

April 2010

Since two months have gone by, it's time for another Augmentative Communication World Network (ACWN) newsletter. Our Augmentative and Alternative Communication (AAC) news in this edition comes from Cambodia, Morocco and Bangladesh. Many thanks to our three contributors. Also, be sure to check out the great websites described in the issue as well as some presentations some of you are doing at the ISAAC Biennial Conference in Barcelona in July. Finally, you'll find Harvey's Place filled with good information.



Ruth Bryce is an Australian Speech Language Pathologist living and working in Phnom Penh, Cambodia. Ruth and her family have been in Cambodia since 2006. She sends the following: "Greetings to friends in the ACWN network".

Cambodia: An emerging AAC country

I work as an advisor to a Community Based Rehabilitation project, "The Little Conquerors", supporting kids with disabilities and their families. My background in Oz was working with people with complex communication needs and as such, augmentative and alternative communication

(AAC) was a large part of my work. I'm passionate about helping people discover their voice and have their say and place in society. For people with disabilities in Cambodia, I see AAC as a useful tool, yet one that is underdeveloped and often unavailable.

In my own experience, I've found it difficult to develop AAC systems that are able to be used by individuals outside of a special school or therapy group setting. Barriers to AAC often include limited time and competing needs of the program as well as cross cultural and linguistic factors. I also find that working under local directorship (people who haven't seen AAC options first hand) can mean that the development of individual AAC systems is less of a priority. In a sense, it's hard to request what you do not know about. Using Beukelman and Mirenda's participation model (1993), people with disabilities in Cambodia face both Access and Opportunity barriers. Access barriers in Cambodia are very obvious – the lack of the actual communication aids, their own physical limitations, *etc.* Opportunity barriers become more apparent over time; *e.g.*, a low position in a very hierarchical society intrinsically means limited opportunities and limited awareness of the right to speak. The children we support come from very poor families. It is a daily issue about whether there is enough food for the family, so speaking to families about facilitating their children's communication must happen within a context that helps the whole family improve their situation and find hope for their future.

I've come up with many questions in my three and a half years in Cambodia. Living with my family in our urban poor community means I spend a lot of time in neighbour's bare houses, experiencing their warmth and generosity as well as sharing their concerns about bringing up kids. Cross cultural issues and the use of AAC brings up specific questions: How does one create individual AAC systems for people in a culture where things are automatically shared, given away freely and the idea of having something for a long time is not particularly valued? How do we promote everyone's right to communicate when culturally children are encouraged to be compliant and quiet?

About our CBR program – The Little Conquerors – <u>www.task.org.kh</u>

Our program runs a therapy group (early intervention type) for kids with their carers twice a week. This also acts as an entry point for many families and becomes a supportive place for families to learn a new understanding of disability, what causes disability, and the potential life ahead for their child. We support a small number of children to access government schooling and have a special school for about 20 students who are currently not able to attend a mainstream school. We have a group of volunteers (all Cambodian) who do regular community education. Our teachers and physiotherapists make regular visits to children in their home. We also support kids with epilepsy by helping them access medication, although we're working to hand this over to our local government health services. At this stage we have regular contact with 135 families. Our staff is made up of 2 teachers, 2 physiotherapists, one social worker and one handyman (who's great at making aids) *etc*. We are often a first point of referral for many different family issues. We support children with any type of disability – many with cerebral palsy but a growing number with severe intellectual disabilities. The project has continued over the last 15 years.

My involvement

Being the only foreigner within our program has meant my input has not been speech pathology specific. Often my role is to help staff reflect on practice and how we better impact the lives of people with disabilities. I connect with the project once a week. In terms of AAC, our focus over the last three years has been to increase the use of visual aids within the special school and to introduce the use of a keyword sign and gesture approach using Khmer signs. This has been a cross linguistic exercise as I teach in spoken Khmer, using a book with Khmer signs written in English! Our signing sessions are very informal and lots of fun. We have definitely seen an increase in the clarity of sign and gesture from a number of students since the teachers have started using keyword signing. We chose to promote unaided AAC initially as a way to encourage the communication skills and opportunities for the children without relying on a communication aid which they could lose, break or give away. Last year I ran some training for our staff which included assessment of children's intellectual ability and appropriate AAC strategies. We are using examples and sourcing photos from the internet and some of the resources sent by Harvey and Sarah in their pack. Being able to demonstrate the development of a chat book or use of object symbols helped staff to see how these aids might benefit the children, although staff saw many barriers to children using them within their home environment.

The development of AAC strategies for our kids seems a slow process. I take hope to make some difference in the random opportunities that present themselves. An example happened this week where an 8 year old child with CP was starting daycare. This child had previously been at home with his family who can respond appropriately to his non formal communication – so they saw no need for an AAC system. As we support the day program to care for this child, there becomes an opportunity to develop an AAC system for him. Hopefully this can be a positive experience for both the child, his family and also can encourage the staff to think about AAC options for other children too.

I'm encouraged by the level of commitment to broadening opportunities for people with disabilities from both their family members and staff. I think over time the use of AAC will increase too. Historically people with disabilities in Cambodia have been beggars in the market. Thankfully the future for our children looks brighter as slowly society's attitudes start to change and they have opportunities to learn and develop.

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Jamal Din Slimani teaches English in Abdelkrim Alkhattabi High School in Rabat. Morocco. In 1997, Jamal received his Master Degree in Speech and Human Communication from Edinboro University of Pennsylvania, USA. He is about to defend his Ph.D. thesis at Hassan II University of Mohammedia, Morocco. Jamal has chosen to share his findings regarding AAC in Morocco via his thesis abstract. Best wishes, Jamal.

The Use of Alternative and Augmentative Communication by Cerebral Palsy Students: A Case Study.

The purpose of my research was to determine to what extent a voice output device can help a cerebral palsy student to study French and to communicate with her peers and her French teacher, in short, to be well integrated into an ordinary class. To this end, we opted for an ecological approach that allowed us to study this case from different perspectives: (1) "micro-systemic" (*e.g.*, the interaction of our subject with family members and her teacher); (2) "meso-systemic" (her interaction with several people on whom she depends, namely educators and administrative staff); (3) "exo-systemic" (the implementation by the Ministry of Education, of the project of inclusive education and the impact of this project on our subject) and (4) "macro-systemic" (societal ideologies that have a strong influence on people's attitudes towards disability and disabled people).

The field study and the interviews we had with our respondents indicated that at

the micro-systemic level, a voice output advice is quite effective for communication in the classroom, especially with the teacher. The device has also enabled our subject to do her homework at home and print it so that her teacher will have no problem reading her answers, something that was impossible before the use of the device because dyspraxia makes it impossible for our subject to write clearly.

Another encouraging result is the acceptance by her classmates of the communication tool. Indeed, recognizing the importance of speech in humans, the classmates do not seem bothered by the tool and even less by the presence of a disabled student in their class. Paradoxically, the problem of acceptance was mainly raised among some teachers who are supposed to have more common sense and moral values than their students.

However, we found that using a voice output device cannot, by itself, guarantee successful inclusive education. Other actors should take part in this inclusion: teachers, the administrative staff, the local educational authorities and, by extension, the Ministry of Education. In addition, certain legislative issues have to be resolved so that the process of inclusive education will achieve its goals.

At the meso-systemic level, we found out that neither the teachers nor the administrative staff had been prepared, via training sessions, to receive a student with a disability in their establishment. These key players in inclusive education found themselves in an incongruous situation. Rather than defying the official instructions from the Academy and the Education Department, these people have decided to accept the situation stoically, waiting for our subject to leave school. Of course, this attitude is not advisable because today's parents of disabled students are increasingly encouraged - by the Ministry of Education - to enroll their offspring in public schools. Instead, the teachers and administrative staff should be required to get training on how to deal with students with disabilities, since it is they who daily face different challenges to the integration of persons with disabilities in regular classes.

As for the exo-systemic level, our study revealed that the Ministry of Education is still lagging far behind in the process of the integration of students with disabilities, although this process was launched almost two decades ago. While the political will is evident today, financial as well as human resources are still scarce. For a project to yield good results, a lot of resources have to be mobilized. Otherwise, it will be nipped in the bud.

Finally, at the macro-systemic level, the findings revealed that there are still many people in our society that are ignorant in terms of disability. When you do not understand something, you try to move away because it disturbs you and makes you afraid. Even a slight disability can take on a bigger dimension in the eyes of the beholders, so that they believe the person is disabled from head to toe.

We believe that this is the result of the cultural conditioning that has plagued our society for decades. This conditioning is done through what is known in sociology as 'socialization agencies', namely: the family, the school, the street, and the media. Through these agencies, we acquire our beliefs, our values, our customs, our traditions, our ideas, and we learn which behaviours to adopt and which ones not to adopt in various societal situations. Unfortunately, some agencies inculcate ideas and attitudes towards disability that are shocking, to say the least. In the media, for example, implicit as well as explicit messages are sent to audiences through awareness-raising campaigns and movies,

indicating that a disabled person is generally poor, illiterate, disgusting, and a heavy burden for the family and society at large. Certainly, those messages reflect a certain undeniable reality, but what we do not accept is their generalizing aspect, prompting many viewers, especially child*r*en, to believe that a disabled person is less than a "normal" one, in almost all domains. We believe it is high time these misconceptions changed and that the agencies of socialization should teach people that a disabled person is a person first, a full-fledged member of society. Yes, it is true that he/she has a disability, but he/she is more similar to, rather than different from, an able-bodied person. Email: jamaldinslimani@hotmail.com

Sharif-Al-Mamun received his Bachelor of Science in Speech & Language Therapy (SLT) at the Bangladesh Health Professions Institute, the academic arm of the Centre for the Rehabilitation of the Paralysed (CRP) - an affiliate of the University of Dhaka - in June 2009. Sharif's internship within the first graduating class of the SLT bachelor program in Bangladesh will finish mid 2010. In 2008 Sharif received the Shirley McNaughton Exemplary/ISAAC Award. He sends us this report from Dhaka:

Low Technology Devices in Bangladesh: Children with Communication Needs.

In my Centre we believe that communication is everybody's right. People with multiple disabilities and complex communication needs have the right to communicate with appropriate support systems. Alternative and Augmentative Communication (AAC) plays an important role in helping them to communicate.

Bangladesh is a developing country. Many people with communication disabilities live in developing countries. We know that AAC is helpful for such people, but it is a very new concept in Bangladesh. Our first class of Speech Language Therapists at the University of Dhaka graduated in 2009. As a member of that class I had the opportunity to travel abroad to conferences and to meet with SLPs, teachers and mentors from many countries. I know, in the future, Speech and Language Therapy and AAC will grow to become a great profession in my country. There are huge job opportunities in Bangladesh. To that end I am applying my knowledge to establish a new communication department in the rehabilitation centre in Dhaka.

I would like to tell you about a child who attends my centre. Rudaba, a 6 years old girl, was diagnosed with Severe Athetoid Quadriplegic Cerebral Palsy. She lives in Dhaka city with her parents and a three years old sister. Her mother reported that Rudaba's delivery was delayed by six days after the recommended date, and hence her daughter faced the problem of oxygen deprivation during the birth. Now Rudaba has vision and hearing problems.

Rudaba goes to a Special Needs School where children with different types of conditions (autism, Down syndrome, learning disabilities) also attend. Rudaba's speech assessment results show that her speech is low in intelligibility, she has complex communication needs and her fine and gross motor skills are poor. She can understand pictures and point easily so it is possible to give her opportunities to express basic needs and wants and to pass on information between different environments, to express her feelings, to ask questions, and to give opinions effectively. Pictures also enrich her vocabulary.

After admission into the Special Needs School, physiotherapists, occupational therapists and special education teachers became involved with Rudaba. She uses gestures, pictures, and pointing for communication. She does not have receptive and expressive language appropriate for her chronological age. Her physical difficulties decrease her opportunities to express herself nonverbally (writing, sign language). She has the understanding of single words and spatial concepts (prepositions, size, *etc.*). She has some social and pragmatic skills (smiling, initiating, requesting, and greetings). She also likes to watch television and enjoys pasting activities. Rudaba faces problems during her physical play. Sometimes her parents do not understand her needs when she expresses herself by using vocalization and gestures.

Rudaba uses six gestures at home and in her school environment (drinking, bathing, hungry, toileting, outing, and calling). She jointly communicates with her partners. To request, something she uses pulling, vocalizing, pointing, and, for protesting, she uses pushing, and turns her attention to others. For greetings, she uses smiling, hand movements, and proximity. In the classroom Rudaba uses pointing and vocalizing to express herself. If teachers do not understand her, they use different sizes of pictures to help her communicate effectively.

For effective communication, Rudaba needs a way by which she can communicate in different settings. A supportive communication environment would also be helpful for her. She needs to participate actively in play time. Mother has reported that if anybody stops their communication in the middle stage or if Rudaba cannot understand another person's interaction, she feels frustrated.

Before selecting the device for Rudaba's communication, Speech and Language Therapists (SLT) assessed her to decide the types of device that would be best for her. Before selecting the device the SLT gave choice making opportunities to her. She replied by pointing to pictures or 'Yes/No' cards.

Her teachers reported that communicative books could be helpful for Rudaba's functional communication. They were thinking of preparing a communication book for her but they did not find any relevant professionals who could help them.

When the SLT talked with Rudaba's parents, they disagreed about the communication system because they thought a communication book might stop or hamper their child's speech development. But after the SLTs explained, mother realized that a picture system could be really helpful for her child's effective communication in different settings.

For making low technology devices, materials are available in Dhaka and can be managed easily. With advice, members of the family can easily make communication displays. Some school teachers are already working with children with communication disabilities by using this type of low technology device.

Society in Bangladesh does not want to accept AAC systems of communication. Proper implementation of AAC is difficult due to the lack of understanding by the public. I am also working to help people become aware of the value of AAC for children with communication problems in Bangldesh.

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RESOUCES ON THE WEB

Anna Reeves is the manager ACE Centre North and the national AAC coordinator in England, a position that was created in response to a government review of services for children with speech, language and communication needs. Anna is now the 'communication champion' for England and is working energetically to drive forward the AAC agenda at a national level. She writes:

The staff of the ACE Centres (Oxford and Manchester) provides help and expertise in the field of Augmentative and Alternative Communication (AAC) and Assistive Technology (AT). Therapists, teachers and technicians provide a range of core specialist services including assessments, equipment loans, training and information, as well as undertaking project and consultancy work for local and central statutory services. Staff of the ACE Centre have provided and are continuing to share their knowledge of augmentative communication in emerging AAC countries. 'Let's All Play' is an exciting 2 year ACE Centre project supported by the Big Lottery Fund designed to empower pre-school children with physical and communication difficulties to participate fully in free and directed play activities...... AND HAVE FUN! Case studies from this project are online. http://www.ace-north.org.uk:80/pages/resources/casestudies.asp

Many thanks to Linda Burkhart for all the free information available on her web site. Linda's material covers AT and AAC Basics, Technology Integration in Schools, a wealth of her presentation handouts, web links along with books and products. Great AAC resources for all of us to share. http://www.lburkhart.com/index.html

http://www.lburkhart.com:80/handouts.htm Linda Burkart 17/2/10

For our friends in Brazil and those interested in World Cup soccer – as I am - Jane Farrall has developed boards and activities to communicate this great event. Jane's Boardmaker Plus interactive activity, set around the 2010 FIFA World Cup, includes 5 different activities: * A simple talking book * a quiz based on information from the talking book * a book with major facts about each country playing * a book about the finals * a quiz about the flags of the 32 countries in the 2010 FIFA World Cup. Janes's file and many other activity sheets are available at http://www.adaptedlearning.com/

<u>The Global Assistive Technology Encyclopedia (GATE)</u> has been created by AbilityNet, the UK's largest provider of advice and information on all aspects of access to technology. The organization's purpose is to provide live and up to date information on everything to do with Assistive Technology. <u>http://abilitynet.wetpaint.com/</u>

The <u>GATE</u> pages on Low Cost Solutions provide a database of shareware programs and utilities that are used by people with a wide range of disabilities. Whether you are a designer looking for tools to assist you in the testing process, have a disability yourself or

know someone who does, this database of shareware and freeware will prove a valuable resource.

http://abilitynet.wetpaint.com/page/Free+and+Low+Cost+Solutions

Presentations at the Upcoming ISAAC Biennial Conference

Thanks to the following colleagues on our email list who have sent information about
their upcoming presentations at the ISAAC Conference, Barcelona, July 24 th – 29 th 2010.
Do look for their presentation dates and times in the conference programme. Send your
titles in and we'll include on the next issue
Creating Opportunities for Social Interaction and Play Using Low to High Tech Devices
with Infants and Toddlers in the Home
Loris Fischer, Cheryl Maruyama.
AAC in Emerging Areas: What kinds of help make a difference?
Harvey Pressman, Gabriela Berlanga
Overcoming Patient-Provider Communication Breakdowns in Healthcare Settings
Harvey Pressman, Sarah Blackstone
Communication Access: Legislation to Action.
Barbara Collier.
International clinicians spotlight AAC techniques and strategies for individuals with
complex communication needs.
Patricia Ourand, John Costello, Melaine Fried-Oken, Bronwyn Hemsley, Yvette
Malek.
AAC Across the Nile.
Yvette Malek
The AAC-RERC Writers Brigade
Sarah Blackstone, David McNaughton, Pamela Kennedy, Johana Schwartz
Introduction to Social Networks: Supporting Interventions that lead to meaningful
outcomes in AAC
Sarah Blackstone, Mary Hunt Berg
Development of Emotional Competencies in AAC: An Area that Deserves Our Attention
Sarah Blackstone

.Harvey's Place

The Central Coast Children's Foundation (<u>www.centralcoastchildrensfoundation.org</u> has supported the creation of a Patient Provider Communication website. A recently uploaded new document **Promising Practices in Overcoming Communication Barriers** by Harvey Pressman and Val Lewis can be found on www.patientprovidercommunication.org Please check it out and share it freely with

colleagues.

LinkedIn Groups suggest the following lowcost/free assistive technology tools HandyBits: voice mail <u>http://www.handybits.com/voicemail.htm</u> ClickNType: virtual keyboard with word prediction: <u>http://www.lakefolks.org/cnt/</u> CameraMouse: <u>http://www.cameramouse.org/about.html</u> Dwell click: <u>http://www.sensorysoftware.com/dwellclicker.html</u> Natural Reader Freeware: <u>http://www.naturalreaders.com/</u>

<u>Getting Started With My Child Without Limits</u> looks to provide parents with the knowledge, resources, and network to ensure their children's future is without limits. <u>http://www.mychildwithoutlimits.org/</u>

Thanks to Graham Clarke for his reference to an interesting article - $\underline{iPad \ drawing \ interest}$ as device for disabled — that relates to the use of the ipad and ipod for people with complex communication needs.

http://www.iol.co.za/index.php?set_id=1&click_id=31&art_id=nw20100418113714900C 458523

I look forward to receiving news of more ISAAC conference presentation. Our June issue will be the last before the meeting in Barcelona. And again, please send our newsletter on to all the people you know who might find it of interest. Our network is certainly growing. Until June. Best wishes, Anne Warrick. awarrick@rogers.com