to the subject matter, academic year and developmental level.

Mcdonnell & Brown (2010) among others, state that AAC helps children with severe speech disabilities acquire the communicative and linguistic skills required to participate in an inclusive school environment. The example we present is a boy whose satisfactory academic and personal progression from age 8 to 13 illustrates how AAC can facilitate participation for a child with complex communication needs. Many studies such as Stoner et al. (2010), illustrate the benefits and challenges of inclusive education using AAC. They emphasize the importance of team roles and responsibilities in AAC selection and implementation. They frequently refer to the 13 indicators of successful AAC in inclusive educational settings described by Soto et al. (2001).

In our case, although each indicator was not always present, most were throughout the period reviewed. In particular, good collaboration between professionals, appropriate AAC supports, trained assistants and the school's inclusion policy have facilitated the task.

## The student, his scholastic background and software applications used

Sam, now 13 years old, has intellectual disabilities and severe speech and communication difficulties. Nevertheless, he easily establishes relationships with people in and outside school.

He uses manual signs, sounds, some words or word approximations, a communication book and a tablet communication device with the Windows program "The Grid 2". He can follow simple conversations about daily events or activities.

He has difficulty with movements requiring spatial or self-awareness and generally poor fine motor skills which makes writing or drawing unfeasible. Although he still requires some help with basic tasks such as dressing, he can walk, run and play sports.

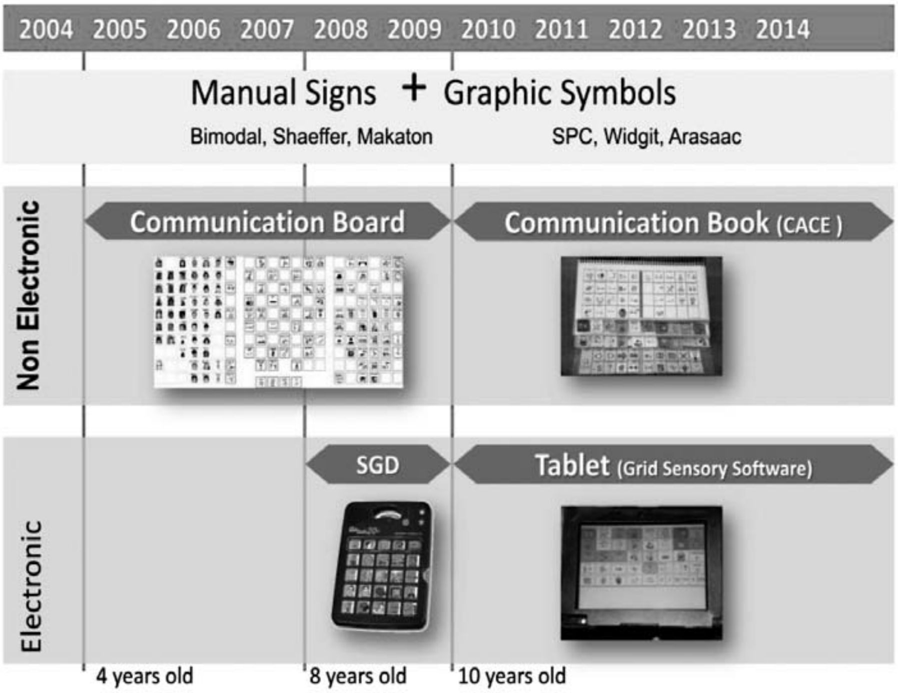

Figure 1: Use of AAC systems and software for curricular adaptations

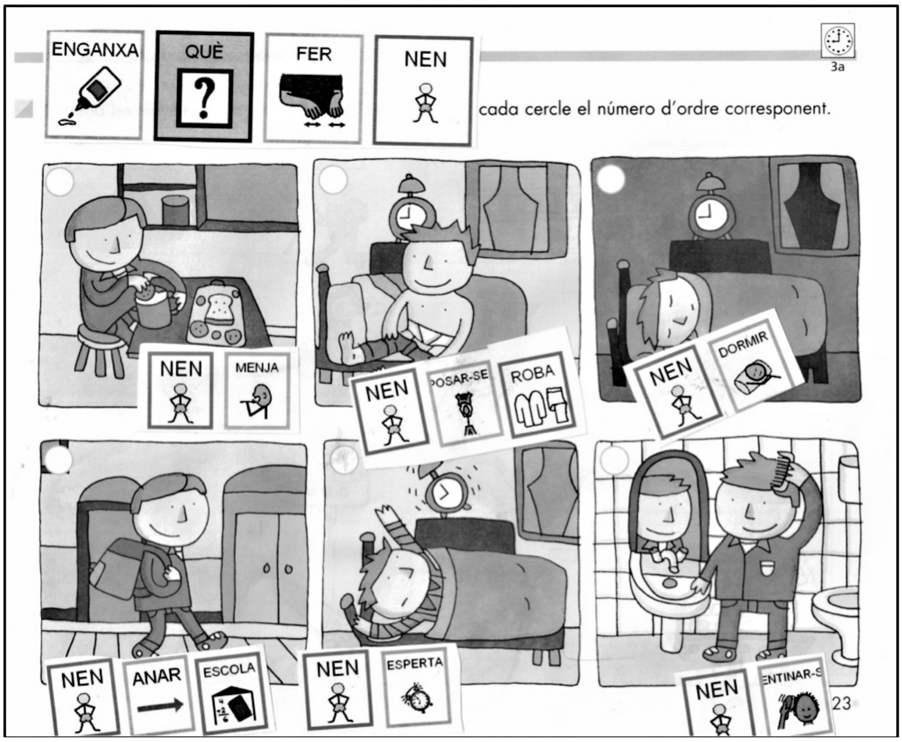

Figure 2

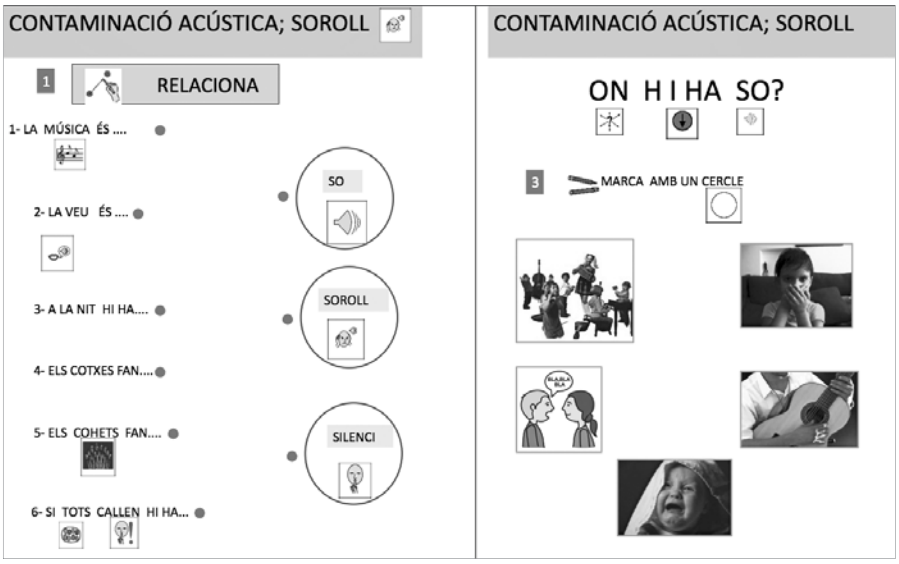

Figure 3 : Activity: Science; Acoustics

He has just finished 6th grade at a local mainstream school. The school has a department to support diversity that meets regularly with the teachers and the regional external support center for AAC. The school has around 1,000 students aged 3 to 18 years old and an average class size of 27 students. Sam has an adapted curriculum and timetable. He receives support from EAP[1], and the school's teaching team and his family.

As we explained in a former article (Sancho, et al., 2013), the student uses graphic and signing modalities. His current communication book, based on CACE-UTAC vocabulary (Soro-Camats, et al., 2010), has about 1,200 mainly PCS[2] or Widgit[3] pictograms and is an exact paper copy from the program he uses in the tablet. (Figure 1)

Professionals use The Board Maker, a communication board software design program, with PCS, ARASSAC[4] or Widget symbols to produce the majority of his curricular material. It is used as cognitive support to organize and remind him of different activities. It is also used to make his **timetable**.

This software has also been used to give **the instructions** for his academic activities. (Having the instructions visually in the form of pictograms helps him remember what he has to do.)

In Figure 2 he has to construct a sentence describing what the boy is doing in the story. As you can see in this particular activity he answers by sticking pictograms to form a sentence. Through time these sorts of instructions have become more elaborate and complex. Instructions of this sort, using a similar structure, are used for all subjects as can be seen in the text book adaptations. (Figure 3).

Subjects such as science, geography or math have been systematically adapted. All the materials produced use graphic symbols to both explain the subject and to complete the exercises.

The exercises in Fig. 3 are from a science module (grade 4) on acoustics. The first one is a matching exercise where the pupil has to join the dots to produce the right sentences: the cars make noise; it is quiet at night...

In the second exercise he has to circle the pictures where he thinks there is a sound.

**Software for communication both face to face and by mail.** 'The Grid 2' is extremely useful for the student to use.

This software allows him to express himself and follow the curriculum by doing class activities such as writing, answering questions, doing his school work etc. For example at lunchtime, one child tells the rest of the students the menu for the day and when it is Sam's turn he uses The Grid with its digital voice[5] on his tablet.

He also uses this communication program to send e-mails to classmates during language class and this has greatly helped him understand and practice the patterns of conversations.

## Some procedures followed during the project

Different AAC systems and educational strategies have been used at the school over the years to help the pupil achieve his academic goals as well as enabling him to communicate and participate in the social life of the school.

The school has kept a record of the activities he completed and the results of set objectives. Every term Sam's different teachers wrote a report. Annually his adapted curriculum was updated based on his achievements and sent to the 'Regional Pedagogic Assessment Team' for approval.

The curriculum has been adapted to allow him to join in some activities at a lower level. Other activities have been specially created to allow him to follow his own curriculum. Furthermore, the same activities may be given to him in successive years although varied according to his development stage. Task objectives are typically transversal, covering different subject areas.

## Adapted activities used at school

Below we will present four examples of activities that have been created for that pupil's academic curriculum.

**Activity 1: Role-play situations** (restaurant, shop) are enacted with each child taking a part. (Figure 4)

The image shows a class activity from second grade, when he was 9, where the pupils take different roles representing a restaurant situation. Some students are customers, others waiters, cooks, cashiers, etc. The format of this activity allows each student to work at different skills such as math, oral expression, social skills, drama… For Sam the main objective was the linguistic function of demand, vocabulary for food and social skills.

One thing to note is that all the students had pictographic symbols in their materials alongside words, thus becoming familiar with Sam's system of communication and involving them in his learning.

Because children with intellectual disabilities struggle with generalizing concepts, it is important that the family knows and practise what they have learned in school on the outside. In this case, the family practiced this activity by going to restaurants and encouraging the boy to ask for his drink using the communication board.

**Activity 2: Reporting experiences.** The second activity is based on a school journal, which is a written and occasionally oral expression of some relevant event. It is a standard primary school activity for all students designed to develop writing skills such as syntax or text organization.

He writes his journal with some help and always uses pictographic symbols. Currently he uses the communication program (The Grid 2) in his tablet to produce the symbols, but other supports were used in the past. His journal is printed and delivered to the teacher, and occasionally he reads it to his classmates using the program's digital voice (Fig.5)

**Activity 3: Classroom presentation.** Using PowerPoint, students describe a geographic area. Sam presents it using pictograms and a recorded voice.

This year for instance he gave his class a Power Point presentation about the Pyrenees. He visited and chose brochures from the tourist office and did research on the internet helped by his sister. As it was difficult to synchronize the tablet voice with the slides, a recorded voice was added.

Although the level of the concepts learned was very different to the level of the other pupils, the skills covered were the same for everyone and included computing, research and public speaking.

**Activity 4: School monitor.** Throughout the school students are given different responsibilities as monitors. Until he was 10 he often helped other children with their monitor duties. Then a new monitor role was created for him, designed to increase his independence and to help him interact with others.

Figure 4: Activity in class: Role Play of a restaurant

Sam went to each class and asked the teacher what materials they needed, such as blue-tack or crayons, using a template with pictograms (Fig. 6). The teacher marked the materials required on the template. In the example belowthe teacher needed 2 packets of blue-tack, 1 crayon, and 3 envelopes. Sam counted what was needed with his helper, fetched them and took them back to the class. The storage room was also adapted using pictograms for this activity.

Sam has been doing this activity for 4 years and the task has become more complex each year. Initially he had 2 classes and now he looks after 8. This illustrates how maintaining a high frequency of practice increases the probability of achieving positive results in children with intellectual disabilities. Going on his own to places was a challenge for him at the beginning and his confidence has with success.

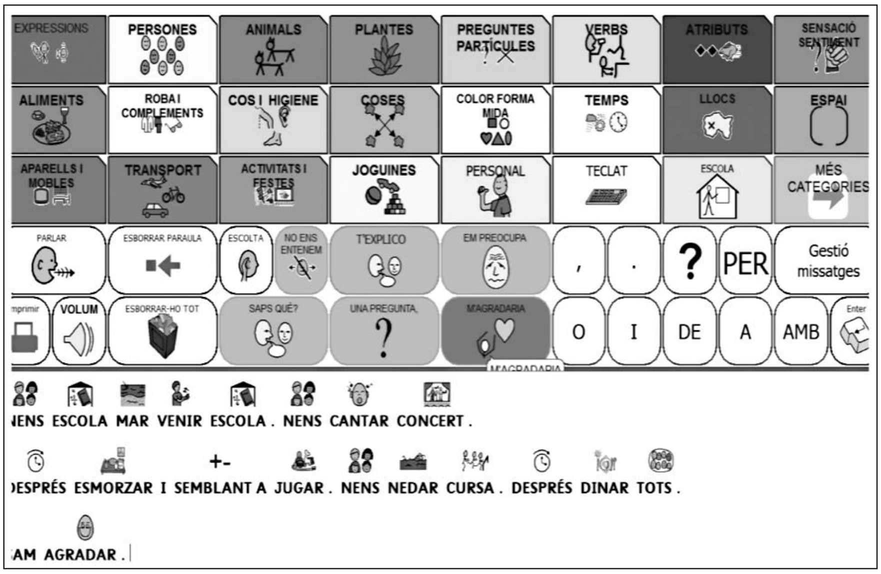

Figure 5: Reporting experiences.

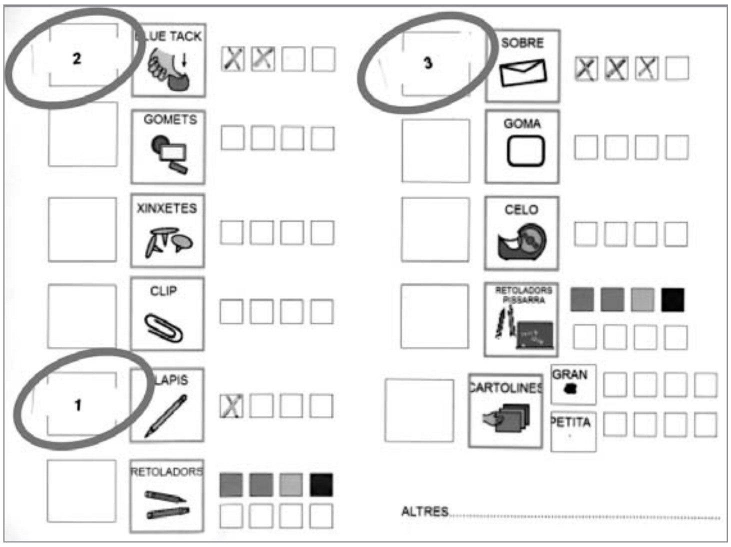

Figure 6: School supplies monitor

Figure 7: School supplies monitor

## Results and Conclusions

The activities presented in this article, along with all the others carried out over this period, have allowed Sam to progress from controlled practice to a freer form. This has helped him understand and cope with many social situations that are challenging for him.

On the academic front, sharing normal teaching and classrooms has enabled him to make the most of his opportunities. Equally Sam's academic learning and social inclusion has benefited the other children. Teachers and parents of other pupils have frequently highlighted the advantages Sam has brought to the class and to the school in general. They point out how the children have learnt to relate, adapt and be tolerant of people with special needs.

Nevertheless, adaptations in this context are complex and require considerable effort, time & training from the teaching team. As Calculator (2009, p.93), states "The successful inclusion of students with complex communication needs will depend greatly on how the educational system responds to these needs." In this case the "educational system" means the entire teaching team (teachers, specialist teachers, speech therapists, assistants, the head teacher, the regional assessment center and the family).

In our opinion a general inclusive curriculum will always need adjustment to individual needs, which may be complex. The development of an inclusive curriculum should enable these changes to be made as a matter of routine.

We can therefore conclude from this particular project that, in line with Soto's findings, some aspects have positively facilitated the outcome of the project and are key to the success of social and academic inclusion of children with intellectual disability in an ordinary school.

Firstly, Sam`s presence as the first pupil with special educational needs at the school brought about changes in their understanding and handling of inclusion. As a result today, 10 years after he joined the school, a total of 16 children with special needs attend the school, an average of 1 special needs pupil per class.

Secondly, a critical element in accomplishing the project was the determination of the director to sponsor inclusion and the creation of a support team to manage diversity.

In addition, the commitment and enthusiasm of the teaching staff were also essential factors in its success.

A fourth factor was the family's dedication to the project, which included creating, in conjunction with the school, a large part of the adapted curricula materials as well as agreeing the learning objectives with the teaching staff.

And finally, mention must be made of the external support given by the specialized AAC team (UTAC) who regularly visited and advised the school, providing technical support and learning strategies that ensured an effective use of the augmentative and alternative communication systems.

## Footnotes

1 EAP. Local government educational collaborative team.

2 Picture Communication Symbols (PCS), Mayer-Johnson products, http://www.mayerjohnson.com

3 Widgit Literacy Symbols, www.widgit.com

4 ARASAAC, www.arasaac.org

5 This software provides for the use of different voices and languages. In this case we used the Catalan male voices of Loquendo, www.loquendo.com

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# Open all hours – Scope's online community

**EMMA STERLAND**
Digital Community and Social Media Executive
Scope (UK)

From bedwetting to sex – no topic goes unturned on Scope's online community, a place for disabled people and their families to talk and share support. The community sits on Scope's website and offers people an opportunity to connect with others in similar situations. It is a lively, friendly forum for swapping ideas and picking up advice.

Recently Communication Matters Trustees took up the invitation to be guest experts, hosting Q&As on AAC, on the online community. Specialist AAC teacher, Marion Stanton and Tom Griffiths, a Clinical Scientist from Great Ormond Street Hospital took the helm for the week. Previous guests have dropped in from organisations such as Mind and Carers Trust, and there are a number of permanent community advisors offering help in everything from speech and language therapy to behavioural support.

One of the most popular features on the community is the tips section – tried and tested solutions to thousands of everyday issues, all contributed by disabled people, parents and professionals. These range from travel to technology, and trickle in daily, as members contribute new tips and share their life hacks.

Helping to run the community is a team of dedicated volunteers, known as 'community champions', who welcome new members and make them feel at home. They come from all walks of life – some are parents, some are professionals and some are disabled people. They have all volunteered their time to make sure the community is safe and supportive.

Niki Michael, who's 10-year old daughter Maria has Dystonic Quadraplegia, is one of the community champions.

"When my daughter was first diagnosed, the Scope forum – as it was then – was a great source of information and support for me," she says. "Ten years later, when I found out Scope was launching an online community, I wanted to be a part of it, as I felt I might have something useful to give back."

"Now Maria is about to go into a mainstream secondary school. She uses a wheelchair and a communication aid, so I'm happy to offer any insights I've gained through raising her. I think it's really important for families of disabled children to look out for one another, support each other and impart their knowledge.

Parents on the community understand completely the stresses and challenges of raising a child with complex needs. My experience as a community champion has shown me that collectively we are stronger and we all have something valuable to contribute."

CM and Scope are pleased to work together to support various projects. Scope's online community is open to parents who care for children and adults with a wide range of impairments, and disabled people who want to connect to others too. To find out more, visit scope.org.uk/community

Scope
About disability

# It talks, texts and tweets – but is it interested in my day?

## Personal experiences of powerful communication partners and support

**PETER ZEIN**

**EMILY GABRIELLE**
(Regional AAC Consultant – North West) Liberator Ltd
emily@liberator.co.uk

### First things first.... a bit about us

I am Peter Zein I am a user of a communication aid myself and I like to tell you about my life story. I want to tell you what I think about different 'languages'. Before I had my communication aid I was using my body language and when I went to Valance school they did learn I had reading problems and spelling problems. I was about thirteen years old and I am saying about that because Valance school did change my life. When a teacher believed in me that was the most important thing about teaching: you need to believe in that person. I think understanding is also important, saying you 'can do' is most important too. One day that teacher said to me about Blissymbols and that is when it did change my life. I did love Blissymbols it is a language of everyday life but it changed my life. Better still, when I did get my communication aid, when I had my Minspeak it changed my life a billion %! Before that I had a 'low technology' book that was okay until you were using trains! You can't call to get off when you want to stop on your station! I had this low technology book for any person to put words in: it is a funny story because I didn't have a word for the station I needed. I ended up going to Margate because I didn't have Canterbury West Station in my book. In Minspeak it does help you to say things like 'big church' (like Canterbury cathedral!) if you don't have the correct word in your language to help that person understand what you want. I am going to stop now I can go on about this. Thank you for reading that little bit of my life.

I'm Emily and I've worked as a Speech and Language Therapist for almost 10 years and have worked with Liberator for the past year. In this time I have been privileged to meet many AAC users and to be able to support them as they face the challenges and successes that come with using AAC. It's been my pleasure to work closely with Pete to explore the themes in this article and I've found it eye-opening, inspirational and empowering!

### Why here and now?

Through both of our relationships with AAC we have seen how communication technology changes and new features and improvements are being added to devices (sometimes at a rapid pace!). Devices are becoming much more technological with increased features which allow greater connectivity with the virtual world through internet access, calls, texting and so on. But at the heart of it the devices are still AAC devices. Devices which provide Augmentative or Alternative Communication (yes – that pesky C word – Communication!) for users who are unable to communicate verbally. Now of course through social media we can communicate with others as many of us do (indeed teenagers seem to ONLY communicate in this way!). However for verbal individuals there are still the joys of face to face interaction and conversation.

After much discussion we felt that sometimes this can be forgotten in AAC – which seems crazy we know! As human beings it's in our nature to want to communicate with others – we seek out interactions. So when we see AAC that isn't being used to actually communicate we wonder, what happened?

### The ride of your life

AAC is a bit like a roller coaster. When you first sit on a rollercoaster you're filled with excitement and anticipation. You see the ride and what it can do and think 'Wow! We have to try that!' So you buy a ticket, you get on the ride. What then follows is a series of twists and turns which give us dizzying highs and spiralling lows. Some of the things you were expecting – but often some unexpected surprises as well. You switch between euphoria, terror and sometimes nausea! Does this sound similar to an AAC journey at all? When getting a new device there's always the excitement of the device, its features, what you think it can do and so on. However once the honeymoon period is over you can often experience the drop when things don't go to plan – maybe not quiet nausea – but certainly unexpected lows! Even Pete – an extremely sophisticated device user has had his low points. He has told us of his ill-fated journey to Canterbury West on the train: he didn't have the station name programmed into his device so he couldn't request his stop and ended up at Margate!

However we feel that AAC is a rollercoaster worth riding – those dizzying highs in AAC far surpass the occasional low.

## So what gets us back on the ride?

When working, with the assumption that the device and the language system are right for the individual, we feel that there are 2 key things that can make the AAC journey easier and ensure that the lows don't stay lows for too long. Luckily these things aren't too technical or expensive! Communication partners and the support they provide to AAC users can be critical in determining the success of an AAC device.

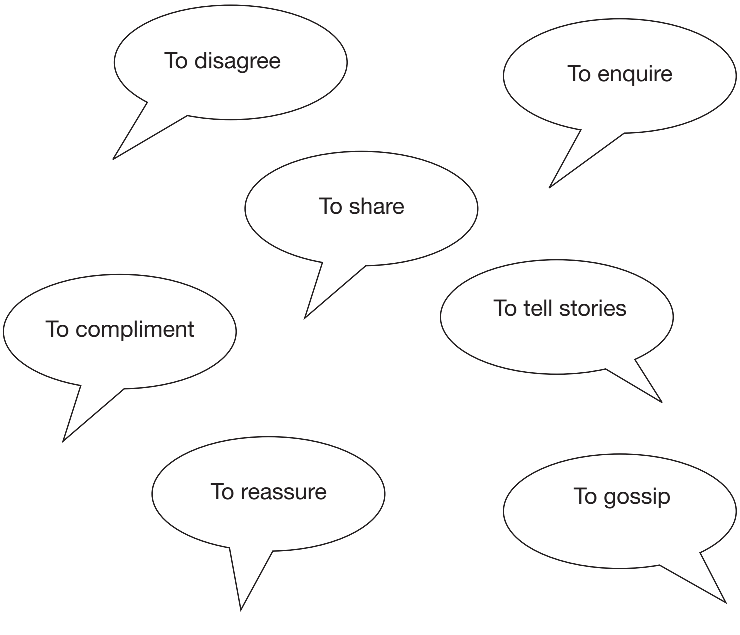
## What makes a great communication partner?

Whilst we don't feel you can write a person spec for the ideal communication partner we do feel that there are certain features and attitudes that mean someone would be a fab partner for an AAC user.

Our top tips for being the best you can!

- **Perseverance** – don't give up if things get tough – stick with it and keep trying. If something breaks – find out how to fix it. If a word you need isn't there – find out how to add it or help the user to find an alternative.
- **Knowledge** – Being comfortable with technology and language the user has. Take the time to educate yourself on how to use it, ask people who know more to share their knowledge with you. We all start with no knowledge of AAC and that's OK! You're not in bad books for not knowing!
- **Dedication** – View the role of Communication Partner as a vocation. Feel privileged you have this amazing opportunity!
- **Encouragement** – highlighting the positives to the person using the device. Don't focus on the negatives. If an AAC user sees you disliking the device it can stop them feeling good about it. Every day you need to say them "how is your sexy voice today?" Don't moan if a device breaks – say "how can we fix it together" "let's see how we can avoid that happening next time".
- **Personalisation** – make sure you know and respect how the user wants to use their device. Make sure that they have the vocabulary to do this! Help them find the experiences they want so they can practice the skills they need to do it again and again! Make sure the support you give is right for the individuals needs – more sophisticated users may not need you often – but you can guarantee they will still need you sometimes.

But what about all the other wonderful reasons we communicate?

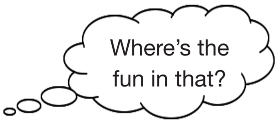


- **Keeping it real** - Think about why we communicate – forget about the beautiful curriculum and focus on the beautiful language of life and the interactions you can have. Think about your favourite things to communicate. Is it to talk about history? Is it to label shapes? Or is it to tell someone you love them?

## Why do we communicate?

We all know the usual communicative functions we think about when first using AAC.

- To request
- To reject
- To comment



But what about all the other wonderful reasons we communicate?

"Just as a dance couldn't possibly be a dance unless people moved to it, so language doesn't become communication until people grow to understand and express it back. It has to be a two-way exchange. This is why ''communicating'' is an action word" (Staehely, 2000)

So we beg you – don't forget all the fun things to communicate about. Listen to what an AAC user is telling you and more importantly hear the message they have to tell you! Why should the things a person wants to talk about or the reasons they want to communicate be any different just because they are using a device?

## The big secret

As we chatted about what makes a great communication partner there was one thing which became glaringly obvious – it isn't rocket science. Remember that pesky C word we discussed – no matter how technological a device is, it is still designed with a clear function – to support a user's communication. Be brave, have faith in what you are doing and, most importantly, be a human being. You can ride that rollercoaster again and again and you know what? It'll probably be the ride of your life!

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# A father writes about the event of his son's investiture into the Scouts

**BOB SAGOO**
Email: bob@ihelpinnovations.co.uk

**CM is pleased to share a story that reflects the best sort of inclusivity, from a parent's perspective. The Scout Association, who we contacted about the story, are proud of the way the local cub group has worked with Harchie and his family to make his time at Scouts both enjoyable and productive. They look forward to a long partnership as he moves through the ranks.**

Harchie is a very bright fun loving 9 yr old. When I think at what he has achieved, and continues to do so, I feel immense pride as a father of such an exceptional child, and also a burning responsibility to help Harchie, and other children fulfil their hopes and ambitions.

With Harchie, as with so many children with Cerebral Palsy, they possess a desire, to experience life and find ways to overcome their physical issues.

I see my role as Harchie's facilitator. I thought it corny, the saying that states, once you become a parent, 'you see the world through your children's eyes'. Now through all aspects of life, be it my business or just watching TV ( we are huge Big Bang Theory fans!) Harchie dictates my ideals and direction.

I have always had this sense that Harchie should and must have as ordinary a childhood as possible, not just for him, but for other children as well. The biggest kick I get is watching him interacting with his peers. They see him as one of them, part of the group.

Children have none of the hang ups we adults have which is also so refreshing. They ask the questions that we have been conditioned not to ask.

When Harchie expressed his desire to join the Cub Scouts, there was no hesitation on my part, just a need to facilitate this in the best way possible.

So moving forward, Harchie using his Tobii Eyegaze, did his Investiture into the 124th Nottingham Scouts as a Cub in the Middleton Pack.

### What next ?

To coin a phrase…”
Where he leads, I follow”

# What goes on in the office?

Hilary Gardner

Emily Campbell

Since Patrick Poon and Peter Head retired in the Spring (and with the relocation of the CM office to Leeds), the new 2 handed team has been hard at work sorting out roles and responsibilities. The trustees thought long and hard about the skill set that was needed to take the charity forward and this was reflected in the job descriptions. It has been suggested that some clarification of how the team is operating might be helpful to those interested in the charity.

**The Office Team.**

Emily Campbell
Hilary Gardner

## General office responsibilities

Emily is the key administrator for CM. She is in the office on a day to day basis and takes full responsibility for database management, membership, invoicing, Friday announcements and all the bookings and enquiries around roadshows and study days. Emily was pleased for the opportunity to take a basic online 'InDesign' course for graphic design which allows us to make small changes to the flyers and artwork produced for all the events. There are more jobs than can be listed here, the biggest of course being conference admin (see below)!

Hilary works for Communication Matters three days a week and wears several different 'hats' as general manager, 'company secretary' and information officer. In these roles she is responsible for forwarding the ideas of the Trustees as well as monitoring key areas of strategy and governance (eg banking, Companies House and Charity Commission requirements). Apart from roadshow and study day organisation Hilary enjoys networking on CM's behalf but with limited expertise in AAC passes on all specialist queries to the appropriate people. At present she is editing the CM journal (now supported by Janet Scott, trustee) as well as producing articles, letters and e-news. Once the office has settled into its new routines, Hilary is looking forward to having more time to work with the Chair on bid writing for specific projects.

Both Emily and Hilary are enjoying taking on editing and adding information to the website (more new skills!) as well as posting on social media eg enlivening the Facebook feed and Twitter.

## Conference

This big annual event has a long build up! The work on this starts even before the last one finishes and the office is involved with planning, adaptations and marketing. The pace quickens at the start of the year with site visits, menu tastings and negotiations. Several months beforehand, especially in late-July, there are registrations for the early bird rate. In early September there is a flurry of last minute registrations as funding is finally agreed. August is full of administration work for conference including anything from sending out letters to presenters about their time slot, liaising with the university conference team about accommodation, catering and parking to printing out feedback forms and name badges. There is a lot of chasing up to be done to ensure delegates send in the required registration and payment information as well as ensuring all the conference signage is correct. There is also liaison with the suppliers re sponsorship, joining information and their exhibition stands. Finally, along with conference registrations comes memberships and everything involved with setting these up. Conference itself proved to be full on from start to finish but was exhilarating because of that! Having the office on site at Leeds has made some aspects of the day to day running of CM much easier especially in relation to the Conference. We are also pleased that we have begun to make good links with the University Business School and other key individuals and organisations in the Leeds area. The new office team will have been in post for a year in February 2016 and are looking forward to facing the next year with more confidence now we have the benefit of experiencing everything once through. The 30th anniversary of CM promises to be an exciting year!

# Developing literacy support for students who have AAC (Augmentative and Alternative Communication) needs and/or SLCN (Speech, Language and Communication Needs)

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The Communication Trust, based upon research evidence, asserts that SLCN is the most common SEN as identified by primary schools and is a feature of many other areas of SEN. The Trust also states that 'There is a very strong link between SLCN and difficulties with literacy.'[1] 10% of all children have long-term SLCN. 7% of all children have a specific language impairment. 1% of all children have severe and complex SLCN.[2] Children who have need to use AAC (augmentative and alternative communication) can face particular challenges in developing language and literacy although many (especially those with physical disabilities) have typical ability to learn language given appropriate instruction.

Research shows that children with poor levels of oral language are very likely to have difficulty when learning to read and write. One of the key predictors of reading success is vocabulary. The wider a child's vocabulary is, the better the development of their understanding and use of grammar. As we grow older much of our vocabulary is acquired through reading. The child with SLCN who struggles to learn to read cannot extend their language in this way and therefore becomes doubly disadvantaged.[3]

Children's language development is enhanced at all ages by interaction. Social interaction can be challenging for those using AAC as opportunities may be few. With older children it has been suggested that social networking offers opportunities for people who use AAC and those who have SLCN. However low levels of literacy create problems for this group when they try to access this predominantly text based facility.[4]

Aware of the need to address the issue of the teaching of literacy to students who have SLCN, and especially those who use AAC, Communication Matters has run a number of literacy focused study days in 2004, delivered by Karen Erikson, and again in 2009, delivered by Caroline Musselwhite. In 2004 Karen's research was already indicating that there was more literacy learning potential in a larger proportion of the group who have severe SLCN than may have previously been thought. However, it was also clear that the approach to learning literacy needed considerable adaptation and individualisation.[5] One of the clear messages from these early introductions was that students who have difficulties with acquiring literacy skills need more rather than less exposure to text in a variety of ways and yet research shows that students with SLCN (and using AAC) do not have as much exposure to literacy as those who are more easily able to acquire literacy.[6]

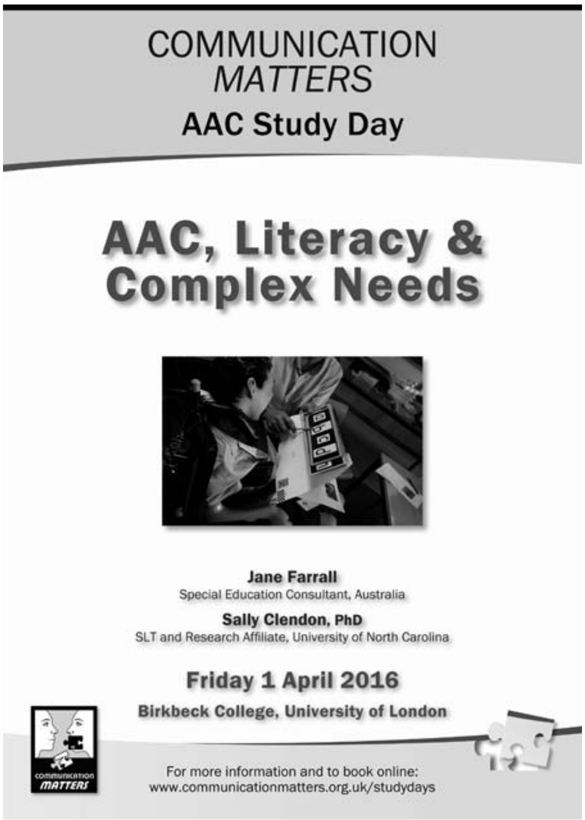
A positive example of literacy exposure comes from the finding that children with Down syndrome who attend mainstream schools outperform their peers who attend special schools in literacy acquisition, arguably due to literacy experience and expectations. There is also evidence that the receptive vocabulary of students with Down syndrome is a stronger predictor of future reading acquisition than phonological awareness. While mainstream approaches may benefit students who have SLCN, they are likely to need extra and sometimes different supports from those that are advocated for non-disabled students (where phonological approaches are most strongly advocated in the UK).[7]

As long as a student (especially one who is an AAC user) is reliant on symbols rather than text they will be restricted to the choices we offer them. Once text based literacy acquisition begins the student may be able to engage in an exploration of language that may lead to them being able to express their own novel utterances. They also become able to develop their literacy skills by adding to their vocabulary store. A key feature of literacy learning involved repeated engagement with the same text, often to the exasperation of the parent who is having to read the same story for what may seem the hundredth time.

In 2015 Communication Matters put on a study day entitled “Symbolisation towards Literacy” which was delivered by Dr Janice Murray from Manchester Metropolitan University and Dr Martine Smith from Dublin University. Martine Smith has identified the lack of repetition as a factor in the difficulty that students with SLCN have with literacy acquisition.[8] The presenters highlighted the importance of maintaining awareness when deciding whether and how to use symbols rather than text to support literacy. The inextricable link between the development of vocabulary and the acquisition of literacy was emphasized. The use of story books, ensuring that the story is repeated sufficiently, with carefully targeted attention to specific texts from the story, was explored. The intention of the exercise was to develop vocabulary alongside literacy.[9]

In recent years a number of practitioners and organisations have attempted to take forward approaches to improve literacy attainment amongst the population of students who have SLCN. Research projects have included those of York University, Centre for Reading and Language (http://crl-research.org/) for instance where the RALI, Reading and Language Intervention, was part of a 5 year project.

Some of the practitioners and organisations involved in creating and using interventions, for those using AAC and those with SLCN, have now come together to encourage a concerted effort to develop evidenced approaches to the teaching of vocabulary and literacy for students (with complex needs) who have difficulty in acquiring both. At a meeting held at the Communication Matters conference on the 14th September 2015 a Special Interest Group of individuals, practitioners and organisations was created. The purpose of the (as yet informally constituted) group is to work together to share information and influence teacher training in relation to the teaching of literacy for those who rely on AAC and/or have SLCN.



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AAC Study Day

AAC, Literacy &
Complex Needs

**Jane Farrall**
Special Education Consultant, Australia
**Sally Clendon, PhD**
SLT and Research Affiliate, University of North Carolina

**Friday 1 April 2016**
**Birkbeck College, University of London**

For more information and to book online:
www.communicationmatters.org.uk/studydays

One scheme already being used internationally, is that devised by Jane Farrell and Sally Clendon, both of whom have been pioneering an approach known as ‘4 Blocks’ in Australia for a number of years. In a nutshell 4 Blocks supports the development of engagement with text through the four platforms of guided reading, self-selected reading, working with words and letters and sounds with writing. These are well understood to be part of any well-adjusted literacy programme but the addition of adjustments so that even students with the most severe language and communication needs can engage with text means that this approach warrants serious consideration. There are other approaches that promote the teaching of text (alongside symbol use) and the group will seek to identify and support evidence based approaches.

As part of this process a 5 day intensive literacy course is being planned to take place in April 2016. The course is being delivered by Jane Farrell and Sally Clendon who are also offering an introductory course on SLCN, AAC and literacy for Communication Matters, on April 1st 2016 (see CM website for details).

It is envisaged that guidance will be developed to support the teaching of literacy for students with SLCN (and particularly those using AAC symbol supports). In the intervening months we will be working with a number of established organisations who are concerned with literacy teaching to develop our aims.

CM has a Googlegroup which you can join to be kept up to date on literacy and SLCN in AAC. Contact manager@communicationmatters.org.uk to join. There is also a Facebook page where you can share ideas and resources: AAC SLCN Literacy

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## #CM Occasional Series: Insights & Interviews

# Interview with Brett Reynolds (Keynote Speaker CM2015 conference)

**CATHERINE HARRIS**
Chair of Trustees

### 1. Hi Brett, can you tell us a little about yourself for these who were not able to meet you in person at the Conference.

I'm a person with Cerebral Palsy, which I have had from birth. For me that means I have trouble with my balance, and, muscle control. As I cannot use my hands I use a head pointer to do what I need to, such as turn the pages of a newspaper or book, do paintings and drawings, switch on things like the TV or DVD player and type on my Dynawrite for communication.

I enjoy painting and drawing when I can get the opportunity.

I enjoy shopping with a helper, bowling, going to see a movie and having a spa to relax my body.

### 2. This was your first trip to the UK. What were your first impressions of the UK?

Yes it was my first in your beautiful countryside and I was impressed by how green everything looks.

I also loved your old pubs and you have great beer.

Everyone associated with the Communication Matters conference were so welcoming and friendly.

### 3. What did you like best about the Conference?

Meeting up with different people from many different parts of the world, coming together and talking about the important subject of communication between people.

I also enjoyed staying at Leeds university - everything was very accessible and I loved the grounds and beautiful old architecture and buildings.

### 4. What did you like the least?

Not having enough time to meet everybody.

### 5. The Communication Access project is obviously a big part of your life. What impact do you think it could have in the UK?

To teach others about how to communicate with people who have communication difficulties.

To raise awareness about AAC.

To make communities welcoming of people with disabilities.

To begin a movement towards a communication accessible world.

### 6. Have you any advice to people who use AAC who are interested in becoming involved in the project?

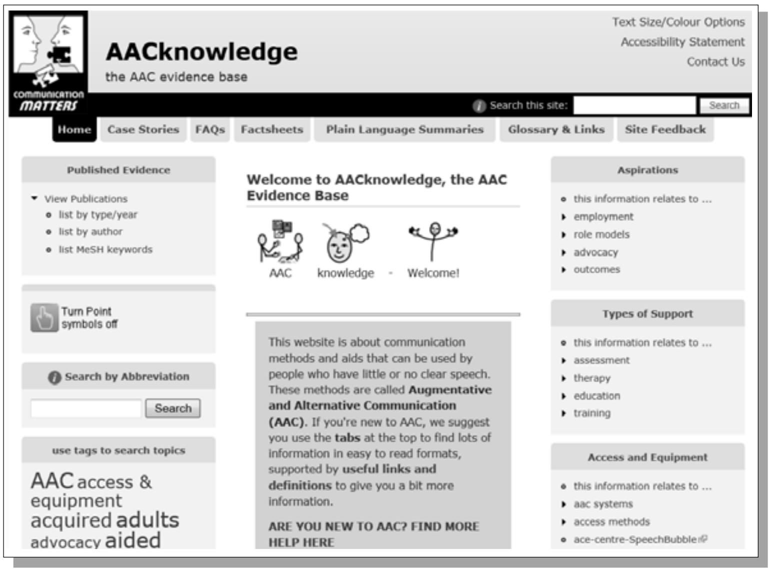
Never let your dreams go. Push yourself to your limits and never give up.

### 7. What is your next focus as we come in 2016?

To continue to promote communication access in Australia

To assist with any potential roll out of communication access in the UK.

## Are you looking for AAC knowledge?



COMMUNICATION MATTERS

AACknowledge
the AAC evidence base

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use tags to search topics
AAC access & equipment acquired adults advocacy aided

Welcome to AACknowledge, the AAC Evidence Base

This website is about communication methods and aids that can be used by people who have little or no clear speech. These methods are called **Augmentative and Alternative Communication (AAC)**. If you're new to AAC, we suggest you use the **tabs** at the top to find lots of information in easy to read formats, supported by **useful links and definitions** to give you a bit more information.

**ARE YOU NEW TO AAC? FIND MORE HELP HERE**

Aspirations
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Types of Support
- this information relates to ...
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- this information relates to ...
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- ace-centre-SpeechBubble

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

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

**The website features:**
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- Factsheets
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HELEN QUILLER

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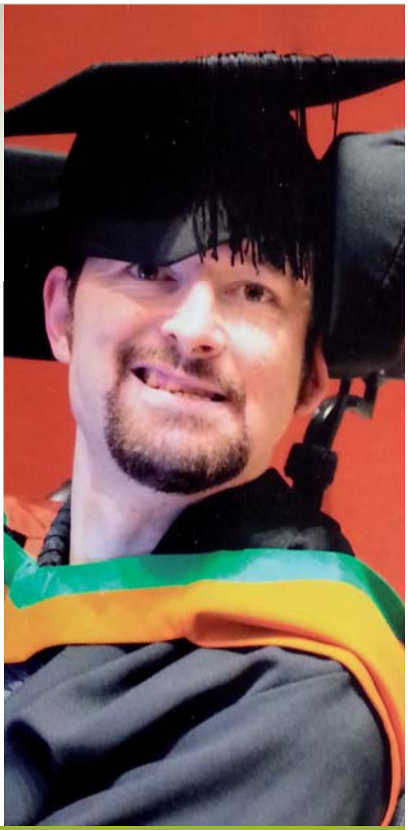
MATT GOPSILL MSc



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