



Augmentative Communication World Network Newsletter

June 2014

Editor: Dorothy Fraser

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www.centralcoastchildrensfoundation.org

Welcome to the June 2014, edition of our Augmentative Communication World Network newsletter. As an introduction to this newsletter, we have included references that affect all of us as we strive to achieve inclusive societies.

The United Nations Convention on the Rights of Disabled People (the Convention) is a statement of the human rights of all disabled people and covers all areas of life. Governments must report on how they will promote, protect, and monitor its implementation.

Articles 9 and 21 are especially important as they require disabled people to have access to information and communication in different forms. These Articles set out disabled people's right to find out and give information and to say what they want, the same as everyone else.

View in Easy Read at:

www.equalityhumanrights.com/uploaded_files/publications/uncrpd_guide_easyread.Pdf

Understanding the United Nations Convention on the Rights of Persons with Disabilities

<http://www.handicapinternational.fr/fileadmin/documents/publications/HICRPDManual.pdf>

A Handbook on the Human Rights of Persons with Disabilities

Editor's note: the following quote from the manual is of special interest to me because of my connections with Serbia: *"The manual was first drafted for a training of NGOs and DPOs in Belgrade, Serbia in September 2007"*

We hope you enjoy reading the updates and news we have received from around the world.

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<http://www.centralcoastchildrensfoundation.org/home/augmentative-communication-world-network/acwn-newsletters>.

[Editors' Note: AAC By the Bay: It's rare that participants at a single conference get to learn about even one or two ground-breaking new ideas in their field. It's quite amazing when they are introduced to four or five in the course of a few days.

It's even rarer that a conference breaks new ground in terms of expanding access to its ideas to a larger and more varied community. It's simply amazing when people from three different continents get to participate actively in the same conference presentations at the same time.

The Bridge School's AAC By the Bay 2014 Conference managed to combine both amazing feats. For example, participants heard, usually for the first time, about:

(1) how to make AAC tools and strategies far more relevant for far more people in healthcare settings,

(2) how to integrate awareness and knowledge of cortical visual impairment into daily classroom practice for the many children with AAC needs and severe motor impairment who also have (previously undetected) cortical visual impairments,

(3) how new ways to provide hands-free, upright mobility for children with severe physical impairments that usually confine them to wheelchairs and/or stationary seats or standers can give them better access to the academic curriculum and impact every aspect of their lives (including their health).

(4) how schools can provide, even for preschoolers with severe physical impairments who rely on AAC, a comprehensive approach to literacy, including a strong emphasis on writing.

The conference matched new ways of thinking about AAC with novel ways of reaching a broader audience. In addition to the in-person audience in San Jose, California, groups gathered in Mexico City, in Russia, in Canada and in thirteen locations within the United States to see and hear the presentations, ask questions of the presenters, and learn about ideas that at other times might take years to migrate to their regions. Through the magic of Cisco technology, people in these other areas were enabled to feel an integral part of the action.

We asked Dr. Vicki Casella, Executive Director of the Bridge School to provide us with an overview of AAC By the Bay. Here is her report.



AAC BY THE BAY 2014: A TRULY INTERNATIONAL EVENT

By

Vicki Casella, Executive Director, Bridge School, Hillsborough, CA

The Conference

The Bridge School's AAC By the Bay 2014 was a resounding success. The conference program brought together national and international leaders in education, augmentative and alternative communication, and research. Cisco, Inc. hosted the event at their Executive Conference Center and sponsored the live webcast of the entire conference to 13 locations throughout the United States, and to one location each in Mexico City; Ottawa, Canada; and the Borovichi Novgorod Region of Russia. Using Cisco technology, all participants were able to view the live presentations and interact with the speakers and the on-site participants.

The speakers touched on critical topics related to providing education and communication services to individuals who use augmentative and alternative communication. A strong focus on literacy was provided by Nicki Nelson, Holly Peartree and Martine Smith with their presentations on the value of ownership in developing content, effective and authentic writing instruction and evidence-based instruction to support reading for children who use augmentative and alternative communication.



Christine Wright-Ott expanded participants' minds with her presentation on mobility and its impact on every aspect of a person's life. She highlighted The Bridge School's emphasis on hands-free, upright mobility for all students and illustrated how it has been integrated into the academic curriculum. Seeing preschoolers usually confined to wheelchairs moving through space on their own power and able to explore and touch what interested them most was a unique experience for many.

Effective self-advocacy depends heavily upon effective communication, and Barbara Collier from Communications Disabilities Access Canada, Lateef McLeod, President-Elect of the United States Society of Augmentative and Alternative Communication (USSAAC), and John Costello, Director and Founder of Augmentative Communication in the Pediatric Intensive Care Units and Acute Care Settings at Boston Children's Hospital gave three complementary presentations from various viewpoints on this topic.



Addressing the needs of children with cortical vision impairment (CVI) is a challenge for everyone working with such students. This challenge is compounded when the child also has severe physical impairments and complex communication needs. Christine Roman-Lantzy and Sarah Blackstone gave a fresh perspective on how to integrate effective CVI

assessment into educational and communication goals across the disability areas. The Bridge School staff has been working closely with Christine to implement cutting-edge interventions in the classroom. Aileen Arai, Caitlin Daly, and Janelle Moynihan demonstrated various strategies and materials they have found effective in working with children with severe physical impairments, complex communication needs and cortical vision impairments.

More information about the speakers and abstracts of the presentations can be found on The Bridge School web site at: <http://www.bridgeschool.org/outreach/aacbtb/index.php>.

The Global Village

This live webcast provided the opportunity for global participation and collaboration. Two hundred and thirty-five participants viewed the presentations, asked questions or made comments to the speakers and shared information regarding their own situations. We had interesting questions and lively discussions from participants regardless of their location and their constituents. Host at various sites included parents, speech and language professionals, educators, therapists, medical personnel and assistive technologists. Without exception, those joining the conference gave a resounding endorsement for repeating the event. The following comments are representative of the feedback received:

“This experience was my first time to attend a conference. I cannot travel due to my disability and never thought I'd be able to go to something like this. What a blessing! You should have more speakers like Lateef. He made me proud!”

“We never saw something like this conference. We are just beginning our journey and now we have better direction. Thank you to all the speakers. Come to our country again.”

“My first ‘International Conference!’ Can’t put into words how helpful this was. I will absolutely return to the next AAC By the Bay and I will be bringing more people next time!”

“I loved that all of the presentations built on each other. I also loved hearing all the questions from the off-site locations. Best AAC conference I've ever attended.”

“Loved that it was broadcasted world-wide. Great to hear the different perspectives.”

“Appreciate that this conference was designed for AAC practitioners. When can I register for the next one?”

“The speakers had a wealth of knowledge and depth of information to present.”

“Thank you for expanding the mindset of society by starting the conversation for justice for persons with disabilities as whole persons that need to be respected, included and active in the community.”

“We appreciate your making this conference accessible to a global audience. What a gift it was to be able to participate without great expense. It was very valuable for us to talk among ourselves about the presentations. You don’t always get to do that in a large conference. Having the webcast was BRILLIANT.”



Twenty-seven educators, therapists, physicians, and counselors from Russia participated. Special arrangements were made for them to view an archived version of the conference due to the time difference, so they saw the presentations the day after the live webcast. They were able to ask questions and get responses.

FROM RUSSIA WITH LOVE!!!

Good morning, We are so happy.
People here are so thankful, you've
totally changed the way they see
these children.



¡¡¡Gracias!!! De México...



We loved participating in the live
webcast. What a wonderful
opportunity to be a part of a global
community.

Ottawa, Canada

CHRISTINE ROMAN-LANTZY'S VISIT TO CATIC IN MEXICO**By****Gabriela Berlanga, Co-Director, CATIC, Mexico City, Mexico**

This story began as part as our International Collaboration Program. Sarah Blackstone and I were consulting about a child with complex communication needs and severe visual difficulties.

We were discussing how to implement communication strategies using his strengths. I was talking to Sarah about how to develop a partner assisted auditory scanning system. She began saying that perhaps we should also help him “see” better so he could learn faster. Until that point, his progress had been rather slow. Sarah mentioned that she had met somebody who might be able to help us.

That is how I met Christine Roman-Lantzy, a specialist in cortical visual impairment (CVI). We talked over Webex, a visual conferencing system. Christine was in Pennsylvania, Sarah was in California, and I was in Mexico with Diego and his parents.

Dr. Roman-Lantzy has created an assessment tool for children with CVI and has written a book about ways to support improvement in vision that was based on the child's score on the CVI Range. We began using the visual strategies suggested for Diego's specific needs and soon began seeing visual progress, which resulted in faster concept and vocabulary acquisition. Since reading her book was not enough for us, in August, 2013, Marcela (co-director of CATIC) and myself were invited to assist Christine in a week-long workshop in Maryland "CVI Phase 3 Workshop". This enabled us to learn more about CVI and to meet Dr. Roman. We soon realized that besides being a genius in what she does, she is also a marvelous human being. We invited her to Mexico, and our dream came true in March 2014 when she came to CATIC in Mexico City.

By then, we had a caseload of at least 15 children who attended our center. Before her visit, only two of the children had been diagnosed by physicians as having CVI. However, we were suspicious about the rest. As part of her visit, she assessed all these children. As a result, we learned that ALL of them had CVI, which in the end happened to be good news because we finally got an answer to the way their vision was functioning and above all, we could understand that we needed to make changes in how we were teaching these children and how we were helping them to communicate so that, as in Diego's case, we would see improvements in vision, learning, communication and self-confidence.

CATIC also organized a CVI Introductory Workshop, which was attended by 50 parents, teachers, instructional assistants, SLP's, OT's and visual specialists. This workshop was a real "eye opener" for all of us and has made a change in the way we teach.

We will never be thankful enough to Sarah for her support through the International Collaboration Program and to Christine for her teaching and the difference she is making in the lives of our children and their families.

TALKING ABOUT EMOTIONS USING CULTURALLY SENSITIVE AAC

By

Ji Young Na, Pennsylvania State University, State College, PA, USA



I speak five different languages. I am a Korean native speaker, I study and teach in English, I am a certified Japanese speaker, and I can speak both Korean and American Sign Languages. Speaking five different languages is wonderful because I can communicate with more people around the world. However, I always keep in mind one very important thing when I speak any language. That is “CULTURE.” I need to be ready to speak not only using a linguistically appropriate language (e.g., Korean or English), but also a culturally appropriate language (e.g., Korean or American cultures). For example, in Korea, a recipient may graciously refuse three times before accepting someone’s gift. Saying “No, thank you”, when accepting the gift is culturally appropriate.

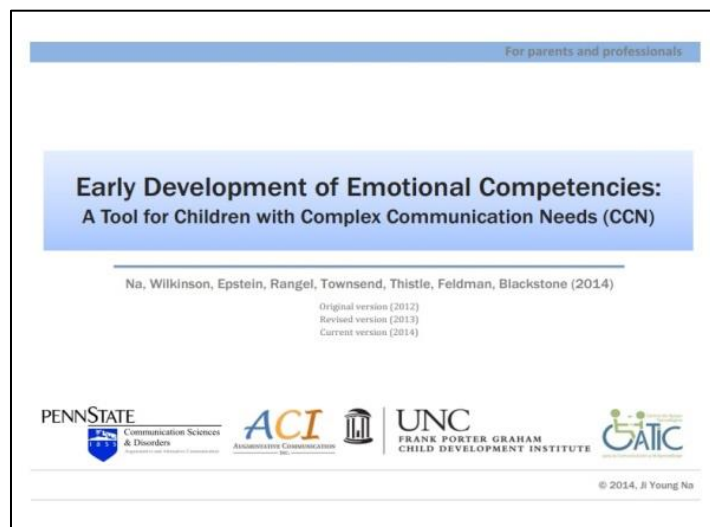
This is true for individuals who use AAC as well. Their AAC systems should have not only linguistically appropriate language, but also culturally appropriate language. Culturally sensitive language is especially important when they talk about emotion because it is well known fact that emotion is culturally grounded for each individual. For example, culturally inappropriate emotion symbols or phrases might not be used by the individual and/or accepted by his/her conversational partners, depending upon the cultural community.

We have developed an assessment tool for Early Development of Emotional Competencies (EDEC) in children with complex communication needs (CCN). The EDEC tool allows

families/clinicians to become more aware of the need for language that enables a child to engage in culturally-appropriate conversations about emotions and emotional situations. It is not a tool developed to diagnose or prescribe; it is not intended to change the behavior of a family. Rather, the EDEC tool is a way to better support the types of communication about emotions that are valued in that family. Using the EDEC, one can gather information that is useful to family members, teachers, and clinicians so teams can better support children with CCN to develop the emotional competencies needed to function effectively and participate actively in their families, schools and communities. The EDEC tool is appropriate for young children (birth-10 years) with CCN, who have very limited speech and language skills secondary to cerebral palsy, Down syndrome, and other conditions. It was not developed for use with children on the autism spectrum.

In order to provide a culturally appropriate assessment tool and to increase awareness about culturally sensitive emotion language in AAC, the EDEC tool is intended for use across different languages. Currently, we have translations in Danish, English, Korean and Spanish. A German version is expected to be ready in the summer of 2014; versions in Dutch and French will be available in the future.

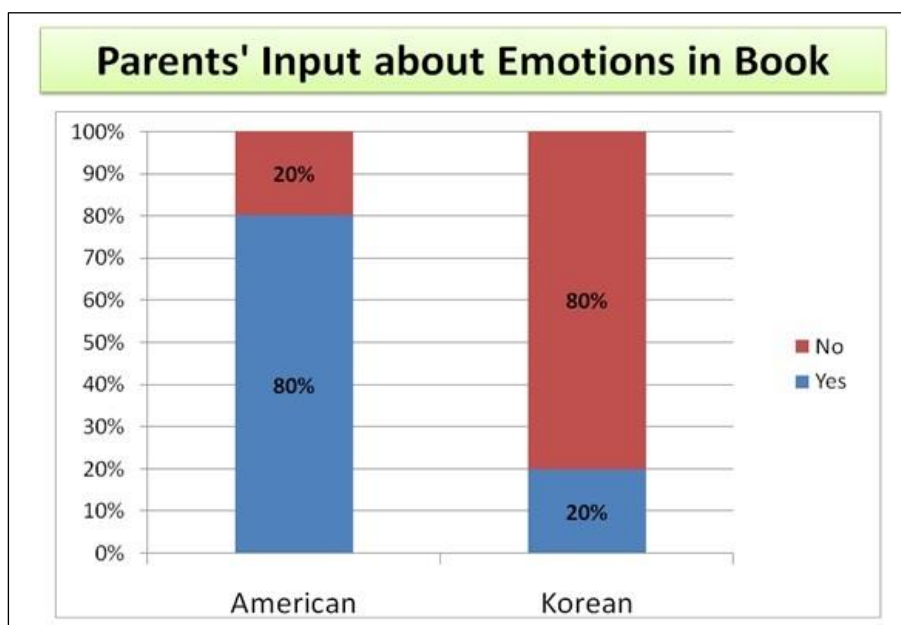
Photos of the EDEC tool



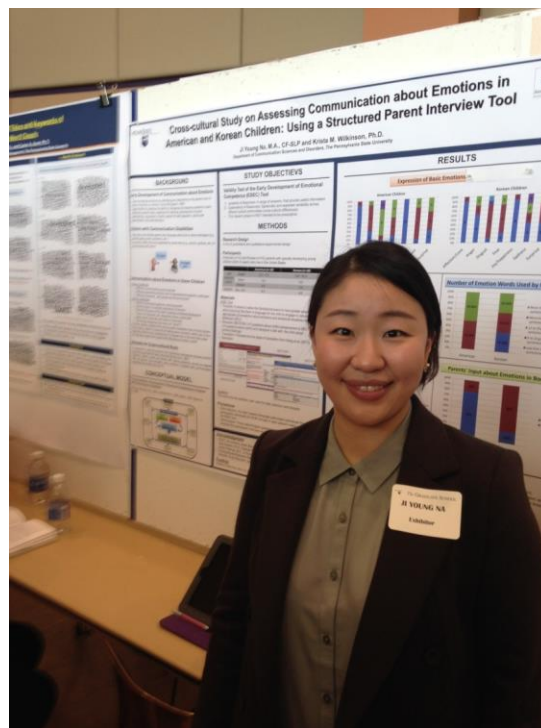
I recently conducted a pilot study using the EDEC tool, which revealed systematic cultural influences on mother-child conversation about emotions. Twenty American and Korean mothers with typically developing children participated in this cross-cultural validation of the EDEC tool.

I found a range of answers within each cultural group, as well as systematic variability across different cultural communities. The most dramatic cultural difference was that American mothers (80%) were far more likely to encourage emotion-related conversation during book reading activity than Korean parents (20%). However, both cultural groups reported the same reasons as to “why they do not encourage an emotion-related conversation during book reading activity.” Those who answered “No” for the question (*i.e.*, 20% of Americans and 80% of Koreans), said their children were “old enough” to interpret the character’s emotions by themselves, and thus, did not need any parental supports. In other words, mothers from these two cultures report having an overall different mother-child conversational style, however, they expressed the same rationale for their decisions. Further data analysis of this pilot study will contribute to a better understanding of cultural and linguistic differences in emotional development in American and Korean children.

Results of the Pilot Study with the EDEC tool



The team that has worked on developing the EDEC tool feels it is critical that individuals who use AAC have ways to communicate their own and others' feelings using culturally appropriate emotion language. We are exploring ways to support the development of emotional competence in these young children. We can begin by supporting families and professionals to have a better awareness about the need for individuals with CCN to have access to emotion language in their AAC systems, beyond happy, sad, angry, so they can have meaningful conversations about their feelings, opinions, interests, and beliefs, as well as their wants and needs.



**Ji Young at the Graduate Exhibition at Penn State, April, 2014.
Poster Session.**

{This study was funded by the federal grant from the U.S. Department of Education (H325D110008). It was completed in collaboration with Dr. Krista Wilkinson. The partial results of this study were presented at the 2014 Graduate Exhibition at Penn State. If you would like more information about this study, please contact Ji Young Na (ijn129@psu.edu) or visit: <http://aac.psu.edu/?p=2051>.}

AAC IN GHANA

[Editor's Note: One of the most practical and effective efforts to introduce and adapt augmentative communication tools and strategies to the cultural and economic realities of an emerging nation is taking place in the schools for children with special needs in Ghana. Supported by regular visits from teams of Columbia University faculty and graduate students over the past several years, teachers from these schools have gathered together in Ghana for an annual AAC weekend retreat.

By introducing practical, inexpensive and culturally appropriate classroom activities, and then periodically reinforcing them, the Columbia teams have helped to make these activities a regional and meaningful part of the school day in unit school classrooms across the country. The article that follows updates this important story--- elements of which we have covered in previous issues of this newsletter. Go to:

<http://www.centralcoastchildrensfoundation.org/home/augmentative-communication-world-network/acwn-newsletters>

ADAPTING AAC IN GHANA'S SCHOOLS

By Cate Crowley, Columbia University, New York, NY, USA

In January, 2014, another team of speech-language pathology graduate students, led by Dr. Cate Crowley of Teachers College Columbia University, journeyed for the eighth time to Ghana. <https://www.youtube.com/watch?v=uJG2K0fBoQ>

Their ongoing work with the "Unit Schools" is one important aspect of their work there. Unit Schools are schools for students with intellectual disabilities and autism. Over the years, in collaboration with the Unit School teachers and the Central Coast Children's Foundation (CCCF), the TC team has worked to introduce AAC in ways that are functional and effective.

One of the first AAC approaches, AAC market cards, were developed six years ago in collaboration with Belinda Bukari, one of the Unit School teachers. The parents of Belinda's students said that they wanted their children to go to the local outdoor market to buy food for their families—a traditional activity for a Ghanaian child. AAC market cards show drawn pictures of individual foods available in the market. Three different cards are available for the three different quantities available. Parents give their children a “shopping list”, with index cards showing what they want and how much they want to spend that day. Then the students go to the market with the cards and do the shopping.

Clement Ntim, an outstanding teacher in the Nkawkaw Unit School, visited Scotland in October 2012 for a month of work experience learning from AAC experts. Clement returned to Ghana and immediately implemented the use of Talking Mats in his classroom.

<http://www.talkingmats.com>

Belinda and Clement have shared the AAC market cards and the communication mats with their colleagues. They presented these strategies at the 2014 Professional Development Retreats for 45 Unit School teachers, administrators of Ghana's Ministry of Education Division of Special Education, and other special and general education teachers. . Over the years, these AAC strategies and several others have been introduced to the students of the Unit Schools and the students are using them in their daily lives throughout Ghana. Go to

<http://leadersproject.org/media/document/augmentative-and-alternative-communication-aac-approaches-pamphlet>

The use of these AAC approaches, adapted so they are functional in Africa, continues to spread. With support from Teachers College Columbia University, CCCF, and the Wyncote Foundation, four of the Unit School teachers, along with Cate Crowley, attended the Fifth Annual East African Disabilities conference in Mombasa, Kenya. Belinda, Clement, and Cate spoke at the conference. The response by the East African conference attendees to Belinda and Clement's talk on their work in Ghana was simply overwhelming. Because these AAC systems were

adapted by the Ghanaian teachers, the very challenging task of adapting AAC approaches for Africa was done in culturally responsive ways, without the need for expensive materials or software programs.

Prior to visiting Mombasa, Cate Crowley send the video tutorials on the AAC market cards and Narrative Stories to several conference participants. They confirmed that the AAC approaches would be useful in many communities where the conference participants worked—in Kenya, Tanzania, Ethiopia, and Uganda. So while in Mombasa, Cate recorded the video tutorials in various East African languages, which have been dubbed and are now available on YouTube.

<https://www.youtube.com/watch?v=hIPIuS0WIGs>

<https://www.youtube.com/watch?v=55kIXDvluWI>

The Ghanaian teachers and the Teachers College team are currently developing video tutorials on Communication Passports and Joint Action Routines for a vocational workshop on making bags out of beautiful Ghanaian fabrics. <https://www.youtube.com/watch?v=cEA8dVXAT1g>

The Teachers College Speech-Language Pathology group returns to Ghana in January 2015. They will be conducting another professional development retreat and AAC will continue to be the main focus.

AAC is alive and well all over Ghana, and because of the commitment of the Unit school teachers, AAC is making a difference for Ghanaian people with communication disabilities.

SCHOOL FEEDING PROGRAMS FOR THE “NEEDIEST” SCHOOL CHILDREN IN DEVELOPING COUNTRIES: DO THEY IGNORE CHILDREN WITH DISABILITIES?

by

Charlotte Carr, Central Coast Children’s Foundation staff

[Editor's Note: Through her research, Charlotte Carr discovered that although issues related to malnutrition were being addressed in many school feeding programs in African countries, these programs often did not include any children with special needs and functional challenges.

She noted that attitudes about people with disabilities are beginning to change. More children with disabilities are being enrolled in schools today. Carr cites the stories of two schools and two Victors, who have never met. One school is in Tanzania and the other is in Malawi. Victor Kasembe is the lead teacher at the Secei Elementary School for Children with Special Needs in Tanzania; Victor Musowa is the Founder of The Rehab Clinic and Education Centre in Malawi.

Recognizing that many students were undernourished or malnourished, both men worked to implement a school feeding program with support from organizations in Canada and the United States. The results are remarkable. Student who have attended are doing better in school and more families are hoping to enroll their children. Charlotte Carr is planning to take the results of her research to advocate for more attention to school feeding programs for children with disabilities in poor areas around the world.]

School feeding programs that target the most undernourished and underfed children in developing countries too often bypass hungry and malnourished children with special needs and functional challenges. How can this be?

Descriptions and discussions of school feeding programs in very poor countries consistently emphasize providing such programs to the “most vulnerable” children in a society. However, there is little to no emphasis on providing these programs to children with special needs. In many African countries, for example, children with special needs and functional challenges are only just beginning to go to school. Children who do not attend school are more likely to be malnourished. In fact, school feeding programs often result in more children enrolling in school, and more children eating healthy food. For children with special needs the benefits of school feeding programs can be far reaching.

The two main goals of school feeding programs are to provide children with access to (1) food

and (2) schooling. School feeding programs have proven to be an effective way to achieve these goals. Children who are malnourished are impaired not just by hunger; malnutrition leads to mental and physical stunting. Malnutrition is different than hunger, in that hunger is caused by a lack of food, malnutrition is caused not only by a lack of food, but by eating the wrong kinds of food. Malnutrition affects the overall health of a person, not only handicapping them, but by putting them at risk for other health issues. (1)



Currently, programs that connect malnutrition to disability are seeking only to prevent children from *becoming* disabled. This viewpoint looks at disability as a *consequence* of malnutrition, which, although true in many cases, it ignores children who are born or acquire a disability. Disability can be a risk factor for malnutrition. (2) (3)

Malnutrition affects educational attainment, and can cause children to perform poorly in school.. The health status and nutrition level of children greatly influences how well they are able to learn. Children who are malnourished and hungry will not do as well as their well-nourished classmates. These children have lower levels of energy, shorter attention spans, and nutrient deficiencies, which can lead to physical and mental impairments. (4)

School feeding programs can reverse the harmful effects of malnutrition. Implementing school feeding programs in schools for children with special needs can benefit them in a number

of ways. For example, the provision of free meals encourages many parents to send their children to school. Therefore, offering a free meal to children with special needs may encourage more parents to enroll these children in school. Healthy meals can help combat the negative effects of malnutrition and increase the child's capacity to learn. Being healthy and receiving an education can also have a strong positive effect on a child's ability to earn money in the future.

Another positive benefit for children with special needs and functional challenges is that school feeding programs promote inclusion in their communities. Not only are these children out of the house and in a supportive community setting, but community members can interact more with them and gain a better understanding of them.

Examples of schools already implementing well-run and effective nutrition and feeding programs include the Rehab Clinic and Education Centre in Blantyre, Malawi, and the Secei Elementary School in Arusha, Tanzania. These schools are running feeding programs in communities that have next to no services available for children with special needs. These programs were established a few years ago and have wonderful and optimistic stories of success as a result of these interventions. These schools demonstrate how to implement effective programs and the tremendous benefits on the children who participate.

- Founder of The Rehab Clinic and Education Centre in Malawi, Victor Musowa cites their school feeding program as one of the great successes of his centre. Musowa says, "It started when we noticed that some of the children showed up at school and cried for hours, and some came with evident malnutrition ... due to no food in the household or because of feeding problems because of their disability."



Musowa recognized that many children in the school were unable to fully participate in class because they were malnourished so he began the school feeding program to provide lunches for all the children at the center. He was able to keep program costs low, only \$100 a year per child. The Rehabilitation Clinic and Education Centre currently has 47 children attending, with 42 children on the waiting list.

- Victor Kasembe, who for several years has conducted a school feeding program at the Secei Elementary School for children with special needs in Tanzania, expects the demand for enrolment in the school and his school feeding program to continue to increase. Currently there are 65 children enrolled, and Kasembe says “The waiting list is almost double the number of the current kids. The number of these kids is expected to increase, as the behavior of alienating these kids is starting to fade away among the people, so the eagerness of educating them is expected to be high.”

These schools are examples of successful feeding programs. In addition to addressing the nutrition needs of children with disabilities, they are motivating families to send their children to school. The word has spread and now many more children want to enroll in these schools, but there is a lack of funding. With more funds, more children could be

admitted, and more food could be provided. Initiatives like these need support. Currently, these schools are some of the only services for children with special needs in their countries. There are only a few organizations currently involved in trying to help.



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PROMOTING PARTICIPATION – A CUTTING EDGE CONFERENCE IN WARSAW, POLAND

Report by Agnieszka Pilch



Agnieszka Pilch

Chair of Speak without Words Association

Every year, The *Speak Without Words Association* tries to organize educational conferences that touch on the most troubling AAC issues in Poland. Between April 12th and 13th 2014, such a conference, called ***From disability to activity: Selecting proper seating, equipment and communication supports as well as preparing a friendly environment for children with disabilities*** took place in Warsaw.

Since Poland suffers from a disturbing lack of occupational therapists, we managed to invite experts from Canada, Germany and Netherlands. The main lecturer at our conference was Mrs. Beata Batorowicz, an occupational therapist (OT) from Canada. To speak with her, she invited OTs Mrs. Nadia Browning from Germany and Koen van Dijk from The Netherlands, as well as Aleksandra Kulis – an occupational therapy lecturer at the Physical Education Academy in Cracow.



Beata Batorowicz, OT from Canada



Nadia Browning, OT from Germany

All the lectures concerned the newest trends in holistic approaches to working with children with disabilities and their families. Topics included (1) ways and rules of selecting the proper supports and strategies enabling children with a disability, mostly motoric and with serious communication problems, to participate in the lives of their families and their immediate environment, including school and kindergarten, and (2) active participation in everyday activities, developing bonds with other people.

We focused mainly on ways to work with the youngest children, such as adjusting their workspace (seating, wheelchairs, *etc.*), choosing low- and high-tech communication supports and developing ways to access these technologies. The lectures combined the latest knowledge of how to work with children with disabilities and practical examples of this knowledge. Reports on the latest research related to these issues proved especially interesting. The last session was dedicated to interactive discussions with participants.

The conference was accompanied by an exhibition of rehabilitation equipment, mainly wheelchairs and seats, but also devices and software to facilitate communication. Conference participants (200 people from all over Poland) were a notably diverse group. There were teachers, speech therapists, psychologists, physiotherapists, computer technicians, AAC experts and parents of children with disabilities. During the break, we shared information about the places in Poland where it is possible to receive AAC support; and subsequently, we put it on the map published on the website of our association.

The organization of this conference was made possible thanks to the huge involvement of the whole board of *Speak Without Words* and a company called Harpo. People, who have worked *pro publico bono* for years, have been trying to promote AAC principles in our country. I'm very grateful for their help.

The subject of our conference attracted huge attention from specialists in many fields. We were exhilarated by a significant turnout of physiotherapists, who are no strangers to the subject of

communication with their nonverbal patients. Without their continued cooperation, our work on communication will not have desired effects.

We hope that our April meeting inspired many specialists to seek out new knowledge of how to support people with serious communication problems to access education, families, their communities and all aspects of society.

A STORY FROM ITALY

by

Deborah Cerantola and Leonardo Colbalchini, Fonte, TV, Italy

Hello everyone,

I'm Deborah, Leonardo's mum. He is here beside me, and we are writing this letter together.

"Hello, my name is Leonardo. I'm almost 12 and I have Cerebral Palsy. I'm a very intelligent boy, really wanting to communicate, but unfortunately I feel like a "prisoner" of my body. I can move alone with my wheelchair but I need someone to help me with everything else. I have a PEG in my belly for feeding and I cannot talk.

"I like using gestures and sounds and if people really don't understand me I use a communication board. My father is called Giancarlo and I have two sisters, Beatrice, who is 17 and Chiara who is 9. Mum will now continue my story. We have decided together what to tell you."

When Leonardo was three we decided to register him in kindergarten and we did not have any doubt which school to choose: the school should be his town school, his school mates should be the friends in his own town. Yes! We wanted Leonardo to be integrated in his community. We were sure this would be an opportunity for him to grow relating to everyday life and "normality" (who can tell what normal is?), and we were sure that it would also be a great opportunity of growth for his school mates to relate to disability.

We met a very good speech therapist who introduced us to AAC, and we began working with this method. We didn't know if it was the right way. What we did know was that Leonardo had a great desire to talk. Although we tried hard, it was difficult for us to understand him and he became less motivated. We started to take photos of Leonardo's daily life, of the most important people and events. At home we stuck images everywhere and, at school, the teachers did the same. We built a first communication board which, at the beginning, was difficult for Leonardo to use.

At the age of 7, Leonardo had to move up from kindergarten to the primary school. It was a huge step ahead and it frightened us a bit. So we went to meet the school principal and the teachers, who accepted him well, from the very beginning. Luckily, we had chosen the town school so, after the summer holiday, when Leonardo moved up to primary school, he was with the same classmates.

This was a point of strength for him. His school mates already knew him; they didn't consider him different from them, but just as a friend needing more care and who had a different way of communicating. The important thing they knew was that he was COMMUNICATING with them and that they could communicate with him. They were taught and began giving him the chance of choice, at first between YES and NO and then between other choices showing him different objects or images and then even asking him different "abstract" things and giving him the opportunity to choose between "the first, second thing I've said?" and he would indicate with his fingers first or second. When he got to use the modality better, a third choice was also introduced.



I must say he was lucky, and it was great seeing mates getting involved with him and believing in him. In addition, all the work the teachers and the personal assistant have done to promote integration has been really important. During the last five years Leonardo has learnt to use efficient gestures to relate with people who know him and his gestures. The interesting thing is that when he comes to new words he sorts out in his mind and plans what to do to create new gestures, along with whom he is relating to. He will make a new gesture, his partner will ask him to repeat the new gesture and check with him if he means that specific thing; Leonardo will confirm or not and repeat, or slightly change the gesture until the partner gets the right meaning. This is how the final choice will become the definite "shared" gesture for the new word. Teachers and mates have learnt this process and each new gesture for new words is shared in the class, among mates and family members.

[Editors' note: In 2000, Sarah Blackstone published a special issue of her *Augmentative Communication News* newsletter on gestures. It remains one of the most useful resources on this topic, and can be downloaded without cost at: http://www.augcominc.com/newsletters/index.cfm/newsletter_26.pdf. ALL of these newsletters ever published (1989-2009) now can be downloaded without cost at <http://www.augcominc.com/newsletters>, and many, on such topics as AAC and health care, Modeling, AAC and disasters, AAC myths, and Social Networks, are as relevant today as when they were when written.]

Leonardo uses a communication board with people who don't know him well. He is learning to use a computer with a voice output device but is actually using it more for school and learning purposes rather than for face- to face communication.

Last year Leonardo attended the catechism course to prepare for First Communion. With the help of a communication board, he was able to have his First Confession and Communion in group with the other children. It was a very great emotion!

Now the next step will be moving to secondary school in September. We are working with teachers to make the transition as simple as possible. His teacher has been taking him to visit the new school, to get to know the new teachers and the new environment. They are introducing AAC strategies to the new teachers so that they will be able to communicate with Leonardo in September when he starts.

At home, we are working on a new personal communication passport that will help to give more detailed information to the new teachers and new schoolmates. We have also discussed an idea with the school director and teachers that, as a whole class activity, each pupil could create their own individual personal communication passport. The school supports this idea.

[Editor's note: *An extensive introduction to developing personal communication passports, along with useful templates, can be found at: <http://www.communicationpassports.org.uk/>*]

I must confess that we were undecided about the choice of the school, if he should attend secondary education in a special school or in the town mainstream school. Finally we have decided he should continue going to the town school, maintaining his integration in the community. We are sure this is the best choice for Leonardo, and it is what *he* wants.

(Editor's note: www.communicationpassports.org.uk/Creating-Passports/Good-Practice/ on this website there is a free to download Good Practice checklist in English, which may be translated into other languages with the following message of conditions from the author Sally Millar "You may download and use this checklist and audit procedures, and perhaps adapt them for your own setting. Please feel free to do so, but please do not publish anything based on these without acknowledging this author and

this copyright document. Good Luck! If you have developed different procedures, it would be good to 'share and compare' - please get in touch." <http://www.communicationpassports.org.uk/Contact-Us>]

ROMANIA

[Editor's Note: *In her role as Senior Representative to Eastern and Central Europe for the Central Coast Children's Foundation (CCCF), Dot Fraser has been working since 2011 with the Teacher Training Centre in Sibiu Romania , Casa Corpului Didactic (CCD), providing workshops for teachers in special education and mainstream kindergarten and primary schools in Sibiu city and county. She filed the following conference announcement.]*



ROMANIAN CONFERENCE FOCUSES ON INCLUSIVE EDUCATION IN SCHOOLS AND COMMUNITIES

The Teacher Training Centre (Casa Corpului Didactic) Sibiu presents an educational festival: *Inclusive education in schools and communities at the Venue Casa Corpului Didactic, Sibiu, Romania, on 12th June 2014.*

The programme includes:

- Plenary sessions with speeches from Representatives of CSI Sibiu, ULBS , CJRAE and Dorothy Fraser – volunteer workshop trainer);
- An exhibition of masks, pop up books and puppets created by pupils in the participating schools as a result of the training programme
- Presentations from participating schools
- Workshops

The project goal is to create a framework for the development and promotion of good practice in teaching by cultivating an inclusive learning environment, both in special education and mainstream education.

Objectives are to demonstrate how to:

- Create an inclusive learning environment
- Promote good practice examples for teaching regarding inclusive education
- Develop school - family-community collaborations
- Stimulate communication, creativity and expressiveness
- Develop social skills, encouraging positive attitudes for oneself and other people through activities and interactive events
- Encourage the pleasure of books, storytelling, and literacy skills
- Develop an interest in volunteering among students and teachers and the community

Activities and papers will demonstrate

- positive experiences in addressing topics related to inclusive education
- elements related to the role of teachers in developing school-community partnerships in the context of an inclusive environment.

All activities are based on the key principles of inclusion, that consider fundamental concepts such as valuing diversity, the right to be respected, human dignity, understanding individual needs, collective responsibility and equal opportunity.

Beneficiaries.

- Pupils with special educational needs in schools in Sibiu county
- Pupils in mainstream kindergarten and primary schools
- Teachers in special education
- Teachers in mainstream kindergarten and primary schools (especially teachers participating in the pop-up books, masks and puppets workshops, organized by Casa Corpului Didactic in Sibiu 2011-2014);
- Teachers, psychologists, speech therapists, itinerant teachers and school counsellors.
- Parents and family members

Duration of the project

May 5, 2014 to August 2014 culminating in the publication of *“Best Practice Guidelines”*.

**SUPPORTING CHILDREN AND YOUNG ADULTS WITH COMPLEX COMMUNICATION NEEDS IN
SERBIA: A REPORT FROM NOVI SAD**

by

Dorothy Fraser



[Editor's Note: *Dorothy Fraser, who edits this newsletter, spends a great deal of time in Eastern and Central Europe representing the Central Coast Children's Foundation (CCCF) as its Senior Representative in this region. In 2012, in response to a request from Serbia to the International Society for Augmentative and Alternative Communication (ISAAC), Dot expanded her international activities to include two communities in Serbia, Novi Sad and Belgrade. These collaborations, initiated through requests to support communication enhancement in special education, expanded quickly to include patient- provider communication and preparation for medical encounters. In the report from Novi Sad, below, Dot updates progress in both these areas, focusing on a three school complex of special educational centres under the management of one director, the Milan Petrovic school complex.]*

March 2014 marked my third visit to Novi Sad and to the Milan Petrovic complex of schools. These are located on three separate sites in different parts of the city catering to children and young adults with complex communication needs, including cerebral palsy, Down's syndrome, autism spectrum disorders and profound and multiple learning disabilities (PMLD). Some of their clients are also blind, or have visual impairments and hearing impairments. The three sites incorporate: (1) a kindergarten, (2) a primary school, and (3) a high school complex on one site that includes a high school, a service centre for adults, and a community centre that provides therapies for children from the community who are not educated at Milan Petrovic schools.

The high school provides a general education curriculum as well as vocational training in many skills and crafts that include knitting, cooking, shoemaking and repairs, metal and wood work.

As part of their vocational training the high school has a positive, every day natural connection with the community. There are doors onto the street for public access so that, for example, people can go to the hairdressers where students have work experience.

The service centre, which is located on the high school site, caters to adults with disabilities giving them opportunities to develop skills and work in a wide variety of professional workshops. They make their own high quality products which are sold in the on-site shop and to other outlets in the local community and beyond.

Families from other parts of Serbia can choose to send their children, adolescents and young adults to Milan Petrovic. Some stay with relatives; others stay in the school's boarding house during week days.

The schools and service centre are very popular, but unfortunately they cannot provide for everyone who would like to attend because they don't have enough classrooms and workshop places.

This year the staff I had met on previous visits invited me to all the centres so we could continue developing our communication projects. Everyone was very welcoming and open to ideas. I spent the first week in the primary school observing individual classes along with the school psychologist, who acted as an interpreter (she knows the children). We had discussion time in each class and, at the end of the week, the staff organized a group meeting to talk about their progress and decide how to proceed. I gave a final presentation which included suggestions for individual students, class layouts, visual displays, and future activities.

The second week I was in a kindergarten class for two days with a special educator. We had stayed in touch by email after my last visit and had lots to discuss about projects already in place and how to develop them further. This time he had additional specific questions for me from parents.

One special moment, which we recorded on video for her parents, was of a young girl on the autism spectrum with visual impairment and no clear speech interacting with us and her obvious delight at her newfound skills using material that Ian Bean had kindly sent me to download and use off line for cause and effect activities. www.ianbean.co.uk



Discussion with one of the high school classes

I spent my final three days at the High School complex, with one day in each “sector” (the high school, service centre for adults, and the community centre).

Throughout my 2 week visit I had opportunities to offer support and advice to staff and the families of individual pupils and help them to create their own material to improve communication. We talked about how and why to use AAC / AT , simple VOCAs and other gadgets, making Personal Communication Passports, information about social networks and communication circles, and the use of Widgeo symbol software. All these materials were provided by the Central Coast Children’s Foundation.

A major theme that emerged from our ongoing discussions and planning sessions was “finding *practical* ways to connect the students of all ages with the world around them.” For example, the director, staff and two young adults with cerebral palsy who work in the IT (information technology) part of the service centre will think about what vocabulary is suitable for younger children. Then, they will start making communication boards and books for the kindergarten and primary school students. They will also prepare relevant AAC material for adults with complex communication needs at the Service Centre using the Widgit symbol software provided.



Making plans for creating communication boards and books

Some other outcomes from this year's visit:

1. Being invited to talk with other groups in the city, including:

The University Medical Faculty: A presentation for staff, therapy students and special education students. Some had attended my previous talks held at the Paediatric Neuro-Rehabilitation Hospital.

2. Planning for an international project that would include the professor of the medical faculty, the head of the nursing department and the head of the speech therapy department. The focus of this project: patient- provider communication .We have already started to talk about ways to apply for funding and I will pursue this further at the ISAAC conference in Lisbon (July 2014).

3. The Academy for Preschool and Kindergarten teachers :

A presentation for staff and students about communication in early years, adapting books, preparing other materials for young children and children with additional support needs and inclusive education. The director of the academy, the professor of the teaching department, staff and students want to set up further projects because they are interested in learning more about practical ways to be creative and develop communication.

I'll be returning to Serbia in the spring of 2015. Until then we will continue to develop our projects by email.

More background information: Milan Petrovic has a beautiful, large house outside the city, with accommodation, a mushroom farm and market garden for young adults, plus many other activities with support workers .



I stayed there on my first two trips in 2012 and 2013, but this time they had no internet connection (an essential for my life style) so I moved into Novi Sad and enjoyed discovering more about the city.



RESOURCE SECTION

VIDEOS

1. **Cortical Visual Impairment and the Evaluation of Functional Vision**

In this webcast provided by the Perkins School in Watertown, Massachusetts, Dr. Christine Roman-Lantzy presents an overview of Cortical Visual Impairment (CVI). This resource is particularly useful in that it provides a transcript divided into the six chapters of the webcast: An introduction to CVI, the importance of early diagnosis, characteristic behaviors of CVI, diagnostic issues, evaluation functional vision and interventions to improve functional vision.

Roman-Lantzy notes that while cortical visual impairment is by far the leading cause of visual impairment in children today, and will likely remain that way, little has been done to improve early diagnosis measures. She notes there are strict protocols to examine children born prematurely for detached retinas and protocols put in place for when children should have eye exams, but that no such protocols exists to monitor or identify children with CVI. Says Roman-Lantzy, "That's actually something that I think is not really difficult to do, but I don't think pediatric specialists have really concentrated on identifying CVI early."

She identifies three major ways of diagnosing CVI: 1) eye exams that examine the way a child actually uses their vision 2) finding out if the child has experienced a big neurologic event which is common for children with CVI and 3) checking for the ten characteristics associated with CVI which include unusual attention to movement and colors. Although these three measures can provide a comprehensive way of confirming the presence of CVI, they are not always used. "And so," explains Dr. Roman-Lantzy, "because there is no declared protocol in the medical community to identify CVI, some children with CVI are given certain kinds of diagnostic tests that are often associated with children with ocular visual impairment."

A diagnostic test called a CVI Range is used to determine the degree of effect of CVI on a zero to ten scale and then to design appropriate interventions based on that range. Dr. Roman

believes it's important to diagnostically match the interventions to that assessed level carefully, "because what we're really trying to do is to encourage children to use their vision in functional routines, in meaningful activities, but by making adaptations to materials and environments based on that assessed score, we can actually encourage use of vision in a really meaningful way."

<http://www.perkins.org/resources/webcasts/cvi-and-the-evaluation-of-functional-vision.html>

2. PrAACtical AAC: Evidence-based principles and practice: Beware the trap of readiness

This video provides an in-depth discussion of best practices in choosing and using AAC devices and displays. Although it's a bit long (over 45 minutes), checking out even just the first ten minutes might be worthwhile for anyone curious about how and why to choose a particular AAC device or AAC app. While some of the mid-tech and high-tech AAC devices mentioned are probably not appropriate to the financial situations of people in emerging areas, the presenters also pay attention to no-tech and light-tech tools (*e.g.* communication boards and communication books).

The two presenters, speech language pathologist Kristen Carroll and AAC training specialist Bonnie Mintun, begin their talk by sharing quotes from individuals that illustrate what it's like to be unable to speak and highlight the important role of communication in quality of life.

Carroll explains: "There are no prerequisites to the use of AAC devices and systems. There is no hierarchy of devices or skills that need to be put in place before a system can be implemented or tried. You don't have to wait for a skill to develop before trying a variety of systems. It's not a hierarchy of starting with no or light tech and moving on up, it's using everything." She provides an example through the story of a young girl named Anna, narrated by her mother. Anna's mother advises parents to push back against what she refers to as a 'trap of readiness;' which she experienced when care providers constantly told her Anna wasn't ready for a certain AAC option and wouldn't be ready to use it.

Instead of waiting for the development of a 'prerequisite skill' (in Anna's case, pointing) before allowing patients to try a tool, the presenters encourage professionals to make a whole toolbox of tools available to patients. "Our philosophy", says Dr. McIntun, "is to learn while doing, don't get ready to learn something."

<http://praacticalaac.org/video/video-of-the-week-aac-evidence-based-principles-and-practice/>

OTHER RESOURCES

1. AACKnowledge: The AAC Evidence Base

The AAC evidence base research project was initiated by Communication Matters, (ISAAC UK) that is involved in a wide-range of activities that promote AAC services. The project supports the collection of consistent and relevant case data *and* more robust data collection. The AAC evidence base website brings together information and research evidence about AAC in one place and in an accessible manner, making it a very useful resources for AAC practitioners in emerging areas.

For those less familiar with AAC, a practical Glossary of Terms is provided with definitions of common terms and links to further information. Also highly useful is the Plain Language Summaries page, which summarizes relevant reports and articles in an easy to understand manner. The Fact Sheet section contains well-organized collections of information on communication aid and conditions that limit communication such as stroke and aphasia.

Perhaps most unique to the website is the AAC Case Stories section, where you can find a collection of case stories from different personal and professional perspectives. In one case study, a speech and language pathologist shares the strengths and challenges of different AAC systems used during her experience working with a client for over ten years. Another tells the story of a man's decline in communication abilities after leaving his supporting school environment. www.aacknowledge.org.uk

2. Tots-n-Tech Oct. 2012 E-newsletter: *Using Visual Supports with Tots and Toddlers*

Produced by The Tots 'n Tech Research Institute, an inter-university collaboration between Thomas Jefferson University and Arizona State University

["Stop Violence Against People with Disabilities"](#) has been published and is available digitally from [Kindle eBooks](#). The editors are Diane Nelson Bryen, professor emerita from Temple University, USA and extraordinary professor in the Centre for AAC and Juan Bornman, Director of the Centre for AAC at the University of Pretoria, South Africa. The book provides a multinational and multidisciplinary perspective on violence and abuse against children and adults with disabilities.

The book's focus is children and adults who have little or no functional speech as a result of a variety of disabilities. Because of this disability, they are especially vulnerable to violence and are often denied access to the justice system. It goes beyond describing the extent of the problem. It focuses on promising practices from across the globe. These promising practices have evolved from seven countries across five continents.

Chapters are modelled on a real case study from the particular country. Of special note is the inclusion of picture-based and text-based communication boards called *You Can Tell and be Heard* in Afrikaans, English, French, Hebrew, Hindi, isiZulu, and Sepedi languages for children and adults.

Stop Violence Against People with Disabilities! An International Resource is intended for peers who work in the fields of disability and law. Persons with disabilities and their carers are the major stakeholders and can learn much from the chapters in the book and the resources provided in the appendices. Abstracts have been written in the home language of the author and in Easy English.

Anyone who is committed to human rights and to ensuring that the *United Nations Convention on the Rights of Persons with Disabilities* is implemented in their countries will benefit from reading this book. As Archbishop Emeritus, Desmond Tutu wrote in the forward "*Stop Violence Against People with Disabilities* is not about charity, but rather the human rights of almost one billion members of humankind". 4

4. **ACCESS FOR ALL: INCLUSIVE COMMUNICATIONS.** Available at

www.efds.co.uk/assets/0000/9149/EFDS_Inclusive_comms_guide_accessible_PDF_APRIL_2014_FINAL.pdf

The guide is written for sport and physical activities - but the content is also relevant for other public sectors looking for ways to be inclusive. It contains chapters on

- Why is inclusive communication important?
- Getting started including
 - Developing an inclusive communications policy
- Using design to improve accessibility
- Inclusive communications better practice checklist
- Resources and further information



CONFERENCES



<http://inclusion-international.org/world-congress/>

“A BETTER WORLD FOR ALL- NO ONE LEFT BEHIND” NAIROBI, KENYA, 10-13 JUNE 2014

Inclusion International and the Kenya Association for the Intellectually Handicapped (KAIH) are organising Inclusion International’s 16th World Congress in Nairobi, Kenya. The event invites

people with intellectual disabilities, their families, organisations and other relevant stakeholders to join the debate on building a more inclusive tomorrow.

The Congress seeks to give people with disabilities and their families, as well as Inclusion International member organisations and partners the opportunity to engage in an open discussion about development measures that need be taken in the following years to create a fair and accessible global society.

The Nairobi event brings together participants from a wide range of countries, sharing experiences and good case practices regarding the implementation of the United Nations Convention on the Rights of Persons with Disabilities throughout the world, and building cooperation between nations and continents



THE 16TH BIENNIAL CONFERENCE OF ISAAC

The 2014 ISAAC Biennial Conference will be held from July 19-24, 2014, at the Lisboa Congress Centre, Lisbon, Portugal. Pre-conference Workshops are scheduled for July 19-20; the AAC Camp will be on July 19-20; and the Main Conference will be held from July 21 to 24. The Research Symposium will be immediately following the Main Conference, on July 25-26.

Presentations feature leading edge research, and clinical and educational interventions and innovations. People who use AAC will share their experiences and perspectives. Posters focus on a wide range of topics, and the Exhibition showcases new technologies or applications of technology, products and services.

For an overview of the Pre-conference Workshops, AAC Camp, and Research Symposium, click on the link below:

- [ISAAC Conference 2014 Brochure](#) (PDF, 375 kB)

[Editor's note] Our poster presentation at the ISAAC conference in Lisbon will be displayed on the final morning Thursday 24th July.

“Expanding AAC and AT Awareness and Use in Poland, Romania and Serbia through International Collaboration”

The poster focuses on an international project initiated by requests for support from professionals working in special education within Poland, Romania and Serbia. The project has grown over the past four years and now extends beyond the education sector to include communication access initiatives in healthcare and other public sectors. The poster will document how international collaborations can serve as a catalyst to changing perceptions and increasing awareness by promoting the need for and use of relevant AAC and AT strategies and materials.

I look forward to this opportunity to share our news.

CLOSING MESSAGE

Thank you to all contributors and a personal big thank you from me to all the people I meet during international projects for their kindness as hosts and for their much appreciated friendship.

Until the next edition of our newsletter

Very best wishes to everyone,

Dot, dotfraser2@gmail.com