

What Is Occupational Therapy?

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The National Fragile X Foundation regularly receives calls asking:

“What is OT?”

“Why does it look like my child is just playing in OT?” and

“What can OT do for my child?”

Although it does sound like occupational therapists may “get people jobs” (a question frequently asked), “occupation” refers to an individual’s primary role, or roles. OT works to help develop the skills necessary for an individual’s current occupation (role), a change of occupation, or to help develop adaptations within a role.

An infant or toddler’s role, is to eat, sleep, play, and develop sensory and motor skills allowing them to explore, move within, and interact with their environment and family. Later, toddler’s and preschooler’s roles expand as they begin to calm and organize themselves with more regularity and independence, and tolerate increasing varieties and amounts of sensory stimulation. They learn how to dress themselves, widen their social circles, increase their language and communication abilities, and further develop their fine motor, gross motor, and play skills. Once a child is in school the demands for academics, organization, speed, and social interactions continue to increase. Their roles as a child widen and become more complex. Their primary occupations of student, son or daughter, and friend, may also now include employee. Adults also have multiple roles including parent, spouse or partner, and employee.

Whenever a child has learning, behavioral or physical difficulties their ability to play and learn will be effected. Depending on the severity and complexity of the difficulties, the child’s occu-

pation may be minimally or multiply affected.

Before beginning a treatment program an occupational therapist must evaluate the child’s needs. This should include observing the child in school and taking particular note of interests, strengths and weaknesses. The evaluation should also take note of the family’s level of involvement and the support resources available.

After an evaluation, what can an OT offer? First, consider the areas of difficulty that a child with FX may have.

Generalized or specific sensory

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defensiveness: It is common for children with FX to have tactile **defensiveness**. This is a tendency to react with negative emotions or behaviors to being touched. Such a child may resist being touched or held, or dislike playing in the sand or finger painting. Tactile defensiveness is rarely seen without the presence of other types of sensory defensiveness.

Sensory defensiveness results in varying degrees of stress and anxiety. To varying degrees a child may exhibit:

Oral defensiveness: an aversion to taste, texture, and/or temperature, often resulting in particular likes and dislikes of foods including avoidance of putting objects in the mouth, and intense dislike of tooth brushing or oral hygiene.

Auditory defensiveness: an over sensitivity to certain sounds, tones,

itches, or rhythm, creating irritability, fearfulness, or an aversive reaction.

Visual defensiveness: typified by over sensitivity to lights, and/or extreme visual distraction. Gaze aversion is sometimes considered a component of visual defensiveness or movement hypersensitivity. Gaze aversion often increases with anxiety, such as in social situations.

Olfactory defensiveness: aversion to direct or indirect odors in the environment. This is a reason for parents, health-care workers and teachers, not to wear perfumes or scented lotions around affected children.

Movement Hypersensitivities /Insecurities: an extreme fear of change in position or movement. Postural insecurity is a fear or avoidance of movement due to poor postural mechanisms. Children with FX may prefer to have both of their feet on the ground or stabilized in some manner. They may be fearful of being in high places, climbing on playground or therapy equipment, and riding on escalators. Even being seated on an adult-sized toilet may further complicate toilet training.

Sorting out these defenses can be difficult, especially with some of the coping strategies that children use. For example, a child with auditory defensiveness may make loud noises in an attempt to control what they hear. Individuals with oral defensiveness are sometimes “mouth stuffers”, or chew on anything available to them. This paradoxical response is present in the FX population.

Many children with FX also exhibit poor self-regulation. They may have dif-

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difficulties with modulation which is the ability to interpret and integrate incoming sensory stimulation. Such a child may talk too loud or too soft, without the ability to control his volume. He may hold onto a toy or person with great force. Children with FX also may display arousal difficulties resulting in sleep disturbances and attention deficits.

Children with FX, especially boys, often have fine motor difficulties, or difficulty controlling their hands and fingers. Handwriting is extremely difficult, likely because of overall low muscle tone, hyperextensible finger joints, poor sensory discrimination, and limited ability to plan and execute complex fine motor actions (motor planning). Fastening clothes, using scissors, moving thorough obstacle courses or performing sequenced tasks may also prove difficult.

Interventions will vary from child to child. And, as children's roles change, so should the focus of occupational therapy. Generally, the majority of children with FX can and do benefit from OT, especially from a sensory integrative approach. Sensory Integration (SI) is a frame of reference that occupational therapists use during their treatment sessions. Many of the sensory difficulties listed above can be addressed by using a sensory integrative approach. In fact, because of the many sensory issues children with FX exhibit, understanding SI is critical.

Occupational therapy can be provided on a 1:1 basis, in a small group, or in consultation. Initially, however, most occupational therapists prefer to see each child individually so that needs can be addressed and reevaluated constantly and immediately. Later, a small group of children with similar therapy needs can be motivating to, and beneficial for,

each child. Unfortunately, "small groups" are more often the result of school district funding and limits than the child's individual needs.

Finally, understand that occupational therapy does not make sensory issues disappear. It can, however, help develop basic skills needed to function more appropriately in home, school, and community environments. OT can provide basic foundation skills that are necessary for learning and maintaining attention. It also helps children feel more comfortable with their own body and to move effectively within their environment.

Occupational Therapy is usually most successful when parents, teachers, and therapists work together to provide consistency, and when specific sensory activities are included in the child's daily routine. For more specific ideas, please speak to your child's OT.

Politics and such...

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While recent events have certainly altered the daily agenda in Washington, work goes on in Committees and Subcommittees on issues near and dear to the fragile X community. Many Congressional Representatives and Senators of both parties recently signed on to letters to the House and Senate Labor-HHS-Education Appropriations Subcommittees urging full funding for the Children's Health Act of 2000 (P.L. 106-310). It is also expected that the report language in the Fiscal Year 2002 appropriations bills will urge NIH to fully implement the specific directives and programs in the Act which will benefit not only those affected by fragile X but also those with autism, juvenile arthritis, asthma, spina bifida, cerebral palsy, epilepsy, Duchenne muscular dystrophy, hepatitis C, traumatic brain injury, tourette syndrome, early hearing loss, and other birth defects, diseases, and conditions. Thanks to all who have again

written their Member of Congress to urge full funding.

The House Energy and Commerce Subcommittee on Health passed the Best Pharmaceuticals for Children Act on October 4 which was another victory for the Coalition for Children's Health- of which the National Fragile X Foundation is one of the founding members- that had backed the legislation. HR 2887 would reauthorize the pediatric exclusivity incentive of the FDA Modernization Act of 1997 which would otherwise expire on 1/1/2002. The bill is now in markup before the full Energy and Commerce Committee. A companion bill passed the Senate Committee on Health, Education, Labor and Pensions and awaits full Senate action. While there is some controversy over the additional profit the 6-month exclusivity extension results in for the drug industry, the fact is that before the act six (6) drugs were

tested on children in the six years before the act. In the ensuing four years since the legislation over four hundred (400) pediatric studies have been done. Those of us in the fragile X world who are familiar with off label drug therapies prescribed for our children welcome additional juvenile studies. The average cost is \$4 million per study.

Finally, our Congressional Mapping Project marches on.

Uncle John's Bandwagon NEEDS YOU! It's the patriotic thing to do. Sign up now to be our person in the 10th District in New Jersey, the 3rd District in Louisiana, the 22nd District in California, et cet. You'll be glad you did. FAX or phone above #s or Email to JoStephx@aol.com. I'm starting to put together the Public Policy Panel for the Chicago conference. If you have a panel candidate to suggest, contact me.