

Building Social Supports: A Guide for Parents

Over the past decade, I have had the pleasure of developing supportive programs for families impacted by fragile X syndrome (FXS). Individuals with FXS often have difficulty establishing meaningful friendships. Limited social skills, social anxiety and an often narrow range of interests contribute to these difficulties. Various interventions can increase the social network of those with FXS. The following ideas are provided to help such individuals and their families.

BUILDING EARLY SOCIAL SKILLS

Parents are in a unique position to assess their child's social strengths, weaknesses and interests and to provide "real life" intervention across childhood. If there is a second child in the home, the child with FXS may have a play partner with whom a variety of social skills may be rehearsed. Basic social skills such as greetings, taking turns, making requests, and simple negotiation can be rehearsed at home, thereby increasing the opportunities for children with FXS to generalize skills to peers they encounter in the greater community.

Parents may have to be more systematic in their approach to fostering friendships for their children affected by FXS, but the earlier that social connections occur and are made a priority, the more success a child can have. Parents may have

children, those with FXS benefit from a range of friendships, from acquaintances to best buddies. In addition, when choosing supportive interventions, parents need to consider individual factors such as the degree of social anxiety, social interest, behavioral perseveration, and frequency of outburst behavior. It is best to schedule only one friend over at a time, to keep the sensory stimulation and social demands at a tolerable level.



MAKING FRIENDS

Most of the adults with FXS whom I work with have limited sources for developing lasting friendships. This is true for both genders. For most people, friendships are the outcome of mutual interests, proximity, shared experiences, and similar values or perspectives. This is no different for persons with developmental disabilities, but often it seems that existing friendships are based more on proximity than on shared interests. Children often develop friendships based on familiarity, due to mutual placement in special education or inclusion programs.

Friendships can often be fostered through a "circle of friends" approach (Perske, 1989; Newton and Wilson, 2003), in which a teacher or other adult at school tries to identify supportive peers who are interested in befriending other students in the school. Interested student volunteers are chosen to befriend children who do not have many social supports.

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to make an extra effort to reach out to other parents in the neighborhood or school setting. They may need to advocate for their child by explaining the nature of FXS and its core symptoms to other parents. By fostering relationships with other parents, it may be easier and more comfortable to get children together. Peers are more accepting of special

needs during the younger years. When relationships are established early, they can pave the way for social support in the future.

It is important to keep in mind that with respect to friendships, quality is more important than quantity. Like other

The role for the peer may be varied, but can include social greetings at the start of the day, walking with an individual between classes, or sharing a table at lunch. Having friends without special needs is particularly important during late elementary school and the transition to middle school, since this is when teasing and bullying intensifies. Bullying may take the form of social exclusion and isolation. Peers can support and protect special needs students from this type of bullying simply by demonstrating social acceptance.

Friendships are also developed through participation in vocational education programs, religious and volunteer organizations, and through supportive or competitive employment opportunities. Religious organizations often have youth groups that create a safe outlet for children with special needs. Regular group activities may be provided through young adulthood. I know some young adults with FXS who have participated in several mission trips. These opportunities have fostered social connections along with pride in helping others less fortunate.

ENHANCING INTERESTS

It is important for families to nurture interests that lead to social opportunity. For example, following a local sports team creates opportunities for conversational exchange, for building collections (hats, shirts, cards), and for participation in a social event (attending a game with a friend). The Special Olympics organization (www.specialolympics.org) provides opportunities across the lifespan for team participation and the making of new friends. By fostering the growth of specific interests and by helping to expand the range of interests of children with special needs, such organizations can increase children's participation in community events and activities.

One client's interest in hiking led her to participate in a hiking club. While she was initially hesitant, the group held various outings including an overnight camping trip! Although it was not a group designed for adults with special needs, it became a safe haven for this woman with FXS. As she began to trust the group, she was honest with other members about her limitations in driving in heavy traffic. The group figured out a way to accommodate these issues so that she could more readily participate in the outings. She took great pleasure in taking pictures while hiking to share with friends and acquaintances. Her employer showed support for her achievements by displaying a collection of her photographs. These positive social experiences were incredibly important for

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from all over the world to come together and learn from one another through young adult panels and family-friendly presentations.

THERAPEUTIC INTERVENTIONS

Social Skills Groups—Participation in a social support group can provide an opportunity for developing social skills across the lifespan. Social skill building groups can be provided at school, through a regional program, or within the private sector. Group size is important: there must be enough participants so that no one experiences excessive social pressure, but not so many that social anxiety and sensory stimulation increase. Groups are most successful when they provide predictable structure and expectations, including consistent participants.

Individuals with FXS can benefit from social groups that include members with a variety of developmental concerns. There is strength in having some diversity in skill levels. It provides an opportunity for those with stronger skills to mentor others who are less socially advanced.

Approximately four years ago, we offered a grant-funded social group at Children's Hospital in Denver to young women with FXS. The group met monthly for one and a half hours with two psychologist facilitators and four regular participants who ranged in age from 18-30, and functioned at a variety of ability levels. Initially, a craft activity was necessary to provide

this young woman, who could still vividly recall situations of social rejection she experienced in secondary school.

LEARNING FROM OTHERS

People with fragile X syndrome are often interested in meeting other individuals like themselves. Obviously this can be best achieved in areas of the country where there is a strong FXS support group or clinic. The biennial International Fragile X Conference (St. Louis in 2008) provides additional opportunities for families

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something for the participants to do while they got together. Conversation was superficial and hard to follow. The young women enjoyed snacks, drinks, and chatting together. The group leaders planned activities and also had occasional phone calls with participants or their parents.

As time passed, the women began to reach out to each other by phone or email in between group sessions. The art activity became less important since members began to initiate discussions about relationships with family members and others. Additional frequent topics included difficulties with work, symptoms of FXS, anxiety and depression. Members learned to turn to one another for advice. In essence, the group evolved to provide the level of support each member sought. Individuals varied in terms of self-disclosure, but everyone participated in and valued the group. As the young women began to have more success in their own lives outside the group, the need for the group and its relative priority in some of their lives changed as well.

Individual psychotherapy or behavioral therapy—While the term “psychotherapy” is often reserved for insight-oriented mental health support for individuals interested in interpersonal change, the act of meeting with a mental health therapist for the purpose of support can be helpful for those with FXS. It can be a vehicle for reviewing social situations, making a plan, and then implementing new social skills. Once skills are learned in a one-to-one setting, they can be applied elsewhere.

Experience with FXS is not a prerequisite for the therapist, but he or she would clearly benefit from learning more about it. People with FXS have a variety of mood, attention, impulse control, anxiety, and regulatory deficits that can lead to behavior problems and interfere with social adjustment. Often these individuals need an ally to translate their underlying symptoms and help explain the triggers to behavioral and social difficulties. Involvement with a therapist can reduce anxiety because the individual feels more supported.

Visual Supports—Visual cues and strategies can help make therapy more concrete. They are very important in reducing the load that is placed into working memory. It is difficult for people with FXS to follow a complex conversation and track verbal information, which many traditional therapies emphasize. Drawing or diagramming a topic as it

is discussed can be very helpful. Not only does it help focus visual attention, it also provides a format for reviewing previous discussions. The therapist does not need to be an artist. Simple stick figures can go far in representing a verbal idea visually and making the conversation more concrete.

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Writing out simple words to go along with key ideas serves to organize memory about the conversation. This technique is equally effective when parents use it to facilitate discussions with their children or when teachers use it to highlight an idea with students. It can be very helpful in diagramming a social situation or rehearsing appropriate ways to respond socially. Paper can be kept in a file for a review of previous sessions or ideas. A dry erase

board is nice because it is more fluid. If a mistake is made (clients often correct drawings), a dry erase board can be edited more easily.

Social scripting—The social anxiety that most individuals with FXS face interferes with their ability to engage in relationship-building activities. Despite the developmental gains that individuals make as they grow older, those with FXS often continue to feel overwhelmed by social interactions. They may have difficulty starting conversations, responding to direct questions, or handling common social situations. On the plus side, they often respond well to social scripting, in which an adult (parents, teacher, therapist), scripts and then rehearses certain interactions. This allows the person with FXS to “memorize” the desired social response, decreasing the likelihood of some other less desirable response.

For example, Frank may convey to his parents that he would like to invite Steve, a peer from school, to go bowling. Despite that he truly wants this to occur, Frank may feel too anxious to ask Steve. A social script can teach him exactly how to approach Steve. It may highlight “when” and “how” so that Frank is more prepared for the encounter. His script may even be written or drawn onto a file card so that Frank

can review it prior to the interaction. He can carry it in a pocket to decrease his relative stress. Even this may not be enough to allow for Frank to make the request.

Since no two people are alike, intervention strategies should be tried and then refined as needed. If Frank is ultimately not able to approach Steve, it should not be considered a failure of intervention. Rather, it is a success because it has provided the information that the level of support was not high enough.

Subsequent strategies might include a familiar adult approaching Steve with Frank, providing proximal support. It may be that the adult needs to initiate the interaction and make the initial request, with Frank providing additional details as he feels comfortable. Frank might prefer to hand Steve a written invitation or with help, perhaps send an email. All of these options allow Frank to enhance his social skills, and with success, to decrease his social anxiety.

Facilitated social interactions—Some individuals with FXS need their interactions with peers to be directly facilitated. This may be particularly true for younger children if they are just starting to have play dates. It may also be true for older children or adults who have had limited social success or who have a history of aggressive behavior patterns. These individuals require supportive scaffolding.

For a play date, it is important to pay attention to structure, organization, and supervision. Structure refers to the specifics of the situation (when, where, what) in concrete terms so that the child knows what to expect. Rather than letting the play unfold, it may be more successful to specify what the children will do. If 6-year-old Joey is having a friend over, what three activities would he like to do? These can be represented using pictures (such as a picture schedule using line drawings or photographs) so that Joey and his friend have a reference point as they progress.

A snack time may be helpful, since snacks are almost always popular with children. Finally, there should be a scheduled timeframe. It is much better to keep the first few play dates too short, with the children wishing for more, rather than to have them too long, with the children pushed beyond their sensory/regulatory capabilities.

There should also be adequate adult supervision. This refers to an active adult in the room who can guide the

process successfully along. It might mean simply sitting on the sidelines, but it could expand to facilitating turn-taking, sharing, or negotiating. For an adult with FXS, a facilitated social interaction might include a structured social event

(baseball game, bowling)

where very similar structure is utilized. A visual schedule may be helpful. It will be useful to review and predict ahead of time what types of behaviors will be expected and what type of events will occur. This may include expectations regarding snacks and vendors, restroom locations, desired social behavior and whether a souvenir will be purchased. By keeping an eye on structure, facilitators can increase the likelihood of success and help

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build ongoing social supports for the future.

Limited social skills, social anxiety and a diminished range of interests often interfere with social adjustment despite a person's desire for social connection. Individuals with FXS often need additional support to create and sustain social relationships within their peer group. ☹

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