

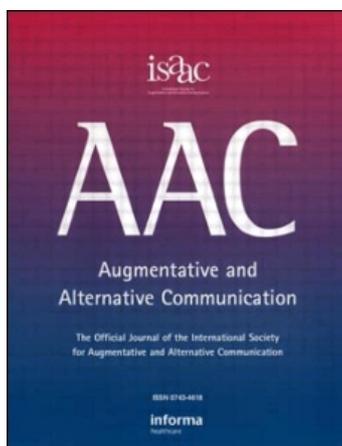
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### A Back Door Approach to Autism and AAC

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# A Back Door Approach to Autism and AAC

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The conventional view is that most individuals with autism or pervasive developmental disorder-not otherwise specified (PDD-NOS) have no significant motor impairments but do have severe intellectual disabilities. These assumptions impact the nature and types of augmentative and alternative communication (AAC) interventions that are typically provided, which tend to be narrowly focused on basic, functional communication skills such as requesting. However, recent research has provided evidence that challenges these assumptions and suggests the potential of intervention approaches targeting motor, language, and literacy development. The author encourages practitioners and researchers to examine current assumptions about autism and to invent and investigate new ways to support people with autism to communicate.

*Keywords:* Autism; Augmentative and Alternative Communication

## INTRODUCTION

From age 6 until I left home after graduating from high school, I lived with my family in a typical 1950s subdivision in northern New Jersey. All of the houses were the same except for the color (ours was grey and yellow) and the basement (some were finished, some were not). All had front doors that opened to the street and back doors that opened to a yard. From the moment we moved in to the house, my mother decreed that the front door was for visitors, who could be relied upon to wipe their feet and thus avoid tracking dirt onto the living room carpet; while the back door was for family, who could not be counted on to do so. Thus, every day, rain or shine, we all (even my father!) trekked around to the back of the house with our school books or grocery bags or whatever to enter the kitchen of our home through the back door.

Many years later, I moved into an apartment that (unlike most) had two doors as well. One day, shortly after I moved in, I invited a friend to dinner and drove to her house to pick her up because it was cold and rainy outside and she didn't have a car. I pulled up in front of my new home, parked, and proceeded to head toward the back door. "Where are you going?" my friend asked. "Inside," I

replied, "The back door is this way." "But why wouldn't you just go in the front?," she asked. The front?! It had never occurred to me to use the front door – even with a visitor in tow! My mother would have been proud!

This story might explain why, throughout much of my professional career, I have used a front door/back door analogy to talk about strategies for supporting students with autism spectrum disorders. To me, "front door strategies" are those that address a problem head-on and directly, and that are obvious under the circumstances. Teaching a child who cannot communicate to speak, or teaching a teenager who makes inappropriate remarks to peers what to talk about, are both examples of front door strategies. In contrast, "back door strategies" are those that are less obvious or direct, and that might even be considered a bit offbeat or controversial. Teaching a child who cannot communicate to read and write so that he or she can express himself or herself in this way, or teaching a teenager how to reduce the anxiety that leads to his or her inappropriate peer comments by using relaxation techniques, are both examples of back door strategies. Especially when front door strategies are ineffective or slow to show an effect, I have often found it useful to ask myself, "Is there

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another way we can make this happen, perhaps through the back door?"

There is no doubt that my back door mentality is what initially attracted me to AAC. First as a graduate student with David Yoder and later as a colleague with David Beukelman, I marveled as I saw people with severe disabilities being escorted through the back door to communication using various AAC tools and techniques. In what other field would someone think of teaching Native American hand signals to people with acquired disorders so that they can communicate (Skelley, Schinsky, Smith, Donaldson, & Griffin, 1975), or of fastening a laser pointer to the toe of a man with myasthenia gravis so that he can spell words on an alphabet display (Fager, Beukelman, Ball, & Jakobs, 2004)? For AAC practitioners, back door-ism has always meant thinking outside of the box, relentlessly searching for a solution even when one is elusive, and – most of all! – believing that there is always, *always* a path to better communication for this person, just around the corner.

Except. Except for individuals with autism spectrum disorders, especially those who are also presumed to be intellectually disabled. Yes, yes, I know we have made progress over the past 20 years in this regard – in most places, individuals with autism are no longer ineligible for AAC supports because they lack “prerequisite” skills, and in many places they at least have access to manual signing or PECS (the Picture Exchange Communication System; Frost & Bondy, 2002), and in some places they are even provided with simple speech-generating devices with a few symbols. I know all this and I applaud the many talented clinicians and researchers whose contributions have resulted in the advances we have made over the years. But is it enough? No. Have we moved forward as much as we could, or should, or need to? No, I don’t think so, not at all, and I think I know why: too much focus on the front door, not enough on the back.

## A FRONT DOOR VIEW OF AUTISM

According to the conventional, “front door view,” the pervasive developmental disorders (PDDs) – more commonly referred to as the “autism spectrum disorders” (ASDs) – include three primary variations: (a) Autistic Disorder (more commonly called simply *autism*); (b) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), “a collection of features that resemble autism but may not be as severe or extensive” (Dunlap & Bunton-Pierce, 1999, p. 2); and (c) Asperger’s disorder, a

diagnosis assigned to individuals who display the social criteria for autism, but have intact language and cognitive abilities. The ASDs occur in all racial, ethnic, and socioeconomic groups and are approximately four times more likely to occur in boys than in girls. A recent report by the Autism and Developmental Disabilities Monitoring Network indicated that about 1 in 150 8-year-old children in multiple areas of the United States are diagnosed with one of the ASDs (Centers for Disease Control and Prevention, 2007).

In general, the symptoms of both autism and PDD-NOS, according to the Diagnostic and Statistical Manual, 4th edition – Text Revision (DSM-IV-TR; American Psychiatric Association, 2000), include significant difficulties with social interaction; delayed or abnormal functioning in verbal and non-verbal communication; and unusual patterns of behavior (e.g. restricted interests, repetitive activities, stereotyped movements, and/or unusual responses to sensory stimuli). No specific mention is made of motor functioning, since motor impairment is not considered to be a “core feature” of ASD. In addition, although cognitive ability per se has never been part of the diagnostic criteria for ASD, both the 1980 and 1994 versions of the DSM noted that 70–75% of individuals with autism also have an intellectual disability (aka mental retardation) (APA 1980, 1994). In the current manual, the authors state that “in most instances, there is an associated diagnosis of mental retardation, which can range from mild to profound” (APA, 2000, p. 71). Finally, conventional estimates are that functional speech fails to develop in one-third to one-half of all individuals with ASD (National Research Council, 2001) and that the presence of useful speech by age 5 is highly predictive of later outcome (Lord & Bailey, 2002).

Given all of this, it is not surprising that teachers, speech-language pathologists, and other professionals assume that most children with ASD over the age of 5 who are unable to talk (a) have intact fine and gross motor skills; (b) have very delayed or disordered language skills; (c) are intellectually disabled to a considerable degree (i.e., at least in the “moderate” range); (d) are unlikely to develop literacy or other “academic” skills; and (e) may – with careful, systematic instruction – learn to use non-technical AAC systems or simple speech-generating devices (SGDs) that enable them to communicate basic wants and needs, at best. In other words, the “front door view” of ASD often results in low expectations (“We have to be realistic”), limited access to instruction in literacy and other academic skill areas (“We need to focus on functional life skills”) and highly structured

AAC interventions that, by virtue of their conservative nature, may place limits on long-term language and communication development.

## A BACK DOOR VIEW OF AUTISM

What's wrong with this picture? "Let me count the ways ...!" (Barrett Browning, 1986). To start, let's examine the (non)-issue of motor impairment in ASD.

### Motor Impairment

As noted previously, the DSM-IV-TR criteria for PDD do not include impairments that affect either voluntary or involuntary movement, despite the fact that even the earliest case studies by Kanner (1943) and Asperger (1944) included numerous descriptions suggesting the presence of impairments in these areas. The omission of this criterion is probably due to the fact that, on the surface, there is no obvious motor abnormality in ASD such as that seen in, for example, cerebral palsy; and because a number of studies have suggested that motor skills are relatively intact or even advanced in individuals with ASD (e.g., DeMyer, Barton, & Norton, 1972; Stone, Ousley, Hepburn, Hogan, & Brown, 1999). However, recent research challenges this suggestion. For example, Provost, Lopez, and Heimerl (2007) found that, out of 19 young children with ASD in their sample, none had gross or fine motor skills in the normal/average range on the Motor Scale of the Bayley Scales of Infant Development II (Bayley, 1993) and on all areas of the Peabody Developmental Motor Scales II (Folio & Fewell, 2000). Dyck, Piek, Hay, and Hallmayer (2007) reported a relationship between motor coordination scores and autism severity in a sample of 29 children with ASD and suggested that "processes underlying motor coordination have been underestimated in explaining [ASD] symptoms" (p. 258). With regard to speech development, Gernsbacher, Sauer, Geye, Schweigert, and Goldsmith (2008) provided convincing evidence that early oral- and manual-motor skills distinguish children with ASD from typically developing children; and also distinguish among children with ASD whose current speech is minimally, moderately, and highly fluent.

In addition, most studies of motor impairment until quite recently have employed simple, familiar tasks that place little or no demand on motor *praxis*. Praxis involves "ideation (conceptualizing what to do) as well as motor planning (organizing a plan of action in time and space), and requires problem solving in order to move in a novel

manner, as opposed to a familiar, previously practiced motor pattern" (Baranek, Parham, & Bodfish, 2005, p. 835). Several well-designed studies have demonstrated that, compared to matched controls, individuals with ASD demonstrate significant praxis deficits in addition to both gross and fine motor impairments (see Dawson & Watling, 2000, for a review). For example, Dziuk et al. (2007) found that an impairment in praxis (i.e., motor planning) performance in 47 children with ASD was broadly associated with measures of the social, communicative, and repetitive behaviors that define ASD. They suggested that "dyspraxia may be a core feature of autism, or a marker of the neurologic deficits that underlie the disorder" (p. 738). Similarly, in a study of 154 children with ASD, Ming, Brimacombe, and Wagner (2007) found that 41% of children aged 2–6 and 27% of those aged 7–18 showed clear evidence of oral motor and/or hand muscle apraxia. This could explain why imitation skills (which are clearly associated with motor ability) that require either oral-facial praxis (e.g., sticking out the tongue, making a happy or sad face) or copying body movements that do not involve the use of objects, are especially difficult for individuals with ASD and may even differentiate them from individuals with other developmental disabilities (Adams, 1998; DeMyer, Alpern et al., 1972; Page & Boucher, 1998; Rogers, Bennetto, McEvoy, & Pennington, 1997; Stone, Ousley, & Littleford, 1997).

Some studies have also examined the prevalence and specificity of involuntary movement impairments in individuals with ASD. Involuntary movements are those that are not under voluntary control, such as tics, akinesia (absence of movement), dyskinesia (impaired, uncoordinated or jerky movement), akathisia (involuntary motor movements or "fidgeting"), bradykinesia (delays in the ability to initiate, change, and/or terminate movement), and gait or posture abnormalities (Baranek et al., 2005). There is evidence that tics, dyskinesia, and akathisia are all associated with repetitive stereotypic behaviors such as body rocking, repetitive self-injurious behavior, and compulsive behavior (Bodfish, Symons, Parker, & Lewis, 2000). However, while a number of studies have reported involuntary movement patterns in at least some individuals with ASD, it is not clear whether these patterns are specific to ASD. One exception was a recent comparative study that provided evidence of significantly reduced postural stability in individuals with autism (ages 5–52), compared to matched controls without disability (Minshew, Sung, Jones, & Furman, 2004).

Together, these studies suggest that motor impairments are much more common than previously thought and may also be associated with autism symptoms. This view has been endorsed by a number of autism researchers, in addition to those already noted (e.g., Hardan, Kilpatrick, Keshavan, & Minshew, 2003; Minshew & Williams, 2007). For example, Minshew et al. (2004) noted the significance of:

... associated symptoms that are not part of [the current] diagnostic constellation but nonetheless appear to be neurologically and clinically important elements of this syndrome. Abnormalities of motor coordination, posture, and gait are among these. Numerous studies have documented clumsiness and gross and fine motor apraxia, which *are now considered integral aspects of autism* (p. 2056; italics mine).

### Intellectual Disability

Another element of the “front door” view of ASD has to do with the co-occurrence of an intellectual disability (ID). As noted previously, all versions of the DSM have included ID as an associated disorder and have either stated or implied that some degree of ID is present in a significant majority of people with ASD. However, recent research has challenged this claim in a number of ways. Edelson (2006) conducted a thorough analysis of the published evidence supporting claims regarding the rates of ID in individuals with ASD, back to 1961 when the first such claim appeared (Creak, 1961). She located a total of 215 published articles of two types: (a) non-empirical articles that reported specific prevalence claims with one or more citations but that did not provide supporting data (e.g., “70–80% of children with autism have IQ scores in the moderate to profound range,” followed by a citation), and (b) empirical articles that reported data that could be used by others to support such claims. She did not include non-empirical studies that merely implied a relationship between ID and autism or that made non-specific prevalence claims (e.g., “approximately half of all children with autism achieve IQ scores in the severe to profound of mental retardation”).

Following a thorough citation trail analysis and examination of the articles themselves, Edelson (2006) found that 74% of all claims regarding the rates of ID in individuals with ASD came from non-empirical sources. Of these, 53% never

traced back to empirical data, and the remaining 21% cited empirical research that is 25 to 45 years old, used inappropriate measures to assess intelligence (e.g., adaptive behavior scales), and/or failed to acknowledge the possible interference of autism on the assessment of intelligence (see Edelson, 2005). In contrast, she found that only 26% of all claims traced back to empirical data. However, in many of these studies, researchers had arbitrarily assigned IQ scores in the severe to profound range of ID to children who were untestable, and then proceeded to use both assigned and “real” scores to calculate prevalence rates. In the end, only 15.7% of all claims traced to studies whose authors based their prevalence estimates on real data only and utilized specific psychometrically valid methods to assess intelligence. Edelson concluded that, although “the practice of claiming that a majority of children with autism are [intellectually disabled] continues largely unabated, ... researchers ... should use caution when making assumptions about or citing claims about the rates of [ID] in children with autism” (p. 74). Her recommendation was echoed in two invited commentaries by well-known autism researchers who referred to her review as one that “ask[s] an important question and provid[es] a scientifically convincing answer” (Ritvo & Ritvo, 2006, p. 85), and that “should encourage all professionals to confront many of the preconceived notions they may have regarding children affected by autism spectrum disorders” (Freeman & Van Dyke, 2006, p. 87).

A related issue is the extent to which intellectual ability can be validly measured in individuals with the unique learning and performance characteristics associated with ASD. Numerous reports acknowledge the challenges facing assessors in this regard, especially when some of the most commonly-used intelligence tests are employed. For example, a study conducted over 20 years ago (Shah & Holmes, 1985) compared the scores of 18 individuals with autism (ages 7–14) on both the Leiter International Performance Scale (Leiter, 1980) and the Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1976). The version of the Leiter used in this study employed 54 items that required only matching ability, to assess a range of concepts ranging in difficulty from the 2-year to the 18-year level. Results indicated that (a) while two participants were untestable with both measures, five were untestable on the WISC-R but achieved scores ranging from 28–106 ( $M = 62$ ) on the Leiter; (b) on average, participants scored 13 points higher on the Leiter than on the full scale WISC-R ( $r = 2-32$  points); (c) Leiter scores were significantly correlated with WISC-R performance scores ( $r = .82$ )

but not with WISC-R verbal scores ( $r = .29$ ); and (d) two participants achieved scores of  $>70$  on the Leiter but not on the WISC-R (i.e., above the upper limit for intellectual disability).

These results are not especially surprising given that, unlike the WISC-R, the Leiter does not require the person being tested to either use or understand speech. Subsequent studies employing other nonverbal measures of intelligence – including the Test of Nonverbal Intelligence (Brown, Sherbenou, & Johnsen, 1997), various block design tasks and, most recently, Raven's Progressive Matrices (Raven, Raven, & Court, 1998) – have all provided evidence of at least normal and often above-average performance by people with ASD regardless of age or ability, compared to normal controls (e.g., Dawson, Soulières, Gernsbacher, & Mottron, 2007; Edelson, Edelson, & Jung, 1998; Edelson, Schubert, & Edelson, 1998; Shah & Frith, 1993; Shah & Holmes, 1985). Unfortunately, results such as these are often challenged as misleading or dismissed outright because nonverbal measures do not assess all of the factors that are believed to comprise the construct of “intelligence,” and are thus seen as merely tapping into the “islets of ability” of individuals with autism (see Gernsbacher, Dawson, & Mottron, 2006). As noted by Shah and Frith (1993):

... the phenomenon of islets of ability has been regarded as something of a myth or else as merely an interesting but theoretically unimportant fact. There have been few attempts to elucidate why islets of ability occur so frequently in autism, or, more generally, how good performance is achieved on certain IQ subtests by individuals whose achievement on other subtests is so poor (p. 1351).

Finally, it is important to recognize that almost all published prevalence studies of PDD since 1998, from countries that include Norway, the United Kingdom, Sweden, Finland, and the United States, have found that no more than half of individuals with PDD have an intellectual disability, with most indicating rates in the range of 26–40% (Centers for Disease Control and Prevention, 2007; Chakrabarti & Fombonne, 2001, 2005; Fombonne, 2003). This suggests that either the earlier estimates related to intellectual disability were erroneous (as is likely, given the Edelson review); or that the cognitive profile of individuals with PDD has changed dramatically in recent years. Regardless, the recent prevalence data – in combination with the results of the Edelson review and studies comparing the results

of conventional and nonverbal intelligence tests in individuals with ASD – suggest that it is important to question the presumption of a strong and common relationship between ASD and ID.

### WHAT DOES THIS HAVE TO DO WITH AAC?

Why are discussions of the possibility of motor impairment and the prevalence of ID important in a discussion of AAC and ASD? Let's start with the latter. There is no question that the assumption that most children with ASD also have a significant intellectual disability leads to lowered expectations. Unfortunately, many professionals forget that the labels “intellectual disability” and/or “mental retardation” simply refer to an individual's scores on a cognitive test which, in turn, may say nothing about that child's ability to learn or about his or her “potential.” As Freeman and Van Dyke (2006) noted, “If the child is not learning, it is not because of the child's IQ – it is [because of] either what we are teaching or how we are teaching [it]” (p. 87). Nonetheless, in the United States and in most other countries, children with autism (with or without ID) are likely to spend the majority of their school careers in special education programs rather than in general education classrooms (U.S. Dept. of Education, 2005). Once placed in special education, they are often not expected to perform because of their presumed intellectual disability and, when they fail to make progress – especially in academic areas – their parents are often told that such learning difficulties are just “part of the syndrome” (Freeman & Van Dyke, 2006, p. 87).

Does this happen with regard to AAC as well? I think it does. In 2003, I noted the preponderance of research studies that have focused on teaching individuals with ASD to use AAC symbols imperatively – that is, to either request, terminate, or avoid items, activities, or events (Mirenda, 2003a). More recently, Wendt, Schlosser, and Lloyd (2006) identified 44 AAC/ASD research articles that were published between 1976 and 2006 and that met a set of inclusion criteria for methodological rigor. Not surprisingly, they also found that the largest group of intervention studies focused on teaching the use of AAC to make simple requests.

This is not to suggest that individuals with ASD should not be taught to use AAC strategies that enable them to regulate the behavior of others by requesting or rejecting; these are among the first communicative functions that develop in typical children, and are important to teach if they do not

develop naturally (Sigafoos & Mirenda, 2002; Sigafoos, O'Reilly, Drasgow, & Reichle, 2002). The problem is that strategies for behavior regulation are often the only communication skills they are taught; thus, requesting and rejecting often constitute both the beginning and the end of AAC for many individuals with ASD. As Janice Light and her colleagues noted, "There's more to life than cookies!" (Light, Parsons, & Drager, 2002, p. 187) – but apparently not if you have ASD, and – I believe – especially not if you are also presumed to have an intellectual disability. "He's not interested in learning to use his AAC system to interact with the other kids," we say as we intervene one more time to prevent Henry from throwing rocks at his classmates while they play soccer next to him during recess. "Jessica only uses one-word utterances on her CheapTalk™," we lament, as we program in yet another page of eight nouns. "Stanley has a thing about the alphabet and truck books, but all he really does is 'stim' on the letters and pictures," we say, "He's not really a reader" (Mirenda, 2003b, p. 271). Translation: Henry, Jessica, and Stanley have all been labeled as having both ASD and a severe intellectual disability, and "everyone knows" that "kids like that" don't interact with peers or develop complex language or literacy skills. "Everyone knows," so no one tries.

A similar problem exists with regard to the issue of motor impairment: "Everyone knows" that individuals with ASD do not have motor impairments and thus do not require alternative techniques or supports to access their communication displays. But what if, as suggested by recent research, a motor and/or praxis impairment is an "integral aspect" of ASD in many individuals? If this is the case, one could argue that the presence of such impairments might help to explain at least two of the four symptoms listed under each of the three main diagnostic criteria for autism/PDD-NOS (Dziuk et al., 2007). For example, one of the symptoms of impaired social interaction is "marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction." In addition to "delay in, or total lack of, the development of spoken language," one of the symptoms of impaired communication is "lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level." Finally, the category of restricted, repetitive behaviors includes symptoms such as the "apparently inflexible adherence to specific, nonfunctional routines or rituals" (hinting at akathisia) and "stereotyped and repetitive motor mannerisms

such as hand or finger flapping or twisting, or complex whole body movements." All of these symptoms suggest the presence of one or more underlying motor impairments that, in combination with other factors, may interfere with the acquisition of new skills, including those required for AAC. Perhaps the child who has difficulty executing manual signs correctly or producing them without verbal prompts has underlying motor coordination and motor planning deficits. Perhaps the adolescent who repetitively activates the same symbols on her SGD and bites her hand when she is unable to stop doing so has an underlying problem with motor control. Perhaps we need to take the motor skills of individuals with ASD into account when planning AAC interventions, just as we do with individuals with more obvious motor challenges.

### **"I Can't Get No Satisfaction ..."**

The central point I am trying to make here is that, in the immortal words of Mick Jagger, we "can't get no satisfaction" until we have figured out how to provide every individual with ASD with a viable, robust, flexible, and generative communication system that will support long-term language development. In order to do this, we must begin to do what AAC practitioners have always done when confronted with people who need our assistance to communicate: presume the potential for competence. This means that, first of all, we ignore the individual's past failure to learn and/or communicate, test scores, IQ/mental age scores, diagnostic labels, lack of "prerequisite skills," and other so-called markers of "potential" (or the lack thereof) (Mirenda, 1993; National Joint Committee, 2003a, b). Moreover, we design interventions that capitalize on specific strengths (e.g., visual memory and visual processing) and we provide compensatory supports to address specific limitations (e.g., problems with language comprehension). In addition, we seriously consider the possibility of an underlying motor praxis or coordination problem that may have significant implications for alternative access and/or for how we provide instructional supports. Then, we approach the individual with the assumption that, "here is a person with ASD who is certainly capable of learning to communicate fully and well," and we proceed to figure out how to help the person do just that. If tried and true "front door" methods don't yield the desired communication outcomes, we dig deeper to try to understand why. We read outside of our areas of expertise to find novel solutions; we borrow ideas from other fields and see where they lead us. We challenge the "people-with-ASD-are-not-

interested-in communicating” paradigm in order to innovate, and we don’t stop innovating until we have found the key to successful communication for each and every person with ASD.

Let’s consider some examples of such counter-paradigmatic AAC/ASD applications that have appeared in the literature over the past few years, starting with instructional techniques. As noted previously, almost all explorations or demonstrations of the effectiveness of AAC with individuals on the autism spectrum have utilized systematic instructional techniques including antecedent interventions to provide communicative opportunities, various types of prompts to elicit responding, systematic fading, and both reinforcement and error correction strategies (see Sigafos, Arthur-Kelly, & Butterfield, 2006). In general, these studies have provided modest evidence that individuals with ASD can learn to use a variety of AAC techniques to request preferred items or activities, reject or terminate undesired items or events, and repair communication breakdowns (Beukelman & Mirenda, 2005).

In contrast, clinicians like Carol Goossens’ have been using a less structured augmented input technique called “aided language stimulation” with individuals (especially young children) with a wide range of disabilities, for many years (see Goossens’, Crain, & Elder, 1992). In simple terms, the technique requires an interventionist to point to key graphic symbols while simultaneously speaking, in the context of naturally-occurring routines throughout the day (e.g., mealtime, bath time, etc.). However, it is only recently that researchers have started to examine the effectiveness of variations of this technique with individuals with ASD and other developmental disabilities. For example, Cafiero (2001) described the use of what she termed a natural aided language intervention (NAL) with Timothy, a 13-year-old adolescent with autism who had no functional speech. Timothy was placed in a special education classroom that focused on life skills instruction; because his “potential was defined by his behavioral and communication challenges, ... academic programming was nonexistent” (p. 181). Prior to the NAL intervention, he was provided with a 16-symbol display of Picture Communication Symbols™ (PCS) to request food choices during the day; however, Timothy used only 6 of the 16 symbols functionally.

During the natural aided language intervention, Timothy was provided with context-specific PCS displays depicting relevant nouns, action words, descriptors, and yes/no symbols. His communication partners (school staff) pointed to key symbols on the displays as they spoke with

Timothy to respond to his initiations, ask questions, make comments, and expand on his communicative attempts. Timothy received no formal instruction on the use of the displays, aside from staff modeling of symbol use during ongoing interactions. During the 3-month period following introduction of the symbol displays, his functional lexicon increased from 6 to 29 words and he began to initiate 2 to 3 word utterances. Over the next 19 months (which included periods of extended summer breaks), his lexicon increased to 67 words, the frequency of his problem behaviors decreased dramatically, and he began to engage in more “academic” instruction as staff’s perceptions of his limited potential began to change. While this report was that of a data-based case study without experimental controls, it was the first to suggest that less-structured natural aided language techniques can be used productively in AAC interventions with individuals with ASD.

Recently, Kathy Drager and her colleagues (2006) provided a controlled investigation using a similar technique that they refer to as “aided language modeling” (ALM). ALM consists of engaging the child in interactive play activities and providing models of AAC symbol use during this naturalistic play. The interventionist uses an index finger to point to a referent in the environment and then immediately points to a graphic symbol of the referent, while simultaneously vocalizing its verbal label. Two 4-year-old children with ASD, Maggie and Sam, were involved in the study. Both used fewer than 30 functional words, attended an integrated day care program, and had no previous AAC experience. Three motivating play activities were selected for each child (e.g., dollhouse, playground) and four target PCS symbols were selected for each activity (e.g., for dollhouse: table, chair, bed, baby).

During the ALM intervention, probe sessions were conducted to assess each child’s comprehension of target graphic + verbal stimuli, comprehension of graphic stimuli alone, comprehension of verbal stimuli alone, and symbol production. Results indicated that both children quickly learned to both recognize and produce the target symbols during the probe tasks, although Maggie’s symbol production performance was less impressive than Sam’s. Functional symbol production was not formally assessed, although anecdotal data indicated that this did occur. Nonetheless, the fact that these two children with ASD learned to recognize and identify symbols through simple symbol modeling in play contexts reinforces the results of Cafiero’s (2001) study and again suggests that the prevailing instructional

paradigm related to AAC and ASD may not be valid. This suggestion is also reinforced by a number of ALM case studies involving children with ASD (Light & Drager, 2005; Light et al., 2005).

A final example comes from the work of Mary Ann Ronski and Rose Sevcik, who developed the System for Augmenting Language (SAL). The SAL consists of five integrated components: (a) a speech-generating device (SGD); (b) individually chosen vocabulary words and visual-graphic symbols that represent them; (c) use of the SGD in natural environments (home, school, and community) that encourage, but do not require, the child to produce symbols; (d) models of symbol use provided by communicative partners (parents, peers, professionals) with whom the child interacts; and (e) an ongoing resource and feedback mechanism. Like natural-language teaching and ALM, the SAL requires that natural communicative experiences be embedded into routines in which children engage during the course of their daily activities, and that communicative partners provide models of symbol use by pointing to the symbols while they speak.

In 1996, Ronski and Sevcik reported the results of a 2-year project in which the SAL was implemented with 13 school-aged individuals labeled as having moderate to severe intellectual disabilities; 2 of the 13 (EC, age 16;7 and MH, age 7;3) also had autism. Both of them learned to communicate via the SAL and were characterized as “advanced achievers” who evidenced a fairly swift acquisition of symbols followed by the emergence of symbol combinations and printed word recognition. In a large-scale follow-up study, Ronski, Sevcik, and colleagues (2007) conducted a parent-implemented SAL intervention with 60 toddlers (mean CA = 29.5 months) with developmental delays who had fewer than 10 spoken words or word approximations. They reported that 11 of the 60 toddlers received independently verifiable diagnoses of ASD within 12 months after entering the study (Ronski et al., in press). Six of the 11 children had been randomly assigned to a SAL-type intervention and the remaining 5 had been randomly assigned to a spoken language intervention (SCI). In the SCI, an interventionist and a parent encouraged and prompted the child to produce spoken words from an individualized target vocabulary set. Each intervention was designed to be 24 sessions (i.e., 12 weeks) in length with 18 sessions occurring in a clinical setting and 6 sessions taking place in the child’s home. Each session was 30 min in length and consisted of three 10-min blocks of play, book reading, and snack activities, using either the SAL or the SCI.

Results indicated that all six of the children with ASD who received a SAL-type intervention were able to communicate with a large proportion (72%) of the symbols on their SGDs after 18 sessions in the clinic; five of the six children maintained their use of the symbols at home. In addition, two of the SAL children began to produce small proportions of spoken words related to the symbols on their SGDs. In contrast, after 18 sessions, only one of the children who received SCI produced spoken words or word approximations for a very small proportion of the target vocabulary. Children who received the SCI had no other way to communicate since they did not have access to symbols on an SGD. These results were comparable to those for children without ASD in the larger study.

Together, the results of these related studies on natural aided language, ALM, and SAL provide preliminary support for the suggestion that language modeling with symbols in natural contexts may be a viable language intervention strategy for young children with ASD. Clearly, much more research is needed in this area; as with all new ideas, we need to be prepared to implement, collect data, modify, collect more data, and refine each approach systematically based on solid research evidence. Perhaps just as clearly, this is unlikely to be a “magic bullet” solution that will be “the answer” for all individuals with ASD. Some individuals may require carefully structured direct instruction such as that provided through the Picture Exchange Communication System (PECS; Frost & Bondy, 2002), Tangible Symbols (Rowland & Schweigert, 2000), or a similar approach (e.g., Sigafos et al., 2006). Some may benefit from a combination of aided language and structured approaches. And some may require other alternatives, such as those that approach communication through the back door of literacy . . .

### Cognitive Dissonance

Most readers will be familiar with the debate that surrounded an AAC technique called facilitated communication (FC) (Biklen, 1990). Briefly, FC involves the use of a keyboard communication device of some type (e.g., a small portable typewriter) on which messages are typed on a letter-by-letter basis. A “facilitator” physically supports the forearm, wrist, and, if necessary, index finger of the typist (i.e., the person with ASD). Initially, the typist is physically prompted to touch the correct letter keys in response to simple questions (e.g., *Where is the letter m? Show me which letter ‘dog’ starts with*). The facilitator provides errorless support, including positive

verbal feedback for correct responses, so that the typist experiences successful interactions. Gradually, the facilitator asks the typist to produce more complex responses, such as his or her name, answers to simple questions, or fill-in-the-blank statements. Eventually, the typist is encouraged to produce messages that are appropriate for communicative interactions. Over time, the instructional prompts and physical supports are faded until the typist is able to compose messages independently.

FC is (to say the least) controversial, primarily because of the authorship question: Is the typist actually typing the message, or is the facilitator doing so? The controversy stems from the undeniable fact that, whenever a facilitator physically supports the hand or arm of a typist, the potential exists for the facilitator to guide the typing process, however unintentionally. Numerous books, chapters, and articles have attempted to answer the authorship question through various research approaches. The vast majority of this research indicates that typists with ASD are easily influenced by their facilitators when composing messages and that facilitators often influence typists' messages without realizing they are doing so (see Jacobson, Mulick, & Schwartz, 1995; Mostert, 2001; and Simpson & Myles, 1995 for reviews). However, a few studies have also found that some typists appear to be able to compose messages without facilitator influence (Biklen & Cardinal, 1997). Thus, the FC conundrum is not an entirely straightforward matter, despite the fact that many professional organizations, including the American Speech-Language-Hearing Association (ASHA, 1995), have issued position statements or resolutions either recommending that it not be used at all or that it be used very cautiously. Given this, it is perhaps not surprising that FC was mostly ignored in the AAC field, with the exception of a few researchers who entered the fray in the 1990s to either dismiss (e.g., Fried-Oken, Fay, & Paul, 1995; Shane, 1994) or support its use (e.g., Calculator & Singer, 1992; Duchan, 1993).

What is the point of bringing up FC in a 2008 article about AAC and autism? Let me first state what the point is *not*. I am neither proposing nor defending the postmodern, social constructivist argument that suggests that studies in which facilitated typists were unable to pass messages accurately when their facilitators were blind to the content are invalid because they employed scientific methodologies that were overly rigid and thus did not allow the typists to demonstrate their true abilities (Danforth, 1997). Nor am I suggesting that the qualitative, phenomenological studies that have been offered as evidence in support of

FC are more valid than experimentally controlled studies (Biklen & Duchan, 1994). I identify firmly with a positivist behavior analytic tradition that embraces the scientific method; thus, based on the research evidence, my reading of the early FC literature is that most of the participants in those studies were influenced by their facilitators – whether consciously or unconsciously – as they typed with physical support. Even now, when I hear of or see a person composing messages with facilitator support to the hand, wrist, or elbow, I am skeptical about the extent to which the messages are indeed the person's own.

At the same time, I experience significant cognitive dissonance because of people like Sue Rubin. Cognitive dissonance is the feeling of “uncomfortable tension that may result from . . . experiencing apparently conflicting phenomena” (Wikipedia, retrieved 4 October 2007). The “conflicting phenomena” will be evident in a brief synopsis of Rubin's story. At age 7 and again at age 12, she achieved intelligence and adaptive behavior scores placing her in the 1–3 year “mental age” range and was considered to have both autism and a severe intellectual disability (Biklen, 2005). She engaged in severe aggressive, self-injurious, and self-stimulatory behaviors. She began to communicate by pointing to letters on an alphabet display using FC at age 13. She is now able to type messages independently. She is a full-time student at Whittier College in California and maintains an above-A grade average. She has become a disability rights activist, keynote speaker, and author, and was also featured in a 2004 documentary entitled *Autism is a World* (Wurzburg, 2004) that was nominated for an Academy Award. In 2005, Rubin wrote:

I have a difficult time communicating with the outside world because other than echolalia and verbal prompting I am very limited in my oral speech. I sometimes feel as if I am the eighth wonder of the world as people stare and marvel at my irregular behaviors which lead to poor assumptions that I am simply mentally disabled with little or no intellectual functioning . . . I am working, as an advocate for all autistic individuals, to let the world know that we are intelligent and witty, and should not be judged for our quirky behaviors . . . (Rubin, 2005, p. 95).

Rubin is one of a number of individuals whose stories make it clear that at least some individuals with ASD who are also labeled as having significant ID can develop high-level language

skills and can learn to read, spell, and write. Of course, this is not a novel idea when one considers the experiences of many individuals who are unable to speak or write because of severe motor impairments such as cerebral palsy; many of these individuals also develop age-appropriate language and literacy skills, either as a result of their experiences at school, at home, or both (Koppenhaver, Evans, & Yoder, 1991). The difference, of course, is that we “know” that many people with severe motor impairments have no cognitive impairments, so we can “make sense of” their skill acquisition as the product of intact intellects. What surprises us in individuals with ASD like Sue Rubin is that, for them, language and literacy development seemed impossible because they were also considered to have severe ID. We need to pay attention to the stories of Rubin and her contemporaries (e.g., Mukhopadhyay, 2000, 2003) and ask ourselves the question: “What’s going on here and what can we learn from it?”

### EYES ON THE PRIZE

Let me recap: I think we need to question what we think we know about people with ASD in general and how we support those individuals whose speech does not develop to communicate through AAC in particular. I think we need to do this because there is a growing body of science that suggests that we might have gotten it wrong, at least some of the time, for some individuals. I think that it is not okay to get it wrong for even one person; when we talk about communication, we are talking about peoples’ lives, no less than that – so there really are no degrees of freedom. If we get it wrong, if we miss the boat – people drown.

I also think that we need to examine these issues carefully and systematically, in the context of science, not emotion. In so doing, we need to keep our “eyes on the prize” in order to conduct research that is both valid and meaningful. The “prize,” in this case, is knowledge and understanding that moves beyond what we already know (or think we know) about people with ASD and how to maximize their communicative competence using AAC. To accomplish this, we need to be bold – not conservative – in formulating research questions and executing studies that push existing boundaries and test hypotheses that may be unconventional but may also lead to new insights and applications.

One way to approach this task is to identify people with ASD who have become competent (and independent) communicators through the

use of AAC (including FC), and then to work backwards to answer the question, “Are there common factors that appear to have contributed to these good outcomes?” If we find any (and I believe we will), we can then design longitudinal hypothesis-driven studies to examine these factors in natural contexts. For example, suppose that one common factor that appears to contribute to AAC competence in people with ASD is systematic literacy instruction over time; this would make sense if literacy is indeed a back door to language development that builds on their relatively strong visual processing skills and ability to learn skills that are rule-governed (Quill, 1997). Given this, we would start by presuming that people with ASD are as likely to become literate as anyone else. We would not discount the interest in letters, printed words, and books that is evident in many young children with ASD (Mirenda, 2003b). Instead, we would encourage their parents to expose them to frequent, enjoyable opportunities to look at books, be read to, draw, scribble, and otherwise explore the printed word. We would make sure that their preschools provide print-rich environments in which they have ongoing exposure to a classroom library of interesting books and other printed materials (e.g., catalogues) and frequent opportunities to write and draw on computers and with various implements (see Koppenhaver & Erickson, 2003). We would teach real reading skills, rather than assuming that functional sight word recognition is the most we can expect to achieve (Kluth & Chandler-Olcott, 2008). To do this, we would begin, even at an early age, to use evidence-based practices to teach phonological awareness skills, letter-sound correspondence, and decoding skills, in the context of motivating, interactive, shared reading activities (Light & McNaughton, 2006). We would encourage the individuals we teach to manipulate letters and printed words and to write words as well, in the context of stories with predictable patterns, familiar story schema, photo essays related to their experiences, and other individualized activities. We would use assistive technologies and carefully-selected software programs to support literacy development, thus building on the computer interests of many people with ASD (Fossett, Smith, & Mirenda, 2002; Mirenda, 2003b). We would provide errorless instruction using physical prompts, augmented input, and oral scaffolding to enable people to type or write, being careful to fade those supports gradually over time with the goal of independent writing. We would do all of these things at the same time as we build language skills, because we understand the intimate relationship between

language and literacy (Light & McNaughton, 2006).

In addition, we would conduct research examining the impact of such evidence-based literacy instruction that is provided regardless of participants' perceived or measured intellectual ability on the development of their language, communication, and literacy skills over time periods of 1–2 years or more. We would even assign participants at random to comparison groups – one group could receive state-of-the-art literacy instruction and the other could receive, for example, state-of-the-art AAC instruction based on another paradigm. We would undoubtedly learn something about ASD, AAC, and literacy instruction from this experiment, and what we learn might surprise us. By doing this, we would also begin to take literacy seriously as a potential back door to communication for many, many individuals with ASD – a back door that has remained locked for most of them to date.

Another way to approach AAC research through the back door is to form hypotheses based on research in related areas. For example, if it is true that at least some people with ASD experience motor planning problems, it would make sense to examine the use of instructional techniques that are specifically designed in accordance with the principles of motor learning. Strand (1999) noted that this is the approach taken by many researchers and clinicians in the area of developmental apraxia of speech, who employ techniques as integral stimulation (Strand & Skinder, 1999) and Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) (see Rogers et al., 2006) to elicit speech. All of these techniques utilize well-known errorless learning techniques such as systematic prompting/cueing, careful prompt/cue fading, distributed rather than massed trials, stimulus variability, specific corrective feedback, and reinforcement of correct responses. In addition, they all require that numerous repetitive-learning trials are delivered during each instructional session, since efficient motor learning requires, above all, practice. Thus, it would not be difficult to design an instructional approach that is based on the hypothesis that many people with ASD and limited functional speech also experience motor apraxia, and then to examine the effectiveness of that approach on AAC acquisition in a series of single-subject and/or small-group studies. Ideally, such studies would be longitudinal in nature, since learning new motor patterns takes both time and repeated practice. It would also be interesting to compare the effectiveness of such an approach with PECS and/or one of the aided/augmented language modeling approaches, all of which incorporate

some but not necessarily all of the techniques that are known to maximize motor learning (see Strand & Skinder, 1999). Again, we would undoubtedly learn something about ASD, AAC, and motor learning from such experiments; and again, what we learn may be unexpected.

Here's another example: Research with typically developing children clearly indicates that the number of words they hear prior to school entry has a tremendous impact on their language and literacy development over time. Typically developing children in working-class families hear approximately 1,250 words per hour (that's 6 million words/year!) and say around 1,500 words by age 3 (Hart & Risley, 1995). For children with ASD who are learning to communicate through AAC, the equivalent to hearing spoken words is seeing graphic symbols (or manual signs) used by others, in natural contexts throughout the day. But how many symbols do most children with ASD see others use before they are expected to produce them? Certainly not 1,250 per hour! In fact, in most cases, the answer is zero – rarely do children with ASD see others communicate with symbols before they are expected to use symbols themselves! Given this, perhaps it is not surprising that most children with ASD acquire – at best – small, functional symbol or sign vocabularies, even after years of systematic instruction.

But what if we were to apply what we know about typical language development to AAC acquisition? This would lead us directly to techniques such as aided language modeling/stimulation (Drager et al., 2006; Goossens' et al., 1992) and the System for Augmenting Language (Ronski & Sevcik, 1996), all of which involve providing symbol (i.e., language) models before expecting symbol use. If we take the research of Hart and Risley (1995) seriously, implementation of these techniques would require “going to scale” by providing at least hundreds of symbol models throughout the day, in an attempt to emulate the 1,250 words per hour heard by typically developing children. Yes, this is a tall order and yes, such research would require considerable funding, resources, and talent – but think of what we could learn, and think of what it might mean to our understanding of ASD, AAC, and language development in general.

## CONCLUSION

I know that the most common response to suggestions such as those I have made here is that they have the potential of giving “false hope”

to the parents and others who struggle daily to create fulfilling lives for people with ASD. But, really, “What [does] hope endanger?” (Savarese, 2007, xviii). For the families of people with ASD, I honestly do not believe that it endangers anything; for many, hope is the fuel that gets them out of bed each morning and gets them through yet another day. We would never tell the families of individuals who are developing typically not to hope that their sons or daughters will be happy, will be successful at school, will get a job, will live in a nice home, will have people in their lives who love and support them, will have good lives – so why do we parcel out hope as through it is in short supply to those who live with people with ASD? No, I don’t think it is families we are protecting when we talk about false hope – I think it is *us*. Hope threatens our own feelings of self-efficacy and professional competence; our own comfort with what we “know” and what we teach others to do; our own ability to stave off the cognitive dissonance that inevitably arises if we hold the experiences of Sue Rubin and other independent typists in one hand and the existing research on ASD and AAC in the other. I think that hope endangers all of that, and so we dismiss it by calling it “false.”

But I also think that hope is what we do, as AAC clinicians; and hope is what we strive for, as AAC researchers. We do not shy away from conundrums; we do not walk away from difficulty; we do not say, “That’s impossible,” even when we are afraid that it might be. We have taken on challenges like this before – with people with cerebral palsy when we first introduced them to Blissymbolics and thus enabled them to develop language; with people with profound motor impairments when we first taught them to use Morse Code or simple scanning devices; and, most recently, with the advent of automatic gesture or speech recognition systems, visual screen displays, and even brain interface technologies that enable individuals with significant cognitive and/or motor impairments to communicate (Higginbotham, Shane, Russell, & Caves, 2007). I think it is time to activate this hope again, this time for people with ASD who are unable to speak, and ask ourselves, “What if we challenge ourselves to invent and investigate *new ways* to support people with ASD to communicate, ways that we have perhaps not considered until now?” *What if?*

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