ALTERNATIVELY SPEAKING

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What's an RERC?

Why are we shining the spotlight on this strange acronym? Why should you read about another obscure government activity? Twenty million dollars, that's why. Over the last two decades, nearly twenty million dollars has been pumped into RERCs that focus on AAC technologies. AAC consumers should be asking questions like: How has that money affected the field of AAC? How has it improved the lives of augmented communicators? Here are some basics to prepare you to ask your own questions.

What's an RERC?

Rehabilitation Engineering Research Centers (RERCs) exist under the Rehabilitation Act of 1973.[1] There are fifteen RERCs in the United States. The shared goal of these centers of excellence is to research, evaluate and disseminate innovative methods of applying advanced technology, scientific achievement and psychological and social knowledge to solve rehabilitation problems and remove environmental barriers.[2] In addition, the RERCs may demonstrate and disseminate innovative delivery models to rural and urban areas, conduct scientific research that assists in meeting employment and independent living needs of individuals with severe disabilities and provide training opportunities in conjunction with institutions of higher education and nonprofit organizations.

RERCs are funded by the National Institute for Disability and Rehabilitation Research (NIDRR). NIDRR sets the research agenda for each RERC grant by publishing a Request for Proposal (RFP) which describes the priority areas.

Each RERC has a different focus. For example, the RERC on Hearing Enhancement promotes technological solutions to problems confronting people who are deaf or hard of hearing. Another example would be the RERC on Information Technology Access which improves access to a wide range of technologies, including computers and the Web, ATMs, kiosks, hand held electronic personal assistants, point-of-sale devices and smartcards, home and pocket information appliances, Internet technologies, intranets, and 3-D and immersive environments for individuals with all types, degrees, and combinations of disabilities. There are thirteen other RERCs which may also be of interest to you. Contact information for all the RERCs is on page eight of this newsletter.

What's the AAC-RERC?

The RERC on Communication Enhancement, known as the AAC-RERC, is a five-year project that began in November 1998.

Continued on page 2

INSIDE THIS ISSUE

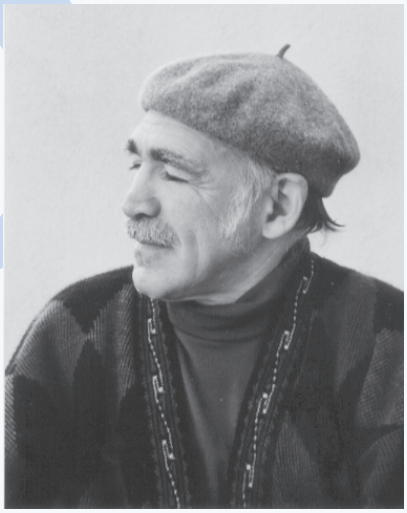
Message from the editor

A quick examination of this issue of *Alternatively Speaking* will reveal I have acquired some sparkling new associates. These people are some of the best and brightest individuals in the field of AAC research. They are all members of an exciting new Rehabilitation Engineering Research Center on AAC (AAC-RERC). Although the AAC-RERC has its administration at Duke University, this is a virtual center with projects spread over seven different sites. We keep in close contact with each other using the tools of modern technology.

My colleague Sarah Blackstone and I are part of this RERC team. Our main job will be information dissemination. I can hear the cries emanating from the peanut gallery already: "You're nothing more than public relations people; spin doctors who'll put the best light possible on everything the RERC does." "You'll be afraid to ask the difficult questions."

My response to this is, "Wait and see." I doubt you'll see *AS* turn into a publicity machine for the AAC-RERC. I see my job as explaining, as clearly as possible, what the RERC is doing with their projects and why they are doing it. But this won't be just a one way flow of information. We want to hear from you. What do you think of the various RERC projects? What would you like to see the AAC RERC get involved with?

I am really excited about working with the members of this team. They are exploring some really exciting stuff that may change the field of AAC. Strong words? You bet. You can read the news first, right here in *Alternatively Speaking*. AS



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Continued from page 1

The AAC-RERC is a collaborative community that will further the development of communication, language, natural speech, discourse skills and literacy of persons with significant communication disorders.

The current AAC-RERC is the first "virtual" center. Staff are located at seven distinct sights: Duke University, the University of Nebraska-Lincoln, Temple University, the University of North Carolina-Chapel Hill, Pennsylvania State University, the State University of New York at Buffalo and Augmentative Communication, Inc.

This virtual AAC-RERC is a bold, new, cost-effective model that promotes close collaboration among leaders in the field at multiple centers to meet the complex challenges of the AAC field.

RERC Activities

Each RERC is affiliated with a rehabilitation setting, which provides an environment for cooperative research and the transfer of rehabilitation technologies into rehabilitation practice. RERCs also work at the systems level to eliminate barriers to fully accessible communications, housing, employment and so on. By partnering with industry, product developers and entrepreneurs, RERCs have the potential to make sweeping changes affecting public policy and the nature of our physical and virtual environments.

AAC-RERC Activities

The AAC-RERC activities, like other RERCs, include carrying out research projects, development projects and training and

dissemination activities. Specifically, the AAC-RERC:

- Studies the effects of attitude and perception on the acceptance and use of AAC technologies by elderly persons.
- Studies organizational strategies for three groups of AAC users with acquired disabilities.
- Improves AAC technologies by studying the organizational abilities of very young children.
- Develops tools, testing procedures and benchmarks of the major performance measures related to AAC device use.
- Runs focus group discussions on the WWW with AAC users, employers and support personnel to help identify important supports and barriers to employment.
- Develops a program which trains, supports and mentors augmented communicators, who wish to become employed using intensive computer and Internet skills.
- Develops a coordinated program which searches out and links promising technologies from a variety of sources with AAC manufacturers and developers in other areas with the objective of improving AAC technologies.
- Develops a menu-based AAC interface that relies on recognition rather than recall memory.
- Develops an integrated literacy software interface and an alternative reading comprehension assessment battery to improve literacy technologies for school-age children with severe physical disabilities.

RERC Cooperation

RERCs cooperate on a local, state, regional and national level with programs, organizations and agencies to develop or deliver rehabilitation technology.

In addition, RERCs may provide information to individuals with disabilities and their parents, family members, guardians, advocates or authorized representatives in an effort to increase awareness and understanding of how rehabilitation technology can address their needs. To the extent consistent with the nature and type of research or demonstration activities, RERCs may inform constituents of the range of options, programs, services and resources available, including financing options for the technology and services covered by the subject area of focus of the center.

AAC-RERC Cooperation

The AAC-RERC has established collaborative relationships with a number of organizations and agencies including ASHA, CAMA, the Federal Labs, ISAAC, RESNA and USSAAC. In addition, each partner collaborates with agencies, schools, hospitals, universities and consumer groups to carry out their projects.

RERC staff are also seeking to establish close collaborative relationships with manufacturers to promote the use of empirically-based technologies for AAC users and are monitoring and seeking out technology developments in both commercial form and pre-release development stages that may affect the engineering and clinical application of technology in the AAC field.

The AAC-RERC is aware of the critical need to involve AAC consumers in research and development and is looking at ways to increase the participation of augmented communicators in the center's activities. Further discussion of current consumer involvement in the AAC-RERC activities is in the "Out and About" section of this newsletter.

RERC Advisory Committees

Each RERC must have an advisory committee. A majority of members are supposed to be individuals with disabilities who are users of rehabilitation technology, or their parents, family members, guardians, advocates or authorized representatives.

AAC-RERC Advisory Committee

The AAC-RERC advisory committee is comprised of individuals from the groups described above. Included are augmented communicators, a consumer advocate, educators, engineers, liaisons from related RERCs, manufacturers, parents and family members of augmented communicators, representatives from AAC organizations and speech-language pathologists. The specific members of the advisory committee are listed on page four of this newsletter.

In Conclusion

Each of the RERCs conducts research leading to "new scientific knowledge and new or improved methods, procedures and devices to benefit people with disabilities."[3] While this issue spotlights the AAC-RERC, it also strives to shed some light on the RERC family. AS

AAC-RERC Partners		
Site	**Project Directors**	**Responsibilities**
Augmentative Communication, Inc.	Sarah Blackstone Michael Williams	disemination, training
Duke University	Kevin Caves Frank DeRuyter	administration, development, disemination, research, training
Pennsylvania State University	Janice Light David McNaughton	disemination, research, training
State University of NY - Buffalo	Jeff Higginbotham	development, disemination, research, training
Temple University	Diane Bryen	disemination, research, training
University of Nebraska, Lincoln	David Beukelman	development, disemination, research, training
University of North Carolina - Chapel Hill	Janet Sturm	development, disemination, training

AAC-RERC Advisory Board		
Kitch Barnicle Trace Center Madison, WI	Arthur Boothroyd RERC on Hearing Impairment San Diego, CA	Gus Estrella UCPA Washington, DC
Melanie Fried-Oken Oregon Health Sciences University Portland, OR	Lew Golinker Law Practices Ithaca, NY	Rick Hohn Dynavox, Inc. Vista, CA
Mick Joyce Center for Delivery Systems Development Madison, WI	Carole Krezman Consultant Berkeley, CA	Tracy Kovach Children's Hospital Denver, CO
Joseph P. Lane RERC on Technology Evaluation and Transfer Buffalo, NY	Peggy Locke CAMA Evanston, IL	Harry Murphy CSUN (retired) Northridge, CA
Pat Ourand USSAAC Evanston, IL	Michael Rosen RERC on Telerehabilitation Washington, DC	Toni Solano Children's Hospital Los Angeles Los Angeles, CA
Pegi Young The Bridge School Hillsborough, CA	AS	

Consumers Talk, Researchers Listen

Many years ago, I participated in an AAC research project as an advisor. A good portion of the project's research consisted of the (able-bodied) researchers testing AAC communication techniques and strategies on each other. Today, the thought of keeping AAC consumers out of the research lab, or even of keeping the research in the lab, seems ludicrous.

The RERCs have a renewed commitment to involve consumers in all aspects of their work. The AAC-RERC has augmented communicators, parents and family members on its advisory board. I am one of the project directors. Many of the research projects include augmented communicators as active members of the research team. Each project involves consumers wherever possible.

At the RESNA meeting in Long Beach last year, the AAC-RERC initiated a special session for researchers and manufacturers to hear consumers' ideas about AAC research. The AAC-RERC, SHOUT and RESNA collaborated to make this event a success. The AAC-RERC supplied scholarships to cover the RESNA conference registration fees of approximately 20 augmented communicators so they could attend this special session. The members of SHOUT, a non profit organization in western Pennsylvania, worked tirelessly to arrange transportation, secure attendant care, and provide overall support for these consumers. RESNA provided the meeting spaces and welcomed the session, as well as the augmented communicators, into their conference.

Several AAC-RERC researchers attended this session along with other researchers and manufacturers who were interested in consumers' ideas about AAC-research. Out of this session came a deeper understanding between the professional research community and the consumer community. Someone suggested that AAC research would be better if more AAC users were principal investigators on AAC research projects. Researchers and manufacturers alike listened to what augmented communicators had to say about AAC research and answered questions about the state of the art of AAC technology.

The success of the meeting in Long Beach has led to further significant collaboration between SHOUT and RESNA to increase consumers' participation in the RESNA conferences. A group of AAC consumers is meeting and attending conference sessions in Orlando, Florida, at the 2000 RESNA conference in June.

The AAC-RERC will sponsor another consumer focus group at the ISAAC 2000 conference in Washington, DC this August. Mick Joyce and I will be leading this meeting. This will be another great opportunity for AAC researchers and manufacturers to hear from consumers.

These collaborative meetings give AAC consumers an opportunity to ask questions of the RERC research partners. Augmented communicators can ask questions such as:

- What does the AAC-RERC see as important consumer issues?
- What is the AAC-RERC doing to improve the design of AAC devices?
- Will these projects make a difference in how I can communicate?

AS

AAC-RERC Across the Ages

I've been associated with Rehabilitation Engineering and Research Centers (RERCs) for many years as a subject, employee, consultant and advisor. I have watched them evolve and grow. I have spoken at their conferences and designed web pages for them. My experience has taught me many things about them. Sometimes RERC's are useful and produce research and products that benefit people with disabilities. Other times they grow into monsters that suck up federal money and do very little except promote the prestige of their staff.

A Trace of History

The early beginnings of what is now known as the AAC-RERC, or the RERC on communication enhancement, started at the University of Wisconsin at Madison in the 1980s as a device development center. It was commonly known as the Trace Center. Trace also developed materials for clinicians. Later the AAC-RERC moved to the Applied Science and Engineering Lab within the A. I. duPont Institute at the University of Delaware. Figure I depicts an evolution that reflects

- changes in the field
- political, economic and university pressures
- shifts in funding priorities.

Forces at work

In the past professional engineers, guided by communication experts, were the driving force behind the AAC movement**.** Not surprisingly, the resulting focus was on device development and system enhancement. Increasingly, however, consumers and researchers from other disciplines have become involved in AAC research. AAC is no longer strictly an engineering challenge, but rather a sociological and psychological one as well. For example, one may have the perfect device, but if no one listens to it in a crowded room because the volume is too low and its presence creates a stigma, then the device actually creates more problems than it solves.

Many of the current AAC-RERC projects address a broad range of linguistic, sociological and psychological issues, which have implications that are important to the field, as well as to future technological and engineering developments.

Future Directions

Rehabilitation research needs are ever changing, and thus, research priorities change as well. Technology is always ahead of public policy. Eventually, the AAC-RERC will move into the device enrichment and validation aspect of research. By enrichment, I mean research on how to actively improve AAC users' quality of life. By validation, I mean a concentrated effort to prove that, in the long run, the purchase of AAC devices will actually stretch the healthcare dollar. This validation will undoubtedly increase access, open new markets, expand competition, drop prices and improve the general quality of AAC products.

The expertise of the AAC-RERC researcher might have to be broadened. Figure 2 shows the evolution of the role of the consumer in the RERC on AAC. In the future, consumers will have to take a major role and serve as primary investigators, consultants, and advisors because they are so intimately involved with the end

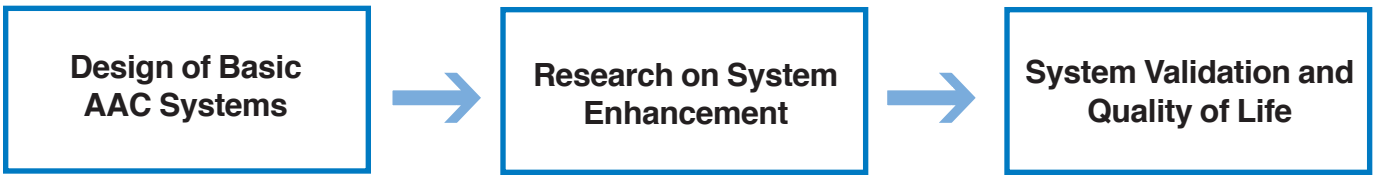

Figure 1: Evolution of the AAC-RERC

By Mick Joyce

product. The research questions of the next decade can only be answered by a high level of participatory action research. Moreover, the research will take on an increasingly interdisciplinary flavor, adding experts in social psychology, healthcare policy and medical sociology, to name just a few.

By expanding the scope of an RERC, the government begins to recognize the fact that disability is not merely a physical condition, but has many sociological and psychological aspects hanging on like blood sucking leeches. AAC researchers also may want to especially sharpen their knowledge in adjunct areas, such as stigmatization, the interplay of aging and disability, and cost-benefit analysis to name a few.

- Spirituality
- Involvement in democracy
- Self-determination and self-advocacy
- Effective health care
- Employment
- Recreation
- Mental health status

All of these issues are part of larger questions:
- Do AAC devices affect the quality of life for users?
- If so, how much?
- How do we design systems that enhance function and the quality of life even more?

As researchers begin to address these questions, we will be in a better position to answer looming public policy questions such as:
- Do the benefits of AAC use outweigh the cost?
- How do we make more positive outcomes happen?
- At what point is there too much technology?

Then AAC as a field will be on more stable ground when competing for limited funding.

Final Comments

When the AAC-RERC began, the problems were basic engineering and access. Designing the bare-bones AAC system was paramount. Today, the accent seems to be on making AAC systems more effective and on developing design features that better address the communication needs and learning styles of specific groups of individuals with severe communication impairments. For example, researchers today are investigating the communication needs of augmented communicators who work.

Future AAC-RERC challenges will be even broader in scope,. We must examine the sociological and psychological nature of the environment where devices are used. This type of research will enrich the lives of users and make sure that AAC consumers have the same opportunities as everyone else to pursue more creditable options in their everyday lives.

Figure 2: Changing roles of AAC Consumers

Unfolding Research Issues

Many research issues come knocking on my mind's door. For instance, I would like to see research on how AAC use affects the following:
- Self-esteem
- Self-perception
- Sexuality and gender expression

Sources & Resources

1. Authority for Rehabilitation Research Engineering Centers is contained in section 204(b)(3) of the Rehabilitation Act of 1973, as amended (29 U.S.C. 762(b)(3)).

2. The February 6, 1997, Federal Register (Volume 62, Number 25) outlines the requirements for the RERCs. www-test.ncddr.org/news/nidrr_brochure.html

3. Poster. Rehabilitation Engineering Research Centers. Available from the National Center for the Dissemination of Disability Research. (NCDDR) 800-266-1832 (phone) ncddr@ncddr.org/ (email) www.ncddr.org (website) 512-476-2286 (fax).

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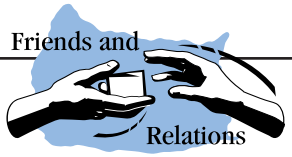
General information about RERCs on the Web:

- National Institute on Disability and Rehabilitation Research (NIDRR) www.ed.gov/offices/OSERS/NIDRR
- National Rehabilitation Information Center (NARIC) www.naric.com
- Office of Special Education and Rehabilitative Services (OSERS) www.ed.gov/offices/OSERS/



The RERC Family

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