

Braden on Behavior

As I was pondering what to write about to introduce my first column, it occurred to me just how adept people with FXS are at telling us what they need using their behavior. Behavior, although maladaptive and aberrant, can become an efficient way to make a point. What a great topic for discussion!

Children learn how effective their behavior is by observing our reactions. For example, when a child is frustrated with a task and is unable to verbally communicate exactly what it is about the task that is difficult, he may employ behaviors that clearly indicate a need to escape. Perhaps he might choose to destroy the task materials, act out or become verbally engaging. Each of these behaviors could bring about a reaction from an adult that would allow the child to avoid the task and either escape by provoking a negative consequence or diverting attention from the completion of a task.

Efforts to consequence a behavior can result in reinforcement which allows the child to habituate a pattern of avoidance. This case study illustrates such an evolution. John disliked writing because it was very difficult for him. When the writing paper, pencil grip and pencil were presented, he became anxious and embarrassed. He wanted to avoid the frustration created by his inability to write. The paper and pencil become the antecedent for him to engage in a behavior that he had learned would result in a predictable outcome. If he was successful in destroying the task materials he experienced immediate relief. If that relief was not salient enough, he was able to avoid further compliance by sitting out or losing a token. He also learned that if he was unsuccessful in his plight to avoid, he could “up the behavioral ante” to provoke a more severe punishment that would provide an even longer period of avoidance and escape.

The solution to creating an effective remedy is to first observe the behavior and then ascertain the function or why the individual behaved the way he did. Only after the function is determined, can effective intervention strategies develop. Intervention at the point prior to the behavior occurring prevents a full blown behavioral episode. As important as determining the function of the behavior, is the provision for a more adaptive method to communicate the need. The flow chart below illustrates a behavioral assessment with function and intervention described.

Functional Behavior Assessment	
Presenting Behavior:	Chris becomes verbally and physically aggressive
How often does the behavior occur?	4 x a day
Where does the behavior occur?	Playground and during unsupervised games
With whom does the behavior occur?	Female peers, age matched

What is the function of the behavior?	Intimidation/Chris gets her way Secondary function/When an adult intervenes, although Chris loses her playground privilege she spends more time with an adult
Intervention Strategy:	Reinforce sharing behavior with peers by allowing Chris to spend time with an adult of her choice

In summary, children need adults to be in charge. Their behavior may result from being afraid and confused. If the adult remains calm and avoids a sudden reaction, the child can more openly anticipate a reasonable remedy which can provide an alternative to expressing need using an escape behavior. Remaining neutral and following a pattern to change a habit will allow for appropriate interaction and improved behavior.

BRADEN ON BEHAVIOR

ANXIETY – JUST HOW BAD IS IT?

Many clinicians who see individuals with FXS hear from parents on a daily basis how anxiety affects their child's behavior. It is not uncommon for a child to throw a tantrum before going on a trip to a favorite play spot, activity or recreational facility. Adolescents and Adults may retreat to a bedroom and refuse to come out. It is hard to understand how these kinds of events can trigger such a negative reaction.

Like many things about individuals with FXS, this scenario doesn't fit a logical pattern. When an activity or experience has been fun, one would expect the child to be excited and recall positive feelings about the experience. There are several important factors to consider in order to better understand this phenomenon.

A person with FXS has difficulty modulating incoming stimuli. We know from a variety of research venues, that too much sensory input and a pervasive discomfort from excitation can promote hyperarousal resulting in "behavioral meltdowns". The mere fact that the child enjoyed the activity at another time isn't enough to override the initial feeling of being overwhelmed.

Anxiety is usually accompanied by physical symptoms such as a racing heart, blushing (red ears or neck), sweating and nausea. Experiencing those physical changes can also create more fear, followed by panic.

The person with FXS may also be impacted by an executive function deficit that interferes with his ability to remember the past experience in a way that would provide reassurance and motivation to try again. When confronted with the excitement, the person with FXS may first become anxious followed by an inability to regulate his arousal level and properly manage his behavior. An attempt to avoid the situation may occur in order to endure the anticipated stress. This cycle feeds the pathology causing the behavior to escalate.

It is counter therapeutic to avoid these family outings and recreational experiences, even though it is at times very tempting. In order for the child to become desensitized, he must experience repeated exposure to the event. This takes a lot of patience with the understanding that if the time and energy is spent early, it will become less difficult and disruptive later.

There are a number of ways parents and caregivers can prepare the child for the activity. Some parents report reading a bedtime story the night before with pictures taken of a fun experience. If the child has a tendency to obsess and worry about the future, it may be better to discuss it right before leaving with time built in to employ a sensory menu. The preparation time includes utilization of calming strategies and an

emergency kit of chewing gum, water bottles, audio tapes, fidget toys and other self calming supplies to take to use on the way to the activity.

It is well known that anxiety can have biological roots. Fearfulness is associated with irregularities in neurotransmitters such as dopamine and serotonin. Studies in the general population show that high levels of the stress hormone cortisol releases when one is anxious. Belser and Sudhalter have also researched the affect of arousal on individuals with FXS with similar results.

Anxiety can have far reaching effects on the life of one with FXS. Each experience can virtually shut down adaptive behavior. The fear can be so intense that the individual with FXS may revert to a primal reaction of flight or fight and become unable to access an appropriate behavioral response.

The best remedy to all of this is the gift of time. Building in enough preparation time to allow for a sensory diet, behavioral story and use of the emergency kit can slow down the process and allow a "slow motion" effect to take hold. This will also give the parents and caregivers sufficient time to react in a calm and supportive way, adding less stress to the mix.

With the holidays ahead and higher probability of novel experiences attached to celebration, take time now to create a specific plan that will allow you to be successful and create the ultimate PEACE ON EARTH.