



Five Ways to Foster Independence

I am often asked by parents to forecast how well their child will succeed later in life. They wonder about their child's ability to live independently, marry, hold a job or go to college. Every person's outcome is related to the impact of his or her genetic condition, emotional status, cognitive ability, family dynamics and environmental support, but it is almost impossible to accurately predict any given individual's future success. The happy fact is that human potential far surpasses any predictive ability I have as a psychologist.

However, after spending many years following individuals with FXS from toddler to adulthood and then interviewing many of them as adults, it is clear to me that certain factors such as early experiences and parental direction do *help* predict successful independence later in life. Here are five of them.

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 initial support from family members to help make the experience 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 as simple as choosing what to order in a restaurant. This process is important because it helps reinforce spontaneous participation. Without such experiences, children are less capable of social interaction, resulting in peer alienation and exclusion.

PARTICIPATION IN SMALL GROUPS SUCH AS GIRL/BOY SCOUTS, LESSONS, CHURCH GROUPS OR CLUBS

This can be challenging because many younger children with FXS are shy and tend to avoid group activities. It is especially difficult for them when the format, participants and

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environment are novel. In such situations, it is easy to give in to a child's tantrum, defiance and fear. Just remember that the longer the avoidance is reinforced (not requiring your child's participation) the longer it will take for him or her to build the confidence necessary to overcome 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 for a child to take the first step. Small-group participation forms a foundation for the experience of membership, which becomes a critical skill in adult life.

DEVELOPMENT OF INTERESTS TO CREATE "COMMON DENOMINATORS" THAT MAKE THE PERSON WITH FXS A MORE VIABLE SOCIAL PARTNER

Many of the adults I surveyed spoke about how they became interested in sports, collections, cooking, music and pop celebrities. These interests led to connections 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, with their generally excellent recall and imitative skills, people with FXS can often talk about these topics like experts and thus garner an elevated status with their peers.

REQUIRING ACCOUNTABILITY FOR SIMPLE TASKS, CHORES OR MAKING SOCIAL PLANS

Building responsibility and stamina can be difficult for those with FXS. Many of the adults I surveyed reported difficulty

staying focused long enough to complete a job task. Gaining the emotional and physical stamina to work a full day was something they had to work hard to attain.

For parents, holding your young child responsible for household chores can be an important first step. Just make sure the task is manageable and can be done independently. As each step of the chore is taught and then expected to be completed independently (with 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, requiring multiple trials before generating 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 in adulthood.

ENCOURAGING AGE-APPROPRIATE DRESS, GROOMING AND PERSONAL HYGIENE

According to the adults surveyed, having to discuss hygiene often resulted in negative feelings, though most of them understood after many difficult conversations that being well-groomed played a large part in their social acceptance. Dressing in favorite clothes that might not be age-appropriate (e.g. wearing a Disney Princess sweatshirt when one is 20 years old) can invite ridicule. Understanding that is an important developmental step, not only for acceptance by typical peers, but also for establishing credibility in the world of work.

These social skills topics can be central to group therapy. The group dynamics can help create allies who collaborate in the quest to follow social standards. Discussing it in a group seems less judgmental or embarrassing and can prompt more honest feedback.

CONCLUSION


The task of attaining independence can be daunting. It is encouraging, however, to watch the progression from dependence to independence. Many adults I have 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 insight is powerful because it comes from those with FXS who have overcome their fears and are now living independent lives.

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, so the range of ability to function independently varies.

Clearly, a few accommodations can make these experiences more palatable and less anxiety-provoking. Such accommodations can make the difference in coaxing a child into participating. Simply avoiding an unpleasant or difficult situation will not teach your child independence.

The bottom line is that in retrospect, 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 made them more comfortable and provided them with the tools to become independent. Although they tend to share as many challenges and setbacks as success stories, what shines through is their resilience and capacity 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 parents feeling both overprotective and derelict 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, so the range of ability to function independently varies. Supporting your child to do as much independently as possible, no matter what his or her level of function, will promote self-determination in the long run. Each day brings new challenges and natural opportunities to teach competence and self-reliance—something we all want and need. 

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