Mastering the Technology

How does an individual learn to communicate with a speech generating device (SGD)? As we shine the spotlight on this question, the short answer is that learning to communicate using an SGD is a complex business, indeed. The journey from having a thought in mind to activating the correct keys on an AAC device in such a way that someone responds can be a long one. Additionally, making an SGD talk in a private, calm practice session is much different from communicating something meaningful, in public, under time constraints.

An AAC-RERC project called Tech 2010 has investigated the question of how individuals learn these skills. Tech 2010 consists of two separate studies: one on the perspectives of individuals who have learned to use SGDs and a second on the perspectives of parents who have assisted their children to learn to use an SGD. This issue of *Alternatively Speaking* discusses the results of these studies. The research team for the first study consisted of two individuals who rely on AAC (Tracy Rackensperger and Michael B. Williams), a family member

(Carole Krezman) and researchers from Penn State University (David McNaughton and Karen D'Silva). The results of this study are published in *Augmentative and Alternative Communication*

INSIDE THIS ISSUE

(*AAC*) as "'When I First Got It, I Wanted to Throw It Off a Cliff': The Challenges and Benefits of Learning AAC Technologies as Described by Adults who use AAC."[1] This Spotlight article highlights some of the learning strategies described in that research paper. The results of the second study, not as yet published, are previewed on page five in the Friends and Relations section of this newsletter.

The research team designed the first study to investigate "the perspectives of competent communicators who used AAC with respect to (a) the process of acquiring and learning to use AAC technology, and (b) recommendations for improving instruction in AAC technology for individuals who use or could benefit from the use of AAC technologies."[2]

A focus group of seven individuals who have cerebral palsy and communicate well using AAC was set up on an Internet bulletin board. Tracy Rackensperger moderated the discussion. Three men and four women, ages 21 to 41 participated in the focus group

Message from the editor

I got my first personal computer somewhere in the late nineteen seventies, barely into the home computer revolution. The thing came with something called a floppy drive, an operating system and a thick instruction manual that looked like it had been mimeographed by my third grade teacher.

Needless to say, my learning curve for this infernal device was as steep as a brisk climb up Mount Everest.
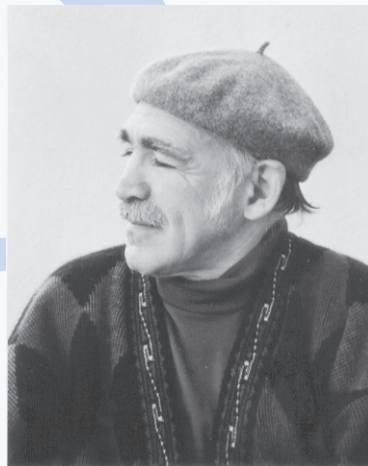
But I did master the beast.

I learned not to fear that thick instruction manual with its cryptic language and strange terminology. I learned to ask a lot of questions of people who were deliriously happy about having a home computer. Finally, I learned to just mess around with the darn thing, and I didn't even come close to blowing up the universe.

Learning to use a speech generating device (SGD) today reminds me of those early personal computing days.

One day a big box arrives at the door. It contains a device and several mysterious looking manuals, along with many pieces of loose paper. You know this is your new communication device, but how do you go about learning to use it?

We explore this question in this issue of *Alternatively Speaking.* Augmentative communicators and parents of children who use SGDs provide a wide range of information and suggestions about what to do after the communication device arrives.

Editor: Michael B. Williams   Technical Editor: Carole Krezman
Guest Authors: Tracy Rackensperger, David Chapple

using pseudonyms so they could speak freely. Over nine weeks, Tracy asked the group fifteen questions, as developed by the research team. The participants were able to see the questions as well as each other's answers on the linked bulletin board pages. Eight weeks after the focus group ended, each participant was given a list of the learning strategies that were mentioned in the group discussion and asked to rate the helpfulness of each strategy as well as their interest in using each strategy.

Six major themes emerged from the focus group discussions: (a) selection of an AAC device; (b) knowledge and skills needed to use AAC technologies; (c) instruction and practice activities; (d) assessment of skill acquisition; (e) recommendations to others; and (f) unrelated statements. This article highlights some of the findings. (To get all the details, ask for a reprint of the *AAC* article.[3])

Choosing

The focus participants wanted a significant role in selecting their AAC devices. Some were unhappy about being rushed to make a decision, overwhelmed by jargon and technology or overruled by the assessment team. Some were happy with the recommendations of their assessment team. Others selected their AAC device based on personal experience and input from others who use AAC. The participants' experiences with device selection differed considerably due to their individual background, preferences and availability of AAC resources in their community.

Getting ready

Linguistic competence, operational competence and social and strategic competence are words that define what it takes to use AAC in the real world.[4] The participants thought it was important to learn how to program their own devices and make their own programming decisions in order to express their individual personalities. Each participant had developed a unique, evolving routine to update and personalize his or her own vocabulary on the device. In addition, some preferred to use spelling with word prediction, some used pre-programmed words and some liked to program frequently used or activity-based phrases. The learning task for some was in remembering the procedures, while for others it was in learning to make customizing decisions.

Unreliable SGDs discouraged participants from going out in the world and slowed their learning of the device. To make minor repairs, participants said they read the manuals and explore the tools within the device. They all had good experiences calling manufacturer's tech support for breakdowns. Since a broken device can't be used to explain what is wrong or what needs to be done, the participants emphasized the need to train aides and family members to troubleshoot a recalcitrant device and to talk to tech support.

Participants described techniques to get people to listen and to repair miscommunications. The authors report, "With familiar partners, simply starting to prepare a message (especially when the device produced audible feedback for key activation) was sufficient to gain attention."[5] With less receptive partners, they used non-linguistic methods such as shouting, tapping and siren blaring. When participants were not understood, they would direct attention to the screen so the message could be read. If that was not practical or successful, they spoke more slowly, adjusting the rate using settings or punctuation. As a last resort, they would rephrase the message.

Practicing

In learning how to use their device, many focus group participants read the manufacturer's manuals. Most would have preferred an electronic version of the manual. Those who used a device with onboard software supports, such as the PRC Icon Tutor, found this technological support helpful. The participants were also interested in online classes and interactive AAC training on the computer, though none had tried it. According to the authors, "All of the participants used more than one learning strategy or instructional activity in learning their technology. In addition, all of the participants identified at least one or more strategies that they would have liked to try, even though they had not used them."[6]

All of the participants found that "fooling around" with their device helped them learn, especially in the beginning.

Participants were divided about the benefit of drill and practice. Some who needed to learn the structured pre-programmed vocabulary in Minspeak-based devices set up a schedule to memorize codes for words at home or school. While dull, this was effective for some, but others found that their learning did not transfer to a clinical setting, much less to real world situations.

All participants found engaging in conversation to be helpful in learning to use their SGD. Most combined use in the community with practice with familiar partners. With unfamiliar partners, some used the strategy of scaffolding their conversations. For example, during a series of excursions into community settings, an aide would assist a little less each time as a scaffold toward independent communication.

Learning independently takes motivation, so most participants also relied on professionals for help. Those who attended manufacturer's workshops found them helpful. Others said they would have liked to go to one. The response to instruction by speech-language pathologists (SLPs) was varied. Two participants had a good experience, two a bad one. Needless to say, the individuals in this geographically dispersed group experienced different SLPs. Of those who did not receive instruction from an SLP, two wished they had the opportunity and another was happy to have forgone SLP services. Those who wanted SLP instruction said they had trouble finding SLPs who had the skills and the desire to instruct an individual on a specific SGD.

Out and About

Tech 2010 Project Recommendations

Technology recommendations

The Tech 2010 research project found that learning to use an AAC device is much more complex and difficult than it should be.[1] Individuals want better learning tools and strategies; they especially want ones that take advantage of interactive computer technologies. They want reliable technology that will be consistently available for learning and use. Individuals of all ages want SGDs that start out easy and grow with the individual's increasing skills and needs.

Service recommendations

Young children need to be given access to SGDs that make sense to them. The training and skills of AAC service providers have not kept up with the changes in technology. Consumers are hard pressed to find the expert support they need to acquire and learn SGDs. More AAC professionals must be trained and the skills of those practicing must rise to the state of the science. This includes making consumer-driven assessment and instruction the standard for the field.

Recommendations to AAC learners

Take charge of the assessment process. Ask questions and try technologies until you are confident of your choice. Consult with others who use SGDs; their experience is valuable. Talk using your SGD daily. Practice, practice, practice. Ask others who use SGDs for tips. Go out into the community with your SGD and use it to live your life. **AS**

Tech 2010

The parents' focus group for the Tech 2010 project had a lot to say about what made learning to use AAC technologies easier and harder for their children. This focus group was comprised of seven parents of children who have cerebral palsy and who use AAC technologies. They participated in a nine-week, focused Internet discussion on how their children learned to use their speech generating devices (SGDs).

The formal paper for this part of the project is a draft manuscript tentatively titled, "A Child Needs to be Given a Chance: Parents of Individuals who use AAC Describe the Benefits and Challenges of Learning AAC Technologies."[7] The authors organize the parents' comments into six themes: (a) issues in the selection of an AAC device; (b) knowledge and skills needed to use AAC technologies; (c) learning supports for operating AAC technology; (d) barriers to learning AAC technologies; (e) assessment of skill acquisition; and (f) recommendations to others.

The parents reported experiencing a lot of frustration trying to get the right technology for their child. Parents who were unfamiliar with speech generating devices and accessories were frustrated because teachers, speech-language pathologists (SLPs) and AAC technology specialists did not know enough about AAC to lead the family in selecting,

Parents Talk

purchasing and setting up an SGD. Parents who knew about AAC and had ideas about their child's needs said they were frustrated by teachers, SLPs and AAC technology specialists who did not listen to them. While some professionals assisted families in getting devices, more often professionals were either not involved or were considered to be a barrier.

Once a device was acquired, many parents learned to operate it so they could teach it to their child. This took expertise in four areas: (a) technical operation and upkeep, (b) strategies for programming, (c) supports to help their child access the device and (d) solutions to technology breakdowns. They gained this knowledge by "reading manuals, attending training courses and using the telephone support provided by manufacturers. Other popular resources included the World Wide Web and online groups such as ACOLUG."[8,9]

Parents had the most difficulty programming, selecting, organizing and updating the vocabulary in the device. Parents reported learning these skills on their own, from an SLP or in a free manufacturer's course. The authors note that many participants felt the training was helpful,

but others felt trainings lacked detailed information. Parents felt they had to learn a great deal about SGDs before they could help their child.

The parents emphasized that children require "constant and consistent access to their devices in order to develop competency."[10] Many parents reported that technical breakdowns

Friends and Relations
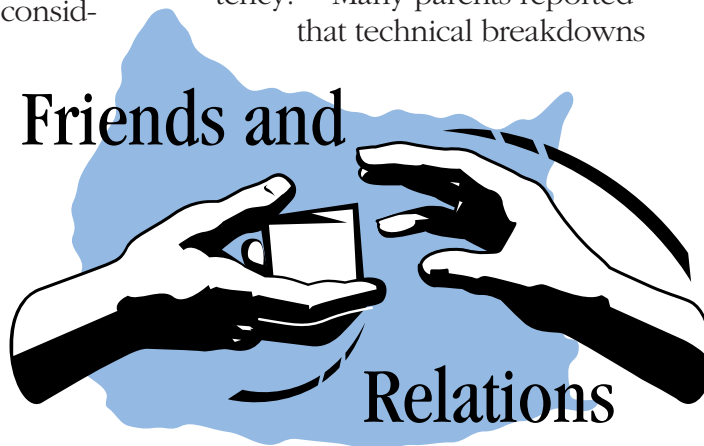
often led to frustration and interrupted their child's learning, which at times led to temporary abandonment.

The focus group also discussed how their children learned to use devices, reporting that many learning strategies were used at home and school. The authors cited "independent exploration, role plays, drill and practice, instruction and practice with family members, learning from other individuals who use AAC, instruction and practice with professionals, technology supports (such as icon prediction), manufacturers' training, manufacturers' technical assistance, and use in the community."[11]

Attracting the attention of communication partners is a skill the parents also talked about. Their children learned a number of strategies to gain others' attention including repeating, rephrasing and increasing the volume of devices. Techniques their children learned to repair communication breakdowns included repetition, giving more information, asking the communication partner to read the screen on the device, signaling a familiar communication partner for assistance and using preprogrammed messages with new communication partners ("Please do not read over my shoulder.").

In conclusion, this research describes the barriers and frustrations the focus group parents experienced in getting an appropriate SGD for their children. It also discusses that many parents first had to learn to operate devices in order to set them up and teach them to their children. Finally, it discusses the wide variety of learning strategies each parent explored in search of the ones that would work best with their child. **AS**

My Story of Learning   AAC
by Tracy Rackensperger

RAVES & REVIEWS

I'd like to take this opportunity to provide a brief description of my personal experiences with learning how to use AAC devices. My experiences have mirrored those of others who rely on AAC.

Over the past 25 years, I have learned to use a variety of augmentative communication devices. Learning an AAC system is a lot like learning how to drive a power wheelchair for the first time: You have to practice, go through a trial and error phase, and, eventually, become a competent user. At least, when learning an AAC system, there's no chance of inflicting physical destruction!

In 2001, I received my current augmentative communication device. I had been eagerly awaiting the new device because my previous device was just not working for me. In the past, I had received my communication technology while in the public school system. Therefore, I had support (in varying degrees) from school to guide me through the learning process.

In my early years, I had speech-language pathologists (SLPs) who worked with me to develop skills to use AAC technologies. There was a strong focus on me learning AAC from a clinical perspective. In other words, I spent a lot of time in speech therapy learning the mechanics of using a device. I attended a school in an educational system where assistive technology was highly thought of and utilized. The focus of my early education involved language and speech development. This prepared me to use augmentative communication in the "real world."

My AAC device arrived while I was in graduate school. At that time, I was involved in my coursework, plus I was traveling very often for advocacy purposes. How was I going to learn my device and not let it affect my ability to complete my coursework and travel? This device was radically different from my previous one. However, I was familiar with some of the software because my first communication device also used it. Time was a big issue for me. I had an erratic schedule and didn't see myself as being able to work with a professional regularly enough to receive a great benefit from their expertise.

In the end, I decided to use books and learning tools to teach myself how to use my new augmentative communication device. I studied these books and materials when I had time and employed other techniques to aid my learning. I attended free online classes provided by the manufacturer. Also, I enlisted assistance from a friend who used the same device to "peer tutor" me. We would meet together at least once a week and go over icon sequences. We would talk about what was happening in our lives using our devices as well. This helped me to develop proficient skills.

The ways one learns to operate his or her own augmentative communication device are dependent on the individual's preferences. As the Tech 2010 research indicated, individuals either used, or would like to have used, a wide variety of tools and techniques to learn AAC. We need to make sure people have access to a variety of tools and techniques that will assist them in becoming skilled at using AAC to communicate. My preferences were to learn at my own pace and integrate my training with my schedule. Others will have their own learning styles and preferences. A continuum of supports, ranging from self-study materials in several media formats to traditional training from AAC professionals, would assist more individuals in learning how to use their augmentative communication devices and in achieving their goals.

AAC-RERC

SPREAD THE WORD

What is the AAC-RERC?

by David Chapple, AAC-RERC Writers Brigade

Allow me to introduce you to a group that places the individual first. Meet the Rehabilitation Engineering Research Center on Communication Enhancement, known as the AAC-RERC, and the people that run it. The National Institute on Disability and Rehabilitation Research (NIDRR) founded the AAC-RERC in 1989. Now it is one of twenty-one currently funded RERCs. The AAC-RERC's mission is to help people who rely on communication aids to meet their life goals. Such ideals drive in-depth research and training programs, to make AAC technologies useful and usable. This group is made up of ten partners and their staff across the country working out of state-of-the-art labs. Quite a few members of this group use AAC to do the work. Getting them involved ties in with the AAC-RERC's motto, "Nothing About Us Without Us." The people who benefit from the research have a say in what is done.

The goal of each of the twenty-one RERCs is to think outside the box to solve rehabilitation problems and barriers, get familiar with new technology, make technology affordable and assist people with disabilities with their employment and independent living needs. They achieve this by applying the latest developments in technology. People with disabilities work closely with the researchers at each RERC.

People who rely on AAC work on many AAC-RERC projects including the training program called the Writers Brigade. Directed by Sarah Blackstone and Johana Schwartz of Augmentative Communication, Inc., the participants master their technical writing skills while spreading the word about the AAC-RERC. I joined the Writers Brigade this year after working with AAC-RERC partners David McNaughton from Pennsylvania State University and Diane Bryen from Temple University. During my time on the Writers Brigade I have been given assignments that highlight the activities of the AAC-RERC. Since their activities are technical, it builds my technical writing skills and employment marketability.

I have worked with partners David McNaughton and Diane Bryen on many projects throughout the years, and they always treated me as a colleague. Once David and I had a casual meeting in the lobby of the hotel during the Pittsburgh Employment Conference to discuss how to get the employer's perspective on having an employee who uses AAC. We exchanged ideas in a lively discussion. The end result of the meeting was David and I co-presented a paper on the topic at the next Pittsburgh Employment Conference. AS

To learn more about the AAC-RERC and to monitor the projects, visit http://www.aac-rerc.com

Sources & Resources

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11. McNaughton et al. (manuscript in preparation)

David Chapple may be contacted at dgchapple@bright.net

Tracy Rackensperger may be contacted at tdoggog@yahoo.com

Thank you to the guest authors and the Tech 2010 research team.

IN THE SPOTLIGHT

Many participants were interested in meeting, observing or conversing with peers who were skilled at using an SGD. Some wanted to ask specific questions about communication techniques. Others were looking for role models who had success with SGDs. Some wanted to share experiences and moral support. Participants were able to find individuals with device experience at AAC camps or on listservs with an AAC focus.

Conclusion

The focus group participants measured their success in learning to use their SGD by their ability to talk in the real world. The participants noted communicating in the clinic or at home was much easier than with unfamiliar partners in the community. They reported satisfaction with their successful verbal exchanges in real world situations. AS