

It's Not If, It's How and When

Toilet Training In Less Than A Century

By Jeffrey Cohen

Potty training. Two words that strike fear in the hearts and minds of all parents of children with fragile X. The neighbor's kid did it at two and they can't stop talking about it. Your older child did it at three and your nephew from Cleveland did it at four, all by himself without any prompting. But your son or daughter is five, no six, seven, or maybe even ten or twelve and still shows no interest. This is beginning to get embarrassing and depressing. What's a parent to do?

Let me first tell you that I'm not a doctor, a psychologist or a behavioral specialist. I'm *just* a parent of children with fragile X. My thoughts are based on my own personal experience, consultation with many "experts," reading, but most importantly on common sense, creativity, "thinking outside the box," and a passionate desire to relate to, interact with, and help my child. In other words, tools that we all have.

First, avoid the mistake that so many others make when interacting with our children. Just like typical kids are all different, so too are all kids with fragile X. They don't all learn the same way or at the same pace and often different and creative approaches are required to learn new skills. The point is that whether you use the approach detailed here or elsewhere in many other good resources *don't feel like you have to follow the instructions to the letter*. Nobody knows your child better than you. Nobody knows how they learn, what can grab and hold their attention, when something is working and when something isn't. After reading this proposed method and any others you find, sit down and really think about how you can modify and adapt the procedure to fit your child.

In our case we started with resources that are often recommended: "*Toilet Training in Less Than a Day*" by Nathan Azrin and Richard Foxx, and "*Once Upon a Potty*" video—both checked out from our public library. The book recommends using a doll as a role model and we decided right away that would be far to abstract for

our son (4.5yrs) so we decided that I would be the role model.

Before reviewing the procedure, first a word on when to begin this process. Remembering again that I do not have a medical or psychological background, I believe that when you are able to interact successfully and have fun with your child, on their level, that it's a good time to start. What I'm talking about is based upon what I still believe was some of the best advice I ever received from any professional about my son. He was evaluated by a psychologist at about age 4 before we even had the diagnosis of fragile X. At an early session he put my son and I in an empty waiting room with a hidden camera to watch us interact. Some toys, chairs, magazines and a tall corn plant, that was it. I tried to get my son to play appropriately with the toys but he had his mind set on that corn plant. Batting at the leaves was to be the activi-

ty of the day and I had to decide whether to fight it or play along. I decided to play along and thus was born the "corn plant game". He'd bat a leaf, then I. He'd bat two, then I'd bat two. Pretty soon we were taking turns, setting the rules, laughing, interacting and having a great time. The psychologist loved every minute of it (the plant could be replaced) and explained that my son and I had stumbled onto what he thought was the secret of reaching him regardless of the diagnosis. Don't try to

forcefully pull him out of his world, go in there with him and begin the interaction on his level with an activity of his choosing. Begin a pattern of interaction and turn taking and eventually the transition to more appropriate activities and interactions will follow.

As it turns out this guy was right on the mark. This was the first of many great games to follow. The "lumpy couch" game and the "jumbling three of anything" game are two that come to mind. The activity was chosen by my son and then we made a fun, laughing, turn taking game out of it.

Which brings us back to potty training. The basic method was to take the procedure from start to finish and break it down into small component parts. Getting up off the couch, walking to the bathroom, opening the door, turning on the light, pants down, sit and go. Each

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activity is done by the role model and then the child. The book said use a doll for a role model but in our case I was the doll. I exaggerated every step and turned each into the kind of game my son and I frequently played. We took turns getting up off the couch and doing each successive step and when my son took his turn and completed each step he was greeted with absolutely wild praise and glee. He loved it. For actual successes we had a celebration fit for a king's coronation.

The procedure also calls for all the salty snacks they can eat followed by all the liquid they can drink. The idea is to keep the bladder full at all times to maximize opportunities. After a success, when you're back on the couch watching the video, check the pants. (Dry pants inspection game.) If they're dry it's time for more wild celebration.

Have plenty of underpants on hand for accidents. Each time one happened he had to change himself and put his dirty laundry in the washing machine. Accidents also set up another game: the walking through the route to the nearest bathroom from the location of the accident game.

In between all this merriment keep the pretzels and pop flowing and watch the video about potty training. No other videos or TV. No other topic for the day or in our case for the entire weekend. It might even be a good idea to let your other kids sleep out. From the time we woke up on Saturday to the time we went to bed on Sunday this is all we did—and it worked. After 2 days we were 75-80% complete. The procedure finished gradually over the next 6 months but we never went back to diapers. Keep a close eye and continue to heap wild praise for success with dry pants inspections.

You might feel a bit silly about all of this and if you're embarrassed pull the shades. But to succeed you'll need to tap into your inner child and have a good time with it. My wife and I still laugh out loud every time we re-tell the story.

Now you know what they say about "always" and "never" so results in every case cannot be guaranteed, but I strongly believe that with the right mix of perseverance, creativity and unbridled fun it's not a question of if, only how, and when. Good Luck!

Editor's Note: Jeffrey Cohen is President of the National Fragile X Foundation and the father of two children with fragile X. His description of his successful experience with his son has appeared on the internet and has been shared amongst many parents. It is meant to be just one parent's description, and is printed in this publication as a reminder to parents that a Ph.D. in special education is not required to toilet train your child with special needs. Nonetheless, many of the specialists do have a great deal to offer in the way of experience, suggestions and insight into the psychological and physical needs of your child.

In addition to the resources mentioned by Jeffrey, we recommend, *Fragile, Handle With Care*, by Marcia Braden, Ph.D., and *Fragile X Syndrome, A Parents Guide* by Jayne Dixon-Weber. Both titles provide very good overviews of the issues regarding toilet training.

As additional sources of information, we suggest an internet search using "toilet training special" as your search text. There you will find many interesting and helpful discussions, suggestions and lists of resources including some specialized products.

As always, a word of caution when searching the internet: Always look for information provided by trained and/or experienced individuals. Be skeptical of claims that seem to defy common sense. Talk with parents of children who have special needs similar to your child's. Most importantly, always check with your doctor before embarking on a new potty training procedure. You always want to rule-out the possibility that physical problems are interfering with your child's ability to develop bladder and bowel control.

Mission Statement of the National Fragile X Foundation

The National Fragile X Foundation unites the fragile X community to:

- Enrich lives through educational and emotional support
- Promote public and professional awareness
- Advance research toward improved treatments and a cure for fragile X syndrome.