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REGULAR COLUMNS

COMMUNICATION MATTERS

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Journal Editors, Artwork & Desktop Publishing:
Sally Millar & Patrick Poon
The CALL Centre, University of Edinburgh
Paterson's Land, Holyrood Road, Edinburgh EH8 8AQ
Tel: 0131 651 6235 Fax: 0131 651 6234
Email: sally.millar@ed.ac.uk
CM Enquiries, Advertising and Overseas Subscriptions:
Tel: 0870 606 5463 Email: admin@communicationmatters.org.uk
CM Website: www.communicationmatters.org.uk
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Fight for Your Rights

WINNER
1999 CM Distinguished
AAC User Award

by Alan Martin

We are delighted to publish this paper by Alan Martin, the 1999 CM Distinguished AAC User. The paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

"Here's a fiver mate. Get yourself a drink." (Aside:"He can have a drink, can't he?") The young man was off the train with his bike by the time I'd prepared to tell him where to put his money! He meant it kindly. He thought he was doing a good turn. He'd have been amazed to know what I was feeling. If he'd thought, just for a moment how he'd feel if a stranger came up to him, and gave him money, he'd realise that it was really very offensive. I wondered what to do with the money.

Actually it would have been quite handy to go towards my phone bill, but I felt that I couldn't use it myself. It sat in my wallet patronisingly for a few days, then I found an appropriate use for it. A new group of people, all with disabilities, from Merseyside, are getting themselves organised to try to change conditions for disabled people. I went along to the first official meeting of the group, to see if it was for me. As usual there was a lot of talking, but everyone there was committed to making things change, by action of whatever sort it takes. We will be forming a company, to promote the social model of disability. To those of you who don't know what that is, then I'll tell you!

The social model of disability looks at disability from the point of view of an unhelpful society which places barriers in the way of people with impairments. I mean physical barriers such as steps, and barriers of rigid attitudes. We intend to fight for rights, not charity. For this to get off the ground we need to send letters, make phone calls and so on. I decided to donate my charity flyer to this cause. I know it will be well spent, but I doubt that the young man who gave it to me would understand. We need to change attitudes to disability right across society, from the highest level of government, through the medical and educational professions, right inside families, and among disabled people themselves.

...the medical model of disability was strongly in evidence.

I went to a conference in July, where the medical model of disability was strongly in evidence. This was not really surprising, as it was a conference for Health Service equipment store managers. I was the sole representative of all the consumers in the country. After I'd given my talk about my experiences of getting equipment to enable me to live independently in the community, many people came up to speak to me. The usual opener was, "Hello! Is this your carer?" I had to say again and again, "No. I have to look after her. She is my enabler. I am her employer. She does as I ask. Within limits, of course."

I find the word 'enabler' needs to be explained. Sometimes people mishear me and say, "Oh your neighbour, how nice." The difference between the two words is quite important. To me a 'carer' would be in charge of me, like a parent to a child, or a teacher to his pupil. A carer would look after my money, and decide how much I can spend, tell me when to get up and what to eat. A carer would make decisions for me, and take away all danger and excitement from my life. A carer would keep me clean, even if I felt like being scruffy. A carer would see me as a responsibility, and not as a real person. To me the word 'carer' makes me feel weak and childlike.

...the word 'enabler' is empowering.

On the other hand, the word 'enabler' is empowering. The enabler is there to lend me his strength when I ask for it. He or she is my employee. I decide what I want my enabler to do. I give the instructions and they will try to fill in for me those things which I cannot physically do. If I decide to keep out of date yogurt in my fridge, then that's my business. Enablers allow me to make mistakes, because that's the fastest way to learn. I take responsibility for myself, and I take risks. That's what makes my life interesting. I feel empowered by my enablers, not disabled and dis-empowered by them.

I try to use my Liberator to help me to change attitudes. Having a communication aid is a bit of a novelty still, to most people. I often get invited to speak and appear in places where I probably wouldn't get noticed without the Liberator. This gives me a chance to do some subtle disability awareness work. I am invited into schools to talk about social services, communication, discrimination etc. and disability awareness always comes into it. I've trained to be a dance workshop leader, and this work is partly to show that disabled people can be creative in spite of what is expected.

I had hoped to do a lot of awareness work by speaking on radio, and appearing on the television. I've been very disappointed to find that the answers to questions I'd prepared for in advance, and which had sometimes taken me weeks to do, were cut down so much that most of what I wanted to be broadcast was lost, and things were taken and used in a way that I would not have agreed to if I'd been consulted. I think that in future I'll get some agreement in advance about what goes out on the air. Many of you will probably get asked to give interviews to the media. I'd like to warn you to think carefully before you agree. I feel that it's okay to give live speeches, because nobody can shut you up once you've started.

I go out every day either on the train or in my wheelchair. I try not to let anything stop me from doing what I want to do. This means that I have a fight of one sort or another, almost every day of my life. This is the only way to really make able-bodied people see me as a real person and not just see the wheelchair. A lot of fights are over access. I've had a few successes in my local community so far. I won't give up until I've made my part of the world fit in with me, so that in my immediate environment I will not be disabled. All the struggles just make me feel stronger – is anyone apart from me, old enough to remember the 'Incredible Hulk' on TV? – I feel like that. Don't give up. Be strong. It's incredibly satisfying to win a battle, no matter how small. Things will get better eventually for people with disabilities. People like us will wear society down, drop by little drop. I want to see a great tidal wave, so that things change before I am dead.

> *The UK's Disability Discrimination Act is a very weak start to real change.*

The UK's Disability Discrimination Act is a very weak start to real change. An Act which is supposed to remove discrimination should be prepared from the start by people with disabilities. It's not much use consulting with them afterwards. I think that this piece of legislation is like the substance which sticks to my wheels and causes a great deal of trouble to get off. As you can see I'm a very polite person, but, it could have been so good but is just weak and full of loopholes. I am writing to Members of Parliament all the time about one thing or another. The more times they get the message the better. If there's something you really feel strongly about, then don't just sit and feel cross, do something. You don't have to apologise for demanding what is right.

My biggest, battle so far has been to get the issue of communication recognised as vital. My argument is that it is a basic human right to be able to communicate. It is a right, not a luxury, or an amusement.

I've spoken and written to those at the highest level of government about this. They say that they are aware of the problems over getting communication aids, but there is a limit to money and they have to prioritise. They say that more research needs to be done to find out how much need there is for aids, and to get figures i.e. so many needed per million of the population, and how much this will cost. But. In the meantime it's okay to waste millions on things like the Millennium Dome in London. It makes me mad to see money wasted on trivial things when there are thousands of people right now waiting for a voice.

Those of us who now have a voice, know what it was like before we had one. We have a responsibility to shout, loudly and bring this issue to the attention of everyone, for the sake of all those who still don't have one. I've got a friend right now; he's about my age. He's been assessed for a liberator. He has begged my enabler to help raise the money to get him one. It's not possible to raise all that money, and he is just one man out of very many.

I want rights, not charity. Surely the provision of communication aids is a basic right. I'm not saying this because I work for liberator. I don't. It's because I feel so strongly about it.

Rights, not charity. Rights, not charity.

Alan Martin
c/o Communication Matters, ACE Centre
92 Windmill Road, Oxford OX3 7DR

A Personal Perspective

by Scott Wood

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

My name is Scott Wood and I am 19 years old. From August of last year, I have lived in my own flat within a residential unit run by 'The Red Cross Society'. There is 24-hour assistance in the Unit to help me with my needs. I like living on my own in Irvine, Scotland. My family live in Ayr, which is only 25 minutes away by car.

Before I lived at Irvine, I used to go to Corseford School in Kilbarchan. I went there from when I was six years old until I was 18. 1 was a boarder there from Monday to Friday, so I was used to being away from home. This has made it easier to be in Irvine, and away from my family.

I go to Motherwell College on Wednesdays and Fridays from my flat at Irvine. I am doing a Communication course for users of Communication Aids. I am enjoying my course, but the travelling and early starts are a pain in the butt! I have cerebral palsy and have never had very much speech, and have used communication aids since I was able to recognise pictures and symbols. I began with a Bliss Communication Board, and used a keyboard on one of the school computers as well. I have been using a Toby Churchill Lightwriter for about two years now. It's been great and gives me a voice — although the accent could be more Scottish! 1 have an attachment to my power chair, which lets me take my Lightwriter with me, and gives me a voice.

I am a big Glasgow Rangers fan, and am a member of The Disabled Supporters Club. My favourite English Club is Chelsea.

Thank you for listening to me, and 1 hope you haven't been too bored!

Scott Wood
c/o Communication Matters, ACE Centre
92 Windmill Road, Oxford OX3 7DR

Life with Toby

by Malini Chib

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

Introduction

It is indeed a pleasure to be speaking in front of all of you who are experts in the field. Compared to each one of you I really am not sure what contribution I shall make, but I will endeavour to present a different perspective.

I am currently doing a part-time Masters in Women's Studies at the Institute of Education in London. I am also a Trustee of the Spastics Society of India, Bombay and in Madras. Having an acute speech problem like I do, I use a number of communication tools to facilitate me in interacting with the outside world. I use non-verbal gestures, the *Toby Churchill Lightwriter,* the computer and the Internet, and of course my own mode of speech! *'Toby'* is always with me for meetings. I feed in the question I want to ask and store them in *Toby's* memory. He has a good memory. When the opportune moment comes, I just press a letter, and then my question is spoken out and displayed. The difficulty is of course when I need to be online and have to ask a question as part of an ongoing dialogue.

My paper is in two parts, the first part will be life before *Toby,* and the second part will be life after *Toby.*

What is Communication?

Communication involves the interaction between two or more people. There are many means of communicating, including non-linguistic cues like gestures, body posture, facial expression, eye contact, sign and body language etc. Communication is vital for human development: to convey ideas, to express desires and feelings, for social interaction and for academic advancement. Hence it is very crucial to develop communication skills from an early age for a complete development of personality.

The right to communicate is both a basic human right and the means by which all other rights are realized. All people communicate. In the name of fully realizing the guarantee of individual rights, we must ensure: that all people have a means of communication which allows their fullest participation in the wider world; that people can communicate using their chosen method and that their communication is headed by others. (TASH 1994)

For a person who cannot communicate, its hugely frustrating, as he/she is unable to convey to the other person what she/he may need or want. So the person automatically becomes passive and relies on the person who is helping him/her. Anne McDonald, who like me has Cerebral Palsy with a speech impediment similar to mine, says in her Web page:

> *"Communication falls into the same category as food, drink and shelter - it is essential for life, and without it life becomes worthless."*

Life before *Toby*

Before *Toby* I used to have a Canon Communicator from the age of twelve. On this machine my words would come out on a strip of paper, which could be torn off and handed over to a listener. Using the Canon was laborious; I found it cumbersome and needed a great deal of effort. It also attracted too much attention. I preferred having an interpreter as it speeded things up. But that had its problems which I'll tell you about later.

Let me tell you a little about my life...My life has been a mixture of the East and West. I was born in India. As no one knew anything about cerebral palsy, my parents decided to bring me to England when I was a year old. Since then I have lived half my life in India, and half in England. So I am torn between two cultures. Most people view me a bit strangely, as I don't exactly fit in either of the cultures, although both of them are in-built in my personality to an extent, in that I would not know what to do without either one of them!

Until the age of seventeen, I went to four special schools. In England, they were the Roger Ascham School in Cambridge, The Cheyne Centre, Cheyne Walk, London and the Thomas Delarue School in Kent. The one in India was the first ever Centre for Special Education in Bombay of the Spastics Society of India, which my mother set up.

The atmosphere both in India and UK was extremely nurturing and protective. However, I consider myself a late developer due to a number of reasons. As far as interpretation of my speech was concerned, which I mentioned earlier, my family members and close friends would interpret freely and used to finish words and sentences for me. This was a practice that began with my teachers in all the schools. This caused many gaps in my learning process. I rarely used an independent communication means or later the Canon, and tended to rely on my family and close friends to interpret my speech. Without communicating one's thoughts and needs, desires cannot be formulated and one becomes passive. I became passive, non-thinking, non-decision making.

The plus point however was having a means of communication, which allowed me to socialise. I got admission into a mainstream college in Bombay, to do an equivalent A levels. It was my first experience of being with hordes of normal people and I noticed the gap acutely between the able bodied and the disabled. The first few days I stood out like a sore thumb. When I said my name it sounded as if I was from out of space.

For the first few weeks I zoomed around saying hello to a couple of people whom I knew. Generally I moved on my own rather than settling down to one particular group. I also noticed that my repartees were not quick enough to be included in a dynamic interactive group situation. I also recognised that people's relationship with me was superficial. My self-esteem took a nose-dive. I began questioning myself: Did I have a personality? Was I a likeable person to be with? Did I have anything to contribute? Did they like me only because of my disability? No one really wanted to get to know me deeply. I soon found that I was being more and more excluded from the social scene because I was disabled and different.

After two years of study I was eligible to take the examinations. The University officials gave me double the normal exam time. My peers had two hours; I was given four hours. I could type but my speed was acutely slow. Questions required essays type answer, some up to four pages long, If I had to type, one answer would take me four hours because of typing with one finger. I therefore needed writers who could understand me. The rule, however was that the amanuensis had to be younger than the student is. While that rule probably suited visually impaired students it did not suit people like me who had a severe speech problem. After much negotiation with the Bombay University, we managed to get double the time as well as choice of writers.

I stayed on to take a BA in History...

The actual process was tedious and an intensely arduous experience. Each paper being four hours long was extremely fatiguing. It was also strenuous for the person who was writing and listening to my monotonous, expressionless speech continuously.

The education system in India teaches students to be like a sausage machine rather than thinkers of the future. I felt as if I was disgorging facts, rather than thinking and creating an answer…a painful process to use my dysarthric speech, which was my biggest barrier.

Despite the tedious way I was examined, I stayed on further to take a BA in History. I studied six papers in History. Three papers were on European history. The other three papers were on Ancient India. I had four writers. For non-disabled students each paper was six hours long. Six hours of continuous regurgitation. They had to understand Sanskrit writers: tongue twister names like Dasadhama Tirthankaras, Anupreksha! Ancient Indian names! My writers patiently listened to my dysarthric speech while I called out each letter, assiduously! The Canon would be always there, in case they did not understand the odd word. The worst thing was that the exam took place in the heat of May. May is the height of summer in India being in the high 30s and low 40s. My throat got so dry calling out long essay type of answers that I could not speak without sips of water. The whole process was exhausting for both the writer and me. Both of us would be ready to get on to stretchers at the end of each exam. This must have been what hard labour was like in prisons of old. Anyway, let me tell you what happened…I passed.

My next academic study took me to Brookes University (then known as the Oxford Polytechnic). I took a course in Publishing. Although, it was great being at Oxford with so many non-disabled people, I felt restricted both in my communication and in my mobility. I had a full-time carer with me which handicapped my confidence. Wherever I went she came with me. My friends too, whenever they came to visit me, talked more to her than me. Carers of disabled people get automatic sympathy. Having a full-time carer also isolated me from the rest of the community as well as it did not give me a chance to interact with the staff and prevented them from helping me. This also impeded my socialisation within the University.

Life after *Toby*

After my studies at the poly, I returned to Bombay and worked as a journalist with the Times of India sister publication Bombay Times. I contributed various articles in different newspapers. I however found the atmosphere stifling: access was difficult inspite of having an electric wheelchair. My poor communication prevented me from entering into any meaningful conversation with my colleagues. While the work was interesting, there was hardly any socialisation.

I returned to England with my mother where she had enrolled at the Institute of Education to do a Ph.D. I felt liberated in that I was able to move around freely. I found people wanted to get to know me and have an independent relationship with me, but communication came in the way and remained the problem. It was at that time while attending a conference on communication that I seriously thought of a more effective means of communication rather than the Canon. I had always felt reluctant to introduce a device between me as a human being and others, but now realised that without some kind of introducer, I would be left without social contact.

We went to Roehampton hospital for an assessment and there I met *Toby Churchill* I instantly fell in love with him, as he was small and compact. What I liked most was that I could carry him in my handbag. I remember very clearly, a cold wet grey day when we met Simon and Tricia Churchill. Meeting them was like a breath of fresh air, as they were so warm and eager to adapt *Toby* to my needs.

Once I got *Toby* I ventured out on my own and found that I made friends very quickly. It was as if people wanted to hear me speak and learn about my thoughts. Having *Toby* by my side, made a tremendous difference to my life. I felt more confident. I could go anywhere and meet anyone on my own. *Toby* helped me to become more assertive. I began to communicate more, using *Toby*. With *Toby,* I felt I began to think, as I no longer could take refuge in silence or garbled responses, and did need to make meaningful responses.

Toby helped me to overcome my shyness. I was for the first time able to interact with strangers on my own without needing a third person to translate my speech. We were living in Bloomsbury and I soon began to move around in the West End on my own!

It was a stressful time for my mother. She would initially come everywhere with me. But her knowledge of directions was poor, not as good as mine. She soon found she was dependent on me and slowly she let go. I got another kind of freedom, which helped my communication. It was an exhilarating experience for me. For the first time in my life, I felt that I was not caged. I felt free. I learnt to do all the outside chores. I could go to supermarkets, and I could buy my own food. I loved going to the supermarkets, chemists, launderette, etc. I whizzed around the aisles, getting what I needed. Frequently other shoppers would pass me an item that I could not reach. The cashiers took out the right amount of change from my purse, and they or other shoppers put the bags of shopping on the back of my wheelchair, and I whizzed home. I started to go to the laundry on my electric wheelchair and the assistants in the launderette put my clothes in for the wash, I waited until my clothes were washed, I then indicated to them to put the clothes in the dryer. The assistants then put the bag on the back of the wheelchair and I proceeded homeward proudly. *I was able to communicate.*

As I zoomed around on my own, I met so many different kinds of people. People usually would come up to help or to converse on a superficial level, which made me feel included. The socialisation made me want to interact with the community more and more.

On my wanderings, I encountered many kinds of experiences. I remember going in Dillons Bookshop once, without *Toby* on me. I wanted a particular book called 'Mustn't Grumble' by Lois Keith. For a few moments I did not know what to do. Then I saw a terminal, which became my saviour. I frantically gestured that I wanted to use the computer. The shopkeeper waited patiently while I laboriously spelt out the name of the book on a computer. I half-heartedly gave the gentleman my phone number, thinking that he wouldn't ring, as he wouldn't have understood my garbled speech. But he did! Three hours later! I went with a great feeling of acceptance and euphoria to pick up the book I ordered. Since then, I would take *Toby* with me. Instead of giving them my phone number, I give them my email address! *Communication empowered me.*

In 1995, I enrolled myself at CityLit and took a couple of courses in Writing. In the classes, I carried a lap-top in order to interact with the other students as it was easier to communicate with and didn't hold up the class. Attending these classes gave me tremendous encouragement. What I found most encouraging is that people treated me like any other person. The only difference was that I spoke with a voice synthesiser. The person who sat next to me usually read out my work. People came up to me and told me that they liked what I had written. By the time I was leaving I had made some friends not out of pity- but through my writing. One lady said to me, "You are a writer first then a disabled person." It was like a Certificate for me!

I also took *Toby* to a conference at The Centre for Disabilities in North State California, which hosts a conference on Technology and disabilities every year. I programmed every sentence on the memory and then Claire my friend who accompanied me, wrote down the letters, which I needed to press one letter at a time. I was terrified because I thought I might press the wrong letter! But I managed to communicate my message.

After having completed a year of my Masters Study I feel that I am more empowered. The Masters has given me focus in identifying what I need. I feel my confidence has increased. The ethos of my department has helped me. They strongly believe in the recognition of diversity, especially women with disabilities. On the first day of the course I was asked by my tutors to prepare a brief introduction of myself. With *Toby,* I described my physical disability. My tutors and peers soon learnt my mode of communication and made it a point to get to know me in depth. After a few weeks, I got the courage to ask questions in class with *Toby*. I whizzed along to pubs, café, and canteens, all that makes life in university bearable! I felt that I could do this with ease with *Toby* by my side. *Toby*, the Email and the Internet, I consider are three of my closest friends and have helped me enormously in developing my self-confidence and self-esteem.

I agree with the DEAL Communication Centre in Australia when they say that the inability to communicate is the most devastating of all disabilities. Without communication you can't enjoy an education, have a full social life, or even ask for a drink. You are doomed to life as an observer. With communication, you can become a participant.

Communication means empowerment. By having Toby, I feel that I am more empowered.

Malini Chib
c/o Communication Matters, ACE Centre
92 Windmill Road, Oxford OX3 7DR

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Joining Communication Matters & ISAAC

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

What are the benefits of Membership?

Members of Communication Matters receive this Journal three times a year, reduced delegate rate at the Annual CM National Symposium, and all the benefits of ISAAC membership. ISAAC membership entitles you to order ISAAC publications at reduced rates (AAC Journal, Communicating Together, ISAAC-Israel Newsletter), and to receive special delegate rates for the Biennial ISAAC International Conference. You also receive quarterly issues of the ISAAC Bulletin and, if you join early in the year, the ISAAC 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: Communication Matters, c/o The ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR Tel: 0870 606 5463 Email: admin@communicationmatters.org.uk Website: www.communicationmatters.org.uk

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Macaw / Spokesman
(Toby Churchill)
Advertisement

Now I Can Say What My Brain is Thinking!

by Nicola Bush

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

Hi my name is Nicola I'm 17 and I love to talk! I want to tell you something about my world.

I was born in Ireland and one of the first things I remember was when my Dad took me and my sisters to where he worked. It was a chocolate factory and it was great! Soon after my family moved to England. I was five years old.

I remember looking at a school with my Mum. It was Foxdenton School and I remember it had a swimming pool. When I went to Foxdenton I couldn't speak to my new friends and I felt dead. I played with them and I spoke with my eyes. They knew my eyes and I felt better. I met a physiotherapist at Foxdenton, Christine, and I thought she was nice. Some of the teachers couldn't understand me and it was frustrating, but I wasn't bothered about it. One day I saw a teacher crying. I wanted to ask her why. I think she was crying about disabled children and I wanted to tell her we are fine.

But I couldn't.

When I was nine, I would lie in bed and wish I could meet someone who would help me to speak.

I was about 10 years old when I was given an ORAC communication aid. I used 2 switches and scanning. My friend, the physiotherapist, helped me to walk in a special frame. I felt fantastic. I loved both my ORAC and my walking frame. I learned to run a little and I learned to talk a little too. I had some jokes in my ORAC but I wanted to do more things. The last year at Foxdenton I was bored and frustrated with everything. I felt dead. I couldn't use my ORAC to say the things that were in my head. I was worried about losing my friend and we 'talked' together. I wanted to say "Thank you very much, I love you and I will always remember you."

But I couldn't.

On my last day at Foxdenton School I felt very sad because I was losing my friend, the physiotherapist and also Gareth my boyfriend. I was really angry with my Dad that day because I wanted to say goodbye to everyone, especially my friend. Dad didn't understand. My friend was crying and I thought, "Touch wood, I will see you again."

In September I went to my new school, Park Dean. I was really sad. I thought about my friend at Foxdenton a lot and (please excuse me) I thought it was Bullshit. I found it hard to communicate. I brought my ORAC to school. I was frustrated. I tried hard with my ORAC but I needed someone to carry it to different classes and to set it up for me. It was a pain. I disliked the scanning on my ORAC. I stopped using it. Then I met a *really* mad woman, Christine Povey. She made me cry with laughing! She made me a communication book and it was a good step. I could use it to communicate with other people. It was great. We went to a Communication User Group meeting and I met Stuart Meredith and Anthony Robertson. Anthony was using a communication machine with a light beam on a headband. Christine had an idea. *It changed my world!*

She thought I might be able to use a machine like Anthony's so I had some assessments. The man from Liberator said I wouldn't be able to use a Head pointer because my head wouldn't keep still and it would be best to use scanning. I really didn't want to and I used my eyes to talk to Christine. Near the end of the assessment she asked if I could try the headband again. I was determined to make it work - and it did! I loved the machine, a DeltaTalker, and Mrs. P. asked if I could loan a machine for a few weeks to see how I got on with it. When my DeltaTalker arrived Mrs. P. and I got together to open the box. We were both really excited. We looked at the machine and she said, "Help! What do we do with it now?!" It was a brilliant day. We were lucky that Helen Whittle and Sally Townend were not too far away at the ACE Centre North in Oldham. Mrs. P. took it to them. They were a great help. My DeltaTalker works when I point a light beam at it. It has really changed my life. I have now met so many people and made lots of friends because I can now talk and I can say what's in my head. I have been able to talk to Mrs. P. about everything...life, love, religion, wars...everything. I spoke to Mrs. P. about my time at Foxdenton School and how I had always wished to see my physiotherapist friend again. I wanted to go back and talk to people about things that had happened when I was there, when I didn't have a voice.

So one day I *did* go back to Foxdenton. It felt great to be alive! I met my special friend and I was able to speak to her for the first time. *It was fantastic!* I loved meeting the staff and being with the children, talking to them and showing them that communication is fun and worth working hard for.

Now, even though I still have lots to learn about my DeltaTalker I am able to help Mrs. P. when she needs me.

I have a penfriend who I write to in Australia. She also uses a communication aid. I want people to know that even though I have cerebral palsy I'm not worried about it. I want people to know I am a person, like them, who can think and feel and I would like to help able bodied people to not be afraid of talking to people like myself.

We ALL have lots to learn.
My world gets better every day.
Before I had my DeltaTalker I felt dead,
Now I am alive and I can say what my brain is thinking!

Nicola Bush
c/o Communication Matters, ACE Centre
92 Windmill Road, Oxford OX3 7DR

Past, Present and Future

by Simon Wilson

This paper was submitted for the CM'99 National Symposium, Lancaster University, September 1999

Hello ladies and gentlemen. I am Simon Wilson, and I am 20 years old. I have had severe cerebral palsy all my life. Having cerebral palsy means that I am totally dependent on other people for my physical needs.

I have been living a normal life, I have my ups and downs like most people. I enjoy life because I know what I want out of it I sometimes think if I did not have Cerebral Palsy, I would not have some special experiences. One experience was I went to Lourdes with a group called the Handicapped Children's Pilgrimage Trust, I went to the Grotto with some helpers. It was special because I could take my time there because I was on my own with some helpers later hi the evening.

I get to meet people, that is great. Because I cannot speak, I listen a lot, and I have taken in that knowledge. I enjoy listening because it is a great way of learning about people and life. In my life I have always had trouble communicating with people. I used to have a word board with a limited amount of vocabulary. The trouble with that was people could not help me to communicate, because they did not know how to use it I began to see the funny side of it after a while.

When I had my first computer, I felt free and it was great. I could drive up to people, talk to them and drive off. Now I can talk to anyone new because I don't need help communicating. Of course, when my computer breaks down, I use a letter board which I need help with. My letter board does not work like word or bliss boards, where people have to find the block, the column and then the word. My letter board is transparent and the letters are on both sides and it is held between the person I am talking to and myself. It is a direct selection method, so if I am looking at the letter N, you would move board until our eyes connect on that letter. There are two advantages of using this. The first one is both people are keeping eye contact. The second one is other people can join in and guess what I am trying to say.

I had a difficult social life when I was younger.

I had a difficult social life when I was younger. I did not like mixing with people of my own age, because I found they did not understand me. The care staff at my secondary school used to make me socialise with the other pupils. I often refused only because they were making me. Since I was about the age of ten, every birthday I used to have a dinner party and I used to invite adult friends because I felt I bonded better with them. With aft my experiences, I think I had grown up too fast

When I was younger, I hated being talked to like I was like a baby. I was mad at them. That was not particularly clever because they must have thought I really was mad. Now when I am treated like that, I just smile through my teeth. When I am out with my friends, usually in a pub, people come up to my friends and say its great you are taking him out They reply he is taking us out I don't really care what other people think or say about me as long as they are not upsetting or affecting my friends. We always joke about how many men I'm going to attract because men always come over and talk to me which I find strange. I keep asking myself why don't I attract girls. In actual fact I think ladies are more understanding about disability than men. In public I am accepted by females better. People say women are more sensitive than men and I believe that, but I sense people who are in below average moods which is a good skill to have. I think most people who are physically challenged with a communication problem have a good sense other people's moods. This is because they have time to study their reactions.

I think most people who are physically challenged with a communication problem have a good sense of other people's moods.

I was studying GNVQ advanced Information Technology at a special college for people with disabilities. It was called Hereward College in Coventry. At first I quite enjoyed it there, but it was very hard work. I started there in 1995 to do the same course but the Intermediate level. That course usually takes two years, but because I was slow at doing the assignments, I had an extra term to complete it. I lived at college and came home every half term. There were three hostels for students to live quite independently. There were six members of care staff in each team. That was not ideal because they had not got the time to help the students with their leisure interests.

I was unhappy there because the college was having more and more students who have learning difficulties or behavioural problems. I found I couldn't mix with them and as a result I sat in my room working or writing letters. I wanted to leave Hereward and continue to study somewhere else. So my parents contacted West Kent College which is mainstream but they take students who have disabilities. We arranged to meet the disability officer. I had already prepared some questions to ask her before I went. When we met, she went through my questions and her answers were impressive and I was really happy because everything was not a problem. What is really impressive that I am gong into mainstream education for the first time. While I am studying at West Kent College, I am going to move into my own accommodation with my own assistants. I have to learn about managing them in a professional way. I think I will enjoy that because it will give me lots of experience of employing carers for the future.

When I leave college, I want to go to university and employ my own carers. At university I want to do a degree in computers, but I want to do something on setting up computers for people with disabilities, because I love helping people to sort out what people need computer wise. I am also interested in counselling disabled people or parents of disabled people. When I say to people this is what I want to do, they always go quiet because I think they think he is disabled and has psychological problems of his own. I feel if I cannot talk about disability, I have not really come to terms with my own problems. OK, I may have problems but I feel proud knowing that I can help people with their problems and them valuing my help. It might benefit parents with a disabled child to talk to someone like me because they will see a person who happens to have a disability instead of a disabled person.

After university I want to get a job working for a computer company doing computer assessments for people with disabilities. I think if people like me work with other disabled people, they would feel they could talk about specialised problems which able bodied people may not totally understand. I think it would be fun to work in the 21st century and to see even more high-tech equipment

Thank you all for listening to me, it has been really great talking to you. I hope I have given you some ideas on life with a disability and how much you can achieve.

Simon Wilson
c/o Communication Matters, ACE Centre
92 Windmill Road, Oxford OX3 7DR

Me and My Lightwriter

by Abigail Patience

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

My name is Abigail Patience and I am 22 years old. My disability is cerebral palsy. I cannot talk and my right side does not work properly.

As a young child I had a communication book as my speech problem had not been recognized whilst I was a baby.

At about the age of seven I started to learn sign language at a residential special school in Sussex. I had a sister who could help me with my signing. I was happy at the school and I went home at the weekends.

I have reached Stage nine in sign language and have now been teaching people to sign. When I was thirteen, I saw a demonstration at school of various speech aids. I had guidance from a speech therapist, I chose to use a Lightwriter. I use it all the time to communicate with people and I use it to talk on the telephone. It has helped to improve my confidence as I can communicate with everyone. Now I am a more outgoing person. Having had a whole world opened up to me; I want to try many more new things.

I go to Bridge Court two days a week, which is a resource center for disabled people. I like meeting and seeing disabled people at Bridge Court. It has helped me in building up my confidence and I am now living by myself in a purpose-built flat. The flat has one bedroom with kitchen, bathroom and living / dining room. The flat has given me more independence. I have more confidence to use sign language, which I am continuing to study with the aim of becoming a teacher.

How to make people understand people with disabilities

We are not different from 'normal' people; we are special people who have different needs. We are proud of who we are and we can live as independently as everybody else can.

I am giving this talk to make you aware that people with disabilities can live a fill life with the same aspirations as you.

We can employ / hire carers from social services in order to give us more independence. We need funds to do this.

Most disabled people would like the opportunity to work and to earn money. Jobs are few and far between and are very hard to come by. Transport is not sufficient and access for wheelchair users is rare.

The government is currently cutting benefits for disabled people with the sole purpose that they will find employment.

Oh, if only this were possible. This is not likely, and the government is introducing these reforms without listening to the disabled community.

I feel that some people are looking at me in a funny way. I have had bad experiences with children calling me bad names and it made me upset. I think that people can't help it. I wish that people could understand and would teach their children also.

I would like to make people change their minds about disabled people. It will make it easier for disabled people like me and the world would be a better place for both disabled and 'normal' people.

I did not have confidence to use the Lightwriter outside because it felt like people were looking at me and calling me bad names. Now I have confidence in myself and to use the Lightwriter for the purpose it was intended – communication.

I can now go shopping and on the bus without worrying that people are looking at me.

I talk to different people and now I am proud of myself.

I am proud of who I am, I have learned to cope with my disability and I enjoy my life.

Abigail Patience
c/o Communication Matters, ACE Centre
92 Windmill Road, Oxford OX3 7DR

Dances of Life

by Bill Robins

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

I would like to introduce myself. My name is Bill Robbins, I am thirty years old. This is personal assistant, Bruce Ashby, and he will be assisting as and when I need him. If you have any questions, please direct them to me, and not to him.

I am a student at The Roehampton Institute in London where I am studying choreography. I also belong to an integrated theatre company called *Amici* where I have performed in three plays which were staged in London and Europe.

My involvement with dance and movement started with classes at the age of thirteen. Dance has helped me to develop my confidence. It has also enabled me to express emotions and feelings in a positive way.

> *To assist me in my dancing and choreography, I helped design and produce a communication tool...*

To assist me in my dancing and choreography, I helped to design and produce a communication tool called a Simpson Board. This is a tool to help me do my choreography using dance notation. The Simpson Board, along with my Bliss Book, enables me to instruct my dancers and tell them what movements I would like them to do.

Last year I taught pupils at Meldreth Manor School where there are students with similar impairments to myself. Using modified versions of the Simpson Board, the pupils were able to choreograph able-bodied dancers, and take part in their own integrated choreography. My ambition to do more of this work provides the main motivation for my attendance at college.

My Personal Assistant

I now employ my own personal assistant (PA) and so I use the computer to keep all my records and do all the books myself. I feel that this gives me a lot more independence, to choose who I want to be my PA - someone I feel confident with, instead of relying on people that an agency sends.

There are formal or serious instances where communication is needed, for example, when running my own interviews or having a discussion with a PA. Having my own voice, which is distinct from theirs, is important to me in a fundamental way.

My AAC Systems

My experience of AAC systems include the use of Bliss charts. I started using these at the age of seven and continue to use them today. I find that some people seem to be afraid to use my Bliss book. This might be because they assume they have to learn how to use it themselves, but in fact all they have to do is turn the pages over and have lot of patience and a good memory to keep up with me. People have also got to give me time to talk, as it takes a while to get my sentences together.

At the age of eight I had a Possum typewriter, operated by a foot switch, which was incredibly slow and noisy. This was the first time that I got to grips with the standard alphabet. Then I moved on to an Apple II computer with a switch scanning communication program called MAC-Apple, which I started using at the age of thirteen.

I had my first portable computer from Cambridge Adaptive Communication when I was twenty-two years old. It was mounted on the back of my wheelchair. I really enjoy using a computer, and now that technology is advancing so quickly, I find that I am able to do more and more for myself.

I feel that once I reached the age of nineteen there wasn't any further help from my school and the education services. This meant that I had to teach myself how to use all this new computer technology from books and advice from friends.

> *I find that people see a physical impairment and not me...*

I find that people see a physical impairment and not me, but when they see me working on my computer they don't know what to say. I can see them thinking that, as I'm in a wheelchair, I shouldn't be able to do anything, let alone work a computer. Yet even with the aid of the computer I still find that there are some people who have a problem with talking to me. I wish people would ignore the wheelchair and computer and just talk to we like a normal person. I feel that not being able to communicate is very hard, and I feel that people don't want to get to know me because of this. If someone finds it difficult to communicate with me then they don't stand a chance of getting to know me.

My first software communication/writing package was called Whiskey. ln 1995, I upgraded again to the Cameleon II communication aid which used the Windows 3.1 operating system. At an adult education art class, I used the aid to create an architectural drawing; it took me six months to complete the drawing. I was, once again, teaching myself as I went along. Last year I moved onto using Windows 95. At first, I was very wary of using this new operating system; you might even have said I was afraid to use it, and I thought there was no way I was going to manage using the Internet or Email.

Accessing the Internet

I first got onto the Internet through the WAACIS project which helps people like myself to obtain the equipment, software and support to access the World Wide Web and Email. The project was being coordinated by Dave Perkins, who was excellent at giving me training.

Unfortunately, apart from getting advice from a friend (who is a lecturer), nobody has taught me how to use Windows 95. I've had to teach myself using books and a lot of trial and error! I would have liked to have had proper lessons but I've had to fight and struggle to get money for this and so far I haven't had much luck to access a class.

The computer I have now is used to give me a voice and to help me to communicate, but I can also use it to run other programs that are not usually accessible to a disabled user. I feel that the Cameleon II is very good for my everyday life because, now that I have Windows 95, 1 can go on-line and look up information that I want, instead of having to ask someone to pick up a book for me.

I always have it in the back of my mind that, whenever I'm on-line, it costs quite a lot of money. The lack of speed when downloading isn't helped by having to use one wretched head switch as it slows me down and increases the cost. This is why I use a CD-ROM Internet directory, using this as a route onto the World Wide Web.

The computer also lets me talk by myself, on the telephone, without having to have someone else help me. When someone else talks for me, they might use their own words and opinions instead of my own. This is why I enjoy using Email, because it gives me the privacy that most people take for granted.

Now that I have this computer it brings a new international aspect of communication as a new possibility and experience. I would like to say that the Cameleon II has definitely changed my life for the better.

Bill Robins
c/o Communication Matters, ACE Centre
92 Windmill Road
Oxford OX3 7DR
Email: brobins@dircon.co.uk

Variety is the Spice of Life

by Sue Clark

This paper describes ways of modifying material for single switch use, and was presented at the CM'99 National Symposium, Lancaster University, September 1999

Keycomm is a Communication Aids Centre which serves the population of Edinburgh and the surrounding area. Its main function is to provide assessment, support and a loan bank of equipment for people with communication impairments who might benefit from some form of augmentative communication system. The Centre also provides support for professionals working in this field.

In our work we see a lot of children and young people who are going to need to access technology through switching because their fine motor co-ordination is not good enough for direct access. It is this group which we are concerning ourselves with in this article. They need to learn switching skills from as early an age as possible and they need a variety of things to practice the use of switches.

Many of you will be familiar with cuddly toys which have been adapted for switches, for example, the pink pig who grunts, the cat who mews, or the elephant who raises and lowers its trunk and then walks a few steps as the switch is repeatedly activated. In our Loan Bank we have all of these as well as an owl, a crocodile and a kitten. But quite soon a child will tire of these 'animated' fluffy toys, so what do you find for them to switch to next?

It is possible to adapt many of- the-shelf battery operated toys for use with a single switch. One way of doing this is by using a *battery device adaptor*. This consists of a double insulated copper plate which inserts between the battery and the casing of the toy. From the copper plate there is a cable to a switch jack socket; inserting a switch into this socket and depressing it closes the electrical circuit which has been interrupted by the plate, so causing the toy to operate. Often a small nick needs to be made in the plastic casing of the toy to allow the cable to pass through; this can be done with a small file. The toy also needs to be turned on to make it work with the switch. *Battery device adaptors* are sold by several specialist companies at about £8 each.

It is also possible to adapt a toy more permanently by finding someone with enough electrical knowledge to get inside the toy or its controller, interrupt the electrics and insert a jack socket (3.5mm if that is the size of your switch jack), provided there is enough space to do this. The socket can often be inserted so that it works as an alternative to the existing switch and not instead of it.

We are always on the look out for different ideas. As well as perusing all the specialist catalogues we regularly hunt the toy shops and catalogues for anything new, Christmas is an especially good time. We also get a lot of good ideas from families who have found things and asked us to adapt them for their child.

Some of the things we have adapted for switch use include a:

- Mini desk top fan
- Monkey which rolls over backwards and forwards
- Car that flips over when it comes up against a solid object

- Fan assisted bubble blower
- *Baby Vision* which plays lullabies and projects a moving picture onto the ceiling of a darkened room
- Bear which sings "A, B, C, D, E, F, G"
- Robot which works off a remote hand held controller - three different switch jacks were inserted into the controller for the robot's three functions (forwards, backwards, music)
- Talking photo cube
- *Thomas the Tank Engine* torch

However, not all battery operated toys are suitable for adaptation - we've had our failures:

- We got a *Space Shooter Gun* but the switch could only be made to turn the light on, not shoot out the coloured disks - as this requires a mechanical, trigger action. Real shame as shooting out the disks is such fun, they go right across a room!
- The *Telly Tubby,* which potentially had four phrases, melted a resistor when we put a switch jack into its voice box! (We might just have been unlucky with our one!)

Having adapted the toys, what makes them more fun?

- The fan, as well as cooling you down, very effectively blows polystyrene chips around. Use it with stories like the Three Little Pigs: "I'll huff and I'll puff and Ill blow your house down".
- For the racing car we had a special track made by Remap so that the car stays in the vision/range of a seated child. The track has a bridge to go under and solid ends so that the car flips over when it reaches them. We can mark a 'STOP' sign on this track and the switch user can practice stopping the car on an exact spot spot.
- The Robot has a basket so it can carry things across a room from one person to another or from one place to another.
- The photo cube holds five pictures/photos and can have a message like "look at the animals we saw at the zoo" recorded into it.
- The torch can be used in conjunction with a latching switch so that the user can turn it on and off with the switch rather than having to hold it on.
- The bubble blower needs someone to dip the bubble wand into the bubble mixture and then hold it up so that the switch user can activate the fan to blow the bubbles - it blows beautiful big bubbles and is a great joint activity.

The possibilities are endless...you just need a good imagination!

Sue Clark, Community Occupational Therapist
Keycomm, St Giles Centre
40 Broomhouse Crescent, Edinburgh EH11 3UB
Tel: 0131 443 6775 Fax: 0131 443 5121

Parents and Enablers Page

by Katie Clarke

It's been yet another extremely busy period which has beena very exciting time for us with Nadia's communication, especially because of some real progress with the Dynavox. We have a great team around Nadia in the school situation: the class teacher and the teacher of the deaf; SNA's; Dynavox support from Alison; as well as new technical support from Graeme, paid for by the Learning Support Service, and who because of his computer knowledge is able to help with programming and has more creative ideas around the possibilities.

One thing Nadia has started to enjoy is playing different card games with the help of her Dynavox. Some of the friends who come around have also been involved in these games and so it creates a nice playing circle around Nadia. Everyone takes it in turns to use the Dynavox to ask each other for specific cards that they need or want to swap and so the communication aid becomes the main voice.

Nadia is really beginning to get a good sense of the possibilities her Dynavox offers her for communication and she is beginning to take more control over what she wants to say through it. She tells her teachers what she wants to tell us about what she did at school and they programme this in. After the weekend we do the same for school. Also, during literacy hour at school, Nadia's teachers programme the book onto the Dynavox and so Nadia is able to more fully participate in the classroom reading and also to demonstrate to us when she comes home. We do her spelling homework on the alphabet page and she does her times tables on the numbers page.

> *Nadia is really beginning to get a good sense of the possibilities [of] her Dynavox...*

We still have problems with the lack of mounting systems and have been trying to get one for her manual wheelchair for well over a year. She has a wide range of equipment that she uses both at home and at school and of course she needs to access the communication aid whilst she is going from one chair to another. I just wish there was one universal mounting system that we could constantly change over with ease.

The other exciting developments are coming through Nadia's cochlear implant. She has made steady progress in her use of the implant, but every now and again it seems that she has a bigger surge forward. We have started playing a listening game which Sean, Nikki and Reay are also interested in. They each have a card which depicts a very busy scene and the accompanying tape plays a short clip of noise and the kids have to put their piece of paper over the part of the scene which they think is making the noise. For example, it could be an animal noise, or children playing, or a car. Nadia has amazed us with how well she is discriminating noises and knows which of her siblings are fighting, crying or shouting. She has now had the implant for two years and is learning to hear many everyday phrases eg do you want chocolate? Would you like ice-cream? Funny how those are the sort of things kids pick up so easily!

All of this, of course, is slotted in around the other bits of chaotic family life. The twins, Samara and Jake, are now very much on the go, and usually in different directions. Samara, at 10 months, has taken to climbing the stairs and our house suddenly looks like a death-trap, with the end of the brick fireplace at the bottom of the stairs and Nadia scooting around in her flourescent Barbie-pink electric wheelchair. I've commissioned Andy to take a sledgehammer to the fireplace, an offer which he accepted with an uncomfortable degree of relish and hand-rubbing.

Family Weekend

Tamsin Crothers and I are planning a family weekend away - for 10 or 12 families, children with communication aids and their siblings - either towards the end of the year or in the spring of next. This will be a sociable get-together, with organised activities for the children and young people and, hopefully, a bit of a chance for parents to socialise. If you are interested please contact us via Communication Matters.

Katie Clarke (CM Trustee)
Communication Matters, c/o ACE Centre
92 Windmill Road, Oxford OX3 7DR
Email: admin@communicationmatters.org.uk

members.aol.com/dds4kids/dynavox.html
Set up by the father of a nine year old DynaVox user, this website has many freely downloadable pre-programmed pages for the DynaVox and DynaMyte range of devices.

iicpindia.com
Indian Institute of Cerebral Palsy (formerly Spastics Society of Eastern India).

www.communicationsforum.org.uk
The Communications Forum brings together the organisations concerned with the needs of people with speech and language impairments.

www.stir.ac.uk/psychology/aac
Find out all about the current and recent projects at Stirling University's AAC Research Unit.

Scope's Communication Aid Campaign

Scope is launching a new campaign to ensure communication aid users and potential users receive the appropriate equipment, training and ongoing support.

Scope hopes to build on the campaigning work already done by many people in the field and establish the right to equipment and support as a human and civil rights issue.

Everyone who is assessed as needing a communication aid or talker should receive one, as of right. Communication is a vital way to ensure people can express individual choice. To be able to communicate and be heard is a human and civil rights issue.

Scope is campaigning to:

- ensure that communication aids and equipment meet the real needs of users
- ensure that communication aids are provided free by the NHS to people who need them
- improve the amount of training to people so that users can get to know how to use their aids better

To help with the campaign, *Scope* is collecting information about disabled people's experiences obtaining and using communication aids.

Scope is asking users around the UK to complete a survey form about their experiences. A report will then be produced based on these findings, which will be used to try and press for change to ensure users receive a quality service in the future.

If you use a communication aid please help with the campaign by completing and returning a survey form.

To obtain a survey form, please contact *Communication Matters* on Tel: 0870 606 5463 Fax: 0131 555 3279 Email: admin@communicationmatters.org.uk, or contact *Scope* directly at: Campaigns, Scope, 6 Market Road, London, N7 9PW Tel: 020 7619 7245 Email: campaigns@scope.org.uk.

Completed forms should be returned to Scope by 15 May 2000. All information you supply in the forms will be treated as confidential.

* * *

COTIS - The Link to Accessible Information

COTIS - The Confederation of Tape Information Services - is a membership organisation that provides support and advice to people who need information in formats other than written English, for example, Braille, large print, audio tape and other national languages.

Members of COTIS include individuals, groups representing disabled people, companies providing material in alternative formats, and organisations such as Local Authorities.

When COTIS was established in 1986 tapes were in vogue as an acceptable format for visually impaired people. Today, although Mrs Jones at number 37 still prefers her Walkman to listen to her local talking newspaper, Phil, an 18 year old student, learns calculus using his computer and a speech synthesiser.

Certain formats have been with us for years — Braille hasn't really changed in over 100 years. Technological advances allow us to communicate faster and produce material in hitherto unknown — expensive — but now highly accessible ways. Whatever the medium, it must be produced to a common standard of presentation, reliability and quality.

COTIS provide support and advice through their guidelines and self-help tapes, pooling shared experience and keeping members in touch through a newsletter, *On track,* which is produced three times a year (in print and on tape) — free to members, £1 per issue to non-members.

If you need or are required to provide information in accessible formats, COTIS can help you find that missing link.

For further details, please contact: COTIS Project Office, 67 High Street, Tarporley, Cheshire CW6 ODP. Telephone (answerphone) 01829 733351.

* * *

Finding a Voice Video

The Kent Language and Communication Appeal is raising funds to set up a Comprehensive Assessment Centre and Follow-Up service for children and young adults who have severe communication difficulties. The money raised will provide education opportunities for parents, enablers and professionals and so ensure that appropriate communication aids are made available to those who need them.

To raise awareness of the Charity and the children we are supporting, the Kent Language and Communication Appeal has produced a video, *'Finding a Voice',* with Bob Holness providing the commentary.

The video will be of interest to groups, schools, corporate sponsors, voluntary organisations and anyone who wishes to support the charity. With more SEN children being included into mainstream school it is paramount that schools are aware of the needs of these children. Another role of the video is to encourage parents to become involved with their child's communication needs.

The video is available from KLCC, 33 Calland, Smeeth, Ashford, Kent TN25 6QD Tel & Fax: 01303 814766. The price is £9.95 plus £2.00 p&p; cheques should be made payable to The Kent Language and Communication Centre.

COMMUNICATION *MATTERS*

CM2000 NATIONAL SYMPOSIUM

A Two Day Residential Symposium on

Augmentative and Alternative Communication

Monday and Tuesday

18 & 19 September 2000

University of Lancaster

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RING NOW

For a CM2000 booking form, ring Communication Matters

0870 606 5463

Email: admin@communicationmatters.org.uk

CM2000 NATIONAL SYMPOSIUM

CALL FOR PAPERS

Hurry! It's time to submit a paper for the Communication Matters CM2000 National Symposium

Although papers on any topic are welcome we would be especially interested in the following topics:

- Use of AAC with different client populations
- Assessment
- Implementation and intervention, including outcomes and evidence based intervention
- Parent and carer issues
- Using the Internet
- Employment
- Advocacy
- Training
- Care in the community
- AAC and the curriculum
- AAC and the home

Papers can be in the following format:

- Practical workshops
- Video presentations
- Case studies
- Research based
- Poster display
- Traditional platform presentations

Please send your abstract (paper copy and in Word 6 or 97 format) **as soon as possible** to the address below. Include: Title, Authors, Aim of Session, and Brief Summary of Key Points, Preferred Format of Presentation. If you require further details, contact Deborah Jans at the address shown below.

D. Jans, KEYCOMM, St Giles Centre, 40 Broomhouse Crescent, Edinburgh EH11 3UB
Tel: 0131 443 6775 Fax: 0131 443 5121 Email: djans@keycomm.demon.co.uk

Trustees News

CM2000 National Symposium

Organisation of this year's Communication Matters National Symposium is well under way. The Symposium will be on the 18 & 19 September at Lancaster University - put the dates in your diary and make sure you book early to take advantage of the reduced rates. There are also a number of places for AAC users and parents at a special rate of only £50 all-in.

To get a booking form for CM2000 or for further information, please ring Communication Matters on 0870 606 5463.

CM2000 Call for Papers

It's not too late to submit a paper for the Symposium. Abstracts should be sent as soon as possible to Deborah Jans at Keycomm (address on previous page). For a copy of Guidelines for Submission, ring Communication Matters on 0870 606 5463.

The CM Distinguished AAC User Award 2000

The CM Distinguished AAC User Award is offered annually in recognition of how hard it is for AAC users to give public presentations and to give AAC users practice in preparing and delivering presentations.

The winner will receive an award of £250 and deliver their paper at the Communication Matters CM2000 National Symposium which they will attend free of charge. The paper will be published in the Communication Matters Journal. The winner will also have their registration fee paid (but not travelling or other expenses) at the next ISAAC Biennial International Conference (to be held in Denmark, 2002) if they wish to attend.

To be considered for the Award, applicants must:

- be a current AAC User member of Communication Matters (free memberships are available, but you must apply)
- submit a written copy or video or audio-tape of a presentation on the theme of **'The Future'** they would like to make at the Communication Matters CM2000 National Symposium; the presentation should aim to be about 15 to 20 minutes long and may include the use of slides, video, overhead projector, music, etc. (Closing date: 30 July)
- not have been a winner of this Award in the previous five years
- supply the name and address of a referee or supporter whom the judging panel can contact if required

The CM Achievement Award 2000

This is a *new* award to acknowledge the achievements of people who have recently made a major breakthrough in learning to use any system to communicate other than speech, for example: using a picture card to order a drink in the pub; using a communication aid to join in school assembly.

Entries can be for individuals or a group. There will be small cash prize, a certificate of achievement and one free place to the CM2000 National Symposium this September. To enter, write a brief description of the child/client's achievements and include photographs or videos of them using their communication system, if appropriate.

Please send your entry by 30 July to Communication Matters, c/o ACE Centre, 92 Windmill Road, Oxford OX3 7DR

News from CASC

Communication Aid Suppliers Consortium

January and February were busy months for CASC members who took the **CASC Road Shows** to well attended venues in Chorley (Lancashire), Shrewsbury and Ireland (Galway Limerick, Tralee, Dublin and Belfast). Scotland is the next national target, visiting Inverness, Edinburgh and Glasgow in May. Other Road Shows will be in Cambridge, Loughborough and Salford - please see the dates below.

CASC Road Shows - March to June 2000

Please make a note of any CASC Road Shows coming to your area - do contact Patrick Poon at Communication Matters (Tel: 0870 606 5463) if you need further information.

Mar	30	**Cambridge -** Professional Development Centre
Apr	5	**Loughborough** - Beaumanor Hall Conference Centre
May	3	**Salford -** Neurocare Centre
May	24	**Inverness -** The Green House Conference Centre
May	25	**Edinburgh -** CALL Centre, Univeristy of Edinburgh
May	26	**Glasgow -** Walton Conference Centre, Southern General Hospital
June	23	**Portsmouth -** Futcher School
June	29	**Bristol -** Claremont School

Can you help host a CASC Road Show in your area?

We are always looking for new venues, so if you would like to host a Road Show (or know a local centre which might be interested), please contact Patrick Poon, the Road Show Organiser (Tel: 0870 606 5463) who would be delighted to discuss this further. Remember, CASC will pay for hiring a suitable venue, lunch and refreshments, and help to draw up a programme and draft publicity material.

Web Site & Contact

To get an up-to-date list of the CASC Road Shows and brief information on each CASC member and a link to their Website, please visit the *Communication Matters* Website at *www.communicationmatters.org.uk*

For more information about CASC, ring Patrick Poon on Tel. 0870 606 5463 or Email: admin@communicationmatters.org.uk, or ring Simon Churchill (Chair of CASC) on Tel. 01962 842792 or Email: simon_churchill@compuserve.com

Do You Need a Small Grant?

Communication Matters welcome applications for small grants. Consideration will be given to applications for projects or activities that further the aims of Communication Matters. Examples include:

- the costs of organising an **AAC User event,** or travel expenses to get to one
- the costs of publishing an **information leaflet**
- the costs of a **social research project**

The applications will be reviewed by the Small Grants Committee and an external reviewer, and the decision of the Committee will be ratified by the Trustees in June and September.

For an application form or more information, contact CM Tel: 0870 606 5463 Fax: 0131 555 3279 Email: admin@communicationmatters.org.uk

The CE Mark and Communication Aids

by John Watts

Communication Matters commissioned this article to help clarify the situation with the European Community's CE Marking regulations for the purchase of communication aids and equipment

What is the CE mark?

An economic objective of the European Community is the free movement of goods. CE marking exists to ensure this through compliance with common standards of all goods sold in the European Union (EU). For several years, the EU has been in the process of classifying goods into categories – toys, machinery, low voltage electrical, medical devices etc. Design and manufacture criteria have been applied to each category, compliance with these criteria is required for sales within the EU. Products that comply are CE marked. No member state can bar imports of compliant products. As technical harmonising directives are agreed, member states must implement them into the national law. The Medical Devices Directive (MDD), implemented into UK law as the Medical Devices Regulations 1994 (S.I 1994 No.3017), entered into force on the 14 June 1998. A manufacturer of a product coming within the Medical Devices Regulations must comply with the technical requirements, as defined within the directive and regulations, and CE mark a product before it is placed on the market.

Why are some communication aids CE marked and others not?

A product is defined as a Medical Device if its primary intended purpose falls within the scope of the MDD. In common with other Directives, the MDD places the responsibility of defining this intended purpose on the manufacturer. Depending on the primary intended purpose, a product might come within the scope of the MDD, another directive, or none at all. For example, someone might use a palmtop computer as a simple communication aid, however this is not the manufacturer's primary intended purpose and so the device would not be covered by the MDD. A very similar machine specifically intended by its manufacturer to be used by as an AAC device would be covered by the MDD. A walking stick intended for ramblers would not be CE marked, but a walking stick intended for a person requiring an "aid to compensate for injury or handicap" (words used in the MDD) would be classified as a medical device. The intended use is defined by the way a product is marketed, if sales literature claims that a device is designed to be used as an "aid to compensate for injury or handicap" then the intended use is covered by the MDD. Products designed primarily as AAC devices are covered by the MDD and should be CE marked to the MDD accordingly.

In the USA communication aids are not classed as medical devices, this has caused confusion to some American manufacturers. Some CE mark their communication aids under the EMC (electromagnetic compatibility) Directive, not the MDD, some do not CE mark at all. If the intended purpose is AAC then the devices should be CE marked under the MDD, this must done through an "Authorised Representative" resident within the EU.

Second hand communication aids may not be CE marked, but anyone claiming that a second hand medical device has been fully refurbished must then CE mark to the MDD.

Does the CE mark matter?

It shouldn't matter, in that all non-CE marked products are covered by Product and Consumer Legislation. However if new communication aids are being placed on the market with incorrect or non-existent CE marking, the legislative knowledge of the manufacturer must be questioned - this would place into doubt the manufacturer's technical competence and therefore the safety and reliability of the product.

What does the CE mark mean?

The MDD requires a manufacturer of medical devices, such as communication aids, to prepare technical documentation, which explains how the device is constructed, include the results of tests and design calculations and carry out a risk assessment. They are required to declare how they meet the "essential requirements", they must register with a Competent Authority and then they may CE mark the device. The Competent Authority is the National Regulating Authority, in the UK it is the Medical Devices Agency, they have the legal right to request sight of the technical documents.

CE marked under the EMC or MDD?

When CE marking under the MDD regulations, the manufacturer has to take account of the EMC requirements as part of the Essential Requirements. If the intended purpose is defined as a medical device then CE marking under the EMC directive alone is illegal as that directive specifically excludes medical devices.

Manufacturers are required to prepare a Declaration under either the EMC or MDD. Requesting a copy of this declaration will provide details of which directive the manufacturer has applied.

John Watts
Email: john@jwatts.demon.co.uk

This article is not a legal interpretation of regulations that implement the Directives in the UK. The reader is advised to seek their own legal interpretations, if required.

About the Author: John Watts is co-editor of *Medical Devices Manual* and has his own consultancy, JJW Consultancy, providing regulatory and quality management support to the medical devices industry and NHS Trusts. (The *Medical Devices Manual* is a practical comprehensive guide to implementing European medical regulatory requirements, published by Euromed Communications.)

Diary Dates

30 March 2000 Cambridge
CASC Road Show at The Prof. Dev. Centre, Cambridge
Contact: Jo Caldwell Tel: 01223 359466

3 April 2000 Wolfson Centre, London
New Developments in AAC
Venue: The Wolfson Centre, London
Contact: Katie Price Tel. 020 7837 7618

3-4 April 2000 Peterborough
PECS: The Picture Exchange Communication System
Venue: Peterborough Contact: P Haughton Tel. 01273 728888

4 April 2000 ACE Centre North, Oldham
Getting to Grips with Inclusive Writer
Cost: £100 Venue: ACE Centre North Tel. 0161 627 1358

5 April 2000 Loughborough
CASC Road Show at Beaumanor Hall, Loughborough
Contact: Helen Nightingale Tel: 0116 235 4374

15 April 2000 Bristol
Afasic Parents' Conference
Cost: from £25 Venue: University of the West of England, Bristol
Contact: Carol Lingwood Tel: 01273 381009

27 April 2000 Perth
Alternative Viewpoints on Augmentative Communication
Venue: Perth Contact: Alison Gray Tel: 0141 531 6269

3 May 2000 Salford
CASC Road Show at The Neurocare Centre, Salford
Contact: Barbara Daniels Tel: 0161 7874253

4 May 2000 ACE Centre North, Oldham
Taking Off with AAC! Maximising Success for an AAC User
Cost: £115 Venue: ACE Centre North Tel. 01257 241428

9 May 2000 ACE Centre North, Oldham
Switched On with PowerPoint
Cost: £50 Venue: ACE Centre North
Contact: Ann or Lisa Tel. 0161 627 1358

17 May 2000 ACE Centre North, Oldham
Getting the Most Out of Windows (95/98) for Learners with a Disability
Cost: £50 Venue: ACE Centre North Tel. 0161 627 1358

18 May 2000 Keycomm, Edinburgh
First Steps in AAC Through Toys & Simple Communication Aids
Cost: free Venue: Keycomm, Edinburgh
Contact: Deborah Jans, Keycomm Tel: 0131 443 6775

18 May 2000 CENMAC, London
Getting to Know the Classroom Computer
Cost: £55 Venue: CENMAC Tel: 020 8850 9229

22-23 June 2000 Glasgow
PECS: The Picture Exchange Communication System
Venue: Glasgow Contact: Phoebe Haughton Tel. 01273 728888

24 May 2000 Inverness
CASC Road Show at Green House Centre, Inverness
Contact: Alan Stewart Tel: 01349 863441

25 May 2000 CALL Centre, Edinburgh
CASC Road Show at The CALL Centre, Edinburgh
Contact: Sarah Marjoribanks Tel: 0131 651 6235/6

26 May 2000 SCTCI, Glasgow
CASC Road Show at Southern Gen. Hospital, Glasgow
Contact: Janet Scott Tel: 0141 201 2619

8 June 2000 Glasgow
Breaking the Boundaries - International Study Day
Hosted by SCTCI and IALP Venue: Southern General Hospital
Contact: Margaret Gordon Tel: 0141 201 5574

12-13 June 2000 Newcastle
PECS: The Picture Exchange Communication System
Venue: Newcastle Contact: Phoebe Haughton Tel. 01273 728888

23 June 2000 Portsmouth
CASC Road Show at Futcher School, Portsmouth
Contact: Rosie Lakin Tel: 01705 375318

29 June 2000 Bristol
CASC Road Show at Claremont School, Bristol
Contact: Sally Chan Tel: 0117 924 7527

17 September 2000 Lancaster
Communication Matters Annual General Meeting
Venue: Lancaster University Tel: 0870 606 5463

18-19 September 2000 Lancsaster
Communication Matters CM2000 National Symposium
Cost: from £235 (£50 for AAC users & parents)
Venue: Lancaster University Tel: 0870 606 5463

2 November 2000 Aberdeen
Tenth Annual Study Day & Equipment Exhibition
Augmentative Communication in Practice: Scotland
Venue: Aberdeen Exhibition and Conference Centre Contact: Deborah Jans, Keycomm Tel: 0131 443 6775

The Mere Oaks AAC Summer Groups

by Lynn John & Tamsin Crothers

The Why, Where, What and How of running an activities week for AAC users and their families.
This paper was presented at the CM'99 National Symposium, University of Lancaster, September 1999

Why?

In October 1997 we piloted an intensive week of activity mornings to offer therapy and fun to our young AAC users and their families. The group was based on the ethos that communication (of all types) should become the central focus of everyone in an enjoyable and motivating environment. Outcomes were reviewed, aims refined, and a further group was offered in the summer of 1998.

We aimed to provide an extension of the groups which run all year, and to involve everyone in promoting social interaction.

Where?

Mere Oaks School is a Special School in Wigan that caters for pupils aged 2-18 with primarily physical disabilities.

Who?

Nine children aged 4-14 were invited. Five families opted to attend the October group and seven attended the 1998 sessions. Mums, dads, siblings, grandparents, carers, and other family members were able to attend for at least one session.

The children used a range of AAC systems, including high-tech aids ranging from Single Message devices to between 8 and 128 locations, stored phrases to semantic compaction. All the students used switches to access their high tech aids. Low-tech communication aids mainly took the form of picture communication books.

We tried to make the staffing multidisciplinary, and there was a wider mix of skills in the second group. The team included a range of the following: Speech and Language Therapists, the Speech and Language Therapy Assistant, a Speech and Language Therapy Student, Nursery Nurses, Physiotherapists, Occupational Therapists, and teachers. Some children (related to staff) also attended, and a previous Mere Oaks pupil came on one day to describe her use of AAC in College.

What?

In October, there was a different theme for each day, covering clothes, food, animals, TV, Halloween and MacDonald's. The Summer Group 1998 took the theme; "Summer Holidays" for the whole week and a different type of holiday was selected on each day:

- Packing
- Blackpool (writing postcards, making icecreams and playing Bingo)
- Safari
- Beach Party (including a dip in the "Mere Oaks Sea" and treasure hunt)
- Disney Land

Vocabulary and activities were chosen to motivate the children, to be within their experience and to allow them to experience success and fun. The Parent/Enabler workshops were hourly sessions covering:

- VOCA programming
- Facilitating communication
- Low tech vs high tech
- Literacy and AAC
- Focusing on children's strengths
- Language development
- A physiotherapy session about the importance of positioning

How?

Each day began with circle time, encouraging all interaction between group members. Parents were responsible for programming in the relevant vocabulary. The children were then split into 1:1 or small groups to practise the day's vocabulary whilst the parents attended the workshops. The children then came back into a group to use the vocabulary in a structured activity. After drinks time, parents and children came together for the morning's whole group quiz/major activity. Each family took homework with them to bring back for the following day's circle time.

On the last day, children and adults received certificates, and took their skills on an outing: to MacDonald's or on the Mere Oaks Picnic.

What was achieved?

Parents

We had aimed to provide families/carers with a support network, to involve them in their child's Speech and Language Therapy, and to provide them with relevant training. We did not dare hope for, and could never have imagined the strength of parent gelling that would occur and their commitment to their child's Speech and Language Therapy.

The parents contributed fully to the team. A pre and post course questionnaire showed that parents had become clearer on the role of the Speech and Language Therapist and therefore they had defined their own roles in promoting their child's communication.

Parents discovered the repertoire of communication skills that their children possess. They shared experiences and ideas related to a wide variety of topics.

Students

Whilst planning the first group, we hadn't expected a large change in the children's communication, since the group was

Lightwriter
(Toby Churchill)
Advertisement

only five days long and we were largely targeting the parents. However, the group really gelled and this has continued through the school year. There was a noticeable increase in assertiveness and initiating communication which was maintained over the last two years. The group improved in accessing their AAC systems and experienced a week of fun, powerful communication.

We feel that the children have also come to view their parents/carers as being involved in their AAC, as well as becoming more motivated to communicate with their peers. They have benefited from the time available to make friends with each other.

Staff

We were able to spend longer, more intense periods of time with the children and could really get to know them better.

Our job has become more defined, empowering parents through increased contact with them and involving them in their child's Speech and Language Therapy. The feedback from parents has held 'summer term burn out' at bay!

The multidisciplinary team worked together, learning from each other and raising awareness of each other's role. They have "faced their fear" of AAC and we hope they feel confident to facilitate communication with and between the non-speaking students.

What now?

Since the first group, parents have met termly to refresh their knowledge/programming skills and to maintain their input into our therapy plans. They are offered the opportunity to help in out therapy sessions, spending a Tuesday afternoon with us on a rota basis.

As we write this paper, we are in the hectic throws of planning the Summer Groups 1999. We hope that this summer will involve parents and carers further and re-motivate them for participating in their child's communication during the coming school year. Since adults and children valued the time available to chat and socialise, we are adding additional, optional activity slots in the afternoons. Whilst these will be co-ordinated by us, it is envisaged that families will participate without us always being present.

In summary, we feel that the groups have become a vital part of our students' Speech and Language Therapy management, promoting communication between all participants and providing an atmosphere of fun and excitement that we hope continue to motivate all involved.

Lynn John & Tamsin Crothers
Speech & Language Therapy
Mere Oaks School, Boar's Head
Standish, Wigan WN1 2RF

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Whose Needs Come First?

The use of Objects of Reference with people who have severe and profound learning disabilities

by Alice Cross & Keith Park

This paper was presented at the CM'99 National Symposium, University of Lancaster, September 1999

Introduction

This paper briefly introduces and discusses some of the practical and theoretical issues surrounding the use of objects of reference with people with severe and profound learning disabilities who do not communicate with intent, and is based on work that is being developed at Charlton Park School in Greenwich, London. The paper has three main propositions:

a. To date, there has apparently been no evaluation of the effectiveness of objects of reference. In practice, the use of objects of reference appears to be developing in an ad hoc and a theoretical manner.

b. Anecdotal evidence suggests that objects of reference are being used with people who do not communicate with intent as if the learner *already understands* that one thing (an object) can represent something else (an activity, a person, etc). This assumption is contentious.

c. There is a need to investigate the process of how objects acquire meaning, or, in other words, *how objects become objects of reference.* Some work at Charlton Park School that investigates these issues is described

The Context

Objects of reference refers to the use of objects as a means of communication, and was first described by Jan van Dijk in the mid-1960s as a means of communication for people with congenital deafblindness. Since then, although the literature is scarce, there has been some examples of work in the United States, Australia, Denmark, and the U.K. A full review of this literature, which provided an introduction the presentation, is in an article entitled 'How Do Objects Become Objects Of Reference' (Park, 1997a). As the title suggests, the article is also concerned with the development of a theoretical model of object use.

Most of the literature reviewed is concerned with the use of objects of reference with children and adults who are *already* communicating with intent. There is very little, if any, literature on the potential use of objects of reference with individuals with profound and multiple learning disabilities who are not communicating with intent.

A literature review (Park, 1997a) identified one particular issue in the use of objects of reference with people with profound and multiple learning difficulties in that the objects of reference - chosen by teachers or therapists to represent significant activities, objects, or people -may be *representational.* In other words, the objects may stand for, or represent, something other than themselves: a purse or wallet for shopping, a piece of material to indicate the sensory room etc. Using objects of reference may appeal to *us* because *we* think they have a 'common sense' value: they are permanent, manipulable, and concrete, and their use should therefore not be problematic. Most of the literature reviewed, however, suggests using them in a way that pre-supposes that the user understands the distance between vehicle (the object itself) and referent (the concept to which it refers). For example, why should a purse represent or 'stand for' shopping? How do we know what an object may or may not represent for someone else? How do objects *become* objects of reference.

A literature review (Park, 1997a) proposed that a provisional model of object use might be designed by using three terms from semiotic theory: index, icon and symbol. These are described by Elizabeth Bates in her pioneering work on early communication and language as follows:

Index: Signs that relate to the things they stand for because they participate in or are actually part of the event or object for which they stand' (Bates, 1976, p2)

Icon: 'Signs that are related to the things they stand for by virtue of some physical resemblance' (Bates, 1976, p2).

Symbols: 'Signs that are related to the things they stand for by an arbitrary bond agreed upon by those who use the symbol' (Bates, 1976, p2).

The Practice

These terms can be illustrated by the following account of two teenagers, Alex and Anna, and their communication needs. Pre-intentional communication may be described as being idiosyncratic, context-dependent and individually directed.

Alex, who is 16 and has multiple disabilities, has been observed by his carer, at dinner times, to 'flutter' the fingers of his right hand, a behaviour that the staff who know him best have interpreted as meaning 'This is nice/I like this/I am comfortable with this.' This behaviour is, in one sense, unique to Alex, and so it is *idiosyncratic;* it only ever occurs at dinner times and so it is *context-dependent.* It is pre-intentional communication in that Alex is not intentionally transmitting a message although the staff are able to interpret it as having a meaning. This is a result of their efforts to communicate to Alex certain essential items: he has been encouraged to feel the plate and spoon, smell the food, listen to the carer talk to him and allow him time to respond in his own individual way. In this way the communication is *individually-directed* in that it aims to help him make sense of his environment.

The final stage of intentional communication - when people begin to use words, signs, symbols, objects or any other communication media - can be described as *conventional,* *context-independent* and *socially directed.* For example, Anna, also 16, is in a school leavers group. All of the teenagers in her group have a severe visual impairment and severe learning difficulties. The group shares an objects of reference board that indicate school activities, school personnel, and school rooms. The system of objects of reference has been developed to be the same for all the group *(Conventional),* it is used across home and school environments *(context-independent)* and one of its aims is communication between the members of the group *(socially directed).*

According to the terms used by Elizabeth Bates, Alex uses an object as an *index,* Anna can use an object as an *icon* and also as a *symbol.* Alex is encouraged to feel the spoon at mealtimes, the cup when he is about to have a drink, and so on. The objects are part of the activity-event, and do not have symbolic value. Anna, and the others in her group, can take an audio cassette from the object board and then give it to someone, indicating 'Put the music on.' The cassette looks and feels similar to the actual tape that is played: it is an *icon.* Anna can also take a bracelet from a piece of card by the door and give it to a member of staff to request 'Let's go out.' This object of reference is abstract and quite removed from the context of the going out - it is a *symbol.*

Investigating Object Use

We have suggested that an appropriate question to ask is: how do objects become objects of reference? In other words, how do objects acquire representational qualities? One possible answer is outlined by Sinha (Sinha, 1988), who describes how objects acquire representational status because of their 'canonicality': this refers to the 'canonical, or socially standard, function of the object' (Sinha, 1988, 105-106). To develop canonical object use describes the sequence of how objects become objects of reference. Sinha makes two important suggestions:

1. '...objects encountered by the infant are *also* social...in that they are encountered within a context of particular social practices and social relations.' (Sinha, 1988, p105)
2. '...the context-of-use of the object commonly achieves., representational status in the structure of the object itself' (Sinha, 1988, pl05)

These statements translate directly into daily practice and, together with the provisional model of object use, offer a theoretical basis for investigating index and icon, and of how objects acquire symbolic status.

1. Index

The Object Related Scheme Assessment is a valuable observational tool that describes the earliest hand functions and hand-eye functions - reaching, holding, grasping, exploring, dropping, throwing, etc.

Although the authors stress that the list is not strictly developmental, it is interesting to note that the two categories 'Viewing the Functional Side' and 'Functional Use' come at the end of the list. These two categories suggest that object are being used according to their canonical function. In other words, canonical function has been *learned from functional use.* The children's use of objects as *index* is compared against their use of objects as *icons.*

2. Icon

Each Wednesday morning at Charlton Park School, a group of children come together for a sequence of activities organised by the speech and language therapist and the physiotherapist. From the perspective of object use, the activities are an investigation into the use of *icon.* Children and staff sing songs and rhymes such as 'This is the way we (clean our teeth, wash our faces, eat our dinner', etc) at which time each child is encouraged to hold and manipulate the toothbrush/ flannel/spoon, etc. There is also a 'Telephone Song' when everyone holds a toy mobile phone, and the song 'Incy Wincy Spider', when everyone holds a toy spider. Early results suggest that there has been noticeable increase in the length of time that the children will hold their objects, and an increase in the children's' manipulation of objects.

Conclusion

It seems reasonable to suggest that, for individuals with severe and profound learning disabilities who do not communicate with intent, it is highly questionable to introduce objects of reference for National Curriculum subjects, or to arbitrarily introduce a set of standardised objects ('toilet' and 'biscuit' appear to be very popular) for a group of individuals who have widely differing communication needs.

Similarly there appears to be no definition, description or evaluation of the idiosyncratic and apparently widely-used terms of 'object cues' and 'event markers.'

It is tempting to suggest that objects of reference are being used in many cases to satisfy the needs of the professionals rather than the needs of the users, which begs the question: whose needs come first?

There is an urgent need for research in this area, and a pressing need for an evaluation study. Our work at Charlton Park School is still in progress and we would be interested to hear from anyone who is developing similar work.

Alice Cross
Speech & Language Therapy
Charlton Park School, Charlton, London SE7 8HX
Tel: 0181 854 6259
Keith Park
Sense Family Centre
Tel: 0181 991 0513

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CATCHNET

The use of telecommunications technology to provide remote support and training to young people with access difficulties

by Andrew Lysley, David Colven & Mick Donegan

Introduction

CATCHNET is a pilot project, which demonstrates some of the potential uses for low cost, 'off-the-shelf' data exchange and videoconferencing technologies in the field of Assistive Technology (AT).

Evidence from many disabled young people, their families and schools shows that access and interfacing to Assistive Technology need constant attention and adjustment. Indeed, the demand for training and support in the use of AT increases with every generation of technological innovation. Faced with this overwhelming demand for help, service delivery centres such as the ACE (Aiding Communication in Education) Centre have been investigating different methods for improving its training and support services. This has been the catalyst and rationale behind CATCHNET. The project is the first step in the process of evaluating to what extent the ACE Centre's current service provisions can be augmented by using mainstream remote telecommunication technologies.

> *...access and interfacing to Assistive Technology need constant attention and adjustment.*

Is it viable to enhance or even replace traditional training and support with remote support interventions? To what extent can remote support services improve the quality of service delivery to geographically less accessible places? Can such remote services successfully occupy some of the vacuum left behind by depleted local and regional provision across the UK? CATCHNET cannot, of course, provide full answers to such interesting questions. But it does give some 'indication of worth'. To reach beyond this insight, more substantial research will be needed to evaluate the true cost/benefits of complementing or substituting *face-to-face* with *remote* training and support services.

The results of CATCHNET have been very exciting, with positive feedback from both users and facilitators. The ease with which support can be provided remotely has been of particular surprise and delight to us. Furthermore, CATCHNET has been mutually beneficial, strengthening the sense of teamwork between user, facilitator and the ACE Centre staff. While our users and their facilitators have gained most from focused and better-directed training and technical support, the ACE Centre has improved its insight into individual user needs within specific, local environments. Improvements in communication, quality of feedback, and attention to detail have been important too.

CATCHNET has, undoubtedly, provided a solid platform for the next phase (TELENET) of our remote support plans where, it is hoped, the long-term benefits, limitations, and costs will be analysed and evaluated in greater detail.

Project Objectives

CATCHNET's central objectives are:

i) To set up and use telecommunications (computer-to-computer and videoconferencing linking) with four individuals based at school or home in the South of England. All four users have severe physical difficulties, affecting their ability to access learning and recreation.

ii) To train the four end users and their facilitators to use complex, mainstream and special needs framework software more effectively.

iii) To raise their levels of skill, independence and self-confidence through remote training and support strategies.

iv) And finally, to evaluate the potential benefit of using remote technologies in the process of 'iterative' software development. Using remote support technologies, can potential users of new Assistive Technology software become more effectively involved in the process of software development and usability testing?

Project Context

Across the country there are currently three major sources of educational support and training available to children and young people of school age who depend on Assistive Technology to support their learning:

- Special Educational Needs Co-ordinators (SENCOs) in schools, most of who have limited experience of children with complex, physical access difficulties.
- Some advisory teachers in LEAs and healthcare professionals such as speech and language therapists and occupational therapists. Few have the specialist expertise required to support our AT client group.
- Special Schools for children and young people with severe physical disabilities.

The use of Assistive Technology with school aged children has become a highly specialised field. The demand, therefore, for ACE Centre services exceeds what the Centre can currently offer.

This demand is because the Centre has:

- An experienced and specialist interdisciplinary team.
- Access to the latest specialised technology.
- A thorough and detailed knowledge of the accessibility problems and issues faced by young people with complex, physical difficulties.
- An acknowledged place at the cutting edge of Assistive Technology development.

While national centres such as the ACE Centre should play a crucial role in describing and establishing ‘models of good practice’, they cannot provide face-to-face assessment and on-going support for *all* those who wish to use the Centre’s service. Time, cost and geographical distance preclude this.

Alternative models, which can co-exist with conventional service delivery models, need, therefore, to be evaluated. CATCHNET has been the Centre’s first step in the process of finding alternative models of training and support. The end goal is to build an effective network of regionally based, multi-professional teams with acceptable levels of clinical and technical competencies in the field of Assistive Technology.

Claire - A Case Study

Background

Claire has athetoid cerebral palsy. She began mainstream nursery school at the age of three and a half years. Her main method of communication is speech, which, although limited by her breathing pattern, is intelligible to her family, friends and those professionally close to her. She was first referred for assessment to the ACE Centre in 1994 to develop her access to the computer.

Claire’s Needs

It was hoped that her involvement in the CATCHNET Project might help to support Claire in the following ways:

- Claire’s literacy skills were at the stage when the transition from a word bank to a word predictor could be considered. CATCHNET would provide the opportunity to support this transition to a new form of text acceleration.
- Using the videoconferencing in CATCHNET, Claire’s physical access to the computer could be observed in situ and adjusted if necessary. This would ensure that the hardware and software kept up with her changing needs and abilities.
- Claire’s Maths skills could be further developed by providing Windows switch access (in this case Switch Access to Windows was used) to Number Navigator and AccessMaths. On-going adjustments to her user interface and on-line training would be available.
- Supporting Claire at home would enable the CATCHNET project team to compare the effectiveness of remote support in a home environment with that of the other students in school environments. Of the four users Claire was the only student to be supported at home.
- Claire was particularly keen to use the computer for recreation. Home-based remote support would provide an opportunity to support this aspiration.

Outcomes for Claire

Most of the contact time with Claire has been via datalink and telephone connection. This has been used to train Claire’s mother in using particular programs and in furthering her understanding of Windows. The main programs that Claire used for her schoolwork were Kidpix, Write (Wordpad), WordAid, AccessMaths, Number Navigator and SAW for access.

- It proved easier to set up regular sessions with Claire’s mother than it would have done with a school. Her timetable was more flexible and she, of course, showed great commitment to the project.
- While rapid progress was being made at home, it proved difficult to keep her school system (not set up as a remote CATCHNET site) in step with this progress.
- Having simultaneous voice and datalinks was essential for effective training.
- Video conferencing was very effective for occasional monitoring of Claire’s seating and joystick/switch positioning.
- Claire’s mother used the training effectively for learning how to configure programs, particularly Number Navigator. She proved very adept at creating new macros (navigation methods) to help Claire with her arithmetic.
- It was useful being able to leave messages on Claire’s computer prior to or after a remote session, so that information could be passed on about changes needed, or those completed. It was then possible for ACE staff to improve Claire’s user interface without anyone being going to the remote site.
- The datalink was very effective at sorting out software problems on Claire’s computer. At one point we even remotely removed a virus on her computer system!

Claire’s Mum on CATCHNET

“The project has helped with Claire’s number development (using Number Navigator). It has also helped her in terms of in information retrieval and access to electronic leisure activities. Because of her physical difficulties Claire is unable to enjoy unaided, independent play (playing with her dolls, dressing and feeding them), for example while I am washing up.

In her play Claire always has to direct adults to do things for her. With her computer she uses her Monopoly game to involve Teddy and Kate (one of her dolls) as ‘real’ players. This gives her lots of independent, imaginary play opportunities. Claire likes to play computer generated cards and draughts downloaded for her via the ACE Centre data exchange link. She uses her CDs for information retrieval, for example, when doing a history project on the Tudors. The CATCHNET link has given both of us confidence in expanding our use of the computer.

CATCHNET offers direct, targeted advice appropriate to Claire’s specific needs...I have calmed down a lot about technology. I feel more competent and confident in its use...I would like to purchase a block of (*remote*) training and support sessions once the project is over. The reason for this is that technology with Claire is dynamic and not available in the normal market place. Her needs require specialist services.”

Benefits to Users & Facilitators

- Users and facilitators do not have to travel or be visited to receive expert specialist advice, training and support. Indeed, for maintenance or user interface improvements, they need not even be near their computers!

- Users and facilitators do not have to learn so much about the technical side of setting up complex systems. Instead, they can concentrate on their use, confident in the knowledge that technical problems such as new or upgraded installations can be remotely facilitated.
- Users can have software modifications customised for their computer systems on site. This removes the need to bring or send their computers to the ACE Centre.
- Using the video link, local professionals and facilitators can be given advice on specific adjustments to seating and computer interfacing.
- The quality of support and training is greatly superior to that offered via conventional telephone, correspondence or e-mail.
- Users and facilitators can receive training in small and digestible bite sizes.
- Users facilitators become greatly *enskilled.*

Conclusion

Telecommunications technologies have already evolved to a point where they are reliable, sophisticated and relatively inexpensive. Videoconferencing will provide first class opportunities for exchanging professional ideas, offering advice and making clinical recommendations related to Assistive Technology. On and off-line datalink maintenance can be achieved easily and inexpensively with single telephone/modem lines.

However, interactive, on-line training ideally requires two separate telephone lines to enable a seamless dialogue to take place between the trainer and trainee. Only where videoconferencing is required, for example when making recommendations about the user's seating, posture and access to assistive technology, are faster and more sophisticated telecommunications technologies such as ISDN lines essential.

Andrew Lysley, David Colven & Mick Donegan
The ACE Centre Advisory Trust
92 Windmill Road, Headington
Oxford OX3 7DR
Email: lysley@ace-centre.org.uk

ACKNOWLEDGEMENT

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A Case Study from Italy:

AAC and Marden-Walker Syndrome

by Loredana Lembo

I have written this case study to give an example of an experience of AAC in Italy, in the city of Florence in Tuscany. In Italy, research into AAC is comparatively new, so it would be of great interest and value to us to receive feedback about AAC in different countries in order to learn and improve our knowledge in this area.

This article tells the story of Michael, a boy of 15 years of age affected by a genetic syndrome called Marden-Walker Syndrome, which is a very rare disorder of connecting tissue; medical literature describes only 20 cases. It is prevalent in males, with a ratio of 11: 3. The gene that causes this pathology has still not been characterized or located. However, recent studies have identified common elements to diagnose the Marden-Walker Syndrome. There is an abnormal increase of the bony structure characterized by a fixity of the joints that causes the slowness of the muscular movements, an irregular development of the spinal column and characteristic facial features, such as a jaw projection, low eyelids, small mouth and eyes and a flat nasal bridge. There is also a mental and emotional backwardness, which is difficult to quantify because the people affected by this syndrome are speechless.

Meeting Michael

Lidia Manca (Michael's learning support teacher) introduced Michael as a hyperactive, anxious boy, with a threshold of fleeting attention and with a total absence of oral language.

I met Michael for the first time in September 1997 in his home and in the presence of his parents and his two older brothers. I was tense and anxious because I had never met this type of pathology in the course of my studies and my working experiences. I didn't know what I could do and what was useful to observe, so I took my lead from Michael. The family was revealed to be very close, dynamic and fully aware of the difficulties that Michael's pathology involves, but also very tenacious in the search of other useful approaches in order to stimulate his communication.

During my visits I always tried to follow the opinions of my patient's family, because I think it is essential that the disabled person develops and uses every day skills constantly in his/her daily life and to his/her and integrates within the familiar sphere in order to extend them to different situations and various environments. It was the way in which Michael welcomed me that convinced me of the potential and the great opportunity for me to participate in stimulating his communicative abilities. In fact the boy was interested and curious about my presence and, holding my hand, he pulled me into his bedroom to show me his computer, his Walt Disney videotapes and a small basket attached to the wall. Whilst he was indicating his toys to me with his index finger, his gestures were accompanied with an excited voice and a big smile; he hit his chest with his right hand, pronouncing his name "Lele". Michael was clearly speaking with me, with a person whom he had just met: he wanted to share with me his games with me, the things that he liked and that they belonged to him, he was showing me his interests.

First Steps with AAC

In October I began my collaboration with the school and my travels to Milan to go to the Benedetta D'Intino Centre where I attended a course on Augmentative and Alternative Communication.

I first heard of AAC during my final year at the University of Florence, in a presentation about a new book written by my tutor, Doctor Giuliana Pinto. She had carried out research into the importance of visual language, studying pre-school children's drawings. She told me she had read an article about a Canadian team able to use different kinds of pictures to communicate with speechless children. I was fascinated by this method, but I set it aside because I was very busy writing my thesis.

However, after one year I met Michael's mother, who explained to me that in Italy AAC had been introduced by Doctor Aurelia Rivarola and her team, who work at the Benedetta D'Intino Centre in Milan.

> *...the boy didn't show any interest [in the communication board]*

Michael had already a communication board that permitted him to say something to other people. Michael's parents had put on his communication board photos of his relatives, his cat and his teachers and some PCS (Picture Communication Symbols) stickers, describing his favourite activities and foods (some verbs: to go, play, eat, drink, look; some sports: tennis, swimming pool, bowls, horse; some foods: fruit juice, tea, pizza, sandwich, pasta). Michael's mother used to put his communication board in his school bag every day, but the boy didn't show any interest and he always put it away as soon as I tried to use it.

Therefore, while I was trying to learn the best way to use the communication board, in agreement with the family and the teachers, I decided not to use it at first and not to add new PCS symbols.

Then I turned my attention to the communicative system that Michael had developed spontaneously, not only in order to get to know him and let him know me, but also to understand his potential and the level of his learning. I wanted to find the right approach to introduce Michael to AAC.

A Dictionary of Gestures

Michael had created a series of gestures that, initially, permitted him to only communicate with his family or with persons who knew him for a long time. In this way his efforts turned to be out in vain and, paradoxically, only those people that could comprehend *his* functional gestures understood him. In effect his family and his friends were his only translators and interpreters, building a sphere around him and pushing him to a total dependency. This in fact built a barrier for Michael in relation to interaction and stimulation from others.

Therefore I tried to understand the meaning that Michael attributed to every gesture and with the help of his brother, Jan, we constructed and designed a Gestures dictionary (Figure 1). I distributed Michael's gestures dictionary inside of his school in order to permit Michael to be understood by everyone without his learning support teacher's help.

> *...he realized the importance of learning the new communication syststem.*

Michael has understood very quickly the importance of such a dictionary and through this experience I was able to make him understanding what the use of the communication board would offer to him. In this way he began to always carry with him the communication board and constantly pointed to the photographs of his family.

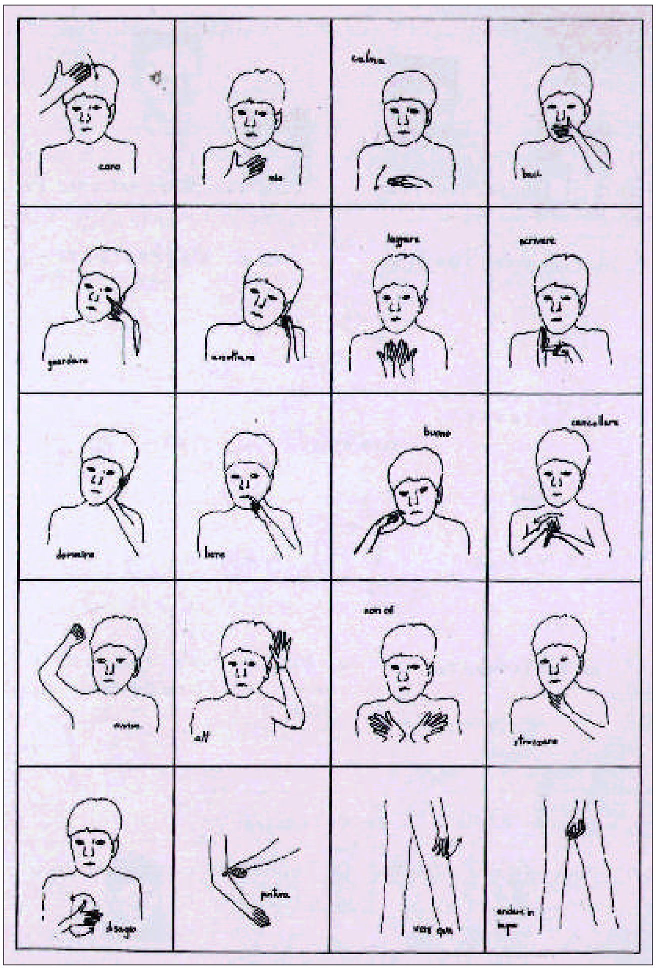

Figure 1 Michael's Gestures Dictionary

The Gestures Dictionary has not only opened a window for Michael but also for the people around him. The tension, the embarrassment and frustration that occurred every time the teacher or the schoolmates were not able to understand Michael is diminished.

Once I had got Michael's attention and motivated him, he realized the importance of learning the new communication system which would permit him to widen and to enhance his strong communicative intention and potential.

Improving Yes/No Response

I tried to improve his response to *Yes* and *No* questions and his choices. Therefore I was particularly careful of the way I spoke with Michael, trying to use simple, clear and direct language, and avoiding rhetorical questions or questions which required multiple answers and an excessive use of subordinated prepositions. Instead, it was more advantageous for Michael, if I used the conjunction 'and' in my sentences. Michael could not answer questions like, "What would you like to eat?". However, if I asked to him, "Would you like to eat an apple?", he was able to answer me, "Yes" or "No".

> *I associated each object with my fingers.*

In order to increase his choices, initially I used the concrete presence of two or more objects, that then I removed from his visual field in order to extrapolate his choices from the context. I associated each object with my fingers – if he wanted to play with the ball, he would hold my thumb; if he wanted to listen to a story, he would indicate this by holding my index finger. We would do the activity that Michael indicated to me, depending on which of my fingers he held.

Using PCS Symbols

In December 1997 I began to teach to Michael the use of the communication board with PCS symbols. Whenever I spoke with Michael or questioned him about something, I myself used the communication board, referring to familiar subjects that Michael was able to communicate through his gestures.

In this way I showed him that he could also communicate by indicating the picture symbols, which were easily comprehensible by his communication partners. The style of these symbols is simple and realistic, and above every picture is the word that explains the meaning.

I have tried to use the PCS board in order to not only enhance Michael's communicative abilities, but also in order to check (or limit) his hyperactivity due to his general anxious state. Using the symbol identified by a picture of a ringing bell, Michael and I have outlined every hour of the morning spent at school and used the PCS symbol of the bell beside each teacher's photograph together with the subject s/he taught.

Michael's eagerness to tell his schoolmates about the lesson he was going to next, using the PCS symbol, following the sound of the school bell, encouraged him to use the communication board more and more each day.

A Turning Point

Michael reached a turning point in January 1998. He was now the one who was taking the initiative and he wanted to increase his vocabulary. As soon as he met me, he used to take the PCS stickers block and together we looked for those words that he wanted to add to the communication board. Moreover he also has developed a particular way of vocalizing in order to tell me that he wished to use his PCS board.

> *In a frentic way, he started to indicate many symbols on his communication board.*

In this way Michael, from expressing simple primary needs, was now able to describe or to demand his favourite activities and was able to tell me about significant events in his life. Michael could tell he had gone in an aeroplane to see his grandparents at Christmas, that his cat was sick or that, one day, playing in the school garden, the football had got stuck in the branches of a tree.

Towards the end of February, I was able to make good use of his enthusiasm and strong emotional involvement. For example, when he remembered his Christmas holiday which he had spent with his grandparents and his cousins in Poland, I suggested to him that he should write a letter. His reaction exceeded my expectations; in a frenetic way he started to indicate many symbols on his communication board. I helped him put the PCS symbols he chose into grammatical order as we wrote the letter (Figure 2).

In March, I tried to extend the use of the communication board beyond the familiar school and home environment. Considering Michael's preferences, I created with the PCS symbols (which Michael chose) some small but specific communication charts (Figure 3). Using these PCS boards, Michael began to go to buy bread in a bakery, a notebook in a store, and fruit juice in a bar.

In May, Michael's learning was progressing much slower because I tried to stimulate his cognitive and conceptual abilities much further by offering him the possibility of spontaneously telling me a story that goes beyond a simple description.

Another very complex element, considering the emotional development that Michael is undergoing as a teenager, is to encourage him to use PCS symbols to explore and express his feelings and emotions. He is not able to, or sometimes does not want to, indicate various feelings, such as fear, anger, pleasure and happiness. My plans are to help him to explore and to express his feelings.

In collaboration with the learning support teachers, we have taught to Michael the alphabet and now he is able to type on the computer every word if we spell them. This proves that Augmentative Alternative Communication is not a barrier to

VI SCRIVO QUESTA PER RINGRAZIARVI

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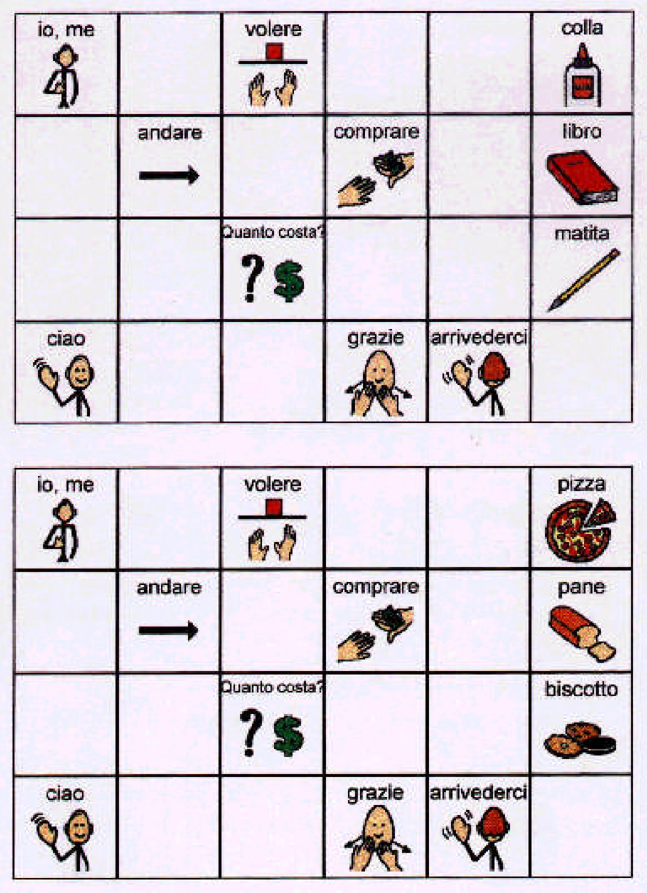
Figure 2 Michael's letter to his cousins in Poland



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ciao			grazie	arrivederci	

Figure 3 Specific Communication Charts

learning to read and write; on the contrary it can help and stimulate these processes.

Reading and Writing

At school we tried to stimulate Michael's reading and writing abilities, reading him many stories that he can write on the computer. We tried to involve all the children in the class in the making of masks and puppets to act out Michael's favourite story. We wanted to give a lively meaning to the written word, and to teach him to respect turn-taking in conversation. But Michael found it difficult to sequence letters in order to produce words that were not familiar to him, and he was not able to write anything spontaneously.

Observing such problems, I think that it is necessary to work also on phonological competence. To be unable to produce sounds makes it very difficult to identify and put together the right letters to create a word. When speaking people read a difficult text or a new word, we try to read slowly with loud clear voice, or we repeat the word in our minds. It is easy to understand the extreme difficulty that a speechless boy finds learning to read and to write.

This is why I think it could be very useful for Michael to use software with voice output able to pronounce every letter as Michael tries to type a word. This will help to make him aware that every written symbol has a sound. Moreover, the enormous interest that Michael has in computer-based activities could greatly help to realize these future goals.

Loredana Lembo
Via Romena 49, 50061 Compiobbi, Firenze, Italy
Email: loredanadifiore@hotmail.com

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Service Delivery Forum

Service Provision and Supply of Environmental Control Systems

by Eileen Grist

An outline of the involvement of a specialist speech and language therapist in Augmentative and Alternative Communication to two UK national committees concerned with Environmental Control Services.

Introduction

During 1998 and 1999 a number of changes took place which were designed to affect the supply, provision and evaluation of goods and services to people who need electronic assistive technology. This covers environmental control devices, voice output communication aids and all associated switches. The main focus of change arises out of *NHS Supplies* and the *British Society of Rehabilitation Medicine*. We have been asked to provide some information about the impact of the above organisations on the provision of environmental control services and outline of the contribution of Frenchay Communication Aid Centre.

The first thing to establish is that there are three major groups that try to influence the service provision and supply of environmental control systems:

1. NHS Supplies Commodity Advisory Group - Electronic Assistive Technology ***(CAG-EAT)***
2. British Society of Rehabilitation Medicine - Special Interest Group - Electronic Assistive Technology ***(SIG-EAT)***
3. National Strategic Group - Electronic Assistive Technology ***(NSG-EAT)***

The second thing to note is that several people are members of all three groups!

The Communication Aid Centre and Frenchay Hospital has provided a specialist service for the assessment, training, education and information dissemination aspects of AAC devices and strategies since 1981. During 1999, we were invited to serve on the above committees. After much reflection about factors concerning time, skill base and geographic representation, we decided to limit our contribution to the NHS Supplies *CAG-EAT* and the British Society of Rehabilitation Medicine *SIG-EAT*. We strongly advised that a speech and language therapist from a more northerly area should be recruited to serve on the *NSG-EAT*. Liz Panton, from *Communicate* in Newcastle, agreed to serve on this committee.

CAG-EAT (NHS SUPPLIES)

Before 1996, the budget for Environmental Control Systems was held centrally by the Department of Health (DoH). The expenditure was dealt with by an approved list of assessors, service co-ordinators and suppliers. This resulted in a limited choice of service and equipment. Little attention was given to clinical audit or to evaluating service outcomes, performance of equipment, budget management or reporting adverse incidents.

In 1996, the Environmental Control Budget was devolved to Health Authorities, mainly Regional but in Scotland and a few areas of England, at District level. The delivery of service to users and the supply of equipment was arranged differently by the various Health Authorities. The Environmental Control Commissioning Group *(ECCG)* was set up to try to address the issues raised and there were moves to develop a national framework. The *ECCG* commissioned the first national contract for environmental control systems which commenced on 1 April 1996. The contract provided a national framework but contained only environmental control systems. The *ECCG* changed its title and is now known as the *NSG-EAT*. Meanwhile, environmental control systems were evolving and advances in electronics enabled some voice output communication aids (VOCA's) to control the environment. *CAG-EAT* were instrumental in approving systems to the contract based on a functional specification.

During 1998 the *NSG-EAT* were keen to develop the national contract to promote a more holistic approach to provision. NHS Supplies began work renewing the contract and involved a number of key people, including industry, trade associations, customers etc. A key brief was to extend the range of suppliers and equipment, include communication aids and encourage collaboration and partnerships. The new national contract for electronic assistive technology commenced on 1 April 1999.

Through the *CAG-EAT* they aim to discuss applications made by all companies who want to provide electronic assistive technology via the NHS contract. In particular they:

- look at the financial employee viability to support the supply and repair of equipment
- evaluate the quality of the product
- check safety issues
- implement appropriate technical standards
- test the functionality of the device

An *Evaluation Sub Group* comprising Lincoln Community Rehabilitation Centre (Roger Potter and Team), and Frenchay Communication Aid Centre (Eileen Grist) has been designated to look specifically at technical, functional and safely aspects of all the electronic systems and switches offered for inclusion in the new NHS contract.

The resulting NHS Supplies catalogue will include electronic equipment that has been thoroughly investigated for safety, compliance and functionality. It is also the intention to produce documentation confirming technical and functional viability of the products, the adequacy of support literature and the safety standard of accessories.

SIG-EAT (BSRM)

The Department of Health provided central funding for the supply of environmental control equipment before the 1990's. In the early 1990's the *BSRM,* whose membership is open to registered medical practitioners who are interested in and concerned with its objectives, formed a Special Interest Group for Environmental Control Services. The aims of this group were to:

- enhance the training of assessors
- provide advice to the *DOH* on professional matters concerned with environmental control systems and services provision

In 1994, this working group published a document entitled *Prescription for Independence,* which was funded by the Department of Health. The main aims were to:

1. Influence changes in current provision.
2. Help to shape the reorganisation and development of rehabilitation services nationally
3. Ensure technical advances were incorporated into equipment provision
4. Create a service structure that ensured the education, training and recruitment of suitable personnel

In the *Summary of Major Recommendations* (Section 9) of this document, mention is first made of the need to integrate other equipment "such as communication aids and wheelchair controls".

In 1997 to 1998, the *BSRM SIG for Environmental Control Systems* became the *SIG-EAT* in order to reflect the widening scope of electronic devices in the field of disability. Although the British Society for Rehabilitation Medicine remains for medical practitioners only, the *SIG-EAT* members decided to widen the skill base of their group membership to include other professions, such as occupational therapy and speech and language therapy, by inviting individual named practitioners to join their committee. A further report was commissioned by the *BSRM* so that it could continue to influence changes and recommend improvements in the service to patients. This report has now been completed by members of the *SIG-EAT* committee, including the non medical members, and will be launched at the British Society for Rehabilitation Medicine meeting in July 2000.

Frenchay Communication Aid Centre's involvement at present is to provide a Specialist Speech and Language Therapist in AAC who will help to contribute to the changes in service that will be recommended to the DOH through the latest Report due out later this year.

In the future, our role could be developed to ensure that:

a. There is a nationally raised profile for speech and language therapists who have a specialist knowledge of AAC. Their expertise can then be used in those assessments for environmental controls where communication is likely to become a factor.

b. These areas of expertise are pinpointed and representatives identified who could be contracted to contribute to assessment, training and implementation of all aspects of AAC so that communication is developed via both electronic and non-electronic means.

c. Coordinators and Providers of services that incorporate electronic assistive technology will be encouraged to broaden the skill base of their assessment teams to include input from other professions.

Eileen Grist
Head of Communication Aid Centre
Speech & Language Therapy Dept
Frenchay Hospital, Bristol BS16 1LE

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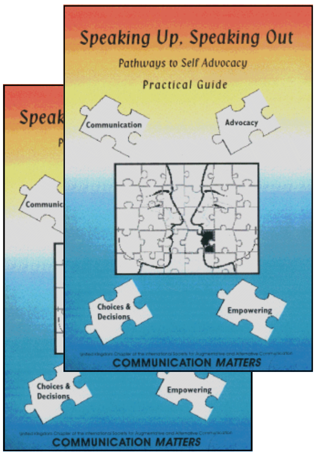

Speaking Up and Speaking Out! Pathways to Self-Advocacy

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. Developed by a special task force of Communication Matters members, the pack comprises two books. One is a comprehensive and detailed Handbook which includes case stories, discussion points and references. The other is a Practical Guide which summarises the main points of the Handbook in a series of photocopiable overheads, checklists and activities designed to help users build an advocacy plan for individuals.

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

Michelle Finds a Voice

This book is a story about Michelle, a young adult with disabilities who is unable to speak or communicate effectively. A number of events cause her to feel unhappy and isolated until she and her carers are helped to overcome the communication difficulties. Various solutions are explored, including the use of signing, symbol charts and electronic communication. Michelle's story is told through pictures alone to allow each reader to make his or her own interpretation, but there is also text at the back of the book to provide one possible narrative for the pictures. The book was created by Sarah Barnett and Sheila Hollins and published by the Royal College of Psychiatrists, with financial support from Communication Matters.

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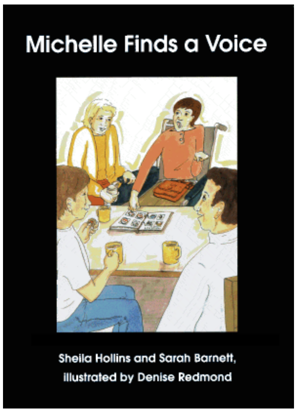

Alternatively Speaking

Published three times a year, this eight page newsletter, from Augmentative Communication Inc. in the USA, contains AAC issues and in-depth reports on topics vital to the AAC community. It is written by Michael Williams, who is an AAC user and serves on ISAAC's executive committee.

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Augmentative Communication News

Published six times a year by Augmentative Communication Inc. in the USA, each issue contains eight pages of in-depth information on particular topics researched and written by Sarah Blackstone.

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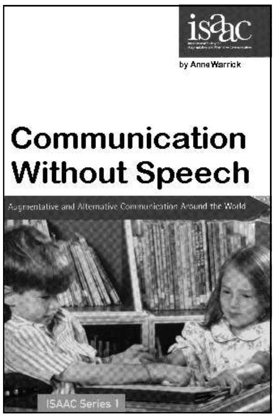


Communication Without Speech:
Augmentative and Alternative Communication Around the World

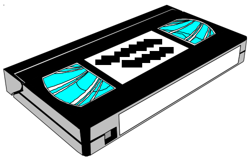
This ISAAC book, written by Anne Warrick, is a highly accessible but very comprehensive introduction to augmentative and alternative communication. It contains lots of questions and practical tips such as vocabulary selection, assessment, education and vocational considerations, making communication boards, and includes excellent photographs and illustrations.

Price: £15 plus £1.50 p&p available 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: £10 to CM members (otherwise £15) including p&p **only available from ACE Centre (ring 01865 759800)**



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