

An Authentic Voice Through AAC for Students with Severe and Multiple Disabilities

“I understand why kids [with impaired speech] scream. It’s frustrating not being able to speak and feeling as a mostly invisible being. Do you know the vintage movie, *The Invisible Man*?

That’s how I felt. My clothes were there, but the body and the soul felt like nothing.

How can you live a life getting treated like that?”

--Jamie Burke



There are few things in this world more frustrating than the feeling that your voice has been silenced. Whether you are struggling to articulate your thoughts or simply being ignored, the sense that your ideas are trapped in your mind is maddening. Marginalized groups have always grappled with this issue. Individuals seen as “less-than” by society have to shout to secure recogni-

tion and work harder to gain the same foothold in a conversation that others are afforded through no special effort of their own. Imagine how difficult it must be to believe that your contributions have value when you are continually dismissed. A very courageous few endure until someone finally listens, while a much larger number resign themselves to the silence.

The tragedy is that the world loses out on the potential contributions of entire groups of people. This is especially true for students with severe and multiple disabilities who don’t have the luxury of communicating in a traditional way. Because they cannot express themselves conventionally, many make the mistake of believing it’s because they are incapable of complex thought. It is crucial



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that we remedy this and find a way to unlock that hidden potential. What if we assumed that every student was capable? What if we considered the possibility that students who had difficulty communicating could be just as brilliant or capable as the garrulous child in the next seat?

In the words of Jamie Burke, a student with disabilities, “I could see the words in my brain but then I realized that making my mouth move would get those letters to come alive, they died as soon as they were born. What made me feel angry was to know that I knew exactly what I was to say and my brain was retreating in defeat. I felt so mad as teachers spoke in their childish voices to me...” (Biklen & Burke, 2006). What a loss it would have been if this young man had never been given the tools he needed to articulate his understanding and experience.

It is time to explore a change in mindset toward students with multiple disabilities as we work toward designing a communication system that gives them the opportunity to convey more than just simple words and phrases and affords them the opportunity to connect with others in a meaningful way. Most importantly, we must begin with the idea of presumed competence.

THE FRAMEWORK OF HIGH EXPECTATIONS

It is all too common for educators to connect early expressive difficulties to a presumption of incompetence. Students are labeled incapable, not because of any proof of their academic abilities, but because of an absence of evidence concerning their academic abilities (Biklen & Burke, 2006). This attitude insists that the student must demonstrate competence in order to be granted it. But we cannot know what someone else is thinking unless they are able to communicate with us. Thus, the least dangerous assumption is one of presumed competence (Jorgensen & Lambert, 2012). When students with

significant disabilities cannot show what they know through speaking, writing or typing, the best approach is to believe that the child can be successful and work to develop supports for that student so they can demonstrate their aptitude. Until those supports are in place, the student’s performance may not reflect their true ability.

With a framework of presumed competence in place, difficulties in performance are not thought to be evidence of intellectual incapacity. Rather, educators assume that students can and will demonstrate complex thought once they’ve had an opportunity to engage with the world (Biklen, 2000). Teachers and paraprofessionals must enter the classroom with this positive belief system in place and have high expectations for every student. It is much too dangerous to presume that a child will never learn, only to discover that success was possible had they been provided with high-quality instruction and assistive technology to support communication and literacy skills (Jorgensen, 2005).

Every student is deserving of what psychologist Carl Rogers called unconditional positive regard, a basic acceptance and support of a person regardless of what the person says or does – or in the case of children with disabilities, what the person can or cannot do. According to Rogers, students who have not been afforded unconditional positive regard come to see themselves in negative ways. When educators and peers do not believe that the child is capable, the child begins to view himself as a failure. This is the foundation of learned helplessness. Conversely, if the adults charged with the task of educating these students walk into the classroom with hope and a presumption of competence, the child will also believe in the possibilities. Remind yourself that:

- All movements, signals, cries and gestures are a form of communication

- Everyone can learn
- Each individual has something valuable to share with you
- You have something positive to share with individuals with severe and multiple disabilities
- Positive experiences lead to success

LIMITATIONS OF CURRENT AAC IMPLEMENTATION

The National Joint Committee’s Communication Bill of Rights maintains that all people with a disability “have a basic right to affect, through communication, the conditions of their existence.” To that end, the guidelines assert that each person has the right to receive intervention to improve communication skills, to be in environments that promote one’s communication as a full partner with other people and to have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992).

Unfortunately, the majority of teachers and therapists focus on the student’s mastery of the AAC system, itself, when communication should be the ultimate goal. AAC use is just one of the many tools that might support a student’s ability to learn language and use it to interact with others. However, many educators misguidedly put the device at the center of the curriculum. Communication is about connection; it is a social accomplishment that “grows out of repeated opportunities for people to work together” (DeThorne, Hengst, Fisher & King, 2014). When you and I interact with others, we have more than just words at our disposal. We make use of nonverbal cues, including body language, facial expression and gestures to enhance our understanding of meaning. Yet, we often oversimplify how language works for students with severe and multiple disabilities, limiting them to



just the AAC system or just one mode of communication.

Present AAC instruction often ignores the communal aspects of communication and views it as an isolated individual ability, a set of “testable skills” (DeThorne, Hengst, Fisher & King, 2014), but communication is much more nuanced. The purposes of communication include:

- Expression of wants and needs
- Exchange of information
- Social interaction

Throughout the course of a lifetime, social interaction makes up the largest portion of our exchanges (Cumley, 2001). Unfortunately, the slowness of AAC systems often interferes with successful interactions, especially in the case of a student with severe and multiple disabilities. In the words of Jamie Burke, “On my part, I must first have a way to indicate I desire to comment. Then, a facilitator must be available to promptly cue my body to get my communication device. Then I need physical support to type. All of this takes too long for typical kids. I have lost many comments that may have engaged friendships because of the complications of this way of communicating” (Biklen & Burke, 2006). So while AAC supports rudimentary speech development and enables communication of wants and needs (Snell, Chen & Hoover, 2006), there seems to be a gap when it comes to sustaining social interactions (Mellman, DeThorne, & Hengst, 2010).

Despite many years of inclusive policies in our schools, many students who rely on AAC continue to be at high risk for exclusion from social groups (Bryen, Carey & Frantz, 2003). Students are “islands in the mainstream” rather than fully participating and successful learners (Biklen, 1985). For inclusion to work, educators must ground the process in what the students without disabilities are doing. It is not enough that the students with disabilities are physically present in the room. It is not enough that they are working on a similar academic skill. They must be engaged with the

rest of the class (Jorgensen & Lambert, 2012). And this is not possible if we don’t provide a method of communication that goes beyond word identification and simple requests. Systems that lack a balance of communication strategies and opportunities can fall short for students regarding their overall communication. Many students get stuck in the early stages of one communication process or another because they are simply introduced to one piece of the Integrated Model of Communication (Conversation, Language and Literacy).

LET’S LOOK AT TWO EXAMPLES

I met Alex while working in a school system where the mission was to work with team members on improving the communication of students who were considered struggling. Alex is fully included in 6th grade. He has developmental disabilities, some behavior issues, severe motor apraxia and is thought to be functioning in the severe range. He sits on the outskirts of the class in almost his own separate classroom as there is always staff with him. He verbalizes Hi and Bye. Below is an example of Alex’s “communication system,” it is a 12-location grid with a core word display on a popular iPad system.

This is a sample of the interaction during discussion about the book “Adventures of Shiloh.”

During the book reading discussion, Alex selected “want.” His paraprofessional went through a selection of his typical wants and needs – drink, bathroom, etc. Verbalizing to him, Alex selected with a nod, “drink.” The paraprofessional responded: “No we have to wait until break.” Alex persisted and selected “want” again and again. Some of the children in the room are giggling and he is starting to disrupt the class. The paraprofessional removed him from class. (This took 15 minutes.) Apparently Alex liked the story and showed interest in the story. She calmed him down and he returned to

class, but the discussion had ended and they were moving on.

This was not the first disruption. In fact, the teacher has complained about the paraprofessional being too loud when she prompts and models Alex’s communication. Alex’s situation is not different from many students in his situation. First, staff assumed that Alex could only use a simple word board because of his physical apraxia, but disregarded his interests, his eagerness to want to talk to others and socialize, and his need and ability to participate in classroom activities and discussions. His current system was simply too limiting for him to effectively participate in an inclusive environment. The team was forward in their thinking that Alex would be fully included, however, they failed to think about how he would communicate in that situation. Alex was easily frustrated as communication was laborious. He had no way to effectively participate in the classroom. He stood out socially because he often had outbursts. When approached by classmates, he usually just repeats, “Hi.” Alex needed a more balanced and robust AAC system so his communication could grow with him, not limit him.

Emma is another student with a similar problem. I met Emma while working with another student in a middle school. Emma entered the Resource Room, and her teacher proudly explained that she was using an iPad with a popular communication application to communicate. My exchange with Emma was as follows:

Emma: Hi, my name is Emma.

Pati: Hi, my name is Pati.

Emma: I have a sister named Maggie. I like Taylor Swift.

Pati: Me too.

Emma: Eat now.

When I returned to the school for a follow-up visit three months later, I ran into Emma. Our exchange went a little something like this:

Pati: Hi, Emma! How’s it going?

Emma: Hi, my name is Emma.

Emma: I have a sister named Maggie.
Emma: I like Taylor Swift
Emma: Eat now.

She was faster this time, so I was unable to get a word in. Six months from the initial visit, I saw Emma again. You can guess how the conversation went. Her progress stagnated because Emma was not taught how to have a conversation, nor was she given opportunities to expand and learn more. It was clear that she had just one page on her system, a social script that did not provide her with enough communication to move beyond this simple exchange. While she was physically capable and seemed bright, Emma was viewed as cognitively impaired by most (adults and peers alike) because her system was failing her. She lacked a rich variety of phrases; she had the same sight word literacy instruction for years. There was no plan in place to help move her communication forward by incorporating the language and literacy aspects of the Integrated Model of Communication. Emma was using the application and that was “good enough.”

THE MISSING PIECES

Now let’s discuss both situations. Obviously, each student requires careful consideration on what system will work best for the student. The AAC system needs to be versatile enough to meet the needs of different language levels, from early to advanced, so it will allow the AAC user to be effective as his/her capacity for language expands and as the demands in his/her environment change. Taking the higher road of presuming competence for both Emma and Alex is a necessity if we expect them to move forward in communication. Communication requires multiple skills, including conversation, literacy and language, and those skills should be integrated into the learning process as early as possible. Light, et.al. discuss the concept of communication competence as different domains: Linguistic domain, Operational domain, Social domain and

Strategic domain (Light, 1989; Light & McNaughton, 2014) Erickson & King-DeBaun, (2004) King-DeBaun (2012) McNaughton, 2014)

THE INTEGRATED MODEL OF COMMUNICATION

Communication requires multiple skills, including conversation, literacy and language, and those skills should be integrated into the learning process as early as possible. Communication partners (educators, therapists, classmates, parents) have to recognize that multiple modes of communication must be recognized and valued. Beyond the AAC system, dialogue with these students can and should involve body languages, such as facial expressions, gestures and eye gazing. To be truly inclusive, teachers can utilize every pupil response strategy whenever possible. Such an approach requires all students to respond to questions simultaneously with a gesture (thumbs up or raised hand) or other nonverbal response (look at the door, close your eyes).

These modes of message transmission are just as valuable as the verbal and written components that we must also incorporate to provide the student with a comprehensive communication system. Of course, it is necessary to differentiate the system based on the individual student’s skill set. Language-based components should include core words; parts of speech, such as adjectives, verbs, pronouns and basic words; or vocabulary commonly used in classrooms, as well as an alphabet display or keyboard for spelling and a set of phrases used for various everyday activities where the timing of communication is an issue. Students need conversational language that is more than fillers or scripted comments. The system can be computerized, an app on the iPad or light tech paper systems when “access” to computerized systems are being explored. Some systems already have all components

of the integrated model built into the system.

The resulting integrated model of communication goes beyond vocabulary acquisition to incorporate support for conversation and socialization. It includes:

1. Social Skills – A collection of core phrases a student can retrieve quickly to have a conversation, participate in a discussion, provide feedback, express opinions, meet personal needs and establish relationships.
2. Literacy/Language Skills – A compilation of core words selected for their strong communicative base that is modeled in appropriate situations within literacy-based activities.
3. Linguistic Skills – Using the building blocks of core words and vocabulary lists, students put together sentences to generate ideas.

For students who have multiple disabilities, the need for an integrated model of communication becomes even greater. For both Alex and Emma, neither had enough communication to support learning and participation in the classroom, as well as social engagement. Alex’s core word board was limiting for him, and his facilitators currently had no plan to move his communication forward. Emma’s board was very limiting, and according to her team, she was a success. They both needed a robust set of conversational language and core words and words for modeling more appropriate language/linguistic skills. Since both students had iPad’s, there were plenty of opportunities in place to use one of the programs already purchased by the school. Typically, most AAC apps have core words, a keyboard and some conversational language. Adapting those systems and adding more conversational language or more core words, etc. could be a viable solution for both students. Most AAC systems need to be customized for students in order to be effective!

First, Alex needed conversational language, and Emma needed more.



All students, especially those in inclusion situations, need the opportunity to participate fully in the classroom. Alex and Emma were at critical ages; both needed a quick method to engage and participate in the conversations of the classroom. Emma needed more conversations and things to say to peers and others, but more importantly, she needed to be on a path that would move her communication forward. She was their “success story;” however, the other aspects of communication, including developing her linguistic, literacy and pragmatic skills, were missing!

Both students needed a roadmap or plan in place to keep their communication moving forward or on track. Mapping out conversations based on what is happening in the classroom, resource room, in the hallway, at lunch and in classroom discussions is essential. Finding the optimum time to model and facilitate those conversations is nonnegotiable. If there is no conversational language on the system, someone needs to add it. Conversation, however, is only one piece of the puzzle. Next, appropriate time in the schedule is necessary for mapping out core words and sentence generation as a teaching element is involved, and the generation can sometimes be slow for students who have severe and multiple disabilities. Facilitators need to be thoughtful about what activities or classes this will be appropriate in. Other considerations will include when the student uses a keyboard or alphabet flipbook for spelling, when to introduce word prediction and when they will dictate using their words. These are the types of discussions that need to happen while planning for communication. Like any student in school, communication is vital for success, but without a plan, it is hard to be successful.

THE PLAN

Here is a simplified example of what a plan might look like.

ARRIVAL

Both Alex and Emma arrive at their school early, rather than rushing to the resource room. The team might brainstorm about communication opportunities that exist as their peers or “peer buddies,” who also arrive early, have a quick hello conversation with the students. (“Peer buddies” are friendly communication partners earning high school credits, are part of a service club or are younger students who have an interest.) When modifying their systems, listen to what the current language trends are with age-appropriate peers. It is extremely important that students sound like their peers when conversing and not like a two- or three-year-old!

CLASSROOM

Given Emma and Alex are included fully with some resource work time, variations of this plan could be implemented for both students. Within classroom discussions, the pace is fast, especially as they get older. These are the questions one might ask: What are all of the other students expected to say? Is there a classroom language that they are expected to use? For example, in Alex’s class, all students used starter phrases. (“I agree with that.” “I disagree with that.” “I have something to add.” “I have a claim.”) These same phrases could open the door for Emma’s participation in the classroom too. Scaffolding and modeling will be essential. For Alex, the use of a foam core board over his iPad directed his attention to only four choices at a time, instead of all 16 choices that could be used. This is important for focus and motor accuracy in situations where timing was essential. Emma had physical accuracy, so we could use her full display of 15 items.

They both also used a commercial system that included core words, appropriate for modeling language and linguistic aspects of communication. The systems also had multiple modes of communication for different situations. For instance, in class discussion, Alex

would make a complete statement, such as “I agree with that,” or “I disagree with that. The teacher was informed that when Alex had something ready for speaking on his device, he would raise his hand, meaning he was ready to talk. Emma was included in more elective-based activities but used a similar protocol. She spent more time in the resource room for academics. The same protocol could be applied in that situation where she needed additional modeling and support in group activities so she could participate with her peers. This keeps both students in the loop in classroom conversations and allows them to participate and communicate with the same expected language as their peers.

Students need to be able to quickly ask for help and ask for a break, especially when they are emotionally falling apart, as in Alex’s situation. All AAC students need to be able to have enough conversational and social language on their device to be able to establish friendships and relationships. (These are not just quick chats, but commenting, sharing stories and news, asking questions and joining in conversations.) Create some easy phrases with real personality options. Let the child show who they are through their communication. Sassy, demanding, humorous, naughty, etc. are all a part of who an individual is. And make sure there is easy access to those phrases all of the time.

IN INDIVIDUAL WORK TIME

For Alex, his paraprofessional could expand on his comments. For example, he might be able to build a sentence that was appropriate to his statement. Since Alex is still in the classroom, it is important to train his paraprofessional to use “device etiquette” - turning down the sound and when she speaks to him, whispering in his ear while modeling to expand using core words or core sentence starters with other words already on his device. She writes what he does in a shared notebook so the all

team members have knowledge of what Alex was communicating to demonstrate his understanding within the class. She could write a quick email or memo for the regular education teachers. She could indicate what was modeled vs. generated independently by Alex.

Emma would have a similar protocol, only hers would be within the resource room. Also, both students need a plan to develop their literacy skills and require one-to-one support time, possibly during speech and resource, for direct instruction of literacy – how to spell, read and generate sentences with select core words.

Communication partners (educators, therapists, classmates, parents) need to understand that multiple modes of communication must be recognized and valued. Beyond the AAC system, dialogue with these students can and should involve nonverbal body language, such as facial expressions, gestures and eye gazing. To be truly inclusive, teachers can utilize every pupil response strategy whenever possible. Such an approach requires all students to respond to a questions simultaneously with a gesture (thumbs up or raised hand) or other nonverbal responses (that mirrors what the students who are nonspeaking are already using as part of their natural gestures).

Communication is the process through which students learn and show others what they know (O’Connell, 2007). In any classroom or social environment where children who use AAC are in the minority, the need for an advantage is paramount. Quality educational programs expect students to take a more active role in discussions, to generate ideas and opinions and to express those ideas via both spoken and written communication. Rarely are these skills fully integrated into the teaching of AAC. The test and retest method of instruction are most common, asking students to identify words rather than generate language of their own. Prompts like “touch the _____, point to

_____”, and show me _____” are illustrations of testing, not communication.

It would take a nonspeaking student with a communication system receiving 30-minute speech therapy sessions two times per week a grand total of 84 years to reach the same amount of language exposure the typically developing 18-month-old child has been exposed to over 4,380 hours of oral language at a rate of eight hours per day from birth (Korsten, 2005). We have to serve these students better and give them the opportunity to connect with peers and adults, using AAC as a means rather than an end.

If we think of communication as the integration of using multiple modes that integrate quick and automatic meaningful comments and questions and more thoughtful generative language in the mix for those learners, we can truly begin to realize their potential and their current understanding. From there, success snowballs. As students perceive themselves to be successful communicators, they are more likely to participate in more challenging tasks, including the development of literacy and language skills (King-DeBaun, 2012).

This snowball effect doesn’t apply to the child alone. Beyond the invaluable boost of confidence the student receives from his/her success in generating meaningful conversation, both peers and adults view that student in a more positive light, as well. Much research has concluded that successful social interactions hinge largely upon the attitudes and perceptions communication partners hold for one another (Richter, Ball, Beukelman, Laser & Ullman, 2003). Once a student begins communicating unique ideas and thoughts, fellow students and staff are motivated to engage in continued communication with the student. Suddenly, the student has a voice.

When we work from a place of presumed competence, we assume relevant meaning from a child’s actions and respond to his attempts to commu-

nicate rather than dismiss those attempts as disruptions. We give students with severe and multiple disabilities extra time to respond and encourage peers to offer these learners a little patience. We focus on communication and connection as the ultimate goal of our time together so that each of us has a voice. Incredible things happen when educators have high expectations for every student.

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ADDED RESOURCES

www.creativecommunicating.com

- Pati has developed various communication products that she currently sells. The Dynamic Communication Book, Speaking Dynamically Pro (Pati/Judy pages for Tobii Communicator), AAC2go pages for GoTalkNowApp, and Light Tech Communication Books Pdf files.

Teaching AAC - a resource file for Getting Started with AAC Instruction

www.totaltalkaac.com - Pati consulted on the design and development of Total Talk Communication app. ■

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