Introduction

Message from Nadia Browning, ISAAC Council Chair:

I hope this finds all of you and your family well. It has been a difficult time all around the world. This edition includes a few of many creative and innovating projects happening around the world as well as Samara’s experience taking part on ISAAC PWUAAC (People Who Use AAC) committee. We invite YOU to learn what our colleagues are doing and to share your creative projects.

The main goals of Communication Support World Network (CSWN) newsletters are to share what is happening in AAC around the world and to promote networking. The content of this edition focuses on news of international and national communication projects, articles and links to resource material, with practical solutions provided by people around the world, kindly sharing information in this time of global crises of the COVID-19 pandemic and of climate change. A global network in action!

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

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My Experience as a Member of the People Who Use AAC (PWUAAC) Committee

by Samara Andressa Del Monte

Samara Andressa Del Monte talks about her experience as a member of the People Who Use AAC (PWUAAC) committee. PWUAAC meets on a regular basis to connect and support individuals who use AAC around the world. For more information: https://isaac-online.org/english/news/pwuaac-online-chats/.

My name is Samara Andressa Del Monte, I am 32 years old, and I have cerebral palsy. I am in a wheelchair, I do not speak, and I have communicated with Blissymbols since I was 6 years old. To type on the computer, I use the assistive technology resources: helmet with tip, ACAT, and eViacam.

Alternative communication has made it possible for me to work as a freelance reporter. I have my own magazine, Mais dEficiente, which aims to alert authorities and mobilize society with necessary actions for people with disabilities and to show how much potential is possible even with so many limitations.

I knew since I started writing about my life at 8 years old that it would be very difficult to achieve my dreams, but it would never be impossible!

My whole story is told in my autobiographical book, written in partnership with my mother, Claudia Del Monte: Samara - In love with life: Cerebral palsy did not stop me from being the protagonist of my own story.

As an ISAAC member, I promote alternative communication in Brazil, and I love meeting people to exchange experiences. While Lateef McLeod was in Brazil, we met and exchanged ideas, which motivated me to participate in these meetings even more.
I am looking forward to the ISAAC Conference in Cancún, as I will be participating with my communication board using Bliss symbols, which I will not let go of for anything!

We, users of alternative communication from all over the world, participate in an online meeting every 15 days. We discuss many diverse topics, mainly the pandemic, and exchange experiences using alternative communication.

Each participant in the meeting uses the technology they are most familiar with, and the topics of discussion are delivered prior to the meeting, so we can think about them beforehand. The meeting is chaired by Lateef McLeod and Kevin Williams, who are both members of the ISAAC International committee.

With participants from the United States, Poland, Spain, and myself from Brazil, the discussion is all in English. Since I don't speak English, my sister helps me out, but I can still interact. They even made me happy by speaking a few words in Portuguese!
Take the Time to Listen: Hear our Music. Hear our Voices
by Shirley McNaughton

This video was made possible by an Ontario Trillium Foundation grant to help groups adapt to the restrictions imposed due to COVID-19.

Our Music Director, Aaron Lightstone, responded to an invitation to the Bliss i-Band Conference to provide the music keynote presentation at “The Power of Music: Innovations in Care" digital conference.

The conference was presented by 'Music Care Conference', which took place from March 16-18. The conference was organized by the University of Nottingham, UK and Room 217 Foundation, Canada.

https://www.youtube.com/watch?v=cTpC5xSUe1s

"Take the Time to Listen: Hear our Music. Hear our Voices." is the first of four narrative videos that we will be producing in 2021. This first video includes several of the i-Band's favourite pieces - with the i-Band's Music Director describing how the i-Band's playing together has changed due to COVID-19. The i-Band's founders also explain how the group began in 2014. Several of the i-Band's members speak with their voice output devices, and share what they enjoy about the i-Band.
Playing Together and Composing Without Borders or Limits
by Elin Skogdal, Einar Berg-Olsen and Tim Anderson

Samspill og Komponering Uten Grenser, SKUG Centre

The SKUG centre is part of the Music and Performing Arts School in Tromsø, Norway - a resource centre where we use assistive music technology to make it possible for people who cannot play traditional musical instruments to create and play music.

By using a combination of computer technology, access technology (e.g., switches, sensors and eye-control) and music technology, there are no limits as to who can learn to play and compose music. Since the project started in 2003 and the opening of the SKUG centre in 2007, the centre has developed a unique specialist competence in this field of work. Students have individual lessons, play in bands or groups, and play at a variety of concerts and performances throughout the year. The aim is that anyone who wants to learn to play should have the opportunity, regardless of their disabilities. "Anyone" includes students who need to use assistive music technology to be able to play independently, such as students who use Eyegaze or switches to control their communication system as well as their musical instrument. Experience from various schools and projects has shown that people needing technology-based instruments are often not included as part of ‘anyone’, therefore, we see it as extra important to create more possibilities to truly include any person who wants to learn to play.

The SKUG centre has about 25 pupils, from 6 to 60 years old, who attend their lesson every week. In addition to the weekly lessons, projects and courses are carried out in kindergartens and schools in Tromsø, around Norway, and abroad.
SKUG collaborates with developers of custom-made and specialist music technology systems, music education organisations, and universities from Norway, England and other countries in Europe. We have found that teaching music using assistive technology is still a very narrow field of work, but over the years we have built up a network of colleagues from several European countries. Since these colleagues are like little specialized islands in the big sea of traditional music teaching and music therapy, many of them have developed their own adapted instruments or music systems. At SKUG centre we try to keep an open mind and try out what is available, and then pick out the instruments or systems that are best for each of our musicians. When we can’t find the instrument that someone needs, we often end up adapting or developing new instruments, or discovering new ways of combining instruments or systems.

The type of instrument or system which is developed and used can vary from place to place, but people working with assistive music technology most often have a common understanding and view of life. We believe that all people are able to create and perform great music; they just need to be given the right tools and possibilities. This view might have grown out of experiencing the endless possibilities that the technology gives you in adapting and creating solutions.
It has been very exciting for SKUG to take part in a variety of collaborative projects with teachers/instructors and students from other countries. The newly-established “Universal Orchestra”, with musicians from Helsinki (Resonaari), Edinburgh (Drake Music Scotland) and Tromsø (SKUG), is a good example of collaboration between specialist music centres and organisations. Universal Orchestra - funded by the Nordic Culture Fund - is an ensemble in which diverse musicians from different countries and “traditions” can come together to create and perform music.

Universal Orchestra at workshop in Tromsø: https://www.youtube.com/watch?v=UNWzZHNB_og&list=RDUNWzZHNB_og&start_radio=1&time_continue=4

Performing music with your eyes

For many people, ‘Eyegaze’ is the best way to control their communication device, and to generally navigate and operate a computer. This same technology can be used to play and compose music, and the SKUG centre is currently receiving funding from Udir (The Norwegian Directorate for Education and Training) to develop a computer-based musical instrument and teaching tools for music-learning activities in kindergarten and schools. The eye- and switch-controlled musical instrument/system is
called E-Musikk, and its main aim is to enable more children and young people to take part in music activities and lessons at kindergarten and school. It also aims to enable children to enjoy playing music with friends and family at home, and in after-school activities.

How can you play with your eyes?

E-Musikk has a series of menus which you can navigate with Eyegaze or switches to choose an activity: playing, composing, learning about music theory or music history.

The navigation or scanning with switches used in E-Musikk is similar to that used in AAC communication systems, Tobii, Rolltalk or Grid Pad. It is possible to use all these systems to run E-Musikk, or you can use any standard Windows Computer combined with switches or Eyegaze. At the SKUG Centre we tend to use a set-up with a Microsoft Surface PC, along with an Eyegaze bar and mountings from Tobii Dynavox.

You can then choose to play a song from different categories:

The menu of song types within the ‘Spille’ option
In some of the songs, or parts of songs, you can play the instrument freely on the screen.

Here is an example of a harp where each string plays when you look at it, or you can trigger it with a switch:

![Harp example](image)

From doing projects in kindergartens and schools, we have witnessed how singing is one of the most popular music activities, and we have therefore seen it as important that people who use AAC should also be able to take part in singing. In E-Musikk, singing phrases are recorded into on-screen buttons, and when a child looks at a button, it sings that phrase. You can choose to show all the phrases of a song on the screen and play any one of them. If this is too difficult, you can choose to have the buttons organised in a sequence. Next, you are guided through the song one button at a time, in the right order of the song. You can also choose to only show one button at a time on the screen. In this way, a child can get to know the song, and practice and learn how to play it.

Similarly, you can play a song phrase by phrase with a switch. For example, here is Arne playing «Vise ved vintersolkvær»: [https://www.youtube.com/watch?v=Jj1cyMFxDoc&t=10s](https://www.youtube.com/watch?v=Jj1cyMFxDoc&t=10s)

The ability to turn supportive features on or off (e.g. organising buttons in a sequence) makes it easier to adapt E-Musikk for people who need different levels of assistance and adaptations to be able to play. Other ways of adapting it are to change the size, position, colour, labels and pictures of the buttons on the screen. You can also choose to use the “play-lock” function, so
that the music from one button has to finish playing before you can start playing a new button. Using this makes it a lot easier to play because musicians don’t need to hold their gaze for a long time on the button/music while it is playing.

It’s been important to us while working with people of varying ages and abilities that everyone can experience that making music is something they can do. In developing E-Musikk and other adapted musical instruments, we see it as important to let the users give a lead on which features may be useful and helpful. Thus, both its features and content have been developed in collaboration with students and teachers from SKUG and schools around Norway.

Adapting and arranging music to suit each person’s instrument and playing abilities and style, is an important part of making an instrument suit the individual musician, as well as making E-Musikk fit into the curriculum of music teaching. One example of content development is a student who wanted to learn to play the guitar with the rest of his class using his eyes. To enable him to do this, we developed a chord library where you can choose guitar chords to play with a song or you can play the chords by looking at the frets of the guitar neck pictured above.
Some people need the screen to be easy to look at, using large buttons, and with only one button showing at a time:

Other people want to read standard notation, and can manage to look at smaller buttons, so can play with finer detail:

Presentation of a young Eyegaze musician

One of our young students, Mia, is nine years old and goes to a mainstream school. She was five years old when she started playing music with her eyes, trying out the very first prototype of our eye-controlled musical instrument. Now she is a member of the E-Musikk reference group, and has helped us a lot in testing features and finding and playing musical content. Mia can’t sing with her voice, but here she is playing E-Musikk to sing the song “Head, shoulders, knees and toes”, with girls from her class doing the movements: https://www.youtube.com/watch?v=-u-Sb5Z5s9o&t=10s

We have explored and tried out various solutions and possibilities with Mia, who gives us feedback on which features she likes and which music she likes to play.
More recently we have developed Eyegaze controlled navigation buttons, so now Mia can choose which music she wants to play. She loves playing with friends from her class or other musicians from “Kulturskolen”. This term, we have been working with Mia as she does a music project with her class on the topic, “Music in Space”. The instruments used in the project are on E-Musikk played with Eyegaze and switches, along with Soundbeam and the ThumbJam app on the iPad.

Mia has shown her friends how to play with their eyes, and they have had the chance to experience the amount of concentration needed to play what you want to play and when you want to play it. It was great to see all the children creating music together in a setting where everyone had equal opportunities to play an important part in creating the final project. As well as learning more about music and having fun together, it gave Mia’s friends a better understanding of how she is playing and communicating. Shared experiences like these provide something to talk about, and the opportunity to make plans for future music projects.
From inclusive education to creative work

With a more inclusive music education system, there will hopefully be more opportunities for people with disabilities to follow a path to become professional musicians. Bringing assistive technology into the music scene as instruments creates more opportunities for active participation by people who are often not even given access to getting onto a stage (e.g. no ramps or lifts). The endless variety of expression which technology-based instruments can provide - either on their own, or in combination with traditional instruments - opens up a new sound world of music, which can give unique musical experiences to both the audience and the musicians taking part. We can now see examples of culture projects and companies where people with disabilities can get a job in which they can use their interests and creative talents. As well as SKUG employing music workers with disabilities, the film company Cam on Wheels in Rotterdam https://camonwheels.nl/, and Digjobb in Norway https://www.elevkanalen.no/open/digjobb, are examples where people using AAC are given the opportunity to do amazing creative work.
Tele-AAC in The Philippines During the COVID-19 Pandemic: Barriers and Challenges Faced by Speech-Language Pathologists

by Ellyn Cassey K. Chua, AAC Special Interest Group of the Philippine Association of Speech Pathologists, University of the Philippines Manila

The Philippines has been systematically training speech-language pathologists (SLPs) to provide AAC services for around 7 years now (Manalansan, 2015). Whilst access to AAC services increased during this time (Manalansan et al., 2018), service delivery challenges remain. With the recent shift to telepractice brought about by the COVID-19 pandemic (Kuvač Kraljević et al., 2020), these challenges were highlighted and compounded by the additional challenges of telepractice.

In order to understand the telepractice barriers and challenges faced by AAC-trained speech-language pathologists in the Philippines, the AAC special interest group (SIG) of the Philippine Association of Speech Pathologists conducted a focus group discussion (FGD) on April 11, 2021. Of the six SLPs who participated in the FGD, three have provided both assessment and intervention services via telepractice, two have provided only intervention services, and one has yet to provide AAC services remotely. Based on this FGD, several barriers and challenges were identified. These can be categorized into 1) factors hindering SLPs from providing tele-AAC services in the first place, and 2) challenges encountered by SLPs already providing tele-AAC services.
Factors hindering SLPs from providing tele-AAC services:

Knowledge of and attitudes toward AAC and telepractice

The most frequently cited and elaborately discussed barrier during the FGD was the difficulty in getting clients’ or families’ buy-in. Although this challenge has been reported prior to the field’s shift to telepractice (Chua & Gorgon, 2019), clients’ hesitations towards AAC seem to have been heightened through the addition of telepractice. As per the SLPs’ reports, most parents prefer in-person assessment and direct intervention, especially when their children present with challenging behaviours.

Parents who agreed more readily to tele-AAC services were apparently those who already had some background in AAC (e.g., parents who are special education teachers). For those parents who seemed hesitant at first, one SLP reportedly started to informally observe the client’s skills for AAC use while waiting for the parents to arrive at a decision. Another SLP shared that they found it helpful to just start using some AAC strategies in therapy. In their experience, when parents saw that these strategies worked for their children, they were more likely to be supportive when the need for a comprehensive AAC assessment was formally brought up.
Clinicians’ lack of preparation time

According to the SLPs who have yet to conduct AAC assessment via telepractice, they lack the time to develop tele-assessment protocols, forms, and materials from scratch. Aside from their standard work duties (e.g. collaborating with clients’ main/other SLP, training student clinicians), telepractice has been requiring them to spend much more preparation time than usual (i.e. compared to what they previously did for in-person therapy sessions). To address this barrier, one SLP’s institution is planning to mobilize their clinicians and student clinicians to collaboratively work on developing protocols and materials.

Challenges encountered by SLPs providing tele-AAC services:

SLP and facilitator skills

The main challenge cited during the FGD was the extra effort required to instruct clients and their facilitators (i.e., parents, etc.) during both assessment and intervention. Whereas clinicians could simply model expected responses during in-person sessions, telepractice forced them to rely on other instructional strategies (e.g., giving verbal instructions, using visual supports). The SLPs shared that instruction was more effortful and less effective for facilitators whom they did not get to train in-person before the pandemic started. To manage this difficulty, one SLP suggested the use of pre-recorded instructional videos. These videos can reportedly be sent to the facilitator for them to study before the tele-session.
**AAC and telepractice technology**

One technological challenge that was brought up was the lack of robust AAC systems (devices, software) that can be lent to clients for trials. One SLP had to let their client borrow one of their own systems despite the risk for accidental damages, etc. Another SLP wanted to do the same thing for one of their clients, but the latter lived in another island group (i.e., group of regions) so it was not practical or cost-effective to send the system via courier. Since it is also unreasonable to make clients pay for systems that might not be recommended to them, the SLP decided to just conduct trials using free AAC apps and manual communication boards.

![A client having a tele-AAC session with Mr. Jeremiah Pinca](image)

Three telepractice-related technology issues were also discussed. First, the SLPs reported that it was difficult to see what their clients were pointing to on their screens (or pressing on their devices). As suggested by one SLP, if a second camera can be acquired, this problem may be addressed by directing this second camera to the client’s device. Aside from seeing what their clients were pointing to, the SLPs also shared the challenges of remotely programming vocabulary into clients’ devices. One SLP mentioned that they had to completely rely on facilitators to add to or edit vocabulary pages. Another SLP shared that some apps have a ‘sync’ feature that allows clinicians to see and edit clients’ pages on their own devices. The last issue raised was the poor or unreliable internet access of SLPs and clients living in disaster-stricken provinces. Typhoons often damage these areas’ electrical and telecommunication lines, so synchronous tele-sessions were sometimes difficult or impossible.
Going beyond barriers and challenges

The input received during this FGD will be used by the AAC SIG in selecting or designing locally relevant continuing education and public service activities. For instance, the FGD results will be forwarded to the resource person who was invited to give a seminar-workshop on tele-AAC assessment later this year.

The AAC SIG of the Philippine Association of Speech Pathologists would appreciate any other solutions to the challenges we are facing during this difficult time. For ideas or suggestions, please email Barbara Munar, MRS-SP, CSP-PASP, the head of the AAC SIG, at pasp.aac.sig@gmail.com.

Acknowledgements

I would like to thank Ms. Barbara Munar and Mr. Jeremiah James Pinca for suggesting and organizing this FGD; the six FGD participants for sharing their experiences; and Mr. Alrenzo Ludwig Domingo for taking notes during the FGD. I would also like to thank Ms. Munar, Mr. Pinca, and Ms. Suselyn Pascual (the current PASP president) for sharing some photos for this article. All client photos were taken and used with consent.

References


Diplomado en Comunicación Aumentativa y Alternativa – First Ever Postgraduate University Program in AAC in Spanish

by Claudia Marimon Rigollet

Claudia Marimon Rigollet and her team from “Buenas Prácticas de CAA”, Chile created the first postgraduate university course certification in Augmentative and Alternative Communication in Spanish. The Universidad del Desarrollo, in Chile, [https://www.udd.cl/](https://www.udd.cl/), recently approved the “Diplomado Comunicación Aumentativa y Alternativa” with a total of 102 hours and 100% virtual communication.

This program was designed with theory and practice aimed to prepare professionals in providing augmentative and alternative communication services to people with complex communication needs in family, school and community settings. Specialized training will be acquired in evaluation, intervention and implementation of AAC systems and practices to support the development of language, communication and literacy for linguistically diverse people.
This course will be delivered by prominent presenters from different disciplines, specialists in AAC, from various countries, with many of the presenters also being ISAAC members. It will also include visiting professors with great experience and international recognition in AAC; and individuals who uses AAC systems and their families who will share their experiences.

This course will be carried out combining a variety of didactic methods adapted to each format. The theoretical development of the course is structured based on learning objectives. Each objective is associated with learning units and one or more activities to ensure aquisition of knowledge. Students will have constant support from their teacher through forums on the platform, with active student participation being encouraged. The program will also end with a case presented by the student.

This first-time course already has 21 students registered from Chile, Costa Rica, Spain, Mexico and Peru. The aim is to keep the classes small to ensure adequate learning.

Claudia and her academic team are excited and motivated to provide education and support to graduate leading professionals in AAC in the Spanish-speaking community.
What is the Play Manual?

by Miryam Pelosi

The Play Manual is a collection of more than 40 videos, including suggestion of related materials and digital games with playful and educational activities: (https://www.youtube.com/channel/UCO78PGYHztPVjM-RvDlq4hA).

In March 2020, Miryam started carefully preparing these resources and posting the videos online. Miryam is an Occupational Therapist and Associate Professor with the Department of Occupational Therapy at the Federal University of Rio de Janeiro (Brazil). She has her Masters and Doctorate in Education from the University of Rio de Janeiro. The material includes videos that show how to play using augmentative and alternative communication. The activities are fun and promote decision-making and use of core vocabulary. Here are some of the videos that Miryam has posted:

https://www.youtube.com/watch?v=TdEKGuhzNgg
https://www.youtube.com/watch?v=pVhW9Jia8B4
https://www.youtube.com/watch?v=9l7cpiXvriA
Resources

- COVID-19 resources on the ISAAC website: https://isaac-online.org/english/covid-19-resources/

- Free COVID-19 communication tools and resources from Patient-Provider Communication: https://www.patientprovidercommunication.org/

- Free material: https://www.widgit.com/resources/index.htm

- The Bridge School has hosted many workshops on Cortical Visual Impairment, among other webinars. Please check them out (it is all free): https://cvi.bridgeschool.org/

- News from the UN Department of Economic and Social Affairs (UN DESA): https://www.un.org/development/desa/un-desa-voice/2021/05

- ISAAC Webinars: Current and Archives: https://isaac-online.org/english/webinars/

- A blast from the past: Revisit the birth and growth of ISAAC, as presented in ISAAC Story 2008. A project of the Friends of ISAAC, this light-hearted video was created in celebration of our 25th Anniversary. Enjoy!
Conference News

The Power of Connecting

ISAAC Connect is an all-virtual event, scheduled for August 9th to August 12th, 2021. Registration is NOW OPEN.

Keeping up with what’s new is critical to your participation in the world of AAC. After a disruptive year, we need to connect more than ever before to keep the momentum going—until we can meet again.

ISAAC Connect provides a new, far-reaching, and inclusive opportunity to assemble virtually on a convenient, easy-to-access platform during this important time between live gatherings. This event focuses on ensuring you are able to connect with the most recent research, industry developments, and key contributors to move your efforts and solutions forward, growing together as a community.

ISAAC: Where the AAC Community Gathers

Don’t forget, ISAAC Conference 2020 has now been re-scheduled for July 30 – August 4, 2022. Updates are available on the ISAAC website.
Farewell Note

Nadia’s term as the Chair of ISAAC will end in September 2021 and Signhild Skogdal will be the ISAAC Council Chair September 2021-2024. It has been a total pleasure connecting with so many interesting people around the world and learning about their work and experiences.

I welcome Signhild as the co-editor of CSWN Newsletter, to join Miroslav in editing the next CSWN newsletter.

Thank you to everyone who shared your ideas, resources and information and all of you who read CSWN, our global newsletter! Our next edition will be published in December 2021. We would love to hear your news. Please submit your articles and/or news by October 15th to signhild.skogdal@uit.no and miroslav.vrankic@eglas.hr. The font is Calibri 12. Our content guidelines are approximately 4 pages and 5 photos. We look forward to hearing from you!

Wish all the best to all of you and stay safe,

Nadia and Miroslav