

A Communication Success Story

Awesome! It's a pretty common descriptor that gets thrown around fairly casually, particularly by the young or young at heart.

It might be applied to a movie or a video game. More seriously, it'll be used for the truly moving things in life, like an intense spiritual experience.



But the seemingly simple application of an objective observation, in this case “awesome,” is a fairly tricky linguistic idea. Most people, of course, take that kind of analysis for granted, but speech-language pathologist Meredith Potts will tell you that, in helping children with disorders that complicate communication, such as autism, it's an often overlooked detail to focus on such seemingly simplistic interjections.

“When you're dealing with communication at the one word level, it gets very monotonous to have the child continually make only requests,” she said. “We should be showing children how to make comments and interjections, to say things are awesome.”

So it's fairly... well, awesome that 7-year-old Shayla Rudd, who only two years ago was nonverbal and communicating with a very rudimentary vocabulary of around 30 signs for nouns and verbs, is on a path to doing just that.

Born at 24 weeks weighing only 1 lb. 7.2 oz., young Shayla has had to overcome a lot of adversity in her life. She was born

with tracheomalacia, or a weakness in the walls of the windpipe, chronic lung disease, and a host of other medical difficulties. Doctors gave her a 40 percent chance to live. At only five months old she had a tracheostomy and other laryngeal trauma that may have caused damage to her vocal cords, and it was only a week shy of her first birthday that she came home for the first time. By age 4 she had been diagnosed with the Autism Spectrum Disorder, Sensory Integration Dysfunction and Attention Deficit Hyperactivity Disorder.

Together, the conditions posed significant barriers to communication, said Shayla's mother Willishia. “We would ask Shayla if she wanted a cookie, and she would sign 'yes,' but we'd give her a cookie and she would sign 'no,’” Rudd recalled. “We'd say, 'don't you want a cookie?' and she would sign 'yes,' but again we'd give her a cookie and she'd sign 'no.' What we didn't know was that she didn't just want a cookie, she wanted a chocolate chip cookie.”

Those kinds of issues -- having to run down long lists of what Shayla might want before coming to the right thing -- led to inevitable frustration and eventually behavior problems, Rudd said. In her initial evaluation of Shayla, Potts noted her aggressiveness and fleeting attention. In therapy, her focus on any given activity would stray in only three to five minutes -- sometimes after seconds.

But a chance meeting changed things. At a therapy session, Shayla's father ran into a friend whose son used a Prentke Romich Vantage Lite device, which, through touchscreen picture icons and learned motor patterns, allows for forming words and sentences. “We really thought it would help her,” said Rudd. “We were trying to find not just anything, but the right thing for her. She didn't have language, and it was too frustrating and limiting for her. She needed something more.”

After the assessment and device trial period had been completed and the Vantage Lite was recommended for Shayla, Potts said in lieu of using a Vantage device (while Shayla waited for her insurance company to approve funding for one), she continued preparing and training Shayla to use

her device by using a standard laptop with simulated version of the Unity language software that would be on Shayla's Vantage and paper print outs of the device screen. Because the laptop program needed to be controlled by a mouse, Shayla was not able to manipulate the mouse to select the words on the screen fast enough to use it to learn the meanings of the individual words during therapy sessions. Since it was important for Shayla to start to learn the motor planning to say words on her device, they practiced the motor plans to select individual words during therapy sessions while they waited for Shayla's personal device. At first, Potts would guide Shayla, hand over hand, to touch the apple and then "verb man." She would then verbally say "eat" (simulating what the Vantage Lite would do) and then provide the natural consequence, by eating something, feeding a stuffed animal, or Shayla would eat or pretend to eat. This process was repeated for several other words, such as "need," "drink," and "stop." Even though accessing these words on her device would require touching two to three pictures with the screen changing after each touch, they practiced just touching the sequence on the unchanging, static, paper manual board.

"There's nothing you can do on paper to make the 'screen' change, but I wanted her start making the movements and for her to start learning the sequences and the word meanings via motor plan training to get that reinforcement."

That was two years ago, a time at which, in initial evaluations, Shayla's mean length utterance (or MLU, a method by which speech therapists can measure speech and gauge language acquisition) was measured at less than that of an 18 month old. Her vocabulary was limited to around 30 one-word nouns or verbs. Earlier this year, her MLU score was measured at 3.49, better than that of a three year old. Her syntactic forms have grown to use nouns and verbs together, to use pronouns and different verbs tenses. She's even added negation with pronouns to her language skills.

"She's answering and asking questions, which is huge," said Potts, who also noted Shayla's increased attention span. She'll sit with an activity in therapy for an hour now instead of minutes. In layman's terms, she's doing things like saying, through the Vantage Lite device: "We are at the house. We are watching a movie."

"My husband and I were like, oh my gosh, I can't believe she just said that," Rudd said of this recent lengthy and unexpected announcement.



But what's more, the increase in communication has allowed for simpler, more direct living, said Rudd. For instance, her parents now know she doesn't just like Sprite, she likes it cold – but with no ice and from a bottle rather than a can. They know she doesn't just like French fries, but curly fries, ideally seasoned curly fries from Arby's. And yes, now she can ask specifically for a chocolate chip cookie thanks to specially programmed buttons in the Unity software on the Vantage.

"Unity is the best visual representation of language on a dynamic communication device available at this time," said Potts. "The representation of vocabulary allows for the natural development of language. It may look hard or difficult starting out, but in the end it pays off with the greatest rewards." Outside the home, Shayla, who loves to read, has become a straight A first grade student. In fact, she's even been known to correct her teacher. On a recent reading comprehension test, she was marked for incorrectly answering that a character from a story was a princess, when

in fact the story said she was. Shayla had the satisfaction of getting to say, "I'm right, and you're wrong." It's not something a child who, only a couple dozen months ago, literally couldn't use more than one word at a time was expected to be able to do.

But perhaps most importantly, Shayla's mother said, the past two years have led to something most people don't even think about: a certain degree of normalcy. She recalls a recent birthday party Shayla attended, her Vantage Lite in hand. The other kids might have seen the device and thought it odd, or perhaps taken it for a toy. But when Shayla arrived, the kids introduced her to those that didn't know her, explaining how she used the device to talk. "I was in awe to see the other kids explaining how it worked," Rudd said. "They didn't say that she was handicapped or what she couldn't do. They just said what she could do."

And what she can do is changing all the time. Though entirely nonverbal two years ago, Potts said she's begun to work with Shayla on verbal speech. It's very much baby steps right now, such as teaching her to phonate – or make sound -- on an exhale rather than inhale, but progress is being made. "I don't know how long it will take for her to have functional verbal speech/language, but it's good that she's showing improvement in that area," said Potts.

But whether Shayla will use her own voice to speak or use a Vantage device in the future, her mother said that initial fears the device would become a crutch of sorts have been overcome by the understanding that the device has enabled communication that wasn't possible before, thus furthering their goal for Shayla to live a more functional and independent life.

Her therapist agreed. "With Shayla, over the progression of time, she's much more in control of her environment than before, and you can see that she knows that," Potts said. "She's communicating, giving directions, making interjections, questioning and negating. Those are really big things that are powerful language tools we take for granted."

For Shayla, in a word, it's pretty awesome.



To see videos of Shayla, read more communication success stories, or learn more about AAC and Autism, visit www.aacandautism.com.