

COMMON AAC MYTHS - SORTING REALITY FROM UNTRUTH

By Patti Murphy

Sorting reality from untruth in decades-old myths can be a complicated but enlightening part of finding the right augmentative and alternative communication (AAC) solutions at any point in time. This article highlights three common myths that may surface while making AAC decisions.

MYTH #1: AAC USE INTERFERES WITH THE DEVELOPMENT OR USE OF TYPICAL SPEECH

Speech-language pathologists and autism specialists often told Kellie Roberts that her son, Chad, stood a greater chance of developing his natural voice without AAC interventions.

"I didn't know any different for a long time," said Roberts of Canton, Georgia. The instructional approach emphasizing verbal speech used in the preschool program for children with autism that Chad attended did not suit him. "I wanted it to work so bad," Roberts said. "There was nothing I wanted more than to hear my child's voice."

While growing up, Chad experienced mixed results when using picture symbols to communicate. Inconsistency among symbol sets used at home, school and therapeutic settings often left him confused or angry, trumping the advantages of having a concrete tool for self-expression. The same sort of thing happened when Kellie Roberts cut pictures from groceries, like cereal boxes, so Chad could request favorite foods. Aggressive behaviors – like waking his mother and leading her by the hand to the refrigerator or car when he wanted to eat or go for a ride at night – became his primary way to get a point across. Then, at age 10, Chad used a speech-generating device, the DynaMyte 3100, for the first time. The pairing of its synthesized voice output with dynamic-display technology offered a calming effect and sense of instant gratification that helped him make sense of language and reduced stress in his interactions, Kellie Roberts said. Communication partners grew more respectful of the limited number of verbal approximations he developed while using it. "It took a very long time," she said. "He can't talk, but I know he can communicate."

Sue Schindler of Cincinnati, Ohio experienced similar breakthroughs as daughter Katy worked her way around communication challenges related to cerebral palsy and cognitive delays. The private speech therapy practice, where Katy received services as a toddler, upheld a philosophy that rewarded children for speaking conventionally. One incentive involved blowing bubbles. A therapist recited lines from a script – "Time for bubbles," "Open the lid," "Pour out the liquid," and "pull out the wand," for example. Parents repeated the lines, as each child was expected to do before performing each step of the drawn-out activity. Schindler was not sure that it held Katy's attention. Nor did she feel comfortable when therapists advised using the rewards system at home. "My feeling was that if a child has the ability to talk, they will. There would be no way that I would deny Katy a glass of milk because she couldn't properly pronounce it," said Schindler, a former special education teacher who now works as a disability advocate.

Early on, Katy and communication partners, who did not consistently understand her natural speech, benefited from a variety of AAC tools. She activated a talking frame, containing her picture, to break the ice with new people and uttered simple messages using static-display speech-generating devices. Another speech therapy group referred Katy to an AAC specialist who evaluated her for a device with a dynamic display. Katy, now 16, got a DynaMyte at age five and a DynaVox MT4 about five years later. Hearing Katy talk in synthesized utterances left Sue Schindler with a bittersweet feeling at first, but she knew the technology was just what her daughter needed. Before these AAC tools, and lacking a more reliable way, Katy had engaged potential communication partners through biting or pinching. "We never realized that her intent was communication versus hurting others," Sue Schindler said. "Once Katy had AAC in place, most of the very aggressive behaviors disappeared." Katy is at her best, she said, when she can let others know what motivates her – whether it's their company, an activity or a place. That, in turn,

has motivated Katy to take ownership of the technology as her voice.

Whether high-tech, light-tech or unaided, AAC methods may promote meaningful interaction in unison with speech. "It is rarely that one or the other is used exclusively, said Kim Milstead Ingram, M.Ed., CCC-SLP, the lead speech-language pathologist at the State Supported Living Center in Austin, Texas. "It is the practitioner's job to clarify that AAC facilitates the acquisition of language, and the most natural and effective mode of communication for a particular individual."

Almost all parents new to AAC ask whether it will hurt their child's chances of talking and a surprising number of clinicians express doubt that it will help, said Vicki K. Clarke, M.S., CCC-SLP, president of Dynamic Therapy Associates, Inc., a Kennesaw, Georgia-based speech therapy practice. Some begin to change their minds when she tells them about research spanning more than two decades that substantiates the AAC-speech correlation. "The problem lies with parents and professionals who never ask the question and simply assume they know the answer."

People struggle with the link between AAC and speech for various reasons.

"Talking is one thing that parents really strive for because that need for normalcy is so important for the parent in early stages of coping with a diagnosis," said Tina Murphy, M.S., CCC-SLP, a speech-language pathologist and AAC specialist with Florida's Palm Beach County Schools. She also encounters teachers who expect children using devices in the primary grades to strive for grammatical perfection when composing a simple request for a cookie. "I often have to explain that these kids should be responding and requesting in the same manner as other children their developmental age," she said. "Even as adults, we don't usually respond in full sentences."

MYTH: #2 AAC HAS LITTLE, IF ANY, BENEFIT FOR INDIVIDUALS WITH PROFOUND INTELLECTUAL CHALLENGES

Questions this myth has long raised for researchers and practitioners include:

- Are there cognitive skill prerequisites for AAC use? (Examples: recognizing cause-and-effect relationships, understanding the means to an end and object permanence – knowing that objects exist even without sensory evidence, such as seeing, hearing or touching them.)
- Can expectations influence outcomes when the person using AAC has intellectual challenges?

Underlying the questions is the presumption that AAC typically benefits those with greater intelligence, though AAC use (particularly light-tech tools and strategies) has become more common since the late 1980s for people believed to have profound cognitive disabilities. Newer research similarly notes the historical prevalence of the belief that such individuals benefited most from unaided communication systems while aided systems primarily benefited those with severe physical disabilities, with or without cognitive impairment (Hourcade, Everhart Pilotte, West, & Parette, 2004).

That way of thinking remains challenging today.

Clarke said sometimes AAC possibilities are discounted for such an individual even while physical challenges are accommodated. "So we give them the \$20,000 wheelchair with the Cadillac features. This is the same child who we give the single message switch for communication. It just doesn't make sense that we give the least technology to the neediest individuals." Having just one option for conveying many thoughts can be demeaning, Clarke said.

Practical issues also come into play for someone with cognitive deficits. "They probably have less ability to problem solve and compensate for their communication difficulty without the advanced features of dynamic display devices," Clarke said, citing the example of auditory messages helping a person with weak visual processing skills to learn the corresponding visual images and ultimately, what a message means. Using motor memory to recall the location of images and reproduce messages also helps many people to learn their AAC systems, she said.

Like all communication, AAC is interdependent by nature. During our interactions, we know that others are listening when they ask questions or tell us to continue. Such responsiveness – along with cues for when and how to communicate – are especially important for augmented communicators with cognitive

issues, with support and prompting to facilitate interactions fading over time.

There may be a risk in over- or underestimating one's cognitive abilities. "Clicking a mouse button to change Web pages or to play a game is a lot different than formulating a thought in your head and finding the correct words on a device to relay that thought," Tina Murphy said. "I had a student who seemed to understand linking and categories and had a good vocabulary, but when it came right down to it, really did not have the ability to use any of that knowledge for communication purposes without being given a model or high-level prompts." Some students with autism, she said, demonstrate an affinity for technology but little concept of its potential role in social exchanges.

Students also surprise teachers in positive ways. "Give a child something to say and a way to say it and voila! Out comes communication. When that child realizes the power that they have once they start using a device, there is no end to what they might say," Murphy said.

The lessons of AAC may be limitless. "It's OK if the technology functions at a higher level than the individual. Sometimes it has to," Roberts said. "Chad will be learning for a very long time, as we all will."

Integrating the three devices Chad has used into everyday situations – from conversations with company at home to telling how his day went at the pizza shop or law office jobs he has through his high school-to-work transition program – has been a trial-and-error process, she said, but the mental retardation that complicates his autism does not block learning. As the DynaVox V, his current device, leads him to the words and phrases, his fingers are waiting to produce messages articulating what's on his mind.

She is perhaps most grateful for an intangible lesson of his AAC use. "The device makes him seem more typical and gives higher expectations to his communication partners."

Ingram echoes that thought. Once devices are implemented, the adults with intellectual challenges her team serves tend to find more opportunities to interact, with or without assistance in communication exchanges. Another improvement: "We often see decreases in negative behavior in people who use this equipment because they have the ability to express preferences and make choices."

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MYTH #3: AAC TECHNOLOGY SOLVES ALL COMMUNICATION PROBLEMS

Katy Schindler is having one of her best years, communication-wise, thanks in great part to her seasoned support team at Princeton High School, said her mother. Conversations the new principal initiates with Katy's staff lend new appreciation for the technology that ensures Katy a voice.

This is not overnight success, Sue Schindler said, but a work in progress, likely to shatter without commitment from adults who make sure Katy uses her MT4 throughout the day. As a parent and in her career, Sue Schindler has often known school teams to encourage device use when students are hungry or doing class assignments, letting opportunities for social communication slip away. "I'll ask if they use their voices at times besides snack time or when they're doing work that requires high concentration. At that point, they start to understand the importance of communication device use."

Understanding that AAC in any form is a means, not the end, of language and communication skills acquisition (Romski & Sevcik, 2005) can be hard. Quick fixes may be popular, but technology and the human resources behind it are imperfect. It takes time for indi-

viduals and their communication partners to develop AAC skills and, usually, to accept their way of communicating. Those reliant on AAC gain linguistic, operational, social and strategic competencies considered necessary (Light, 1989) for successful communication at varying rates. Limits inherent to the technology – its speed, artificial nuances of even the more realistic and pleasant-sounding synthesized speech, and limited availability of vocabulary in some cases, for instance – present challenges. There are also inconsistencies from generation to generation of the technology to deal with, Schindler said.

Ingram and her team train communication partners to have realistic expectations as a friend or loved one adopts a device as their voice. These include allowing ample time for message completion, honoring the person's preferred level of assistance and responding to messages spoken through the device.

Transitions to AAC require a balanced perspective. "There is a fine line between realistic expectations and having high enough expectations that the child starts using it" and language skills are an important part of the equation, Murphy said. "A student in fifth grade should not always be communicating in one-word answers just because that is what others understand."

Clarke, who is Chad Roberts' speech therapist, said Chad may not understand all the vocabulary on his device, but understands the positive response he gets by conveying messages clearly. Kellie Roberts is thrilled with the habit of expressing likes and dislikes in full sentences her son has acquired through consistent device use. "I used to think that if you showed Chad a picture, then of course he would be able to communicate. But what made sense to me was different than what made sense to him." Conversation for its own sake is not so motivating for Chad, and he has trouble expressing himself when sick or angry. But meaningful communication is possible if you catch him before the anger escalates, Kellie Roberts said, an example of the human element that completes technological solutions. "Partners are important."

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