



## “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 quite common.

Why would hearing “Happy Birthday” provoke such a strong reaction?

*Even something as innocuous as a casual compliment can result in a behavioral episode for a child who cannot tolerate being in the limelight.*

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 how 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 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 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 the most 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 for release of the anger is usually the mother. The anxious reaction escalates into a fight-or-flight scenario, 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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