

June 2022

Find out what is happening in AAC around the world.

And connect.

In this edition:

- Making playgrounds and museums accessible
- Inspiration and collaboration in Region 2
- From idea to an award-winning team of mentors
 the Atmentor journey
- Crowdsourcing AAC translations
- First person with Kristy Lipe
- Diego's story, from Santiago de Chile

Co-editors:

Signhild Skogdal, Chair of the ISAAC Council Miroslav Vrankic, Chair of ISAAC BUILD Committee



Table of Contents

Important Notice – 2022 Special Meeting of the ISAAC Council	3
News from ISAAC-NF	4
Inspiration and community in region 2	6
The Atmentor Journey	9
AAC for Bilingual clients in the UK	12
News from Kristy Lipe	14
AAC Mentoring Program at Amancay Rehabilitation Center	15
Conference News	18
Farewell Note	18

The CSWN Newsletter is published twice each year by the International Society for Augmentative and Alternative Communication (ISAAC) 312 Dolomite Drive, Suite 216 Toronto, ON M3J 2N2 Canada Phone: 905-850-6848 Fax: 905-850-6852 Email: feedback@isaac-online.org Website: www.isaac-online.org

The December 2021 issue and CSWN archives can be viewed on the ISAAC website at: <u>https://www.isaac-online.org/english/news/cswn-newsletter/</u>



Important Notice – 2022 Special Meeting of the ISAAC Council

In accordance with section 11.5 of the Bylaws of ISAAC, this is the official notification that a **SPECIAL MEETING** of the **ISAAC Council** is being called by Juan Bornman, President and Signhild Skogdal, Chair of the ISAAC Council.

Date: Friday, September 23rd, 2022 Time: 11:00 to 15:00 (Toronto time) – <u>Converted World Times</u>



<u>Registration Required</u> (Meeting will be held on Zoom)

In accordance with section 11.5.2 of the Bylaws of ISAAC, the business to be conducted at this Special Meeting will be as follows: 1.Introduction to Council of 2022-24 EB members and thanks to outgoing EB membersJuan Bornman and Tracy Shepherd (5 min)
2.2021 Audited Financial Results Franklin Smith and David Fosbery (15 min)
3.Presentation of 2022 / 2023 Emergency BudgetFranklin Smith (15 min)
4.2022 Auditor ApprovalFranklin Smith (5 min)
5.By-Laws and Governance HandbookTracy Shepherd (90 min)
6.Social Break Gabriela Berlanga (20 min)
7.Council Reports Signhild Skogdal and Catia Crivelenti de Figueiredo Walter (90 min)
8.Closing RemarksSignhild Skogdal (5 min)

Called by the President of ISAAC, Juan Bornman Called by the Chair of the ISAAC Council, Signhild Skogdal June 1st, 2022



News from ISAAC-NF

by Maartje Radstaake

In the past year we've finished a few projects that we would like to share with you.

Playground boards

Every playground should be accessible for anyone, that includes individuals with complex communication needs (CCN). As clearly stated in the UN Conventions on the rights of individuals with disabilities, there should be no obstacles for participation. To stimulate communication and play between individuals with and without CCN we created AAC Playground Boards. Using the pictograms, you can say it's "boring" if you want to "stop", or maybe you want to go "home" or you really "like" another child. The boards can be used by anyone and are especially useful for those who have trouble communicating with and/or understanding verbal speech (in our case: Dutch). It is therefore not only a tool for those with CCN, but also for refugees or individuals who do not speak Dutch (yet) due to immigration or age. With the cooperation of both Picture Communication Symbols (PCS) and SymbolStix (SS) We are able to provide free downloads which are of sufficient quality to print on A0.

Besides the individual advantages in the playground, we also hope that they will a) foster inclusion of individuals with AAC in broader society, as AAC is more visible for the general public and b) introduce AAC to those who have never heard of it (and might need it). You can download the AAC Playground boards here: <u>https://www.isaac-nf.nl/overons/artikelen-en-onderzoek</u>.





Museum cards

Together with the Dutch organization for individuals with severe intellectual disability (EMB Nederland) we created Aided Language Displays for the museum. These cards can be used in all kinds of museums, preferably together with core words from personal AAC materials or devices. It can be used by anyone and functions both to increase communication towards the AAC user as communication coming from the AAC user. On the back of the card we explained what modeling entails and how this card can be used. It's been distributed to 300 museums in the Netherlands and Belgium and can be downloaded here: <u>Nieuwsbrief - Over ons - ISAAC-NF</u>



"The success of AAC" – a short movie

With help of the Dutch Angelman syndrome parent organization (vASN) we've made a short film about AAC. This film shows inspiring examples of Augmentative Alternative Communication (AAC). It shows common myths in the AAC world and shows how AAC helps in expressing yourself. No one is too limited, too young or too old to learn AAC. It can be watched with English subtitles here: <u>The success of AAC.mp4 on Vimeo</u>. We joined up with de vASN to apply for funding to tour though the Netherlands to teach and inspire others about AAC. The funding was granted and we've visited the first out of 40 institutions, schools and/or specialized day care centers. Every session starts with the movie and is based on our "AAC Guidebook", which can be found on our website. It's a bundle of clinical experience and scientific knowledge and it has been sent to more than 600 institutions, schools and specialized day care centers in the Netherlands.





Inspiration and community in region 2

by Margit Grønkjaer

Region 2 consists of Norway, Poland, Sweden, Netherlands/Flanders, Russia, Ukraine, and Denmark

So far, Region 2 has been the most active region in ISAAC International, we have already had 4 meetings and have planned a meeting for the start of September.

The number of meetings exceeded what we were asked for by the Chair of the Council, and that fact shows that we find it meaningful to exchange ideas and challenges in this forum.

At our meeting in June, I asked for input from the countries for this article and I got some answers from all participating countries.

Common initiatives ongoing and planned

In March, Janice Light was contributing to the Danish physical conference with a digital presentation, and users from the region had the option to participate on Zoom with 37 attending the online version.

At the start of June, we had a common regional webinar with David Mcnaughton on transitions. 39 were participating from all countries except Russia.

Ukrainians from Odessa were a larger group, participating for free. Other countries paid to finance the translation into Polish. The translation is now complete and has been sent to the Polish participants.

Two more webinars are planned:

19th of August: Janelle Sampson, Australia: **Considerations for assessing, planning, and** evaluating meaningful outcomes in AAC. Using a roadmap instead of a recipe.

And 23rd of October: Catherine Harris: Communication Access UK

All webinars will be translated at least to Polish, and if needed and possible to other regional languages.



Dreams of future

We could take part in the future in each other's conferences both virtually and perhaps physically if we get some funding.

Examples of collaboration – ongoing and future

The Netherlands have given us inspiration by sharing their playground initiative that we could translate from their website. Also, they have made a very nice movie trying to puncture the myths of AAC. At the meeting, we watched the movie together and we asked them to subtitle it in English for people who do not understand Dutch. They did so immediately, and after that we will produce subtitles in Swedish, Norwegian, Danish and Polish as well. These examples are described by Maartje Raadstaake elsewhere.

Also, the Dutch chapter had made communication boards for Rijksmuseum in Amsterdam, succeeding to get press attention on the event.

Inspiration and energy to the local work in ISAAC Chapters

We all feel that we can give and take inspiration from the other chapters in issues such as: how could we get more members? How can we balance giving value to the members and still reaching out to as many as possible?

The Dutch chapter had made communication boards for Rijksmuseum in Amsterdam, succeeding to get press attention on the event which is an example of inspiration in PR work.

We all try to optimize our *websites*, and could we help each other with this? Should we make a regional design model?

We all try to involve more AAC *user activities*, and we are listening and learning from each other's initiatives. For instance, Norwegian AAC users attended the Danish conference on Zoom listening to Frank Dalhoff, AAC user, telling of his experiences in making art.

Polish experiences with user discussion clubs are interesting and the Norwegian project on mentors will be interesting to follow in the future.

Different countries have different challenges in *legislation* – the right to communicate, the funding of devices accessibility in the community and so on.



In Denmark, we had a fine input from other countries when we raised the question of Autism and AAC.

Both in the comforting way: "We are having challenges as well", and in good examples from others.

We all find that we can fetch energy and good examples from our regional community. After these 4 meetings, we know each other better and even have contact between the meetings. If we should tell something to the other regions:

The more meetings the more knowledge of each other's forces and challenges, the more meaningful the existence of regions becomes. Get started, and it will grow.



The ATmentor Journey 'Inspire, include, achieve.'

by Gregor Gilmore (ATmentor) and Andrea Sharples (Director, ATtherapy)



Within this article, ATtherapy and ATmentors would like to share with you our exciting journey looking at the growth of AT Mentors from an idea to an award winning, professional team of mentors supporting others using AAC.

ATtherapy is a specialist, independent speech and language therapy service based in the UK. Our team consists of 24 therapists, supported by assistants and assistive technologists as well as a growing team of ATmentors. ATtherapy supports people with a wide range of communication needs, with AAC and AT as a passion within our team. AT mentors are now a key part of the AT therapy group.

So, why did ATtherapy feel the need to develop the ATmentor service? As a team of therapists, we were experiencing some barriers introducing and building AAC skills. Some AAC users in the UK, particularly those in mainstream schools, may have reached teenage years and never met anyone else communicating in the same way as them. Due to this, some families and users themselves did not have a long-term vision of what can be achieved with AAC and people were isolated. As a team of therapists, we were frequently contacting experienced AAC users and asking for advice to support our beginning or less confident AAC users. As a result of their lived experiences, AAC users have innovative, unique, practical solutions to difficulties AAC users are facing.

We needed a team of experienced skilled AAC users to support people just beginning on their AAC journey. We also wanted to create a mentor career pathway for proficient, confident AAC users.

So, how does it work? The ATmentor service can take direct referrals for mentoring, or therapists can identify the need for mentoring. Mentees are then offered a free taster session



and are encouraged to go to the ATmentor YouTube channel to see more. Following this, mentors are matched to mentees and the mentors and therapists will set aims and visit the mentee jointly for at least the first session. From this point on, the journeys are individual, and the mentor will plan sessions, write up case notes following the visit and become part of the clinical team supporting the mentee.

There are a diverse range of sessions which are all tailored to the individual mentee. Sessions in the mentees home take place with activities such as playing games, quizzes, pamper sessions or having take-out food. Sessions in the community may take place, e.g. at a bowling alley or cafe. Many mentees like to practice role plays at home, then in the following session take this practice into the community, e.g. ordering in a coffee shop. During the recent COVID-19 lockdown, sessions took place online, meaning that mentees did not miss out on vital help and support though this challenging time. Video support, with mentors and mentees exchanging personalised videos made for each other, have proved to be an innovative and motivating way for mentors and mentees to stay in touch. Mentors also deliver training packages to support staff at home and school and have also delivered at conferences e.g. Communication Matters and ISAAC Connect.

Working at ATmentors is a professional career and not a volunteering role. ATmentors are fully supported to ensure that they progress and develop in their mentoring skills. Regular workshops on topics such as confidentiality, activity planning, writing up case notes and networking take place. Regular clinical supervision and annual appraisals, provide feedback on how mentors are performing at work and discuss targets for professional development. Mentors report this structure and having a paid job gives an increased sense of value to the role. Mentors can progress through from trainee mentor to highly specialist mentor by completing training and meeting appraisal goals. Professional mentoring qualifications funded by the National Lottery Community Fund and developed with the support of Communication Matters have provided opportunities for training and support.

"Young people who use AAC can have limited opportunities to get out and about and meet other people who use communication aids. Everybody has a role model. Think who yours was growing up." Gregor Gilmore, ATmentor.



In 2019, the ATmentor service won the AAC user award at Communication Matters. This was one of the proudest moments, for the service to be recognised by the UK AAC Community and by Communication Matters, the UK chapter of ISAAC.



The ATmentor service continues to grow from strength to strength with many ideas for future development.



Gregor Gilmore ATmentor

Andrea Sharples Director, ATtherapy

info@attherapy.co.uk www.ATtherapy.co.uk

June 2022



AAC for Bilingual clients in the UK

by Will Wade

Ace Centre is a UK based charity supporting anybody who needs access to technology for communication or learning. We work across the UK from our two sites in Greater Manchester and Oxfordshire and we support many people directly and indirectly through free information appointments, helpline and free resources – including training - online. For example, we have a range of free eBooks that can be viewed online or on a tablet device at https://acecent.re/ebooks - supporting getting started with AAC for families and professionals – as well as a lot of downloadable charts and templates to get you started.

Our vision is to help create a society where everyone is given the support they need to communicate, be understood and fulfil their potential. To do this means that as well as providing this support by creating new resources, we also aim to keep resources alive which are essential to many people. We don't want to do this in isolation; there is a vast network of family members and professionals in the field across the globe who can help build communication resources.

For example, Speakbook (<u>https://acecentre.org.uk/resources/speakbook</u>) is a free and simple communication tool that was developed by Patrick Joyce who had Motor Neurone Disease (MND / ALS). Patrick realised that there was a need for a cheap and easy-to-use way of communicating for people who can read and spell and can move their eyes, but struggle to point with their finger or hand. So, he developed a template for a communication book which you populate with your own messages. It also provides access to an alphabet chart. While originally developed for people who have MND, Speakbook has been shown to be useful for anyone who is literate and requires a communication tool that they can access with their eyes. For years, professionals in the community have been using and sharing Speakbook with families and found it to be an invaluable resource.

After Patrick sadly passed away, the project became hard for people to find. As Patrick had put the original project under an open licence Ace Centre were able to continue his work and reshare the project.

Additionally, we could redevelop it so it could be available in even more languages. Through crowd sourcing the required translations and adaptations we are now able to share SpeakBook in 10 languages (Afrikaans, English, French, German, Maltese, Portuguese, Spanish, Swedish, Turkish & Zulu) – in both 'colour' and 'colour blind friendly' versions.



We would love to see this project grow and grow. If you can create a translation in another language, please join the project and use the website to create your translations: <u>https://poeditor.com/join/project/wKsMtKRLIj</u>. Just add your translations – many versions require subtle changes e.g., different keyboard layouts or different words. We can make these changes for any language that you require. Just get in touch <u>enquiries@acecentre.org.uk</u>

In the future we hope to have many of our free symbol and alphabet boards in different languages. We are looking for people who understand AAC and can translate from English into another language. If this sounds like you, then please email <u>enquiries@acecentre.org.uk</u> with your details and we will reach out when we are ready for translations. Thank you!



News from Kristy Lipe

by Kristy Lipe

Hello CSWN Newsletter!

I'm Kristy Lipe, I'm thirty-one years old and I'm coming to you from Memphis, Tennessee! I have cerebral palsy, but that doesn't stop me from doing much! I use the Accent 1400 and I operate it with a Freedom Switch. I use the Unity 144 system and I've been using this Unity system since kindergarten. I'm one of the PRC Ambassadors and I love showing people just how awesome communication devices are and how they can really open and impact the world of a child or an adult! My interests include fitness and wellness, theater and dance! But on a really nice day I'm usually running in my wheelchair around the block or lifting weights outside! I took taekwondo for eight years and I'm a 3rd degree black belt and three time world champion in ATA. I continued my education after that because I had a calling to do ministry, so I have a certificate in Ministry and Leadership from Moody Bible institute in Chicago.



Living the everyday life with a communication device is so cool, I couldn't be as independent or creative as I am without my Accent. Art has always been one of my strengths and right now I'm teaching myself to do graphic design on the Mac app, Vector and I love it! Having a communication device lets me be a normal young adult too! I can make plans with my friends or cousins and I don't have to worry about if they don't understand me because I always have my Accent with me! And at home I can be pretty self sufficient and independent with it too! I keep a shopping list in my Notes app on my Mac so whenever I'm out doing something I can keep up with everything and manage myself! But the thing I love doing the most with my Accent is being an advocate for others with Special Needs! I feel like that's my purpose in this life! I've gotten to witness a lot of really amazing things so I really hope I can keep advocating for others as time goes on!

Kristy Lipe

June 2022



AAC Mentoring Program at Amancay Rehabilitation Center

by Claudia Marimón Rigollet

Amancay Rehabilitation Center is located in Santiago de Chile in South America. Amancay provides assessment, intervention and support to individuals of all ages who can benefit from Augmentative and Alternative Communication systems. The AAC evaluation and implementation program is led by Claudia Marimón Rigollet, a special education teacher and member of ISAAC for many years. Claudia has recently joined the BUILD Committee and shares her experience with us:

At the BUILD Committee, we are developing a mentoring program to support users, families and professionals who can benefit from the orientation, guidance and experience of a mentor in different AAC needs.

This year I met Diego and his mother, who attends Amancay Center for his rehabilitation. His physical therapist referred him to Augmentative and Alternative Communication to identify his abilities, communication needs and use of assistive technology for learning.

Diego is a sweet, observant boy who visually explores the environment from his wheelchair. He engages with people using his eyes. Diego is attentive and interested in the stimuli and activities proposed.

Diego has an Emergent Communicator profile. He communicates using a combination of body expression and sounds, understood by his mother. He has not yet acquired an expressive communication system through symbolic systems.





Diego's mom, Yasna, tells us that she can understand some things he wants to say, but many times she has to guess and that frustrates him. Diego was born with a hereditary congenital neuromuscular disease that although causes muscle weakness is usually non-progressive. (Nemaline myopathy type III).

Based on the application of the AAC Checklist, it was decided to evaluate Diego using the Eye-Pointing Classification Scale which allows describing the behaviour of his eye gaze. According to this scale, the level that best describes the behaviour of Diego's gaze (at the time of evaluation) is Level IV: Fixed Gaze. Diego manages to fix and maintain his gaze, actively and constantly, on objects or faces.

In order to motivate Diego to achieve more active participation, activities were carried out on the computer with an "eye-tracking" device and specialized software. A Tobii Dynavox device with a PCEye 5 camera with Look to Learn software was purchased with resources provided by one of the Professors of the CAA Diploma at the Universidad del Desarrollo.



Diego and his mother were very emotional and excited that this system allowed Diego to control simple activities with his eyes. This experience motivated me to start this mentorship. We know that learning to communicate using eye gaze technology requires resources and training.

We started by introducing concepts of augmentative and alternative communication, access method, use of the devices and the strategy used to support Diego to communicate and the role of the communication partner.

Eye Gaze technology is a learned skill and must be trained and developed. Diego will continue his evaluation/intervention process using high-tech devices and software in sessions at the centre and with activities at home with low-tech resources.



With the aim to develop cognitive and motor skills necessary to learn to use the Eye gaze for a variety of daily activities and communication, the environment was designed to provide opportunities for him to participate and communicate, improve access and eliminate barriers.

Based on this evaluation, we contacted the special school where Diego attends so that they can implement these strategies and resources with him in the school environment. It is suggested to start the working:

- With regular and frequent sessions
- In short, sessions, to reduce the effects of fatigue
- Begin by focusing on skills (eg, cause and effect, focus, permanence) through activities or games
- · Make use of a variety of modelling strategies

The mentoring includes support and intervention of the Amancay professional team and the design of an individualized training plan.

The team believed that this technology is required for Diego's personal use in his home as he is expected to learn to use this system for communication. His mother was advised to explore options for help in our country.

His mother has been supported in obtaining all the necessary documentation to apply for these grants, as soon as possible. I do not rule out the possibility of resorting to contacts through ISAAC and our BUILD Committee, if we are unable to obtain aid in Chile.

While this whole process continues, Diego enjoys his sessions and advances each day in his communication and learning.

We, as a Center and personally as a mentor, feel very proud of the effort and dedication of Diego and his family, in this dream of giving Diego a voice and the right to communicate.



Conference News

ISAAC Conference Cancún is scheduled from July 24 – July 27, 2023 in Cancún, México!

Visit the <u>Conference Cancún webpage</u> for details.

ISAAÇ CANCUN MEXCOO COMMUNICATION EVOND BOOTRS OMMUNICATION BIY 78-127, 2023

<u>ATAAC 2022</u> conference on the advanced technology for people with disabilities will be taking place in Zagreb, Croatia from September 29 – 30, 2022.



Farewell Note

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 2022.

We would love to hear your news. Please submit your articles and/or news to signhild.skogdal@uit.no and miroslav.vrankic@eglas.hr. The font is Calibri 12. Our content guidelines are approximately four pages and five photos.

We look forward to hearing from you!

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