

Family Stories

by Mia Emerson, CCC-SLP

The other day, I was working on the computer in one of my classrooms when I heard a recorded voice say, "Hi, my name is Sherry." Sherry, one of my students, recently got a voice output augmentative device. I assumed she had just activated her greeting message. I turned around to greet her. She was nowhere to be seen. Instead, standing next to Sherry's device, was Mary, who has Rett Syndrome.

Mary is 9 years old and full of vinegar. She coyly glanced at me to make sure the message had gotten through and impishly galloped off to another corner of the room. I chuckled and then shook my head in amazement. I thought back on a scene four years ago when I first met a very different Mary. She came to us as a kindergarten student enrolled in our primary classroom for the developmentally impaired. She was aloof and frequently unhappy. Mary's communication skills consisted primarily of idiosyncratic behaviors that needed to be carefully interpreted by those close to her. During the previous year, a good deal of effort had been put into validating her communication attempts. This was done by consistently responding to specific behaviors in a predictable manner. Mary was beginning to understand that she had some positive control of her world by repeating certain behaviors. She also had been introduced to some very concrete symbols. A spoon represented eating and a roll of toilet paper represented a trip to the bathroom. These symbols were used primarily to aid Mary in transitions. By showing her these items, she began to anticipate meal time and a trip to the bathroom.

In her first year with us, we built on this foundation by associating more symbols to routine occurrences throughout the day. We also provided Mary with frequent choices between different food items and leisure activities. Initially, we simply held up two items in our hands, verbally requested a response, and waited for her either to look or reach for one. We then began to provide choices using something that represented the item. A piece of a cereal box represented cereal or an album cover represented music. We were even able to use some photographs to which Mary would point, to represent choices and activities. Mary made impressive progress during that first year with us. This progress was, in large part, due to the driving force and commitment provided by her family and her dedicated classroom aide. It also became obvious that Mary was very motivated to communicate with us.

I began my second year with Mary ready to introduce more small steps to expand her ability to communicate. I was comfortably nestled into this plan until I got a pivotal phone call from Mary's mom. She began by telling me that some girls with Rett syndrome had benefited from the use of voice-output augmentative devices. These devices can range from being quite simple, using recorded speech or primitive computer speech with very limited message storage, to extremely sophisticated systems. She then asked if I thought we should consider one for Mary.

I was caught totally off guard. I am conservative when it comes to recommending these expensive technological wonders. I had always thought that voice-output systems for people at Mary's communication level merely provided bells and whistles and did little to encourage communication growth. I recognized that they simplified the listener's job of understanding the message. However, I felt that all of us in Mary's sheltered world were so invested in her that we didn't need the help of such a device. But then there was her mother, waiting for a response. She is extremely knowledgeable about Rett syndrome and I had never known her to push for Mary in the wrong direction. I found myself agreeing to look into some devices.

We have the advantage of having a special education technology center in our state. They have several different augmentative systems that can be checked out for three week periods. With their advice, we began to try out some devices. Luckily, Mary could activate these devices by touching a picture, rather than using a more complicated access method. We soon found out that Mary did not respond well to using a device with artificial sounding computer voices. However, she was quite interested in activating devices with recorded speech. We finally selected the Digivox from Sentient. It is similar to other low-end augmentative devices on the market but it seemed particularly suited to Mary's needs. It has several levels. These levels can be thought of as pages in a book. You can program each page to reflect

different communication needs. For example, Mary has one level that is very specific to home and another that has some general school vocabulary. Each level can be programmed to provide from one to 48 different messages. The multiple level feature and the flexible number of message areas have proven to be indispensable. Additionally, the use of recorded speech enabled us to use familiar voices on the device.

Mary's parents pursued funding for the device through their insurance. This was justified because Mary had no clear method of showing when she was sick and, with little voluntary control over vocalization, she could not reliably even gain attention to get help. We had been warned that this process could take up to one year. It did, in fact, take ten months from the time we selected the device until it was delivered. While we were waiting for the device, we resorted to my "small step" plan. Mary gradually could use some line drawings, rather than more concrete photographs, to relay her messages. This skill helped us keep up with her growing expressive vocabulary. We kept several of her pictures in a communication notebook. We also posted pictures on the fronts of cupboards, doors, walls, and the refrigerator at school. Mary's family did the same at home.

We received the Digivox at the beginning of Mary's 2nd grade year. She had been in a regular first grade class for portions of the day during the previous year. Mary began second grade as a member of a regular 2nd grade class, with support being provided by an instructional aide in the classroom. She was also "pulled-out" of the classroom for some specific skill training. When the device arrived, Mary's family took primary responsibility for programming and maintaining it. Mary's aide supervised its use during the school hours and her classroom teacher made suggestions for content. I would make suggestions for the vocabulary, help in developing overlays (the "pages" for the levels), and generally troubleshoot. This team approach resulted in an augmentative device that, eventually, proved to be relevant and motivating to Mary. We did not necessarily see an overnight miracle. Mary needed to be prompted or reminded frequently to use her device.

At first, her peers viewed the device as an oddity. In an attempt to make the device more tempting to Mary and less strange to her peers, we made a "friends" level. We reduced individual pictures of the students so we had everyone in the class represented on the board. Then Mary's mother had each student record a message to Mary. Each student's message was activated when Mary touched the respective picture. Activating these messages instantly became one of Mary's favorite activities (especially, I was told, in the wee hours of the morning). Additionally, her friends were thrilled to be part of Mary's device. This really became the turning point for Mary's communication.

I am enthusiastic about Mary's growth in communication. She is very intentional in her communication attempts, whether they are initiated using the Digivox, body gestures, or facial expressions. It is hard not to attribute much of this growth to the voice-output device. Interestingly enough, though, I don't think that the device directly triggered her growth. Rather, because her "listeners" could understand her more easily when she used the Digivox, we began to view her as a more legitimate communicator. We responded to all of her attempts more consistently, no matter the method she used. Thus, Mary communicates with us more frequently because her attempts pay off for her.

Mary is nearing the end of 3rd grade. Her use of the Digivox has continued to grow. She is using the device more spontaneously as time goes on. She sometimes combines symbols to express herself. For example, she activated "I'm sick," and "home," last year to send us a very clear message. This skill is synergistic as it allows her to come up with novel phrases that we had not necessarily anticipated when developing the "single thought" vocabulary. She is also beginning to use "yes," and "no," in response to questions. And now, as she showed me the other day, she is using it to express humor.

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