Myths are popular beliefs that are false or unsupported by facts.

Misconceptions about augmentative and alternative communication (AAC) continue to keep people with complex communication needs (CCN) from getting the help they need when they need it. Regrettably, far too many of these myths and misconceptions are still being perpetrated or perpetuated by speech-language pathologists (SLPs). Clinicians in hospitals, clinics, schools, rehabilitation programs, private practices and care facilities are joined by physicians, teachers, nurses, professors and other practitioners in fostering unfounded perceptions about AAC.

All this is happening in an area of practice where people must really depend on knowledgeable professionals to help them make decisions about what to do. Your uncle Charlie is likely to know very little about the world of communication disabilities unless and until someone he knows has a condition that makes it difficult to produce intelligible speech. And what could Charlie tell you about AAC? Forget it.

What are some of the current myths and misconceptions that undermine the use of AAC treatment approaches today? Why do they persist despite 30 years of evidence that counters them? What impact do these myths and misconceptions have on people with CCN? How can we dispel them? What responsibilities do AAC professionals have in changing the perceptions of families and professionals who impede or postpone access to AAC services?

This issue of Augmentative Communication News aims to address some of the misconceptions people have about AAC. The goal is to provide information that can be used to respond to the concerns of individuals with CCN and their family members, as well as to those of the professionals who work with them but may know little about AAC.

Young Children
False beliefs, widely held

It is in the first three years of life that a child’s brain is producing most of the new synapses (pathways between brain cells) that will appear in his or her lifetime. . . Those synapses that are used repeatedly tend to become permanent. Those that are not activated tend to disappear. It is also in the first three years that the child makes the most dramatic gains in language. There is an explosion in vocabulary and sentence use.

An intervention delayed beyond the first three years of life may be an intervention with a far less significant impact. Research now shows that children have the potential to learn faster and more easily when they are young—this is just as true for children with disabilities. Early intervention programs are widely accepted as especially necessary for young children at risk for severe communication impairments.

In a recent article entitled “Augmentative Communication and Early Intervention Myths and Realities,” Romski and Sevcik conclude that, based on what we know today about language and communication development and about the efficacy of AAC treatments, it is reasonable for young children with CCN to receive AAC services during their early development to augment their natural speech and to support their development of language and communication. These researchers listed myths they feel contribute to young children being inappropriately excluded from AAC services. Cress and
Other decision-makers by providing guidance to other professionals who work with these children and their family members, to aid in the clinical decision-making process. Another role is to talk openly about fears and address any misconceptions that influence this process.

The eight pages of this issue hardly scratch the surface of the many myths about AAC. The first two sections discuss myths about the use of AAC with Young Children and Adults with Acquired Disabilities. The third section addresses myths about Equipment. On the Web highlights a website aimed at dispelling myths about AAC.

**Common misconceptions**

Families of young children with CCN may find the decision to begin using AAC a difficult one to make. They often are heavily influenced by the recommendations of service providers. Thus, speech-language pathologists and other professionals who work with these children should be prepared to assist parents and other decision-makers by providing the best available evidence about AAC. Unfortunately, professionals may not always be aware of relevant research or may even choose to ignore it, as illustrated in Examples #1 and #2.

**Example #1. A “wait and see approach”**

Tony was a two-year-old child with autism spectrum disorder (ASD) who had no functional speech and did not use symbols to communicate (words, signs or pictures). He did, however, vocalize his pleasure, anger, etc. and used body language and some gestures to express his interest (or lack of interest) in objects, desire for certain foods and activities, etc. He responded to names of people/objects and simple commands (e.g., come here, stop, etc.), albeit inconsistently. Tony attended an infant/toddler program for children with disabilities. His mother had tried using “baby signs” and wondered if picture symbols might help him communicate, since he loves books. After an evaluation, the team (a speech-language pathologist, occupational therapist, behavioral psychologist and infant specialist) suggested taking a “wait and see” approach before introducing any AAC strategies. They said it was important to focus on getting Tony to “talk.” Not surprisingly, the family’s concerns that non-speech modes might interfere with Tony’s speech development were strengthened.

**Here’s what the experts say.** “No one treatment method has been found to successfully improve communication in all individuals who have autism… The goal of therapy should be to improve useful communication. For some, verbal communication is a realistic goal. For others, the goal may be gestured communication. Still others may have the goal of communicating by means of a symbol system such as picture board.” In a literature review, Mirenda reported that AAC approaches for children with autism do not interfere with speech, and that, in fact, speech often improves, as do language skills and behavior after the introduction of AAC approaches.

**Comment.** It is not reasonable to take a “wait and see” approach when a child is unable to communicate effectively now. Tony’s mother’s instincts to try signs and pictures/symbols were grounded in what she knew about her son and are substantiated by research and best practice. Personal biases and opinions that are refuted by existing evidence do not constitute best practice.

**Example #2. Picture symbols approach**

Deanna’s case, her family and teachers rejected the recommendation of the AAC team and decided to focus solely on remediating her speech problem. Both children, especially Deanna (whose severe dysarthria precludes her from ever developing intelligible speech), have lost valuable time in their language, literacy and communication skill development. They have also missed
out on important experiences with other children and on being active participants in their own learning. Families, teachers and professionals must work with facts, not myths or opinions, to make decisions about intervention. It is often up to an AAC team or professionals who work in the area of AAC to “sell” these facts to families and other services providers.

**Dispelling myths**

Some common myths about children that persist today are discussed below and summarized in Table I.

**Myth: AAC hinders or stops further speech development.** Speech does not decline or stop developing when AAC interventions are employed. In a comprehensive meta-analysis of AAC interventions and natural speech production in individuals with developmental disabilities, Millar, Light and Schlosser considered all published peer-reviewed studies between 1975 and 2003.8 Participants in these studies were mostly children with autism, mental retardation and other developmental disabilities (e.g., cerebral palsy). The AAC techniques employed included manual signs, low-tech displays and speech generating devices (SGDs). Results of this meta-analysis revealed that:

<table>
<thead>
<tr>
<th>MYTH AND MISCONCEPTIONS</th>
<th>THE EVIDENCE</th>
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<tr>
<td>AAC hinders or stops further speech development.</td>
<td>AAC approaches, e.g., signs, pictures, speech generating devices (SGDs), do not hinder speech development. In fact, speech often increases during AAC treatment approaches.</td>
</tr>
<tr>
<td>There is a representational hierarchy of symbols from objects to written words.</td>
<td>Children can learn to understand and use a variety of symbols at a very young age through repeated exposure to the symbol and its referent in natural contexts.</td>
</tr>
<tr>
<td>Children must have certain skills to benefit from AAC, e.g., be a certain age, have a particular cognitive level, etc.</td>
<td>There are no prerequisites for communication. AAC focuses on all aspects of communication and communication begins at birth. AAC is an appropriate intervention approach for anyone with complex communication needs (CCN).</td>
</tr>
<tr>
<td>AAC is a last resort and means professionals are giving up on speech.</td>
<td>AAC is within the scope of practice for speech-language pathologists. It is a &quot;front-line&quot; strategy for children with CCN.</td>
</tr>
<tr>
<td>SGDs are only for children with intact cognition. (See Equipment)</td>
<td>There are many types of SGDs. An AAC assessment can determine which device(s) and other AAC approaches can best meet the needs of a specific child.</td>
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No individual demonstrated decreases in speech production as a result of AAC intervention, 11% showed no change, and the majority (89%) demonstrated gains in speech.9

In addition, their analysis showed that increases in speech production did not always occur immediately after initiation of the AAC intervention. “In 21% of the cases reviewed, speech gains were observed after a lag of 6–25 sessions.”10

These researchers concluded that the fears of parents and professionals about the potential negative impacts of AAC intervention on speech production are completely unfounded. In fact, there is empirical evidence to support the counter claim that AAC intervention actually facilitates the production of natural speech. The evidence also reveals that AAC interventions can have significant benefits on the development of communicative competence and language skills.

Others have reported similar conclusions.2,3,7 In short, current research strongly counters the myth that AAC negatively affects speech in individuals with developmental disabilities.

**Myth: There is a representational hierarchy of symbols from objects to written words.** The myth really is that young children can’t understand symbols, so they can’t

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**Example #2. An artificial choice**

At five years of age, Deanna was enrolled in a private kindergarten program that did not “offer” AAC services. She has cerebral palsy and severely delayed speech secondary to speech motor impairment (severe dysarthria). Her local school district assessment team had documented her receptive language at close to age level. Her expressive language was severely limited, as was her participation in class. Her best control site was her head although she preferred using her hands. The team recommended that Deanna receive AAC services with goals to (1) model the use of graphic symbols/text immediately across contexts (to build a large vocabulary), (2) purchase a speech-generating device (SGD) to use at school and in the community, (3) adapt and use a computer for academics and to play with same-aged peers and (4) train her primary communication partners to use various AAC approaches as appropriate across contexts. Deanna’s parents wanted her to speak. They believed that AAC would interfere with speech development, as did the private school staff. Attempts to counter their beliefs were unsuccessful. She remained at the private school for two more years, making minimal progress on her speech, language and communication goals.

At age 8, Deanna was enrolled in a school that offers AAC services. She now uses an SGD at school and low-tech communication displays with partner-assisted scanning. Her speech is still not functional; however, she is developing literacy skills and can generate simple messages. She has made friends in the school and is beginning to play an active role in her class. Her parents now support the use of AAC, including an SGD.

**Comments.** Professionals can help families avoid an “either” speech “or” AAC approach to intervention by making the evidence clear. When families are reluctant, it makes sense to agree to proceed slowly so the positive impacts of AAC approaches on speech, language and communication, as well as on academic and social development, can be demonstrated. Personal biases and opinions that are refuted by existing evidence do not constitute best practice.

**Continued on page 4**
use AAC strategies. Recent literature does not support the idea of a hierarchy. Rather, there is evidence that very young children (chronologically and developmentally) can learn to use “baby signs” and abstract symbols before they learn to talk.\textsuperscript{11,12} Research also shows that very young children with CCN are able to use digital photos, abstract symbols and speech output devices during play and other activities and while reading books with trained adults.\textsuperscript{13} Providing repeated access to symbols embedded in meaningful, interactive contexts enables children with CCN to develop language and communication skills, albeit not all at the same rates, of course.

Exactly how children acquire and learn to use nonspeech symbols is still being sorted out.\textsuperscript{14} Key instructional strategies are still being defined. Even so, research suggests that with repeated exposure and modeling, some children with CCN can learn to use symbols embedded in meaningful, interactive contexts in their first year of life.\textsuperscript{13}

Myth: \textit{Children must have certain skills to benefit from AAC (be a certain age, have a particular linguistic/cognitive level, etc.)}. There are no basic prerequisites to communication beyond being conscious.\textsuperscript{15} Likewise, there are no prerequisites to AAC.\textsuperscript{4} Human beings don’t have to earn the right to communicate. As Cress and Marvin point out:

\begin{quote}
Beginning communicators have historically been considered too young or too pre-linguistic and therefore have not been introduced to AAC systems until behaviors, thought to be prerequisites, have been noted. Recent research and theories about early communication development have challenged this traditional practice and broadened the scope of what is considered to be AAC.\textsuperscript{16}
\end{quote}

No one, at any age, relies solely on speech to communicate. We all use multiple modes throughout life. Infants use gestures, vocalizations and body language, and their signals are interpreted by their caregivers. That’s the beginning of communication. As children grow and develop, their communication needs expand, and so must the modes and communication strategies they will use. Emerging evidence shows that the sooner AAC interventions are begun, the better the speech, language and communication outcomes are likely to be.\textsuperscript{2,3,11,13}

That said, while there are no prerequisites to communication or AAC as a treatment option, there are certain skills needed to use specific types of AAC techniques, technologies and strategies. For example, to use manual signs requires moving one’s hands and fingers (and having a partner who understands signs); to use a complex SGD may require an ability to spell or select symbols to generate utterances, and so on.

**Myth: AAC is a last resort and means professionals are giving up on speech.** AAC is a widely recognized intervention for severe communication impairments in children.\textsuperscript{17} It is within the scope of speech-language pathology practice and a front-line treatment for children at risk for severe communication impairments.\textsuperscript{18} As soon as severe communication problems are identified, the evidence shows that professionals should consider AAC interventions to enhance and support speech and to allow language to develop.

**Summary**

A paradigm shift in our understanding of the way the brain works and how language develops has drastically changed best practice in speech-language pathology. It is the responsibility of the practicing professional to be aware of current research and to adapt to these shifts in best practice.

**Adults with Acquired Disabilities**

**Myths and misconceptions**

Myths and misconceptions about AAC continue to impede adults with acquired disabilities who have complex communication needs (CCN). While the general public knows about hip and knee replacement surgeries and understands the role of many prescription drugs, few know about AAC for adults until they, or someone they know, lose the ability to produce intelligible speech.

AAC treatment approaches have benefited adults with a variety of chronic and degenerative diseases and conditions for decades. Sadly, however, many individuals with acquired disabilities today are denied access to AAC because medical professionals in their communities are either not aware of AAC as a treatment approach or choose not to offer it to their patients and clients.

Beukelman, Yorkston and Garrett capture some of the false beliefs of family members, speech-language pathologists, physicians and other professionals.\textsuperscript{19} They, and others, continue to provide evidence to dispel many of the myths that interfere with AAC services for people with chronic acquired conditions and degenerative neurological diseases.\textsuperscript{20}
Chronic acquired conditions. AAC is an effective way to treat the CCN of adults who have had a stroke, injury or medical condition (e.g., disease, surgery) that results in severe speech and language impairments. Thus, AAC interventions are offered in intensive care units (ICUs), hospitals and rehabilitation centers, as well as in long term care facilities and people’s homes. They may be implemented for just a short time or, when necessary, over the long term, to help individuals with a variety of chronic conditions maintain important relationships with their family and friends and maintain at least some of the adult roles they enjoyed prior to acquiring their disability. The evidence shows that AAC strategies are widely used by individuals with:

- Severe aphasia (e.g., communication displays and books, maps, gestures, photos, calendars, topic setters, alphabet boards, AAC devices). 21
- Locked-in syndrome (both low- and high-tech). 22, 23
- Traumatic brain injury, Guillain-Barre, etc. (both low- and high-tech). 24, 25

In short, when adults with chronic acquired conditions have CCN, appropriate AAC treatments should be introduced, modified as the person improves and maintained over the long term, as needed.

Degenerative neurological conditions. People with amyotrophic lateral sclerosis, multiple sclerosis, ataxia, dementia, etc. may gradually lose their ability to speak, as well as struggle with language and cognitive deficits that affect communication. The research shows that AAC approaches are effective in treating their communication problems and can enable individuals to remain more independent, as well as maintain their social networks and fulfill desired roles within their families and communities. 26 In addition, AAC approaches can help individuals participate in decisions about their health and end-of-life care. The research shows that

- People with ALS should receive AAC services well before speech becomes unintelligible. 26
- The critical time to refer for an AAC assessment is now predictable by monitoring rate of speech. 27
- More that 95% of people with ALS accept and use SGDs until a month or so before death. The average time of use is more than two years. These individuals also find low-tech strategies helpful. 24
- Individuals with multiple sclerosis, progressive aphasia, ataxia and other degenerative neurological conditions with CCN benefit from the use of AAC intervention. 26
- People with dementia benefit from the use of a range of AAC strategies to both support communication and improve organization and daily functioning. 29

In short, the efficacy of using AAC with adults who have degenerative diseases is well-documented in peer-reviewed publications.

Common misperceptions

Most of the myths about AAC discussed earlier also pertain to adults with acquired disabilities and are contradicted by research evidence. For example,

- AAC does not interfere with the return of speech after a stroke, illness or injury or hasten the loss of speech from a degenerative disease. It is much easier to talk than use AAC approaches; and people who can use their speech do so, even when it is impaired.
- There are no prerequisites for using AAC. Although there are many variables to consider in an AAC assessment, there are no cognitive, physical or situational conditions that have to be met to introduce AAC treatment. 20 There are, of course, specific skill sets required to operate different types of AAC devices, techniques and strategies.
- AAC is not a therapy of last resort. It is a mainstream approach to the treatment of CCN. It can be used in conjunction with therapies aimed at restoring and maintaining speech and language skills. 18

Service delivery systems for adults with acquired disabilities are often fragmented because AAC interventions are carried out in many different settings (ICUs, hospitals, rehabilitation centers, home health agencies, private practices and long-term care and palliative care facilities). In Example #3 on page 6, Mr. Jones and his family faced an unexpected barrier when they decided to explore AAC. His physician was unaware of the benefits of SGDs and his speech-language pathologist was focused on swallowing. Neither was supportive of AAC services, despite the wide recognition of AAC as “best practice” in the literature and by professional organizations. Luckily, the Internet was a wonderful resource for the family and, in the end, Mr. Jones’ physician was supportive. In the future, it is likely he will refer patients with ALS to SLPs who can meet his patient’s communication and swallowing needs.

Dispelling myths

Myths about AAC services for adults with acquired disabilities relate to common misperceptions among professionals and agencies.

Myth: AAC is not a speech language pathology service. Therefore, SLPs can discharge people who require AAC from their caseloads. The American Speech-Language-Hearing Association’s Scope of Practice for SLPs (2001) lists 13 areas under the Scope. Second on the list is AAC:

Establishing augmentative and alternative communication techniques and strategies including developing, selecting, and prescribing of such systems and devices (e.g., speech generating devices). 18

SLPs who work in facilities where people with acquired disabilities are served should be providing AAC services or making appropriate referrals. However, this is often not the case. For example,
A county hospital in an affluent area where many people choose to retire has an active rehabilitation department that offers inpatient and outpatient speech-language therapy, occupational therapy and physical therapy services. Despite the availability of a team, the speech-language department does not offer AAC services. According to a supervisor, the department focuses “on the restoration of speech, not on compensatory intervention approaches.” There is no other facility in the area where adults with acquired disabilities can get help if they have CCN. This means that each family has to struggle to find someone to help them.

Aren’t facilities that purport to provide services to adults with degenerative conditions and chronic acquired disabilities responsible for helping people compensate for their losses? AAC treatment is an important component of rehabilitation services. Maintaining the ability to communicate is often the key to one’s quality of life:

“If all of my possessions were taken from me with one exception, I would choose the power of communication, for by it I would regain all the rest.” Daniel Webster

Myth: Only AAC specialists have a role in the provision of AAC services. There is no “specialty recognition” for SLPs who provide AAC services. Assistive technology specialists may or may not know much about AAC. While not all SLPs develop the passion or the competencies to work with complex AAC problems, basic interventions are not complicated, are within the scope of SLP practice and are easily implemented. When SLPs do not accept this responsibility, adults with acquired disorders are denied access to the services they need to communicate—services that are substantiated by evidence and widely accepted as best practice for people with severe communication disorders.

Mr. Jones developed ALS in his late 60s. His neurologist did not mention the possibility that he might lose his speech. When he began to have speech and swallowing problems, the doctor referred him to a speech-language pathologist for treatment. The family found references to speech devices on the Internet; however, the neurologist refused to refer him for an AAC evaluation and actively discouraged them from pursuing one. The speech-language pathologist indicated she did not “do” AAC. Luckily, a rehabilitation facility that offered high quality AAC was in his community and the family made a self-referral. The AAC assessment resulted in a recommendation for an SGD; and the paperwork required by Medicare was prepared. To everyone’s surprise, the physician refused to sign the prescription. The AAC team sent the physician several articles documenting the acceptance and use patterns of AAC technology by persons with ALS. Within a few days, the AAC prescription arrived, signed by the physician, along with a brief note—“Thanks for the update.”

Comment. Professionals may not always be aware of research about AAC or about the positions of their professional associations on AAC as an approach to treatment. For example, neither the physician nor the speech-language pathologist were adequately informed about the benefits of AAC or their responsibility to facilitate access to AAC technologies. According to the National Institute of Neurological Disorders and Stroke:

As ALS progresses, speech therapists can help patients develop ways for responding to yes-or-no questions with their eyes or by other nonverbal means and can recommend aids such as speech synthesizers and computer-based communication systems. These methods and devices help patients communicate when they can no longer speak or produce vocal sounds.

According to the American Speech Language Hearing Association, the role of the SLP in ALS is as follows:

As it becomes more difficult to understand the speech of a person with ALS, therapy focuses on teaching strategies and techniques to maintain functional speech such as slowing down speech or using a communication aid to supplement speech. The eventual focus of therapy is on selecting and using augmentative and alternative communication (AAC) aids (e.g., speech synthesizers, computer-based communication systems, responding to yes-no questions with eye movements) and other non-verbal techniques to express one’s ideas and needs. Therapy never focuses on strengthening muscles, as exercise to fatigue can actually hasten neurological deterioration. Additionally, speech drills can be so tiring that the person is too fatigued to use speech muscles for communication purposes.

Myth: Speech generating devices (SGDs) are only for children and adults with intact cognition. As discussed earlier, the literature is rich with case examples and research studies that demonstrate that children with developmental disabilities, including those with significant cognitive disabilities, can and do learn to use SGDs to communicate. Research also shows that many adults with acquired disabilities use SGDs to meet at least some of their daily communication needs. There are more than 100 SGDs on the market today with a variety of features—something for almost everyone. At one end of the spec-
Here are some things I am tempted to say when out and about in the community:

- This? (referring to my device). It is a toy, a video game.
- The reflective dot I wear on my head is a Hindu ornament (referring to my HeadMouse® dot).
- I operate my device telepathically.

Myth: There is a “perfect” device for every person. As Michael B. Williams has said, No one communication mode, no AAC device, no low-tech board, no gestures, signs or speech, could possibly meet all my communication needs all of the time. I use multiple communication modes. I communicate in many ways. I select the best mode depending on the location, with whom I am communicating and the purpose and content of the communication.32

Summary
AAC encompasses a range of communication technologies, as well as body-based modes. AAC intervention can help determine what approaches individuals need under which circumstances, and then help them get access to everything they need, and learn to use each method effectively.

BUT WAIT. There’s more. Go to www.augcominc.com
Read what AAC colleagues from around the world say about myths and AAC. Quotes from Sudha Kaul (India); Martine Smith (Ireland); Kit Dench and Nora Rothschild (Canada).

Also, link directly to some of the resources mentioned in this issue.
References


10. Ibid p. 258.


Resources

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