

Braden on Behavior

Gaining Independence Ways to Foster Independence

I am often asked by parents to forecast how well their child will succeed later in life. They ask my opinion about their child's ability to live independently, marry, hold a job or go to college. Of course, the outcome is related to the impact of his or her genetic condition, emotional status, cognitive ability, family dynamics and environmental support. Offering an answer is almost impossible because the human potential far surpasses my ability to predict future success with any kind of accuracy.

It is interesting, however, after spending many years in this field, to follow the changes in individuals with FXS from toddler to adulthood. Looking at the lives of many who are now adults, it is clear that there are a number of factors that seem to predict successful independence later in life. After interviewing a number of adults with FXS, these key factors were identified to play a significant role in promoting independence.

- **Encourage participation in a variety of experiences within their home communities**

These experiences can include going out to dinner, visiting relatives, attending family gatherings, traveling with the immediate or extended family, and spending time in unfamiliar settings such as camps, school functions and sports events. These encounters allow for more support from family members so that the experience is less frightening. As the child becomes more comfortable, the family supports can be faded and replaced with friends, camp counselors or teachers. Many of these experiences require decision making even if as simple as making a choice of what to order at a restaurant. This process is an important one because it helps reinforce spontaneous participation. If not addressed, it can later contribute to peer alienation and exclusion of the person with FXS.

- **Encourage participation in small groups such as girl/boy scouts, lessons, church groups or clubs**

This can be especially challenging because many younger children with FXS are socially shy and tend to avoid group activities especially at the outset. When the format, participants and environment are novel, it is especially difficult. It is easy to give in to the tantrum, defiance and fear, by acquiescing. Just remember that the longer the avoidance is reinforced (not requiring the participation) the longer it will take to build back the confidence necessary to overcome the social fear. There are a number of programs that provide an age appropriate "buddy" or a parallel activity for people with special needs. Having a sibling participate in a parallel activity can also provide the support necessary to take the first step. This is particularly important

because it forms a foundation for membership, which becomes an important life skill that will transcend into adult routine.

- **Encourage the development of interests to create “common denominators” that make the person with FXS a more viable social partner**

Many of the adults surveyed spoke about how they became interested in sports, collections, cooking, sports statistics, music and pop celebrities. These interests lead to creating a connection with others their age. For example, knowing a lot about professional football teams, players and rankings is always a good conversation starter. As a matter of fact, people with FXS can actually talk about these areas like experts and in many ways garner an elevated status with their peers.

- **Require accountability for simple tasks, chores or making a social plan**

Building responsibility and stamina can be difficult for those with FXS. As a matter of fact, a number of the adults surveyed reported difficulty staying focused long enough to complete a job task. Gaining stamina to work a full day was something they had to work hard to ascertain. Holding a younger child responsible for household chores can be the first step. Making sure the task is manageable and one that can be done independently is important. As each step of the chore is taught and then expected to be completed independently (no help from parents) it can be linked to a series of tasks to complete an entire job. Learning to follow through is very difficult and requires multiple trials in order to automatically generate a consistent response. Taking telephone messages and returning telephone calls to set a social plan can also be difficult and sometimes frustrating. This life skill is far-reaching and noted by many as difficult even as adults.

- **Encourage age appropriate dress, grooming and personal hygiene**

According to the adults surveyed, having to discuss hygiene often resulted in negative feelings. Most of the adults surveyed understood after many difficult conversations that being well groomed played a large part in their social acceptance. Also, understanding how dressing in favorite clothes that might not be age appropriate (wearing a Disney Princess sweatshirt when you are 20 years old) can be the target for someone who is delayed or socially strange. These factors, although difficult to address, are critical to acceptance by typical peers and are necessary to demonstrate in the world of work.

Often these topics are the center of group therapy when teaching social skills. The group dynamics can be helpful in creating allies in the quest to follow social standards. Discussing it in a group seems less judgmental or embarrassing and can prompt more honest feedback.

Conclusion

When it is all said and done, this job of encouraging independence can be daunting. It is encouraging, however to watch the progression from dependence to independence. A number of the adults surveyed remember being angry at their parents for expecting them to go places they disliked, especially unfamiliar places or restaurants that were noisy and required a long wait. This is so powerful because this insight comes from those with FXS who have overcome their fears and are now living independent lives. Clearly, a few accommodations can make these experiences more palpable and less anxiety provoking. The accommodations will allow the child to participate. Simply avoiding an unpleasant or difficult situation will not teach your child independence.

The bottom line is that in retrospect, these adults who have become independent are advising parents to continue to include their children in these activities even when it is difficult. They have experienced positive results and feel that learning these lessons when they were younger has made them more comfortable and have provided them with the tools to become independent. Each of them shared as many challenges and setbacks as success stories. What seemed to shine through was their resilience to be able to problem solve their difficulties and ultimately become more independent.

Making the decision to foster and then expect independence causes parents great trepidation. The relentless angst leaves the parent feeling both overprotective and derelict all at the same time. It is hard to recognize what is "normal" given the challenges facing each person with FXS. There is a great deal of variance among those affected by FXS, and so is the span of ability to function independently varies. Supporting your child to do as much independently as possible, no matter what level of function, will promote self-determination in the long run. Each day brings new challenges and natural opportunities to teach competence and in turn self-reliance; something we all want and need.

Braden on Behavior 5-09 Avoidance Comes In All Shapes and Sizes

I have written a number of articles about the function of avoidance and its connection with anxiety. This has been a topic of discussion in many behavioral articles because it is so prevalent in the FX population. Often, avoidance is linked with aggressive behavior especially in those who are more impacted by the FX gene and those who carry the burden of significant anxiety. The fact that they are unable to cognitively mitigate the feeling of being anxious causes them to respond to their anxiety in an aggressive manner just to avoid the feeling.

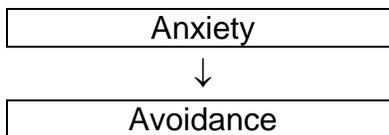
This article examines the issue of avoidance and posits a variety of ways avoidance is manifested throughout the range of affectedness. Avoidance does in fact serve the purpose of escape or prolonging the inevitable. Usually the individual with FXS avoids something that is novel and unfamiliar or uncomfortable. Not having prior experience with a specific issue, person or activity becomes so aversive it is difficult to coax cooperation. The level of affectedness dictates the level of sophistication of the response. For example, a girl with FXS may be afraid to initiate a telephone call. She will choose to call at a time when she knows the individual she is calling is away from home so that she can leave a message and not have to talk directly to a person. It may be inevitable that she will eventually receive a call back from the message she left, but it is not her immediate concern. The motivation is to avoid the contact just as a male with more significant impact may hit someone to avoid a specific event. That is why there is much lament and shame after the behavioral episode is over.

The avoidance behavior can range from physical aggression, shyness, exaggerating, excuse making, lying, or physical absence. Understanding how these behaviors are linked to avoidance has been extensively explored with those individuals who are more significantly affected because the behaviors are more overt and dangerous than other behaviors. It is, however, just as important to understand how other less overt behaviors become coping mechanisms for those less affected by the gene. Providing an understanding tied with more adaptive strategies is essential to their ability to function and gain access to a less restrictive community.

These avoidance behaviors can be so subtle, that the significance is lost. There are times that the excuse making can become so habituated that those hearing the excuses lose perspective and regard the person making them as dishonest and never to be trusted. Avoidance transcends from a manifestation of anxiety into a character flaw innate in their personality. This is not true for those who have simply engaged in these behaviors as a way to deal with their fear and avoid feeling anxious. Because the behavior is subtler and more complicated, it can be mislabeled concealing it from being targeted as a behavior requiring intervention.

Many individuals with FXS avoid disappointing others around them. This creates such intense feelings that the need to avoid overrides any concern about the consequences that may follow. For example, one might disregard rules that lying and exaggerations are wrong because the need to please someone is stronger. The intensity of the feelings associated with disappointing others drives the behavior. It is not unusual to be consulted about individuals with FXS who have made purchases for friends using family credit cards or have taken things from the family home in order to keep a friend. There is a myriad of outcomes that can be a byproduct of this behavior. In many ways, although important to remediate aggressive behavior, the more subtle attempts to avoid something unpleasant has more far-reaching consequences. It is not uncommon for females with FXS to become so anxious that they are unable to leave their homes, participate in social events, drive, attend school or even eat or sleep. The end result can be just as harmful and ultimately must be resolved.

The chart below highlights the behavioral manifestation of anxiety



| Overt | Subtle/Less Overt |
|--|---|
| <ul style="list-style-type: none"> ● Hitting others ● Self abuse ● Running ● Throwing things ● Destroying property ● Cursing/yelling, etc. ● Crying ● Refusals | <ul style="list-style-type: none"> ● Lying ● Making excuses ● Exaggerating ● Hiding ● Staying home (agoraphobic) ● Somatisizing ● Withdrawal |

The essential difference between these two types of responses is that one (overt behaviors) requires the assistance from the environment or another person to provide the reprieve from the situation that is creating the anxiety. The remedy is simple because it is based on teaching the individual with FXS how to show and talk about the anxiety. Providing alternative, replacement behaviors is the last step in the process of remediation. Once the person with FXS accesses more acceptable ways to deal with anxiety, it is easy to teach replacement behaviors that will garner a more positive outcome.

The less overt responses become much harder to modify because they are essentially more socially appropriate and harder to target with immediate certainty. For example, hiding from unpleasant or uncomfortable experiences is much easier to ignore than is biting one's arm when uncomfortable. It is literally a case of the squeaky wheel getting the grease. It is also more difficult to link the behavior with the avoidance function in the case of the less overt behaviors. In addition, the person with FXS has learned how to incorporate the behaviors into their personal repertoire, which tends to be accepted as a character flaw, which allows for more slack to be cut. It is often more difficult for the individual to accept the remedial therapy, because it is perceived to be intrusive. The individual may have a higher level of skill development and therefore uses more subtle ways to fight the intervention, replacing one avoidance behavior with another until the pressure to change is removed.

The problem will not be solved in this article, but it is important to paint the avoidance behaviors with a broader brush, including some of the less overt behaviors. The need to understand the function of these behaviors whether it is the overt or less overt varieties is critical in the management and remediation of avoidance.

Braden on Behavior Oh, that Sense of Humor

Much has been written about the illustrious sense of humor demonstrated by males with FXS. The timing and spontaneity of their responses often comes so naturally that they could succeed as stand up comedians. Recently, I was reminded of how easy it is to get caught off guard by the humor when trying to redirect a behavior. One's first inclination is to laugh which is obviously not an appropriate response, but easy to compromise.

Because the comments are often so cleverly delivered, the engagement is effortless and usually results in a pleasurable interaction. Many times the humor is indigenous to a personality style and ultimately results in friendships and acceptance from others. In other words, it is a characteristic that serves them well and is quickly integrated into their response style.

Laughing at a comment that is made in response to a directive gives the person with FXS a mixed message and may reinforce an inappropriate behavior. Parents can also be conflicted by this phenomenon. When the child follows a redirection with a clever barb, the infraction can be camouflaged by the humorous comment, permitting the behavior to go unchecked. The behavioral remedy is compromised by the inclination to laugh and be distracted.

The sense of humor has a positive affect because there are often opportunities to use it to enhance social interaction and to bring enjoyment to the family. Growing the humor and finding ways to make it an essential component of a relationship should be the focus. Encouraging the person with FXS to deliver jokes, is a good way to support the prowess in an adaptive way.

Another similar behavior that manifests in a parallel way, is that of borrowing lines or scripts from cartoons, video games and movies. These phrases can be infused into the conversation in a way that is seamless. The phrases flow naturally which makes it more difficult to detect, especially when inappropriate. Males with FXS often enjoy watching superheroes because they can identify with the heroes as strong and brave; attributes that are especially appealing. These phrases can be used in a way that can be threatening and out of place. For example, walking up to a stranger in Wal-Mart, holding up a fist and saying, "I'm gonna pound you" is not a good way to greet someone. Even though family members tolerate this behavior at home, when demonstrated in public it can have devastating effects. Teaching a replacement behavior such as a greeting or offering an interesting remark can generate a more positive outcome in a variety of environments.

If we analyze this from the perspective of one with FXS, the perplexity becomes even more evident. The ability to make others laugh bodes well for acceptance

and reinforcement from others. The reaction from others can bring great pride and happiness, especially when so many other tasks and skills are difficult to achieve. This prowess levels the playing field and puts a positive spin on the level of positive interaction with others. The difficulty arises when it is necessary to discern in what context and when the humor is appropriate. If people laugh regardless of the context or timing, it makes discernment impossible which often results in wrongful doing. What a dilemma for the one with FXS. On the one hand, the ability to make others laugh brings immediate notoriety and garners positive reaction but collapses under certain circumstances. To make it more confounding, the humorous comments bring different responses based on environment and people.

The best solution to support the person with FXS is by carefully monitoring your reaction to the humor or borrowed scripts. Even though the comments are often clever and funny, be more cautious in your evaluation and when the humor is not appropriate, don't laugh but rather redirect a better response. In order to help the person with FXS learn to distinguish the difference between when the remark is appropriate and when it is not, it is our responsibility as the adults in their world to begin at an early age, to reinforce (laugh or respond in an positive way) only those times when the remark is appropriate to the situation. In addition, we can teach them a hand signal or catch word, which will enable them to interrupt a phrase, comment or line so that they can be more socially compliant in a public venue when teaching a more adaptive response is more difficult.

The sense of humor is a precious gift and one that many of us have come to adore. Let's be mindful of how this attribute can be a conduit to better social engagement and acceptance by responding in a positive way only when appropriate and redirecting a different response when it is not.