

A Communication Success Story

GETTING TECHNOLOGICAL: A BOY WHO LOVES GADGETS DISCOVERS A NEW ONE

Cohen Pearson avidly embraces technology. Sometimes too much so, actually, as the 4 1/2-year-old has been a little too rough on two iPhones, three iPod Touches and two laptops – so far. But when juice was spilled on the keyboard of laptop number three, Cohen's mother, Kelly Pearson, said she simply could not be mad, even if it meant another trip to Cohen's beloved Apple store to buy laptop number four, because the accident was followed by a simple “sorry.”



That apology might or might not be enough to melt a parent's heart coming from most kids, but Cohen isn't like most kids. At age 2 he was diagnosed with autism after six to eight months of tests and therapies and trying to get him to the right person. Aside from one utterance of “purple” at about nine months, he'd never been verbal – even babbling – and, having been born five and a half weeks premature, had hit milestones like sitting up and walking fairly late.

After the diagnosis came familiar signs, like hand flapping and squealing and not paying attention to his name. For the family, it was the beginning of what has been an endless search for aid and answers: speech, occupational and physical therapy, nutritional adjustments – “you name it, we have

tried it. Every weird therapy I'd read about on the Internet that worked for one kid out there somewhere, we'd try it,” said Kelly, explaining that Cohen has other health concerns as well.

In the meantime, “he's been kicked out of every preschool within driving distance because the people there haven't understood the situation well enough to want to work with him,” Kelly said. She explained that, although Cohen is in a public school for special needs children, the family is moving from Mississippi to Florida this spring so he can attend the Emerald Coast Autism Center in Niceville.

THE POWER OF 'PLEASE'

Communication has always been a frustration, so much so that Cohen has hurt himself, “all because he wanted to watch Elmo instead of the Wiggles,” but he was unable to communicate it, said Kelly.

It was one such incident earlier this year, when Cohen almost broke his nose and gave himself a concussion, that convinced his parents to once again try something new: the Prentke Romich Company (PRC) Vantage Lite device, which uses specifically programmable buttons that, when touched, will speak aloud for the user.

Kelly said she was dubious of the approach at first, fearing that Cohen would not ever speak for himself if he had the Vantage Lite to speak for him. “I kept thinking if I get him this, he's not going to talk,” said Kelly. “I never had that mindset that this would be giving him a sure form of communication when everything else was just taking a chance” to try to get him to use his own voice.

But after having attended a workshop on Language Acquisition through Motor Planning (LAMP) in January, 2010, Kelly opted to try this kind of alternative and augmentative communication (AAC).

To determine what would work for Cohen, he was evaluated by Lynn McConnell, a speech language pathologist with the T. K. Martin Center for Technology and Disability at Mississippi

State University, who said it's important to understand the "cause and effect" aspect of communication. Very quickly Cohen picked up that he could "say" something using the Vantage Lite and Lynn would respond, just like a normal conversation. "He really shows tremendous potential," she said. "He's really a smart, smart kid. He's got all this bottled up inside, and he needed to get it out."

As Kelly and her husband remained out of sight, Lynn would read a little bit from a story, and Cohen would tell her to continue by pressing the button for "more," or "read more," or "read more more more more more." And then, unprompted, he hit the button for "please." "As a parent, you always say 'do this please' and 'do that please' and 'thank you,'" Kelly said. "To hear [him use 'please'], I just teared up. It was the cutest thing I'd ever heard."

'MOMMY, DRIVE'

It didn't take long to decide to purchase a Vantage Lite, though the Pearsons did spend some time shopping for one as their private insurance did not cover it. They managed to purchase one that was like new in an auction on eBay. Cohen would have preferred it to be green like the one in the evaluation, but it would do.

An all-nighter to study and learn the programming, and it was time to hit the ground running. And that is what Cohen has done as Kelly estimates she's added five to 10 words a day in the first two months of using the Vantage Lite. "Two months ago it was 'drink,'" said Kelly. "Then it was 'want drink.' He's just started using 'I,' [as in 'I want drink,'], and I had nothing to do with that."

But the message isn't always that simple. A recent hospital visit for another round of being poked by needles provided an opportunity for Cohen to express his intent in a different way. When the doctor came in, it was, "Mommy, sunglasses," "Mommy, drive," and "Cohen go home." "He was telling me, 'Get your act together and let's get out of here,'" Kelly said.

That he doesn't use his own voice to say these things is no longer a concern. "The frustration with communication is absolutely gone. If he can't tell us what he wants, he hovers over 'the Talker,' and if he still can't give us an answer, he'll give us something very close.

"The only frustration is when I can't do absolutely what he wants me to do." That's meant having to do a lot more explaining. For example, Cohen says he wants to see a specific friend but it's late enough that said friend is in bed (as Cohen probably should be). Kelly said she's thrilled he can make that request, but she is now having to find ways of explaining that it can't always be immediately fulfilled.

And, of course, there are some tasks the Vantage Lite is not up to. Cohen has his favorite blankets and one day Kelly said she found him in a tug of war with their therapeutic puppy, Emma, relentlessly commanding her to "stop, stop, stop" on his talker. Emma, unfortunately, would not listen.



MORE THINGS TO LOVE

But Cohen's growth in communication has not been one way and has not been entirely on the Vantage Lite, his mother said. Indeed, she and her husband have found that he is more responsive when questioned. "Cognitively, we've known he's smart. But receptively, we'd have to ask him 12 times 'do you want juice' before he'd answer. Now, we don't have to badger him anymore" because he will answer the first time.

And his voice on the talker has not been limited to simply using it to say words. In fact, he loves the alphabet page, and will use it to spell names, colors and all sorts of words Kelly

readily admits she had no idea he even knew how to spell. In that way, the past two months have allowed for a kind of bonding.

“It’s a lot more doing things together,” Kelly said. “Instead of my husband and I telling him what to do, he’s telling us what to do. Sometimes that’s frustrating, and sometimes it’s wonderful. But in that way he’s more like a normal kid.

“Obviously, of course, we love him no matter what, but I guess we’ve discovered more things to love about him because he can tell us so much more.”



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