



Oppositional... Or Merely Anxious?

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.

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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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The Adolescents and Adults Project


Editor's Note: "Beyond the I.D.E.A.—The Adolescents and Adults Project" is a new venture from the NFXF that will, among many things, result in the creation of user-friendly educational and other resources designed with parents, doctors, therapists, group home staff and employers in mind. Interested readers are encouraged to contribute to the project in any way that suits them—financially, with their expertise, and/or with suggestions and questions. The report below summarizes a session at the 9th International Fragile X Conference that was devoted to the project. The session leaders were Robert Miller, NFXF executive director, John Harrigan, parent and NFXF president, Phil & Barbara Porterfield, parents and contacts for West Virginia.

This session at the 9th International Fragile X Conference in Washington, D.C. provided an opportunity for parents to tell the session leaders what they, as parents, need from the NFXF to better help their adolescent and adult children become and continue to be self-sufficient and productive citizens. Approximately 40 family members attended the session. Their comments, suggestions and requests are summarized below. The Adolescents and Adults Project team, as well as the NFXF staff, will evaluate all of these ideas and incorporate them into our materials and planning process.

- Focus on things that make a difference in fragile X, for example: aggression. What can be done to prevent young men and women with fragile X from developing aggressive behavior?
- Build an early-on interest in a vocation, including more pre-vocational training ideas.
- Provide factual, basic information regarding the transition from school to adult services. For example: SSI, in-home services, Medicaid, residential services and employment opportunities.
- Provide training for government officials who make decisions affecting the lives of persons with fragile X, including police and fire.
- Write about the pros and cons of guardianship.
- Share more success stories.
- Provide more help to those diagnosed with fragile X late in life.
- Develop a knowledge base that includes specialized financial services for those affected by fragile X.
- Clarify federal services versus state-based services, including "hidden" services.
- Provide state-by-state comparisons of services.
- Develop the National Fragile X Foundation's affiliated resource groups and parent contacts so that they may better help parents identify services specific to their state.
- Develop ways for parents to impact the poor quality of many group homes.
- Research and educate regarding how to develop and maintain social skills for children and adults with fragile X.
- Emphasize that teaching self-help skills early in life leads to independence later in life.
- Talk more about private services such as religious institutions. 

BRADEN ON BEHAVIOR

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If we provide them with a way to communicate distress without acting out, we can help release them from feelings of guilt and embarrassment associated with a behavioral reaction. This kind of behavioral support helps the child to gain control of and ultimately manage his own behavior. 

REFERENCES

- Cohen, I. L. (1995). *A theoretical analysis of the role of hyperarousal in the learning and behavior of fragile X males. Mental Retardation Dev Disabilities Res Rev* 1:286-291.
- Miller, L. J., D. N. McIntosh, et al. (1999). *Electrodermal responses to sensory stimuli in individuals with fragile X syndrome: a preliminary report. Am J Med Genet* 83(4): 268-79.