

Strategies and Tools to Assist Young Children with FXS

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Plan Ahead

- Use our knowledge of FXS emotional, cognitive and behavioral phenotype to plan ahead so that behavior issues are reduced and supports are in place
- Provide support for sensory modulation/arousal
- Provide support for communication
- Teach using simultaneous processing
- Create predictable, functional routines supported by visual schedules and visual supports

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Preschoolers with FXS

- Behavioral Phenotype: hyperactivity may be extreme, verbal perseveration can become problematic, often become stuck on ideas or situations so transitions can be very hard. Disruptive behaviors (noncompliance, physical aggression, throwing things) increases
- Anxiety symptoms, reddening of face and ears, activity level increases, hide face, gaze avoidance, social shyness, cover eyes, chew more intently, task avoidance or trying to flee situation

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Structure and Routines

- ❖ Structure the day across predictable and consistent routines
- ❖ Provide for choices within structure
- ❖ Facilitate smooth transitions with warnings
- ❖ Inclusion of a sensory diet
- ❖ Visually organized environment
- ❖ Clear limits and natural consequences
- ❖ Minimal set of work rules

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Healthy Habits: Establishing a Sleep Routine

- Important to establish bedtime routines that occur in the same way each day
 - Consistent bed time
 - Similar sequence including trip to toilet, brushing teeth, putting on pajamas, reading books, lights out
 - Address sensory/regulatory needs within this routine
 - Rough housing late in the day, but not at bed time
 - Heavy blanket, sleep sack or soft stuffed animal
 - Something to chew on while settling down
 - Dim the lights about an hour or 2 before bedtime to keep melatonin production increasing for sleep

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Sleep Hygiene

- If your child needs you to be present to fall asleep, then he will need you to put himself back to sleep if he awakens in the night
 - Try to begin to reduce your role in falling asleep
 - Rub his back while sitting in a chair next to bed, rather than laying in the bed
 - Don't give fluids other than water at bedtime (avoid milk or juice in a sippy cup)
 - If your child awakens in the night, you can return him to bed, but do not make it into a big production. Sit next to bed not in it, so you can sneak back out.

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Things to Avoid at Bedtime

- Televisions in rooms, or falling asleep to tv or videos, as children get older it becomes harder to establish healthy sleep patterns
- Falling asleep next to another person
- Bottles/cups of milk or juice (it can rot teeth)
- Stimulating play that leads to increased hyperarousal
- Having bright lights on, it affects melatonin production which can increase sleep difficulty

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Healthy Habits: Brushing Teeth

- This can be a challenge because of sensory issues and often leads to tantrums or avoidance
 - Experiment with a range of types of toothbrushes
 - Battery operated
 - Big handle, small handle
 - Different flavors of toothpaste
 - Start with limited amounts of toothpaste if needed
 - Keep it short and sweet to build a new routine

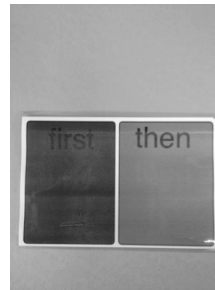
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Healthy Habits: More on Teeth

- Give opportunities for kids to chew or suck on tooth brushes at other times of the day to get use to the brush
 - Create a routine that is consistent such as singing the Happy Birthday Song or ABC's while you brush child's teeth
 - Use visual support such as a visual sequence schedule
 - Keep the sequence the same:
 - First brush teeth, Then read favorite book

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First-Then



- ✦ **First** put your shoes on, **then** you can go outside
- ✦ **First** brush your teeth, **then** favorite book.
- ✦ **First** finish task, **then** free choice.

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Dressing Routines:

- Start the routine where you want it to happen
- Have a chair to help provide stability for pulling on underwear, socks, and pants.
- Clothes should be easy on and easy off
- Teach children to put dirty clothes directly into hamper (have one in their room)
- Lay clothes out in the order they will be put on
- Use the same sequence each time
- Backward chaining works well for dressing/ undressing

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Dressing... Continued

- Try to provide support while still allowing for independence
- If your child has strong preferences/opinions about clothes, pick them out the night before
- Consider visual schedule:
 - First get dressed, then eat breakfast.
- Remember simultaneous not sequential cuing

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Routines for Meal Time

- First wash hands, then we eat.
- Food is a primary reinforcer- the behaviors your children exhibit while eating, will be reinforced if they like the food.....SO.....
- Meals should happen at a chair at a table in the kitchen or dining room...not on the run around the house.
- If your child gets up from the table, put their plate up until they return to sitting.

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Healthy Habits: Meal Time, Continued:

- Have predictable seating, with favorite placemat and dishes present
- Try to have everyone sit at same time
- Turn TV off, this is a time for social interaction
- Allow children to request “more” by providing small amounts of favorite foods, with more nearby, visually present but out of reach
- Model use of table manners, napkins, utensils

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Healthy Habits: Meal Time Continued

- Use an object or picture to provide a prompt for conversation.
- When they are done eating, they can be excused....BUT....
- Remember your “First...Then”
- First let’s wipe/wash hands, then you can play or
- First let’s clear your plate, then wash hands and play

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Bath Time:

First take bath, then PJ’s or first try potty, then bath

- Bath is a great time for working on :
 - Dressing and undressing
 - Body parts
 - Pouring and dumping in a controlled setting
 - Beginning self help skills: use of washcloth, washing hair, drying self off
 - Imitation on objects with bath toys, vocalizations, sounds, blowing skills (blow bubbles in bubble bath)

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Creating Health Bathroom Routines

- Before you worry about toilet training your child, establish regular routines which occur in the bathroom
- Teach child to wash hands at sink on a stool
 - Provide visual steps to help with learning the routine

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Bathroom routines Continued

- Have child sit on toilet before bath to help “de-mystify” toilet
- Have child complete sequence (pants down, sit, wipe, pants up, flush, wash hands)
- Teach concept of wet versus dry as you check the diaper or during play routines
- Begin to add a second predictable time for practicing sitting on the toilet
- Provide special bathroom toys to encourage sitting

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Sensory Diet

- ✦ A Sensory Diet should be developed by or in conjunction with an occupational therapist.
- ✦ A sensory diet is a structured set of activities that occur on a daily or weekly basis and help to meet an individual's sensory needs.
- ✦ A sensory diet is individualized and based on each individual's sensory processing abilities and deficits.
- ✦ There are some general principles that help to guide the development of sensory diets

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Heavy Work:
active pressure input to the muscles through pushing, pulling, carrying

- ✦ Heavy work is also generally very calming.
- ✦ These activities can be easily incorporated into daily chores or exercises
- ✦ Heavy work activities include the following:
 - ✦ Pushing a grocery cart
 - ✦ Pulling a heavy wagon
 - ✦ Carrying trash or laundry
 - ✦ Climbing stairs
 - ✦ Push-ups
 - ✦ Carrying a back pack

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Deep Pressure Input: Input Through the Muscles, Joints, and Skin

- This type of input is generally very calming
- It can be done safely and easily
- Activities that provide deep pressure include:
 - ✦ Swaddling or wrapping in blankets
 - ✦ Piles of pillows for nesting or cuddling
 - ✦ Weighted blankets
 - ✦ Wearing ace wraps, spandex, or other type clothing
 - ✦ Compression pants
 - ✦ Massage

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Use of a Sensory Choice Board



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Sensory Tool Box



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Hand & Mouth Fidgets

Hand and mouth fidgets are often effective with individuals with Fragile X Syndrome because they provide heavy work activities for the mouth and hands and they can be substitutes for more destructive or annoying behaviors.

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Physical Structure Forms the Base of Visual Support

- ✦ The physical structure of the environment should not be overlooked as fundamental to basic visual supports
- ✦ Segment the environment to make things visually clear
- ✦ Use furniture placement to create smaller spaces
- ✦ Make a smaller space for children who need more structure
- ✦ Minimize opportunities for a child to leave setting they are supposed to be in

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Physical Space Should Be Structured



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Physical Space Can Communicate Expectations



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Why use Visual Strategies?

- Individuals with FXS are VISUAL LEARNERS
- Due working memory problems, they have a hard time holding onto what is expected
- Due to anxiety, they worry about what is happening, how long it will last, what will come next
- Anxiety and Hyperarousal decrease their ability to access skills

Visuals alleviate these difficulties and foster higher level performance

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4 Key Questions to Visually Structured Routines

- ✦ What am I supposed to be doing?
- ✦ How long will it last?
- ✦ How do I know when it is done?
- ✦ What should I do next?

These 4 questions then repeat in a continuous cycle

Adapted from:

Developmental FX

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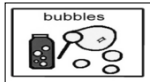


- Mike is just beginning this system. He needs to be directed to go to his schedule using a transition strip. He then takes the next item (left to right) from his schedule, and goes to where he is directed. The round block has a spindle at the work area as a receiver spot. The cup tells him to go to the snack area, and the diaper means that it is bathroom time.

Schedules may use:



- an actual object



- an icon or photo of the object

bubbles

- written text

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Schedules Support Adaptive Skills



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Visuals Help Teach Regulation



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Visuals Support Work Systems



Now that I'm here... how much work will I be doing?
When will I be finished?

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Work Systems



Division TEACCH
Treatment and Education of Autistic and related Communication-handicapped Children
THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL
Work - Play - Training - Games - Jobs - Activities of Daily Living - Activities of Community Living

REMEMBER the 4 QUESTIONS!
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1, 2, 3...

- 1 = Prompt
- 2= Warning/Guide
- 3= Consequence

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1, 2, 3...

- If Jonathan engages in oppositional behavior or does not follow a request, rule or limit, then give him approximately 10 seconds to respond and praise him if he complies. If he does not comply state "That's 1". Wait approximately 10 seconds.
- Warning/Guide: Use a firm tone of voice, "You need to ...(original demand), That's 2." Praise if complies.
- If he resists or behavior escalates, "That's 3." Don't engage in argument or discussion. Remove preferred activities. Ignore until compliant or direct to Time out.

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Positive Reinforcers

- Edible
- Sensory
- Natural
- Material
- Social
- Generalized Reinforcers- (something to be exchanged later)



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Using Time Out

- Does not need to be a specific place
- Does need to be time away from your attention
- Needs to be linked to a specific act or behavior
- Needs to be used in a consistent manner
- Should be imposed immediately following the behavior
- ✦ Do not engage in repartee
- ✦ Do not address behaviors that occur on the way
- ✦ If he/she gets up put them back
- ✦ This is one component of a behavior plan
- ✦ Decide what you are going to say before you start

Riley and Epstein

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