



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 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 persevere 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.

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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

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Clinic at the Emory University School of Medicine. The program has been the dream of Dr. Stephen Warren, a member of the team that discovered the FMR1 gene in 1991. Stephen is a member of our scientific and clinical advisory committee.


Long a leader in the Fragile X research community, Emory now joins the ranks of the very few full-service, multi-disciplinary diagnostic and treatment centers for Fragile X in the country, and, indeed, the world. To top off our weekend, later that day I joined fellow board members Jeffrey Cohen, Bill Parker, Arlene Cohen, and consultant Serena Lowe at the Centers for Disease Control to collaborate on the development of the first ever National Fragile X Public Health Program funded by Congress in this year's budget. (See Public Policy Update on page 6)

All of the items mentioned above require effort, organization, staff, and money. Much of it is possible due to the success of our recent annual fund campaign. For those of you who contributed—thank you! We have again exceeded our goal and are approaching \$155,000 as we go to press.

Our budget for 2005 is just over \$1 million—all of it privately raised.

We can and need to do more in terms of fundraising. If any of you can help—in small ways or large—there's no time like now. If your resource group hasn't done a fundraiser for The NFXF in a while—or ever—there's no time like now. Contact Linda Sorensen, our development and membership coordinator. She's looking forward to hearing from you—New York, L.A., Houston, Seattle, St. Louis, Miami, and all points in between! We are all in this together. This is your foundation.

I am proud of how far we have come, but not at all complacent. There is so much more to do. I would like to thank the entire board for their incredible work at the strategic planning session in Atlanta.


Now let's get it done, together. 

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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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The guiding principle for parents is to remember that teachers and parents are on the same team with the same overall goal—creating and implementing an education plan that works for the child. If team members can keep in mind that what gets done for the kid is more important than who does what, the process will work better for everyone. 

Steve McKee is vice-president of The National Fragile X Foundation Board of Directors and serves as chair of its awareness committee.

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This article series originally ran in Arc InSight, a magazine focused on children and adults with special needs.