December 2021
Introduction

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 the news of international communication projects, developments in the field of AAC and the successes of this past AAC Awareness Month campaign in October.

By Co-editors Signhild Skogdal (Chair of the ISAAC Council) and Miroslav Vrankic (Chair of ISAAC BUILD Committee)

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The name of the Nika Project originates from a Zulu word, meaning “to give, to supply.” Since starting in 2014 in South Africa, the Nika Project team of volunteer speech-language pathologists, assistive technologists and educators has traveled to over ten countries to provide AAC and AT tools for teachers, students and families. When international travel halted in March 2020, the Nika Project pivoted to respond to the restrictions imposed by the pandemic. This article describes how the Nika Team transitioned to virtual connections with international partners, rising to the challenges and continuing to collaborate across cultures and languages to enhance AAC services.

A Short History of the Nika Project

The development of the Nika Project began with a personal contact by a teacher from South Africa in 2013 that led a team of eight Nika volunteers, including; three speech-language pathologists, one special education teacher, a nurse, a librarian and two assistive technology specialists, to travel to Khulani, a small rural school in eastern South Africa. During their two-week trip, the Nika Team worked with 30 teachers and over 300 students with disabilities to use refurbished tools including iPads, iPhones, and digital cameras for students to communicate and learn. They also rebuilt a technology lab for staff training and hosted training for five additional schools and over 130 government officials. This trip provided the
impetus for continued expansion and development of what became a Nika approach to international projects - repurposing and redistributing technology tools to special needs communities and enabling the transformation of education and communication in an understandable and sustainable model. Now, eight years later, the Nika Project has conducted projects in Brazil, Argentina, Guatemala, Peru, Trinidad-Tobago, Nigeria, UAE, Saudi Arabia, India, Sri Lanka, Bali, Kuala Lumpur, Malaysia, Philippines and the Micronesian Region. It has also undertaken projects in the San Francisco Bay Area within the USA.

**Transitioning Nika Components to Online Formats**

In early 2020, plans were underway for two Nika Project teams and 13 Project Building Bridges students to travel to Peru and India. At that point the pandemic hit. Faced with the alternative of going online, the Nika Project determined the components that could be implemented through telepractice (Anderson, et al., 2012). The refinement of the Nika model that resulted was shared in an ASHA presentation for its annual conference of November 2021.

In the past year, the Nika Project has engaged in international collaboration mostly through the Zoom medium, but also utilizing some Google Meets, TeamViewer and Webex meeting tools.

**University Mentorship with Future Professionals**

One of the key tenets of the Nika Project is to enhance professional development through teacher training and partnerships with local universities. An example is our partnership with the Universiti Kebangsaan Malaysia (UKM) to expand their AAC program. Beginning in the summer of 2018, the Nika Project developed graduate student mentoring with San Francisco State University’s Project Building Bridges, through a federal grant to prepare SLPs with culturally responsive AAC competencies (Solomon-Rice, Soto & Robinson, 2018). The transformative experiences of six Project Building Bridges students who traveled with the Nika Team to Bali, Malaysia and Kuala Lumpur, Indonesia provided the structure for further university mentoring programs.
Highlights of International Projects Online

Team Peru: Nika Project mentors and seven San Francisco State SLP students in Project Building Bridges began in summer 2020 to partner with teachers in remote areas of Iquitos and Cuzco in collaboration with Peruano Institute and continue this work in spring and summer 2021.

Team India: Nika Project mentors and six San Francisco State SLP students in Project Building Bridges began in summer 2020 to partner with the interdisciplinary team at the Cadre School in Kerala, India and continue this work in spring and summer 2021.

Collaborating Across the Pacific (CAP) Academy: Launched in spring 2021, CAP is a multi-university project with the Nika Project that includes graduate students and faculty from University of Hawaii, teachers in training through the College of the Marshall Islands and Project Building Bridges SLP students at San Francisco State University.

Nika’s Continuing Efforts to Send AAC and AT

Although COVID-19 caused the shutdown of Nika personnel traveling to other countries, we continued to ship AAC and AT to those who requested it. There were eight recipient sites in the United Arab Emirates, India, Sri Lanka, Philippines, and Trinidad-Tobago:

- Twenty-four AAC devices were shipped to eight sites
- Seven access switches shipped to four sites
- One Headpointer and two large keyboards were shipped to one site
Donation of AAC equipment was shipped from Nika team in USA to University of the Philippines Manila. It arrived safely and it will be used at UP CAMP Clinic for Therapy Services for the benefit of children with complex communication needs in the Philippines.

AAC Development Partners

As the Nika Project matured through conducting international projects, we began to examine various AAC tools that could be meaningful to the variety of cultures that exist globally. We were especially interested in AAC tools whose visual symbols could reflect the cultural representations of the country it was being used for, and the ability to have spoken output in as many languages as possible. Sharing online for support and training was another key factor. Other considerations were its use for low and high-tech AAC options. Finally, we considered the types of resources a user must have to benefit from such an AAC tool, so customization of AAC in rural areas with limited resources had to be taken into account. Two of the tools that met these criteria included CoughDrop which is open source cloud-based AAC software, and PicSeePal, low-tech AAC that is customizable and durable.

Outcomes and Lessons Learned

We have learned there is evidence for building relationships across cultures through our practice of "deep cultural listening" to partners and communities we serve. The expansion of open source AAC tools is beneficial. Building university mentorships helps sustain the
continued and successful use of AAC. It pays to network. The outcomes of Nika’s international collaboration show promise for a small, non-profit organization such as Nika to connect with international partners and advance access to communication and learning for people with special needs and their families, especially in underserved communities of the world.

– David Goldberg, MS, ATP
Pioneering AAC work in Zimbabwe

by Nothando Mtungwa

My name is Nothando Mtungwa and I am currently pursuing a PhD in Augmentative and Alternative Communication at the Centre of Augmentative and Alternative Communication at the University of Pretoria. My passion is on raising AAC awareness especially in rural communities in Zimbabwe. I am taking part in research on low cost AAC communication interventions that could benefit children with complex communication needs. I have also collaborated with professionals to raise awareness on AAC through webinars.

Currently in Zimbabwe, there is a shortage of qualified professionals to support children with complex communication needs such as audiologists, speech and language pathologists and special needs education professionals. The available services are not affordable and accessible to all populations of children with disabilities, especially in rural communities. This shortage of professionals has resulted in challenges in identification and assessment of complex communication needs. Several children with communication impairments have never received any AAC intervention, thereby excluding them from participating in society. What could help improve AAC knowledge and provision of services in Zimbabwe is training of professionals in AAC and in identifying and assessing complex communication needs. Training of caregivers is also very important as they can be instrumental in supporting individuals with communication difficulties and raising awareness in the community. The involvement of policy makers is also crucial in-service provision as there is no policy that is binding in terms of service provision for persons with disabilities. Among reported disabilities in Zimbabwe, the highest number is communication disabilities, therefore there is an urgent need for action. Giving individuals with disabilities an equal voice will enable them to participate and play an active role in decision making.
Currently in Zimbabwe, most of the children with disabilities are out of school and cannot attend mainstream schools due to the lack of suitable infrastructure and trained teachers. Those who have had access to primary education have not been able to proceed to secondary education due to lack of facilities that can provide for their needs. Most of the children with complex communication needs have never received any communication intervention and special needs schools only limit their interventions to braille and sign language. Receiving a diagnosis for a disability is a challenge and specialist services are not affordable to most families. Special needs facilities lack resources such as assistive devices and trained teaching personnel and funding from government. Most funding mainly comes from charity as there is no intentional policy related to special needs provision. Another major barrier that individuals with disabilities face is cultural barriers and stereotypes, most children with special needs who do not receive early interventions is due to the belief that a disability is a “curse that needs to be removed”, hence, alternative forms of interventions are sought.

The importance of educating a child with disabilities is not viewed as a priority to most families due to the expenses associated with that and the high rates of unemployment, and a struggling Zimbabwean economy exacerbates the situation. In rural communities, the nearest mainstream schools do not have the capacity to cater to children with learning difficulties, while most special schools are in urban areas and are not affordable and accessible to most of the population.

Another challenge is the Zimbabwean curriculum which is not flexible and inclusive enough to cater to children with disabilities. They are taught using general methodologies and expected to write common national examinations. Moreover, there are funding deficits in Zimbabwe’s education sector in general, and the education of persons with disabilities is even more affected as there is no specific fund for them. Most public schools have not been designed to include people with varying levels of disabilities and that is the reason why a considerable number of children with disabilities never get access to education.
Hermann Halberstat is an AAC advocate who is making a difference in the state of Rio Grande do Sul in Brazil

by Nadia Browning, Hermann Halberstat and his mother Cimone

Here we talk about Hermann’s recent accomplishments. Herman loves to travel, listen to music and be with friends. He graduated this year as a Computer Technician.

Hermann and Cimone are involved in several “lives” about AAC in Facebook. Their main goal is to bring AAC awareness to politicians. They believe that the path to include individuals with complex communication needs whose AAC is to promote education that can lead to creating laws and information centres. Their latest “live” was with Eduardo Bonatte, the president of FAMURS (Federação das Associações de Municípios do Rio Grande do Sul) that included 497 municipalities in the state of Rio Grande do Sul. Eduardo agreed to create a THEMATIC CAMERA to address public policies for people with disabilities in all the 497 municipalities of the State of Rio Grande do Sul.

Hermann and Cimone also spoke with Eric Lins, the state deputy of Rio Grande do Sul, who will create an information centre for assistive technology, research and access for individual with disabilities in the state of Rio Grande do Sul.

Below are the links to the “Live” with Eduardo Bonatte, the president of FAMURS. https://m.facebook.com/story.php?story_fbid=1619120671629929&id=100005960348108

Hermann and Cimone are dedicated to the mission of expanding the awareness and understanding of AAC as a mode to create laws that would enhance the lives of individuals with complex communication needs in Brazil. Thank you Hermann and Cimone!
Samara continues her mission to advocate for AAC world

by Nadia Browning

Samara recently got the council in two municipalities in Sao Paulo (Brazil) to approve a Bill for October to become the Month of AAC Awareness

This article was based on the article that Samara Del Monte wrote to the magazine: Revista Nacional de Reabilitação Reação Ano XXIV - Ed. 139 Setembro/Outubro 2021 (https://revistareacao.com.br/wp-content/uploads/2021/10/ED-139.pdf)

Samara Del Monte is a journalist and creator of the magazine Mais Deficiente (More Efficient). From a very young age, she has been using Bliss symbols as a primary way to communicate and she writes on her computer wearing a special helmet. Samara graduated in journalism and is currently studying philosophy. Samara has other articles published in previous editions of the CSWN Newsletter. You are welcome to connect with Samara via her e-mail: samarandresa@gmail.com

The Bill No. 137/2021 of the Municipality of Diadema (Sao Paulo) and the Bill No. 51/2021 of the Municipality of Jarinu instituted October as the Month of Awareness and dissemination of Augmentative and Alternative Communication. These two cities in the State of São Paulo are the pioneers in declaring October as AAC awareness month.

Samara explains: “I spoke with the council of Diadema, Lilian Cabreira, who soon proposed to draft the bill that was sanctioned by Mayor José de Filippi Júnior. Then I went to the city of Jarinu and lectured to the cities’ Department of Education, in which were present mayor
Débora Prado and councilors João Lorencini Neto and Alessandro Marcelino de Campos. I didn’t miss the opportunity to make the same suggestion and they accepted it immediately.”

Samara was in line with the 2021 AAC awareness theme for ISAAC Brasil: “ALTERNATIVE COMMUNICATION: LET’S TALK?”. The idea is to rescue the true meaning of AAC as dialogue, interaction and conversation, strengthening the place of voice and protagonism of people with complex communication needs.

Samara continues to inspire all of us with her dedication to improving the lives of individuals with complex communication needs. Thank you Samara!
AAC Awareness Month – AAC Campaign

by Jess Bartram, Liné Kruger, Malikah Parker, Gonda Olivier, Pauline Prinsloo, and Jodi Zimmerman

How it all started

We are a group of final year Master’s degree in AAC students at the Centre for AAC, University of Pretoria in South Africa. During one of our AAC online discussion weeks, we were encouraged to reflect on our part in advocacy by addressing a question on the speech-language pathologist’s (SLP) role within a collaborative team approach to AAC assessment. This led us, as a group, to reflect and appreciate our role and responsibility as a SLP. We needed to challenge our knowledge and current effort to initiate advocacy campaigns and to spread the word, promote self-advocacy of our clients with disabilities and advocate for agency and rights of people with disabilities within their community.

Through the amazing and inspiring leadership of Professor Juan Bornman, we realised that AAC professionals play a critical role in addressing communication skills, and how we are importantly positioned to positively impact learning and skill development within a human rights paradigm - as communication is a basic human right! We all have a deep-rooted appreciation for our role as advocates and enablers for persons with communication disabilities and their families within a team context and how this impacts the life outcomes of these individuals.

Consequently, there was a desire to create greater awareness about AAC, using existing social media platforms such as Facebook groups and YouTube. Our vision entailed sharing posts in order create international AAC awareness, inspiring a societal movement through our campaign. With the support of the International Society of Augmentative and Alternative Communication (ISAAC) and the Centre for Augmentative and Alternative Communication (CAAC), this became a reality. What better than the perfectly timed AAC awareness month.
And what a campaign it was! It included a variety of 1-2 minute videos that were posted daily from persons using AAC who shared their stories and interests of poetry and art, and from educators, caregivers, and clinicians around the world who shared their stories, provided tips, motivation and ideas that helped generate a bank of resources and knowledge for many of the persons who watched these videos. Our aim was to keep the videos short and powerful as to highlight focal barriers and facilitators within the lives and contexts of persons using AAC, increase interest, and to inspire people throughout the month of October. It was a success!

Click on the following link to see the wonderful videos that were shared throughout the month: https://www.facebook.com/centreforaac

**AAC as a means to self-advocate**

The South African disability advocates who use AAC said that this initiative provided them with a means to communicate with others, which is an effective method to spread the word of the countless opportunities provided by AAC itself. AAC provides all individuals with the means to tell their story, to help others, and to advocate for themselves and others. The AAC awareness campaign provided them with the opportunity to tell their own story and to articulate the joys, possibilities, and challenges they experience on a daily basis. They expressed that this opportunity to self-advocate is also important in providing them with a means to communicate with others.

**Anxious advocates**

Being an advocate is no easy task. It requires compassion, strength, enthusiasm, and many other wonderful human qualities. We admit to feeling just a bit anxious in the beginning, as some of us have never done something like this before. It required a massive step out of our introverted comfort zones, to press record on that camera and speak about this topic we care so deeply for, in the hopes of informing at least one person of the benefits of AAC. That was the major motivation to take that big step to inform and create awareness for AAC – for the benefit of those struggling to communicate in society.
Thank You!

Advocacy requires some form of extroversion. It requires an advocate to put themselves ‘out there’ for the cause, however ‘there’ can be way beyond their comfort zone. Therefore, we commend and thank everyone who had the courage to participate in our campaign! You made a real difference!
Communication and life skills at the Technical Museum

By Elin Skogdal, Hilde Fresjarå and Tim Anderson

On Saturday, October 30, 2021, the Technical Museum in Oslo and Digjobb arranged an exciting day where anyone who visited the museum could try out making music, playing games or communicating using eye control, switches or breathing.

The Technical Museum has 25 topical displays and 100 interactive installations where you can learn about transport, planes, industry, music machines, oil, plastic, clocks, computers, telephones and a lot more. Due to the fact that you can learn by trying out technology in all the interesting installations, the museum is very popular with people of all ages. From an earlier collaboration between the museum and Digjobb, we found this to be a good place for people to experience how you can express yourself using eyegaze, switches or breath control.

Digjobb is a meeting place for those who can perform digital work tasks and those who need a short-term job. Some of the jobs the Digjobb workers are doing are testing the accessibility and user friendliness of web sites or apps.
Other jobs involve composing music, translating text, symbolising text, or even writing a book. Many of the workers use AAC or other types of assistive technology to perform their job tasks. This makes Digjobb a unique workplace where people developing accessible websites or apps can employ testers with special competence as the end users.

Music is another focus area for some of the Digjobb workers. This includes translating and testing music software being developed, as well as composing and performing music. Visitors to the museum could experience and try out several ways of making music using assistive music technology.

One of the technologies was shown at the museum by Ruud van der Wel from the Netherlands. He is the founder of the ‘My Breath My Music’ Foundation, and has developed The Magic Flute which is an adapted wind instrument. You can play by blowing and changing the pitch by moving your head up and down.

The flute has also been further developed and combined with iPad apps (GroovTube) to be used for breathing exercises. Visitors could try out how to play flute or video games using your breath or switches.
A music group from a day-care center in Oslo held a concert. They combined traditional and eye-controlled instruments, and there was a large and appreciative audience.

Nicolai Ruud from Digjobb also played a concert with his band, and ended the day with a jam session with GroovTube, trombone, keyboard and E-Musikk (eyegaze):

As well as performing music, Nicolai also sold cards that he had painted using eye-gaze:
Those who visited the museum could also meet SKUG (Play and Compose Without Limits), which is a centre for adapted music education at the Music and Art school in Tromsø. SKUG uses assistive music technology to create instruments which can be played in many different ways, allowing people with severe physical disabilities to learn to play music. Musicians can play using switches, sensors or eye-gaze.

Several of the musicians performing at the museum were playing using the “E-Musikk” software as their musical instrument, and visitors could try singing songs, or playing guitar solos and chords with their eyes.

Those who visited the museum that day could also meet companies that work with aids for alternative and augmentative communication (AAC). Most of the visitors were unfamiliar with this type of aid, and were amazed at what was possible.

It was a great day with a lot of engaged audience.
Resources

**ALTERNATIVE PENCIL** is a way to teach literacy to individuals with complex access & communication needs. Below are two websites explaining about alternative pencils:

  - This site includes many videos of individuals using alternative pencil

- [https://www.med.unc.edu/ahs/clds/alternative-pencils/](https://www.med.unc.edu/ahs/clds/alternative-pencils/)
  - Centre for Literacy and Disability Studies
  - This site includes downloadable practical resources

**SENSORY PROCESSING** challenges are found in many children and adults.

The below information (1) brings awareness & understanding on what sensory processing means, and (2) suggests some strategies to help the individual to cope with sensory processing challenges.

- [https://www.youtube.com/watch?v=D1G5ssZlVUw](https://www.youtube.com/watch?v=D1G5ssZlVUw)
  - A child's view of sensory processing.
  - This video highlights some of the common sensory processing challenges and suggests strategies used that help this child.

- [https://theinspiredtreehouse.com/10-calming-sensory-strategies-for-school/](https://theinspiredtreehouse.com/10-calming-sensory-strategies-for-school/)
  - 10 strategies with calming sensory strategies to help kids remain focused, engaged, and content in the classroom.
Conference News

ISAAC Conference Cancún is currently scheduled to take place from July 30 – August 4, 2022 in Cancún, México! Visit the Conference Cancún webpage for more details to be released.
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 May 2022. We would love to hear your news. Please submit your articles and/or news by mid-March 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