



Communication Support World Network Newsletter

November 2017 issue

Introduction

The main goals of CSWN newsletters are to share what is happening in AAC around all continents and to promote networking. CSWN includes articles, resources, and additional information. The articles are about conferences and 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 hearing your news! CSWN depends on you to read and submit, so how about we make CSWN “our” newsletter!

By Nadia Browning and Dorothy Fraser, CSWN Co- editors

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

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TABLE OF CONTENTS

<i>SHARE: The Bianca Project 2017 — Introducing Symbols within a Romanian Children’s Centre, Sibiu, Romania</i>	<i>3</i>
<i>“Spread the Word! Make a Change for Communicating Better!” The 11th Eastern and Central European Regional AAC (ECER-AAC) Conference, Bucharest, Romania</i>	<i>6</i>
<i>Using AAC at Maternity Wards at Oulu University Hospital, Finland.....</i>	<i>9</i>
<i>ATAAC Conference, Zagreb, Croatia</i>	<i>12</i>
<i>Communication Matters (ISAAC UK) — Annual AAC Conference at the University of Leeds, September 10 – 12, 2017.....</i>	<i>14</i>
<i>"The Standards of Patient Care in a Coma," Scientific and Medical International Conference, organized by The Foundation “Światło”, Toruń, Poland, September 7-8, 2017</i>	<i>16</i>
<i>The Foundation “Światło” in Toruń, Poland.....</i>	<i>20</i>
<i>AAC Strategy: Mosaics from Hungary.....</i>	<i>22</i>
<i>Seeing in the Dark: Group Works to Connect People with Disabilities with Hurricane Help.....</i>	<i>26</i>
<i>Resources.....</i>	<i>29</i>
<i>ISAAC Conference 2018.....</i>	<i>31</i>
<i>ISAAC 2018 Short Film Festival.....</i>	<i>32</i>
<i>Farewell Message.....</i>	<i>33</i>

SHARE: The Bianca Project 2017 — Introducing Symbols within a Romanian Children’s Centre, Sibiu, Romania

By Samantha McNeilly, Occupational Therapist

For the past eight years the charity SHARE has coordinated the Bianca Project, in which newly qualified Occupational Therapists (OTs) and Speech and Language Therapists (SLTs) volunteer in a centre for children with complex disabilities in Sibiu, Romania. The centre consists of five homes where the children live together in groups of up to ten. The children have a range of disabilities and needs, such as developmental disorders, sensory processing difficulties, movement difficulties, and learning difficulties. As a team of therapists, we work with the children and centre staff to support the children in learning new skills, participating in activities of daily living, such as meal times, and having lots of fun doing it!



Figure 1. The Bianca Project volunteers, 2017

In previous years, a few of the main aims of our work have been to support the children to eat independently, to play and manipulate toys, and to regulate their sensory needs. During the summer of 2017, a new focus was introduced: to support the children’s communication by using techniques, such as the introduction of symbols, to develop their understanding and use of language. The majority of the children are non-verbal and use a variety of facial expressions, vocalizations and gestures to express their feelings and wishes. However, for some this can be unclear.

Symbols for communication have not been used within the centre before and were new for both the children and the staff. The Director of the centre was shown YouTube videos of children using symbol communication books. Very soon the Director was supporting the implementation of symbols and suggested children I should work with. For two weeks, I modelled the use of symbols through activity boards during meaningful activities, such as play.

A main objective of the summer was to get the carers on board with using symbols. I wanted to show the carers what was involved in teaching or modelling the symbols to the children and how it could be incorporated alongside their routine. To do this, I needed to use the symbols myself and show the carers how and when they could be used.

Highlights of the Trip

One of the children I worked closely with during the summer is a teenage boy I have known for the past five years. In the past, he has shown frustrations at not being able to express his wants and needs successfully. He is an avid bubble blower and really enjoys social interaction. Trying to model on the move with such an active boy was a challenge; holding and blowing the bubbles whilst holding the symbol chart and modelling their use. After observing how and what I was modelling, one of the carers helped me with this and took the bubbles from my hand and began to play with the child. I was then able to model her language and add comments. This really enriched the interaction and the accuracy of modelling the right symbols at the right times. Importantly, after this shared collaboration the carer showed an interest in the symbols and if the child decided to play with bubbles would ask me where the symbols were to join in.



Figure 2. Modelling symbols during bubble play

I began introducing core word boards (see *Figure 3*) to a 17-year-old child. I could use them in a variety of activities that were interesting to him, from bubbles and music to sensory activities, such as rocking side-to-side. This gave me frequent opportunities to model the

language in different contexts. Towards the last few days whilst playing on the trampoline, I stopped bouncing. The young man independently reached towards the board and tapped on the “more” smiling. When I explained to the carer that the child had used the symbol, they congratulated him and expertly acknowledged what a great achievement it was!

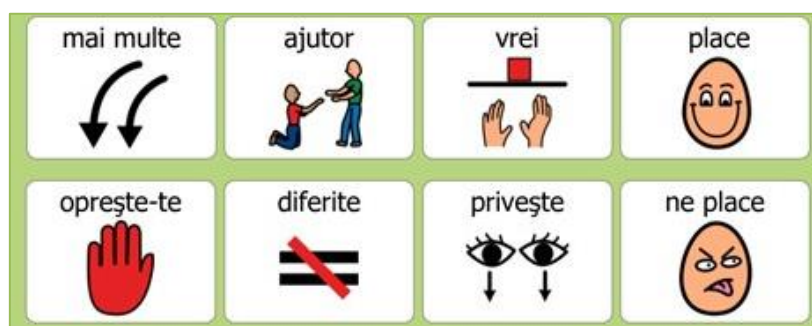


Figure 3. Core word board example

The older, more agile children live in House 5. The carers are keen to enhance the children’s independence in their activities of daily living. After seeing me modelling during play, one of the carers asked for choice boards to increase the children’s’ independence at snack times and during activities. The carer had been keen to use symbols within the bungalow however was not sure how. It was great to hear from a carer’s perspective what they feel would support their communication with the children and how we can work together as a team. A variety of boards are now available to support daily activities, such as getting dressed, enjoying meal times, bathing, and playing with toy cars.

In summary, having only two weeks to introduce the modelling of symbols for receptive and expressive communication to the centre was a challenge due to limited time. However, the use of symbols was widely accepted and even used by some of the children. Even in two short weeks, we saw some great achievements. A number of carers showed their support and understanding of what we were trying to do. With valued support from the centre’s Director, I hope to start the Bianca Project 2018 by discussing with the carers the children’s communication needs and how we can all work together to support the children.

SHARE: The Bianca Project, [read more at www.helpshare.uk](http://www.helpshare.uk)

“Spread the Word! Make a Change for Communicating Better!” The 11th Eastern and Central European Regional AAC (ECER-AAC) Conference, Bucharest, Romania

By Professor Doru Vlad Popovici, Mariana Meran, Alina Stefania Tutu, Madalina Constantin, Loredana Adriana Tudorache, and Daniela Cara

In 1997, the first Eastern and Central European Regional Augmentative and Alternative Communication Conference took place in Hungary. Since then, every two years, different countries have organized Regional Conferences, enabling more people to learn about AAC and many specialists to exchange their experiences. In 2017, Romania had the honour to organize the 11th Eastern and Central European Regional Augmentative and Alternative Communication Conference, an anniversary edition celebrating 20 years from the beginning. The Conference, held in Bucharest from July 4 - 6, was organized by the University of Bucharest, Faculty of Psychology and Educational Sciences, in collaboration with Special School Saint Nicholas, ActiveWatch and Omnia Comunitaria as NGOs.

This conference represented an opportunity to bring together in an academic and multicultural context both specialists from countries with a long tradition in using AAC and professionals who have just started to implement this strategy, in order to provide equal opportunity in communication for all disadvantaged persons. Besides specialists, people who use AAC and their parents, students, teachers, representatives of educational authorities and NGOs were invited.



First day of conference



Elina Ino's presentation

The conference was attended by a large number of participants (over 150) from Romania and 15 other countries: Bulgaria, Cyprus, Finland, The Netherlands, Hungary, Iran, Italy, Republic of Moldova, Norway, Poland, Russia, Slovakia, Sweden, UK, and USA. We had the great pleasure to have as keynote speakers many professors and specialists with great AAC

experience: Dorothy Fraser (Scotland), Sofia L. Kalman (Hungary), Aldona Mysakowska-Adamczyk (Poland), Stephen von Tetzchner (Norway), Agnieszka Pilch (Poland), Alina Smyczek (Poland), Ruth McMorran (UK), Magnus Magnusson (Sweden), Liya Kalinnikova Magnusson (Sweden), Maurice Grinberg (Bulgaria), Dr. Vicki R. Casella (USA), Douglas Watt (UK), Magnus Sundelin (Sweden), Kaveh Vefagh (Sweden), Doru Vlad Popovici (Romania).

The program included 14 plenary presentations by keynote speakers, 22 parallel presentations, 11 workshops, and a poster session. At the same time, an exhibition of AT-AAC devices and software was held in the University hallway with participants from WIDGIT, HARPO, TOBII and ABLETECH.



HARPO's exhibition

At the board meeting, representatives of Eastern and Central European countries established directions for action during the next period, and decided on the country that will organize the next biennial Conference in 2019: Slovakia. In the closing ceremony, our partners from Active Watch – an NGO active in this field – organized *The Gala of People with Disabilities*, an event broadcast by national television. On this occasion, Slovakia took over the conference flag. Also, the most important specialists in AAC were recognized for their work.



Handing over the conference flag to Slovakia



Dorothy Fraser receiving an award

At the end of this event, Vladut Stamate, a young student with neuromotor disabilities, launched a challenge for Romania with the theme "I want a voice for my mind", through which specialists and authorities are asked to develop AAC solutions accessible to every Romanian who has difficulty in communication.



"I want a voice for my mind!"

In addition to the conference program, we organized a city tour and a traditional dinner, an opportunity for our guests to establish new and useful relationships. They also had the opportunity to discover Peles Castle (former home of the Romanian royal family) and Bran Castle (Dracula's Castle) in a day trip in the beautiful Carpathian Mountains.

For the organizers, the 11th ECER-AAC conference represented a consolidation of an old partnership, a team effort to which was added a precious contribution by 30 student volunteers from the Special Psychopedagogy Department.

Under the coordination of Professor Doru Vlad Popovici, Professor Florin Verza, and Mrs. Director Mariana Meran, deep involvement was provided by Alina Stéfania Tutu, Madalina Constantin, Loredana Adriana Tudorache, Elena Dragan Cara, Daniela Cara and Nicoleta Anghelache.

Special thanks also to ActiveWatch, through Mircea Toma, Cristina Stan, and Radu Răileanu, and to our sponsors: Dedeman, Tymbark, Alka, Art Caffé, and Kung Fu Pizza.

The main results of the conference were:

- a. An exchange of experience with other countries in Eastern and Central European region, regarding innovations in AAC;
- b. Broadening of implementation of AAC, by including many participants from countries where AAC is not in general use, or widely understood;
- c. Providing a significant contribution to the implementation of AAC development in the Eastern and Central European region, by inviting keynotes speakers.

We hope that the impact of the conference will be considerable, by developing applied research in special education (priority therapy, language, and communication), by increasing the quality of education in special schools and inclusive schools, and to improve the quality of life for people with complex communication support needs in Romania and other Eastern and Central European countries.

Using AAC at Maternity Wards at Oulu University Hospital, Finland

By Katriina Rinne, Haltija Group

Oulu University Hospital is located in Oulu, Northern Finland, and serves as the central hospital for the Northern Ostrobothnia region. It is the northernmost of five Finnish hospital districts and responsible for the care of 29 municipalities and a population of 400,000 people, or 740,000 people when special care needs are included.



Figure 1. Oulu University Hospital. Photo Source: Wikipedia

Communicating with Non-Finnish-Speaking and/or Illiterate Clients at Maternity Wards

Misunderstandings resulting from poor communication can easily result in conflict or unnecessary worry amongst new mothers, who may be in a fragile emotional state due to hormonal changes. It is in everyone's interest to facilitate mutual understanding so that the clients and their new-born babies get the best possible care.

While the use of AAC is fairly common in Finland, specifically in special education and with disabled users, it hadn't been tested at maternity wards before this experiment. We at Haltija decided to embark upon this project after informal discussions with midwives at the Midwives' Conference in Turku in May 2016 and finding out that communicating with clients who have immigrant background presents a daily challenge at maternity wards throughout the country. The lack of a common language is an even bigger issue with illiterate clients, with whom midwives are unable to use translation tools such as Google Translate.

Making of the Maternity Communication Book

So far, most usual solutions to communication problems have been the use of gestures or self-invented sign language, interpreters and, as previously mentioned, translation tools such as Google Translate. As Widgit's distributor in Finland, Haltija had already translated their *First Response Communication Book* into Finnish. We decided to base our *Maternity*

Communication Book on that, as many of the general questions and care procedures are identical in general health care and maternity wards. The midwives from each maternity ward gathered their wishes, and the head nurse sent them to us.

The project started in June 2017 with a meeting with the midwives in Oulu. A workgroup consisting of head nurses was formed to plan the book in cooperation with Haltija. The head nurses gathered a list of all the symbols for different care situations they needed. Their needs were summarized to form the first draft of the maternity book. The book was then reviewed by the midwives, and improvements were made according to their recommendations. Not all of the needed symbols existed, so Widgit's graphic designers drew the missing symbols needed for the book. Symbols were drawn according to specific instructions from the midwives.

Once ready, we travelled to Oulu to introduce the use of the communication book at the maternity wards. The maternity wards were given 12 copies of the communication book and they were used both in deliveries and neonatal wards. The midwives were given a short course on how to use the symbols. As the use of AAC was new to them, they said they would have profited from a better introduction to AAC and more detailed instructions on how to use the *Maternity Communication Book*.

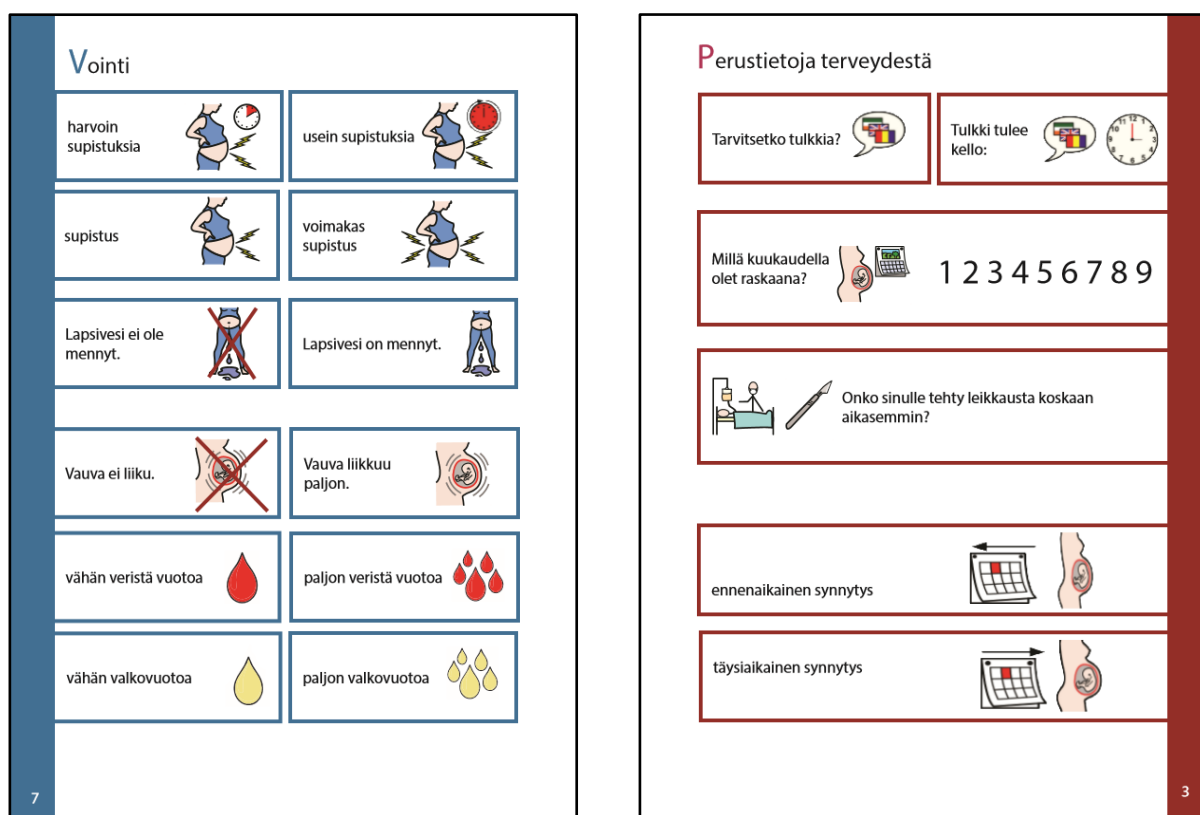


Figure 2, 3. Printscreens from the Haltija and Widgit's Maternity Communication Book

Feedback

The aim of the *Maternity Communication Book* was to help with everyday issues related to patient care, diet, breastfeeding, and background information. It was found to be most useful in handling these everyday care matters, especially in emergency situations that needed to be handled right away, where no interpreter was available. The midwives were content with having the book ready, even though during use they found that some of the symbols should have been different. They found most symbols to be good and appropriate for maternity use. The *Maternity Communication Book* has not replaced using interpreters, except in the previously mentioned emergency situations. However, the midwives thought that having the *Maternity Communication Book* at hand, in addition to using interpreters, was useful.

This article is based on phone and email interviews with head nurses Pirkko Nikula and Terhi Tuomaala at Oulu University Hospital's maternity wards.

ATAAC Conference, Zagreb, Croatia

Press Release

ATAAC 2017:

Together we can build the world for everyone



Zagreb, Croatia - More than **900 participants** from many different countries came to the International Conference on Assistive Technology and AAC ([ATAAC](#)) in Zagreb, September 13-15, 2017.

Leading world experts and users of Assistive Technology (AT) and Augmentative and Alternative Communication (AAC) came to Zagreb to present their knowledge and share their experiences. This year, there were [34 speakers from 9 countries](#) including Ian Bean, John Costello, Jennifer Abramson, Dorothy Fraser, Aldona Mysakowska-Adamczyk and many [others](#). Feedback was excellent, with the average grade given by conference participants being 4.7 out of 5; 96% of attendees said they would like to come again next year. Those were three amazing and unforgettable days of education on AT and AAC.

In addition to **Lectures**, each day there were 60-minute **Workshops**. Participants learned directly from the experts about how to effectively use Assistive Technology in their work or everyday life.

Moreover, there were **Poster Presentations** by therapists and organizations using AT in their work and/or working in the field of AAC. This was an excellent opportunity to present themselves and their work and to connect with others in developing AAC methods. This year's conference resulted in many local and international contacts and cooperation between different organizations.

In the **Exhibition Area**, everyone had the opportunity to see and try different aids for persons with disabilities. Participants enjoyed discovering and testing different communication aids, eye-gaze control equipment, educational toys, various switches, alternative computer access equipment, therapy aids, educational software, environmental control devices, etc. Leading world manufacturers of assistive technology solutions from England, Sweden, USA, Germany, Austria, The Netherlands, Finland, and Croatia presented their products in the showroom.

The conference was organized by [E-Glas](#), Faculty of Engineering, University of Rijeka and Faculty of Education and Rehabilitation, University of Zagreb. It was held under the patronage of the President of Croatia, Kolinda Grabar-Kitarović; the Ministry of Health; Ministry of Demography, Family, Youth and Social Politics; and the City Assembly of the City of Zagreb.

ATAAC 2018 will take place in Zagreb from October 17 to 19. The registration form and schedule will be available in December 2017 on [the conference website](#).

Want to find out more about ATAAC 2017? Take a look at [this video](#) and these [photos](#).

Cover photo (Full Size): <https://drive.google.com/open?id=0B5F-OROgvxNITXNMeGxZczVDZTA>

Communication Matters (ISAAC UK) — Annual AAC Conference at the University of Leeds, September 10 – 12, 2017

By Ruth McMorran, Co-Chair

In recent years we have seen attendees from outside the UK and this year was no exception, with presenters and delegates from Australia, Belgium, Brazil, Cyprus, Denmark, England, Germany, Israel, Japan, Malta, the Netherlands, Northern Ireland, Norway, the Republic of Ireland, Russia, Scotland, South Africa and Wales, making this a truly International conference.



As the conference opened, we were joined by our sister organization 1Voice as part of their 1Voice1Day event, where everyone enjoyed games from around the world.

The Jamie Munro Inspiration Award was launched at this year's conference. Jamie Munro, who died suddenly in December 2016, was the Information Director at Inclusive Technology. His work had an impact on the lives of so many people and Communication Matters presented this award in his memory. The presentation was made by Martin Littler, CEO of Inclusive Technology, to Helen Dixon, an inspirational speech and language therapist who works in Cumbria. Helen is also a trustee/director of 1Voice.



This year's Keynote presentation was delivered by Bronwyn Hemsley (Associate Professor at The University of Newcastle, New South Wales, Australia), who spoke about "The Empowerment and Safety of People with Communication Disability in Social Media."



The Plenary address was given by Lisa Simpson, a Liverpool-based choreographer. Lisa has quadriplegic cerebral palsy and no verbal communication; therefore she choreographs using the Simpson Board, an inexpensive but priceless tool that enables people with disabilities to choreograph their own work.

The social program at the conference is equally as important as the academic program, giving all delegates the opportunity to catch up with old friends and colleagues, make new connections and generally “let their hair down.” This year the theme was “Around the World.” There was excellent food, live music, a chocolate tombola, a world quiz, a stand-up comedy set from our Patron, Lee Ridley (known to many as the Lost Voice Guy and winner of the BBC New Comedy Award 2014) and, of course, the traditional CM conference disco. Here are a few snapshots of the fun activities!



*All photographs by the official Communication Matters
Conference Photographer - Sam Knapp
(www.samknapp.photography)*



CM's 32nd Annual Conference will be held at the University of Leeds from September 9 – 11, 2018. We would be pleased to welcome you to the UK for our conference next year!
www.communicationmatters.org.uk

To mark the end of AAC Awareness Month 2017, please watch the fabulous new CM video on <https://youtu.be/AAl-XKpZLq0>

By Janina Mirończuk

The 3rd International Conference showed and approximated the problems of this medically and socially marginalized group of people, which is baffling. Any of us can, in a short moment, find ourselves in this group. In one minute, a traffic accident can change the whole life of a person and their family. Sudden cardiac arrest and stroke are the next most causes of Unresponsive Wakefulness Syndrome (apallic state).



Introduction by mgr. Janina Mirończuk, President of the Foundation "Światło"

The conference was attended by speakers from five European countries, several Polish universities, Jagiellonian University (JU), Nicolaus Copernicus University (NCU), and Gdańsk University of Technology (GUT), and from Russia.

The aim of the conference was to develop a standard of patient care in and after coma. This conference, as have the previous ones, integrated academics and practitioners. Only through such integrated actions can we all contribute to the progress in the field of diagnosis and treatment.

The greatest contribution to the conference was by Dr Marek Binder from the Institute of Psychology at the Jagiellonian University, who has been working with the Foundation

“Światło” for many years now. As a member of the Scientific Council, he prepared the conference program.



In his inaugural speech, “Pave the way to consciousness: modern achievements in the field of diagnosis and treatment of patients suffering from severe stroke,” he reviewed current achievements with an attempt to evaluate what should or should not be called the standard in patient care. He also presented and discussed the Coma Recovery Scale.

This topic was further discussed by Prof. Włodzisław Duch (NCU) in his speech, “Prospects of research on disorders of consciousness.” Thoughts, images, sounds, and intentions have until recently been inaccessible to common research methods. However, through functional neuroimaging the mind slowly loses its private character. By observing brain activity, we can observe many processes before they become conscious, to create a map of brain activity corresponding to different concepts and watch dreams. Direct brain-computer interaction makes it easier to control external devices by thinking and regulating your own brain. This allows you to influence the brain by stimulating it with various methods – magnetic field or electric current. New multichannel transcranial stimulation devices and ultrasound stimulation devices, which are in the preliminary phase of research, offer hope for the development of non-invasive methods of awakening from coma, an alternative for deep brain stimulation.

The presentation on how to examine a patient with severe Disorders of Consciousness was by dr hab. Iwona Sarzyńska-Długosz (from 2nd Department of Neurology, Institute of Psychiatry and Neurology in Warsaw). This very interesting and practical presentation, given by a doctor with great experience in the field of patient care of people with severe Disorders of Consciousness, emphasized the most important path towards success, which is early diagnosis and intensive therapy. Working with a person with a different level of consciousness requires an exceptional approach to health care.

A speech given by Dr. Jan Lavrijsen from the Netherlands was full of vital information, with the undeniable claim that a person with varying degrees of brain damage can hear, feel, and

often see. In the Netherlands, national standards of care and knowledge are used to create personalized care plans for patients in special circumstances and their families.

The lecture and workshop on Basal Stimulation by Frieder Lückhoff emphasized care and therapy that became a form of contact between the “expert” and the patient.

The subject of rehabilitation of patients with Disorders of Consciousness was presented by prof. dr hab. Magdalena Hagner-Derengowska.

We were delighted by the participation of Mrs. Dorothy Fraser from Scotland. Effective communication between the patient and health care professionals is an indicator of high-quality health care and has a direct impact on the quality of patient care, treatment outcome, safety and satisfaction. In her speech, Mrs. Dorothy Fraser addressed these particular aspects.

This lecture was further developed by Dr. Bibianna Bałaj (NCU) on the topic, “Methods, tools and forms of communication for people with physical disabilities.”

Communication with a patient with brain damage was also the subject of speeches by Dr. Jacek Matulewski (NCU), Dr. Michał Joachimiak (NCU), mgr. Szymon Murawski (JU) and mgr. Anna Wójcik-Krzemień (JU).



It is worth noting that we also had our volunteers, long-time friends and family members in the room. Interest in the conference was at a high level.

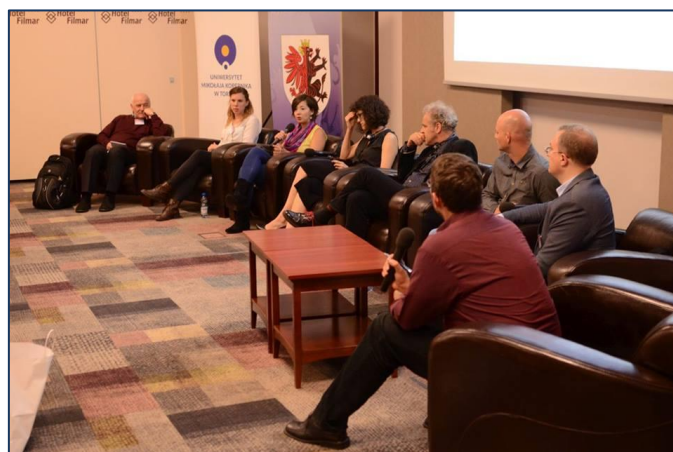
Young researchers from Europe presented their scientific achievements in the field of diagnosis and treatment of patients with brain injury. Dr Davinia Fernandez-Espejo from the

University of Birmingham, in her speech “I can only imagine; the overt versus covert paradox in the Vegetative State,” proves that some patients in the Vegetative State communicate with their doctors. Dr. Athena Demertzi from the Coma Science Group in France presented results of functional neuroimaging that help to diagnose the patient. Ph.D. student Geraldine Martens, also from the Coma Science Group, presented results of brain stimulation in Minimally Conscious State.

Professor Andrzej Czyżewski from the Gdańsk University of Technology (creator of Cyber-Eye) commented on the topic of evaluation of the emotional state of people in coma, based on hearing research and brain wave analysis. The Conference was also attended by Dr. Joanna Strzemecka with a unique topic, “Comparison of concentration of selected cytokines in serum of patients with Disorders of Consciousness after Traumatic Brain Injury, patients awakened from this condition and healthy people.” This was a very interesting subject, emphasizing the need for further research and high socio-health expectations.

The subject that is associated with people with brain damage was presented by Dr. Viktor Vasilievich Zubkov from the Moscow State Medical Institute in his presentation titled, “Prospects for using stem cell technology in the treatment of severe damage to the nervous system.” Cell therapy evokes many emotions, but also hope, and the interest of the participants was great.

The Conference was a success. The implementation of the standards of treatment in diagnosis, therapy, and rehabilitation will not be easy or immediate, but provides the basis for research and observation to plan actions for groups of people who have not been talked about until recently. How to implement scientific achievements in practice was explained by Dr Jan Lavrijsen. Everything is still ahead of us.



Conference discussion was led by a panel of national and international presenters

The Foundation “Światło” in Toruń, Poland

By Janina Mirończuk

The Foundation “Światło” in Toruń Poland has been running a facility for people with Unresponsive Wakefulness Syndrome (apallic state) since 2003.

This group of people was, until now, marginalized medically and socially. Our Facility for 46 beds was the first one in Poland to accept patients in this condition.

Rules for taking care of patients can be formulated as follows:

1. The patient can see, feel and hear, but doesn't communicate with us the way we'd want him to.
2. We have 5 senses – taste, sight, touch, smell, and sound – and this is the field of our actions.
3. "Awakening" is a recollection of the past, which can be a great help and motivation to live.
4. In abnormal health we seek to ensure a normal life.
5. The patient used to live with his family and in his community and this fact is of great importance in our proceedings.
6. From the first contact the entire team provides the patient with a sense of security and motivation to get out of this state.
7. These people are alive but they live differently
8. The hardest part is working with the family so that they can understand and accept the changes that occur in lives of their loved ones, because they all expect a miraculous awakening.

Priorities in the procedure can always change, but for a physiotherapist, psychologist, speech therapist, doctor, nurse, and medical caregiver the most important indicator is the condition of the patient, which determines the individuated treatment.

The vast majority of our patients are young people injured as a result of traffic accidents, then people who have had heart attacks, sudden cardiac arrests, and strokes. Fifty-eight patients have woken up. These are people who, in full mental contact, in a wheelchair, with crutches or on their own, went on to further rehabilitation.



*1st person to wake up, cutting the cake at the conference
with the President, Janina Mirończuk*

Waking up is another difficult moment in their lives, but it is also a challenging time for their families. Our patients need further rehabilitation. Very often the family becomes tired of taking care of the patient. Therefore, the Foundation organizes rehabilitation meetings once or twice a year for people awakened from coma and their caregivers, and organizes various types of activities for their children, for example, joint trips.

For more information, please visit www.swiatio.org.

AAC Strategy: Mosaics from Hungary

By Monika Toth¹

From the Past to the Present

The first step of introducing AAC was 30 years ago by Sophia L. Kalman², who introduced and started to teach the Bliss language and established the Bliss Foundation. This centre had been growing and became an AAC centre in the country. At present it provides different services, e.g., offering different services for students with special communication needs (assessment, individual and school programs), AAC training on graduate and post-graduate levels, and dissemination of information. The Foundation also provides counselling for families, runs a school and a loan service for AAC devices, and is involved in research, development and publishing.

Recently the Bliss Foundation celebrated its 30th anniversary and in honour of this historical moment a conference was organized in Budapest. Sophia L. Kalman wrote this short summary:



Sophia Kalman

“Thirty years in the life of an NGO is a respectable length, especially considering the stormy years of the Eastern and Central European region during this timeframe. Therefore the conference held in Budapest, October 6, 2017, had three aims. The first one was understandably to celebrate the 30th anniversary of the Hungarian Bliss Foundation not only surviving, but also flowering during these long years. The second aim was to demonstrate the exciting combination and cooperation of many different areas surrounding and influencing AAC, like SLP, IT, assessment, legislation, quality improvement, stem cell research, linguistics, etc. High-ranking academic presenters talked about their research and offered insight into the future as well. Last but not least the conference provided an

exceptional opportunity for practicing AAC instructors from all over the country to share their work, successes, and doubts; 21 presentations and 11 posters represented the broadest variety of AAC, e.g., its use in CP, ASD, Angelman syndrome, stroke or deafblind clients. The interest was tremendous, for the 150 available spaces almost double the prospective participants applied.

“Sponsors and volunteers also helped the successful organization: the Ministry for Human Resources provided financial support and Ericsson offered the lecture hall, while the video documentation, the musical performance, the organizing team, editing of the conference publications and much more, all involved serious volunteer work. Publishing the scientific volume titled *The Colours of AAC* was also made possible by nine acclaimed international authors’ contribution. In summary, one could say that this conference had been not only a celebration of a small Hungarian NGO, but was also a tribute to the love and commitment toward AAC and to people making all the efforts to support those in need of it.”

This conference also had proved that during these years AAC has been slowly spreading out among professionals and families, and also in special institutions/schools, especially in those with individuals with autism, intellectual disabilities, physical and sensory impairments. In the past decades, there has been a growing tendency in international and Hungarian literature for ICT tools to be used and included in AAC, the tendency being especially marked in the past decade when mobile technologies gained ground.



¹ Monika Toth is working in the Equal Opportunities of Persons with Disabilities Non-profit Ltd. (FSZK) as a coordinator of the AAC project. This organization is working under the coordination of Ministry for Human Resources and responsible for several national projects and programs.

² Dr. Sophia L. Kalman, Former President of the Board of Trustees, Paediatrician, Ph.D. in Psychology, t.professor of ELTE University, Dr. habil. in Linguistics, Doctor of Medical Law

Over the last year the Hungarian Angelman Foundation coordinated a great **pilot program**³. Six non-verbal children (aged: 3, 5-11) and their families participated in this program for two months, and during this time four AAC professionals assessed the children and supported the families, mainly at home. At the beginning of the program the assessment was made by the online version of Communication Matrix (Rowland 1996, 2010). In addition to direct observations, parental interviews were also used.

Direct observations targeted several key dimensions of communication (e.g., frequency; form, including AAC; functions; partners, initiation, intentionality, spontaneity) in three different contexts: (1) in a special playhouse with peers and professionals, (2) at home with parents and siblings, and (3) in the children's institutions, e.g., nursery, kindergarten, school. The observer spent five to six hours observing each child before discussing the results, expectations, and needs with the parents. After this they planned individualized training goals for each child in the field of expressive communication and other goals for establishing essential social-communicational skills for later AAC use (e.g., improving and changing meaningful activities, making choices, developing receptive communication, answering a request or instruction, and establishing social interactions). The appropriate long-term goals were discussed with parents.

In spite of the short period of this program the results were very significant. Each child started to use AAC at home and some at the institutions as well. The professionals concluded that the efficiency seems dependent on the intensity of the training and that parents need more support to achieve planned goals. Together the professionals and family members concluded that AAC is a promising opportunity to develop social and communicative skills among the children with Angelman Syndrome.

During the last years there were strong initiatives, especially by different NGOs and parent organizations, to lobby for qualitative and quantitative services and devices for persons with complex communication needs (CCN). In 2007 some professionals have been developing a national AAC strategy plan in the help of the Equal Opportunities of Persons with Disabilities Non-profit Ltd. (FSZK). Based on this document, an AAC strategy plan⁴ was revised, which is supported by EU fund and coordinated by the FSZK Organisation. According to the objectives, the actions are going to be fulfilled between 2017 and 2021.

³ Ágnes Havasi– Brigitta, Miksztai-Réthey – Réka, Kádár (2017): *Family support on augmentative and alternative communication (AAC) for raising communication skills of children with Angelman Syndrome - preliminary case study with 6 families*

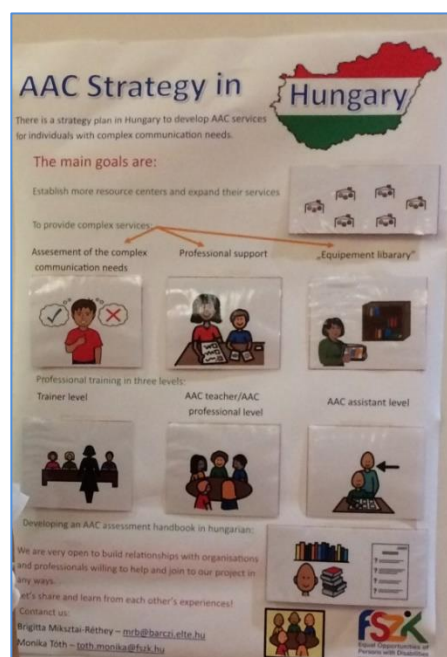
⁴ EFOP 1.9.2 Providing and developing access for individuals with disabilities to the special and public services - <http://fszk.hu/>

The main objectives are:

1. Survey on national level among the individuals with CCN to examine the AAC usage and needs.
2. Establish six resource centres in the country and work toward developing more complex services, like providing AAC assessments and professional support for individuals, families, teachers, and care providers, and also supporting them with devices.
3. Professional trainings at three levels: for AAC professionals, AAC teachers and AAC assistants.
4. Developing an AAC assessment handbook in Hungarian.
5. Purchasing a great number of AAC equipment and devices and placing them into the centres.

We are very open to building relationships with other organizations and professionals who would like to help or share their experiences with us.

For more information, contact monika.toth@fszk.hu.



Seeing in the Dark: Group Works to Connect People with Disabilities with Hurricane Help

By Belo Cipriani

Published 09/21/2017

https://www.huffingtonpost.com/entry/new-website-helps-people-with-disabilities-after-hurricanes_us_59c00989e4b0171e676578a0?ncid=engmodushpimg00000006

People with communication disabilities such as ALS (Lou Gehrig's disease), Down syndrome, aphasia cause by a stroke, and some forms of cerebral palsy and autism, are the most vulnerable during and after disasters like Hurricanes Harvey and Irma. In many cases, these individuals get separated from their helpers, lose access to their speech-generating devices and their low-tech tools, and get relocated to places where they are unable to receive the proper support.

The United States Society for Augmentative and Alternative Communication (USSAAC), a 501(c)(3) non-profit established in the 1980s, has launched two websites through the San Francisco-based disaster relief portal <http://www.Recovers.org>, to help people with disabilities and their families who have been affected by Harvey and Irma.

Harvey Pressman, co-chair of the society's Hurricane Relief Committee, said, "USSAAC's decision to launch its two Recovers sites came about through the confluence of two separate events: 1) Sarah Blackstone's earlier experiences managing an extensive and successful AAC recovery effort in Louisiana and Mississippi in the years following Hurricane Katrina, and 2) her more recent experience in her own local area launching and managing a Recovers.org site in response to the most expensive wildfire in American history...."



Sarah Blackstone. Photo Courtesy American Red Cross, Monterey Peninsula

Blackstone, who is one of the founders of USSAAC and [received recognition from the American Red Cross for her relief efforts during the 2016 Soberanes fire in California's Garrapata State Park](#), said that for individuals who cannot use natural speech and have been affected by Harvey, the situation is pretty grim.

"One mom in Texas has two children and one, age 6, has autism, is non-verbal, and lost an iPad and apps in Hurricane Harvey," said Blackstone. "This mother also takes care of her grandfather who had a laryngectomy and cannot speak and is so weak he can no longer use his electrolarynx. So, two people in her household have severe communication disorders and she's now living in a hotel."

Pressman stated that stories about people with communication disabilities in Florida are just starting to trickle in following Irma.

"A single mom," said Pressman, "with a child with autism and two other children with special needs wakes up to find her bottom floor flooded, the speech-generating device her autistic child uses to communicate under water, and the need to immediately evacuate."

"A woman," continued Pressman, "whose elderly dad lives with her and depends on an electronic device loses power."

"A family with a child with cerebral palsy is evacuated and has to leave behind a \$6,000 speech generating device that has been destroyed in the storm," he added.

The Recovers.org site works as a network that matches both individuals and organizations to people who need help, as well as to people who can offer assistance.

"You go on and say 'I need ...' or 'I can do this...' or 'I can contribute these items...' or 'I want to donate...' and, voila, things begin to happen," said Pressman.

USSAAC's Recovers.org sites have already received donations from two companies that produce augmentative and alternative communication, or AAC, products, Saltillo and Prentke Romich, as well as several monetary donations and volunteer hours from USSAAC members.

Pressman pointed out the need for donations is dire, as USSAAC provides a type of support not offered by any other type of nonprofit or agency.

"USSAAC has customized the general purpose Recovers.org portal to provide the highly specialized support and services that neither groups like the Red Cross nor other non-specific disability groups have the capacity to provide: the devices, tools, and support

services required by individuals with complex communication needs whose communication supports have been taken away by the disaster,” he explained.

Blackstone, 73, and Pressman, 81, are a Monterey, California-based couple who have dedicated their lives to helping people with disabilities. Blackstone is an international expert in the field of augmentative and alternative communication and Pressman is an educator who has run employment projects for people with disabilities.

To support people with disabilities affected by Harvey, visit <https://harveyaac.recovers.org/>.

And to support people with disabilities whose lives have been impacted by Irma, visit: <https://aacdisasterrelief.recovers.org/>.

Also, [watch this video clip](#), which was made to honor Blackstone as a Red Cross Disaster Services Hero: <https://www.youtube.com/watch?v=rYVOTXqFGKE&feature=youtu.be>.

Belo Cipriani is a disability advocate, a freelance journalist, the award-winning author of "Blind: A Memoir" and "Midday Dreams," and the spokesperson for Guide Dogs for the Blind. Learn more at www.belocipriani.com.

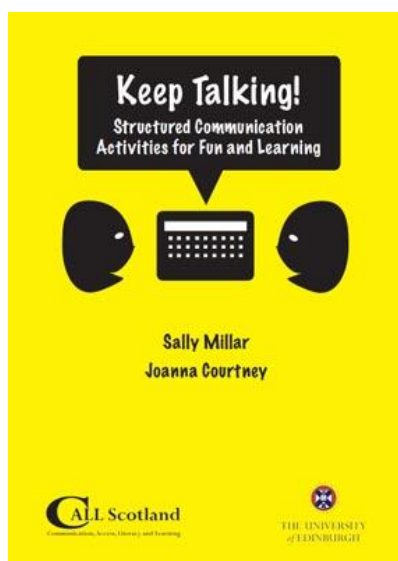
RESOURCES



<https://www.crporegon.org/cms/lib/OR01928264/Centricity/Domain/53/communication%20bill%20of%20rights%202.pdf>

Call Scotland, University of Edinburgh, Scotland has a vast amount of information available on their website <http://www.callscotland.org.uk/home>

For example, <http://www.callscotland.org.uk/downloads/books>



<http://www.callscotland.org.uk/downloads/books/keep-talking>

<http://www.callscotland.org.uk/downloads/posters-and-leaflets/ipad-apps-for-learners-with-dyscalculianumeracy-difficulties>



ADDITIONAL INFORMATION — CONFERENCES

ISAAC Conference 2018

The poster features a vibrant aerial photograph of a coastal city, likely Gold Coast, Australia, with a mix of urban buildings and green spaces meeting a sandy beach and turquoise ocean. The text 'isaac' is in a stylized white font at the top right, with the full name 'International Society for Augmentative and Alternative Communication' in smaller text below it. The main headline 'REGISTRATION IS NOW OPEN' is written in large, bold, yellow capital letters across the center. In the bottom right corner, there is a small globe icon next to the text 'AACross All Areas', 'ISAAC 2018 GOLD COAST AUSTRALIA', and '21-26 JULY 2018'.

isaac
International Society for Augmentative and Alternative Communication

REGISTRATION IS NOW OPEN

AACross All Areas
**ISAAC 2018
GOLD COAST
AUSTRALIA**
21-26 JULY 2018

ISAAC is excited to announce that registration is now open for the 18th Biennial Conference of the International Society for Augmentative and Alternative Communication, being held at the Gold Coast Convention and Exhibition Centre on the **Gold Coast, Queensland, Australia**, from **July 21 through 26, 2018**.

The ISAAC 2018 Conference provides four days focusing on the latest in research and clinical innovations in AAC plus social events with fantastic networking and entertainment. The conference also includes an exhibit with opportunities to meet representatives from companies who work for best outcomes in communication for all.

As well as the main conference, registration for the Pre-Conference Workshops and AAC Camp is also open. ISAAC 2018 Pre-Conference Workshops offer an opportunity to hear about best-practice in AAC from presenters around the world. The AAC Camp, "Let's Get Real" is themed around reality TV and will provide lots of fun and learning for AAC users of all ages.

Register today at www.isaac-online.org and we'll see you on the Gold Coast, Australia in July 2018!

For more information on ISAAC Conference 2018, please [click here](http://www.isaac-online.org).

ISAAC 2018 Short Film Festival

You are invited to enter the [ISAAC 2018 Short Film Festival](#)!

Explore your creative side and enjoy a red carpet experience at ISAAC Conference 2018! The ISAAC 2018 Short Film Festival will take place at the Welcome Reception on the evening of July 23rd, 2018. The top ten films will be screened at that time.

We are looking for newly created films to showcase the theme of the conference:

AACcess All Areas.

Films can *raise awareness* of AAC in all aspects of life and in all communities, *inform* about ways people who use AAC can access all areas, or *inspire* by telling the story of someone who uses AAC. Submissions can focus on sub-themes related to employment, diversity, justice, culture, relationships, social media, developing nations in AAC, and the Asia-Pacific Region.

Tips on how to make your short film are posted on the ISAAC website, along with an entry form and all the other information you need to know to get started.

The submission deadline is April 16, 2018.

The Short Film Festival winner will receive a one-year pre-paid membership to ISAAC for 2019, sponsored by ISAAC Australia (terms and conditions apply).

Discover your untapped storytelling potential by creating a short film for our [18th Biennial Conference](#) on the Gold Coast, Australia. Let's reach across the world to AACcess All Areas!

Regards and thanks,

[Franklin Smith](#)

Executive Director

FAREWELL MESSAGE

We hope you enjoy our CSWN newsletters. Please feel free to send us your feedback. CSWN is distributed twice a year and our next edition will be in April 2018. Tell us about your news (articles, additional information and/or resources) before March 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,

Nadia and Dorothy