EDUCATIONAL ISSUES

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Introduction

After accepting the diagnosis, parents move on to face their next challenge; determining what to do to enhance their child's functioning. The mission becomes one of deciding how they can best facilitate successful intervention, and in so doing extend to their child's best possible opportunity to learn.

In order to meet this challenge, a number of questions and answers have stimulated clinicians to investigate answers related to the prospect of educational strategies, placement options, and characteristics of services.

Because the educational setting is one in which the child spends a great deal of time, it is paramount to provide the best learning environment possible. This paper has been developed to assist parents and professionals in understanding the vast array of needs, special education services available, effective methodology and ways to advocate for the child.

Due to the relatively new discovery of the fragile X gene, schools personnel are often uninformed about the syndrome. Many times, parents become the informants through default and feel compelled to provide professional articles, written information and feedback from conferences to school personnel. In addition, parents learn how to manage children with fragile X through necessity and therefore are able to suggest strategies they have developed through experience.

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 help to ameliorate learning deficits. In addition, the emphasis shifts from curriculum designed for the traditional learner in the school population, to an individualized prescription. Because the educational needs greatly vary, services also vary. These educational services can range from partial to full day placement in self-contained classrooms, to inclusion in regular education classrooms.

Currently, special education training is rooted in "needs based instruction". This kind of instruction requires the identification of needs and then develops instructional programs to meet those needs. There is a movement in special education toward non-categorical placements. The theory espouses that if a student is significantly affected by handicapping conditions, his needs will be greater than someone who is mildly affected. For example, in a non-categorical construct, a severe needs placement would include children with a variety of etiologies, but commonly linked by the extent of services necessary to benefit from an educational experience.

The difficulty of the non-categorical construct lies in implementation. For example, even though an individual with head injury may require a moderate needs program, her fragile X counterpart may have very different needs that require very different intervention. The non-categorical system will educate these two very different children in the same special needs classroom and often with an identical program.

Dr. Robert Hodapp, an assistant professor of Special Education at UCLA, has written a number of articles related to including etiology in special education. His thinking is that "best practices" in special education can only be enhanced with increased awareness of etiology.

Dr. Hodapp, along with Dr. Elizabeth Dykens, searched the literature to determine if, in fact, etiology was excluded. Their search found that even though in medically oriented journals research compared behavioral differences among etiology, the special education and psychology journals did not.

It seems prudent to examine etiology in order to develop effective methodology. It is analogous to treating medical conditions by experts who are untrained in remediating specific conditions. As more information about learning style, processing needs and behavioral intervention becomes available, it is critical to include that information in an IEP.

Placement and Characteristics of Services

Placements vary and can include specialized delivery systems, which use a variety of related services providers. Services can include, but nor be limited to, transportation, recreational activities, speech/language therapy, behavior management, occupational therapy, interpreters, large print texts, and many others. Having these services included in an IEP is contingent upon an agreement that the related service is necessary in order for the individual to benefit from education experiences.

For example if a child exhibits sensory integration deficits, as is often the case with fragile X children, the educational intervention would include input form an occupational therapist trained in sensory integrative therapy. If the therapist felt that the sensory deficit was interfering with the ability to benefit from an educational placement (noise distraction, proximity to others creating irritability, or visual input causing confusion). Occupational therapy would be included as a related service. The IEP would reflect the amount of time the therapy would be included in the school day as well as how it would be included. For example, the service could range from direct service be the therapist certified in OT, to consultation to the teaching staff, using adaptations of furniture, weight vest, or other environmental adaptations.

Interdisciplinary Approach

When a variety of services providers are required to assist the special needs child, and interdisciplinary approach is employed. An interdisciplinary approach is one in which all disciplines are included in the decisions related to the child's placement programming. 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 behavior problem may be a response to an environmental condition. If the response is treated simply as a behavioral problem without identify the condition in the environment causing the problematic behavior, the intervention will fail.

Least Restrictive Environment

In 1975, the Federal Government passed special education legislation mandating that all handicapped children were entitled to a free and appropriate education within the "least restrictive environment" (LRE). That simply means that the individual with the disability is entitled to the same education as non-handicapped peers. In order to provide and appropriate education, the needs must be identified and carefully accounted for. The symptoms commonly associated with fragile X vary in range of severity. This obviously impacts the spectrum of affectedness and services. In other words, the severity dictates the need. The need must then be met in the best learning environment possible.

The Staffing Process

The special education process begins with an initial referral followed by testing and assessments. After all the assessments have been completed, a meeting is called to inform the parents of the results and to establish educational needs. The meeting is called an IEP (Individual Educational Plan) staffing. This meeting can be intimidating to parents who are experiencing it for the first time. Usually, all service providers who know or have evaluated the child will attend. Often, administrators (school principal, special education director) will also be in attendance. Parents are encouraged to bring friends, advocates and/or individuals who have provided private therapies to the child. It is permissible to tape the meetings so that an exact record of the discussion can be made. Some parents attend with an attorney who specializes in school law. This usually is in cases when resolution has been difficult.

The spirit of the Federal Mandate is to include a parent as an equal member of the team. Parental input is an integral part of the process and must never be discounted. Parents are encouraged to prepare for the meeting ahead of time and offer goals, intervention strategies and other pertinent information as an equal member. The staffing moves through a designated process. Each school district determines their own order or style, but essentially includes the same components. The process most often follows this sequence:

1. Current level of functioning, test results and dates of administration, diagnostic information, social and developmental history, medical history
2. Needs
3. Goals: long term, short term, general and non measurable
4. Characteristics of services: related services, environmental adaptations, service providers, and amount of time for each related service
5. Determination of handicapping condition
6. Placement decision and consideration of extended school year eligibility
7. Parental rights and due process

A document is drafted during this meeting, which becomes an educational contract between the parents and the school district. This contract is called the Individual Education Plan, or IEP. As described above, there are a number of components essential to include in this document. One of the most important is a copy of the parental rights and due process procedures. This document provides parents with the appellate process following any unresolved issue. Even though parents must sign the document at the end of the meeting, the signature does not automatically denote agreement. Parents may sign the document and add the phrase, "signature denotes attendance but not agreement."

This staffing process is one utilized nationally. The rules and regulations regarding the implementation 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 to parents of children who are handicapped.

In order to prepare for the IEP conference, it is important to understand the learning styles and how maximum potential can be achieved. What are the specific needs demonstrated by the individual with Fragile-X and how are those needs best met? The following information is designed to provide an understanding of a genera learning style and methods of intervention that have been used successfully to improve overall functioning.

Fragile X Learning Styles

The world is experienced differently by the fragile X learner. Tasks that appear to be simple to some can often become monumental to an individual with fragile X. Frequently, parents report that facts are remembered never having been taught. Performance is often inconsistent and seems to vary with environments, people, and days. It is easy to understand the frustration that builds as a result of the variations in performance. The frustration often manifests in irritability and subsequent behavioral problems.

This given, it is easy to understand that individuals with fragile X rarely benefit from traditional methods of educational instruction. Research has proven that individuals with fragile X process information globally. This means that they organize information most efficiently in a simultaneous fashion. In other words the whole or "gestalt" brings meaning to the parts, rather than in a sequential way in which parts form a whole. This style is analogous to putting a puzzle together after first seeing the whole. The initial exposure allows the individual with fragile X to formulate a schema or organizational blueprint that he can use to visually recall the image, and then recreate it by putting the pieces together.

The simultaneous processing style has intrigued a number of educational researchers. Simultaneous processing requires the ability to organize information using the whole as a point of reference for learning. One researcher (Kemper et al 1988) studied the cognitive performance of 40 males, half were diagnosed fragile X and the other half was generally developmentally delayed. She found that even though the overall IQ was lower for the fragile X sample, the achievement score (reading and spelling) were higher. In addition, she found the simultaneous processing ability was greater for individuals with fragile X. This finding generated from research has become the impetus to developing strategies that focus on those simultaneous strengths and allows individuals with fragile X to access information within an educational setting. Traditional methodology on the other hand, teaches skills through a scope and sequence, logically building one fact upon another. Unfortunately, for the individual with fragile X, this sequential approach requires a processing style, which is difficult and meaningless. The result too often is academic failure.

Educational interventions which have proven effective are those which capitalize on the learner's processing strengths. For example, reading is the best taught by using a sight or whole word approach. The Logo Reading System is an example of such a program. This program utilizes familiar fast-food logos to teach basic word identification. The learner can identify the logos without instruction, thus building confidence and decreasing anxiety. As the structure is imposed, the learner begins to tolerate the instructional design and makes sense of it.

Another reading method that has proven to be successful utilizes whole word patterns (b_in t_in s_in) or visual configuration (candy, daddy, etc.). This approach provides a visual pattern, or schema, which enhances memory. It and is more successful than a traditional phonetic approach. Phonics is often difficult because it requires blending sounds from left to right in a sequential manner in order to form words. Some have found success using a multi-sensory approach to reading such as Orton-Gillingham. Even though there is phonetic emphasis, the kinesthetic and visual cues give meaning to the auditory or phonetic component.

Math is more difficult for individuals with fragile X because it is sequential in nature. Even at the simplest level one must respond with a certain sequence of numbers that have contextual relationship to one another. Interestingly, subtraction is often more easily understood because the whole problem is seen first and then numbers can be taken away. Teaching math through visual patterns allows the learner to conceptualize and understand basic computation. Touch math has

also been proven successful because it allows the learner to visualize the numerical value while using a visual overlay (1 2 3, etc.).

Materials that are concrete and based on real life experiences can also provide better understanding to the individual with fragile X. For example, reading labels, weighing produce, and counting money provides a meaningful way to understand abstract concepts. This methodology exceeds traditional instruction, work sheets, of computational exercises.

Summary of Instructional Strategies

Several approaches that capitalize on the learning style strengths have been tested with small numbers of individuals with fragile X. Most of the information presented in this paper has been observed, without the credibility of scientific study. Nevertheless, these strategies have guided many individuals with fragile X to successful learning. These approaches are easy to employ. Often the curriculum can be modified to use "real life" materials or to present information in a simultaneous fashion.

Spelling: Spelling is best taught using whole words or configured images. The use of reverse coaching (spelling the word backward from right to left) to establish memory for difficult words has been effective. The individual with fragile X may have misspelled a simple word so many times that it has become habituated in the misspelled form. It is difficult to "undo" a habit and even more difficult for an individual with fragile X. This approach can be helpful in breaking habitual chain.

Math: The use of touch math, experiential, real life math activities and patterns is the best means of instruction. Use board games to teach counting and one to one number correspondence. It is critical to use tangible or concrete materials whenever possible because math abstractions are very difficult to understand.

Reading: The use of incidentally acquired information incorporated into a reading program is often successful. In addition, introducing a picture with the printed word and then gradually fading out the picture can be a useful way to teach vocabulary in an incidental fashion.

Highest Interest and Associative Learning

High interest and associative learning relies heavily on high interest materials. An interest inventory and parent interview can help provide those areas of interest to be incorporated into teaching methods. This approach requires more creative energy, but yields a significant pay off. Examples of ways to incorporate this strategy are numerous. For example, one individual who had great difficulty with geographical concepts learned the location and names of states and capitols while pretending to be a television weatherman. The high interest and dramatic involvement increased his success and rate of learning. Another who was interested in baseball cards, learned states and cities based on major league team locations. He enjoyed collecting the cards and the novelty provided interest.

Play and Board Game Approach

The use of play and board games can be used to teach in a non-confrontational manner. Games can become an effective educational tool for learning math concepts, developing fine motor control, and practicing social skills such as; waiting, turn taking and sportsmanship. Often, individuals with fragile X fail to access information when they are asked a direct question. It appears that the anxiety created interferes with performance or ability to respond "on the spot". If the learning experience is game-like, the perceived expectation is less threatening and more spontaneous responses occur.

Visual Pragmatic Approach

The basic assumption behind visual pragmatism is the fragile X learners' need to organize into visual images. If the environment of academic information is vague, the learner will become disinterested, confused and perhaps behaviorally disruptive. If visual images can be remembered the success rate increases and attention improves. The use of visual cueing with photographs, videotapes, or rebus picture can help with establishing pragmatic language. This method has been used to help the individual with fragile X process the sequence of the day in order to establish a schedule. Seeing the wholeness of the day's continuum promotes understanding and serves to reassure the individual with fragile X.

Concrete Real-Life Experiences

Concrete real-life experiences seem to provide to the individual with fragile X meaningful information, which is remembered, and more easily applied. The use of grocery store items to teach reading and math is an example of this strategy. Allowing the individual with fragile X to experience learning contributes to enjoyment and reduces anxiety. The use of drama, humor and music and be used to enhance learning. A natural environment is more conductive to application of concepts when they are not understood in the traditional classroom setting.

Conclusion

The educational arena presents a wonderful challenge. Traditional teaching methods are often ineffective and have contributed to the deterioration of behavior and overall school performance. Parents should be aware of the methods available to elevate their child's performance. It is important to establish a team approach with the school from the very beginning. The parent as a consultant can provide a rich resource of general knowledge, developmental history and types of effective intervention. Successful methodology for individuals with fragile X is at the infancy and needs constant stimulation to grow. It is that challenge which will help establish reliable methods of intervention, and ultimately a means by which the fragile X learner can be guaranteed an opportunity to reach full potential

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