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Communicating Through Behavior

NFXF Quarterly Summer 2003

As I was pondering what to write about to introduce my first column, it occurred to me just how adept people with fragile X syndrome 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 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 illustrates a behavioral assessment with function and intervention described.

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.

Functional Behavior Assessment	
Presenting Behavior:	Chris becomes verbally and physically aggressive
How often does the behavior occur?	4 times 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

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Anxiety – Just how bad is it?

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Many clinicians who see individuals with fragile X syndrome hear from parents on a daily basis about 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 fragile X, 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 fragile X 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 fragile X 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 fragile X 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 release when one is anxious. Belser and Sudhalter have also researched the affect of arousal on individuals with fragile X and found similar results.

Anxiety can have far reaching effects on the life of one with fragile X. Each experience can virtually shut down adaptive behavior. The fear can be so intense that the individual with fragile X 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

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Putting the "I" Back Into the "BIP."

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The Behavior Intervention Plan (BIP) is included in the 1997 amendments to the Individuals with Disabilities Education Act (IDEA). In general, the amendments include:

- More collaboration with relevant education personnel to resolve behavior problems that may interfere with academic progress.
- Team exploration of strategies and support systems to address any behavior that may impede the learning of the child with the disability or the learning of his peers.
- If a disciplinary action is leveled, the IEP team meets within 10 days to perform a behavioral assessment to collect data necessary to formulate a Behavior Intervention Plan or if one already exists to review and revise as necessary.
- Additional inservice and preservice to learn how to develop

The need to properly assess behavior of those with special needs was driven by the fact that behavior often interfered with the ability of one with special needs to be educated in the least restrictive environment.

When the special needs student becomes disruptive, noncompliant or avoidant he can become estranged from his peers and isolated from the social interaction necessary for meaningful inclusion. The behavior becomes a discipline issue which in reality is more likely a manifestation of the disability.

Disciplining the behavior out of a challenged student is impossible, especially if it is a manifestation of the disability. IDEA requires that the IEP include a BIP in lieu of a traditional school discipline policy when behavior impedes learning and is a manifestation of the child's disability.

In order to properly design a good BIP, a number of preliminary steps must be taken. Creating an effective BIP for individuals with fragile X syndrome is similar to designing a sound instructional program. Recognizing that the environment plays a major role in the way a student with fragile X syndrome learns and behaves is critical. Identifying overt behaviors (physical aggression, yelling out, destruction, etc.) although important, does not identify the cause of the aggression. It is my contention that if the behavior reaches an aggressive level it is most likely due to a weakness in the behavioral support system. There are usually antecedents (triggers) that when unaddressed contribute to the behavioral escalation. For example; if a child becomes silly when presented with a transition and is simply admonished without any modification, the behavior will continue, because the function of the behavior has not been addressed. The student's behavioral repertoire will change to meet his need to avoid. Without modifications, the behavior will escalate to an aggressive form (hitting, kicking, yelling). When the level of aberration is increased, it can no longer be ignored and the behavior serves the ultimate purpose; to make the transition stop.

This above example highlights the need for a Functional Behavior Assessment (FBA). This assessment is designed to identify the contextual factors that contribute to the behavior. When properly conducted, the FBA identifies the conditions under which the student is successful or unsuccessful. In the example given it may initially appear that the student is oppositional whenever asked to comply, but the student may anticipate a fearful experience created by the unknown. Because the student lacks the ability to express the affective nature of his behavior, he must act it out. Often with students with fragile X syndrome anxiety becomes the driver for aberrant behaviors. The underlying fear must be addressed in order to effectively intervene.

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Because students with fragile X syndrome demonstrate a behavioral delay— the behavior does not always immediately follow the antecedent—the FBA should be conducted over several days and should utilize a team of professionals from a number of disciplines. When a team approach is used, the assessment gains perspective. The educator may be able to determine that a skill deficit is the antecedent, while an occupational therapist might identify an environmental antecedent that has sensory implications (loud sounds, proximity or crowded conditions) and a speech therapist might identify an expressive language deficit that causes embarrassment that results in aggressive outburst.

After assessing the function of the behavior the intervention begins. Often, a student with fragile X syndrome has habituated a behavioral response so a prosocial response needs to be taught. This is the true essence of the BIP; teaching an intervention that replaces the maladaptive behavior.

The reason for writing this article is to highlight the importance of the intervention portion of the BIP. Without the focus on "I", the BIP is simply a piece of paper to document behavioral episodes. Designing an intervention requires careful consideration. It is necessary to identify the antecedent, but equally important is finding ways to teach the student new coping strategies. With proper support the student gains benefit from the intervention and becomes more prosocial in his reactions.

Plan to be proactive and understand that IDEA provides ways to keep the student with fragile X syndrome viable and included with typical peers.

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EDITOR'S NOTE: Marcia Braden, PhD, is a psychologist and a longtime advisor to the National Fragile X Foundation. She is also the author of the acclaimed book, "Fragile, Handle With Care", *and a nationally known lecturer on fragile X. Her sessions at the NFXF's International Conferences are always "standing room only".*

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In The Beginning . . .

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Thinking back to our First National Fragile X Conference in 1987, I remember feeling excited and proud. We had finally pulled the experts together to provide a real conference. I was thrilled to have been invited and looked forward to meeting many of the fragile X experts that I had cited in my dissertation research. To think that I would meet Dr. Stephanie Sherman, Dr. Ted Brown and Dr. Optiz, just to name a few. It was such an incredible opportunity and I was truly humbled.

The conference was in Denver at The Clarion Hotel in December — not exactly a great time to travel to the Rocky Mountain state, but we were on a mission! It would be a two day conference — Thursday and Friday. My topic was entitled *"Techniques, Strategies and Identification of Learning Idiosyncrasies in the Fragile X/Autistic Patient"*—what a title! If I used that title today, I'd need several days to do it justice. But in 1987, I was just beginning to scratch the surface. Having seen less than fifty males with fragile X, I had begun to put a cognitive profile together, but with many unanswered questions.

The scientific presenters were exploring prenatal diagnosis, recombinant DNA technology and somatic cell hybrid studies which were new theories then concerning the etiology of fragile X syndrome. We were really at the infancy of our development.

My usual charge in this column is to write something about behavior, but nostalgia is taking over and I want to reflect on just how much more we now know and how far we've come. It is rewarding to recognize how much more we understand those affected by the elusive gene we have had a love-hate relationship with for twenty years.

In retrospect, perhaps the most important lesson I've learned is that this group of individuals is like none other. The people affected by fragile X syndrome have been relentless in their efforts to show me what they need. Their patience with me and my mistakes has been comforting. I have attempted to respond to their needs by applying a variety of educational strategies and behavioral principles to make them feel more productive and successful. The carriers have provided an added bonus because so often, they can verbalize those things that others with a full mutation have trouble articulating.

The educational outcome for those affected by fragile X syndrome has improved with the passage of I.D.E.A. (Special Education Law) and its subsequent amendments. This is a big change from where we were in 1987. We are now more able to provide a free and appropriate education to all children and we are compelled to include students with special needs in the least restrictive environment.

As I looked through my notes used to prepare for my lecture in 1987 (yes, there is a diagnosis in the fact that I still have those notes), I chuckled at some of my discoveries and thought the list would be useful to share:

- Great sense of humor— I love these guys!
- Easily excitable— I must be calm when interacting with them.
- Like to help others— love to have special jobs.
- Seem to get nervous or anxious when complimented (this was hard for me to explain).
- Phonics is a black hole; but I've seen them read— why is this?
- Their moods can change— delightful and suddenly anxious and resistant.
- Smarter than any IQ measure indicates.

- Able to imitate accents, intonation patterns, etc.
- Food likes are based on textures not taste.
- Problems with certain kinds of clothing, fabric, etc.
- Love music, cooking and sports.

Well, looking back on this list, I realized that a lot of the information gleaned through my early observations are still right on target, but we are now better able to meet those needs through technology and educational strategies.

Perhaps the most salient realization is that from the very beginning I saw these individuals as malleable and open to remediation when certain techniques were used. Their behavior could be modified, especially if we accounted for their fear of making a mistake, being embarrassed or frightened. The depth of understanding we now have in 2004, has enabled us to successfully craft behavioral remedies that recognize and include antecedents which contribute to their behavioral difficulties. Instead of spending our time and energy on developing consequences that "teach a lesson," we now focus on what causes the behavior to be present. Instead of waiting for a student to act out, we now intervene before the acting out is necessary. Instead of modifying a behavior using a consequence or punishment, we address the reason for the behavior and hope to eliminate the need for a consequence.

When I look back on the tremendous contributions so many gifted clinicians have made, I am in awe of all that has been accomplished. I find myself reflecting on one of Thomas Edison's famous quotes and feel we have embraced it with a passion "If there's a way to do it better…find it."

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Oppositional… Or Merely Anxious?

NFXF Quarterly Summer Fall 2004

I'm often asked, "Is he just defiant, or is there something else going on? He refuses to comply and he seems to want to manipulate me."

Actually, children with or without FXS learn to maneuver in their environments in order to survive and thrive. In order to discern whether a behavior is oppositional or merely a reaction to anxiety, pay attention to your reaction. If you provide social attention (Everyone's looking at us; what do you want?), emotional attention (What's wrong, why are you crying?) or negative attention (Stop that, you won't get ice cream if you continue to yell), you are most likely reinforcing a behavior that will persist.

I've talked a lot about the need to break behavioral chains by changing the habituated responses of the caregivers. This strategy can be an effective way to change a behavioral outcome. Change your response, and see if the child's behavior changes. If it does, then the defiance you experienced was most likely oppositional because your reaction affected the behavior. On the other hand, if the behavior continues to escalate even after dutifully changing your reaction, the child is most likely reacting to his physiological system. A number of researchers have noted that children with FXS have higher levels of physiological arousal in stressful situations (Cohen, 1995, Miller et al. 1999).

Generally, oppositional behavior in children with FXS escalates when the stressful event persists. If the child reacts to stress, the defiance will increase as the stress increases. If the stressful condition is modified, the reaction changes because it is no longer necessary for the child to react to the stress, proving that the behavior is a reaction to the anxiety. If the behavior occurs randomly and in isolation, it most likely is not a reaction to stress and therefore not anxiety-driven.

Sometimes, it is a challenge to eliminate the condition that causes the child to become anxious and oppositional. Perhaps a novel experience—going to a new school, joining a club, attending a youth group—elicits an initial reaction to avoid the experience. In these situations it is important to encourage the child to increase his tolerance and experience the new situation. This can be accomplished by providing desensitization through a gradual process. First, expose the child to the novel experience with a set end-time. As the child becomes comfortable, you can lengthen the time you expect him to tolerate the experience. It is important to be concrete and exact with the desensitization process. Consistency helps the child trust this process. Knowing that there is a specific, predictable ending allows the child to relax and successfully participate.

Timers, pagers and token boards can be used to provide a tangible reminder of how much longer the experience will last. A token board is a version of a token economy but can also be used to signal completion of a task. The board becomes a motivational tool to provide tangible evidence of progress toward a goal. This tangible evidence is in and of itself reassuring. Providing verbal reminders of an abstract end-time (10 more minutes) is not helpful. When the child is stressed, 10 minutes may as well be an eternity.

The token board can also provide distraction when a child's anxiety becomes overwhelming. As the child pays attention to the tokens being moved, he is distracted from the anxiety-provoking event. The tokens can be moved across the board to provide a visual count of how much time has passed and what remains. Customizing the board by using pictures and tokens that reflect special interests provides familiarity, which is comforting.

In summary, remember that children with FXS often fear their own anxiety and become even more upset during an emotional meltdown. This anxiety impacts their ability to function in the mainstream and access their environments.

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Have Purpose, Will Transition

NFXF Quarterly Winter 2005

Transitions can create havoc in the lives of many with FXS. Anything from changing a driving route to moving into a new house can shake the foundations and cause a behavioral outburst.

During our parent consultation clinics, occupational therapist Tracy Stackhouse, speech/language therapist "Mouse" Scharfenaker and I create significant transitions when we ask parents to bring their children to us. Often, this occurs in a hotel conference room several miles away from the child's familiar environment. As we have struggled to deal with the fallout from these necessary transitions, we have discovered ways to reduce their impact on behavior. Obviously, this is essential to our ability to evaluate a child's learning, speech and sensory functioning.

We have found that creating a mission or purpose for the child helps to reduce negative effects of the transition. The child's commitment to a purpose gives meaning to the transition and reduces the anxiety often created from not understanding why it is happening. If the child has a specific purpose when entering the conference room, the fear of the unknown is replaced with a purpose, and a mission is set.

Our strategies have included asking the child to bring something into the conference room from the front desk (notepad and pencil) or from the restaurant (sugars and creamers) in order to set up a conference room coffee bar. Although somewhat contrived, these strategies can often be more effective in reducing the behavioral fallout from transitions than others described in the literature.

Sometimes, preparing for the transition creates so much anxiety that the child can do nothing but perseverate about it. The upcoming doctor's appointment, field trip or new day care setting becomes the total focus of conversation. The obsession with the transition becomes yet another behavioral issue to contend with. Again, we may help the child better prepare by having a job for him to perform (setting up a display, filling a box, finishing up a task as part of the field trip, delivering a gift to to the new day care provider). It is critical that the child feels the job or mission is important, and that he has the necessary skills to carry it out.

A case study using this kind of intervention involved a child who had difficulty transitioning from his mother's car for the morning drop-off at school. He would often hit and kick the paraprofessional assigned to bringing him into the school. A variety of strategies were implemented, and although somewhat helpful, the behavioral episodes did continue intermittently. It was only when the staff created a ritual that was reinforcing to the child that the behavior changed and the transition was tolerated. The transitional ritual required the child to bring pennies from his mother as he left the car, carry the pennies into his classroom, and place them in a bank. The pennies were then exchanged for tickets and other items of interest later in the day. Again, the strategy provided the child with a means (bringing pennies) to an end (achieving a successful transition) that overrode any fear or anxiety created by the transition.

Many books and articles have been written about how to support a child with special needs when making transitions. Such strategies may include (but not be limited to) giving reminders of an upcoming transition, using a timer or hour glass to mark time prior to the transition, singing or playing a song that signals the transition, providing a picture schedule of the daily events with particular emphasis on the changes, and providing a transitional object, picture or toy that might facilitate a smoother transition.

In the case of those with FXS, habituation of a ritual provides the child with the comfort of a recurring routine. It is my experience that people with FXS habituate rituals to mitigate the anxiety

they feel about events that have no predictability or consistency. It is the unpredictability of an event that feeds anxiety. Complementing an imminent change with a habituated ritual will shift the focus from the unknown to the known, making the transition more tolerable.

Designating a specific role (delivery person, coffee bar helper, ticket collector, hall monitor, office helper, PE assistant) creates a mission that becomes the focus and overshadows the transition that follows. The success of these strategies depends on the creation of the contrived missions and the consistency of the implementation.

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"Reality" Check

NFXF Quarterly Spring 2005

A note from Marcia Braden: *Normally, my column focuses on issues that typically get my attention through parents' requests for help. The issues are usually common to those with fragile X syndrome. This column resulted from a conversation I recently had with my friend and colleague, Dr. Karen Riley, assistant professor of child, family and school psychology at the University of Denver. After pondering the idea, I asked Karen to join me in writing the column. She eventually agreed to write most of it—and I took full advantage of her offer.*

Reality shows have taken over our television programming. Rather than watching fictional characters perform comedic, suspenseful or dramatic scripts, we now observe "real" people compete, struggle, argue and live their lives. These programs entertain us and sometimes attempt to educate us. Various "pop psychology" programs, including Dr. Phil and The Super Nanny, have crossed over to providing parenting advice. The success of these programs validates the notion that parents in our society are continually reevaluating their parenting strategies and looking for a particular approach that will work for their child. Families that include children with fragile X syndrome share similar concerns but are faced with additional challenges. That is the topic of this column.

Popular parenting advice, whether it comes from a television show, self-help book or prepackaged program, can provide insight and applicable strategies. While the information can be helpful, it can also be misleading enough to cause parents additional stress, especially in families of children with special needs.

There are several factors to consider when evaluating the applicability of a parenting program for children with special needs—specifically those with fragile X syndrome. One important point to bear in mind is that these programs were designed to address the behavioral needs of typically developing children. The children of most viewers have intact sensory systems that provide accurate feedback from the environment. Their language systems are capable of both comprehending and remembering verbal directions. Given the difficulties children with fragile X syndrome have in these areas, it is critical that we view the advice offered by "reality parenting" programs through lenses tinted by knowledge of our children's strengths and weaknesses.

This process can be difficult to navigate. Possibly the best way to explain it is to provide an example. In a recent episode of the "Super Nanny," children were having difficulty sleeping alone, and with following their mother's directions. The Super Nanny recommended creating a routine around daily activities that involved parents spending time with each of the children separately. She also recommended developing a bedtime routine that included specific guidelines for putting the children back in their beds each time they got out. The parents employed this tactic through 45 minutes of screaming and crying, after which the children finally fell asleep.

The Super Nanny also recommended placing the children in the "naughty chair" when they did not follow their parents' directions. The parents were instructed to discuss the situation with their children and place them in the naughty chair for one minute for each year of their age. The children were then told that when they said "I'm sorry," they would be allowed to rejoin the family. Once the children left the naughty chair, their parents talked with them about why they had been placed there.

The parents expressed sadness while they watched their children struggle with the new expectations and consequences for their behavior, and they continually questioned the new approaches. They received support, encouragement and direction from the Super Nanny, and by the end of the program the children's behavior had improved.

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At first glance many of the Super Nanny's suggestions would seem applicable to parents of children with fragile X syndrome. This includes the implementation of daily routines and adhering to a consistent set of previously agreed upon consequences. The naughty chair is a new and clever way to refer to "time out," which can be an appropriate consequence for misbehavior by children with fragile X syndrome. But the manner in which these approaches are applied is where we must pause. Several points bear mention here:

- The Super Nanny provides the children with a great deal of verbal explanation, which is counter-therapeutic to individuals with fragile X syndrome. Short and concise directions are more effective for children with language delays and attention issues.
- The formula of one minute in the naughty chair for each year of age is too long for children with developmental delays and poor impulse control.
- Time out should be linked to a specific behavior, and when the time has elapsed the child should be allowed to rejoin the classroom, group or family activity. But the Super Nanny requires children to apologize before they can rejoin. If they do not, she recommends placing them back in the chair. Requiring a child with fragile X syndrome to apologize confounds the presenting infraction with a behavioral dilemma. The child is not only being punished for the original infraction, but then runs the risk of additional punishment for being unable to apologize. This complex behavioral expectation can be provocative. For example, we know that individuals with fragile X syndrome are often unable to speak on command due to their language delays and performance anxiety. Holding out for an apology may distract from a positive and compliant outcome.

This short scenario illustrates how one popular parenting program can provide helpful strategies, while at the same time being a prescription for frustration and failure. So what is the bottom line?

Watching parenting programs and/or reading books on the subject can be helpful and somewhat inspiring and "normalizing." These programs show how many families struggle with some of the same issues facing families of children with fragile X syndrome. A new approach can sometimes become a creative remedy for an ongoing behavior problem. The key is to understand that these programs were creating for typically developing children— and thus require adaptation to the specific circumstances you may face in parenting a child with fragile X syndrome.

In summary, use these guidelines when considering the application of popular media approaches.

- Remember that most programs are developed for typically developing children who do not have a neurobiological disorder.
- Before implementing any plan, review it with someone who is familiar with fragile X syndrome and your child.
- Programs that involve discussion and explanation need to be reviewed carefully, as children with fragile X syndrome have language delays and sensory deficits.
- Prioritize the behaviors you want to target. Choose to change behaviors that are most debilitating to the family's well-being and harmony. These may differ dramatically from those that present in families of typically developing children.
- Understand that parenting is both one of the most challenging and rewarding experiences in a lifetime. Stay the course and celebrate the successes!

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BACK TO SCHOOL WITH A BANG

My usual topic has been modified to fit the back to school theme because going back to school after a relaxing summer can be quite a challenge. The fact that transitions back to school can be anxiety provoking sets the stage for this column.

Summer break usually includes a variety of outdoor experiences, which incorporate physical activity. The school-learning environment is different from the less structured activities of the summer. Even though the imposed structure of the classroom can be somewhat positive, it is the transition of getting ready to go back into the classroom that can makes it difficult.

There are several strategies that can be of help in guiding a successful transition. If the student is going back to the same school with the same teaching staff, the transition process is easier and requires less support. When the student changes schools, neighborhoods, or programs the support requires additional strategies.

Prior to the start of school, take digital pictures of the school, classroom, playground or school ground and school staff. These pictures can then be incorporated into a story about going back to school. The student can either read or be read the story. Repetition of the story can provide familiarity and predictability, making the unknown or novel experience less intimidating. Another option is to make a video of the school facility along with a welcome message from the teaching staff that will support the student. Other staff members working around the school (janitors, school secretaries and cafeteria staff) should also be included. Watching the school video will become a pastime that is both enjoyable and a positive strategy.

Whenever possible, it is helpful to find classmates to accompany the student with FXS when going back to school. This buddy can describe differences to the student with FXS over the phone or internet. Establishing a routine to walk to school with a friend or sibling, ride together in a carpool or school bus is helpful. Routine brings predictability, which is self-calming and reassuring. When the early morning routine becomes habituated, entering the classroom and starting the day, simply becomes an extension of that process.

If your child is going back to the same school in the fall, often, social stories can assist in a less direct way while reducing the anxiety created from concern and worry about the upcoming school year. The stories can include a story line about how exciting it is to go back to school. The story can conclude with a description of the strategies mentioned above, list names of classmates and a biography of the new teacher.

Beginning the year with a bang can be positive and less intimidating when proactive strategies are employed. It is very important to take time to plan the transition before school starts so that the beginning can prompt a positive outcome. We know that individuals with FXS habituate routines rather quickly, and find comfort in the sameness of the repetition. Making that routine available before the first day of school, will certainly increase the likelihood that the rest of the school year will be positive and productive. Good luck with your transition and may this school year be the best ever.

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The Role of the Family System on Behavior

Recently, I have had the opportunity to assist several families in managing behavior problems that have affected the entire family. During the problem-solving phase of our interaction, it is often clear that certain aspects of the family system contribute significantly to the targeted behavior of the child affected by FXS. Even though the family may be aware of the tenets of positive behavior support, that awareness can be lost in the "moment," or maybe not even acknowledged due to particular patterns that have been embedded into the family system.

The families indicated that the most difficult times to manage their child(ren) with FXS are during the "hurried" portions of the day. The before-school routine is especially difficult, and often the most likely to trigger behavioral aggression or outbursts. The analysis itself is easy: "Everyone is rushed, so the person with FXS shuts down under the pressure." More difficult is the task of deciding how to structure the morning with less chaos. If the person with FXS feeling the pressure, so is the family system. Most families have a number of people impacted by the tight morning schedule. Parents are getting ready for work and children are scurrying to find their homework, book bags and gym clothes—all of it under a time constraint.

Because the child with FXS has the most difficulty dealing with the anxiety of being rushed, the entire family runs the risk of that child's behavioral episode affecting everyone's morning. Without overtly planning it, the family employs methods of adjustment to keep the system running smoothly. These adjustments may include ways to pacify the child affected with FXS that are not always behaviorally sound. The problem is that even though the short-term fix keeps the morning up and running, the child with FXS becomes accustomed to the adjustment, demanding it again the next morning as a way to gain prediction and preserve sameness. This may not be significant in isolation, but if the system adjusts every day in order to "keep the lid on," the entire morning routine becomes an opportunity for the child with FXS to become more confused and frustrated because the expectations around the "routine" don't conform to the otherwise prevailing behavioral norms of the family. [MARCIA: FELT LIKE THAT NEEDED AN EXPLANATORY LINE ABOUT THE SOURCE OF THE CONFUSION/FRUSTRATION FOR THE CHILD]

Perhaps even more salient is the emotional byproduct this readjustment brings to the family. Each family member not affected by FXS experiences an imposed reaction that can breed resentment and anger. In a recent consultation, two children not affected by the gene shared their resentment about keeping their brother with FXS happy in the morning. They felt as though their parents "gave in" far too often, but they also felt trapped because if the behavior escalated, the entire family risked being late and upset. In addition, they disliked the emotional loading they experienced when the behavioral episode occurred right before leaving for school.

The solution we brainstormed was to practice a morning routine during a weekend, with the family continuing to incorporate that routine on a consistent basis on school days. A backup plan was put into place if the child with FXS had a behavioral episode that would impact the other family members' morning schedule. Interestingly, the routine became habituated in just a few days. There may be many reasons this plan worked so quickly, but the most obvious was the fact that the entire family could relax in the morning because they were able to affect a positive change. They also knew they had a backup plan that would preclude a negative outcome. This plan also provided the child with FXS a predictable routine, which reduced his anxiety level as the family system operated in a consistent manner.

This issue is not unique to this family. Sometimes, we focus so much on the behavior of the child with FXS that we fail to see the interaction between the child and the family system. Before embarking on any behavior plan, look at the system maintaining the behavior, and consider the environmental factors that may be contributing to it.

Marcia Braden is a psychologist and special education consultant in Colorado Springs who specializes in Fragile X. She is the author of Fragile: Handle With Care, *and creator of the* Logo® Reading System.

Braden on Behavior

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Reading, Writing & Behavior?

by Marcia Braden PhD, NFXF Quarterly Fall 2006

With the school year in full swing, I am reminded about the significance of appropriate educational supports. In my role as a consultant, I have encountered on numerous occasions a lack of understanding about how important the learning environment is to behavioral outcome. An interesting study by Symons, Clarke and Roberts (2001) concluded that engaging children of elementary age with FXS was strongly related to the environmental and instructional quality of teachers and classrooms. The authors found that the ways in which teachers structured and arranged the classroom environment was more important than were the specific aspects of the child's FX status such as severity of affectedness, medication usage or dual diagnosis.

This documents what we have experienced clinically for years. Best practice for those affected with FXS means providing a learning environment that allows them to access the curriculum in ways that minimize disruptive behaviors and even further, without a teacher being overly concerned about functional levels or complex diagnoses.

Even though the Fragile X community has worked very hard to include children with FXS with their typical peers, the educational systems often fall short in their mandate to provide a free and appropriate education. The issue of appropriate education has been debated through many due process hearings, culminating in a number of landmark special education decisions. In my view, an "appropriate" education requires accommodations and adaptations specific to a special education student's condition. For example, students with FXS have a keen sense of belonging, especially when they notice their level of performance is not on par with the typical peers surrounding them. This can have a significant impact on their behavior. Learning is contingent upon engagement. When a child is disengaged it becomes critical to assess any factors that contribute to that disengagement.

One antecedent that is often overlooked when assessing engagement is the curricula and lack of necessary adaptations. When there are students with FXS in a classroom, the curriculum must include adaptations that incorporate what we know about their learning style. If adaptations specific to FXS are not provided, the student may lack the skills to respond successfully.

It is not uncommon to observe students with FXS working hard to avoid curricular expectations, especially when their skill set is inadequate. The student with FXS may see no other option than to respond with some form of aberrant behavior in order to avoid the failure. Neglecting to account for this possibility when formatting an instructional model is a recipe for disaster. In addition, failing to consider the arrangement of the classroom and environmental adaptations may also contribute significantly to aberrant behaviors.

Too often, educators consider behavioral issues to be separate from the instructional program, making it easy to lose sight of the curricular factors that may be contributing to a problem behavior. With the reauthorization of the Individuals with Disabilities Education Act (IDEA), there is now an emphasis on implementing interventions that are scientifically based. It is no longer acceptable to determine special education eligibility simply on the basis of student failure. Now, if the student fails, the intervention itself must be analyzed, along with the student's response to the intervention. This shift supports the need to implement appropriate intervention strategies that include remedies specific to the child's condition, and long before a behavior intervention plan is developed. It also highlights the need to look beyond the identified behavior and to address other factors that might be contributing to the behavioral response.

The tendency to focus on isolated behavioral episodes before considering the environmental, curricular and instructional methodology is no longer accepted. The evidence is clear, the mandate has been clarified, and the students will ultimately thrive within this new approach to behavior

intervention. The simple take-away lesson is this: Before your child's teacher targets a specific behavior, he or she must carefully consider your child's level of engagement and how it might be enhanced through environmental adaptation and instructional design.

Marcia Braden is a psychologist and special education consultant in Colorado Springs.

BEST PRACTICE SUPPORTS FOR STUDENTS WITH FRAGILE X SYNDROME

Environmental Accommodations

- Provide structure and predictability of schedule
- Provide opportunities to be included with typically developing peers
- Reduce level of noise, proximity of other students and EA's
- Use natural lighting whenever possible
- Avoid crowded areas; help student gradually desensitize to large crowded environments
- Encourage opportunities to move
- Remove or minimize stressful events whenever possible
- Provide support for transitions, i.e. transitional object, job or task to rove from one location to another

Curricular Adaptations

- Use teaching triad (indirect instruction with another student)
- Provide small group instruction
- Provide visual supports such as charts, diagrams, pictures and color coding
- Provide nonverbal feedback
- Provide sensory intervention with an OT
- Use hands-on materials to teach math (and remember it is a very difficult academic area for these students)
- Teach reading using a visual approach
- Provide alternative means of responding to written tasks
- Use technology to augment writing
- Enhance learning by using high-interest material

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Public or Private?

Including people with handicaps in our communities poses significant challenges. While inclusion helps increase normalization, it also increases vulnerability to community risks and hazards. How do we prepare children and adolescents to access their communities without running the risk of their being exploited, or showing affection in inappropriate ways, using sexual language that may be misconstrued, or touching body parts that could bring legal action or at the very least a disgruntled public?

If we simply advocate for opportunities to be included and leave it at that, we are not fulfilling our obligation to those who do not automatically develop or naturally demonstrate prosocial behavior. We teach academic skills in a systematic fashion, skill- streaming the ones we feel are most salient for each level of functioning. Why then do we assume matters of prosocial behavior will develop without direct instruction?

People with FXS experience a unique social dilemma because on the one hand they express a desire to be social, but when given the social opportunity, they can become so hyperaroused that they retreat and prefer to watch from a distance. This approach-avoidance behavior can become a deterrent to acceptance and experiences of social reciprocity. I have discussed this phenomenon in a prior column with respect to the role that anxiety plays in social integration. This article, however, is focused on teaching more prosocial behaviors, absent anxiety.

In 1981, two very brave female professors at Portland State University began to discuss and write about how people with disabilities need prosocial and sex education training. At that time many people believed that persons with disabilities belonged in institutions and that to even fathom social/sexual relationships among those with mental or physical challenges was perverted and taboo. I was fortunate enough to have known those women, and I benefited from their mentoring. Twenty-five years later we can truly say, “We’ve come a long way baby.” But we have further to go.

Strategies to reduce the anxiety provoked in social venues are certainly important in our quest to foster more natural social interaction. There are, however, other important skills to becoming more accepted in a very discerning social society. Teaching children at an early age how to discriminate between public and private provides a rule-based strategy that can use visual supports. This process begins early so that the child comes to understand the concept of public and private places, people and behaviors. It also can lay the groundwork for responding to more abstract social dilemmas that present throughout the life span.

For example, a very young child may be allowed to remove his pajamas and underwear in preparation to dress for the day while watching his favorite cartoon in the family room. As the child grows older, this standard becomes less appropriate, yet the behavior has become so embedded into his daily routine and schedule that it becomes difficult to change. It is also hard for the child, as he gets older, to understand why the behavior is now inappropriate and no longer tolerated.

Another example is when as an adolescent, a boy chooses to unzip his pants to tuck in his shirt. That behavior is considered private, allowed only in a private setting such as the bedroom or bathroom. If that lesson is not learned early and the behavior takes place in public, it might be construed as a sexual act or as pre-perpetration behavior.

Training to distinguish clearly between public and private can also be critical to a child’s avoiding exploitation. Knowing that touching and hugging is a private behavior that should only be demonstrated with private people such as family members and *not* strangers

may provide a safety net and subsequent protection. Learning a concrete rule-based structure eliminates any guessing or evaluative process in situations that might result in an exploitive relationship.

Teaching prosocial behavior works best using real life photographs and video vignettes that demonstrate appropriate social interactions using the private and public context. The structure of this type of program provides reinforcement so that when similar real life situations are encountered, the learned skills can be applied and the behavior corrected in a safe and caring environment.

Teaching to discriminate between private and public behaviors and then matching those behaviors to public and private places and people provides a simple, concrete method to shape safe behavior. It also allows for immediate redirection from a parent, caregiver or school staff when unsafe behavior occurs. If, for example, when the person with FXS engages in behavior that should be demonstrated only in a private place, the parent can say, “Stop, that’s private,” and redirect him to a private place like a bathroom or bedroom.

The chart below (*on the next page)* is an example of a matrix of behaviors identified as either private or public, along with corresponding people and places used in this program.

BEHAVIOR

Public Behavior

- Blowing your nose
- Holding hands
- Talking on the telephone
- Dancing
- Shaking hands, high-fives
- Hugging or being hugged
- Pats on the back
- Kissing on the cheek
- Eating
- Riding public transit
- Smiling at another person
- Giving compliments

Private Behavior

- Wearing pajamas
- Urinating, having a bowel movement
- Masturbating
- Dressing and undressing
- Changing underwear, Depends
- Flatulating
- Kissing
- Taking a bath or shower
- Intimately touching others (private areas)
- Cursing
- Zipping and unzipping pants
- Changing tampon or sanitary napkin
- Closing bedroom door
- Standing very close to someone
- Keeping a secret
- Brushing teeth
- Putting on deodorant
- Giving out address or phone number
- Insulting others
- Writing in a diary

LOCATIONS

Public Places

- Public restrooms (school, church, restaurant)
- Theaters
- Restaurants
- Living rooms; common rooms
- Buses and public transportation
- Library
- Classrooms and playgrounds
- Automobiles, trains, airplanes
- Stores, shopping malls
- Church, synagogue
- Public park, amusement park
- Museums

Private Places

- Bathroom at home
- Bedrooms
- Hotel rooms
- A private place with a door closed
- Doctor’s office/examining room
- Airplane bathroom

PEOPLE	
Public	
• Postal carrier, delivery person • Bus driver • Waitperson • Plumber	• Teacher • Acquaintances • Policeman, fireman
Private	
• Mom, dad, sibling, grandparents • Girlfriend or boyfriend • Spouse	• *Pastor, priest, rabbi • Close friend • Doctor, dentist, therapist

*Depending upon the context these individuals could be considered Private or Public

Providing good modeling and consistent intervention to distinguish public from private spheres must begin at an early age. Engaging the child in a structured program to teach these issues at a young age will pay off as a child matures, when acceptance is often determined by prosocial behavior. People with FXS have so much to offer. It would be a grave disservice to our society to limit their free access to communities due to inappropriate social behaviors. Yes, we've come a long way baby, but the best is yet to come!

Braden on Behavior

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"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.

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Ten Rules of Behavior Management

1. *Never force eye contact except when teaching social engagement.*
2. *Be consistent.*
3. *All behavior serves a purpose, so analyze its function before implementing a plan.*
4. *Remember that sensory input can have a direct relationship with aberrant behavior.*
5. *Remember that behavior is often a means of communicating.*
6. *Target one behavior at a time.*
7. *Count frequency and duration before you decide to target a specific behavior (because it may not be as bad as you think).*
8. *Behavior does not occur in a vacuum; consider the context.*
9. *Use a multidisciplinary team when creating a behavioral remedy.*
10. *Don't battle biology. (The "Dr. Karen Riley Rule")*