

Managing Behavior

Note: Content here was combined and adapted from original articles and help from Tracy Murnan Stackhouse, Sarah K. Scharfenaker, and members of the NFXF team.

When discussing Fragile X syndrome and behavior, it is important to note that, like every person, the focus should be on the individual. Many behaviors are positive, and it is those behaviors you will see most often, in addition to challenging behaviors.

Behaviors (both positive and negative) are a form of communication. Understanding factors that influence behavior problems can help prevent future challenges.

A proactive approach with appropriate support is important to foster positive outcomes and set up the individual with FXS to succeed in their home, school, or community.

One of the most important things you can do to support an individual with FXS is to start with your own emotional regulation. This might sound simple, but it can be challenging, especially when the behaviors are happening. When you are regulated, your loved one with Fragile X has a better chance of staying calm, learning more easily, and feeling secure. Your calm becomes their calm.

For more personalized support, consider consulting a speech-language pathologist, occupational therapist, or behavior specialist experienced in FXS.

Related Treatment Recommendation

Behavioral Challenges in Fragile X Syndrome

The most common behavioral challenges seen in FXS include those associated with generalized anxiety, social interaction difficulties, ADHD, self-injury, and aggression.

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Anxiety and Social Avoidance

What Anxiety and Social Avoidance Might Look Like: Difficulty with transitions, avoidance of eye contact, resistance to new situations, perseverative (repeated) questions/phrases, and strong reactions to perceived stressors.

Why Anxiety and Social Avoidance Are a Challenge: Anxiety can interfere with learning, social development, and daily routines. Many individuals with Fragile X have difficulty expressing or managing their thoughts, emotions, and reactions, which can lead to meltdowns or withdrawal.

Helpful Strategies

Predictability & Routine: Visual schedules and consistent routines help reduce anxiety about what's coming next, so consider an app like Choiceworks.



An example of a visual schedule. Having a set routine in place and being able

to see it clearly can significantly reduce hyperarousal and free up mental energy.

Thoughtful Introduction: Slowly introduce new people or environments, starting with brief visits or short interactions.

Calming Techniques: Breathing exercises, sensory breaks, or safe spaces for downtime can help the child self-regulate.

Social Stories: Short, personalized stories that clearly and reassuringly explain social situations and expectations.

A few social story resources:

- Social Stories: A collection of free Social Stories from various online resources. (*Source: ABA Educational Resources*)
- Special Education Social Stories: A collection of free social stories developed by Watson Institute consultants designed to teach appropriate behaviors and social skills for children with special needs. See all of their special education resources. (*Source: The Watson Institute*)
- Social Stories for Autistic Children – The Ultimate Guide: A complete guide to social stories, including videos and free downloads. (*Source: Autism Parenting Magazine*)
- Templates for Personalized Teaching Stories: A collection of customizable social stories (Word docs) to personalize with your own pictures to help your child know what to expect in various situations. (*Source: Autism Speaks*)

Age-Specific Strategies for Anxiety and Social Avoidance

These are suggested ages only, you may use these at different ages and stages. Not all strategies may be applicable or of interest to your loved one.

Under 5



Picture books or simple social stories: Use picture books or simple social stories to prep for transitions or new events.

Parallel play: Encourage low-pressure social settings and parallel play — playing nearby or side-by-side but not directly with another child.

Safe zone: Provide a "safe zone" at home or daycare, such as a tent or a beanbag corner.

First-then language: Use first-then language, as in "First math, then snack."

School Age



Visual schedules with first-then language: Continue to use visual schedules and first-then language ("First math, then snack").

Research social situations: Role-play or rehearse social situations before events.

Coping strategies: Teach basic coping strategies and emotion regulation skills, such as “count to 5” or “squeeze a stress ball.”

Self-advocacy skills: Teach and practice self-advocacy skills, such as asking for a break.

Teens & Early 20s



Mood tracking: Use picture-based mood-tracking tools and consider journaling.

Emotion regulation: Reinforce and practice emotion regulation and self-advocacy skills.

Structured social groups: Support structured social groups, such as clubs, therapy groups, or special needs meetups.

Adults

Predictable routines: Create predictable routines with posted daily or weekly calendars.



Activities: Support job or community activities with built-in breaks.

Self-regulation apps: Use self-regulation apps, such as Breathe+, Headspace, or Calm (Apple | Google Play).

Additional Anxiety and Social Avoidance Resources

Strategies for Day-to-Day Life: Daily strategies from the authors' evidence-based practice and knowledge of the neurocognitive development of children with Fragile X syndrome.

Managing Anxiety ... What Works And Why?: Why individuals with Fragile X syndrome are anxious, including strategies for caregivers on how to manage and prevent triggers.

Proactive and Reactive Behavior Management for Your Child: Understand the etiology of behavior related to Fragile X syndrome to create proactive strategies and manage that behavior.

Preparing for the Return to Routine After a Long Break: Tips for Educators, Employers, and Caregivers: Strategies to manage changes in routine and get everyone back to a typical day-to-day routine.

My Child Won’t Answer Questions!: One of our most popular articles provides tried and true strategies to engage with your child with Fragile X syndrome and foster ongoing, simple conversation.

Oppositional or Merely Anxious?: When they refuse to comply and seem to want to manipulate, are they just defiant, or is there something else going on?

Building Social Supports: A Guide for Parents: Individuals with Fragile X syndrome often have difficulty establishing meaningful friendships. Limited social skills, social anxiety, and an often narrow range of interests contribute to these difficulties. Here, we discuss various interventions that can increase their social network.

View all anxiety related articles →

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Sensory Processing Issues

What Sensory Processing Issues Might Look Like: Overreaction or underreaction to sounds, textures, lights, smells, or touch. For example, they may cover their ears, avoid certain fabrics, or be picky eaters.

Why Sensory Processing Issues Are a Challenge: Sensory sensitivities can cause discomfort or distress in everyday environments like school or public spaces, making it hard to participate in daily activities.

Helpful Strategies

Environmental Modifications: Reduce stimuli in home or classroom settings. Examples include noise-canceling headphones, dim lighting, and soft clothing.

Desensitization: Slowly and gently increase exposure to triggering stimuli with positive reinforcement.

Sensory Diet: An occupational therapist (OT) can create a custom plan with regular sensory activities tailored to the child’s needs. Examples include jumping, swinging, and deep pressure. Also read Concept and Use of a Sensory Diet and view our two webinars below:

Watch: The How-Tos of Sensory Diets in Fragile X Syndrome: Learn how a sensory diet is an occupational therapy intervention strategy devised to attain and maintain appropriate daily arousal states.

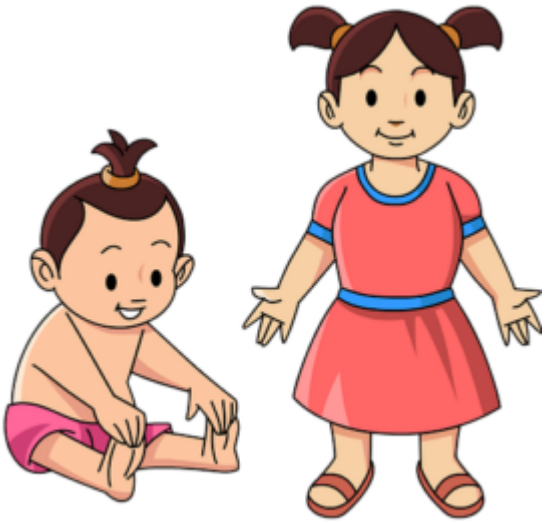
Watch: Hands-on Sensory & Body-Based (Somatic) Self-Regulation for Hyperarousal & Anxiety in FXS: Tracy Stackhouse addresses the struggle of anxiety, hyperarousal, sensory reactivity, and behavior that arise from internal and external overwhelm.

Age-Specific Strategies for Sensory Processing Issues

These are suggested ages only, you may use these at different ages and stages. Not all strategies may be applicable or of interest to your loved one.

Under 5

- **Tactile play:** Provide daily tactile play, such as using sand, rice bins, or playdough.
- **Soft fabrics**: Use soft fabrics and tagless clothing.
- **Deep pressure**: Offer deep pressure via blankets, rolling, or big hugs.
- **Wearable tools**: If needed, you could consider using wearable tools such as Chewelry or “chewable jewelry,” which is designed to provide safe oral sensory input.
- **Sensory diet**: Work with an OT on a sensory diet.





School Age

- **Sensory diet**: Continue to implement a sensory diet.
- **Fidget items**: Allow fidget items and wiggle seats in the classroom.
- **Sensory-safe spaces**: Provide sensory-safe spaces at school and home.
- **Wearable tools**: Continue to use wearable tools like Chewelry if needed.
- **Choice boards:** Create choice boards for preferred sensory breaks.

Teens & Early 20s

- **Self-awareness:** Reinforce self-awareness of sensory needs, for example, “I need my headphones.”
- **Choice boards:** Reinforce helpful tools like choice boards for preferred sensory breaks.
- **Wearable tools:** If needed, consider continuing or introducing wearable tools like Chewelry.





Adults

- **Adjust their environment**: Adjust their workplace or home environment by limiting noise, using soft lighting, and planning downtime.
- **Public space planning**: Support with public space planning, such as carrying sunglasses and earplugs.
- **Self-advocacy skills**: Continue reinforcing self-advocacy skills for asking to step away from overwhelming environments.

Additional Sensory Processing Resources

When Disappearing Acts Are a Good Thing
Marcia Braden on recognizing the signs of hyperarousal in children with Fragile X syndrome, and how and why it often precedes self-removal.

Concept and Use of a Sensory Diet
A treatment that includes activities tailored specifically to each child's or adult's (and their family's) specific sensory processing issues.

View all related sensory processing articles →

Related Treatment Recommendation
Read more

Sensory Processing and Integration Issues in Fragile X Syndrome

Sensory-based hyperarousal is the most prevalent, troubling, and defining characteristic in Fragile X. Learning to manage hyperarousal proactively allows people to grow into themselves, not out of the problem.

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Hyperactivity and Attention Difficulties

What Hyperactivity and Attention Difficulties Might Look Like: Difficulty sitting still, short attention span, impulsivity, and frequent switching between

activities.

Why Hyperactivity and Attention Difficulties Are a Challenge: These behaviors can affect learning and make it hard to follow directions, stay on task, or complete activities — especially in structured settings like classrooms.

Helpful Strategies

Movement Breaks: Schedule short, active breaks to help with focus, such as jumping jacks or stretching. Other examples include heavy work, like moving sports equipment, lifting something heavy, moving furniture around, or carrying a heavy backpack; and vestibular input, like going for a walk, doing wall push-ups, swinging, or using a skateboard. *(Vestibular input is the sensation of any change in the movement or position of the head. Receptors in the inner ear are activated by fluid in the ear canals as you move.)*

Chunking Tasks: Break big tasks into small, manageable steps with visual or verbal cues. Use backward chaining rather than forward chaining. Backward chaining is sharing the expected result and demonstrating the steps in reverse order. Forward chaining uses sequential steps, such as a checklist, to show progress toward the desired result.

Clear, Simple Instructions: Use short, direct language and repeat instructions calmly when needed.

Age-Specific Strategies for Hyperactivity and Attention Difficulties

These are suggested ages only, you may use these at different ages and stages. Not all strategies may be applicable or of interest to your loved one.

Under 5

- **Movement games**: Before seated tasks, use movement games, such as obstacle courses or animal walks. Wiggle seats or balance cushions can also be used for sitting still.
- **Keep it short**: Keep tasks short and interactive.
- **Songs or chants**: Use simple songs or chants to keep focus — for example, a

"clean-up" song for house chores.





School Age

- **Mini-steps:** Break tasks into mini-steps with checklists or visuals.
- **Movement breaks**: Incorporate movement breaks based on the individual's needs. This can be determined when creating the individual's sensory diet.
- **Timers and checklists**: Use timers or checklists for time management.
- **Reward systems**: Use reward systems, such as token boards or sticker charts, for motivation and reinforcement

Teens & Early 20s

- **Timers and checklists**: Reinforce using timers or checklists for time management.
- **Structured activities**: Help build executive function skills through games or structured activities. You use executive functioning skills to manage everyday tasks like making plans, solving problems, and adapting to new situations.
- **Visual organizers**: Use visual organizers for school or job tasks. This could include task planning apps like Google Keep, Todoist, or Trello.





Adults

- **Task planning apps**: Continue to implement task planning apps.
- **Reminders**: Support using reminder systems, timers, and scheduled breaks.
- **Modeling**: Encourage modeling and working alongside a partner for focus-intensive tasks.

Additional Hyperactivity and Attention Difficulties Resources

Executive Function
Executive function refers to mental processes (executive functioning skills) that help you set and carry out goals. What conditions or issues can affect executive function? Can executive function levels improve? (Source: Cleveland Clinic)

Hands-on Sensory & Body-Based (Somatic) Self-Regulation for Hyperarousal & Anxiety in FXS
In this webinar, Tracy Stackhouse, MA, OTR, addresses the topic of individuals with Fragile X syndrome often struggling with anxiety, hyperarousal, sensory reactivity, and behavioral difficulties that arise from internal and external overwhelm.

Hyperarousal in Fragile X Syndrome

Teaching individuals with Fragile X syndrome personal stress-reducing strategies, such as “square breathing,” muscle relaxation techniques, and visualization of tranquil places can help them cope with unavoidable exposures to stimulation. Learn more about this plus other current treatment recommendations.

Go to the treatment recommendation
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Aggression or Self-Injury

Strategies for Addressing Aggressive Behavioral Outbursts in Adolescents and Adults with Fragile X Syndrome

Learn how to minimize aggressive behaviors, plan the steps to take during an incident, and develop steps to take following an incident.

Read

What Aggression or Self-Injury Might Look Like: Hitting, biting, head-banging, or other behaviors directed at oneself or others, often during stress or frustration.

Why Aggression or Self-Injury Is a Challenge: These behaviors can be dangerous and emotionally taxing for families and may lead to exclusion from programs or services.

Helpful Strategies

Functional Behavior Assessment (FBA): A behavior therapist can help identify the "why" behind the behavior, including escape, attention, or sensory. If issues persist, consider reevaluation.

Teach Replacement Behaviors: For example, using a card to request a break instead of hitting. Teach these replacement behaviors when the individual is calm, not during a crisis.

Reinforcement Systems: Reward positive behaviors immediately and consistently.

Age-Specific Strategies for Aggression and Self-Injury Difficulties

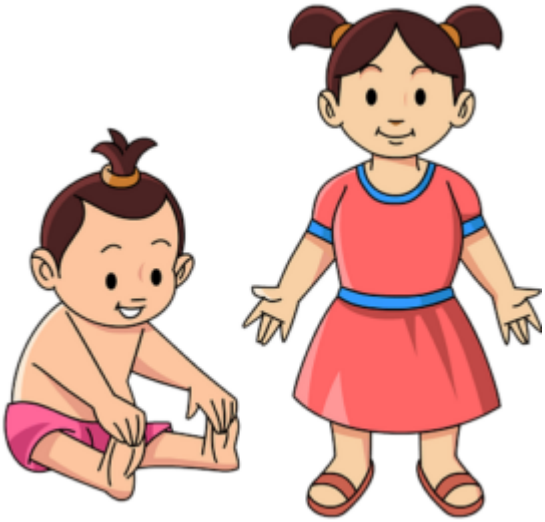
These are suggested ages only, you may use these at different ages and stages. Not all strategies may be applicable or of interest to your loved one.

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Under 5

- **Cues and gestures**: Use picture cues or gesture signs to express needs, such as needing a "break."
- **Redirect**: Redirect with sensory input, such as squish balls or swinging.
- **Praise**: Praise and reward positive behaviors quickly and consistently.

- **Emotional awareness**: Build emotional awareness using “feelings scales” or emoji cards.





School Age

- **Replacement behaviors**: Teach and reinforce replacement behaviors, for example, saying “help” instead of hitting. Remember the importance of being regulated during these moments.

- **Calm down**: Use calm-down plans and visuals for de-escalation.
- **Emotional awareness**: Use “feelings scales” or emoji cards to reinforce emotional awareness.

Teens & Early 20s

- **Emotional awareness**: Continue to build on emotional awareness and communication using feelings scales or emoji cards.
- **Behavior plan**: Involve them in creating a personalized behavior plan.
- **Role play**: Practice scripts or role-play alternative responses to stress.





Adults

- **Support team**: Ensure access to a behavior support team if needed. This could include BCBAs (board-certified behavior analysts), behavioral therapists, or other professionals experienced in behavioral support.
- **Calming strategies:** Offer calming techniques, such as music, pacing, or weighted items.

Additional Aggression or Self-Injury Resources

Assistive Technology: Introduction, Overview, and Applications for FXS

Watch Drs. Laura Greiss Hess and Kerrie Lemons-Chitwood help us understand the use — and complexities — of assistive technology from early childhood to special education IEPs through to adulthood.

Behavior Apps

- Vroom Tips: Turn shared, everyday moments into brain-building with science-based tips and tools.
- iRewardChart: An app for parents and caregivers to give rewards (stars) for good behavior with positive reinforcement.
- **Breathe, Think, Do with Sesame** (Apple / Google Play): Helps teach skills

such as problem-solving, self-control, planning, and task persistence. See more from their collection of Social Emotional Skills resources.
- Touch and Learn – Emotions: Helps kids identify and name emotions, facial expressions, and body language.
- Avokiddo Emotions: Explore feelings in a free-play style, with no rules or expectations other than having fun while learning fundamental social skills.
- GoNoodle (Apple / Google Play): Videos for elementary school kids that focus on movement, mindfulness, and self-discovery.
- The Social Express (Apple): An engaging, educational curriculum for all ages with social learning challenges.
- ClassDojo: Helps teachers and families collaborate to support social-emotional learning.

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Communication Difficulties and Frustration

What Communication Difficulties and Frustration Might Look Like: Limited verbal communication, echolalia (repeating phrases), or trouble expressing wants and needs, which can lead to tantrums or behaviors.

Why Communication Difficulties and Frustration Are a Challenge: Communication barriers often result in misunderstandings, increased frustration for both the individual and the caregiver, and difficulty developing peer relationships.

Helpful Strategies

Be Patient: Auditory processing delays may impact how the individual with FXS responds. They may need additional time to process and respond.

Modeling & Repetition: Speak slowly, repeat key phrases, and model responses without pressuring them to talk.

Collaborate with SLPs: Speech-language pathologists can offer tailored approaches for expressive and receptive language needs.

Augmentative and Alternative Communication (AAC): Tools like picture boards or speech-generating devices can reduce frustration and support language

development. You may need to request an evaluation, such as an AAC assessment, to find the best fit for your loved one. Also watch:

Watch: Assistive Technology: Introduction, Overview, and Applications for FXS: Drs. Laura Greiss Hess and Kerrie Lemons-Chitwood help us understand the use — and complexities — of assistive technology from early childhood to special education IEPs through to adulthood.

Age-Specific Strategies for Communication Difficulties and Frustration

These are suggested ages only, you may use these at different ages and stages. Not all strategies may be applicable or of interest to your loved one.

Under 5

- **Use sign language or PECS** (Picture Exchange Communication System): For basic requests.
- **Narrate daily life in simple words**: For example, “You’re brushing your teeth!”
- **Celebrate all forms of communication**: Gestures, pictures, sounds.
- **Pair up**: Introduce a peer buddy or support person to help practice communication.





School Age

- **Incorporate AAC (augmentative and alternative communication) devices or apps**: For use when speech is limited. See Proloquo2Go or TouchChat.
- **Use visual choice boards:** For activities, food, and routines.
- **Encourage play**: Including turn-taking games and shared storytelling.
- **Continue to pair up**: With a peer buddy or support person to practice communication.

Teens & Early 20s

- **Offer topic boards for conversations**: Such as hobbies or daily routines.
- **Support social scripts for common settings**: Such as ordering food.
- **Supported communication**: Use text-based or visual apps.
- **Continue to pair up**: With a peer buddy or support person to practice communication.





Adults

- **Supported communication**: Continue to use text-based or visual apps.
- **Encourage functional communication**: At work and in community settings.
- **Focus on self-expression tools**: Such as art, photo albums, or journaling apps.

Additional Communication Difficulties and Frustration Resources

Watch: Encouraging Early Communication in Fragile X Syndrome: Anne Hoffman discusses how to recognize communication that is already occurring, expand on current communication attempts, encourage additional communication opportunities, and build positive and reciprocal interactions.

Watch: Language for Learning: How to Encourage More Complex Language: Anne Hoffman discusses developing language past the one-phrase level. Learn important strategies to encourage production and comprehension of more complex language, including building up their vocabulary and using longer descriptive and multi-clause phrases.

ACC Apps

Proloquo2Go: A communication app for non-speaking children and adults to express themselves and take part in conversations. It can be personalized to cater to individual needs and various disabilities.

TouchChat: A communication app with customizable features and a range of vocabularies, languages, and voices.

Related Treatment Recommendation

Language in Fragile X Syndrome

What does language development look like for individuals with FXS? We discuss receptive language (what is understood), expressive language (how an individual communicates), pragmatics (how language is used), and speech (how sounds and words are produced).

Go to the treatment recommendation