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Upfront

Bob Dylan taught us that "you don't need a weather man to know which way the wind is blowing." Well, that's probably more true in politics than it is in AAC. In AAC, it helps every so often to get some experts together to gauge the direction of prevailing currents and trends. This is basically why the Rehabilitation Engineering Research Center (RERC) on Communication Enhancement (AAC-RERC) recently held its State of the Science Conference (SOSC) in conjunction with the *21st Annual International Technology and Persons with Disabilities Conference* in Los Angeles. During three fully-packed days, more than 70 invited participants—researchers, individuals with complex communication needs, family members, clinicians, educators, policy makers, advocates, manufacturers and developers from within and outside the AAC industry—listened to, commented on and discussed a wide range of topics. These topics related to the current status of, and potential future directions for, AAC.

Funded by the National Institute on Disability and Rehabilitation Research (NIDRR), RERCs are mandated to hold a SOSC in year three of their five-year grant cycle. The following descriptions provide some background:

The RERC on Communication Enhancement, known as the **AAC-RERC**, is a virtual center with seven sites and ten partners. It conducts research, development, training and dissemination projects in areas that will assist people who use augmentative and alternative (AAC) technologies to achieve their communication goals across environments.[1] The AAC-RERC receives approximately $950,000 per year during its five-year funding cycle.

NIDRR is an institute within the U.S. Department of Education that conducts programs of research and related activities to assist in the achievement of the full inclusion, social integration, employment and independent living of people with disabilities.[2] NIDRR's total reported funding for 2005 was $97,625,584.

NIDRR funds 23 **RERCs.** Each conducts programs of advanced research of an engineering or technical nature in order to develop and test engineering solutions to problems of disability.[3] The 2005 budget for all 23 RERCs was $19,383,779, representing just under 20% of NIDRR's total

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Principles

Key Principles in AAC

Sarah W. Blackstone, Michael B. Williams and David P. Wilkins

The first presentation at the AAC-RERC State of the Science Conference (SOSC) delineated six key AAC principles that have guided activities within the AAC-RERC since 1998.[5] [See Table I on page 2.] While not meant to be comprehensive, the principles served as a backdrop for the SOSC presentations and subsequent discussions, and they continue to act as a foundation for AAC-RERC partners in their work. The principles are predicated on several basic assumptions:

- Communication is a complex, dynamic and transactional process.
- AAC seeks to enhance communication across the broad spectrum of communication options.
- An AAC system refers to and includes body-based modes, as well as technologies (electronic and non-electronic), techniques and strategies.
- AAC techniques, technologies and strategies are not, in themselves, end goals. Rather, they are a means to a variety of ends, as determined by individuals with complex communication needs (CCN).
- The ways we communicate have changed dramatically over the past few years. The

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design and development of AAC devices and instructional strategies that support their use should take these changes into account.

Principle 1. ***People who rely on AAC participate actively in all AAC-RERC activities.***

AAC would not exist without individuals with complex communication needs (CCN). Their voices are the most important for us to listen to, but often the most difficult to hear. Individuals with CCN have opinions, abilities, characteristics, cultural backgrounds, preferences and priorities that deserve to be recognized, understood, respected and addressed when designing, developing, delivering and evaluating AAC systems and services.

Using multiple strategies, such as telework, online focus groups, virtual network computing applications, email, phone, conference calls and face-to-face meetings, many individuals who rely on AAC are participating in the RERC in multiple roles, in many meaningful ways. Table II lists the roles and the numbers of individuals with CCN, as well as family members, who are involved in AAC-RERC activities.

Principle 1 can be encapsulated in the phrase, *Nothing about us without us*.

Table I. Six Principles discussed at the AAC-RERC SOSC

1	People who rely on AAC participate actively in all AAC-RERC activities.
2	Widely accepted theoretical constructs are specifically addressed in the design and development of AAC technologies and instructional strategies.
3	AAC technologies and instructional strategies are designed to support and foster the abilities, preferences and priorities of individuals with complex communication needs, taking into account motor, sensory, cognitive, psychological, linguistic and behavioral skills, strengths and challenges.
4	AAC technologies and instructional strategies are designed so as to recognize the unique roles communication partners play during interactions.
5	AAC technologies and instructional strategies enable individuals with complex communication needs to maintain, expand and strengthen existing social networks and relationships and to fulfill societal roles.
6	AAC -RERC outcomes are realized in practical forms, such as guidelines for clinical practice, design specifications and commercial products. The social validity of these outcomes is determined by individuals with complex communication needs, their family members, AAC manufacturers and the broader community.

Principle 2. ***Widely accepted theoretical constructs are specifically addressed in the design and development of AAC technologies and instructional strategies.***

The AAC-RERC partners identify and define the theoretical constructs that underlie their research and development activities. This principle recognizes the need to work from well-grounded, widely accepted theoretical constructs, rather than from the beliefs, hunches or favored ideas of individuals or entities.

Theoretical constructs are subject to debate and can change to reflect new information and thinking. Relevant constructs in AAC often originate in other disciplines, such as cognitive psychology, psycholinguistics, computer science, sociology, *etc*. Examples of constructs that strongly influence AAC-RERC work include distributed cognition, learning theory, connectivity, literacy and social networks. In addition, widely accepted constructs of language, language development and communication underlie AAC-RERC projects.

Language. The theoretical constructs of language and language development are now understood from a semantic-pragmatic, multimodal viewpoint, with an emphasis on language use, rather than linguistic forms.[6]

Communication. Communication as a construct is understood as the joint establishment of meaning between interactants, which addresses the key roles of communication partners on

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budget).

This issue of *Augmentative Communication News* highlights content from the six SOSC presentations and some of the wide-ranging discussions that followed each one. PowerPoint slides for these presentations are posted on the AAC-RERC website.[4] Articles encompassing the presentations and subsequent discussions are currently being prepared for publication in the *AAC Journal.* I encourage you to visit the AAC-RERC website and look at the presentation slides. Then feel free to make comments and share any perspectives about the state of the science in AAC you might have.

Sarah W. Blackstone, Ph.D. CCC-SP

AAC-RERC
SPREAD THE WORD

Seven AAC-RERC sites: Augmentative Communication Inc., Children's Hospital-Boston, Duke University, the Pennsylvania State University, Temple University, the University of Buffalo—New York and the University of Nebraska.

Ten AAC-RERC partners: David R. Beukelman, Sarah W. Blackstone, Diane Nelson Bryen, Kevin Caves, Frank DeRuyter, Jeff Higginbotham, Janice Light, David McNaughton, Howard Shane and Michael B. Williams.

Table II Participants in the AAC-RERC: 1998 to 2006

	Types of Roles	Persons w/ CCN	Family members
1	AAC-RERC advisory board	3	3
2	Project advisory boards	19	15
3	Staff	17	1
4	Consultants	39	7
5	Co-authored/authored articles	17	4
6	Presented at conferences	21	15
7	Taught/co-taught courses	19	14
8	Project manager, co-investigator	4	2
9	Subject participants	240	111
	TOTAL NUMBER	376	170

both sides of the communication interaction.[7]

These constructs currently form the basis for projects that enhance AAC technologies and instructional strategies for very young children, individuals with autism and adults with aphasia. Researchers in the AAC-RERC take into account the use of multimodalities, the unique roles of communication partners and the positive effects of scaffolding on language development and message co-construction.

In a nutshell, the AAC-RERC looks to science and scholarship to ground its work.

Principle 3. *AAC technologies and instructional strategies are designed to support and foster the abilities, preferences and priorities of individuals with complex communication needs, taking into account motor, sensory, cognitive, psychological, linguistic and behavioral skills, strengths and challenges.*

People with CCN are a diverse group of individuals, and they are also a "low incidence" population. In designing AAC systems, it is essential to consider the characteristics and abilities, as well as the goals, preferences and priorities of individuals with CCN. One way to do so is to use ergonomics, a science that applies these considerations to the design and development of products and product features. Blackstone and Williams discussed three types of ergonomics, all of which are relevant to AAC:[8]

- **Physical**. Considers how systems can be better designed to interact physically with people. [Anthropometrics, biomechanics, health & safety]
- **Cognitive**. Considers how systems can be designed to support better cognitive functioning. [Human performance theory, engineering psychology, behavioral decision theory]
- **Macroergonomics**. Considers what factors come into play during interactions among people and how environmental constraints can affect human-machine systems. [Systems theory, organizational psychology]

The AAC industry seeks to feature ergonomically-sound technologies (low- and high-tech), techniques and strategies in products designed for individuals with CCN. It is, however, a small industry with limited resources. This makes it difficult for AAC manufacturers to conduct the types of research needed to gather ergonomic data and to use that data in the process of AAC system design and development. In fact, AAC manufacturers do not systematically beta-test AAC products with groups of individuals with CCN, for whom they are designed, before releasing them to the market.

In accordance with this principle, researchers in the AAC-RERC conduct projects that aim to address the physical as well as the more challenging cognitive/linguistic and environmental issues that can undermine the use of AAC technologies. One major goal of AAC-RERC partners has been to increase the learnability and usability of AAC technologies by groups who are currently underserved (*e.g.*, people with autism, aphasia, locked-in syndrome, very young children and beginning communicators). Examples of research and development projects include:

- Developing an eyesafe laser for people with locked-in syndrome (Nebraska).
- AAC systems for aphasia and for individuals who rely primarily on their speech (Nebraska).
- Scanning for young children and individuals with cognitive challenges (Penn State).
- Multi-modal access to AAC systems (Penn State).
- AAC systems and instructional strategies for beginning communicators (Penn State).
- System features that support communication and learning for children with autism (Children's Hospital-Boston).
- System components that result in increased usability, interconnectivity and interoperability of AAC and mainstream technologies (Temple, Duke and Buffalo).
- Performance measurement tools (Buffalo).

Principle 3 reminds us to think "People First."

Principle 4. *AAC technologies and instructional strategies are designed so as to recognize the unique roles communication partners play during interactions.*

Successful AAC interventions can be highly dependent on communication partners. For example, primary communication partners often play multiple roles in the communication lives of individuals who rely on AAC. They may be conversational partners, AAC facilitators, trainers of new communication partners, advocates, technicians and caregivers.

This principle recognizes that AAC professionals should consider a range of actual and potential communication partners when designing, developing and implementing AAC technologies, techniques and strategies. Because communication not only occurs face-to-face, but also over email, by phone (land and cell), through instant messaging, list servs, blogs, *etc*., AAC systems must take into account how to support interactions with a range of familiar and unfamil-

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iar communication partners, using a variety of formats.

It is also important to consider the capabilities and needs of communication partners. For example, if partners have difficulty hearing or understanding a speech generating device (SGD), then they may need to rely on a visual display. For partners who are unable to read but who can hear, intelligible speech output is required. When partners live hundreds of miles away, they may want to talk by phone, and so on. AAC-RERC projects investigate ways to support both interactants during face-to-face interactions, as well as ways to make asynchronous methods of communication more accessible.

Principle 4 reminds us that it takes *two to tango,* and that both partners need to develop dancing skills.

Principle 5. ***AAC technologies and instructional strategies enable individuals with complex communication needs to maintain, expand and strengthen existing social networks and relationships and to fulfill societal roles.***

Functional communication is not an end in itself: it is a means to many ends. The most important outcomes of AAC interventions often extend beyond the act of communicating. This principle recognizes that successful AAC outcomes lead to individuals with CCN making personal choices, participating in desired activities, building/sustaining relationships and social networks, becoming employed, succeeding in school, engaging in chosen family, community and societal roles, *etc*.. The extent to which these outcomes occur, however, will depend not only on access to AAC tools, techniques and strategies, but also on the extent to which public laws and policies insure and protect the basic civil rights of individuals with disabilities.

AAC-RERC partners conduct projects and engage in activities that increase employment (Penn State, Temple), build social networks (ACOLUG list serv), disseminate information about AAC to multiple stakeholder groups (the AAC-RERC Writers Brigade, AAC-RERC e-newsletter, AAC-RERC Webcasts, *Augmentative Communication News, Alternatively Speaking*), develop adult vocabularies to increase participation (Temple), provide "just-in-time" access to information (Buffalo), increase access to mainstream technologies (Duke) and so on.

Principle 5 reminds us that AAC technologies and strategies should help individuals be all they can be.

Principle 6. ***AAC-RERC outcomes are realized in practical forms, such as guidelines for clinical practice, design specifications and commercial products. The social validity of these outcomes is determined by individuals with CCN, their family members, AAC manufacturers and the broader community.***

Principle 6 "sets the bar." If the AAC-RERC is successful, AAC stakeholders will value, adopt and use the research, development, training and dissemination outcomes of the AAC-RERC, *i.e*., the outcomes will have social validity. AAC-RERC researchers often use participatory action research (PAR) designs and seek to disseminate the results of projects to multiple stakeholder groups. Outcomes are meant to influence technology development, result in commercial products, contribute to the evidence base in AAC, inform clinical practice, increase awareness and influence public policy.

The AAC-RERC's Tech Transfer Plan guides relationships with the AAC industry. Currently, partners are working with several AAC manufacturers on products. Other examples of measurable outcomes and impacts include: articles in peer-reviewed journals; citations by others; other AAC-related publications/materials; trained professionals from multiple disciplines; increased skills, participation and leadership capacities of individuals who rely on AAC technologies; improved public policy and dissemination activities that meet the needs of multiple stakeholder groups.

AAC-RERC partners are providing evidence that influences strong, theoretically grounded clinical practice and impacts policy. This includes evidence on how to support early reading and writing skills, the usability of devices with young children, the kinds of representational and organizational strategies young children need, ways to teach scanning to beginning communicators and the use of visual scene displays with specific groups (very young children, autism, aphasia). In addition, published research results exist on communication partner perceptions and preferences for AAC technologies, the timing of AAC interventions for people with ALS, barriers to employment and successful employment strategies and the performance of AAC technologies under various conditions.

Finally, the outcomes of AAC-RERC activities have led to an expansion of funding for AAC technologies and services and the growth of AAC training programs for engineers, speech-language pathologists and educators.

To summarize, the value of AAC will only be realized when it's available to and usable by all those who want and need it.

Access to AAC

Past, Present and Future

Howard Shane, Jeff Higginbotham, Susanne Russell and Kevin Caves

Presenters on this subject sought to broaden our perspectives on access to AAC methods over time.[9] Shane reviewed history from the 1940s to the present, pointing out that, early on, only people who could point and were literate had "access" to AAC methods (*e.g.*, letter board, typewriter).

> *...It was a huge manual typewriter with glass keys that my grandfather had for writing sermons and political rants. Grandpa put me on his lap to read me stories, then showed me how the typewriter keys made words and stories.* (circa 1940) **M. B. Williams**

> *As teachers and I became acquainted and as I progressed up into the grades, we tore off the back cover of an old book, and the alphabet was printed on it in large letters in horizontal lines. This was always kept on my desk in front of me, and whenever it was my turn to recite in class, the teacher would come and have me spell out the words which she or my classmates couldn't understand. This might sound like a long and tedious procedure. And don't ever think it wasn't.* **F. Hall Roe**

Electronic innovations in the 1960s yielded the first dedicated communication devices, *e.g.*, the POSSUM communicator, the TIC, the Autocom and the Communicator. Scanning was introduced. By hitting a switch, an individual could move an indicator (cursor) from one letter or message to another. Scanning opened the door to communication for almost anyone, regardless of the extend or severity of their physical involvement.

In the 1970s, some professionals and family members began to explore the use of manual signs and picture boards with children and adults who were not yet literate. This provided them with access language. Also, the one-of-a-kind communicators of the early 1970s began to be manufactured; and the AAC industry was born.

During the 1980s, manufacturers introduced rate enhancement techniques, such as abbreviation expansion, encoding and linguistic prediction techniques. While somewhat effective at increasing the speed of message transmission and reducing keystrokes, these techniques also increased the cognitive and linguistic demands on their users.

The advent of the microprocessor revolutionized mainstream technology in the 1980s; and this change was reflected in the kinds of AAC devices that became available. Also, laws were passed that mandated basic civil rights for people with disabilities (in at least some countries), and access to communication began to be a public policy issue.

In the 1990s, funding barriers began to fall; and the AAC industry grew. New features of AAC technologies (*e.g.*, dynamic displays; intelligible synthesized and digitized speech; smaller, more powerful devices; highly accessible symbol sets; specific language- and communication-based software) further extended access to communication devices. Unfortunately, complex speech generating devices (SGDs) were very difficult for individuals with complex communication needs (CCN), family members and service providers to learn how to use.

Today, the most challenging access issues in AAC are (1) decreasing learning demands and (2) solving the psychosocial and environmental constraints imposed by today's SGDs. Higginbotham presented four levels of considerations for improving access to AAC technologies in the 21st century:

1. Characteristics of specific access technology options (*e.g.*, will eye-safe laser, eye-tracking, brain interface and gesture recognition applications be useful? If so, under what conditions and circumstances).

2. Physical (motor and sensory) characteristics, goals and preferences of individuals with CCN and their communication partners.

3. Cognitive/linguistic characteristics, goals and preferences of individuals with CCN and their partners.

4. Social communicative factors that reflect the joint action demands of various communication situations. For example, would having access to "just-in-time" information support interactions? When is co-construction useful and when isn't it?

This session then turned to several key issues, especially those related to rate and to the potential of new access technologies.

Rate

The presenters asked, "Is rate overrated?" Higginbotham shared comparative data that encapsulated the current "state of the science" on communication rate, which is typically measured in words per minute (wpm). Most studies report between 5 and 20 wpm (with scanning being the slowest). Even the fastest (utterance-based device) yielded results of only 60 wpm. In other words, the potential rates of all AAC devices fall significantly below normal conversational rates of 150 to 180 wpm.[9]

The authors also noted that calculations of keystrokes or linguistic output of AAC devices are inadequate measures of communication rate. In considering the con-

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struct of *rate* in AAC, wpm is not the only important factor. Other key variables that underlie the efficiency and effectiveness of communication exchanges are (a) the use of multiple modalities during face-to-face interactions, (b) the types of communication tasks undertaken, *e.g.*, conversation, email, *etc*., (c) the roles communication partners play during interactions, (d) the timing of multi-modal communication behaviors and (e) the impact of the social and physical context on interactions.

SOSC participants also discussed how rate issues differ during asynchronous communication exchanges (*e.g.*, email and instant messaging). Access techniques that provide positive supports during face-to-face communication may be largely irrelevant for communication across space and time (*e.g.*, talking on the phone, using email, blogging, lecturing).

Discussions on rate continued beyond the SOSC. For example, Tracy Rackensperger recently posted a follow-up question about rate in AAC on ACOLUG. She wrote,

> *Opinions about the subject of access, rate and its importance produced lively discussions at the State of the Science Conference. No one was disputing that rate is an important factor in communication. The issue, as explained at the conference, is that AAC technology continues to be incapable of producing the words per minute rates of typical speakers. Therefore, some believe there has been an overemphasis on "speeding up" AAC devices, knowing that they might never give individuals abilities to mirror the rates of their peers.*[10]

Colin Portnuff responded,

> *It seems very clear to me that we should be able to switch modes in our devices from the fastest method to the most flexible method at will. Then, if we need to say one of the 50 most frequent things, we should be able to do it with a single gesture, but we should always be able to say whatever we want as quickly as possible.*[11]

New AAC access techniques

The SOSC participants discussed a variety of AAC access options that are not yet readily available. These include gesture recognition, dysarthric speech recognition, adaptive scanning, use of ambiguous keyboards, utterance-based devices, eye-tracking and brain interfaces. They also talked about the need for more personalized synthesized speech output that interactants would find more desirable and the promise of combining AAC access techniques (multi-modal access).

The future

SOSC participants felt a variety of questions deserved further consideration:

1. How can we combine the strengths of different modalities?
2. Will we find ways to take advantage of the spatial aspects of communication (*e.g.*, gesture recognition technologies)?
3. Can AAC technologies learn to ignore extraneous movements?
4. How might newer access technologies affect the symmetry of interactions? Can communication technologies be designed in ways that help maintain a partner's attention?
5. Under what circumstances will co-construction be shown to be both useful and desirable in improving access? When won't it be?
6. Are we proceeding from an adult model and trying to apply it to children? (again!) What access considerations should we be emphasizing for children? For individuals with significant cognitive challenges?

Interconnectivity

Enhancing AAC Connections

Frank DeRuyter and Kevin Caves

The third SOSC presentation highlighted ways technologies link together, with a special focus on how speech generating devices (SGDs) currently support (or restrict) the use of mainstream technologies.[12] DeRuyter and Caves pointed out that many people now pay their bills online, use a cell phone, download music from the web, do their shopping online, surf the web, use instant messaging, send text messages and so on. There was a strong consensus among conference participants that individuals with complex communication needs (CCN) should have access to the same mainstream technologies so they can participate in daily activities and assume a variety of family, community and societal roles across domains, including:

- Social (*e.g.*, e-dating, Myspace)
- Employment (*e.g.*, telecommuting)
- Recreation/entertainment (*e.g.*, gaming, audio, video)
- Communication (*e.g.*, Internet blogs, chats)
- Commerce (online shopping)
- Information (news, technical support)
- Learning (Internet searches, online courses, Webcasts).

In 2006, technology is more powerful, pervasive, ubiquitous, affordable and, in general, it is easier to use across a variety of life domains. However, few of the

activities described above can be accomplished using an SGD. In fact, mainstream technology products are often not very accessible to people who rely on AAC systems. DeRuyter and Caves discussed three areas that affect the ability of individuals with CCN who rely on SGDs to access commonly used mainstream technologies.

Public policy

Laws now exist that address the rights of people with disabilities to access technology. In the U.S., policy gains have included third party funding for dedicated SGDs, consideration of assistive technologies for students with disabilities in their Individual Educational Plans and recognition of AAC by the FCC in Section 225 of the Telecommunications Act. However, policy issues that relate directly to connectivity in AAC remain unrealized. In fact, current funding policies for SGDs actually restrict access to mainstream technologies.

Participation of individuals with CCN

For years, AAC manufacturers have employed individuals who rely on AAC devices in some aspects of their work. More recently, constituency-driven participation has occurred in the research domain as well. NIDRR has been a leader in requiring researchers to conduct participatory action research. In 2000, the AAC-RERC jointly conducted a "Demand-Pull" Conference with the RERC on Tech Transfer (T2RERC). This group identified the following unmet AAC technology needs for people with CCN:

- use cell phones, computers, Internet and appliances of daily living;
- have universal wireless interface capabilities;
- access wireless information networks;
- increase AAC device advanced processing and storage capabilities;
- Be assured of privacy and security;
- Have device reliability.

Technological developments

Since the 1970s, AAC technologies have evolved from one-of-a-kind devices developed by families or within labs, to the emergence of microprocessor-dedicated devices in the 1980s, to a shift toward digital, microprocessor-based AAC devices in the 1990s. Most SGDs today, however, continue to lack a seamless integration with mainstream technologies. No doubt this reflects, at least in part, current funding requirements that SGDs be dedicated devices.

DeRuyter and Caves suggested there is a need to address two separate but related issues when linking AAC and mainstream technologies:

1. Interconnectivity. The ability to link AAC devices with specific hardware and software, typically from different manufacturers, to accomplish specific tasks, *e.g.*, talk on a cell phone, use serial keys, access Internet information, enable Bluetooth, *etc*.

2. Interoperability. The ability of a system (or a product) to work with other systems (or products) without any special effort on the part of the customer, *e.g.*, Plug and Play, UpnP, HID, V2, and so on.

SOSC participants discussed several ways commercial technologies might be used by individuals with CCN. For example, text messaging devices (*e.g.*, BlackBerries, pagers, cell phones) could be interfaced with SGDs. Currently these devices are not able to connect or operate easily with SGDs.

The future

The potential of the digital age is not being realized for people who rely on SGDs to communicate. In fact, the digital divide may be growing for people with CCN. Areas needing research include how to access mainstream IT infrastructure, and how to operate and use SGDs and mainstream technologies with ease. One approach discussed was to investigate the use of optimized interfaces for specific tasks like Web browsing, sending instant messages and Web crawling.

SOSC participants felt that enhancing connectivity for individuals who rely on AAC will require support from the broader technology industry and from the government, as well as from AAC manufacturers. The AAC-RERC is currently participating on standards committees, such as the V2 effort (an interoperability standard aimed at mainstream technology developers). In addition, the AAC-RERC is working to increase the awareness of mainstream industry about issues that affect people with CCN. For example, mainstream technology companies (cell phone manufacturers, computer manufacturers, *etc*.) change the designs of their products frequently, but the AAC industry is small and has limited resources, so it can not respond to these changes quickly, or at all.

Currently, mainstream technology manufacturers do not build universal interconnectivity or interoperability features into their products. They are being encouraged to do so. However, even if/when they do, SGDs must also include features that will permit mainstream technologies to "talk" to them.

To provide interoperability and interconnectivity for AAC and mainstream technologies, many additional barriers need to be overcome. For example, individuals with disabilities may be unable to pay for extra communication

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technology, or to cover the monthly costs of services (*e.g.*, the initial purchase and monthly fees for a cell phone). Perhaps public utilities can subsidize these costs. Vocational rehabilitation programs and employers may also need to step up to help people with CCN connect SGDs to a variety of mainstream technologies on the job. It will almost certainly be necessary to remove the current disincentives for AAC manufacturers to incorporate features that enable SGDs to access mainstream technologies. Other areas discussed included:

1. Participants supported the need for children to access mainstream technologies for a variety of purposes. They noted that today their same-aged peers are heavy users of mainstream technologies.
2. Technologies like GPS and RFID may offer individuals with cognitive challenges new ways to access just-in-time vocabularies, as well as to increase their independence and safety.
3. AAC manufacturers may need to purchase development "kits" that enable them to incorporate features that enable SGDs to connect with mainstream technologies. Currently, kits are expensive and beyond the reach of many AAC manufacturers.
4. Because the AAC market is small, the AAC community needs to build partnerships with larger disability groups who also can benefit from more open-ended and seamless access to a variety of mainstream technologies (e.g., people with visual impairment, the elderly).

Beginning Communicators

Improving AAC Outcomes

Janice Light and Kathryn Drager

This presentation highlighted the use of AAC with beginning communicators, *i.e.*, young children and others with complex communication needs (CCN) who are just starting to develop language, literacy and communication skills.[13] Kathryn Drager summarized current research and suggested future priorities for improving the outcomes of children with CCN.

Light, Drager and their colleagues at Penn State are working to define more carefully the abilities, characteristics and preferences of young children with CCN. Enlightened by the results of a series of earlier research projects, they are incorporating design specifications for AAC systems and instructional strategies into the development of prototype devices and supporting strategies, and then testing these approaches with young children with developmental disabilities (cerebral palsy, Down syndrome, autism spectrum disorder).

What we know

Young children with CCN come from many language, socioeconomic and cultural backgrounds and have a variety of disabling conditions. According to recent research, more than 11.5% of preschoolers enrolled in special education services in the United States today can benefit from AAC interventions.[14] This constitutes a significant number of young children and raises concerns about whether enough professionals are prepared and early intervention programs exist to serve the needs of these children. Unfortunately, recent studies suggest that a very small percentage of children with CCN are being referred for AAC services before the age of three.[15] This is a major concern because these children are at risk not only for communication problems, but also for other developmental problems (*e.g.*, challenging behaviors). There is a compelling need to provide appropriate AAC services as early as possible to support the development of these young children.

Research has established that SGDs, as currently designed, are often not easy for young children to learn or to use. For example, current ways of representing and organizing language on SGDs do not take into account the abilities, characteristics or preferences of young children. Light and Drager are testing alternative approaches to language representation and organization. One approach is called visual scene displays (VSDs).

VSDs can be used on both high- and low-tech devices. Basically, instead of placing pictographic symbols in boxes, VSDs use digital photos of familiar experiences, situations or contexts and embed language under "hot spots" within these scenes. Children use these scenes to explore, learn and communicate with familiar partners (*e.g.*, parents).

Researchers introduce the VSDs by modeling the use of a low-tech or high-tech device during favorite activities (*e.g.*, storybook reading). Drager played several videotaped examples showing very young children using VSDs to communicate during fun activities.

The presentation also included information about the intelligibility of digitized and synthesized speech in SGDs. Data shows that young children find machine generated speech less intelligible than natural speech. Researchers also found that young children's understanding of single words generated by SGDs is not very good (55 – 77%). In addition, caution should be used before having preschoolers record in the digitized speech devices of their peers with CCN. The digital recordings of four-year-old children are significantly more difficult to understand than the recordings of six- to eight-year-old children.

To date, research does not exist that suggests that one type of intervention strategy is more effective than another with young children. In fact, many approaches can be successful. Strategies used to teach language and communication using AAC range from very structured behavioral approaches to child-centered, social pragmatic interventions. Thus, AAC practitioners can draw from a variety of methods and select an approach that is best for a particular child and his/her family.

Research has demonstrated that family members (and other communication partners) can be taught to modify their communication behaviors to support language and communication development. After only a short period of instruction, parents can learn to use expectant time delay, respond to a child's communicative attempts, ask open-ended questions and model the use of an AAC system (low and/or high tech, gestures/signs). Communication partner training not only improves the adult's interaction skills, but also leads to an increase in the child's participation in activities and during interactions. Thus, family members should be included as an integral part of AAC interventions with young children.

Applying what we know

Current studies at Penn State focus on very young children with cerebral palsy, Down syndrome, *etc*. (ages 8 months to 40 months old) and children on the autism spectrum (ages 39 to 66 months old). Researchers are using a single subject, multiple baseline design. At baseline, all the children used fewer than 25 symbols expressively (across modalities). Currently, children have been involved in the project from a few months to almost two years.

Each child in the study is introduced to AAC technologies (*i.e*., an SGD and low-tech displays) designed to be appealing and easy to use in meaningful social contexts. In addition, facilitators (parents) are taught to model the use of the SGD, signs and/or low-tech displays during play, social routines, games, and reading activities. Researchers conduct weekly sessions with each child and his/her parents in the child's home. Between visits, parents carry over what is taught. Researchers are collecting data on a regular basis. Some initial results are:

1. All children demonstrate a significant increase in their rate of turn-taking behaviors immediately after introduction of an AAC system.
2. All children have made substantial gains in semantic development/vocabulary acquisition. For example, one boy with Down syndrome had six concepts at baseline (age 15 months.) After 11 months of intervention (age 26 months), he had more than 400 unique vocabulary items. He also had 43 sound effects and more than 200 lines from songs or books in his device. His system had 260 pages with more than 1800 buttons because some items (*e.g*., *mommy*) were repeated on multiple pages.
3. All children have increased their rate of vocabulary acquisition, in some cases significantly, and at rates that compare to typical children.
4. Most children are combining concepts to communicate more complex messages.
5. All children use their AAC systems (low and high tech) with parents and teachers to communicate, play and learn new concepts.
6. Most children use their systems with other children, *e.g*., during shared reading, singing, and play activities as well as when they are by themselves.
7. Some children are developing phonological awareness and literacy skills.

These data lend strong support to the need for beginning communicators to have access to age-appropriate AAC technologies and instructional strategies.

During the discussion period, SOSC participants asked a number of questions about the nature of the ongoing research at Penn State. They were interested in hearing more about the research design, ways in which data are collected and coded and so on. For example, participants wanted to know:

Whether researchers measured language comprehension? (*Not formally.*)

How new vocabulary is added? (*Vocabulary is selected based on the interests of each child and introduced through modeling.*)

How turns are counted? *(Turns are*

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Beginning communicators,Cont. from page 9

defined as intentional communicative acts directed toward a partner. A turn is coded after the use of a symbolic mode, e.g., sign, aided AAC speech/speech approximation.)

How children transition from visual screen displays to more traditional grid displays? *(Children start with VSDs and move to hybrid displays—grids and scenes. As they acquire more vocabulary, they learn to navigate between pages through modeling.)*

Several themes also emerged during the discussions. An obvious one is that higher expectations result in higher performance. We must increase our expectations of young children with CCN and give them the tools they need to develop. A second theme is that there is a growing need for service providers to deliver AAC services across all the settings where young children can benefit.

The future

The SOSC participants agreed that there are still many unanswered questions.

- How will AAC manufacturers enhance the appeal of AAC technologies for children?
- How will AAC manufacturers reduce learning demands?
- How will AAC technologies allow facilitators (parents, teachers, therapists) to program "on the fly"? How will they support just-in time programming?
- How will AAC technologies be designed in ways that can meet the changing developmental needs of young children and make developmental transitions more seamless?
- How will AAC manufacturers provide technologies that serve as dynamic interactive contexts and integrate communication, play, social interaction, emergent literacy/learning, entertainment, telecommunication, companionship and artistic activities?
- How will parents and AAC professionals learn to support the use of AAC technologies and strategies during interactions with young communicators?
- How will parents and AAC professionals teach communication partners to interact more effectively with young children who use AAC technologies and strategies?
- How can we help AAC advocates to change public policy so that young children with CCN are identified earlier and can participate more fully in early intervention programs that support the use of AAC technologies and instructional strategies?
- Is there a way to close the substantial gap that exists between the current state of the science and clinical practice in ways that substantially benefit young children with CCN?

Adolescents/ Adults with DD

Enhancing Participation & Access to Meaningful Roles

David McNaughton and Diane Nelson Bryen

McNaughton and Bryen addressed ways in which AAC technologies and instructional strategies can enhance participation and increase access to meaningful adult roles for adolescents and adults with developmental disabilities and complex communication needs (CCN).[16] They reviewed existing data about the impact of AAC on societal roles across three domains: education, employment and post-school adult living and relationships.

Education

Individuals with CCN face many challenges at the high school level. Among those noted were: (1) a lack of teachers with training in AAC, (2) inappropriate curriculum for students who rely on AAC and (3) difficulty managing workload, educational assistants and social interactions in school.

McNaughton described a research project designed to assist adolescents and young adults in dealing with a range of problems, issues and barriers. Young adults and adolescents who use AAC technologies were mentored over the Internet by trained mentors who also relied on AAC. Each pair worked together to help solve problems and develop strategies for coping with high school or preparing for independent living.[17]

Project results were very positive. All mentees made progress toward or achieved their stated goals. The study clearly demonstrated that adolescents and young adults who rely on AAC technologies and strategies can benefit from peer mentoring over the Internet. Researchers also noted, however, that some high school students were not able to participate in the project because of limited language and literacy skills. They suggested that future mentoring projects should investigate ways to support participation by individuals with a wide variety of communication and literacy skills.[18]

McNaughton then presented research showing that success in

college requires individuals to have strong literacy skills, a competitive general education high school background and access to a computer-based AAC device.[19] Successful college students are able to ask and answer questions, lead and contribute to discussions and use voice output or written text for examination activities.

SOSC participants noted that all college students today rely heavily on email and the Internet. This means that individuals with CCN must use AAC technologies that can easily connect to mainstream technologies, *i.e.*, interconnectivity is important. As Bob Williams said:

> We must engender digital independence among youth who rely on AAC...the more acculturated people with significant disabilities become to doing everything from reading, writing, listening to music-making purchases, pursuing a career and connecting with family and friends online, to going wireless on the commode, the more personal independence they're likely to experience in life.[20]

Employment

Bryen and colleagues at Temple and McNaughton and colleagues at Penn State have conducted studies related to employment and AAC. Current barriers to employment for individuals with CCN include societal prejudice, technology difficulties and breakdowns, lack of transportation, the need for assistance with activities of daily living (ADLs) and a lack of previous work experiences. In one study, the benefits of telework (*i.e.*, using the Internet to connect to the workplace from home) were described. These included a flexible schedule, working from home, broader social networks and the ability to rely on familiar people to support ADLs. It was also noted that telework has some disadvantages, such as technical and equipment issues that may not be readily addressed, and limited social interaction with one's co-workers.

Bryen briefly described two programs developed at Temple aimed at improving the employment opportunities and related skills of individuals with CCN.

1. *Augmentative Communication and Empowerment Supports (ACES)*. A two-week face-to-face immersion program with a year of follow-up training and support in communication, computers and information technologies, self-determination and empowerment.[21]

2. *Augmentative Communication and Employment Training and Supports (ACETS).* A five-to-ten day training program, focused exclusively on employment, with one year of online job coaching after the session ends.[22]

These programs have led to increased employment opportunities and experiences for those who participate.

Post-school adult living

A variety of issues confront adults with developmental disabilities in their communities. For starters, the transition from adolescence to adulthood is often fraught with challenges. During this time, decisions are made about where to live, who to live with, how to spend time, how to deal with medical and healthcare issues, as well as how to address concerns about personal relationships, sex, safety, work and leisure activities.

Underlying success in fulfilling desired adult roles is often dependent on the ability to communicate and to find needed supports. Areas discussed included:

Living arrangements. Bryen pointed out that many postings on the list serv ACOLUG (housed at Temple) relate to barriers individuals with CCN face that impact various types of living arrangements, such as negative societal attitudes and difficulty finding competent personal care assistants (PCAs).

SOSC participants discussed issues related specifically to PCAs (*e.g.*, low salaries, lack of training) and ways to make training more accessible, *e.g.*, on the Web, a list serv for PCAs and individuals with CCN.

Victimization, abuse and crime. Bryen and her colleagues at Temple have reported a high incidence of abuse and crime by individuals often known to adults with CCN.[23] They have begun to address the problem by developing specific vocabulary to help individuals in reporting crimes and in communicating concerns about inappropriate behaviors.

SOSC participants also noted that significant problems exist. Several individuals at the SOSC shared personal experiences, as well as stories about others' experiences. Individuals with CCN have had difficulty gaining access to the legal and judicial systems. All agreed the AAC community needs to address these problems. Several SOSC participants are currently working with the United States Society of Augmentative and Alternative Communication (USSAAC) to further define the problem, compile existing case law and then disseminate the information in ways that make it readily available to others.

Community living. AAC technologies and strategies are often key components to successful community living for adults with CCN. Bryen noted that in the state of Pennsylvania, 30 percent of individuals served by the Office of Mental Retardation could benefit from some type of AAC approach, but only 10 percent use AAC technologies and strategies. It appears that few professionals share information about AAC technologies and strategies with the parents of adults

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with severe cognitive disabilities. Two of the major problems noted were: (1) a lack of funding for AAC technologies and services and (2) a lack of trained personnel.

Developing, maintaining and sustaining social networks.

The importance of building and maintaining strong social networks for adults and adolescents with developmental disabilities was also discussed. In addition to maintaining existing networks of family and friends, participants discussed the increasing importance of the Internet and the Web in building social networks. For adolescents and adults with developmental disabilities, access to the Internet can provide ways to get information, work, engage in e-commerce and participate in recreational activities (*e.g.*, music, e-books, gaming). Unfortunately, access today is still made difficult by some Web browsers and screen readers and PDF. Also, many adults with CCN are not literate, so their access to the Internet is limited. [See White Paper on access to the Web.][24]

Future directions

SOSC participants agreed that to assume adult roles and participate in one's community, adolescents and adults with developmental disabilities and CCN need access to AAC technologies and strategies. With these tools, they can engage in face-to-face communication, talk on the phone, conduct business, get their social and medical needs met and maintain and build social connections. Without a range of AAC options, adolescents and adults with developmental disabilities and CCN are at high risk for abuse, victimization and crime.

Currently, individuals with CCN and developmental disabilities continue to be underserved by adult programs. Participants discussed the need to make changes in a number of areas.

- AAC systems need to be able to perform all necessary academic and workplace functions (*e.g.*, calendar, address book, calculator, notetaking, *etc*.)
- AAC systems need to include embedded technologies *(e.g.*, integrated cellphone in AAC devices).
- AAC systems need to be easy to learn, use and maintain and have clear guidelines for how to add new vocabulary.
- Policy changes are needed to support academic, workplace and community participation. Better funding supports are required and funding programs should not restrict the variety of functions in AAC technology.
- Professionals, family members and individuals who rely on AAC need more information about AAC technologies and instructional strategies.
- At the preservice levels, undergraduate and graduate schools need to cover pertinent issues that relate to adult roles, participation in desired activities and the use of AAC approaches.
- At the inservice level, professionals need to incorporate up-to-date approaches to the solution of communication problems in adolescents and adults with developmental disabilities. These solutions require the use of AAC and mainstream technologies.

Adults with Acquired Disabilities

Use of AAC to Enhance Social Participation

David R. Beukelman, Susan Fager and Laura Ball

Beukelman focused this presentation on adults with acquired disabilities and degenerative diseases who use AAC technologies and strategies to maintain social participation.[25] Unlike children and adults with developmental disabilities and complex communication needs (CCN), individuals with acquired conditions have lived some portion of their lives with typical speech and language ability. Usually, they have developed social networks and participation patterns that immediately or gradually are impacted with the loss of their ability to speak. Given their age, some of these individuals, or their frequent communication partners, experience problems with hearing, vision or cognition. In addition, AAC services for adults are not well coordinated by any single agency, as are services for children by the public schools. Rather, AAC services may occur at home or in hospitals, ICUs, hospice or long-term care facilities. Family members often must support and facilitate the use of AAC approaches, even though they usually have limited training and expertise in using AAC technologies.

Beukelman presented research about AAC interventions with specific groups of individuals with complex communication needs and discussed future implications. He talked about individuals with amyotrophic lateral sclerosis (ALS), traumatic brain injury (TBI), and brainstem impairment, noting research on demographics, acceptance and use, the types of AAC approaches people rely on over time and the kinds of supports they may require. In addition, he reviewed information about the use of AAC approaches with individuals who have chronic/severe aphasia, progressive aphasia and dementia. While there are limited data about the use of various AAC approaches with these groups, some research does exist that describes the benefits of various AAC technologies and strategies. Finally, he discussed what is known about individuals with Parkinson's disease, multiple sclerosis (MS), Huntington's disease and myasthenia gravis. Data on these groups are sparse and published articles are typically case reports.

A number of factors can affect the use of AAC technologies and strategies when adults have acquired conditions. These include current medical practices, acceptance and use by individuals with CCN and their family members and the design of AAC technologies.

Medical practices

Advances in medical practices can influence outcomes and the demographics of people with neurological conditions. In turn, these factors may influence the nature and timing of AAC interventions. For example, many individuals with ALS are given the option of relying on invasive ventilation to extend life. If they choose to do so, AAC practitioners need to plan ways to accommodate their deteriorating motor condition. Extending life may increase the need for AAC interventions that will enable these individuals to maintain communication and their quality of life.

Individuals who experience cerebral or brainstem strokes, as well as people with TBI, also benefit from improved medical practices. Care at the emergency and acute levels is able to reduce swelling and bleeding in the brain, which may decrease brain damage and improve outcomes. Also, new medications for dementia may lessen the negative impacts on cognition and communication. In these cases, improvements in medical care may reduce the need for AAC interventions.

Acceptance and use of AAC

The acceptance and use of AAC has increased, which probably reflects several factors. In the United States, for example, most individuals with insurance can acquire AAC technologies (with some notable exceptions). In addition, many adults and their family members are more accustomed to using computer-based technologies in their everyday lives. This can mean less resistance to AAC technologies and accessories when they are needed.

Design of AAC technologies

Beukelman noted that design features of AAC technologies are different for different groups of individuals with acquired disabilities and CCN. For example, individuals with ALS typically do not have cognitive and linguistic impairments, while individuals with aphasia and dementia often struggle with language. In addition, some conditions are degenerative (ALS, MS, Parkinson's disease, progressive aphasia) while others are static (aphasia, TBI). AAC technologies for those with degenerative conditions need to be flexible to accommodate changes in an individual's needs, preferences and capabilities.

Discussion of different groups

Amyotrophic Lateral Sclerosis (ALS). The Nebraska ALS database, with 157 individuals, shows that at the time of death, 95 percent were unable to speak. Nearly all relied on AAC technologies and strategies until the last month or two of life, and they used AAC for a variety of purposes. These individuals required on-site facilitators to support their use of AAC. Research shows that a vast majority of facilitators are female family members, mostly wives and daughters, who provide support because they are available and willing to help. Almost none have extensive technical backgrounds beyond conventional word processing.[26]

Beukelman expressed concern that some individuals with ALS are not being referred for an AAC assessment early enough. He stressed how important it is to refer individuals for an AAC assessment *before* they lose their speech. A decreased rate of speech, not intelligibility, predicts the timing of a referral.

> When speaking rate reaches 125 words per minute, the client should receive an AAC assessment. Once sentence intelligibility drops below 90 percent, speech deterioration often occurs quite rapidly, not allowing enough time to complete an AAC assessment, recommend AAC options, order and purchase technology and train the individual with ALS and his or her AAC facilitator.

Traumatic Brain Injury. More than half of individuals with TBI who are unable to speak when they enter active rehabilitation recover their speech as their cognitive problems clear. The rest of these

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individuals are unable to meet their needs through natural speech because of persistent motor speech disorders. When professionals have recommended a speech generating device (SGD) for someone with TBI, Beukelman reported that studies show that a high percentage of individuals used the device initially, and more than 80 percent continued to use the device after five years. In addition, data revealed that when low-tech AAC displays were recommended, 100 percent of individuals accepted them and 63 percent were still using them after three years. The reason for discontinued use was primarily because the individual had regained functional natural speech.

Nearly all individuals with TBI in the reported studies relied on letter-by-letter spelling despite the availability of other strategies on low-and high-tech devices. They tended to use low-tech displays more often for conversation (80%), while they used SGDs to talk on the telephone, tell stories, write and express detailed needs.

Beukelman also showed SOSC participants the results of research that demonstrated that supporting residual speech using alphabet boards improved intelligibility. The individual points to the first letter of a word (and sometimes a topic) to supplement his or her speech. The average impact of alphabet supplementation is about 25% for sentence intelligibility. However, the impact can be quite variable, so a trial is needed to determine the impact of this intervention for an individual with TBI.[27]

Brainstem impairment. Very few (0% to 25%) individuals with brainstem impairments recover functional speech. These individuals rely on both high and low-tech AAC. Some use direct selection techniques and other use scanning techniques to access language. Some remain "locked-in" and rely on eye-gaze and signals (dependent scanning).

Beukelman described an exciting project involving an eye-safe laser pointer that is helping some individuals with locked-in-syndrome to develop sufficient head control to access AAC technology using the laser pointer.

Severe chronic aphasia. Demographic data concerning the use of AAC approaches by people with aphasia is limited. For example, low-tech AAC approaches are often used, but not necessarily considered by professionals or family members to be AAC. AAC devices are reported to be used to accomplish specific tasks, such as answering the phone, requesting help, saying prayers, or ordering at restaurants.

To date, the design of most AAC devices does not support people with aphasia and their communication partners to interact about a wide range of topics. Thus, Beukelman and his colleagues at the University of Nebraska are currently developing a prototype device that uses visual scene displays (VSDs). These provide individuals with chronic, severe aphasia a way to engage in meaningful social interactions with familiar partners on multiple topics with essentially no training. The personalized digital photographs of favored activities provide contexts that permits co-construction and allows communication partners to support conversations over multiple turns.

Other conditions. Many other adult populations currently benefit from the use of AAC approaches. These include people with primary progressive aphasia, dementia, Parkinson's disease and multiple sclerosis. Beukelman pointed out that some guidance exists in the literature about supporting people with primary progressive aphasia and dementia using AAC approaches. A considerable amount of intervention and technical research is underway and will be reported in the future. Less is known about other conditions.

The Future

During the discussion period, SOSC participants noted the aging of the general population. Participants expressed concerns about the limited number of professionals who are currently prepared to provide AAC services to adults with acquired conditions. There is a growing need to ensure that appropriate AAC technologies and strategies are available to people with acquired conditions and CCN when they need them.

SOSC participants also discussed the key roles family members play in successful AAC interventions and considered ways to deliver instruction and support to these individuals.

On the Web

The AAC-RERC website—www.aac-rerc.com— includes three webcasts that review and expand on some of the ideas presented at the SOSC. They include:

1. Supporting successful transitions for individuals who use AAC (*David McNaughton*).
2. AAC Intervention to Maximize Language Development for Young Children (*Janice Light*).
3. AAC and Aphasia: A Review of Visual Scene Displays (*David R. Beukelman*).

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