

EDUCATING SCHOOL PERSONNEL AND OTHER PARENTS ABOUT FRAGILE X SYNDROME

Jayne Dixon Weber

Educating School Personnel

Some ideas to think about:

- Ask for 15 minutes at an all-staff faculty meeting. If that is not possible, ask to meet with all of the teachers who will be directly interacting with your child — before school actually starts.
- The information can be presented formally with you standing up in front or you can all be sitting around a table, however you are most comfortable.
- Have handouts on fragile X syndrome so you do not have to discuss each and every characteristic. Keep in mind that you want to inform, not overwhelm. Present the information you feel is most important for them to know about your child and how he or she is affected by it. Not every characteristic is seen in every child. Bring your child with you or have pictures of him or her. You want the staff to see that fragile X syndrome is more than a list of characteristics, some of which are not seen very positively. We are talking about a child, a child who likes to do activities that every child likes to do, and one who also has fragile X syndrome.

The outline below can be used to prepare for your talk. Expand on it as time allows and know that as time goes on, the teachers and other support personnel will have additional questions about fragile X syndrome.

What is Fragile X Syndrome?

In simple terms: Fragile X syndrome is a genetic condition where the X chromosome is broken or has a fragile site. The body does not produce a certain type of protein (or not enough of it) and it is this lack of protein that causes developmental delays in all areas.

Characteristics of Fragile X Syndrome [Use the brochure and touch on the highlights]

Some common characteristics of fragile X syndrome include delays in speech, motor (gross and fine), and cognition skills. Behavior can sometimes be challenging. However, children with fragile X syndrome are usually very social and like to be with other people. They imitate what goes on around them, both in what they see and hear, so it is important they be with typically developing children.

Learning Styles and Strategies [Use “Teaching Boys With Fragile X Syndrome”]

Address the sensory issues first: seat location, lighting, noise, visual distractions, regular opportunities to move around. Associated activities: schedule, structure, routine, predictability, transition activities, process for handling schedule changes and fire drills. Academics: modified materials, repetition, use areas of high interest, peers, paraprofessional/special education teacher.

Child’s Strengths

Whenever possible, use your child’s interests in learning. For example: If your child likes trucks, use them for counting, colors, naming parts, big/small, reading books, making books, measuring, sight words, how they are used.

Summary

Talk about the activities you like to do as a family. Describe the things your child likes to do at home. Give them a personal glimpse of your wonderful child!

Educating Parents of Typical Children

Some thoughts to keep in mind:

- Many parents did not grow up around children with disabilities. They surely were not educated with them like they are today.
- There is a level of ignorance about people with disabilities in general and there can also be fear associated with that ignorance.
- Some parents will be interested in learning about your child, others could give a hoot.
- Some parents will be glad their children are in the same class as your child, others won't.
- Some parents will ask for written information on fragile X syndrome.

Educating other parents, for the most part, will be done on an informal basis — talking with them before or after school. The questions will probably be about the biology and genetic aspect of fragile X syndrome, as well as ones that are more personal — questions about your child's behavior and your family life. Just remember that you do not have to share anything that you feel uncomfortable sharing. Again, like you do with the teachers, help others see the "child" in your child.