

Welcome to our first Augmentative Communication World Network (ACWN) newsletter of 2011. In this issue you will find articles from Mexico and Columbia. They tell of exciting augmentative and alternative communication (AAC) developments in emerging countries. You'll also read about some exciting upcoming conferences in Poland, South Africa, Switzerland and Australia. Finally, a few programs and many new resources are briefly described.

Gabriela Berlanga was the recipient of the Bridge School scholarship in 2004. Since returning to her home in Mexico City, Gaby has led the very successful AAC developments in that city and throughout Mexico.

UPDATE FROM CATIC (MEXICO)



CATIC, Centro de Apoyo Tecnológico para la Comunicación y el Aprendizaje. Lic. Gabriela Berlanga, Director

For those who don't know us, CATIC is a therapy center that I started in 2005 with my friend and colleague Marcela Manzur after I spent a year as the Teacher in Residence at The Bridge School, where I learned all about AAC.

The two main goals of our center are to provide direct services to people who require Augmentative and Alternative Communication (AAC) and also to teach as many parents and professionals as possible about AAC so that more people in Mexico can provide these necessary services to those who so desperately need them in our country.

I am writing this article to talk about the new things that we have been doing, hoping that our ideas can help people who are also working towards disseminating AAC in their own countries. I think it is important for people to know what we are all doing around the world so that we can share ideas, materials and information.

Almost 6 years after we began CATIC, one of the biggest changes in our center is the number of people we serve. After some years of training, we now have a marvelous group of Speech Language Pathologists (SLPs), Psychologists and Teachers who have learned about AAC and are therefore able to treat around 80 children and adults with complex communication needs. As I mentioned, this was possible not only because of the training our staff got, but also, because with time, more and more parents got to know other children who use AAC and thus, started believing in its power.

We have also started teaching at one of the Universities here in Mexico (Universidad de las Américas). We have had the good fortune of having these students and students from other universities who, with our supervision, are able to come to our Center and help us serve children who are economically disadvantaged.

One new and exciting event for us was an AAC camp that was held last summer here in Mexico City. As usual, we had the support of The Bridge School, by having one of their SLPs, Kelly Reinheart, join us. We also welcomed one of their teachers: Caitlin Daly. We took the ideas we had observed at The Bridge School camp, where both children and professionals who wanted to learn more about AAC were welcome. Kelly, Caitlin and CATIC staff trained other professionals who were then able to put the different AAC activities they were learning into practice.

We have also started a preschool program, with the idea of preparing children who need AAC for their entrance to school. These preschool children come everyday during school hours and have a "school like" routine. We provide them with an efficient AAC set of communication tools that will facilitate their entrance to school. Above all, we try to ensure active participation through AAC, thus increasing their chances of having a more successful entrance to mainstream schools.

Most of our staff had the chance of attending ISAAC 2010 in Barcelona and came back with many ideas. One of the most important things we realized was that we needed to have more presence in homes and schools to promote the use of AAC in meaningful situations. After Barcelona, we started providing services at home and in schools with wonderful results. We are anxiously waiting for Caroline Musslewhite's "Circle of Friends" workshop that will be held in Mexico City. From this workshop we will learn more about improving this type of service.

Before I leave this article I'd like to mention that a new project is being developed with Dr. Sarah Blackstone, The Bridge School and Cisco's Global Education Program. I look forward to telling you about this project in a future newsletter.

Finally there is one thing I must say to the professionals who are trying to open the doors of AAC in their countries: Ask for help, our AAC field is full of wonderful giving people who are always willing to support us.

Gabriela Berlanga caticgaby@gmail.com

Clara Lucia Avila Lozano is a Special Educator and Speech Therapist working in Fundacion Integrar in Medellín, Colombia. Fundacion Integrar is a special school for children with autism and cognitive disabilities. You can find more information about Clara and the school's programmes at www.fundacionintegrar.org.

This question arises in my country (Colombia) when we work with people with autism.

The fact that a person thinks in images is not easy to understand, even more so when we are used to people who are able to hear, listen and respond with typical communication skills. When thinking of AAC maybe the first thing that comes to mind is: why would anyone who can hear well use augmentative communication? Will AAC systems be difficult to learn with the result that children and adults might not want to make the effort to learn it? If AAC is not tried, this can leave students with no means of communication. What could be a better way to show us the reality of using visual tools than to be able to take the place of the person with autism? In that sense, it becomes useful to read something written by a person with autism:

"I THINK IN IMAGES. The words are like a second language to me. I translate written and spoken words into movies with color and sound which passes in my head like a video tape. When somebody talks to me, their words are immediately translated into images. Those who think in words (thinkers based in language) find it hard to understand this phenomenon (thinking in images)."

"Thinking in pictures", Temple Grandin, 1995.

Thinking in images for a person with autism, is to be closer to reality, to the world and to information that is different from that which we usually know. It is a way of organizing information emphasizing the vision of the world rather than the construction based in words that we usually learn. Temple Grandin (1995) expresses this concisely when she says that:

"One of the most profound mysteries of autism has been the extraordinary ability that most people with autism have of being excellent for visual-spatial skills, while having very poor verbal skills. When I was a girl and a teenager, I thought that everyone thought in images. I didn't have an idea that my processing was different. I hadn't really analyzed the differences until now. The autistic person has difficulty to learn things that can not be thought of in images. The easiest words to learn for an autistic persona are nouns, because they are directly related to images. Written words are too abstract to remember, but I could remember, with a lot of effort, around fifty phonetic sounds and a few rules. Children who have a more limited function often learn better by association with labels put next to the objects around them. ("Thinking in pictures", Temple Grandin, 1995)

What would you normally do if the person you are talking to doesn't understand? You would probably point, make a gesture, make an action, or draw the item you want to talk about. How many other things would you do? In the end, you adjust to the communication mode of the person you are communicating with. So what then is Augmentative and Alternative Communication (AAC)? I believe it is: 'Any strategy/method designed to support, improve or augment the communication of individuals who do not verbally or independently communicate in all situations' (Beukelman, D., Yorkston, K. & Dowden, P., 1985).

Augmentative and Alternative Communication has not been seen as a strategy so that children can really communicate, but more as an additional communication method for the people and children who will use this type of communication *i.e.*, AAC. Not so.

"A lot of families are reluctant to use this type of communication because they are concerned that this becomes an obstacle for speech development. However, there is evidence that some non verbal autistic children who learned to use signs or visual tools, eventually learned to talk." Konstantareas, 1996; Magiati & Howlin, 2003

Even after having theoretically based information about the visual strength of people with autism, the establishment of AAC has not been easy to promote. In Fundación Integrar the use of AAC is being applied by awareness and training activities that are based on the learning and sharing of augmentative communication based on life experiences.

The strategies we now use are:

- 1 Make parents and teachers aware. The *right of children to communicate* is emphasized independently as is the way lack of communication happens. We ask "How does it feel not to be able to communicate?" We try to eliminate the beliefs and myths around AAC.
- We provide theory to parents and professionals. The topics are: What is communication and what are its components? How do we determine the communication needs of students and their environment? What tools within the environment can we use? What type of activities support the use of AAC?, What kind of Communication Boards or displays are available?
- We teach how to create an augmentative/alternative communication system: We determine the most appropriate system for the student by taking his or her skills into account. We determine the most appropriate vocabulary according to the needs of the environments in which the child lives and learns. We use easy access resources, where many visual systems can be used such as objects, photographs, drawings and written words. We make sure that the visual representation can be easily understood.
- We share experiences between communication partners. This experience gives an opportunity to ask; "How did you feel creating the augmentative/alternative tools?" "How did you choose the visual elements you used?" "Were there changes generated in the environment because of AAC?" "What have you learnt that you can share with others?"
- 5 We apply all our teaching in the environment: Every parent and professional that participates in our workshops creates a communication system according to the needs of their child or student and their environment. They share the system with their immediate network, family and friends, and thus they increase the circles of people their child can communicate with. They share the results of the system in their environment with their partner or group.

Our results show that 100% of the professionals who work at Fundación Integrar established AAC systems with their students. This resulted in better interaction and a reduction of behavioral difficulties related to the each student's inability to communicate. Students also increased the use of declarative communicative functions, such as describing and telling their experiences to others in a clear way. In addition, some of the students asked questions more consistently. This has shown us that the use of communication systems that allow children to understand and express their needs is a powerful tool. 100% of the parents who attended the training established communication displays in accordance with the needs of their children and their child's environment. This strengthened the value of communications and created more opportunities for their children to communicate.

These are some examples:



Pasaporte personal



Libros de recuerdos



Mi experiencia en casa



Libros de conversación



Mi libro de experiencias



We now know that:

Our experience allows us to confirm what Catherine Lord wrote in *the Journal of Autism* and *Developmental Disabilities*, 30, 265-266, 2000: 'There is no evidence that the alternative methods such as the images or sign language or gestures, slow the progress of those who are going to talk'.

- ★ Due to its relative strength in visual-spatial skills in individuals with Trastorno del Espectro Autismo (TEA), communication systems with visual components are frequently more meaningful and efficient than verbal language.
- ★ Communication systems that include images, photographs or written words have generally been very useful for both understanding speech and encouraging verbal expression.
- ★ For communication to happen there has to be a speaker and someone to talk to—i.e., communicative interaction.

Quite definitely, the use of AAC systems will support instead of interfere with the development of spoken language.

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RESOURCES

NEWSLETTERS

It is a great pleasure to introduce the Patient Provider Communication Newsletter, developed and written by Harvey Pressman and Sarah Blackstone. Like the ACWN newsletter, it is available from the Central Coast Children's Foundation (CCCF) and Augmentative Communication Inc. on a new web site:

www.patientprovidercommunication.org

International Patient: Provider Communication Newsletter

The Central Coast Children's Foundation (CCCF) and Augmentative Communication Inc. (ACI) are publishing quarterly issues of this e-newsletter, beginning in January, 2011, in response to the growing body of peer-reviewed literature that describes the serious impact that communication barriers and breakdowns can have on patient safety, "seminal" (negative) events, increased medical costs, hospital recidivism (re-admission) rates, and length of stay.

The newsletter collects and disseminates practical information about cutting edge approaches to improving Patient:Provider Communication (PPC) across healthcare settings, and shares information about laws and policies that may make an impact on practice. It is part of a new PPC international initiative.

Pressman and Blackstone report: "For the past two years, we have coordinated a PPC Forum that promotes collaboration and communication among some PPC pioneers, mostly from North America. Currently, we maintain a website [www.patientprovidercommunication.org] and hold monthly "Second Friday Forums" (PPC conference calls). Forum participants produce useful documents, give conference presentations and write articles for publication, many of which are available on the PPC website. We hope to share these more widely through this e-newsletter."

Other Newsletters

There are other organizations and ISAAC Chapters that publish newsletters that may be of interest to ACWN newsletter readers:

ISAAC Chapters: on-line at www.isaac-online.org

Interface: from South Africa at http://www.interface-sa.org.za/newsletters.html

Deepshika: from India on-line at www.iicpindia.org

Building for Generations: http://www.buildingforgenerations.com/

ONLINE MATERIALS: Websites and blogs

ACCPC is a national, non-profit Canadian organization that undertakes social innovation projects to promote awareness, justice, enhanced quality of life and community participation for people who use augmentative and alternative communication (AAC). Barbara Collier, Executive Director, ACCPC. barbara.collier@sympatico.ca

Justice and Advocacy.

Communication Access to Justice (CAJ) is operated by Augmentative Communication Community Partnerships Canada (ACCPC). http://www.access-to-justice.org/

Many people who have limited or no speech use augmentative and alternative communication (AAC) systems. AAC includes communication displays and devices that people use to communicate their messages. Clients with communication disabilities have a right to:

- Use a variety of ways to communicate
- Have communication assistance that ensures the accuracy and authorship of their messages
- Have their testimony recorded in ways that protect the integrity of their communication
- Receive information in ways they can understand and access

In April 2011-ACCPC Communication Access Resources will launch a web-based training resource for businesses and services.

Pathways Pretoria, South Africa

Pathways is a nonprofit organization initiated in August 2002 and co-founded by parents in their quest to find basic school accommodations for children with various disabilities.

The Pathways mission is to provide our children and young adults with the necessary skills for independence and integration; to develop their potential to the maximum, through appropriate education based on relevant learning experiences. Our aim is to:

- provide optimal stimulation to children living with severe disabilities;
- empower every child to communicate, acquire functional literacy, numeracy and life skills in order to successfully participate in their communities;
- facilitate opportunities for young adults with disabilities to become meaningful employed, and
- empower and facilitate families and caregivers to support their children in becoming respected members of society. http://www.ptapathways.co.za/

I am told that a blog is often a mixture of what is happening in a person's life and what is happening on the Web. It's a kind of diary and informational guide. And there are as many unique types of blogs as there are people. Two of our network friends, Joanne Fry and Cate Crowley, write blogs which we can all share. Their blogs tell of their AAC

experiences as well as their friendships and daily living in different countries and cultures. Enjoy!

<u>www.aacineastafrica.blogspot.com</u> will tell you of Joanne's experiences in Tanzania and Kenya. Not only will you be able to read about the AAC workshop Joanne gave in Mombasa but you can also read about her train journey, the new friends she met during her travels, animal life and the recreational activities which are enjoyed by everyone.

Cate Crowley's blog which can be reached at http://www.ineesite.org/index.php/blog is about Ghana. Scroll down the page to: http://ghana's Unit Schools Integrate Learners with Disabilities. When Cate visits Ghana she is accompanied by students from Columbia Teachers College. They share their experiences at http://ghana-slp-2011.blogspot.com/ Cate also blogs from Bolivia when she takes students from her bi-lingual, bi-cultural SLP Master's program there every June.

See http://www.tc.columbia.edu/news/article.htm?id=6409)

VIDEOS

If you are involved in Advocacy and Independent Living the following video will be of interest to you. In addition to the sites I have listed there are many others on Youtube. Just search Independent Living. http://www.youtube.com/watch?v=dupabkw46Qk

International Development Research Centre (IDRC).

Handicap International (HI) has just released the first part of a new series of short videos titled "Six questions on inclusive education." The films present the opinions of Handicap International staff and local partners working on the inclusion of children with disabilities in education in Burkina Faso, Madagascar, Niger, Senegal and Togo. http://www.handicap-

international.org.uk/what_we_do/inclusion/inclusive_education/six_questions/

CONFERENCES

POLAND: Aldona Mysakowska-Adamczyk from Poland writes: June 30 – July 2, 2011

The Polish AAC Society "Mowic bez Slow"/"Speaking without Words/" will be presenting the 8th Eastern and Central European Regional Augmentative and Alternative Communication Conference, www.aac2011.org.pl/en/index.html

The conference will be held in Warsaw, the capital of Poland, June 30 - July 2, 2011, under the theme Let's Talk Together - AAC in Europe.

The Eastern and Central Regional AAC conferences have been held every two years since 1997 in order to share knowledge and experience among AAC communities of the region. As Europe is becoming more and more integrated, the need to open the borders between the AAC communities from various corners of Europe seems particularly urgent. The organisers expect about 400 participants, representing the majority of European countries. The organisers also hope to encourage participants to establish new models of collaboration. Hopefully this will

assist people with no or very little speech, whichever European country they come from, to develop a common vision for the future.

On behalf of the organisers I look forward to welcoming you to Warsaw!

SOUTH AFRICA August 1 – 4, 2011

Beginning a New: 2nd Regional African AAC Conference 2011.

The conference will be held in Boksburh, SA at the Birchwood Hotel & OR Tambo Conference Centre.

The Centre for Augmentative and Alternative Communication, together with INTERFACE with the support of ISAAC (The International Society for Augmentative and Alternative Communication) is pleased to host the 2nd Regional African AAC Conference. The main conference will consist of 3 strands. These represent the different contexts in which AAC intervention takes place and highlight the relevant stakeholders involved in the process of AAC intervention, research and service delivery:

AAC for empowerment will focus on issues directly relating to individuals who use AAC. Topics include advocacy and empowerment, employment, self-determination, personal narratives and the use of AAC technology.

AAC in education will focus on issues around the inclusion of individuals who would benefit from using AAC strategies to enhance their communication and academic learning.

AAC in health will focus on issues around the provision of services to individuals and their families.

For more information regarding the conference please visit our conference webpage: http://tinyurl.com/AAC-in-Africa-2011 or contact Liezl Maasdorp at 012 420 2001 or liezl.maasdorp@up.ac.za

AUSTRALIA May, 2011

Barbara Collier, Director of ACCPC will be giving a keynote address and workshops at the AGOCSI conference in Adelaide, Australia in May 2011.

SWITZERLAND May 19-21

ISAAC Fribourg 2011

The Francophone chapter of ISAAC will hold a three-day conference this May in Fribourg, Switzerland. From May 19-21, participants will have the chance to listen to and engage with a broad array of perspectives on augmentative and alternative communication – from researchers to professionals to the people with complex communication needs themselves. Participants will attend lectures and break out into small workshops on the various ways to enhance AAC. The overall objective is to give each participant a wide range of tools and ideas for helping people with communication needs. The Francophone ISAAC is open to all practices and methods: technological or non-technological means, pictograms, gestures, signs, other codes. Our wish is to bring together these diverse points of view and present them as is to the participants:

- Testimonies from those who use communication systems, and from their families and loved ones
- Field professionals
- Theorists and researchers

Besides lectures in the plenary sessions, thematic small-group workshops will be offered. We hope that participants can emerge with a head full of both simple and grand ideas to aid patients in their progress and development. No matter the size of the endeavor, the goal is for them to express their abilities and develop their potential.

You can read more about the Francophone ISAAC's work by visiting our website at www.isaac-fr.org, or the site of the international association, as ISAAC is present in 53 countries: www.isaac-online.org

MOBILE DEVICES AND COMMUNICATION APPS

A Free Download of the AAC-RERC White Paper: www.aac-rerc.com

The Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC) offers this paper as a means for raising issues related to mobile technologies and AAC Apps and to encourage discussion and collaboration among AAC stakeholders. In order to gather information in a timely manner, AAC-RERC staff interviewed more than 25 AAC "thought leaders" between January and March, 2011, representing multiple stakeholder groups. Interviews were conducted by phone, e-mail and Skype. In the paper, they acknowledge that while their input is limited and change occurs daily, it is important to address key considerations that will affect people with complex communication needs around the world. This white paper is available as a downloadable pdf at

http://aac-rerc.psu.edu/index.php/pages/show/id/46

PAST ISSUES OF THE ACWN NEWSLETTER

Since December 2009 ACWN newsletters have referenced conferences, assistive technology, video, etc. and "Harvey's Place." When people write to me they often ask "Do you have any information on Peru – or India?" Below is a list of the countries sited in past newsletters and where exciting AAC programmes are emerging. All past ACWN newsletters are available in full at www.centralcoastchildrensfoundation.org

ACWN Newsletter Country References.

Dec 2008: South Africa: Malta.

Feb 2009: Jordan.

April 2009: Beijing; India; Peru; Brazil.

June 2009: Mexico.

August 2009: Malawi; Singapore. October 2009: Russia. Malta; India. December 2009: Panama/Chile; Peru. Feb 2010: Ghana; Saudi Arabia; Cuba.

April 2010: Cambodia; Morocco; Bangladesh. Summer 2010: South Africa; Tanzania/ Kenya.

Fall 2010: Columbia; Peru.

Winter 2010: Tanzania; Peru; Columbia; Kenya.

HARVEY'S PLACE.

During the past three months Harvey Pressman and the Central Coast Children's Foundation staff have been busy collecting information on apps and the way they can be used to support communication. It's called "FREE AND INEXPENSIVE APPS FOR PEOPLE WHO NEED AUGMENTATIVE COMMUNICATION SUPPORTS," and will soon be available on www.centralcoastchildrensfoundation.org. Here's an excerpt from the introduction:

"We have tried especially to focus on apps that will not break anybody's bank, especially for people who don't happen to live in the ten richest countries in the world. While the number of mobile devices in poorer countries is not necessarily as high as in some of these rich areas, the rapid growth of mobile devices even in some of the poorest countries in the world cannot be denied, and the pace is only going to quicken.

Our list begins with over thirty totally free apps which, taken together, could provide a lot of new kinds of help for someone who may well never be able to afford one of the \$8,000 (US) speech generating devices currently on the market. We have also cut off our list at \$40.00 (US), in hopes that it will prove especially useful for people with small pocketbooks but big ambitions."

iPads as Assistive Technology: 30 Apps for Augmentative and Alternative Communication (AAC).

Andy Brovey recently led an introductory workshop for Communication Sciences and Disorders university faculty. One of the resources he prepared was a list of iPad apps that might be useful in classes with the department's students or in the clinics with the children they serve. Many of these apps have versions for the iPhone and iPod touch devices.

http://ipadacademy.com/2010/12/ipads-as-assistive-technology-30-apps-for-augmentative-and-alternative-communication-aac

A T Mac: Empowering Disabled Apple Users. This website covers all Apple products with a slant towards disability. This website is about users with a disability, adaptive and assistive technology, and making accessible programs and content. I aim to cover all Apple products including all Mac OS X computers – the iMac, MacBook, Mac Mini, Mac Pro, and older models; the iPod range; the iPhone and iPod Touch/iTouch; the iPad range; and other products such as the Apple TV and Apple's remote controls, mice and keyboards. http://atmac.org/about

iPad, iPod and iPhone: What Can I Say? A presentation from BETT 2011. On the 12th January, Will Wade, Occupational Therapist, ACE Centre, UK, gave a rather rapid overview of using iOS devices in the field of AAC. The presentation is available here for your viewing pleasure but do note you will need about an hour to watch it! Will also expands on video by writing down the main aspects of the presentation - with the ability to download some of the resources and follow the links.

http://www.communicationmatters.org.uk/news-item/2011-video-aac-apps-ipad-ipod-iphone

CALL (Communication, Access, Literacy and Learning) Scotland, is a small unit within the Moray House School of Education, The University of Edinburgh. The CALL is both a Service and a Research Unit. Developed initially by Sally Millar, a new app for Communication Passports will be launched by Easter 2011. Easy to use, pages are

presented in an index form and new pages can be created, edited and deleted as required. Each page can contain its own background image, text, images, recorded sound files, symbols and more. To be informed when it's released simply fill in the 'Register Your Interest' form. http://www.communicationpassports.org.uk/Home/

In closing this first newsletter of 2011 please remember that I am always pleased to hear from anyone working to promote AAC in developing/emerging countries throughout the world. As Gabriela reminded us 'We have so much to share' and so many people with years of AAC experience who are ready and very willing to support their colleagues. I look forward to lots of email or snail mail during the next three months.

Your next newsletter will arrive at the end of June 2011. Best wishes until then. Anne.

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