

Data Privacy and Security for AAC

March 30, 2021 11 a.m. – 1 p.m. ET

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On March 30, 2021 ISAAC will host a two-hour webinar presentation plus panel discussion on *Data Privacy and Security in AAC*. This topic will be discussed by six experts, each approaching the issue from different perspectives. Read their bios and a summary of each perspective, below (*in alphabetical order*), following the introduction of our Webinar Moderator, Tracy Shepherd:



Tracy Shepherd, Moderator

Tracy Shepherd is a speech-language pathologist who has a longstanding passion for AAC. She works in the [Augmentative Communication Service](#) at Thames Valley Children’s Centre in London, Ontario, Canada and as a Clinical Education Coordinator at the [Centralized Equipment Pool](#) (operated by Holland Bloorview Kids Rehabilitation Hospital) in Toronto.

She has held several positions including ISAAC Canada President (2009 to 2013) and was on the ISAAC Executive Board (2014 – 2018). Tracy co-chaired the 17th Biennial conference in Toronto, Canada in 2016, “Bringing us Together.” Currently, Tracy is the President-Elect of ISAAC International.

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Russell Cross

Russell Cross is a speech-language therapist and the Language Systems Product Manager at [PRC-Salttillo](#). A Psychology and Linguistics graduate from the University of Lancaster in the UK, with a Post-Graduate qualification from the University of Central England, he has worked in the field of AAC since 1984. Russell is a co-author of the Unity series of language application programs, author of the WordCore software, and developer of the Realize Language AAC data analysis website. He is a member of the Royal College of Speech and Language Therapists, ASHA, ISAAC, and the Assistive Technology Industry Association (ATIA) Research Committee.

In the field of AAC, the collection and analysis of client-generated data has been an integral part of good practice long before the invention of the array of high-technology devices now available to aid communication. The major difference between now and, say, 40 years ago, is that modalities for collecting data have changed, allowing for not only the accumulation of very large data sets but also for this to be done in a way that can be invisible. For example, prior to having any capability to log data use in a device, it was always possible to manually jot down what someone said and subject the written script to analysis, whereas now it is possible to log time and content for every keystroke in an AAC device.

The challenge practitioners in the field have to face is that of continuously re-evaluating how to adapt to meeting the needs of (a) client-clinician confidentiality and (b) data privacy. The notions of “informed consent” and “privacy” are not new, but as technology evolves, the ways in which these can be protected and modified have to be monitored. Even the very definition of “privacy” is unlikely to be the same today as it was in 1981, and the changing expectations of PWUAAC need to be taken into account if data logging for clinical and educational purposes is to work both securely and effectively. And it is with the help of the AAC community that ISAAC can work towards improving solutions for data security and personal privacy at the levels of (a) clinical/educational practice, (b) technology, (c) training for the community, and (d) legal standards.

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*Melanie Fried-Oken, Ph.D. is a Professor of Neurology, Biomedical Engineering and Otolaryngology at the [Oregon Health & Science University \(OHSU\)](#) and Director of the REKNEW research projects (**Realizing Expressive Knowledge in Everyone With Communication Impairments**). As a leading international clinician and researcher in the field of Augmentative and Alternative Communication (AAC), she provides expertise about Assistive Technology for persons with acquired disabilities who cannot use speech or writing for expression. She is PI on federally funded grants to research communication technology for persons with dementia, ALS, and other neurodegenerative diseases, including a translational R01 from NIH/NIDCD on brain computer interfaces for communication.*



Melanie Fried-Oken

As AAC technology continues to embed Natural Language Processing into devices to improve the rate of communication and provide personalized language options to end users, it is critical that we have large databases with words produced by people who rely on the technology. The development of word databases presents many challenges related to privacy, identity, storage, and confidentiality that must be addressed.

People who rely on AAC embrace the technology for many different reasons. Those who learn to use AAC as they develop language have different challenges from people who are losing their speech and language skills and must rely on AAC technologies as new ways to express themselves. Each potential user has reasons why personalized language models stored in their devices may be advantageous and simultaneously dangerous. We recently completed a qualitative research study, where we collected data from 75 adults with neurodegenerative disease about their preferences for language storage related to identity, agency, and privacy. We are beginning to analyze the data and find trends that should influence the AAC field.

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Dave Hershberger

Dave Hershberger is CEO of [PRC-Salttillo](#), based in the US. His career has been dedicated to Assistive Technology. Trained as an Electrical Engineer, Dave developed AAC devices for Prentke Romich Company during the 1980s and early 90s. He then founded Salttillo Corporation in 1996. Over the past few years, he has brought the two companies together under the PRC-Salttillo umbrella.

The collection and analysis of data enables us to create more effective and more usable tools for people who use AAC. Take word prediction, for example. We use language usage data collected from a large group of individuals to create an effective “off the shelf” prediction system. Then, by collecting data when someone is using the system, the system can “self-adjust” to correspond to the individual’s vocabulary choices, speaking patterns, or even the conversation topic. As technology becomes more sophisticated, it becomes possible to monitor more aspects of how individuals interact with their systems. This can lead to data-driven improvements in how devices are designed, adapted, and implemented.

However, data collection can also be invasive. As manufacturers and professionals, we need to be transparent in specifying the data we would like to collect, who has access to it, how we protect its privacy, and how we use it. We need to do a better job of educating on the benefits of the data collection, along with the associated risks. Ultimately, the decision needs to be with the individuals using the technology – a reality made more complicated by the fact that many of the individuals who have the most to gain (and lose) are minors.

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Fil McIntyre is the Manager and Assistive Technology Lead for [TechAbility](#) – a service that supports specialist settings in the UK. He consults with and delivers Assistive Technology training to colleges and adult support providers. Prior to this, Fil managed an Assistive Technology team at Beaumont College, a highly specialist college for post-19 students. He has also delivered training and support to every post-16 college in Scotland, worked as an AT Trainer for Inclusive Technology, and been an assistive technologist since before the term made it to the UK! Fil lives in the Northwest of England where the sun occasionally shines so he can head out for a hike in the Lake District.



Fil McIntyre

At the webinar, Fil will discuss the conflict between data rights and human rights. Prompted by the loss of an iPad, Fil was concerned that over-enthusiastic data protection could lead to the safety and rights of people who use AAC being in jeopardy. Those who require images may have many pictures and names stored on their devices. If the device is owned by an organization, this loss is considered a data breach. Organizations may therefore be cautious about adding such data.

Fil will outline a balanced approach to ensure that the safety or right to speak of people who use AAC is not impaired, while ensuring minimal risk of privacy breaches.

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David Niemeijer

Dr. David Niemeijer is the CEO and founder of [AssistiveWare](#), based in Amsterdam. With over 20 years of experience, David is a pioneer in the field of Augmentative and Alternative Communication (AAC) and Assistive Technology. He has created software for people with physical, vision, and communication challenges, including the award-winning Proloquo2Go software. Today, AssistiveWare serves over 450,000 customers worldwide with products localized in many languages. David has presented at major international Assistive Technology and Augmentative and Alternative Communication conferences such as AGOSCI, ASHA, Closing the Gap, Communication Matters, CSUN, ATIA, and ISAAC.

People who use AAC have the right to the same level of privacy of conversation as speaking people. Data logging, as currently implemented in many AAC products, dates from a time when asking for consent was considered enough to protect the privacy of those who use AAC. Today's best privacy approaches focus on privacy by design over privacy by policy. This is about collecting only essential data and making sure that whenever possible this data is aggregated and anonymized to protect people's privacy. What is not collected or does not leave the user's device cannot do any harm. The AAC field can learn a lot from these practices.

Developers can look into ways to better protect the privacy of people of all ages who use AAC, in relation to parents, teachers, and therapists. At the same time, they can provide the kind of insights that therapists and parents are looking for to help people who use AAC grow in their communication and language skills. People who use AAC more than anyone else depend on being able to express their most personal and intimate thoughts through an electronic device. That gives a huge responsibility to the manufacturers and developers of such products to ensure the autonomy and privacy of their users. Developers need to collaborate with people who use AAC, therapists, and others to deliver relevant language and use insights without compromising the privacy of people who use AAC.

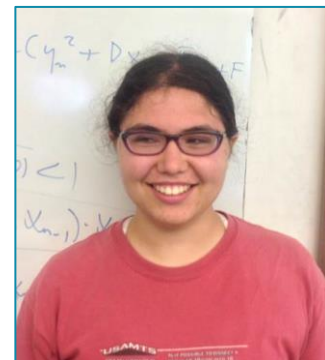
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Alyssa Hillary Zisk (they/them/theirs) is an autistic doctoral candidate in Interdisciplinary Neuroscience at the [University of Rhode Island](#) in the US. They have several forms of experience with AAC: personal part-time use, research in the context of AAC for speaking autistic adults, and research in the context of brain-computer interfaces for people with amyotrophic lateral sclerosis. Alyssa is an experienced teacher, both face to face and online, and their apparent lack of eye contact is not an artefact of webinars or camera placement.



Alyssa Hillary Zisk

It is possible for an individual who uses AAC to have certain forms of privacy on Facebook that we do not have in daily life. Type something on Facebook, choose your privacy settings, and post it. If you locked it to your friends, or to a subset of your friends, the claim is that no-one else will be able to see it. There are ways around it, but the design is not built to say certain people you interact with will always be able to see everything you post, or everything you type but decide not to post. You can block your therapist on Facebook. In fact, you probably should. Type something in an AAC app with a LAM file. Whether or not it is ever spoken, anyone with access to the file can see what you wrote, and when. Any caregivers see it. Therapists can see it. This privacy invasion, which even Facebook will let you prevent – remember, you can block anyone – is marketed as a feature. It will continue to be marketed as a feature until AAC is marketed to users, not professionals. Designing and marketing for users, not for professionals, parents, or any other “stakeholders,” is a prerequisite to us getting actual privacy.