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# Upfront

Effective communication is recognized as a priority across the healthcare continuum because it directly affects the quality of patient care, safety, medical outcomes and pa*tient satisfaction.*<sup>1</sup> *Augmentative and* alternative communication (AAC) techniques, strategies and devices can significantly alleviate communication problems and barriers and should be a major component of the arsenal of communication resources available across healthcare settings. While typically designed for people with complex communication needs (CCN), simple communication displays, speech generating devices (SGDs), eve gaze techniques, special call alarms and alphabet boards can help many other communication vulnerable patients reducing medical errors, lessening the length of hospital stays, increasing patient safety and lowering costs.<sup>2,3</sup> Communication barriers in healthcare settings have many causes.

Language issues. Language and cultural differences often underlie communication problems in healthcare settings.<sup>4</sup> For example, many people in the U.S. do not speak English as their primary language. Also, those who are deaf/hard of hearing often have difficulty communicating with healthcare workers. Trained interpreters can help these individuals negotiate the healthcare system.<sup>5,6</sup> AAC strategies and assistive technologies can also help mightily.

<u>Stress, confusion and psychiatric condi-</u> <u>tions</u>. Medically-related situations may trigger emotional responses in patients and/or in providers that make effective



Augmentative **A@N** Communication News

> and efficient communication difficult. AAC strategies, tools and the training needed to use them well can support improved interactions. Increasingly, first responders and emer-

gency personnel depend on AAC tools and strategies to communicate more effectively with some of their patients.<sup>7</sup>

Lack of access to auxiliary aids. People who rely on hearing aids, glasses and/or AAC technologies may not have access to them in health-related situations. As a result, interactions with healthcare providers may be difficult. Simple assistive technologies can augment vision and hearing when glasses and hearing aids are unavailable. Generic low-tech AAC displays, devices and strategies can also help.<sup>8-13</sup>

<u>Medical interventions</u>, Medical interventions (e.g., intubation or a tracheostomy) may result in a temporary loss of speech. In addition, patients may have injuries or conditions that cause

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Clinical News

# Communication access across the healthcare continuum

Can you imagine nurses and other healthcare providers routinely using simple AAC approaches as a way to support *all* patients who experience communication difficulties? This is beginning to happen. In fact, the train is leaving the station and the AAC community should do more than just sell tickets. It's time to climb aboard.

## Background

Early in the development of the field, the AAC community devel-

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www.patientprovidercommunication. org

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*How AAC teams can benefit from EVIDAAC* 



oped and encouraged the use of AAC devices, aids and strategies. Back then, we focused primarily on school-

aged children and adults with motor impairments (e.g., cerebral palsy and motor neuron disease.) Today, we've expanded our vision and AAC approaches are widely utilized with individuals-across the age span-who have communication challenges secondary to cognitive, language, physical and multiple disabilities. This article suggests we take another step forward and use AAC for anyone who is "communication vulnerable," *i.e.*, struggles to communicate in a particular setting. We can begin this journey in healthcare settings, where

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the need is so urgent.

# **Communication barriers**

Access to effective communication is a critical component of best practice and quality care across the continuum of healthcare.<sup>1-3,14</sup> Healthcare providers often lack the training needed to cope with their patients' communication difficulties. Patients routinely face a wide-range of intrinsic and extrinsic factors that preclude successful interactions with healthcare providers.

Language barriers. Most healthcare providers now serve people who speak multiple languages, including those who rely on sign language. When patients and providers do not speak/understand the same language, communication becomes very difficult.<sup>4-6</sup> AAC strategies can help overcome language barriers.

<u>Cultural barriers</u>. People from different cultural backgrounds do not necessarily share the same knowledge or expectations about healthcare services. One widely discussed barrier is low *health literacy*.<sup>15</sup> Health literacy is "an individual's ability to read, understand

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communication difficulties. Responses to medications can also interfere with communication. AAC approaches may help patients participate actively in their care and interact with family members and healthcare providers.<sup>11-14</sup>

Other key barriers to patientprovider communication involve factors related to healthcare providers. Many do not know how to employ an arsenal of simple AAC tools and strategies when communication "isn't working." Additionally, AAC specialists too rarely think "outside the box" or advocate for the use of AAC as part of the arsenal of tools available to all patients who have *difficulty communicating, across* healthcare settings. This issue of Augmentative Communication News is part of an effort by an ad hoc group to increase awareness of patient-provider communication

and use healthcare information to make decisions and follow instructions for treatment."16 Studies show that people who have low-health literacy include the elderly, minority populations, immigrant populations, low income groups and people with chronic mental and/or physical health

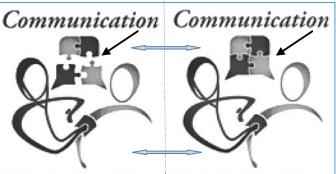
conditions.<sup>17</sup> AAC approaches provide supports that can increase participation and foster understanding for people wiht low health literacy.

<u>Behavioral barriers</u>. People under stress, those with psychiatric conditions, patients on medication and individuals with disabilities that influence cognition (*e.g.*, dementia, autism, severe developmental disabilities) may have difficulty comprehending and following directions. Providers can use AAC strategies, such as augmented input, to increase active and constructive participation.<sup>11,18,19</sup>

<u>Physical barriers.</u> Patients who wear glasses, use hearing aids and/or rely on

issues. Clinical News considers communication barriers and the role of AAC across the healthcare continuum. On the Web introduces a new patient-provider communication website. Equipment highlights communication resources for healthcare settings. Governmental discusses The Joint Commission's proposed standards and University/Research spotlights research. Finally, the EVIDAAC article addresses benefits of the soon-to-belaunched EVIDAAC website. Sarah W. Blackstone, Ph.D. CCC-





Is The Joint Establishment Of Meaning Is The Joint Establishment Of Meaning

Figure 1. Communication process. Go to http://patientprovidercommunication.org for animation

> AAC devices may not have access to these auxiliary aids during a medical emergency or while in the hospital. This can result in crucial communication situations becoming even more difficult.<sup>8-14</sup> In addition, patients who are temporarily unable to produce speech because of medical procedures (*e.g.*, intubation) need consistent access to alternative communication tools and strategies.<sup>12-14</sup>

# Providing communication access

Successful communication requires the joint establishment of meaning.<sup>20</sup> Both the healthcare provider and the patient need to "possess the skills and knowledge required for participation within the communicative interaction."<sup>21</sup> This means that successful interactions are always co-constructed, involving a constant interplay (often unconscious) among partners. Each interactant brings his/her unique characteristics to the exchange, using aspects of the physical, social and cultural context, prior knowledge, shared experiences and linguistic and nonlinguistc utterances to construct meaning.22

The icons above are meant to be animated in order to illustrate the dynamic nature of the communication process between a patient and a healthcare provider. [See <u>www.</u> <u>patientprovidercommunication.org</u>] Initially, during an interaction, not all "puzzle pieces" fit together. Interactants must complete the puzzle



conjointly, using various strategies, which linguists call pragmatics. Successful communication occurs when the pieces of the puzzle fit together.<sup>22</sup>

Communication in healthcare settings is particularly challenging. For starters, the "puzzle" is often complex and has to be completed quickly. Typically, the interactants (patient-provider) are strangers, the situation is stressful and the stakes are high. When interactants don't speak the same language, or they are unable to speak to, listen to or understand each other, what begins as difficult can quickly become impossible.

Efforts to improve patient-provider communication, a high priority across the healthcare continuum, depend on the skills and abilities of healthcare providers as well as patients. To be successful, healthcare providers need communication training and patients need access to an arsenal of communication tools and strategies, including some simple, easy-to-use AAC approaches.

# The healthcare continuum

The continuum of healthcare reflects the multiple settings in which people seek and receive health services. It includes preventative and routine care, as well as care for acute and chronic medical conditions, from conception to death. Communication difficulties run rampant across the continuum.

**Doctors offices, community clinics, schools, correctional facilities, etc.** Doctors, nurses, community health personnel and the patients who seek their help face many potential pitfalls when communicating with one another. Due to time constraints and/or a lack of training, healthcare providers may direct their attention to a family member, friend or caregiver, essentially ignoring the patient. This can short-circuit



Figure 2. Tips for Emergency Responders

effective patient-provider communication.

Currently, few community healthcare providers are aware of, or know how to support, the communication efforts of patients who struggle to communicate with them. Medical and professional schools and healthcare administrators are beginning to realize the importance of communication training and some provide it, albeit in often inadequate doses. For example,

A video entitled "*Listening*" has messages from patients and family members to doctors and other medical staff and ideas about how to communicate more effectively. The video aims to "save lives, save money, and build value in the communities."<sup>23</sup>

Emergency medical care. Common entry points into the healthcare system are medical emergencies caused by an acute illness or injury. Stricken individuals and their family members need to be able to communicate quickly and effectively with first responders (police, firemen, emergency medical technicians) and with doctors and nurses in emergency rooms. These interactions can be very difficult, not only because of critical medical issues, but also due to the ambient noise, anxiety and confusion that accompany these events. Exacerbating the problem may be differences in language, cultural background, pre-existing disabilities and the health literacy of the patient. A lack of communication training and skills on the part of healthcare providers can also play a major role.

First responders and other healthcare providers who know how to use communication tools and strategies are likely to have an easier time with people who are communication vulnerable. A growing number of first responders carry Tips<sup>24</sup> [See Figure 2] and/or have vocabularyspecific communication displays in their vehicles [See Figure 3].<sup>25,26</sup>

[Note: The Institute on Disabilities at Temple University, with funding from the AAC-RERC, recently developed vocabulary and a communication display for use in emergency preparedness. *Emergency Communication 4 ALL*—*Picture Communication Aid.* It is available in English and Spanish and may be downloaded for free.]<sup>25</sup>

Intensive care units. To survive life-threatening situations and ensure the delivery of quality care, communication barriers in ICUs need to be alleviated. Many healthcare providers in ICUs still struggle to communicate with patients who are unable to use speech because of (1) medical or surgical interventions; (2) an illness, such as a stroke or laryngeal cancer or (3) an injury (e.g., traumatic brain injury or high spinal cord injury). Patients who are conscious must be able to express their needs and feelings and ask and respond to questions. Several articles discuss how to use AAC tools and strategies in hospital ICUs.

1. Costello describes the use of AAC interventions in pediatric ICUs at Children's Hospital-Boston. He interviewed patients, family members and medical staff, noting that nurses and other critical care providers report substantial difficulty interpreting patients' communication attempts. Costello advocates for pre-operative as well as post-operative AAC interventions for surgery patients. He helps children select vocabularv in advance and use digital voice message banking. Costello stresses the importance of providing communication devices and methods that are minimally frustrating and maximally useful to the patient, family and staff.27

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2. Happ, Roesch and Garrett describe the use of electronic speech generating devices (SGDs) for temporarily nonspeaking adult patients in ICUs. They studied eleven critically-ill patients on mechanical ventilation. Results showed these patients communicated more frequently when they had access to an SGD than they did otherwise. The researchers identified five barriers to using SGDs in ICUs: (1) staff unfamiliarity with the device, (2) time constraints, (3) poor device positioning, (4) complex message screens and (5) deterioration of a patient's condition.<sup>28</sup>

3. In their book chapter, Garrett, Happ, Costello & Fried-Oken (2007) discuss reasons why ICU staff need to provide access to AAC technologies and strategies. They describe and illustrate the use of (1) natural communication signals and gestures, (2) pre-existing sensory aids, (3) ways to support attention and comprehension and (4) ways to support expression in ICUs.<sup>29</sup>

4. Patak and his colleagues developed the Vidatak boards (commercially available in 17 languages and as a picture board). Go to <u>www.vidatak.com</u>. They report on a study of 29 patients in the ICU on mechanical ventilation—70% experienced less frustration when they had access to a communication board.<sup>30</sup>

5. Improving Communication in the ICU is a concise summary of the need for communication access in ICUs. Written by a team consisting of a physician, nurses, researchers, policy makers, as well as staff from The Joint Commission, a nongovernmental, healthcare accreditation agency, this article specifically mentions the value of using AAC approaches.<sup>31</sup>

#### Acute and rehabilitation

**hospitals.** Faced with increasingly diversified patient populations, many hospitals are adding bilingual staff and using telephone translation services to communicate with non-English-speaking patients.<sup>4,6</sup> However, trained interpreters are not always available and, while volunteers (*e.g.*, family members, friends, caregivers) can help, they can often introduce additional difficulties.<sup>32</sup> When AAC approaches are included in an arsenal of communication



Figure 3. Triage nurse with a communication board.<sup>34</sup>

tools and when healthcare providers know how to use them, successful patient-provider communication is more likely for *all* patients.

1. In New Jersey, nurses and other health care professionals are finding that a two-sided communication display is a handy tool.<sup>33</sup> As part of its 2007 Strategic Plan to Eliminate Health Disparities, the New Jersey Department of Health and Senior Services (NJDHSS) distributed more than 2,200 symbol boards to facilities across the state in an effort to ensure that all patients receive effective medical care. By report, the boards are used most frequently on medical-surgical units and in triage units. One nurse wrote:

I remember a gentleman from somewhere in Asia who came in. He was pointing to his belly. We used the board, and he pointed to the pictures representing the belly and using the bathroom. So we could assess that he was having abdominal pain and probably diarrhea. Then we pointed to the picture of vomiting. He shook his head no, so we were able to rule something out. When he came in, he had been looking at us blankly, wondering how he was going to communicate. Then we pulled out the board, and off we went.<sup>34</sup>

2. Communication Matters, the United Kingdom's ISAAC chapter, has a free and downloadable series of leaflets. One brochure, *Communicating with patients who have speech/language difficulties: Guidance for medical & nursing staff*, helps medical and nursing staff communicate more effectively with patients who have speech, language or communication difficulties due to injury, illness or learning disabilities. General and specific tips to support communication are included.<sup>35</sup>

3. Edited by Beukelman, Yorkston and Garrett, the book *Adults with Acquired Disabilities* includes 400+ pages, CD-ROM with useful forms,

ideas, tips and strategies. Chapters contain in-depth information about how to support communication for specific populations across healthcare settings: amyotrophic lateral sclerosis, aphasia, brainstem impairment, dementia, head and neck cancer, Huntington's disease, multiple sclerosis, Parkinson's disease, primary progressive aphasia, spinal cord injury and traumatic brain injury.12

[See volume 19#4 of Augmentative Communication News for a brief summary of some of the chapters.]<sup>36</sup>

4. Balandin, Hemsley and their colleagues have reported on the hospital experiences of Australians with acquired disabilities9 and cerebral palsy<sup>37</sup> who rely on AAC. For example, they found that individuals with CCN experience a range of difficulties in hospitals (discomfort, lack of participation in their own care, frustration, feelings of isolation, increased length of stay, etc.). They also report that nurses and caregivers<sup>8-9,38</sup> identify a number of strategies healthcare providers can use to enhance communication. These include accessing and knowing how to use AAC equipment, taking time to communicate, asking caregivers for tips and providing a way for patients to get attention, etc.8-9,37-38

5. Augmentative and Alternative Communication In Acute And Critical Care Settings, by Richard Hurtig and Debora Downey, is a 200+ page "how to handbook" aimed at providing protocols and implementation strategies for using AAC approaches with people in acute care facilities. Written for SLPs and medical staff who work with patients who experience a temporary or permanent loss of oral language, chapters include information about the use of assistive technology, assessment and implementation protocols, adapted switches, the Iowa AAC templates, device mounting, access issues, pain management, environmental controls and more. Case examples illustrate challenges and successes in providing AAC to non-oral patients in acute care settings.13

**Home Health**. Little information is available about communication difficulties that occur between patients and healthcare providers



in homes and group home settings. However, it is unlikely that healthcare providers are aware of, or know how to support patients who are communication vulnerable. Recent trends in home health services may help some because distance communication options (email, videophone, instant messaging) are becoming more available to people in rural areas, as well as those who find traveling or speaking difficult.

Miyasaka, Suzuki, Sakai & Kondo conducted a study in which Japanese doctors assessed the clinical impact of a home videophone system for the families of children receiving home respiratory care. Results showed a videophone system significantly reduced the number of house calls by physicians, unscheduled hospital visits by patients and hospital admission days. Patients and health care professionals found the videophone system both acceptable and beneficial, and researchers concluded that it improved the quality of pediatric home ventilatory care.<sup>39</sup>

Long term care facilities. Nursing home residents and their healthcare providers confront challenging communication situations. This is particularly true for patients with dementia and for nursing aides, who are rarely trained to provide communication supports. According to Michelle Bourgeois,

Dysfunctional interaction patterns place residents at risk for an impoverished quality of life and the staff at risk for a variety of physical and psychiatric health effects and burnout.<sup>40</sup>

In a study of seven nursing homes, Bourgeois and her colleagues investigated the effect of memory aids on conversations between nursing aides and residents with dementia. Residents were given a memory book with autobiographical material. Aides received one hour of inservice training and were then coached in the use of the memory book in care settings until they reached 80% accuracy (an average of 8 sessions; range from 3 to 15 sessions). Two five-minute videotaped interactions-one at baseline without the memory book; one post treatment session with the memory book. Results showed that the training and memory book intervention improved the quantity and quality of conversational interactions between nursing aides and their patients. Also, nursing aides generalized new skills acquired in the care setting to other conversational situations without additional training.<sup>40</sup>

In Victoria, Australia, the state Department of Human Services has determined that successful communication with patients with dementia is an essential component of hospital and nursing home care. Nurses report that using multimodal strategies, including verbal communication, body language and written messages, is helpful. Also helpful is open communication between healthcare providers and family members to obtain detailed patient histories and an understanding of the patient's cognitive deficits, sleeping patterns, preferred activities and supports that help the patient cope with dementia. 41

#### Hospice and End of Life

Palliative care means the active total care of patients whose disease is not responsive to curative treatment. The goal of palliative care is achievement of the best quality of life for patients and families. Effective communication is an essential component of palliative care.<sup>42</sup>

In the *European Journal of Palliative Care*, Salt, Davies and Wilkenson discuss the role of the speech-language pathologist on palliative care teams, noting, in one study, that 74 of 91 hospice patients had communication impairments due to the progression of their disease. They note that the use of low-tech AAC tools can support both comprehension and expression.<sup>43</sup>

Costello stresses the need for professional preparedness and involvement in providing communication options for children who are dying. He describes a broad range of AAC approaches, e.g., a multiple message voice output display with personal voice-banking, a single message SGD and picture communication displays.44 He notes that "although there is quite a bit of research, writing and ethics discussions on how to communicate with the patient and family in palliative care, the importance of supporting the patient to be an active member of the team in end-of-life discussions is just beginning to be recognized as an area of study."45

Stuart shares her experiences in providing AAC as part of a palliative care team in a pediatric hospital. She suggests using AAC systems that (1) enable children to have fun and engage in familiar activities; (2) are error free; (3) allow children to talk about a range of topics including their feelings about dying; (4) are durable and (5) can adhere to infection control requirements.<sup>46</sup>

Fried-Oken and Bardach's article suggests a framework for considering end-of-life issues and discusses the use of AAC with adults with degenerative conditions (*e.g.*, as amyotrophic lateral sclerosis and brain tumors). Included are comments from patients. These underscore the urgent need people have to communicate at the end of life.<sup>47</sup>

# Summary

AAC technologies and strategies, and the expertise needed to use them, have vast and underutilized key roles to play in helping improve the quality of healthcare and the delivery of patient-centered care.

The good news is that some individuals, from within and outside the field of AAC, are pioneering efforts to solve or mitigate communication problems in various healthcare settings, using simple, eminently practical and readily available AAC tools and materials. These efforts include practical training protocols for healthcare providers and ideas about how to tweak the environment so that patient-provider interactions are successful. The bad news is that only a miniscule percentage of those who need to know about these strategies and tools are even aware of their existence. Current efforts to spread the word are too often puny or ineffective. Some good efforts are in their infancy, but available solutions are still far too rarely used to maximally benefit patients and their healthcare outcomes.

This article advocates for a broader application of AAC approaches across the continuum of healthcare so that patient-provider communication is improved for *all* patients.



# On the Web

# www.patientprovider communication.org

In 2008, an ad hoc, independent group of individuals concerned about patient-provider communication (PPC) started emailing one another. Largely instigated by Harvey Pressman. President of the Central Coast Children's Foundation, this group has evolved into a forum that is developing and sharing resources, documenting communication difficulties between patients and healthcare providers across the continuum of healthcare and discussing tools and strategies healthcare providers can use to ameliorate these communication problems. The forum includes speech-language pathologists, doctors, nurses, educators, researchers, policy makers and language interpreters, etc. who work in hospitals, universities, businesses, nonprofit organizations, professional organizations and an accrediting agency. [See Table I.]

# With a little support

In 2009, the Rehabilitation Engineering Research Center on **Communication Enhancement** (AAC-RERC), Augmentative Communication Inc. and the Central Coast Children's Foundation offered to support the development of a PPC website and to host monthly conference calls so participants could discuss common issues. Participants also formed subgroups to work on specific projects. For example, Wilson-Stronks, Patak and Costello presented a web seminar, hosted by The Joint Commission about PPC. Others have met to discuss issues related to emergency preparedness,



the PPC website and the Joint Commission's draft standards. [See Governmental.]

# The PPC website

The goal of the PPC website is to provide practical information to healthcare providers, family members and patients. The site provides a platform for group members to share information and easily access articles and presentations. It also enables visitors to comment on articles and/or suggest other sources of information and their opinions.

Currently, five sections are on the website.

**Home Page.** Welcomes visitors to the site and announces the latest article posted on the site.

**About PPC.** Briefly lists participants in the forum and where they work.

**Articles.** Shares articles on various topics related to PPC. Invites

Table I. Participants in	the PPC forum	
AAC-RERC- the Rehabilitation Engineering Re- search Center on Communication Enhancement	Frank DeRuyter, Sarah Blackstone	
AAC TechConnect	Debby McBride	
American Speech-Language-Hearing Association	Diane Brown, Steve White, Amy Hasselkus	
Augmentative Communication Community Partnerships	Barbara Collier	
Augmentative Communication Inc.	Sarah Blackstone	
Boulder Community Hospital	Juli Trautman- Pearson, Debby McBride	
Central Coast Children's Foundation, Inc.	Harvey Pressman	
Children's Hospital of Boston	John Costello	
Children's Hospital-Denver	Tracy Kovach, Lisa Martin	
Duke University	Frank DeRuyter	
Duquesne University	Kathy Garrett	
International Connections	Robert Burgener	
Institute for Ethics at the American Medical Assoc. & University of Chicago Hospital	Matthew Wynia	
Iowa State University/Hospital	Richard Hurtig, Debora Downey	
tternational Language Services, Inc. & National Karen Ruschke ouncil on Interpreting in Health Care		
Louisiana State University Health Sciences	Meher Banajee	
Polyglot Systems, Inc.	Charles Lee	
The Joint Commission	Amy Wilson-Stronks, Tina Cordera. Erica Galvez, Isa Rodriguez	
University of Michigan/Vidatak, Inc.	Lance Patak	
University of Southern Mississippi	Tim Morris, Beverely Morris	
VA Gulf Coast Veterans Health Care System	Katy Gift	

#### comments. Current articles include

1. Overcoming communication barriers in emergency situations.

2. Communication access within medical settings.

3. Communication with patients who have speech/language difficulties.

(4) Emergency Preparedness & AAC

(5) Communication with people who have acquired disabilities and complex communication needs (CCN).

#### Annotated Bibliography.

Provides brief summaries of articles/ documents that relate to communication barriers in healthcare settings and how to overcome them. Many citations link directly to the article.

**Presentations.** Shares PDFs of PowerPoint presentations. Current presentations include

**Call to Action: Improving Care to Communication Vulnerable Patients** by Stronks, Patak & Costello, 2009.

**Improving Communication Effectiveness in Health Care Settings** by

Trautman & McBride, 2009.

Meeting Patient Communication Needs With Evidence-Based Practice by Patak, 2009.

Forum participants maintain the site and strive to make it current, relevant, useful and easily accessible to anyone. All comments and suggestions are welcome. Others enthusiastically interested in participating should contact us.

For additional information, to share information, etc., contact Sarah Blackstone at sarahblack@aol.com or Harvey Pressman at presstoe@aol.com. Phone: 831-649-3050.





# Equipment

# Communication On the Spot!

The On the Spot Tool Kit and On the Spot Resource Book were developed at Colorado's Boulder Community Hospital by Juli Trautman Pearson and Debby McBride, to address a wide range of communication needs in healthcare settings (*i.e.*, emergency rooms, ICUs, hospitals, acute rehabilitation, outpatient facilities, skilled nursing facilities, home health and hospice). According to Pearson,

Communication is one of the most valuable tools patients have to navigate their medical care. Simple-to-use tools can support any patient who is vulnerable to communication mishaps due to difficulties hearing, reading, writing, speaking or accessing a call system.



# Communication Tool Kit

The On the Spot Tool Kit was developed to make it easier

for healthcare providers to access simple communication tools to enhance patient/provider communication. [See Table II.] The kit is meant for use by medical staff (nurses, aides, doctors, occupational therapists, *etc.*) and can be housed at the nurses' stations and restocked as needed. The items included help to reduce communication barriers, medical errors and other negative events.

Trautman Pearson and McBride, who are speech-language pathologists (SLPs), developed the kit in response to the expressed needs of nursing staff at Boulder Hospital in Colorado. They recommend that nurses and other healthcare providers receive training in the use of the



Figure 4. On the Spot Communication Tool Kit items. The kit includes basic, lowcost communication aids, materials and instructions. It offers administrators a "one-stop shopping" solution.\* Table II illustrates some of the items included in the kit.

To date, *On the Spot Tool Kits* are being used throughout Boulder Community Hospital on each nurses unit (neuro, telemetry, maternity, medical/surgery and rehabilitation) with positive results. Staff report an increased awareness of communication vulnerability and applicable

\* Purchasing policies at hospitals can complicate the acquisition of such a range of resources from (frequently small) vendors.

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Table II. Some items from the On The Spot Communication Tool Kit				
PocketTalker & accessories	Magnifier page	Clip board	Dry erase board	
Amplified sound increases hearing ability. Useful when hearing aids are unavailable.	Enlarges text so patient can read if glasses are unavailable.	Holds paper, communication dis- plays, forms, instructions, <i>etc.</i> Has helpful tips on the back.	Write/draw messages. Supports com- prehension and expression. Has helpful tips on the back (shown above).	
Picture communication boards: English/Spanish	English/Spanish cards	Health care communica- tion board tablet	Vidatak EZ communication boards	
I AN I MAT Dimensional discussion   I AN I MAT I MAT I MAT   I MAT I MAT I MAT I			hànar Linith Banah Bhan Bhan Bhan Bhan Bhan Bhan Bh	
Point to messages, symbols, words, pain scale and alphabet.	16 cards with useful words and phrases in English and Spanish, <i>e.g.</i> , comfort, orientation, pain, <i>etc</i> .	Point to messages, symbols, words, pain scale and alphabet. English only.	Point to specific messages. Has pain scale, alphabet and words. Available in 17 languages and a picture board.	

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resources. Patients are participating more fully in their care. The SLP department has also noted an increase

in consults for AAC assessments. [Note: Boulder Community Hospital was recently recognized by The Joint Commission and the Commission on Accreditation of Rehabilitation Facilities (CARF) for its excellence in addressing communication needs.]

# **Resource Book**

The 106 page *On the Spot Resource Book* is meant primarily to help SLPs in healthcare settings who do not necessarily know much about AAC. It provides resources to help them support patients, nurses and family members when temporary, chronic or changing speech and/or language difficulties occur. The book has six clearly illustrated sections with easy-to-implement ideas.

**1. ALPHABET/SPELLING**. For literate patients. Twenty plus pages with low-cost, easily accessible tools and instructions.

Writing boards: Simple dry erase boards and clipboards for writing, with valuable writing strategies on back.

Letter boards: Easily copied direct selection and scanning communication boards. Landscape or portrait view with ABC and/or QWERTY layouts and contrasting backgrounds. Also, boards for partner-assisted scanning arranged according to most frequently occurring letters.

**Word boards**: Easily copied topic and phrase boards. Instructions on how to use an EZ Communicator; a Word Power OnBoard and a pocket-sized Daily Communicator. Also includes how to determine text size for a patient.

**The Writer**: How to use a typing device without speech output, but with word prediction.

#### 2. PICTURES/SYMBOLS.

For persons with cognitive and/or language difficulties who are less successful using traditional letter boards. Thirty-five pages of easy to copy and use materials relevant to



Figure 5. On the Spot Resource Book

healthcare settings with instructions on how to make a communication book of meaningful images using photo books and/or a velcro file folder.

**Images:** Maps, calendars, emotions. Yes/No indicators and pain scales.

**Commercially available picture boards**: Critical Communicator Picture Board, Daily Communicator (Pocket sized) and Health Care Communication Board.

**Modified pictures**: Includes varied symbol types, sizes (smaller vs. enlarged pictures) and contrasting backgrounds.

**3. BOARDS IN DIFFERENT LANGUAGES**. For people who don't speak English. Commercially available boards in different languages (highlighting those in Spanish), including the *EZ Communicator, Critical Communicator* and *Daily Communicator boards*.

4. MODIFICATIONS. Twentytwo pages of ideas and strategies about how to provide voice output, amplification and magnification to improve communication access, as well as various ways to access call bells.

**Voice Output**: The *Go Talk, Talking Photo Album.* 

Amplification strategies: *PocketTalker* (hearing), *Chattervox* (voice), *Sprint Relay* (phone use).

**Enhancing vision**: Magnifying glass or page.

**Call bells**: Examples of modified call bells so patients with physical limita-

tions can access an alerting system.

**Physical access strategies**: Keyguards for letter boards, modified pointers, partner assisted scanning, eye movement systems (eye gaze system, eye link) and a Yes/No Topic Book.

**5. BEDSIDE RECOMMEN-DATIONS**. Easily copied, posted and given to anyone who needs to communicate with a patient.

**Instructions**: How to use Partner Assisted Scanning, a Yes/No Topic Book, an Eye Gaze System such as *Eye Link*.

Writing Strategies: How to help someone with arm weakness or limited control communicate *via* writing.

**Communication Recommendations**: (for Aphasia): How to use key words. Ways to indicate Yes/No.

Adaptive Tools: How to use all the tools a person has to foster successful communication.

**6. PAPERWORK**. For SLPs. Easy-to-complete forms to document what was tried with patients and implemented successfully. Can become part of a more comprehensive assessment by a speech-language pathologist/audiologist if communication difficulties persist.

# Case Examples\*\*

1. The medical team was preparing to extubate Mr. K. from the ventilator. An ICU nurse felt he'd have increased intent to communicate as his sedation wore off, so she pulled the Vidatak Communication Board and the Picture Communicator from the *Tool Kit*. Once Mr. K. was conscious, his nurse reviewed both boards with him. Mr. K. immediately pointed to a board to communicate that he was thirsty and his mouth tasted awful. As a result, the nurse used a suction toothbrush and applied a mouth moisturizer to relieve his discomfort.

2. Ms. S. was rushed by ambulance to the ER because of chest pain. Once her condition was stable, the staff gave her multiple forms to complete and read. However, she had left her reading glasses at home. She might have decided to "just sign on the dotted line," but she asked a nurse if he had time to read

<sup>\*\*</sup> Thanks to Juli Trautman Pearson for these informative and illustrative case examples.



all of the information to her. Instead, the nurse gave her a magnifier page and she was able to read and complete all paperwork independently.

3. Ms. A. was receiving a treatment for lung cancer that involved the use of ototoxic medications. At baseline, Ms. A. did not have hearing aids, although her hearing was not very good. Due to respiratory distress after a lower lobectomy, she was intubated in the ICU. The noise from the pump, combined with her ototoxic meds, made it difficult for her to fully participate in conversations with her doctor, family or hospital staff. A nurse provided her with a Pocket Talker amplifier. Her communication partners helped her put on the earphones and then talked into the amplifier's microphone so she could hear what was being said.

4. Mr. W. had a left CVA, aphasia, a right hemiparesis and difficulty communicating. His yes/no response appeared accurate (for basic questions) and he could recognize familiar/common words. Although he couldn't say where he lived, he pointed to his hometown when given a choice of four cities. He could point to, or trace in the air, the first letter of a word using his non-dominant hand, but he could not spell. The *Assessment Hierarchy and Evaluation Form* in the *On the Spot Resource Book* allowed the

# Governmental

# Advancing effective communication, cultural competence & patientcentered care by Amy Wilson-Stronks

The Joint Commission<sup>\*</sup>, a non-governmental healthcare accreditation agency, recently released a set of draft standards aimed at advancing effective communication, cultural competence and patient-centered care practices in hospitals.<sup>\*\*</sup> These standards build on ongoing research conducted by The Joint Commission SLP to identify some tools and strategies that could facilitate his communication. These included a dry erase board, a communication book (with words and pictures copied from the *Resource Book*), as well as the use of key words and the Written Choice Communication Technique. Also, bedside recommendations were copied from the *Resource Book* and posted at his bedside.

5. Mr. A. had a brainstem stroke and was in an acute rehabilitation facility with severe-profound spastic dysarthria. He could finger point with limited accuracy. His yes/no responses were accurate, although holding his head up was difficult, and when he got emotional, he was unable to nod his head. The Assessment Hierarchy and Evaluation Form allowed the SLP and Mr. A. to determine his strengths and consider his communication options. He decided to use a keyguard over a white-on-black letter board (from the Resource Book) and spell messages. He also used a topic/ phrase book (copied from the Resource *Book*) to select topics. Then, he would wait for his communication partner to flip to the tab of the category he wanted and scan through individual messages using partner-assisted scanning. Bedside recommendations were also posted.

> as part of its Hospitals, Language, and Culture: A Snapshot of the Nation study.\*\*\* The draft standards provide baseline expectations

for hospitals accredited by The Joint Commission in regard to care systems that are responsive to patients' unique needs. It is hoped that when finalized these standards will be adopted for inclusion in accreditation requirements for hospitals.

# Background

The Joint Commission has addressed patient's rights in its accreditation standards for decades. Within these standards has been the patient's right to effective communication. However, as is clear through the review of sentinel event data and a voluminous literature, effec-

# Summary

The On The Spot Tool Kit and On The Spot Resource Book provide practical, easy, low-tech solutions for communication problems that occur during medical interventions, acute injuries and acute/chronic illnesses. These tools also can address language and cultural differences when trained interpreters are not available. Trautman Pearson and McBride join an increasing number of AAC specialists who daily demonstrate the value of AAC and speech language pathology in healthcare settings. Their resources are useful for anyone who confronts communication barriers in healthcare settings, from first responders to hospitals, rehabilitation, hospice, home care and all points in between. For more information, contact AAC Tech Connect at info@aactechconnect.com or 866-482-2279.

*On The Spot Communication Resource Book* \$99 (Introductory Price); *On The Spot Tool Kit* \$699. Go to <u>www.aactechconnect.com</u> to order and check out other options.

tive communication is more than a patient's right, it is essential to patient safety and quality of care. As the Joint Commission staff studied how culture and language can impact communication in diverse patient populations, they recognized there are other communication "vulnerabilities" that may impair effective patient-healthcare provider communication. These include difficulties with speech, hearing, vision, physical disabilities, disease and medical procedures that interfere with effective communication.

Commission staff also recognized that individual and institutional factors can affect communication. The draft standards highlight, both while leaving institutions the flexibility to create systems that meet their unique needs.



<sup>\*</sup> Formerly known as The Joint Commission on Accreditation of Health Care Organizations

<sup>\*\*</sup> This project is funded by The Commonwealth Fund.

<sup>\*\*\*</sup> This study is funded by The California Endowment.

### Governmental, Continued from page 9

A series of government and healthcare studies and policies over the past nine years have helped shape The Joint Commission's understanding of effective communication, cultural competence and patient-centered care, as well as increased the level of attention paid to healthcare disparities and the quality of healthcare. [See Table III.]

# **Issues addressed**

Areas addressed in the draft standards include (1) the collection and use of demographic data for both service provision and strategic planning, (2) assessing patient communication needs and providing resources to meet those needs and (3) developing systems of care that promote equity, respect and inclusion. Because communication can be impaired by a multitude of factors, The Joint Commission does not claim that addressing these issues is an easy task. However, several new requirements, if included in the standards, could improve the quality and safety of care provided to patients. Sixteen issues are addressed in the draft standards.

- Staff training on cultural sensitivity. Staff and licensed independent practitioner
- training on the use of communication tools. Use of population- and patient-level
- demographic data.
- Identification of the patient's communication needs.
- Address communication needs across the care continuum.
- Provision of language access services and auxiliary aids.
- Assessment of patient understanding. Inclusion of health literacy needs in learning needs assessment.

# Table III. Chronology of events shaping The Joint Commission'sproposed standards

	proposed standards			
2001	Office of Minority Health releases National Standards for Culturally and Linguistically Appropriate Services (CLAS)			
	Institute of Medicine releases its <i>Unequal Treatment Report</i> identifying racial and ethnic health and health care disparities.			
2003	The Joint Commission begins to evaluate its standards against the CLAS standards and recom- mendations in the <i>Unequal Treatment Report</i> . Gaps are identified, but the field is not yet ready to implement suggested strategies. The Joint Commission decides not enough is known about the capacity of health care organizations to adopt culturally/linguistically appropriate services.			
	The Joint Commission receives a generous grant from The California Endowment to study how hospitals across the nation are addressing issues related to language, culture and health disparities. Technical advisory panel convened; project advisors appointed to assist with research.			
2003 to 2006	<i>Hospitals, Language, and Culture: A Snapshot of the Nation</i> study is conducted. Findings show much is being done to address language, culture and health disparities, but efforts are not always consistently implemented. Awareness of recommended practice and legal supports for language access is limited.			
	Hospitals, Language, and Culture: A Snapshot of the Nation, Exploring Cultural and Linguistic Services in The Nation's Hospitals: A Report of Findings is released in March.			
2007	The Joint Commission completes pilot study investigating relevance of Limited English Profi- ciency to adverse events in Hospitals. <i>Language proficience and adverse events in US hospitals:</i> <i>A pilot study</i> published in the <i>International Journal for Quality in Health Care</i> . Demonstrates that language barriers appear to increase risks to patient safety.			
2008	One Size Does Not Fit All: Meeting the Health Care Needs of Diverse Populations, the second report from the Health, Language, and Culture study is released. It provides promising practices and a framework for action to improve care for diverse patients.			
Aug 2008	The Joint Commission receives grant from The Commonwealth Fund to develop standards to advance effective communication, cultural competence and patient-centered care in hospitals. Standards build on the work of the <i>Health, Language, and Culture</i> study. Expert panel established to guide the development of the standards.			
May 2009	Draft standards to advance effective communication, cultural competence and patient-centered care in hospitals released for public comment.			
Aug 2009	Revision of draft standards based on analysis of public comments, expert opinion and pilot test- ing. Implementation guide under development to help hospitals meet the standards.			
Fina	Final standards will be available in January 2010 for implementation by the field in January 2011.			

# ASHA on Health Literacy

The American Speech-Language-Hearing Association has initiated an effort to make written materials more accessible to the general public. Adhering to the principles of plain language and addressing health literacy issues, ASHA is revising its pamphlets and website so they are more readable, user friendly and targeted for the general public. Check out:

- 1. Tips for talking to your audiologist or speech-language pathologist: <u>www.asha.org/public/talkingwithaudorslp.htm</u>.
- 2. Questions to ask about new products or treatments: www.asha.org/public/speech/ consumerqa.htm.

The *ASHA Leader* published 3 articles by Amy Hasselkus, Associate Director of Health Care Services in SLP. She says, *Health literacy is not just a problem for the patient, client or family. Healthcare providers also have a responsibility to be sensitive to a client's cultural needs and provide appropriate and understandable health information.*<sup>48</sup>

Contact Amy Hasselkus at <u>ahasselkus@asha.</u> org.

Access *The ASHA Leader* articles at (1) www.asha.org/publications/leader/ archives/2009/090120/090120d.htm; (2) www.asha.org/publications/leader/ archives/2009/090210/090210c.htm; (3) www.asha.org/publications/leader/ archives/2009/090324/090324e.htm

Collection of patient-level demographic data. Documentation of need for mobility assistance. Documentation of the use of language access services and auxiliary aids.

- Accommodation of patient's cultural and personal beliefs.
- Accommodation of patient's religious and spiritual practices.
- Non-discrimination in care.

Inform patients of right to receive language access services.

Unlimited access to designated patient advocate.

# The impact

Although it is not yet clear which proposed standards will be approved, final standards will be available in January 2010 for implementation by the field in January 2011. An implementation guide that will help hospitals meet the new standards will include information about the use of AAC tools, strategies and technologies.

Amy Wilson-Stronks, Principal Investigator of the Hospitals, Language and Culture study, can be reached at <u>awilson-stronks@jointcommis-</u> <u>sison.org</u>. To access publications, go to <u>www.</u> jointcommission.org/patientsafety/hlc





# Evidence: Using AAC to support patient-provider communication

This article highlights some sources of evidence that address the use of AAC by healthcare providers across settings. These sources, as well as current research initiatives described here, may serve to broaden minds and help the AAC community advocate for *all* patients who struggle to communicate in healthcare settings.

#### 1. A narrative review article. A

systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication by Erinn Finke, Janice Light and Lisa Kitko. Reviews evidence from 1990-2007 regarding nurse-patient communication and AAC in the Journal of Clinical *Nursing*.<sup>11</sup> The authors completed an extensive literature search, which revealed 23 articles, of which 12 met their criteria (i.e., appeared in a peer-reviewed journal, written in English and used primary research methodologies). Participants in selected studies were patients with CCN, nurses and unpaid car-



ers. Researchers identified what participants defined as barriers to communication in hospitals, as well as what strategies helped them overcome these barriers. [See Table IV.]

For example, barriers included nurses not having knowledge about a variety of communication supports or access to tools that could help them interact successfully with patients. Also, nurses reported overly rigid time constraints. Success was more likely when nurses were willing to ask for assistance, spend time with patients and share information with other staff about how to communicate with a patient. Being familiar with a range of communication tools and strategies also made a difference.

Researchers concluded that these factors can improve patient-provider communication: (1) availability of AAC tools and strategies, (2) quiet environment, (3) smaller case loads for nurses and (4) presence of family/friends.<sup>11</sup>

#### 2. Books on the use of AAC in healthcare settings.

Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions (2007)<sup>12</sup> and Augmentative and Alternative Communication in Acute and Critical Care Settings (2008).<sup>13</sup> Described on page 4 of this issue, these books offer a plethora of research findings, practical ideas and strategies for supporting patients across the continuum of healthcare. While aimed at speech-language pathologists, other healthcare providers will find portions highly useful.

Table IV. Communication barriers and supports: Nurses and patients with CCN <sup>11</sup>			
What are barriers to communication?	What helps?		
1. Most interactions are task-focused, nurse-con- trolled and focus on physical needs and medi- cal/care procedures.	1. Prior training and experience working with people with disabilities.		
2. Interactions often do not result in needs being met.	2. Looking for nonverbal cues to make sure patient understands.		
3. Nurses lack knowledge about AAC.	3. Sharing information with other medical staff.		
4. Some nurses feel that providing communication tools is "not my job."	4. Following written directives of patient/family about how to communicate with the patient.		
5. It takes more time to care for and communicate with patients who are communication vulnerable.	5. Willingness to take time and be persistent until the patient's message is understood.		
6. Nurses lack access to communication tools.	6. Being familiar with/using AAC approaches.		
7. Patients often don't have a way to gain the staff's attention.	7. Asking family, speech-language pathologist, <i>etc.</i> to make suggestions.		
8. When a nurse is not assigned to care for the same patient over several days, the continuity of care may be compromised.			
9. Presence of family members.	9. Asking for help when communication is dif- ficult.		

# Some current research activities

Several researchers around the world are addressing issues that aim to improve patient-provider communication across healthcare settings. The following are some examples.

University of Iowa, USA. Richard Hurtig describes work underway at the University of Iowa Hospitals and Clinics, a 500+ bed medical facility. Recognizing the importance of communication and the challenges patients who don't speak English or who have temporary or permanent communication impairments face, he and doctoral students Debora Downey and Lauren Zobow are conducting studies designed to support patient-provider communication in acute care settings.

Downey is developing and testing an online introductory tutorial for nurses and other healthcare providers by educating them about AAC so they can provide communication supports to patients.

Zobow is identifying professional and institutional barriers to the delivery of AAC services in hospitals by conducting initial interviews with target groups. From these, she will develop a survey, administer it nationally and analyze the results.

In addition, Hurtig is working with hospital administrators to embed questions about patient communication in hospital-wide electronic charting protocols. Sample questions include

Can the patient communicate effectively and efficiently? Does the patient require the use of glasses? Hearing aids? Does the patient use any assistive technology? Can the patient use a call button? and so on.

Because this is part of a hospitalwide database, the SLP Department can identify patients who have difficulty communicating throughout the hospital at any time.

#### University/Research, Cont. from page 11

Another project is the evaluation and use of the *IOWA Protocol*. The aim is to enhance patient-caregiver communication for all non-oral patients and patients who do not speak the language of healthcare providers. Goals are to put AAC solutions quickly in place at the bedside and to train SLPs and other providers to use AAC strategies with patients. Typical interventions include call button modifications, environmental controls and communication templates designed for specific units.

**Dundee, Scotland**. Annalu Waller and doctoral students Kathleen Cummins and Suzanne Prior are conducting research on patientprovider communication issues in hospitals. Earlier, Judson, Waller, and others worked on the ICUTalk, a device designed to meet the needs of patients in the ICU.

The Dundee team followed a user-centered methodology to develop a simpleto-use AAC device with a pre-stored, vocabulary of 200 items (8 categories) and an alphabet. Vocabulary items were selected on the basis of patient and nurse interviews and observations. Researchers introduced the ICUTalk to patients at Ninewells Hospital and collected data for one year via questionnaires and automated logging. Results suggested that patients learned to use the device after about 5 minutes of training. Two problems were noted: the size of the device and patients' difficulty accessing desired vocabulary. Today, a decade later, Ninewells Hospital staff reportedly continues to use the ICUTalk. (Researchers concluded that the device is not a viable commercial product, but are making the software available as opensource on the Oatsoft Portal www.oatsoft.org/Software/ icutalk/)

Currently, Cummins is studying barriers between nurses and people with CCN who are hospitalized and use AAC. She is developing online training modules for nurses so they can better address the communication difficulties experienced by their patients, thus improving the hospital experience for all. Working with Annalu Waller, Thilo Kroll and Susan Balandin in Norway, Cummins is interviewing AAC stakeholders and nurses to develop these modules and will then evaluate their usefulness as training modules in hospitals in Scotland and Norway.

Prior's study aims to create "add on" items to the electronic patient records of people with CCN. Items will address basic care needs, cognitive levels and communication needs. In focus groups, adults who have CCN and some cognitive impairment identified information they wanted in their hospital records. To ascertain the perspectives of doctors, Prior held a forum theater session whereby two adult actors who rely on AAC and two professional actors enacted scenarios based on real life experiences. The scenes depicted problems that occur when doctors are not fully aware of the medical histories of patients with CCN and/or how they communicate. The audience, comprised of newly qualified doctors, were asked what information they might need to access in a patient's electronic record. Based on these results, Prior is developing a software program for use in hospitals. She notes, not surprisingly, that perspectives of adults with CCN and doctors are quite different.

Australia. Researchers at the University of Queensland and Latrobe University in Australia continue to work on patientprovider communication issues. They have previously noted that individuals with developmental and acquired disabilities and CCN are hospitalized more frequently than people without disabilities, particularly as they get older.

Bronwyn Hemsley, a post doctoral fellow at the University of Queensland, continues to investigate the communication experiences of people with lifelong disability who are in the hospital. In her Ph.D. studies, Hemsley worked with Profs. Susan Balandin and Leanne Togher to develop an *Information Kit* for Family Carers of Adults with Cerebral Palsy and CCN in Hospital. The *Kit* incorporates information, tips and strategies aimed at supporting patientprovider interactions using various AAC approaches. She says,

Since there is no research literature that tests the usefulness of generic low-tech systems on the ward, it is not possible to say whether or how widespread publication of such systems would be of benefit, and further research in this area is urgently needed.<sup>49</sup>

Over the next four years, Hemsley, Balandin and Linda Worrall are collaborating on a Communication in Hospital project with hospitalized adults who have developmental disabilities and CCN. In Phase I Hemsley is interviewing paid carers, hospital nurses and adults with development disability and CCN in the hospital. In Phase II she will observe interactions between individuals with CCN and hospital healthcare providers. She is also involved in a set of projects, Children Communicating in Hospital: The Path to Better Health Care, looking at ways children with CCN communicate in hospitals and what barriers and strategies to communication exist for them and their healthcare providers. This work extends her previous research with adults.

Robyn O'Halloran at LaTrobe University has developed a functional communication measure for patients with acquired communication disability in acute hospital settings. Previously, she documented the numbers of patients unable to communicate their needs in acute hospital stroke units and the multiple factors that influence their ability to communicate with healthcare providers.

**Norway**. Susan Balandin at the University College Molde in Norway continues her collaboration with researchers in the UK and Australia. A current interest is the transition from pediatric to adult healthcare services for young people with CCN.\* She and her Norwegian colleagues are currently working with Telemed Norway to develop a series of lectures by people who use AAC about their healthcare interactions. She will explore the use of

<sup>\*</sup> She recommends *Beyond Words Book Series*, full-colour picture books addressing problems children and adults who are not literate may face. Sample titles are: *Going into hospital*, *Going to the doctor*, *Looking after my breasts*, *Getting on with epilepsy*. Go to www.intellectualdisability.info/how\_to/ beyond\_words.htm





# EVIDAAC Evidence in Augmentative and Alternative Communication

# How AAC teams can benefit from EVIDAAC with Ralf Schlosser

Suppose a clinician and the family of a young child with autism are considering the use of the Picture **Exchange Communication System** (PECS) as a beginning communication strategy. Both the clinician and the family are interested in knowing whether there is any research evidence to suggest that PECS is indeed effective in helping young children with autism make requests and comments. Despite the best of intentions, most augmentative and alternative communication (AAC) teams simply do not have the time to find existing evidence or the expertise to appraise its reliability and validity. Current options for finding and appraising evidence in the area of AAC remain limited for several reasons:

1. As a field, we lack a large database of individual, peer-reviewed, methodologically sound research studies on topics of interest to clinicians who work in AAC, family members and individuals who use AAC. The populations who rely on AAC approaches are diverse and small in number and the field still has too few researchers and/or master clinicians worldwide who conduct and publish clinically-oriented research in peer-reviewed journals.

2. Finding existing studies and review articles is tedious and time consuming. For example, one has to search for articles using general-purpose databases (*e.g.*, ERIC, PsycINFO) or web-based search engines such as Google Scholar.\* Because AAC-related articles are published in many different journals, multiple databases and other sources must be searched.

3. Once located, articles need to be read to determine which are relevant to the clinical questions being asked.

4. Finally, someone needs to evaluate the selected articles according to their relevance to a particular client and his/her circumstances and determine whether conclusions are valid and reliable and therefore, trustworthy. To do so, research designs and methodologies must be carefully evaluated using predetermined criteria. This step not only takes time but, for many clinicians, is beyond their level of expertise.

# What is EVIDAAC?

In October 2009, EVIDAAC will launch its website [www.evidaac.com] and the field of AAC will have an accessible and usable database of appraised research evidence. Thus, AAC team members will be able to go to a single source, type in a few keywords or select from a list of clinical questions, to initiate an online search of relevant evidence. For example, a team might select "autism" as the population of interest, and "child" as the age range. The team could see immediately that both single articles and review articles are available. Rather than having to begin reading individual studies, the team can decide to begin by requesting abstracts of the review articles and as well as EVIDAAC's appraisal ratings for each article. This enables them to assess (1)which review articles are most relevant to a particular child and his/her environment and (2) which review articles appear to be most trustworthy methodologically.

Together with the AAC team members' knowledge of the client and his/her circumstances, their sound clinical judgement and the preferences of the family and person with complex communication needs (CCNs), EVIDAAC offers a way to deepen and advance the use of evidence informed practices.

The international EVIDAAC team consists of

Ralf Schlosser, Northeastern University, Patricia Dowden, University of Washington and Sarah Blackstone, Augmentative Communication Inc. [USA]; Jeff Sigafoos, Victoria University-Wellington [New Zealand]; Pammi Raghavendra, Novita Childrens Services, [Australia] and Gunther Eysenbach, University of Toronto, [Canada].

# The EVIDAAC process

The EVIDAAC team searches for and appraises existing evidence in the area of AAC and then publishes their results on the EVIDAAC website in a form that is easy for clinicians, individuals with CCN and family members to access. The process is as follows:

Selecting clinical questions. The EVIDAAC team identifies clinically-relevant questions based on available research evidence. Once a potential question is identified, team members begin to search for further evidence.

**Locating evidence.** The EVI-DAAC team regularly conducts electronic database searches following the guidelines set forth in Schlosser, Wendt, Angermeier, & Shetty (2005). They use the following databases:

Cumulative Index of Nursing and Allied Health Literatures (CINAHL), Educational Resources Information Center (ERIC), Language and Linguistics Behavior Abstracts (LLBA), Medline, PscyINFO, Scirus, and Web of Science.

In addition, they may conduct hand searches of selected journals and search reference lists in relevant books.

Selecting articles to appraise. The following criteria determine whether the EVIDAAC team will

<sup>\*</sup> While ERIC and Google are freely accessible on the Internet, PsycINFO requires a subscription.

#### appraise a study or review article:

1. The study or review article has to fall within the realm of AAC based on the 2002 ASHA definition. See below.\*\*

2. The study or review article must examine the efficacy, effectiveness or efficiency of one or more interventions. Studies related to assessment, diagnosis, prognosis, as well as surveys and qualitative studies are <u>not</u> included.

3. Individuals with disabilities and/or their communication partners are the focus of the intervention study. [Research with non-disabled participants is not appraised because it requires replication with disabled participants in order to inform evidence-based practice.]

4. The study/review is published in a peer-reviewed journal in English. [Note: Other languages are a future possibility.]

**Appraising study and review articles.** At least two members of the EVIDAAC team and/or EVI-DAAC Editorial Board appraise and independently rate each study or review article. They reconcile any differences before ratings are posted.

**Appraisal scales.** Scales are selected according to the type of research design used in the study or review article, as shown in Table V. The higher the score derived from the scale, the more solid the research evidence and the more trustworthy the researchers' conclusions.

**Final steps**. When the appraisal process is complete, the team posts the title, abstract and results of the appraisal on the EVIDAAC website.

# Summary

The EVIDAAC site, when launched in October, will contain information about approximately 40 studies and 20 review articles that

Table V. Designs and appraisal scales				
Design and Appraisal Scale	Description of Design			
Randomized Controlled Trial (RCT) Adapted PEDro scale (maximum points possible: 12)	An RCT compares at least two treatments (one of which can be a no-treatment control or a wait-list control condition) with random allocation (participants are randomly allocated to groups for either the treatment being studied or control/placebo using a mechanism, such as coin toss, random number table, or computer-generated random numbers) and compares the outcomes. Pseudo or intended-to-be-RCTs are also included in this category wherein participants are allocated to groups for treatment or control/placebo using a non-random method (such as alternate allocation, or by odd or even client numbers).			
Non-RCT Adapted PEDro Scale (maximum points: 10)	A non-RCT is similar to an RCT in that it compares at least two treatments (one of which can be a no-treatment control or a wait-list control condition). However, participants are not randomly allocated to groups. Rather, they are selected based on disability or outcome. Then information is obtained about previous exposure to a treatment or other factor being studied.			
Case series Adapted PEDro Scale (maximum points: 4)	Case series refers to a group(s) of participants who are exposed to one treatment. Outcomes are measured before and after exposure to the treatment.			
Single-subject experimental designs (SSEDs) – evaluating effectiveness of one intervention EVIDAAC Single-Subject Scale (maximum points: 10)	SSEDs use repeated measurement of a dependent variable and demonstrate experimental control through manifestations of experimental effect at different points over time (a) within a single participant (within-subject replication) or (b) across different participants (between-subject replication). SSEDs may involve only one participant or several participants. Each participant serves as his/her own control.			
<b>SSED</b> – comparing effectiveness of two or more interventions EVIDAAC Comparative Single-Sub- ject Design Rating Scale (maximum points: 19)	Comparative SSEDs compare the effectiveness, efficacy, efficiency of two or more interventions. The scale uses a com- bination of items from the SSED scale, as well as other items that apply only to comparative acquisition designs.			
Systematic reviews EVIDAAC Systematic Review Scale (maximum points: 16)	Systematic reviews "adhere closely to a set of scientific methods that explicitly aim to limit systematic error (bias), mainly be attempting to identify, appraise and synthesize all relevant studies (of whatever design) in order to answer a particular question" (by Petticrew & Roberts, 2006, p. 9).			
Systematic review and meta-analysis EVIDAAC Systematic Review Scale (maximum points: 20) relate to clinical questions, suc	Systematic reviews that employ statistical means for the analy- sis of pooled data from multiple studies.			

relate to clinical questions, such as

#### What are the effects of:

1. AAC interventions on natural speech production?

2. Manual sign intervention on speech production?

3. Manual sign intervention on manual sign production?

4. Functional communication training on challenging behavior?

5. PECS on expressive communication?

6. Treatment packages that involve the use of SGDs on requesting behaviors?

7. Milieu and naturalistic teaching on production/expression?

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<sup>\*\*</sup> AAC refers to an area of research, clinical and educational practice, and involves the study of and, when necessary, compensation for, temporarily or permanently, the impairments, activity limitations and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication. (ASHA, 2002)



# Resources

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