

December 2018

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 Co-editors Nadia Browning (Chair of ISAAC Council) and Dorothy Fraser (Chair of ISAAC BUILD Committee)

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As one of the Mexican delegates, I am very pleased to announce that the next ISAAC Conference will be in Mexico.

First of all, given the current situation of the world, it makes me very happy to realize that even when some people are trying to separate our world apart, ISAAC is showing how, on the other hand, professionals can collaborate together to better serve people with complex communication needs. It is a great honour for us as Mexicans to be collaborating with our fellow North American friends, USSAAC and ISAAC International, to hold the 19th Biennial Conference of ISAAC in Riviera Maya, Quintana Roo, Mexico, August 1 – 6, 2020.

Our second motivation is knowing that, through this conference, the location and translation services will offer all the Spanish speaking community an invaluable opportunity to participate in such a wonderful event. We are very happy to be able to break the barrier of language and, for this time, to offer this great opportunity to Spanish speaking professionals, parents, and AAC users.

And last, but not least, we are very excited to be able to welcome to Mexico our wonderful worldwide ISAAC community. Mexico is a country full of beautiful people, beaches, culture, gastronomy, traditions, folklore, and lots of fun. We are very excited to be preparing our sites and social events so participants can make the most of their visit.

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My Little Projects

By Sharon Teo, Person with Motor Neurone Disease (MND), Singapore

I did it!

My article, "Tobii, My Personal Communicator," was published online on CSWN Newsletter April 2018. Many congratulated me for taking the effort to write. I should make good use of my time and do what I want and able to do. What will I be sharing this time?

I made a new friend through Tobii. He was a Singaporean but emigrated to Australia. He read my interview "Help Me Speak Initiative" on The Straits Time last year and found my contact. He shared challenges faced by other MND patients, also known as Amyotrophic Lateral Sclerosis (ALS). The journey is not easy. Patients are not ready and they will need more care as the disease progress. However, the advance in technology has a wide range of devices to help them commute and communicate. Communication Therapy and Meditation are platforms for them to release their frustrations and stress. Let go the past. Live for the present!

My sharing on the benefits of using the Tobii was very well received by MND patients at the MND Support Group. It enables a patient the privacy to communicate at his own pace without having to rely on others. It will become the patient's voice should he have difficulty talking at a later stage.

Mid-Autumn Festival

13 September 2018 was Mid-Autumn Festival (Lunar month August 15th). The moon is always very huge, round and bright on this particular night. We call it the full moon. There is a legend to this festival.



Photo A: Lunar month August 15th is Mid-Autumn Festival.

Chang Er, Goddess of the Moon and Houyi were wife and husband and immortals of the heaven. Emperor Jade had ten sons who all turned into suns and destroyed the crops on the earth. He could not stop their bad doings and ask Houyi for help. Houyi used his archery skills and shot down nine sons and left behind one to keep the people warm. The Emperor was angry and banished Houyi and Chang Er to the Earth as mortals.

Houyi sought help from the Queen of the West. She gave Houyi a pill of immortality which he would only need to take half to return to the heaven. Houyi kept it safely in a box. One day, Chang Er found the pill and was curious. When she heard Houyi was returning home, she panicked and swallowed the whole pill. She immediately felt herself getting lighter and was floating away from her husband. Houyi could not bear to shoot her to bring her down. She was separated from Houyi and they could only meet on this day. Chang Er flew to the Moon and had a rabbit to keep her company. Can you see these two figures together when you look at the moon on this day?



Photo B: A giant lantern of Chang Er, Goddess of the Moon.

We celebrate this occasion eating moon cakes, mini yam, sipping Chinese tea and lighting up lanterns using wax candles or batteries. It is beautiful when you hang them in the garden or along the corridor. It is also a time when family members get together and chat while admiring the moon.

The baked mooncakes with lotus paste are traditional and most popular as gifts. Snow skin mooncakes are available in assorted flavours and are cooling to your taste buds but have to be refrigerated to preserve their quality. The mooncakes are packed in an attractive box of 4.

I recall I ate mooncakes by the boxes when I was young and ended up with stomach upset. I just couldn't resist. I would cut the mooncake into 8 parts and told my grandfather the General led his army to capture the provinces in China. I ate them part by part and left 2 small parts for my grandfather when my story ended. He said "You finish all lah!" and continued reading his newspaper.



Photo C: Enjoying Low Sugar Lotus Paste Mooncakes and Chinese Tea.

Photo D: The traditional lanterns lighted using candles.

Chinatown is the prominent landmark displaying the brightly lighted handcrafted huge lanterns and selling mooncakes and sweet goodies. It is also a time when everyone local and tourists will come to admire and enjoy the ambience.

How do I celebrate the festival this year? I guided some students to fold butterflies to decorate my lantern. It was a fun session and my lantern was very pretty. I hung it (Photo E) in the Garden Lounge where everyone could admire it.



Creativity Art

I love creative art and am now working with a volunteer to draw cartoons on eggshells. They can be displayed pieces on a work desk or presented as gifts. Can you imagine many happy Humpty Dumpty dressed in pretty outfits sitting on a wall? It's awesome! (Photo F)

My Sharing in Mandarin

I was invited to share how I live my life with MND. Titled "How Much Time Do I Have?" it captured the attention of over 250 people in the audience. They were healthcare professionals and caregivers. Some were moved to tears. Speaking in Mandarin was my first time and a challenge to me but I made it.

Photo E: Wow! Look at those colourful paper butterflies.



Photo F: Eggshells artwork.

Time with Medical Students

I shared my journey and challenges at each stage of MND with the medical undergraduates as part of their academic exposure. Patients will find their journey very frustrating, emotional, fearful and directionless. Patients will also need more care to help them walk the journey and use their strengths to live life to the fullest. I prepared my power point using my eye-gaze device for my sharing. The students could not believe it and asked me "You mean you use your eyes to create them? How?"

I encourage patients to stay positive and take control of situations and do what they can with their existing capabilities and support available. They will discover new things that will be interesting to them.

Editor's note: Sharon wrote this article independently using her Tobii.

How Justin Clark's Fight for Independence Transformed Disability Rights in Canada

In 1982, Clark sued his parents for the right to leave the institution they placed him in as a child. It was a pivotal moment in the Canadian disability rights movement, and still has echoes today. David Gutnick's documentary revisits the landmark case.

CBC radio presented on Sunday Nov 23, 2018, a case of a nonverbal young man (early Bliss user) who won a case in court for independence. Still remembered and celebrated! Worth listening:

https://www.cbc.ca/listen/shows/sunday-edition/segment/15636150

Polish Support for Ukraine: Developing AAC

By Agnieszka Pilch, Deputy Head Teacher and Head of AAC Step by Step (Krok za Krokiem) association, Zamość , Poland

The *Step by Step* association in Zamość, Poland, for helping children with disabilities has been supporting various centres and charities working with children with disabilities (mostly movement impairments) in Ukraine – Lviv, Bila Tserkvya, Kamyanyets Podilskyi, Kiev, Lutsk, Poltava – for over 20 years.

This cooperation involved implementing a model of integrated education, rehabilitation and social support based on the conductive education system that was introduced in Zamość 27 years ago. Among the components of this cooperation was sharing our AAC knowledge with our Ukrainian partners. As part of various projects, the Ukrainian specialists attended complimentary courses organized by our association and in turn our professionals visited Ukraine as volunteers to work with children with disabilities as well as their therapists.

A few years ago, Kremenets joined the group of places supported by the *Step by Step* association. This town and its surroundings are home to about 200 children with disabilities and the nearest rehabilitation centre is around 90 kilometres away. This created a need for a place where the families of such children could receive professional and comprehensive support.

Dr Maria Król and a team of the association and school employees of *Step by Step* got involved in this project. As part of our work, we took several trips to Ukraine during which we met the parents and their children, consulting with them and suggesting various solutions. We also invited a couple of mothers from Kremenets along with their children to our school in Zamość. During the week-long stay we had an opportunity to prepare basic guidelines for work to do at home, including AAC.

The problem with helping children with disabilities, especially multiple disabilities, in Ukraine, is that many of them aren't entitled to education and those who are cannot always count on professional help, especially with AAC. During my stay in Kremenets in 2017, when I went there with a group of volunteers, I consulted 12 children of various ages that required AAC, most of them with CP. None of their parents had ever heard of AAC.

The biggest problem was that they had no chance to continue working with an AAC professional. We had to come up with efficient communication strategies on the spot.

Thanks to the help of my Ukrainian friend, dr Anna Zaplatinska from the Draganov University in Kiev, (who was one of the first people to attend training and internships in Zamość), I had

no difficulty in communicating with the children and parents as well as creating several simple strategies to enhance communication that would be useful at their homes.

Throughout my consultations I kept mentioning Dorothy Fraser, who shared her ideas for simple AAC solutions at a workshop in Zamość. I hope she would be proud of me if she saw me creating E-Tran frames out of 2 laminated pieces of foil stuck together with scotch tape in which I cut out a rectangular hole. The set featured symbols in Ukrainian for "yes," "no," "more," "stop," a couple of toys, and a "blue tak" adhesive strip.

Editor's note from Dorothy: Happy to know the idea worked for you and your project.

The Internet turned out to be very useful and thanks to direct e-mail and Facebook contact we managed to carry on the work started in Kremenets with two families of children requiring AAC.

Our recent visit this October involved opening a small rehabilitation centre founded by an association of parents from Kremenets.



Agnieska Pilch and her colleagues working with Ukrainian children and families Photographs by Mr Artur Kuliński

It is struggling, however. There are not enough specialists employed, the budget is low, while the amount of children needing high quality support is high. We are very glad that during our last visit we could have classes with our Ukrainian colleagues in a humble, but their own, building.

SHARE: The Bianca Project 2018

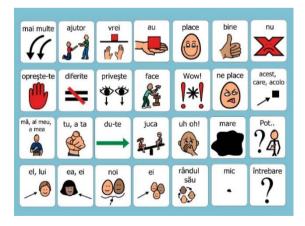
Introducing Symbols Within a Romanian Children's Centre: One Year On By Samantha McNeilly UK, AAC Consultant: Occupational Therapist

In 2017's November CSWN newsletter, I introduced you to the charity, SHARE- a UK based charity that has been providing health and education support in Romania for the past 24 years. A main focus of SHARE's work is the Bianca project, in which newly qualified Occupational Therapists (OT) and Speech and Language Therapists (SLT) volunteer in a centre for children with complex disabilities in Sibiu, Romania. In 2017 we began introducing AAC in the form of communication boards, working with some children and modelling the use of symbols to the carers. One carer in particular was keen to explore the use of AAC and we concluded 2017 by agreeing to work together the following year and asking to keep any communication boards I had created.

Summer 2018

In the summer of 2018 I met a child new to the centre; a young boy with athetoid cerebral palsy which leads to unintentional movement in his limbs. He can mobilise in a wheelchair and enjoys interaction. He was able to vocalise and use some gesture, however this was clearly not enough for him... he had a lot to say!

I began using the boards and pointing to the symbols (modelling) communication boards during motivating, fun activities, such as bubbles and building blocks. The SHARE therapists began modelling words such as "more", "like" and "look" on the board with four rows of 7 words. The words were "core" words, ones which we frequently use throughout the day.



Each time we stacked a block I pointed to *more* and, as we matched colours, I commented on how I was *looking* for the red block. After only 20 minutes of using the board with me pointing to the words as I spoke, when we made a great big tower he pointed to "good" and gave me a thumbs up- copying the picture on the symbol.

Fig 1. Core word board, 4x7 symbols per page

He was able to directly access all the symbols and if he incorrectly targeted a cell, would move his finger along the page, smiling when touching the desired cell. He would occasionally use the stop symbol, despite enjoying the game. When he did so I would respond, stopping momentarily whilst he vocalised to show me he wanted to continue. In this case I would model the word "more" and he would copy, excited to continue the game.



Fig 2. Modelling core words during play



After a successful summer, his carer asked to keep the communication board we had been using- and wrote his name on the reverse in bold letters. She had felt the symbols were useful and asked me to create resources for the other children to support them in learning about the seasons and time concepts.

After such a successful summer we decided to return in October for a week, to provide the requested resources and meet with other members of the disciplinary team.

Fig 3. Building blocks

October 2018

I landed in Romania late Saturday night and woke up to an email from the child's carer and his new teacher! The carer has spoken with his teacher about the aided language input (modelling) we had introduced during the summer and suggested we work together, keen to put us in touch. The child was now having 180 minutes of 1-1 teaching per week. On the Tuesday we met and she told me his goals in teaching and current activities; such as counting conkers and matching them to numbers on cards; all activities not only supporting his understanding and teaching him new concepts, but targeting his fine motor skills too. His teacher had knowledge of AAC from working at previous schools however felt unsure on how to begin and in the future to develop a comprehensive system.

We spoke about my clinical reasoning for starting with a large number of cells per page; how physically he can access all the cells and how I have seen him visually search and isolate single cells we have been using such as "more." It is important for us to use the symbols with him with no expectation for him to use the symbols, however when he does, we respond appropriately so he can hear the word, see the symbol and see the action. Within class, we spoke about using the board alongside current activities and perhaps focusing on only a few symbols initially.

The Ace Centre's free iBook, "Getting Started with AAC: Using Low Tech Symbol Based Systems with Children" (<u>http://aacbooks.net/book2/</u>), was a particularly useful tool to show examples of other children and young adults using AAC and provide some context and real life examples to our discussions.



We used the board in different environments and contexts; from indoor play within the centre to chatting about the playground toys. A highlight of the trip was when two of my colleagues were engaged in other activities and the child mobilised towards them, communication board on his lap. When he reached my colleagues, he vocalised and waved the communication board at them- signifying he had something to say.

Fig 4. Core words in the park "let's GO on the roundabout" "Wow!"

Other members of the centre staff team and another child's teacher became interested in the use of AAC after watching us play and communicate using it one afternoon. The child knocked over building blocks, covering his mouth with his hand and pointed to "uh oh" as he did so. This led to discussions about the potential for other children to be provided with symbol-based communication systems and how we can further work together to promote an environment filled with multi-modal communication.

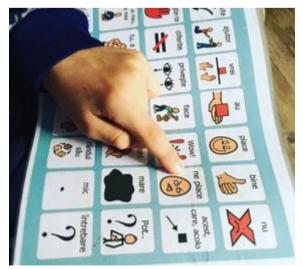


Fig 5. Playing indoors "I don't like"

For the future

After such a positive year with the use of AAC being welcomed within the centre SHARE are eager to return to the centre. The teacher and I agreed to keep in contact, to provide support regarding implementation and review how we can increase the vocabulary as required. I plan next summer to spend time with the teacher to create together a communication book with core and fringe vocabulary to expand his communication and allow him to communicate wherever and whenever he wants.

I am not aware of symbols being used within the centre previously, so this is a new and exciting challenge. We are keen to complete some short continuing professional development (CPD) sessions for other carers, about what AAC is and how they can model symbols in a busy environment.

We hope that we can continue introducing children to symbol language and hope to tell you this time next year that several children are using communication systems.

https://www.helpshare.uk/

Evaluating an AAC training for special education teachers in Sri Lanka

A low- and middle-income country By Nimisha Muttiah, Kathryn D.R. Drager, David McNaughton & Nadini Perera

This article is available on the ISAAC website, here.

The Bridge School and Cisco

Building a Global AAC Community



The Bridge School has hosted a biennial AAC By the Bay conference since 2005. The first conferences were held at San Francisco State University and, from the outset, attracted an international audience. Participation was limited to a specific physical location, but the presentations had a global appeal.

In 2012, The Bridge School forged a relationship with the Educational Division of Cisco and the conference was hosted at the Executive Conference Center in San José, California where we were able to take advantage of the in-house technology their company offered. Once we realized the potential of the Cisco global network, we negotiated to have the AAC By the Bay conference live-streamed internationally. One of The Bridge School board members, a senior vice president at Cisco, served as the sponsor of the event. In 2017, we expanded our outreach and with Cisco technical support, the AAC By the Bay conference was live-streamed to 37 off-site locales in 8 different countries. Ultimately, the conference reached over 900 participants in the United States, Canada, Mexico, Singapore, Thailand, Argentina, Poland, Ireland and Russia.

The most critical element in building this capacity was establishing a relationship with a company that valued a global community. Aligning our vision of an international community focused on providing an education for children and adults with severe physical impairments and complex communication needs with a corporation's commitment to "Connecting people and ideas for a better world" was essential to the success of this effort.

Building the global community takes time and effort from everyone involved in educating and supporting individuals who use augmentative and alternative communication. The Bridge School's Teacher-in-Residence program has provided us a strong base for international outreach and the BUILD community in ISAAC has strongly supported our efforts at disseminating relevant information. These professional connections benefit all of us as we continue to grow the community.

The next AAC by the Bay conference will be held on April 25 - 26, 2019, and in addition to onsite participants, will also be live-streamed internationally. We're anticipating an even larger distribution of the event this year. Anyone interested in participating can get more information from The Bridge School website at:

http://www.bridgeschool.org/outreach/aac-by-the-bay/.

Please join us!

Exciting News from Communication Matters

By Ruth McMorran, Co-Chair Communication Matters (ISAAC UK) - The UK charity for AAC



At Communication Matters we support and celebrate all forms of communication, the people who use them, the professionals and families that support them and the companies that provide them.

At our annual conference we present two awards in memory of inspiring individuals, Jamie Munro and Alan Martin. These awards not only serve to remember two valued members of our community, but also highlight the achievements and influence of particular individuals through their work or artistic skills.

We know that there are many more individuals, groups and companies who should also be celebrated for their contribution to the world of AAC. Communication Matters is preparing to champion these achievements with our first ever AAC Awards to be held at Leeds University on Friday 11th October 2019.

Description of Awards

The ceremony will feature eight awards, reflecting the diversity of the AAC community:

The Jamie Munro Award

An award for an inspiring individual, whose work has had impact across the entire field of AAC. This award is in memory of Jamie Munro, who inspired all he worked with during his career as an AAC supplier and developer.

The Alan Martin Award

An award presented to a person who uses AAC who has made a significant contribution to the arts. This award is dedicated to the memory of Alan Martin, who championed the arts and creative inclusion through his work as a dancer, a musician and comedian.

The AAC Innovation Award

An award given to a particular product, resource or supplier that has demonstrated "outside the box" thinking.

The Rising Star Award

A newcomer to the world of AAC who has made particular impact over the past year.

Setting of the Year

An award for a setting or context that has promoted AAC in a particularly creative or inclusive way. SAVE THE DATE! AAC Awards 2019 Friday 11th October 2019 University of Leeds

The Research Award

An award given to a researcher, a published paper or project which has furthered the evidence base around AAC.

The Student Award

An award for a student, project or group in an AAC-related subject which has promoted understanding of AAC in their university, college or community.

Outstanding Community Inclusion

An award for a person or community who have shown exceptional awareness and support for AAC users and their needs.

It is no coincidence that the awards will be held in October, which is AAC Awareness Month and we intend to hold the ceremony every two years going forward.

The awards will continue our valued partnership with MEETinLEEDS, and together we want to raise the profile of AAC in the city and beyond!

Communication Access UK: The Journey Continues...

Report from Catherine Harris, Pilot Project Lead, November 2018

It was good to be able to give an update at the Annual Meeting and then present two sessions about Communication Access UK at the Communication Matters Conference 2018. The title of the first session was "The Journey Continues...." "Journey" has been and continues to be an appropriate term to describe the experiences through the two-year pilot project for Communication Access UK. As with so many journeys, it is not always as simple and straightforward as it may first appear and takes much longer than estimated on Google maps! There have been ups, downs and holdups and we are still travelling!

The aims of the pilot were to

- To launch a symbol for communication which is recognised throughout the UK
- To develop a communication training package for businesses
- To test out resources with staff at the University of Leeds as a pilot site
- To involve people with communication support needs as mystery customers and presenters to deliver training
- To train at least 3 other businesses before the end of the pilot phase

These aims have all been met although it is recognised that it was perhaps an ambitious vision. There is still a lot more to do! However, a useful part of the pilot has also been to highlight issues to find what works, what does not work and what factors have had a significant impact on the delivery and potential roll out.

A steering group, running parallel and overlapping with the pilot project, has been focussed on the symbol consultation and development, standards and a longer-term strategic plan. The Steering group has representation from Communication Matters (CM), Royal College of Speech and Language Therapists (RCSLT), Headway, Motor Neurone Disease (MND) Association, Stroke Association and the recent addition of representatives from Disability Rights and the Disability Business Forum.

The Symbol

Following a very extensive consultation process, we do now have a symbol for the UK which is being further evaluated through the early adopter phase.



Although an international symbol for communication access would be the preferred option for some, this has proved to be unachievable at the present time for many and complex reasons. The two-stage UK wide consultation resulted in over 6,000 responses. In the second

round with over 3,000 responses, 26% were from people with communication support needs, which was really encouraging. The views of AAC users have been well represented.

Training

Training packages have been developed and trialled at the pilot site of the University of Leeds. Over 100 staff from a variety of staff groups including hospitality, catering, admin and security teams have attended workshops and have shaped the content and format of the presentations. There was the request for a short acronym or prompt to aid recall following training. The TALK prompt has been tested over a three-month period with people with communication support needs, including AAC users, SLTs and business contacts, and has received positive reviews.

T- TIME A – ASK WHAT HELPS L-LISTEN K- KEEP TRYING

This prompt has now been integrated into the training for face to face service delivery staff.

Early Adopters

AAC Hubs, Specialist FE colleges and SLT departments are being encouraged to become early adopters of the symbol and to engage with local businesses to promote CAUK. In addition to workshops at the University of Leeds as the pilot site, training workshops are being delivered by the project lead to local businesses in Southbourne on Sea, Bournemouth, SuperTram Sheffield and a small pub chain as part of the pilot.

Central to the vision and success of CAUK is having input and feedback from people with communication support needs including those who use AAC and the involvement as mystery customers and workshop presenters. This is something we are keen to continue.

Where do we go from here?

The steering group are now working on:

- Brand development and promotion of symbol
- Case for support for financial planning
- Coordinating full launch of symbol
- Potential of an "Alliance" to take CAUK forward
- Promoting public sector (including government), private sector and wider third sector adoption

As the pilot project lead, I have found this to be an exciting roller coaster ride! And it is not over yet! CM has started something that could be very significant in improving the experiences of people with communication support needs in the community.

Please contact CM if you would like to join us on the journey:

accessproject@communicationmatters.org.uk

Asperger Syndrome and Adult Relationships with Neurotypical Partners

Information provided by James Gault, who has been diagnosed as being on the Autism Spectrum Disorder (ASD) high functioning (Asperger Syndrome)

Communications

How do we communicate?

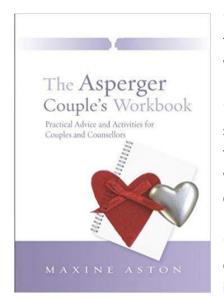
Dr Albert Mehrabian is often quoted as saying that the meaning of a message is communicated in various ways:

- i. 7% in spoken word
- ii. 38% by the tone of the speaker's voice when speaking those words
- iii. 55%. by the speaker's body language, for example facial expressions

So, 93% of communications is nonverbal!

For a neurotypical¹ this does not pose an issue because they have the ability to "read" what the other person is saying to them in the nonverbal manner as well as the verbal.

Quote from The Asperger Couple's Workbook



"Asperger Syndrome (AS) can affect some of the fundamental ingredients required to make relationships work, such as emotional empathy and communication.

"This workbook provides couples affected by AS with strategies that will benefit their relationship together, and their family as a whole. With candid advice, activities and worksheets, the book explores a variety of approaches that couples can use to improve their relationship.

"Whilst acknowledging that all relationships are different and each needs to be viewed as a unique case, the author identifies specific issues that can be problematic in an

Asperger relationship. The book provides a range of ideas based on years of research and counselling experience and covers crucial areas such as verbal and non-verbal communication, sexual issues, parenting and home life. This practical book is designed for use by couples and families affected by AS, either on their own or in conjunction with a counsellor."

¹ NT, NTs or Neurotypical refer to people who are not on the Autistic spectrum.

Examples of Mood Charts

The Developed Mood Chart

#	Item	Description	Score
1	Angry at Partner		
2	Angry at someone or something else		
3	Sad / Down		
4	Stressed / Anxious		
5	Confused / Not understanding		
6	Needing Space		
7	Feeling Tired		
8	Feeling of losing control / Rejected		
9	Feeling Irritable		
10	Not feeling well / In pain		
11	Feeling as if heading to sensory overload		
#			0

#	ltem	Description	Score		
1	Angry at Partner	Misunderstood what they were saying to me. This upset me.	6		
2	Angry at someone or something else	Person was talking too fast and I could not understand them. This made me stressed.	7		
3	Sad / Down	That I am unable to understand what NTs are saying to me.	8		
4	Stressed / Anxious	Having to talk to people makes me stressed and anxious.	8		
5	Confused / Not understanding				
6	Needing Space	With all the activity I need my own space.	7		
7	Feeling Tired	Being stressed and anxious makes me very tired.	9		
8	Feeling of losing control / Rejected				
9	Feeling Irritable	NTs misundertand me a lot of the time.	6		
10	Not feeling well / In pain	Pain in side and back has been bad the last couple of evenings. Bad headaches all today	10		
11	Feeling as if heading to sensory overload	Due to all of the above.	7		
		#	68		
	6 days since last meltdown				

Other Aids to better Communication for a person with Asperger's Syndrome

A credit card sized, two-sided, laminated card that on one side contains information on people talking to me and what they can do to lessen my stress/anxiety.

a. To the Person talking to me if I feel Stressed or Anxious

I have Asperger Syndrome please be patient. Thank You.
When communicating with me please:
Speak clearly and slowly to me and be descriptive. I cannot read non-verbal communication which is usually done through facial & hand gesture.
I take everything literally, no idioms or metaphors.
Please also take into consideration the surroundings as I am hypersensitive to the following:
Light; Sound; Motion; Temperature; Smell and PEOPLE
I get very anxious when in crowded areas that have noise and background chatter and is lit brightly. So not a good place to be.
If you think I am rude or arrogant then my apologies, as I may be stressed and anxious. If so then I may walk away.
If I need assistance, contact my partner on ***** *** ***

b. To remind me how to act when talking to people

The other side contains information for myself that I must remember to adhere to when talking to people. For example, I must remember to allow them to have their say.

I must remember that when talking to people
Don't expect immediate replies as people don't think as fast, like myself.
Be respectful and allow them their say. Don't interrupt.
Respect the person's right to have a different point of view.
If I feel I'm not understanding the statement, ask for clarification If feeling stressed & anxious, tell them and excuse yourself.
Be aware of how you speak to people. Be nice, not arrogant.
When Travelling
Condition yourself for possible Delays. Change is inevitable.
Have plans for when things get out of hand (control).
Ensure that mobile phone has plenty of charge.
Take money, insulin and sugar with you to cover all eventualities
If I need assistance, contact my partner on ***** *** ***

James's Recommended Reading List

General Asperger Books covering a multitude of subjects:

- 1. The Complete Guide to Asperger's Syndrome by Tony Attwood
- 2. Asperger's Syndrome for Dummies by Gomez Mason
- 3. Communication Issues in Autism & Asperger Syndrome by Olga Bogdashina
- 4. Sensory Perceptual Issues in Autism & Asperger Syndrome by Olga Bogdashina
- 5. Theory of Mind and the Triad of Perspectives on Autism & Asperger Syndrome by Olga Bogdashina
- 6. The Essential Difference Men, Women and the Extreme Male Brain by Simon Baron-Cohen
- 7. Zero Degrees of Empathy by Simon Baron-Cohen
- 8. Asperger Syndrome and Anxiety by Nick Dubin
- 9. Very Late Diagnosis of Asperger Syndrome (Autism Spectrum Disorder) by Philip Wylie

Specific Autism and Asperger Related books with regards to Relationships:

- 1. Life with a Partner or Spouse with Asperger Syndrome by Kathy J. Marshack, Ph.D.
- 2. An Asperger Marriage by Gisela & Christopher Slater-Walker
- 3. The Asperger Couple's Workbook by Maxine Aston
- 4. Marriage and Lasting Relationships with Asperger's Syndrome by Eva A. Mendes

AAC Awareness Month 2018

Updates and photos from International AAC Awareness Month celebrations around the world are posted on the <u>ISAAC website</u>.

In addition, a comprehensive report from Russia is posted <u>here</u>, under the title *ISAAC CSWN Newsletter, December 2018: Linked Articles*.

Conference News

ATAAC Conference in Zagreb Croatia October 17th to 19th, 2018



Presenters and volunteers



Participants

More and more, inclusive education is becoming a standard followed by kindergartens and schools all over the world. Introducing assistive technology (AT) and augmentative and alternative communication (AAC) in the classrooms dictates a higher demand in having a conference like ATAAC. It is the fastest growing and one of the biggest conferences in the world dedicated to children and persons with disabilities, their parents and a wide range of experts who work with these children and persons.

ATAAC conference brings leading world experts and users of assistive technology and augmentative and alternative communication to Zagreb to present their knowledge and share their experience. The goal of the conference is to introduce AT and AAC to all participants, in a way that is accessible and understandable to everyone in the audience.

What can you expect?

The ATAAC 2018 conference took place in Zagreb for the third year in a row. Lecture and workshop topics were carefully chosen to represent practical work with children and persons with various developmental difficulties, with a strong emphasis on early education of children with disabilities. These three days in October stand to be the "must-be" spot for all wanting to hear more about AT and AAC.







At the ATAAC conference you can find out all about novelties in AT software and hardware, good practice examples of implementing AT and AAC in pre-school and primary school classrooms, advice in workplace adaptation, while world leading experts from the field of speech-language pathology, special education and occupational therapy talk about assessment, implementation and evaluation of working with AT and share their tips and tricks with you.



All the attendees visit the exhibition area to see and try different aids for persons with disabilities. Leading world manufacturers of AT solutions from England, Sweden, USA, Germany, Austria, The Netherlands, Poland and Finland present their products in the showroom. The attendees are welcome to see the presentations of different communication aids, eye-gaze control equipment, educational toys, various switches, alternative computer access equipment, therapy aids, educational software, environmental control devices, and many more.

ATAAC watch on-line

Not everyone can travel to Zagreb to be part of the ATAAC conference, so in 2018 the Watch On-line option was introduced. It is a feature for all those interested in participating and hearing first-class lectures on advanced technologies for persons with disabilities.

All of the lectures and product demo presentations were available for the participants to watch on-line for 10 days after the last day of the conference, so everyone could follow it at their own pace.

The opportunity to feel the ATAAC global collectiveness was captured by many persons wanting to learn more about this subject, so the conference counted participants from more than 30 countries from all over the world including Australia, New Zealand, USA, Russia, Ghana, and UAE.



Miroslav Vrankic, conference organizer, welcoming Ghanian Watch- Online participants. *see article from Ghana (page 29)

ATAAC 2018 by the numbers

In 2018, more than 35 lecturers from more than 10 countries shared their knowledge and experience in working with children and person with disabilities with an audience consisting of more than 1,500 participants. The average grade of ATAAC 2018 conference was 4.7 out of 5, with 93% of participants wanting to return and attend in 2019 as well.

Satellite conference in Belgrade, Serbia

ATAAC 2018 conference had a satellite conference in neighbouring Serbia. Many lecturers who spoke at the ATAAC 2018 in Zagreb, combined with new faces of world leading experts in AT and AAC, made Belgrade a two-day oasis for learning about assistive technology and augmentative and alternative communication.

With topics dedicated to AAC and AC in the workplace, schools and kindergartens, poster presentations of Serbian experts introducing their work and many opportunities for quality networking, several hundred participants went back to their workplaces full of knowledge and new ideas.

ATAAC 2019 (October, 15-17)

In 2019, the ATAAC conference will take place October 15-17, in Zagreb, Croatia.

Just like every other year before, the conference will bring together outstanding and wellknown experts to talk about AT and AAC willing to share what they know and to work together on a better world, a world of equality.

The Watch On-line feature will be free for all interested students worldwide and for the audience from the emerging AAC countries. It is an event not to be missed - in person or online. Find out more here: <u>www.ataac.eu</u>

Ghana Educators Tap into International Resources

By Belinda Bukari

The Central Coast Children's Foundation, as part of its commitment to empowering teachers in the area of Assistive Technology, and Augmentative and Alternative Communication (AT/ AAC) has over the years supported teachers from the Special Units for the Intellectual and Developmental Disabilities in Ghana.

To help enable the leaders of Ghana's schools for children with disabilities to take advantage of a rare opportunity, the foundation found a way to connect these leaders virtually to an international conference on assistive technology and AAC by participating in the "watch on line" option.

The Assistive Technology and Communication (AT/AAC) 2018 conference in Zagreb on October 17- 19 2018 brought leading world experts and users of assistive technology to present their knowledge and share their experiences. To most special educators in Ghana, attending such a conference would be prohibitively expensive and enormously complicated. Instead, they came together at the Capital View Hotel in Koforidua, near Ghana's capital, to view via Internet the entire proceedings of the conference, to help them learn new ways to help their students with communication challenges and figure out how to use this new knowledge.

In Koforidua, Ms. Belinda Bukari, head of Ghana's Unit for the Intellectual and Developmental Disabilities, Special Education Division, Ghana Education Service welcomed special educators from around the country to the conference. She explained how they had been selected to participate in the conference and how it was determined how participants from Ghana could benefit from the conference, by bringing on board six special educators to join Ms. Bukari to participate in the conference virtually.



Joining Ms Bukari were:

- 1. Samuel Kissi : Adukrom Methodist Unit (Teacher)
- 2. Felicia Agyeman: Akuamoah Acheampong Unit, Nkawkaw (Teacher)
- 3. Frank Musah Dahamani: Aboom Unit, Cape-Coast (Teacher)
- 4. Francis Darko : Aboom Unit, Cape Coast (Teacher)
- 5. Kwaku Nkum Yeboah, Catholic Special Vocational School, Takoradi (Teacher)
- 6. Gladys Ayaw Oduro : Koforidua School for the Deaf EID Unit (Unit Head).



The participants acquired knowledge and got to learn for the first-time strategies, skills and experiences on the use of AT/AAC for students with complex needs. Among the topics they found relevant to their needs were:

- 1. Best practices and examples using AT in the classroom
- 2. Integration of children with developmental difficulties into the educational system
- 3. Early education programs
- 4. The use of Assistive Technology at the primary level
- 5. Determining best access methods for persons with physical/or visual impairment.
- 6. Supporting language development with AAC
- 7. Sensory stimulation and integration in multi-sensory environment
- 8. Autism and AAC: controlling behaviour issues
- 9. How to teach children with autism using technology

Based on the various presentations, issues that were highlighted included:

- 1. Exploration of the environment/independent living and life-long learning using ATAAC
- 2. Curriculum
- 3. Funding
- 4. Assessment
- 5. Accessibility
- 6. Awareness
- 7. Sensory rooms/early stimulation
- 8. Stakeholder collaboration or engagement
- 9. Teacher competence
- 10. Resources(materials)

OBSERVATIONS

The group observed that there was focus on:

- 1. Who uses AT/AAC, who teaches it and who assists the users
- 2. Early interventions
- 3. Use of AT/AAC as rewards
- 4. Clearly defining one's objective
- 5. Proper assessment
- 6. Appropriate selection and use of AT/AAC
- 7. Identifying and building on the interest of the child
- 8. Multidisciplinary approaches to AT/AAC

CHALLENGES FACING GHANA

After participating in the conference, the group sat to deliberate on some issues we in Ghana face in the delivery of Special Needs Education with regards to the use of Assistive Technology both in the Special and Mainstream schools.

- 1. Issue Pupil/Teacher Ratio
- 2. Inadequate support services
- 3. No clear policy on accessibility (universal design)
- 4. Inadequate capacity building of teachers
- 5. Lack of professionals and inadequate materials for assessment
- 6. Curriculum (AT/AAC programs not factored in and inflexibility)
- 7. Inadequate knowledge on AT/AAC and lack of commitment on the part of stakeholders.

EVALUATION

- 1. Participants said the practical approach the various presenters used enhanced their understanding.
- 2. Participants said training contents, lodging, feeding and transportation were much appreciated.

RECOMMENDATION

- 1. It is recommended that more personnel who deliver special needs education undertake courses in AT/AAC.
- 2. The Special Education Division should create/fuse AT/AAC into the education of the intellectually and developmentally disabled unit.
- 3. There should be a follow-up on participating teachers to see how they doing things differently with the knowledge acquired in their respective schools.
- 4. The need for stakeholder engagement on issues of the curriculum and how AT/AAC can be included and ensuring that people adhere to the rules on universal design and accessibility.

REMARKS

The participants are very grateful to the 'CENTRAL COAST CHILDREN'S FOUNDATION for this great initiative. We are very much appreciative of all who contributed financially to ensuring the success of this program. Special thanks go to Harvey, Sarah, Cate, and Dorothy for their enormous support and assistance.

Lastly, we are indeed grateful to Miroslav Vrankic and the AT/AAC Team who worked tirelessly to get things to go smoothly for us. We appreciate your support so much. Forever grateful to All.

The First International Conference "Augmentative and Alternative Communication," November 12th to 14th, 2018, Sofia, Bulgaria

By Maurice Grinberg & Evgeniya Hristova ASSIST – Assistive Technologies and New Bulgarian University

The First International Conference "Augmentative and Alternative Communication" (https://aac2018.assistfoundation.eu), organized by "ASSIST - Assistive Technologies," took place in Sofia, Bulgaria from 12 to 14 November 2018. The conference was supported by the Bulgarian Ministry of Education and Science (MES), UNICEF – Bulgaria, and the International Society for Augmentative and Alternative Communication (ISAAC). The sponsor of the conference was Microsoft Bulgaria.

The main goal of the conference, especially as the first Bulgarian conference on AAC and assistive technologies (AT), was to present the best practices and the progress in the usage of modern approaches to address the communication needs of children and adults with communication difficulties. This goal was achieved and about 350 people attended the conference and were introduced to various approaches and methods of AAC and AT. The conference brought together all stakeholders in the field including representatives of the ministries, municipalities, educational institutions, social service providers, and people with disabilities and their families.

The participation and support of the conference by MES and UNICEF – Bulgaria were essential for the success of the conference as they were a guarantee of the importance of the topics discussed, which generated a large interest among professionals in the field. The conference was opened with short speeches by Denitsa Sacheva, deputy minister of Education and Science and Dr. Jane Muita, UNICEF representative in Bulgaria.

Of course, the most important factor for the success of the conference was the keynote speakers. The talks and the workshops provided state-of-the-art information about the modern approaches, policies, methods, and technologies for AAC and AT. Keynote speakers at the conference were:

- Prof. Stephen von Tetzchner (University of Oslo, Norway)
- Dr. Kristine Stadskleiv (University of Oslo Hospital, Norway)
- Yonit Hagoel-Carnieli (National Center for AAC "Ezer Mizon," Israel)
- Aldona Mysakowska-Adamczyk (ISAAC-Poland)
- Dorothy Fraser (ISAAC BUILD Committee, UK)
- Assoc. prof. Maurice Grinberg (Foundation "ASSIST Assistive Technologies" and New Bulgarian University, Bulgaria)
- Dr. Evgeniya Hristova (Foundation "ASSIST Assistive Technologies" and New Bulgarian University, Bulgaria)
- Greta Gancheva (MES, Bulgaria)

A major part of the conference program was aimed at providing a fair picture of the state and the perspectives of AAC and AT usage in Bulgaria. In the organized panel discussion about the policies in Bulgaria participated representatives of the main educational institutions expected to provide support to the process of inclusive education:

- Blagovesta Borcheva, state expert in the Inclusive education directorate of the MES, Bulgaria.
- Milen Nakov, director of the Center for Special Educational Support, Pleven, Bulgaria
- Hristo Hristov, director of the Regional Center for Support of the Process of Inclusive Education, Targovishte Region, Bulgaria

Similarly, a section of the conference was devoted to the sharing of experience and good practices by Bulgarian educational centers already using AAC and AT:

- Foundation "ASSIST Assistive Technologies"
- Center for Special Educational Support, Pleven, Bulgaria
- Regional Center for Support of the Process of Inclusive Education, Targovishte Region, Bulgaria
- Foundation "Karin Dom," Varna, Bulgaria
- Daycare center for children with disabilities, Svishtov, Bulgaria

One of the distinguishing features of the conference was the presentation of personal experiences by people who use eye-gaze control for communication – Angela Pencheva (writer and actress), Anna Krasteva (7 years old) and Sasho Iliev (pupil, 15 years old).

The satisfaction survey conducted among participants show that 99.2% would recommend the conference to their colleagues and 96.2 would attend the next conference on AAC and AT if organized in the future. More than 50% of the participants gave an excellent overall assessment of the conference, with an average rating of 4.65 (1 = "unsatisfactory" to 5 = "excellent").

The conference was covered by two national television stations – Nova TV and Bulgarian National TV – and other internet media, with numerous publications and reports. The Bulgarian National Radio was a media partner of the conference and included interviews and information about AAC and AT in several of its programs. The first day of the conference was broadcast on the Facebook page of "ASSIST – Assistive Technologies" and has been viewed to date by more than 600 people.

Based on the very positive feedback about the conference given by all participants, we already look forward to the organization of the second conference on AAC in Bulgaria in 2019.

AAC in Czech Republic – First national AAC conference, October 2018

By Jana Šarounová, Centre for AAC, Prague

AAC History in our Country

AAC was completely unknown in our country before the Velvet revolution in 1989. Nonverbal people were considered mostly as mentally handicapped and no one worked with them on language development or literacy, if there was no speech. Speech therapists, social workers and teachers had been isolated from new trends in "western" countries. In the early nineties, after borders opened, some people learned about AAC possibilities and became enthusiastic.

The Ministry of Education organised some study visits in Scandinavian countries and initiated the release of first publications about AAC. It was one way that information about AAC came to our country.

The other "route" had been led by Lucie Laudová who was the first member of ISAAC from the Czech Republic. She attended some conferences, found new contacts and then she founded an Association for AAC, in 1994. She also organised the first AAC courses which were taught by Judy Wine and Pnina Bialik from Israel. Even today some participants remember, how exciting it was for them, when a boy with cerebral palsy asked for a kiss from his mum through a Big Mac! It seemed like a release from prison.

Lucie started working with potential AAC users, she was alone in the beginning and she mostly visited people in their homes. In 1997 the Centre for AAC was founded in Prague, where we started working together. We translated Boardmaker database and cooperated with a Czech company which started to sell communication aids (the first ones were from Attainment Company and we thankfully remember how nice Dan Hanson always was and when he even gave us some VOCAS for free). The cooperation with people from Widgit was always very friendly and nice from their part and we made a translation of their software programme, Symwriter.

We also joined the activity about Eastern and Central European AAC conferences- the second one was held in Prague. These conferences started a co-operation with other post-communist countries that had similar problems in AAC establishment. We sometimes felt that international ISAAC conferences were wonderful but maybe a little far from our needs, because we needed "milk". On the other hand, we understood that we could not invent something what had been already invented, but we had to learn from those who are further ahead.

AAC in the Czech Republic Nowadays

And what about AAC awareness in our country in 2018?

I think people generally know what AAC means. We have enough "hardware" available now (localised software with symbols both for printing of communication boards and direct communication through PC, tablets, eye gaze systems, communication aids, sign systems, AAC courses on universities etc) but maybe we do not have enough "software" (meaning knowledge of how to build vocabulary, how to model, how to train AAC in everyday situations, how to make it funny and motivating – because not every activity with symbol is really a communication).

We host many courses for AAC and have held activities to spread awareness of AAC for the general public. <u>www.alternativnikomunikace.cz</u>



Invitation to a café. Coffee in silence, using AAC to communicate

But - until now, we never had a national AAC conference, although these conferences had been held in some post-communist countries for many years. What a shame!

First National AAC Conference

An immediate impulse for a national conference was an informal meeting in 2015 at our centre in Prague, initiated by two members of ISAAC BUILD subcommittee - Dorothy Fraser from UK and Aldona Mysakowska-Adamczyk from Poland.

They shared ideas from ISAAC with 15 AAC interested people from the whole country and encouraged us to organise a national conference.





Dorothy with Jana, Lucie and Aldona, signing to indicate AAC should lead to CAA (**C**ommunication **A**ccess for **A**II)

It took three more years, but finally we organised our first national conference in Prague in October 2018 (symbolically in AAC Awareness Month). We started to arrange it one year before. A conference committee was composed of people who we knew work with AAC at a good level. For the organization we joined with an association of social services providers in Czech Republic which had a lot of experience regarding holding conferences.

We decided to organise the first conference as a one-day meeting for the beginning, just with invited speakers because we really wanted to motivate people to participate.



We invited two foreign speakers (not only symbolically it was Judy Wine from Israel as one of two lecturers of our first AAC courses in 1995 and Dorothy Fraser as a person who "pushed" us to organise the conference and was always involved in AAC development in the Czech Republic).

We also tried to invite people from our country who

could give examples of good AAC practice or had good knowledge about an AAC method and we wanted to include case studies from people who use AAC or their family members. We also organised an AAC aids and resources exhibition.

Interest exceeded expectations – there were 250 participants and more applicants who unfortunately could not participate because of the conference room capacity. There were some small organizational problems, but I think the conference was really successful. Participants highly appreciated presentations from Judy Wine and Dorothy Fraser (both speaking about vocabulary choosing and implementing AAC into everyday life in home, schools or social facilities), but also some "local" speeches were excellent. I really liked presentations from two teachers in "my" section-who both work in special schools.

One of them – Lenka – spoke about AAC implementation into everyday school life with all pupils, using a lot of sources and also iPads apps. Children were really cooperating and each of them (even those ones with severe complex needs) had possibilities for communication. The other speaker – Bohdana – introduced group sessions at their school, led by a clown who communicates with children by AAC aids and comes up with a lot of funny or even crazy activities. Children were highly motivated to use their AAC cards, boards, tablets or VOCAS. Another very interesting presentation was by a mother of a child who communicates through My Tobii and Grid 3 – these technologies really changed his life and as his mother said, from "a foreigner among us," he became an "unbelievable joker."

And the Future?

We hope, it was just a start for national AAC conferences in the Czech Republic. We would like to organise other ones in future years, maybe for more days and hopefully for more participants and also speakers. We hope this conference also helped to increase the interest for international AAC conferences and that a lot of people will participate in the biennial Eastern-and Central European AAC Conference next year, hosted in Bratislava, Slovakia.

ECERAAC Conference, Bratislava, Slovakia July 1st to 3rd, 2019

The 12th biennial Eastern and Central European Regional AAC Conference "AAC All Day" will be hosted in Bratislava, Slovakia on July 1st - 3rd, 2019.

The ECER AAC Conference is a unique opportunity to meet, discuss, share your experiences, your successes and issues you face within AAC.



Resources

Ace Centre, UK: AAC Awareness Month, 31 Tips for 31 Days

https://acecentre.org.uk/aac-awareness-month-31-tips-for-31-days/?fbclid=IwAR1eguiIJUybsxYRRbkJzJGzpXZF7TgtcUSiXdLcnRlOwqcIWxMbuxBDF8

Afasic's mission:

Afasic promotes understanding, acceptance, equal opportunities and the inclusion into society of children and young adults with speech and language impairments. <u>https://www.afasic.org.uk/resources/free-downloads/learning-about-impairments</u>

Makaton signing and symbols: What it is and why use it? https://www.bbc.co.uk/cbeebies/grownups/makaton

"Helping disabled gamers play Minecraft" https://www.youtube.com/watch?v=isEfnEPoSE0&feature=youtu.be

Wordless picture books are a lovely way to engage children in the storytelling process https://www.whatdowedoallday.com/wordless-picture-books

Information for people working in less resource settings https://adapt.csp.org.uk/system/files/working in less resourced settings 2017 0.pdf

Farewell

Thank you to everyone who contributed information and all of you who read CSWN, our global newsletter! Feel free to comment and connect.

Our next edition will be published in July 2019. We would love to hear your news. Please submit your article and/or news by June to: <u>nadiabrowning@gmail.com</u> and <u>dotfraser2@gmail.com</u>.

The format is Calibri Font 12, with a guideline of approximately 4 pages and 5 photos.

We look forward to hearing from you.

Wishing you all Happy Holidays,

Nadia and Dorothy