

BRADEN ON BEHAVIOR

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.

Braden on Behavior

Have Purpose Will Transition

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

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

We have found that creating a mission or purpose for the child helps to reduce the negative effects of the transition. Being committed to a purpose gives meaning to the transition and reduces the anxiety often created from not understanding why it is happening. For example, 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. We have suggested that the child bring something into the conference room from the front desk as a delivery, or from the restaurant (sugars and creamers) 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 persevere about it. The upcoming doctor's appointment, field trip or new day care setting becomes the focus of conversation. The obsession with the transition becomes yet another behavioral issue to contend with. Again, the child may be better prepared by having a job to perform as part of the field trip or a gift to deliver to the new day care provider. It is critical that the child feel that the job or mission is important and that he has the necessary skills to carry out the mission (set up a display, fill a box with a material, finish up a task.)

A case study using this kind of intervention involved a child who had difficulty transitioning from his mother's car in the morning drop off at school. He would often hit and kick the Para professional assigned to bringing him into the school in the morning. A variety of strategies were implemented, and although somewhat helpful, the behavioral episodes continued on an infrequent basis. 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 an end to a means and over rode 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. Typically, the strategies include; 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 just to name a few.

In the case of those with FXS, habituation of a ritual provides the child with comfort created by a recurring routine. It is my experience that people with FXS habituate rituals to mitigate the extraordinary events of life that have no predictability or consistency. It is the unpredictability of an event that feeds anxiety. Replacing an imminent change with an 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.

Normally, my column focuses on issues that typically get my attention through parents' request for help. The issues tackled are usually common to those with fragile X syndrome. This column content resulted from a conversation I recently had with my friend and colleague, Dr. Karen Riley. After pondering the idea, I asked if Karen would join me in writing this quarter's column. She agreed to writing most of the article and I took full advantage of her (offer). I feel it is a good diversion from my normal content and hope you agree.

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A Real-Life Reality Check

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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; thus putting their concerns and worry to rest. Families with children with fragile X syndrome share similar concerns but are faced with additional challenges.

Popular parenting advice whether it comes in the form of a television show, a self-help book or a prepackaged program can provide insight and applicable strategies. While this information can be helpful it may be misleading enough to cause additional stress, especially for families with children with special needs. The trick is trying to determine which programs can be helpful and which strategies should be adapted.

There are several factors to consider when evaluating the applicability of a parenting program for children with special needs and specifically those with fragile X syndrome. Although some of the strategies can prove helpful, it is important to remember that these programs were designed to address the behavioral needs of typically developing children with intact sensory systems that provide accurate feedback from the environment and language systems that are capable of both comprehending and remembering the verbal directions that are provided. When attempting to employ any of these strategies, one must first critically view the program through lenses tinted by our knowledge of the strengths and weaknesses of children with fragile X syndrome.

This process can be difficult to navigate. Possibly the best way to explain this process is to provide an example. In a recent episode of the Super Nanny the family was faced with children who were having difficulty sleeping alone and with following their mother's directions. The Super Nanny recommended creating a routine around daily activities that involved spending time with each of the children separately. She also recommended developing a bedtime routine that involved specific expectations and guidelines for putting the children back in their beds each time they got out. The parents employed this tactic and through 45 minutes of screaming and crying, the children stayed in their beds and finally fell asleep. The Super Nanny also recommended placing the children in the "naughty chair" when they did not follow their parent's 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 were allowed to rejoin the family. Once the children left the naughty chair, their parents talked with them about the situation that had occurred and why they had been placed in the naughty chair. The parents expressed sadness while they watched their children struggle with the new expectations and consequences for their behavior and 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.

At first glance many of the Nanny's suggestions would seem applicable to a family with a child with fragile X syndrome; including 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 inappropriate behavior for children with fragile X syndrome.

The manner in which these approaches are applied is where the scrutiny should begin. The Super Nanny provides the children with a great deal of verbal explanation. This much verbal instruction is counter-therapeutic to individuals with fragile X syndrome. Short and concise directions are more effective for children with language delays and attentional issues. One minute per year for time spent in the naughty chair or in time out is too long for individuals 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 re-enter the situation i.e. the classroom, group or family activity. The Super Nanny requires the child to apologize after their time in the naughty chair has elapsed. If the child does not apologize the Super Nanny recommends placing the child back on the naughty 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 could provide helpful strategies and at the same time be a prescription for frustration and failure. So what is the bottom line? Watching these types of programs and/or reading books on parenting strategies can be very helpful and somewhat inspiring and normalizing. These programs show how many families struggle with some of the same issues that a parent of a child with fragile X syndrome might be dealing with. A new approach can sometimes breathe life into a creative remedy for an ongoing behavior problem. The key is to understand that these programs were developed for typically developing children.

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

1. Remember that most programs are developed for typically developing children who do not have a neurobiological disorder.
2. Before implementing any plan review it with someone who is familiar with fragile X syndrome and your child.
3. Programs that involve discussion and explanation need to be reviewed carefully, as children with fragile X syndrome have language delays and sensory deficits.
4. Prioritize the behaviors you want to target. Choose to change behaviors that are most debilitating to the family's wellbeing and harmony. These may differ dramatically from those that present in typically developing peers.
5. 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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The Role of the Family System on Behavior

Recently, I have had the opportunity to assist several families about 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 tenants of positive behavior support, that awareness can be lost in the “moment” or maybe not even acknowledged due 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” time frames of the day. For example, the before school routine is especially difficult and often the most likely to trigger behavioral aggression or outbursts. The quick analysis is...“everyone is rushed, so the person with FXS shuts down under the pressure”. The more difficult task, is deciding how to structure the morning with less chaos and more structure. Not only is the person with FXS feeling the pressure, but so is the family system. Most families have a number of people impacted by the tight schedule in the morning. For example, parents are getting ready for work and the other family members are scurrying to find their homework, book bags and gym clothes under a time constraint.

Because the child (ren) with FXS has the most difficulty dealing with the anxiety of being rushed, the entire family runs the risk of a behavioral episode affecting everyone’s morning. Without actually planning it, the family employs methods of adjustment in order to keep the system running smoothly. These adjustments may include ways to pacify the child affected with FXS that is not necessarily behaviorally sound. The problem is that even though the short-term fix gets the morning up and running, the child with FXS becomes accustomed to the adjustment and the next morning demands it as a way to gain prediction and preserve sameness. This may not be significant in isolation, but consider the fact that if every day the system readjusts to “keep the lid on”, the entire morning routine is no longer a routine, but an opportunity for the child with FXS to become more confused and frustrated.

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 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 in the morning.

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

back up 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, and a consistent morning routine was reestablished. 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 due to the fact that they were able to affect a positive change. They also knew they had a back up plan that would preclude a negative outcome. This plan also provided the child with FXS with a predictable routine, which reduced his level of anxiety as the family system operated in a consistent and predictable 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 the aberrant behavior.