AT – IN DEPTH

Challenging our belief systems regarding people with autism and AAC: Making the least harmful assumptions

By Joanne M. Cafiero

In this issue, our featured columnist is Joanne Cafiero, Ph.D., Autism and AAC Consultant, Cafiero Communications, LLC, Rockville, Maryland. Join us, as Joanne challenges the reader to ask, "What are the most common assumptions AAC practitioners make concerning people with Autism Spectrum Disorders (ASD)? What do the terms "low functioning," "no communicative intent" and "language and cognition not measurable" mean? How do those terms impact the quality of AAC supports and interventions that are provided? This article will challenge these and other limiting terms and world views and hopefully provide another belief system from which a practitioner can operate."

What are the most common assumptions AAC practitioners make concerning people with Autism Spectrum Disorders (ASD)? What do the terms "low functioning," "no communicative intent" and "language and cognition not measurable" mean? How do those terms impact the quality of AAC supports and interventions that are provided? This article will challenge these and other limiting terms and world views and hopefully provide another belief system from which a practitioner can operate.

For over fifteen years, AAC supports have been provided for individuals with ASD. Prior to this time, implied but not identified AAC in the forms of visual schedules and prompts were found to be effective in self-management, dealing with transitions and simple communication. A diverse and substantial body of research supports AAC for individuals with ASD: Functional Communication Training with AAC (Mirenda, 1998), Aided Language Stimulation (Goossens', Crain & Elder, 1992, Dexter, 1998), Natural Aided Language (Acheson, 2006; Cafiero, 2001, 1995), Picture Exchange Communication (Bondy & Frost, 2001), the System for Augmenting Language (Romski & Sevcik, 1996, 2006), and AAC with SGDs (Schepis et.al, 1998). In addition, the characteristics of AAC and the learning styles of individuals with ASD interface. Table 1 (below), shows this correspondence.

Autism and intelligence

In the current version of DSM-IV-TR it is noted that "in most cases, [in autism], there is an associated diagnosis of mental retardation which can range from mild to profound." (APA, 2000, p.71). In fact, in previous versions of this manual, mental retardation was noted to occur in 70-75 percent of all children diagnosed with ASD. Interestingly, however, in 1943, when Dr Leo Kanner first described individuals with ASD, he stated, "even though most of these children were looked upon, at one time or another as feebleminded, they are all unquestionably endowed with good cognitive potentialities." (p.247). Kanner's statements were based on observation, however, in 1958, another study collected empirical evidence that showed mental retardation to occur in 30-40 percent of the children. What is

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Learning Styles in ASD	Features of AAC
Visual processor	Visual cues
Difficulty with change	Static and predictable
Motor difficulties (apraxia)	Simple motor act required
Interest in inanimate objects	nanimate objects are tools
Difficulty with socialization	Buffer and bridge between communication partner

Table 1.

responsible for this obvious discrepancy of 40 percentage points? In a systematic evaluation of data regarding mental retardation and autism, it was found that 74 percent of the claims came from invalid sources, 53 percent of which were completely unsubstantiated. How could this happen? First it was found that tests administered to children in these studies were developmental measures and did not truly measure cognition. Secondly, many of the tests were language based and therefore inappropriate for children with ASD. Third, the interference of autistic symptoms masked cognitive abilities, and in many cases, an unanswered item on a test was considered a failure. (Edelson, 2006). What appears to have evolved is a context and culture among Special Education practitioners that assumes mental retardation is a likely feature in autism.

The least dangerous assumption

In 1984, Anne Donnellan introduced the concept of "the least dangerous assumption." This means that... "In the absence of absolute evidence, it is essential to make the assumption that, if proven to be false, would be the least harmful to the individual." This implies a deep humility of the part of the practitioner, and a profound respect for the individual with disabilities (1984).

An essential part of the Special Educators' mission is to make decisions for our students based on information and assumptions. We write IEPs, conduct assessments, develop and adapt curriculum, create communication systems, and provide AAC tools and services. What are our belief systems concerning students with ASD and how do these beliefs and assumptions shape our practice? In a research study with a sample of 8 special education ASD practitioners, it was found that those practitioners who believed their students to be more cognitively and communicatively able, had more

complex curricular adaptations, a more visually engineered environment, and students engaging in more academic behaviors than practitioners with similar credentials but different belief systems (Cafiero, 2006). When in doubt, and with autism, there are always doubts, we must make the least harmful assumptions about our students.

Autism, AAC, and the least harmful assumption

The Center for Disease Control has just released its most recent statistic: the incidence of autism is now 1 in every 150 children. In December, the Combating Autism Act was passed, allocating 2 billion dollars for autism research and intervention over the next 5 years. This is a 50 percent increase over past funding levels. Will AAC interventions and tools be funded or some of funds go to less empirically validated, but better marketed strategies? As Special Educators and AAC practitioners we are stakeholders in these developments. Making the least harmful assumption will insure that our students will have access to the tools needed to exercise their most basic human right: the right to communicate. Making the least harmful assumptions will also impact the kind of AAC tools and strategies that we recommend for students with ASD.

Compelling Issues to Consider

• Motor planning

As special education practitioners we are trained to observe our students and make assumptions based on those observations. We are also trained to utilize standardized assessments, which may support or refute our observations. We operate within this context: If the student knows it, she will be able to show it. In autism, however, the difficulty with motor planning seriously impacts the student's ability to show what

they know. In a sample of children collected by Greenspan (1992), it was found that half of all children with ASD had severe motor planning dysfunction. This means that they could not show what they know. Adults with ASD report that they feel an actual "inertia" and are often unable to initiate an action. (Sullivan, 2002). AAC requires motor planning and practitioners must address this difficulty in both the assessment and intervention process.

• Unconventional learning trajectories

ASD practitioners know that each student in the spectrum is an individual with unique learning styles and sequences of skills acquisition. We simply cannot superimpose typical communication development on the developmental sequences of students with ASD. In addition, it is critical to note that different learning styles and trajectories do not mean deficient learning styles and trajectories.

• Challenging behaviors

Challenging behaviors are most often the result of an inability to communicate. These behaviors become habitual ways of responding when a person with complex communication needs is not provided with AAC. Sadly, these challenging behaviors become the rationale for NOT providing an AAC intervention. Practitioners reason that behaviors must be brought under control before AAC is introduced. Or that it is not safe for an aggressive person to have an AAC device. These belief systems set in motion a cycle of despair for both the practitioner and the student. Whether young or old, aggressive or passive, or even a previous history of AAC failure, every person is entitled to the tools for communication. It is our task, as Special Educators and AAC practitioners to be inventive as we address these behavioral challenges while providing appropriate AAC.

• Facilitated Communication (FC)

Dare we mention the "FC" word? Facilitated Communication is a prompting strategy that fell into disrepute in the last decade. While not empirically validated, small qualitative studies report individuals with ASD who transitioned from the physical support of facilitation to independent typing communication. It is difficult not to be haunted by those reports. FC is a strategy

that assumes within each person with ASD is relatively intact, but locked language. It is the opinion of the writer that the AAC practitioner adopts the FC philosophy of innate communicative potential of the individual.

Changing our assumptions: Enhancing our practice

• Assessment

How do assessments shape our practice? The literature review on autism and mental retardation mentioned above shows that incomplete, non-validated information shaped not only DSM-IV's criteria for ASD but also an entire professional culture and mindset. In addition, the issues of motor planning, receptive and expressive language differences negatively impact assessment. It is critically important to identify communication needs and the ways to address these needs. Social Networks (Blackstone & Berg), primarily utilizes a model of concentric circles of existing and potential communication partners, rather than what a person can or cannot do communicatively. This assessment is open-ended enough to consider the student with utmost respect, and recommend interventions that address the people and places communication needs to occur.

• Eligibility

Who is eligible for AAC? Any person with complex communication needs, regardless of age. From the first ASD diagnosis, communication is always the primary challenge for families. There is no reason not to provide AAC for our youngest children with complex communication needs. AAC can pre-empt the development of difficult behaviors and using AAC does not assume that the child is incapable of speech. Since there is a increasing body of research validating that AAC increases speech production, the fear that it inhibits speech has absolutely no validity (Romski & Sevcik, 2006; Cafiero, 2004; Dexter, 1998).

AAC practice: Some "out of the box" considerations

Interventions

• Picture Exchange Communication Systems (PECS)

PECS is often the first AAC intervention provided for children with ASD. Indeed, some beginning practitioners consider AAC to mean only PECS. While PECS is an elegantly structured, ABA strategy, it is primarily for communicative output. Receptive language (input) strategies are essential. How long does a student stay in PECS mode? In light of the impact of motor planning and sensory issues on communicative output, and compelling information on autism and mental retardation, it is imperative for practitioners to again, make the least harmful assumption when considering students for PECS and transitioning them from PECS to more complex systems. Assuming the potential for receptive language, PECS should be paired with receptive language input.

• The Augmented Input Strategies

The "augmented input strategies:" Aided Language Stimulation (Goossens', Crain, & Elder, 1992), Natural Aided Language, (Cafiero, 1995, 2001) and System for Augmenting Language (Romski & Sevcik,) all require that the speaking communication partner use the AAC tool for augmented input. These strategies intrinsically assume communicative potential. Augmenting input increases both augmented and spoken output of the AAC user (Cafiero, 1995, 2001; Dexter, 1998; Romski & Sevcik, 2006). In spite of the fact that the aided language strategies have been around for over 15 years and are empirically validated, it is not uncommon to walk into an autism classroom that is as quiet as a tomb. What are the assumptions in this case? The students have nothing to say? Staff are unskilled AAC facilitators? In other instances, AAC is provided and the student is expected to miraculously begin using the device. The assumption here negates the concept of communication as a partnership.

• Fine tuning Natural Aided Language

Creating communication tools and selecting vocabulary will be impacted by the practitioner's belief system. A rich vocabulary selection with nouns, verbs, adverbs, adjectives and culturally trendy comments assumes receptive and expressive communicative potential. In addition, AAC not only provides the venue for existing, but unexpressed language, but the stimulus for the development of non-existent symbolic language.

Providing receptive language input means the speaking partner is pairing key words with the symbols on a communication display or device. This language modeling is a seamless component of interactive communication. The speaking communication partner responds; he reinforces by repeating, expands by including new vocabulary and repairs by modeling a corrected communicative unit. Respecting the AAC user and the nature of the communication relationship implies that the speaking partner accept clear communication and not demand that the AAC user fix an incorrect, but clear exchange. Repairing can occur incidentally within the response by making a reflection statement with augmented input: "Oh, you mean you need your wallet." Communication partners need to accept clear communication without prompting more grammatically correct exchanges. In this way the flow of the interaction is not interrupted.

• Physical prompting within the augmented input strategies

Individuals with ASD have difficulty sorting out and responding to the most relevant cues, whether they are auditory, visual, or tactile. Therefore, physically prompting communication should be minimized.

Many students with ASD who have been physically prompted to use AAC consider the physical prompt an essential component of communication. They will grab a finger or hand of their communication partner while they are receiving or expressing language. This preempts the development of independent communication skills.

• Practicing with the AAC device

If a student plays with or 'stims' on a SGD, practitioners may remove the device or assess that it is not an appropriate AAC tool. Consider the behaviors of typically developing students and even practitioners when they first get their hands on a SGD. Everyone wants to "try it out." This is a normal response to novel electronics. Some practitioners consider playing with the SGD as "practice" and provide practice and exploration time for their students prior to engaging in communicative exchanges.

• Tests, quizzes and AAC

The third letter in AAC is "communication." Communication is not testing or drilling, but affective connection between two people. Beware of using a device for drills and practice. There have been reports of students rejecting their devices because they have been used for "work" rather than communicative interactions. The tool or device then becomes an aversive. If, and only if, the device is viewed by the student as his voice, it may be used for academic tests, but only with extreme caution and respect.

• Beware rigid timelines

Making arbitrary timelines, such as "I'll do this for two weeks and if I don't get any expressive language, this must be the wrong intervention" can be harmful. ASD presents with unpredictable, inconsistent and uneven learning profiles. The knowledge base of the neurological features that should guide our practice is meager at best. If the student does not respond expressively but attends to the communication display there is an indication of interest and some comprehension. The mantra should be "Don't give up." A parent of a now articulate teenaged AAC user reported to me that she used her child's SGD for 2 years, for receptive input before her child generated output. To cover all our bases and compensate for what we do not know about ASD, practitioners must use multi-modal AAC, always providing a quick and effective way for the student to communicate his/her most critical needs, while providing rich and natural language input that assumes communicative potential.

• Consider action research

Outcomes-based AAC interventions provided for people with ASD are necessary as good practice. In addition, with the passing of the Combating Autism Act of 2006 data will be mandatory for receiving funds for innovative research projects. Every AAC practitioner should consider contributing to the "big picture." This means sharing your work with the ASD and AAC community (through journals and conferences); whether it is original promising practices or replication of other research.

Summary

As Practitioners in the field of ASD and AAC, I believe we are on the crest of a breakthrough. We acknowledge what we don't know about each of our communication partners with ASD. And we acknowledge what we don't know about ASD in general. Then as AAC practitioners, we approach each of our communication partners with humility and openness. It is only when we make the least harmful assumptions about their communicative potential, can we open the door to the realization of this breakthrough.

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