

## Maya's Voice

Maya sits in her chair on the deck. It is a beautiful afternoon and there is much activity outside to entertain her. A small bird pecks at the bird feeder above her head. Question after question tumbles through her eight year old mind. "What kind of bird is that? It must have a name. That seed looks black. I wonder what kind of plant it would grow into. Can that bird fit inside the bird feeder?" Suddenly, a squirrel flits from a tree branch and hops onto the feeder, sending the bird scurrying away. "Where did he come from?" she wonders. "I hope he doesn't eat all the bird seed." But of course, he is a very hungry and quick squirrel and the feeder is soon empty. "Why do they call it a bird feeder if squirrels can get to the seed too?" she wonders. "Someone needs to get the birds more seed." Although Maya's grandma sits a few feet away and would love to engage in this conversation, Maya is silent. All her questions go unanswered; all observations go unconfirmed. None of her ideas can be expanded upon. Maya is

unable to give voice to her thoughts. She has a form of cerebral palsy which so dramatically affects her physically that she is unable to coordinate her breathing or move the muscles of her mouth to form the words. Her ideas are perfectly formed. Her questions are succinct and valid. And they remain silent.

The fact that words remain unspoken doesn't mean Maya doesn't communicate. She and her family developed a form of nonverbal shorthand that allows her to indicate when she is hungry, tired or needs a change of activity. She is clear when letting others know if she likes or dislikes something. But she depends on her communication partner to know her shorthand and to ask the right questions. She has had no means of initiating a topic of conversation, asking questions, telling jokes, or relating details. All of the nuances of one's personality which are conveyed in the words we choose, the inflections we use, all of these subtleties are unavailable to her. Seeing Maya, it is easy to conclude that her depth of thought is reflected in her verbal output.

Until just a few years ago, Maya's communication was limited to answering "Yes" and "No" through facial expression. She communicated excitement, happiness and enjoyment through peels of giggles. She communicated disappointment, unhappiness, discomfort and anger by what could only be described as "pitching a fit". Not a lot of subtly can be communicated through smiles, giggles and howls. She was, and still is, at real risk of developing a passive response to life. It takes great strength of character to persevere in expressing one's spirit when almost all of your attempts are met with misinterpretation on the part of those with whom you interact.

I have had the opportunity to get to know Maya (not her real name) over the past year and to observe how quickly she is able to learn. She is blessed with family members and a school community who are committed to expanding her communication options. As I have come to know Maya, and others with similar communication challenges, I have learned how important my role is as a **careful** communication partner.

## The critical role of the communication partner...

When interacting with a person who is non-verbal, it is easy to fall into one of a few "communication traps". First, it is easy to assume that the non-verbal person is unable to understand you. Often the conditions that result in their inability to talk can also affect the person's ability to register accurate body language. People who are non-verbal due to autism are often not able to express a full range of facial expressions. Their vocal intonations don't necessarily match the intent of their message. This can result in real confusion on the part of their communication partner. Often their affect can appear "flat" and one assumes that they do not understand because they are not physically responding. In Maya's case, her cerebral palsy affects her ability to produce subtle facial expressions. It also takes more time for her body to process and manifest these expressions. So a communication partner might assume she doesn't understand because there can be considerable lag-time in her response. When we underestimate a student's abilities, we are undermining their learning in some obvious and some subtle ways. By

assuming a student doesn't understand we overly simplify our own language. In doing so, we limit the level of ideas we present to the student and, inadvertently, can limit their learning. When we over-simplify our language, this also sends the message to the child that we don't have confidence in her ability to learn. And others around the student are likely to underestimate her abilities as well.

Another pitfall we can encounter in communication with a non-verbal partner is to assume that she is the eight year old equivalent of Stephen Hawking and is destined for a career measuring time warps and explaining the universe. When establishing a relationship with a non-verbal student, most of the time you have nothing to lose if you assume they understand as well as other children their age. However, for those charged with teaching these students, it is critical to know a student's level of understanding in order to build a solid base for learning. When there is solid evidence that a student demonstrates some skills and lacks others, teach to her strengths and

support her growth, just as we do with any student.

A third and dangerous assumption when communicating with a person who is non-verbal is the tendency to misread their communication and think that we *know* their thoughts. This is a dangerous assumption because it can leave the non-verbal partner feeling particularly helpless in the communication. She is trying to communicate a particular idea, but her partner misreads and is sure they understand something else.

In developing an alternative communication system for a non-verbal child, it is critical to provide a means of expressing one's own thoughts and personality in a way that a variety of communication partners can easily understand. What follows is the journey Maya has taken toward this end - clear communication of original ideas - and the paths that we think lie ahead for her.

**Chronology of Maya's Communication System Development...**

As mentioned before, Maya's initial communication "system" consisted of smiling when answering a question in the affirmative, and looking away when answering in the negative. She also giggled to communicate a variety of positive messages and howled to communicate a variety of negative messages. Needless to say, this system relied heavily on listener interpretation and therefore was of questionable reliability. As Maya developed more control over her motor skills, when she was about 5 years old, she was able to move her right arm in a sweeping motion across the right half of her wheelchair tray. At the same time, she began to recognize the words "Yes" and "No" when they were color-coded (green for yes, red for no).

When Maya was about 6 years old, it became apparent that she recognized that picture symbols could represent words. (It was likely that she had this ability prior to age 6, but her motor impairments made it difficult for others to know it.) She began to show others this knowledge in two ways. First, when given an array of several pictures of activities to choose from, Maya would **hold/maintain** her gaze on a particular picture. When asked to verify whether that was the

activity she intended, she would point to "Yes" on her board. This allowed her communication partner some level of assurance that they weren't "putting words in her mouth". An even more objective method of this same type of communication was available to Maya on a computer. Maya's motor difficulties made it impossible for her to operate a keyboard, mouse or joystick. She could, however, activate a button switch using her right arm. Programs were developed that offered her a selection of four to eight picture words. The computer could scan through the choices, highlighting them one at a time, and she could touch her button switch when the "correct" answer was highlighted. The computer then spoke her selection. Thus began Maya's love affair with the computer!

When it became clear that Maya was able to communicate choices using eye gaze and using scanning on her computer, school staff were able to begin to assess her knowledge base. Using pictures, she could communicate her understanding of word meanings and word relationships. She could show that she understood spatial concepts (e.g. under, between, end) and temporal concepts

(first, then, beginning). She identified colors, shapes, numbers and letters. She is beginning to show her recognition of words. She now uses a talking word processor with an alphabet word bank to write spelling words. As you can imagine, using a computer that must scan each letter before you choose one is *extremely* time intensive. Anytime she makes a mistake, she has to wait until the computer scans to the "erase" choice before she can correct it. Spelling one word on her spelling list can easily take 15 minutes. But oh, the power!

Maya also uses a simple voice-output device with her button switch. This device scans eight picture choices and plays a recorded message when she hits her button to select a message. She tends to use this device to exercise control in her environment, generally to choose an activity, change or stop an activity.

I know what you are thinking, "Maya still has to depend on others to give her the words she can choose from.", which brings us to her current communication system. Maya needed a system which was flexible enough to provide a lot of word choices and unlimited ways for her to combine words to create messages that were her own. She

needed a system that allowed her to express her inner voice. It had to be a system which allowed her the accuracy that scanning provides, but also will allow her to use it as a touch screen keyboard if her motor skills improve to that level in the future.

In order for Maya to receive her personal augmentative communication system, an assessment was conducted to determine that she could use a device and that she could communicate messages that were medically necessary (medical insurance being the funding source). When she clearly demonstrated the need and the capability, her insurance company's initial response was that it wouldn't fund the device because it considered the need for communication a "convenience" rather than a medical necessity. Imagine your life without the power of communication. Does the idea of "convenience" come to mind?

After further review, it was determined that Maya was an appropriate candidate for a communication device. This summer Maya received a computer-based personal communication system called a Vanguard. This system provides a 3000 word vocabulary which can be combined in a wide

variety of sequences to communicate nearly anything Maya wants to say. Learning the vocabulary and how to combine word sequences into messages is a daunting task; but because it will provide Maya a means of telling others all those thoughts that have remained silent for years, it is a task worth undertaking.

### **What does the future hold for Maya?**

Short-range plans for Maya include learning to use the Vanguard with its sophisticated picture-sequence based system. For Maya, and for those involved in her learning community (home, school, and therapy), it will be almost like learning a new language. When using any alternative communication system, conversation exchanges are much slower than those using spoken communication. Learning this new "language" that the Vanguard utilizes will speed up these exchanges to the extent possible. On one hand, we all feel a need to quickly teach the technology that will allow her to voice her thoughts as soon as possible. On the other hand we are realistic. We

know that, just as Maya's communication messages will take some time for her to create, teaching the communication process will take time as well.

For students like Maya, development of literacy skills is critical. You are only truly able to say anything you are thinking if you are able to spell it. So all throughout her schooling, Maya will continue to work on developing her ability to write. Her Vanguard includes a keyboard that can work with a computer. Literacy activities are pre-programmed into her device. There are also some tools that will support her writing in the future. One of the most useful tools is called Word Prediction. Word Prediction will provide guesses for words Maya is typing so she doesn't have to type entire words, thus speeding up the process. For example, if she is typing "president", she only needs to type "p-r-e" before "president" is one of the 5 guesses presented to her.

Because Maya has demonstrated that her understanding is similar to her non-disabled peers, it is important that she receive opportunities to learn the same curriculum in the same rich learning environment. For students with significant motor impairments, it is often a challenge to provide

them with hands-on learning experiences that are similar to those of their peers. Maya and Maya's classroom teacher will continue to need the physical and learning supports provided by a capable and caring para-educator. This instructional support person has the task of continually deciding when to provide support and when to step back to let Maya learn as a part of a peer group. And when Maya needs to learn from her own mistakes! While developing communication skills, it might be helpful for an adult to initially assist with successful communication exchanges; however they need to quickly step back and let conversations occur naturally. The key will be to let Maya's learning reflect the learning of her peers as closely as possible.

As is the case with any student, Maya's learning will continue to blossom when she is provided with a broad learning curriculum and appropriate material supports, while learning alongside non-disabled peers whenever possible. In addition, Maya will need ongoing technology support for the tools that, for her, mean the difference between silence and voice.

## **A Voice for Maya**

Daniel Webster once said, "If all my possessions were taken from me with one exception, I would choose to retain the power of communication, for by it I would soon regain all the rest". I am sure that it would be impossible for any of us to imagine how our lives would be different if we were unable to communicate with others. Maya is just at the threshold of experiencing the richness that successful communication exchanges will add to her life. Maya's family is looking forward to hearing as well seeing Maya grow.

Back on the deck, a few years from now.... Maya is sitting in the sun. She is watching two squirrels engaged in a battle over a peanut. She looks over at her sister, reading in a corner of the deck, and smiles. She bends over her Vanguard and giggles. In a couple of minutes, Maya's family hears a quiet synthesized voice saying, "Hey Mom! Grandma! Come here! I need to tell you something..."

[If you are interested in learning more about Augmentative and Alternative Communication, the following websites are good places to start:  
To read profiles of people who use augmentative and alternative communication everyday, visit [http://depts.washington.edu/enables/profiles/profiles\\_at\\_aac.htm](http://depts.washington.edu/enables/profiles/profiles_at_aac.htm)]