

Braden on Behavior

When A Disappearing Act Is A Good Thing

About a month ago a parent of two children with FXS, Arlene Cohen, suggested that I write about how individuals with FXS remove themselves from stimulating situations in order to allow for time alone and the self-preservation that flows from it.

Coincidentally, shortly after I received Arlene's request, I attended a family wedding where I had three days to observe the behavior of a family member named Tim who has FXS. As you can imagine, all of the festivities made things rather hectic. Even though Tim enjoyed most of the wedding weekend, we frequently found ourselves asking, "Where's Tim?" After looking around, we would find him in a bedroom watching *Wheel of Fortune* or an old sitcom, happy as a clam. What was behind his retreat? His need for a break from the noise and chaos – happy though it was – in order to regroup and calm himself. Invariably, he would emerge comforted and relaxed.

This is a common occurrence. The fact that people with FXS can self advocate in this way is compelling. The process of recognizing when one's own sensory system can no longer tolerate a certain level of input is called regulation. It is a skill that we actively teach younger children with FXS. The process of teaching the child how to recognize the signs of hyperarousal can often take a long time. Tracy Stackhouse, OTR, often designs programs to teach regulation. Most of the work comes from teaching the child to recognize when he or she is overwhelmed and then apply strategies to deal with those needs.

It is not at all uncommon for these individuals to go through a "Now you see me now you don't" "staging. The person with FXS may be the life of the party, expending a great deal of energy to be so, and then suddenly disappears without bravado or attention drawn to himself. The disappearance might last three minutes or half an hour - it is as if the individual knows exactly how long he needs to get centered before returning. When this process is prematurely interrupted, the outcome can be very negative.

Sometimes, when the person with FXS removes himself from an activity that is arousing and in many ways exciting, the caregiver feels obliged to engage him in order to ensure his participation. In these instances, the caregiver's need to include the person with FXS trumps the preference that the person is communicating - to simply be alone for a while. As this interchange becomes more direct and confrontational, the person with FXS becomes increasingly resolute and oppositional, and a negative outcome often results.

When the person with FXS is younger and less capable of self regulation, loud noises and busy environments often cause behavioral excesses, aggression and non compliance. The function of the behavior is to show protest and discomfort. The child soon learns that when he demonstrates aberrant behaviors that simply cannot be ignored, the adults remove him from the situation. The result is the same as is the practice of self-removal, but the means to achieving that end is less optimal. When the person is able to remove himself independently, of his own accord and on his own terms, the result is much more rewarding for all parties.

As has been discussed in prior columns, behavior can often be misunderstood and punished because the parent or caregiver does not recognize its function. Looking beyond the behavior to what it is attempting to communicate and achieve is paramount to successful programming.

The decision of a person to remove him- or herself from a difficult situation in order to avoid a negative outcome is remarkably self actualizing. In the interest of self-preservation, the child with FXS is able to avoid an embarrassing experience and thus gain a healthy measure of independence. It is a skill, like all skills, that benefits from the continued practice that is encouraged by the significant adults in a child's life.

The next time your child attempts to avoid an over stimulating activity, remember that he just may be attempting to regulate his reaction before he becomes so hyperaroused he cannot properly control his behavior. There will be time to desensitize this reaction while providing appropriate supports in the future. Allowing him to express protest in a more adaptive way can become a measure of independence and a foundation on which other skills can be built.

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Anticipate, Plan, Prepare: Behavioral Supports for FXS

During several recent school consultations it became apparent to me that we still struggle to provide a learning environment for students with fragile X syndrome (FXS) that supports their best behavioral outcomes. A number of issues continue to hinder our quest to improve students' classroom behavior.

In most cases, the focus on behavior in the classroom relates to aggression toward an object or another person. Aggression in this case is defined as pinching, grabbing, pushing, hitting and kicking. Because these behaviors are aberrant, they are more frequently identified, counted and analyzed than other more benign behaviors. While it is easy to target behaviors that are dangerous and interfere with learning, they are difficult to treat because the cause is less obvious.

One of the most frequent mistakes is to prematurely eliminate supports when the student demonstrates, in isolation or under controlled learning, a level of competence that seems to render supports unnecessary. During my recent observations, I compiled a list of supports that are important to consider when aggressive behavior escalates in the classroom.

Visual Schedule

Given that a simple change in schedule can be the catalyst for behavioral outbursts, establishing a predictable schedule seems obvious, but is often overlooked. Depending on the level of their affectedness, some students with FXS cannot tolerate any change, so they need a variety of supports to prepare for it. One such support is a written schedule that can provide a snapshot of the day's overall structure. A written schedule is ideal for someone with FXS because it utilizes many of the processing strengths we see in this population. Visual icons provide a conceptual gestalt of the day and an understanding of how events will unfold. Sometimes, after a student begins to habituate to a daily schedule, the visual support is eliminated because the team believes it will benefit the student's progress toward independence.

It is important to realize, however, that the day's schedule is critical scaffolding that supports a positive behavioral outcome. The schedule is a tool to reduce anxiety, created by a fear of not knowing what lies ahead. It allows the student to self-regulate break times and much-needed sensory input. We all rely on some form of to-do list, day timer or palm pilot, even though we may know our schedule. It is reassuring nevertheless to have what is expected of us written down somewhere, and to know if the expectation will change.

Academic Challenge

Given the cognitive challenges that students with FXS face, academic achievement is difficult for them. They learn best with high-interest materials. Many of these students

are included with neurotypical peers throughout the day and are exposed to age-appropriate interests and behaviors. They are great imitators and notice how other students behave. The literature is full of anecdotal examples of learning styles and successful learning strategies gained from this exposure.

The student with FXS may feel embarrassed and engage in disruptive behaviors when a task is presented that is uninteresting or below the norm. For example, if the task for neurotypical peers is writing about the science lab and the student with FXS is given a puzzle of Winnie the Pooh, the dramatic difference in the caliber of the task can create conflict in the student with FXS. Unfortunately, this is more typical than one would imagine.

On the other hand, if the task is too difficult and the student is simply placed with his neurotypical peers to “absorb without support,” it may be equally as embarrassing. The student may exhibit behavior that is a reaction to feelings of failure and embarrassment.

Sometimes even with support the content is so difficult that the student cannot understand the information and is frustrated that the expectation of using the support does not pay off. For example, having the social science textbook read to the student using “Kurzweil” (computer software that reads the student’s text) may not hold his or her interest because the content is too difficult to understand without adaptations.

Social Inclusion

There are a number of ways to include students with FXS in a social environment with their neurotypical peers as well as school staff. Including the student with FXS in school-related activities such as drama, music and sports provides venues where social skills can be practiced. Contact with neurotypical peers provides good opportunities to foster friendships outside an academic environment. Encouraging tasks that can be accomplished within the school community provides a sense of belonging and reinforces that wonderful trait of cooperation. Having a job with specific responsibilities can elevate self-esteem and confidence. Many jobs such as library aide, cafeteria worker, memo delivery, attendance courier, or teacher aide have proven to be successful and rewarding to students with FXS.

Scheduled Breaks

Interspersing tasks throughout the school day provides opportunities to vary sensory input. Many students with FXS require prescribed sensory breaks during the day. These breaks can be as vital as any required course. Planning sensory breaks can be challenging, so it is critical to include an occupational therapist with specific sensory integration training in developing a schedule that provides appropriate intervention. Waiting until students with FXS are overwhelmed by a task before providing a break becomes a reactive measure and usually fails because the behavior has already begun to escalate.

The student with FXS may also experience low muscle tone, which makes it difficult to stand or sit for long periods. Opportunities within the schedule to increase physical endurance can be a proactive strategy to remedy discomfort created by periods of physical activity later in the day.

Responding to a student who refuses to walk, sit or stand can be challenging. What often follows is a mix of lying down, dragging feet or falling onto the floor. This can be difficult to remedy because the student may be bigger than the instructor. It also poses ethical dilemmas regarding physical management. Establishing a proactive strategy is a more effective way to reduce the likelihood of physically managing the behavior.

Token Systems

The student with FXS often needs reassurance or encouragement to meet the demands of increased length or complexity of tasks. The use of a token board or some type of token system allows the student to understand expectations in a very concrete way. The token system is flexible and can be used to meet individual differences based on concentration and overall ability.

Often the length of a task becomes so overwhelming that the student engages in behavior that promotes escape or task avoidance. Anxiety contributes to the behavioral cycle, and often results in behavior escalation because the task length and expectation has not been communicated to the student. The token board is a proactive measure that provides necessary support to reduce anxiety and communicate task expectation in a systematic and non-threatening way.

Another benefit of the token system is it provides an opportunity to delay reinforcement. Typically when a new task is being taught, reinforcement is delivered immediately, sometimes even if the student attempts a response. Later, after the task becomes more complex or lengthy, it is not always appropriate to reinforce every trial or portion of the task. Building a work ethic and stamina requires less frequent reinforcement, which in turn increases the expectation before reinforcement is delivered.

The token system can be used at school, in the community and during work tasks of any nature. It is an easy strategy to implement and can be portable and available in any venue. Building task tolerance, length of engagement and work stamina are all skills that can be acquired using this system.

Transitional Object or Activity

I discussed this strategy in the winter, 2005 issue of the *Foundation Quarterly*. ("Have Purpose Will Transition," <http://www.fragilex.org/html/news2005.htm#>). It is an integral behavioral support that needs to be included here. The idea of numerous transitions during the day can be daunting to a student with FXS. The anxiety created by the idea of shifting focus, location and task in a matter of minutes can be debilitating.

When one thinks about a transition, it raises obvious questions. Where will we go? What is expected? How long will I be gone? Will there be a new teacher there? How crowded will it be? These questions can all heighten concern and apprehension, which are difficult to diffuse or redirect, especially during the transition.

A proactive strategy can help the habituation process. Using something as simple as a pass or card picked up prior to the transition can set the stage for the change and redirect focus. An activity such as carrying a crate of newspapers, stack of books or folder of memos can also shift the focus from the transition to completing the task, which brings the student into the next environment.

Providing supports throughout the school day is beneficial because it allows fewer opportunities to exhibit behaviors such as protest, frustration, embarrassment and confusion. These remedies can be easily integrated into the day and take less time to implement than a succession of behavioral interventions.

The strategies discussed here are by no means all-inclusive and should be used as a template upon which others can be added. The goal is to be proactive in effectively supporting the student and reducing the need for behavioral interventions.

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