ALTERNATIVELY SPEAKING
VOL. 8, NO. 1

Writing from Experience

This issue of *Alternatively Speaking* shines the spotlight on the questions, "Why do we write?" and "Why do we read what people who rely on AAC have written?"

The content of most writing by people who rely on AAC has nothing to do with augmentative communication. This writing is concerned with the focus of one's life or life's work: A student may write essays or research papers; an employee may write memos or work orders; some may compose songs, poems or correspondence for personal or social satisfaction. Even those who write professionally often find their subject matter to be far from AAC, just as astrophysicist Stephen Hawking writes about events that are out of this world.

Disability is not usually the focus of one's life or life's work. Let's take John Hockenberry as an example. Hockenberry covers global events as a correspondent for a major news organization. The stories seldom mention his use of a wheelchair. However, after a time as a professional journalist, he had something to say about life in a wheelchair and wrote *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence.*[1] By writing about their own experience, people who rely on AAC define the needs of people with complex communication disabilities, describe the tools that can level communication barriers and imagine the research that can create change.

INSIDE THIS ISSUE

Our culture

Literature can help an individual find his or her place in the world. Literature by individuals with a common characteristic (such as having complex communication needs) can create a cultural identity amongst these individuals. Discovering that one's personal "problems" or "defects" are not individual flaws, but characteristics shared and accepted by others creates identity, community, culture and the impetus to forge forward.

Stories can help people who rely on AAC discover their own unique identities in a larger community of others who rely on AAC. Cultural storytelling strengthens any community. As Maxine Hong Kingston said about the stories her mother told her about growing up Chinese in California in *The Woman Warrior: Memoirs of a Girlhood Among Ghosts,* "…I saw that I too had been in the presence of great power, my mother talking-story."[2] Since our parents don't rely on AAC and since our family members can not provide us with that

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Message from the editor

I've been a writer for more than forty years. I didn't wake up one day and decide to follow in the footsteps of Ernest Hemmingway, knocking out a daily dose of declarative sentences. No, the writer's cloak enveloped me slowly over many years.

At various times during my life, I've written passionate political polemics, a children's newsletter, smartly crafted cultural criticism worthy (at least in my opinion) of publication in *The New Yorker*, and deeply felt personal essays on what it's like to live with a disability.

Writing has never come easily for me. If I'm lucky, words will march from mind to computer screen with military precision, but most of the time I find myself slogging through some mysterious linguistic swamp at two o'clock in the morning, fighting off self-doubt and self-censorship while trying desperately to hook up with my unseen audience.

Then there's the mechanical thing—the sheer physical difficulty of getting the words from my mind into my computer's memory one-letter-at-a-time. If this weren't enough, there's always the lurking danger of computer twitches and glitches that magically make all those words you've sweated over for so long suddenly vanish with no hope of retrieval. It's enough to make me want to smash my computer monitor and seek solace in some mindless sitcom.

But I don't. I know if I want to change people's perceptions about people who use AAC, writing is the most powerful tool I have. I wrote my first article about having a disability in the early nineteen-seventies. I was reluctant to do so. I didn't want to be typecast, and besides, who wanted to read about disability? Apparently a lot of people did. My first disability piece led to a regular column in a radical weekly rag called *Grassroots*. I wrote under the name Quasimodo and produced some of my best stuff for that publication. My favorite Quasimodo piece is reprinted in this issue of *Alternatively Speaking*.

I often hear the complaint that the media don't cover disability issues well. That may be true, but I used to listen to a rock station that had a newsman who signed off his segments with, "If you don't like the news, go out and make some of your own."[4] And, I would add, write about it, too.

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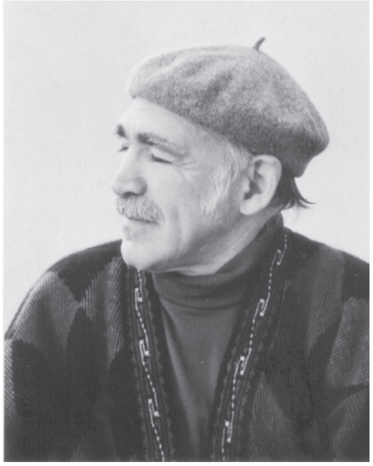
piece of cultural knowledge, we have an imperative to share our stories with each other.

Perspective

Writing creates a trail of cultural history. Today, people with communication disabilities are primarily described by a wide variety of professionals using the language of their professions. Since not many people who rely on AAC are practicing engineers, linguists, speech language pathologists, physicians, occupational therapists, educators or assistive technology experts, the professional descriptions of the abilities and disabilities of people who rely on AAC is necessarily that of outsiders, who use paradigms that do not relate to our daily experiences.

This view from outside is only part of any picture. No picture can be complete without a view from the "inside," as Kenny Fries says in *Staring Back: the Disability Experience from the Inside Out*.[3] Without the contributions of our writers, our history is incomplete. Telling our own stories is one way for people who rely on AAC to put on record the truth about the AAC experience—as it should be told, by those who live it.



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Reading about the AAC Experience

All powerful writing is influenced by the author's personal experiences. The selection of books that follows presents examples of fiction and non-fiction currently available in English that document the cultural histories of people who rely on AAC. Six are readily available; the others can be obtained as noted.

Beneath the Surface: Creative Expressions of Augmented Communicators. Edited by Michael B. Williams and Carole J. Krezman.[5] (2000)

Bent by Mick Joyce.[6] (2005)

The Bird with the Broken Wing by Sue Ann Easley.[7] (1994)

The Diving Bell and the Butterfly: A Memoir of Life in Death by Jean-Dominique Bauby. (1998)

In A Struggling Voice: The Selected Poems of Robert R. Williams by Bob Williams.[8] (1989)

Journey Out of Silence by William L. Rush.[9] (1986)

Look Up for Yes by Julia Tavalaro & Richard Tayson. (1998)

Meaning of a Disability: The Lived Experience of Paralysis by Albert B. Robillard. (1999)

My Left Foot by Christy Brown. (1990)

Psalms of Praises by Rick Hohn.[10] (2004)

Reflections from a Unicorn by Richard D. Creech.[11] (1992)

Speaking Up and Spelling It Out: Personal Essays on Augmentative and Alternative Communication. Edited by Melanie Fried-Oken & Hank A. Bersani, Jr.. (2000)

Stories to be Told: Selected Poems of Robert R. Williams by Bob Williams.[8] (2003)

Straight Talks from My Desk, Volume One by Jon Feucht.[12] (2004)

The Tan Car by Jon Feucht.[12] (2003)

Under the Eye of the Clock by Christopher Nolan. (2000)

A Day in the Life

by Michael B. Williams

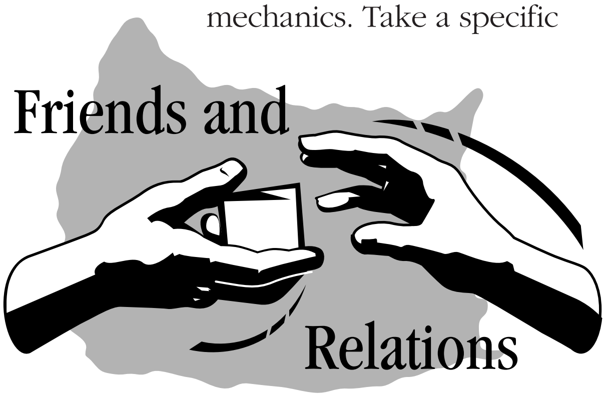
Originally published in Berkeley's *Grassroots* newspaper on July 17, 1974

I consider myself to be a patient individual. I will sit for long periods of time and attempt to explain my particular disability to anyone who might inquire about it. This is just good public relations. But sometimes the strands of my understanding are strained beyond the breaking point.

Consider, if you will, this series of recent events: I wake up one morning in pain. I had fallen the night before, and now my ribs feel as if they have been through a practice session with the Miami Dolphins' first-string line. I blink at the new day awhile and then decide it would be a good idea to have my doctor check things out. My attendant calls and attempts to make an appointment, only to discover that my doctor is in the process of moving his office. Like a nomad of the Sahara, he is somewhere between here and there and is unavailable for consultation.

My side sends a sharp tweak of pain to my brain. The Big Guy upstairs is giving me a cosmic jab in the ribs. But fear not. I'm given the name of another doctor who is minding the store while mine is in transit. An appointment is secured and I hustle my ribs down to his office.

Now you may consider doctors, as a class, to be of above-average perception. My experience with the medical profession has demonstrated just the opposite. Doctors, on the whole, are nothing more than sophisticated auto mechanics. Take a specific complaint to them and they can usually trace the difficulty, but God forbid they should encounter a patient out of the ordinary least they freak out.



This doctor is no exception. I roll down to his office in my electric wheelchair. I maneuver the beast down the narrow office corridor to the examining room, being careful not to mar the mahogany veneer that graces the walls. With the help of my attendant I hoist myself onto the table and take off my shirt.

Enter the physician. He greets me with a cheerful, "Hello." I, not wishing to be out-classed in the repartee department, shoot back with an even merrier "Hello." This disciple of Hippocrates immediately smells something amiss. My speech is unclear. He decides to try a different tack with me.

"You're having a problem with your ribs?" This question is uttered as if from a stage, even though I am but three feet from the doctor. My attendant fills in the details of my mishap.

His hands are on my rib cage now, feeling, prodding, thumping.

Thwack! Thwack! "Have you coughed up any blood?" Thwack! He's at my ear now, using the same volume as before.

He is addressing my attendant too, but he uses a normal conversational tone with her. All the while, I'm giving the doctor more details about my condition via my alphabet board. My attendant reads off the sentences as I spell them out.

"My, isn't it remarkable how he communicates with you," the good doc says.

Suddenly I find myself in the midst of some strange opera buffa in which I'm both performer and audience. I'm no longer a person that one interacts with, but merely an object to be discussed.

X-rays are ordered and taken. They reveal no cracks. I'm just sore.

It is now well into the day, and I roll down Shattuck to the new cheese shop that has just opened in my neighborhood. I make my

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A Call to Write

By Johana Schwartz

I obtained my AAC device in order to express myself. I sought a communication device to give me the power to say what I want to say. I consider myself articulate, with ideas and opinions that I want to voice. My device allows me to speak these musings. The device takes care of speaking, but other issues, like mobility barriers and lack of networking opportunities, keep me from having access to everyone who might like to hear what I have to say.

What is the solution? Using an AAC device to write, and then to submit the written work to publishers.

We can use our communication devices to write, as well as to speak, and when we do, we gain the additional benefit of being able to publish our work. When we submit stories, poems, essays and opinion pieces to magazines, newspapers, literary journals and book editors, we get the word out about ourselves and share what is on our minds with a large number of people. By publishing our works, we can expand our networks and connect with a wider variety of people than we ordinarily could.

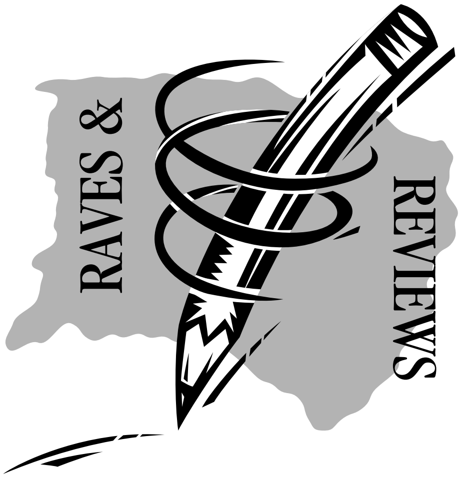
By writing and submitting a manuscript, we make an important statement. Until now, the world has not seen enough writing by people who rely on AAC about their experiences. That canon of literature is still emerging. I can think of a few: *The Tan Car*, a book of poetry by Jon Feucht; *Beneath the Surface*, an anthology of creative work by people from around the world; the ongoing publication, *Alternatively Speaking*; and, most recently, articles by the AAC-RERC Writers Brigade. While there are indeed other publications by individuals who rely on AAC, there are not nearly enough. More people should write with the goal to publish. Individuals who rely on AAC devices must develop a canon of literature that will demand to be both recognized and reckoned with. People who use AAC are rarely represented in bookstores. As of now, the work of these individuals often goes unnoticed or is overlooked. We can change this by sharing our experiences in print, which builds awareness with the public.

Furthermore, we hold the power to portray our population as we want to be seen and to take control over how readers perceive us. We should write in order to represent our unique circumstances accurately and realistically and not let other people speak for us. Think about books that include a disabled character: Tiny Tim in Dickens' *A Christmas Carol*, the monster in *Frankenstein*, the phantom in *The Phantom of the Opera*, Beth in *Little Women*. All these characters appear oversimplified as either saintly or evil. The lives we live are more complex than that; we need to show ourselves as flesh and blood, not metaphors or literary tools.

It is time for us to turn on our devices, tell our stories and share with the world who we are.

Bill Rush

(1955-2004)



We lost one of our pioneers in the AAC field late last year. Bill Rush died December 13th, 2004 at the age of forty-nine.

Judging from the responses on the ACOLUG listserv to the announcement of his death, few people knew who Bill was. This is unfortunate. Though young in years, Bill was one of the "old guys" of AAC.

Although he seldom ventured far from his Nebraska roots, this Midwesterner had a key role in bringing AAC to the attention of a wider world.

The narrative of Bill's life has a familiar ring to those of us who grew up in the era before disability rights legislation. Everything was a hassle, a fight, a struggle, but Bill used the tools available to him to push for his rights and the rights of all people with disabilities.

He became the first member of his family to go to college, graduating with a degree in journalism from the University of Nebraska.

During his time at the university, *Life* magazine did a feature story on Bill which helped propel the field of AAC into the national consciousness. Over the years I've heard several professionals say this article helped convince them that AAC was more than a passing fad.

I met Bill in the late 1980s at an ISAAC conference in California. At six feet tall and thin as a rail, he cut an imposing figure. Bill wasn't shy about sharing his opinions either. After observing him awhile, I thought, Now there's a real leader.

Bill met his future wife, Christine Robinson, at that conference. She was an occupational therapist from Canada. Bill and Chris carried on a long-distance, ten-year courtship; Chris sorted out her immigration to the United States while Bill worked on the state of Nebraska to change its rules so that people with disabilities could marry and still keep their state-provided medical coverage.

Bill wrote and spoke out tirelessly about the issues that impact the lives of all people with disabilities. He did so not for the glory of self promotion but because it was the right thing to do.

Bill's hometown newspaper published a New Year's Eve editorial on noted Nebraskans who had died in 2004. It described Bill this way:

"Bill Rush, 49, rolled his wheelchair onto the University of Nebraska-Lincoln campus in the 1970s to succeed where no one like him ever had. Rush refused to be a victim of cerebral palsy. Typing with a stick attached to his forehead, he wrote articles, op-ed pieces, a manual on how to refer to people with disabilities and an autobiography that served as a handbook on how to live independently."[13]

Towards the end of his autobiography, *Out of Silence*, Bill comments on his graduation from the University of Nebraska. Although he was referring to a specific event, his words sum up his life. Bill says:

"In February 1983, I was one of the 25 million people to watch the last episode of M*A*S*H. It seemed that it mirrored my life. The personnel of the good old 4077 had survived with their sanity. So had I. No one was a hero at the 4077. I wasn't a hero. They just did their best. So did I."[14]

Amen, Bill. Amen.

AAC-RERC
SPREAD THE WORD

Writers Brigade: Year Two

In 2004, the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC) launched the Writers Brigade, an innovative project that enhances the AAC-RERC's dissemination efforts while building a foundation for long-term consumer involvement in AAC research and development.

The Writers Brigade, led by project manager Johana Schwartz, is a cohort of writers who use augmentative and alternative communication. These writers enhance their own technical writing skills and employability as they write articles highlighting current research and development activities within the AAC-RERC.

Over the past year, thirty-four articles authored by participants in the AAC-RERC Writers Brigade were published in more than nine print and online newsletters and magazines. Every participant has seen his or her work in *Augmentative Communication News*. One article appeared in *Advance*, a magazine for speech-language pathologists and audiologists. Several writers have been published in *Speak Up!*, USSAAC's magazine. One writer is currently reformulating an article for *New Mobility*, at the invitation of that magazine.

The success of these writers is supported by a rigorous, yet completely accessible, yearlong mentoring experience via email and a listserv. The project manager provides online mentoring, individualized attention and customized feedback. Each writer has assignments, which include developing a plan, using editing software to support the writing process and evaluation of the process. Writers are paid for their work. Participants to date include Joe Hemphill, Tracy Rackensperger, Tom Younkerman, Bill Geluso, Ana Berlowitz and David Chapple.

At the end of year one, the writers completed a questionnaire about their experiences. All agreed that the project manager had provided them with the support they needed to write and revise assigned articles. They reported improvements in their ability to write in different styles for targeted publications and reported they benefited from working with a skilled editor on assignments. Specifically, they said they had learned how to organize their thoughts, use words more effectively and succinctly, use simple language with a reader-friendly voice and write in ways that were more interesting. (Several also reported that their punctuation and grammar had improved.)

The writers stated that they took pride in seeing their writing in print and felt it was important to get paid for their work. They also said that working for the AAC-RERC has expanded their vitae and employment opportunities. All strongly recommended the Writers Brigade to others.

Clearly, the writers value their experience with the Writers Brigade, and the variety of published articles greatly expands the AAC-RERC's dissemination efforts. Of equal importance is the project's focus on involving more individuals with complex communication needs in AAC research and development activities. This project increases each participant's ability to read about, discuss and write about AAC research and development. Each writer leaves better prepared to critique, participate in and direct research. Perhaps some will continue to advance AAC research and development.

Johana Schwartz assisted in the preparation of this article.

For additional information, go to the AAC-RERC website http://www.aac-rerc.com and subscribe to the AAC-RERC e-newsletter. You can also check out conference presentations on the Writers Brigade at http://www.augcominc.com.

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Sources & Resources

1. Hockenberry, John (1996) *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence*. New York: Hyperion.

2. Kingston, Maxine Hong (1989) *The Woman Warrior: Memoirs of a Girlhood Among Ghosts*. New York: Vintage. p.20.

3. Fries, Kenny (1997) *Staring Back: The Disability Experience from the Inside Out*. East Rutherford, NJ: Plume Books.

4. Wes "Scoop" Nisker reported the news on San Francisco radio station KSAN for 25 years. He wrote *Crazy Wisdom* and *Buddha's Nature*.

5. *Beneath the Surface* is available from ISAAC at www.isaac-online.org; (416) 385-0351 or from Augmentative Communication, Inc. at www.AugComInc.com; (831) 649-3050. ($22 US)

6. *Bent* is available from Mick Joyce, 4 North Allen St., Madison, Wisconsin 53705. (ezgo.joyce@att.net) ($14.75 US)

7. *The Bird with the Broken Wing* is available from the AAC Institute Gallery. www.aacinstitute.org ($12.95 US)

8. Bob Williams' books are available from Betty Robichaw, Temple University, Institute on Disabilities–RA 423, 1301 Cecil B. Moore Avenue, Philadelphia, PA 19122 (robichaw@temple.edu) *In a Struggling Voice* ($15 US); *Stories to be Told* ($25 US); Both for ($35 US). Checks only, payable to Temple University.

9. *Journey Out of Silence* is available from Christine Robinson, 512 Village Ave, Lincoln, NE 68503. ($10 US) for paperback; ($15 US) for spiral bound.

10. *Psalms of Praises* is available from Selah Publishing Group at (800) 917-BOOK or www.selahbooks.com ($10.99 US)

11. The printed version of *Reflections from a Unicorn* is out of print. An electronic version is available from Rick Creech, 3312 Ridgeway Rd., Harrisburg, PA 17109. (rickcreech@comcast.net) ($8 US)

12. John Feucht's books are available from the AAC Institute Gallery. www.aacinstitute.org *Straight Talks* ($15.95 US); *Tan Car* ($12.95 US)

13. *Lincoln Journal Star.* <http://www.journalstar.com/articles/2004/12/31/editorial_main/doc41d5db68d4a9b968707363.txt>

14. Rush, William L. (1986) *Journey Out of Silence*. Lincoln, Nebraska: Media Publishing. p. 213.

Thank you to Johana Schwartz who may be contacted at johana.schwartz@stanfordalumni.org

Continued from page 4

selection and am about to leave when the clerk makes the following remark, clothed in tones of incredulity:

"Hey, he understands everything you say to him!"

Pinballs of anger shoot off inside my head. This merchant of Muenster and I have been exchanging greetings with each other for the past two months as we pass on the street, but now he's surprised to discover I'm not the primitive he thought I was.

I manage to keep my temper at bay, settling instead for my attendant's cool defense, "Oh, yes, he's a complete human being."

The morning dissolves into afternoon and we are on Telegraph Avenue doing errands. We decide to stop for coffee at an outdoor café. We sit down and order and are chatting away when a boy of about twelve appears out of thin air. He stands and stares at me.

"That'll cost ya a quarter," I spell out on my board. My attendant conveys the message, but the lad doesn't take the hint.

"Why can't he talk?" says the boy. My attendant starts to explain, but I cut in and tell the boy to shove off.

Now if any one of these incidents had happened to me during the course of a day, I could have handled it with the proper diplomatic polish. But the three acting in concert proved too much to manage. I didn't want to be an object. I didn't want to explain my existence one more time. I didn't want to be a bridge of understanding. All I wanted was to drink my coffee in peace.