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2016

AUGUST 2016 VOLUME 30 NUMBER 2

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VOLUME 30 NUMBER 2
AUGUST 2016



*Thank you to Sam Knapp, our 2015
Alan Martin Arts Award winner,
for this self portrait.*

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View from the Chair

Trustees' news July 2016

Highlights

This is always a busy time of year with the conference planning and preparations now in 4th gear!

30th Birthday Conference Sunday 11th-13th September 2016 – Miss it or Miss out!

Tea Party

Make sure you plan your journey to arrive in time to enjoy our 30th Birthday Tea Party which is to be held between 2-4pm next to Storm Jameson (Charles Morris Hall) with music from 'Jazz on the Lawn'. We are very grateful to Leeds University MeetInLeeds Conference team for supporting and donating this event. We are hoping for sunshine! It should be a lovely start to the 2016 Conference.

Programme

The Conference programme is shaping up well and is available on the website in draft form. We were delighted to receive more abstracts than ever before although this meant some disappointment when a proportion of abstracts had to be turned down. Most people have given us positive feedback about the new ExOrdo submission template which has made the application, review and selection system much more streamlined and time efficient. The presentations are grouped under 3 streams which are research, professional practice & personal experience. Technology presentations are available from our exhibitors & the developers as well as people who use AAC. The personal and family experience papers are again strong this year alongside a growing number of education based papers. We're also pleased to see the return of the poster stream, on Monday & Tuesday with a different set on show each day and the authors available in the breaks to answer questions. The exhibition again will be a central meeting point with the opportunity to extend knowledge, experience new technology and to meet the suppliers face to face.

Keynotes

We are very pleased to be able to welcome two renowned Keynotes this year;

Dr Angharad Beckett is Associate Professor of Political Sociology and Deputy Director of the Centre for Disability Studies at Leeds University. Her primary research interest is 'disability politics' and the creation of enabling and inclusive societies. She has undertaken research into citizenship for disabled people and disability activism and published a book on the topic. Recently she has been working in the area of Inclusive Education and Inclusive Play, seeking to understand the barriers for disabled

children and the potential for play to encourage positive interactions & friendship between disabled and non-disabled children. Angharad has worked with students who use AAC while at Leeds University. Angharad will be presenting on Monday morning.

Martin Pistorius (born 1975) is a freelance web developer, IT consultant and author best known for his 2011 book *Ghost Boy*. The book is an international and New York Times best seller and recently received Audie Award for best autobiography 2016. Martin has used AAC since the age of 25. He currently communicates via a computer with dedicated AAC software, an iPad, and other means. Martin worked at the Centre for AAC at the University of Pretoria for four years before moving into the IT sector. He holds a first class honours degree in Computer Science from the University of Hertfordshire. He has given presentations all over the world including delivering a keynote at CM conference in 2011 & a TedX talk in 2015. Martin married Joanna in 2009 and lives in Essex. He will be presenting on Tuesday afternoon.

Progress on Communication Access for All project (CAfA) – see article on pages 4–5.

Following Denise West and Brett Reynolds' keynote at the 2015 CM Conference, Barbara Solarsh from Scope Australia has been over (May 2016) to talk to Trustees and to present to potential trainers for the Leeds area, including AAC users. All these speakers have been inspirational in sharing the Australian journey towards Communication Access. Following the conference, the trustees debated whether CM could launch this project in the UK on our own but decided that collaboration with such a large undertaking was essential for maximum impact. Alongside Stroke Association and RCSLT a Stakeholders day was held on June 10th to launch the project in the UK. Representatives from over 60 charities were invited to attend and there was an opportunity to share the project aims and begin the consultation process towards agreeing on a symbol for the UK & the development of possible accredited training. There will be opportunity to attend presentations at the CM Conference, and you can read more on the progress to date within this Journal edition.

Intern

We are always looking for new opportunities and are delighted to welcome to our new intern Peter Fuzesi. Peter is funded by ESRC North-West Doctoral Training Centre, as part of his PhD programme, to work with CM for 5 months. Peter is researching the development & service delivery of assistive technology. He will be



helping with conference, evaluating the CM websites and collecting some data for us. We hope some of our supporters will meet him in the next few months & he will certainly be at conference. Peter is based at Lancaster University. Thank you to Simon Judge, Barnsley Assistive Technology team for recommending CM to Peter!

ISAAC

This year the 2016 ISAAC conference is being held in Toronto from 7th-11th August. The Chair of CM is expected to attend the ISAAC council chapter meeting with the second representative, Neil Hanson. This meeting is held on the day before the conference starts and is an opportunity for all to contribute on the various agenda items. This is not quite as straightforward as might be anticipated as English is not the first language for the majority of participants and the business can move fairly quickly. CM is now one of the largest chapters with more than 350 members. It is therefore important that we ensure that decisions which are taken are in the best interests of all concerned. Over the years there have been regular discussions as to the ISAAC affiliation. At the present time the Board feel we are 'better together' (does this sound familiar?) but we have previously talked over the possibility of having a survey of members about this issue in the coming months so watch this space.

New stage-new opportunities

As the time approaches for me to hand over the baton to a new Chair(s) I want to express my thanks again to the work of the trustees and others without whose support it would not be possible to achieve so much. The last few years has seen much change for CM with the new venue for Conference, retirement of Patrick and Peter, the move of the CM office to Leeds and restructuring with the appointment of new staff, Hilary Gardner and Emily Campbell. We also have the additional support of a book keeper, accountant and web technician when we need it. We have an intern working with us for the first time. We have representation on the Specialised Healthcare Alliance (SHA), the Communication Trust Consortium

(TCT) and policy group, and the AAC sub group for complex disability equipment. CM has been invited to have input into the Scottish and Welsh AAC projects and we have seen significant changes to funding of Specialist AAC services in England. We have updated our Journal and website and are about to launch our new logo! We continue to involve AAC users in all our activities.

Personally these last four years as Chair was initially a steep learning curve and sometimes a roller coaster ride! However, it has been an exciting time of numerous opportunities to raise awareness, promote interest in AAC and input into policy. The best part though has been the networking with AAC users and others passionate about what AAC can achieve for people across the UK and the world. Thankyou for this opportunity to serve in this way.

I hope to continue to support CM as an 'active friend' and wish the new Board every success in this next stage of the journey.

Catherine Harris



Good News for CM!

Communication Matters applied for a grant to the John Ellerman Foundation (www.ellerman.org.uk). The Good News is that we have been awarded £50,000 towards core costs over two years! The grant includes money that will support the Communication Access pilot business-training project and support more AAC users to attend CM meetings. There is also money to enhance and develop CM websites. We are delighted with this development and there will be more information at conference.

Communication Matters and the Communication Access Project – June 2016

CATHERINE HARRIS

Chair of the Board of Trustees for Communication Matters

In November 2011 this new symbol (figure 1) for communication access was launched in Australia by Scope's Communication Resource Centre. This was the culmination of five years' work by people with complex communication needs (CCN), in partnership with the Communication Access Network (CAN) in Victoria and key stakeholders. Communication Matters (ISAAC UK) has been working towards rolling out a similar project across the UK. The work has two elements, that of developing a 'Communication Access Symbol' and secondly developing 'accessible business' training, involving people with communication difficulties (who may use AAC) in its delivery.

A COMMUNICATION ACCESS SYMBOL?

We have come a long way in terms of access. We all recognise the wheelchair symbol which is one of the top 10 symbols recognised around the world. More recently the symbols for hearing impairment and visual impairment are used in public places. There has been progress in promotion of the value of better signage and accessible information. The 'last piece of the jigsaw' is recognising the needs of those with a communication difficulty who may or may not be using Augmentative and Alternative Communication (AAC).

Communication difficulties are often described as hidden disabilities. We know that a communication impairment can impact on making relationships, social and emotional wellbeing, education and employment. Using, promoting and supporting communication access training,

in order for a business to display the symbol, would provide a better experience for all people and especially for those with a communication impairment.

We first heard about the concept of a national symbol for communication access in 2013 when there was a parallel presentation at the CM annual conference. It immediately resonated with those who attended. There have been many smaller projects across the UK which have raised awareness and offered training but there have always been issues around sustainability. CM trustees felt that now was the time for some joined up thinking! Following much research and many skype calls we were delighted to have Denise West and Brett Reynolds as our keynote speakers at the 2015 CM Conference. They were inspirational in sharing about the Australian journey.

Communication access is an important part of removing barriers to equal citizenship for all. It is a part of the United Nations Declaration of the Rights of Person with Disability (2006) of which the UK is a signatory. This affirms that communication access is a right not a privilege, and when businesses, organizations and services display the symbol for communication access & act accordingly, they are playing an important role in turning these rights into the everyday experiences of people with complex communication needs.

COMMUNICATION ACCESS ACCREDITED TRAINING

The Australian project has launched a symbol in Victoria which is underpinned by benchmarked standards. In order

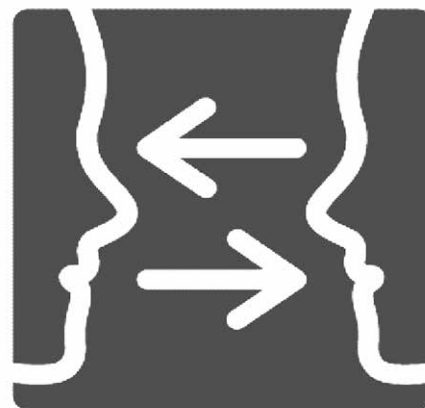


Figure 1

for a business or service to be awarded the symbol they are required to have a 'communication access assessment'. This assessment is completed by a person with a communication disability who is a trained to be a Communication Access Assessor. Businesses, services and organizations who are judged to be 'communication accessible' based on criteria and will then be able to display the symbol.

A UK COLLABORATION

Although in some ways it would have been nice for CM to launch this project in the UK on our own we have recognised that we are a relatively small charity with limited resources. Although we punch well above our weight, if we really want to see this project have national long term impact, the trustees felt we needed to work in collaboration with other organisations. We have been open in our discussions with Scope Australia and have continued to learn from each other. Since September 2015 we have initiated meetings with various other UK charities to share the vision.



Figure 2

With support from the Stroke Association and RCSLT a Stakeholders day (figures 2 and 3) was held on June 10th to launch this project in the UK. Representatives from over 60 charities were invited to attend and there was an opportunity to share the project aims and begin the consultation process towards agreeing on a symbol for the UK. The core elements to be included in any training in order to acquire the symbol, is also to be discussed further.

Catherine Harris and Toby Hewson delivered presentations to introduce the work which CM have done around the project to date. Flora Goldhill, Director for Children, Families and Social Inclusion, Department of Health (England) also gave a presentation to offer her support. There were table discussions to discuss the various symbols available and to collate the principles we would want to replicate from other projects and the assets we have as a sector. The outcome from this meeting was very positive with the majority of people excited about having a national and possibly international symbol for communication access. Inevitably some people are playing 'catch up' but there was a consensus that together we would have far more impact and influence.

The steering group is due to meet again at the end of June with a consultation on the symbol planned for the autumn. CM delegates at conference will have the opportunity to attend further workshops about Communication Access and the training, with an introduction to being a

'mystery customer' and to contribute service user feedback on a potential symbol.

This project meets all of the aims of CM:

- Increasing awareness about communication and AAC
- Improving service standards
- Encouraging research
- Lobbying government for change
- Involving people who use AAC in all the charity's activity

CM is well placed to be a lead partner in this project. We have done the ground work and set the ball rolling. Four AAC

users have already had introductory training about being assessors. We will continue to have a key role within the steering group. During this consultation phase we are very fortunate to have the services of an intern, Peter Fuzesi, who will be working with CM from July to November 2016. He is funded through the North west Doctoral Training Centre grant body and we are sure will be a real asset in the coming months.

It is recognised that in the longer term this work would need to be co-ordinated by a paid project lead who is focussed on the task and can ensure that to project aims and outcomes are met within the agreed time frames and therefore the project has significant funding implications. It is envisaged that shared bids will be submitted to the relevant grant-giving bodies. CM has started by making grant applications to support a pilot training involving people who use AAC. Leeds University have already approached CM to be involved in this. We will also be hoping to identify local CM 'Champions' to drive the project forward.

We feel that achieving wider recognition of this symbol and the need for support business training will result in better understanding and experience for all who find communication difficult. This is an exciting opportunity to work in collaboration to make a greater impact-national and international.

For more information visit
www.communicationmatters.org.uk
www.scopevic.org



Figure 3

Review of prevailing terminologies in the area of Augmentative and Alternative Communication

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ABSTRACT

We investigate the use of the term 'Augmentative and Alternative Communication' (AAC) by means of bibliometric analysis. Given that AAC is the accepted term for the field and the varied non-verbal systems, the findings of this study suggest a strong North American/United States influence on dissemination of knowledge in AAC. It also suggests the need for inter-cultural dialogue and collaboration.

Keywords: AAC, bibliometric analysis, literature review

INTRODUCTION

Collaboration among researchers needs a common theoretical platform upon which information can be shared, including eg. common terms to reference theories, practices, and perspectives. Hence there is a need for unification of terms. An area where terms take on different meanings is the field of Augmentative and Alternative Communication (AAC) (Kangas & Lloyd, 1990; Lloyd and Blischak, 1992).

AAC emerged as a field and gained recognition as an important area in clinical practice in education and research since the 1970s (Zangari et al., 1994). With the establishment of this emerging field, in the 1980s Lloyd (1985) proposed the standardization of a glossary of terms and concepts used in the AAC, including the term AAC in area-related literature. One of the main purposes for this proposal was to develop a consistent logical term for AAC, which could facilitate the international and transdisciplinary development of the

field (Lloyd & Kangas, 1988). Indeed, an ISAAC terminology committee formed in March 1988 with the purpose of conducting research towards the standardization as well as the systematization of the terms used to represent visual-systems communication declared in 1992 "Augmentative and Alternative Communication" (AAC) the official term for the field (Lloyd & Blischak, 1992).

For a consensual adoption of the AAC term, three documents on the policies and recommendations were published in the *Augmentative and Alternative Communication Journal* of the International Society for AAC (ISAAC), originally published in 1985 (Lloyd, 1985; Lloyd & Blischak, 1992; Lloyd & Kangas, 1988; Kangas & Lloyd, 1990).

In short, the first document, published by the ISAAC Governance and Committee Activities on AAC Terminology and Issues, provided a list of descriptors and concepts, meant for use by authors involved in the development of the field (Lloyd & Kangas, 1988). In this list, the AAC term is included as one of the thirteen concepts recommended by ISAAC. In the second official document, the same ISAAC committee agreed on promoting regular reviews of terms used in the field in two-year intervals, thereby updating keywords and concepts in the AAC field (Kangas & Lloyd, 1990). The third document responsible for making the AAC terminology "official" was published two years later ("AAC Terminology Policy and Issues Update") and established AAC as a term and a field in the United States.

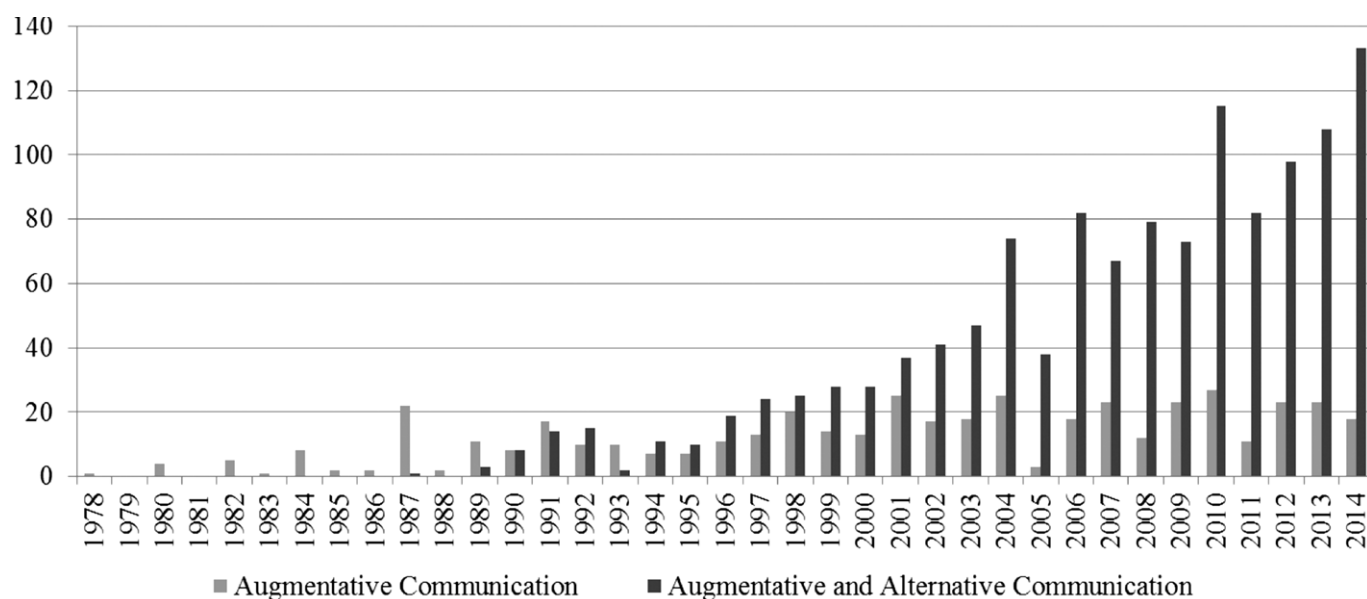
Some studies aimed at the use and overall acceptance of AAC as a term were done by Von Tezchner & Jensen (1996) who made an analysis of the scientific production in AAC in the AAC journal (the eight first issues 1993-1994, totaling 52 articles) and the evidence-based practice (EBP) study in AAC by Schlosser et al. (2005), that gives an overview of research on AAC until 2005.

In this paper we used bibliometric analysis for assessing quantitative parameters of AAC-related publications. The goal of the study is to verify the use and overall acceptance of the AAC term in research studies published by international journals in the field of AAC, as well as to obtain a broad spectrum of research in international literature on AAC.

METHOD

The method is based on bibliometric analysis, which is defined as the quantification of production indices and the overall dissemination of scientific knowledge by means of quantitative and statistical techniques (Araújo, 2007). According to Ensslin & Ensslin (2012), observable parameters are the theme-related papers, the literature references used and the most cited authors, journals and papers. Three databases were searched in April 2015: SCOPUS, Web of Science, ScienceDirectPubMed. The keywords used were "Alternative Communication" and "Augmentative and Alternative Communication." In each database, the title of article, the abstract and the keywords were used as main search objects.

Figure 1: Publications using the terms AAC or AC over time, from 1978 until 2014, according to EndNote®



RESULTS

From the 21,915 titles in SCOPUS, 883 documents were found which used AAC as main topic topic. From the 18,711 titles in Web of Science, 634 records related to AAC were found. The search in PubMed yielded 435 documents pertaining to the AAC field.

The total number of records obtained from the three databases comprised thus 1,952 documents. Filtering procedures were used for extracting duplicated records from the sample. The redundancy check yielded 690 duplicated records, resulting in a total of 1,262 valid documents used in this analysis.

A general conclusion suggests that the AAC terminology has been accepted by the scientific community and has been used more often in this area. The term AAC was systematically used in scientific works published from 1994. Figure 1 represents a timeline of frequency of publications using the terms "Augmentative and Alternative Communication" or "Augmentative Communication".

The prevalence of this term from 1994 could be a result of the last AAC Terminology and Issues Update published in June 1992 (Lloyd & Blischak, 1992). The second observation is that while the frequency of the term AC in the literature remained stable across the 4-decade period, the frequency of AAC as the term referring to non-verbal communication has steadily increased.

Table 1 presents a list of the 10 countries with the highest percentage of

publications, between 1978 and 2014. The United States is the most productive country in the field of AAC. With respect to the list of 10 countries with the highest contribution of publications, the English-speaking countries represent just over 85% of the publications. Results illustrated in Table 1 corroborate findings from another study (von Tetzchner & Jensen, 1996), where the authors analyzed 52 papers published only in the AAC Journal between 1993 and 1994; among 52 papers, 41 (78%) were from the United States.

Tables 2 and 3 present the ranking of the publications found by journal title, using both EndNote® and SCOPUS searches. Again, a list of the 10 journals with the

Table 1

10 countries of origin and percentages for AAC topic papers according to SCOPUS

Country	N	%
United States	482	54.59%
United Kingdom	88	9.97%
Australia	77	8.72%
Canada	69	7.81%
Italy	33	3.74%
Sweden	30	3.40%
New Zealand	27	3.06%
South Africa	21	2.38%
Norway	19	2.15%
Netherlands	16	1.81%

Table 2

10 journals with the most frequent publications on the topic of AAC according to EndNote®

Journal Title	n	%
AAC: Augmentative and Alternative Communication	416	32.96%
Disability and Rehabilitation Assistive Technology	44	3.49%
Journal of Speech, Language, and Hearing Research	31	2.46%
American Journal of Speech Language Pathology	30	2.38%
Assistive Technology	29	2.30%
International Journal of Language and Communication Disorders	16	1.27%
Aphasiology	14	1.11%
Revista Brasileira de Educação Especial	13	1.03%
Child Language Teaching and Therapy	13	1.03%
Communication Disorders Quarterly	12	0.95%

Table 3

Journals with the most frequent publications on the topic of AAC according to SCOPUS

Journal Title	N	%
AAC Augmentative and Alternative Communication	346	39.18%
Journal of Speech Language and Hearing Research	29	3.28%
American Journal of Speech Language Pathology	24	2.72%
Assistive Technology	15	1.70%
Disability and Rehabilitation Assistive Technology	14	1.59%
International Journal of Language and Communication Disorders	13	1.47%
Child Language Teaching and Therapy	13	1.47%
Communication Disorders Quarterly	12	1.36%
Aphasiology	11	1.25%
Journal of Developmental and Physical Disabilities	11	1.25%

Table 4

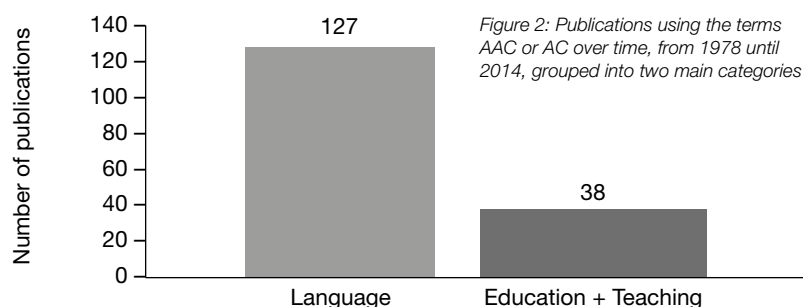
Documents by affiliation (10 most relevant) using SCOPUS

Affiliation	n	%
Pennsylvania State University	75	8.49%
University of Nebraska - Lincoln	40	4.53%
University of Sydney	31	3.51%
Northeastern University	28	3.17%
University of Texas at Austin	23	2.60%
Universiteit van Pretoria*	23	2.60%
University of Toronto	21	2.38%
Università degli Studi di Bari*	21	2.38%
Victoria University of Wellington	20	2.27%
University of Dundee	19	2.15%

Table 5

Ranking of discipline areas publishing on the topic of AAC according to SCOPUS

Subject Area	N	%
Medicine	676	76.56%
Health Professions	571	64.67%
Computer Science	232	26.27%
Social Sciences	186	21.06%
Psychology	166	18.80%
Arts and Humanities	81	9.17%
Neuroscience	52	5.89%
Nursing	47	5.32%
Engineering	29	3.28%
Biochemistry, Genetics and Molecular Biology	22	2.49%



most publications and related percentages is provided. The bulk of the scientific production is published in the AAC Journal. However, a difference in journal ranking is found between both search engines. For example, the Journal of Speech, Language, and Hearing Research appeared in both search engines with the same number of papers, but there was a discrepancy in the number of papers for Disability and Rehabilitation Assistive Technology.

Figure 2 shows journal publications on AAC during the time frame 1978-2014 whose titles contain the descriptor Language and those with the Education and Teaching descriptors. Grouping journals into these two categories occurred by assigning "Language" to journals on Speech Therapy and Social Psychology, and "Education" to journals on Education and Teaching.

Table 4 represents the 10 universities where published research originates on the topic of AAC. Pennsylvania State University ranks first, followed by three other institutions, two of which are located in the United States. Eight of the 10 universities listed are located in an English-speaking country.

Table 5 provides a listing of the most frequent disciplines publishing on the topic of AAC. The total number of hits does not correspond to the total number of publications, as the same paper could be classified as pertaining to more than one discipline area. Medicine and Health Professions predominate, while Computer Science ranks as the third subject area in importance. This may be due to the development of software and hardware for AAC.

Tables 6 and 7 provide a listing of the most productive authors, according

Table 6

10 most productive authors on the topic of AAC according to EndNote®

Author	n	%
Light, J.	63	4.99%
Beukelman, D. R.	44	3.49%
Sigafoos, J.	43	3.41%
O'Reilly, M. F.	42	3.33%
Balandin, S.	40	3.17%
McNaughton, D.	39	3.09%
Schlosser, R. W.	36	2.85%
Alant, E.	33	2.61%
Lancioni, G. E.	28	2.22%
Sutton, A.	19	1.51%

COMMUNICATION MATTERS

National AAC Conference

30th Anniversary Year

11th - 13th
September 2016
at
University of Leeds



Don't miss out on the 30th Anniversary celebrations at the
National AAC Conference which brings together people who use AAC,
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Table 7

10 most productive authors on the topic of AAC according to SCOPUS

Author	n	%
Light, J.	47	5.32%
Beukelman, D.R.	34	3.85%
Sigafoos, J.	32	3.62%
Balandin, S.	32	3.62%
Schlosser, R.W.	29	3.28%
McNaughton, D.	24	2.72%
Lancioni, G.E.	19	2.15%
Alant, E.	18	2.04%
Ganz, J.B.	15	1.70%
Soto, G.	15	1.70%

to searches done with EndNote® and SCOPUS. English speakers are among the most frequent ones. The most productive author is American, affiliated with Pennsylvania State University, Department of Communication Sciences and Disorders. The second and third most prolific authors are Australians from the University of Sydney, Children's Hospital Education Research Institute, and Deakin University in Melbourne.

CONCLUSIONS

The time frame for this study was from 1978 to 2014, so findings should be considered with this time frame in mind. A limitation of this study is that only three databases were used to identify relevant publications. Given that AAC is the accepted term for the field and the varied non-verbal systems, the findings of this study suggest a strong North American/United States influence on dissemination of knowledge in AAC. It also suggests the need for inter-cultural dialogue and collaboration.

The last issue of the Governance and Committee Activities concerning AAC Terminology and Issues (Lloyd & Blischak, 1992) could be attributed as one of the major causes for the widespread use of the term.

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Congratulations to CM

BHTA

British
Healthcare
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‘BHTA congratulates everyone involved with Communications Matters on their 30th Anniversary’

Steve Perry

MARKETING AND COMMUNICATIONS MANAGER

Next year is BHTA centenary year (1917-2017) we are asking members to send in any pictures, stories and memories relating to the history and development of the trade association.

Please send these to Steve Perry at steve.perry@bhta.com

Communicating with my Eco 2

SCOTT STACK

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OBJECTIVES OF THIS ARTICLE

I want to share how my device works and explain the benefits it has made to my life as my communication has developed. I will also tell you what I am working on at the moment.

How I use AAC

I use AAC for talking every day, especially in my office at the University (see figures 1 and 2 on p.13). I can use different ways to communicate with, but I prefer to use my Eco2 whenever possible. I have been working with communication devices since I was 17 years old. I cannot read, but I have a low level of word recognition. I am single switch user. I press the switch in my headrest when the scanner is over the icon I want to use. It is time consuming and tiring. But it is the best way for people to understand me and for people to get to know me.

Scanning method

I have changed scanning method. I only have to press my switch 4 times for a word, whereas before I had to press it 6 times. This has helped me to communicate much quicker. I cannot imagine not having my communication aid. If it breaks and I have to send it away, I feel ill. This happens quite a lot now.

WORK

Last year, I felt my communication was good enough to be able to start working. I also wanted an office to have my own space to focus on improving my communication even more. I asked Dr Lynsey Parrot (Senior lecturer at Marjon



University, Plymouth), who I met through her personal research for her thesis, to help me. After my ongoing persistence she offered me an office and a job as an assistant lecturer for the speech and language department. At first it was a 12 week placement. But then I was asked to go back in September 2014. And I have now recently signed a contract.

Roles include:

- Helping in lectures.
- Having tutorials with students.
- Attending meetings.
- Time spent in my office developing my communication.



I got my staff name badge!



VOCABULARY

As my life is constantly changing, new words and phrases always need to be added to my AAC communication system (Eco2). Luckily I have my staff to help me. But nothing is put onto my device, without my knowledge or permission.

Choosing icons

My key worker tends to be the person who does this for me. But I am not expected to use new words and phrases straight away. I need to choose the 2 icons I want to press to access the new word or phrase. I usually do this with word association.

For example to say - The University of St Mark and St John

I press:

HOUSE

(names of buildings I visit)



And then:

TOUCH

(picture of computer).



This makes the learning process easier for me.

When new words and phrases are added to my device, it is really important I spend time practising them. Repetition helps me to remember. I spend time both at work and at home practising. I also sometimes need to learn what the word means, and when to use it in sentences and conversations, appropriately.

CONCEPTS

I am now developing my communication further, to start expressing my opinions on different ideas. I want to be able to join in conversations much easier.



To communicate, I make up sentences word by word, which takes time. So I find it difficult to join in conversations because I cannot keep up with the speed of people talking. I have written my thoughts into my device, and they are ready to access whenever I want to. I have decided to call these thoughts: **concepts**.

Usually, I press 2 icons to say one word, or one pre stored sentence.

But now I am learning a completely new process of choosing 3 icons, to express specific ideas on specific subjects



Work My Family My Eco2



So for example:

I am working as an assistant lecturer, for the speech and language department, at the University of St Mark and St John in Plymouth.



This second icon is the one I use for all things related to the University of St Mark and St John.

I go to work 3 days a week: on Tuesdays, Wednesdays and Thursdays.



Practising concepts at home – using my staff's lockers

Then the last icon changes depending what I specifically want to say.

The final icon will be dependent on which 'buzz word' I want to use – what, when, who, why, or how.



I write the pre stored thoughts myself. I spend a lot of time, both in my office, and at home, practicing my concepts, so that in the future I can join in conversations much easier. I understand that this is only a brief explanation into my new way of communicating, but it is a whole different presentation in itself.

As time goes on, my thoughts and experiences constantly change and adapt.

Therefore I am always updating my concepts, and adding new ones.

CONCEPT ROW FOR THE CONNECT PROGRAMME

Taking Charge of Conversations

I like to take charge of conversations. When I am not interested in a conversation I can use my concepts to change the topic, and therefore join in. I hope I have given you an insight into the importance of my communication.

*If you would any further information please contact:
sstack@marjon.ac.uk*

My Isolation Bubble

Information about the author

Gavin is a secondary school student and is just going into his 4th year. In addition to his studies, he is an accomplished RaceRunner¹ who competes nationally and internationally and is a 5 time world record holder. In 2012 Gavin won the Young Scot Sports Award for sporting excellence and for his work in an ambassadorial role within RaceRunning. He is competing in the CPIRSA European Open Championship in Copenhagen this summer.

Gavin is an Ambassador for CP Teens² and has been involved in highlighting the importance of AAC through the Scottish Government funded Right to Speak/Now Hear Me³ programme. Gavin has been interviewed for radio and television on a number of occasions and took part in filming for Now Hear Me programme. He has given a number of presentations using his Nova Chat including at the 2014 Paediatric Physiotherapy Conference.

Gavin has ataxic cerebral palsy, which affects his speech, co-ordination and gross and fine motor skills. He began using high-tech AAC at the age 4 and currently uses a Nova Chat as well as Makaton signing.

Gavin's very insightful paper highlights the challenges he encounters daily and I am grateful for him sharing his views with me, and with you all. If you would any further information please contact – linda.page@aapct.scot.nhs.uk



Do my peers know I am here? I do not want to be just someone who makes up the numbers in a class, a club, or a squad. At the moment, I am just that – one of the numbers.

My bubble is non sound proof so I can hear and understand what people say. My bubble is clear so I can see everything that surrounds me. However, my bubble cannot transfer my physical voice so only when I use communication aids is my voice heard. And so, I am isolated: cut off coldly from communication.

Are my peers really too scared to communicate with me? Do they really hate me? Is it really because I have done something to upset them? Maybe they don't suspect that I long to join in. Perhaps they do and are uncertain as to how to help me. I don't know the answer to these questions. I wish I did but all I can do is speculate what may be the answers....

I guess I am pretty annoying when I cause

chaos in the school foyer. People squash themselves against the wall in order to give way to me as I pass through with my walker and my helper pulling my trolley equipment. I cannot readily say or sign 'Thank You' to let them know that I appreciate their support and 'Sorry' for when I run people's toes over (which happens, most days!). And the same goes for when people open doors for me. The best I can do is smile and hope it translates to what I would like to say. Usually, my personal support assistant and I try and beat the rush before the bell goes but sometimes we get delayed with various things and it is not always possible.

I have also been known to get a bit red-faced and a bit teary whenever I am being given into trouble, regularly, I get referred to as a "goody two-shoes". I do not know whether my peers consider this to be a flaw in my personality as they seem to have more resilience than me! I often blame this on my disability but I know

that I perhaps should not. I always want to do the right thing, make the right decision, and get the right answer. I am sure we all do.

Watching my classmates whizz past me in physical education is not enjoyable. It is almost embarrassing considering my sporting success. It is very frustrating for me as I struggle to haul my walker around the corner, especially as I know what I'm capable of. I wonder if others realise that if I had the correct equipment- my Running Bike - I could keep up with them or even be faster than them! Instead I watch, from my bubble, as my peers race into the horizon. As it is with my voice, do others even realise what my capabilities are?

I call myself 'a conversation spectator' because whenever I am surrounded by my peers, I often find myself overhearing conversations wishing I could be involved. Their banter flows fast and light footed, unconstrained. I have not got the confidence to make myself included in their

colloquy, my exchanges are laboured and plodding, constrained in the bubble. At the moment, I mostly find it easier talking with adults as they generally have more understanding and more experience of communicating with people who have the same or similar disabilities as me. I certainly have longer conversations with adults than I do with people around my age. I do not mind having 'friend-like' conversations with adults, as it enables me to pop my bubble momentarily, however it quickly reforms around me as I realise adults should not have to act as a 'friend'. I enjoy talking to adults but I would enjoy it more if I was talking to my peers, I consider some adults to be a friend but I know I have to learn to make more friends with my age group because it is not the same.

It is ironic that I can stand up and present something in front of fifty plus people without too much bother but when I am tasked with engaging myself in more conversations in class – I just crumble! It sounds crazy but I am too worried about

how they will react if I try to involve myself. I am uncertain and I feel they are uncertain too. Maybe I have to make my peers more aware of my needs but also my abilities!

A few of my peers do make the effort of communicating with me and try and include me in whatever they can. They make me feel valued in a class where so many people look at me blankly. As a result of their kind actions, they allow me to come ever so close to popping my bubble but I am lacking the frequency of conversations that so many people take for granted. I have the most amazing life that I could possibly ask for. I have probably experienced much more than people who are a similar age to me have. I consider myself to be extremely lucky but social isolation is a daily challenge.

I need to find the way to show my peers that I can talk, shout, discuss, argue, laugh, joke, and tweet just like they can! I may need support to communicate but I

believe there is nothing different or wrong about that! If I can somehow grow in confidence and initiate more interactions then hopefully my peers will see my personality coming through and reciprocate.

With every conversation that I am included in and with every presentation that I present to my classmates, I will feel I am getting closer to finding a solution to popping my bubble forever!

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- 1 www.racerunning.org - international RaceRunning website
- 2 www.cpteensuk.org - a non-profit organisation helping teenagers & young people with Cerebral Palsy and similar disabilities.
- 3 www.nowhearme.co.uk – information and advice about AAC

PhysioNet

Helping the disabled overseas

We are grateful to this charity for taking a few boxes of redundant amplifiers and digital recorders which had been sent to the office.

They will deliver them to an overseas hospital rehab department and schools, alongside their more usual mobility equipment, donated from across the UK. While we (and probably Physionet) do not have the capacity to make this arrangement on a regular basis we were pleased to see old (but still working) resources, no longer required here, could be found a home in services in developing services.

Thank you Physionet!

Most recently they have delivered to places like Fiji & Bhutan and you can see more on their website is <http://www.physionet.org.uk/>



**SALLY FEATON (MAKATON TUTOR) AND
KATE MCCALLUM (SLT AAC TECHNICIAN)**
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'Sign Out Loud's' aim has always been to inspire Beaumont College's population to embrace signing. At CM 2015 we shared approaches and techniques used to transfer skills learnt into the classroom and beyond. We presented a practical session about Makaton which was enjoyed by many.

Makaton is a multi-modal language approach used at college to support learners who have difficulties with both expressive and receptive language. Many students who use AAC use sign as a backup as a way to support their communication when the aid is not available to them.

For communication to be effective both communication partners need to understand the message being conveyed by sign so signs need teaching. With a staff group of over 300 and a student population of around 90, 18-25 year olds we faced a

challenge getting sign to be used as part of a valid communication method.

The college began to use sign round 16 years ago but due to staff changes, regular teaching had ended and there was a noticeable drop in the use of sign within college. 'Sign and sing' was a very popular session but it stopped.

Seven years ago the SLT's supported Sally to train as a Makaton tutor. At college today all staff are given a one day introduction to Makaton. Staff training is provided to those of highest need – priority – keyworkers, tutors. 'Sign of the Day' is accessible to all staff via a notice board



We knew 'Sign and Sing' needed to be re-introduced, but we also knew that it needed a re-vamp; so 'Sign Out Loud' was born. Now 'Sign Out Loud' is providing the opportunity for motivating refresher training weekly. It is an optional fun session which offers both staff and students a way of learning and refreshing their Makaton skills in a relaxed environment. Guided by the students and staff who choose songs, we translate these suggestions into sign. These are then taught to the staff and students during 'Sign Out Loud'.

Many of the songs are current and reflect the music choice of the students who are 18-25 years old. A key emphasis is placed on learning core signs through the songs but fringe vocabulary is included depending on the context and relevance to the meaning of the song.

Initially the response was slow but the 'Sign Out Loud' team have had T-shirts made and wear them to publicise the group on the day.

Now high numbers are attending weekly. We did a questionnaire amongst teaching staff who reported that the transfer of learning was evident in sessions as they noted seeing lots more turn taking, social interaction, vocalisation, shared attention & listening skills and improvements in emotional & physical wellbeing.

'Sign Out Loud' has been actively embraced by the Equality and Diversity Team and we have been invited to teach and share songs appropriate to the different E&D

"I feel more confident signing in sessions and it has made me feel like signing is normal and accepted. Before I came to 'Sign Out Loud' I felt embarrassed to sign because nobody else did, now lots of people are signing and it's great".

Our future plans get bigger and bigger: We aim this year to share Makaton 'Sign Out Loud' with the wider staff team – weekend staff and day team staff. The local community on the main stage at the Accessible Festival, Carnforth Carnival and Charity Stars. We featured in the Makaton Advent calendar and this year, we are presenting at ISAAC – Canada and CM this coming September.

Supporting parents/carers of young people who use AAC, using evidence-based workshops

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Family members, in particular parents/carers, provide the most significant social opportunities for children who use AAC parents help their children to achieve their communication potential (Huer & Lloyd, 1990).

In this article we will describe:

1. A review of the evidence base for support provided for families of children who use AAC.
2. An audit of local AAC support provided to families carried out by an AAC service.

3. The development of new workshops for parents/carers to enhance support provided by the AAC service.
4. Feedback from the workshops.
5. A case study of one family who attended the workshops.

1. Reviewing the evidence base

An advanced search of an electronic database was carried out in June 2014 – this gave 213 peer-reviewed journal articles. Two main fields of research were revealed; questionnaire-style studies asking parents/carers what support they would like to receive, and intervention studies where

support was provided and outcomes were assessed. Common themes across the evidence base included:

- Operational instruction (learning how to use and program the device).
- Information about AAC options – for now and the future.
- Planning for developing their child's AAC skills – for now and the future.
- Integrating AAC into the home environment and routines.
- Improving communication partner skills.
- Advice for parents about supporting their child to use AAC with other people.
- Opportunities to network with other families of AAC users.

The image shows a collage of workshop materials. The top left document is the 'CODES FRAMEWORK' from the KeyComm Resource Centre, Edinburgh, with contact details for Deborah Jans. Below it is a form titled 'AAC at home & the CODES framework: Supporting my child or young person to develop and use their communication skills in new ways'. This form includes a section for '1. How does the young person communicate at home, with family and in the community?' with checkboxes for various communication methods like gesture, facial expression, eye-pointing, body language, vocalisations, speech, signing, photos and symbols, communication device, and using objects. To the right is a questionnaire titled '4. What does the young person usually do on [Saturday]?' with a section for 'Who do they meet?' and a list of activities. Below the questionnaire is a list of communication roles: Responder, Messenger, Narrator, Director, Presenter/trainer, and Questioner, each with a brief description of their role.

Examining the evidence base in more detail

The evidence base

Part 1: What support do families want or find useful?

The literature search revealed a group of questionnaire- or interview-style studies asking families about their experiences of support received, and what further support they wanted. Main themes in responses included:

- Instruction so that they fully understand how to operate, program and maintain the AAC device (Parette, Brotherson & Huer, 2000; Angelo, 2000; Bailey, Parette, Stoner, Angell and Carroll, 2006).
- Information about what communication devices and access options are available and might be suitable in the future, so that they can take an active collaborative role in planning for their child's communication needs (Goldbart & Marshall, 2004; Starble, Hutchins, Favro, Prelock & Bitner, 2005; Angelo, 2000).
- How to integrate AAC use with the home environment and routine at home (Angelo, 2000; Starble *et al.*, 2005).
- In-home training for parents and siblings to become better communication partners (Parette *et al.*, 2000).
- Support in helping their children use their AAC devices with the extended family (Parette *et al.*, 2000) and in the community (Starble *et al.*, 2005).
- To make contact with other families that use AAC (Parette *et al.*, 2000).

The evidence base

Part 2: Intervention studies with families

Another area of the evidence base was a group of studies looking at interventions provided to families, and their outcomes. Unfortunately there was only a limited evidence base in this area. Most published articles were case studies or had very small sample sizes. There were some promising outcomes in terms of parental satisfaction with training or effect on parent's communication skills/knowledge, but there were no direct measures of outcomes for the actual child who uses AAC's communication skills. Recurring targets for interventions studies were:

- Communication partner skills, such as using a shorter utterance length (Ronski, Sevcik, Adamson, Cheslock, Smith, Barker & Bakeman, 2010); using pauses/waiting and allowing time for child to communicate (Ronski *et al.*, 2010; Basil, 1992; Starble *et al.*, 2005); and responding to any attempts by child to communicate (Basil, 1992).
- Creating communication opportunities, such as offering choices (Ronski *et al.*, 2010); and using open questions (Basil, 1992)
- Providing information about AAC device options (Starble *et al.*, 2005; Bruno & Dribbon, 1998).
- AAC device operation and management (Bruno & Dribbon, 1998).
- Facilitating parent networking (Bruno & Dribbon, 1998).

2. Auditing what we already do for parents

Next, we wanted to look at the support already provided for families of children who use AAC, and compare it to what the evidence base suggests is needed or useful. We evaluated support provided jointly by KeyComm – an AAC service in Scotland – and by local Speech and Language Therapists (SLTs) responsible for the children's SLT input. In June 2014 a small number of case files were randomly selected from the paediatric AAC user case files at KeyComm. The case notes were then examined to establish what support and intervention had been provided for families/parents/carers. This support was compared with the types of support generally requested or provided with successful outcomes in the evidence base.

The findings were as follows:

- Operational instruction was consistently good in all the cases examined.
- Information for parents/carers about the range of AAC devices available – those that would be appropriate for their child now and those that might be useful in the future – was variable. In some cases this was very good, and in some cases minimal.
- Parental involvement in planning for developing child's AAC skills was also variable. Parents were invited to AAC assessments, reviews and target-setting; but when they could not attend the appointments at school went ahead without them.
- Advice on how to integrate AAC use within the home environment and routine at home was again variable. Some cases had an initial home visit or meeting with parents where ideas and advice was discussed; in other cases this was not explicitly recorded in the case files so may not have happened.
- At present, training for parents and siblings to become better communication partners was not provided.
- Help for parents support their child's use of AAC with other people was also an area of weakness.
- There was no deliberate provision of opportunities to network with other families of children who use AAC, although sometimes these opportunities would be available at the local special schools during school events.

3. The parent/carer workshops

Parent/carer AAC workshops were designed to support parents to become more confidently involved in planning for use of their child's AAC device within the home and in the community; to become more confidently involved in target-setting for the development of communication skills; and to provide an opportunity for parents/carers to network with other families of children who use AAC.

The workshops started with a warm-up activity; parents/carers were encouraged to discuss the different ways that a person could communicate, and they shared with the group how their young person communicated.

There was an introduction to the CODES framework – a framework which is used to support setting communication targets for children who use AAC in Edinburgh and the Lothians. This introduction focussed on the social areas of the CODES framework; discussing the communicative functions that a child could carry out using their device (eg. greeting, requesting) and the social roles that they could take (eg. initiating, responding).

Parents were then asked to think about a typical weekend day for their child, and what activities their child would usually participate in. They were asked to come up with two ideas for new ways their child could use the AAC device – considering what social roles and communicative functions their child could develop.

Finally, parents were asked to create an action plan for making their ideas happen. They detailed what preparation was needed, what support they needed for this to happen, and who could provide this support.

4. After the workshops – what happened next

The action plans devised by the parents/carers were shared with local SLTs, so that they could support and follow-up specific ideas. For example, one SLT helped by adding appropriate vocabulary to their child's AAC device for use at the local cinema.

Feedback was gathered both immediately following the workshop, and later from local SLTs. Feedback forms were all positive. There were other positive outcomes that were more difficult to measure; parents gave each other peer support and shared their experiences and ideas with

each other. Local SLTs reported increased engagement from the parents – parents proactively asked for support and were more confidently involved in setting communication targets.

5. A case study

At a pilot parent/carer workshop in September 2014, both parents of a 10 year old girl "Zara" attended. Zara has a diagnosis of Autism and associated learning difficulties. She goes to a special school. Zara has been trying a high-tech AAC device called a NovaChat to support her communication since June 2013 (for over 1 year).

Prior to the workshop parents/carers had received an initial home visit when Zara received the device. SLT and KeyComm had also met with parents and teachers at school to discuss what to focus on with the device. Zara was using the device well for developing her understanding and use of like/don't like and to tell her home-school news.

At the workshop, the/her parents decided that they wanted to develop Zara's ability to use her news page in a more flexible and functional way eg. telling Dad about her day when he gets home from work. They wanted in the future for Zara to be able to use her NovaChat at the cinema to say hello to the cashier and ask for tickets. They felt that now that Zara was developing her early literacy skills it was appropriate to add a link to a keyboard page.

Following the workshop, Zara's local SLT reported increased engagement from her parents, who asked to review her CODES framework (communication targets) with the SLT and teacher in October 2014. It was decided to target Zara's use of social greetings, her labelling of simple emotions happy/sad/angry (later with a "because" page to develop Zara's ability to express and explain her emotions) and to start taking messages around school and asking for items from other classes.

Later in November 2014 it was reported that Zara was now becoming very interested in the process of programming her news, and was helping to type in the final word of the sentence.

In Summer 2015 it was reported that Zara has learnt to program her news button independently using the past tense correctly, taking the device and spontaneously typing in "I watched Cars" and "I ate fish and chips". She then uses this button

appropriately when she sees Mum/Dad to share her news.

Conclusions

It would be useful for future parent workshops to evaluate the impact of the workshops in more detail; by looking at communication skills before the workshop and six months on from the workshop. At KeyComm Resource Centre, we are currently seeking funding to continue to develop, deliver and evaluate our parent/carer AAC workshops.

Thanks to KeyComm Resource Centre, NES (NHS Education for Scotland) and MMU (Manchester Metropolitan University).

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'Sex, Drugs, Death and God' – Chailey Heritage Tackles more AAC Tabboos

HELEN DUNMAN

Chailey Heritage Foundation

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Helen Dunman has taught in special schools for 25 years. Her specialism is PSHE. She is a member of the SHADA working party (Sexual Health and Disability Alliance) and is particularly interested in empowering students with complex communication needs and severe learning and physical disabilities to communicate fully and openly about sensitive subjects.

I teach personal social & health education (PSHE). Although I work with students in the 16+ Department, I have overall responsibility for this subject throughout the school. Our students' needs are very complex. Most students have Severe to Profound and Multiple learning disabilities, although a minority have moderate learning disabilities and all have severe physical disabilities. Many students also have complex sensory and medical needs and the majority of our students use alternative forms of communication.

Many students in the school use the Chailey Communication System (CCS) which was devised by speech and language therapists and school staff over twenty years ago. The system is divided into a number of categories eg. 'People,' 'Places,' 'Mealtimes,' 'Body' etc and each category is divided into subcategories. Students use the system in a book or VOCA format, with or without Widget symbols. The system can be used in full or in an abridged format according to the needs and ability of the student. The system can also be customised and added to, if required.

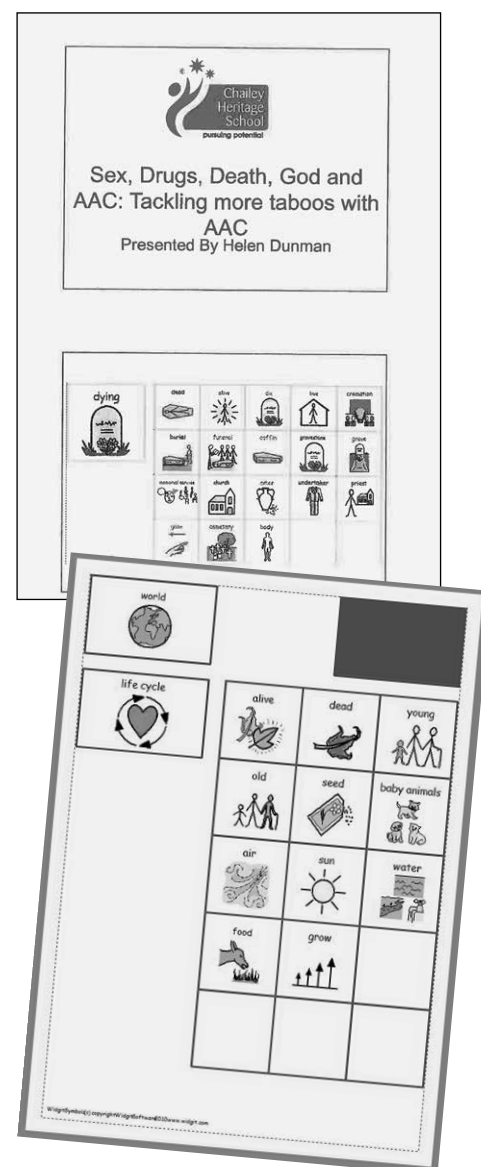
In this article, I would like to outline how I have facilitated greater communication

and empowerment for AAC users, with severe learning disabilities (SLD) and complex medical needs to communicate about 2 of the most challenging subjects in the PSHE curriculum, namely 'Death' and 'Medication'.

Some years ago AAC users in my PSHE class asked me to help them talk about sex and relationships in a more detailed way, feeling that they didn't have the necessary vocabulary in the CCS to do this, despite being competent AAC users, they wanted more! The students in this group, mainly had Moderate Learning Difficulties (MLD) and were well able to ask for what they needed, initiate conversation and be really assertive, so my job was easy, I simply worked with a SLT to make this book come about, with the help of the students. (See previous paper 'Sex, Drugs and AAC'.)

What was needed?

The students I now teach have severe learning difficulties and as a result, have a tendency to be very passive, finding it difficult to initiate any sort of conversation and to ask questions. Many of the AAC users are still learning their way around the system and communicate at a 2-3 word level. I was struck that some of the verbal students in the group, who were cognitively at a similar level to the AAC users were asking questions about death, following the death of one of the students and it struck me that the AAC users would find it a real challenge to navigate around the system. On closer inspection I found the system to be lacking any words associated with death apart from 'Dead'.



My aim was to make it as easy as possible for AAC users with SLD to ask questions and make statements about the tricky subject of Death.

We are constantly wanting to ensure that all students have a voice and are

empowered in all areas of their lives, this is particularly challenging for students with SLD and requires carefully thought out facilitation from staff. I was approached by one of the doctors who wanted to talk about how we could facilitate students in taking a more active contribution to their MDR's (Medical Reviews) encouraging them to question, comment and generally communicate about all the medication and therapies they receive. This again is a potentially tricky subject as families, carers and the medical profession, understandably often have strong views regarding the (often complex) decisions around medication and therapies for individual students. My aim, again was to come up with a way of making communication about this topic as easy as possible for this group of AAC users.

Making it easier for pupils to communicate about death

I felt that the best way to enhance communication would be to add another page called 'Death' to be added to VOCA's. I decided to organise it into 3 sub-categories 1) Factual words associated with death eg. dead, alive, coffin, funeral etc. 2) To include our full 'Feelings' category 3) Spiritual Words associated with death. This was much more tricky! After thought I decided that owing to the population of the school and the severity of our students learning difficulties, it would be more useful to just stick to very basic religious/spiritual words mainly associated with Christianity, as this language would be more familiar to our students. I did, however, write a piece at the bottom explaining that although this page contained religious words it was up to the user whether they wanted to use them and that as a school we were not promoting any belief system. Also that this section could be added to and personalised, which could embrace any faith relevant to the AAC user. Finally, I included a last sub-section where I listed a few 'Question' words. I then introduced this to my PSHE group and asked both AAC users and verbal students to check it over and give it a test run, this page was then typed up with symbols and added to AAC devices /Books. It was great to see that the students were immediately able to use the pages to ask questions and to make comments. One student asked 'Who buried?' and 'Who cremated?' which started up a discussion about the choices involved before people die about what their wishes might be after death. Another student said

"God belief, no" to indicate that he didn't believe in God. The students who can use speech also found it useful to use the pages during the discussion as it helped to organise their thoughts for the abstract concept of death.

Making it easier to talk about medication and therapies

We started this piece of work by inviting one of the school doctors to come and talk to the students about medication, basically giving them the clear message that they should take as active a role in this part of their lives as possible, they should ask questions about why they are on certain medication, what the side effects might be, what the alternatives might be, pros and cons of suggested surgery. Physio, SLT or OT therapies were also included in this. I suggested that again we came up with another subsection to the Body Section of the CCS for AAC users, the students seemed enthusiastic about this and so I added these sub-sections: Medicines, Operations (to be personalised for each student), Health Questions eg. 'Will I feel sick?', Health Phrases eg. 'I don't want this medicine anymore', Physio Activities, OT activities, SLT activities. I then took these sub-categories to the group who had a few more suggestions for the 'Health Questions and Phrases', we had verbal students in the group who were able to make suggestions which the AAC users wanted included. This was then typed up with the symbols and added to AAC devices or books.

AAC users can now communicate about death more easily and in more detail. AAC users are now able to contribute to their MDR more fully and are able to feel more empowered by asking questions and generally communicating about their medication, therapies and general health, having been given the language in their AAC with which to do this. Before an MDR students are given a form to fill in, using their AAC which can then be taken straight to their MDR. Some students have requested to do activities such as yoga and have been able to ask if a nicer tasting medicine was available for them. Other students have asked to do more or less of particular physio activities.

What has happened since these pages were developed?

Talking about death

We had a staff discussion and felt collectively that it was really important that

we don't just present students with the 'Death' pages after an event but that we all become more accustomed to using this language more frequently. Linda Deacon, one of my teaching colleagues, suggested that we broadened the pages out to become the 'Life and Death' pages, which could then be used in Science or Environmental work. Drawing the children's attention to a living and dead insect and matching these to the relevant symbols on the pages, are great learning opportunities and can get everybody more comfortable with using this language. Linda and I drafted out an extension symbol page, including simple vocabulary for life and death in the context of nature and the life cycle.

Communicating with children and young people about death can feel quite scary and especially so if the young people have learning disabilities. So shortly after the pages had been added to the system, I ran training for staff in how to talk to our students about death and how to deal sensitively and appropriately with questions they may ask about death. Feedback from staff was very positive and staff reported that they felt more confident about using the new pages and talking with students about this sensitive subject.

We have also gone on to develop activities that teachers and residential staff can draw on, in the event of a death. The additional 'Life and Death' pages are central to this work.

Talking about Medication and Therapies

In discussion with the school doctor who started this conversation, we felt that it was important that the students were asked questions about their medication and therapies on a regular basis and not just when they are due for an MDR. So on a termly basis (and more often if appropriate) we use the Medication/Therapy pages and ask students if they have anything they want to comment on or ask about their medication and therapies.

Conclusion

In most cases our students find it very difficult to advocate for themselves, so it's up to us as staff to think of creative, easy and practical ways to help AAC users with SLD and complex needs to communicate to the best of their ability. I have no doubt that like the main CCS, these additional pages will evolve, be personalised to the needs of the individual AAC user and continue to empower our students.

AAC Hacking

KATE MCCALLUM & FIL MCINTYRE

Email: Kate.McCallum@scope.org.uk

'Everyone can communicate. Everyone does communicate.'

Beukelman & Mirenda 1998

Beaumont College offers both residential and day programmes to young adults learners who have both physical and learning disabilities. Our aim is to empower learners to take responsibility for their own lives.

Kate McCallum has a passion for AAC and has worked in the field for 16 years. She has now been at Beaumont for 12 years. She is a skilled and experienced Communication Technician who specialises in all areas of AAC. She has a degree in Occupational Therapy and believes strongly in creating a Total Communication Environment for students with complex needs.

Fil McIntyre is a highly specialised Assistive technologist who has been working in the field of AT and AAC for 13 years. They both work within a large MDT which includes the Student, SLT, OT, PT, AT, parents, care and education staff along with other outside agencies. They both make bespoke items, to facilitate access to AAC and AT. In this article they share some of the day to day AAC hacks they are involved in creating.

We started to think about the hacks we perform at work. No day is ever the same and we do a really wide range of tasks, the majority of which involve hacking. By hacking we don't mean sitting down and writing some code (though the thought is always there). We mean adapting different communication approaches and strategies according to the specific needs of the students here at College.

We know people all around the country are doing similar things to us but we wanted to share our ideas and good

practice in the hope that we are able to support someone who perhaps doesn't have a dedicated team supporting them.

Here we go;

Objects of Reference (OOR) are objects that have a special meaning assigned to them. They stand for something in the same way that words, letters or picture symbols do.

People who use them might be at a early stage of understanding, so words, symbols and pictures do not yet hold meaning for them. They may also have a visual impairment so pictures would not be accessible to them.

If that's the case, you can buy a limited selection of OORs but they are expensive. Ideally the items used should be tailored to the individuals need(s), so we make them.

Finding the materials involves trawling around the pound shops; skip diving, and using FreeCycle. Other people's junk is usually our treasure, eg. the nurses, give me the unused feed sets, so I can make an OOR for someone who is peg fed. The Physios give me their old mats and I chop it up, IT give me their old computer

keyboards etc, and we always make a large batch so when they are lost or destroyed I can just pull out another from the cupboard.

Sensory bags and sensory stories

There are many companies making some fantastic story bags and sensory stories. Eg. <http://www.bagbooks.org/bookshop/shop>; <http://www.rompa.com/sensory-seeking-home-pack-sensory-profile-pack.html>

Again they are expensive and you can bet the story the tutor actually wants is either out of stock or there is no budget left. So we create resources for Tak Pac boxes, and Sensory bags. Again the £1 shops, skip diving, and using Freecycle helps a lot.

I've just begun to make resources so the Aesop's Fables are a sensory experience





and accessible to people with Profound & Multiple Learning Difficulties. You can buy sensory stories but they are mainly aimed at youngsters, not adults. I as an adult love a good book but often this is an opportunity seldom experienced by people with PMLD.

Tactile Communication Aid to support someone with Cortical Visual Impairment. We have a number of students who need AAC, they have significant physical and learning disabilities and CVI. Auditory scanning is not an option for a number of different reasons, so I found an old Tech/Speak in the cupboard, pulled it apart and I printed off the overlay and laminated it, using matt laminate, and opened up my box of tactile bits. I have found that things stick better to matt laminate. Scratching the surface with sand paper helps too. I made the tiles using different materials and attachment methods. (Due to a lot on interest from people wanting to do this themselves I now have a 'How to' Guide, available on request). The person using this is learning where the different words are stored/located. To assist physical access issues, I have blocked off some of the cells. I did this with the caps until I ran out, then used laminated black card taped in place for the remaining section.

THE VELCRO RULE: (other adhesive backed, hook and loop fasteners are available): clean the area you need to apply the Velcro to. Dry it well. Apply it (rough side on the thing you are sticking, to avoid injury) and WAIT (24hrs) (not always possible but it will help the Velcro stick)

Custom built trays

Some people have skeletal challenges which mean they sit in a moulded/cast wheelchair. Sometimes a standard tray is not available or comfortable to use.

I make the initial design out of cardboard and sticky backed plastic. (Spot the avid Blue Peter fan). Then we had it made in Perspex and fit the aid to it.

Fabric AAC Solutions

We have a number of students who when distressed or needing to express their feelings throw or destroy things. So they and others don't get hurt, their high-tech voice is not broken, causing further distress, and most importantly their voice is not taken away, we began creating fabric AAC solutions. So we started to create wearable AAC printed on tubby grip or cotton hankies. These don't hurt when thrown or fall out of reach.

Cheap Reflective Dots

Not bespoke but I contact the local cycling clothing manufacturer and ask for reflective dots (for use with a head mouse) or a roll of them for free rather than spend ridiculous amounts on the real thing. (I've had the original roll for the past 8 years). A skin test is always recommended but so far we have had no issues.

Wires, brackets & bespoke builds

We make bespoke brackets to hold a head mouse or speakers in a head rest for an auditory prompt, because the user can't tolerate having an earpiece in as it causes pressure sores.

We fix switches – they break all the time,

the wire is caught in a wheel, chewed by the dog.... You name it I've heard it, including "I ran over the communication aid with the car", amazingly the device involved in the RTA still works. Some of the excuses people generate are quite creative... sadly the most common one is "I just found it like this".

I find countless ways of attaching switches to headrests and different parts of wheelchairs. My current favourite is the elastic straps which are used by people who use leg catheter bags. They are non slip on one side and Velcro to anything. Wonderful. I've even begun to disguise them from their original use with creative designs with marker pens.

Velcro boards, wedges & foil boxes

I make Velcro boards and wedges for a whole bunch of reasons. You can buy these but often they are just not quite the right size or angle. I made friends with our local estate agent and he gives me their old for sale signs and I make the shape I need and cover it in Velcro. They are super light and super strong.

Custom keyguards and touch guides

Keyguard or touch guide because the one supplied does not guard the area of the screen needed by the user and/or the keyholes are too small, or because one does not exist for the language pack. (Common with homemade language packs). We have a local highschool who have a very Tech DT department and they kindly cut any design we need.

If you want to hear more ideas please come along to our talk at #CMconf2016.



How do adults with severe acquired communication difficulties make decisions about, and experience, the communication methods they use?

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The following research took place in 2015 and was part of the fulfilment of the degree of MSc in Assistive Technology, from the Faculty of Health and Life Sciences, Coventry University.

Introduction

For adults who have communication difficulties as a result of an acquired disorder such as motor neurone disease (MND) or stroke, using alternative methods to communicate is complex. They have gradually or suddenly lost their speech or language and enter a 'world of AAC' in which they must make decisions about and learn how to use new technologies. From my experience of working as a Speech and Language Therapist (SLT) with adults, I had made observations regarding the use of AAC, in particular an increase in the use and preference for digital communication and social media over face to face communication.

With the introduction of the NHS specialised commissioning contract for AAC (NHS England 2014), we need to ensure that services provided are evidence-based and person-centred. This will be a challenge in the face of new technologies and an increasingly medically complex population which is growing older. The

information gained from this research is of significant relevance at this time of change in AAC service provision.

Literature review

A literature review was undertaken prior to the study to provide a solid knowledge base for the research and to identify gaps (Table 1). There was found to be a lack of research pertaining to the views of adults with acquired disorders regarding communication methods - particularly in relation to digital communication and social media. The majority of studies explored the views of caregivers rather than adapting research methods for individuals with communication needs. Clarke et al (2001), Murphy (2004) and Iacono et al (2013) adapted their data collection tools to enable participants with communication needs, and this is reflected in their rich data. Baxter *et al* (2012: 124) concluded; 'There seems a need for further studies to overcome the challenge of user's limited communication to further explore their experiences'.

Research aim and objectives

Aim of the research:

To explore how adults with severe acquired communication difficulties experience and make decisions about, the communication methods they use.

Objectives:

1. To explore individual perceptions of different communication methods
2. To explore the decision-making processes of adults choosing communication methods for use in different situations and with different communication partners
3. To determine what facilitates this decision-making

Research methods

A qualitative phenomenological approach was chosen as it aims to describe an experience - communicating using alternative methods (AAC-low or high technology) - in all its density and richness, allowing readers to appreciate the worlds of others. For the participant, phenomenology can enable self-exploration and help in the search for meaning to life's changes (Finlay 2009).

Purposive sampling was used to enable selection of individuals who could offer descriptions of using AAC. Participants were recruited from the 'Compass' assistive technology service within the Royal Hospital for Neuro-disability (RHN), Putney. RHN is a charity which provides rehabilitation and long-term care for adults with acquired neurological conditions. The participants were seven male residents (Table 2).

Table 1 Articles reviewed during the literature review

Author (s)	Title of Article	Journal	Methodology	Study Participants
Bailey, R.L., Parette, H.P., Stoner, J.B., Angell, M.E. and Carroll, K. (2006)	Family members' perceptions of Augmentative and Alternative Communication device use	Language, Speech and Hearing Services in Schools	Semi-structured interviews	6 family members 7 children of junior high school or high school
Baxter, S., Enderby, P., Evans, P. and Judge, S. (2012)	Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis	International Journal of Language and Communication Disorders	Systematic review	
Brownlee, A. and Bruening, L.M. (2012)	Methods of communication at end of life for the person with Amyotrophic Lateral Sclerosis	Topics in Language Disorders	Survey	625 family members/ caregivers
Clarke, M., McConachie, H., Price, K., Wood, P. (2001)	Views of young people using augmentative and alternative communication systems	International Journal of Language and Communication Disorders	Semi-structured interviews and focus groups	23 children and young adults AAC users
Fager, S., Hux, K., Beukelman, D.R., and Karanounis, R. (2006)	Augmentative and Alternative Communication use and Acceptance by Adults with traumatic Brain Injury	Augmentative and Alternative Communication	Survey	3 Speech and Language Pathologists (Therapists)
Hodge, S. (2007)	Why is the potential of augmentative and alternative communication not being realised?	Disability and Society	Semi-structured interviews	12 children 19 adults with communication difficulties
Iacono, T., Lyon, K., Johnson, H. and West, D. (2013)	Experiences of adults with complex communication needs receiving and using low tech AAC: an Australian context	Disability and Rehabilitation: Assistive Technology	Semi-structured interviews	15 adults (10=Learning disabilities, 5= acquired disorder) 12 support staff
Lund, S.K. and Light, J. (2007)	Long-term outcomes for individuals who use Augmentative and Alternative communication: Part 3-contributing factors	Augmentative and Alternative Communication	Semi-structured interviews	7 adult AAC users 10 of their relatives
McKelvey, M., Evans, D.L., Kawai, N. and Beukelman, D. (2012)	Communication styles of persons with ALS as recounted by surviving partners	Augmentative and Alternative Communication	Semi-structured interviews	6 partners of deceased individuals with MND
Murphy, J. (2004)	"I prefer contact this close": Perceptions of AAC by people with Motor Neurone Disease and their communication partners	Augmentative and Alternative Communication	Semi-structured interviews and observation	15 individuals with MND and 13 close relatives/ friends.
Rackensperger, T., Krezman, C., McNaughton, D., Williams, M.B. and D'Silva, K. (2005)	"When I first got it, I wanted to throw it off a cliff": The challenges and benefits of learning AAC technologies as described by adults who use AAC	Augmentative and Alternative Communication	Internet Focus Group	7 adults with cerebral palsy. AAC users.
Van der Meer, L., Sigafoos, J., O'Reilly, M.F. and Lanioni, G.E. (2011)	Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: A review of the literature	Research in developmental disabilities	Systematic review	7 studies

Ethical approval was obtained from Coventry University, the RHN research department, and the Integrated Research Application System (IRAS). Informed consent was sought for the data collection, video recording, and data dissemination. Consent procedures were adapted to facilitate participant's understanding of their involvement in the study, such as pictorial support for consent (Figure 1).

Data collection

Semi-structured interviews were used as these enable a researcher to illuminate and probe responses (Kvale 1996). Participants were videoed to access non-verbal communication. They selected which communication methods they wished to used (Table 2).

Figure 1 Participant consent form – Adapted format

Consent form for patients-sample page only (Please tick box)





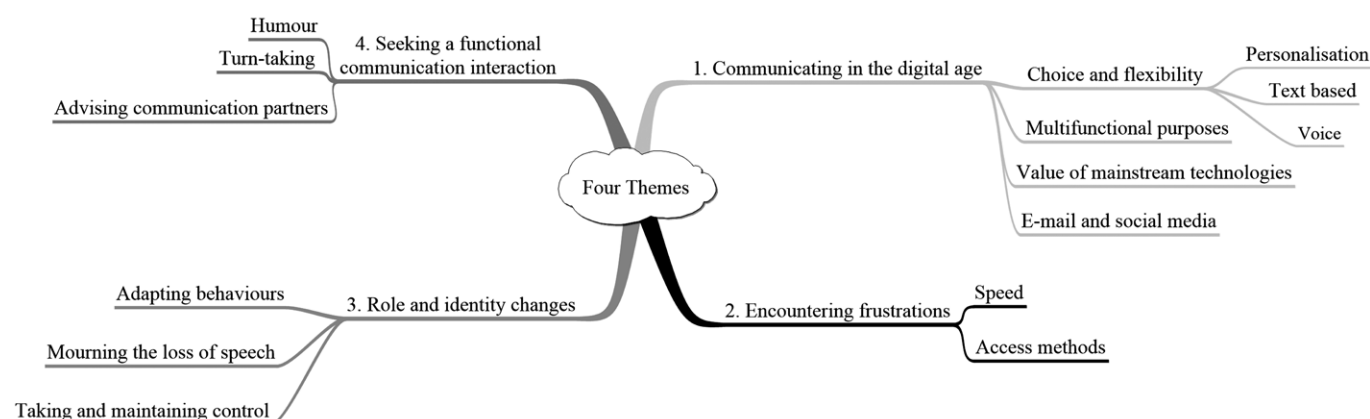
<p>5. I give permission for responsible individuals from the Hospital or the University to have access to my research data</p>  <input type="checkbox"/>	<p>7. I agree to take part in the above study</p>  <input type="checkbox"/>
<p>6. I am happy to be video recorded</p>  <input type="checkbox"/>	<p>Your research data will be recorded in a confidential database of research participants managed by the Hospital Research Department.</p>  <p>It will be destroyed after 8 years.</p>

Table 2 Description of research participants

All participant's names have been replaced with pseudonyms to ensure confidentiality

Participant	Age	Medical diagnosis	Low technology methods used	High technology methods used	Date of interview	Place of interview	Communication methods used during interview
Geoff	55	CVA-2011	Partner scanning on an alphabet chart	Switch scanning on a Windows tablet	18/02/2014	Room of participant	Low tech method (High tech not working) and E-mail when high tech working
Chris	61	CVA-2003	None used	iPad-communication app	10/03/2014	Day room in ward	High tech method and e-mail
Pete	53	Motor Neurone Disease-onset- 2010	Partner scanning on an alphabet chart	Eye gaze on an all in one computer and eye gaze camera	10/03/2014	Room of participant	High tech method and e-mail
Dave	45	Traumatic Brain Injury-1993	Partner scanning on an alphabet chart	Lightwriter SL40	10/03/2014	Day room in ward	High tech method and e-mail
Gary	46	Traumatic Brain Injury-1990	Directly pointing to letters on an alphabet chart	Switch scanning on a Lightwriter SL87	12/03/2014	Room of participant	Low-tech method
John	47	CVA-2011	Partner scanning on an alphabet chart	Eye gaze on an eye gaze computer	28/03/2014	Day room in ward	Low and high tech methods and e-mail.
Mike	70	Huntington's disease	Directly pointing to letters on an alphabet chart or to a yes/no sign	iPad-communication app	01/04/2014	Room of participant	Low-tech method

Figure 2 Key themes of research

Six to eight open questions were asked eg.: 'Can you tell me what it is like to use communication aids to communicate with others?'

'How do you choose which aid to use when you are communicating and why?'

Generating in-depth data in the interviews was challenging due to the participants' limited communication methods. Some of the participants stated that they found it easier to provide complex information via e-mail so this was used. The participants responded well and it provided rich data.

The final stage of the phenomenological process involves developing an understanding of the main ideas the participants were expressing. The videos were transcribed and the data was analysed using Colaizzi's (1978) method of thematic analysis.

Results

Four key themes were established (Figure 2):

1. Communicating in the digital age

Participants cited e-mail as a valuable method of communication and the preferred method for some interactions, with the extra time it provides for constructing messages cited:

"I can express complex information better" [via e-mail] (John)

Social media was also valued for speed over communicating face to face:

"It's hard to keep up with conversations [face to face]. Conversely, when I'm using text-based media it's fine. So Skype messages and Facebook or

Twitter are perfectly useable" (Pete)

Mainstream technologies were useful to some participants, particularly the choice and flexibility they provide:

"When the iPad came on the scene it was a massive leap forward in communication skills and people could understand you much better and of course you have the various apps that come with it" (Chris)

2. Encountering frustrations

Participants expressed frustration in using communication aids especially in face to face communication:

"Talking to people feels a bit slow. It can be frustrating. I have a lot of thoughts in my head and it's slow to do that." (Pete)

Access to communication aids was a source of frustration due to the efforts required. Pete stated that alternative access methods should be a priority for AAC developers:

"I would love to see support for more input devices"

3. Role and identity changes

Using different methods of communication was found to have an impact upon participant's own and other's perceptions of them.

Identity was linked to a preference for digital communication by Pete when he stated why he preferred interactions to take place digitally:

"Particularly with people I don't know very well I can come across as normal. Which is good...I think people generally make snap judgements about others based on their looks.....If their perception of me is limited to the sparse medium of text, they're forced to evaluate me on what I've written, not how I look or how I put my thoughts together"

Communication aids appear to help construct an identity and maintain previous roles. Dave described his previous role as a ladies man and how:

"I used to be an outrageous flirt. I found my Lightwriter excellent for chatting to the girls"

For Chris it was key in adapting to the new role that he had had forced upon him post-stroke:

"It (communication aid) has opened up a new way of living for me"

4. Seeking a functional communication interaction

This final theme was highlighted by participants when they described what features of AAC limited or enabled a good conversation. This included voice:

"The synthetic voice is very easily understood" (Chris)

Sharing a joke was highlighted by Pete as something that was lost when using a communication aid:

"Humour relies on the speaker's inflection. The computer voices always use the same inflection, which can itself be amusing, but generally makes telling jokes tricky...Witticisms depend on timing. It's hard to be witty with a communication aid"

Discussion

This study has highlighted some important views held by adults who have acquired communication difficulties towards the different methods they use to communicate.

The benefits of using social media by AAC users has been supported by studies with children and adolescents (Raghavendra et al 2013, Hynan, Murray and Goldbart 2014). Due to their physical and communication difficulties, the participants in this study have limited social networks and so digital technologies can potentially play a role in developing friendships and decreasing feelings of loneliness. Social media and AAC needs further research including; how it is being used, better access to it and communicative competence using it, in order to provide an evidence-base for this growing area.

This study also found that adults value mainstream devices. This has implications for technology development as currently it is largely driven by the needs and preferences of the masses therefore they do not always meet the needs and skills of individuals with complex physical and communication needs (Beukelman 2012). It is important to ensure that provision for individuals who require adaptations and specialist soft and hardware does not diminish. To date, there has been minimal research exploring the effectiveness of mainstream devices as communication aids.

Participants in this study highlighted frustrations with the technologies they use and this was supported by the literature reviewed, particularly around ease of use. Further research and development into access, speed, and interfaces with social media need to be considered. As this study and others found, users desire to be involved in the design of communication systems (Rackensperger et al 2005, Iacono et al 2013).

These preferences for digital communications raises the importance of ensuring we are planning an SLT workforce to support this demand. Technology has been recognised as a key driver in future demand and supply for the SLT workforce by the Centre for Workforce Intelligence (2014). They described SLTs as needing to support the usage of new technologies, and ensuring they have a sound clinical basis, with technology training included in undergraduate courses.

This study found that the experience of

using different methods of communication can impact upon one's self-identity and social roles. For individuals with progressive conditions, they may be afraid of losing communication functions as these are connected to their identity (McKelvey et al 2012). Communicating digitally appears to assist in providing an alternative identity for individuals who use communication aids. Online communication has been found to increase opportunities for self-determination and self-representation for adolescent AAC users (Hynan, Murray and Goldbart 2014). Also linked to one's identity is voice. Good voice quality was cited as an important feature of communication aids in this study, previously cited as a critical factor in the acceptance and use of AAC (McKelvey et al 2012). This finding provides support for voice or message banking, as it enables a person's own voice to be stored for use later with their communication aid.

The sub-theme of mourning for the loss of speech found in this study has been found in previous research with individuals with acquired communication difficulties (Blom Johansson et al 2012). Some individuals may not be ready for AAC and they may require counselling and support as they adapt to the changes they are experiencing.

E-mail was found to be a useful data collection tool, enabling the participants to answer questions at a time convenient to them, at their own pace, and without the pressure of a researcher present. However, participants did require access to it and face to face contact was still important in developing rapport and observing non-verbal communication.

Limitations of the study

The participants were all male, of the same ethnic group, from the same hospital, and it would have been beneficial to explore the experiences of individuals from a greater cultural, linguistic and socio-economic diversity.

The study did not involve any individuals with language difficulties or cognitive difficulties. Participants with these difficulties would have added more diversity to the data and added to its transferability.

Conclusion

This research has found that adults with acquired communication difficulties find mainstream technologies, such as iPads, and digital communications, such

as e-mail and social media, to be beneficial in everyday communications and, in some situations, preferable to face to face communication.

The results gained from this study can contribute to the care delivered to adults by informing AAC assessment, device and software development to ensure that these are current, evidence-based and person-centred. The results also have implications for SLT training, as our future clinicians must be prepared to support and assist individuals in accessing the world of technology & social media.

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Functional Communication Training using image2talk app to reduce problem behaviour

FIONA WILSON

Email Fionawilson74@gmail.com

I am a special needs teacher and I designed and developed a communication app for students in my school. I qualified as a primary school teacher in 1997 and taught in mainstream primary schools in Scotland and Ireland for ten years before moving into special needs and for the past eight years have been working with students, aged between ten and eighteen on the autism spectrum, also presenting with moderate or severe learning disabilities.

I presented a poster at the CM2015 conference titled 'Functional Communication Training using image2talk app to reduce problem behaviours'. The student in this study was a fourteen year old male on the autism spectrum with severe learning disabilities. He presented with problem behaviours, namely, assaultive behaviour, property destruction, loud vocalisations and self injurious behaviours. He had a long history of these behaviours and they caused great concern to his parents, siblings, care givers and education providers.

At the initial stages of the study, I carried out functional assessment interviews with his parents and care givers and I collected data around the occurrence of these behaviours. Incidence analysis showed that behaviours were more likely to occur when the student was presented with a work related demand, the behaviours also increased in frequency immediately after lunch.

From the information gathered I was able to develop a plan. We made environmental accommodations in the class in the form of making a break area which

included highly preferred items such as a physio ball and hollow sounding toys. We focused on functional communication training as the student was emitting behaviours to escape work tasks so I put a picture of his break area on image2talk and access to his break area was contingent on appropriate asking rather than hitting out. We had to start this functional communication training initially by prompting the student to tap the image to request a break before he emitted any problem behaviours. The student soon learnt to use image2talk to request a break.

Alongside the direct intervention of functional communication training to request a break we introduced a preferred sensory activity after lunch. Preferred sensory activities were introduced by offering a choice of sensory activity on a row within image2talk app. One of the sensory activities the student preferred

was water play. He had access to a bath in school and when he chose to have a bath we also taught skills such as washing hair and dressing independently, using a picture schedule and drawers with pictures of the clothing items on the front.

Increasing the student's functional communication skills significantly reduced problem behaviours. Alongside the direct intervention of functional communication training to request a break the student increased his prompted requests and his spontaneous requests. His overall use of image2talk on his iPad increased and his communication skills were generalised across his home and residential environments.

Presenting my poster at CM2015 was a great experience. I was able to attend some really interesting presentations as well as meet parents, teachers, speech therapists and other professionals and share my experiences.





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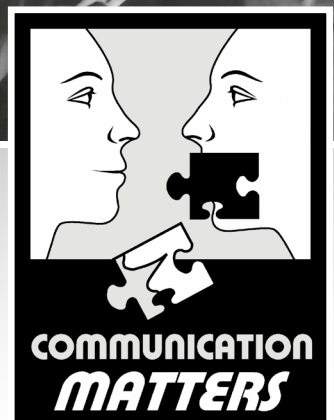
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Partnership Working with Health and Social Services in developing a Pathway to AAC and Technology

SANDRA MILLER, JANE DONNELLY

FAACT

IAIN ROWBOTHAM

Fife Community Support Services

Email: Sandra.Miller@fife.gov.uk



The aim of this article is to share the outline, delivery methods and outcomes of a joint venture between the Fife AAC Team (FAACT) and Fife Community Support Service (FCSS) staff to improve communication and AAC outcomes for adults with learning disabilities.

The initiative goes under the acronym PAACT – *Pathway to AAC and Technology* – and was funded from within the Scottish Government ‘Right to Speak’ initiative. With the availability of mainstream technology to support communication – especially iPads etc – came an increase in requests from staff and parents re the suitability of communication apps etc. Although a Service User could swipe through screens on an iPad and perhaps access photos, music and/or games, this did not necessarily mean they would be able to access/use a communication app to support functional communication. Consequently, while appropriate for some, there was a general lack of understanding/confusion around the communication pathway and pre-requisites required for successful use of any communication system, including the place of low tech, use of visuals etc. up to dedicated AAC systems and/or, indeed, the use of mainstream technology eg. iPad or tablet with appropriate communication apps.

The timing for this initiative was fortuitous, as FCSS was changing the way its service was delivered, namely moving from a centre-based service to a more

community-based service, with Service Users accessing activities out in the community on a regular basis eg. swimming, bowling, cinema etc..

As a result, some resources that staff would normally use to support those Service Users with communication and/or comprehension issues would need to be adapted for a more ‘active’ day, becoming more portable and easily accessible for staff, who themselves were possibly no longer accessing a base on a daily basis.

In addition, the PAACT initiative also sat well within the vision for ‘Keys to Life’, the new learning disability strategy in Scotland, following on from, and building on the principles and successes of ‘The same as you?’ the original review of services for people with a learning disability, published in 2000. (Scottish Government Keys to Life, 2013). eg. ‘*Active Citizenship*: People with Learning disabilities are able to participate in all aspects of community and society.’



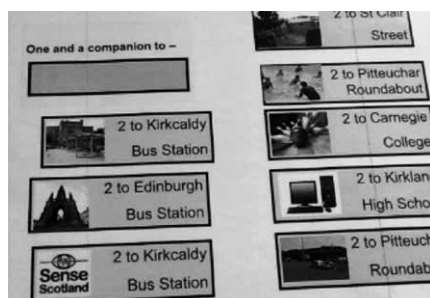
**The keys
to life**

The Initiative

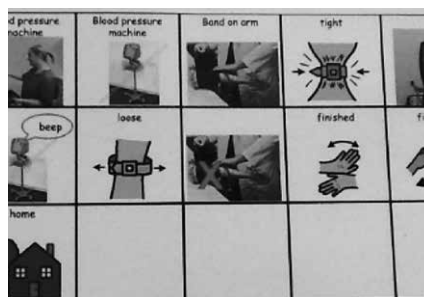
Firstly, we ‘bought’ time for identified staff to lead the Project: two members of FFAACT – initially to plan a project outline, based on the outcomes of an Engagement Event. A group of possible interested parties were invited, both from Local Authority provisions and 3rd Sector organisations. From those invited FCSS and Scottish Autism indicated a willingness to become actively involved. Following this event, a Coordinator and three Communication Development Workers from FCSS were funded for 1 or 2 days per week for 18 mths/2 years respectively. An initial programme of enhanced training was delivered to the Development Workers who then went back into their workplaces to offer support to their colleagues, eg. with consultation and advisory sessions.

The Development Workers also developed a bank of both generic and bespoke resources, made available to FCSS staff on a shared drive, to help support their Service Users become more functional and independent communicators when accessing their programme of community-based activities/travel/preparation for appointments etc. See examples on next page.

Scottish Autism also identified 2 key-workers who have benefitted from some key training, although not to the extent of that of the FCSS staff. The initiative was overseen by a Steering Group with senior representation from all interested parties



Travel and appointment resources



to monitor progress and help plan strategy. An audit was carried out within FCSS to gauge possible gaps in staff skills and knowledge around the effect of a learning disability on communication and why AAC strategies could help support comprehension and communication and enhance Service Users' engagement in their community activities.

Within the audit, some areas requiring revisions were highlighted: it was also clear from feedback that staff preferred to have 'ownership' of training delivery, rather than coming from an external service, which is what had happened previously.

Rationale for Training:

Based on the Conscience Competence Model developed in the 1970s by Noel Burch, Gordon Training International, our aim was to move as many staff as possible through from level 1 – unconsciously unskilled – to at least levels 2 or 3, obviously taking into account staffs existing skills and experience.

1. Unconsciously unskilled – we don't know that we don't have this skill, or that we need to learn it.
2. Consciously unskilled – we know that we don't have this skill.
3. Consciously skilled – we know that we have this skill, but have to think about how we use it.



4. Unconsciously skilled – we don't know that we have this skill, we just use it instinctively.

Triangle of training:

Level 1: the effect of a learning disability on communication – the 'WHY' – delivered by the Coordinator.

Level 2: use of signing; use of visuals, writing Communication Passports – the 'WHAT', delivered by Development Workers. In addition, a core, Adult Learning Disability (ALD) Vocab was also commissioned by FAAC from Signalong®.

Level 3: Talking Mats training, delivered by 3 FCSS staff members who trained as Talking Mats Trainer; bespoke systems/software etc. (FAACT).

Additional supports

A communication jigsaw was developed to help staff remember all the areas that may possibly be affected by a learning disability, with suggested strategies that may be used.

In addition, a 'Communication Profile' was developed to help staff recognise issues a Service User had, identify strategies to try – having understood why they do! – and a method to ensure the information was shared with other FCSS staff.

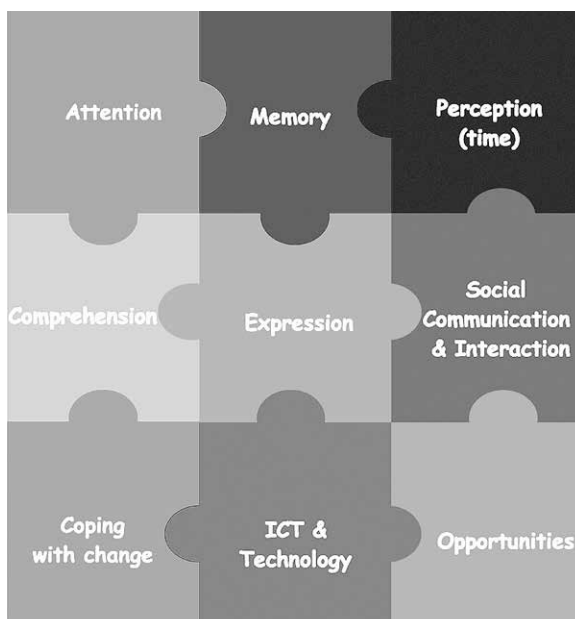


One piece of ongoing work is to focus on the transition process from High School into FCSS, offering a forum for discussion, training and improved identification and sharing of relevant communication information.

Outcomes

The results so far have been very encouraging.

- Staff in general now have an increased understanding of the progression of Service User skills and ability and the knowledge to plot where they are on the 'communication pathway' and identify appropriate 'next steps' with continuing support from Communication Development Workers.
- Communication is now on the agenda of every Key Group meeting and



information is shared with all team members so that there is consistency and persistency in the supports used.

- A group of additional communication 'Linkworkers' has now been added to support the Development Workers in the provision of resources and advice.

- Level 1 training has now been recognised as fundamental to any employee joining the FCCS workforce and is now part of their Induction process.
- There is a focus on communication as part of pre-Level 1 Induction Training, using the online modules available on the website www.aacscotland.org
- Senior Management from FCSS have recognised the value of the outcomes of the PAACT initiative to the extent that all three geographical areas in Fife offering this service have continued to fund part-time communication posts post 'Right to Speak'!

Next steps:

We have already had interest from and delivered presentations to other similar services on the process and how it has worked within Fife, but our main aim now is to write the process up to share more easily with others. We recognise that we had the 'luxury of seconded time through the 'Right to Speak' initiative but we believe the process to be robust enough to enable its adaptation for other circumstances.



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International collaborations with Poland

Expanding AAC and AT awareness and use in education, healthcare and other public sectors for social justice; enroute to an inclusive society

DOROTHY (DOT) FRASER

Member of Communication Matters (ISAAC UK)
Senior Representative to Eastern and Central Europe
Central Coast Children's Foundation¹
Member of ISAAC BUILD Committee
Email: dotfraser2@gmail.com

Introduction

For the plenary session "AAC around the World" at Communication Matters 2015 conference I was invited to be a co-presenter with Professor Gregor Renner, Germany, President of ISAAC², Dr Janice Murray, UK, chair of ISAAC Council and Aldona Mysakowska Adamczyk, Poland, chair-elect of ISAAC Council and member of ISAAC BUILD committee.

My role in the plenary; to present examples of my collaboration with Poland, demonstrating practical ways that CM board of trustees and members could also become involved in for future developments in Poland and with other AAC emerging nations in Europe.

My involvement with Poland

I first met Polish AAC specialists in 2007 at the 6th biennial Eastern and Central European AAC (ECEAAC) conference hosted in Prague, Czech Republic, which I attended to expand projects supporting the development of AAC in Romania. We remained in contact and several years later, in 2011 at the 8th biennial ECEAAC conference hosted in Warsaw,

my presentation topic, "Patient – Provider Communication" led to requests from Poland for collaborations to support their aim to expand their national awareness and use of AAC.

My Polish hosts have explained that by providing international support and working together we can encourage the need for AAC and emphasise relevant ways to promote the best possible communication for people with complex communication needs. Their aim is to make changes and develop nationally through international collaborations: to improve the situation for people of all ages with Communication Support Needs and their communication partners. They are looking for advice and practical ways through projects for PWUAAC, their families, professionals in education, healthcare and other public sectors and also for the general public.

They are eager to learn from ISAAC developed AAC nations how to share, promote and apply up-to-date information including research and practical strategies, ways to overcome existing barriers, how to strengthen their knowledge and build on this with current international resources.

Initially I was invited to three cities by Polish members of ISAAC and the Polish national AAC association "Mowic bez Slow" (Speaking without Words). Through their contacts and national AAC network our projects have expanded over the past few years to involve people in more Polish towns and cities and have opened up potential opportunities for further developments.

I provide training in education, health care and other public sectors through workshops in schools, presentations at universities and conferences, including information for local authorities and government officials. I also participate at symposiums, national and international conferences and give presentations at hospitals and universities for staff, therapists and students. My presentation material is translated in advance and given to the hosts for distribution to participants and to put on their websites.

To help promote awareness for the general public as part of Poland's programme of activities during International AAC Awareness Month I have given interviews for local radio and television.

Activities

Healthcare: In 2012 the Academy of Physical Education (AWF) in Poznan jointly hosted a study day with Harpo, the Polish AT/AAC distributor company. As a guest presenter my topic was "International Communication Strategies in Healthcare; Theory and Practice". Aims "To share and promote creative, effective methods to improve patient-provider

Background information from Poland

Aldona Mysakowska Adamczyk

Although AAC was introduced in Poland 30 years ago it is still an ISAAC emerging AAC nation. Poland was one of the first countries interested in AAC, but with no resources, no research and no facilities to develop like Western countries, it remained stuck for a long time at a low level of AAC due to political, social and economic reasons. As the situation in the country has changed in these areas there is a high need also to develop and expand in the AAC field.

communication and to raise awareness of its importance to quality healthcare.”

I included information from the Patient – Provider Communication Forum³, Polish translations of Widgit symbol support health care material and Communication Matters Focus on leaflet “Communicating with Patients who have Speech/ Language Difficulties”.⁴

This initial project has since been developed further as part of my ongoing collaboration with Krok za Krokiem (Step by Step) Association in Zamosc.

Some of the outcomes – including presentations in several other towns and cities.

- The need for improving patient-provider communication is now becoming more recognised by health professionals who are sharing their experiences with colleagues in order to expand this.
- Resources supplied as part of our International Patient Provider Communication (IPPC) Forum projects (including Polish translations of Widgit health care material) are in use in some rehabilitation hospitals and hospices with positive feedback from staff and patients.
- Training for nurses is available through local AAC professionals.
- Information on how to implement patient-provider communication has been requested by other hospitals and hospices. This includes material translated into Polish.
- Krok za Krokiem participated in the preparation of the Polish versions of Widgit health care material, which you can access at <http://www.widgit.com/products/health/patient-communication-sheet.htm> and <http://widgit-health.com/downloads/medical-encounter-board.htm>.

More information about Widgit health materials can be found at <http://widgit-health.com/downloads/languages.htm> and <http://widgit-health.com/news-projects/index.htm>

Education and connecting with society

I run workshops for staff and families on a variety of topics chosen locally for education, for medical encounters and connecting with communities for children and adults who use AAC/AT.

In special education schools I observe

individual children, therapy sessions and class activities with follow on sessions of discussion and advice for staff and families. I also have discussions with adults who use AAC, their communication partners and their AAC providers.

Over the years my involvement with education has grown. We continue to have similar sessions with feedback and further suggestions for staff and families who are keen to expand AAC within the curriculum and beyond, for life skills and inclusive societies.

Changes have been implemented during our 4 year collaboration and are still growing, for example:

- perceptions on the need for AAC/ AT for communication enhancement in all aspects of life not only for school curriculum or school age
- transitions from school to adult life
- more / different vocabulary and opportunities provided for social interaction using AAC in schools eg. an informal AAC club with social circle time for all ages and stages of pupils using AAC
- opportunities for adults and children to develop their connections within local communities
- for young adults who use AAC, living together in a specially designed house, developing their independence by providing them with their choice of vocabulary and supporting their aims for social justice through examples from UK. This has led to better relationships and happy atmosphere for the residents who use AAC, their peers and their communication partners

Regarding ISAAC international and BUILD subcommittee for Europe. I have had discussions with Gregor Renner, President of ISAAC, who has told me that other less developed AAC nations could benefit in the future from expertise Poland acquires through International collaborations. As co members of ISAAC BUILD subcommittee for Europe, Aldona Mysakowska Adamczyk, chair elect of ISAAC council and I have regular discussions on how we can work together to further establish international links. Through international connections and national Polish networks we have discussions with SLTs, other AAC specialists and local authority officials who would like to have collaborations with UK and make plans for more opportunities to strengthen AAC/AT within Europe.

Conclusions

Resources from the UK and other AAC developed nations are proving to be extremely useful for PWUAAC, families and professionals already familiar with AAC, to help them expand their knowledge and apply in their own situations.

Health care professionals and local authorities, previously unaware of AAC, appreciate information on research from Communication Matters eg. Shining a Light⁵ and information from Scottish Government initiatives, Principles of Inclusive Communication⁶ Right to Speak⁷ and Now Hear Me.⁸

Post script after the CM 2015 conference

Communication Matters board of trustees and members agreed to form a collaboration with ISAAC BUILD European sub committee and are now sharing CM resources and expertise to help support emerging AAC nations in Europe.

References

- 1 www.centralcoastchildrensfoundation.org
- 2 www.isaac-online.org
- 3 patientprovidercommunication.org
- 4 www.communicationmatters.org.uk
- 5 org.uk/shining-a-light-on-aac
- 6 <http://www.gov.scot/Resource/Doc/357865/0120931.pdf>
- 7 <http://www.gov.scot/resource/0039/00394629.pdf>
- 8 <http://www.nowhearme.co.uk/>



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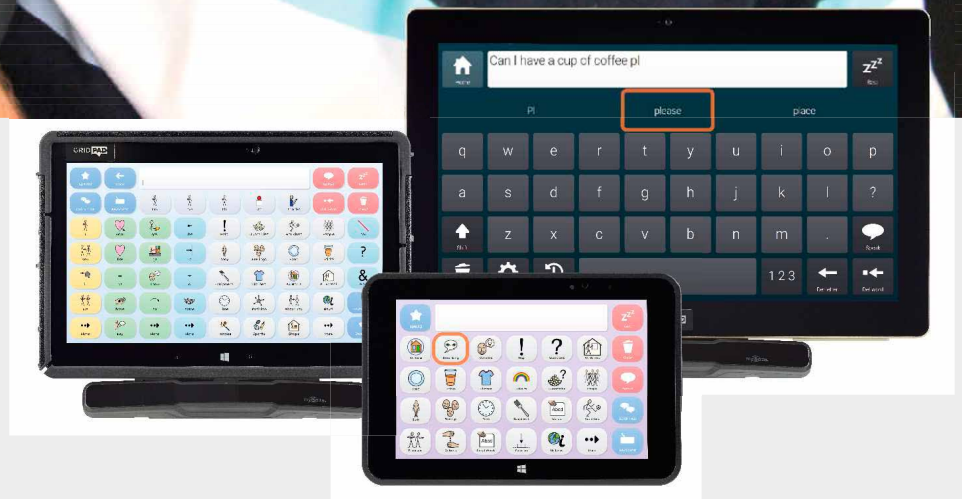


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