# Augmentative A VIII Communication News

Volume 15 Number 1

# Upfront

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has. 1 Margaret Mead

Over the past twenty-five years, individuals in the AAC community have been changing the world of AAC. At the ISAAC Biennial Conference this past August in Denmark, for example, participants heard tales of systems change from Poland, China, South Africa, Brazil, Egypt and several other countries. These first-hand reports, and others told at conferences around the world, capture some of the ways individuals have collaborated on systemic change, so that people with severe communication impairments can access the communication tools and techniques they need.

This issue of Augmentative Communication News highlights examples of how people can change AAC service delivery systems. The articles describe how committed people have created changes in educational, clinical and governmental practices at the local, regional and national levels. Clinical News, by Carole Zangari, makes some general points about systems change and AAC. Her article is followed by four case examples. Gail van Tatenhove, a private practitioner, shares a longterm program initiative designed to meet the needs of adults with

developmental disabilities. Carole Zangari and Gloria Soto provide insight into making changes in person-

nel preparation programs within universities. Joanne Cafiero discusses large-scale change in a public school setting serving students with autism spectrum disorders (ASD). In the last case example, Penny Parnes describes a bottom-up approach (in Canada) and a top-down approach (in Thailand) to changing public policy. The AAC-RERC section focuses on technology transfer, and explores what tech transfer means and how it is carried out.

The idea for an issue of ACN on systems change issue originated from attending a conference

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# Clinical News

#### Making inroads: Systems change in AAC Carole Zangari

Most AAC practitioners work hard and accomplish wonderful things for and with their clients. Some have also learned how to 'work smart' and to work in ways that influence long-lasting change. These AAC professionals have directed their energies, consciously or not, to changing systems so that they work better for everyone. So have some individuals who rely on AAC and

some family members of individuals who use
AAC. Such individuals are often committed to building capacity and sharing and passing on

what they know, as well as facilitating the growth of clients,' students,' friends' or family members.' They strive to improve the systems they work within. This *modus operandi* often results in long-lasting and wide-spread systems change.

To understand how systems work and how they can be changed in the area of AAC, we need to understand more about the processes involved. This article provides a very brief overview.

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#### **Systems**

We all have a working knowledge of systems, based on our daily experiences at home, at work, in the community and in society as a whole. Some systems are institutional (*e.g.*, the health care system, school district, mail service), while others are more specific or personal (*e.g.*, family system, company bookkeeping system.)

Kauffman (1980) defines a system as a "collaboration of parts that interact with each other to function as a whole." Systems, however, cannot be understood solely through examination of their component parts. Typically, a system will contain characteristics not found within any of its individual

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session, chaired by Carole
Zangari, at the American SpeechLanguage-Hearing Association. I
wish to thank those who have
willingly reported their experiences in these pages and to
acknowledge the relentless efforts
of so many others who have
worked successfully to change
AAC service delivery systems.
Because of this advocacy, more
people are able to enjoy their
right to communicate and to
exercise their freedom of speech.

#### **Year 2003**

This issue begins the 15th year I have written and published Augmentative Communication News. It's been an interesting journey with lots of surprises. Some of you have been with me all the way; others are new subscribers. I want to thank all of you for your support.

components. Thus, understanding systems requires not only an understanding of the components, but also insight into the relationships among those components, and consideration of those relationships in their dynamic contexts.

#### **Systems change**

"Systems change" refers to a process that permanently modifies a system. It is a long-term, systematic approach to changing the way things work, and differs from nonsystemic approaches to change, which lack longevity and continuity. A systems change process simultaneously involves and is directed at multiple stakeholders. It takes time to see results. However, the additional energy and resources a systems change process consumes

From now on, ACN will be published quarterly (January, April, July, October). Enclosed (for those who already registered) is the 2002 ASHA CEU test. Please read the instructions carefully.

As a new year begins, my hope is we can all put more resources toward changing systems to provide better solutions to the communication problems faced around the world. Let's keep forging ahead, working together when we can, to make communication more accessible and enjoyable for people with complex communication needs. Happy New Year to everyone.

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



on the front-end often pay off handsomely at the back-end, because the system ends up functioning in new and better ways for multiple stakeholders.

As Henry Louis Mencken reminds us,

For every complex problem there is always a simple solution. And it is wrong.<sup>3</sup>

The AAC field is replete with complex problems that require a thoughtful approach. Consider the example of a student needing an AAC device. A school principal might offer to fund the device from the school's discretionary funds. This action provides quick access to the device and lessens the workload of the speech-language pathologist, who might otherwise have to find funding for the device. While this is a simple solution, it is not the most desirable one.

A systems change approach would address the funding issues from a more systemic perspective. If a funding mechanism exists, the funder should not, for convenience sake, be absolved of responsibility. Rather, the funder should be encouraged to "do the right thing." If no funding mechanism exists, the principal, director of special education and staff should develop a plan to enable all students with AAC needs to obtain devices. In fact, providing a simple solution for one student may make it even less likely that other needy students gain access to AAC devices and services. Depending upon the situation, of course, a short-term solution should be implemented while longer-term solutions are planned.

# Implementing systems change

The systems change process begins when individuals take the time to reflect and gain understand-



ing of a system that isn't working. Questions that can generate relevant information include:

- 1. What is the organizational culture of the system?
- 2. How are decisions made?
- 3. What influences how resources are allocated?
- 4. What are the formal and informal mechanisms for communication?
- 5. How does consensus-building occur?
- 6. What leadership styles predominate?

Once a better understanding of the operation of the existing system is gained, options for change can be considered. Mechanisms for changing systems often include: (1) modifying goals, (2) changing the rules and (3) altering feedback mechanisms.

**1. Modifying goals**. Before making decisions about changing goals, those pursuing a systems change approach require significant input from a variety of stakeholders. It is helpful to acknowledge upfront

that some goals will conflict with others, and that new goals may need to be generated.

2. Changing rules. A first step is to identify what rules exist. While formal rules may be easy to identify, informal rules are often more difficult to discern. Thus, identifying existing rules and recommending changes to them can be a complex endeavor.

#### 3. Altering feedback loops.

Systems have both positive and negative feedback loops that provide some balance to the system. Negative feedback loops, which serve to make the system resistant to change, may need to be adjusted if, instead of balancing the system, they are overly restrictive. Positive feedback loops, which may amplify changes in the system, may need to be adjusted in order for the system to operate effectively as it changes.

# Systems change applications in AAC

Though the concepts and processes involved in systems change

may seem far removed from daily AAC-related activities, they have a direct bearing on the effectiveness of AAC interventions. We know that people with complex communication needs, no matter where they live, often face policy, funding, attitudinal, knowledge, and skill barriers at the local, regional and national levels. In fact, the Participation Model,4 which is widely used as a guide to AAC intervention, is designed to help AAC stakeholders identify, assess and remediate barriers to opportunities. Sometimes a systems change approach is needed to remove these barriers.

The systems change process requires significant input from a variety of stakeholders. Even with substantial participation and opportunities for input, stakeholders frequently undergo an adjustment process during the transition to a new system. Reactions may include shock, denial, depression and anger, as well as perseverance and hope.

influence the ways in which private practitioners provide AAC services. For example, families may hire a provider to "fix things" that don't seem to be getting fixed by a school-based therapist. Administrators may hire a private practitioner to act as the outside expert to appease staff or family members. Intervention teams may perceive private practitioners as competition for service dollars. In any case, private practitioners who work in the area of AAC may face acrimony and confusion about their role in the intervention process.

Because attitudes and funding issues directly affect service delivery in AAC, private practitioners

### Case Example #1

# Facilitating changes in AAC service delivery

#### **Gail van Tatenhove**

There are many kinds of private practices—large and small, general and specialized. My practice is small and specialized. This article is a personal story of how a small, private practice that specializes in AAC assessments and intervention went through a systems change process, and how an adult day-care program in Florida has benefited over the past ten years.

### Economic and attitudinal barriers

Private practitioners face attitudinal and economic barriers to the

delivery of AAC services. They often are dependent on funding agencies that have established policies and payment plans, and they may need to find economical ways to manage the financial realities of their practice. This can mean billing for direct time spent with a client/family, as well as finding ways to cover the costs of other services provided on behalf of clients (e.g., programming devices, developing materials, troubleshooting, training partners, etc.).

Stakeholder attitudes also

Case Example #1, Continued from page 3

must find ways to define their role so they can: (1) benefit the individual with communication difficulties and (2) build consensus and enthusiasm in places and situations where it is often lacking.

This article illustrates the outcomes of an ongoing and successful AAC intervention program that was designed to be cost effective and collaborative. It describes a unique approach that utilizes individuals who rely on AAC as key participants in the AAC intervention process.

#### **Quest North**

Quest North is a work-training program in Central Florida. It serves approximately 80 clients a year with a range of disabilities. Funding for AAC services comes from United Way dollars. In 1990, I agreed to provide AAC services to five individuals at Quest North. All had high-tech AAC devices (Touch Talkers or Light Talkers), but no one had received consistent speechlanguage pathology services.

Problems at Quest North included: (1) devices not being maintained and cleaned; (2) mountings and switches not checked; (3) individuals not using their devices at work, home or in the community; (4) devices used only during "therapy" times, which rarely occurred; (5) limited, activity-based language programmed in the devices; (6) individuals not knowing the vocabulary in their devices; and (7) negative attitudes about AAC devices.

Administrators at Quest North agreed that the current service system wasn't working. Together we established four goals to improve it: (1) to provide consistent AAC services; (2) to improve client's communication skills with AAC



devices; (3) to improve staff support for communication and participation in activities; and (4) to provide basic technical support and maintenance for AAC devices.

Goal #1. Providing consistent AAC services. The administration committed financial resources for speech-language pathology (SLP) treatment and consultation services one day per week (7 hours). In addition, they provided resources for an individual who used AAC to conduct peer-to-peer lessons and act as a role model three mornings per week. This individual was paid an hourly rate plus transportation costs. On-site staff provided supervision.

As the SLP, my responsibilities included defining, in detail, the peer coach job, hiring the individual and providing ongoing training and support. I identified two primary job responsibilities for the peer coach: (1) conducting vocabulary training sessions, either 1:1 or in groups and (2) acting as an advocate for the five clients who used AAC devices for daily communication.

Selecting and training peer coaches. Beginning a peer-coaching program means first selecting and

training the right person. Peer coaches should be competent in their use of an AAC system, know about AAC devices, and have good interaction and pragmatic skills. They should communicate using relatively good syntax and grammar, be able to generate language word-by-word, construct sentences and know important strategies to organize vocabulary (e.g., Minspeak, page/location, word prediction). A job description for a peer coach might include:

- (a) Understanding the basic operation and vocabulary organization of clients' AAC devices;
- (b) Having a sufficient rate of communication (*i.e.*, initially hire someone who is a direct selector);
- (c) Being able to produce hard copy from the device or from a computer;
- (d) Having sufficient motor skills to manage materials, e.g., flip pages in workbooks (modified with page protectors, foam separators);
- (e) Having consistent and reliable independent mobility;
- (f) Having a consistent health and attendance record;
- (g) Being able to maintain timelines and schedules.



#### Table I. Tips for training peer coaches in AAC (Gail vanTatenhove)

- 1. Ask the individual to reflect on any previous coaching he or she may have received and to discuss the positive and negative aspects of these experiences.
- 7. Preprogram sentences into the peer coaches's device so he or she can easily provide feedback during coaching sessions, *e.g.*, "You have the right picture, but the wrong part of speech."
- 2. Use role-playing. Have the peer coach take on both roles (coach and trainee).
- 8. Teach peer coaches how to help clients use a device for daily communication.
- 3. Use videotaping during training sessions, review tapes together and discuss ways to improve coaching strategies.
- 9. Teach peer coaches how to provide technical support and maintenance for AAC devices.
- 4. Train peer coaches to recognize: (1) when opportunities to talk are missed; (2) if no opportunities were given and (3) when opportunities were not taken.
- 10. Show peer coaches how to teach clients to (a) inform communication partners about what to expect and (b) ask communication partners to wait while they prepare a message.
- 5. Show peer coaches how to promote opportunities to increase interactions.
- 11. Show peer coaches how to provide a hierarchy of prompts.
- 6. Teach peer coaches how to help clients learn to operate a device.
- 12. Support the peer coach in modifying the communication behaviors of staff.

Being an interaction coach is very difficult, even for typical speakers, because it requires a deep knowledge of each individual's available vocabulary, as well as an understanding of the communication process. Therefore, it is important to realize that training peer coaches is an ongoing process. Over the years I have found several strategies to be useful. These are listed in Table I and include the use of (1) modeling, (2) role-playing, (3) direct teaching about equipment and (4) mentoring about how to provide feedback and facilitate interactions.

facilitate interactions.

Goal #2. Improving communication skills using AAC devices.

Improving the communication skills of the clients at Quest North required two major changes:

- 1. Revamping AAC devices. No real improvements could occur until activity-based vocabulary was replaced with a solid, core vocabulary, so that individuals could generate language independently.
- 2. Structuring peer-teaching lessons. I provided the peer trainer with specific lessons. These included:
- a. *Vocabulary Training*. Many clients used devices with MinSpeak. I set up vocabulary-training routines that

required each individual to rehearse one or two key words to reach automaticity. For example, if the key word was *get*, rehearsal sentences might include *get away from that, get me up, get some for me, I don't get it.* If the word was *me*, rehearsal phrases might include 20 phrases with *for me* and 20 phrases with *to me* 

b. Conversational scripting. Creating scripts capitalized on the "teachable moment" and provided for success. The peer coach and I wrote "scripts" using a computer template with sentences and icon sequences. For example, instead of saying Halloween, the individual was taught to use phrases, such as It is Halloween. We are having a party. We are having pizza on Halloween. Jan is buying it. Are you coming?

The scripts were slipped into a plastic folder and placed somewhere accessible. The peer coach then reviewed the scripts and initiated situations to practice them.

- c. Structured "fun" things. We modified board games, card games, etc. in ways that were age appropriate, adaptable and provided teaching and rehearsal opportunities.
- d. Brainstorming and generalization activities. The peer coach met with the group on a regular basis. During these meetings, the coach helped individuals brainstorm ways to say and use target vocabulary. These meetings encouraged group and individual responsibility for learning targeted vocabulary.

e. AACell. The AACell was formed as a company. Each individual signed a contract prior to joining the company. The contract included guarantees about providing outside peer coaching, moneymaking opportunities and the potential to participate in the PRC Ambassador program and present at conferences and local meetings. The group worked to change attitudes about learning to communicate more effectively, and showed members that becoming a more competent communicator could result in real monetary value.

f. *The "Talker Club."* The club began with five individuals from Quest North. It is now called *MaxSpeakers* and has 47 members from five counties. Members are given responsibilities, such as writing newsletters or chairing meetings. All club activities require the use of communication skills.

Goal #3. Improving staff support for communication and participation in activities. Staff who work at Ouest North are like staff who work in other Adult Day Programs. Most receive low pay, get little recognition and have minimal AAC training. Not surprisingly, they are often transient workers. Several strategies were used to increase staff support for the communication efforts of individuals who use AAC devices at Quest North. However, the major responsibility for changing attitudes and behaviors was assigned to the peer coach.

Three mornings a week the peer coach worked directly with staff to mold a more positive attitude toward AAC device use. During that time, the coach used an AAC device and did some direct teaching. While chatting with staff, the coach demonstrated that there is more to communication than expressing wants or needs. This was in direct response to staff comments, such as "I know what he/she wants, so I don't see value in AAC device use."

Case Example #1, Continued from page 6

In addition, the coach monitored whether individuals had access to their AAC devices and how often they were using them to communicate. For example, the coach might ask a staff member, "Where is John's device? Why isn't it on his chair?" It was hard for staff to make excuses when someone using an AAC device was asking these questions.

Most importantly, the coach reinforced staff when someone offered a client choices or encouraged a client to use a device. The coach would routinely thank staff for "waiting" and for "being patient" during interactions with someone using an AAC device.

Another approach to improving staff support was the yearly AAC training agenda at Quest North. Training was simple and interspersed throughout the year. The speech-language pathologist funded a monthly AAC prize for the staff member whom the clients voted as "most deserving of the month." Prizes included certificates for a meal at a local restaurant and a cleaning lady for a half-day.

# Goal #4. Providing basic technical support and maintenance for AAC devices.

Staff at Quest North were initially intimidated by the technical support and maintenance required for AAC devices. A booklet was created, called "Take Care of Technology," which contained all the records on each device being used at Quest North. Key staff members were taught how to call manufacturers for support, box up devices to be returned for repairs, and record the outcomes in the booklet. Charging and cleaning devices were assigned to reliable staff members, with

monitoring by the peer mentor or the individuals using AAC. Finally, the therapy room were organized and labeled to help people easily find chargers, keyguards, cables and papers describing technical operations.

#### **Outcomes at Quest North**

More than a decade later, communication is a non-negotiable right at Quest North. There are nine people with high-tech AAC devices who use them every day. Each device has a robust core vocabulary; and each person has reached a high level of communicative competence. Devices are consistently maintained.

Today, everyone involved at Quest North is enthusiastic about the use of AAC. In addition to their personal AAC devices, clients can now access simple digitized speech devices placed throughout the facility to enhance everyday living. For example, a BigMac<sup>5</sup> is posted outside the lavatory so people can call for an assistant using language; a One-Step device<sup>6</sup> is placed on the side of the vending machine to request help in purchasing something; and so on.

AACell members work in the community as paid coaches, volunteer coaches and PRC Ambassadors. Everyone has presented a paper at a USSAAC or ATIA conference. One person works part time at a local school and two make support materials for local SLPs. Another outcome of the past decade is the product *Stepping Through Unity*, based on the Quest North peertraining program.

#### **Summary**

In 1990, we started with one peer coach and five individuals who had (but weren't using) AAC devices. Now, 12 years later, we have five peer coaches. Some work in adult day programs; others work in local schools. These individuals also have a small cottage industry making AAC materials.

A private practice in AAC offers the flexibility to initiate innovative programs and serve clients in a variety of settings (*e.g.*, schools, workshops). This, in turn, enables private practitioners to use resources from one setting to serve AAC needs in another setting (*e.g.*, making materials for school clinicians). Since many individuals who rely on AAC do so over their lifetimes, this service delivery approach can provide continuity and make transitions easier.

#### Recommendations

Before starting a similar program, I would advise practitioners in private practice to do the following:
(1) Seek full administrative support;
(2) Start small and simple; (3)
Prepare a budget; (4) Build relationships with key staff; (5) Expand your vision of what is possible and (6) Be prepared to work more BEFORE you work less.

I recommend that AAC practitioners consider hiring adults using AAC devices to provide direct services under the supervision of a speech-language pathologist or other licensed professional. These supportive services may include making materials using computer software such as Boardmaker <sup>8</sup> and/or Microsoft Word. In addition, I recommend we collectively begin to advocate for using the paid services of individuals who rely on AAC in schools, clinics and hospitals.



### Case Example #2

# AAC systems change in higher education Carole Zangari & Gloria Soto

Integrating augmentative and alternative communication (AAC) coursework and practicum experiences into personnel preparation programs in speech-language pathology, special education, rehabilitation engineering, occupational therapy and other healthrelated disciplines is critical to the long-term success of AAC as a field. Without adequately trained professionals, future generations of individuals with AAC needs will not have access to the expertise and resources needed to develop communicative competence, participate fully in their families and communities and determine the direction of their lives.

Current issues in personnel preparation programs include: (1) development of coursework in AAC, (2) development of competence in AAC evaluation and intervention approaches, and (3) experience with AAC tools and technologies. In most cases, addressing these issues in our colleges and universities requires a systems change approach.

#### Making the case

Building a case for including AAC in university programs is generally done through a process of negotiation. Change agents build their case by accumulating information (supportive data) that constituent groups will find meaningful and persuasive. For example, a department chair is likely to respond to changes made in the requirements of

accreditation bodies. On the other hand, a faculty member who is teaching a course in a particular content area, such as adult motor

speech disorders, may respond to information that shows the need to include content on AAC (e.g., percent of people with ALS who develop severe dysarthria). Finally, a clinic director may react to demographic data showing the large percentage of new graduates who are likely to serve clients with AAC needs in their work settings.

#### **Building capacity**

Another important aspect of AAC systems change in university settings is to build capacity. Establishing partnerships and coalitions between university and community-based entities, and then utilizing these allies in a mutually beneficial fashion, is a strategy that can support systems change.

For example, a university program with few AAC technology resources may find an ally in a regional/state assistive technology (AT) project. Sharing equipment may be advantageous to both parties. The AT project may need to expand the availability of its technology to members of the community; and university students may need to complete projects using AT equipment. In another example, a support coordinator, whose job it is to assist individuals with disabilities to access needed services, may be a good ally for a university clinic director looking to increase public awareness of service availability and to extend the university's outreach in the community.

Expanding capacity often requires collaboration, and taps the ability of university professors to

delegate tasks, redefine lines of authority and empower other stakeholders. Identifying one's allies and working together to find ways to meet everyone's needs can build the university's AAC program, as well as develop 'win-win' partnerships with colleagues in the community.

#### **Thinking smart**

University programs with limited resources can develop their AAC programs through activities that fulfill more than one programmatic need. For example, by modifying course requirements, AAC elective courses can be offered for both university and continuing education credits. Also, AAC equipment from a university clinic can be used in coursework to help future professionals develop competencies in AT applications.

Professional preparation programs can also promote long-term changes when professors model systems change and advocacy approaches and encourage students to become "systems thinkers." Faculty can structure opportunities for students to see the complexities of AAC users' lives. They can help students build professional relationships with AAC users, and support them when they encounter barriers. They can also guide students through the process of identifying problems and coming up with appropriate solutions. Having learned about and observed advocacy in action, future professionals will be better prepared throughout their careers to assist the individuals they serve.

# Case Example #3

# An AAC-based program for children with autism

#### Joanne M. Cafiero

The Frederick County public school district is a fast-growing rural and growing suburban school district in Maryland that serves 39,000 children. Of these, 4,400 are enrolled in special education programs and 200 have a diagnosis of autism spectrum disorder (ASD). In 1997, no specific program for children with ASD existed within the school district. Most of these children were enrolled in either communication classrooms in a Special Education Center (not specifically designed for children with autism) or in their local school, with supportive services. Some were kept at home or attended private schools.

There was general agreement among administrators, staff and families that everyone would benefit from a district-wide systems change approach to ASD services. District personnel had noticed an increase in the number of children with ASD; and parents were demanding intensive intervention approaches (particularly Discrete Trial Training). During 1997-98, parents, administrators, teachers, occupational therapists, speech-language pathologists, early intervention specialists and a university consultant began a series of monthly forums that lasted for the next eighteen months. The purpose of these meetings was to develop a research-based program, with an emphasis on providing communication options in a systematic manner to students with ASD.

The process resulted in the Challenges Program.

As the university consultant, I played

several roles in this systems change process, which included providing training to staff and families, helping stakeholders identify key components of an exemplary program, conducting literature searches, presenting research at the monthly forums and serving as a general resource for parents who had questions about various intervention methodologies. I also provided mentoring to teachers to ensure they received the supports they needed to insure their job satisfaction. Teacher dissatisfaction creates turnover and wastes existing resources. Almost simultaneously, I was serving on the National Academy of Sciences taskforce on Autism.9 The taskforce identified elements of effective programming for children with ASD. These elements were incorporated into the Challenges Program: (a) early entry; (b) ongoing teacher training; (c) parent involvement; (d) typical peers; (e) focus on communication; (f) systematic, planned instruction focusing on engagement; (g) outcomes-based interventions and (h) data collection and analysis.

# Components of the Challenges program

The Challenges (CH) Program now has four classrooms and an outreach component. Originally, however, there was only one Challenges classroom.

#### Challenges I

The first Challenges classroom opened in 1998 to serve five preschool children (ages three to six years) with ASD. Staff included a teacher and two full-time and one half-time assistants, plus part-time

#### **Reflections of an SLP**

After practicing for 25 years in eight different states, this is the best program I have ever worked in. It is research-based, using best practices. The assumption is that communication is a key element to the program and is built into the program. My role as a speech-language pathologist is to facilitate, adjust and fine tune, because the communication supports are already built in. I can do higher level communication interventions because the environment is already engineered for communication.

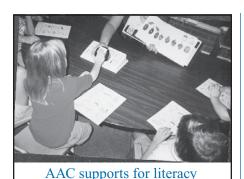
Mary Ann Moses, M.S. CCC/SLP

services from a speech-language pathologist, occupational therapist, psychologist and physical therapist. While recognizing the need for a high ratio of staff-to-students, we did not want to create an overdependence on one-on-one supports, so staff made adapted materials and collected data, as well as supported students. Today, the CH I (preschool) classroom serves six students with ASD.

The CH I classroom, like all CH classrooms, is engineered for communication. Children have activity centers with interactive language boards so that they can fully participate in each activity. Teachers post schedules and make visual supports accessible for everyday activities and for transitions between activities. For example, during Morning Circle time, children use the graphic symbols in their books to express the day, month, year, weather, what they are wearing and so on.

Teachers post behavioral expectations using pictures and symbols. In addition, they engineer typical play activities with visual symbols and AAC devices. Teachers also use visual token systems and visual negotiation tools such as "first do this, then you can do that."





#### **Challenges II**

The Challenges II classroom emerged as a natural extension of CH I. Parents requested a continuation of CH I because they believed that the state-of-the-art program, which children received in the early intervention class, could be duplicated at the elementary school level only in a similar program. The class, for children from ages 7 to 10, began in 2000.

Children enrolled in CH II classrooms come from their local schools, full inclusion preschools and the CH I classroom. Goals are to offer an intense level of communication training and academic support, as well as inclusion experiences. The general education curriculum is adapted with visual supports, photographs and tangible symbols. Today the two CH II classrooms each have at least two computers with Boardmaker<sup>8</sup> and Writing with Symbols 10 software, IntelliTools<sup>11</sup> and a variety of AAC devices.

Literacy is a primary focus in all CH classrooms. Maintaining a home-school journal is one of the daily activities. Children select an icon representing an event or activity each day and craft a sentence on the computer. As a result of this daily journaling, many students have demonstrated gains in functional literacy skills.

Typical peers join the children with ASD for play, free time and selected academics. In addition,

every environment in the school is marked with visual symbols so that children can find their destinations by matching a transition card to the symbols outside the classrooms.

#### **Challenges III**

Challenges III is designed for middle school students, ages 10 to 13. It opened in 2002; and, like other Challenges classrooms, CH III is engineered for communication. Teachers use visual supports (e.g., communication boards for cooking, physical education, music and community outings), visual activity schedules and visual prompts to enable self-cueing. These supports provide a means for students to participate independently in activities. In addition, CH III staff adapt curriculum and use digital photographs to support students in learning new tasks. As in CH I and II classrooms, the development of literacy skills is seen as an essential and integral part of the program. In fact, students are often seen quietly pointing to visual symbols while reading and turning the pages of an adapted book.

#### **Outreach program**

To promote change in the way our district serves children with ASD in other settings, Challenges staff are available to all district children with ASD, including those who do not attend one of the Challenges classrooms. Any staff member who works with a child with ASD or family member can request individual support at any time. The ASD consultant, assistive technology specialist and other support specialists go to local schools to provide training, mentoring and monitoring of student(s) on an "as needed" basis.

#### Staff development

Staff development is a valued and supported component of the Chal-

#### Table II. Checklists for Challenges Teachers (Joanne Cafiero)

**Engineered** environment checklist

Helps teachers monitor how they set up their classrooms

**Incidental** teaching using **AAC** checklist

Helps teachers, aides and clinicians monitor how well they stimulate language in a natural, minimal prompt way.

**Prompting** inventory checklist

Lists various types and levels of prompting to encourage staff to diminish students' dependence on adult prompts.

AAC vocabulary checklist

Helps teachers design aided language communication boards to enable staff to model the use of visual symbols for communication.

**Observational** checklist of preferred reinforcers

Helps teachers identify what motivates each child.

objectives checklist

Communication Helps teachers to write meaningful, measurable IEP objectives.

lenges program. Staff receives onthe-spot and in-service training throughout the school year. There is a system-wide, two-day autism cadre training each year. There is also an intense 40-hour Challenges only training program in the summer. Staff set yearly goals and assess their progress toward these goals. In addition, teachers routinely use a series of checklists as guidelines. These checklists (see Table II) support teachers, while providing them with the autonomy and freedom to manage their classrooms.

Another option for professional staff is a course on Assistive Technology for Students with Autism Spectrum Disorders offered by Johns Hopkins University. This course is a requirement for a master's level graduate certificate called Teaching Students with Autism. The certificate requires completion of a total of four courses (15 credit hours).

Because parents and staff understand that turnover is detrimental to any program, Frederick County

Case Example #3, Cont. from page 11

School District nurtures and supports its staff. Administrators understand that a big part of retaining good teachers is treating them as professionals. Staff members participate in the ongoing research that enhances the CH program and co-author articles. They are encouraged to present at national and international conferences.

#### Parent involvement.

Parents participate as active members of the Challenges Program. School personnel not only value their input, but they also recognize that without parent support, the program could be diverted and distracted by parents wanting the "latest trend" in autism practice.

Parent-school communication is maintained using daily home-to-school communication notebooks, student home-school journals, open visitation in observation rooms with one-way mirrors, parent participation at CH planning meetings and parent-teacher conferences.

#### **Accountability**

The Challenges Program is databased and decisions are made accordingly. Several standardized measures are used, including the Vineland Adaptive Behavior Scale, Leiter International Performance Scale-Revised, Brigance and Gilliam Autism Rating Scale. Staff participate in ongoing research to investigate questions that relate directly to the program, such as:

- 1. What are the effects of interactive language boards on the initiations and responses of preschoolers with autism?
- 2. What are the effects of AAC adaptations on the engagement time of children with ASD during Morning Circle?
- 3. What is the impact of a balanced

#### One parent's thoughts...

The Challenges program in Frederick County has been amazingly beneficial for my son, who is a 10-year-old with autism. His language and communication skills have exploded during his years with Challenges; and he continues to make strong academic progress.

As a special education teacher, I know what it takes to put together and implement a cutting-edge program for children with such unique learning needs. Frederick County has made a solid commitment to meet those unique needs, and continues to improve on the programs week by week. My son can't wait to go to school; and he does not struggle behaviorally in school. His successes tell me that the Challenges staff is doing everything right."

Rose Kraft, Special Education teacher; Former chapter president, ASA; parent of 10year-old boy with autism.

literacy program on the communicative interactions of children with ASD and their caregivers?

4. What are the effects of pictures cues, word cues and picture-plus-word cues on the intelligibility of the utterances of children with ASD?

Each year staff prepares a report for the Board of Education that includes outcomes data, pre- and post-testing information and the results of research studies. The Director of Special Education also presents the successes of the children, conference presentations and parent testimonials to the Board.

Data collected throughout the year supports a positive feedback loop. Staff and family members can approach the IEP process more scientifically. Administrators can use these data to keep the Board of Education aware of the program and to support funding requests.

#### **Outcomes**

Four years ago, the Frederick School District introduced the Challenges Program to support the education and communication of five children with ASD. Today, there are four self-contained classrooms: one at the preschool level (CH I), two at the primary level (CH II) and one at the middle school level (CH III), serving 25 children with ASD. In addition, CH program staff provides support and training for personnel working with other children with ASD in the district. Because of the CH outreach, many children with ASD are now being served in their home school or regional pre-schools, rather than in Challenges classrooms.

Another outcome is the 40-hour summer program for new staff, SLPs, assistants, OTs, PTs and transportation workers. Hundreds of people have attended this training on AAC and Autism. In addition, six staff members have now received their graduate certificates from Johns Hopkins University on *Teaching Students with Autism*. This was made possible with support from the State of Maryland.

In summary, before 1999, many children with ASD were not being served in the district. Today, the Challenges Program offers children with ASD an intensive communication and academic program that is data-based and represents best practices.

Outcomes are positive for children, staff, families and the school district. Children are being served better, in a more cost effective manner. They are making progress and enjoying school. Staff are building skills that benefit their students and advance their careers. Parents are more secure knowing that their children are receiving state-of-the-art programming. Administrators are proud to have an exemplary program that is meeting the needs of children with ASD more effectively and efficiently.



### Case Example #4

# Promoting AAC systems change in Thailand and Canada Penny Parnes

This article documents my personal experiences over the past few decades with changing governmentrelated systems in two countries— Canada and Thailand. During the 1980s I was involved in a grassroots AAC systems change effort in Canada. More recently, in Thailand, I have been participating in a topdown AAC systems change approach involving government officials and the royal family. In both countries, the health-care and educational systems have undergone significant changes. New laws and shifts in public policy have enabled many more (but still not all) individuals with severe communication impairments to access the services and equipment they need to communicate effectively.

In the early 1980s, when I was working as a clinician in Ontario, I personally witnessed momentous changes and improvements in the lives of people who participated in AAC interventions. At the same time, I realized that AAC services and technologies were not yet available to large numbers of people. Very simply, it seemed unacceptable that individuals who might benefit from AAC services and devices were unable to access them.

I have learned that trying to create opportunities for individuals who use AAC requires both a strong grassroots effort and a committed top-down approach. Ultimately, existing laws have to be altered and

new laws created. Public policy and funding streams have to be changed; and society has to acknowledge and

honor the rights and needs of people with severe communication impairments. I always knew my daily work as an AAC professional had to include an effort to influence clinical practice and public policy.

#### **Grassroots approach**

At the center of the effort to change the system in Ontario were the clients and families who fought for their rights to access AAC services and technologies. In addition, there were ever-expanding circles of people (*i.e.*, clinicians from a myriad of disciplines, teachers, device developers and manufacturers) who worked tirelessly as advocates to make societal change possible. While I cannot fully reconstruct this process, some of the factors I recall are described below.

Everyone did his or her part. Personally, I took on larger and larger administrative roles in my agency and in my province, in order to gain a higher level of influence in the system. I tried to work "from the inside" to create change for people who used AAC and those who could benefit from AAC. For example, I became vice president of my agency (a major rehabilitation facility), chaired numerous committees and even, for a time, worked part-time for the government agency that funds AAC devices in Ontario.

Through these experiences, I soon realized that we would have to change the law and influence public policy to ensure the rights and entitlements of people who use AAC, and to sustain and advance the field. The results we saw in Ontario during the 1980s were

dramatic and obviously successful, because today AAC is an acknowledged part of the health and education systems in Ontario, Canada.

However, many people in Ontario who require AAC still do not have access to what they need. We have a shortage of clinicians and a shortage of training. We have many remote areas where services are not yet available. These issues are the next steps in Ontario.

Will the system move forward to address these issues? Not without continuing influence and unrelenting pressure at all levels. Today's governmental priorities are to reduce spending and not to expand programs. While the focus of the 1990s was on family- and consumer-centered service and on listening to consumers, our current governments seem to be headed in a different direction.

Fortunately, laws exist, public policies are in place and some service delivery systems are operational. Even so, without ongoing advocacy on the part of individuals who use AAC, family members and the professional community, we could easily lose ground.

#### Top-down approach

In 1991, the government of Thailand passed the Rehabilitation Act, which extended to Thai citizens with disabilities the rights to participate in an appropriate education and to work so they might live a more "normal" life. One of the initiatives resulting from this legislation was the establishment of a committee under the chairmanship of the Royal Princess of Thailand. One objective of this committee was to support the use of information technologies to enhance the quality of life of the "disadvantaged," including persons

Case Example #4, Continued from page 13

with disabilities. The committee included representatives from government agencies, groups representing people with disabilities and non-governmental groups.

While Thailand is a democracy, the royal family is held in very high regard and works tirelessly for the good of the people. The people of Thailand and the Thai government take very seriously any initiatives or requests made by members of the Royal Family. The Princess, Her Royal Highness Princess Maha Chakri Sirindhorn, has had a longstanding interest in information technology and is well known in Thailand for this interest. She loaned her name and her support to this initiative. Her patronage encouraged various groups to work together. She also created interest at a high level within the government. As a result, we have been able to move the agenda for persons with disabilities forward rather quickly over the past five years.

I was approached to help advance the initiative because of my previous involvement in Canada's systems change for persons with disabilities, and because of my work in Asia on the International Centre for the Advancement of Community Based Rehabilitation at Queen's University.

The committee maintained a strong focus on the needs of all disability groups. During the first two years, the committee developed a strategic plan for the country, incorporating the following principles:

- Assistive technologies (AT) and services should be driven by the needs of the population, and the consumers themselves must be involved in all aspects of the development.
- The focus of AT and services must be on functional outcomes rather than disability types or technology types.
- Attention to devices must include attention to support strategies and delivery systems.



- Development in the area of AT must build on the strengths of Thailand itself and should be supported by the culture, religion and infrastructure already available. Thailand is a country that embraces community involvement and family units.
- The system must be flexible and appropriate to the culture. It should include sophisticated, specialized centralized care and grassroots, community-based approaches.

In late 2000, the plan was presented to a large meeting of stakeholders in Bangkok. Since then, the committee has undertaken several additional initiatives:

- 1. The development of a training curriculum for those who deliver services to disabled children, including special education teachers from throughout the country. Using a "train the trainer" concept, the goal is to develop a large cadre of people able to work with persons with disabilities.
- 2. Establishing policies for the delivery of government-funded assistive devices.
- 3. Creating "Centers of Excellence" that are mandated to stay up-to-date on developments of technical devices and to serve as a showcase for the country.
- 4. Fostering a research program to import, modify and support the development of devices appropriate for the needs of the country.

The program has unfolded quickly and is beginning to drive the agenda for persons with disabilities in Thailand. In addition, it is being shared with other countries in the Asian Pacific region as a model for development. In October 2002, a meeting was held in Bangkok with

delegates from Laos, Philippines, Vietnam, Malaysia, and Indonesia. Supported by UNESCO, each country sent one grassroots person and one government person in an attempt to facilitate both bottom-up and top-down approaches to systems change.

#### **Summary**

Ontario, Canada and Thailand now have systems in place that support persons who use AAC. In Ontario, this initiative occurred because of a bottom-up approach, but is maintained today with support from the top. In Thailand, change began predominately as a result of a top-down approach. To be successful, however, the grassroots must implement it.

Systems can be influenced and changed from both levels. We need programs that can demonstrate the impact of what AAC can do; and we need to influence and sustain the commitment of governments and policy setters to move systems quickly forward and ensure they will outlast any of us as individuals. Only when we are relentless in these efforts can we be assured that people who rely on AAC will gain access to their rights to communication and participation in our societies.





Technology transfer" refers to a wide-range of activities and processes including: (1) conceiving of a new application for an existing technology, (2) converting research into technical and economic development, (3) licensing intellectual property to a manufacturer for production in a product, (4) reducing an idea to practice in a prototype and (5) recording technological concepts in a professional paper or patent application. According to the Rehabilitation Engineering Research Center on Technology Transfer (T2RERC), the tech transfer process is a substantial undertaking that incorporates all of these elements. 12

An example of tech transfer in the AAC area is the transfer of DECTalk software to AAC devices. This occurred when Digital Equipment Corporation agreed to license DECTalk to AAC manufacturers in the early 1990s. The transfer of this particular mainstream technology quickly revolutionized the intelligibility of speech output devices and has improved the lives of many thousands of people. <sup>13</sup>

The technology transfer process can involve legal contracts and formal agreements or can occur quite informally. It can also be facilitated. One example of a process designed to stimulate tech transfer is called "Demand-Pull." Within the AAC community, this process was undertaken during 2000-2001 by the T2RERC in collaboration with the AAC-RERC. The goal was to transfer emerging technologies from mainstream manufacturers and advanced tech-

nology laboratories to assistive technology manufacturers. 12

Technology transfer is not specific to assistive technology. For example, the pharmaceutical, automobile, computer and agricultural industries depend heavily on research and development (R&D) to produce new technologies for the mainstream marketplace. Their future solvency and the growth of their companies depend upon successful technology transfer. Major companies fund R&D projects internally; and many also support researchers at private companies and within universities.

In the world of assistive technology, resources are fewer and markets are much smaller. AAC manufacturers, for example, do not typically support research programs at universities, nor do they have leading AAC researchers on their payrolls. Nevertheless, AAC companies have managed over the years to update AAC technologies; and to offer newer and better products to individuals with complex communication needs.

Product designs and developments in AAC are often based on the experiences of engineers and clinicians who participate in the development of these products, rather than on the results of AAC research. Thus, today's product designs tend to reflect the AAC manufacturers' relationships with clinical and consumer communities, rather than current technolgy-related research results.

# AAC-RERC technology transfer approaches

The National Institute for Disability and Rehabilitation Research (NIDRR), which funds the AAC-RERC, requires that technology transfer occur within each of the 15 Rehabilitation Research and Engi-

neering Centers (RERCs). NIDRR expects some of the R&D work they fund to be incorporated into commercially available assistive technology (AT) products. The AAC-RERC priorities were set prior to the five-year funding cycle by NIDRR, not by the AAC manufacturing community or the AAC-RERC.

Over the past four years, the partners have made an effort to establish close relationships with many AAC companies. The nature of these relationships ranges from full partnerships in the development of a product, to information sharing about technology, to information transfer about the needs and abilities of individuals who rely on AAC that may affect the way the field views technology. Some AAC-RERC technology transfer relationships are described below.

1. Early, ongoing relationship with manufacturer. In one scenario, an AAC-RERC partner and a manufacturer form a partnership at the beginning of a project. The researcher conducts research, then both partners shape that research into a product or product features. One example is the ongoing collaboration between the University of New York at Buffalo and Enkidu, Inc. They have developed automated data-logging tools, including a standard logfile format and a program for analyzing logfile data (ACQUA). Enkidu and Saltillo products now include data-logging software and logfile specifications. The analysis software is also available to the manufacturers of other AAC devices.

In another project, the AAC-RERC partner at the University of New York at Buffalo, Enkidu engineers and experts from other universities and research centers are

AAC-RERC, Continued from page 13

collaborating to develop an utterance-based communication device. Collaboration was facilitated, in part, by obtaining Small Business Innovative Research Grants (SBIRs) through the National Institute of Deafness and Other Communication Disorders (NIDCD). Such grants are specifically designed to assist researchers and developers make prototypes and test promising technologies, and are available through most federal granting agencies.

2. Shorter-term relationships with specific manufacturers. In this instance, the AAC-RERC partner develops a prototype or produces design specifications and then actively searches for a partner in the AAC manufacturing community to bring the concept/prototype to market. Typically, researchers approach one company at a time, beginning with the company they feel would be most interested in incorporating the R&D into their product line.

AAC-RERC partners have established this type of relationship with several manufacturers:

- Eye Safe Laser. This product was conceptualized by AAC-RERC partners at the University of Nebraska in collaboration with InvoTek, Inc. This laser is a pointer and has successfully gone through both Phase I and Phase II SBIR processes. It is currently in the hands of an AAC company that plans to manufacture and market it.
- Voice Access System. The voiceactivated access system was developed at the University of Nebraska and InvoTek, Inc. It is in a Phase I SBIR. A prototype is currently being field-tested. The

- AAC-RERC is looking for a manufacturer who will incorporate this system into the next generation of AAC devices.
- AAC menu. The AAC menu is an approach to vocabulary organization. It has been field-tested with several populations and found to be easier to learn, faster and preferred. Researchers at the University of Nebraska are currently looking for a manufacturer to incorporate the AAC menu into future products.
- Head contact microphone. This
  microphone was developed by
  the Navy Seals and later adapted
  for use by firefighters. It can be
  mounted on the head or throat.
  Originally evaluated and modified for use by individuals with
  disabilities by AAC-RERC
  partners at Duke University, the
  microphone is now available
  through Luminaud as an assistive
  technology product.
- 3. General transfer of information designed to impact technology development. AAC-RERC researchers and developers also provide AAC manufacturers with information about technology in the form of design specifications, critiques of existing technology, specific information about vocabulary algorithms, representation and organization of symbols, and so on. In doing so, they hope to impact the field at large and to influence the way people think about AAC technology. Examples include:
- Information about learning to write. AAC-RERC partners at the University of North Carolina-Chapel Hill have an agreement with Don Johnston, Inc. to work collaboratively on this project.
- Information about attitudes regarding AAC device features.

- University of Nebraska researchers have conducted several attitude studies with various population groups and are currently sharing these results.
- Information about employment and AAC. AAC-RERC partners at Penn State University and Temple University have information about features of AAC technology that would be particularly helpful in the workplace. Temple University has identified vocabulary pertinent to the workplace, which is available on their website. Penn State University has conducted several Internet focus groups and sent preliminary information to all AAC manufacturers, offering to share results in more depth upon request.
- Design specifications for cellular phone technology and AAC devices. Temple University and other AAC-RERC partners are making information available about the importance of including cellular phone capability in AAC devices. A few manufacturers (e.g., Dynavox, Inc. and Enkidu, Inc.) now have products that provide this capability.
- Important information about the difficulties that typically developing children encounter learning to use existing AAC devices is being shared with AAC manufacturers. Penn State University partners are following up by testing alternative representational and organizational strategies, and will be sharing these results with AAC manufacturers.
- AAC-RERC partners at Penn State University also have embarked on discussions with an AAC manufacturer about AAC



device features that specifically appeal to young children, based on their research.

#### **Summary**

The AAC-RERC has participated in and initiated many technology transfer activities over the past four years. By establishing early partnerships with manufacturers, and by transferring early prototypes and design specifications to manufacturers, AAC-RERC partners have sought to move specific products and product features to market.

In addition, they have developed intellectual property and made an effort to share it with the AAC community, including manufacturers. All partners have presented information at conferences and written articles for peer-reviewed journals; and most participated in the Demand-Pull Conference mentioned earlier. Finally, the AAC-RERC held a State of the Science Conference in August 2001, which considered what we know and in what directions we should be heading to better meet the technology needs of people who rely on AAC. Articles from that conference are being published in Assistive Technology during 2003.

[Special thanks to David R. Beukelman, Jeffrey Higginbotham and Kevin Caves for contributing to this article.] For additional information about activities within the AAC-RERC go to <a href="www.aac-rerc.com">www.aac-rerc.com</a>

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#### Resources

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