

ESTABLISHING A SCHOOL PROGRAM FOR A CHILD WITH FRAGILE X SYNDROME

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1. Learn as much as you can about fragile X syndrome.
2. Become familiar with state and national laws. Secure a copy of your state's special education law book. Contact your protection advocacy, child advocacy, ARC, or other advocacy agencies for written materials and advocacy training courses.
3. Parents of special education children need to be involved in their child's program. Visit your child's class regularly and have open communication with the teacher and support personnel. Observe your child's therapy session. When your child is scheduled to have a program change (or when you can feel he/she needs a change from the current program), visit all other program possibilities, even if they weren't suggested by your school district.
4. The program for your child with fragile X must be multidisciplinary, including sensory integration, speech, occupational, and physical therapies. While you are working to create an optimal multidisciplinary program appropriate for your child, try to obtain the best possible services in the interim. This may mean obtaining public or private schooling and therapies while working to make the school program fit your child's needs.
5. When looking for or creating a program for your child, make sure you set goals. Even though there is a vast range of functioning levels in the fragile X population, there are many common characteristics and needs.

Goals

- The program must be multidisciplinary.
- The program must provide for the child's sensory integration needs. This includes an occupational therapist trained and experienced in sensory integration therapy several times a week, an appropriate location for the therapy, equipment to meet needs (which also could be used by other students), and provisions for the occupational therapist to educate other staff members working with the child about their sensory needs.
- The program must address strengths. Almost all parents of fragile X children, and many professionals working with them, agree that the present assessment tools do not adequately demonstrate the strengths of the child. We must make sure when placing and teaching children with fragile X syndrome that their strengths (often demonstrated through informal means of assessment) are taken into account.
- The program must help remediate weaknesses. Typically, there are weaknesses in math, sequencing, abstract reasoning, and fine motor skills. Programs need to address these weaknesses, using strengths as much as possible to help remediate them.
- Programs need to be in a school where the child could stay throughout elementary years, and where there are "normal" role models. Change is difficult for children with fragile X syndrome. In addition, it takes time for support staff to become educated. Since fragile X children have great imitating skills, emerging social skills would develop best where other children know the child and where they would have a consistent environment.
- Hold a pre-IEPC meeting. Determine what would and would not be provided. Plan your IEP early enough so you can work out any difficulties.
- Make sure you have copies of all your child's reports and make sure the sources are familiar with your child.
- When creating your child's IEP, get everything in writing: goals of the therapists who will be working with the child, the length and frequency of therapy, etc.