

# COMMUNICATION *MATTERS*

**NOVEMBER 2008** Volume 22 Number 3

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)



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COMMUNICATION MATTERS JOURNAL

VOLUME 22 NUMBER 3  
NOVEMBER 2008

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## COMMUNICATION MATTERS JOURNAL ISSN 0969-9554

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Registered Charity No. 327500  
Company Registered in England & Wales No. 01965474

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### Copy Submission

Preferred text format: Microsoft Word  
Preferred graphics/photo formats: JPEG, TIFF  
Copy deadline: 20 February 2009 (Vol 23 No 1)

The Communication Matters Journal is the official publication of Communication Matters / ISAAC (UK), and is an ISAAC affiliated publication.

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# Give Me A Choice!

## In praise of low-tech AAC

### CATHERINE HARRIS

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### INTRODUCTION

The great thing about low-tech AAC is that it does not break down! It may get lost but can usually be replaced relatively easily. People with progressive neurological conditions may use a Voice Output Communication Aid (VOCA) as their primary method of communicating but a preference for using low-tech charts in some settings may be underestimated. In addition it is always good practice to have a low tech alternative for situations when it is difficult to use the aid or when it is not working. There are different text-based low-tech systems which can be used with auditory scanning or eye-pointing. It is important to recognise that people have different preferences as to the method which suits them best and it may be helpful to introduce a choice of techniques.

### METHOD

It was decided to investigate whether any one method was preferred. In a recent multi-disciplinary workshop in Gloucestershire discussing communication difficulties in MND, three different methods were introduced, explained and demonstrated. Then the 30 participants were asked to rate the methods for themselves in terms of ease of use, efficiency and speed.

The three methods are outlined and illustrated below.

### How to use an Auditory Scan Alphabet Chart

1. Agree how non-speaker will indicate the target letter (head nod, blink, thumbs up, etc).
2. SPEAKER reads down the numbers 1-5 and watches for response to identify the row the letter is in (Figure 1).
3. SPEAKER reads along that row of letters until target letter is identified.
4. Write letter down!

This alphabet layout groups the vowels down the left-hand side of the chart for easy selection.

1	A	B	C	D	wrong	space
2	E	F	G	H	YES	NO
3	I	J	K	L	M	N
4	O	P	Q	R	S	T
5	U	V	W	X	Y	Z

Figure 1 An Alphabet Chart for Auditory Scanning

### How to use an Eye-Communication Frame

1. Position the frame between you (Figure 2).
2. Eye-point to indicate which corner the letter is in.
3. SPEAKER confirms selection: this corner.
4. Eye-point to indicate colour of the target letter.
5. SPEAKER confirms selections: this corner, colour —
6. Write letter down!

The Eye Communication Boards used were purchased from Frenchay Communication Aid Centre in Bristol.

### How to use a 6-Grid Alphabet Chart for eye-pointing

1. The chart (Figure 3) is used with a 2 hit system of eye-pointing. The 'reverse' chart can be used by either conversation partner according to preference.
2. The eye-pointing system user first identifies which box the letter is in and then which letter it is within that grid. Eye pointing targets: top left, top middle, top right, bottom left, bottom middle, bottom right.



Figure 2 Using an Eye-Communication Frame

- For example, if Z is the target letter then indicate middle bottom then middle top.
- The conversation partner should look at both eye-pointing positions before confirming the target letter.
- Have a pad and paper ready so you can write down more complicated messages!

This system was demonstrated by Kathrin Lemler, the Keynote speaker at the Communication Matters CM2007 National

the three methods related to ease of use, reflecting individual preference. The Eye Communication Board was rated as most efficient with least errors being made and the 6-grid alphabet chart was rated best for speed. There was a common feeling that all methods needed to be introduced clearly and time allowed for practice and familiarisation.

#### RESEARCH TASK

A research task is to compare the three different eye-pointing systems (Figure 4).

Symposium. The text layout was the same as she used on her VOCA which was accessed by eye-pointing. When she used the low-tech method with her mother they did not use the prompt chart as the system was so familiar to them both.

The feedback from the workshop reported almost equal numbers for each of

Use these three methods to spell out a word of at least 8 letters or a short phrase.

For each method, record:

- the word or phrase;
- how long it took to spell it out;
- using a rating scale of 1-5, where 1 is easy and 5 is difficult, how easy/difficult was it to use the system.

After trying all three systems, indicate your preferred method by putting a tick alongside the appropriate box.

#### CONCLUSION

It has become apparent that it is difficult to predict the preference of an individual in terms of low-tech AAC methods and that, where possible, choice should be considered. It is common practice to recognise personal choice when investigating high-tech AAC solutions, so maybe it should not come as a surprise to recognise personal preference related to low-tech methods. \*

Catherine Harris,  
Speech & Language Therapist

For information on the Eye Communication Board, visit [www.cacfrenchay.nhs.uk](http://www.cacfrenchay.nhs.uk)

YES		SPACE						NO		
V	W	X	Z	3	4	8	6	0		
S	T	U	Y	Z	1	5	6	7		
D	E	F	J	K	L	P	Q	R		
A	B	C	G	H	I	M	N	O		

A	B	C	G	H	I	M	N	O
D	E	F	J	K	L	P	Q	R
S	T	U	Y	Z	1	5	6	7
V	W	X	2	3	4	8	9	0

YES		SPACE						NO	
-----	--	-------	--	--	--	--	--	----	--

Figure 3 A 6-Grid Alphabet Chart

RESEARCH TASK	
A COMPARISON OF 3 DIFFERENT EYE-POINTING SYSTEMS	
Use these 3 methods to spell out a word of at least 8 letters or a short phrase. For each method record:	
<ol style="list-style-type: none"> <li>the word or phrase</li> <li>how long it took to spell it out</li> <li>using a rating scale of 1-5, where 1 is easy and 5 is difficult, how easy/difficult was it to use the system.</li> </ol>	
After trying all three systems, please indicate your preferred method by putting a tick alongside the appropriate box.	
<div style="border: 1px solid black; padding: 5px; margin-bottom: 10px;"> <b>6 Grid Alphabet Chart</b>            1. 2. 3.         </div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 10px;"> <b>Auditory Scan Alphabet Chart</b>            1. 2. 3.         </div> <div style="border: 1px solid black; padding: 5px;"> <b>Eye Communication Board</b>            1. 2. 3.         </div>	

Figure 4 Research Task Sheet



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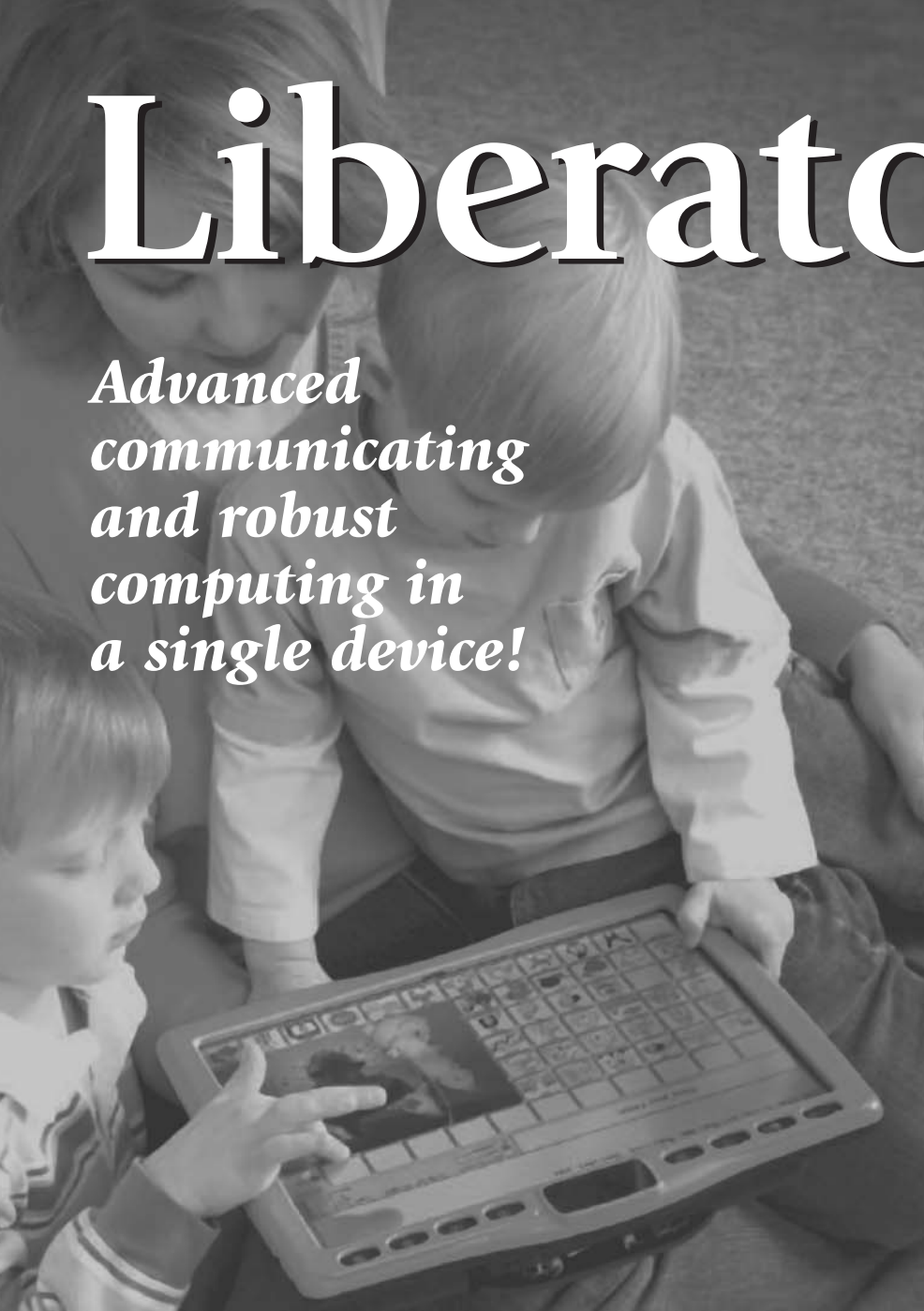
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# Kingsley Communication

## Enabling all pupils to communicate

**KEVIN LATHAM**

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### INTRODUCTION

During the Autumn term 2003, Kingsley School restructured its classes to integrate pupils with profound and multiple learning difficulties (PMLD) who had up until then been taught in a specialist class. The school undertook a series of training sessions devoted to 'optimal learning' and learning styles which facilitated fully differentiated lessons – giving pupils the opportunity to access lessons and learn through their favoured style: visual, auditory, kinaesthetic, musical, etc. Throughout the following months, analysis of pupil involvement using the Primary Effective Early Learning (PEEL) programme (Centre for Research in Early Childhood, University College of Worcester, 1995) was

undertaken to look at the levels of involvement and types of interactions of pupils with PMLD within the mixed ability groups (Figure 1). Levels of involvement were noticeably lower within the PMLD population; interactions were predominantly adult initiated and very few were with other pupils.

The staff at Kingsley were acutely aware of this issue and after discussions it was highlighted that a major factor was communication. A voluntary group of staff from across the school decided to meet to discuss the provision for Objects of Reference. However, the remit of the group changed before the first meeting to look at the provision for communication for *all* pupils in the school, whatever

their formal mode of communication (speech, sign, symbol, photographs) including objects of reference. The issue of informal modes of communication (vocalisations, gestures, etc) were to be picked up through the use of communication passports being introduced by the speech and language therapists.

The Communication Group – including teachers, class staff and a speech and language therapy assistant – set a clear aim for their work: to put in place systems enabling all pupils to communicate in their preferred mode with all people in the school, pupils and staff, and wherever they are in the school. Initially this seemed a simple prospect but a few minutes of discussion revealed the enormity of the task. The group would have to take into account pupils who use speech, signing, symbols, photographs and objects of reference; and put in place a system to enable pupils with complex communication difficulties to talk to each other in the classroom, on the playground or in the dining hall.

Before the Communication Group could start to discuss any systems, the issue of standardising communication had to be resolved. If communication is not standardised then it cannot be a formal mode of communication and the number of people a pupil can communicate with is extremely limited. Speech is a standardised mode of communication as the vast majority of pupils in our schools use English, and signing has various formal languages. However, when objects of reference are mentioned it is a different matter entirely.

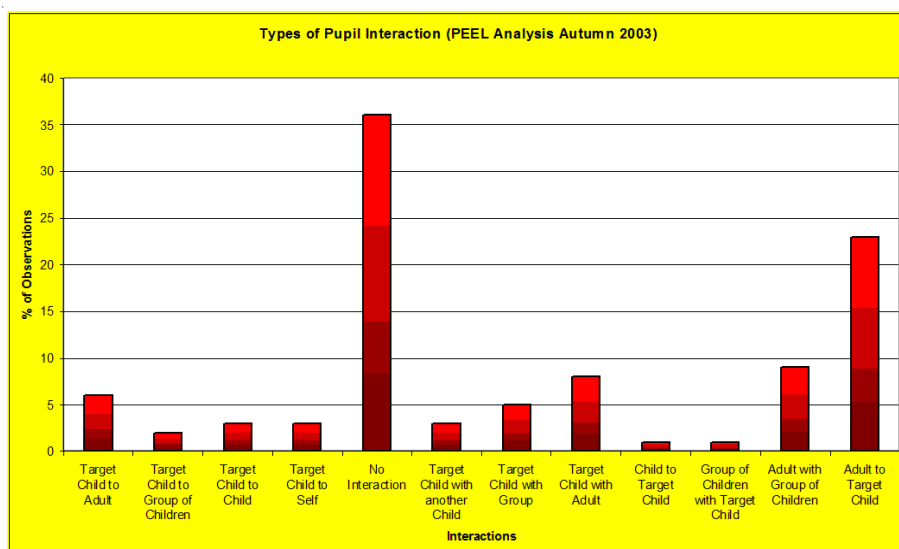


Figure 1 Types of Pupil Interaction (PEEL Analysis) – Autumn 2003



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## OBJECTS OF REFERENCE (OR)

What are Objects of Reference? OR are objects that have special meanings assigned to them – they *stand for something* in much the same way as words do, whether spoken, signed or written. OR need to be separated in definition from objects as the OR need not have any features in common with what they represent, but derive their meaning through association. For example, a small toy bus is an object and may be used to represent going out on the school bus, but it is not an object of reference. The OR may be derived from the pupil's experience of the bus such as the seat belt or seat material. The pupil derives their own meaning. Imagine a pupil who is visually impaired and a wheelchair user, they may never touch or see the whole mini bus. How can they derive meaning from a toy bus?

Within special education, OR have predominantly been used to inform pupils of their daily timetable and to prompt the transition between activities, the OR being presented to the pupil. However this does not constitute a communication system, as it is all one-way. For OR to be used as a communication system they should be used in two-way situations, enabling pupils to interact with others (family members, staff and peers) to 'chat', request activities and inform others of their needs.

The Communication Group needed to consider OR as part of the communication continuum and how they would be used by our pupils, both as a communication system in themselves but also as a stepping stone to what has been considered as more formal levels of expressive communication (Figure 2). Historically, objects of reference have not been seen as a formal mode of communication but following the publications *Planning, teaching and assessing the curriculum for pupils with*

*learning difficulties* (QCA 2001) and *The National Literacy Strategy: Framework for teaching* (DfES 2001) OR have been referred to as tools to be used for reading and writing. If a pupil places an object, they are then making an intentional mark and **writing** in their preferred medium, which can then be read back. If the OR are presented to the pupil, the pupil is **reading** through their preferred medium, gaining information using their preferred medium. In this manner objects of reference are being used as common symbols shared among a wider community and therefore constitute a formal mode of communication (Rowland & Schweigert 1998). OR occupy a distinct place in the wider field of formal communication, offering a means of formal self-expression in the tactual domain.

"All children ... need to be able to learn and play and develop alongside each other..." (The Rt Hon Charles Clarke, 2004). For children to do this they need to be able to communicate with each other, which they cannot do unless they are using the same language. As a special school we cater for large numbers of pupils who are using OR and symbols and therefore we felt that it was our duty to provide the pupils with a system through which they can understand each other and so learn together.

## WHOLE SCHOOL APPROACH TO OBJECTS OF REFERENCE

The Communication Group decided that the school needed to have a whole school approach towards the use of objects of reference (OR) as we needed to implement them as part of the school's communication policy. Therefore we had to consider:

1. If OR are to be used as a communication system, there needs to be some form of standardisation so everyone under-

stands their meaning, and also so that they can be used throughout the pupil's whole school experience (day to day and throughout the years). The use of OR can also be seen as part of the learning process and so should be able to be used as part of the progression for pupils onto pictures and symbols, etc.

2. For OR to have meaning, their implementation should be led by the pupil, i.e. the OR used are decided by the pupil through the meaning or experience derived from the activity.

The Communication Group decided that pupils need to be able to develop their own OR, deriving their own meaning from activities, etc. However, the school would also develop its own vocabulary as a framework to guide the development of the pupils' formal communication.

## KINGSLEY VOCABULARY

The communication group discussed the implementation of a 'Total Communication' philosophy in the school, through which all pupils have the opportunity to learn and communicate using whatever mode of communication they feel comfortable with. Total communication also lends itself to the teaching of communication in a holistic manner, considering the continuum of communication. The school has been fully signed up to individual learning styles and our pupils should also have the opportunity to develop their communication in the same way (visual – symbols / signing, kinaesthetic – signing / OR, auditory – speech). The implementation of a whole school total communication strategy was not as straightforward as giving out banks of OR and symbol cards and putting OR on doors. As well as the production and purchasing of all the resources, staff needed training in unfamiliar modes of communication. The implementation of total communication needs a carefully planned approach with much consideration of how, when and where the different modes are to be used, and their purpose.

The communication group quickly decided upon the various formal modes of communication to be used: speech – English; signing – British Sign Language (BSL), adapted as necessary for the physical needs of our pupils and used to support English language (as we are talking about total communication) rather than using the BSL signing convention of language; and symbols – Picture Communication System (PCS) symbols, as used with Clicker and Boardmaker software.

The Communication Group started by compiling a list of 'high frequency' words that pupils would want to use: "come here", "go away", etc and then considered

Type of expressive communication	Vocal	Gestural / visual (person based)	Gestural / visual (externally based)	Tactile / haptic
Non-intentional	Cries in response to personal need	For example: arches back in displeasure	Looks at things	Touches things
Intentional	Deliberately cries / vocalises to show need	For example: reaches out to be picked up	Points to things	Consciously manipulates objects to communicate for example: hands adult toy to play
Symbolic	Makes personal utterances: for example says 'mmm' meaning 'hairdryer'	Makes personal signs: for example flaps hand for 'yes'	Points at pictures Scribbles / draws	Uses Objects of Reference
Formal	Speaks (using words)	Uses conventional signs	Points at symbols / words Writes (print)	Uses Braille / Moon

(Ockelford 2002)

Figure 2 Objects of Reference & Types of Expressive Communication



each mode of communication (speech, signing, symbols, OR, photographs) and how they all link together in continuum of communication. Once the list was compiled the small task of producing the resources took place.

The Kingsley School Communication Group launched the high frequency vocabulary with training for parents and staff during the summer and autumn terms of 2004. Resources produced by the group were in classes during the first half of the autumn term. Assessment of the communication needs of our pupils was undertaken and throughout the year various communication aids were introduced, and methods of use for the different modes of communication. Following whole school training delivered by Clare Latham in September 2004, communication boards and books (Latham 2004) have been introduced. The training also highlighted the use of a relevant core vocabulary (Latham & Miles 2001) appropriate to the level of language development of the child. Fortuitously the high frequency vocabulary developed by the Communication Group was very similar to the core vocabulary proposed by Latham & Miles. To aid the use of OR and symbols across the school, departmental teams have developed a consistent approach to making the resources available. Each class has a consistent 'communication area' so pupils who are able to do so independently can locate and access communication resources. Communication trays are used to make OR accessible for pupils. In addition to the availability and use of communication aids across the school, staff training has increased their awareness of pupil needs – to be responsive to communications and to make the environment communication-friendly. Following on from the high frequency vocabulary, the Communication Group developed an area vocabulary and produced "Tell Me" boards. The "Tell Me" boards are sited around the school, including the playground and toilets, to enable pupils who use symbols – including the high proportion of our pupils highlighted as users of speech but who need symbols to consolidate understanding – to communicate anywhere in the school. Consideration was made for pupils moving on to secondary school, and we have started working with the Wren Spinney school to which our pupils with more complex needs will be transferring. Pupils with communication difficulties have communication passports in place, and all pupils have communication profiles highlighting targets for the development of their communication. Following the next round of PEEL observation in 2006/2007 we were able to

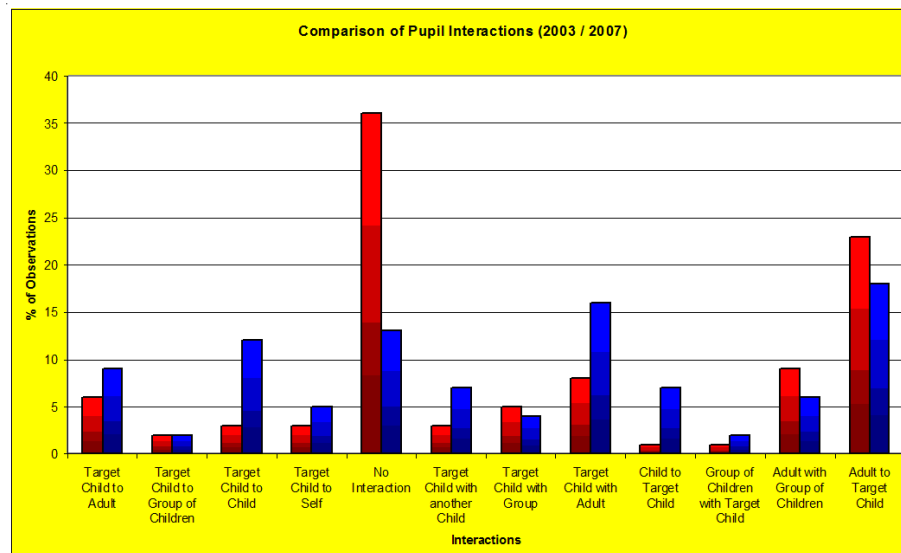


Figure 3 Types of Pupil Interaction (PEEL Analysis) – Comparison 2003 & 2007

re-examine the effectiveness of our approach to communication. We were pleasantly surprised at the reduction in 'no interactions', but the interactions that most pleased us were the 'Target child to child' and 'Child to target child'.

We were happy that we had started to put in place systems to meet our initial aim of giving our pupils a voice, but we were still a long way from being a 'Total Communication' school. An enormous amount of work had been carried out and practise had greatly progressed but we all knew that as a school we could be doing a lot better: we had many staff unable to think of the individual.

Following CM2006 and a talk by Rachel Key and Ann Miles on signing, both our school and Wren Spinney became involved in the programme 'Developing and Using Signing' (Hawkins *et al* 2006) which was developed in conjunction with Signalong at The Redway School. The course, even though focusing upon signing, concentrates upon the importance of putting the individual at the centre of the approach and introducing the appropriate vocabulary at the appropriate time. We have gone back to square one and started training in the theory of development of communication – what individuals need at various stages and what staff need to put in place rather than providing everything at once.

The implementation of total communication is still in its infancy at Kingsley. However, some of the feedback from classes that have got to grips with the system has been extremely positive. The aim of the vocabulary system was to enable pupils to talk to each other, and there have been instances of pupils with moderate and severe learning difficulties using OR with pupils who have PMLD. In one example, a pupil has used objects to

help peers with PMLD to make choices and express their needs. The introduction of a total communication philosophy has given pupils the opportunity to develop their communication skills, enabling them to use symbols and signs as prompts to communicate verbally. It has given our pupils with more complex communication difficulties the scope to develop their language using OR, leading to photographs of the objects and developing the use of symbols. The work of the Communication Group, and the whole staff at Kingsley, will be ongoing to support the individual needs of our pupils. We will strive to enable all pupils to communicate with anyone they encounter, even if only to say "Go away!" \*

Kevin Latham, Teacher

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# Children Without A Voice

**DAWN DAVIES**

Email: [dawnedavies14@hotmail.com](mailto:dawnedavies14@hotmail.com)

One parent's mission to give children in Co. Durham the right to a voice and be heard, via AAC Communication

**Augmentative and Alternative Communication (AAC)** describes communication methods used when the usual methods of speech and writing are impaired. However, parents in County Durham, where I live, say there is a severe lack of AAC use and speech therapists and LEAs do little, if anything, to promote the use of AAC.

In February this year, I decided to take a positive step towards giving families information on AAC. I am a single parent and my son Jake, 5, is one of the lucky ones in that he has been given a high-tech AAC aid provided via County Durham LEA under their 'Loan for Life' policy. Jake is the first pupil at Broom Cottages Primary School to have a high-tech aid and is setting a precedent for more children with communication difficulties to follow.

After launching an appeal for families with disabled children to contact me, I embarked on meeting 27 families of children with profound communication and speech difficulties. My mission was to see if they knew anything about AAC or had access to communication aids. My

journey took me from my home village in Ferryhill across to Hartlepool, Darlington and Newcastle and villages and towns in between. The majority of families knew nothing about AAC and communication aids. It was clear that no professionals had informed these families, from a wide range of ages and social backgrounds, how a communication aid could benefit their children.

I funded the project on a tight budget but managed to meet and photograph these children for a photographic exhibition held at Ferryhill Town Hall in August 2008. I was surprised and delighted to win the Over 18s photographic award and receive a presentation from the Deputy Major. She plans to show the exhibition in a larger form in Bishop Auckland next year.



One of the young people I photographed is Michael Reed from Chilton, Co Durham, who has a condition known as Apert Syndrome and doesn't talk. He uses a high-tech AAC aid known as the Pathfinder to communicate. He has had to go to an SEN Tribunal in order to be allowed to use his communication aid in school. In July, Michael and other teenage communication aid users from the charity *1Voice* were filmed by Scope as part of their BT-funded *No Voice, No Choice* campaign.

# New Software Upgrade Offer for WWS users...



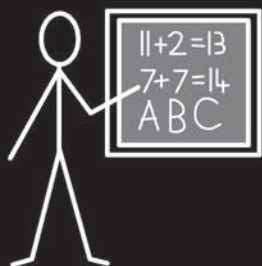
Writing with Symbols (WWS) is now over ten years old! So Widgit has begun to look to the future with the Communicate: Series and will no longer provide program and symbol updates for WWS.

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Michael Reed at the photographic exhibition

In August Michael attended the ISAAC International Conference in Montreal, Canada, where he filmed workshops by experts on AAC and literacy to use in a documentary he is making about AAC and to help support AAC awareness. October is ISAAC's International AAC Awareness Month and Reading Month. Michael held reading events at Chilton and Clayport Library, Durham, and at Broom Cottages School where he and his friends talked via AAC and read a story he has written to promote AAC use. He and his family continue to raise awareness of AAC issues in Co Durham.

One family I met had been given access to an old-fashioned and out-dated machine. After meeting me, the parent was empowered to visit a Communication Matters Road Show in Murton to learn more about modern AAC aids. She is intent on having one each for her son and daughter. I managed to get a further four families to attend the



Road Show to see for themselves what AAC aids are available.

If I have managed to spread the word of AAC to these families then hopefully they in turn can tell more of their friends and keep sharing the knowledge. It is heart-breaking to see these families denied the very tools that could help their children. Other families have since contacted me to say that they now felt empowered to ask the schools and speech therapists that they wish to be considered for AAC assessment. Once a parent knows about

AAC then they must have a referral to the *Communicate* team, in Newcastle upon Tyne, who will carry out an assessment, often in the child's home. The companies who make the devices such as Liberator, Dynavox, Techess, Widgit, Possum and others are more than happy to give parents free loans of a device for a trial period.

More professionals and speech therapists should inform parents of AAC de-

vices. My priority is giving parents knowledge about AAC and this is something I intend to keep on doing, wherever I can. Over the past 18 months change has been slowly happening in Co Durham, and the Local Education Authority now offers a 'loan for life' for the purchase of the AAC devices.

County Durham, as part of its commitment to Every Disabled Child Matters, wants to work closely with parents to find out what improvements they want in services, and to share knowledge. The County is also putting together a new directory to signpost parents to services and equipment as the old guide is very outdated - contact Elaine Wilson at the Children's Network Office, County Hall, Durham City (tel 0191-383 3875). I am actively working with the information office to ensure that communication issues and AAC information are included in the new directory. I intend to keep highlighting the issues around AAC.

There is a DVD of teenagers using AAC aids available from *1Voice*, priced £8. It is a very powerful tool to give hope to families. I encourage more role models to come into the area - into mainstream schools, special schools and colleges - to show families just what can be achieved.

What is not acceptable in today's highly technical age is to keep on denying AAC to children and families when these aids are available and are the future of communication for those without speech.

The *Silence Is The Loudest Voice* photographic exhibition on AAC awareness which was held at the PAGE Centre Shop, Thames Centre, Newton Aycliffe, will be held again in Spring 2009 at the Discovery Centre, Bishop Auckland. \*

Dawn Davies, Parent



Many children and adults have plenty to say, but are unable to control their mouth muscles to speak clearly. They can use aids such as pictures, written words and technology to communicate.

**1Voice** takes a family and social perspective on communication and recognises the great need for adult role models to inspire children and families alike. **1Voice** promotes families supporting each other to overcome the isolation that being unable to speak can bring.

For more information, visit [www.1voice.info](http://www.1voice.info) or contact Katie Clarke at email: [info@1voice.info](mailto:info@1voice.info) or phone on 0845 330 7862.

**1 Voice** is run by a team of families, role models and professionals in consultation with children to provide a network of information and support for children and families using communication aids.

For more information please contact:

**1 Voice**  
PO Box 559, Halifax HX1 2XL  
Tel: 0845 3307861  
Email: [info@1voice.info](mailto:info@1voice.info)  
[www.1voice.info](http://www.1voice.info)

## Augmentative and Alternative Communication

This is the official journal of the International Society for Augmentative and Alternative Communication (ISAAC), published quarterly by Taylor & Francis Ltd, UK. AAC publishes original articles with direct application to the communication needs of persons with severe speech and/or communication impairments for whom augmentative and alternative communication techniques and systems may be of assistance.

**CM Members rate (per year):** £56 (£33 student/retired)  
(£163 ISAAC Institutional/Corporate)

## Unterstützte Kommunikation

This ISAAC affiliated publication is published four times a year in German by ISAAC-GSC. **CM Members rate (per year):** £36

## AGOSCI in Focus

AGOSCI in Focus (formerly AGOSCI News) is the newsletter of the Australian Group on Severe Communication Impairment. It is an ISAAC affiliated publication and is published twice a year. **CM Members rate (per year):** £21

## ISAAC Israel Newsletter

ISAAC Israel Newsletter is an ISAAC affiliated publication. Published annually in the spring of each year, in Hebrew with a few English abstracts.

**CM Members rate (per year):** £18

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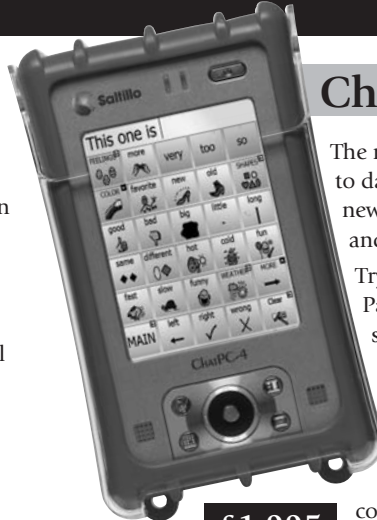
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# What Dance Means to Me

**ALAN MARTIN**

Email: [mouse\\_on\\_the\\_move@btinternet.com](mailto:mouse_on_the_move@btinternet.com) [www.mouseonthemove.uk](http://www.mouseonthemove.uk)

**A large part of my dance work is done** with children and young people in schools, both mainstream and special schools.

I will give you a short account of my dance career which started in 1996. It has taken me from a very bored user of a social services day centre, where I nearly died of *frustration*, to a self-employed creative dance worker, and has totally changed my life.

I have called this article 'What Dance Means to Me'. I could summarise that in one word: *everything!* But that would make this article very short, so I am going to try to explain what it is about dance that has given me a reason to get up in the morning, and a focus to my life. Dance means different things to everyone. I believe that I am the only communication aid and electric wheelchair-using dance practitioner in the country.

To me, the meaning of dance is more than just about the dance. It is about the fact that it is me that is doing it. As a person who uses AAC to communicate, I'm showing that I can take part in the arts and mainstream life. To a person who was marginalised for the first 31 years of my life, this is a tremendously big deal.

## THE CANDOCO DANCE COMPANY

When I was younger, my only experience of dance involved alcohol, clubs, pubs and lots of clowning about. I felt that I needed to be quite drunk before I had the confidence to join in. Usually, only good friends who knew me very well were prepared to try dancing with me.

I thought that the idea of me dancing was completely mad until I met the Candoco Dance Company. I went on the Candoco course just for a laugh and did not expect them to find a way to include me. I attended a one week course in Liverpool in 1996 and the experience was life changing. Candoco is the best known inclusive dance company in the world and showed me that everyone can dance, with disability being no barrier to taking part. The course ended with a public performance. This was my first experience of performing and the feeling was exhilarating and also scary. I felt like laughing and crying at the same time when I had finished performing.

## EARLY PERFORMANCES

I belonged to a local Phab club who were interested in doing some dance performance. We employed dance professionals who had experience with inclusive dance to train us and we gave several public performances. I got a great thrill from performing, and felt that dance was another way for me to communicate. I loved dancing with my Phab club. One of my performances included a poem that I wrote, and spoke on my communication aid. This gave me the first opportunity to use AAC in a public place and I felt proud



to be able to do it. Taking part in dance was making me feel very happy and excited. I could feel it opening new doors for me. I had very strong opinions about how inclusive dance should be done and I wanted to start leading my own dance sessions. This gave me a goal to aim for in my life which was positive, and having this positive goal helped in many other aspects of my life.

## DEVELOPING SKILLS

North West Disabled Artists Forum, based in Liverpool, was running many interesting activities at this time. One course that I applied to attend was the workshop leadership skills course held at Liverpool Institute of Performing Arts. This gave me the training to run creative arts workshops. The experience of being a student at a world famous performing arts college was amazing. I felt that I had a lot to teach the non-disabled students about inclusion as

well as learning a lot myself. It was very hard work as I was not used to studying but the motivation of a future in leading dance kept me going and I passed with a good grade. For a person who had no school education, this was a very big deal indeed.

Cheshire Dance ran courses and also Ludus, Blue Eyed Soul, and many other organisations. I attended numerous courses on, among other things, child protection, health and safety, creative dance, contact improvisation, management, funding, marketing, and too many other things to list. I felt that I was gaining skills that would turn me from a participant in dance sessions to a well-prepared professional dance leader. It made me feel good to know that all this experience was moving me towards my goal.

The organisations I joined were integrated organisations but which had not previously had any disabled people in them. This made for some interesting and mutually educational experiences both for myself and those on the courses. I do not believe in segregated institutions and prefer to see full and equal inclusion in all aspects of life. So why not dance? I began to see the links between disability equality training and my participation in these courses. Just by including myself in I felt like a trail blazer for other disabled dancers coming after me.

#### MILLENNIUM AWARD & DANCE WORKSHOPS

In 2000 I was successful in getting a Millennium Award which enabled me to run inclusive dance workshops for a full year, culminating in a public performance which I organised singlehandedly. I wrote the music, designed costume, staged the dance, invited the audience, did the lighting plan – everything. It was the best experience and it ended with me feeling exhausted but having learned a huge amount. It was extremely hard work but it meant so much to me to have done it. It also meant a lot to the dancers who took part, most of whom were my personal friends.

My first dance workshop for children was in Oxford where I ran a fun day for children learning to use communication aids. This went so well that I decided that I really had to do more. I began to realise that my work was about more than just dance, it was about being a role model for children with disabilities and to also change the attitudes of their parents and teachers. I was invited to the Liverpool Institute of Performing Arts to give a dance workshop to the students on the course that I had done the year before. This gave me many new contacts in other parts of the country and subsequently I was invited to work in Hebden Bridge and other interesting venues.

#### TOWARDS SELF-EMPLOYMENT

I attended many meetings at my local job centre and had interviews with job brokers. All that I was offered for work was in arts administration which was not what I wanted to do. After many fruitless months of trying to find suitable employment, and after attending a business management course, I decided that self employment was the way forward for me. All my experience in working voluntarily gave me the basis for a sound business plan. In March 2004 I gave up most of my benefits and set up my own business. It was a bit scary at first. I wondered if so many people would want me to work for them when I began to charge a fee. But it made me feel tremendously proud of myself to be embarking on earning my own living, as this was never considered a possibility before.

I had plenty of support and help from my job centre. Access to Work helped with my additional needs and their assistance helped to level the playing field so that many barriers to work disability were removed. For example, they gave me pay for a support worker who assists me with things I can't do for myself, like driving, lifting equipment and administration tasks.

Ideally, I would rather work with completely inclusive groups. That is, a real mix of abilities. These groups produce the most creative work. I feel that I'm contributing in some way to full social inclusion of people with disabilities when I am teaching disabled and non-disabled people to dance together. It's most satisfying to achieve this.



#### WORKING WITH SCHOOLS

I realised that making a film of children was an increasingly big issue, especially in my area. So for my next project, an after-school inclusive dance club which was held locally, I employed an artist to draw line images of our dance activities. This was both to record a feeling of the work we'd been doing and also to use in the project evaluation. The drawings far exceeded my expectations and were exhibited publicly in Liverpool for a month last Christmas.

Last year I was taken on by a group of primary schools in Oxford. I worked for two weeks, visiting a different school

each day. These were mainstream primary schools which had asked for themes of friendship, and one asked for healthy eating. It was great fun and amazing how quickly the children accepted me. I had some wonderful letters from the children and headteachers when I got home. One of my most recent jobs turned out to be the most challenging but also the most satisfying. I was asked to work at a summer school in Sheffield for young people with severe learning disabilities. I worked with them for five days and gave 15 dance workshops. We were covering the topics of what they felt and liked about themselves, and what they enjoyed doing and wished to do more of. It was exhausting work but after a few days recovering I feel I'd love to do much more of that kind of work.

My most prestigious job so far was earlier this year when I worked for Manchester City Council with a group of young people with disabilities to devise a dance to show what Manchester meant to them. My group was given the key words 'United, City' to make a public performance in Urbis, a large new museum building near Manchester Cathedral. This was one of the Liverpool 08 events and we may be asked to perform again at their closing ceremony in December.

#### COMPOSING MUSIC

Round about the same time that I had my first taste of creative dance, I also started dabbling in writing my own music. I learned how to use computer software to produce original sound tracks by mixing and editing samples and also creating my own sounds. This turned out to be a useful skill when I needed original music for giving public dance performances. It enabled me to choreograph dance and compose suitable accompanying music at the same time, and also saved having to pay royalties to other composers and musicians. It made dance especially satisfying when I knew that the music was my own as well.

#### THE IMPORTANCE OF AAC

You must understand that I wouldn't even have been able to communicate to anyone that I wanted to attend that first dance course if I had not just started to learn to use my first communication aid.

Having no effective communication until I was 31 meant that I just had to go along with activities that other people thought would do me good – bingo, basket weaving, and similar. I had always felt myself dancing, inside my body, when I listened to music but the idea of someone like me actually dancing seemed quite ridiculous until my experience with Candoco. After that, nothing seemed impossible and my feelings about myself started to change.

Dance means so much more to someone like me than to a person who has always been able to take part in any activity they chose. At first it meant self expression, enjoyment, social contact. As time went on, it gave me the motivation to further my education and enrol for many courses to help me progress my dance career. It gave me a reason to persevere with using my AAC devices and to start to master literacy. Before having to take written exams there had been no pressing need, in my view, to learn to read and write.

### INCLUSIVE CREATIVE DANCE

There are enormous benefits to taking part in the kind of dance that I do, both for me as the leader, the participants, and also the audience or spectators if there is to be a showing of the work. My genre of dance is non-stylised creative dance. This means that anybody can take part, whatever age or shape, and there is no fear of failure. All my participants enjoy what they do and get a feeling of fun and satisfaction from the sessions. Benefits are many and, just to name a few, flexibility and strength develop, and a feeling of being part of a group. Physical fitness as well as feelings of creative expression are part of every session.

One of the fundamental principles of community dance is that it is fully inclusive. What is dance anyway? Does it depend on pointing toes and making the correct steps, or is it about movement and emotions? I believe passionately that everyone can dance. We may dance differently but it's still dance. If a person can move any part of their body, even just eyelids or mouth, then they can still enjoy the pleasure of dance. Some people carry too much baggage about what dance really is. I have some trouble, in my own area of the country, persuading community dance organisations that inclusive dance is not just about including dancers from diverse ethnic backgrounds but dancers with a whole range of abilities. What I do is certainly not wheelchair dancing, so please don't call me a wheelchair dancer.

### DANCING TO COMMUNICATE

When I'd been doing dance for a few months it dawned on me that I had found a new method of communicating with other people. For a person who has no meaningful natural speech, any method of communicating is crucial. I had my communication aid to help me say specific things – names of people, places, and narrate happenings. But even with a good device there is so much human emotion that you can't communicate. Dancing let me express empathy with other

people and emotions, joy and fun, as well as things like enjoyment and enthusiasm.

As well as communicating emotions, I found that the body language used in dance was available to me. I made up lots of dances to express feelings and, as anyone who watches creative dance knows, there is a whole collection of things to be shown through dance – comedy, humour, fear, and so many things that I am still discovering them. I discovered that dance is a great way to break through and communicate with people who do not understand speech. Some people with autism and other learning disabilities have trouble making sense of spoken words, but if they copy my moves and I reciprocate by copying their moves, we can establish a communication system based on mutual human understanding.

I've told you how dance has benefitted me as an extra communication method but it's given me much more as well. Physically, my health has greatly improved – my strength, flexibility and overall fitness have increased, but also my feelings of self worth, happiness and satisfaction. As well as these benefits, participants in my sessions can gain leadership skills, learn cooperation, and team working, as well as self expression.

For more than half my life I was not used to thinking in words and language. My thoughts were all in moving images and so it is still difficult for me to put some ideas into words. I know that something happens when I dance and when I give dance workshops, that is like magic. Some people do things that they have never done before. Things come together in ways that I have not planned. Maybe it is just a collective feeling of cooperation or of having a new, exciting, enjoyable experience. Even without all the costume, props, and sparkly fabrics that I use in my dance, there is a feeling of expectation and willingness to participate, even with the most truculent young people. I feel a tremendously uplifting and empowering experience, and this has lasting benefits both to me and the participants.

People who watch my work and attend the performances can actually witness ability rather than disability and may be challenged, seeing unexpected talents from my groups of dancers. I have already said that I prefer to work with groups of people with mixed abilities, non-disabled dancers with dancers with disabilities. These groups are the most interesting. It is always my earnest desire that the applause of my audiences is meaningful and not, in a patronising way, just because some dancers have disabilities. I think it's insulting when I see people clapping when the work is not very good quality.

Although in the past I have done some work with disability arts organisations, I do not feel that it is promoting the inclusion of people with disabilities into mainstream society to have such segregated organisations. These days, I avoid anything about disability arts and join in as many mainstream dance and arts activities as I possibly find time for. I belong to the Foundation for Community Dance which is the leading community dance organisation in the country and a source of great experience and understanding about the whole issue of full inclusion. My aim is to educate all dancers into understanding that all people can dance, irrespective of age, shape or ability. I have undertaken a research project to discover all the varied and exciting ways that non-disabled people can dance with people who use electric wheelchairs. I used professional dancers to work with me and had much of our work recorded on video to share with the wider community.

### THE MEANING OF DANCE

So, the meaning of dance to me? It is my reason for getting up each day. It is my means of earning my living. It is my source of exercise and main social opportunity. It is a great universal communication method. But, most of all, it is my means of showing the world that people with different bodies and ways of doing things are equally valuable and creative as anyone else and are part of a full and inclusive society.

Those things are relatively easy to explain, but what I find hard to put into words is the way that, when I dance, I feel different to usual – I feel like I'm flying, as if a new energy is coming into my body. I can imagine a wire pulling at the top of my head, moving me, and making me feel wonderful. I can't logically explain this. Maybe it's the way my brain works but with music and dance I become a different person, just for a few moments. I become free and graceful and lose the annoying stiffness that is usually part of me.

### WHAT NEXT?

My plans for the future are firstly to write my first full length book about what dance means to me. I hope this may lead to the means to acquire my own fully accessible dance studio, close to where I live. Ultimately I want to be fully occupied teaching inclusive creative dance practice to people in my part of the country and developing my present work showing dancers how to include people with disabilities in all aspects of dance. \*

Alan Martin  
Dance Workshop Leader, Actor  
& Disability Awareness Trainer



## What is Communication Matters?

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

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

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

## What are the benefits of Membership?

Members of Communication Matters receive:

- The Communication Matters Journal three times a year.
- Reduced rate at Communication Matters Study Days.
- Reduced delegate rate at the Annual Communication Matters National Symposium.
- Regular electronic newsletters with the latest news in AAC developments, information about Communication Matters Road Shows, study days, other events, and more.
- Access the member's area of the CM website.
- All the benefits of ISAAC membership, including ISAAC publications at substantially reduced rates (AAC Journal, ISAAC-Israel Newsletter, AGOSCI News), and special delegate rates for the Biennial ISAAC International Conference. If you join early in the year, you will receive a Membership Directory.

## How do I become a Member?

**If you live in the UK**, you can become a member of Communication Matters (and therefore of ISAAC) by contacting:  
Tel: 0845 456 211 [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)  
[www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

**If you are outside the UK**, you can become a member of ISAAC or subscribe to this Journal by contacting:  
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## What is ISAAC?

- ISAAC stands for International Society for Augmentative and Alternative Communication.
- ISAAC is a big international organisation that focuses on AAC.
- ISAAC was formed in 1983 and has over 3,700 members.
- ISAAC members live in more than 50 countries around the world.
- There are ISAAC Chapters in Australia, Canada, Denmark, Finland, French-speaking Countries, German-speaking Countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Sweden, United Kingdom and United States of America.

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

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

## What does ISAAC do?

- Advocates for augmented communicators & their families.
- Supports the use of AAC around the world. This includes countries that do not know about AAC.
- Has an exciting awards & scholarship program for members.
- Encourages the development of AAC products & services.
- Produces a series of books for people involved in AAC.
- Has an international conference every two years.
- Sponsors a peer-reviewed scientific journal – Augmentative and Alternative Communication (AAC). Peer-reviewed means that each article is anonymously reviewed by three people who are experts to see if it is suitable for publication. Visit the website at: [www.isaac-online.org/en/publications/aac.html](http://www.isaac-online.org/en/publications/aac.html) for more details.

## What do ISAAC members receive?

- Full access to *ISAAC Information Exchange* the new web-based version of what was *The Bulletin*. *ISAAC Information Exchange* is a dynamic international resource for sharing knowledge, experiences and perspectives on AAC.
- Access to ISAAC website and past Bulletin articles
- An International Directory with a list of all ISAAC members. A new Directory is published every year.
- ISAAC members can buy the AAC Journal at a 54% discounted rate.
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- ISAAC members network with professionals & AAC users world-wide.



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## TRUSTEES' NEWS

### FROM LIZ MOULAM, CHAIR OF COMMUNICATION MATTERS

The Annual Meeting at the CM2008 National Symposium endorsed the decision of the Trustees to seek funding to employ paid staff to continue to develop Communication Matters as the leading organisation for everyone involved in the field of AAC in the UK. This is now moving ahead, with bids for funding now being submitted. The next stage will be nail biting as we wait to hear whether we have been successful or not – and in some cases it will be several months before we know.



John Bercow MP - CM2008 Keynote speaker

Immediately following CM2008 – the 'most successful conference ever' according to delegates because of the range of speakers, quality of papers, networking opportunities, exhibition and the Abba night – opportunities have continued to jump into Communication Matters' path to meet our aim of raising awareness of AAC. In early October there were two meetings that are having a dramatic impact on how the future of Communication Matters is being shaped:

#### **Collaborative Research Proposals**

Eight institutions and organisations, that had self-selected themselves through an open process during the summer, joined Annika Dahlgren-Sandberg, an international AAC expert from Gothenberg University, and myself, to discuss what was needed to influence policy and decision making both locally and nationally. At this stage I am unable to share exactly where we are at because of the process of tendering to put the bids together but be assured it's a very exciting time with Communication Matters making its first foray into establishing robust data for prevalence of need and current services. The aim of this is to submit a bid to the BIG Lottery for research across the UK in early 2009.

#### **Standards for AAC Provision**

Following the exceptionally well attended discussion at CM2008, 22 people attended a further meeting in London to work on standards for AAC provision for people of all ages in the UK. Others who were unable to attend the workshop have subsequently input through an email discussion group.

A consultation document will be available in the members' area of the CM website until the end of December. This is an exciting challenge that ties into the Bercow implementation in England, and we have been told is very timely for Northern Ireland (currently restructuring their provision) and Scotland (reviewing provision). Meanwhile, a bid has been made to the DCSF for funding to take this forward to allow for widespread consultation and piloting of the standards for AAC provision.

#### **INTERNATIONAL AAC AWARENESS MONTH**

October 2008 saw activities happening up and down the country for International AAC Awareness Month. Thank you to everyone who has done something in their own school or community.

Special thanks must go to Terry Gibson and her son Michael Reed (page 31) and also to Dawn Davies and her son Jake (page 9) who have made an enormous impact in the North East and done an excellent PR job.

On 23 October the Trustees were delighted to invite the winners of the UK story reading contest to **Downing Street** by kind permission of Alistair Darling, Chancellor of the Exchequer, and his wife Maggie. It was a magnificent evening, with a number of influential guests, that will be remembered for a long time by everyone lucky enough to attend. If you are sitting comfortably then read all about it on page 17.

#### **BERCOW REPORT IMPLEMENTATION**

Information from the Bercow Implementation is slow to filter through. The DCSF is committed to the Communication Council and the role of the Communication Champion and we await more information which we will share with you through the e-News. The long awaited DoH Child Health Strategy is now due for publication at the end of November, having been delayed two months.

#### **NEW BOARD OF TRUSTEES**

As we move towards Christmas the new Trustees are settling into their roles. We welcome as full Board members Joanne Anderson, Sally Chan and Gillian Hazell. They join Trustees elected for a second term – Neil Hansen, Anna Reeves, Trish Davidson and myself – as well as the incumbent trustees Cathy Harris, Bernie Henderson, Toby Hewson, Simon Judge and Tina Voizey. We were in the happy position to also be able to co-opt Dithe Fisher, Judith de Ste Croix and Sandra Hartley who will serve for one year, after which they may choose to stand as full Trustees from next September.

Finally, I wish you all a Merry Christmas and a Happy New Year.

**Liz Moulam**

Email: [lizcommatters@aol.com](mailto:lizcommatters@aol.com)





## eCAT NEWS

### WHY A TRADE ASSOCIATION – AND WHY BHTA?

I wonder when you book your annual sojourn in sunnier climes whether you always check that the Travel Company you are using is a member of ABTA, or whether, when you have any work done on a gas installation in your home you ensure that the company or workmen are CORGI registered. I would expect the answer to be "yes" – it makes sense – it gives that sense of security, knowing that there is an umbrella organisation that is monitoring members, setting standards and that you can take complaints to if you do not get satisfaction from the original supplier.

And that is part of the objective of BHTA (the British Healthcare Trades Association) – to monitor members, set and control standards of customer service and to be there if or when things 'go pear-shaped', acting as an arbitration service if necessary. Now before I get into trouble with Communication Matters' commercial members that are not members of BHTA, I should point out that some commercial members are members of other trade associations that they feel are more appropriate (e.g. where their main area of interest is, say, education rather than assistive technology/AAC). Also, just because a commercial member is not a member of BHTA or any trade association does not mean that you should not deal with them or that they don't offer as good a product or service as any member company.

That said, I would like to explain why companies join BHTA. It *does* give that overall framework to work to and it *is* a badge to say that the company is being monitored and there *is* a system in place for action to be taken when clients are not treated justly or fairly. There is a 22-page Code of Practice that all BHTA members sign up to; you can read the Code of Practice at [www.bhta.com](http://www.bhta.com) – look for a 'tab' across the top of the Home page.

When companies sign up to such a Code of Practice, which has attained 'stage one approval' under the Office of Fair Trading's Consumer Codes Approval Scheme, then you should be able to depend on that company and know that they have a high standard to live up to. Members also benefit from gaining information from the BHTA about changes in the law which might affect them, access to Government officials when appropriate, and even an insight into what is being discussed in Parliament regarding Health issues and funding. There is also access to professionals' organisations for assistance and a special company insurance scheme. So members get a lot from being in the trade association.

But in the end trade associations are there for the benefit of the public as much as for the members. Overall I personally believe that having suppliers part of a recognised trade association, such as BHTA, adds more professionalism and even credibility to any industry as a whole.

**Dave Morgan**, Chair of eCAT section, BHTA  
Email: [david.morgan@dynavox.co.uk](mailto:david.morgan@dynavox.co.uk)

## HOT NEWS

### YOUR INPUT NEEDED – CONSULTATION ON STANDARDS FOR AAC PROVISION

Members of Communication Matters are invited to visit the members' password protected area at [www.communicationmatters.org.uk/members](http://www.communicationmatters.org.uk/members) to download Communication Matters' consultation document on Standards for AAC Provision.

If you have forgotten the password, please email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

Send your comments to [lizcommatters@aol.com](mailto:lizcommatters@aol.com) by 31 December 2008.

### YOUR HELP NEEDED WITH FUNDRAISING

#### Raise money for Communication Matters every time you search the Web!

Now it's easy to raise money for Communication Matters every time you search the Web, and there's no cost to you!

Just use the **Everyclick search box** whenever you want to do a search in your web browser and Everyclick will make a donation to ISAAC (UK) / Communication Matters.

It's simple to sign-up to Everyclick – go to [www.everyclick.com/isaacuk](http://www.everyclick.com/isaacuk) and then click the 'Start Fundraising' button – remember to specify ISAAC (UK) as the charity to receive the donations. Thank you in advance for your support.

### Join The FSI Challenge – 6 June 2009

If your appetite has been whetted to help raise money to support the work of Communication Matters, why not join the **FSI Challenge** on 6 June 2009? The FSI Challenge is a 4km or 10km walk or run in the Derbyshire Peaks in aid of a charity of your choice – Communication Matters, of course!

The Trustees invite anyone interested in walking or running the long or short course to raise money for Communication Matters. The accessibility of the route is being checked out as there are already two volunteers who use wheelchairs wishing to participate.

For more information, please contact Patrick Poon at [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

### With Thanks...

Over £700 were raised by a raffle and quiz at the CM2008 National Symposium this year. We would not have had such a fantastic result without the generous support of the many **AAC suppliers** and **individuals** who contributed prizes, and the delegates for buying the raffle tickets. Many thanks to the helpers selling the raffle tickets. This money will be used to help fund **two places** for people using AAC to attend next year's Symposium. A Big Thank You to everyone involved, and also to Toby Churchill Ltd for sponsoring the sparkly Abba disco at CM2008!

Grateful thanks also to **Cathy Harris** in Gloucestershire for organising a fantastic Charity Ball which raised £350 for Communication Matters.

# A Brilliant Evening at Downing Street

## LIZ MOULAM

Communication Matters, c/o ACE Centre, 92 Windmill Road, Oxford OX3 7DR, UK  
lizcommatters@aol.com

The story of Communication Matters' Story Reading Reception held during the 2008 International AAC Awareness Month

**"I will tell you a story..."** Now the number '11' usually comes after the number '10' but for several lucky people Communication Matters did things differently!

The story begins when, after months of planning, hours of phone calls and a multitude of emails between Patrick Poon (Communication Matters' administrator) and Pauline North (Downing Street Events Manager), guests and dignitaries gathered for a memorable reception at No. 10 Downing Street. It was a night of story telling, and this is the story of that night as seen through the eyes of many who attended.

We hope this article captures the words and feelings of some of the guests who attended the Communication Matters Story Reading Reception on 23 October 2008 and gives you a chance to step in-



Ashleigh outside No. 10 Downing Street

side and share a truly amazing and unforgettable experience.

Roland Gooding, Head of Valence School, writes:

"We had time for a meal in a restaurant off Trafalgar Square. When it was time to go, Carys and Colin got the buses and the rest of us made our way on foot and wheels to Downing Street. Unfortunately we caused a big security headache as it had been arranged that we would arrive in the buses, but all was well in the end and, after security checks, we were all allowed through.

To our surprise the venue had been changed and we found ourselves entering that famous door of No. 10 Downing Street. As some of us gathered in the entrance hall waiting to use the loos and for others to arrive, who should come to greet us but none other

than the Prime Minister, Gordon Brown, who spoke to everyone and shook hands. He told us that we were very welcome in Downing Street. Later on, when some of us had moved upstairs to the State Rooms where the reception was held, he spoke to some other students and despite the ban on photographs he agreed to have his photo taken with Stacey who he said had a beautiful smile."

Gordon Brown, an innocent bystander on the night, clearly made a huge impression on younger guests. Ryan thought he was a kind man. The highlight of Emma's trip was when Gordon Brown said to her, "Hello, have a nice day". Stacey said "I loved having my photo taken with Gordon Brown" (but because the photo wasn't taken by the official photographer we cannot show it).

On arrival, guests were escorted upstairs to the State Rooms and given drinks and canapés.



Guests arriving in the State Room

Alan Martin writes:

"Inside, I realised that I was wheeling over carpets that had seen hundreds of famous feet. It was a funny feeling to think of all the people that had been



Pauline North & Patrick Poon discussing final preparations at No.10

here before me. It's one of the most famous places in the world. There were lots other people who use wheelchairs there, as well as me, and it was good to see that the people at Number 10 had tried to make the place as accessible as possible. The feeling was welcoming, and friendly, not scary as I'd feared. All the staff were very helpful, and I soon felt at ease. Even though there were many antique and unique furnishings, it felt quite homely."



Maggie Darling (right) welcoming Trustee Simon Judge

Ryan was hungry but really liked the little nibbles. He also thought the inside of Downing Street was "much bigger than it looked from the outside." Matt C said, "I really enjoyed going somewhere famous and I did not realise it was that big" whilst Matt J agreed saying "I liked the building and saw the back garden". Suzie joined the boys: "I didn't realize that the dining room was so big!!!" We went into both State Dining Rooms at Number 10 and they were magnificent.



Ryan liked the nibbles

The formal part of the evening started with an introduction from Liz Moulam, Chair of Trustees, who told the audience about



Suzie was surprised by the size of the dining room

the very difficult decision the Trustees had to make when the staff at Downing Street asked if the event could be moved from No. 11 to No. 10 to help with the access! With probably the quickest vote in the committee's history, all the Trustees said "Yes!". Liz outlined how the Trustees had seen the opportunity to use the ISAAC 'Many Stories - One Voice' contest to raise AAC awareness in the UK during October, the AAC International Awareness Month but could not have dreamt of a more prestigious venue or more gracious hosts than Alastair and Maggie Darling, Chancellor of the Exchequer and his wife.



Liz Moulam, Chair

Communication Matters had been delighted when it was announced at ISAAC 2008 in Montreal that Sean Lucas - aged 7, from Swindon - had been awarded the international youth prize for his entry *MI6 Rescue*. All the UK entries had been returned to Communication Matters for an independent judging panel to assess the entries anonymously on content, structure and originality for our own UK awards. Sean Lucas was confirmed as the UK's under 11 winner, Beth Moulam the aged 12 to 16 winner with *Just Talking* and Alan Martin the adult winner with *Secrets*.



Sean Lucas - International & UK winner

In true storytelling mood, guests were invited to sit on the carpet and make themselves comfortable. Then the story telling began. Dr Nicola Grove, Founder and Director of the *Unlimited Company of Story Tellers*, enthralled us with her speech.

## SPEECH BY DR NICOLA GROVE



Dr Nicola Grove - Guest Speaker

When I was little, I was hungry and thirsty for stories, and I would pester my grandparents to tell them. And sometimes, when my grandma tired of my endless demands, she would respond thus:

I'll tell you a story  
About Jackanory  
And now my story's begun  
I'll tell you another  
About John his brother  
And now my story is done.

When you are trying to think about how to define something and its appeal, it is often instructive to start with a negative. This little verse is profoundly unsatisfying. Why? It has some of the crucial elements of a story: a beginning, a middle and an end, and it has characters. But it does not fulfil its promise, the promise (in Helen Machen's words) of opening a magic door into yesterday, or tomorrow, or an imagined world. Because for a narrative to become a story certain things have to be in place that are missing here. A story has to matter. It has to mean something. It has to engage our attention and our emotions. It has to take us beyond the here and now to a remembered or imagined place where, most important of all, something happens.

The stories submitted by the entrants to this wonderful competition are not Jackanory stories. In every one of them something happens that makes us sit up and take notice. In every one of them we encounter feelings we can recognise: of surprise, bewilderment, excitement, fear, laughter, pride, embarrassment, jealousy, love and longing. And in every one of them there is a mystery character - can you guess who this is?

Robert Gilham describes this protagonist as 'the book of magic and clues', that allows our entrants to communicate their thoughts and feelings and desires - the communication aids that for the first time



in history have really given freedom and independent expression to a group of people who face the most severe challenges imaginable in taking an active role in their own lives and in our society. I say "who" because it is noticeable on reading the stories how personalised these devices feel to their owners – *my* Tellus, *my* Vantage, *my* AAC phone, *my* Dynavox, *my* Tobii. And these writers are so aware of the power that they have gained by being able to voice their stories. What are the meanings that they share?

I'll quote from some of them, but every story on the Symbolworld website [1] is worth reading, so I urge you to go and find them for yourselves.

Michael, Andrew, Gemma, Jake, Robert and Sam: "I wanted to say: I've been there and there and there, and I've been right to the top of there, but no-one helped me." Barry Smith: "Cerebral palsy is only a part of who I am. People pat me on the head, they see my wheelchair first and my communication aid second. [People] do not want to know what I am saying to them. But, you can have a voice hearing all over the world if you are online."

Christopher George: "I happened to upload a few videos of me using My Tobii to YouTube, because I felt like had to show the world how great power I have in my eyes. I thought that people would be amazed but they weren't. One morning Jess's message waited for me. She had visited her friend who is a My Tobii user just as I am. She reckons that 'it was really inspirational for him to see someone older than him using the device, and also quite cool'. If I only had a positive impact on Jess's friend for this one occasion, I say it was worth it already. Every time I think of this, I feel well appreciated again and again. Indescribable feeling..."

Lisa Maria Eastwood: "Though I say it myself, I was fantastic! West End, here I come." And surely the best wedding vow you've ever heard, by Matthew Paulton: "I love you more than chocolate. You make me so happy I want us to be married for one thousand years."

Through these stories, the authors share the message that people who are communicatively challenged are just like everyone else in their feelings, their aspirations, their sense of humour, their fears, the support they gain from friends who campaign with them. What they all demonstrate are values that we who do not share their difficulties can learn from: perseverance, sheer bloody mindedness, and a desire to advocate for the many many children and adults, here in the UK and of course all over the world, who have not had their advantage of what should be the

basic right of everyone – a voice to tell a story.

I commend to you in particular the winners of this competition, who have shared with us the full range of what a story has to offer. From the ordinary anecdotes of 'just talking' which remind us of the importance of warm everyday interactions to the heroic exploits of MI6 agents (I am sure Daniel Craig will not be slow to pick up on the role of a talker in thwarting international crime) and the use of treasure to buy more AAC devices for those who don't have them.

And finally, I hope all the legislators here this evening will make time in the next session of Parliament for Queen Piggy's new laws described by Michael Z, Andrew, Gemma, Jake, Robert and Sam: "Everyone to be taught to read and write, whatever their disability. Everyone to learn about AAC and meet an AAC role model. No more age testing – focus on language. Everyone to use AAC for one week a year. Everyone to have an AAC phone, like hers."

#### STORIES BY SEAN LUCAS, BETH MOULAM AND ALAN MARTIN

Toby Hewson boldly followed Nicola by reading Sean's story in his absence. This was a polished performance, followed by Beth brilliantly reading her story 'Just Talking' and then Alan Martin using both recorded and synthesized speech to bring great humour to his story 'Secrets'. The audience listened raptly to these stories from truly inspirational storytellers.

The icing on the cake was a story reading by Maggie Darling herself. She read 'No Means Yes', part of the Quirky Tails Collection by Paul Jenkins. Alan Martin commented that "It was a special surprise that Maggie Darling read us a great story,



Maggie Darling captivates the audience with her reading

which showed that she understood the importance of good communication." Maggie did real justice to the story, which was chosen for her by Roz Brown, one of the contest's judges. It is well worth a read and in true quirky style underlined the importance to us all of both verbal and non-verbal communication with its twist at the end!

Following the readings Alistair Darling, Chancellor of the Exchequer, kindly presented certificates to the winners. Beth said "I felt really proud when Alistair Darling gave me my certificate, it was like being a film star having my photo taken."



Alistair Darling presenting award to Beth Moulam

The evening continued with animated discussions and celebrations as guests enthusiastically talked about the stories and AAC. Trustee Gillian Hazell commented afterwards: "It was a superb evening. The best thing about it was the faces of the young people (those I could see) while the story reading was going on. You could have heard a pin drop. Magnificent!"

"All the people were so nice," said Beth Moulam, "including the 'men in black' (custodians) with their ear pieces. The disabled toilet was downstairs. Near the end, I needed personal care; C. and I went towards the chair lift and the custodian took us to the Prime Minister's own toilet off



Toby Hewson reading Sean Lucas's story

<sup>1</sup> [www.symbolworld.org/stories/cm\\_stories](http://www.symbolworld.org/stories/cm_stories)



Alan Martin receiving award from the Chancellor of the Exchequer

his office, WOW! The seat must have been made for him because it was a bit big for me! Just think, the only other female to have sat on that throne might have been Margaret Thatcher! I wonder if that is a favourite place for thinking and a bit of quiet?"



The 'Men in Black'

Stacy said, "I enjoyed the stories." and Matt C added, "Hearing the different stories that the people read to us was, I thought, excellent and really enjoyable to listen to".



Stacey enjoyed listening to the stories

Nickie Wren of The Makaton Charity said that "the real joy was that it was a marvelous occasion for the winning storytellers

and readers and everyone who uses AAC and is somehow involved with AAC. Everyone at Downing Street was so friendly and helpful, from the police officers and security staff to the team at Number 10 and not forgetting Pauline (Downing Street organiser) who was lovely. Maggie Darling was a superb host, taking the time to speak with everyone."



Trustee Neil Hansen with Baroness Masham

Suzie said, "It was a pleasure to be invited and thank you to everyone who has made it possible". And Megan commented: "It was a very good experience. It was nice to meet Gordon Brown and Alistair Darling." The night was one full of cherished memories.



Roz Brown and son

Roz Brown, who came with her 5 year old son, said, "I had to chuckle when I overheard him saying to his babysitter on Saturday when she asked what he'd been up to, 'Oh, I just went up to Downing Street and met the Prime Minister.' Clearly an everyday occurrence for this young man!"

Yaffa, now age 10, said "We had a nice chat with Maggie Darling and when she found out it was my birthday on the following Sunday, she sent me a card."



John Bercow MP & Trustee Anna Reeves



Liz Moulam with Alistair Darling

Alan Martin summed up the evening for us all: "I felt that Communication Matters had made a really important point, in a really important place, to *really* important people, about the value of AAC in people's lives. I hope this story reading event raises awareness of AAC among the people who can really make some difference. Thank you Liz and the Trustees for organising this event, and for caring about all those people who do not have AAC yet, including many of my friends."

## FINALLY

The Trustees of Communication Matters would like to thank Gordon Brown, Prime Minister; Alistair Darling, Chancellor of the Exchequer, and his wife, Maggie; Pauline North and all the fantastic staff at Downing Street for making this event such a success. Their hospitality was amazing and we have been honoured to have been able to make ourselves 'at home' at Number 10.



Terry Waller (Becta) with Janet Larcher (former Chair of Communication Matters)

Thanks also goes to Becta for their generous sponsorship of the evening, and to Mark Edwards of RTS Communications who supplied the audio equipment and expertise free of charge so that the monies could go to supporting people who use AAC.

You can listen to the audio recording of the readings, and read all the entrants' stories at [www.communicationmatters.org.uk/aacawareness](http://www.communicationmatters.org.uk/aacawareness).

The UK stories can be read with symbol and speech support at [www.symbolworld.org](http://www.symbolworld.org) and all the stories entered in the international contest are now available at [www.aacawareness.org/collectiontoc.html](http://www.aacawareness.org/collectiontoc.html) \*

Liz Moulam, Chair of Communication Matters





## **AAC STUDY DAYS – 2009**



### ***“Guess What Happened Today!”***

Enabling Children with Complex Communication Needs to Tell Stories

27 January 2009 at The Institute of Child Health, London

28 January 2009 at The Together Trust, Cheadle, Manchester

3 February 2009 at The City Chambers, Edinburgh

### ***Eye Gaze Technology***

*(date to be confirmed)*

March 2009, London

### ***The Basics of AAC***

13 June 2009, London

### ***Literacy for ALL***

*(to be confirmed)*

5 May 2009, London

7 May 2009, Manchester

11 May 2009, Dunfermline (\*)

### ***AAC Study Day***

*(details to be announced)*

November 2009

### **COST**

(All except \*) £85 for Members of Communication Matters; £110 standard rate;

£45 for people who use AAC or family members

(\*) £85 for early booking; £95 standard rate; £45 for people who use AAC or family members

**More information at [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)**

Enquiries Tel : 0845 456 8211 Email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)



## DIARY DATES

14-16 January 2009 London

### Special Needs Fringe

Contact: 0800 975 6090 [www.inclusive.co.uk](http://www.inclusive.co.uk)

14-17 January 2009 London

### BETT 2009

[www.bettshow.com](http://www.bettshow.com)

27 January 2009 London

### Enabling Children with Complex Communication Needs to Tell Stories

Contact: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

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28 January 2009 Manchester

### Enabling Children with Complex Communication Needs to Tell Stories

Contact: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

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29 January 2009 Oxford

### Getting Motivated by AAC (including environmental control)

Contact: ACE Centre 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

2 February 2009 London

### Clicker 5

Contact: Cenmac 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

3 February 2009 Edinburgh

### Enabling Children with Complex Communication Needs to Tell Stories

Contact: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

5 February 2009 Edinburgh

### Books for All: Making Audio Resources

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

10 February 2009 Newcastle upon Tyne

### Therapy Outcome Measures

Contact: Communicate 0191 287 5240 [communicate.editme.com](http://communicate.editme.com)

26 February 2009 Edinburgh

### Software Information Day: Sherston Software

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

March 2009 (TBC) London

### Eye Gaze Technology (to be confirmed)

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

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5 March 2009 Edinburgh

### Software Information Day: Texthelp Systems

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

11 March 2009 Bristol

### Widgit Day

Contact: PCAS 0117 353 3613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

12 March 2009 Edinburgh

### Software Information Day: Dolphin Computer Access

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

4 March 2009 Oxford

### Recording in Mathematics for Students with Physical Disabilities

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

19 March 2009 Edinburgh

### Software Information Day: 2Simple Software

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

## DIARY DATES

26 March 2009 Edinburgh

### Routes for Learning for Pupils with Profound and Complex Support Needs

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

23 April 2009 Edinburgh

### Software Information Day: TAG Learning

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

25 April 2009 Edinburgh

### Family Technology Fun Day

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

27 April 2009 London

### Clicker 5

Contact: Cenmac 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

5 May 2009 (TBC) London

### Literacy for ALL (to be confirmed)

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

COMMUNICATION  
MATTERS

7 May 2009 (TBC) Manchester

### Literacy for ALL (to be confirmed)

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

COMMUNICATION  
MATTERS

7 May 2009 Edinburgh

### Software Information Day: Inclusive Technology

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

11 May 2009 (TBC) Dunfermline

### Literacy for ALL (to be confirmed)

Contact: ACIP: S 0141 201 2619 (SCTCI)

13 May 2009 Edinburgh

### Using ICT with Early Years and Primary Children with Communication Support Needs

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

19 May 2009 Oxford

### Switches – who, why and how?

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

21 May 2009 Edinburgh

### Software Information Day: Crick Software

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

13 June 2009 London

### The Basics of AAC

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

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15 June 2009 London

### Clicker 5

Contact: Cenmac 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

24 June 2009 Oxford

### AAC – What is there to say?

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

20-22 September 2009 Leicester

### CM2009 National Symposium

Contact Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

14 October 2009 Oxford

### Developing and Supporting Low Tech Communication Systems

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

November 2009 (TBC) TBC

### Communication Matters Study Day (to be confirmed)

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

COMMUNICATION  
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# The ISAAC 2008 Conference

LIZ MOULAM, JOAN MURPHY, SANDRA HARTLEY & BETH MOULAM

The experiences of four members who attended the ISAAC 2008 Conference in Montreal

## LIZ MOULAM WRITES...

Communication Matters funded me, as Chapter Chair, to attend the ISAAC 2008 Conference in Montreal. It was definitely interesting, informative and hard work! Here is a summary of some of the things that happened.

My daughter Beth aged 14 attended in her own right. She and her Dad (as her Personal Assistant) were sponsored to be there by Toby Churchill Ltd as Beth presented her own paper.

### SATURDAY 2 AUGUST 2008, 1:30PM TO 5:30PM

Prior to the Board meeting, There was a governance meeting discuss the proposed changes to the ISAAC constitution. This was the chance for each Chapter (represented by the Chapter president and a Board representative) to ask questions and discuss what the changes really would mean. It raised many concerns from around the world about the proposed changes that would put the running of the organisation into the hands of only six people. The new proposals would replace the Board with a Council, and the current Executive Committee with

an Executive Board. Concerns raised by the UK included:

1. The Council Chair, who would have a place on the Executive Board, must represent the views of the Council, not their own views. It was also agreed that the all decisions by the Executive Board must be made unanimously, ensuring the agreement of the Council.
2. Feedback from Council on budget issues should be taken into account by the Executive Board. Agreed in line with item 1 above.
3. By-laws should not be amended without consultation with the Council and again decisions will be in line with item 1 above.
4. An officer can only be removed from the Executive Board by using the same procedure as for removing an ordinary member.

The Board and Executive members, who worked really hard to get the proposals ready to discuss in Canada, went away



and worked into the night taking on board the comments made by attendees. The next stage is to amend the ISAAC by-laws; these are currently with the legal advisers. The latest document is available in paid-up members' area of the CM website.

### SUNDAY 3 AUGUST 2008, 9:15AM TO 5:30PM

There was a Board meeting was for outgoing officials in the morning, followed by one for incoming officials in the afternoon.

The morning started with discussions about the changes suggested the previous day. The existing Executive put forward a motion for the existing Board to accept the changes and move to change the by-laws. After discussion the UK proposed that we added a further motion to see the changes in writing before moving to the by-laws, as attendees were in general agreement this would be a rubber stamping job and should be voted on by all Chapters. This additional motion got a clear majority vote and the steps suggested to safeguard the views of the Chapters were agreed in principle. What was clear was that it is very challenging for those representatives of Chapters where English is not their first language to understand easily the subtleties of the legal word. (Subsequently there has been an on-line vote and the changes will go ahead with a very small majority – there was still some dissent). The UK voted to accept the changes as our recommendations were taken on board.

One major concern raised by Chapters was the C\$40,000 that must be committed by a host nation of an ISAAC conference to ISAAC. This means that not only must the host nation aim to cover all its own costs but it must also cover the monies required to run the secretariat/ISAAC operation. For 2008, C\$85,000 was paid to conference organisers to facilitate the event; for 2010, Spain have undertaken to organise this themselves without this additional cost.

In the afternoon many of the items agreed in the morning were discussed again because the attendees changed from the old to the new Board members. The Board were shown the proposed budget. Under questioning from the Chapters, the current Executive Committee expressed confidence that the budget figures would be met.

#### MONDAY 4 AUGUST 2008, 9AM TO 5PM

First day of conference started with a plenary. Sessions ran in blocks, each day interspersed with long breaks when it was possible to attend the exhibition and view posters. At 11am there was a low-key press conference for the Many Stories One Voice contest and winners. The youth award went to Sean Lucas of the UK and I accepted his award in his absence. The adult award went to a lady from India.

At lunchtime, the Chapter Presidents met with the Executive Committee to discuss the administration of activities within ISAAC; setting up Google groups for more effective communication; changing the format of the Council/Board meetings for future conferences to one meeting rather than an outgoing board meeting and an incoming board meeting; potential sites

for ISAAC in 2012 (no decision yet); the work with the United Nations; and a host of smaller items. Finally the importance of LEAD, READ and BUILD – there has until recently been very little information available for Chapters so we should keep an eye out for future information.

During the day I had numerous meetings with UK delegates, especially with some concerns about the make up of the new board – three of the new Executive members will be living in USA and one in Canada.

#### Papers attended:

- Toby Hewson – *Come to My House*. This is a paper Toby presented at CM2007 (I was unable to attend in the UK) and covered his journey to his current home with the challenges he has overcome on the way.
- Diane Bryan, Martin Pistorius, Mel Smith, Sarah Lever – *Leadership amongst people who use AAC* – ISAAC's project LEAD. Diane began by talking about what are leaders, with examples. Martin, Mel and Sarah have all taken part in versions of the Temple University ACES programme.

Diane asked five questions about their lives and the importance of leadership which they each answered. As a young person who uses AAC and following her involvement in the pre-conference workshops, Beth was also asked to answer the final question about the importance of leadership for people who use AAC. Responses from all four are due to be posted on the ISAAC website.

#### TUESDAY 5 AUGUST 2008, 9AM TO 5PM, FOLLOWED BY THE MEMBERSHIP MEETING

Again a full day. Before lunch there was the Words+ presentation by India Ochs, a thought provoking piece about modern day slavery in the Western world. Toby Churchill was presented the Fellowship Award which was collected by Simon and will be awarded to Toby at CM2008. Unfortunately, the membership meeting wasn't well attended as it was poorly advertised.

#### Papers attended:

- Susan Baladin – *Providing feedback to research participants with complex communication needs*. A really interesting session about the various ways in which researchers have provided feedback to participants, the ethics of providing feedback and the benefits participants get from this. Emphasis was on avoiding reliance on normal dissemination routes as these were inaccessible to participants.

Methods used included focus groups, video footage, 1-1 sessions, and for a poet writing poetry.

- Meredith Allen – *The Power of Speech*. A well structured presentation about the impact of words, first looking at the speeches of well known orators and then moving on to talk about how AAC empowers people. Meredith used anecdotes from her own experiences which made the session interesting and real.
- Mel Smith, et al – *Out of the Box: Using Technology to follow your dream*. Mel led a version of the Temple University ACES programme in Australia. Temple run the course as a two week residential block but in Melbourne this was run as four weekend courses over a year covering four blocks: 'Daring to Dream', technology, communication and advocacy & leadership. The session used visuals and examples of the delegates experiences to explain the process and what they achieved. Great session.

#### WEDNESDAY 6 AUGUST 2008, 9AM TO 5:15PM

Started at 8am with a meeting with Sarah Blackstone and Janet Scott to discuss details of CM2008.

Once more a busy day, Cathy and I presented our paper on 'Sharing Resources across the ISAAC Chapters'. At lunchtime there was the Chapter meeting attended by around half the delegates from the UK.

#### Papers attended:

- Cathy Harris and Liz Moulam – *Sharing Resources across the ISAAC Chapters*. Sharing the *Focus On* range of leaflets and the *Power of Communication* DVD with other Chapters and giving them permission to translate providing they credit Communication Matters with the original work.
- Mel Smith and Libby Price – *Our European Adventure*. A humorous look at Mel and Libby's trip to Europe for ISAAC 2006. They spent much time planning to ensure that all Mel's access needs could be met yet came across many challenges.

It was a salutary lesson for all people who use wheelchairs to check out what people mean when they say they have a lift (how big is it?) and the bathroom is accessible (does it have rails? suitable toilet seat? walk in shower?) and ensuring that pre-booked trains and public transport provide a wheelchair space of the right size/shape.

This could have been a much longer session as they had to skip a lot of the challenges due to questions from the audience. Thought provoking!





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- Alan McGregor – *Me and My Twin*. An interesting and entertaining look at Alan's childhood and life to date with an able-bodied twin and what this has meant for school, work, travel and life in general.
- Beth Moulam – *Life is Beautiful If You Let It Be*. Beth presented completely independently using a switch for PowerPoint, and her Lightwriter. A well attended session. I am, of course, biased!

#### THURSDAY 7 AUGUST 2008, 9AM TO 4:30PM

Once again a non-stop event, meetings with Caroline Musselwhite to discuss the proposed study day for spring/summer 2009. Discussions with Janet Scott and then various other people about the UK research strategy culminating with talking to Annika Dahlgren Sandberg from Sweden who is the winner of the 2008 AbleNet award. Annika has subsequently agreed to join the Independent Research Panel.

#### Papers attended:

- Janet Larcher – *Special Measures Procedures and the Role of Registered Intermediaries in the English Legal System*. A fascinating look at how the intermediaries scheme has developed and what part it plays for people with communication impairments and how the intermediary works with the judge and legal teams. To be presented at CM2008. The interest meant that Janet ran out of time due to the questions from the audience.
- Toby Hewson, Janice Murray and Janet Scott – *Findings from a leadership programme set up in the UK with people who use AAC*. A comprehensive look at the process taken to appoint the UK Leadership Trainee including the rationale and experiences of the Deputy Chair who uses AAC. A good base from which to do a followup session at CM2009 and ISAAC 2010.
- *AbleNet Literacy Award/Distinguished Lecture* by Annika Dahlgren Sandberg, Sweden. \*

Liz Moulam

Chair of Communication Matters / ISAAC-UK

#### JOAN MURPHY WRITES...

At the main conference I chose sessions relevant to both my clinical and research work and brought back handouts, papers and notes to share with colleagues. For me, the presentations relating to adult-acquired difficulties were of particular clinical relevance and these included:

- Personnel framework for ALS (L Ball, USA)
- AAC decisions for people with aphasia (J Lasker, USA)

- Visual Scene displays with people with aphasia (A Dietz, USA)
- Text messaging with picture symbols (M Buchloz, Sweden)

The most exciting presentation in relation to possible future research was given by Barbara Collier on *Access to Justice for people who use AAC* and the wackiest presentation was *Six Speaking Chairs* by Graeme Pullin from Dundee. As always, the discussions between and after the formal sessions with colleagues from around the world were particularly enjoyable and fruitful.

I am very grateful to Forth Valley NHS and the University of Stirling for their support in helping us to attend the Conference. \*

Joan Murphy, AAC Research Unit, Stirling

#### SANDRA HARTLEY WRITES...

ISAAC was a very busy conference and exhibition with a great buzz about it. The pre- and post-conference sessions were excellent and extended an already packed week but with little feel of 'chore' about them. It is always great to hear about what is happening around the globe in the world of AAC.

The exhibition itself was non-stop, with lots of excited overseas delegates interested in our new SL40. International delegates were keen to see what was new and find out when things would reach their countries. We were a big team but none of us had a moment to spare!

The organisation of the event was fantastic, a hard act to follow, but follow we will as the ISAAC Biennial Conference heads off to Barcelona in 2010. \*

Sandra Hartley, Toby Churchill Ltd

#### "LIFE IS BEAUTIFUL IF YOU LET IT BE" PAPER PRESENTED BY BETH MOULAM

*'For millions of years mankind lived just like the animals. Then something happened which unleashed the power of our imagination. We learned to talk.*

There is silence surrounding me, I can't seem to think straight

I just sit in the corner, no one can bother me

I think I should speak now, I can't seem to speak now

My words won't come out right, I feel like I'm drowning

I'm feeling weak now, but I can't show my weakness

I sometimes wonder, where do we go from here

*It doesn't have to be like this*

*All we need to do is make sure we keep talking'*

Pink Floyd (1994)

The song is by Pink Floyd, I have used these words to open all my presentations for over 2 years because the words are so powerful for me. It is how I felt before I had an electronic communication aid. I have always been able to talk, and I will never stop, but some people will never understand me. Having a communicator means I can give context to my speech or have a spontaneous conversation.

The paper I gave in Montreal shared why ISAAC is so important to me, what I got from going to the ISAAC 2006 conference in Düsseldorf, Germany, and what a brilliant difference it has made to my life. I explained that the last two years haven't all been good, I have had some black times too, so my talk was about what happened and how the low times have made the good times better.

Two years ago when I went to Düsseldorf, I was 12. At that time I talked about my life, the challenges of learning to use a communication aid, my different equipment and my aspirations for life. Looking back the most important thing about Germany was not the people I met from around the world, it was the friends they have become. They come from Australia, Germany, Austria and Hungary. Many of them are so special they have helped me to understand and make sense of some of the challenges in my life. Some have motivated me to write poetry and I will share some of this below. I only write poetry when I am feeling really happy or sad, angry or excited. Somehow I can't do it at any other time.

At the end of my presentation in Germany I got many questions. It made me realise people were really interested in how I felt when I was young, and first learning how to use a communication aid. It also made me feel special. They waited for me to answer questions and during the rest of the conference they kept coming to talk to me. I even had a researcher ask for my opinions about her research. Eventually I took part in her study about teenagers and our identity.

Düsseldorf was so good that I felt on top of the world. I loved it that people had time to talk to me. I felt safe so I spent time on my own without Mum and Dad, and I've spent two years dreaming about being at ISAAC in Montreal. But, it wasn't all good. When we got back home from Germany I became really unhappy and it took a change of school to make me be myself again.

When I'd started mainstream secondary school in September 2005 everyone was sure it was the right choice of school.

Unfortunately it didn't last. By the end of the first year things were starting to change. My homework was taking about 15 hours a week and I struggled to do my end of year exams with little help. No-one believed I'd done a presentation in Germany, even with the photos. The video had broken so I couldn't show them that. They also seemed to think that making things right to start would mean I would be cured and suddenly able to do everything like the others. In the end I stopped trying to communicate except with one teaching assistant and to answer questions in class. Why should I make all the effort if they didn't try too?

Pink Floyd suddenly seemed a bad idea too. I had it on my alarm clock and instead of making me feel good it made me want to stay in bed and hide. I kept thinking, where do I go from here? Over a few months I became ill. Some of the teaching assistants were unhelpful. When the work wasn't made accessible, I had to type. They kept telling me to type faster and started giving me lots of typing tests. Even now I can only do about 9 or 10 words a minute. I could never finish the work. After Germany I knew life could be better. As things got worse I wanted to spend time in my world. My world is all the places where people understand me.

My world is very special. I think this poem sums it up. It was written as I waited to be able to go to the next ISAAC conference.

### Montreal

It is now next year,  
That doesn't seem so long.  
Six months down and only eighteen  
more to go.  
I can't wait to see you all again, in my  
world.  
A place where you will give me time, to  
express my feelings, fears and hopes.  
  
We know the dates, August 2008.  
The time, for 5 whole days.  
The place, Montreal, Canada.  
A world away. MY WORLD!  
I'll see you there, I know I will,  
And we can make it OUR WORLD!  
Oh yeah!  
You are my friends.

Lots of people helped me through my tough time. Montreal was written for Meredith Allen and Mel Smith from Australia. Mel has inspired me to carry on writing my poetry. Toby Hewson is there for me too, he is like a big brother. Everyone at ISAAC is very special – they take the time to listen and to understand me.



In the big wide world people just don't get IT which is why I am so comfortable with people who know about AAC.

I'm just a teenager like my friends. I made a sign because sometimes it annoys me when people stare at me when I'm out. I do just the same things as other teens. I love shopping, eating out, the cinema, music and dancing. I go to London on the train and into my local town on the bus. When I'm older I intend to drive, work, live independently. I hope to have a family. The challenge is to get people to see me, not my chair or my communication aid.

My new school gets 'it'. I wrote this poem a few weeks after I went to Valence.

### My School

Valence is my school,  
Valence feels like home.  
The place I feel I have a proper  
education.  
No fuss, no worries.  
We just get on with it.  
They look after me, they understand  
me.  
Now I know how unhappy I was before.  
  
Thank you Valence.  
You are like my family.  
You care, you smile, you listen.  
Everyone is very kind.  
You make me feel confident,  
You make me feel happy.

Another part of my world is One Voice. This is a charity that put on activities for children and young people who use augmentative and alternative communication. This is where I first met role models, including Toby. With them I am growing up with other teenagers like me. This year we have done about transition to adult

life. Last year we made a film called 'Listen to Me'. The film is on YouTube ([www.youtube.com/watch?v=v5ZiUnU80eo](http://www.youtube.com/watch?v=v5ZiUnU80eo)) and we have won some awards, including the Diana Award given by the prime minister. I did the film because it's really important for people to know how we want to be talked with.

When we went to Düsseldorf I found lots of things I wanted at the exhibition. I got a mount nearly straight away. I am now on my fifth different communication aid in 10 years as I have moved on to be good at reading and spelling. The latest is the new Lightwriter, they must have heard me say what I wanted! I still think the Lightwriter is incredible, getting the right communicator is very important. Everyone, whatever age they are, needs a voice.

For two years now I have been telling people how I feel about being a communication aid user. I have done several presentations and some training courses plus been in The Times newspaper and I'm going to a conference in Greece soon too. I know I can't speak for everyone who uses a communicator because we are all different, but hopefully I have been able to let people know that having a voice is essential and what it feels like to be different.

This is my summary of the last two years. It has been a bit like a fair ground ride.

### Since Germany

On a high.  
Whoops.  
Down and low,  
sad and slow,  
sick and tired,  
bored and blue.  
  
Pulling up.  
High in the sky.  
Bright and light,  
laughter and joy,  
sun and shine,  
life is mine.

In summary, I am what I am (I heard Shirley Bassey sing this on the TV when they showed Glastonbury), and I'm happy to be me. ISAAC makes me feel good and feeling good helps me deal with the challenges of life. I am looking forward to Barcelona in 2010 – see you there!

By the way, Mum won't let me come to Communication Matters Symposium, she says I have to be at school. But I hope one day soon to join you there too. \*

Beth Moulam, Student

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# Travels with My Laptop

SARAH EZEKIEL



*Standing is Scary*



*Funky Me*

I was diagnosed with Motor Neurone Disease in April 2000 whilst seven months pregnant with my second child. At the time I couldn't have envisaged the way in which my life would change completely. My only apparent symptoms were slightly slower, slurred speech, weakness and muscle wasting in my left arm. They appeared suddenly in February that year and I thought perhaps I'd had a mini stroke. Looking back I've realised that my very first symptom, emotional lability, started around April 1999. I would laugh or cry excessively and inappropriately. One memorable incident was when I was driving daughter Aviva and my mum home from a shopping trip. Aviva was rude to my mum, and my mum told her off. I attempted to do the same, because I was extremely angry. All that came out was hysterical laughter. My mum refused to talk to me for several days after that and I was seriously bewildered!

Soon after giving birth I experienced rapid loss of motor skills in my hands and within a few months my legs became weaker. After several painful falls, I started using a walking stick, then a frame, and now a wheelchair. I was 34 years old and I became a non-entity in my mind, and as my speech worsened, was treated as one by the majority of people. It feels like I'm a foreigner in my own country speaking with a MND accent! Things often get lost in translation which is frustrating but also amusing sometimes. Getting my laptop

with the *EZ Keys* communication software made me English again, or should that be American?!!

After I was diagnosed, I found myself on an emotional rollercoaster. I divorced my husband in 2004 and was awarded full custody of our children. We have 24 hour care, for which I'm extremely grateful.

I started attending my local hospice in April 2001; they now take care of all my medical and palliative needs. I really wasn't keen to go there but believe it has literally been a life saver. When I first went there I was a skinny, depressed wretch! I felt that my GP was frightened by my condition, but the hospice medical director knew how to help me. I slowly regained my confidence and some weight and no longer suffer from depression. I attend their gym twice a week and believe that regular exercise has helped me to stay mobile. I've also had several alternative therapies at the hospice, including hydrotherapy, aromatherapy and reflexology. The hospice is a wonderful resource which has helped me to live and enjoy life.

Having been an extremely active woman, losing the use of my arms was devastating. I started to miss practical things like using my computer, reading books and newspapers, writing letters and everything else that we all take for granted. The first piece of equipment I asked for was a page turner to enable me to read. I was told that they were ineffective and very ex-

pensive. With a young baby and myself to tend to, my carer didn't have time to sit with me to turn over pages. So reading was *out* and how I missed that. I consoled myself with audio books but they weren't the same as seeing the words and being able to go back and read bits again.

As my speech deteriorated my speech and language therapist arranged for me to get a Lightwriter with a pressure switch that I operated with my foot. The pressure on the switch had to be constantly adjusted with a screwdriver. I never used it.

As already mentioned, one of the greatest things to have happened to make all this bearable was obtaining my laptop. My MND Association visitor told me she had seen a man with MND using a laptop with a chin switch. Hector Minto from Possum came to demonstrate a laptop at my house in December 2004, and the rest, as they say, is history. I am constantly in contact with the outside world and do not feel socially isolated any more. I'm never bored and I can read e-books, which is bliss.

I soon started to look for a new challenge. I considered Open University but they only had one course that I could do on-line. My brother suggested I write my story and I started in August 2005. I kind of got way-laid by other events but I do intend to finish it. It has sex, drugs and rock & roll – so it has got to be a bestseller!

Possum asked if they could take some PR photos of me. When their photographer,

*continued on page 35...*



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# From Autumn to Autumn

**TERRY GIBSON & MICHAEL REED**

Email: [terryjohnmick@yahoo.co.uk](mailto:terryjohnmick@yahoo.co.uk)

A busy year of AAC awareness raising and other activities for a mother and her son who uses AAC

**We have had a very busy AAC year – too much to fit into a single article. This is just the first instalment! First of all – where have we been and what have we been doing?**

## **1VOICE – ‘UNDER THE SEA’ BLACKPOOL, NOVEMBER 2007**

We had a great time at the 1Voice ‘Under the Sea’ weekend. This was also the first experience for our friend Dawn and her son Jake of being with this very special group. Michael was a trainee Role Model. He welcomed families on the Friday evening, and then helped with the siblings’ movie workshop on the Saturday. We filmed snippets of the whole weekend and the performance ‘HMS 1Voice’ on the Saturday evening, which Katie Clarke introduced as the next 1Voice Number One hit, and aptly so. It really was brilliant, with another cool music track from Andy.

## **29 DAYS CREATIVE ADVENTURES IN LIFE PLANNING – FEBRUARY 2008**

In February 2008 County Durham Adult Services and Cap A Pie Theatre Company hosted a month of workshops at The Store, Dipton, where artists worked with 100 adults with learning disabilities doing drama, animation, movie production, felt

making, collages, digital image profiles and full-sized body images. Their aim is to make every participant a Person Centred Plan and a personal DVD of their part in the workshops. The overall DVD of the month arrived last week and the personal DVDs could be ready by Christmas.

Jane Few Dodds from New College Durham ran the Body Image workshops. She gave Michael a set of labels to stick on his picture and write on about his life and life goals. He was enjoyably engaged for two days while she and Adult Services staff gathered information about him and the other participants.

We used Jane’s idea in our own workshops get to know each other, and then adapted the activity for story ideas and story character profiles by using a different set of labels. We plan to take the idea further and make Communication Passports and Person Centred Plans with our friends.

## **LEARNING DISABILITIES PARLIAMENT 10 APRIL 2008**

Michael was the guest speaker at the County Durham meeting of the Learning Disabilities Parliament. He talked about: his time at the 29 Days Festival; his health; how he communicates; his interests; the



Michael at Body Image Workshop

1Voice Listen to Me project and Diana Award; Scope’s No Voice, No Choice campaign launch at Westminster; AAC Role Models; Communication Matters; and ISAAC International AAC Awareness Month. He invited everyone to come along to our *Many Stories – One Voice* workshops. He showed the 1Voice *Listen to Me* and Communication Matters *Power of Communication* DVDs, and his presentation had lots of pictures to support everything he talked about.

June was election time for the Parliament, and on 3 September Michael was sworn in as MP for Sedgfield Locality. He is Minister for Arts & Media and Minister for Communications.

## UN Convention on the Rights of Persons with Disabilities

At 'Any other business' Michael asked the Parliament to petition the UK government to ratify the UN Convention on the Rights of Persons with Disabilities. He presented Members with the December 2007 special issue of the Rehabilitation International Review journal about the Convention, a CD with the PowerPoint presentation that RI delivered at the ISAAC Conference in Montreal, articles about the Convention, and a template letter that the Parliament, and any other organisation can personalise, sign, and send to the Prime Minister.

At the first locality meeting after swear-in Michael introduced the Convention by showing a cut down version of the RI PowerPoint and using ReadPlease to read the text that he cut and pasted from the PowerPoint, and Articles 21 and 24 that we had copied from the UN website.

Interest was high and there will be an hour long workshop at the next full meeting in County Durham Council Chambers on 17 November. Hopefully the Parliament will act quickly as we think other organisations that are petitioning the government are asking for Ratification by December.

### MANY STORIES – ONE VOICE WORKSHOPS APRIL-OCTOBER 2008

We did our first two workshops in April at Chilton Community College and The Store at Dipton. Michael gave talks on *What Makes a Good Story*, and we painted full-sized body images of ourselves that we used to illustrate our story characters – us.



Michael with the Mayor of Chilton

We held another 20 workshops in libraries and community colleges around the county, those closest to where we live and go to school. We talked about who, what, where, why, and did some character profile work and storyboarding. We all had issues about not being able to talk to our friends at school who have no AAC at all. We thought about which words would be most useful to put on the eye-gaze frames we designed for our friends in our story, *The Winning Ticket*.

In October we read our own stories and some others from the *Many Stories – One Voice* Online Collection at three libraries and two schools. Students from another two schools came to hear us at the libraries. Our readers used Michael's communication aid, the *ReadPlease* free text-to-speech programme, and audio recorded into the PowerPoint stories to read aloud. We printed out a selection of the stories and gave them to the schools, along with *Many Stories – One Voice* book-marks, and 1Voice Newsletters and leaflets for each group. Chilton Mayor and Town Clerk came to our first reading.

We live far apart with going to special school so we travel 50 or 60 miles before and after a workshop picking up and dropping off. At most of the later workshops we had just Michael's car, Mum driving, and either three friends, or a helper and two friends.

We hope to become a funded Arts and AAC research project, so we can carry on working together and include more people, learning and teaching as we go by using special information from ISAAC and Communication Matters experts in our workshops, and making something of it all that we can share and present.

### 1VOICE TEENAGER'S PROJECT – JULY 2008

This year's theme was 'Lost in Transition'. There were transition workshops for teenagers and parents. On Sunday the teenagers gave presentations about transition. Scope filmed the weekend to go towards the AAC DVDs they are making as part of their BT Funded No Voice, No Choice campaign.

Sadly, some of us are too old to be 1Voice teenagers next year, but we hope to work together more on our transition and becoming AAC Role Models. We are sure this is not the last exciting project we will do with 1Voice!

### ISAAC CONFERENCE, MONTREAL AUGUST 2008

Being with 1,200 people with a common interest – AAC – was absolutely out of this world. Meeting up with friends from the UK, and people whose work we have appreciated for years or who we have worked with via email and Skype, but not met; the seminars, the social programme, the people... It was all brilliant.

At the *Many Stories – One Voice* press conference Michael introduced Josh and Caleb Hurd's reading of the winning youth story, *MI6 Rescue*, from Sean Lucas, UK, and ISAAC President Sudah Kaul's reading of the winning adult entry, *The Undefeated*, by Barsha Battacharya, India.

Michael described the AAC Awareness Month at the People Who Use AAC committee meeting, and we uploaded a movie clip of it to YouTube [www.youtube.com/watch?v=\\_pBbdyBD9ME](http://www.youtube.com/watch?v=_pBbdyBD9ME).

There's a lot more video material to come.

We tried to get to as many Literacy and language-based AAC workshops as we could, and filmed everything. Information in movie format is so much more accessible to many than written papers and reports, which some people don't or won't read and some can't read. Now Michael has some very special memories, and very special knowledge that he can re-visit, share with others, and use to verify our own work.

### COMMUNICATION MATTERS NATIONAL SYMPOSIUM – SEPTEMBER 2008

At Communication Matters we got to a good selection of workshops by friends who use AAC – Alan Martin, Danny Stanton, Toby Hewson. Congratulations on your independence, Danny! Michael wants to be on your waiting list for some excellent training in being a Role Model, Toby. The students from Newman School presentation, *One Year in Film*, was wonderfully familiar – they wrote this as a story for *Many Stories – One Voice*, and their other story, *Hide and Seek*, is one of the stories we have been printing out and giving to schools.

Michael slept on a comfy leather couch outside Bruce Baker's presentation, *Saving Time in the Classroom for People Who Use AAC*. He missed a few workshops due to headaches – which he has had a lot of recently due to a cerebellar abnormality.

Luckily we filmed Bruce's workshop, and have a further two hours of footage of Bruce at ACE Centre Oxford, 26 September, where he gave his excellent critique of standardised testing, an overview of all the standard tests currently used, lots of information on language acquisition, and how to level language intervention at the mental age given for a person via a standard test.

All of these activities and presentations have given us ideas and we have been working hard on three key areas in particular:

1. Vocabulary selection and organisation
2. Using Powerpoint to help read stories (and potentially as a communication aid)
3. Literacy teaching and learning, and campaigning for these.

*Read on below for a 'taster' of some of these ideas and developments...*

### CORE VOCABULARY RESEARCH

We co-wrote with friends a story for the *Many Stories – One Voice* collection, called



*Piggy's AAC Phone* ([www.symbolworld.org/stories/cm\\_stories/24/01.htm](http://www.symbolworld.org/stories/cm_stories/24/01.htm)). As an experiment, we used the Highlight feature in MS Word to blot out all the high frequency words from the research by Marvin et al: *326 Words of Highest Frequency collected from six 3-4 years old speaking children in 3 classrooms*. (Language sample compiled by Marvin, Beukelman and Bilyeu. Wordlist provided by Prof Bruce Baker, Portland College, UK, March 2003.) This was to prove how essential these high frequency words are. We found that without them, the story was mostly gone and just made no sense.

We then also counted all the words in Piggy's song, *A Little Help from My Friends*, and checked to see how many of the words are in the 440-word General Core Vocabulary\*. This was to find out how useful the core words are. We found that the answer to this was 75% of the Total Different Words, and 85% of the Total Running Words. This result verifies resoundingly the choice of vocabulary added to Piggy's phone in our story.

In the story, Piggy is sending the lyrics of her song to her music-composer boyfriend by text message, and having to press each button up to 4 times just to type one letter. Her new cleaner, a char-

acter based on the Hoover Z vacuum with a Pathfinder communication aid for its foot, comes into the room.

Z can say and type whole words with just 2 button presses, one to select a word group, and one to select a word from that group. He connects himself to Piggy's phone and quickly sends her song for her. Then he calls upon his friends, the linguist, the language analyst and the computer programmer, to make an AAC system with 440 core words for Piggy's phone, so that from now on she can send 85% of her words with just 2 button presses.

Many, many disabled people are not given access to or taught these core words.

Watch this space for more ideas... \*

Terry Gibson & Michael Reed

#### FURTHER INFORMATION

The transcript of Michael's 'What Makes a Good Story' talk can be read on the Story



'Miss Piggy's Phone' story for the *Many Stories - One Voice* writing contest

Tips page of the AAC Awareness website [www.aacawareness.org/story.html](http://www.aacawareness.org/story.html)

The *Many Stories - One Voice* Online Writing Collection of over 100 stories, essays and poems, written by people from 13 countries, aged between 6 and 65, and who all use AAC, can be downloaded from: [www.aacawareness.org/index.htm](http://www.aacawareness.org/index.htm) The UK story entries can be read with symbol support at [www.symbolworld.org/stories/cm\\_stories/index.htm](http://www.symbolworld.org/stories/cm_stories/index.htm)

The core vocabulary wordlists mentioned in this article can be found at [www.aacawareness.org/Vocabulary.html](http://www.aacawareness.org/Vocabulary.html)

...continued from page 31 *Travels with my Laptop*

Simon Donnelly, showed me his work I knew that he could capture the way I feel about MND. He very kindly borrowed a studio in London and brought a make-up artist. It was a wet November day when I had my first photo shoot, and it was real fun. He indeed saw the complexity of my disease, my pain and mobility problems. I still like to look funky and have an exuberant love of life which I hope shows. The photographs have helped me to draw attention to MND and I'm very pleased with them.

Social networking sites have become an invaluable tool for me to raise awareness of MND. I use Myspace and Facebook to blog about life with my illness. As I can't speak well the internet is a great way for me to connect with other people. I am now featured on websites such as DIPEX and the MND Association, where I share my experiences of MND. I'm also a member of patientslikeme. Their goal is to enable people to share information that can improve the lives of patients diagnosed with life-changing diseases. To make this happen, they have created a platform for collecting and sharing patient data and are establishing data-sharing partnerships with doctors, pharmaceutical and medical device companies and research

organisations. I find the forum incredibly useful to discuss and share information with other patients and carers. I no longer feel so alone since finding patients like me. Everyone there is very supportive, from other patients to the admin staff. We are a great international MND community!

My most recent project was helping to make an advert for the MND Association. It basically shows a woman going through every stage of MND until death in sixty seconds. I was the body double to show the deterioration that MND causes physically. My first film set experience and I really enjoyed doing it. I had to take part in some of the final scenes, wearing only underwear with a crew of about thirty strangers. It was set in a freezing room and there was lots of hanging around but it was a fantastic experience. It's called 'The Unseen Assassin' and should be shown in cinemas before the feature film. I think the advert will be shocking and disturbing but MND is a terrible illness, so I believe the film is an appropriate representation. Hopefully, it will raise more awareness and we will be nearer to finding a cure. The director, Jim Weedon



and all of the crew, gave their time for free to make this advert.

I enjoy this part of my life very much and I'm pleased we have the technology to enable me to speak publically. I thought my diagnosis of MND was the end of my life but I now think that it was the start of a more interesting one. I'm grateful for every moment with my children who are growing into kind and caring individuals. I think they have benefitted from seeing MND close up. Although I wish that I were able to do more with them physically, I like to believe they haven't suffered too much because I'm ill. \* Sarah Ezekiel



# Supporting Children Who Use AAC in Mainstream Education

## Tips for fun, motivation, and success

### DAISY CLAY

Specialist Teacher Advisory Service, Hampshire Children's Services, UK  
Email: daisy.clay@gmail.com

I entered the world of AAC in October 2006, fresh from university with no experience of AAC beyond the preparation I had carried out for my job interview. If I am entirely honest, before becoming aware of this opportunity to work with children using communication aids, my only prior awareness of AAC users was what I had seen and heard of Professor Stephen Hawking himself! So it is safe to say that the learning curve was steep, and now as I look back over my time in the field of AAC, it astounds me to realise just how much I have learned (not to mention how enjoyable and fulfilling the experience has been).

What prompted me to put pen to paper, well, fingers to keyboard, are the particular successes that occur time and time again in my visit notes. That is, there are certain activities and ideas that I have found to work especially well, whether my aim has been to demonstrate to the child the value of their communication aid for participation and social interaction, or to motivate the child to use their communication aid by enabling them to have fun with it. It is these activities and ideas that I will share with you now, and I hope that they may be as useful to others as they have been to me.

My role is to support children who use voice output communication aids (VO-CAs) in mainstream education in Hampshire. This involves working with the children, their families and staff in schools, giving advice on how to program the VOCA, what to program, and how the VOCA can best be used in class. Whilst the children use a variety of VOCAs between them, from light tech to high tech, it is the work that I have done using high-tech dynamic screen devices that I will be referring to.

However, I should add that these ideas are by no means my own unique and original creations – my training and experience has involved a great deal of shadowing and working with other AAC professionals, from whom I have learned so much – and these ideas are, in my opinion, the best bits of the practical experience I have gained from this. (I would especially like to thank Jane MacKenzie and Janet Larcher.)

So really I am just spreading the word, just as the words were passed to me originally! What is key is that they are the ideas that I have found most successful. This article is based mainly on my experience with children in mainstream primary and



Thomas happily telling me his news. On this particular occasion he was telling me that he had gone sailing at the weekend, and got really really wet!

preschool settings, although it is hopefully all transferable.

### **"AND WHAT DID YOU DO AT THE WEEKEND?" - THE IMPORTANCE OF A HOME-TO-SCHOOL NEWS PAGE**

Observe any mainstream classroom on a Monday morning, and you will find children excitedly discussing with their peers what they did at the weekend – where they went, what they did, who was there. Often, there is a dedicated time slot for children to share their news with the rest of their class. For children using AAC, the role of their communication aid in this can be vital.

For one child I work with, Thomas, his news page is undoubtedly his favourite page, and he loves to begin each of my visits to school by navigating straight to his news page. As physical access is quite difficult for Thomas, his parents program in each piece of news as a single hit message. When Thomas shares each 'news bulletin', he is able to communicate even more to you non-verbally, with the sparkle of his eyes and the swell of his grin at a particular time to let you know that his favourite part of going to the park on Saturday with Mummy and Daddy was going on the swings. He always has several pieces of news to share, and it just goes to show how busy the social life of a 6 year old can be!

For another child, Joe, who can find communication a daunting and difficult process, since providing him with a communication aid, creating a personalised news page for him seems to have been a huge success. Initially, Joe was very reluctant to use his communication aid. Now, several months later, Joe's mother makes sure that every week his news page contains the vocabulary he will need to share his news from the weekend. And Joe is usually keen to share this news with the other pupils in the class, something that he would previously have been unable to do. He has also been enjoying the praise and rewards that he receives for telling his news so well, and being able to keep everyone up-to-date with the latest superhero films.

#### "CAN I TELL YOU A JOKE?" (EVEN IF IT'S REALLY AWFUL!)

How do you make a sausage roll? Push it down a hill! Included in the pages of the *Infield Dynamic Vocabulary* (IDV) are classic jokes just like this one, and they have gone down an absolute storm with the children who have used them.

One boy I supported took several months to get over the hilarity of the joke about the frog's favourite drink... CROAK-a-cola. Yes, I can hear you groan, but he loved it, especially the added burp sound effect at the end! And importantly, something that the children enjoyed most about having access to a page full of jokes was the reactions they could elicit from other people.

A common goal among those supporting children using communication aids is to maximise their interaction and communication with other children, and joke pages serve this purpose excellently. James, who although at just 5 years old does not yet fully appreciate word-play jokes, quickly realised the positive reaction he could get by telling jokes. He has now learned the conventions of joke-telling: you start with a question or statement,



Home, School news page

wait for a response from your communication partner, and then reply with an answer – impeccably mirroring everyday communication. Although James may not fully understand the jokes themselves, he nevertheless loves to share in everyone else's laughter, sometimes to the point where he leans back in his chair, holds onto his stomach, and yells out his own raucous laugh!

#### ACCESS TO A KEYBOARD PAGE AND EXPERIMENTATION WITH LANGUAGE

Whilst some communication aid users will use text, others use symbols, and some use a combination of both. A child using symbols can also benefit from access to text using an alphabet page. Just as typically developing young children enjoy experimenting with language, be it through combining different speech sounds or writing letters on a page, many of the children I work with also enjoy experimenting in a similar way, although using natural speech or handwriting may be either very difficult or simply impossible for them. By providing the child with a keyboard page on their communication aid, I have seen various ways the page has been experimented with and enjoyed.

#### Writing their name

When a typically developing child in a mainstream school is presented with a pencil and paper, often, the first word they wish to write is their name. Similarly, when I have presented children with a page showing the alphabet, the response I have often gained without prompting is for the first word they write to be their own name. And for many,

they are incredibly pleased by this, just like the child with a pencil and paper.

#### Learning the 'important' words

Presenting one particular child with a keyboard page had fantastic results. After writing his name, the next words that Rupert wanted to write related to two of his favourite interests, 'titanic' and 'tank'. To do this, he wandered off without warning (not entirely uncharacteristically), and soon returned with his favourite book of the moment, all about the Titanic. Carefully studying the book cover, he placed his finger underneath the title and copied the letters into his communication aid, and was delighted to hear the word Titanic spoken back to him. Rupert then navigated to his 'things I like' page to find the word tank, which he selected and navigated back to the keyboard page. The word remained at the top of the screen, enabling him to copy the letters one by one, and again, he showed pleasure at hearing his carefully crafted words spoken. Furthermore, he showed pride in himself.

#### For communication

Rupert continues to delight in using his keyboard page, and although he is still



James telling me some of his favourite jokes

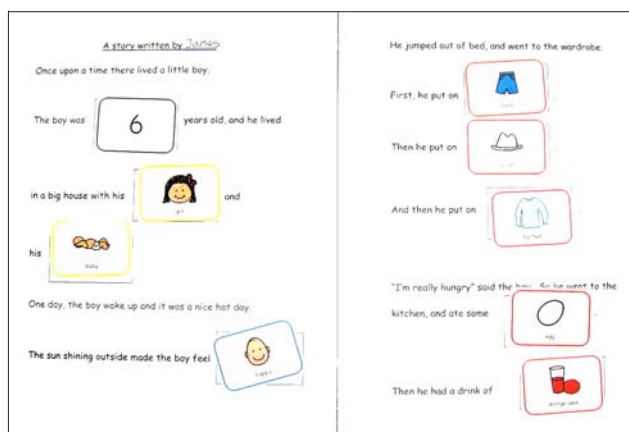


Photo of two pages from a story that James wrote, using a template I made, loose symbols made from screen prints from IDV A and his Dynavox V (and IDV A)



'Dear Zoo' IDV page

largely reliant on symbols, he is showing an increasing interest in communicating by spelling out key words (he has never been keen on those pesky little in-between words!). On a subsequent visit to see Rupert he used the keyboard to independently spell out the words "tiger", "tank", "book", and "home". When I asked if he had a book about tiger tanks at home, he confirmed this excitedly. (Not just any tanks, tiger tanks, and he is very clear on this!).

Not only is he learning new words in this way, the keyboard page has been a much needed renewal of his motivation to use his communication aid.

### Pure experimentation

An early memory from my own childhood is of combining letters randomly on paper and presenting them to my mother asking "What does this spell?". She often responded that "dspkg doesn't spell anything darling". I hadn't yet discovered the value of the vowel. And just as I had done, the children I work with like to play with letter combinations, yet a communication aid removes the need to ask someone else what that word spells thanks to the 'Speak All' function. Yes, this does provide mixed results depending on the software of the communication aid and the type of voice selected, but it's all good fun and a potential learning opportunity too.

### BLANKETY BLANK! WRITING STORIES FROM A TEMPLATE

Another of my childhood memories is relevant here. I used to love writing my own stories (often giving myself a starring role). For a young child using a communication aid there are many potential obstacles to this, particularly where all the 'little words' of language are concerned. So, to overcome this, I created a basic story template full of gaps that could be filled using words from most basic vocabulary page sets. For example, "Once

upon a time, there was a [insert type of person - girl/boy or man/lady]. They were [insert a number] years old. It was a [insert weather] day."

Not only did children thoroughly enjoy "writing" their own story, but it was a great way to assess how well they were able to find and categorise words. Another enjoyable aspect to the activity was that once a word had been chosen for the blank space, pre-prepared loose symbols were stuck in place with Velcro, so that the story could be 'read' to someone else (in some cases any passing adult who didn't get away quickly enough!). The children are also keen to cast themselves as the leading role in the story.

### READ-ALONG STORIES

Just as I have found story writing to be a useful activity, so is enabling children using VOCAs to read along with a story. The best stories for this are those with repetitive lines, such as "We're Going on a Bear Hunt" and "Dear Zoo". The *Ingfield Dynamic Vocabularies* (IDV) contain pre-made pages for this exact purpose, but you could make up your own pages for other books.

On one occasion, for example, I used the Dear Zoo pages from IDV with a child in his pre-school. The child enjoyed following the story in the book, using his communication aid to join in, as well as making use of a nearby box of toy animals. Part way through the story, two other children wandered away from what they were doing, eager to join in with the fun.

### PLAYING GAMES!

Playing games may seem an obvious motivator for

children, regardless of whether they use AAC or not, but the use of a communication aid within a game can serve other purposes too. All children love to win games, so this can be a great boost to the child's confidence in using their communication aid. Games are also good for encouraging social participation using a communication aid by involving other children.

I discovered "Kim's Game" not long after I started my job, and have made use of it so many times since then. I don't know exactly who Kim is, but thank you for your game! For anyone not familiar with the game, the premise is to lay out several objects on a table, and to have a page on your communication aid that lists these items.

Also on the page is a sentence starter "I think you have taken", as well as some game vocabulary like "I win" "your turn" etc. You then hide an object and the person using the communication aid must guess what has gone. It is great to take it in turns to hide the object, and for whoever is guessing to use the communication aid.

The adult can model how to play the game to the child in this way, and it is also a



Fat Controller game card





Fat controller game - Dylan and Mabel

Dylan is using the My Tobii on the right of the picture to ask his friend Mabel which engine The Fat Controller is hiding behind (see photo of the Fat Controller game card). Dylan usually uses a DV4 with head switches, but has been trying out the My Tobii as well. On this occasion he was asked if he wanted to use his DV4 or the My Tobii and he chose the latter.

great way to encourage children to begin combining more than one button press to form a sentence. I have also found that no amount of 'hamming it up' is too much for young children – "oh goodness, what *have* you hidden from me? Oh this is hard!". If the child particularly enjoys beating you, you can count how many guesses it takes you, just to heighten your defeat, and the fun.

At this point, I will take a step back and listen for a chorused reply when I ask the question "Have you ever worked with a child with a love for all things Thomas the Tank Engine?" For one such child, his LSA had already seized upon this, and created her own version of Where's Spot, or rather "Where's the Fat Controller?". (For anyone unfamiliar with the Spot the Dog books, on every page is a possible hiding place for Spot covered by a flap of paper which is lifted to look for the elusive animal).

For Dylan's variation of the game, a page was made for his communication aid containing some pictures of Thomas the Tank Engine characters. This page was then printed, laminated, and each character cut out to make a flap, and each character flap stuck onto a big sheet of card to create hiding places for the Fat Controller (also known as Sir Topham Hatt I discovered – perhaps it is no longer deemed politically correct to refer to his weight...).

Also on the communication aid is the sentence starter "Is

he behind...", together with celebratory vocabulary of "I'm right!". As well as encouraging two way communication, anticipation, and memory skills, Dylan loves to play this game, and so it serves as an excellent reward when he has been working hard (or a promised reward to motivate work in the first place!).

## FAVOURITE TOPIC PAGES

This may seem obvious to many already, but I felt it impossible to write about what

works well in supporting children with communication aids without stressing just how important it is to create communication aid pages that are dedicated to their favourite topics. As I have mentioned already, Joe loves superheroes, and so his mother created several pages about each of his favourite characters and he really likes to share this love of his with other people.

Not only is it highly motivating to be able to talk about things that you love, but it is just unfair for a child not to be able to access vocabulary about the things they are most passionate about. Who would want to talk about animals in general if you can't also tell someone about the menagerie of chickens, dogs, and guinea pigs

you have at home. I'm actually thinking of a particular child here, who has all these animals, and delights in telling people their names, and with good reason: Dora and George the guinea pigs and Rosie the dog have regular enough names, but her two pet chickens are named Korma and Kiev!

## ACCESS TO THE EXTRAS

Whilst the article up until now has focussed on the experience I have had with primary and preschool age children, when it comes to secondary school age children, there is a clear winner in what has been most appreciated – access to emailing and Instant Messaging!

Instant Messaging is where two or more people can chat over a network (usually the Internet) in real time, so person one types a message and sends it to the other, who receives the message within moments and responds with their own.

As my role is technically to support inclusion of pupils using communication aids (and their access to the curriculum), I feel that it is essential that where possible, pupils using communication aids have access to the same social practices as their peers.

Both the teenagers I am considering here are switch users, and so needed specially created pages on their communication aids to allow them access to emailing and Instant Messaging. *The Grid 2* Computer Control page set includes pages for just this purpose. I cannot stress enough how important I think this is, and I know they would both agree – probably using smiley 'emoticons'! \*

Daisy Clay  
AAC ICT Technician



Using MSN with Grid 2 and switches



# ESSENTIAL PUBLICATIONS

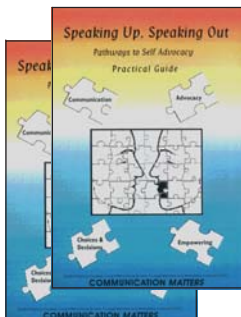
## FROM COMMUNICATION MATTERS



### The Power of Communication (DVD)

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

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



### Speaking Up and Speaking Out! Pathways to Self-Advocacy

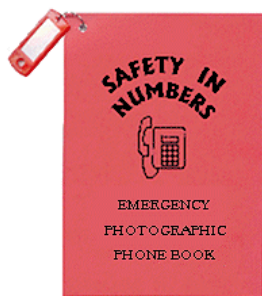
This pack is intended for carers, facilitators and others concerned with the advocacy needs of people with severe communication difficulties who need or use AAC. It is useful for staff development, especially for those working with adults. The pack comprises two books: a comprehensive Handbook and a Practical Guide.

Price: £30 including p&p available from **Communication Matters**

### Michelle Finds a Voice

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

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



### Safety in Numbers: A Photographic Phonebook

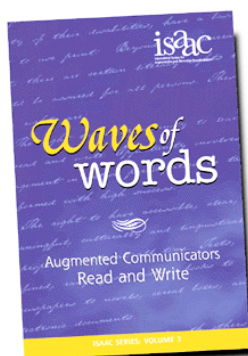
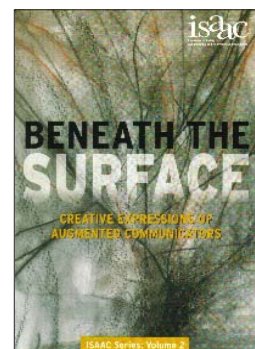
This photographic phone book is for people who find reading difficult. The pack includes an information page with key information about the person, several blank pages ready to add photographs or symbols, space for additional notes for an enabler, babysitter or other adult, a tag to make the book easy to hold as well as identifying the owner, and a page of symbols for common services printed on labels ready to stick in.

Price: £3.50 including p&p from **Communication Matters**

### Beneath the Surface

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

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



### Waves of Words

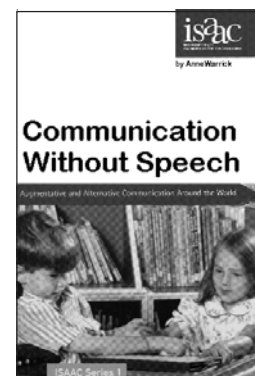
The challenges confronting individuals with severe communication disabilities are chronicled in this ISAAC book. The focus is on the strategies that teachers, therapists and individuals who rely on augmentative communication from around the globe have used to produce ultimate success in the struggle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

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

### Communication Without Speech

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

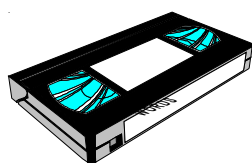
Price: £15 plus £1.50 p&p from **Communication Matters**



### In Other Words (ISAAC video)

This 30 minute awareness raising video was produced in the UK by Caroline and James Gray. It is an excellent introduction to the field of AAC and would be great to show parents and students from a variety of disciplines, as well as to staff new to AAC.

Price: £12 to CM members (otherwise £17) including p&p  
**ONLY AVAILABLE FROM ACE CENTRE (Tel: 01865 759800)**



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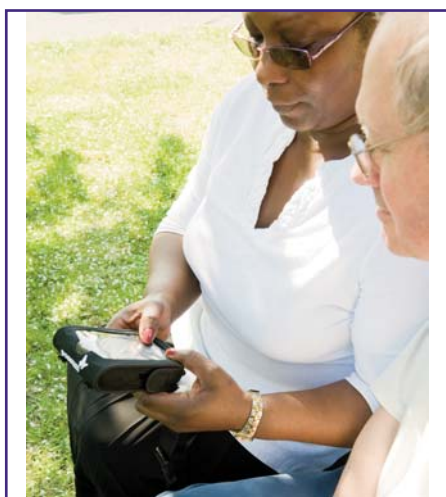


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