## My name is Jill Clark



I use my communication aid (AAC) to... communicate with my family and friends and it ables to do my job.



## Join the campaign

#MyCommunicationMatters campaign

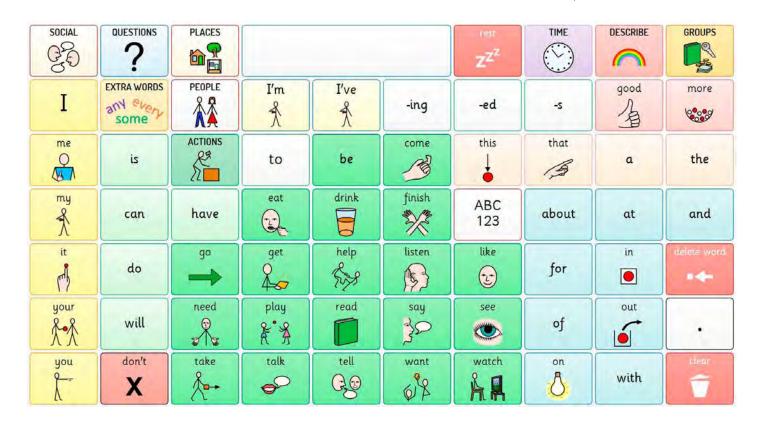
#### JULY 2017 VOLUME 31 NUMBER 2

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

Topics include: You Matter training courses – Eye Gaze Club – Developing shared reading – Classroom teaching core words – Being AAC dependent – Unspoken Voices Project: gathering perspectives – VOCA adult learning disability groups – Not the Royal Highland Show!



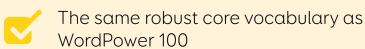
## WordPower 60 for Grid 3



## A proven model of AAC

WordPower provides a robust, evidence-based vocabulary that makes developing novel sentences both quick and intuitive.





- Accessible for people who need larger and fewer cells on their screen
- Ideal for non-verbal users with developing literacy
- Designed by Nancy Inman M.A.T., CCC-SLP
- Included with Grid 3



### **Contents**



Jill is taking part in our social media AAC awareness & fundraising campaign '#My CommunicationMatters' which will go out on our Facebook, Twitter & LinkedIn etc. Want to take part? Please send us a photo and we ask you to answer the question 'I use my AAC device to...' for you to say exactly what you would like to say about what AAC enables you to do

#### COMMUNICATION MATTERS JOURNAL ISSN 0969-9554

Communication Matters / ISAAC (UK) Leeds Innovation Centre, 103 Clarendon Road, Leeds LS2 9DF, UK Tel & Fax: 0845 456 8211 Email: admin@communicationmatters.org.uk Website: www.communicationmatters.org.uk Registered Charity No. 327500

Company Registered in England & Wales No. 01965474

#### Editor Emily Campbell

Email: admin@communicationmatters.org.uk.

#### Design & Production

Kaarin Wall & Emily Campbell

#### Advertising and Overseas Subscriptions Tel & Fax: 0845 456 8211

Email: admin@communicationmatters.org.uk

#### Copy submission

Preferred text format: Microsoft Word Preferred graphics/photo formats: JPEG, TIFF Copy deadline: contact editor
The CommunicationMatters Journal is the official publication of Communication Matters / ISAAC (UK), and is an ISAAC affiliated publication.

The journal provides a forum for discussion, and views The journal provides a forum for discussion, and views expressed in any section of this publication are the views of the writer(s) exclusively: publication in this journal does not constitute endorsement by Communication Matters / ISAAC (UK) or ISAAC of those views expressed. This is no way affected by the right of the Editors to edit all copy published. Publication of advertisements in this journal is not an endorsement of the advertiser nor of the products and services advertised. Communication Matters reserves the right to reject or cancel without notice any advertisement. Copyright for all published material is held by Communication Matters / ISAAC (UK) unless otherwise stated.

- 2 Co-chairs' Report
- 3 **CM News**
- You Matter

Amanda Bousaki and Deborah Pugh

Welcome to Eye Gaze Club

Helen Dixon

**Developing shared reading for pupils** who use AAC (a case study of share reading between EYFS and KS2)

Stacey Ladbrook and Sarah Smith

- **Choose Your Words teaching core words** in the classroom
  - J. Marden
- 18 What I feel about being AAC dependent

Maddy Norman

The Unspoken Voices Project: gathering perspectives from people who use alternative and augmentative communication (AAC)

Katherine Broomfield

**Voice Output Communication Aid groups** for adults with learning disabilities

Grace Law and Catrin Williams

Not the Royal Highland Show! 25

Janet Scott

## **Co-chairs' Report**

## **Toby Hewson & Ruth McMorran**

Life at Communication Matters seems to have been really busy throughout the spring and start of the summer.

Some of you might have noticed changes on the CM website. There is a new homepage and new member's only resources. You will find some resources from the recent Literacy Study Day are already there and footage from the Speechless production is coming soon. We plan to add more information following this year's conference.

At the beginning of July, Ruth had the opportunity to visit Bucharest to present a keynote address at ECERAAC - the Eastern and Central European Regional Conference on AAC. It was great to hear some of the leading lights in AAC from across this region highlighting the CM website as one of the best places to find resources and information.

Preparations for CM 2017 are now underway. We received well over one hundred abstracts and the successful presenters have all been informed. Currently we are preparing the conference programme and hope to have a draft version on the website before too long.

We look forward to receiving your nominations for both the Alan Martin Award and the Jamie Munro Inspiration Award.

The Alan Martin Award is presented annually for significant contribution to the Arts by someone who uses AAC. So far, the award has been presented to poetry, drama, photography and animation. We're excited to know what art forms will be represented by this year's nominees.

A new award for 2017 is the Jamie Munro Inspiration Award. After his sudden death in December 2016, several of the CM Supplier members suggested we should pay tribute to Jamie's commitment to the AAC world. And so, a man who was inspirational to many people will be remembered each year at the Communication Matters Conference. We are seeking nominations from anyone who uses AAC or who works in the field of AAC. Nominees should be someone who is inspirational in the world of AAC. This could be an AAC user, an inventor, therapist, designer, teacher, supplier...... anyone who is inspirational to you.

You can find further information on how to make your nomination for either award on the website.

Finally, there have been changes at the CM Office. Hilary Gardner has left Communication Matters to focus on her role in a new charity which will fund research into developmental language disorders. Hilary joined CM in January 2015 when we moved our office from Leith, near Edinburgh, to Leeds. She helped to ensure we made a smooth transfer to our new home. Hilary provided valuable support to the current and former Chairs and Trustees in key areas such as event planning and importantly, in successful funding bids for projects that CM is taking forward. Hilary will remain in touch with CM as an associate member.

By the time you read this we will have attended the **1Voice National Residential Weekend** at its new location at Derwen College in Oswestry. The Trustees of both Communication Matters and **1Voice** are working hard to build more links between the two organisations.

We look forward to seeing as many of you as possible at CM 2017 in Leeds in September.

#### **Communication Access UK (CAUK)**

We are now over 6 months into the pilot project and things continue to move forward with new contacts made and more opportunities to share about the vision of launching a symbol for communication access in the UK.

#### **Symbol Consultation**

The second stage of the symbol consultation has now closed with over 3000 responses being received through the online survey and hard copies received by post, Thank you to all who have contributed their opinions and comments. As expected, a wide range of views have been received presenting a slight dilemma for the steering group as we seek to agree on the next steps. Overall the majority decision is that '2 heads' represents total communication most clearly but, in the light of numerous comments received as to how this could look, it is felt that we still do not have a definitive symbol. There has also been considerable support for the 'message bubble' from the feedback from business. We are now taking further advice as to how we proceed. Although on one level this has been frustrating, we are taking a longer-term view as this is something which needs to have sustainability and maximum impact. The good thing is that the minimum standards have now been identified! It is likely that there will be a final stage consultation which is planned for September with a launch planned in early 2018 so watch this space!

#### **Introductory Workshops**

Parallel to the symbol selection the work on the pilot training continues and this continues to be exciting. As previously noted, workshops were facilitated earlier this year at Star, Treloars, Beaumont and Percy Hedley specialist Further Education colleges to introduce the project and to encourage participation in the symbol consultation. Following these, mystery customer visits have been conducted by some students and we have now begun to receive completed mystery customer questionnaires which are being used to give baseline data and as marketing tools.

The first introductory workshop specifically for stroke survivors was facilitated at the Bury Speakeasy Group in June. Workshops have also been facilitated at the Ipswich and Brighton CM Roadshows and at Ingfield Manor school. Experience of a local project was shared by the SLT team in Surbiton.

#### **Resources and Training Materials**

Training workshop materials have been developed and tested. There are now outlines for Introduction to CAUK, Mystery Customer training, and Workshop presenter training as well as presentations and resources to use with businesses. The mystery customer questionnaires

## **CM News**

have been modified in response to feedback and are now available in text and symbol supported versions. The intention is to roll these out using a 'Train the Trainer' model.

#### **Growing the Team!**

A flow chart and application form have been developed to support the selection process for 'recognised trainers'. There are now 6 AAC users who are potential workshop presenters. We are very pleased to recently welcome

Gill Pearl (based in Bury) to the team. The aim is to have trainers and mystery customers around the UK so that we can more efficiently provide training to businesses as appropriate. There will be opportunities to find out more in September at the CM Conference.

Please make contact if you would like more information or would like to work with us to facilitate a workshop for your school, college, service or team. Bookings are now being taken for the period September to December.

#### **AACknowledge Entries (April - June 2017)**

Our AACknowledge online evidence base presents information in a variety of accessible formats to help anyone who needs access to up to date information on best practice, services, case stories and research. By having more accessible information CM hopes to improve services and empower individuals to find the solutions they need.

#### **Recent Bibliography Entries**

- Alzrayer, N M Banda, D R Koul, R, 2017. Teaching children with autism spectrum disorder and other developmental disabilities to perform multistep requesting using an iPad. AAC, 33/2, 65-76
- Batarowicz, B King, G Vane, F Pinto, M Raghavendra, P, 2017. Exploring validation of a graphic symbol questionnaire to measure participation experiences of youth in activity settings. AAC, 33/2, 97-109
- Blischak, D Lombardino, L Dyson, A, 2003. Use of Speech-Generating Devices: In Support of Natural Speech. AAC, 19/1, 29-35
- Childes, J M Palmer, A D Fried-Oken, M Granville, D J, 2017. The Use of Technology for Phone and Face-to-Face Communication After Total Laryngectomy. American Journal of Speech-Language Pathology, 26/1, 99-112
- Clarke, M Soto, G Nelson, K, 2017. Language learning, recasts, and interaction involving AAC: background and potential for intervention. AAC, 33/1, 42-50
- Copple, K Koul, R Banda, D Frye, E, 2015. An examination of the effectiveness of video modelling intervention using a speech-generating device in preschool children at risk for autism. Developmental Neurorehabilitation, 18/2, 104-112
- Deckers, S R J M van Zaalen, Y van Balkom, H Verhoeven, L, 2017. Core vocabulary of young children with Down syndrome. AAC, 33/2, 77-86
- Drager, K D R Light, J Currall, J Muttiah, M Smith, V Kreis, D Nilam-Hall, A Parratt, D Schuessler, K Shermetta, K Wiscount, J, 2017. AAC technologies with visual scene displays and "just in time" programming and symbolic communication turns expressed by students with severe disability. Journal of Intellectual & Developmental Disability, on-line
- Ferm, U Bloch, S Saldert, C, 2015. Negotiating disagreement in picture symbol supported decision making. Journal of Interactional Research in Communication Disorder, 6/2, 131-156
- Finke, E Davis, J M Benedict, M Goga, L Kelly, J Palumbo, L Peart, T Waters, S, 2017. Effects of a Least-to-Most Prompting Procedure on Multisymbol Message Production in Children With Autism Spectrum Disorder Who Use Augmentative and Alternative Communication. American Journal of Speech-Language Pathology, 26/1, 81-98
- Grove, N Woll, B, 2017. Assessing language skills in adult key word signers with intellectual disabilities: Insights from sign linguistics. Research in Developmental Disabilities, 62, 174-183
- Higginbotham, D J Engelke, C R, 2013. A Primer for Doing Talkin-interaction Research in Augmentative and Alternative Communication. AAC, 29/1, 3-19
- Kent-Walsh, J Murza, K A Malani, M D Binger, C, 2015. Effects of Communication Partner Instruction on the Communication of Individuals using AAC: A Meta-Analysis. AAC, 31/4, 271-284

- Mirenda, P, 2017. Values, Practice, Science, and AAC. Research & Practice for Persons with Severe Disabilities, 42/1, 33-41
- Moffatt, K Pourshahid, G Baeker, R M, 2017. Augmentative and alternative communication devices for aphasia: the emerging role of "smart" mobile devices. Universal Access in the Information Society, 16/1, 115-128
- Nathanson, E, 2017. Native voice, self-concept and the moral case for personalized voice technology. Disability & Rehabilitation, 39/1, 73-81
- Paterson H L, 2017. The use of social media by adults with acquired conditions who use AAC: current gaps and considerations in research. AAC, 33/1, 23-31
- Rombouts, E Maes, B Zink, I, 2017. Beliefs and habits: staff experiences with key word signing in special schools and group residential homes. AAC, 33/2, 87-96
- Sigurd Pilesjö, M Norén, N, 2017. Teaching communication aid use in everyday conversation. Child Language Teaching and Therapy, on-line
- Simacek, J Dimian, A F McComas, J J, 2017. Communication Intervention for Young Children with Severe Neurodevelopmental Disabilities Via Telehealth. Journal of Autism and Developmental Disabilities, 47, 744-767
- Singh, S J Hussein, N H Kamal, R M Hassan, F H, 2017. Reflections of Malaysian parents of children with developmental disabilities on their experiences with AAC. AAC, 33/2, 110-120
- Tanner, K Hand, B N O'Toole, G Lane, A E, 2015. Effectiveness of interventions to improve social participation, play, leisure, and restricted and repetitive behaviors in people with autism spectrum disorder: a systematic review. American Journal of Occupational Therapy, 69/5

#### **Recent Plain Language Summaries**

- Ballin, L Balandin, S Stancliffe, R J Togher, L, 2011. Speech-language pathologists' views on mentoring by people who use speech generating devices. International Journal of Speech-Language Pathology, 13/5, 446-457
- Deckers, S R J M van Zaalen, Y van Balkom, H Verhoeven, L, 2017. Core vocabulary of young children with Down syndrome. AAC, 33/2, 77-86
- Deveney, S Cress, C J Lambert, M, 2016. Parental directiveness and responsivity toward young children with complex communication needs. International Journal of Speech-Language Pathology, 18/1, 53-64
- Logan, K Iacono, T Trembath, D, 2017. A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. AAC, 33/1, 51-64
- Mandak, K O'Neill, T Light, J Fosco, G M, 2017. Bridging the gap from values to actions: a family systems framework for familycentered AAC services. AAC, 33/1, 32-41
- Moffatt, K Pourshahid, G Baeker, R M, 2017. Augmentative and alternative communication devices for aphasia: the emerging role of "smart" mobile devices. Universal Access in the Information Society, 16/1, 115-128
- Paterson, H L, 2017. The use of social media by adults with acquired conditions who use AAC: current gaps and considerations in research. AAC, 33/1, 23-31
- Nathanson, E, 2017. Native voice, self-concept and the moral case for personalized voice technology. Disability & Rehabilitation, 39/1, 73-81

### **You Matter**

#### **AMANDA BOUSAKI**

Speech and Language Therapy Services, Central and North West London Foundation Trust – Milton Keynes Community Services Email:Amanda.bousaki@nhs.net

#### **DEBORAH PUGH**

Greenfields Specialist School for Communication, Prentice Court, Northamptonshire NN3 8XS Email:deb.pugh@greenfields.northants.sch.uk



'You Matter' Education Edition and 'You Matter' Family Edition: bringing together families of children who use AAC and their supporting professionals.

#### Introduction

The provision of augmentative and alternative communication systems, both low and high technology has developed rapidly over the last ten years. In recent years the implementation of AAC for children and young people has changed from a focus solely on the child to a greater emphasis on the family. Parents play an important role in providing social opportunities to facilitate their child's use of AAC systems and yet many studies (Angelo et al., 1995; Bailey et al., 2006; Hodge, 2007) report a lack of training and support for parents in using AAC. 'You Matter' (Family Edition and Education Edition) addresses this challenge and is designed to support and empower educational staff and families of children who are using aided communication.

#### What is it?

'You Matter' consists of two training courses for parents, carers and professionals of children who use low or high tech AAC. Both courses focus on the underlying concept that the communication partner is central to the child/young person (CYP)'s success in using aided communication methods. It develops the participants' own knowledge of aided communication, exploring the child's communication strengths and needs and

matches this to effective communication partner strategies whilst holding central the hopes and aspirations of the family and the CYP.

'You Matter' was developed in 2011 as part of the Becta 'Innovative Projects' funding in partnership with the ACE Centre. Following comprehensive feedback from participants and tutors, the revised 'You Matter' Family Edition was launched in 2016. The course has eight sessions which can be delivered flexibly over two full days or over four mornings/ evenings. The training pack is an 'off the shelf' resource consisting of all the materials to support the running of the course:

- PowerPoint presentation with further video support materials in the revised edition
- Tutor Guide taking the course leader step-by-step through the course materials
- Simplified Participant's Guide that can be used for future reference with handouts that summarise the child's communication stage, the strategies to use and how each participant will implement actions following the course
- Resource Pack with examples of different symbol-based communication charts and all the handouts and

activity materials to support learning and the running of the course.

An additional half day provides individualised communication support and looks at each child's personal aided communication system. This session supports parents/educational staff to gain confidence with the programming of the child's communication device and/or the creation of other low tech materials customised to the child's specific needs.

'You Matter' Education Edition is a one day training course designed to support and empower education staff working with children who are using aided communication. The level of specialist support is variable across the UK and this course addresses this gap in training by providing practical advice and learning that can complement the support received from services such as Speech and Language Therapists and Specialist teachers. It condenses the content of the Family edition to accommodate the need to minimise time away from the classroom. 'You Matter' Education Edition has six sections and incorporates time for personal reflection encouraging learning to put into practice once participants return to the classroom. The sections are:

• An Introduction to Aided Communication

- Learning to tell stories through aided communication
- · Selecting Vocabulary
- Strategies to make aided communication successful
- · Making it work
- · The inclusive classroom

#### **Why Training Matters**

'You Matter' applies the principles of person-centred principles where parents and professionals are seen as equal partners with a view to achieving better outcomes for children using aided communication. It supports the SEND reforms (The Children and Families Bill, 2014) by focusing on the hopes and aspirations of both families and professionals. 'You Matter' considers communication now and the communication skills that participants hope the child will achieve in the future. The latter can be a difficult and emotive area and You Matter encourages participants to take control of using aided communication and provides positive and practical ways to support the child's AAC needs. This is achieved through the use of structured aided communication stages and strategies and the identification of barriers that can obstruct successful implementation of aided communication and provides essential time to problem solve and plan the solutions to move forward.

The introduction of aided communication can be challenging and the amount of information is often overwhelming for parents (Pugh, 2015). 'You Matter' supports a common understanding of terminology used and enhances communication between Speech and Language Therapists and parents/professionals. It has been developed with the belief that knowledge leads to empowerment resulting in shared ownership and joint decision-making for all who support the CVD.

Parents of children using AAC have described becoming socially isolated (Goldbart and Marshall, 2004), 'You Matter' provides opportunities for parents to meet other families who use aided communication and encourages the sharing of experiences and learning from each other. This is a powerful means of peer support, providing insight that no professional can provide first hand. Every family and educational staff member is unique and the course has been devised to be a learning experience for both tutors and participants.

#### **Feedback from Courses**

Thirty families attended 'You Matter' courses from 2012-2016 and the feedback received was very positive. All of the families found the course met or exceeded their expectations and the sessions were well-led:

"It's been brilliant to spend time with professionals who have such value for AAC and are interested in helping our children find their voices"

Following the course, families completed a Participant Feedback Form identifying how helpful they found the sessions in the 'You Matter' course (see Figure 1).

Families were also asked to indicate how confident they were in managing different aspects of their child's communication system (see Figure 2).

Several families were not confident with the technical aspects of programming their child's high tech device. This has been shown in other studies (McNaughton et al., 2008; Pugh, D. 2015; Gribble et al., 2014) and highlights the importance of training parents to develop

their confidence in using AAC technology. Following the course, 100% of the participants were 'Confident' or 'Quite Confident' in selecting a meaningful vocabulary for their child with a range of communicative functions using 'core' and 'fringe' vocabulary. Families were able to identify their child's current expressive aided communication stage showing that parents are experts on their children (Marshall and Goldbart, 2008).

Families reported gains in their own learning from the information given both in the sessions and the Participant handbook.

"I enjoyed learning how to make a difference by using AAC"

"I will take all the information I have received and try to develop more communication at home"

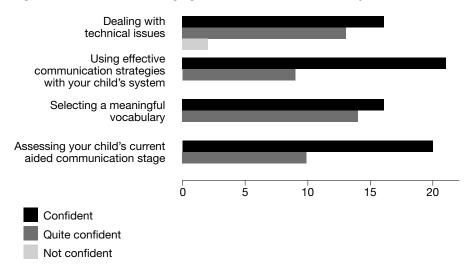
Many parents felt the course developed their knowledge, skills and confidence in using their child's communication system.

"I have renewed enthusiasm to develop communication with my son"

Figure 1: Participant feedback

Sessions	Not helpful	Helpful	Very Helpful
Concerns/pressures/hopes		9	21
Five stages of aided communication		7	23
Selecting appropriate vocabulary		8	22
Adult strategies to facilitate aided communication		6	24
How to involve others		10	20
Solving problems		11	19
Implementing your goals		9	21

Figure 2: Confidence in managing their child's communication system





## NEW: A FREE MULTI-ACCESSIBLE AAC INTERFACE FOR LITERATE USERS

To find out more about Amego and how it works with Mind Express call us on 01476 512881



#### THE POWER OF MIND EXPRESS SOFTWARE:



#### COMMUNICATION

NEW 'SCORE' Vocabulary Set – Making AAC access to fringe and core vocabulary as easy as possible.



#### **EDUCATION**

Great new games and resources, ask us for more information.



#### ASSESSMENT

MaximEyes – The all new Eye Gaze assessment tool from Jabbla

#### BUT DON'T JUST TAKE OUR WORD FOR IT...



"Lauren (15) is now able to access a complex communication system set out in a simple logical way with Mind Express, giving her independence, control and a better quality of life."

JUDY KING, INDEPENDENT SLT



"It is difficult for me to communicate verbally, but I still think & I love to talk - and that's where my Mobi 2 using Mind Express comes in. By using it I can say what I need, and what I want. My Mobi is my best friend." HANNAH JAMES

#### FREE LOANS AVAILABLE: Find the AAC device that works for you.



Smart 3 Zingui 2



Tellus 5





Allora 2



"A boost in confidence regarding the way we are currently using AAC"

Although the short term evaluations of 'You Matter' are positive, further follow up of the families is needed to assess the long term outcomes achieved.

#### Conclusion

Parents and carers are essential communication partners for children using aided communication and crucial to the success of its implementation; however the use of these systems remains challenging and can leave families feeling isolated. You Matter brings together parents and their supporting professionals with a view to achieving the best possible outcomes for the child using aided communication. It promotes the positive role of aided communication, increases awareness and knowledge in the belief that everyone close to the child makes a real difference.

 $Available\ from: www.acecentre.org.uk$ 

#### Acknowledgements

We would like to thank Katharine Buckley and the Northants AAC team for their invaluable input. The authors would like to thank all the parents who have contributed to the development of You Matter.

#### References

Angelo, D.H. Jones, S.D and Koskoska, S.M. (1995) Family perspective on Augmentative and Alternative Communication: families of young children. Augmentative and Alternative Communication, 12(1), pp.13-22

Bailey, D.E. Parette, J.R, Stoner, J.B. Angell, M.E and Carroll, K. (2006) Family Members' perceptions of Augmentative and Alternative Communication Device Use. *Language, Speech & Hearing Services in Schools*, 37 (1), pp 50-60



Goldbart, J. and Marshall, J. (2004) "Pushes and pulls" on the parents of children who use AAC. Augmentative & Alternative Communication, 20(4), pp. 194-208.

Gribble, T. Firth, R. Cattani, A. and Carroll, L (2014) Increasing the Communicative Opportunities for VOCA use through staff/parent training *The Journal of* Communication Matters/ISSAC (UK) Vol 28 (2),pp. 9-11

Hodge, S. (2007) Why is the potential of augmentative and alternative communication not being realized? : Exploring the experiences of people who use communication aids. *Disability & Society*, 22 (5), pp. 457-471

Latham, C. and Bousaki, A. (2012) You Matter The Journal of Communication Matters/ ISSAC (UK) Vol 26(1), pp.11-13

Marshall, J. and Goldbart, J (2008) 'Communication is everything I think' Parenting a child who needs Augmentative and Alternative Communication (AAC) International Journal of Language & Communication Disorders Vol 43 (1) pp. 77-96

Pearce, C. and Pugh, D. (2012) AAC in Northamptonshire: Involving Parents Communication Matters Journal Vol 26(2), pp. 17-19

Pugh, D. (2015) Listening to different voices in families *The Journal of Communication Matters/ISSAC (UK)* 



## Focus On leaflets

Please contact us to place an order, they are available individually or as a set of eight. Free, but donations are always welcome.

## **Welcome to Eye Gaze Club**

#### **HELEN DIXON**

Cumbria Partnership NHS Foundation Trust. Email: Helen.dixon2@cumbria.nhs.uk

The first rule of eye gaze club is that you **do** talk about eye gaze club hence this article.

Eye gaze club started because there were a number of young people using or learning to use their eyes to communicate in the vicinity of Kendal in and it was felt that it would be useful for them to get together. Eye Gaze Club meets at least once most school holidays and a number of times during the summer. It has been running for almost 2 years.

Originally we just spoke of it as a group, one of the parents started calling it eye gaze club which has changed the feeling and made it much more a social as well as therapeutic group. This feeling was also helped by the fact that our first meeting happened on one of the young people's birthday and her Mum brought cake for everyone.

The main reasons for starting the group in the first place included

- To decrease possible isolation as not all the young people had opportunities to meet others using their eyes to communicate
- To give opportunities for mutual family support as we have some very skilled parents who are generous with their knowledge, skills, advice and resources
- To provide access to role models. One
  of our young people has been using
  eye gaze technology for a number of
  years and another had some experience so were able to help those newer
  to both high tech eye gaze and low tech
  eye pointing

- To provide mutual therapist support.
   The therapists supporting Eye Gaze
   Club had a range of experience with using eyes to communicate and so were also able to learn from each other and mostly from the families who are very much the real experts
- To help the young people develop their skills in using their eyes to communicate
- More fun activities are possible in a group

We have four regular members of eye gaze club. Our expert is Oli who has been using eye gaze for a number of years. He is in a mainstream primary school and will transfer to secondary school in September. Oli was a proficient low tech eye pointing user from a very young age and also uses a high tech eye gaze system. Oli is working on further developing his conversation skills and acts as a role model in the group.

Molly is our apprentice. She has been using eye gaze technology for just over two years. Molly also started using low tech eye pointing from a very young age and then progressed quickly to also using a high tech system. Molly attends a different mainstream primary school. She is working on developing her sentence building skills.

We have two members who are newer to using eye pointing and eye gaze. Bethany attends a special school and has in recent years shown that she is ready to communicate more. She has surprised everyone with things that no one realised she knew.



Poppy is only just starting to work on using her eyes to communicate through a high tech system as well as using low tech. Poppy is in yet another mainstream primary school.

The young people usually come with their parents. We have also been joined by one of their learning support assistants, nurses, and other therapists. In the interests of providing information which some people may want, while in many ways their ages and conditions are irrelevant, at the time we started eye gaze club Oli and Bethany were 9, Molly and Poppy were 4. Two of the club members have cerebral palsy and two have Rett syndrome.

The speech and language therapists work for Cumbria Partnership NHS Foundation Trust. There are four therapist who have been involved. Generally two attend each meeting.

As a volunteer with 1Voice Communicating Together I understand the importance of role models. 1 Voice role models 'successfully use AAC in their lives and act to inspire children at our events as well as raise expectations of families

and professionals' www.1voice.info. At Eye Gaze Club the children can all act as role models as they all have different skills not only in using low tech eye pointing and high tech eye gaze but also in the activities we do.

At Eye Gaze Club we encourage the use of both high and low tech methods of communication. When we first started meeting neither Bethany nor Poppy had their own systems. We had an old system which had been returned to us when someone got a new one. With all their vocabulary on this was so slow as to be unuseable but when we took all their package off and put on a limited number of pages specifically for use in Eye Gaze which included pages for our activities, Simon Says and some vocabulary for a chat. With this fairly limited vocabulary it worked well enough for our purposes. Poppy and Bethany took turns to use it. In terms of low tech we had e tran frames and used symbols as well as photographs of the group members. Poppy brought her own encoded boards some of which were Oli's old ones which his parents had given her.

We tend to plan about four activities for each meeting but generally do not manage to do all of them. The most important thing is that we have plenty of time for the young people and their parents to chat. We play games such as skittles, hoopla, Halloween and a game with spiders where the young people can

choose colours, whose turn it is, how many they have knocked down. It was during one of these games that Bethany's Mum discovered for the first time that Bethany could count. We have an orchestra where the young people choose their instruments, who should play and whether the music should be fast, slow, loud or quiet.

We have written a number of stories with each member of the group contributing. The first was our Easter story. Each child's contribution is in italics and initialled. The story was written by Oli, Molly and Poppy.

"Once upon a time there was a rabbit and a chick (P) who went to the hairdressers (M). The rabbit (M) said "Happy Easter". (M) The chick (P) bought an Easter Egg (P). Then they went for a trip on the Flying Scotsman Steam train. It is fast but not as fast as Mallard which goes at 125.5 miles per hour. (O) They stopped at a station and a lamb (M) got on the train. Suddenly there was an earthquake. (M) The rabbit (P) hurt its ears and its eyes.(P). A paramedic (M) came and made it better. Then they went for ice cream and cake (M)."

We have since written a number of stories based loosely on the theme of the meeting. The other activities also relate to the theme where this is possible and appropriate. Molly introduced us to the Storybots app. She likes to listen to the alphabet songs so at the end of the group the members would choose a letter and we would listen to that song.

We feel eye gaze club has a number of benefits.

- It gives the members the opportunity to develop their skills in a situation where using your eyes to communicate is normal
- They are able to use the system in a more social situation and also to develop and demonstrate their skills
- They can use Low Tech Eye Pointing in a situation where it is valued
- The members had access to a high tech system to practice
- They are able to develop their skills in a less pressured situation than when a loan is your opportunity to 'prove' that you can use a system
- · There is access to role models
- Parents provide each other with mutual support
- There are opportunities to share resources – symbols boards, vocabulary packages
- The club is a way of Increasing Therapists' confidence in working with people using their eyes to communicate
- It has increased awareness of using your eyes to communicate within the wider team

Working for the NHS we are encouraged to ask for feedback so we asked the parents what they felt about Eye Gaze Club.



'We love coming to eye-gaze club: it's great fun for Molly and for us as parents, too. It gives us ideas for things we could do at home and take in to school - we especially enjoyed the story-telling activity. There is lots of time for the children to chat and for us all to follow their direction: it's a place where they know their communication is understood and matters." "The children all go to different schools, and don't often see other people using eye-gaze, so it's lovely for them to have a chance to socialise with each other."

"As a family, eye-gaze club helps us feel supported and less isolated on our 'eye-gaze' journey."

"The children take part in games and singing, they are included from the start giving them the opportunity to engage with everyone and express their choices, opinions and needs. There's lots of chatting and it's great for the kids to have an audience where their voices can be heard. It builds great confidence and allows characters to shine. In a noisier and busier environment this is not always possible."

"As a parent it gives me the opportunity to learn new skills, which will assist me in Bethany's learning and also a social gathering with friends who are on the same journey, who offer extra support." Most importantly Molly said "Thank you". "I'm having fun"

Our future plans for eye gaze club are to continue, to possibly invite new members. We also want to develop a communication club in another part of our trust where there are a number of young high and low tech communication aid users but not as significant number using their eyes. They would benefit from getting together with others in a slightly more formal setting than at our local 1Voice activities which already provide the opportunity for them to meet socially. We would like to seek funding for a newer eye gaze system to have within the department, mainly for assessment purposes. We would also like to make links with other eye gaze clubs or groups if these exist anywhere.

The second rule of eye gaze club is that you do talk about eye gaze club. I wrote an article for our local trust newsletter. I wanted to raise awareness of communicating with your eyes across our trust both of high tech eye gaze and also highlighting the importance of low tech. As a result of the article the Trust Communications Department sent out a Press Release. I was contacted by the local

radio station who sent a report to one of our meetings. He had a go on our old eye gaze system, recorded part of the meeting and talked to the children and parents. They then requested one of us to go on the radio live to talk about it. Two versions of the broadcast were played at least three times. Eye Gaze Club was also featured on the Trust website, Healthy Cumbria Facebook, Cumbria Crack Facebook, the Bay Radio Website, The North west Evening Mail, The Smartbox Community Facebook, Partnership News (The Trust on line Newsletter), The News and Star, The Cumbria Crack Website and Trust Talk the Trust magazine which was where I intended it to go in the first place. I also gave a talk about it at Communication Matters. The Royal College of Speech and Language Therapist have also expressed an interest for their Bulletin.

We do always say "Welcome to Eye Gaze Club" at the beginning of meetings. My son pointed out the resemblance to a film which led to the first and second rule of Eye Gaze Club. I did not really think the second rule would take us quite so far. I have now watched Fight Club –I prefer Eye Gaze Club.



10

# Developing shared reading for pupils who use AAC (a case study of shared reading between EYFS and KS2)

#### STACEY LADBROOK AND SARAH SMITH

Woodlands School, Forty Foot Road, Leatherhead Surrey, KT22 8RY Tel.:01372 377922 www.woodlands.surrey.sch.uk

Woodlands School is a school for pupils aged between 2-19 years old who have complex learning and communication needs, including ASD and PMLD. The school won the Shine a Light Award for Augmentative Alternative Communication in 2015.

Throughout the primary school, including the Early Years Foundation Stage (EYFS), there is a focus on supporting the implementation of Balanced Literacy Instruction, a strategy for teaching literacy that is designed to support pupils with Special Educational Needs to develop literacy skills. This strategy is used alongside PODD and other AAC systems.

This case study focuses on an EYFS class and a Key Stage 2 (KS2) class, who both use a range of AAC including; Makaton, touch cues and high and low tech PODD systems. We have incorporated these communication methods across the curriculum on a daily basis. This has enabled us to focus on developing key literacy skills such as reading, writing and communication.

One important aspect of the Balanced Literacy Programme is shared reading. We will discuss how EYFS and KS2 have linked together to develop a shared reading time. The study will show how emergent and conventional learners with Special Needs can support one another to develop key literacy skills.

Throughout this Case Study we will show how children have developed their confidence with shared reading and building peer relationships. We will discuss the progress that has been made and what the next steps will be.



#### What Did We Do?

We took the conventional readers from the key stage 2 class and mixed them with the more able emergent group from the early years class to form one group, the second group was made up of the remaining emergent learners.

Once a week they would spend an afternoon together sharing books and a range of letter activities.

To support their communication skills we provided the children with aided language displays and also within the PODD devices we added appropriate vocabulary to support the task.

We modelled using symbols and signing throughout as required to support their understanding.



#### **Conventional learners**

Throughout the week the children would read their independent scheme reading book daily to an adult. This complimented the daily word work and phonic activities.

The children were also exposed to a range of guided reading tasks. They were developing their knowledge of the structure and layout of books.





Through the reading of books they developed an awareness of how words worked in a story and how to deliver an effective story.

For those who struggled with vocalizing the story we modelled how to tell a story using the PODD devices and their communication books.

During the shared reading session they would read a book to one peer at a time. They would use aided language displays to say things such as "read a book", "turn the page", "finished", "more" and "I like this". They enjoyed engaging with the children's other communication aids such as eye gaze devices, high tech PODD iPads and signing.

#### **Emergent Learners**

We started by encouraging the children to explore a range of books in the classroom, however it was found that the children were not engaged with books alone. From this we decided that the children required more play based learning around letters in order to develop their interest in books

We set up a range of activities based around the story books in order to engage them further. These activities included puzzles, mark making in a range of sensory materials, playdough, magnetic letters and songs.

We introduced the children to the books whilst they engaged in their activity and modelled the story alongside their play. Over time we made other books available, the children began to pick them up and became more engage with books.

During these sessions the children had access to similar AAC input to the other group in order to develop language and communication.

#### **Findings**

We found that the children were more enthusiastic and inspired to do their daily reading as they knew they were going to be reading to a peer later in the week. They therefore felt it was important to develop their reading skills so that they could share with the other children.

Their confidence in delivering stories grew and they were able to engage the listener by using a range of techniques such as questioning, prediction and clarification.

As the project has developed and the sessions have progressed the children have taken more ownership of the task. They have been more pro-active in guiding the sessions and developing communication with their peers. This has included asking questions, sharing the experience of exploring the book and model answering the questions posed using a range of AAC.

The conventional learners became more confident with a range of communication aids.

The children in the emergent group are showing more interest in books and letters since this project began. They are now independently engaging with a range of different books and letter activities outside of these sessions.

The children have become more confident using a range of different AAC communication methods, sharing their own communication methods and using them for purpose.

#### What Next?

For the conventional learners already taking part in these sessions we aim to embed these skills further; by giving them the opportunity to support the new children in the groups to gain these skills.



For the emergent learners we are aiming to sustain and further develop their interest in letter activities. As a result we are hoping that this total communication approach, including the use of eye gaze devices, high tech PODD iPads and signing, will support the needs of all of the learners with regards to developing shared reading skills.



## Choose Your Words – teaching core words in the classroom

#### J. MARDEN

AssistiveWare

Email: j.marden@assistiveware.com

How many times has this happened to you? You've come back from a conference or read an article that really got you thinking about implementing core words with your students who use AAC. This will be great! I can use modelling to teach my students to communicate using the most frequently used words! They can use core words as building blocks to put together sentences that I would never would have thought to program for them! They'll be on their way to truly generative language, and I'll be freed from endlessly programming the words for this week's school lessons!

You can't wait to share with your fellow teachers and therapists! You make them core word displays and show them how many sentences they can make with the core words. But instead of sharing your excitement, they sound confused and overwhelmed:

- · That's too many words for my students
- My students won't understand these words - they only understand nouns
- My students haven't mastered choice making yet - how can I give them all these abstract words?
- How would I teach abstract words like "do" and "it"?
- This won't work with the school curriculum I have to follow I need curriculum vocabulary like "Battle of Hastings" and "evaporation" so my students can participate in class

Unfortunately, this is a common reaction to the introduction of core words into a classroom. Implementing core words requires a shift in teaching techniques, and you'll need support materials and ideas to bring your fellow teachers and therapists along for the journey. Fortunately, with core word's increasing popularity, there are more and more resources for teaching core words in the classroom. This article discusses a new collection of materials introduced in September 2016 - the AssistiveWare Core Word Classroom (coreword.assistiveware.com)

The idea behind the AssistiveWare Core Word Classroom is not to create a curriculum. We've found that most teachers already have curriculums they're trying to adapt for their AAC users. Instead, we've created resources you can use to adapt your existing lesson plans for your students who use AAC. These resources will not only help you to teach core words, but to expand your students' communication beyond requesting, and to grow their grammar skills.

## Modelling as an AAC teaching tool

Students who are learning to use AAC need to see examples of how to use their AAC systems. Just as we wouldn't expect a typically developing child to learn to talk without seeing or hearing the adults around him talking, we shouldn't expect a child who needs AAC to figure out how to use his system without seeing the adults around him using the system to communicate. We recommend modelling (also known as Aided Language Stimulation, Aided Language Input, or Natural Aided Language) as your go-to teaching technique. With modelling, you point to key

words on a core word display as you talk with your students. You can model all the time, not just during speech, snack, or morning circle. Any time you would talk to a typically developing student, you can also model to a student learning AAC.

So now we hope we've convinced you to model. But what words should you model? Do you need to model every word you say, or can you model key words? What kind of word combinations should you model? How can you use core words to express your ideas?

The AssistiveWare Core Word Classroom materials will help answer these questions. The materials are built around a framework called the 3W's:

- WORDS the core words that could be used during a particular activity
- WHYS the many different reasons why we communicate
- WAYS the ways we combine words and add inflections to create grammatical sentences

#### WORDS are the core of the 3W's

Core words are those 50 to 400 words that make up most of what we say in typical conversation and writing. Many studies across different languages and age groups have found that about 50 words account for 40 to 50% of what we say, 100 words account for about 60%, and 200 to 400 words account for 80% of the words we use every day.

If we give AAC learners quick access to these core words, we're providing them with a powerful tool to communicate

whatever they want to say. Rather than relying on preprogrammed sentences or phrases such as "I want" and "I see", they can choose from a relatively small set of words to create their own sentences, express a wider variety of ideas, and work on more advanced grammar. Rather than learning new curriculum nouns for each new lesson, they can build their language skills by using a consistent set of flexible words to answer questions about curriculum topics.

## WHYS are the reasons we communicate

One of the key factors that can limit our students' communication development

is restricting our modelling to requesting and choice making. These are relatively easy to teach, and give a lot of initial "bang for your buck". However, there is so much more to full communication! What if all you could do was request? How much would you have inside that you couldn't express? How interested would other people be to talk with you?

We've found that one of the best ways to make sure you're modelling a wide variety of reasons to communicate is to have a list of these reasons. A list can give you ideas, and can help you see if you're leaving important reasons out.

There are many lists of communication

functions or intents. We've created our own for the 3W's, but feel free to use any list you're familiar with. We've divided the Why's into three groups. In the first group, Expressing Needs and Wants, you have Whys that allow you to get someone's attention, make choices, ask for something that isn't present, and refuse something.

The second group of Whys, Getting and Giving Information, allows much more complete and sophisticated communication than just expression of needs and wants. With these whys, you'll be able to ask and answer questions, express opinions, describe, explain, plan, and tell stories.

Ass	sistiveWare	Core Wor	d Classro	0m				
CORE WORDS FOR SHARING BOOKS								
VERBS	DESCRIBING	QUANTITY	PRE- POSITIONS	WHICH	QUESTIONS	PRO- NOUNS	CONJ.	SEQUENCE
want	not	more	on	this	what	1	and	now
go	all done/ finished	some	in	that	where	it	because	again
like	different	all	ир	these	who	you	or	next
stop	good	very	here	those	when	he	50	before
help	new	too	for	somebody	why	she	then	after
get	long	one	to	something	how	we	until	first
look	nice	any	there		how long	your		last
put	ready	every	with		how many	our		just
open	quick	enough	about			us		late/ later
do	bad	really	together					soon
is	old	much						never
can	other	many						always
have	favorite	most	-					
see	great						4	
turn								
find	happy							
give	afraid							
think	hurt						1 = -	
change	mad							
show	sorry							
listen	tired					-		
pick	excited							
read	silly							
remember	bored							
wait	frustrated							
guess	sad							
decide	lonely							

There will be much fringe vocabulary in books. It is okay to use core words such as it, that, there, as you are pointing the objects in the book, rather than always navigating to the nouns.

The Words table in a Core Word Planner.

Social interaction is the third group of Whys. Here you'll find simple social acts like greeting and thanking, conversation skills, flirting, and negotiating.

## WAYS are the structure of language

The last W, Ways, stands for the way you combine and change words, or the syntax and morphology of a language. There are many ways to combine and modify words. Typically developing children start out using one and two word sentences with little need for grammar. As they grow, they learn the grammar of their language by hearing many examples of sentences. An important part of learning grammar is

the ability to experiment and get feedback - to try making sentences and seeing how other people react, and if the sentences sound right. AAC users need the same models and the same practice opportunities to understand and use grammar.

## Adding the Whys & Ways - the Core Word Planners

Core Word Planners support the Per Activity Words approach. These planners take a single activity, and break down the 3W's that can be used for that activity. Each Core Word Planner starts with a Words table. This table lists core words that are useful for the activity. These words are categorized by word kind, e.g.

verbs, pronouns, questions, etc. They're ordered by frequency of use and the order in which they are acquired by typically developing language learners. Green words are the most frequently used and earliest acquired; Yellow words are next; and Orange words are the most advanced. Words in all groups can be modeled to all students - students don't need to master Green words before they can see Yellow or Orange ones modeled! Feeling words are listed separately - they are Blue to show they should be modeled whenever any situation that involves these feelings comes up.

Next comes the Whys & Ways Table. This table gives suggestions for modelling the

AssistiveWare Core Word	d Classroom				
WHYS & WAYS FOR SHARING BOOKS					
WHYS REASONS TO COMMUNICATE	WAYS TO USE THE TARGET WORDS				
EXP	RESSING NEEDS AND WANTS				
Choice making	that, that one				
Gaining attention	look!				
Requesting	want, want more, want that, want (something) differen want do it, I want read more, I want to read that can I do it? can I see it?				
Refusing, rejecting, protesting	not that, something different, stop, stop reading! finished / all done, finished / all done reading				
GETTI	NG AND GIVING INFORMATION				
Simple commenting	look, see it, good, bad, look at that like, like that, like it, I like that				
Express feelings	When relevant, discuss character feelings during reading of a book. Also can discuss how reading the book made you feel, e.g. scared, excited, bored.				
Asking for information	what? what that? what is that? what next? what now? what did he/she/they do? what happened? what do you think will happen? what do you think he/she/they will do? where? where it? where is it? who? who that? who is that? who did it? why? why do it? why did he do that? why did that happen? how? how do you know? how did he do that? guess, can you guess what happens next? is something there? is somebody there?				
Discuss (comments/directions)	get, get it, get book, get more, get (something) different, get it now, get it later read, read more, read (something) different, read again, ready to read, read it quickly, finished reading, read together, read with, read to turn, turn it, turn quickly, turn now				
Give opinions	vorite, what favorite? (e.g. favorited page, favorite aracter, favorite picture, favorite part of the story) e, I like, I like it, I like it when, I like but not, I like but not, I like but not, I like ton't like, I didn't like it when, I n't like it because, I				
Give descriptions	old book, new book, long story, quick story nice, great, good, bad it about				

The Whys & Ways table in a Core Word Planner.





A Core Word Modelling Guide.

The Whys & Ways table for a Core Word of the Week Planner.

core words to your students. These ways are split into the different reasons to communicate, or Whys, which appear in the left column. In the right column are the Ways - single words, phrases, and sentences that you can model for each Why. The phrases and sentences are in order of increasing length and complexity, to give you ideas you can use with students of different language skill levels.

Last, each Core Word Planner includes extension ideas and literacy activities to extend learning around your central theme.

## Differentiate Your Modelling - the Core Word Modelling Guides

Each of the Core Word Planners has a matching one page Core Word Modelling Guide. The Modelling Guide breaks the Core Word Planner's Whys & Ways table up into three different language levels - green, yellow, and orange. "Green" students are those who are just starting out.

Maybe they are not yet using any words on the AAC system, or perhaps have started pointing to one word at a time. For these students, you might model single words, with some 2-3 word sentences. "Yellow" students are those who are already producing 1-2 word combinations on their AAC system. For these students, modelling 3-6 word sentences and simple inflections would be appropriate. "Orange" students are those who are already producing 3-6 word combinations on their AAC system. For these more advanced students, model longer sentences, joining ideas and more inflections.

For each color level in the Modelling Guide, the words and ways have been organized into 3 main communication function categories:

- Needs & Wants requesting, rejecting, gaining attention
- Giving/Getting Information questioning, commenting, describing, planning, explaining

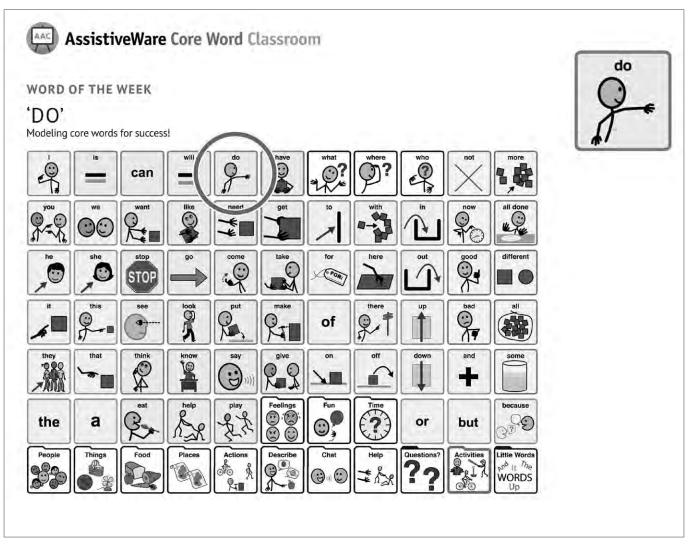
Social Interaction - politeness, social routines, teasing, joking

The Modelling Guide can be used as a cheat sheet during the actual activity, to help teaching staff remember to model a wide variety of whys and ways, as well as to differentiate their modelling for the different learners in the classroom.

## **Core Word of the Week Planners and Displays**

Core Word of the Week Planner is a version of the Core Word Planner for one or two core words of the week. These planners have a Whys & Ways table that give examples for modelling the word(s) of the week, as well as extension ideas and literacy activities.

The Core Word of the Week Display gives you something to hang up around the classroom to show the words you're working on, how to find them in your AAC system, and examples of how to use them for different Whys and Ways.

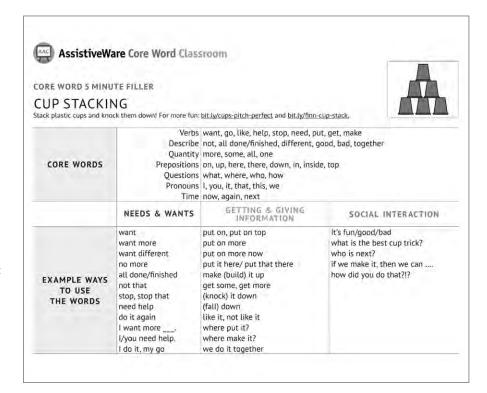


Above: A Word of the Week Display. Below: A 5 Minute Filler for stacking cups.

#### **Five Minute Fillers**

Last but not least, the 5 Minute Fillers are a way to take advantage of spare moments in the day to do a quick, fun activity and get some core word modelling in. There are 5 minute fillers for bubbles, Mr. Potato Head, watching YouTube, cup stacking, dress-up, memory games, and much more. Each one page 5 Minute Filler gives you Words, Whys, and Ways to model during a fun activity.

We hope you enjoy the AssistiveWare Core Word Classroom as much as we enjoyed creating it! Like all good things in life, it's a work in progress - so let us know what you think at coreword@assistiveware.com so we can keep making it better!



## What I feel about being AAC dependent

#### **MADDY NORMAN**

Email: madeleine.norman@btinternet.com



I have severe cerbral palsy. I have been using AAC of one kind or another since I was 5. Here is some of the issues that I feel are a problem for AAC device users in the 21st century.

#### **Public perception**

Most people never come across people who use aac. So they are either embarrass or frightened to approach me direct often asking my carers or dad questions. However since I had the Tobii which has a English sounding voice people are more willing to talk to me directly.

#### In practical situations

These can be something as simple as going to the loo or more complex ones like bus drivers presuming it's a health and safety risk. Although these are rare it can be annoying. However I have not come across any issues with private transport like some communication matters members.

#### Autonomy vs robot syndrome

It is important to give this aac user time to participate and articulate conversations, don't read our mind or second guess what we want to say, hence the robot syndrome. However some cases this maybe personal preference - again always ask.

#### Conclusion

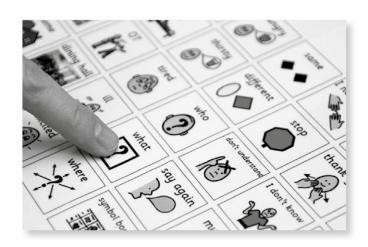
Until AAC users are generally more widely recognised these problems will continue. But some progress is being made through new devices and more awareness.



## Communication **Matters**

more than just talking

# Voice Identity in AAC Study Day



Banking your voice, messages & language
Leaving a communication legacy

## Thursday 2 November 2017

Shropshire Conference Centre, Mytton Oak Road, Shrewsbury, SY3 8XQ





## 2017 FREE Roadshows

Get the latest from AAC suppliers! BOOK online now

- Cardiff 22nd November
   Holiday Inn, Cardiff City Centre
- Ashford 29th November
   Ashford International Q Hotel



More in 2018 to be announced!



To find out more and book at http://www.communicationmatters.org.uk/page/road-shows-diary Email: admin@communicationmatters.org.uk



The CM Office staff and trustees are beginning to plan our 2018 Roadshows. From January 2018, we will be introducing a payment of £10 for a place at a Roadshow, this is due to increased costs and an increasingly high dropout rate on places booked and confirmed on the system.

There will be a reduced charge of £5 for those who are members of Communication Matters, PwuAAC and their family members will also be charged £5, one accompanying personal support assistant will be eligible for a free place.

This fee will be non-refundable but will be transferrable. Attendees will be able to register and pay for Roadshow places on the Communication Matters website. It will be possible to make these payments online.

The Board of Trustees thank everyone for continuing to support Communication Matters by attending Roadshows across the UK.

# The Unspoken Voices Project: gathering perspectives from people who use alternative and augmentative communication (AAC)

#### **KATHERINE BROOMFIELD**

Gloucestershire Care Services NHS Trust & Sheffield Hallam University Email: Katherine.broomfield@nhs.net @kathbroomfield unspokenvoicesproject.wordpress.com

The Unspoken Voices Project is a PhD study that seeks to develop a greater understanding about why people do and do not use communication aids and how they view success with using them. The following article provides some background to the project, the research plan for study and its potential impact on the experience of people who rely on communication aids.

#### **Background to the Project**

I am a speech and language therapist and have led a local AAC service in Gloucestershire (part of the adult speech and language therapy service) since 2012. Our service assesses and provides basic communication aids such as low-tech, paper-based systems and direct-access, high-tech devices. As a team, we have worked hard to establish a good quality local service. We developed processes and systems that support the speech and language therapy team to embed AAC as part of their therapy tool box. We also benefit from funding that enables us to have a library of equipment for demonstration and loan.

As the clinical lead for this service, I was particularly interested in how to reinforce the quality of the assessment and support that we provide to people in need

of communication aids. I also wanted to understand how to improve people's experience of using them. In 2014, I secured funding from Health Education England (South West), to carry out a clinical academic internship at the Bristol Speech and Language Therapy Research Unit, under the supervision of Professor Karen Sage. I used the internship to find research about methods to best support the implementation of communication aids. I also carried out interviews with people who used the SL40 Lightwriter to understand more about their experience of using a communication aid and what supported, or prevented them from communicating. A poster of the findings from these interviews was presented at the Communication Matters conference in 2016.

#### The literature to date

My search uncovered limited information about why some people use communication aids effectively and others do not; nor about what 'successful communication' means to people who rely on communication aids and what they feel best supports them to achieve this. The interviewees who used the SL40 Lightwriter reported very different views on successful communication aid use. They also provided some interesting insights into how to

improve the support that NHS services provide when issuing AAC equipment. I was able to interview 6 people for this project, all of whom were adults who had received support from one AAC service. The results of the literature review and the interviews generated further questions: Did the experiences of the Lightwriter users resonate with other people who rely on different communication aids? What support do other communication aids users receive? What helps or hinders people engagement with communication aids? How can we improve how we gather feedback from AAC service users?

I therefore applied to the National Institute for Health Research (NIHR) for funding to carry out further research to help provide answers to some of these questions. The clinical doctoral research fellowship programme funds NHS allied health professionals, nurses and midwives to engage in a PhD training programme in order to carry out research that will be of benefit to NHS services and patients. I was awarded the grant in 2016 and started my PhD in April this year. I am registered part-time for my PhD at Sheffield Hallam University and have support from the Barnsley Assistive Technology team and Gloucestershire adult speech and language therapy team.

## The 'unspoken voices' project plan

This project aims to develop a patientreported outcome measure (PROM) for use by NHS services, to gather the perspectives of people who use communication aids about the equipment and the support they receive. to achieve this, the study has three stages. Firstly, I will carry out a more extensive and specific review of the existing literature to make sure we know what is already known about important outcomes for communication aid users and what supports people to achieve these. The review will look particularly to see if there are already perspectives from the people who rely on communication aids. During stage two of the project, I will interview young people and adults who find themselves at different points across the AAC pathways - from assessment and provision of equipment to the use of communication aids in people's homes, schools and communities. I will approach existing AAC services to recruit participants to be involved in the interviews. The final stage of the project will establish areas of consensus about what outcomes are important for users of AAC equipment and services and will engage the wider community of people who use communication aids. I will approach the Communication Matters 'RIN' – 'research involvement network' for participants to be involved with this stage of the study.

The unspoken voices project aims to answer some of the questions that I have uncovered during my quest for information to improve a clinical service. It also provides space and time to really listen to people whose voices are often unspoken or unheard. I feel privileged to have been granted the opportunity to engage with people who use communication aids and their friends, families and carers throughout this project in order to find out more about their experiences, hopes, needs and expectations. I have recruited a project advisory group made up of users of AAC, who will provide an expert view and critical feedback throughout the project so as to ensure it remains focused on people who use communication aids. I also want to engage with the wider community of people with complex communication aids through organisations such as Communication Matters and via social media. I will be blogging (unspokenvoicesproject.wordpress.com) and tweeting (@kathbroomfield) project updates but am also happy to send out information in good-old-fashioned email, or even post. I welcome any suggestions and feedback on how you think I can best achieve this, or indeed on anything that you have read in this article that interests you.

Katherine Broomfield is funded by the National Institute for Health Research Clinical Doctoral Research Fellowship. The National Institute for Health Research (NIHR): improving the health and wealth of the nation through research. Established by the Department of Health, the NIHR:

- funds high quality research to improve health
- · trains and supports health researchers
- provides world-class research facilities
- works with the life sciences industry and charities to benefit all
- involves patients and the public at every step



Jamie Munro was the Information Director at Inclusive Technology. He presented at many CM Roadshows and Conferences and was a leading figure in the field of Assistive Technology; his work had an impact on the lives of many.

After his sudden and unexpected death in December 2016, several of the CM Supplier members suggested we should pay tribute to Jamie's commitment to the AAC world. And so, a man who was inspirational to many people will be remembered each year at the Communication Matters Conference through the Jamie Munro Inspiration Award.

## Jamie Munro Inspiration Award

#### Who can make a nomination?

Anyone who uses AAC or who works in the field of AAC.

#### Who can you nominate?

Nominees will be someone who is inspirational in the world of AAC. This could be an AAC user, an inventor, therapist, designer, teacher, supplier..... anyone who is inspirational to you.

#### How do you nominate?

Submissions, ideally by video clip (maximum three minutes), telling us how and why your nominee has inspired you. However, if it is difficult for you to produce a video clip, an audio clip with some text and photos would also be accepted.

#### Where do you send your nomination?

To the CM Office (admin@communicationmatters.org.uk)

#### When do you send your nomination?

From now until Thursday 31st August 2017. We look forward to receiving your nominations.

The winner will be announced on Sunday 10th September at the Communication Matters Conference and the award will be presented by Martin Littler, Chairman and CEO, Inclusive Technology.

## **Voice Output Communication Aid groups for adults with learning disabilities**

#### **GRACE LAW AND CATRIN WILLIAMS**

North West Boroughs Healthcare NHS Foundation Trust Email: catrin.williams@nwbh.nhs.uk

# "Communication is recognised as an essential human need and, therefore, as a basic human right."

Thurman 2009

Grace and Catrin are Speech and Language Therapists within Halton Community Learning Disabilities Team. The team comprises of Occupational Therapy, Physiotherapy, Clinical Psychology, Speech and Language Therapy and Psychiatry who all work collaboratively around the clients they support.

#### **VOCA** group

Over the last few years the Speech and Language Therapists within the team identified the need for an innovative approach to AAC intervention for the clients they support. Previously the support to develop AAC use had focused on 1:1 direct therapy with the client and carers. However, this resulted in poor generalisation of learnt skills and carers often placed responsibility on the client for success of the aid. We felt a new approach was required to increase the carer's understanding of their role, develop conversational skills and promote social inclusion. From here we developed a Voice Output Communication Aid Group which ran in 2014 and 2015.

#### Aims

- To raise awareness of the role of the communication partner in supporting a client with a VOCA.
- 2. To support staff in developing skills to becoming an effective communication partner.
- 3. For clients to develop their skills and confidence in using their aid and begin to generalise those skills.
- 4. A chance to interact with other VOCA users in order to increase social acceptance.

Prior to the group sessions, carers were invited to a 'communication partner' training session. This outlined the rationale for VOCA's and how they impact the success of these. Initially the group ran for 6 weeks, with a 2 hour session each week. The clients engaged in drilling games, discussed their interests and were able to participate in conversation with their peers. We had originally hoped to demonstrate to carers more ways of using the aids in real life settings. However, it was found that the clients required further support to develop their skills in using their aids. When we reflected on this, we decided to offer a second group (known as level 2) for these participants with the focus on community engagement. Within level 2, the clients were supported to use their skills in the community. We visited supermarkets, pubs and cafes where the clients were able to build confidence in communicating with new people. We saw our clients gain confidence in being able to complete tasks independently, such as ordering a drink, that others take for granted. There was also opportunity to explore how VOCA's can be used within everyday activities such as baking and crafts. This had the joint benefit of developing the client's skills but also modelling to carers that the aid does not have to be removed when things get messy.

Following the groups, outcome measures indicated not only an improvement in our clients' abilities to use their aids functionally but also carers felt more confident as communication partners.

#### Case example

Barry was referred to the service for support around his expressive communication. He came to us having historically used a GoTalk 25+, which he used when attending level one of the VOCA group. During these sessions it was identified that Barry could potentially use a more complex system. Barry also had the opportunity within the group to see his peers using tablet devices and communicated to the therapists that he would like a tablet device. Between level one and level two, Barry was assessed by a speech and language therapist and funding was obtained via ACE Centre North. Barry received an iPad with Grid 2, which was introduced shortly before level two of the VOCA group. Barry engaged well in level two and his ability and confidence with the aid significantly improved. Following the group, staff reported an increase in aggression and Barry becoming withdrawn. The underlying issue was identified because he was enabled to express his thoughts and opinions using his VOCA. Barry is now settled, happy and a confident AAC user.

#### Summary

Over recent years VOCA's have become more accessible due to the introduction and affordability of tablet devices. This has led to these devices having multiple uses and no longer functioning as dedicated communication aids. The challenge now is to think of ways to encourage successful use of these devices within an ever growing population of users.

Catrin and Grace presented at CM2016 to outline the development and structure of the VOCA group. We found the day overall to be a useful source of professional development with many interesting topics up for discussion. Our current focus

is on developing a resource pack to support other clinicians to run similar groups which we hope to have available later this year.

#### References

Thurman S. (2009) *Communication is a basic human right*. BILD, Kidderminster.

## CALL FOR NOMINATIONS 2017....

#### The Alan Martin Award

Presented annually at Communication Matters Conference for significant contribution to the Arts by someone who uses AAC

#### The Background to the Award

This award, first presented in 2013, is in memory of a remarkable man who was amongst other things a dancer, a musician and comedian who worked for the inclusion for all people within the arts whatever their disability. For 16 years Martin attended and presented at CM conference. Sadly he passed away in December 2012.

Alan often told the young people who he worked with:

"Never let anybody tell you that you can't do something because of a disability."

#### So far the award has been presented to poetry, drama and photography.

**Barry Smith** received the award in 2013 for his poetry. The breadth of his work gives a real insight into the life and experiences of people who use AAC and have physical as well as communication challenges in their life. There is an interview with Barry in the CM Journal Vol 29 (2) 2015 and his poetry is on the CM website.

**Kate Caryer** received the award in 2014. Kate is a writer, ex Channel 4 continuity person and actor. The Unspoken Project CIC brought 'Speechless' to the stage at conference 2016. A summary of a video of the premier will shortly be available as an educational resource on the CM website.

**Sam Knapp** received the award in 2015 for his creative photography. Sam has a website where you can buy his work. He does photo booths, landscapes and street photography. Twitter @Samknapp http://www.samknapp.photography/

**Jemima Hughes** won the award in 2016 for her work with animations over several years. Her work can be seen on YouTube at http://randomacts.channel4.com/post/149327322436/first-acts-jemima-hughes-imagination-a https://www.youtube.com/watch?v=kYHm1ZviwjM, https://www.youtube.com/watch?v=X8TDk\_QjLqY

### What Art form will the award go to in 2017?

Please send your nominations to the office by post or email at manager@communicationmatters. org.uk with a short explanation of the reason why you think this person would be an ideal recipient of the Alan Martin Award. Please attach an example of their work if possible. The award will be judged by the Trustees (& hopefully 1Voice Trustees as happened last year). A shortlist of 3 will be drawn up and the final decision will be announced at the conference on Tuesday afternoon plenary and awarded by the last year's winner.

#### Rules:

The person must be 18 or over. The person may be amateur, be in arts education or gain income from their Art. Any form of creative output can be considered. The person should not have received the Alan Martin Award before (in the last 5 years).

Closing date September 1st.

## **Not the Royal Highland Show!**

#### **JANET SCOTT**

Written on behalf of the Augmentative Communication in Practice: Scotland Email: enquiries@acipscotland.org.uk

On Saturday 24th June Augmentative Communication in Practice: Scotland hosted an alternative to the Royal Highland Show, which was taking place on the same day. There were no Highland cows, ponies or sheep on show - instead there was a range of different accessible technologies for making music, creating art, playing games, having fun with photos and for communication. Six people came along with their family member or carers to the Technology Discovery Day and Consultation Event in Edinburgh for adults who use AAC. Although the numbers were smaller than we'd expected, the people who were there were able to discover lots of new and exciting technology and to talk to other people who use AAC, their carers and professionals.



There was plenty of time just to chat.



The day was sponsored by a generous donation to Communication Matters made by the family of Cecilia Mulgrew, the parent of a young man from Scotland who uses AAC. Cecilia believed passionately in providing positive opportunities for young people with communication support needs. She was an artist, so we were glad to be able to offer a range of different "art" activities in the morning.



In the afternoon we were joined by Julie Carr and Jean Alexander from the Assisted Communications Team at the Scottish Government. This part of the day was an opportunity to share information about new developments and to get feedback and views from everyone.

Debbie Jans provided a brief update about the new Scottish legislation for AAC provision and support.

Ruth McMorran (above right) talked about the Communication Access project and the communication access symbol.







Although the first phase of the symbol consultation is now over, we were given an opportunity to vote on our symbol preferences (left). We used stick on stars to vote. No-one voted for this symbol:





## National AAC Conference

10th - 12th September 2017 at University of Leeds



Don't miss out on the National AAC Conference which brings together people who use AAC, families, professionals, researchers and AAC suppliers

New for 2017: members and non-members rates!

#### Conference Programme

A busy two and a half days covering a wide range of topics: practical solutions, personal experiences, latest research, plus clinical and technological developments in the field of AAC.

- plenary sessions
- · full seminar timetable
- case studies
- workshops
- poster session
- exhibition
- social events
- · networking

#### Conference Registration

- Conference opening & AGM on Sunday 10th September
- Registered delegates have full access to all conference events plus plenty of networking opportunites
- Registration includes refreshments and lunch.
   Residential places include evening meals plus breakfast

The conference is supported by our organisational members – meet them at the exhibition and get hands-on experience with the latest technology.

Find out more at:

www.communicationmatters.org.uk/page/conference

SUBSIDISED places are available for people who use AAC, their PAs & families. There is a fund for first-time attendees, do apply early to be considered

- Plenary, seminar rooms and exhibition hall are close together in pedestrianised campus
- · All areas are fully wheelchair accessible
- High standard of residential accommodation with accessible rooms

Communication Matters is the UK wide charity which works for and brings together everybody who has an interest in AAC (Augmentative and Alternative Communication)



Registration opens January 2017 - for more information visit: www.communicationmatters.org.uk



Janet Scott and Bernie Brophy-Arnott adapted the Talking Mats AAC Service Evaluation script and symbols<sup>1</sup> for a group discussion about what people felt about the AAC service they've received to date. Participants were also asked for their hopes and vision for future AAC services and what they thought "support for AAC" should include.

The questions asked were:

- How do you feel about the assessment process?
- How do you feel about how long things took?
- How do you feel about the funding for your AAC?
- How often do you see members of the AAC team – and ongoing support?
- How do you feel about what happens when your equipment breaks down?
- How do you feel about the process when you need a replacement machine?
- How do you feel about being able to access services if your needs change and you need to be reassessed?
- Did anyone teach you how to use your AAC? – How do you feel about it?
- Did your family and friends get any training on your AAC?



People came from different parts of Scotland, and obviously their experiences were different. Most people were happy with the assessment process and with the funding process for their communication aid. People said that the assessment had been "exciting" because they had been given a voice for the first time. For both these questions, one person indicated they were unsure. Everybody indicated that they felt that there was little problem about being able to access services if they needed a reassessment. However the time taken for an assessment/reassessment was an issue for some people.

Feelings about support, including training in the use of the communication aid, were more variable and more polarised – with some people indicating that they felt that they (and their family and friends) had received good support and training, while others said they'd received "zero". Again there were different experiences relating to the process of getting a replacement communication aid. Everybody had something negative to say about how they felt when their communication aid breaks down: "frustrating", "sad". Communication aids breaking down, and poor battery life were common themes in discussion.





We used poster boards to create a group Talking Mat.





When asked for their vision for AAC people made really powerful statements:

To be treated with dignity and respect.

To be heard. To be listened to.

For my opinion to matter.

What does "support" mean to you?

- More teaching
- · More awareness
- · More training
- Consistency when transitioning from child to adult services
- Assessment
- · Training more in depth and ongoing
- More awareness amongst people who don't use AAC
- More options for using aids in the community and in life
- More training for doctors and nurses, and people like that

Everybody had a chance to speak during this consultation, and everybody did speak. Julie and Jean will take this information back to their work in the Scottish Government.

All day Joanna Courtney had been asking people what they thought of the voice in their communication aid, and whether or not they would welcome a more



personalised voice e.g. one with a regional accent. Joanna reported back the findings of this survey (left). Everybody felt that it was important to be told about the different voices and accents available at the time when they were being assessed for a communication aid. Some people were aware that synthesised voices were available, but they wanted to stick with the voice they'd used for several years, others were unaware that there might be a choice. Some people did not have much choice of a voice because of the AAC system they were using.

At the end of the afternoon Gillian McNeill presented Sandra Miller with a symbolised certificate to thank her for all her work in AAC (below). We all wished Sandra a happy retirement.

#### **Footnote**

1 Talking Mats (2015) Augmentative and Alternative Communication (AAC) Service Evaluation (Available at: http://www.talkingmats.com/wp-content/uploads/2013/09/AAC-service-Evaluation-script-and-symbols.pdf)





## Communication **Matters**

more than just talking

## History of Communication Matters Book

Order your copy from the office - FREE - (only pay p&p)

## CM Lapel Badges



Order yours from the office - £2 each -

## 'Focus On...' AAC leaflets



Order yours from the office - FREE -(only pay p&p)

The leaflets in the 'Focus On...' series are on topics related to AAC written in a clear style.

Available in printed form and as PDF files on our website: www.communicationmatters.org. uk/page/focus-on-leaflets

# Other Ways of Speaking booklets



Order yours from the office - FREE -(only pay p&p)

Information about children & young people who use a variety of different ways to communicate & how you can support them.

Available in printed form and as a download from our website: www.communicationmatters.org. uk/publications/other-ways-of-speaking

Email: admin@communicationmatters.org.uk



Find out more at www.communicationmatters.org.uk





**ISAAC** is excited to announce the 18<sup>th</sup> Biennial Conference of the International Society for Augmentative and Alternative Communication, **ISAAC 2018**, will be held at the Gold Coast Convention and Exhibition Centre in **Gold Coast, Queensland, Australia,** on **July 21-26, 2018.** 

**JOIN US** for AAC events and perspectives, the latest in research and clinical innovations, workshops, seminars, exhibits, social events, entertainment — everything you have come to expect from an ISAAC conference, and more!

Mark your calendar today, and save the date for ISAAC 2018 in Australia!

For more information, visit us at **www.isaac-online.org** and follow #ISAAC2018 on Twitter.

Supporting the needs of people living with communication

difficulties across the UK.



INTRODUCING THE ALL NEW MOBI 3 WITH:

Ameg

A fully accessible AAC device for maintaining contact with loved ones, communicating and for controlling the home.

- CONTACT
- COMMUNICATION
- CONTROL



Try before you buy



Available with a capacitive or resistive screen

Mobi 3 with Tobii Eye Tracker



### **TRY AMEGO:** email sales@techcess.co.uk

### Our customers choose us because we provide...

- FREE consultations on most types of talking technology (AAC) from keyboard text to speech, right through to more complex eye gaze based devices
- FREE loans try before you buy
- FREE unlimited telephone support
- Speedy repairs completed in our UK workshop with loan devices available where appropriate

#### Join us at the CM **National Conference**



10-12 SEPT 2017, LEEDS

#### MEET US AT OUR SEMINAR:

INTRODUCING The new MindExpress vocabulary package for adult literate users.

#### VISIT OUR EXHIBITION STAND:

As usual, the team at Techcess will be available on their stand to say 'Hi', answer questions and demonstrate the latest AAC products including the all new Mobi 3.

Come and visit us to find out how we make a difference to the lives of our customers.

## tobii dynavox

The new range of AAC and Access from Tobii Dynavox

# When great minds meet, special things happen.







I-110 From £3199\*



EyeMobile Plus From £2445\*



I-Series+ From £5690\*



PCEye Mini From £849\*



PCEye Plus
From £1189\*



EyeR £199\*



Snap + Core First £150\*



Pathways for Core First £FREE



Communicator 5



Gaze Viewer

## Boardmaker<sup>®</sup>

Want to hear more about our new exciting products? Please visit tobiidynavox.co.uk or contact us at 0114 4810011 and sales.uk@tobiidynavox.com