

Braden on Behavior
Is Your Child's Behavior a Manifestation of His Disability?

Recently, I have been consulted on several cases related to students with FXS being suspended from school because their behavior was believed to be threatening or dangerous in a school setting. The student was then suspended through a manifestation hearing until further investigation could be carried out. Clearly whenever this happens it begs the question, "was the behavior a manifestation of FXS?" In other words was the reason for the behavior related to the FXS behavioral or cognitive phenotype? By that, I mean was the threat actually intended to be a threat which had potential to be carried out, or was it a reaction to an event or circumstance? Before considering suspension and possible expulsion it would be important to determine if threatening someone may have been the only way that the person with FXS could express the gravity of the personal discomfort associated with the event.

These types of behavioral infractions only serve to provide more evidence that a functional behavior assessment FBA is imperative whenever a behavior is suspect. It is absolutely critical to assess the nature or the function of a behavior so that the school personnel understand why the behavior is occurring. It is simply not enough to deem the behavior as one of escape without considering the behavioral correlates. Several investigators have explored the possibility of higher cortisol levels after exposure to novel social situations being linked to avoidant behaviors.

There is a significant body of research suggesting that many individuals with FXS exhibit some level of anxiety (Hessl et al., 2002, Baumgardner et al., 1995, Hatton et al., 2003). Those individuals who are unable to regulate their anxiety must rely on those around them along with the environment to assist. A student, who is more challenged, will learn to act out in order to communicate discomfort. As the student's behavioral pattern becomes habituated, he learns that if at one level his need to escape does not get noticed, he will simply act out more so that someone will address it. Often with the remedy comes a sanction which involves removal and provides the student with relief.

Because the public school system now employs zero tolerance for violent behavior or threats, this issue has become increasingly more timely. Simply explaining away the student's threatening behavior as part of being FX is no longer acceptable. Even though special education law clearly mandates allowing for special considerations whenever discipline is needed, that determination must be decided on prior to the suspension, otherwise the threat is treated just like any other typical student without special needs. The student with an IEP who has been identified as a student with special needs can be afforded an alternative to school discipline policies but only when it is specified in a behavior intervention plan. No longer can the student's behavior be addressed on a "wait and see"

basis. If the student has a history of anxiety which has resulted in threatening behavior, it must be analyzed and the function documented to avoid future misunderstanding.

The school staff is trained to be hyper vigilant in their recognition of threatening behavior and to preempt any threat or act of violence. They are taught that it is not their responsibility to assess the lethality of the threat, but rather to report it and then allow those individuals who are experts, to determine the severity and motivation. If the suspended student is one identified with special needs, it is mandated that the staff first determine if the incident is a “manifestation of the disability”. The problem is that often, the individual with special needs is not given special consideration because the behavior was never documented as a manifestation of a diagnosis or condition such as FXS. This is often where the process falls short and the behavior of the student with FXS is not properly remedied. If the staff, parent or caregiver advocates for the student during the manifestation hearing and the consensus verifies the fact that the behavior is a manifestation of the disability, the process ends and the student returns to school with a behavior intervention plan in place whenever the behavior occurs. If there is inconsistent evidence or no consensus then an independent evaluation can be requested but the student is precluded from attendance during the fact finding stage so that no harm can come to anyone while things are being sorted out. It is much more prudent to have this all determined during an IEP meeting in order to avoid the manifestation hearing and all subsequent remedies required.

Often, even though the independent evaluation can be provided by the school district, the person conducting the evaluation may not be an expert in FXS and may misinterpret the intent of the threat by determining that the behavior is not a manifestation of the disability. This can then cause the student with FXS to be separated from his school community. As has been well documented, individuals with FXS often become rueful and sad whenever they feel estranged from their peers. They might perseverate on the incident that occurred and find it uncomfortable to return to school the longer the suspension continues. This reaction may become even more debilitating than the initial infraction. In a recent case when I was contracted as an expert to provide an independent evaluation, the infraction occurred just prior to May and the student did not return to school until early November.

A particularly important adjunct to the prescribed remedy is to target verbal and physical threats, so that the student’s behavior can be modified and shaped into a more adaptive way to express discomfort or anxiety when reacting. Doing this at an early age will help the child understand the gravity of the reaction so that the behavior can be reduced and eventually eliminated. The function of a threatening and violent behavior is most likely a primary reaction to an event or circumstance that has evoked a significant amount of anxiety. Sometimes these reactions can be provoked by sensory input that may be difficult to control. It is in this context that a threat can be misunderstood and explained away by

misconduct or a serious behavioral episode. Something as simple as an alarm or school fire drill can cause one with FXS to threaten to kill someone or set the school on fire because the reaction to the sensory input is so extreme. Those observing such a reaction without training or understanding will respond in a way that can be punitive or frightening.

When a student with FXS is admitted to a school program or when an IEP is reviewed, be sure to examine very carefully any role anxiety has played in his behavior and discuss thoroughly the behavioral phenotype related to anxiety. It is always prudent to request a functional assessment of the behavior as a proactive strategy so that any subsequent discussions can form the foundation for sound behavioral programming and the elimination of any misunderstanding that could ultimately result in suspension or expulsion.

REFERENCES

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Braden on Behavior side bar
The Ten Deadly Sins of Poor Behavior Management

- Never force eye contact except when teaching social engagement
- Be consistent
- All behavior serves a purpose, analyze the function before implementing a plan
- Remember that sensory input can have a direct relationship with aberrant behavior
- Remember that behavior is often a means of communicating
- Target one behavior at a time
- Count frequency and duration before you decide to target a specific behavior because it may not be as bad as you think
- Behavior does not occur in a vacuum; think outside the box
- Utilize a multidisciplinary team when creating behavioral remedy
- Don't battle biology (Dr Karen Riley)

Braden on Behavior

“Happy Birthday” Meltdowns and Other Behavioral Conundrums

A client asks: “Why does my child cry when people sing ‘Happy Birthday’ to her? Many years ago when I first heard this from a parent of a girl with a full mutation, I thought it was rather strange and perhaps something unique to this child’s behavioral repertoire. Later, after meeting other families of children affected by FXS, I learned that this was not an anomaly, but rather quite common.

Why would hearing “Happy Birthday” provoke such a strong reaction?

The answer is really quite simple. Children with FXS tend to find it very uncomfortable being the center of attention. The focus that comes with the singing, and then being urged to blow out candles and make a wish can result in a complete meltdown and behavioral nightmare. The problem is then compounded on every subsequent occasion, when the memory of being overwhelmed by all the attention becomes reenacted. Often, the “gestalt” (wholeness or totality) of the experience becomes so solidified that it is very hard to convince the child that it will not make her anxious the next time it happens. To make matters worse, the child may find it difficult even when the song is sung to someone else. Parents point out that the anticipation of a birthday party for another family member can be so intense for the child with FXS that the family decides to exclude the song in its celebrations.

This is an excellent example of a child with FXS packages an experience and continues to respond to it in the same way each time it occurs. Even something as innocuous as a casual compliment can result in a behavioral episode for a child who cannot tolerate being in the limelight. Giving a compliment is considered a standard social nicety, but in the case of one with FXS, it gives way to a negative result.

Another example is of such a conundrum is when a child anticipates a special occasion with great excitement, only to melt down behaviorally when the time comes. The paradox of the child who has been speaking nonstop about an upcoming vacation, only to react with a behavioral meltdown, is perplexing and difficult to resolve for parents. Unfortunately, the excitement and anticipation of the vacation gets translated into anxiety and even terror for the child, who becomes stymied and is forced to retreat into a familiar comfort zone.

What about the other classic scenario of a child who sees her teacher at the supermarket? For the child with FXS, this situation can cause her to become so overwhelmed that she responds with aggressive behavior, to the extent that it is necessary to exit the supermarket. This can dumbfound a parent, who knows that the teacher is a favorite and the child talks about him all of the time. Why then, does the child respond to him in such a negative way outside the school setting?

The context of the relationship and the element of surprise that accompanies seeing the teacher at the supermarket, out of his usual context, create a significant shock, and the

child is flooded with anxiety. The child's confusion surfaces, along with an inability to adapt and respond. Again, this example illustrates how an unexpected event, out of context, can cause a significant behavioral incident.

Another conundrum: Mothers, who are usually the primary caregivers, report more aggressive behavior directed toward them than other family members. How can this be? The very person who offers support and comfort seems to be more susceptible to attacks. The answer follows a peculiar logic: The child sees the mother as an agent of great power in reducing anxiety and providing comfort. When something unexpected happens, the child anticipates his mother's intervention to reduce his discomfort. If immediate relief is not experienced, he becomes disappointed and angry. The closest target to release the anger is usually the mother. The anxious reaction escalates into a fight-or-flight reaction and the mother bears the brunt.

Other families have reported frustration over the fact that their child rarely engages in spontaneous communication, but when he does, uses profanity and four letter words. What's more, the context is perfect and the articulation very clear. This is frustrating because the family's aspiration for the child to communicate gets juxtaposed against this inappropriate verbal response. Often, when a child has not experienced the power of communication in traditional conversational exchange, a strong reaction from others around him such as a grin, giggle or even reprimand, becomes highly reinforcing. The more negative the reaction, the stronger the motivation to continue "communicating" with cursing and four letter words.

Even though these examples present as conundrums, the common thread is the extreme reaction individuals with FXS have to an unexpected or anxiety provoking experience. Anxiety in these individuals results from being hyperaroused. The state of arousal may vary with each person, depending on the situation or the child's level of affectedness. For both the child and parents, learning how to regulate the child's arousal before it transforms into anxiety is the key to better behavioral control. Unexpected events cannot always be avoided, but having proactive strategies in place can be an effective remedy for parents. Anticipating those situations that may seem exciting and fun to others, but difficult to those affected with FXS, will save the family from behavioral episodes that spoil the fun for the entire family.

Some parents feel that giving information too far in advance only fuels the anxiety engendered by "waiting." The remedy varies, but at the very least, it is important whenever possible to prepare the person with FXS by presenting an agenda, calendar or social story about the upcoming event. Present the remedy in a very calm and non-emotional way, saving the excitement for the actual experience. In the event that the element of surprise cannot be anticipated, an emergency kit with distracters and appropriate escape strategies should always be available as a carefully calculated reactive measure. With understanding and a few simple strategies in place, otherwise difficult situations can be managed successfully, and the family can enjoy happy occasions together.

Functional Behavior Assessment-What is it?

Often when I am consulted about behavior, the first question I ask is, “why do you think he is engaging in this behavior, or what is the function of his behavior?” Explaining what has happened or giving details of the incident in question is not enough because it does not provide the necessary information to solve the problem. I need to know more about why the behavior occurred and less about what occurred.

As I think about the progression of our understanding of behavior and more importantly, how to structure behavioral treatment, I am encouraged that we now view things much differently.

When I first began speaking about the behavioral patterns in those with FXS, I was intrigued by the intention of the behaviors. The ABC model that has now become commonplace among behaviorists, was especially challenging to implement because the antecedent to the behavior was not easily identified. Identifying the antecedent and understanding the function has since formed the cornerstone of sound behavior intervention and best practice with those affected with FXS.

Recently, with the reauthorization of IDEA (Individuals with Disabilities Education Act) there is more emphasis on teaching students with disabilities in the general education environment. Individuals with disabilities are no longer identified by their deficit, but rather by how the system has failed to teach them. Behavioral issues as they present in the classroom cannot be detrimental in accessing a free and appropriate education. Therefore, managing behavior in the classroom has become more comprehensive and requires sophisticated methodology. The challenge is to encourage general educators and specialists to collaborate on ways that the student with disabilities may be more successful in a general education setting. In addition, the general education climate needs to be more conducive to resolving behavioral problems that may interfere with academic progress. The long range goal is for the student to be able to manage behavior in a broader venue such as the community and place of work.

Earlier standards used to identify behavior have been abandoned. For example, the identified behavior may be inappropriate, but the function is not. Defining the function puts to rest antiquated measures of dismissing behavior as inappropriate. We now analyze the behavior with concern for the “reason” or “cause.” Focusing on the topography (what the behavior looks like) yields limited information. The same behavior may have a myriad of causes depending on the student, setting or diagnosis. Therefore, when the function is identified, a more salient and individualized intervention and positive behavior support plan can be developed.

The functional assessment enables the observer to go beyond the symptom to the root of the behavior. This diagnostic feature provides a much richer yield by including in the intervention design a way to remediate the targeted behavior while providing positive support to replace the targeted behavior.

There are number of formats used to assess behavior using an FBA. The amendments to IDEA advise that a functional behavior assessment be provided, but do not require or suggest specific procedures to use while conducting the assessment. There are, however, some steps in this process, which need to be followed in order to properly complete the assessment.

The first step, although fairly obvious, is to identify the behavior. If the definition of the behavior is vague, it is more difficult to systematically count and measure. In addition to defining the behavior in a clear and concise fashion, the behaviors should be observed over time, settings and activities. This allows the team to understand the nature of the behavior as well as to determine the scope as it relates to time or environment. Realizing that some behaviors are influenced by other factors such as hunger, illness or other physical causes is often overlooked. Careful consideration related to specific physical factors must be discussed before determining if the behavior should be targeted for intervention.

After defining the behavior, the function of the behavior can be determined. The function may be to express avoidance, protest, lack of understanding or confusion, sensory discomfort or need to escape. Rarely is the function simply to "misbehave". If we know the function, we can then design a behavioral remedy that will address the function; such as providing a sensory diet, devising a more adaptive way to express protest, or presenting a system by which a need to escape or leave can be signaled.

Learning to define behavior by function will continue to provide for a better diagnostic and effective intervention.