



## When Disappearing Acts Are A Good Thing

About a month ago a parent of two children with FXS, Arlene Cohen, suggested that I write about how individuals with FXS remove themselves from stimulating situations in order to allow for time alone and the self-preservation that flows from it.

Coincidentally, shortly after I received Arlene's request, I attended a family wedding where I had three days to observe the behavior of a family member named Tim who has FXS. As

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you can imagine, all of the festivities made things rather hectic. Even though Tim enjoyed most of the wedding weekend, we frequently found ourselves asking, "Where's Tim?" After looking around, we would find him in a bedroom watching *Wheel of Fortune* or an old sitcom, happy as a clam. What was behind his retreat? His need for a break from the noise

and chaos—happy though it was—in order to regroup and calm himself. Invariably, he would emerge comforted and relaxed.

This is a common occurrence. The fact that people with FXS can self-advocate in this way is compelling. The process of recognizing when one's own sensory system can no longer tolerate a certain level of input is called regulation. It is a skill that we actively teach younger children with FXS. The process of teaching the child how to recognize the signs of hyperarousal can take a long time. Tracy Stackhouse, OTR, often designs programs to teach regulation. Most of the work comes from teaching the child to recognize when he or she is overwhelmed and then apply strategies to deal with those needs.

It is not at all uncommon for these individuals to go through a "Now you see me now you don't" staging. The person with FXS may be the life of the party, expending a great deal of energy to be so, and then suddenly disappears without bravado or attention drawn to himself. The disappearance might last three minutes or half an hour—it is as if the individual knows exactly how long he needs to get centered before returning. When this process is prematurely interrupted, the outcome can be very negative.


Sometimes, when the person with FXS removes himself from an activity that is arousing and in many ways exciting, the caregiver feels obliged to engage him in order to ensure his participation. In these instances, the caregiver's need to include the person with FXS trumps the preference that the person is communicating—to simply be alone for a while. As this interchange becomes more direct and confrontational, the person with FXS becomes increasingly resolute and oppositional, and a negative outcome often results.

When the person with FXS is younger and less capable of self-regulation, loud noises and busy environments often cause behavioral excesses, aggression and non-compliance. The function of the behavior is to show protest and discomfort. The child soon learns that when he demonstrates aberrant behaviors that simply cannot be ignored, the adults remove him from the situation. The result is the same as is the practice of self-removal, but the means to achieving that end is less than optimal. When the person is able to remove himself independently, of his own accord and on his own terms, the result is much more rewarding for all parties.

As has been discussed in prior columns, behavior can often be misunderstood and punished because the parent or caregiver does not recognize its function. Looking behind the behavior to what it is attempting to communicate and achieve is paramount to successful programming.

The decision of a person to remove him- or herself from a difficult situation in order to avoid a negative outcome is remarkably self-actualizing. In the interest of self-preservation, the child with FXS is able to avoid an embarrassing experience and thus gain a healthy measure of independence. It is a skill, like all skills, that benefits from the continued practice that is encouraged by the significant adults in a child's life.

The next time your child attempts to avoid an over-stimulating activity, remember that he just may be attempting to regulate his reaction before he becomes so hyperaroused he cannot properly control his behavior. There will be time to

desensitize this reaction while providing appropriate supports in the future. Allowing him to express protest in an adaptive way can become a measure of independence and a foundation on which other skills can be built. 


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## FROM THE PRESIDENT

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Of course, the NFXF will want to tackle all of these problems and more! They are all fundamental to our mission of enriching lives, raising awareness and advancing research on behalf of the Fragile X community. But all this takes money—a lot of money. This month you will be getting requests to donate in support of all the foundation activities mentioned, and much more. I know the economy is tenuous. But the needs—and accomplishments, and goals—of your


foundation are great, the opportunities are here, and the work is more important than ever. Please be generous in your support of the foundation that works so hard on your behalf. It WILL make a difference! 

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## FROM THE EXECUTIVE DIRECTOR

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- Research is advancing rapidly and the promise of powerful new treatments is real. The NFXF-initiated Fragile X Clinical & Research Consortium will be in the forefront of seeing that the necessary studies take place, in the shortest time possible, and that as new treatments are proven safe and effective, they benefit ALL families. (See cover story on page 4.)
- The push for newborn screening is gaining traction and will increasingly inform us about how to provide treatment and services to very young children.
- The largest-ever survey of families impacted by Fragile X is beginning to pay dividends in our understanding of the specific challenges facing them.
- Adults with fragile X syndrome and other intellectual disabilities will increasingly benefit from the work of the NFXF-founded Collaboration to Promote Self-Determination. (See article next issue.)

Yes, even heading into our 25th year, it feels ever and again as if our work has just begun. Please help The National Fragile X Foundation ensure that every family benefits from the progress we are making on so many different fronts. You can do so by giving to the NFXF Annual Fund. (The appeal should be arriving in your mailbox soon if it hasn't already—or else just use the remit envelope tucked into this issue of your journal.) Your entire donation is tax-deductible, and please never hesitate to contact me to talk about how your gift will be used. I never grow tired of discussing how your involvement and contributions to the foundation benefit the entire Fragile X community. 

*Robert Miller has been executive director of The National Fragile X Foundation since 1999. Email: [RobMiller@FragileX.org](mailto:RobMiller@FragileX.org)*