

Down Syndrome News, Vol. 27, No. 4

Better Late Than Never – How David Finally Learned to Use the Bathroom

By Linda Moran, Ridgewood, NJ

“Don’t worry. He won’t be in diapers when he enters high school.” We’ve all heard this advice as it pertains to typical kids. It’s intended to help us relax — and it’s true. But what about our children with Down syndrome? Our son, David, took so long to train that he threw this advice into question. If you have or work with a child with DS, you know what it means to adjust expectations.

Although many children with DS are trained completely by age five, the range of what’s typical is quite broad—some say anywhere between three and 11. Those numbers gave us some comfort, until David turned 11 and there was still no end in sight.

We had tried the standard method, suggested by a specialist, of putting him on a schedule. David likes schedules and memorizes his school schedule each year. But, starting in kindergarten, whenever we tried to put him on a schedule for using the bathroom, he would rebel, and withhold his urine all day until he went to sleep. Since our doctor advised this was not good for David’s health, we had to quickly give up.

Over the years, we read books, tried various approaches, and consulted psychology, special education and medical experts. We were perplexed, and spent long months doing nothing at all. Some experts felt we had started too late. Others felt that David was just “not ready.” But what does that mean? Looking back, perhaps David was just not ready to give up control. That condition could reinforce itself forever.

Now he was 11, had outgrown night-time pull-ups, and was wearing adult diapers. The school psychologist and special education teacher were befuddled. And we, his parents, were exhausted and resigned. The school called in a behaviorist, but we didn’t have much hope. We were in for a surprise.

Jacqueline Dubil-Craig, with her master’s degree in Applied Psychology, and a background working with children with autism, was, it turned out, just what the doctor ordered. Dubil-Craig concurred with us that this was not a potty issue any more. From our point of view, David’s power struggle with us was akin to that of a teenage girl with an eating disorder.

According to Dubil-Craig, it all came down to reinforcers. “I look at everything in terms of reinforcement,” said Dubil-Craig. “The highest reinforcer is the control he is exerting over you.” She explained that all the positive reinforcers we had tried (stickers, favorite foods and his interest in schedules); and all the negative reinforcers we had tried (no computer use in school), had less meaning to him than the power he was holding over everyone.

What she prescribed was so simple. It seemed, at the surface, to be something we had already tried, but we actually had not. She told us we were to show no interest in whether David used the bathroom. On the other hand, his toys would care deeply about it. All his favorite toys were to climb up on a high shelf, which would come to be known as the deprivation shelf. Each time he wanted a belonging, the toy would inform him (in my flat voice) that it would be happy to come down after he pees. For three weeks, those toys didn't budge, just as Dubil-Craig had predicted.

As we were instructed, never once did we, his parents or siblings, say a word about the toys or the bathroom. Then one day David got fed up. He wanted his favorite toy, a Madeline doll. We heard a flush, and then David emerged from the bathroom with a grin and reported, "I peed." Down came the Madeline doll, with no words of praise.

The power struggle had now shifted to David and the Madeline doll. We were out of the loop. But what was next? When would the doll return to the shelf each time? Could we direct David to "go" before a long car trip? We made it up as we went along, but stayed strict about one thing — we ascribed all enthusiasm and control to his Madeline doll. She was in charge now. Sometimes we would have to go behind closed doors to shout for joy.

After about six weeks, we sensed it was time for underwear. In David's mind, pull-ups get changed when wet. Since his pull-up was never wet, he would wear it until the elastic wore out. One day his gym teacher noticed a wad of bulk down around his knees inside his pants. It was an old, stretched out, dry pull-up.

Would he do any better changing underwear every day? We solved that problem with a laundry marker and the day of the week printed on each pair of underwear. Now, David was happy to match the correct underwear to the correct day of the week. It was four weeks short of his 12th birthday, and six weeks since the deprivation shelf was created. David was now in underwear, even at night. We extinguished the shelf.

In the final analysis, this method capitalized on David's social strength by creating a relationship between himself and a doll, and then later, between David and his underwear. We would say, "Your underwear wants to stay clean and dry." It was never, "*We want* your underwear to stay clean and dry." The wording is subtle, but it worked. The focus now was away from his relationship with us. "By acting as though you did not care whether he used the bathroom or not, his control reinforcer was removed," says Dubil-Craig. "Suddenly, depriving him of his favorite toy became meaningful again."

Today, upon reflection, what finally worked was both the easiest and the hardest. It was the easiest because we didn't have to go with him or be controlled by a schedule. It was the hardest because we had to stifle all enthusiasm. Had we shown excitement, we would have unwittingly recharged the power struggle. According to Kim Casey, M.S.,

Special Ed., all children, regardless of age or disability, need to have a say in their own lives. “If we constantly are battling with our children to gain control,” says Casey, “then everyone loses and nobody really has any power. If you have the last say in every battle the child does not learn from the situation.” David now was enjoying having control over his own toileting.

Now that David is trained, he still holds it for a long time. We hope to proceed cautiously with shifting him to a reasonable schedule. For the moment, trying to convince him to go before a long trip, means he holds it even longer. We have had to leave him alone and trust him to know what he needs — that is appropriate for an adolescent. Some things about David are quite on target.

We may never know whether David could have trained years earlier than he did. However, his lack of fine motor coordination plays a role in his ability to use the bathroom independently. According to Marlene Targ Brill, author of *Keys to Parenting a Child with Down’s Syndrome*, physical readiness for toileting includes fine motor skills. Even at age 12, he needs to wear elastic waist pants with no zipper. Had he trained earlier, he would have been dependent on our help. Given his strong dose of stubbornness, coupled with our preoccupation with three younger children, it’s possible the timing could not have been different.

As is often true with our wondrous children, the question of whether the ending of this story is neat and tidy is a matter of perception. When it comes to David doing his “number two,” he awakens at night, changes his own dirty underwear, finds a plastic bag, carefully wraps up the mess, and leaves it in the kitchen for us to find in the morning. He awakens no one. Honestly, I can’t complain.

Editor’s note: Linda Moran lives with her husband and four children in Ridgewood, NJ. She writes about advocacy, disabilities, parenting, and self-help and was delighted to report that just a few weeks after writing this article, David began using the toilet for his “number two.” To contact Moran, visit her Web site at www.lindamorán.net.