

Guest Editorial

Communication Access for Children: The Role of Augmentative and Alternative Communication Technologies and Strategies in Pediatric Rehabilitation

The success of pediatric rehabilitation efforts depends on many factors. Far from the least of these is the ability of health care providers to sustain productive communicative interactions with patients and their family members. In fact, in the most exhaustive study to date of the “root causes” of sentinel events in medicine, The Joint Commission ranked communication breakdowns at the very top of the list (62%) [4].

When communication barriers and breakdowns occur in healthcare environments, one significantly underutilized resource is augmentative and alternative communication (AAC). This issue of the *Journal of Pediatric Rehabilitation Medicine* focuses on the specific ways in which AAC strategies, technologies and resources can support young people with severe communication challenges in healthcare environments and their communities. Providing communication access to young people who are temporarily unable to use their speech to communicate, or have chronic disabilities that interfere with communication, is mandated in our schools and now widely recognized as essential to quality healthcare.

From a policy as well as a practical perspective, this issue, with its focus on communication access, seems especially timely. Government and health care facilities/agencies have increasingly recognized that effective patient-provider communication is necessary for patient safety, improves positive patient outcomes and reduces healthcare costs [2]. For example, The Joint Commission, a non-profit agency that accredits many healthcare organizations in the United States, has *New and Revised Standards & Elements of Performance for*

Patient-Centered Communication that will take effect January 1, 2011. These standards specifically address issues of effective patient-provider communication and improved health literacy in hospitals.

“Patients with communication problems are at an increased risk of experiencing preventable adverse events, and patients with limited English proficiency (in the U.S.) are more likely to experience adverse events than English speaking patients.” [5]

Similar requirements are emerging in other sectors. For example, the U.S. Department of Health and Human Services’ *National Action Plan to Improve Health Literacy* encourages government and healthcare providers to improve how health information is shared and used [6]. The *Agency for Healthcare Research and Quality* has established health literacy as a universal precaution, similar to hand washing as a way to minimize risks to patients [3].

This issue considers the use of AAC strategies and technologies with children and youth who face severe communication difficulties. AAC is an internationally accepted treatment approach for children with severe communication impairments. Recognizing that communication encompasses more than just spoken words and often includes consideration of gestures, eye gaze, body postures, sign language, photographs, printed words, objects, picto-ideographs, Braille, speech generating devices, and communication displays, the American Speech-Language-Hearing Association defines an “AAC system” as an integrated group of components, including the speech, writing, symbols, aids,

strategies, techniques and technologies used by individuals to enhance communication" [1]. In the United States, for example, speech generating devices and AAC services are funded by most insurance programs and companies and considered as habilitation and rehabilitation services and technology within the Health Care Reform Act.

The authors of the six related articles in this issue represent the Rehabilitation Engineering Research Center on Communication Enhancement, known as the AAC-RERC, which is funded by the National Institutes for Disability and Rehabilitation Research in the United States. AAC partners are associated with Duke University, the University of Nebraska, Lincoln, the University of Buffalo, the Pennsylvania State University, Temple University, Oregon's Health Sciences Institute, Children's Hospital Boston, Augmentative Communication, Inc. and Innvotek, Inc. and have conducted research and development projects, while engaging in technology transfer and knowledge translation activities since 1998. The AAC-RERC's mission is to benefit individuals with complex communication needs (CCN) in their daily lives. (Go to www.aac-rerc.com to view a description of projects, publications, webcasts, presentations, resources and features.)

The AAC-RERC partners hope that the information shared in these articles is useful clinically and perhaps can stimulate future research. Pediatricians and other medical and rehabilitation professionals are often the first professionals with an opportunity to identify and refer children with CCN to programs that can support access to AAC and functional communication. The "take away" message is that children with limited communication abilities, including those with severe and multiple disabilities, benefit from using AAC approaches and, therefore, so does society.

The series begins with Beukelman and Ray's article on *Communication Supports in Pediatric Rehabilitation*. The authors discuss the role of team members in meeting the needs of children with CCN over time. It is the collaborative participation and insights of a child's family and other team members, not the AAC expert alone, that ultimately determines good communication outcomes. They also note the challenging and dynamic nature of supporting children with CCN: "Only an exploration process, built on trust, can lead to appropriate and timely communication interventions for children with developmental and/or acquired disabilities."

Much of the research on AAC interventions has focused on children with developmental disabilities, such as cerebral palsy, autism, Rhett and Down syndromes.

Drager, Light and McNaughton review that literature and discuss the demonstrable benefits of AAC interventions on communication, as well as on the behavior, language development and speech outcomes of children with CCN. In their article, *Effects of AAC Interventions on Communication and Language for Young Children with Complex Communication Needs*, these authors stress the importance of early intervention.

Augmentative and alternative communication intervention in children with traumatic brain injury (TBI) and spinal cord injury (SCI) focuses on the importance of providing communication access to children after a severe injury to the head, neck or spine. Fager and Spellman note that while limited research exists in the pediatric literature with regard to AAC interventions, the literature for adults with TBI and SCI is encouraging. While calling for more data-based studies, the authors cite case examples to illustrate AAC interventions with children with TBI and SCI in acute care and rehabilitation hospitals. They also discuss the importance of ongoing AAC interventions for children whose speech, language and communication impairments persist.

Costello, Patak and Pritchard describe the use of AAC interventions in pediatric intensive care units (PICUs). Their article, *Communication Vulnerable Patients in the Pediatric ICU: Enhancing Care through Augmentative and Alternative Communication*, describes three phases of AAC and assistive technology interventions currently used at Children's Hospital Boston. Their case examples illustrate how medical staff can work together to ensure communication access for children of all ages throughout their stay in the PICU. They discuss the temporary need for AAC tools and strategies, how to prepare children and families in advance when medical procedures might result in communication difficulties and how to ensure that children with existing communication disabilities gain access to their AAC tools throughout a hospitalization.

In the article, *Communication Matrix: A Clinical and Research Assessment Tool Targeting Children with Severe Communication Disorders*, Rowland and Fried-Oken introduce an assessment instrument designed to evaluate the expressive communication skills of children with severe and multiple disabilities. They also discuss the use of an online associated database to collect research data about early multi-modal communication skills in children with severe impairments, regardless of diagnosis, native language or country of residence. These data may serve as clinical benchmarks to determine the success of rehabilitation in children who are learning or re-learning to communicate, as

well as broaden our understanding of pre-speech communication development and the acquisition of symbolic communication through speech and non-speech symbol systems.

Finally, McNaughton, Balandin and Kennedy remind us that children grow up. *Health Transitions for Youth with Complex Communication Needs: The Importance of Health Literacy and Communication Strategies* highlights the challenges youth face as they transition from the pediatric to the adult healthcare system. The authors suggest that pediatric rehabilitation specialists can play a key role in preparing these young people by teaching them how to describe their health needs, schedule services, and self-advocate with health care specialists. AAC tools and strategies can offer multiple supports as youth learn to negotiate the healthcare system as adults with disabilities.

The AAC-RERC appreciates the opportunity to contribute to this excellent journal. We are working to identify and develop better AAC tools, technologies and strategies for children and youth with CCN and recognize a need to reach out to the broader community and form productive partnerships. Communication is endemic to being human and a door that opens all other doors; it behooves us to learn as much as we can from each other and we invite your comments.

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Conflicts of interest

None reported.

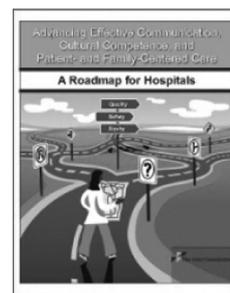
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Appendix

The Joint Commission new and revised standards

The following are the *new and revised* Standards and elements of performance for Patient-Centered Communication extracted from the Pre-Publication Version of The Joint Commission. They apply only to the Hospital Accreditation Program at this time. Go to www.jointcommission.org/.../Post_PatientCenteredCareStandardsEPs_20100609.pdf.



Pictured here is the Implementation Guide that accompanies the new and revised standards. Available for downloading at <http://www.jointcommission.org/NR/rdonlyres/87C00B33-FCD0-4D37-A4EB-.21791FB3969C/0/ARoadmapforHospitalsfinalversion727.pdf>
Standard HR.01.02.01. The hospital defines staff qualifications.

Elements of Performance for HR.01.02.01

NEW: Note 4. Qualifications for language interpreters and translators may be met through language proficiency assessment, education, training, and experience. The use of qualified interpreters and translators is supported by the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Title VI of the Civil Rights Act of 1964.

NEW Standard PC.02.01.21

The hospital effectively communicates with patients when providing care, treatment, and services. This standard emphasizes the importance of effective communication between patients and their providers of care, treatment, and services.

Elements of Performance for PC.02.01.21

NEW 1. The hospital identifies the patient's oral and written communication needs, including the patient's preferred language for discussing health care.

Note 1: Examples of communication needs include the need for personal devices such as hearing aids or glasses, language interpreters, communication boards, and translated or plain language materials.

NEW 2. The hospital communicates with the patient during the provision of care, treatment, and services in a manner that meets the patient's oral and written communication needs.

Standard RC.02.01.01

The medical record contains information that reflects the patient's care, treatment, and services.

Elements of Performance for RC.02.01.01

NEW 1. The medical record contains the following demographic information:

- The patient's name, address, date of birth, and the name of any legally authorized representative
- The patient's sex
- The legal status of any patient receiving behavioral health care services
- The patient's communication needs, including preferred language for discussing health care

Note: If the patient is a minor, is incapacitated, or has a designated advocate, the communication needs of the parent or legal guardian, surrogate decision-maker, or legally authorized representative is documented in the medical record.

NEW 28. The medical record contains the patient's race and ethnicity.

Standard RI.01.01.01

The hospital respects, protects, and promotes patient rights.

Elements of Performance for RI.01.01.01

NEW 28. The hospital allows a family member, friend, or other individual to be present with the patient for emotional support during the course of stay.

Note 1: The hospital allows for the presence of a support individual of the patient's choice, unless the individual's presence infringes on others' rights, safety, or is medically or therapeutically contraindicated. The individual may or may not be the patient's surrogate decision-maker or legally authorized representative.

Note 2: The hospital prohibits discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression.

NEW 29. The hospital prohibits discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex sexual orientation, and gender identity or expression.

Standard RI.01.01.03

The hospital respects the patient's right to receive information in a manner he or she understands.

Elements of Performance for RI.01.01.03

NEW 2. The hospital provides language interpreting and translation services.

Note: Language interpreting options may include hospital-employed language interpreters, contract interpreting services, or trained bilingual staff. These options may be provided in person or via telephone or video. The hospital determines which translated documents and languages are needed based on its patient population.

NEW 3. The hospital provides information to the patient who has vision, speech, hearing, or cognitive impairments in a manner that meets the patient's needs.