



LIVING THE FRAGILE X WAY

We understand that individuals with Fragile X Syndrome have a specific learning style. We also know that anxiety and hyperarousal are two of the most incapacitating features of the disorder. “Living the Fragile X Way” means *understanding* how individuals with Fragile X learn and how they perceive the world, and, in applying this knowledge, determining the appropriate strategies to help them be successful in daily life, whether at work, at play or at school.

The strategies outlined below are based on best practice from multiple disciplines. They need to be used prescriptively, as not *all* of these are necessary or appropriate for all individuals with FXS. These strategies need to be used under the guidance of a team familiar with the individual.

These strategies can be divided into three basic categories:

- **Sensory Based Strategies:** These are strategies based on sensory integration theory and include strategies for calming, organizing and self regulation.
- **Routine Based Strategies:** These are strategies for keeping the day organized, maintaining routines and keeping anxiety about the uncertain and arousal at bay and are based on the use of schedules and visual supports.
- **Language Based Strategies:** These are strategies that capitalize on the “incidental learning” strength of individuals with FXS. We can take advantage of this learning style when trying to shape or change behaviors through specific language and social based strategies.

Specific strategies include:

Sensory-based strategies:

- Sensory Diet
- Fragile X Emergency Kit
- Sensory Choice Board
- Self-regulation Programming

Routines-based strategy:

- Schedules
- Routines
- Structure

Language-based strategies:

- Side dialogues/self talk
- Social stories
- Video modeling
- Use of Mantras
- Use of rhythmic voice and interaction

RESOURCES

Websites:

www.developmentalfx.org	The Developmental & Fragile X Resource Centre
www.marciabraden.com	Marcia Braden, licensed psychologist, FXS specialist
www.fragilex.org	National Fragile X Foundation
www.fraxa.org	Fragile X Research Foundation
www.do2learn.com	Materials and learning ideas
www.usevisualstrategies.com	Visual strategies for home and school
www.teacch.com	Tools for teaching
www.thegraycenter.org	Information on social stories
www.tvteacher.com	Handwriting
www.watchmelearn.com	Social story-like DVDs for a variety of social situations

Books

Most of these are available through Amazon.

Visual Strategies for Improving Communication and Solving Behavior Problems in Autism by Linda A. Hodgdon

Fragile X Syndrome: Diagnosis, Treatment, and Research by Randi Jenssen Hagerman (Ed), Paul J. Hagerman (Ed)

Children with Fragile X Syndrome: A Parents' Guide by Jayne Dixon Weber

Speech & Language Development & Intervention in Down Syndrome & Fragile X Syndrome by Joanne E., Ph.D. Roberts, Robin S. Chapman, and Steven F. Warren

The Source for Fragile X Syndrome by Gail Harris-Schmidt

Fragile X Fragile Hope: Finding Joy In Parenting A Child with Special Needs by Elizabeth Griffin

Sensory Integration and the Child: 25th Anniversary Edition by A. Jean Ayres

The Sensory-Sensitive Child by Karen A. Smith

Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Integration Issues by Lindsey Biel Nancy Peske

The Out of Sync Child and *The Out of Sync Child has Fun* by Carol Stock Kranowitz

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