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 consequate 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 difficulty 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 coritsol 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.

Braden on Behavior

What Have I Changed My Mind About?
What I Know Now That I Didn't Know Before

With a little inspiration from the editor I decided to embark upon this question for this article. Having been involved in FX intervention for 30 years, this question has certainly presented itself to me many times. Theory and practice often develop together, but after some time and additional experience theories tend to change. I think because there is so much variance in FX population, it requires clinicians to be on the lookout for new ideas and methodology in order to be affective with those we see in our clinical practices. Although much of the methodology is steeped in empirically based research, there are areas of behavior that seem to need constant assessment. I have targeted a few of these issues below.

1. Change of schedule or routine

   We often recommend that parents and teachers forecast upcoming events in order to prepare the person with FXS for a novel experience. When a schedule changes, we tell parents to write a social story, in order to avoid the element of surprise. This approach often works well, but there is a subset of people with FXS who, if prepared too far in advance, become so anxious about the upcoming event, that the obsession over the change overshadows the benefit of prior preparation.

   The answer is to know how to modify the intervention based on the response. Sometimes, simply providing more indirect intervention with another adult a day before is more effective. Having a conversation within ear shod (side dialogue) may prove better than making the changes in the visual schedule or reading a social story days in advance.

2. Approach-avoidance

   The phenomenon of approach-avoidance can interfere with many kinds of interaction. Generally, the prescribed remedy is to allow the person with FXS to first observe and later when comfortable, begin to participate. It is alleged that avoiding a forced interaction will reduce the anxiety responsible for shutting down a response. I now understand that increasing the likelihood of spontaneous participation requires more than simply more wait time. Although this can be an important support, it is equally as imperative to recognize how the lack of executive functioning impacts participation. Executive function deficit, which is widespread in this population, can significantly thwart any attempt to participate. Waiting until the person is comfortable does not adequately address the difficulty with initiation. Often, prompting the first step can encourage participation and allow the person with FXS to be successful. Therefore, the problem is more complicated than earlier believed and through experience we have come to understand what is necessary in order to provide better intervention.

3. Creating a supportive work environment
   Past experience has defined the best working environment for those with FXS as one that matched interests with job tasks. Following children into adulthood provided the impetus for this information. Based on work history, factors were considered and evaluated to determine the best support for a successful outcome. In addition, creating a quiet, predictable environment seemed to help the person with FXS progress vocationally. Although these characteristics seem to be important to predicting success, it now appears that there are basic features that if unaccounted for may contribute to inadequate performance or ultimately termination. The fact was that even though the person with FXS seemed well suited for the position, longevity of employment became compromised.

   Because the world of work seemed unrelated, the basic constructs often incorporated in the classroom eluded the workplace and contributed to failure. Breaking work up into shorter segments, allowing for frequent breaks, posting visual icons to illustrate a production sequence, and including a visual schedule or workroom rules seems to allow for success and longevity of employment. Avoiding situations that produce excessive pressure is also critical. For example, scheduling an individual with FXS to work during high volume activity or when demands are high may create so much anxiety, that the worker with FXS would fail. These components are far easier to provide when employed by small companies or family owned business. This also allows for gentle support or understanding whenever redirection or criticism is necessary. In sum, although it is very important to provide a job that matches skills with job tasks and interests, it appears to be even more important to support the worker so that the skills can be developed and the worker can remain employed.

4. Using the telephone
   Generally, telephone use (answering the phone and sustaining a conversation or initiating a call) is very difficult. Past experience encouraged phone use by setting up scenarios hoping to provide the motivation to answer and make phone calls. Although this seemed to provide short-term successes, the phone use did not generalize to environments outside my office. Understanding that motivation to make a phone call as a leisure skill (something to do to gain pleasure) is not realistic and does not withstand the test of time I have now begun to place the person with FXS in a place of need so that phone use becomes a way to solve a problem. For example, if a caregiver is late for an appointment pickup, the person with FXS has to call in order for the pick up to occur. This becomes self-motivating as it serves a very direct and pragmatic purpose. I have learned that making a call for social reasons somehow eludes one with FXS. Phone use has a practical application and when provided in that context, the outcome is more spontaneous and efficient.

These are only a few examples of ways I have changed my mind about intervention. It is always important to continue to evolve ideas so that we are more able to meet the many needs of those with FXS.

Behavior

Assessment Considerations for Children with Fragile X Syndrome

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The focus of school psychologists has shifted in many ways in recent years, nowhere more greatly than in their role in the assessment of special education students. Advances in medical, psychological and educational research have both improved and further complicated the assessment process for those individuals with neurodevelopmental disorders such as fragile X syndrome. The difficulty for psychologists lies not only in dealing with the developmental and behavioral characteristics associated with various disorders, but also with the challenge of finding the best match between the child and the many assessment tools that are available to them.

There is currently little empirical information to guide the process. Additional research and support is necessary for practitioners and the families and students whom they serve.

We know that each child is an individual with unique strengths and challenges, and there is truly no one-size-fits all assessment tool. Ideally, allowances and adaptations have to be made to suit every child's unique profile, but this ideal presents daunting challenges to the educational system. In addition, information that could be used to shape the assessment process often times exists outside the field of education. This valuable information needs to be shared and applied.

Basic profiles of children with known conditions such as FXS can provide clinicians and educators with a framework from which to begin. Substantial data on the behavioral traits seen in FXS and their impact on the assessment process is now available to us. Putting such data to use during an assessment and its eventual elaboration into classroom instruction is a worthy goal.

Before proceeding further, let us distinguish between *assessment,* defined as the process of gathering information from a variety of sources, using a variety of methods that best address the reason for evaluation; and *testing,* which is limited to administration and scoring of tests. Clearly, these activities are not mutually exclusive, nor are they interchangeable. Each process has a unique outcome and requires a unique approach. Sculpting the assessment process to address the outcome is not the only challenge; the child's needs must also be considered. Unfortunately, time and policy constraints in the school setting often make this a hit-or-miss endeavor.

Psychologists typically assess children using the tests or methods that are available within their district or practice, and/or the ones with which they are most familiar. Lack of information in the literature to guide test selection, the generalist approach to special

education, and the strong psychometric qualities of the tests currently utilized perpetuate this practice and suggest that alternatives are either unnecessary or unavailable. This common approach of using the same tests for all children often leads to incomplete data, inconclusive findings or ineffectual information, creating frustration for all involved.

Although specific knowledge regarding disability-specific profiles and developmental trajectories has exploded during the past decade, we still lack information regarding recommended assessment practices for individuals with most neurodevelopmental disorders. This assessment of children with FXS serves as a case in point.

It is perhaps not surprising, given the constellation of characteristics in children with FXS, that their parents are frequently presented with reports and/or IEPs (Individual Education Plans) in which their child is deemed "untestable." Understanding the profile of the individual within the context of their diagnosis is clearly the first step in completing a successful assessment. This information is readily available. What has not been explored is the integration of this information into the assessment process. Integration requires an understanding of the disorder, intentional tool selection, and appropriate administration strategies.

Guidelines for Test Administration

Though nothing substitutes for experience, understanding the phenotype (observable characteristics) of individuals with FXS is not only crucial in choosing appropriate assessments but also determines how one administers them. Individuals with FXS can become hyper-aroused very quickly and remain so for a long period of time, thus interfering with the assessment process and compromising its findings. It is important that the evaluator understand how to keep the child calm, focused and on task. Adhering to guidelines and accommodations will help create a testing situation in which valuable information is acquired.

Obviously, the test administrator should follow protocol described in the testing manual. But other considerations come into play with fragile X syndrome, just as they do with other conditions that cause different behavioral patterns. The Fragile X Clinical and Research Consortium is examining this issue in order to provide information and guidance to parents as well as professionals, with the overall goal of improving assessment practices for children with FXS. We have provided a few guidelines for assessing these individuals that we feel will begin to define best practice for test administration. Ideally, the administrator should:

- Introduce her/himself to the child in a very casual and unassuming manner. An overly official and distant introduction tends to cause heightened anxiety in children with FXS.
- Never walk into the classroom and take the child out for testing without preparation. This may include having the child become accustomed to the room in which he/she will be, ensuring that the room is free of distractions at the time

of testing, and that there will be no other people in the room to distract the child. It may be necessary to observe the child on several occasions prior to the testing, in a variety of environments, in order to make adequate preparations.

- Minimize, to the degree possible, noise intrusion from the halls, loudspeakers or nearby street. It is also important that sunlight or other visual distractions be minimized in order not to distort the stimuli.
- Provide a schedule of the assessment process (what will be done first, how much time with be spent testing, and how it will end) prior to beginning. In addition, explain when the assessment will take place in accordance with the school day schedule. This may help to reduce the anxiety created by the anticipation of when the testing will take place. This will also reassure the child that he/she will not be removed from the classroom during a favorite activity.
- Not sit across from the child during test administration, but at an angle or beside the child instead. Typically, individuals with FXS do not respond well to direct eye contact, so this must be avoided.
- Allow opportunities for breaks and movement. Parents/teachers should be asked if there is a favorite reinforcer that can be presented as a reward for good performance during these breaks. Additionally, a “transition object” may help the child go from place to place. It is important however, that reinforcers or transition objects not become a distraction (e.g., the child asking repeatedly for the juice, cracker or blanket).
- Be aware that the impulsive nature of the child may interfere with his/her performance. Ask the child to wait or cover the stimuli before giving him/her an opportunity to respond.

Summary

The role of the school psychologist is changing, as is the understanding of children with delays attributed to known causes. The current climate and information available to us not only allows for a shift in the assessment practices of children with FXS and other neurodevelopmental disorders, but indeed mandates change. While it is unrealistic to expect school psychologists to be experts in all neurodevelopmental disorders, it is just as unthinkable to ignore the wealth of information now available regarding specific conditions. Communication and collaboration among all parties working on behalf of children have thus never been more important. Educators, psychologists and medical professionals need to cross disciplines and partner with one another in order to inform the practices of the others. Parents have a huge role to play in actively advocating for these partnerships.

It is an exciting time in the education of children with FXS. Great advances in genetics, behavioral science and education much better inform our efforts to understand such children, their behavior, and the best way to educate them. Parents need no longer expect to receive reports stating “the child was deemed untestable.” Instead, they can look forward to reports that delineate the child’s strengths, deficits and plans for future growth.

We understand that school psychologists are not the only professional engaged in assessment practices. We are part of an experienced group of professionals also working on this issue through the Fragile X Clinical and Research Consortium. Our group hopes to provide targeted suggestions regarding assessment practices across ages, disciplines and settings, all in an effort to optimize the assessment process for children and families affected by FXS.

Proactive or Reactive?
Dealing with Behavior Management

Being part of the behavior symposium in Detroit proved to be interesting and very enlightening. During the symposium there was a fair amount of discussion about the importance of behavior intervention. Behavior management continues to be of significant importance to parents and professionals.

I have thought a lot about this and have decided to make it the topic of this column. In my opinion, understanding the etiology of behavior, in people with FXS, is critical when creating proactive strategies. Knowing the triggers and manipulating the environment can often prevent the person with FXS from engaging in the problem behavior.

This became apparent recently when consulting with a family whose son engaged in self-injurious behavior SIB (hitting his forehead with his fist) when he was in noisy or crowded environments. The trigger was not obvious because he loved going to restaurants and looked forward to going until he got to the door. The obvious remedy was to avoid all crowded and noisy places, but how realistic is that? Not only is it unrealistic but not a good way to increase independence.

Best practice would be to identify the antecedent and develop ways in which the person with FXS can be desensitized to the environment. We would call this a lesson in self regulation. In other words, the person would learn that before he enters a noisy environment, he would put on his ear pods and play music on his I-pod, or wear headsets that would muffle the sound. This would teach replacement behaviors that could help him throughout his life span.

The other part of the discussion coming out of the behavior symposium was the emphasis on the consequence- especially when the consequence could in fact help maintain the behavior. Taking the example above, removing or avoiding loud environments could be construed as a consequence. When the person enters the noisy environment and engages in SIB by hitting his head, he is removed from the environment learning that when he is in that environment, if he hits his head, he is removed from what to him is aversive. This example provides an interesting contrast between proactive and reactive strategies. I contend that both may be necessary but that putting more energy and emphasis on figuring out the antecedents makes more sense in the long run.

The example above is not unique. After getting background information and observing a number of behaviors, there appears to be similar antecedents that relate directly to the etiology. In an attempt to make sense of the problem behaviors, I comprised a list from 50 intake forms and clustered them into categories. The chart that follows lists a variety of behaviors most often presented in the intake. The chart clusters the behaviors and lists corresponding remedies. I hope you will find it helpful when considering behavioral remedies.

Behavioral Cluster: Change in Routine	Remedy or Intervention
• He has difficulty reacting to changes • He shows strong reaction to changes in routines	• Set a visual schedule; if a change is scheduled, train the child to anticipate a change by placing a ? in the schedule to prompt the change • Write a social story about the schedule and changes in routine
Behavioral Cluster: Transition	**Remedy or Intervention**
• He acts out when we arrive at places of high interest and preference • He stalls when entering a building • He gets in the car but won't get out when we arrive at our destination	• Crossing the threshold creates much anxiety because he cannot anticipate what is happening on the other side. Give them a task or job to do when crossing the threshold or getting out of the car
Behavioral Cluster: Self Abuse	**Remedy or Intervention**
• He bites his hand when stressed • He pounds his head with his hand • He slaps his face very hard when he is told "no"	• Provide calming activities within a sensory diet; consult an OT • Redirect or teach a replacement behavior • Restructure the way he is told "no"
Behavioral Cluster: Sensory	**Remedy or Intervention**
• He stuffs his mouth • He pulls his brother's hair • He pushes his mouth against my face and then might bite me • He chews his sleeve or his shirt • He covers his ears • Won't wear shoes and has to wear sweats	• Monitor the bites he takes • Remove food between each bite • As he approaches turn your face away very quickly and give him a chewy • Encourage using ear pods, or earphones • Introduce sandals and flip flops, encourage wearing softer tailored pants
Behavioral Cluster: Inattention	**Remedy or Intervention**
• He seems distractible when he has to sit for longer periods of time • He shows poor impulse control and it usually gets worse when under pressure	• Use a token board to summon attention and to provide a tangible way to show how long he needs to attend • Provide self regulation to slow down. Introduce deep breathing exercises, counting to 10