ALTERNATIVELY SPEAKING
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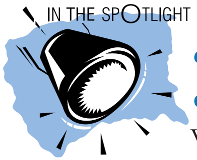
AAC Summer Programs



Leisure time and what to do with it is a vexing problem for people who use AAC and their families. Mobility and communication difficulties often hinder AAC users from taking part in social and recreational activities. This can mean long stretches of loneliness while others are having fun.

Until recently, summer recreation programs were seldom utilized by augmented communicators. Even camps designed for people with orthopedic disabilities were not equipped to handle some of the needs of people who use AAC.

Not anymore. Thanks to the efforts of Tracy Kovach of Denver, Colorado's Children's Hospital and others, augmented communicators now have the opportunity to fully participate in recreational activities at camp. Kovach established *Talking With Technology* seven years ago in the belief that communication skills could be taught in an environment that is both stimulating and fun. According to Kovach[1] some of the main goals of camp are to:

- have fun.
- learn that through communication you will have more participation.
- meet other augmented communicators who really use their devices and be motivated by them.

Most summer programs in the United States offer AAC training for the participant and an accompanying adult in a camp-like setting where they can participate in traditional camp activities such as swimming, hiking and sleeping under the stars. Table I summarizes the main features of some of these programs.

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There is a strong therapeutic element associated with many of these programs. Speech language professionals and graduate students help with the communication aspects of the program. Although the emphasis is on fun, there is always a hint of therapy in the air. The AAC user is often asked to bring along someone who regularly works with him in order to provide continuity to home and school.

One program is unique in many ways: It is held on a college campus in a very urban setting; there are no horses or boats; it's an institute not a camp; and participants are adults who rely on AAC. The *Augmentative Communication Empowerment Support (ACES)* program realizes that communication is only the first step on the long road to full participation in the community. *ACES* is an intensive, community building experience that helps people develop a literal, social and political voice.[2] In addition to learning how to access the core vocabulary of their voice output communication devices, enrollees meet, interact and are mentored

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Message from the author

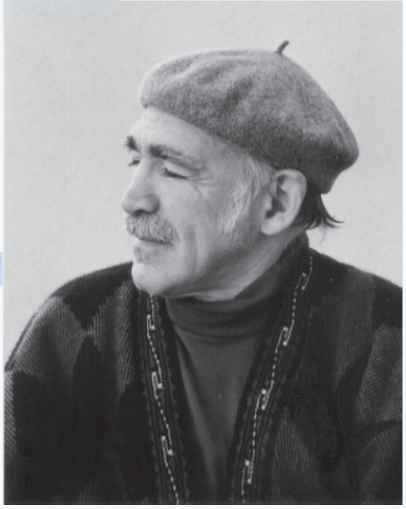
I want to alert my U.S. readers to something that's happening with the U.S. Congress.

As you know, the relationship between the state and federal government is undergoing a great change. Many people believe that less government is better government and that states should have a greater say in how federal funds are spent.

In addition to this shift in philosophy, there is also a concerted effort afoot to reduce the power of special interest groups in Washington. One method of doing this has been proposed by Representative Istook of Oklahoma. He is the lead sponsor of the Istook/McIntosh/Ehrlich amendment.

Dubbed the "Silence America Amendment" by its critics, it would impose restrictions on how every nonprofit organization that receives a federal grant spends its non-federal funds. It would punish any organization that spends more than five per cent of its budget, excluding federal grants, on advocacy in any of the previous five years.

I believe this particular legislation has serious implications for the disability rights movement and people who rely on AAC. Organizations such as UCPA, Hear Our Voices, ASHA, USSAAC, TASH, RESNA and The ARC can collect the voices of people with disabilities and advocate successfully for disability rights legislation. As single voices, we may be silenced. Please contact your federal representatives and tell them how you feel about the Silence America Amendment.[5]



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by leaders of the disability rights movement and graduates of the *ACES* program.

Empower's Alternative & Augmentative Communication Camp and Expo has a very interesting mentoring program: Able-bodied teenagers who have been extensively trained in AAC and disability awareness use communication systems during camp activities. The young campers are reported to be thrilled to see older kids accepting their communication styles.[3]

Choosing the right program depends on what experiences one is looking for. Be a good consumer:[4]

- Don't rely on just the advertised information.
- Research your program options.
- Ask questions about the program's activities and staff.
- Make sure expert AAC users will be present.
- Will you get what you pay for?

The goal of any summer program ought to be to provide experiences not available at home. Camp should be about having fun, being more independent and resourceful, meeting new people and learning new things about yourself in a totally different setting. Camp should never be solely about therapy. If it is, somebody isn't doing their job.

Table I. Some AAC Camps & Summer Training Institutes

Table by Michael B. Williams & Carole Krezman. *Alternatively Speaking.* Augmentative Communication, Inc. 408-649-3050

	Communication Technology Camp (3 days)	**Building Bridges Camp (1 week)**	**Empower's Alternative & Augmentative Communication Camp and Expo (3 day weekend)**	**Camp Chatterbox (1 week)**	**Talking with Technology Camp (1 week)**	**ACES: Augmentative Communication and Empowerment Supports (5 days + 7 days tutor training)**
Setting	Bloomington, IL. Easter Seals campground on lake	Cupertino, CA Crippled Children's Society of Santa Clara County camp in mtns	Columbus, OH at Recreation Unlimited campground on lake	Hackettstown, New Jersey Easter Seals campground	Denver, CO Easter Seals campground in Rocky Mtns.	Philadelphia, PA on Temple University campus
Equipment	Must have own voice output system.	Should have own voice output system; Some loan/ rental equipment possible.	Candidates for AAC are welcome. Equipment to try or borrow.	Must have own voice output system. Equipment to try.	Must have own voice output system.	If participant doesn't have voice output system, rental provided for 8 weeks.
Ages	7-16 years.	6-18 years.	All ages.	5-16 years.	6-21 years.	Adults 18+ years.
Camp/Home Continuity	Summary report sent home with family. Encourage teacher and/or therapist to attend.	Bring an adult trainer from home or school if possible.	Encourage teacher and therapists to attend.	Bring parents. Training is provided to parents to become facilitators.	Bring an adult who is working with camper and AAC system.	Must bring tutor whom ACES will train; 1 year follow-up technical assistance; help to secure funding for equipment.
Personal Care Assistance (PCA)	Provided as needed.	Provided.	Bring own PCA.	Bring own. Some PCA available.	Provided.	Provided as needed.
Family Policies	Siblings welcome. Parents discouraged.	Siblings welcome. Parents discouraged.	Bring the whole family.	Siblings welcome. Parents encouraged.	Siblings encouraged. No parents.	No policy.
Mentors, Role models, AAC Users on Staff	No.	One staff member relys on AAC. Visitors.	Non-disabled, AAC-trained youth role models.	Visitors. Older campers may serve as role models.	Adult AAC user(s). Older campers may serve as role models.	AAC mentors & empowerment instructors.
Professional Opportunities	Graduate students and professionals work/learn.	Graduate students and professionals work/learn.	Graduate students and professionals volunteer.	Professionals work/learn.	Graduate students and professionals work/learn.	Tutor, student, professional work/learn 12 days.
Applications Due for 1996	May 15	March 31	July 1	Families: June 1 Interns: February 15	March 1	March 31
Cost (Some costs may be covered by 3rd party payors.)	$125 per camper. $25 per counselor.	$950 per AAC user. $350 per sibling. $425 per Trainer.	$75 per person.	$450 per child with 1 parent. $600 per family of 4. $$50 per additional sibling. $200 per intern.	$1430 per child camper. $200 per sibling. $330 per trainer. $200 per PCA.	Approximately $3,000 for participant and tutor. (Includes PCA, equipment rental, 1 year follow-up.)
Contact	Danila McAsey CTC '96 c/o Speech & Language Rehabilitation Services, Ltd. 416 St. Marks Ct. Ste. 400 Peoria, IL 61603 309-676-1212	Cassie Sementelli Bridge School 545 Eucalyptus Avenue Hillsborough, CA 94010 415-696-7295 ext. 108	Becky Scholl Empower RD#1, Box 15b Irondale, OH 43932 614-544-5305 / 800-982-3671	Joan Bruno, Ph.D. CCC-SLP Children's Specialized Hospital 150 New Providence Road Mountainside, NJ 07092 908-233-3720 ext. 250	Tracy Kovach The Children's Hospital, B030 1056 E. 19th Ave. Denver, CO 80218 303-861-6024	Diane N. Bryen, Ph.D. Graciela Slesaransky Institute on Disabilities/UAP 423 Ritter Hall Annex Temple University Philadelphia, PA 19122 215-204-1356 / 800-204-7428

Come Fly with Me

A long distance trip often means getting "there" on an airplane. Now most people have no problem with air travel. They buy their tickets, pack their bags and climb aboard their silver winged bird. Passengers with disabilities, especially those who use battery-powered wheelchairs, have a much more difficult time with air travel than ordinary mortals.

When a person who uses an electric wheelchair rolls up to an airline ticket window, he is often greeted with something akin to the evil eye. This is because most airline employees still are unfamiliar with the rules and regulations that govern acceptance of battery-powered wheelchairs on flights within the United States. These rules and regulations are covered under the Air Carrier Access Act of 1986 (ACAA).

Although the ACAA covers a broad range of subjects about disability and air travel, this article focuses on how an airline passenger with a disability can handle his or her electric wheelchair.

Here's the bottom line: Although airlines are required to carry battery-powered wheelchairs, they can require wheelchair passengers to do certain things. Table II. gives nine tips to make traveling with an electric wheelchair easier.

The ACAA distinguishes between wheelchairs that are powered by wet cell and those powered by gel cell batteries. Most electric wheelchairs come with wet cell batteries. They are like car or boat batteries, and, since they can leak acid if they are turned over, they are considered hazardous materials by the airlines. The ACAA requires them to be removed from the wheelchair and placed in special boxes which the airlines provide. Airline personnel are required to help passengers do this. Most newer chairs are built to make this relatively easy. Uncover the batteries, unsnap a couple of plugs and lift the batteries into the airline-provided boxes. Try it at home or at your wheelchair repair shop first to make sure you know what you are doing. I've labeled my batteries and their appropriate locations on the wheelchair "left front" and "right front" so when I get to my

Table II. Travel Tips for You and Your Electric Wheelchair

1. When making airline reservations, tell them that you are a person with a disability who will be traveling with a battery-powered wheelchair. State how many batteries you have and what type they are (wet cell or gel cell).

2. Arrive at the airport more than one hour before the scheduled flight. The ACAA requires that you talk to an airline agent one hour before the flight leaves, and sometimes the wait for your turn is lengthy.

3. When you're getting luggage tags for your bags, be sure to get one for your wheelchair.

4. When you get up to the ticket counter, tell the agent that you are traveling with your battery-powered wheelchair. State how many batteries your wheelchair uses and what type they are (wet or gel cell). If the wheelchair uses wet cell batteries, request that airline battery boxes be brought to you. Be sure to ask for one box for each battery your wheelchair uses.

5. When you're at the ticket counter, tell the agent when and where you would like to give up your wheelchair. Each airport and airline have different abilities and preferences. Negotiate. I ask to stay in my power wheelchair until just before it's time to board the plane.

6. Be sure the person at the counter knows that you want your wheelchair checked through to your final destination. Ask for your wheelchair (and batteries) to be brought to the boarding gate of your final destination.

7. At the boarding gate, speak to those agents to confirm that they know exactly what you need.

8. While at the boarding gate, ask the agent to "gate check" your wheelchair. This will help ensure that your wheelchair will be brought to the gate at your destination.

9. You're now at one of the most critical junctures of your flight, the pre-boarding process. An airline staff member will take you down the jetway to the door of your plane. If you can't walk and have not brought someone to carry you, you are transferred to an "aisle chair" which is narrow enough to be rolled on the plane. First, however, you should supervise the airline staff as they remove the batteries from your wheelchair and pack them in their boxes. Only then are you ready to get on the plane.

destination, tired and in a hurry, it is easy to put the chair back together.

Gel cell batteries do not leak acid, are not considered hazardous materials by the airlines and do not need to be removed from the wheelchair. So why doesn't everybody use them? They have less speed and a shorter range than traditional batteries. They also cost much more. Some frequent travelers find them to be the only solution, as do some people whose customized or older model wheelchairs are difficult to dismantle.

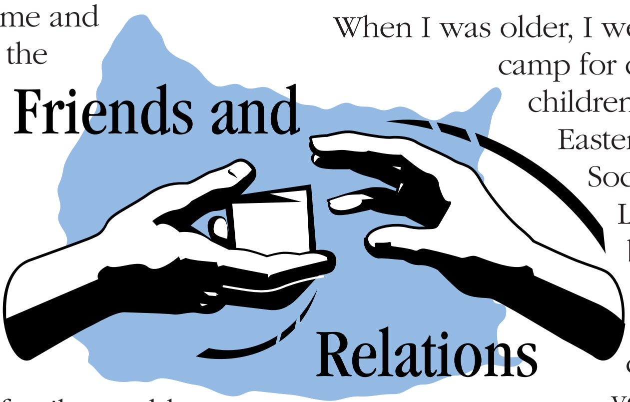
I take the joystick off my wheelchair and carry it onto the airplane along with my communication device. I want to make sure it doesn't get smashed by other suitcases. I usually put my headrest in my suitcase the night before since it also might get damaged.

Where and when do you send the wheelchair down to the baggage area? The first priority is to get the wheelchair and passenger safely on and off the airplane. The passenger's comfort is a second priority and the airline's convenience is third. Each airport, airline and passenger have their own preferences about where to make this transfer: at the ticket counter, the boarding gate or the end of the jetway. According to the ACAA, the passenger may choose the location, as long as it is "possible." Air travel is not easy for people who use wheelchairs, but with the implementation of the Air Carrier Access Act of 1986, it **is** possible.

Summertime Blues

As a child I used to hate summer with a vengeance. Not that I loved school all that much, I wasn't much of a scholar then. I didn't experience that sudden burst of joy that most kids have when they realize the school term has ended, and the whole summer stretches out before them like a verdant carpet of dreams.

I'm really a homebody. I like my familiar surroundings and routines. I do not like to go away for weeks at a time and contemplate the wonders of nature while living out of a tent and cooking over a campfire.



Every summer my family would pack up the car and head for somewhere. The destination was always chosen by my father, who, as his vacation drew near, would grandly announce, "This year we are going to—." After this pronouncement, my dad would pull a chair up to his desk, get out his crisp new maps and chart our route. This was done with the utmost care and was designed not with the maximum sights to see in mind, but with the maximum miles we could travel in a day. Oh, we saw the sights all right, but they went by our eyes like a speeded up movie.

Not that I was interested in seeing the sights. I sat in the back seat of our car and worried about whether my spastic bladder would be relaxed enough at the next pit stop to empty itself, or whether I would have to wait another few hundred miles before I could try again. The same went for my bowels, but they were even more incorrigible. This is what I remember most about our vacations as a kid—fighting my lower body functions to the death.

When I was older, I went to a camp for disabled children run by the Easter Seal Society. Looking back on it now, I realize the camp was a very beautiful place nestled in the mountains of Southern California. It was really nice with a big lodge, a pool, cabins, tents and plenty of paved walkways. It was state of the art for its time.

I hated it. It was a traumatic experience. I was totally unprepared for spending time away from my parents. I don't remember if they tried to sell me on the idea of camp. I just was put on a bus and driven up into the mountains where I spent a month being bored out of my skull.

I was about the only kid there with dysarthric speech. I had no effective means of communica-

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tion, only a very primitive point and grunt method along with a more sophisticated system of air writing—forming the shape of individual letters in the air with my index finger. Yes, these worked; I could say anything I could spell, but it was tedious and left me totally at the mercy of my "listener" and his patience for deciphering letters drawn in the air. One thing was for sure, I could never become a campfire raconteur.

Although I was well into my teens when I had my first camping experience, I found myself totally unprepared for the event. Upon arrival I soon discovered I was an academic little snob in a sea of bubbling adolescent sexuality. Besides being familiar with worldly things I barely knew about, these kids could socialize up a storm. I, on the other hand, had trouble carrying on a decent conversation with my family. Most of these kids went to school with each other for a zillion years; I didn't know anybody.

Then there was the fact that most of the campers could push themselves around in their wheelchairs. I was still trying to play Mr. Normal and traversed the hilly terrain walking in my halting gait. Getting from my cabin to the main lodge, which was a half-block away, filled me with terror. Would I make it to the lodge safely, or would I be blind-sided by some husky milk-swigging teenager who could push his wheelchair a thousand miles per hour on a straight away?

Then there were the camp activities designed to include everyone. Sure, they were. There was outdoor swimming in an unheated pool—the perfect activity for someone who's spastic. I was chilled for hours after taking one of those refreshing dips.

The arts and crafts period presented me with another wonderful camping experience. Lets see, there was wallet and lanyard making as well as the ever popular ceramics. I really enjoyed these fine motor activities. They reminded me of occupational therapy; the only difference was the instructors wore flannel shirts and blue jeans instead of white smocks.

Songs and stories around the campfire were something else I could really get into. Not! All I got out of this activity was a life long "appreciation" of the song *John Jacob Jingleheimer Schmidt.*

I don't want to leave the impression that camp was all bad. There was one activity that I enjoyed very much. One counselor had a penchant for American musical theatre. He shared his enthusiasm for this art form with a small group of us everyday before lunch. We would all sit in a corner of the lodge and listen to this guy tell the story of a musical as he played the recording of it. So what I remember most about camp is not the noble pine and babbling brook, but Mary Martin and Ezio Pinza singing *Some Enchanted Evening*. I'll take this over a nature walk any day.

A Doctor

Books about disability come in three basic formats. First there is the true-life medical tale usually written by a doctor or medical reporter with literary skills who can communicate a complex set of scientific facts to people with little or no scientific background. Then there is the personal story written with the help of a reporter. Finally, there is the personal story written solely by the disabled person.

Oliver Sacks is one of the premier science writers in the world. He is a neurologist and the author of numerous books including *Awakenings* and *The Man Who Mistook His Wife for a Hat*. Sacks' most recent work, *An Anthropologist on Mars,* is a collection of seven portraits of people with various neurological conditions. These are—in Sacks' words—"tales of survival, survival under sometimes radically altered conditions—survival made possible by the wonderful (but sometimes dangerous) powers of reconstruction and adaptation we have."

Sacks is a master at blending straight narrative with a scientific and historical perspective. These pieces are really mini-lectures on the various neurological conditions at hand (autism, Tourrete's syndrome, total color blindness and amnesia, among other things). Thus, when Sacks discusses Mr. I, an artist who experi-

and a Reporter

ences total colorblindness after a relatively minor traffic accident, he not only relates the facts of the case, but also includes a lot of information on the theory and philosophy of color, from the thinking of Isaac Newton to Harold Land, inventor of the Polaroid camera. These scientific sidebars are fascinating in themselves and add much to the enjoyment of the essays.

As fine as this book is, Sacks can't help sounding like a physician with his clean, clinical narrative style. It's almost as if he has his readers inside an observation room equipped with a one-way mirror and Sacks is calmly supplying narration to the scene.

There are no problems like this with John Hockenberry's Moving Viola*tions*. The book is a fine example of what happens when you combine a disabled person's personal narrative with a reporter's eye for detail. In the case of *Moving Violations,* the disabled person and the reporter are one and the same, and from the opening sentence Hockenberry takes his readers on a wild ride.

Hockenberry is presently a reporter on the ABC-TV magazine show *Day One*; before that, he did extensive work for National Public Radio—reporting from the Middle East during Desert Storm, hosting his own show called *Heat* and serving as moderator for the NPR call-in show, *Talk of the Nation*.

But being a reporter was the last thing on Hockenberry's mind as he hitchhiked with a friend along an interstate highway in Pennsylvania one February afternoon in 1978. Two girls picked them up and headed on down the road. The girls had been driving eighteen hours; Hockenberry and his friend were tired, too. Soon everybody was asleep in a speeding car. It went over an embankment, and Hockenberry was on his way to a new life.

The clarity and intensity which Hockenberry brings to the events just prior to and after the accident is amazing. This is no observation room with a one-way mirror; the reader is in that car hurtling into space.

Moving Violations covers all the standard subjects of a good "crip" book—rehabilitation, sex, depression, anger and employment—without getting trapped in a triumph-over-tragedy epic. What comes through in this book is Hockenberry's keen analytical skills. From the start he viewed his disability as a complex problem to be solved rather than an obstacle to be overcome. This isn't to say that he is a Mr. Spock on wheels who views everything through the lens of logic. Far from it. Hockenberry has flashes of anger in him which light up the emotional skyline for miles, whether he is arguing with a policeman about the legality of having a wheelchair hanging off a pick-up truck, or taking out his wrath on a New York City taxi cab one snowy Christmas Eve because its driver refused to put his passenger's wheelchair in the trunk.

Indeed, there is enough here to keep the most ardent disability rubbernecker creeping along for hours. But there is something else that raises *Moving Violations* to another level: the story of disability in the Hockenberry family, which runs through the pages like a dark and mysterious force. This story is one of the major highlights of the book.

Hockenberry is a master at bringing the disability experience to life. People with disabilities will find themselves going, "Yes!" and "Ah ha!" as they move through the pages of this book and discover their own experiences and emotions put into words for the first time.

Ultimately *Moving Violations* contains truths about disability that disabled people already know but able-bodied people have yet to learn. It's one of those books to hand friends who ask, "Hey, what's it like having a disability?" Just say, "Read this, we'll talk later."

Young Voices

When I was a teenager, summer camp wasn't a very good place for someone who couldn't talk well and needed AAC. Do children today like camp? Do they like it well enough to want to go again? I talked to Elissa who lives in southern California and uses her foot to control her Liberator. She works as a counselor at the Bridge Camp. April, who is an experienced camper, also had something to say.

"What did you like about AAC camp?"

"This camp is special to me because when I was a young girl I didn't have a camp to go to that was for kids with communicating problems. I feel this camp is special to younger kids. It is about time—People see that communicating is important. Now I wish they had more camps like this for AAC users to go to. I feel really valuable here because I am helping all the people here. That is my big wish—to help young people who can't communicate. I have found my wish. I thought I would never help people who can't communicate—Now I am. I am enjoying being up here with AAC users." **Elissa, camp counselor**

"Can I go to camp Cassie, please I love camp and I like camp. It is fun at camp. Call my mom if I can go to camp. please please please please!!!!" **April, camper**

Thanks to Cassie Sementelli for her assistance.

Next time we will be talking about telecommunications. I want to know

"How Do You Telecommunicate?"

You can write to me: Michael Williams, Augmentative Communication Inc., One Surf Way, Suite 237, Monterey, California 93940.

You can send me a fax at (408) 646-5428.

You can send me electronic mail at mbwill@well.sf.ca.us

Sources & Resources

Thank you to Diane Bryen, Tracy Kovach, Becky Scholl, Cassie Sementalli and Gail Van Tatenhove for information about AAC camps and institutes.

Thank you to Bob Kossloff and DREDF for information about air travel.

[1] Tracy Kovach (March, 1995). Personal communication.

[2] Diane Bryen (March, 1995). Personal communication.

[3] Becky Scholl (September, 1995). Personal communication.

[4] Gail Van Tatenhove (September, 1995). Personal communication.

[5] Washington Watch. (September 26, 1995). United Cerebral Palsy Associations, 1660 L St., N.W., Washington, DC 20036. 800-872-5827.

More resources for air travel

New Horizons for the Air Traveler With a Disability, a booklet describing U.S. air carrier access regulations, is available from S. James, Consumer Information Center - 5C, P.O. Box 100, Pueblo, CO 81002. Enclose fifty cents for mailing. Don't fly without it!

The U.S. Department of Transportation complaint telephone number is 202-366-2220. Listen to the recording and leave a complaint.

The U.S. Federal Aviation Administration has a consumer hot line. Call 800-322-7873 to record your questions or problems.

Ira Laster at the Department of Transportation might also have the answers you seek. His telephone number is 202-366-4859.

Gail Van Tatenhove has written a do-it-yourself guide to starting and running your own AAC camp. It should be available by December 1995 from the Prentke Romich Company. 800-262-1984.