

A Little About Our Collaborators:

Gaby Berlanga Ramirez & Marcela Manzur Camacho, CATIC:

Gabriela Berlanga Ramirez and Marcela Manzur Camacho are speech-language pathologists and the co-founders of CATIC. Gabriela was a recipient of the prestigious Teacher-in-Residence Award at the Bridge School in 2004-05 and holds a degree in Human Communication from the University of the Americas. Marcela also holds a degree in Human Communication from the University of the Americas, with specializations in Speech, Hearing and Assistive Technology. Both contribute to the important work done at the Center for Technological Support for Communication and Learning (CATIC) in Mexico. Separately and jointly, they have presented at major international AAC conferences in Spain, Canada, the United States, Peru and Colombia, and were the organizers of the first two AAC conferences ever held in Mexico.



Dr. Sarah Blackstone, Augmentative Communication, Inc.

Dr. Sarah Blackstone is acknowledged as one of the leading AAC experts in the United States and the world. A Fellow of the International Society for Augmentative and Alternative Communication (ISAAC), a former president of that international organization, and a recipient of a special clinical award from the American Speech, Language and Hearing Association, Dr. Blackstone compiled the first textbook in AAC in the 1980s, and for over 20 years wrote and published the leading newsletter in the field. Dr. Blackstone has also, for the past thirteen years, played a key role in the AAC Rehabilitation Engineering Research Center in the United States, a U.S. government funded project to promote cutting-edge research in AAC. Dr. Blackstone has provided ongoing support, advice and counsel to CATIC since its inception.



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Applying International
AAC Expertise at the
Local Level

Mexico Leads the Way

What is it?

CATIC in Mexico and ACI in the United States have joined hands to create a unique collaboration that is bringing the expertise of leading international experts to bear on the solution of problems of Mexicans with severe communication (and other) disabilities.

Through the use of some of the latest available technologies, staff from Mexico and experts from around the world are able to (1) video record clients in their natural home and school settings, (2) review the videos, (3) confer with each other from their home offices, (4) develop/support action plans for each individual, (5) confer with clients, their family members, their teachers and others, and (6) assess progress and formulate new goals on an ongoing basis.

At the core of the effort are CATIC Co-Director Gabriela Berlanga Ramirez and ACI President Sarah Blackstone. Gabriela identifies and secures commitments from clients and families, while Sarah (a) provides the expertise from her repertoire of skills and knowledge, developed over a long career of leadership in Augmentative and Alternative Communication and/or (b) recruits leading experts (occupational therapists, vision specialists, vendor consultants, *etc.*) in fields outside her area of expertise. These experts then join in video conferences from their base of operations.



How is this project unique?

Teleconferencing is used to provide services to individuals in a growing range of professions (medicine, psychology, executive coaching). But this is the first time a service like this has been offered to help equalize access to high-quality AAC services for people with disabilities anywhere in the world. It's the only disability service that can visually record clients in their natural environments (home or school), send the video recordings to experts around the globe and then provide face-to-face interaction from the office of the local provider. Intermittent observations and consultations over time allow the time and space to provide on-going collaborations with local staff and family members.



Core Objectives

Through the use of some of the newest technologies made available by the Global Education Program of Cisco Systems, as well as the support of Dr. Sarah Blackstone and The Bridge School, Mexican children and young adults with disabilities who use Augmentative and Alternative Communication (AAC) tools can now be observed during school and/or home. These observations are providing information that enable their parents, teachers and therapists to receive consultative advice, mentoring and suggestions from top-level international experts.

The aim of these interventions is to promote greater communicative participation at home, school and in the community for each client, and to assess their needs and strengths from a broader and deeper perspective. The collaboration among families and professionals fosters the ongoing support that each child needs to develop greater communicative, social, and emotional competencies.

Enduring Outcomes

- (1) Growth in staff sophistication and intervention skills
- (2) Increased comprehension of therapeutic objectives and ways to support them on the part of family members
- (3) Introduction of action planning formats for individual students
- (4) Higher expectation levels for participants
- (5) Networking among AAC experts that improves the lives of children and families in Mexico



Indirect Benefits for Children Not Included as Direct Project Beneficiaries

It has already become apparent that benefits to the clients who are the direct recipients of project services are filtering through to other CATIC clients. Other CATIC staff are rapidly adopting new ideas that are working for project participants. Three examples: (1) Efforts to provide the benefits of “upright” walkers for one wheelchair-bound child have created an interest (and demand) for upright walkers from more than 12 CATIC families, (2) Detection of a previously undiagnosed cortical visual impairment in one project child has led to the evaluation, diagnosis, and treatment of several others, and (3) Introduction of sign language to young children who are already using aided AAC is resulting in an increase in language production and use for these children across environments.



Raising Expectations

The CATIC-ACI initiative has produced surprising early results in terms of the increasing ambitiousness of the goals of the clients, their families, and the professionals who serve them. Family members have quickly comprehended that greater achievements are possible – in independent communication, in literacy, in independent mobility, and ultimately, in independent living.

This revolution of rising expectations has swiftly reverberated beyond the participating families, to other CATIC clients and other families in Mexico City, and to other professionals involved with CATIC participants. One example: An effort to experiment with the utility of a hands-free, vertical “walker” for a single client quickly produced requests for a similar opportunity for twelve families, and has already resulted in a marathon six hour virtual consultation from Christine Wright-Ott, a Bridge School occupational therapist and the developer of the KidWalk, for six different children.

“This project is *not* about technology, it’s about equality of access. Leveling the international playing field in AAC will be a long and arduous process, but this is a remarkable step in the right direction.”

Harvey Pressman, President
Central Coast Children’s Foundation



How does it work?

The trajectory of service for each client follows a series of similar steps:

Step 1: CATIC meets with parents and/or school staff to explain the project and get written permission to take videos. Specific situations where support is needed are discussed and prioritized.

Step 2: Teachers, family members and therapists record the child during specific every day activities (as determined in the meeting).

Step 3: Sarah watches the video, multiple times, takes notes, and reviews information about the child.

Step 4: Sarah Blackstone and CATIC therapists meet in a video conference to consider the case and watch the videos together. They then discuss possible action steps, assessment, measures, *etc.*

Step 5: When necessary, Sarah contacts an additional expert from the United States or another country to obtain specialized perspectives.

Step 6: Video conference with Sarah, CATIC’s therapists and international expert (in some cases) to draft a written action plan (translated into Spanish when necessary).

Step 7: Video conference between Sarah and CATIC’s therapists, parents, and/or school staff to discuss and finalize the action plan.

Step 8: Baseline data collected and changes over time are recorded to evaluate changes, improvements and adaptations needed for the action plan.

How did it start?

In January, 2011, Gabriela Berlanga Ramirez and Marcela Manzur Camacho proposed a project to Sarah Blackstone (Augmentative Communication Inc.) and Harvey Pressman (Central Coast Children's Foundation) in which CATIC would offer families an opportunity to access ongoing consultation with Sarah regarding their child's AAC program. Over time, they refined the parameters of the program to include Sarah's option of bringing in additional international experts as needed, and CATIC staff created a brochure to inform parents about this new option. They agreed that CATIC would set the costs and retain a percentage to ensure that families who were interested but unable to afford it, would be able to participate. (ACI donates all consulting fees back to CATIC to support assistance to those families.) They agreed that when issues arose that were beyond the scope of Sarah's expertise, she would enlist support from other professional experts.

Gabriela and Marcela spread the word about this exciting new opportunity to CATIC's existing clients and, by mid-2011, the first participants were ready to begin.



Why is this so significant?

Globally, equality of access to available AAC services and interventions is hugely inadequate. Within developed "first world" countries, availability and quality of AAC interventions varies wildly from city to city, and state to state. People with communication disabilities in many areas often have no access to AAC services, or only occasionally can access minimal or uneven services. Rarely can they access the best the field can offer.

In addition, much recent research demonstrates the importance and the value of interventions that extend beyond the clinical setting to the child's "real world" in school and at home. CATIC has always been in the forefront of such activity in Mexico, joining the broader international trend to supplement in-office interventions with observations and activities in the child's school and home. This crucial kind of support is now being significantly enhanced by sound advice from leading practitioners in AAC and other relevant professionals around the world.

CATIC Strengthening

CATIC has itself been strengthened immeasurably by taking the initiative to launch this International Expert Project. CATIC has quickly built on its growing local reputation to provide the best of "first-world" services in a country where so much of the disabled population still receives "third-world" services.

The ability to leapfrog the quality of comparable local services has also enabled CATIC to solidify its standing as the "go-to" agency for families uneasy with the status quo who feel that local professionals have a limited vision regarding future possibilities for their children. Along with a general strengthening of CATIC staff capabilities and commitment, CATIC also has new opportunities to expand its existing programs and establish new innovative programs.

Special Moments

As with any project that demonstrates the untapped capacities of people with disabilities, a few special moments help to illustrate the broader accomplishments of the daily efforts to open new avenues for children in the project. Some examples: (1) a child with a previously undetected cortical visual impairment (CVI) issues makes his first obvious visual response, and begins to use a vertical walker that enables him to begin to see his world, (2) a little girl surprises her parents at a Mother's Day school celebration by joining in as the class serenades the Moms, using the signs that the staff taught them at the suggestion of an international consultant, (3) a twenty-year old guy with cerebral palsy in Mexico City gets his questions about life and love answered by a 75 year old guy with cerebral palsy in Berkeley, California, through the magic of WebEx communication, (4) that same twenty-year old, when denied his constitutional right to vote in the national election by virtue of his disability, gets the support of his family, and exposure in the media, and wins the right for himself and others to cast their votes.

Benefits to CATIC Staff

CATIC's initiation of the International Expert Project has produced some unexpected benefits for the entire CATIC staff. As clients involved make progress more rapidly and reach milestones previously unexpected, staff motivation, staff skills, and staff belief in the value of AAC interventions seem to rise commensurately. Seeing dramatic results for a few clients helps raise confidence in their capacity to assess clients' needs more comprehensively (e.g., as with previously undetected cortical vision problems) and to respond to these needs more robustly. CATIC's staff psychologist has also been able, via the WebEx technology, to become a vital part of a new and separate research project initiated by Dr. Blackstone, involving researchers from the University of North Carolina and Penn State University. This project is creating a new tool for assessing emotional competence for children with complex communication needs. It is being translated by CATIC staff and field-tested in Mexico City as well as in the U.S.



Project Impacts

The project's impacts have spread beyond the individuals served to other CATIC staff and their clients and to the parents of children involved. Gaby has been surprised and gratified to see Sarah's impact on family members as well as their offspring, helping, for example, to elevate the parents' appreciation of the importance of communication skills beyond the immediate home environment and resulting in the parents themselves spending more time stimulating communication skills. Gaby believes that Sarah's ability to win over the parent's trust so quickly comes not just from her experience and international reputation, but also from Sarah's ability to communicate a genuine sense of caring through the face-to-face contact made possible via the virtual connection.

Who are the other experts?

Leading professionals with needed supplementary skills are recruited as the need arises. Two early examples involve a young boy who was identified as possibly having Cortical Visual Impairment (CVI) and a little girl who is a candidate for a vertical, hands-free mobility intervention.

One of the world's leading pioneers in CVI, Christine Roman-Lanzky, accepted the intriguing challenge of providing long distance tele-support to CATIC staff and the family of the young boy in question. From her base in Pennsylvania, she evaluated videos, consulted with Sarah and Gabriela, virtually "met" the client and his family, and suggested a series of new interventions and equipment to help support the boy.

The little girl was fortunate to receive supplementary support from Christine Wright-Ott, an occupational therapist who consults with The Bridge School and is the inventor/developer of a "hands-free" walker for children with limited independent mobility. This walker is currently used extensively for both classroom and recreational purposes at The Bridge School.

Who are the collaborators?

In launching this bold new experiment, CATIC and ACI have had the good fortune to have three valuable collaborating entities, each bringing different resources to the table:

(1) The Bridge School, which has provided support in enlisting additional sources of help and just-in-time technological troubleshooting,

(2) CISCO Systems, which has donated the Flip cameras used in the homes and schools and provided its advanced WebEx web conferencing system to all participants, and

(3) The Central Coast Children's Foundation has helped crystallize the original concept and continued to provide ongoing public information services, technical support, and resources directly to CATIC.



Reaching Out to Low-Income Clients

In their initial planning, Gaby and Sarah decided to create “scholarship” funds out of what would ordinarily be paid as consultant fees to Sarah, for low-income individuals from Mexico City who might otherwise be unable to afford the services of CATIC’s international experts project. That idea has now morphed into a plan to provide outreach support to a non-profit agency serving poor children with disabilities in a small city fifty miles to the northwest of Mexico City. The new plan will extend the project’s benefits to a whole group of underprivileged people who would otherwise have no opportunity for this kind of support.



The Value of Video

The use of Flip video cameras to record project participants in their natural family and community settings has proved crucially important to the project’s success. The video recordings: (1) enable international consultants to observe clients in a way never before possible, (2) enable CATIC staff to get a more comprehensive picture of clients’ needs and skills, (3) form the basis of informed consultations among international consultants, CATIC staff and CATIC clients, and (4) promote additional “buy in” for family members, in terms of supporting greater independent communication within the home setting and a stronger commitment to therapy goals. Video also provides a window for all CATIC staff into a broader way to assess clients’ needs and capacities.

Why does it work so well?

CATIC and ACI staff members have been pleasantly surprised by the initial impacts on project participants. Children are recording steady (and, in some cases, remarkable) progress on specific achievement goals, which are being carefully monitored through the use of action plans and periodic assessments and reassessments. Indices of family participation, commitment and enthusiasm are beyond expectations. Professional growth among CATIC staff is being clearly accelerated.

What accounts for these early and surprising progress indicators? Those involved point to a number of possible explanations: (1) The Berlanga – Blackstone “simpatico” connection cannot be minimized as an explanation of how smoothly the project got off the ground and how seamlessly the communication of two professionals with different first languages works, (2) Sarah’s world-wide connections with experts around the globe are probably unparalleled, as a result of both her long-time leadership in the international AAC community and her twenty years as publisher/writer/editor of the leading international newsletter in the field, (3) the new technologies in use are opening up new ways to provide more comprehensive and more continuous interventions over both time and space, (4) participation in this kind of cutting-edge demonstration of new ways to provide world-class services to people with disabilities in underserved areas is energizing to the professionals, the parents and the clients involved (Mexico City, with over 18 million inhabitants, had almost no available AAC resources or services before Gabriela and Marcela initiated CATIC some seven years ago), and (5) family members who see early results understand that this project represents a whole new dimension of opportunity that they never realized was possible.

