

The Conference Experience



It would be hard to miss the bright light of publicity surrounding AAC conference announcements. This issue of *Alternatively Speaking* explores why someone who relies on AAC to communicate would willingly bear the expense and trouble intrinsic in traveling with a disability to participate in an AAC conference.

Regional, national and international organizations with an interest in AAC sponsor conferences. Examples are the international biennial conference sponsored by ISAAC and the many national and regional AAC conferences such as the USSAAC conference in the U.S., the Communication Matters conference in the U.K., the AGOSCI conference in Australia, and the ISAAC Norway and ISAAC-GSC conferences.

Some conferences are focused on a specific aspect of AAC. Examples are the Communication Aids Manufacturer's Association Tours and the Pittsburgh Employment Conference for Augmented Communicators. Other conferences target a single segment of the AAC community, such as conferences about people with autism or aphasia.

In addition, many other conferences offer a significant number of AAC sessions. Closing the Gap, the RESNA conference, Assistive Technology Industry Association conference, Association for the Advancement of Assistive Technology in Europe conference, TASH conference and CSUN

Technology and Persons with Disabilities conference have a strong AAC emphasis.

The conference program

A lot goes on at conferences. Some activities are clearly marked in the published program, the official guide to conference events. Other activities are spontaneous, by invitation or informal.

The formal part of a conference program usually depends on a lot of people listening to a few people present their ideas, research, strategies or technologies. Listening to an expert talk about something that really interests you can make your trip worthwhile. Even better, being ready after the lecture with a related question can help clarify your understanding of the material presented. Best of all, asking a question that adds to or challenges the presentation can enhance everyone's understanding of a subject.

Some conferences feature discussion or "town meeting" sessions. After a short presentation, the microphone is passed around so those in the room can trade ideas about the topics at hand. Augmented communicators and their families, who may feel they have

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Message from the editor

When you look up the word conference in the Merriam Webster Online Dictionary, this is the first definition you'll see:

"A meeting of two or more persons for discussing matters of common concern."

Like all definitions, it's technically correct but boring as hell.

My parents never used such formal terms with me ("Son, we'd like to call meeting of two or more persons to discuss matters of common concern"), but when they uttered the words "Family Conference" I knew we were not going to talk about raising my allowance.

I've since discovered that most conferences don't have this ominous air about them.

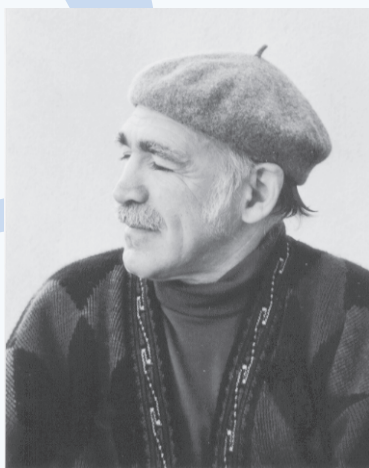
I attended my first formal AAC conference in the mid-eighties. It was held at a university close to my home, so I didn't have the expense of travel or lodging. I made my first AAC presentation at that conference, a three minute affair chiselled out phoneme by phoneme and then recorded sentence by sentence on audio tape.

That short presentation has long since made its way into outer

space, but the memory of that conference still is with me. I discovered I wasn't the only augmented communicator in the world. I met a guy from North Carolina who was using the same primitive speech synthesizer I was; then there was the guy who was using the newly released Speak 'N' Spell toy as a talking alphabet board.

Twenty years later, I'm still friends with these guys as well as the then-budding academic types who attended the conference. Of course, we are all gray around the temples now, but we still have the same goal of improving life for all augmented communicators.

I have met many interesting persons at conferences over the years. Perhaps I'll meet you at the next conference I attend.



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listened enough and are ready to contribute to a discussion, sometimes favor this session style. Once in a while, the discussion turns into action, and those who want to work on an idea or create change form an on-the-spot working group that meets during the conference or works via email after the conference. For example, the topic of AAC technology and privacy came up in one of these discussions a few years back and has resulted in an issue of *Alternatively Speaking*, several articles in other publications, and a number of additional conference presentations.

Large conferences often have poster sessions. The authors of a poster session stand next to a two dimensional display (poster) and describe their topic to people who pass by. Sometimes posters are set up too high or too close together, limiting access by people who use wheelchairs. Even so, a poster session can be a great opportunity to talk one-on-one with people who are working on an interesting project and may even serve as a place to meet others interested in the same topic.

The exhibit hall

Bigger conferences have exhibits or vendor booths. The people who make and sell AAC stuff are right there waiting to talk to you about their products. These vendors usually encourage people to try their wares and are full of information and wisdom about their products and how to use them. Many of the vendors also are interested in hearing about unmet AAC needs and recommendations for improvements in AAC technologies. Fortunately, more and more

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Editor: Michael B. Williams Technical Editor: Carole Krezman
Guest Authors: Meredith Allan (Australia), Tracy Rackensperger (USA), Graham Clarke (South Africa)



vendors employ “consumer consultants” who demonstrate products and answer questions.

Just like in the big city mall, sometimes the shoppers are as interesting as the products for sale. The exhibit hall is a great place to people watch, to see AAC in action, to chat with an expert clinician, talk shop with an engineer, and share solutions with other augmented communicators and their families.

Informal happenings

The excitement of the exhibit hall often carries over into the quieter hotel lobby, the pool, and, for the adults, the lounge. Sometimes it’s easiest just to post yourself for a while and let the experience come to you.

Frequently, augmented communicators who are beginning to see some success in their lives after years of solo trial and error are willing to mentor younger augmented communicators by providing support and sharing experiences.

There is always time for recreation during a conference. Some of my best AAC memories are of visiting the Liberty Bell during a conference in Philadelphia, of seeing the Franklin Delano Roosevelt monument with friends in Washington DC and reading Martin Luther King’s famous words on a memorial sculpture in San Francisco with a younger augmented communicator. It may seem like play, but bringing the real world into the conference or the conference into the real world makes the experience last.

What to bring

With a few important exceptions, traveling to a conference is the same as traveling anywhere. Business cards are the primary tool of conference participants. If you are at all interested in work, never leave home without a resume. If you have prepared remarks for a presentation, town meeting or forum, bring a paper copy just in case technology fails. A spare power strip or extension cord can also be extremely useful.

Conference organizers always hand out a registration packet bursting with paper. Although it is incredibly boring to sit alone and go through the packet, the conference will go more smoothly if you do. Put your name tag and any meal tickets or event passes somewhere secure. Divide the rest of the information into three piles: “read now,” “read at home,” and “trash.” Check for notices of special interest receptions or last minute meetings buried amongst the advertisements. Also check for exhibitors’ offers of free products to those who stop by their booth.

The conference program is the part of the registration packet that requires the most attention. Each participant has his or her own way of selecting sessions. Whether you use a yellow highlighter pen or an electronic organizer, decide what you want to do during the day and note the times and locations.

All the talking at conferences is backed up by a lot of paper. Most conferences provide a conference bag for participants to stuff with papers and product samples. If you have any question about whether the conference bag will work for you, bring your own.

One extra item to put in that bag would be a disposable camera. Take pictures of people and ask someone to take a picture of you with a new friend. When you are back home, you will be glad to have these snapshots.

Although you may be familiar with the weather at the conference site, large hotels and conference centers have their own weather. If you are sensitive to temperature, note that conference rooms tend to be very dry and either a bit chilly or quite warm.

Count on the unexpected to happen. The communication device gets a bug, the personal care assistant gets a bug, the hotel room has bugs. Sometimes the unexpected works out for the best. Once, I was just beginning to engage a large audience with my presentation when the lights went out. The whole hotel was dark. Someone in the audience jumped up to shine a flashlight on the display of my AAC device, and, taking a deep breath, I continued with my remarks. Years later, no one remembers the topic of the presentation, but everyone remembers the community spirit in that dark room.

The AAC community

Conferences pull together a diverse group of participants with a common interest in AAC. Participating in a conference is invigorating, refreshing and exciting. Sometimes I don’t want it to end, but I always go home with a fresh perspective on my work, a validation of my experiences, and a greater understanding of AAC and the diversity of people who rely on it.

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Journey from Cape Town

by Graham Clarke

I feel that all of us who are unable to speak should make a concerted effort, sometime in our lives, to attend an AAC conference. It's not only an incredible experience, but exposes us to a "family" of people that share the same feelings, objectives and desires that exist within us.

In August of 2002 I undertook such a challenge, going from Cape Town, South Africa to Denmark to attend the International Society for Alternative and Augmentative Communication (ISAAC) conference. I had decided to travel "solo" with only my communication device, my power wheelchair and Russel, my caregiver.

When we arrived at the railway station in Odense, I realized that we were truly on our own and that it was up to us to make our trip either a success or a failure.

We called for an accessible taxi and waited on the sidewalk. A lady walked across and asked about the technology she saw in front of me. It turned out that she was a speech therapist from a center in Odense—our first Danish acquaintance. I told her where I was from, why I was here and invited her to come to the conference for a couple of hours. I thought she'd find walking around the exhibition hall rather interesting. Then our taxi arrived and drove us to the hotel.

When we arrived at the conference hotel, I instantly felt at home. Some of the preliminary meetings had just ended, and we immediately began to meet people. Eventually, we went to our room for some much needed sleep. We'd been thrown off by the late sunset. In Odense, the sun sets just before ten o'clock in the evening!

In the morning, I went down to the lobby while Russel got himself ready for breakfast. I met people from all over the world who were involved with the conference. That evening we went out to dinner with ISAAC's Executive Committee and some Board members. It was a fantastic evening. The food and company were outstanding. We shared a large omelette that was covered in the most amazing crackling and bacon. We then walked down to a park and had delectable ice cream. I thoroughly enjoyed myself and knew I was experiencing the spirit that exists among those involved in AAC. My disability seemed irrelevant.

The days prior to the conference were spent meeting people, going to the supermarket and setting up the computer so I could email the folk back in South Africa. Once, when I was driving around the hotel looking at things, I felt somebody hugging me from behind. A whole crowd



of South Africans was standing there! It was like coming home!

Monday was upon us, and the conference began. People were off in every direction to attend lectures. Once again, I was bowled over by the bond that exists among all the folk with some connection to AAC. I met hundreds of people who share the same interests. I even missed one or two lectures as I got caught up in conversations.

The final conference day arrived and the closing ceremony brought that AAC spirit to the fore again. The future was plotted out rosily, our interest and love for AAC was cemented, and the ceremony came to a close. It was amazing (and sad) how quickly the conference hotel emptied. A busy community had flourished for a couple of days, and now an uncomfortable silence settled over the place. I started preparing psychologically for our departure.

We arrived home in Cape Town the following day. As I disembarked, I imagined myself punching the air and saying "WE DID IT!!!!" We were awfully tired, but the feeling of great accomplishment overrode our tiredness.

What an incredible experience! **A**

Working a Conference

by Tracy Rackensperger

Attending an augmentative communication conference may not be a top priority in your life. You may be wondering, “Why would I want to go to a conference? I have to get time off from work, make travel arrangements, and generally juggle my life around going somewhere.”

I have been attending conferences for a few years now. I started out serving as an ambassador for an augmentative communication (AAC) device manufacturer at AAC conferences near my home. I still enjoy serving as an ambassador for these local conferences.

These days, I also travel nationally to conferences sponsored by various organizations and advocacy groups. I attend conferences because I understand the critical need for people with disabilities to advocate for themselves as well as the many opportunities conferences hold for people with disabilities.

I have attended more than fifteen conferences during the past two years. It is amazing for someone who never flew prior to 2000 to now be a frequent flyer. The conferences I attend are all of interest to the disability community and cover a wide range of topics, such as augmentative communication, affordable housing, self-advocacy, self-determina-

tion, transportation and independent living. My travels have taken me from my home just outside Orlando, Florida to Providence; Washington, DC; Minneapolis; and even Las Vegas. At some conferences I am strictly an attendee, for others I give presentations. They have all been empowering experiences.

Networking opportunities

Conferences are not just about attending sessions and workshops. The greatest experience is

sions that arise from the workshops and sessions people attend and find interesting.

Networking at conferences also gives individuals the opportunity to forge long-lasting relationships with others. Whether it is with another person who uses AAC or a professional working in the field, by attending conferences individuals receive a chance to create a connection with others. In my own personal opinion, networking is definitely the greatest reason to attend a conference.

Be your own advocate

A conference is a unique environment where all participants gather to gain knowledge from each other and contribute to a particular field, such as AAC. It is a place where all stakeholders come together.

It seems obvious that we should have input into what happens in our lives. However, self-advocacy and self-determination are still relatively new concepts to many individuals. Some manufacturers and researchers are just beginning to ask people who use augmentative communication, as well as parents of people who cannot advocate for themselves, to contribute to the knowledge base.

I find it worth my time to attend conferences and advocate on my



networking and talking to individuals from all over. People who use AAC have a chance to interact with each other, as well as with educators, researchers, therapists, manufacturers and others.

Conferences provide a forum where all stakeholders connect to learn from each other and bring new ideas to the table. It is an excellent opportunity to improve your life and the lives of people who use AAC by participating in the spontaneous, lively discus-

A Spirit of Adventure

by Meredith Allan

If it weren't for conferences, I would never have travelled outside my own country of Australia. As my confidence has grown, I have even travelled overseas by myself. Everywhere is a long distance from Australia, so I sightsee and take tours to compensate for the expense and distance of flying to a conference.

Ultimately, the destination is the conference, and it is the safe, secure environment of the conference that enables me to travel outside the world I know.

The first overseas conference I went to was the ISAAC (International Society of Augmentative and Alternative Communication) biennial conference in 1998. I loved Ireland, the city of Dublin and the whole environment of being somewhere different.

Initially, all I wanted to do was stay in the manufacturers' exhibit area to see all the different AAC devices and get advice on the easiest way to communicate. It was like being a kid in a toy store—everything you wished for right in front of you. Even better, because you could play with the latest AAC devices and software.

Then there are all the presentations, workshops and mini-seminars. First, I went to papers of friends from Australia. Then I experimented a bit and listened to "famous" people present their papers. Then, after I met a few more people, I went to their presentations.

At later conferences, I have become more discerning; I mainly go to presentations by people who use AAC because that is what interests me the most.

Practicality has also come into my decision making; I choose sessions that will be presented in the same room or nearby locations!

As the years go by and friendship circles grow, I look forward to meeting up with old friends and making new friends.

The forums for people who use AAC are where I meet my fellow travellers in AAC. I begin to hear others' stories. They share my hurts and dreams. They are patient while I talk and hear my words. It is a space like nowhere else. When everyone speaks at once, I laugh with joy as there are few places on this earth where I can do that and know I will be allowed time to speak again.

Throughout the conference, over meals, in hallways and at the bar (even at midnight!), there are always people to talk with. If batteries did not have to be recharged, I would have to find another excuse to get some sleep!

I attended the ISAAC Research Symposium at Trinity College immediately after the ISAAC conference in Dublin. To actually live on campus and meet in the hallowed halls of Trinity College was all part of the adventure.

At the 2000 ISAAC conference in Washington, DC, the President's Reception was in the Smithsonian



Museum of Natural History! We ate our meal in the foyer under a stuffed mammoth. These were extraordinary experiences that can never be replicated.

The 2002 ISAAC conference in Denmark offered day tours of Legoland and a post conference cruise to Norway. Although the President's reception was held at the Convention Centre, it turned into a very wild night with dancing to a Blue's Brothers band.

While I try to travel in the country that hosts a conference, it is not necessary to do so to experience the culture and the country. The conference organizers always make sure the attendees have unforgettable memories.

For example, all who attended the Silent Voices conference in Calcutta in 2001 experienced the hospitality and culture of the Indian people. The heat hits the traveller immediately upon disembarking from the plane. The traffic in Calcutta was unique and the organized shopping tours fantastic. The visits to rural West Bengal and the Historical Park were incredible. The conference itself was also memorable and I had a fabulous time.

A conference is never just a conference. It is an experience of adventure and memories.





State of the Science in AAC

Most of us know about the annual assessment of a country known as the “state of the nation.” When researchers periodically take time to reflect on, sum-up and assess the impact of their work to mark progress and steer future work, the process is called “state of the science.” The RERC on Communication Enhancement (AAC-RERC) sponsored a conference to do just this. The State of the Science Conference (SOSC): Accessing the World through AAC Technology was funded, in part, by the National Institute on Disability and Rehabilitation Research (NIDRR). It was held in conjunction with the 2001 United States Society for Alternative and Augmentative Communication (USSAAC) conference in St. Paul, MN.

An important outcome of that conference will soon be available. Volume 14, #1 of RESNA’s *Assistive Technology Journal*®, is entitled *Special Issue: Papers from the RERC on Communication Enhancement State of the Science Conference*. A limited number of discounted copies of the journal are available upon request.

The SOSC in AAC began with the in-house production of seven “white papers.” These white papers each took a hard first look at one aspect of current AAC technology research. An eclectic group of 53 AAC stakeholders were invited to read the papers and come to the SOSC prepared

to share their opinions and experience. Participants included AAC consumers and family members, manufacturers, researchers, service providers, policy makers, educators, and other AAC experts. The SOSC participants spent three days discussing important AAC issues introduced by these white papers.

The white papers were formally presented as part of the scientific program of the USSAAC conference, making it possible for over 250 USSAAC and 53 SOSC conference participants to hear each white paper presented. The participants in the SOSC discussed each paper and reached some degree of consensus about future priorities. After the conference, USSAAC and SOSC participants were encouraged to provide additional information and comments through the AAC-RERC website for one month. The white papers were also posted on the AAC-RERC website so people who were interested in the discussion, but could not attend the conferences, could add their comments. The AAC-RERC partners incorporated all information from the SOSC discussions and comments submitted via the website into the revisions. The final peer-reviewed versions of these papers constitute the special issue of *Assistive Technology*.

- 1) “Future AAC Technology Needs: Consumer Perspectives.” *Sarah W. Blackstone, Michael B. Williams, and Mick Joyce*
- 2) “Improving the Design of AAC Technologies for Young Children.” *Janice C. Light and Kathryn D. R. Drager*
- 3) “Improving AAC Use for Persons with Acquired Neurogenic Disorders.” *David R. Beukelman and Laura J. Ball*
- 4) “AAC Performance and Usability Issues: The Effect of AAC Technology on the Communicative Process.” *D. Jeffery Higginbotham and Kevin Caves*
- 5) “Enhancing Participation in Employment through AAC Technologies.” *David McNaughton and Diane Nelson Bryen*
- 6) “Enhancing Literacy Development through AAC Technologies.” *Janet M. Sturm, Karen Erickson, and David E. Yoder*
- 7) “Connecting AAC Devices to the World of Information Technology.” *Kevin Caves, Howard C. Shane, and Frank DeRuyter*

For additional information, go to www.aac-rerc.com



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Sources & Resources

The AAC-RERC may be contacted at www.aac-rerc.com

Meredith Allan may be contacted at mmallan@netspace.net.au

Graham Clarke may be contacted at grahamclarke@telkomsa.net

Tracy Rackensperger may be contacted at tdoggog@yahoo.com

Thank you to all of the guest authors as well as to the organizations that sponsor these useful conferences.

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own behalf. People who use AAC bring the additional perspective of someone who actually lives with augmentative communication.

AAC professionals and others are still constantly learning about people's needs and desires and rethinking their own stereotypical beliefs. The presence of people with disabilities assists in their rethinking. I am definitely not the type to let other people make decisions about my life. When it comes to furthering the field of AAC, I want to work with individuals to improve technologies. If you want to shape your life and the technologies you use, attend a conference and say what is on your mind!

Opportunities to learn

Finally, consider attending a conference because of the innovative presentations that take place. These presentations give the latest news and research about AAC. This is your chance to

hear from the experts—consumers, researchers, educators, etc. about the things that shape your life. The old truism, “knowledge is power” definitely applies to people who use augmentative



communication. We all have different AAC sub-topics that we are interested in studying. I am waiting for the day when an AAC device will translate my spoken words into something the general public can understand. I love to verbalize and find this the fastest way to communicate. The only problem is people who do not know me cannot understand me at all unless I use my device.

Because of this, I am very interested in research on speech recognition technology.

Summary

Conferences provide insight on many fronts. First, they allow opportunities for individuals to network and exchange information with all stakeholders. Second, conferences allow people who use augmentative communication to have a voice in their lives. Finally, conferences let all individuals benefit from hearing the latest news and research about augmentative communication. **A**