



July 2017 Edition

INTRODUCTION

Welcome to this first ISAAC edition of *Communication Support World Network* (CSWN) newsletter previously produced by Central Coast Children's Foundation (CCCF).

The main goals of CSWN newsletters are to share what is happening in AAC around all continents and to promote networking (as said in the title). CSWN includes articles, additional information and resources. The articles are about your personal experiences, with insights and information that can assist others on similar paths. Additional information includes future AAC conferences and events happening in your area. Resources are usually websites that you have come across and found very useful for your day-to-day activities in AAC. We are open to hear your news! CSWN depends on you to read and submit, so how about we make CSWN "our" newsletter!

by Nadia Browning and Dorothy Fraser, Co-editors

The CSWN Newsletter is published twice each year by the International Society for Augmentative and Alternative Communication (ISAAC)

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The July 2017 issue and archives can be viewed on the ISAAC website at
<https://www.isaac-online.org/english/news/cswn-newsletter/>

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ISAAC Pleased to be Publishing CSWN Newsletter

by Franklin Smith

After eight successful years of publication by the Central Coast Children's Foundation (CCCF), the *CSWN (Communication Support World Network) Newsletter* will now be published by ISAAC.

The changeover from CCCF to ISAAC is one suggested by CCCF, and mutually agreed upon by both ISAAC and CCCF. ISAAC will be working to ensure the smooth integration of *CSWN* as another important aspect of our ongoing communication and engagement with all our stakeholders.

ISAAC is also pleased to announce that the *CSWN Newsletter* will continue publication under the leadership of co-editors Dorothy Fraser and Nadia Browning.

Under its original name, *Augmentative Communication World Network (ACWN) Newsletter*, the *CSWN Newsletter* was founded by associates Sarah Blackstone and Harvey Pressman, with the late Anne Warrick as the first editor and Dorothy Fraser continuing as editor in 2012. We acknowledge with thanks the efforts of these individuals over the years to ensure the ongoing publication of the *CSWN Newsletter*.

The *CSWN Newsletter* highlights international connections and support for AAC, and the dynamic work being done by people in many places around the world.

To view past issues, please visit the [ISAAC website](#). The same archives also reside for the time being on the [CCCF website](#).

Regards and thanks,

[Franklin Smith](#)

Executive Director

The Salvation Army Uganda AAC Project

By Kristine Stadskleiv, Stephen von Tetzchner and Kerstin Hellberg

The Salvation Army of Uganda and Norway cooperates to bring augmentative and alternative communication (AAC) to children in Kampala, Uganda.



The Salvation Army is an international, Christian organization that in addition to being a church also has a longstanding tradition of providing relief and social services. In Kampala, the Salvation Army runs the orphanage and centre 'Home of Joy' for physically disabled children. The orphanage is currently the home of 40 children and youth, many of whom have cerebral palsy. Some of these children are unable to speak and need other means of communication, such as manual signs and graphic symbols.



Figure 1: Pictures from the Salvation Army Home of Joy in Kampala, Uganda

The knowledge about AAC is very limited in Uganda, and many children who would benefit from AAC are not given access to this important intervention, because carers and professionals do not know about it. During this project, AAC has been introduced to Home of Joy, and also disabled children who are not living at Home of Joy, are introduced to AAC when their parents bring them there for training. As part of the project, some Universities and Hospitals in Kampala are offered basic AAC training.

The project started with a visit to Home of Joy in May 2016 from the Norwegian team: Professor Stephen von Tetzchner from the University of Oslo, special educator Kerstin Hellberg and psychologist Kristine Stadskleiv from Oslo University Hospital. It was a joy to be able to provide graphic symbols and enable communication for children who had never had access to it. The staff at Home of Joy participated fully in the training, and has followed up the AAC training between our visits.



Figure 3: Examples of symbols on a daily schedule

We could see improvements in basic communication skills and understanding of the use of graphic symbols in several of the children. An emphasis is placed on integrating the use of AAC into daily life and activities that are meaningful for the children, such as play and music. Joining in music and letting the children choose songs and instruments have sparked joy, initiative and participation.

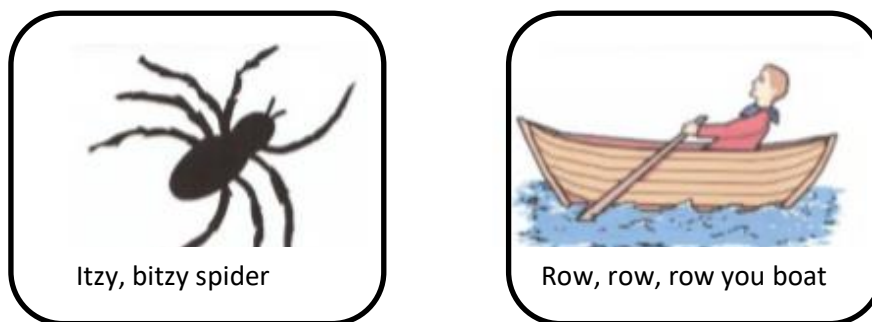


Figure 4: Examples of symbols for choosing between songs

The children needed time to understand that they could use the graphic symbols to express themselves, as this was a new experience for them. Care was therefore made in using the symbols in activities with the real objects. Locally made instruments and toys and using the free software Pictoselector help keep the cost of making graphic symbols down.



Figure 5: Examples of combining symbols and real object when presenting children with a choice of instruments

We experienced that also the speaking children and their non-disabled siblings really enjoyed the toys and play activities, and that integrating the use of graphic symbols into play activities enabled the disabled and non-disabled children to play together. This is an important resource for the disabled children.



Figure 6: Symbols for doll play activity and children engaged in doll play

In addition to communication, we have focused on providing the children with joyful and meaningful activities. Some of the children made very little spontaneous use of their hands, together with the staff we therefore made activity boards during the last visit, where the children could feel and explore different textures and make sounds with different objects.



Figure 7: An example on an activity board for exploration and development of a sense of agency

The project will go on for four more years. Some of the challenges ahead are how to provide better splints and wheelchairs to the children, give them access to epilepsy medication and other forms of necessary medical follow-up, as well as expand the use of AAC and the local development of the communication aids to the participating children and other children in Uganda who need it.

[Link to Victor Musowa's article about Malawi](#)

Six Years of Experience in Augmentative and Alternative Communication: The Journey So Far in Ghana

By Belinda Bukari, June 2017



JUNE 2017

The journey of Augmentative and Alternative Communication (AAC) all began after I competed in the Bridge School Teacher-in-Residence Award scheme in 2010 and received the award at the ISAAC international conference in Barcelona, Spain. Unfortunately, there wasn't the chance to go to the Bridge School but my Sponsors, Central Coast Children's Foundation arranged for me to go to Pathways Pretoria in South Africa where I did my internship in 2011.

At Pathways, I learnt a lot about picture symbol communication in teaching and learning. There was an opportunity to participate in a Conference where I presented on the award winning AAC Market Cards. I learnt from other presentations some strategies that could also help in my work in Ghana.

In 2012, Cate Crowley, the programs coordinator for bilingual extension institute, Teachers College, Columbia University (who also happens to be the one who introduced me to AAC in 2009) came with her graduate students where we created many resources that enhanced the communication needs of pupils with intellectual disabilities and autism through the yearly Professional Development Retreat Program. The program brings together two teachers from each of the 23 unit schools for the intellectually disabled. Teachers work in groups with students from the Columbia University to create resources for their respective schools where I continuously shared my experience in Pathways on ACC strategies and how local materials can be used in creating resources to enhance effective teaching and learning.



The year 2013 saw me in Mombasa Kenya for the East Africa Conference on 'Communication Disability' where I did a joint presentation with Clement Ntim and Cate Crowley of Teachers College on AAC Market Cards. The trip was made possible by Wyncote Foundation and Central Coast Children's Foundation.

In our Columbia University's Professional Development Retreat in 2015, I continued to share my knowledge and skills in classroom management strategies with reference to Augmentative and Alternative Communication where parents are also allowed to participate during classroom activities. Some of the works that we've been able to do to are the AAC Market cards, Curriculum name labels, Communication Passport, Word Walls, the Five Finger Story retell, Calendar, Schedule, Talking Mats as well as no technology strategies.



Later 2015, I was moved to the Division of Special Education of the Ghana Education Service where I was tasked with the responsibility of the Head of Unit of Education for the Intellectually Disabled.

My work at the division enabled me to do training for teachers and some selected members of District Education Directorates on Screening in the identification of children with Intellectual Disabilities and how to manage them effectively in the mainstream schools

where the area of communication is very paramount thereby using the platform to talk about AAC.

I have continuously trained teachers in the segregated special schools on the use of picture symbol communication in enhancing the communication needs of our students.

Currently, there's an ongoing capacity building training of some selected special schools by kind courtesy of MTN Mobile Network support in their yearly contribution to society where some of our special schools have been selected across the country. Capacity teachers will be built around using picture symbols in their daily teaching and learning.

MOVING ON:

- I am still looking forward for an opportunity to receive in-depth training on AAC where application of at least medium to high technology AAC Devices are used. It is interested to note that Ghana has a policy on Inclusive Education now and students with mild to moderate disabilities including those with cerebral palsy and autism are admitted into the mainstream schools. This implies that there is the need to train and equip teachers with needed skills and resources in managing the communication needs for such categories of children
- The need to establish an AAC Centre in Ghana.
- There should be a continuous sensitization and training of teachers on new trends in the management of communication needs of persons with communication difficulties.
- As an advocate of AAC, I keep sharing the knowledge on every platform I get to impart knowledge unto others and I believe that with support from all of us, Ghana will become one of the proud countries to champion the cause of Augmentative and Alternative communication.

[Link to Harvey Pressman's report about Ghana](#)

Camp CATIC-TOMACOCO: Our First Camp Experience in Mexico

By Gaby Berlanga, CATIC Director, Mexico City



CATIC had the idea of organizing a summer camp for children with complex communication needs (CCN) for years. My dream began after I attended The Bridge School's summer camp. I fell in love with it.

It was during Dr. Karen Erikson's recent workshop for therapists and parents in Mexico, however that prompted action. After Karen described Camp Alec <http://www.campalec.com> to the parents, they began to talk about traveling to The United States to attend "Camp Alec." Finally, Karen pointed out that the language spoken at Camp Alec is English, soooo "Why not hold a literacy camp in Mexico?"

Immediately, our parent group leaders, Wendy Moreno and Gabriela Mangino, began to make it happen. Their first step toward planning a 2018 CATIC Literacy Camp with Karen Erikson was to plan a shorter camp experience for children with CCN and siblings in 2017.

We began looking for accessible campsites and organizations to work with us. Finally we found a great location, Tomacoco, a campsite with inclusive services and identified organizers who were willing and able to serve people with disabilities.

Our First Camp CATIC-TOMACOCO took place in June 2017 and was a big success. Many of our students slept overnight without their parents for the first time and this was very exciting for them. We all played games, sat around bonfires, attended disco night, went over

the hanging bridge and the zipline. Adults participated by pushing children in their wheelchairs uphill and on the grass, and supporting their participation in all activities.



“We were physically exhausted for a week, but being able to see how happy the children were was an experience I will never forget.”

We also accepted children without disabilities in the Camp. Many were the siblings, cousins and the friends of our students. They had a wonderful time too.



It was interesting to see how siblings, friends and family members created their own support groups. They had some incredible conversations. For example, I overheard one 6 year old child tell others in the group, “It is not correct to say ‘disabled people’. You must say ‘people with disabilities’.”

It was also wonderful to see how proud siblings were of our students. The CATIC teachers, personal assistants and Tomacoco staff did a wonderful job throughout the experience. They gave every bit of their energy to ensure children had an amazing experience.

We look forward to having Dr. Karen Erikson at our first "Literacy CATIC Camp" in 2018. Finally, thanks to our international friends for their support and guidance.

[Link to Yvette Abdel Malek's Report from Egypt](#)

News from a Recent Visit to Russia:

Expanding Existing International Collaborations with Caritas, St. Petersburg



By Dorothy Fraser

Background information

Caritas Educational Centre for Social Service in St. Petersburg provides a range of training activities for professionals working with people with disabilities.

Quote from Caritas: "The ultimate goal of our work is to improve the quality of life for people with disabilities through -

- Training and professional support to professionals and family caregivers
- Assisting professionals to better understand the needs and the interests of people with disabilities
- Promoting a more effective social inclusion of people with disabilities to ensure a decent, safe and happy life for them."

Establishing more connections with Caritas through existing collaborations with Poland

In December 2015 I met Bozena Kondrusik from Caritas at an international conference in Poland organized by the Step by Step Association (Krok za Krokiem) in Zamość, which was celebrating its 25th anniversary. The theme of the conference was, "Step by Step to Participation - from a patient to citizen - promoting the bio-psycho-social model of disability and the concept of ICF (International Classification of Function)." Bozena was interested in my presentation and topics for workshops on AAC for Adults and Patient-Provider Communication and she suggested I should come to St. Petersburg to expand AAC knowledge based on my collaborative projects with Poland.

Aldona Mysakowska-Adamczyk from Poland has strong links with Caritas, has participated in several international AAC projects in St. Petersburg, and is familiar with the city and Russian language. When she told me we were both invited to provide training in May this year, I was delighted to accept.

Together with Bozena and Irina Tekotskaya from Caritas, we planned our workshop content. Some material was sent in advance for translation into Russian, including PowerPoints, handouts, and also a Communication Matters “Focus on” leaflet, “Communicating with patients who have speech and language difficulties: Guidance for medical and nursing staff.”

We started by running a joint presentation on Introductory AAC, hosted by a local school in the city of Novgorod.



Participants came from Novgorod city and region, and included parents and teachers (special educators) from schools, speech therapists, psychologists, university professors, and students.

Our aim was to promote ways of communication and participation of children with disabilities, by sharing information and examples of our practical experience of implementing AAC in education and daily life situations.

Workshops in St. Petersburg

Aldona's collaboration with Caritas Educational Centre for Social Service started in 2012. Since then she has been actively involved in AAC conferences and workshops organized by Caritas in St. Petersburg. During this visit, Aldona provided two days of workshops on implementing early literacy for children with communication needs.



The first day the workshop was hosted by one of the local kindergartens for its own staff and some teachers from another kindergarten in the same part of the city.

Aldona's second day workshop, on the same topic, was hosted at Caritas Centre for teachers and professionals from St Petersburg and other Russian cities' kindergartens and schools. For some participants it was a continuation of their AAC training, done in collaboration with Caritas Centre and Polish professionals.

They were joined by a university professor from Belarus who came to St. Petersburg especially for this training and to discuss future international collaborations.



Tatiana Sinitsa from Minsk University in Belarus chatting with Aldona after the workshop

Workshops in St. Petersburg

The purpose of my two days of workshops in St. Petersburg, requested by Caritas, was to expand AAC awareness and use for people working with adults with complex

communication support needs and for health care professionals, demonstrating practical ways to make communication easier - for the patient, for families and care providers.

My workshop topics included:

- What is AAC?
- Who needs AAC, permanently and temporarily?
- How to be a good communication partner
- How to prepare for a medical appointment
- How to communicate effectively with patients in hospital and other medical settings

Participants from St. Petersburg, Moscow, Perm, and other cities came from a range of professions – psychologist, teachers, therapists, pediatricians, an SLT student and university member of staff, homecare providers for elderly and staff from a psychiatric unit.

They worked in small groups followed by demonstrations and whole group discussions on applying AAC in their own work situations.



Using material donated to ISAAC BUILD projects with emerging AAC nations at ISAAC 2016 conference in Toronto

The emphasis on Day 2 was AAC for adults, for the aging population and those with acquired neurological conditions. We also discussed ways to be effective communication partners and overcome barriers for inclusion in general society, with examples from videos made by people who use AAC.



"Round table" discussion led by Irina Tekotskaya and Victoria Ryskina

On our final day Aldona and I were invited to participate in a roundtable discussion with local leaders in the field of AAC. I was asked to share information about my workshops, as the topic "AAC for adults and medical settings" is relatively new in Russia.

Aldona's comments at the end of the discussion supported the local aim of establishing an AAC association. The meeting was recorded by a journalist.

For future international collaborations, this was a wonderful opportunity for us to listen to and learn from parents, therapists, teachers, and others as they explained the current situation for AAC provision from their own perspective and their future aims.

AAC and Religion in Poland

By Agnieszka Pilch

The 2nd conference about AAC in religion, titled “Speechless talks ... about life, faith and love,” was organized by the Catholic congregation of the Silent Workers of the Cross on May 12-13, 2017, in Głogów, Poland.



During the conference participants shared their experience of providing people with disabilities with full participation in social and religious life.



Among the participants were specialists working with people with disabilities, as well as AAC specialists, AAC users with their families, priests, nuns and religion teachers.



Two adults who use AAC , Agnieszka Bal from Warsaw and Tomasz Grabowski from Głogów, gave lectures and courses.

Dr. Beata Batorowicz from Canada also made a special guest appearance.

We are glad that the subject of including people who use AAC into the Catholic lifestyle in Poland is becoming increasingly known. The Catholic University of Lublin will host the next conference on AAC in religion in November.

Conference News

AAC by the Bay Conference, March 23-25, 2017

[Link to Harvey Pressman's Report on the Conference](#)

11th Eastern and Central European Regional AAC Biennial Conference July 4-6 , 2017

By Dorothy Fraser

Background information

This is the 20th anniversary of the biennial conference, which started in 1997 in Hungary. Since then, every two years, many countries have organized and hosted the regional conference, enabling more people to learn about AAC.

This year the conference was organized in Bucharest, Romania, at the Psychology and Educational Sciences Faculty, University of Bucharest.

Participants came from Romania, many other European countries and also from the USA. New contacts were established and old and new friendships strengthened.

The warm welcome we received at the opening reception continued throughout the conference, providing us all with traditional Romanian hospitality.

The three-day conference was in two languages, Romanian and English, with simultaneous translations. The program included a wide range of topics presented at plenary sessions, workshops, platform presentations, poster sessions, and an exhibition hall, where companies demonstrated their resources.

I am sure the success of this international conference will support the Romanian hosts' chosen theme, "Spread the Word! Make a Change for Communicating Better!"

(Please Note: More details will be featured in November 2017 edition of CSWN.)

Additional Information – Conferences

August 22 - 25, 2017 – Conference in Brazil

VII Congress of Alternative Communication, ISAAC Brasil, Natal / RN, Brazil.

More information [here](#). Register (www.isaacbrasil.org.br) [here](#).

September 7 - 8, 2017 – Conference in Poland

“The standards of patient care in a coma.” Hotel Filmar, Toruń, Poland www.swiatlo.org

September 10 - 12, 2017 – Conference in the UK

Communication Matters (ISAAC-UK) Annual Conference, University of Leeds, England
www.communicationmatters.org.uk/page/conference

September 13 - 15, 2017 – Conference in Croatia

AT/AAC Annual Conference , Westin Hotel, Zagreb , Croatia www.ataac.eu

Resources

Ace Centre <http://acecentre.org.uk/resources>

The Ace Centre has alphabet and symbol-based charts that are free to download at

- <http://acecentre.org.uk/alphabet-charts> and
- <http://acecentre.org.uk/symbol-charts>

These sites also include lots of information and ideas, such as examples of activity based symbol charts (reading, play and others) and links to a variety of videos (such as demonstration of the use of eye pointing to symbols on an E-tran frame and others).

Additionally, there are three Apple iBooks designed to help families and professionals to get started with Augmentative and Alternative Communication

“Getting Started with AAC” <http://acecentre.org.uk/getting-started-with-aac-books>.

Books were developed through grant funding from the Department for Education National Prospectus Grants Programme 2013-2015. The project involved a consortium of ACE Centre, Communication Matters and 1Voice.

The books can be downloaded from the Apple bookstore or read online:

Book 1 – “Getting Started with AAC: Designing and using alphabet charts”

Book 2 – “Getting Started with AAC: Using low tech symbol based systems with children”

Book 3 – “Getting Started with AAC: Access to low tech symbol based resources when pointing is difficult”

Resources in English and other languages with options for translation and free distribution

Communication Matters (ISAAC-UK)

“Focus on...” Leaflets

The eight leaflets in the “Focus On...” series are on topics related to AAC. They are written in a clear style by Communication Matters. The leaflets are available in printed form and as PDF files to download; click on each topic:

First Steps, What is AAC? What can I say? Let your Hands do the Talking, Using Symbols for Communication, Speaking with Someone who uses AAC, Accessing Communication Aids and Computers, Communicating with Patients who have Speech/Language Difficulties

ISAAC members are free to translate the “Focus on...” leaflets into their national language, providing the following wording appears in the translated material: “Originally published in English and copyright by Communication Matters / ISAAC-UK.”

Email admin@communicationmatters.org.uk for a copy of the master artwork for translation.

The leaflet *Communicating with Patients who have Speech/Language Difficulties* is already available in both Polish and Romanian translations and is currently being translated into Russian .

<http://www.arasaac.org/>

This resource is available in MANY languages. Colleagues in Brazil use it a lot - it has many resources:

“The portal offers ARASAAC graphic resources and materials to facilitate communication for those with some sort of problem in this area. This project has been financed by the Department of Education, Culture and Sports of the Aragonese Government and coordinated by the General Directorate of Innovation, Equality and Participation of this department.”

Resources for Medical Encounters with options for translation

Widgit Health Products are developed in partnership with community and healthcare professionals to help ensure that the right support is available for everyone . Links for resources in English and other languages . Many are free to download.

<https://widgit-health.com>

<https://widgit-health.com/downloads/languages.htm>

Resource from France in French:

DES FICHES GRATUITES POUR EXPLIQUER LA SANTÉ AVEC DES MOTS SIMPLES (FREE SHEETS TO EXPLAIN HEALTH WITH SIMPLE WORDS)

For information about the project in French or to translate information to your own language - click on www.santebd.org or <http://www.santebd.org/application-mobile.html>.

Elisabeth Negre and others in France have been working on this FREE product. There are 16 medical subjects. It is on the web, free and available for translation. There are also free apps on iOS and Android. Elisabeth says the project has much support and encouragement from all over France from people of all ages with/without communication disorders and from professionals.

Farewell Message

We hope you enjoyed our first ISAAC edition of CSWN newsletter. Please feel free to send us your feedback. CSWN is distributed twice a year and our next edition will be in November 2017. Tell us about your news (articles, additional information and/or resources) before October 1st and we can share it in our next edition.

How to submit? Easy! Email us your information in English, Calibri 12 Font, 2 to 4 pages (maximum) and 2 to 5 photos (maximum).

Email: Dorothy dotfraser2@gmail.com and Nadia nadiabrowning@gmail.com

Thank you for your interest in CSWN and we look forward to hearing from you.

Best regards to all of you,

Dorothy and Nadia