

First Words

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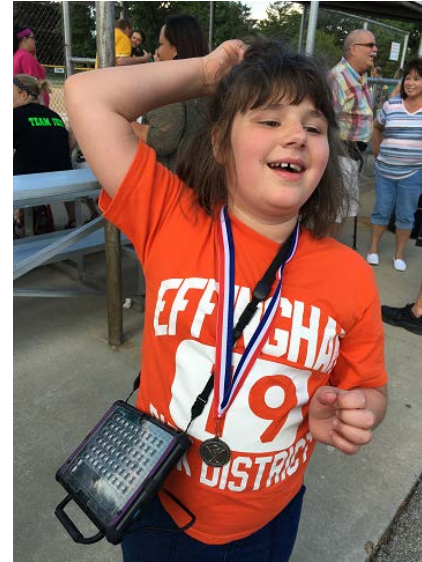
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Those first words are everything. There's nothing like hearing your child say "mama" while grinning and pointing. But when those words come and then disappear, or don't come at all, there's no clear path for what happens next. As parents, we're not prepared for asking difficult questions or hearing uncomfortable answers. We rely on each other and our gut feelings. As speech pathologists, we don't have a rule book for introducing augmentative and alternative communication (AAC). We rely on listening to families, watching our clients, clinical judgment, and trial and error.

In my capacity as a Speech Pathologist/ Regional Consultant for Prentke Romich Company (PRC) I've encountered hundreds of children and their families/ support teams. I've had to wrestle with discord between family wishes for their children's communication and my professional judgment. I've had to balance the communication option that I am certain will be successful in the long term but doesn't have the short term success that the team wants. This precarious balance has never been more evident than in my work with girls with Rett Syndrome. Which language system is best? Which access method will be most efficient? How can I encourage implementation of AAC when there are so many other obstacles families are facing? Three girls have shaped how I work with individuals with Rett Syndrome, and they have all taught me different things by letting me into their lives.

Chrissy taught me that words matter. I met her when she was about 4 – a strong-willed, determined little girl who broke out in huge grins when her parents or princesses were involved. I worked with her before her diagnosis of Rett, and she used her hands to access Unity (a language system with hundreds of pre-programmed words). She wasn't always exactly on target, but she loved exploring. And we knew that she was being intentional about her message when she repeated a word or phrase several times and then switched her gaze to us. At one point, her therapists and I took away some of the words to help her learn the "important ones," leaving her with about 10-20 words. This didn't go over well – her enthusiasm for using the device stopped. Once we added in more words, however, she forgave us and jumped back into exploring and using the device intentionally. Words matter. We needed the option to start simple, but in order for success to occur we had to think big.

Jordynn taught me that access options are important. Jordynn is three – a social, active little girl who has eyes that you can get lost in. When we started looking at AAC, her speech pathologist had recommended the NuEye eye gaze access method because of her Rett diagnosis. Her desire to touch the device, however, led Jordynn’s mom and I to think more about touch access instead. When that proved to be inaccurate, even using really large buttons, we then trialed NuPoint (PRC’s head mouse). Although Jordynn had good head control, her head movements and her eye movements weren’t coordinated, so she would look at a button on the screen with her head turned in another direction and select the wrong word. We finally came back to the initial recommendation of NuEye. Jordynn did beautifully with 15 buttons on the screen and especially enjoyed using the core words to help her mom read books and her fringe words to select what type of food she wanted. I apologized to Jordynn’s mom for trying out the different access options before ultimately circling back to NuEye, but she kindly noted that she was thrilled to see all the different access options available. Knowing those options existed not only helped cement her commitment to eye gaze, but also gave her comfort in knowing that there were additional access options available if necessary.



Finally, Mary taught me that a network of support is essential. Mary is a sweet 12 year old whose smile lights up a room. After years of using low-tech boards and books, she began using an Accent 1400 with NuEye late last year. When she first started, and with the addition of daily therapy, she was successful with 28 buttons on a screen, but with many of the buttons hidden. After a summer break where travels precluded much device use, she started this school year struggling to be successful. Phone calls, online trainings,



and in-person visits helped re-establish positioning and fine-tune calibration. But more was needed to jump start communication. So I called in back-up. An experienced colleague suggested we enlarge the buttons on the screen to focus (at least for a while) on increasing Mary’s confidence and ability with eye gaze in general. It truly takes a village to support a child with AAC: the device itself is a start, but the enthusiasm, dedication and hard work of those surrounding the child and that device that are essential

ingredients to communication success. One person can't do it, one website can't do it – a full network of support resources is crucial.

Words matter. Access options are important. Support is critical. These are the lessons I've learned from working with girls with Rett Syndrome. I've watched as within the AAC industry device hardware/ eye gaze systems have improved, vocabulary options have expanded, and support resources have become more individualized. All of these mean better communication outcomes for individuals with Rett syndrome and others who use AAC. But we still have lessons to learn, and improvements to make, and keeping the conversation open and learning from each other is a start.