In this issue, we introduce you to the AAC-RERC Writers Brigade, a variation on the idea of a writer’s workshop, in which individuals with disabilities hone their skills to write about cutting-edge research and development work that addresses the needs of people with disabilities like theirs. These writers: (1) become primary agents in spreading new ideas, (2) become better writers as they develop marketable technical writing skills, (3) add a list of published articles to their resumes, (4) develop their interviewing skills, (5) contribute to the dissemination efforts of the researchers and (6) become more adept at communication with researchers, professors and other leaders in their community. Who better to write about what an organization is doing for individuals than those whom the work is meant to benefit?

The writer’s workshop concept is at the heart of the AAC-RERC Writers Brigade, which began in early 2004 and just recently completed its first five-year funding cycle. Writers Brigade members write technical articles about the work of the AAC-RERC’s ten partners.* Funded in part by the National Institutes on Disability and Rehabilitation Research (NIDRR), Augmentative Communication, Inc. carried out the project with Johana Schwartz, who uses AAC technologies, as project manager. For Consumers highlights practical reasons for setting up a Writers Brigade, briefly describing “how” and “why” a clinician, company or organization might wish to implement the idea. Clinical News provides more information about the AAC-RERC Writers Brigade and some reflections. AAC-RERC announces our hot-off-the-press “how to” manual entitled AAC-RERC.

For Consumers

What is a Writers Brigade?

The concept of a Writers Brigade begins with a writer’s workshop and takes off from there. It is a dissemination and knowledge transfer activity undertaken by an organization or entity that focuses on improving the lives of people with a particular disease, condition or disability. A Writers Brigade is a Nothing About Us Without Us knowledge translation (KT) strategy. Very simply, it supports individuals with an inherent stake in an organization to explain and/or advocate for the important work of the organization. Because Writers Brigade members telecommute from their homes or offices, the program is accessible to many potential members with disabilities.

After an application and selection process, the Writers Brigade members undertake a series of paid assignments to report on the activities of the organization. Brigade members work at their own pace, with a manager/editor who gives customized feedback for each of several drafts. Once an article is ready, it is submitted for publication. A Writers Brigade is led by and comprised of individuals with the disease, condition or disability of concern to the organization. Participants are paid for their writing assignments.

In the AAC-RERC Writers Brigade, members were expected...
to write three articles in about one year. In addition, they honed their employment-related skills writing business letters, interviewing researchers, maintaining an up-to-date bibliography and resume and networking with other professionals.

The goals of the AAC-RERC Writers Brigade are to:

a. Increase the dissemination and use of information, materials, technologies and instructional strategies developed within the AAC-RERC so that they reach relevant stakeholder groups.

b. Increase the meaningful participation of individuals who use AAC in all aspects of AAC-RERC activities.

c. Increase the technical writing skills of individuals who use AAC as they build a portfolio of published articles, increase their employment options and expand their social networks.

As a result of the AAC-RERC Writers Brigade’s efforts, the dissemination efforts of the AAC-RERC have extended well beyond the traditional peer-reviewed journals and conference presentations to reach important stakeholder groups within and outside the AAC and assistive technology communities.

While the AAC-RERC Writers Brigade is comprised of individuals with communication challenges, many opportunities exist for implementing a Writers Brigade. For example, there could be a “New York Schools Writers Brigade” that writes about controversial issues, staffed by high school students; a “Twin Cities Writers Brigade” that publishes articles about wellness programs for cancer survivors”; an “ATIA Writers Brigade” that reports on new assistive technologies and so on. You get the idea.

**Why do it?**

The most important reason to have a Writers Brigade is simple. It is the right thing to do. Any entity that aims to improve people’s lives should strive to employ and empower the people whose lives they are trying to improve. A Writers Brigade can do both. It provides part-time employment for people with disabilities while helping them develop skills that are transferable to a broader marketplace.

A Writers Brigade also expands traditional top-down approaches of dissemination through professional journals and conference presentations to include two-way, ongoing interactions between individuals with disabilities and the research and development communities that endeavor to address their needs. It broadly publishes information about important activities or products of an organization in ways that are accessible to people who most need to know.

Another reason is that the Writers Brigade translates important information to major stakeholder groups at minimal cost. Thus, it has a favorable cost-benefit ratio. As one member said,

> The total cost for the Writers Brigade program is minimal compared to the benefits accrued by the researchers, the developers, the individuals who participate in the program, the organization and the funding agency.

Writers Brigade alumni replied “yes” to the question, “Should other organizations adopt a program like the Writers Brigade?” Here are some of their reasons.

1. Participants published over 100 articles. Our voices are being heard. There’s no one more qualified to write about

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**Rebecca Barbush, Lauren Baxter, David Chapple, William Geluso, Joe Hemphill, Mick Joyce, Pamela Kennedy, Matthew Kim, Lateef McLeod, Tracy Rackensperger and Tom Younkerman**
Reflections on the AAC-RERC Writers Brigade
by Johana Schwartz

The AAC-RERC Writers Brigade is a writer’s workshop for people with disabilities that provides constructive writing instruction, meaningful work experience and ongoing publishing and networking opportunities. Augmentative Communication, Inc. started the AAC-RERC Writers Brigade in early 2004 and hired me, a young writer and editor, as its manager. When we began, there was no instructional manual for the workshop. Rather, we made it up as we went along, using feedback from the eleven individuals who participated.

Over the past few years, the project accomplished what most companies and organizations value, i.e., the involvement of an articulate consumer group and publicity at minimal cost. Investing in people who use AAC technologies and in the Writers Brigade was a strategic and intelligent action.

It is important to note that the Writers Brigade is not a sheltered workshop where the members are coddled. It is a competitive atmosphere. Members do important work, get published and collaborate with colleagues. Members learn to identify the accommodations they need in order to work and strive to meet the high standards set by the organization.

A Writers Brigade uses a telecommuting model for work. This had multiple advantages, including an ability for staff and members to be productive without buying and maintaining an office or going back and forth to work. For example, members and staff of the AAC-RERC Writers Brigade worked in nine different states across three time zones from their homes and offices, using their own equipment and personal supports.

The AAC-RERC Writers Brigade is unique because all its members, as well as the editor/manager, use AAC technologies. This means they can share certain insights and experiences and bring these to the task of writing technical articles about an area of AAC.

The AAC-RERC Writers Brigade became far more than a writer’s workshop. It developed a structure that fostered leadership, confidence and independence. Members gradually assumed leadership roles by mentoring new members and by influencing how the program was run.

Sharing what we learn

We compiled curriculum information and “lessons learned” into a guide. Over the past year, we selected topics, drafted chapters and collected examples of procedures used to conduct the day-to-day work of the Brigade. This project grew into a 150 page downloadable e-book that includes what one might need to carry out a similar program. Members of the Brigade contributed to the guide with their quotes and by having shared their experiences and constructive inputs.

Clinicians, researchers, administrators and leaders of disability-related organizations who share the “nothing about us without us” principle in their daily work are invited to begin their own Writers Brigade.
SPREAD THE WORD

Announcing: The free AAC-RERC Writers Brigade Guide by Johana Schwartz

Sarah Blackstone, project director of the Writers Brigade, and project manager Johana Schwartz have co-written a 150 page, easy-to-read “how to” manual entitled: AAC-RERC Writers Brigade: Knowledge Translation through a Writers Workshop: A Guide for Individuals and Organizations. The goal of the Guide is to inspire other organizations, programs and companies to reproduce a writers workshop that hires people with disabilities to write about their organization’s projects and activities.

The Guide is based on the results of a Rehabilitation Engineering Research Center (AAC-RERC) project, and its publication coincides with the start of the second AAC-RERC Writers Brigade, also funded by the National Institute on Disability and Rehabilitation Research. The Guide has two purposes: (1) encouraging other organizations to implement a Writers Brigade program and (2) supporting the start up efforts of the second AAC-RERC Writers Brigade.

Chapters topics include:

1. Starting a Writers Brigade Program. Discusses the leadership team and recruiting, selecting and orienting new members.

2. Communication Strategies. Highlights the use of email, the Writers Brigade listserv, a Writers Brigade FaceBook group, weekly agendas and monthly reports.

3. The Writers Brigade Program. Covers the processes employed: making assignments, drafting/editing/revising articles, submitting articles for publication, etc.


5. Technical Articles. Provides step-by-step instructions about how to assign and edit articles. It also goes through the steps of getting an article published and gives examples of each step in the process.

6. Acquired Professional Skills. Discusses invoices, business letters, interviewing techniques, networking, etc.

7. Program Evaluation. Describes ways to assess the outcomes of the program, including exit interviews and surveys for current members and alumni.

8. Outcomes. Discusses some results of the first five years of the AAC-RERC Writers Brigade. Includes information about the members’ technical writing skills, publication records and employment status. It also includes the ideas of alumni about how to improve the program.

9. Appendices. Provides the bibliographies of all AAC-RERC Writers Brigade members through 2008 and some sample autobiographies.

The AAC-RERC invites others in government, industry and the disability community, as well as those in health care and educational settings, to set up a Writers Brigade that meets their organization’s unique knowledge transfer needs. Family members themselves might implement a program like this, or might take the idea and propose it to an appropriate organization. Given all the Internet networking and support groups out there now, families can be, and are, much more proactive than was possible in the past.


For additional information, email Sarah Blackstone at sarahblack@aol.com

The AAC-RERC section is partially funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under Grant #H133E030018. The opinions herein are those of the grantee and do not necessarily reflect those of the U.S. Department of Education.
Some outcomes of the AAC-RERC Writers Brigade

Eleven individuals who use AAC technologies participated in the Writers Brigade from 2003 to 2008, each for about a year. At any one time, the cadre of active Writers Brigade members included the manager and two to five writers. As one person left or completed the program and became an alumnus, another writer was recruited as a member. The manager led the group for five years and during that time, eleven members successfully finished the program. The project manager also contributed articles. Including the manager, we have data on 12 individuals. All five women and seven men had complex communication needs (CCN). Their ages ranged from twenty-something to sixty-something. All but two individuals reported having cerebral palsy; other diagnoses were Friedreich’s Ataxia and an acquired quadriplegia. All reported having dysarthria and/or dysphonia that made their speech difficult to understand. They used AAC and a range of assistive and mainstream technologies,

Speech generating devices such as the DynaWrite, Mercury, Pathfinder, LightWriter and Message Mate.

Other technologies for writing including Co-Writer, Speaking Dynamically Pro, Text Aloud, Nextup Talker and the IntelliKeys Classic Keyboard.

One member reported having a high school diploma; three had begun attending college; four had a bachelor’s degree and four had a master’s degree. Most members had never written a technical article prior to joining the Writers Brigade; however, many had written in other genres and published their poetry, essays, op-ed and fiction pieces. When asked how the Writers Brigade was different from their other experiences, one member said, One thing that really needs to be driven home to other organizations is the fact that you actually pay individuals. There are many opportunities for people who use AAC to volunteer their services, but far too rarely are such people valued and recognized for their contributions via the social norm of being paid.

The goals or desired outcomes of the Writers Brigade project reflected the principle of “nothing about us without us” and were three-fold:

a. Increase the dissemination and use of information, materials, technologies and instructional strategies developed within the AAC-RERC so that they reach relevant stakeholder groups.

b. Increase the meaningful participation of individuals who use AAC in all aspects of AAC-RERC activities.

c. Increase the technical writing skills of individuals who use AAC as they build a portfolio of published articles, increase their employment options and expand their social networks.

The manager of the AAC-RERC Writers Brigade, Johana Schwartz, tracked improvements in the technical writing skills of members, as well as their publication records and employment status. She used surveys administered at various times (e.g., after each assignment, at the end of a writer’s tenure with the Brigade and yearly for all members and alumni). She kept records of publications and employment for all members and for alumni.

Outcomes: Technical Writing Skills

Reported outcomes are both qualitative and quantitative. For example, when comparing drafts of articles written by members at the beginning and end of their Writers Brigade experience, Schwartz noted that grammar, spelling, organization and interest-related factors had improved. One member stated, The Writers Brigade impressed on me that I need to make sure that every piece I send out must be the best I can produce. I even check all my emails now for spelling and grammatical mistakes. People reading my writings see what kind of a person I am.

Their evaluations after an assignment revealed that during the process of writing technical articles, members learned to avoid punctuation, spelling and grammatical errors and to take responsibility for self-editing and proof reading. One member wrote in a self evaluation, I feel the organization of the information in my article was better. My article seems clearer and includes more information about the subject. It sounds strange, but I also feel simple areas like punctuation were improved.

Members also learned that technical writing requires that they convey more information in less space. One person told the manager, You showed me how to say what I wanted in fewer words. You suggested better word choices to express myself. Best of all, you didn’t try to change what I wanted to say.

Writers Brigade members who graduated from the program emerged as published journalists. Many have continued to broaden their technical writing and publishing skills through:

Short sidebars, web announcements and articles in newsletters for AAC-RERC research partners.

Consumer reviews of technology for AAC/AT publications.

Articles about disability-related issues and opinion pieces for AAC manufacturers and editors of other publications.

Continued on page 6
University/Research, Continued from page 5

Alumni said they enjoyed learning first hand about breakthroughs in new AAC technologies. Several also commented that they had more confidence in their writing skills and with this came an ability and readiness to voice their concerns. They described themselves as activists and self-advocates:

The Writers Brigade opened many opportunities for me. It helped me to expand my ability to write technical articles. It also gave me the confidence to approach editors and new publications. The Writers Brigade has been, and continues to be, an important influence in my writing career.

Outcomes: Publications

People who use AAC technologies are not always used to being heard. Being published transcends physical obstacles, like limited mobility and dysarthric speech. As shown in Table I, publication outcomes for the group clearly demonstrate that the Writers Brigade alumni turned their knowledge about technical writing into a very successful publication record.

Prior to joining the Writers Brigade, only six members had published their work for a total of 26 citations. Of these, only two had written a technical article. In contrast, during the year (or so) they participated in the Writers Brigade, members collectively accrued 108 citations. Their articles, some of which were co-authored, covered AAC-RERC projects conducted by researchers at Pennsylvania State University, the University of Nebraska, Temple University, the University of Buffalo-New York, Augmentative Communication Inc., Boston Children’s Hospital and Duke University. Topics ranged widely from literacy, telework and employment to the use of AAC technologies with young children, children with autism, adults with aphasia and adults with traumatic brain injury. Members also wrote about the AAC-RERC webcast series, issues related to the usability of AAC technologies, access to AAC and mainstream technologies, vocabulary sets and webcrawling.

Between 2004 and 2008 the bylines of Writers Brigade members appeared in many different print and online newsletters, magazines and journals. Their efforts at sharing technical information significantly increased and expanded the knowledge translation activities of the AAC-RERC. As a result, the AAC-RERC was able to target and reach a broader-based constituency of individuals with an interest in AAC. Articles were placed in these publications:

- Advance Magazine (distributed to thousands of speech-language pathologists);
- ATNetwork: Assistive Technology Tools for Living (distributed widely online);
- the ConnSense Bulletin (goes to hundreds of individuals and organizations interested in assistive technology);
- AAC-RERC E-newsletter (universities and individuals, including the entire RERC network);
- Augmentative Communication News and Alternatively Speaking (international readership of consumers, manufacturers, researchers, policy makers and practitioners);
- SpeakUp (USSAAC’s newsletter), the American Speech-Language-Hearing Association’s Special Interest Division 12 Perspectives in AAC (distributed to over 1000 members).

The publication records of alumni varied widely, ranging from a few publications to more than 40 citations. These differences reflect numerous individual factors including the interests, experiences and personal goals and job responsibilities of members. For example, some self-identified as poets, authors or journalists, while others said they wrote often because it was a job requirement. In any case, most alumni have continued to write and publish their work.

Over the past few years, alumni have published six technical articles, a script for a webcast, two books of poetry, several poems, a play, two short stories, articles in a monthly newsletter for a university and several op-ed pieces for newspapers. In summary, the publication outcomes of the Writers Brigade reflect an increase for each member and a dramatic increase in publications about AAC-RERC activities. This represents an important improvement in knowledge translation for the AAC-RERC.

Outcomes: Employment Status

As shown in Table II, eight members reported they were not currently employed when they entered the Writers Brigade. One member was working full time as a special education teacher. Three members were employed part time: one by an AAC manufacturer; one by a university and one as a consultant on a grant. Members of the AAC-RERC Writers Brigade worked part time as independent contractors and were paid by ACI, Inc. for completion of each assignment. The manager earned a monthly salary as a part-time employee.

In December 2008, six alumni reported being unemployed. Five said they were working part time and one person was working full time.

In comparing the employment
status for the group over time, one might conclude that minimal change has occurred. However, this is misleading. In fact, five of the twelve participants experienced a change in their job situations.

- The person who was working full time when he began the project is now temporarily unemployed. He is recovering from a difficult surgery and plans to return to work when he is able.

- The individual who is now employed full time was working part time when she entered the Writers Brigade. She said that the AAC-RERC network helped her get her current job at a university.

- The two alumni who were employed part time when they entered the program continue to work at their jobs in the technology area.

- Three of the four people who were unemployed and looking for work when they entered the program are now employed part-time. All are working in jobs related to the AAC field. All attribute their current employment to the networking they did through the Writers Brigade.

- Five members who are unemployed are not looking for work because they are retired, have health issues or, as one person said, “I have given up.”

- One alumnus continues to look for a job.

Despite the improved employment status for some members, all continue to face barriers. Researchers confirm that individuals who use AAC technologies confront enormous barriers when they seek employment. These include problems with access to personal supports on the job, transportation, equipment set up and maintenance, health and endurance issues. Other barriers include the negative attitudes of employers about people with disabilities and the limited experience in employment situations that most people who use AAC technologies bring to the job market. One of our most prolific members was told by her local rehabilitation counselor, “You are too disabled to work.”

Employers need to understand that people with disabilities face not only barriers as described above, but disincentives when they try to work. For example, because the AAC-RERC Writers Brigade manager received a monthly salary, she risked losing the services she needed to work, as well as the support she needed for personal care assistance, health care and housing. She faced equipment problems and issues related to her living situation during her tenure as manager. As Johana Schwartz described,

\[ \text{I experienced problems working from my home, especially since I have moved a lot. Finding a good workplace with minimum interruptions is exceedingly important for high-quality and critical writing.} \]

\[ \text{In addition, she had to learn to negotiate the intersection between employment-related issues and government entitlement programs in the U.S., such as Social Security benefits. She said,} \]

One of the most trying aspects to being the Writers Brigade manager was justifying my income and keeping my Social Security benefits. Even though I was making an amount under the cutoff, it was tedious to report my income. I always felt I was in danger of losing my SSI or SSDI benefits, even though I clearly need them. I spent time every month reporting my income and copying my receipts, only to learn that my submissions were unopened and undocumented for an entire year. Ultimately, I managed to sort out the chaos.

Always the advocate, Schwartz persevered and said that with perseverance came some rewards.

As the manager, I also received assistance and advice from the AAC-RERC and Vocational Rehabilitation Services to get the equipment that I needed to do my job.

### Summary

The outputs and outcomes of the AAC-RERC Writers Brigade from 2004-2008 are impressive, and great credit goes to all members and staff. The project positively addressed all its goals. Most importantly, it enhanced the knowledge translation efforts of the AAC-RERC while expanding the involvement of people who use AAC technologies in the day-to-day activities of the center.

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Pre WB</th>
<th>During WB</th>
<th>Post WB</th>
</tr>
</thead>
<tbody>
<tr>
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<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Employed Part Time</td>
<td>3</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Employed Full Time</td>
<td>1</td>
<td>1</td>
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**Table II. Pre and Post Employment Status of Writers Brigade Members**
Evidence in Augmentative and Alternative Communication

Tracking the evidence in AAC

EVIDAAC is a three-year project funded by the National Institutes on Disability and Rehabilitation Research. Its goal is to help practitioners gain easy access to “appraised” evidence in the area of augmentative and alternative communication (AAC). Ralf Schlosser, from Northeastern University, who directs the project, is working with Jeffrey Sigafoos (Victoria University of Wellington), Gunther Eysenbach (University of Toronto) and Pat Dowden (University of Washington). Also working on the project are Pammi Raghavendra (Novita Childrens Services, Inc.) and Sarah Blackstone (Augmentative Communication, Inc.) This international team is developing a web-based database of evidence in the area of AAC. The database, known as EVIDAAC, is meant for practitioners (speech-language pathologists, occupational therapists, physical therapists, special educators, rehabilitation engineers, etc.), as well as individuals using AAC, their families and other stakeholders. Because it will be web-based, it can be used from one’s home, car or office, making the information easily accessible and available when it is needed.

The really good news is that the AAC research base has now matured to a point where a substantial number of studies and reviews are added annually. However, this makes it impossible for any single individual to appraise the available evidence in AAC in ways that help with decision-making. Even so, practitioners, as well as individuals using AAC and their families are still expected to use evidence-based practices when they consider assessment and intervention protocols, a particular AAC technology or strategy, etc.

Clearly, there is an ongoing, unmet need for AAC stakeholders to access relevant evidence more easily and to have some assurance that the quality of evidence warrants their attention. To accomplish this requires several components.

First, there must be an infrastructure that can support and maintain easy access to the evidence. Second, the evidence must be reviewed objectively, so that one is able to distinguish evidence that is of high-quality from other evidence. This is known in the literature as pre-filtered evidence, meaning that “…an individual or group of individuals with expertise in a particular substantive area has reviewed and presented the methodologically strongest data in the field” (Melnyk & Fineout-Overholt, 2002, p. 263).

EVIDAAC will provide the infrastructure, using the World Wide Web as a portal so AAC stakeholders can be more aware of existing evidence. While new for the area of AAC, this approach (web-based database) already exists. See examples below.* Most aim to assist practitioners in the appraisal process. The problem is that these services are of limited or no value to AAC stakeholders because AAC has little, if any representation as an area of research and practice in these data bases. Also these databases are not accessible to people with disabilities. Thus, AAC stakeholders currently have nowhere to go to obtain appraised evidence specifically for AAC. EVIDAAC will systematically address this unmet need.

EVIDAAC staff are currently field testing a protocol that is designed for practitioners to use in gaining access to evidence through EVIDAAC. Soon, they will begin testing the usability of EVIDAAC with individuals who use AAC and their families.

For more information, contact Ralf Schlosser at R.Schlosser@neu.edu