

Sean Chronicles
Sept. 2008

Sean's Gentle Request

He's going to be 29 in November. His verbal communication did not begin with a cry at his birth. He uttered no sound at his birth except his fast-paced and shallow breathing. He stayed in a special pediatric hospital separated from us by an incubator, his little body covered with monitors. Each daily visit began with the first shocking sight of him covered by a blanket of multi-colored wiring. And he was always silent.

Then one day he grinned when I put my finger through the opening in the incubator and gently touched his tummy! I cried! That was the day that told me he wasn't going to die after all. The daily visits went on for weeks. Mick and I took a bus every day back and forth to the hospital where the most severe pediatric cases were under intensive care around the clock.

It was somewhere within those first weeks that we realized without a doubt that Sean couldn't hear. His heart had been a little off, but that had righted itself. But he was not hearing.

After what seemed a very long month, Sean finally came home. He was still silent. He just lay there in his little bed. He didn't even look around. His eyes were cloudy with cataracts. But he was home. I touched him as though he were made of the thinnest glass. I was so afraid to hurt him or cause him any discomfort at all.

Once morning as I changed him, he belted out a shriek of laughter that almost knocked me off my feet. From then on, he'd burst into laughter that pierced the air and anyone within hearing distance couldn't help laugh too.

Over the years, Sean has learned to communicate in various ways – never with spoken words but using a mixture of signs and gestures. At a school for the deaf and blind, the idea of an object cue was introduced into his vocabulary. Specific objects meant specific activities: a special spoon meant a meal, a coin purse meant going out to shop, a small piece of sponge meant going to the swimming pool, etc. Every activity had its own object cue. The object cue concept carried through when we moved to America and while the objects changed, Sean understood the concept very well.

All through his life, his teachers and we at home have worked hard to help Sean initiate communication. The vast majority of interaction and communication has been FROM others TO Sean. Getting him to initiate communication seems to have been the big challenge for all. And from what we have learned, this is pretty typical in dealing with a deaf and blind person. It is much easier for them to sit and wait for something than to request something or start an interaction.

Wherever Sean has asked, or initiated, we have tried to go with him on it. No matter what time of day or night, no matter the request. It's been a huge challenge sometimes when life demanded we be doing something else and pressures were on. But wherever possible, we have supported Sean's initiations to the utmost. We saw what happened with children who had no such interaction or whose environment provided too little sense stimulation: some children by the age of 12 banged their heads against walls just for any tactile stimulation. They were put in helmets to keep them from damaging their brains or fracturing their skulls. No, that was not going to be Sean.

Language has always been a challenge. Both vision and hearing losses make language learning very difficult, but Sean has still learned a great deal of meaningful signs. And creatively, he has made up a few of his own much to the surprise of his teachers. He had a fascination for balloons as a small child. He loved them and would play with them until they popped. His sign for a balloon was a series of quick exhales through his mouth. How he made that connection I'll never know because he never blew them up himself, but he'd hand one to someone else to blow up for him, and then he'd play with it. But he KNEW that the person had to blow it up. And he made that "exhale sign" when he saw a balloon. (After the cataracts were removed, he had some limited residual vision so he could see some things. He uses his residual vision every day.)

One of Sean's favorite activities as a child was taking his clothes off. He was great at it! He'd sit outside in the back yard playing with a twig or whatever else occupied him. 30 seconds later there he was, all his clothes off, basking in the sunshine, happy as a clam at high tide. I hardly ever actually saw him take his clothes off. One look outside would show him fully clothed. The next instant he was naked, still examining the twig an inch from his face as though nothing had happened at all.

He'd take his clothes off in the back seat of the car while I drove to...anywhere. A glance back in the mirror would show him without clothes, legs folded, sitting on the seat as he looked up into the sunshine. His clothes, socks and shoes were strewn all over the back seat. He always seemed happier with his clothes off.

I'd have to double and triple check him before I stopped the car anywhere. Even the fast food drive-throughs! And while I drove in traffic, when Sean decided those clothes were coming off, we were the object of quite some looks from neighboring cars.

But I digress.

All these years we have encouraged Sean to initiate communication rather than just wait for some from someone else. The more signing he learned, the more he began to initiate. This has gone in waves over the years depending on whether he was happy in school, whether he felt as though the people dealing with him were on his side, and depending on how much he was being encouraged for "speaking up" in any way he chose.

Over the last several years, he has gotten good at asking for food if he's hungry by finding a plate or saucer and bringing it to me. That doesn't happen often simply because his meals are on a pretty good schedule. He has a great appetite and he can pack away plenty of food. This man is not going hungry! But that's one example.

Another example is that for the last year or so, his dad has been taking Sean out for walks in the evenings when the weather permits. Sean really likes these evening walks. His object cue for these, is his tennis shoe. He will find his shoe and hand it to Mick. Mick, lovingly, will usually get up and put his boots back on and take Sean and one of our dogs out for a walk.

The most common request is "more Gatorade". Sean will bring his plastic glass to us at any time of day or night if he wants a refill. Sometimes this is in the middle of the night. Sometimes it's in the pre-dawn morning. Any time.

When handed a piece of clothing, he will put it on usually. Or he will sit with hardly anything on, getting cold, without any initiation to put more clothes on. Clothes off? Sure. But that's why I monitor how cold or warm he

is almost constantly. The one thing that Sean has NEVER done is dress himself or even show any interest in putting more clothes on than he has. Until today.

During the middle of last night, he had an accident in his bed. Mick was awake because he goes to work early, and he bathed Sean, got all the bedclothes into the wash and saw to it that Sean was snuggled back into a clean, dry bed, before leaving for work. Sean hadn't wanted to put any nightclothes on after that so Mick let him curl up under one of his thick comforters.

Mick woke me to let me know what had happened before he left. Then I went back to sleep. The sunshine was flooding into the room when I woke up, and a naked Sean was standing near my bed. In his hands he held a bundled pair of socks. He held them out to me. Now, Sean is perfectly capable of putting socks on, but he hadn't done that. That wouldn't have told me anything. I might have figured that Mick left him under his covers with only his socks on.

No, Sean had brought the pair of socks in to me. It was his very smart way of telling me that he wanted my help to get him dressed. And so I assisted Sean first with the socks, then clean underwear, his jeans, a clean shirt and then getting his teeth brushed and his shave done. Sean smiled to me. What a great way to start the day!

Nancy Wenlock
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