

December 2020

Introduction

Message from Nadia Browning, ISAAC Council Chair:

I would like to start this issue of *Communication Support World Network* (CSWN) newsletter by recognizing Dorothy Fraser's contribution and dedication as a co-editor. Dorothy (previous Chair of ISAAC BUILD Committee) has been a main editor (then a co-editor) of the newsletter since 2011. She has volunteered her time and expertise in search for news, articles and resources that can contribute to our constant learning. Dorothy is now retiring. We are pleased that Miroslav Vrankic from Croatia, the current Chair of ISAAC BUILD Committee, is the new co-editor of CSWN newsletter.

THANK YOU, Dorothy! and WELCOME, Miro! I feel so grateful to be around individuals like you two, who are kind and dedicated to the cause.

Communication Support World Network (CSWN) newsletters aim to share articles and links to resource material. We need your input and participation to ensure that the CSWN newsletter embodies the interests of all of us. PLEASE submit news and resources that you have found helpful.

Miro and I look forward to hearing from you. We hope you enjoy reading this edition, which includes interesting articles and resourceful links. Feel free to connect with us (co-editors).

By Co-editors Nadia Browning (Chair of ISAAC Council) and Miroslav Vrankic (Chair of ISAAC BUILD Committee)

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The December 2020 issue and CSWN archives can be viewed on the ISAAC website at: https://www.isaac-online.org/english/news/cswn-newsletter/



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A Story from Croatia - Growing with AAC

by Ana Alapić



My name is Ana Alapić and I am the mother of a beautiful boy, Mate, who is 11 years old and has spinal muscular atrophy (SMA) type 1. Mate was diagnosed with SMA at the age of six months. The doctors said that he would not be able to breathe on his own, that he would breathe using a ventilator, that he would eat using a nasogastric tube, that he would be using a wheelchair. When I realized the disease was going to take away his ability to speak and mimic, I was devastated. How will he tell me what hurts him, if he's hungry, if he's cold, what he wants and

how he feels? None of his doctors in the intensive care unit could tell me how I was going to communicate with my son.

I believe that everything happens for a reason. Shortly after this painful knowledge, I came across a documentary about a man with locked-in syndrome due to multiple strokes, who communicates using a camera that monitors his gaze. Then I started exploring the possibilities for Mate.

A year and a half later, thanks to family, friends, the local community, and complete strangers who participated in the humanitarian action for Mate, a communicator came to our home. Mate was three years old at the time. Although the communication program was in English (because it did not exist in Croatian at the time), he quickly figured out how to manage it with my help. I made cards adapted to Mate's age and recorded the text in Croatian in my voice. Mate's enthusiasm for finally being able to do something on his own, his happiness and pride when he solved the task set before him, I can't put into words at all. He showed me he knows a lot more than I imagined. He also showed me that he has a sense of humour. He realized that he could influence whether he learns or not. Sometimes we would work 45 minutes, and sometimes I would give up because even after my persistent pleas he wouldn't open his eyes when I put the communicator in front of him. The problem was that we had no professional help in Sisak (our hometown). Mate was often frustrated by me being first a nurse, a physiotherapist, a teacher, and then a mother. But we've made progress. The most important thing for me was to teach him how to communicate with people around him.







I didn't even think about school until I watched a video clip about a boy in the USA (diagnosed with SMA) who attends school. I thought, maybe this is possible in Croatia, too? To be able to go to the school, to determine the program and the model of his education, he had to pass a psychological evaluation. Thanks to the fact that we worked a lot on assisted communication and that he uses the communicator very well, this was possible. At this assessment, he showed that he could read all the letters, numbers, and read and write simple words.

Mate went to regular preschool. With him, nine other children attended the group, led by a kindergarten teacher. Mate was the only child with developmental disabilities in the group. Due to the exceptionally good work of the kindergarten teacher to involve Mate in all activities of the group, the children accepted him, socialized with him, and helped him. Together they celebrated birthdays, acted in shows, and went on excursions and workshops. In that year Mate matured emotionally. In agreement with the kindergarten and school employees, I decided that Mate should once again attend preschool so that we could all prepare as best as possible for first grade. The plan was to educate Mate in the regular primary school, and combine classes in our house with classes at school for his socialization.



Today Mate is in 4th grade. He masters the curriculum without problems. He has wonderful teachers who are always one step ahead to adapt everything on time so he will be able to participate fully in all activities. His classmates took to him very well. The way Mate communicates triggers in them additional curiosity and attention.







Mate serves as an example to others in Croatia on how to include children with SMA on a ventilator in school and I am extremely proud of that. Already, in the last three years several other children have been included in schools on the principle that we have included Mate.

It's been eight years since Mate and I set foot in the world of assisted communication. We took it one step at a time, and prepared and organized carefully, armed with information. I assumed what might be a problem with him getting into school and tried to clear the barriers in advance. Our presence in society and at social events, since Mate was discharged on a ventilator 10 years ago to home care from the intensive care unit, has contributed to the fact that our local community was prepared to include Mate.

Now, because of the coronavirus pandemic, he attends classes only at home. Thanks to the communicator, his teachers in school get feedback online on his progress at home with his home teacher.

Mate is now in therapy that has stopped further progression of his disease. This allows him to learn how to use a customized mouse so that he can use the communicator and control the computer with his hands in addition to eye gaze.



Needs Assessment of AAC in Vietnam

by Gwendalyn Webb and Kate Margetson, with special thanks to Dr. Huỳnh Thảo

Background

A recent project to gather information about the needs of people who use AAC in Vietnam was supported by the collaboration between organisations of Trinh Foundation Australia, and Humanity and Inclusion.





Photos 1 and 2: Speech pathology students from the University of Newcastle, Australia with students from The Kianh Foundation, Vietnam using low tech AAC





Photo 3: A core vocabulary board used at the Kianh Foundation in Vietnam

This project was adapted to an online format due to constraints relating to the COVID-19 pandemic.

From April to August 2020, Ms. Kate Margetson, Technical Consultant, and Dr. Thảo Huỳnh, Technical Assistant / Interpreter, conducted this project, which had a focus on the use of Digital Technology and Augmentative and Alternative Communication in Speech and Language Therapy (SALT) in Vietnam.



Photo 4: Kate Margetson (Technical Consultant, Trinh Foundation) and Dr. Cao Bich Thủy (Head of Rehabilitation Department, Da Nang University of Medical Technology and Pharmacy), with the TalkTablet AAC app



Digital technology is increasingly being used as part of Speech and Language Therapy globally. This project sought to gauge the need and value of digital technology in the rapidly expanding profession of SALT in Vietnam. The project considered digital technology for AAC and also for other SALT professional activities, e.g., data collection or calculations. The specific aims of the project were to:

- 1. Map current practices in the use of AAC and other digital technologies in SALT across Vietnam
- 2. Identify AAC and digital technology needs for people with complex communication needs (CCN) and SALT services in Vietnam
- 3. Provide specific, practical recommendations for developing and enhancing AAC and digital technology types, intervention approaches, training, and support.

Method

Key contacts across Vietnam who specialized in SALT and AAC were identified and invited to be interviewed for the project. Special educators who were known to be specialists in AAC were also invited for interviews as this profession also works closely with children who have CCN. A total of seven online meetings were conducted via Zoom, with translation provided by the technical assistant where necessary. This included four Speech and Language Therapists and four Special Educators from North, Central, and South Vietnam. Most worked mainly with children and one worked with adults.

We invited people who use AAC and families of children who use AAC to be interviewed or trial some AAC apps, but they were not available.

In addition to the interviews, people across Vietnam were invited to complete online surveys via emails, social media interest groups, and posts. A total of 54 professionals and 23 parents of children with CCN completed surveys.

Results

The 54 professionals who participated in the survey reported that they provided support to people with a variety of diagnoses, consistent with SALT caseloads internationally. In the parent survey, the children's ages ranged from 2-10 years old. Diagnoses included autism, intellectual disability, and cerebral palsy. Data collected during the interviews and from the surveys were analyzed to identify current practices and needs, as described below.



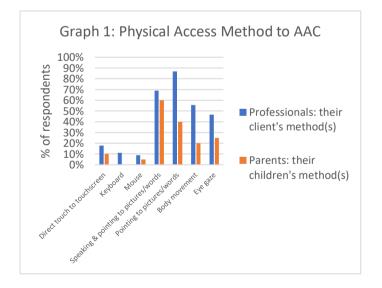
Communication capabilities and practices

Professionals reported that many of their clients had complex communication needs. Nonverbal communication methods were most frequently used by the children of the parent respondents, compared with verbal methods. The professionals indicated that they mainly used low-tech aided AAC with their clients.

The most frequently used AAC reported by both the professional and parent groups were picture symbols and photographs (including on boards) and communication books.

Fine motor capabilities and practices

Many professionals reported that they had clients with limited fine motor skills who were unable to point to pictures, buttons, or a touchscreen. Only a small number had clients who physically accessed their AAC via technology (touchscreen/keyboard/mouse); most reported that they had clients who accessed their AAC via pointing to pictures, or speaking and pointing. Many professionals reported that they had clients who used body movement or eye gaze to communicate, which may have been in addition to other methods. Similarly, parents reported that not many used technology to access AAC; rather, most relied on pointing to pictures with or without speaking the words at the same time (see Graph 1).



The professionals reported that their clients mostly used AAC during therapy and less outside of therapy. In contrast, most parents reported that their children used AAC at home with them, and less in speech and language therapy. Just under half of the professionals had attended training in AAC, and just over half the parents had received training in AAC.



Professionals and parents reported that they regularly used digital technologies, such as iPads or smartphones, with their clients or children for a variety of purposes e.g., education, play, watching music or videos, and managing behaviour.

Key themes from interviews and surveys

Professionals and parents identified many benefits of AAC, namely to:

- increase opportunities to communicate,
- improve communication,
- support comprehension,
- support education and improve children's behaviour.

They noted challenges, including:

- limited resources in Vietnamese,
- time consuming to create resources,
- cost of equipment,
- physical access difficulties for people with motor difficulties,
- difficulty training families and teachers in how to use AAC,
- limited professional skills and training in AAC,
- issues with digital technologies.

The following needs were identified: to develop and promote,

- Community awareness and knowledge about AAC in Vietnam.
- Professional support, e.g., as one participant noted: "Not all clinicians and parents understand AAC, its role and how to apply it properly."
- Access to AAC; cost and location were identified as inhibiting factors for many.
- More variety in options for AAC systems and resources: "All types of AAC, aided or unaided, need to be developed in Vietnam. Especially high-tech AAC because there is a constant lack of access to these resources."

Recommendations

The findings from the interviews and surveys informed the recommendations outlined below. An *action plan* for progressing AAC in Vietnam needs to involve:

- Evidence-based practices for AAC implementation, including
 - person-centred, individualized intervention, and
 - multimodal options for communication training of communication partners.



• Funding for culturally-appropriate AAC apps and resources that meet the needs of users. This includes the translation of appropriate apps and resources into Vietnamese, which provide the option for alternative access (e.g., via a switch). Figure 1 shows AAC apps to be considered in Vietnam.

Figure 1: Apps that are already available in Vietnamese (or soon to be) Apps with potential for limited use in Vietnam Recommended apps for translation in Vietnamese



- Supporting families and increasing community awareness about AAC and the needs of people who use AAC.
- Providing professional development opportunities.

Acknowledgement

We would like to acknowledge the professionals and parents who generously donated their time to help us further understand the needs of people who use AAC in Vietnam. This will enable organizations and individuals to continue to strive collectively to improve the quality of life for people who use AAC in Vietnam.



Establishing an Augmentative and Alternative Communication (AAC) Lending Library in Sri Lanka

by Nimisha Muttiah, Ph.D., CCC-SLP and Shanika Sewwandi, B.Sc.

Augmentative and alternative communication (AAC) is an emerging field in Sri Lanka. Currently, there is only one pre-service training program for speech-language pathologists in the entire country. Recently, the university was successful in establishing "Ayati," a national centre (https://www.ayati.lk/) that is a public-private partnership providing free services to children with disabilities around the country. In 2017, we developed Avaz Sri Lanka, the first-ever AAC communication app that can be used on iPads and Android devices in the local languages Sinhala and Tamil. Although we were successful in developing and launching this communication app, many of the families we see at the centre were unable to afford a tablet to install and use the app with their children. Therefore, although many of the children may have benefited from using the app to communicate, we were unable to provide them with the communication app as we did not have tablet devices that could be provided to these families. In addition, since we did not have any in-house tablet devices or communication apps at the centre, we were unable to even trial the communication apps with the children to determine their effectiveness.

In addition, many of the undergraduate students in the speech therapy program reported that they had limited opportunity to have hands-on experience using Avaz, as well as to learn how to program the communication app.

However, all this changed due to a generous grant of 14,000 euros (approximately US\$16,000) from the Wilde Ganzen Foundation (<u>https://www.wildeganzen.nl/over-ons/english</u>) and Ear Lanka Foundation (<u>http://earlankastichting.nl/</u>) to establish the country's first-ever high-technology AAC lending library. Dr. Robert Van Der Hulst and Mrs. Henriette M. Warendorf, our colleagues from the Netherlands, were instrumental in assisting us to obtain this grant and launch the high-tech AAC lending library.

The aims of the lending library are as follows:

- 1. Trialing communication apps with children who have complex communication needs (CCN) at the Ayati centre,
- 2. Establishing whether the child with CCN could effectively communicate using the communication app in order for parents to consider investing in the purchase of a tablet device and app,
- 3. Loaning tablet devices and apps to families to take home over short periods of time to use the communication app at home in order to determine its effectiveness,



- 4. Training parents to program and troubleshoot the communication apps,
- 5. Providing undergraduate speech and language therapy students an opportunity to interact with communication apps and train them how to program these.

The lending library currently has 45 Android and iPad tablet devices with communication apps loaded on them. Some of the communication apps (other than Avaz Sri Lanka) that are available on the devices are: Jab-Talk, Proloquo2go, and Scene Speak. We have also purchased other useful apps, such as literacy apps (MDA Reader, Phonics Keyboard, Book creator) and a few CVI friendly apps.

The lending library was launched in June 2020. Since then, we have trialed high-tech communication apps with 44 children who have CCN. At present, we have loaned tablets to nine families to use the app and devices in their homes with their children with communication difficulties. Two children with CCN whose families were unable to afford these high-tech devices were able to obtain donor tablets due to showing how effectively their children were able to communicate using the apps. Five parents (who were able to afford the devices) recognized how effectively their children used the communication apps and made the decision to purchase tablets with Avaz Sri Lanka for their children. In addition, during these last four months, 42 parents of children with CCN were trained on how to use and program the communication apps. Over 50 undergraduate speech and language therapy students in the program were able to trial high-tech communication apps with a number of clients they were working with.

In addition to speech-language pathologists, occupational therapists, physical therapists, and educators who work at the Ayati centre also had the opportunity to borrow the tablet devices and use them with the children they work with. All this was achieved in spite of the reduced number of clients we have been seeing due to the COVID-19 pandemic. We are hoping to provide many more children with CCN access to communication through the lending library.



Shanika trialing a communication app with a child with an Ataxic degenerative condition.





Nimisha trialing Avaz Sri Lanka with a child diagnosed with cerebral palsy



Training a parent on how to use and program the communication app

We are grateful to the AAC provider companies who gave us access to free codes of their apps, such as: Attainment Company, Avaz, Smartbox, Speak for Yourself, AssistiveWare, and PRC-Saltillo. Special thanks to Lauren Schwartz Gonzales for writing to these companies to arrange the free codes for us.

If you would like more information about this project or if you would like to donate a tablet device to a family in need, please contact: Dr. Nimisha Muttiah, Senior Lecturer (<u>nimisha@kln.ac.lk</u>) Department of Disability Studies, University of Kelaniya.



A Busy Time of Waiting in Australia

by Darryl Sellwood

It has been a bizarre 20 months since finishing my PhD. There has been a lot of waiting. For the previous six years I had been immersed in academia, investigating the experiences of people who have communication and physical disabilities in developing romantic and sexual relationships.

In the early months of 2019, it looked like it was going to be impossible to submit my thesis before the deadline. I asked the Dean of Graduate Research for an extra month extension. She agreed on the basis that I had to promise to get it finished in the revised time frame and for an extra incentive she said she would buy me a bottle of whiskey if I met that target.

Around the same time, my supervisor advised me not to go to the WOMAD music festival, which I always love to attend in March. I was so determined to go that I made sure I finished the final draft of my thesis the day the festival started!

After I finally submitted the thesis in April, my first response was relief. I was exhausted and elated and proud of what I had achieved, and terrified it wouldn't be good enough. It was hard to know what to do while I waited for my thesis to be assessed. I tried to keep busy but I was so drained from the PhD marathon it was difficult to focus or do anything really productive.



I was fortunate to be able to take a holiday for a few weeks in June 2019 up through the middle of Australia. It was a great way to take my mind off the waiting.



While I was in Alice Springs, I met an emu who thought my hat looked tasty and tried to peck it off my head!



I loved exploring Darwin and had some adventures in Kakadu National Park.

Eventually I got the good news that my thesis would be accepted after some minor amendments. I was so excited but a bit disappointed that I had to wait for another three months before I could graduate and be called "doctor." My supervisor, quite reasonably, wanted to be at the graduation so I agreed to wait until she was able to attend the ceremony in December.



Looking back now I realize that waiting only three months and being able to have an in-person graduation ceremony at all, are real luxuries. It was lovely to be able to go out for dinner to



celebrate with the key people that supported me through the PhD journey. Again, what luxury!

When 2020 began it seemed like half of Australia was on fire. We are accustomed to summer fires down here, but this was on a different scale. It was such a weird way to start the year.

I was still trying to figure out what life after my PhD looks like when COVID-19 hit. At first it was just something happening in other parts of the world but it quickly arrived closer to home. As the pandemic spread, I was feeling anxious and knew I needed to be prepared if things went badly wrong.

There were a couple of months where no one really knew what they were doing. Even the support worker agency was scrambling trying to get new procedures and policies to adapt to a landscape that seemed to change every couple of days.

There has been talk in the AAC world over recent years that people who rely on AAC need to have emergency plans and alternative communication tools available. COVID made me get around to setting up my own emergency pack. This includes information about me, such as my name, disability, medications, and even my likes and dislikes. One of my dislikes is gherkins! But I like dill pickles. Go figure. Important stuff in an emergency.

I have also included information about my communication techniques and an alphabet board and some simple communication pointing boards. Based on what I learned from someone in Germany, I included instructions for using the communication boards with eye movements in case I am unable to point.

I have been conducting university lectures and workshops for many years. During COVID, the universities shifted to remote teaching.

This presented new challenges and I had to adapt the interactive material to be delivered online. Surprisingly, the heavily interactive workshop for occupational therapy students proved to be very successful. This made me realize there may be opportunities to offer similar lectures internationally.

In May, in the midst of the stresses of living through a global pandemic and with significant restrictions on public gatherings, I was advised that I was one of a handful of winners of the Vice Chancellor's Award for Doctoral Thesis Excellence at Flinders University.





After some more waiting, the award was presented in September 2020.

I also finally collected that bottle of whiskey from the Research Dean. It was worth the wait!

Adelaide has been very fortunate with COVID. We only had a few cases and never went into full lockdown. We still have some restrictions; however, we are now enjoying life in a nearly normal way.

I'm currently in my first post-doctoral position as a research fellow with Professor Arciuli at Flinders University on a COVID-related project: investigating online literacy instruction for children with development disabilities. I'm looking forward to exploring other employment opportunities within the university in the years ahead.



Resources

• ISAAC Webinars include a world of information

Please check out our Webinar Archives on the ISAAC website.

Would you like to present a hosted or sponsored webinar through ISAAC International? Please return <u>this form-fillable PDF</u> with details of your proposed webinar and preferred time slot, to <u>Franklin Smith</u>, ISAAC Executive Director.

ISAAC VIRTUAL ONLINE LEARNING: DON'T MISS OUT!

Have you explored ISAAC's free online learning opportunities? ISAAC-sponsored online learning environments feature topical and practical presentations, often with take-away resources for people who use AAC and their families, students, teachers, therapists, researchers, and organizations.



Webinars sponsored by USSAAC are offered six times annually. A recent presentation featured tips from front-line staff working in hospitals experiencing a surge of patients temporarily unable to speak due to COVID-19.

An ISAAC-Canada series, new in 2020, had Gaming and AAC as its popular debut topic.

Spanish-language webinars are part of our ongoing special events.

The ISAAC Online Journal Club is held from time to time, as a forum for a discussion of issues around AAC.

ISAAC continues to offer **Sponsored Webinars**, featuring many of the key companies in the assistive technology industry. Additional sponsored webinars will continue to be announced by eblast and on the ISAAC International website at https://www.isaac-online.org/english/webinars/.





• AAC Awareness Month

We would like to remind everyone to look at ISAAC's website for the creative ways that our community has found to celebrate <u>International AAC Awareness Month</u> in October 2020.

• Educational resources created by Communication Disabilities Access Canada (CDAC)

A new CDAC resource, "<u>Communication Supports in Exercising Capacity, Choice and</u> <u>Autonomy</u>," contains recommendations on how Canada can implement Article 12 in the United Nations Convention on the Rights of Persons with Disabilities. It includes perspectives from people who have lived experience of communication disabilities, speech language pathologists, family members, AAC clinicians, healthcare, community disability services and a human rights lawyer. Click <u>here</u> for more details.

• Podcasts that express the views of people who use AAC

<u>Black Disabled Men Talk</u>: A series of conversations among Black disabled men.

<u>Ouch – the Cabin Fever Podcast</u>: Interviews life hacks, and things you don't say out loud.

<u>Disability Visibility Project</u>: An online community dedicated to creating, sharing, and amplifying disability media and culture.

<u>The Triple Cripples</u>: Intended to be a platform that highlights the lives and loves of disabled black and non-Black Women, Femmes and Non-Binary People of Colour.

<u>Power Not Pity</u>: A podcast the centres and celebrates the lived experiences of disabled people of colour.



Conference News







ISAAC se complace en anunciar que el próximo XIX congreso de la Sociedad Internacional de Comunicación Aumentativa y Alternativa se ha sido reprogramado para 2021. Según lo planeado originalmente, la Conferencia se llevará a cabo en el Centro Internacional de Convenciones (ICC) de la bella ciudad de **CANCÚN**, contigua a la Riviera Maya de la costa del caribe mexicano.

31 DE JULIO - 1 DE AGOSTO, 2021

Campamento de CAA, Talleres Preconferencia, Juntas Ejecutivas y del Consejo

2 - 5 DE AGOSTO, 2021

Congreso principal en el ICC de Cancún, México

Rodeado por la cultura maya y con fácil acceso a playas hermosas, tiendas, restaurants y tours tanto de Cancún como de la Riviera Maya, el congreso de ISAAC contará con eventos de CAA, perspectivas, lo último en investigaciones e innovaciones clínicas, talleres, seminarios, exposiciones de las compañías más importantes, eventos sociales y entretenimiento. Todo en un sitio culturalmente único.

¡Anótalo en tu calendario y aparta la fecha para ISAAC 2020 (ahora 2021) en México!

Para mayor información, consulta nuestro sitio web www.isaac-online.org y síguenos en Twitter #ISAAC2020



www.isaac-online.org



Farewell Note

Thank you to everyone who contributed information and all of you who read CSWN, our global newsletter! Our next edition will be published in May 2021. We would love to hear your news.

Please submit your articles and/or news by March to <u>nadiabrowning@gmail.com</u> and <u>miroslav.vrankic@eglas.hr</u>. The font is Calibri 12. Our content guidelines are approximately 4 pages and 5 photos.

We look forward to hearing from you!

