

Welcome to the Augmentative Communication World Network (ACWN) and our third quarter, 2011, newsletter. The past three months have been busy for those who have planned and attended conferences on augmentative and alternative communication (AAC). This issue has news from Poland, Slovakia, Kenya and Ghana. Thank you to Aldona Mysakowska-Adamczyk, Belinda Bukari and Martina Kukumbergova for their reports. Two friends from Kolkata, Barsha Bhattacharya and Shraddha Khator, have written with their insights into daily living from the perspective of those who rely on AAC to communicate. Dorothy Fraser from Scotland has contributed interesting web sites. So let's read.

Report from the

Central and Eastern European Conference, Warsaw, July 2011 By Aldona Mysakowska-Adamczyk

aldona.adamczyk@gmail.com



Touring Warsaw - Happy in the rain.

The 8th Regional Central and Eastern European Conference on Augmentative and Alternative Communication was held in Warsaw from 30th June to 2nd July, 2011.

The conference was organised by the Polish AAC Society "Mowic bez Slow" (Speaking without Words) in co-operation with the Special School Complex # 109 in Warsaw; Harpo (an assistive technology company with headquarters in Poznan), and the Academy of Special Education in Warsaw, the venue where the conference was held.

The wife of the President of Poland held the Honorary Patronage of the conference, and a letter from the First Lady was presented at the welcoming. The Minister of Education was present at the Opening Ceremony and wished the conference great success. Hopefully, AAC developed a new meaning at the governmental level.



Augmentative Communication World Network's Presentation

The conference was aimed at bringing together AAC users, families and professionals from different settings and different countries to discuss issues important for people with limited speech, and to take the opportunity to facilitate national and international collaboration. This big international event held under the theme "Let's Talk Together – AAC in

Europe" was a great opportunity to promote and move forward the field of AAC in the region. The conference was well attended, with about 400 participants from 22 countries. Most were therapists and teachers from small centres in Poland, where AAC is still an emerging area. It was very interesting and valuable for all participants to listen to so many well-known speakers from Poland and abroad! Among the international speakers were: Erna Alant, Anne Warrick, Stephen von Tetzchner, Kathy Drager, Sophia Kalman, Kaisa Launonen, Darryl Sellwood and Vicki Casella (Bridge School).

Three busy days were filled with a program of concurrent sessions, workshops, posters and an exhibition, with 15 booths displaying the latest in Assistive Technology. A total of 70 presentations were delivered.

It was the first time in Poland that AAC users and families had a discussion forum. This was a moving experience, and for some, it was a moment of identifying themselves as members of this group. Participants discussed plans for starting a Polish ISAAC Chapter, which will hopefully be developed in the near future.



Our celebration dinner at the Palace



One of many shared sessions

All presentations were simultaneously translated into Polish and English, and the conference proceedings were published in both languages.

After each busy conference day, a special evening social program was scheduled: a Polish Evening with lively music and delicious food, an elegant Gala Dinner and a Warsaw guided tour.

Representatives from all Eastern and Central European Countries present also met to talk about the place and program of the next conference. Discussions are still in progress, with Russia, Slovakia and Ukraine being considered as possible next hosts in 2013.

Many people complimented not only the high standards of presenters, but also the unique atmosphere and enthusiasm created during the conference. Inspired by this great meeting, we look forward to continuing the collaboration through the network that was created.

[For more information, contact Aldona Mysakowska-Adamczyk at aldona.adamczyk@gmail.com]

Report from Ghana on a Visit to South Africa

By Belinda Bukari

belindabukari@yahoo.com

Belinda Bukari serves as Principal and Teacher in a school for children with special needs in Ghana, and is the first Ghana educator to introduce AAC into the Ghanaian special needs system.

Augmentative and Alternative Communication has barely started in Ghana. After the Central Coast Children's Foundation (CCCF) granted me their Scientific Study Travel Fellowship Award, I had the opportunity to attend the ISAAC Conference last year in Barcelona. I then put my new AAC knowledge into practice as soon as I returned home.

In December last year, all the unit school teachers for special needs children received AAC training. This included the ways in which teachers could use AAC in handling pupils with communication difficulties. There were demonstrations of various assistive devices and materials that teachers might apply in their classroom teaching in order to augment their students' speech.

This year, I was given an opportunity to spend a week as a Teacher-in-Residence at a school in South Africa (Pathways - Pretoria) which provides intensive stimulation for pupils with severe disabilities. I also attended the 2nd Regional African AAC Conference in Boksberg, South Africa, where I presented a paper ("Bringing AAC into the Classroom in Ghana"), again under the sponsorship of CCCF.

I gained a lot of experience from the Pathways teachers, pupils and the facilitators. Pathways has a unique curriculum. This includes communication that entails "12 Jiffy Rules" when working with children with severe disabilities. These rules were very special to me, because they say that one must make sure that the child has some way to communicate: speech, visual displays, communication boards, gestures, and/or voice output. The rules also recommend the encouragement of eye contact during communication, giving each child an opportunity to participate, and ways to draw them into activities, choice making, and opportunities to learn. I also saw classroom schedules, which consisted of daily plans along with schedule analysis and organization of themes - all taught through visualization.

Communication with pupils at Pathways is multimodal and is accomplished through speaking and vocalization, gestures, objects, pictures, photos and line drawings and the use of a voice output system or communication device. When pupils at Pathways are 18 years, they are sent to the Pathways Studios, where they are taught employable skills. I had the opportunity to spend a day with five of these young adults. I visited their work places and found that they were managing very well at their posts.

The main conference also featured many new ideas regarding how people are using AAC in their schools and organizations. Most of the sessions that I attended were on Education and Empowerment, since these topics are most appropriate for my situation.

My presentation on "Bringing AAC into the Classroom" interested many people. The key topics related to the AAC training of all unit school teachers in Ghana, parental education on the use of AAC, the practical steps we are taking to introduce AAC to the universities and other stakeholders, the marketing of AAC cards and curriculum name labels that we currently use, and an explanation of our use of the Basic Communication Package developed in South Africa. ISAAC President Erna Alant pledged her support in donating AAC materials to our school.

I also attended a research seminar with the theme "Ethical Consideration in Research with People with Disabilities." Researchers presented papers on Ethics and Communication, Considering Risks and Benefits for people with Disabilities and many other interesting topics.

The conference and my Pathways residential experience have equipped me with many new ideas, and I will use any opportunity I get to educate teachers, parents or anybody who needs to understand how AAC can be utilized. I hope also to spread the concept further now that I am enrolled in a new graduate program: Disability, Rehabilitation and Development. Ghana still has a long way to go in the field of AAC, and I urge everyone to find a way to help us to spread our message. Ghana and I are grateful for the support that CCCF has provided to this end.

[For more information, contact Belinda Bukari at belindabukari@yahoo.com]

AAC in Slovakia by Martina Kukumbergova

mm.minarikova@gmail.com

Martina Kukumbergova is a Speech Language Therapist working in Slovakia. Martina's interest in AAC originated through the Bridge School, Hillsborough, USA, and through Trinity College, Dublin, Ireland. During a temporary hiatus, Martina worked for Sun Microsystems. Thankfully, the mother of a fourteen-year-old girl requiring AAC brought Martina back into the field. A big welcome back, Martina. Now, read what can be accomplished in just eight short days.

How to raise public awareness and interest regarding the benefits of AAC in young children?

Our non-profit organization KOMUNIKUJME SPOLU n.o. was established last year with the goal to spread the word about AAC and to increase the use of AAC in Slovakia. We are also working to create a collaborative network among parents of non-speaking children, special



AAC with family support

education teachers, paediatricians, speech therapists and other care providers across the country.

It was not an easy task, but we were lucky, thanks to Nadácia VÚB, which had supported our 2010 *'Introduction to AAC and Its Use in Children'* Project. This project was hosted by TETIS s.r.o., a Rehabilitation Centre providing specialized care to

children of early ages until the age of 15. The Centre presented us with a great opportunity to work an hour a day for eight days in a row with afflicted children as well as their parents. This resulted in an intense experience on both sides. The project involved non-speaking toddlers together with pre-school aged children and all of their parents.

Our gratitude goes to everybody in the Central Coast Children's Foundation for providing us with several VOCAs (*e.g.*, Big Mack, Step by Step, Quick Talker and iTalk2) and the Talking Photo Albums. Thanks to these materials we were able to demonstrate to the parents how their children could actively participate in play and how we can consequently use these situations to 'teach' children communication skills.

Why did we start this project?

There doesn't seem enough information on AAC in Slovakia. Also, not many parents pay much attention to the development of their children's communication skills, and furthermore, there are

very few local specialists that direct their attention this way too. What we miss is an aimed AAC intervention, especially in very young children.

What was our plan? Four Steps

1. To introduce AAC to the parents: What is it? What are its benefits? Who are potential users? What are the known facts and myths about AAC?



"This is what I'm saying."

2. Following in practice: We chose graphic signs and presented their use during play. Then, using these signs, we supported the parents to play with their child.

3. We explained communication strategies like the importance of waiting, observing, imitating, *et.al*. What we found was that some parents were using these approaches already, yet without a conscious thought and without the notion of what to expect from their child.

4. Finally, to follow up at home and in the children's school environment.

What did we learn?

Parents of older non-speaking children seemed content because they believed that they could understand most of what their child was trying to communicate. They had some time to get used to the situation. On the other hand the parents of younger children seemed more frustrated when it came to communication with their children. Often they searched for help; however, their search was not always successful.

We also found that working only with parents is not sufficient; getting AAC known among specialists, mainly paediatricians, is needed. They are the ones that concerned parents usually rely on.

Parents' daily schedules are often very tight and thus any other idea we suggested or recommended to them was just another task, a challenge or a burden to them, and even if they liked the idea of AAC, many times they simply could not carry out our program. However, for those who choose to continue, using the AAC became a part of their daily routine.

We have come to the conclusion that most people, when acquainted with AAC, like the concept of it and are willing to go forward and cooperate.

What did the parents say they have learned?

Many parents agreed and pointed out that communication training and strategies were especially useful. They could finally follow their child's reactions and felt that they were receiving some sort of feedback, which, under the circumstances, was a great step forth. They were very happy to learn about these strategies and even happier to find out that they have been using them all along and that they have been doing a good job. Some parents who have started using graphic signs at home have also asked the other family members to join in by acting out the use of these signs.

Our future plans

So far we have two goals we would like to achieve. The first one is to cooperate with rehabilitation centres and special schools that non-speaking children attend. The second one is to raise awareness of parents and specialists about the concept of AAC.

It is a great reward for us to hear that people are becoming interested and hungry for information. Recently more special educators have been requesting information on AAC and about our work. Therefore, we have decided to organise a seminar for them *–Introduction to AAC--*which we would also like to present as our activity within the AAC Awareness Month. The Central Coast Children's Foundation provided us with very useful resources. We now use their books to prepare materials for our seminars and self-education pamphlets, and we would also like them to be used by the students at the Department of Communication Disorders at Comenius University in Bratislava.

At the moment we are distributing leaflets to help us introduce AAC at the offices of neurologists and paediatricians offices, and in rehabilitation rooms and centres.

In September 2011 we are participating at the Selling and Presentation Market, where various handicrafts and presents made by people with special needs are being sold. They all come from people housed by non-profit organisations, which further present their activities via posters, leaflets and other advertising articles.



"I'm looking. Just wait please."

In November 2011 there will be an International Conference organized by the Department of Psychology at Comenius University in Bratislava, called: *Personality in the Context of Cognition, Emotionality and Motivation III.* Using a conference poster, we will present and introduce

AAC. We will also be adding a short contribution to the anniversary volume of *Psychologica 41*.

Over the last few years, at the ISAAC Conferences, we have had the opportunity to meet many AAC specialists. We hope that, eventually, if we manage to awaken more interest in the public and our local specialists, we might be able to ask them to visit and hold workshops for us here in Slovakia. Slovakia will then slowly start moving towards losing the label of an 'AAC emerging country'.

The time we spent working on this project was fruitful and inspiring. We hope that the parents of children with Cerebral Palsy had a chance to widen their horizons and at the same time we are happy to admit that we have learnt our share from the parents themselves.

We would like to thank the Central Coast Children's Foundation for their material support, Nadácia VÚB for their financial sponsorship and both for their belief in us.

[For more information, contact Martina Kukumbergova at mm.minarikova@gmail.com]

Insights from India

by Barsha Bhattacharya and Shraddha Khator

Barsha Bhattacharya and Shraddha Khator are members of Ankur, an advocacy group of the Indian Institute of Cerebral Palsy. They are both pursuing vocational training in computers. Barsha has a keen interest in poetry and writing poems. She uses special software called 'Sanyog' with a switch to write in Bengali, her mother tongue. Shradda writes stories and wishes to become a published author. Both young women have worked as research assistants for the research and development projects on AAC taken up by the National Resource Centre for AAC, Indian Institute of Cerebral Palsy. They also participate as instructors for different courses on AAC run by the Indian Institute of Cerebral Palsy.

I Communicate with the World

by Barsha Bhattacharya barsha.bhattacharjee11@gmail.co

I am Barsha Bhattacharya, a member of Ankur, the advocacy group of the Indian Institute of Cerebral Palsy. If I want to talk about the role of AAC in my life, it cannot be done in just a few words. I have made friends with AAC, made it a part and parcel of my life.

From my childhood, I started using a spell board for the purpose of studying and talking to the teachers and friends in



Bhasha composing a poem

school. But later on I learnt about the rhythm of poetry, the magic of rhyming. So, I started writing about my feelings and emotions in small poems. AAC was the only means that I could use for writing. I used to spell my words and some one used to write them for me. I felt wonderful when I saw my own poems in black and white.

I started using a computer with switches, but it was in English, so I could not use it for creative writing. Then came 'Sanyog', which is a dream software for me. Using this software I can type in Bengali on my own with the help of a switch. This gives me the independence of writing. Previously, when I used to spell words for someone to write them, my thoughts used to get interrupted. But now I can write freely and my string of thoughts is never broken.

It is very different when one writes a poem. When we just talk about our ideas and feelings to someone it is communication between two persons. But when we write a poem or a story we want to share our thoughts with many people. We want to reach out to people whom we know and most importantly, whom we do not know at all. These unknown people come to know me only through my words. I communicate with the world.

When someone reads out my poem and it brings an applause I feel that I am successful in communicating with them. Here also, technology has played an important role. Today, I use a small digitized VOCA, "Kathamala", to read out my poems to an audience. This makes me feel more confident and makes the audience accept me better. Then they have no doubts that I am reading my own poem. So you see how AAC technology has been crucial for me to reach out to people and to continue my creative writings.

I want to share some of my experiences of poetry reading with you. Recently when I was asked to read out my poems in the Kolkata Book Fair, I was really nervous. It is the largest book fair on the sub-continent, and pulls in a huge crowd. I have always read my poems to small groups of listeners, so I was shaky about facing a big crowd. It was a crowd indeed, but when I finished reading and looked up from my Kathamala, there was a big applause. People whom I did not know at all clapped to cheer me. I was on top of the world.

I had another marvelous experience of reading my poem to Mr. Gopal Krishna Gandhi, the ex-Governor of our state, who was our patron. I read my poem using a laptop computer and a power point presentation, where one of my friends recorded the poem. I read the poem slowly. When I finished reading, Mr. Gandhi came up to me. His eyes were moist with tears. He blessed and encouraged me. That was one of the most treasured moments of my life.

We all know communication is a basic human right. We just need the means and facilities and AAC methods and technology to assist us, and we need a space for ourselves to exert this right. [You can contact Barsha @ <u>barsha.bhattacharjee11@gmail.co</u>]

A Lost Kite in the Sky of Life?

by Shraddha Khator

skhator11@gmail.com



Shrada writes with her 'scribe'.

My name is Shraddha Khator. I am a member of 'Ankur', the advocacy group of the Indian Institute of Cerebral Palsy (IICP). I have completed my secondary level at school and am pursuing vocational training courses in computers from IICP. I have always expressed myself through AAC. It has helped me to study, to write poems and stories, and above all to make friends.

There are only seven colours in the rainbow, but our thoughts are full of so many colours and shades. Friends make our life colourful. One may wonder that how a person who has no speech and is physically totally dependent on others can express her feelings to others and make friends... But, it is easy!

A smile helps to attract others and when you smile, you get a smile in response. Sometimes it is a mere expression; still it is the first step to begin a friendship. But there is strange warmth that only my heart knows, that I want to share. And it is possible to do so if I use AAC. Yes, I can express all my feelings through AAC, by pointing on the spell board with one little finger. All my words are at my fingertips! Now, I can make friends; can share my emotions, thoughts, and ideas with them.

When I try to make a list of the names of all my friends, in India and overseas also, I myself get surprised to see such a long list. If I start talking about my friends, it will take days. So, I would like to share a very special experience of friendship with you.

Once I had a crush on one of my friends. It was just a teenage crush. I forgot altogether about my disabilities, that I was totally dependent on a caregiver and could not walk and talk. I proposed to this boy and wrote him a nice long letter... the reply was negative. But so what? I was successful in expressing my most delicate emotions. And life moves on anyway

Friends are the richest pleasure for me; their presence makes my day bright and sunny. When I am sad, they make me glad. My best friend is the one who brings out the best in me and makes me forget my disabilities. There is no age bar in friendship. I have teachers much older than me who are my friends. I have some friends who are much younger than I am and some who are of my own age. But I must say that possessiveness is not good for friendship, it needs to be a balanced relationship. My friends often have inspired my imagination, and I have written some short stories, where I write about some of my friends, maybe some incidents of their life. They become characters in my stories.

I would like to share my experience of the AAC week with you. It was a wonderful experience. I went to visit a 'normal' mainstream school with the 'Ankur' group. We staged a skit for them, chatted with them for some time, and then asked for their opinions. Students there had no ideas about AAC users. But their response was very positive. They were a bit nervous at the beginning but after talking to us, they realized we were just as 'normal' as they were. I made friends with some of them.

My 'ambition' is to be a famous writer someday and it is possible only if I use AAC. My immediate aim is to learn by using the internet. The reason is obvious; I want to use technology to make friends more easily in the World Wide Web. Let us generate a spirit of friendship because it is a god's gift. It is good to know that I am not alone. I am not a 'Kati Patang', a lost kite in the sky of life.

[You can contact Shraddha Khator at <u>skhator11@gmail.com</u>]

Two useful resources

Dorothy Fraser

Dorothy Fraser, a physiotherapist from Scotland, represents the Central Coast Children's Foundation in Eastern Europe. Dorothy is presently spearheading the development of AAC in Romania via the Augmentative Communication World Network and CCCF's Patient Provider programme. She reports on the Hello Campaign and the Widget Symbol Resource Packs.

Hello Campaign, UK										
Hello tott. Jisten-Lake Port	Sitemap	Contact Us Accessibility	Press and Media	AAA Text only Search Sponsored by	PsychCorp Iour PLASSON					
Introducing Hello	Get Involved	Latest News	Your Stories	Resources	Our Partners					
Alterno Commu	er is Internative and Inication Ness Mont	Augmento	ıtive							
Image: Second	Centrements Guing yeaple a Mate. Remember 2007 The Makedos Chaity	CENMAC RU PG from to SS from to	ert equal							
New video, T	he Way We Ta	alk			000					

Being able to communicate is vital for all children, so that they can make friends, do well at school, and live life to the full. But more than a million children have some form of communication difficulty that limits their true potential. It is easy for you to help children learn and improve their communication skills and *Hello* is here to help you. *The Way We Talk* is the latest video from the *Hello* campaign, showing how speech, language, and communication needs can appear and be remedied in some children. www.hello.org.uk

Widgit Symbol Resource Packs

A Sip	Symbols & Inclusion	The SIP Project	Evidence & Practice	Resources & Tips	Related Projects	Widgit Warwickshire County Council				
Home										
Symbols Inclusion Project (SIP) Resources and strategies for supporting inclusion The Symbols Inclusion Project (SIP) is a collaboration between Widgit Software and Warwickshire IDS (Integrated Disability Service) on the use of symbols to support inclusion and curriculum access. The purpose is to create genuinely inclusive learning environments for all children and young people. FREE and low-cost Resources to download and use in your school! Full resource list										
	eds of symbol	materials by	subject							
Impact related	d to Every Ch	ild Matters								
Case Studies	on Teachers F	Practice			A REAL OF					
Communicatio	on Friendly Er	<u>ivironments</u>								
Other symbol	projects with	in Warwicks	hire .							
Site Map for th	e SIP site									

Widgit, in partnership with many professionals, has created hundreds of free and low-cost resource packs. **Widgit** produces a wide range of symbol-supported learning materials and symbol stories, including extensive topic-based packs 'ready to go' for special and mainstream education, developed by the Symbol Inclusion Project. The Symbols Inclusion Project (SIP) is collaboration between Widgit Software and Warwickshire IDS (Integrated Disability Service) on the use of symbols to support inclusion and curriculum access. The purpose is to create genuinely inclusive learning environments for all children and young people. Find out more: www.symbolsinclusionproject.org.

ISAAC Travel Assistance for ISAAC 2012 in Pittsburgh, USA

ISAAC has limited funding support for *ISAAC members* from countries where AAC is 'emerging' and for people who use AAC to attend. Application forms are available on line (www.isaac-online.org). **Submissions must reach ISAAC office by 11/15/11.**

I continue to receive informal AAC news of AAC courses that are being planned for Ukraine, Russia, Poland, and Sweden in 2012. Sarah Blackstone has recently returned from France and Belgium, where she presented on Social Networks, Patient:Provider Communication, and Emotional Development. AAC use and research continues to grow in Hong Kong (where AAC specialists are hard at work helping to plan a new Children's Hospital) and AAC will be expanded in Korea through a new alliance with the Bridge School, USA. AAC is on the move worldwide.

Until our final newsletter for 2011...Anne Warrick. awarrick@rogers.com