

ALTERNATIVELY SPEAKING

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Saying It your Way

I have been shining the spotlight all around, looking high and low for the best way to communicate using AAC. Have you been looking around, too? If money was no object, could you obtain the perfect way to augment or replace your speech? This article suggests there is no one perfect way.

No one communication mode (an AAC device, a low-tech board, gestures, signs, speech), for example, could possibly meet all my communication needs. I use multiple communication modes—I communicate in many ways. I select the best mode depending on the location, with whom I am communicating and the purpose and content of the communication.

Here are some questions to help you decide for yourself whether you want to use multiple communication modes, too:

Breakdowns

Do you have a job, an active life or responsibilities that demand that you have a back up way to communicate?

Wet environments

Do you worry about your communication system while you walk through the storm, hang out at the pool, or take a shower?

A good position

Can you communicate when you are seated in an airplane seat, on a Ferris wheel, in bed, lounging on the sofa, playing on the floor or picnicking on the grass?

Hostile environments

Can you have fun knowing your communication system is safe from sand at the beach, from menacing shadows in an iffy neighborhood, from the celebrating hoards at football games?

Unwilling partners

Trying to argue with a stubborn family member, boss or friend can be difficult if the communication partner is expected to do more than try to open his or her ears. Ever had someone walk away while you were still pounding out a pithy point?

Light

Do you need a communication system that works in the dark or that works in bright light?

Noise

Can people hear your witty remarks at a cocktail party, your sweet nothings at the local pub, your wild cheering at a stadium event, your shouts for a turn on

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Message from the editor

Twenty years ago, I experienced attitudes of annoyance and frowns of frustration whenever I whipped out my home-made letterboard. Such things weren't done in polite society.

I started writing articles about personal computers and their implications for people with disabilities in the early 1980s. Published in small, disability oriented quarterlies, these pieces were well received, but I almost immediately forgot about them.

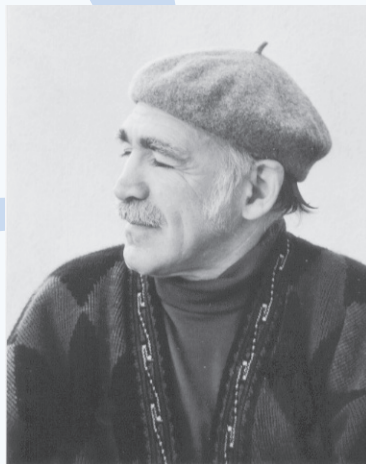
Then, one day I got a letter from John Eulenberg of the Artificial Language Laboratory at Michigan State University. Dr. Eulenberg said he would be coming to Stanford University for a year's sabbatical, would I be interested in working with him on a project involving speech synthesis. I jumped at the chance, not knowing where it would lead.

This is how I entered the field of AAC. I soon discovered a small core of dedicated people who had radical ideas about people with dysarthria and how to help them. These new ideas came as a shock to this guy who gleefully had abandoned his traditional speech therapy sessions in his late teens. Here was a brave new world of speech therapy with

mutated emphasis on those voice and articulation drills of my childhood.

I have seen many technological developments since my initial jump into AAC, but the thing that drives the field now, as then, is the dedication of its people. Their work forms the cornerstone of the case for funding AAC devices. Without these dedicated people and without this knowledge base, the fight to fund AAC devices would have been a flop.

I squeal with glee at each technological advancement in AAC, but I raise my glass in tribute to the dedicated people of the field. Without them, we would still be doing those voice and articulation drills of yore. **A**



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the school yard, your request for clean-up time in an active classroom?

Whispers

Can you whisper to your classmate when the teacher's back is turned? Can you quietly discuss adult matters while your sweet daughter falls asleep in the next room?

Limited partners

Can you just as easily communicate with your deaf mother, the six-year-old neighbor and your blind co-worker as with anyone else?

Phone

Can you use the telephone? Can you make an emergency phone call? Can you make a private or confidential phone call?

Computer

Can you jump the digital divide to email, chat, download, message and search?

Power

Are you going to be able to talk when the power goes out? On that camping trip to the desert? At the end of a very long day?

Size

Can you get off the bus, into the toilet stall, up to the table and through the door?

Language

Do you want to get an "A" in that advanced French class? Does your family speak a language at home that is not the one you use at work or school? Is there more than one language used in your community?

Vocabulary

Do you have access to the vocabulary you need to chat politely with your auntie over tea, to joke with your pals over a

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Total Communication

by Martin Pistorius, South Africa

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beer, to ace a job interview, to report a crime?

Speed

Can you grab the interest of communication partners before their attention wavers?

In conclusion

I suggest that everyone needs more than one way to communicate. We all need access to multiple communication modes to be able to say everything we need and want to say, whenever and where ever we happen to be and to whomever we choose. It's your responsibility to seek out and learn to use the communication modes that will allow you to be your unique self, a multi-modal communicator.



Social Networks

A new assessment tool that can help you identify the variety of your communication needs has recently been published by *Alternatively Speaking's* publisher, ACI. *Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners* can help families and clinicians imagine opportunities for communication. For more information go to www.augcominc.com.

Total Communication means that we who use AAC have a way to communicate in every situation and circumstance that life presents. Achieving Total Communication is a considerable challenge.

Professionals tend to focus on communication needs.

(I'm hungry, I'm thirsty, I need the bathroom, I'm in pain.) One could even argue that professionals too often look at AAC from the family or caregivers' point of view and not the AAC user's.

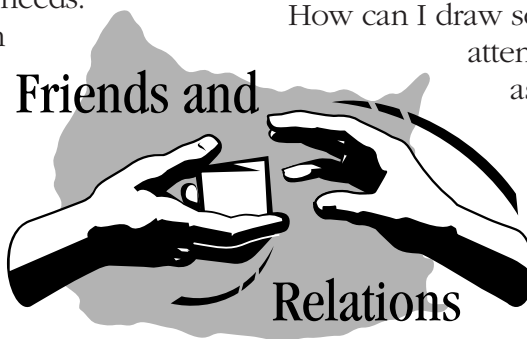
While communicating aspects of daily living is very necessary, it is probably the least significant aspect of AAC for an AAC user. Personally, being able to communicate what I'm thinking and feeling, and why, is as important as saying thank you and just generally expressing my appreciation of things, people and life in general.

The Individual

It is absolutely vital that the individual's needs are addressed first and foremost, not the needs of the family or caregivers. The word "individual" here is extremely significant because the Total Communication system must be tailored to each individual's unique needs.

We need to look at every aspect of our lives, from the time we wake up in the morning, until we get up the following morning. We need to be able to communicate 24/7 like so-called "normal" speaking people do. For example, I might start by thinking about communication while in bed.

How can I draw someone's attention? As much as I love AAC devices, I don't sleep with one. An accessible bell or alarm is all that is necessary.



AAC users who are lucky enough to have a partner need to be able to communicate additional messages in bed such as "Not tonight honey, I've got a headache," "That feels good," or even just the boring, old "Good night, sweet dreams." In this scenario, gestures may be the best option.

We also must be able to communicate in the bath or shower, where AAC devices can't go. What happens when, for example, the water's too hot, or the AAC user just wants to lie in the bath and relax? A communication board that is laminated or gestures and vocalizations can work in this environment.

People who spend considerable time outside may not find dynamic display devices ideal.

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Dynamic displays are notoriously difficult to see in sunlight.

Our communication partners also must be considered. For example, if the AAC user interacts with children who are not yet literate, or wants to communicate in group settings, using an alphabet board won't be effective.

Devices

Most of us need at least one dedicated AAC device, a computer and a cell phone. In our modern digital age, it is essential to realize that just one system or device can not meet all our needs. Cell phones are vital for us to call for help and communicate with our personal assistants, amongst other things.

The only problem with technology is that sooner or later IT WILL FAIL!! For me, this is a huge and, quite frankly, frightening reality, because I don't have any backup system whatsoever! Other than my alphabet board, I use a standard off-the-shelf laptop computer with dedicated AAC software.

My computer is literally my interface to the world. It's my voice, in every sense of the word. With it, I talk to people face-to-face or over the phone, give speeches, write letters, email, even chat online. It enables me to be employed. With it, I am empowered and able to make a contribution to society and communicate in any forum. Without it, I am unable to work, plus I'm nowhere near as effective a

communicator with my alphabet board. Not to mention the fact that alphabet boards can't send and receive email.

As I live in South Africa, I selected an off-the-shelf laptop for my communication device because, should it break down (God forbid!), I could get it repaired locally. Dedicated devices need to be shipped back to the supplier, invariably in the USA, and then repaired and returned. This occurs at the AAC user's expense (including export and import duties!) and normally takes approximately a year, leaving the unfortunate AAC user without a voice.

Conclusion

Total Communication means we must learn how to use different communication approaches so we can communicate in every possible situation. In order to achieve Total Communication, all facets of life in the 21st century need to be looked at, from making a phone call to surfing the Internet. Each of us who uses AAC must be equipped with more than one means of communication such as gestures, keyword signing, communication boards, a computer and at least one communication device. Each must also have at least one backup system. In addition, communication partners and the environment must be considered. When we use Total Communication, we can communicate in every situation, as independently as is possible.

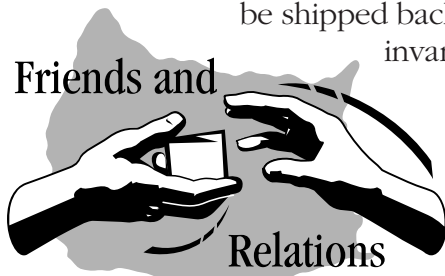
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When someone has difficulty speaking, he needs to develop numerous methods of communicating because no single method will work in every situation. I have cerebral palsy and part of my handicap is having a speech impairment.

I have found that my speech is the hardest aspect of my disability to accept. I'm almost sixty, and communicating like others still is the most difficult challenge I face everyday. My wheelchair, for the most part, has helped me to reconcile myself to the fact that I can't walk because my wheelchair gets me to most places I want to go. The wheelchair is becoming more accepted because more people who use wheelchairs are going out into public. However, not being able to communicate is a much larger barrier because most people with communication problems don't venture out into the world.

When I was young, I was eager to learn more about people and life. I wanted my brother to tell me about everything he did at school. I asked him all about the things he had done playing with the other neighborhood kids. The more he told me, the more I wanted to be part of that world



Friends and

Relations

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Not One Way to Communicate

by Joe Hemphill

outside our bedroom. But I couldn't talk with the other kids. For someone like me, who truly enjoys other people, not being able to communicate was a great frustration.

My own voice

Various methods have made communication a little easier for me. First of all, I developed my own voice as much as possible because most people communicate through the spoken word. This is how other people expect you to communicate because everyone does. I was lucky enough to attend a day school or special education program where speech therapists worked with me to use my own speech as much as possible.

At home, I also was encouraged to use my own voice all the time. My parents taught me to say words such as "please," "thank you" and "yes" and "no" even though these words don't sound the same as when other people say them. Still, saying the right word in a particular situation can help communicate what kind of person I am and let others know that I am aware of what is happening. I have worked very hard to use my own voice to communicate.

Body language

Body language, including a smile or other facial expression, can convey a lot in a very short time because it is natural and expected. I always say, "Thank you," and smile when someone helps me in a market. I have worked hard to include body language in all of my communication and to make it expressive so it can help convey my emotions and needs.

Letterboard

After many years of using just my voice and body language, a speech therapist introduced me to a letterboard. This was both a happy and sad day because it meant that my own voice wasn't enough for me to communicate in the world.

A letterboard can come in many shapes and forms depending on whom will be using it. My letterboard is a small piece of plywood with all the letters of the alphabet stuck on it. My letterboard is small enough to slip into the side of my wheelchair and has the letters arranged like a keyboard so I can find them fast. My letterboard is especially good because it can go anywhere with me and it's easy to pull out and use. Once people know about my

letterboard, they often pull it out for me when I enter a restaurant or store. My letterboard is the simplest type of communication device. My letterboard also lets me still use my own voice because I just spell the words people don't understand.

Communication device

Even though my letterboard helped a great deal, I needed a faster method of communicating, so I began the search for an augmentative communication device. After several years, another speech therapist showed me the Message Mate. The Message Mate is a good communication device for me because, after this device is programmed, very little training is needed. I consider my Message Mate just an extension of my letterboard. Instead of just spelling one word at a time, my Message Mate lets me say whole sentences at once.

I have found that people are comfortable with me using the Message Mate because it allows me to communicate more like most people talk. This is more natural. I use my Message Mate along with my own voice. In some cases, I use both my letterboard and my Message Mate along with my own voice to communicate.

The computer

Over the years, my computer has developed into my most flexible and beneficial communication device. The computer is the most accurate way for me to communicate because I can use the exact words I want. With my Message Mate, I am

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Confessions of a Multi-modal Man

by Michael B. Williams



I use the Liberator, Lightwriter and letterboard everyday at various times during the day. Why do I need three devices? Isn't one sufficient? In a word, no.

If I didn't have the Liberator, I wouldn't be able to give any of those sparkling speeches I'm noted for. But the Lib is big, awkward and heavy. I carry the Lib on my lap, and it's very hard on my knees. You want to know why I don't mount the Liberator on my damn wheelchair? The short answer to this question is, I don't want to mount the Liberator on my damn wheelchair. Okay? Call me silly, but I don't want tons of assistive technology dripping off my chair. It scares people off to see all that technological firepower coming at them. You think I'm kidding about this? I'm deadly serious.

There's a more important reason I don't mount the Lib on my wheelchair. Sitting here, I may look very disabled, but actually I have quite a bit of functionality in my body. I can transfer in and out of my wheelchair by myself fairly easily. This allows me to do some very important personal things without the help of other people. Things like go to the bathroom. Have you tried to negotiate your way into a public bathroom stall with a big old communication

device mounted on a wheelchair? You may get in the stall, but how do you get from your wheelchair onto the throne without falling on your ass as you hold onto the grab-bar and gingerly attempt to swing past your communication device and lower yourself onto the seat? That, too, dear reader, is why I don't mount the Liberator on my wheelchair.

I bet you never expected to read anything like that in this newsletter!

Here's another thing to ponder. Observe the size of the Liberator. Notice its rather large footprint. Now imagine you have a really hot date and you want to book a table at a swank restaurant. How big a table do you book? If you book a table for two, one of you ain't gonna eat or one of you ain't gonna talk because the Liberator soaks up too much table space. If you book a table for three, you risk igniting the ire of the maitre d'. Either way, your evening is a bust and your budding relationship is down the tubes.

You're asking yourselves, what would Michael Williams do at a critical time like this? Well, I'll tell you what I'd do. I'd use either one of the following handy-dandy AAC tools. The letterboard lies nicely next to you on the

table. Its basic black contributes an additional touch of suaveness to an already elegant dining ambience. The letterboard, however, also provides a slightly more intense conversational experience. Your partner watches intently as your hand glides slowly across the smooth surface of the letterboard. Your long, lean finger languishes lovingly over each letter as it slowly constructs linguistic meaning out of chaos.

Don't care for such intensity? Try the Lightwriter. It's small, it's simple, it's elegant. And, yes, dear reader, it provides the perfect atmosphere for conversation while dining. It sits primly on a corner of the table. Your partner need only flick a glance to the screen now and then to see what you are saying. And you have the added assurance that if your partner misses something, you need only push the talk button at the end of your thought, and the Lightwriter will say it for you.

And that, dear reader, is why I use more than one communication device.

A



Spread the Word:

AAC-RERC Plans for 2003-2008

by Johana Schwartz

The Rehabilitation Engineering Research Center on Communication Enhancement, informally called the AAC-RERC, has been recognized for its excellence by being awarded its second five-year grant. The National Institute on Disability and Rehabilitation Research (NIDRR) will fund the AAC-RERC from 2003-2008.

The AAC-RERC will continue to address key areas of importance for individuals who rely on AAC technologies. The AAC-RERC is known for its innovative approaches and its commitment to including people with complex communication needs in all aspects of its work.

The research team

The AAC-RERC currently has ten partners who work at seven institutions located throughout the country. Michael B. Williams, the editor of *Alternatively Speaking*, is one of the partners. Howard Shane, a highly respected AAC researcher at Children's Hospital Boston will be joining the creative team. The ten partners are David Beukelman, Sarah Blackstone, Diane Bryen, Kevin Caves, Frank DeRuyter, Jeff Higginbotham, Janice Light, David McNaughton, Howard Shane and Michael B. Williams.

The partners also draw on the resources of leading high-tech

companies and organizations outside the AAC-RERC. Some of these collaborators are the Department of the Navy, Don Johnston, Inc., Enkidu Research, the Federal Laboratory Consortium, InvoTek and Zygo Industries.

Upcoming projects

All the partners use state-of-the-science research and development tools to work on projects that were identified as priority areas within the AAC community. Here is a brief look at some of the project areas that the AAC-RERC will work on over the next five years:

- Building literacy skills for people who rely on AAC technology.
- Improving AAC technologies for very young children and for people with severe cognitive and linguistic challenges, people with autism and adults with aphasia.
- Increasing the success of AAC technology in different social settings, such as the workplace, in conversations and in the community.
- Developing new kinds of AAC user interfaces, such as speech recognition, gesture recognition and direct interface with the brain.
- Developing tools to evaluate

how people use their communication devices.

- Operating everyday technologies, such as computers, telephones and light switches with AAC devices.
- Providing information about laws and regulations that affect access to AAC technology.
- Training people who rely on AAC technology to report on these projects.

Spread the word

The AAC-RERC partners have pledged to keep all members of the AAC community updated on their progress in these areas. Scientists, manufacturers, educators and service providers, as well as people who use AAC technologies and their families, will be kept informed of new developments.

Look for reports on AAC-RERC projects in upcoming issues of *Alternatively Speaking*. In the meantime, to learn more, visit the AAC-RERC website at www.aac-lerc.com.



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Sources & Resources

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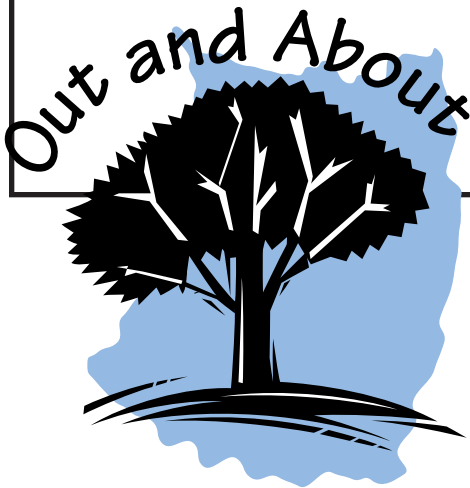
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Thank you to all of the guest authors.

Earlier versions of "Not One Way to Communicate" by Joe Hemphill were previously published in *The Fresno Bee* and the newsletter of the Central Valley Regional Center.

Michael B. Williams is featured on a new video and DVD that supplement *Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners*. An earlier version of "Confessions of a Multi-modal Man" is available on the DVD. The DVD is called *Social Networks DVD* and the video is called *Social Networks VHS*. For ordering information, contact Attainment Company at www.attainmentcompany.com or ACI at www.AugComInc.com



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limited to what is programmed into it. In using my letterboard, I spell out keywords so people can understand the main or important things I want to get across. When I speak, I can't always use the words I want. But with the computer, I can use the exact wording I want.

The computer technologist at United Cerebral Palsy has set up my computer so I can use it efficiently. The computer has opened up many ways of communicating for me. I write emails, faxes and letters to many people including my doctors, social workers, creative writing teacher, other students at college and government officials. Using the

computer, I can take an active and independent role in my own daily activities and advocate for myself and other disabled people. In addition, my computer has a program that will speak what I type, and I can use this program over the phone. My computer has given me many ways to communicate.

Many methods

Only one way of communicating is not enough. Someone with a speech disability needs to learn to use many methods of communicating all through his life.

Around family and close friends his own voice may be enough, and, indeed, he should learn to use his own voice as much as possible. His own voice will help him fit into the world and is the most accepted way of communicating. However, once he grows beyond his family and close friends, he may discover that his own voice isn't enough.

Most people in the larger world don't, and won't, take time to understand someone who has difficulty speaking. The world is fast-moving, and people have enough trouble keeping up with what is going on. Here's where a speech device may help the person who has difficulty with communicating fit into the world. A speech device may be as simple as a piece of plywood with letters or as complex as a computer with all types of programs that are used to communicate. The person may find it necessary to use more than one communication device simultaneously.

The person who has difficulty speaking has to be ready to adapt to whatever situations he finds himself in and be ready to use any or all the communication methods and devices available.