

Upfront



This, the final issue of *Augmentative Communication News (ACN)*, is about the future. Thinking about the future almost always means reflecting on the past, musing about what “coulda been” and then engaging in some speculation about what’s to come. No one has a reliable crystal ball. Even stalwart predictions sometimes miss key events and/or innovations that can change the very way we think about things.¹

But, from time to time, AAC gatherings encourage reflection in order to forge paths to a better future. For example, in 1992 the National Institute on Disability and Rehabilitation Research sponsored a two-day *Consensus Validation Conference on AAC Intervention*.² Participants, who represented all AAC stakeholder groups, convened to consider the past, present and future of AAC. The group addressed six questions:³

1. What is AAC and who can benefit from its use?
2. What are the nature and scope of AAC interventions? What are the essential components?
3. What relationships should exist among consumers, “family,” service providers, community, manufacturers, researchers and funding sources to achieve effective outcomes?
4. What are effective consumer and societal outcomes and benefits that can be expected from AAC intervention?
5. What is the relationship of AAC to expressive and receptive communication processes?

6. What are the research and education issues that need to be addressed?

Similarly, the *State of the Science in AAC Conference*, which is hosted

every four years by the AAC-RERC, brings stakeholders together to review and recast issues related to AAC research and technology. These results are published in peer-reviewed journals.^{4,5}

The millennium and ISAAC’s 25th Anniversary also have offered forums for reflection. For example, a special anniversary issue of the *AAC Journal* is edited by Janice Light and David McNaughton.⁶

For this issue of *ACN*, I interviewed some AAC experts about how they view the future. [See

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For Consumers

Casting the net and broadening the vision for AAC

This section predicts the continued expansion of communication enhancement services and technologies to new populations. It also advocates for ongoing, creative efforts to meet the very diverse needs of individuals who face communication challenges.

Who benefits from AAC?

Over the past thirty years, AAC interventions have become increasingly inclusive and are now benefiting individuals of all ages who have

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difficulty communicating for a myriad of reasons. The definition of AAC has remained fairly stable—the use of a variety of standard

and special modes and means of communication to support people with communication challenges to communicate effectively across environments and partners—but we have expanded the vision of who fits under this umbrella.

In the beginning, we had too narrowly defined “who benefits from AAC” and actually excluded some individuals with severe communication disabilities. Among the sidelined were individuals with sensory impairments and those with significant cognitive disabilities. The

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rationale was that other specialists were already serving these groups, and we were trying to avoid territorial disputes and controversies, such as the debate in the 1970s and 1980s over the use of sign language. In any case, what happened was we divided up the body (*i.e.*, you take the ears; you take the eyes; we'll take the mouth and a bit of the brain).

Big, big mistake! Obviously, effective communication requires all body parts, as well as the brain and willing communication partners. AAC professionals today understand that AAC interventions

are more effective when multiple professionals share their expertise. Tragically, territorial battles persist in some places. When that happens, absolutely no one benefits.

By the 1990s, most family members, teachers, practitioners, researchers and manufacturers knew that AAC strategies, techniques and/or technologies could effectively support the communication efforts of most individuals with severe communication disabilities, including those with significant language and cognitive disabilities and those with severe, multiple disabilities.

Throughout the 1990s and beyond, practitioners and researchers

demonstrated that AAC strategies and technologies not only helped individuals express language, but also could support language comprehension and help people complete tasks, participate in a range of activities, mediate behavioral difficulties and successfully take on a range of valued social roles.

Yet another factor in the expansion of AAC services has been the globalization of the field. Initially, AAC services emerged in parts of North America and Western Europe. Now, AAC has gained a strong foothold in Australia, New Zealand and parts of India, and services are spreading rapidly into South and Central America, Africa, Eastern Europe and throughout Asia. Membership in the International Society for Augmentative and Alternative Communication (ISSAC) reflects this growth. It was founded in 1983 with about 100 members from four countries and today has thousands of members from more than 60 countries.

AAC services have also expanded to meet the needs of individuals across the entire age span. Initially, school-aged children and adults with acquired disabilities in hospitals and rehabilitation centers were the focus of our interventions. Today, AAC approaches (*e.g.*, gestures, manual signs, communication displays, speech generating devices (SGDs) and other mainstream and assistive technologies) are being used to help infants and toddlers at risk for developing speech and language. Also, AAC strategies and technologies are supporting people at the end stages of life. Today, AAC treatments are being considered from cradle to grave to support communication.

The most recent growth in AAC approaches relates to helping individuals who may not have a named

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Resources.] All agreed we've accomplished many things and that the future holds great promise.

For Consumers highlights the question "Who benefits from AAC?" and argues for an ever more inclusive vision. **Clinical News** advocates for adopting the ICF as a way to frame and ground our clinical practices. **University & Research** focuses our attention on the need to educate many different stakeholder groups to ensure the future of the field. **Governmental** explores ways to advocate for AAC and includes ideas about how to use demographic data to affect funding policies. (I've omitted the **Equipment** section—partly because new technologies were the focus of the previous issue. Let's hope that emerging technologies are ever smarter, more powerful and easier to use. Most importantly, they must make a meaningful difference to people who face significant communication challenges.)

These efforts to forecast the future will probably miss the mark and ultimately fizzle—it's the nature of the task. I do understand

that I am undoubtedly leaving out something really important.

For example, at the 1992 Consensus Conference, no one predicted the World Wide Web—and it was launched just six months later.⁷ Such profound, unanticipated changes affect what we do in AAC and how we do it.

And, on the other hand, I risk rehashing the same old stuff.

In these pages you'll find comments that do indeed rehash concerns about (a) providing more access to AAC services; (b) training more AAC professionals and maintaining their levels of expertise; (c) finding more reliable funding sources for equipment and services and (d) doing a better job in our clinical practices while amassing more and better evidence to inform the field.

Thanks to all who helped me grow and learn over the years. Good luck on the road ahead, and Happy New Year to you and yours! 🌊

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



disability, but who become “communication vulnerable” in particular situations.⁸ Examples include individuals who may face linguistic and cultural barriers during an emergency or disaster. Police officers, fire fighters, emergency medical personnel and shelter workers may not understand the language or culture of the victims and/or refugees they are trying to help. When trained interpreters are not available, lives may be lost, injuries may go unattended and conditions may worsen unnecessarily. Therefore, an increasing number of emergency medical personnel and community helpers are learning about simple AAC strategies and tools to help overcome the linguistic and cultural barriers they sometimes encounter on the job.

[See *ACN* vol. 19 #4. <http://www.augcominc.com/newsletters/>]

Other communication vulnerable individuals are found in intensive care units, emergency rooms and on surgical units of hospitals. Nurses, doctors, respiratory therapists, speech-language pathologists and other hospital personnel are using AAC approaches to communicate with patients who are unable to speak and/or understand what others are saying because of a medical procedure or recently acquired disease or condition. Research shows that effective communication between patients and healthcare providers improves outcomes, reduces the length of hospital stays, lessens the number of sentinel events in hospitals and supports the goal of improved patient-centered care. In fact, effective communication between patients and providers is a *standard of care* for hospitals seeking accreditation in the United States.⁹

[See *ACN* vol. 21 #2. <http://www.augcominc.com/newsletters/>]

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Twenty Years of Acknowledgements

This is the last issue of *Augmentative Communication News (ACN)*, and I wish to thank everyone who has subscribed over the past 21 years for their ongoing support. I’d especially like to acknowledge the folks I’ve interviewed. No one has ever refused to share her/his ideas, expertise and opinions. This openness, I believe, is endemic to the area of AAC, and I hope it continues.

I want to recognize Gary Pooch who was the co-founder of *Augmentative Communication News*. In 1987, he said to me, “Someday I’d like to publish a newsletter.” I replied, “I know just the topic,” and that’s how it all began. Gary died in 1993, but *ACN* is in part his legacy, and he is remembered with love and appreciation by family, friends and colleagues.

As every writer knows, the key to a writer’s success is having a good editor, and I’ve had two of the best. Carole’s Krezman’s insights have made me think more deeply. . . What did I really mean? Why hadn’t I thought about...? Harvey Pressman’s flair for the written word challenged me to write more crisply, analytically and honestly. As editors, they share a hatred for long, convoluted sentences and the passive voice. Both are sticklers for punctuation and spelling. Neither has ever read anything he/she couldn’t improve (including newspaper articles, road signs and menus). This means, of course, that all typos and errors in *ACN* are entirely their fault. (I’ve always wanted to say that!)

In 1998, I became a partner in the AAC-RERC, a NIDRR funded Research and Engineering Rehabilitation Center. This Center helped support *ACN* and *Alternatively Speaking* for a decade. Most recently, the AAC-RERC enabled us to provide hundreds of newsletter issues on our website for free. [Go to www.augcominc.com/newsletters/.] Many thanks to the AAC-RERC partners (Frank DeRuyter, Dave Beukelman, Diane Bryen, Kevin Caves, Melanie Fried Oken, Jeff Higginbotham, Tom Jakobs Janice Light, David McNaughton, Howard Shane and Janet Sturm). A special thanks to AAC-RERC partner, Michael B. Williams, the accomplished speaker, writer and editor supreme of *Alternatively Speaking*.

Finally, appreciation goes to my vivacious family for the many joys and insights they bring. Most especially, to Harvey Pressman, who not only has always supported me in my work, but has now taken up the AAC cause. Together with our friend Anne Warrick and staff at the Central Coast Children’s Foundation, Harvey works tirelessly to bring AAC resources to people in developing areas throughout of the world. My hero!

I am fortunate to work with, live with and love people who care so deeply about others and who feel passionately about the right of ALL people to communicate their unique thoughts, ideas and authentic selves. Doing things that make a meaningful difference in the lives of others is what matters. . . but, you already know this and are hard at work making it happen. So, keep on keeping on, stay in touch and, again, thanks. It’s been a great ride.

Sarah [www.augcominc.com and sarahblack@aol.com]

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Finally, as Ruth Sienkiewicz-Mercer, author and AAC user said in 1992, the question shouldn't be "who benefits," but rather "who doesn't benefit from AAC."¹⁰ Of course, individuals who use SGDs and other AAC techniques and strategies benefit, but so do their friends, family and communication partners. In fact, society in general benefits from those who need AAC approaches having access to them. As stated in the Consensus Panel's report:

Through AAC, families and friends come to know the thoughts and feelings of loved ones. Health-care workers have greater opportunities to learn first-hand what individuals feel and can then more efficiently meet their needs. Employers have a larger pool of prospective qualified employees.

Someone with the capability of expressing needs and wishes, who joins the workforce and pays taxes, becomes a more active, wiser consumer. Also, society has the advantage of ideas and knowledge from an involved, contrib-

uting member of the community who is no longer a passive recipient but an active voice able to instruct, encourage and lead."¹¹


Summary

As our vision of "who can benefit from AAC" has expanded, so have the tools, strategies and technologies that we employ to enable people to communicate more effectively. Examples include:

- People with limited movement may use sophisticated eye gaze and head pointing technologies to access communication boards, SGDs and computers.
- Individuals with autism may choose to carry an SGD to use in the community or may rely on visual supports in their classrooms to help them make transitions, regulate their emotions and communicate more effectively.
- Patients who are intubated and can't speak or operate a nurse call signal can use an adapted

call button to request assistance and a communication board to ask questions and express their needs to nurses, as well as to share their fears and feelings with family members.

- An adult with a developmental disability can use AAC to report a crime. She works with a trained communication assistant assigned by the courts to testify in court, accessing relevant vocabulary on a display prepared in advance.
- A toddler with Down syndrome can use an SGD to take turns while playing a game with his sister. He can also use it to participate in story reading with his mom.

AAC is offering more options to more people than ever before. We need to prepare for an ever more inclusive and expansive, more ambitious role for AAC in the future. 

Clinical News



old concepts and models of interventions with clinical practices that are more consistent with the ICF and the 21st century.

The ICF: Framing and grounding clinical practice in AAC

The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) is widely accepted and does a really nice job framing clinical practice in AAC.¹² Unfortunately, the ICF is still not well known or widely used by the AAC community. Comments from those interviewed (see **Resources**) about their future visions of clinical practice in AAC suggest we need to finally "get with it" and replace

What is the ICF?

The ICF was accepted in 2001 by the WHO's 191 member states. It unifies two previously dominant models of disability (*i.e.*, the medical model and the social model).¹³

- The medical model views disability as a feature of a person, caused by disease, trauma or other health condition. As such, it requires care by a professional; the goal is to "correct" the problem for the individual. The medical model is not a complete frame for AAC because

it does not address the social, environmental and political aspects of severe speech and language impairment and other cognitive and physical disabilities.

- The social model of disability looks at disability as a socially-created problem rather than one caused by attributes of an individual. While it acknowledges that some people have physical, sensory, intellectual or psychological variations, the social model demands a political response and requires that societies change their attitudes about disability and make necessary physical, social, political and environmental accommodations. The social model is not a complete frame for AAC because most people with complex com-

munication needs (CCN) do want some type of medical interventions to communicate and can't afford to wait around for society to become enlightened. They need to participate and communicate "now."

Both the medical and social models have valid aspects. The ICF framework combines them to create a *biopsychosocial* model of disability.¹⁴ This model takes into account both the health condition and functional capacity of the individual, as well as the personal and environmental contexts within which the person lives. Within the ICF framework, communication access becomes a human rights issue. It is a good fit for AAC.

AAC and the ICF

The ultimate goal of AAC interventions is to increase functional communication so that individuals with CCN can participate actively in all aspects of their daily lives, realize their personal goals, reach their potential and have a high quality of life. As such, AAC treatment priorities go beyond restorative therapies (articulation, language development, speech and language remediation) and beyond providing individuals with compensatory strategies, tools and technologies.

Consistent with the ICF and with the goals for AAC interventions, speech, language and communication functions are not "ends" in themselves, but rather the means to many ends in personal, social, emotional, linguistic and cultural realms. Thus, desirable AAC intervention strategies seek ways to increase an individual's participation in daily activities, expand social networks and enable the individual to take on desired social roles in their homes and communities.

This requires that AAC practitioners shift from their current focus on services delivered in clinics, offices and classrooms, to services that positively affect what happens in the communities where individuals who use AAC live, work, recreate and relate to others as a natural part of their daily lives.

The ICF and children. Many of those interviewed noted that by adopting the ICF model, AAC practitioners would better serve children with CCN. They made several interesting points.

Families. Given the personal and cultural differences in how family's function, good AAC outcomes are most likely to occur when we empower parents and caregivers to encourage and value authentic communication with their children. As Mats Granlund from Sweden has purportedly asked, "Whose child is it anyway? We must include the parents in meaningful ways.

Authentic communication means being real and genuine during interactions. Sadly, interactions between individuals who use AAC and their partners often violate characteristics of authentic communication. Examples include when communication partners (1) pretend to understand when they don't, (2) insist that someone use their device to say what they just signed, (3) avoid someone who uses AAC because they know it will take time to understand the message and (4) ask questions with known answers.

AAC practitioners. Within the ICF framework, clinicians and teachers can think of themselves as being positive, external influences, providing the means and trying to influence communication, participation and developmental processes. The AAC practitioner, therefore, needs to know and be

A multi-country AAC study

By adopting the ICF, we are still free to recognize, address and track outcomes across domain levels and to study gains in speech, language, literacy as well as the impact of AAC interventions on developmental or restorative processes. For example, a cohort of AAC researchers from 15 countries is working collaboratively on a cross-sectional research project under the leadership of Stephen von Tetzchner from Norway. This study will ultimately involve more than 100 children with limited speech, motor impairments and "normal" intelligence who use AAC techniques to communicate and the same number of typical peers, matched for age, gender, grade in school, *etc.*

Researchers will ask each child to complete a series of tasks using their AAC systems (if they have CCN) or their speech. According to von Tetzchner, one key outcome of the project will be a book describing the study and its results. Project results will most certainly broaden and deepen our understanding of how language develops and is used by children who rely on AAC, and how that compares to what their typical peers do to carry out the same set of tasks.

The research team is hoping to present some preliminary data at the ISAAC Conference in Barcelona, Spain, in July 2010.¹⁵

accepted by the child and family, but does not necessarily work with the child directly. Rather, the AAC practitioner would aim to support parents, caregivers and siblings, as well as friends, aides and teachers, to communicate more effectively

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with the child, and to help the child communicate more effectively with them. The message (both verbal and nonverbal) from AAC practitioners to family members should be “You can do this and I can help you,” not “I can do this and you can help me.”

Several experts I interviewed noted that family members often feel frustrated, angry and even abandoned when they are not seen as key partners in the AAC intervention process. Because many lack support and even acceptance in their own communities, they often face a “turbulent journey.” Our job is to make it easier, not more difficult. AAC practitioners who listen with their ears, eyes and hearts can better support families and thus, will result in better outcomes for children.

The ICF and intervention strategies. The interviewees discussed several widely accept AAC intervention approaches.

Scaffolding and modeling. As noted above, authentic communication with individuals who use AAC is essential, and scaffolding by the practitioner who is offering support, tools and guidance to family and friends is consistent with the ICF. Modeling (aided language stimulation/augmented input) is not necessarily the same as scaffolding. The point was made that the purpose of modeling as a scaffolding technique is not to get someone to imitate you, as in “Do this.” Rather, it should be a demonstration of how the individual might solve a problem.

Another area discussed was the use of multiple modes of communication. The rhetoric is that everyone communicates using many communication modes, tools and technologies and that AAC is not just about technology; however, in practice it is still not happening.

We have to truly BELIEVE in multi-modality, not just talk about it. We’ve actually seen the use of low-tech and light-tech approaches diminish over time. Recently, thank goodness, we are beginning to see various forms of high-tech and light-tech coexisting again.

Effective communication requires the use of multiple modes. AAC practitioners need to acknowledge, accept and value ALL modes. We need to focus on how individual’s participate in their various roles, from the time they get up until the time they go to bed. Our job is to help them figure out what modes and means of communication they want to use, when and how. The reality is that some work better in some situations or with some partners. You don’t want to use a hammer when what you need is a screwdriver.

For example, a combination of familiar gestures, a preprogrammed speech button that tells about an event at school and an enthusiastic family works well for a child at the dinner table.


On the other hand, communication with unfamiliar partners will be more effective when individuals with CCN use conventional forms of expression. SGDs not only have intelligible speech output, but also they attract attention, suggest competence, increase expectations and opportunities and enable the user to deliver quick, canned messages, as well as construct unique ones.

The ICF and service delivery systems. Our institutions and agencies continue to make it easier to provide “treatment” in segregated rooms and “practice” using AAC tools with therapists and teachers, than to support the preferred communication efforts of people with CCN during interactions with their families and peers in authentic situations. While it is often difficult to direct clinical and educational resources toward services in an individual’s home and community, it can and does happen. Here are a few examples.

- Family-centered models adopted by early education programs.
- A new summer program in Norway will bring families of children with CCN who use AAC (with a focus on SGDs) to a two-to-three week summer “camp” modeled after a similar program for the families of deaf children. The Norwegian government will refund families for lost income so all members can attend. The opportunity will be offered every summer until a child is 15 years old.
- AAC practitioners in private practice go to people’s homes and community-based activities to do assessments and support and monitor AAC interventions. Some practitioners who work in schools and clinics have been able to convince administrators of the value of community-based interventions.

Summary

Consistent with the ICF, it’s time to refocus our attention on the authentic communication that takes place (or needs to take place) within each individual’s personal and environmental context. This is not unique to the area of AAC. A recent article in the *Journal of Positive Behavior Interventions* states that the primary concern of intervention is quality of life. According to the psychologist Edward Carr,¹⁶

Our vision is to “create meaningful lives, and not simply eliminate psychopathology.” This vision “spurs us to change systems and not just people, a vision that motivates us to seek collaborative possibilities with our colleagues in many different sciences so that we can transcend our superficial differences and focus on deeper commonalities. It is a vision that holds promise for each one of us so that at the end of our lives we can say, ‘I made a difference.’” (p.12). 

University & Research



Priming the pump: Future educational challenges in AAC

Education at all levels is important to the continued growth of a field. At a basic level, increasing awareness about the field of AAC remains an ongoing goal. Most important, however, is the need to continuously build and maintain a strong, creative, energized and diverse AAC workforce.

The field's future depends on how successfully we educate people so that a variety of AAC stakeholders are available to take on various roles. As shown in Table I, David Beukelman and his colleagues suggest there are several groups who play key roles in the successful delivery of AAC services to adults and children with severe communication challenges.¹⁷ Obviously, the individuals who have CCN are most important, but the focus here is on their AAC support teams.

AAC Finders. Finders include physicians, nurses, speech-language pathologists, social workers, family members and friends of people with communication challenges. These individuals typically have limited knowledge of available AAC options, but they know enough to make referrals for AAC services.

Networking with finders is important, and educating them requires that the AAC community make a special effort to build awareness among healthcare professionals, educators and the general public.

Clinicians in general practice. This group includes speech-language pathologists, teachers,

occupational therapists, nurses and other healthcare and education professionals who work with individuals who might benefit from AAC, but do not feel comfortable working with AAC devices or other types of assistive technology (AT). They do know about and may use low-tech AAC options with certain clients/students/patients. Some may also use speech generating devices (SGDs) which they become familiar with. AAC professionals often network with these professionals and may mentor and support those who wish to learn more about AAC.

Educating general practice clinicians about AAC can (and should) take place at both the preservice and inservice levels. Information about AAC approaches needs to be included in coursework at the preservice level and offered to professionals as part of their continuing education.

AAC intervention specialists. These speech-language pathologists, educators, teachers, occupa-

tional therapists and manufacturer representatives work mostly (or exclusively) in the area of AAC/AT services. They also support other professionals and family members to carry out AAC interventions across all environments. They typically handle the funding issues for AAC technologies.

Most are active members of the AAC community, belong to AAC-related organizations, read AAC-related journals and attend AAC conferences and workshops. Educating this group takes place at the preservice level through AAC coursework and clinical practicum experiences, and continues through continuing education activities. AAC intervention specialists often use the Internet to seek information, participate in online training opportunities, connect with colleagues and maintain interactions with AAC users.

AAC Facilitators. AAC facilitators include instructional aides, spouses, parents, caregivers, job coaches and personal aides. They

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Table I. Varied roles of personnel in AAC services¹⁷
from Beukelman, D., Ball, L. & Fager, S., 2008.

Personnel	Examples of roles these individuals play
AAC finders	Aware of current, appropriate communication options for individuals with complex communication needs (CCN). Identify persons with CCN and refer to appropriate providers. Certify AAC prescriptions (physicians).
General practice clinicians	Implement low-tech AAC materials and high-tech options in restorative/developmental and compensatory interventions and monitor their impact. Prepare and support AAC facilitators and instruct communication partners.
AAC intervention specialists	[See general practitioner above.] In addition, they help obtain funding for intervention technology, support general practice clinicians, provide continuing education to AAC finders, collaborate to support technology transfer and research, support AAC professional organizations and activities and provide expert testimony for legal and policy proceedings.
AAC facilitators	Support implementation of multi-modality interventions, instruct communication partners, support unfamiliar listeners, maintain AAC technology, prepare low-technology materials and serve as a liaison with other AAC personnel and commercial companies.
AAC experts	Promote, sustain, and enhance AAC services at program or agency level. Engage in pre-professional preparation and continuing education of finders, general practice clinicians, AAC intervention specialists and AAC experts. Develop AAC policies, conduct AAC research, collaborate to support technology transfer, prepare AAC educational materials, participate in the leadership and management of AAC professional organizations, and provide expert testimony for legal and policy proceedings.

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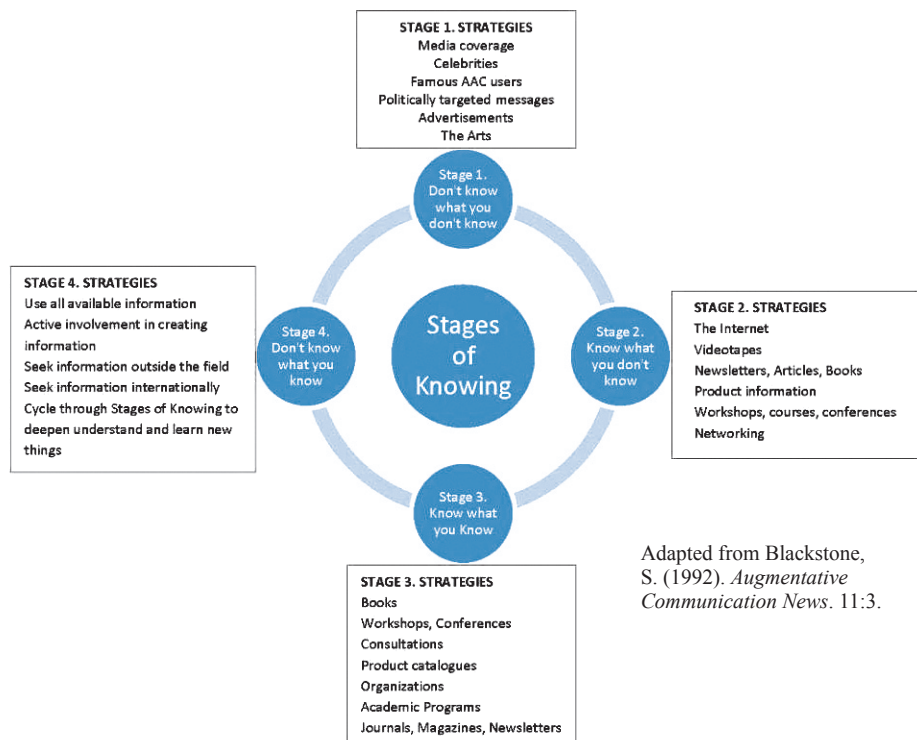
provide AAC users with day-to-day assistance and support and are often key communication partners. Many spend more time with individuals who use AAC than almost anyone else. In addition, they help support interactions with less familiar partners and maintain equipment.

Given the nature of communication and the complexity of AAC tools and strategies, these individuals require ongoing training and support. Sadly, they rarely get it. They are least likely to be trained and most likely to be underpaid.

Educating AAC facilitators requires a renewed effort by AAC intervention specialists and experts, both to develop and deploy training programs that can address their needs. The AAC community also needs to advocate for the recognition that facilitators deserve. They can determine the success (or failure) of AAC interventions.

AAC Experts. Experts are involved with issues that relate to the development of knowledge about AAC/AT, the efficacy of AAC interventions, policy issues and the translation of knowledge to multiple stakeholder groups. They include university faculty, AAC researchers, individuals who use AAC technologies, master clinicians, technology developers and policy makers. These individuals are “self-starters,” highly committed to the field and leaders in AAC-related projects, organizations and programs.

Educating this group generally requires enabling them to (1) engage in ongoing collaborations with other experts, within and outside the field of AAC, (2) carry out their research agendas, (3) develop new technologies and strategies, (4) write and publish articles and books, (5) teach the next generation of AAC clini-



Adapted from Blackstone, S. (1992). *Augmentative Communication News*. 11:3.

Figure 1. Stages of Knowing and Strategies for Learning in AAC¹⁹

cians and researchers and (6) oversee projects that advance the field.

Stages of knowing

Chuck House’s Stages of Knowing is a paradigm that represents a dynamic continuum of knowledge development within a field or discipline.^{18,19} As such, it recognizes that people are at different stages of learning and have different learning styles and preferences.

As shown in Figure 1, these stages describe a progression that begins with the novice (*Don't know what you don't know*) and develops through various learning stages (*Know what you don't know*) and (*Know what you know*) until one becomes an expert (*Don't know what you know*). These stages complement Beukleman’s personnel chart by reminding us that learning is, in fact, a cyclical process and that certain types of learning tools and strategies are likely to be more effective at one stage than another and depend, to some extent, on the kind of role someone is playing in a field.

Stage 1. Don't know what you don't know. Educating people who *don't know what they don't know* first requires raising their awareness. Finders are often at this stage. It is important to package information about AAC for this group so it is (1) readily available, (2) interesting, (3) not too long or detailed and (4) appealing.

Videotapes and stories about people who use AAC can increase awareness and capture the uninitiated. Other effective strategies at this stage are media coverage, exposure to knowledgeable celebrities and famous AAC users like Stephen Hawking, targeted advertising spots and success stories that are told through mainstream books and movies, such as *My Left Foot* (1989) and *The Diving Bell and the Butterfly* (2007). The Internet may be an effective resource for some finders

Stage 2. Know what you don't know. This is a tough stage for most people because when

adults *know that they don't know*, they can become anxious and feel overwhelmed. Not surprisingly, some choose not to seek additional information; others become more engaged. AAC finders and general practice clinicians may pass through stage 2, but some go no further.

These learners often require repeated exposure to targeted information to build confidence and increase their knowledge. AAC intervention specialists and experts can play a crucial role when they network with them and provide support. The Internet is a particularly effective resource for people at this stage because it is available all the time (24/7), easy to search and provides multiple options for information transfer, *e.g.*, Google, YouTube videos, Blogs, Listservs, Twitter and so on. Videotapes, newsletters, articles and books can also help. Learning how to operate a specific SGD with a particular student or patient can make a huge difference.

While some stage 2 learners might attend an AAC workshop or presentation, most will choose to search the Internet for specific information or rely on a trusted AAC intervention specialist for help.

Stage 3. Know what you know. These individuals typically include AAC intervention specialists and facilitators. They are knowledgeable about a range of AAC strategies, devices and techniques and comfortable with what they know. They are also motivated to increase their knowledge base. Most are aware of their own strengths and limitations, know how to work as a team member and how to recommend, implement and get funding for appropriate AAC strategies and devices.

To gain more knowledge, these individuals typically read AAC texts, journals, magazines and

newsletters. They also participate in and present at workshops and conferences (online or face-to-face). They are comfortable using a variety of SGDs and other AAC technologies and strategies and stay in contact with manufacturers and their representatives.

To “stay current,” they rely on multiple information sources. Some participate in AAC organizations and educational activities and programs. They often consult and network with colleagues, family members of people who use AAC, manufacturers, as well as individuals with CCN.


Stage 4. Don't know what you know. Most AAC experts work at AAC full time and are immersed in the field. Many specialize in one particular area (*e.g.*, adults, children, literacy, access issues, people with autism or amyotrophic lateral sclerosis) but all maintain a broad view of the field. They may teach, write, do research, develop materials, mentor others, engage in clinical work and hold leadership positions at both the national and international levels.

AAC experts actively seek information from outside the field and collaborate with their colleagues in the international AAC community. They are constantly recycling their knowledge and revising and deepening their understanding of issues and practices in AAC. They perceive new learning as an ongoing requirement and use all available avenues to pursue knowledge.

Summary

For a field to survive, new ideas, approaches and technologies must emerge and new generations of finders, general practitioners, facilitators, intervention specialists and experts must be engaged, mentored,

encouraged and supported. While all AAC stakeholders need information, they do not need the same amount or types of information. In addition, they have different learning styles and preferences—some will prefer attending conferences or workshops while others will choose to stay close to home. In addition, financial resources will influence the choices people make. Some employers may support the learning process and others may not.

In short, future generations of AAC stakeholders have multiple and diverse information needs that must be addressed. This requires a complex, diverse and multi-faceted system of knowledge translation. In any case, the systems need to work because individuals with complex communication needs are depending on it. 

Governmental



Arguments for funding AAC technologies and providing AAC services

Making the case for AAC often means making some fundamental arguments in favor of AAC coverage and funding support, such as:

Making and remaking the case for AAC with Lew Golinker

There are four ways to answer questions: (1) Some should be answered categorically (straightforwardly yes, no, this, that); (2) some should be answered with an analytical (qualified) answer (defining or redefining the terms); (3) some should be answered with a counter-question and (4) some should be put aside.²⁰

“How can we make a case for AAC?” This question has been asked for a long time and for many reasons. It has been asked by educators seeking to persuade department chairs and administrators to add courses on AAC and AAC content to courses or to establish and maintain AAC related clinical programs. It has been asked by clinicians seeking to ensure they are paid appropriately for their time. It has been asked by advocates seeking to secure funding for speech generating devices (SGDs).

Even after years of asking this basic question, it remains relevant and will into the future. There still are students in speech and language programs who have minimal exposure to AAC content in their pre-service programs. There are still far too few AAC clinics for such students to have hands-on opportunities to work with people with complex communication needs (CCN). The rates paid to practitioners for AAC related activities is an ongoing challenge. And, even though we have managed to persuade all governmental and private systems of third party health benefits in the United States to cover and provide SGDs, we still have specific sources that refuse SGD

1. Not being able to speak or communicate has dire consequences. Children and adults who have severe communication impairments are unable to express their most basic needs, ask questions, exchange information, get an education, work, form relationships with others, and in effect, live a decent life. They will remain dependent on others. Many will be excluded from day-to-day activities at home, in school and in their communities. They are at high risk for crime, abuse, poor health and marginalization.

2. AAC is a widely accepted treatment for severe communication impairments. Evidence in peer-reviewed journals and refereed papers demonstrates that AAC treatment approaches (e.g., speech generating devices, communication boards, partner training) increase functional communication skills, which leads to improved health and safety, increased academic success, employment, greater involvement in family and community and a higher quality of life. In some cases, speech intelligibility improves after AAC is introduced. There is absolutely no evidence that AAC interferes with or delays the development of speech and/or language in children or the restoration of speech/language in adults with acquired disorders. In fact, the evidence suggests it sometimes helps.

3. Children and adults with a wide range of disabilities benefit from AAC services and technologies. Evidence supports the use of AAC with children and adults across a wide variety of diagnostic categories. This includes evidence of effectiveness with very young children and people at the end stages of life, as well as individuals in other age groups. These individuals may have chronic or temporary conditions, and developmental as well as acquired disabilities that affect communication.

4. AAC and SGDs are consistent with and “fit” within the scope and purposes of most benefits and funding programs. To enable people to speak and communicate is just one of many reasons benefit programs were created, thus coverage and funding for AAC services and SGDs must be viewed as within the scope of these programs.

coverage or threaten to withdraw their SGD coverage. In many other parts of the world, the situation is no better.

The question, “How can we make a case for AAC?” requires a careful response. It is clearly not a yes/no question, nor one that can be put aside. Rather, it is question that requires an analytical answer. But first, we must ask some counter-questions—“Who wants to know?” “To what end?”

A first step in arguing for AAC is to point out that supporting AAC is of extraordinary importance: it will make a huge difference in people’s lives. [See the box above.] Even after a generation of advocacy, many policy and decision makers are still neither unaware that people with CCN exist, nor do they understand the importance of gaining access to communication through the use of AAC.

Another question—“Who needs or can benefit from AAC?” should be addressed when making a case for AAC, and this requires demographic data.

Demographic studies

Over the past 25 years, the field of AAC has amassed data across multiple demographic studies. Sometimes, researchers have asked general questions to ascertain the need for AAC services in an area, such as:

- How many children of a certain age have difficulty communicating and might benefit from AAC services in the U.S.?
- How many adults are unable to meet their daily communication needs using speech and could benefit from AAC services in Canada?

Other times researchers may ask questions that get at more specific information:

- What is the need for AAC within a certain group of individuals with specific disabilities (cerebral palsy, traumatic brain injury, autism, motor neuron disease, aphasia)?^{21,22,23}
- How many children who attend special schools or classes in a country have severe communication impairments and could benefit from AAC services?²⁴
- How many people in a state/area (ages two years and older) are nonspeaking, and what kinds of disabilities do they have?²⁵
- What is the need for AAC services in particular settings (*e.g.*, hospitals, schools, day programs for adults)?¹⁶⁻³¹

Variance in these data occurs because researchers ask different questions and make different assumptions about (1) what consti-

Table II. Estimates of need for AAC in the the U.S. based on NZ study

Data source (from NZ)	Results of NZ study	Equation for U.S.	Estimate for U.S. based on NZ study
Sutherland, Gillon & Yoder (2005)	.15% of general population or 6000 people in NZ may need AAC	300 million x .15% percent	450,000 people may need AAC in the U.S.

tutes AAC intervention (*e.g.*, use of high and light tech devices, use of communication boards), (2) who is surveyed (*e.g.*, speech-language pathologists, teachers, nurses or administrators), (3) who comprises the universe of beneficiaries (*e.g.*, adults of a certain age, children in school, adolescents with specific disabilities) and (4) who is left out of the survey (*i.e.*, not counted).

As illustrated below and discussed in the Beukelman and Mirenda text³², current demographic data in AAC suggest the prevalence of people with CCN may range from as few as 0.1% to 4% of a specific population, depending upon the study. For example,

- The United States Census Bureau has estimated that 2.6 million people, age 15 and older have some difficulty having their speech understood by others. Of this number, 610,000 are unable to have their speech understood at all.³³
- Compiling data from earlier studies, results suggest that between 0.2% to 0.5% of school-aged children worldwide have a severe speech impairment and can benefit from AAC.³⁴
- Approximately 1.5% of Canadians over the age of four years have difficulty speaking and being understood.³⁵
- The number of adult Canadians with significant speech impairments increases with age (from 0.8% at ages 45 to 54 years and 4.2% of people aged 85 years and older).³⁶

- In the United Kingdom, 1.4% of the general population has a severe communication disorder.³⁷
- 0.12% of people in Victoria, Australia have speech that is inadequate for communication.²⁵
- 0.06% of people in Hungary have severe speech disorders. [Note: people with aphasia, other acquired disorders and those with autism were excluded.]³⁸
- Of the 5430 children and adolescents (ages three to 21 years) who attend Israel’s special education classrooms and schools, 40% have complex communication needs (CCN).²⁴
- In New Zealand, 0.15% of the general population has CCN secondary to a variety of conditions. Children ages 5 to 10 years of age are most likely to receive AAC services.³⁹

Estimating the need

While estimating the need for AAC services will be based on existing prevalence data, it is important to select studies that are most relevant to the case being made.

Table II, for example, illustrates a calculation that estimates the prevalence of people who can benefit from AAC in the United States with its roughly 300 million people. The estimate is based on a New Zealand study,³⁹ which was selected because it (1) was completed recently and (2) queried speech-language pathologists about people with AAC needs. The NZ researchers reported that 0.15% of the NZ population

Continued on page 12

Governmental, Cont. from page 11

could benefit from AAC services (about 6000 people). Applying these data to the United States (as shown in Table II), we can estimate that 450,000 people in the U.S. could potentially benefit from some type of AAC.

Someone else might decide to use another study or studies to estimate need. For example, to get the attention of an organization, government agency, school district or hospital administrator, an advocate might use the Canadian study by Cossett & Duclos, which reports that 1.5% of people over the age of four years have significant communication difficulties and may benefit from AAC.³⁵ [In the U.S., this could mean that 4.5 million people might benefit.]

Researchers and manufacturers also might choose to use bigger numbers to attract money for research. National and international organizations may rely on higher estimates to draw more attention to the AAC cause. A “problem” that is seen as big and important may be harder to ignore than a small problem.

However, sometimes smaller is better. Big numbers can scare away sources of help (e.g., government and private insurance programs, hospital and school administrators, etc.). Thus, Golinker advises advocates take a more nuanced approach.

We do not want funders, policy wonks or legislators to see the problem as too big or too expensive. Rather we want them to understand that providing for AAC services and technologies is something big for people with CCN that is relatively easy to achieve but rather small in cost.

Estimating the demand

It is important to realize that the demand for AAC services will be

Case Example:

Making a case for Medicare funding in the United States

Go to <http://www.augcominc.com/index.cfm/funding.htm> for a copy of the proposal to Medicare and the final Coverage Policy

In the late 1990s, when the U.S. government considered funding SGDs through Medicare, staff at the U.S. Department of Health and Human Services in Washington, D.C. asked a group of AAC professionals to provide certain information. The field needed to make the strongest case possible because (a) Medicare funding for SGDs would help thousands of adults with CCN for decades into the future and (b) other U.S. insurance companies and government programs would likely adopt Medicare’s policy to fund SGDs and related AAC services, meaning millions of children and adults throughout the nation would also benefit. In other words, the stakes were very, very high. To make the case we needed to:

- 1. Demonstrate the effectiveness of SGDs with specific groups.** We provided peer reviewed articles to document the effectiveness of SGDs and other AAC approaches with individuals who have severe speech and language impairments, focusing on those who were Medicare eligible. The term “unable to meet one’s daily communication needs” was used to describe people with CCN. We included diagnostic categories such as brain stem stroke, laryngectomy, cerebral palsy, aphasia, Parkinson’s disease, multiple sclerosis, amyotrophic lateral sclerosis, and so on.
- 2. Estimate the numbers of people who are eligible for Medicare and would be likely to want to use an SGD.** We used available demographic data to estimate both the need and the demand. We provided estimates of those in “need”: people who were Medicare eligible and likely to benefit from AAC (e.g., over 65 years old; under 65 with CP, ALS, aphasia). We then provided a second estimate of “demand,” much smaller than the first, of people likely to have an AAC assessment that results in a recommendation for an SGD.
- 3. What is the potential cost to the Medicare program if funding for SGDs is approved?** We argued that the costs to the program for SGDs coverage could not be calculated on the basis of “needs” alone, and especially not AAC services needs. We stated that the costs to Medicare must be calculated based on an estimate of SGD demand, which will be only a small fraction of those eligible for Medicare who have CCN. While “need” can be estimated based on severity of impairment, “demand” will require awareness of AAC, the ability to find a service provider to conduct an assessment, recommend equipment and carry out a treatment plan, and acceptance of an SGD as a communication tool. All of these factors will significantly limit the number of people with “need” who will seek an SGD in any year.

much smaller than what is documented in demographic studies. This is true for several reasons:

- Many people with CCN (and their families) are still unaware that AAC strategies/technologies exist.
- Some practitioners in health and educational settings may not know about AAC services and may not refer individuals to AAC professionals.
- There is a limited supply of trained AAC professionals.

- Not everyone who can benefit from AAC services and/or AAC technologies will want them.
- Some families and practitioners may be unaware that funding is available.
- Beneficiaries of some benefit programs may not know how to navigate the system.

In short, demographic data can help define the need for AAC, but do not predict the demand for services. In addition, the demand for AAC services can not predict the demand for equipment (e.g., SGDs).

Other factors are involved and must be considered, especially when estimating costs.

Estimating costs


A realistic and pragmatic approach should be taken when estimating costs. For the Medicare coverage process, which is described briefly on page 12, we initially estimated that 47,000 people in the United States might require an SGD over the period of a year. This represented about 0.1 percent of those eligible for Medicare (about 43 million) based on the Bloomberg and Johnson study in Australia.²⁵

From this estimate of “need”, we further estimated that only a few hundred Medicare beneficiaries per year actually would be able to secure an evaluation, have an SGD recommended in a year and thus, would “demand” SGD funding from Medicare. We also estimate that the “demand” would increase about 50% for the first five years.

As it turned out, we underestimated the actual demand for SGDs among Medicare beneficiaries. However, the actual number of Medicare SGD claims, after almost a decade of funding, has only risen to about 2,400 devices per year. This means that SGDs are probably reaching only 5% of Medicare recipients who may need them.

Notwithstanding our error in estimating demand, the costs of SGD coverage to Medicare is insignificant.

The Future

Currently many efforts are underway to change public policy and provide better access to AAC around the world (e.g., the United Kingdom and Singapore). More will emerge in the future. As advocates, we must remain vigilant, persistent and thoughtful in our efforts to make the case for AAC. 

On the Web



<http://aac.unl.com>.

The University of Nebraska-Lincoln website contains a wealth of information

on both general AAC topics and more specifically on topics related to adults with acquired communication disabilities. The site is managed by David Beukelman. Pages include:

Demographic information, Academic resources and references, presentations by University of Nebraska staff and students, Intervention resources, Aphasia assessment materials, Early intervention in AAC, Severe disabilities, Connecting Young Kids (YAACK), Vocabulary and Links to AAC vendors and other AAC sites.

www.aac-rerc.com

The AAC-RERC website is a portal to information about the research, development, training and knowledge translation activities of the center. Funded by the National Institutes on Disability and Rehabilitation Research, it provides access to useful presentations and a popular series of 12 webcasts:

- Maximizing the Literacy Skills of Individuals who Require AAC
- How Far We've Come, How Far We've Got to Go: Tales from the Trenches
- AAC: A User's Perspective
- AAC for Aphasia: A Review of Visual Scenes Display Project
- AAC and College Life: Just Do It!
- Visual Immersion Program (VIP) for Individuals with Autism.
- AAC Interventions to Maximize Language Development for Young Children.
- Overview of the Health-based Funding Programs that Cover Speech Generating Devices.
- Seating and Positioning for Individuals who use AT

Some key AAC resources

Augmentative Communication News and *Alternatively Speaking* are closing shop and will no longer be reporting information to the field. No problem, because today there are many wonderful, accessible resources. The following are far from inclusive, but they will lead to others and help practitioners, family members, people who use AAC and educators find useful and relevant information.

www.augcominc.com.

The Augmentative Communication, Inc. website now has all the back issues of both *Augmentative Communication News* (1988-2009) and *Alternatively Speaking* (1994-2009) available online for downloading (at no cost). Issues are grouped in categories by date and topic. Searchable topics include:

AAC-RERC, Adults, Advocacy, Children, Clinical Issues, Education, Literacy, Policy, Research, Specific disabilities, Technology and more.

Currently, the newsletters that are most often downloaded are:

AAC-101: A crash course for beginners
 AAC in emerging areas
 AAC in today's classrooms
 Communication access and AAC
 Developmental apraxia of speech and AAC
 Digitized speech devices
 Individuals with autism spectrum disorders
 Modeling the use of AAC
 Myths about AAC
 Visual scene displays

In addition, the ACI website has useful information about the *Consensus Validation Conference* and funding. (Discussed in this issue on page 1 and pages 12 and 13).

Continued on page 14

On The Web, Continued from page 13

- Supporting Successful Transitions for Individuals who use AAC
- Adding Projects for People with Disabilities to Engineering Design Classes
- Disaster Preparedness for People with Complex Communication Needs

<http://aacliteracy.psu.edu>

Based on research by Janice Light and David McNaughton, this website offers guidelines for teaching literacy skills to learners with special needs (*e.g.*, autism spectrum disorders, cerebral palsy, Down syndrome, developmental apraxia and multiple disabilities).

The website complements the *Accessible Literacy Learning (ALL) Curriculum*, which is now available from Dynavox Mayer-Johnson.⁴⁰

<http://aackids.psu.edu/>

This site provides step-by-step guidelines for early intervention activities that can maximize the language and communication development of infants, toddlers and preschoolers with special needs. It is based on the research of Janice Light and Kathy Drager.

www.setbc.org/

Special Education Technology British Columbia provides information about ongoing projects and includes useful learning resources for the AAC/AT community:

AAC Low-Tech Toolkit (2009). Documents and webcasts describing an AAC non-tech toolkit for teachers and speech language pathologists to support students with communication challenges.

Assistive Technology: Considerations for School-Based Teams (2009). A collection of webcasts featuring Penny Reed discussing issues important to school-based teams implementing assistive technology.

Autism and Developmental Disabilities (2008). A series of six webcasts created for Autism Awareness Month in October 2008. Presented by Pat

Mirenda and Karen Bopp.

Dynavox Series V Resources (2009). A collection of presentations and materials to support teams working with students using the Dynavox V Series of speech generating devices.

Extreme Make-Over: The AAC Edition (2009). A collection of webcasts by Gail van Tatenhove with information and strategies to help teams design AAC systems for effective integration in schools.

www.accpc.ca/

Barbara Collier's website is where you need to go to learn about social justice issues, communication access to community services, abuse prevention, attendant services, transition to adulthood, self-determination and advocacy, personal safety, healthy relationships and conflict resolution

<http://depts.washington.edu/enables/>

This site is no longer being updated; however, there are videos showing people using a variety of AAC strategies, techniques and technologies. It also has information that dispels myths about AAC intervention and strategies.

www.communicationmatters.org.uk/

The Communication Matters website offers a free newsletter with useful ideas as well as other downloadable materials (*e.g.*, "How to be a good listener").

www.med.unc.edu

The University of North Carolina has two websites :

The Center for Literacy and Disability Studies website has handouts and strategies that address reading and writing for all students. Their Tar Heel Reader library has a plethora of accessible books for beginning readers.

The Early Childhood Resources website offers presentations, handouts, materials and the *Bridge Assessment*.

www.caac.up.ac.za/

The Center for Augmentative and Alternative Communication (CAAC) in South Africa website posts back issues of its newsletters, which often have interesting implementation ideas.

Other important AAC websites

Google Videos and Utube

Just do a search for augmentative and alternative communication and see what comes up.

<http://aacinstitute.com>

Lists AAC books and programs and has specific information for parents and people who use AAC.

www.bridgeschool.org/

Focuses on school issues, curriculum and evidenced-based strategies for children. Great materials and strategies.

www.aacintervention.com/

Caroline's Musselwhite's website. Has practical ideas that reflect her creativity and passion for making things fun and meaningful.

www.lburkhart.com/

Linda Burkhart's website. Suggests many creative approaches and has materials for children with Rett syndrome.


<http://www.aacfundinghelp.com/>

Lew Golinker's website. Has everything you need to know about funding in the U.S.

www.scopevic.org.au/

Scope's website in Victoria, Australia. Offers downloadable, useful material about AAC and community-based services.

and, the list could go on . . .

"A conclusion is the place where you got tired of thinking." 

Resources

Sincere and hearty thanks to my colleagues for their help with this issue. Their ideas are woven throughout, as are ideas from readings and those interviewed during preparation of the last issue, volume 21 #3.

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