

# **DEVELOPING AN IEP FOR INDIVIDUALS WITH FRAGILE X SYNDROME**

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## **Introduction**

The passage of P.L. 94-142, Education for all Handicapped Children Act of 1975, was the most significant legislation ever enacted to meet the needs of all special needs children. In 1986 it was expanded (P.L. 99-457) to include requirements to children ages 3-5 years.

In 1990 the Handicapped Children's Act was changed to Education of Individuals with Disabilities (IDEA). The name of the act was changed along with several changes related to inclusion. Inclusion simply brings a stronger emphasis to what was implied in the earlier act. In other words, more emphasis is to be placed on including the person with a disability in the regular mainstream of society. The emphasis includes preschool, public school evaluations and community placements.

Other changes included more emphasis on training specialized and non-specialized personnel to adapt to the inclusionary emphasis. There is also more emphasis on technical assistance, instructional media and transition from school to community. The thrust to instruction occurring within the regular education environment has provided the necessity for regular educators to become more aware of the needs of persons who are disabled. The role of the special educator has shifted from being a direct provider to a consulting role for regular education teachers.

This law brings with it a mandate to develop an IEP (Individualized Education Program). The IEP is an educational blueprint of the educational program. It requires the inclusion of current levels of performance, goals and objectives, the extent to which the child is included in regular education and the procedures used to meet the goals. The development of an IEP occurs while meeting with school personnel familiar with the child, parents and other outside agents or advocates. Often, the meeting includes many special educators who may use familiar acronyms or professional jargon unique to their academic area. Parents can feel overwhelmed and intimidated by this process. One parent wrote of her experience in hopes of providing insight into the process and exactly how difficult it was for her:

The first staffing we experienced was when our son was 11 years old; it was especially stressful. Walking into a room of strangers was overwhelming. Knowing we were going to be told all of our son's faults was embarrassing.

There must have been six people in the room as we entered. We knew only one of them. Others kept coming in chatting and laughing with the other strangers. To these teachers, aides, therapists, psychologists and the principal it was "all in a days work". To us as parents, it was very intimidating and it was a very emotional experience. For us to retell our son's story was sad and hurtful. He was a fun loving kid but his severe outbursts had kept him out of public schools. Now we were tense and unsure if these people would be able or even want to keep him in their school. Since age five other schools had refused to take him saying he was too disruptive for them. Some would take him on a trial basis but it would last only a month or two. Since age five and a half he had been in private schools for emotionally disturbed children except for a couple of trials in public schools.

We knew nothing of the Public Law or the staffing process. Many of the words and abbreviations used were unfamiliar to both of us. We felt ignorant and at the mercy of strangers, with no idea of an alternative school if these professionals all agreed our son should not be accepted into their school. (We had just moved to a new state.)

We knew our son was hard to handle, yet we also knew he had the ability to learn. How was he going to reach his full potential? That was our greatest desire for him--whatever level that potential would be.

Looking back to that first frightening staffing I wish the staff members had introduced themselves as they entered the room and included us in their conversations to make us feel a part of the group instead of outsiders. Any experience with our son would have helped us relate to them as well. Usually everyone introduces themselves at the beginning of the staffing. That time could be saved and parents could feel more at ease if each person talked to the parents as they entered the room. It would help put the parents at ease and help them sort out in their minds (before the staffing starts) how each person fits into the education of their child. To me, the staff was not thinking of us. I felt like this was our staffing and they acted like we just happened to be there.

Both my husband and I were good students in our school years. We made good grades and were never in trouble. It was difficult for us to deal with a child with disruptive behaviors. We tried everything professionals suggested, but the outbursts continued even if at a lesser degree. We loved our son and wanted the best for him. We did not want him to be hurt, nor for him to hurt others.

In his early childhood, we had been told by two psychiatrists to institutionalize him because he would never learn anything. Two other psychologists took him into their programs believing that he could learn. At this staffing or any meeting we relived these diagnoses and wondered which way these professionals would decide and we worried if we would say the right things.

Over the years I have learned that most staff do not realize the agony parents go through at a staffing. So much is at stake and we don't want to make a bad impression or forget something important.

Other things I have learned are:

1. **Never go to a staffing alone.** Take someone or several someones who understand the procedure and can advocate for your child. Stress often causes parents to be tongue-tied or forget all the issues one wants addressed. If you cannot find someone who is familiar with the staffing process take a friend or relative who knows your child well. At the very least take a friend for moral support.
2. **Be prepared.** Know your child's rights. Know the laws. Understand your rights as a parent. Become familiar with your staffing procedures. You will be more confident and your child will have a better program.
3. **Have a list.** List all the needs of your child. You may get nervous and forget all you want to discuss. It will be a help for staff to hear all you want for your child. Even if you don't get everything on your list they will have heard it and it will be something they can think about. They may later agree to work on an area you suggested in the past.
4. **Know you can call a staffing at any time.** If you want to change your child's program you can call a staffing at any time.

Unfortunately, this experience is not uncommon. The process was developed to support parents and children and yet it can become somewhat unfriendly. Parents are an integral part of the process and must be guaranteed convenience, advanced notice and full understanding of the

information shared. Most parents have had little prior experience with this process and often report apprehension. Even though parents are asked to contribute, they feel so intimidated by the professionals, they fail to respond.

During the staffing you may hear about special education. The title clearly connotes a "different" or "separate" education. "Special" has been used to delineate an educational process, which utilizes methods and interventions, which will help to ameliorate learning deficits. In addition, the emphasis shifts from a curriculum designed for the traditional learner in the school population to an individualized prescription. Because the educational needs vary greatly in a number of areas services also vary. These educational services can range from partial to full day placement in self-contained or regular education placements. These placements can include specialized delivery systems using related services providers. These services can include transportation, recreational activities, speech/language therapy, behavior management, occupational therapy, and many others. The key to these services being included relates to a need to benefit from educational experiences.

An example of the need for a related service would be if a child exhibits sensory integration deficits, as is often the case of children with fragile X, the educational intervention would include input from an occupational therapist trained in sensory integrative therapy. If a variety of professionals are required to assist the special needs child, an interdisciplinary approach is employed. An interdisciplinary approach is one in which all disciplines are included in the decisions related to the child's placement. This approach has been especially effective with students with fragile X due to the complexity of their educational needs. In other words, it is often difficult to identify one area of need without including others. For example, a behavioral problem may in fact be a response to an environmental condition. If the response is treated simply as a behavioral problem without reference to the condition in the environment creating the problematic behavior, the intervention will fail.

This process is one utilized nationally. The rules/regulations regarding the employment of this process are interpreted in a similar but separate way in each state. It is important to understand how your state interprets the Federal mandate. Most states have a Legal Center for Handicapped Citizens which can provide additional assistance.

This section has been prepared to assist in the IEP process so as to provide a pre-conference handbook. Additionally, it is my strong contention that parents should take a friend, advocate, or private agent familiar with the child and fragile X syndrome to assist and support them.

### **Developing an IEP For the Individual with Fragile X**

#### **Needs:**

\*These needs have been taken from a variety of IEP's written for individuals with fragile X.

- 1) Increase ability to tolerate change in routine/environment
- 2) Sensory integrative therapy
- 3) Increase receptive and expressive language levels
- 4) Increase frequency of spontaneously initiated verbal interactions
- 5) Increase intelligibility of speech
- 6) Increase independent toileting
- 7) Increase tolerance for a variety of foods

- 8) Increase attending behaviors: at task, sitting, and delayed reinforcement
- 9) One-to-one instruction for novel tasks
- 10) Inclusion with typical age-appropriate peers when appropriate
- 11) Decreased mouthing, hand biting or finger/clothing chewing
- 12) Increase competency in play skills
- 13) Increase fine motor skills
- 14) Decrease tantruming while providing ways to calm self
- 15) Decrease ritualistic and obsessive behaviors
- 16) Decrease person/environment specific behaviors
- 17) Increase tolerance to touch or a variety of textures
- 18) Decrease anxiety
- 19) Initiate calming of self

**Cluster of cognitive, communicative, and sensory symptoms which interfere with learning:**

- 1) Hypersensitivity to visual, auditory, olfactory, and tactile stimuli
- 2) Difficulty with motor planning and sequencing
- 3) Attention difficulties: hyperactivity and impulsivity
- 4) Difficulty making physical transitions
- 5) A learning style that is primarily global in nature
- 6) Social anxiety
- 7) Communication difficulties: phrase, topic and sentence perseveration
- 8) Cognitive deficits ranging from learning disabilities to mental retardation

**Strengths/idiosyncrasies of the fragile X student:**

- 1) Visual memory - related to spatial/placement of objects, order, or format
- 2) Simultaneous learners - the "gestalt" is most easily remembered
- 3) Facts are most efficiently retrieved through contextual cues or associations
- 4) Incidentally acquired knowledge - demonstration of knowledge, which has never been formally taught

- 5) Socially motivated - enjoys social interaction with peers and adults
- 6) Imitates speech and voice intonation patterns
- 7) Understands concepts when illustrated during the time of the presentation - less intimidated when asked to give a visual response or to formulate one through pictures
- 8) Acutely aware of environmental conditions such as noise, changes in physical appearance, visual properties (hyper vigilance)
- 9) Excellent sense of humor - engages peers or adults in humor, accurately utilizes humor in an appropriate context
- 10) Often very receptive to helping or working cooperatively

**Components Essential To An IEP** ©Copyright 1989 Marcia L. Braden, Ph.D.

- EDUCATIONAL HISTORY: Schools attended
- STATUS: Current level of functioning, updated testing data, dates of administration, names of tests
- PROGRESS: Progress to date, data from prior behavioral objectives and long-term goals
- NEEDS: Educational needs generated from status and progress reports
- GOALS/STO: List of prioritized goals generated from needs, short term objectives (STO) must be measurable with method of assessment
- CHARACTERISTICS OF SERVICE: List of support services, curriculum, behavioral component, type of delivery, extended school year, etc. necessary to meet the goals
- PRIMARY PROVIDER, TRANSPORTATION NEEDS, DATE OF NEXT REVIEW, ETC.: Person who is considered "case manager"
- NOTICE OF PARENTS RIGHTS - DUE PROCESS IDEA

**Characteristics of Services:** © Copyright 1989 Marcia L. Braden, Ph.D.

1. Language-based curriculum; emphasis on language acquisition for the majority of the day.
2. Consistency between home and school.
3. Speech/language direct services, to include augmentative training if needed.
4. To direct sensory-integrative recreation as a related service.
5. Classroom with limited distractions during instructional period (small group or 1:1 instruction).
6. Predictable schedule with structured routine.

7. Inclusion with normal peers.
8. Social skills training.
9. Systematic presentation of tasks; using task analysis and trial-by-trial data collection.
10. Individualized instruction with modified curriculum.
11. Behavioral monitoring to decrease the frequency of maladaptive behavior and decrease anxiety.
12. Incidental learning experiences to include indirect teaching strategies.
13. Recreational therapy.
14. Community-based instruction.
15. Vocational training.
16. Calming menu/OT Lab.

**Programming Goals for an Individual Education Plan:**

Taken from Fragile X syndrome: Diagnosis, Treatment, and Research. Edited by Randi Jenssen Hagerman, M.D. and Amy Cronister Silverman, M.S.

1. Sensory integrative therapy to:
  - a. Decrease hypersensitivity to tactile, visual, olfactory, gustatory, and auditory stimuli
  - b. Increase tolerance of change in routine and environment
  - c. Decrease mouthing, hand biting, chewing on clothing
  - d. Decrease ritualistic behaviors
  - e. Improve gross and fine motor skills
  - f. Improve motor planning skills
2. Speech/language therapy to:
  - a. Increase receptive and expressive language levels
  - b. Increase mean length of utterance
  - c. Increase problem-solving skills
  - d. Increase play skill competency
  - e. Increase use of a variety of speech acts
  - f. Decrease verbal perseverations
  - g. Increase frequency of spontaneously initiated verbalizations
  - h. Decrease fast rate and oral and speech dyspraxia
3. Combined sensory integration and speech/language therapy to apply basic sensorimotor strategies into developing speech, language, and pragmatic skills.
4. Educational intervention to:
  - a. Increase attending behaviors in all situations
  - b. Increase independent toileting
  - c. Decrease person/environment specific behaviors
  - d. Decrease tantruming
  - e. Increase play skill competencies
  - f. Increase mainstreaming with normal age-appropriate peers

### **Educating School Systems about Fragile X Syndrome**

Due to the relatively new discovery of the fragile X syndrome, professionals are often uninformed. Many times parents become the informants due to the lack of professional journal articles, written information, or teacher training related to the syndrome. That interaction can be misperceived and can set up a power struggle between parents with requests and traditional teaching methods.

An effort to educate school systems has offered a number of interesting challenges. This handout is designed to provide information to be shared with school personnel. The information has been generated from a variety of experiences with fragile X individuals in a number of states and in a number of educational settings.

It is by no means intended to be the "end all", nor will it provide all needs or every goal, but rather it is my hope that it will serve as a starting point to expand services to students with fragile X.