

SOCIAL DEVELOPMENT IN MALES WITH FRAGILE X SYNDROME

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PRESCHOOL (3-5 years)

- Highly social: wants to interact; observes others, but usually from a safe distance.
- Initiates social interaction: may greet others, “hi man, hi boy.”
- Environment: easily provokes anxiety resulting in overstimulation. Typical defenses are tantrumming, dropping to the floor, perseverative noises or words, chewing on clothing, mouthing objects, turning head, hiding behind hands, toys, parents leg.
- Arousal system: this system is hypersensitive to sound, lighting, touch and routine. May result in a panicked reaction.

ELEMENTARY SCHOOL (5-12 years)

- Anger and frustration: may now be more aware of differences in ability as compared to typical peers.
- Social awareness: sees and perceives interaction around him and may feel left out. Lacking language skills to express emotional hurt.
- Environment: large rooms (gymnasiums, auditoriums, malls) give too much sensory stimulation – noise becomes a significant source of distraction.
- Nighttime anxiety: fear of going to sleep, may perseverate on related break-ins, TV programming, etc.
- Schedule and routine changes: spontaneous plans, new people, and travel may cause anxious reactions and create panic.
- Reliance on certain individuals for safety and reassurance.
- Lack coping strategies: higher level cognitive functions may not be developed. Negotiating, understanding abstractions, decision making are difficult.
- Poor reasoning skills: sequential deficits result in getting stuck on one point and obsessive tendencies interfere with acceptance.

ADOLESCENTS (13-18 years)

- Male/female attraction and need for sexual contact, hand holding, kissing.
- Sexual experiences may be affected by tactile defensiveness
- Sexual curiosity: embarrassment often caused by social reaction and feedback.
- Masturbation: may be sexually excited, seems to be common at this stage.
- Natural biological urges: developmentally age appropriate.
- Sexual fantasies: enjoys hearing typical peers talk about girlfriends and dating.
- Girls initiating contact, may become too intimidating and overwhelming.

ADULTS (19+)

- Relationships: often unable to maintain a relationship.
- Using the telephone: telephone contact is difficult – forgets to give messages, dislikes returning phone calls, making calls to set a plan or make a date.
- Shuts down emotionally when overwhelmed by the demands of a relationship. Becomes withdrawn and isolated in order to regroup. This is often perceived as rude or inappropriate and self-centered.
- Difficulty reasoning interaction, demonstrating empathy, meeting emotional needs of others.
- Gets over relationship break-ups easily.
- Obsesses about what is said to him by others, forms fantasy relationships.

SOCIAL INTERACTION SKILLS	STRATEGIES
Greetings: this is especially difficult when shaking hands, requiring eye contact, or tolerating any type of touch such as hugs or an arm on a shoulder.	Consistent social skill training is imperative. Use sunglasses first to help desensitize the directness of the interaction, fade the use of sunglasses to clear glass and then eventually to greeting without any visual occlusion.
Initiating and maintaining appropriate conversation.	Redirect conversation, hold up visual cue to "STOP" and return to topic of discussion. Teach rote introductory phrases that can be used to initiate conversations.
Responds appropriately to signs of emotional distress by others in the environment.	Use pictures and practice generating adaptive responses to emotional distress. Use therapeutic materials that teach emotional labeling and identification. All Feelings Are OK, Face It, Face Your Feelings (Center for Applied Psychology)
Refrains from laughing, noise making, and motor excesses during times when anxious.	Teach the individual with Fragile X to replace maladaptive behaviors with self calming strategies. Model deep breathing or blowing out a candle to initiate exhaling instead of laughing.
Refrains from aggressive or violent outbursts whenever embarrassed, complimented or criticized.	Train strategies to replace outburst when agitated. (Taking a walk, listening to music, shooting hoops or leaving the situation).
Adjusts to changes in schedule, routine, personnel, and social circumstances.	Use picture schedules, signal changes by changing pictures, introductions ahead of time, carefully planned transitions.
Practices grooming to include clean, kept hair, brushed teeth, clean mouth and nose area, use of deodorant, clean glasses lenses, and appropriate clothing. Typical peers are very cognizant of these differences and tend to discriminate against those who present as unkept or different.	Use of a pictorial chart with sequence of the grooming activity. Use a check, counter, chip or some tangible marker so that each step of the task has been accounted for and focus can be directed to the next step.

SOCIAL ACCEPTANCE	STRATEGIES
Feeling rejected by typical peers	Develop more opportunities for one to one interaction
Unable to adequately relate socially	Utilize extended family members or older friends to encourage and support social engagement
Behavioral outbursts become more socially debilitating	Discourage participation in anxiety provoking activities, large groups, gymnasiums, close proximity to other people

LANGUAGE DEVIANCES	STRATEGIES
Verbal interaction is difficult	Speech/language, social group therapy
Confused by verbal and social nuances	Utilize visual cues (photographs, video tapes or drawings) whenever possible to illustrate social nuances
Difficulty using verbal skills to express feelings	Process feelings later after negative feelings have subsided
Use third person "he" to talk through the incident.	This makes the discussion less threatening and indirect.

OBSESSIVE AND COMPULSIVE TENDENCIES	STRATEGIES
Perseverative language about the perceived insult or emotional injury	Encourage conversation about the incident and/or obsession
Obsessional thinking of perceived emotional injury	Help develop super powers, fantasies about how a similar incident will be handled the next time, Ex: you could ask X to follow you and watch you, etc.
Oversensitivity to an altercation or disagreement	Referral to a physician to assess efficacy of medication.

SOCIAL SKILLS TRAINING MODEL	
LEVEL I	
Turn Taking with an Adult	
<ul style="list-style-type: none"> • Parent/teacher chooses a toy or activity of high interest • Adult verbally models "my turn" or if the individual is nonverbal, points to self and takes a turn • Adult gives the individual game piece, toy, etc. and says "your turn", pointing to him and shaping the pointing to self 	<ul style="list-style-type: none"> • Individual indicates desired object, toy or activity • Individual waits his turn and imitates the role model • Individual points to himself, picks up toy, game piece and takes a turn
<u>This process continues for at least five exchanges</u>	
Variations: Pegs, lego building, drawing a person (hangman), drawing cards from a deck, passing objects back and forth, etc.	
Turn Taking with Another Child	
<ul style="list-style-type: none"> • Adult acts as facilitator and prompts whenever necessary 	<ul style="list-style-type: none"> • Individuals wait and take turns, pointing or verbalizing when it is their turn

LEVEL II	
Verbal Exchange with an Adult While Developing	
Spontaneously Initiated Verbal Interaction	
<ul style="list-style-type: none"> • Adult gives individual a compliment – “I like your shirt” • Individual repeats – “I like your shirt” 	<ul style="list-style-type: none"> • Individual responds with “thank you” • Adult responds with “thank you”
As the interaction becomes spontaneous and the individual initiates the compliment without prompts from the facilitator, the adult begins the generalization step.	
<p>GENERALIZATION STEP: This step can be facilitated by a visual cue such as pecs, photograph, icon, rebus symbol or sentence strip.</p> <p>Trainer holds up visual cue to prompt a broader array of complimentary statements. For example, picture of a face to prompt facial features, or a sentence strip to cue, “I like your lego space ship”, “I like your drawing,” etc.</p>	

<u>LEVEL III</u>	
Verbal Exchange Using Facts of Already Mastered in Isolation	Personal Information
<ul style="list-style-type: none"> Adult asks (from a list of personal information questions) "Do you have a brother?" "What is his name?" "Do you have a pet?" "Where do you live?" 	<ul style="list-style-type: none"> Individual answers the question and asks the same question
<p>GENERALIZATION STEP: Adult facilitates this interaction between two students and prompts whenever necessary.</p>	

LEVEL IV	
Taking Turns Talking to an Adult	
<p>This level is facilitated by a traveling notebook provided by parents to teacher/therapist. The parent includes information related to an experience, event, book read, movie, trip taken, etc. This information forms the basis for discussion. It is later replaced by a chart that the child fills in and uses in place of a sentence strip.</p>	
<ul style="list-style-type: none"> Adult says "Talk to me" and passes talking stick to the individual. If necessary prompts discussion about an event discussed in the notebook. Adult asks questions related to the information shared and begins to count the number of reciprocal exchanges dealing out cards. 	<ul style="list-style-type: none"> Individual responds with information about a specific event, movie, or experience. Individual responds to the question and offers a reciprocal response. A card is given after each appropriate exchange.
<p>At the end of the discussion, cards are counted and tallied on personal interaction sheets.</p>	
Taking Turns Talking to Another Group Member	
<ul style="list-style-type: none"> Adult facilitates interaction between two individuals within a group milieu Adult begins the discussion with "Talk to (other group member) about your trip to the zoo (or any other event noted in the traveling notebook)" 	<ul style="list-style-type: none"> Members pass the talking stick back and forth. The stick cues the turn and reinforces waiting a turn. Individual responds to other group member, but waits his turn.

LEVEL V	
Taking Turns Talking and Listening	
<p>This level is to reinforce the importance of sharing talking time and listening. Questioning after listening is prompted verbally or with a visual icon or symbol. Formulating questions appropriate to the discussion is also reinforced. The use of cards and the talking stick can also be employed to signal the speaker.</p>	
<ul style="list-style-type: none"> Adult holds up visual icon, current event from a newspaper or presents an idea to be discussed Group member formulates a question about the 	<ul style="list-style-type: none"> Group member responds with appropriate verbal exchange Group member passes talking stick to group member of his choice and listens

subject discussed	<ul style="list-style-type: none"> • Group member answers the questions and listens
<p>Variation: Discussions can be based on newspaper events (can use weekly readers or kids sections of the newspaper), sports events (males with fragile X syndrome usually love sports), contrived scenarios about taking a trip to Disney World, a local amusement park, TV game show, etc.</p>	

Suggested Social Skills Curricula

Teaching Children With Autism to Mind-Read

P. Howlin, S. Baron-Cohen and J. Hadwin
 John Wiley & Sons. 1999
 ISBN)-471-97623-7

What Does It Mean To Me?

C. Faherty
 Future Horizons. 2000
 (817) 277-0727
www.futurehorizons-autism.com

Social skills and pragmatics

Comic Strip Conversations

Carol Gray. Jenison Public Schools.
 Future Horizons. 1994
 (817) 277-0727
www.futurehorizons-autism.com

The New Social Story Book

Jenison High School Students. Ed.: Carol Gray
 Future Horizons. 1994
 (817) 277-0727
www.futurehorizons-autism.com

Navigating the Social World

J. McAfee
 Future Horizons. 2002
 (817) 277-0727
www.futurehorizons-autism.com

The Original Social Story Book

Jenison High School Students. Ed.: Carol Gray
 Future Horizons. 1994
 (817) 277-0727
www.futurehorizons-autism.com