

Braden on Behavior

Behavior Modification in the Community

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(Editor's note: This is the second of a four-part series addressing the subject of managing behavior in children with fragile X syndrome. Subsequent articles will address behavior at home and in social settings. Contact: info@marciabraden.com)

The first article in this series discussed how difficult it is to apply stringent behavioral strategies to reduce problem behaviors in the classroom. The key is to understand that behavior doesn't occur in a vacuum. What happens *before* a problem behavior (its "antecedents") dictates to a great degree what that behavior will be. When a teacher learns what the triggers are for any given child, he or she can tailor, to the degree possible, an appropriate intervention or prevention strategy. That in turn allows for more success in the overall plan.

This classroom approach is not much different in general than what parents or other authority figures in the community must do to help shape behavior in positive directions. But specific circumstances vary greatly from classroom to home to community. This article goes beyond the school environment and examines managing behavior in the community.

It is obvious that the challenge is greater in the community because the environment is much larger and more difficult to predict. The many different community settings and stimuli make it more problematic for parents and the children themselves to navigate behavioral obstacles.

Public feedback to parents about their child's challenging behavior can even come to include accusations of abuse, neglect or at least poor parenting. Taking a child into a public community environment can thus be daunting and in some ways, holds a parent hostage. Sometimes parents refrain from including their child because the child's behavior has the potential to pose a safety hazard.

Avoidance Is Not a Solution

Sadly, the obvious—or at least easiest—remedy to avoid discomfort and potential humiliation is to exclude the child from community-based activities. In order to do this, one parent or a sibling must stay home or provide an alternative activity that is easier to negotiate. This method of managing the situation, although understandable, is sorely lacking because the child misses opportunities to modify or learn new behaviors that can make him more functional in community settings.

That said, it is very difficult for parents to endure the challenge, especially if past experiences have been difficult or were so traumatic that neither the child nor the parent wants to get anywhere near a similar circumstance.

With behavior magnified in large, complex community settings, identifying the antecedents can be more challenging than it is in the relatively more controlled setting of a classroom or home. Antecedents might include multiple and different noises, events, people, and varying locations that include serial transitions, to name just a few.

The fragile X syndrome behavioral phenotype includes an attention-deficit/hyperactivity disorder in about 80 percent of people affected by the condition. This issue complicates the predictability of behavior because the environment is loaded with unforeseen events that can easily lead to behavioral outbursts. The following example was presented to me in my practice several weeks ago. The antecedent was not apparent for reasons I discuss below.

The Situation: Antecedent Confusion

The parent of a child with FXS wanted to take her child to get a haircut. The problem was that the hairdresser had previously worked out of her home (a much smaller and predictable environment), but moved her business to a busy strip mall. Because the child knew the hairdresser and was comfortable with her, the mother felt it was important to continue with her despite the move. They had gone through the process of desensitizing the child's head to touch, to the noise and vibration of shears, and to washing his hair in a big sink with a hose rinse. Anyone who is around children with FXS knows what accomplishments these are!

In the mother's mind, the major challenge was going to be having her son navigate a busy parking lot with many distractions. What she didn't foresee was that the mere change in the customary route to the hairdresser's caused her son so much anxiety that they never even made it to the parking lot. It was not until she analyzed what caused her son's outburst in the car that she realized she had focused on the wrong stimuli.

The son's behavior in this situation related to another hallmark of the phenotype—*anxiety*. Her child became obsessive and compulsive about the route and direction they were taking because he expected his parent to go to the hairdresser's home. His expectation had not been met, and because the environment was unfamiliar, his anxiety was mounting, eventually becoming the catalyst for a fight-or-flight reaction.

Even though the mother had been aware of how changes in routine— in this case the route to the hairdresser—could contribute to problematic behavior, she was so overwhelmed with the thought of taking him into a busy and dangerous parking lot that she did not properly prepare him for the change. When children with FXS find the ability to self-regulate their behavior challenged in this way, aggressive and self-injurious behaviors may occur.

Keep It Simple With Task Analysis

Making behavioral changes in the community environment is complicated and requires an understanding of both the phenotype and antecedents. Earning tokens or stars on a chart may not be enough to encourage compliance. Denying access to an event or activity as a way to induce cooperation usually won't work because it reinforces the very thing the child is trying to accomplish—escaping the anxiety that has built up around participation, no matter how much she may ultimately enjoy it.

Clearly, the problem behavior in the case cited here resulted from changing routes to go see the hairdresser. I discussed this with the mother in detail, carefully probing her experience. In order to make the task of managing her son in this situation less wieldy, it was important to reduce the complexity of the overall target and focus simply on introducing him to the new route and what was, in essence, an entirely new environment. This process is called “task analyzing.” Simply put, the task (or string of tasks) is broken down into small pieces so that the child can succeed and the parent is not so overwhelmed.

We decided that in order to desensitize the child from the reaction to the first failed encounter, it was necessary for us to change the route and give him a fresh start. Luckily, one of her son's favorite food chains was in the same strip mall. While the mother had originally thought the restaurant would be a major distraction for him once they entered the parking lot, she had not considered using it as a positive vehicle to introduce him to the hairdresser's new location. This time the plan was to drive into the parking lot to get her son a snack. He expected this and was familiar with the route. The next step was to nonchalantly mention to her husband on the phone (this is called a “side dialogue”) that Sherry had moved her shop to the strip mall where the food chain was located. She handled it as if it was new information and simply a coincidence.

By the way, if the husband had not been available, a “contrived” call would also have sufficed. The important point is that the “conversation” was overheard indirectly and her son actually pointed to the sign that had been in the hairdresser's home shop, commenting, “Look mom, new place Sherry.” His mother acted surprised and asked if he wanted to go in. He refused that invitation, but she had planned for the refusal and called Sherry on her cell phone to see if she might be free to come out of the shop to say hello. This was all prearranged, and it worked well.

Make a Step-By-Step Plan

After that trip, the next step was to explain to her son that they were going to visit Sherry's new shop, and when he finished his haircut, Sherry had a coupon he could use at his favorite chain to get a snack. His mother made it clear that he had to use the coupon and it would happen *after* the haircut. She also put this on the electronic schedule on his iPad,

using the app “Choiceworks.” She even enhanced it by importing pictures she had taken at the strip mall, one showing the mall sign, another of Sherry standing by her shop with the food chain in the background. Generally, we do not recommend that persons with FXS be photographed or videotaped in these situations because they tend to find it anxiety-provoking to see.

Over the following month, the mother and son reviewed the schedule and plan for the haircut, followed by the coupon for the restaurant snack. His mother was concerned that he might always need a snack when he got a haircut, but she hoped it would eventually become unnecessary. In any case, we decided that she needed a Plan B just in case her son perseverated on the food and would not go in to get the haircut. His mother was prepared to take him back home without the haircut or snack. She also decided that he would not be allowed access to the restaurant *unless* it was paired with a haircut.

In this case, the problem behavior was solved because the parent was made aware of why her son was reacting the way he was, and that he could be persuaded to try a different approach. This will not be the end of our analysis, however, because he has difficulty going to other appointments—including those with me! His mother and I have set up a stringent routine for him to follow when he arrives at my office, so the situation is gradually improving. The chart below lists the steps of our programming so that we are all able to follow the procedure, which helps him trust the plan and reduces his anxiety.

Step	Outcome
1. Mom pulls up to the building.	Child gets out of the car when prompted.
2. Child enters building with his mom and goes directly to the work room.	Child is reinforced with a token.
3. Child sits at worktable.	Child earns another token.
4. Child begins the first task.	Child is earns another token.
5. Child completes the last task in the series.	Child counts tokens and waits for the adult to walk him to the waiting room where he is given his iPad with a favorite game. This allows the therapist and his mom to consult about his session. This consult lasts only 5 minutes, as promised to the child.

As the child becomes more successful with this program and is able to sustain his attention, he will be expected to perform a longer string of tasks, making his time in the office longer to last the entire session. He is motivated to earn the tokens because it signals the session completion. This works because he is motivated to go home, where it is less demanding.

His parent follows an exit procedure exactly as presented so that he has no surprises to make him more anxious and cause a fight-or-flight reaction. He is escorted to his car, buckled in and given a snack while his favorite video is playing—but only if he follows the protocol. If he does not, he can be rewarded with a less desirable reinforcer. It is tempting to give in to the child's demands when the session has gone well, but remember this level of compliance is tied to a chain of behaviors, one of which is to get into the car, buckle up and wait for Mom to give the reinforcer. It sets the stage for compliance throughout the activity, and if one or two steps are unsuccessful, it will dilute the efficacy and open the door to negotiations and noncompliance.

The Importance of Flexibility

These solutions have proven successful with this child, albeit with some changes and careful attention to details. If his behaviors had been treated with a stringent and inflexible behavioral bent not geared to the FXS phenotype, some of the pieces would have been lost. The steps might have been modified, but would the parent ever really understand the function of her son's behavior? Further, would she consider how the uniqueness of her son's phenotype played into his behavior?

Unfortunately, life is not always predictable, and "stuff happens." In order to succeed and not become overwhelmed, it is advisable for parents of children with FXS to choose one activity at a time and carefully analyze the steps required to make that activity successful. After determining the steps, identify those that are most difficult or most likely to cause outbursts. Analyze potential antecedents that may contribute to outbursts or other forms of resistance. Again, take time to think about the activity and how the characteristics of the phenotype might make things difficult for your child. Always consider how your reaction to the behavior may be maintaining it.

Keep these points in mind and you'll have a good start on enjoying late summer and fall outings that are rewarding for your child and the entire family.