

CFIDS Association of America

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Educational Rights, Responsibilities and Options

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A mother sits across from the school psychologist while he explains the results of her daughter's special education evaluation. The psychologist holds up a piece of paper with a shakily drawn house with 3 stick figures in front. The mother is told that the poorly drawn house and the shaky stick figures could indicate that her daughter is "emotionally dependent and possibly school phobic." Hoping that it would be a positive sign, the mother points out that the stick figures are holding hands.

The psychologist explains that there is a "significant drop" of 21 points on the WISC-R intelligence test from earlier testing when her daughter was placed in gifted classes. This "profile suggests difficulties with memory, concentration, and attention." He explains that while her "ability to process information auditorially is excellent, this is in direct contrast to difficulties with math computation done in her head." The psychologist says that while testing, her daughter seemed "distractable and impulsive" which demonstrates poor planning and organizational skills.

"Are there problems at home?" the psychologist asks...

ASSURING SCHOOL SUCCESS

After medical care, school is the most important consideration in the lives of young persons with CFIDS (YPWCs). School is central to a child's development. The classroom is where children spend most of the day learning to be happy, successful, and productive members of society. Parents and teachers must work together in a partnership based on mutual respect. They are working towards the common goal of the best and most appropriate educational services for that child.

Chronic fatigue and immune dysfunction syndrome (CFIDS) is a complex illness that has been widely debated within the medical community, leading to misinformation and confusion; therefore, positive interaction and communication with teachers is vital for the parents of a YPWC. The lack of understanding, in combination with a pattern of CFIDS symptoms that may wax and wane, makes it unrealistic to expect that a school would have an educational plan for a YPWC. Most parents find it necessary to educate the school about CFIDS while at the same time working to identify their child's unique academic strengths and weaknesses.

Many parents have described feeling so overwhelmed by the ordeal of attaining an actual medical diagnosis that they really dread having to tackle yet another potential obstacle, the school. One mother said, "I was just waiting for things to return to normal and I realized that this might be 'normal' for our family for a while." Parents have said that by becoming educational advocates and working with the school, they felt empowered. In a seemingly out of control situation, they felt that they were working toward the goal of a greater understanding of CFIDS while helping their child to succeed in school. Although there are other options, the best results seem to come to fruition when there is an atmosphere of mutual respect and positive communication.

In becoming educational advocates, parents need to have a basic understanding of what federal laws or regulations may apply to YPWCs. It's necessary to make a distinction

between laws that address civil rights and those that are education laws. Civil rights laws like the Federal Rehabilitation Act of 1973 (Section 504) and the Americans with Disabilities Act (ADA) make it illegal to discriminate against a person with a disability. Education laws like the Family Education Rights and Privacy Act (Buckley Amendment-FERPA) and the Individuals with Disabilities Education Act (IDEA) specifically address educational issues. This article will briefly define and discuss the above laws and how they may relate to YPWCs.

EDUCATIONAL ADVOCACY -- WHERE DO PARENTS START?

Parents are the ultimate educational advocates. Every time they attend a parent-teacher conference, go to a school board meeting, or review a homework assignment, parents are taking a pro-active role. They are defining what their child's educational future will be. CFIDS adds a new dimension to this role; therefore, it's necessary that parents have some additional information about their child's educational past. This information will help to identify the child's unique learning style to see if the onset of CFIDS has in anyway altered his/her educational ability or performance.

FAMILY EDUCATION RIGHTS AND PRIVACY ACT (FERPA)

This federal law is commonly referred to as the Buckley Amendment or FERPA. FERPA gives parents (and students 18 years and over) the right to have access to their child's educational records, the right to have the records amended, and the right to have some control over disclosure of the records. Educational records are defined as those records that contain information related to a student and are maintained by an educational agency. These may also include disciplinary records, psychological reports, or health files.

FERPA states that parents may "inspect," "review," and "challenge" any information that they feel is inaccurate, misleading, or a violation of any rights. The material in this file should be objective, not subjective like an opinion or comment that is unverifiable. The records should not have comments of a personal, subjective nature such as the mother is "crazy" or a child is "lazy" (actually seen stated in school records).

Parents should make a request in writing to inspect all educational records. This letter should include a request for those records in the main school office, guidance office, and the health office. The school is allowed to charge a small fee for the copies but not for the time required to make the copies. Parents are encouraged to review these records and to contact the school with questions. If parents wish to "challenge" a part of the file, they should do so in writing and state the reasons as to why the information is "inaccurate," "misleading," or a "violation." If the school disagrees, the parents may contact the state education department or the U.S. Department of Education to file a complaint.

It's a good idea to keep updated copies of a YPWC's educational records. It's helpful to know what records, testing data, or comments will be following the child all the way through his or her academic life. It will provide a comparison which may give some clues as to how CFIDS is affecting learning. There may be evidence in the file that will help justify a request for additional specialized services if the child is not achieving up to his/her pre- illness state. Parents should keep track of this information, which is more detailed and complete than a report card.

LAWS THAT MAY PERTAIN TO A YPWC's EDUCATION

Every disabled child in the United States is entitled to a free, appropriate public

education . YPWCs have the right to participate on an equal basis with their peers. This is not to say that they should be given preferential treatment or an unfair advantage. They should have access to any necessary educational resources needed to reach their full educational potential. YPWCs should be at the starting line of the race, not 10 feet behind their healthy peers.

Studies have shown that CFIDS may cause physical and cognitive symptoms that may affect academic success. The impact on education and learning depends on the severity of the symptoms and the time absent from school. There is a continuum of educational services, as there is of symptoms. In cases, a YPWC may not need any additional support services. In severe instances, a YPWC may need to receive instruction in the home. As educational advocates, parents must know their legal rights and be knowledgeable about the options available.

THE FEDERAL REHABILITATION ACT OF 1973, SECTION 504

The Federal Rehabilitation Act of 1973 is considered to be the hallmark civil rights statute protecting the civil rights of people with disabilities. There are four sections, but Section 504, having to do with non-discrimination under federal grants, states...

"No otherwise qualified person with a disability in the United States... shall, solely by reason of... disability, be denied the benefits of, be excluded from participation in, or be subjected to discrimination under any program or activity receiving federal financial assistance..."

Section 504 assures "equal" opportunities for children and youth with disabilities in schools receiving federal funds (preschools, elementary, secondary, and post-secondary institutions). Essentially it says that a school may not discriminate on the basis of a disability if it receives operational funds from the federal government. 504 is considered to be the preeminent legislation when dealing with post-secondary education. Complaints are referred to the Department of Education's Office of Civil Rights (OCR) to be investigated, making this an issue of civil rights. This differs from the Individuals with Disabilities Education Act (IDEA) where complaints are taken to an educational agency.

A YPWC may be considered to be an "individual with a disability" and qualify for protection under this civil rights statute. A "person with a disability" includes:

- 1) "any person who has a physical or mental impairment which substantially limits one or more major life activities" such as caring for oneself, walking, breathing, learning, working, etc.
- 2) or "has a record of such an impairment," such as educational, medical or employment records
- 3) or who is "regarded as having such an impairment," whether true or not.

A YPWC would have to meet one of these criteria to be considered a "person with a disability." Section 504 lists eligible conditions such as epilepsy, asthma, arthritis, diabetes, specific learning disabilities, and mental retardation because these conditions may "substantially limit" the ability to perform a "major life activity" such as walking, standing, sitting, etc. These definitions are purposely broad so as not to exclude a person whose particular disability might not be mentioned in the regulation itself, as is the case of CFIDS.

The impact of Section 504 on educational services is that disabled YPWCs may request

modifications, accommodations, or auxiliary aids which will enable them to participate in and to benefit from the educational program. Again, this is broad and non-specific with regard to education because it is not an educational law as is the IDEA. However, more YPWCs may qualify for services under 504 because it doesn't have the requirement that CFIDS be adversely affecting educational performance.

YPWCs may seek protection from discrimination and be afforded "reasonable accommodation" under 504 to avoid being classified and designated as special education students. They may request a "504 Plan" that would include any program modifications, related services, or auxiliary aids that are needed. These might include testing modifications, books on tape, special transportation, etc. It's important to note that there is no requirement for a written plan under this federal law. There may be requirements within individual state regulations or school districts may have guidelines for written plans. Because of this and the lack of set time limits, a "504 Plan" requires a very good working relationship between the parents and the school.

ANOTHER APPROACH: SPECIAL EDUCATION

Historically, little attention was given to the needs of persons with disabilities. In response to parental advocacy, the courts began to address this issue. Beginning with the Federal Rehabilitation Act of 1973, the era of disability civil rights began. In 1975, Public Law 94-142 became the hallmark piece of legislation that addressed the special educational needs of children with disabilities. This law has been amended several times. At this time the most recent re-authorization is:

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

The IDEA guarantees a free, appropriate public education to eligible children/youth with disabilities, assures due process rights, and mandates education in the least restrictive environment possible. The main objectives of the IDEA are:

- 1) to guarantee a free appropriate public education including special education and related services for eligible children/youth with disabilities;
- 2) to see that the decisions made about the special education services are fair, appropriate, and provided in the least restrictive environment;
- 3) to assure that the rights of children/youth with disabilities and their parents are protected by due process;
- 4) to provide federal funds to assist state and local governments in providing special education services. This is an important distinction as schools providing services under 504 receive no additional federal monies to do so.

To qualify for special education services under the IDEA, a YPWC must have a disability that is "adversely affecting educational performance." This is different from 504 where a YPWC may receive accommodations as a "disabled" person with no educational problems. For example, an academically successful physically challenged person may only need special transportation or occupational therapy and be serviced under a 504 plan. Another physically challenged child may be having difficulty achieving up to his/her expected level of performance and needs special education services under the IDEA.

There is a list of educational disabilities or classifications under the IDEA. The disability category or classification that may apply to YPWCs is called "other health impaired." The

definition states:

Other health impaired is "having limited strength, vitality, or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes, which adversely affects a child's educational performance".

This definition includes some possible examples of health impairments but does not include all of them. It was written in broad terms like the "disability" list in 504 so as not to exclude other chronic illnesses like CFIDS.

If eligible under the IDEA, a YPWC will receive special education services which are expressly designed to meet his/her unique needs. This includes an "Individualized Education Program" (IEP) (with educational goals and objectives), related services (physical therapy, occupational therapy), adaptive aids (calculator, word processor, books on tape), testing modifications (extended time limits, answers recorded in any fashion), special transportation (door- to-door), etc.

It's understood that there seems to be a stigma attached to special education. There is a perception of that "little classroom" in the basement with students who are very developmentally delayed and who are taunted by their "normal" peers. Hopefully, this is changing as more students with special needs are receiving services in regular classrooms. But, as with everything, the more severely impaired student is whom we think of when we hear the words "special education." Although the definition of "other health impaired" was written over 20 years ago, few students are identified and receive services under the IDEA.

YPWCs are SPECIAL and deserve whatever helps them to succeed in school. Is being known as a YPWC any less of a stigma then being known as a person with a health impairment?

THE SIMILARITIES AND DIFFERENCES BETWEEN SECTION 504 and IDEA

Section 504 of Federal Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA) strengthen each other in that schools must provide a "Free and Appropriate Public Education " for disabled children/youth along with non-disabled peers to the maximum extent appropriate (least restrictive environment), at no cost to the parents.

There are 2 major differences.

- 1) A child may be considered as having a "disability" under Section 504 but may not qualify for services under the IDEA. To be eligible for special education services under the IDEA, the disability must be adversely affecting the child's educational performance. Section 504 is broad and the IDEA is more specific.

- 2) IDEA establishes a federal grant program to assist states in providing special education and related services to eligible students. Section 504 is not an education law or a federal grant program. It is a civil rights statute that prohibits discrimination on basis of a disability. States must comply with 504 to retain federal financial assistance, but they do not receive federal funds to pay for services provided to students with disabilities covered under 504.

Like any law, the IDEA is subject to change. These changes may come from courts or Congress. Judges make written decisions in response to lawsuits based upon how they

interpret the law. There is also much discussion within state legislatures about the allocation of special education funds. Some states are considering putting a cap or limit on how much each school district can spend on special education. This will put pressure on districts to not classify new students under the IDEA. Based upon what is now being proposed by Congress and some state governments, it will become increasingly difficult to get services under 504 or the IDEA, especially for YPWCs whose needs for special services may be questioned.

WHERE DOES THE AMERICANS WITH DISABILITIES ACT (ADA) FIT IN?

The Americans with Disabilities Act of 1990 (ADA) is the civil rights guarantee for persons with disabilities. The ADA provides protection from discrimination on the basis of a disability. It also extends the rights established by the 1973 Federal Rehabilitation Act to accessibility and employment in the public and private sector, public accommodations, services provided by state and local governments, and telecommunication relay services. The ADA should be taken into consideration for a YPWC college student or a YPWC while working or looking for employment.

For example, under 504 of the Federal Rehabilitation Act, a YPWC college student would only have been entitled to receive special accommodations if the learning institution was receiving federal monies. Under the ADA, that civil rights protection has been extended into the private sector. A private educational institution has to ensure the same accessibility rights and reasonable accommodations to a YPWC with a documented disability.

The Americans with Disabilities Act (ADA) may protect YPWCs in the employment world. A YPWC who gets a part-time job may need some special accommodations in order to work. Recently, a YPWC was doing well and was able to work. As suggested by the ADA Job Accommodation Network, the YPWC got a note from the physician stating that the following "reasonable accommodations" were needed in order to perform the "essential functions" of the job. This YPWC needed to be able to drink water, use the restroom, and have assistance when lifting heavy objects. With these accommodations, the YPWC was able to take the job as a cashier. The ADA didn't require that this YPWC get preferential hiring or special treatment because it isn't an affirmative action program. The ADA allowed this YPWC an equal chance to get and to keep the job.

IS CFIDS AN EDUCATIONAL DISABILITY?

CFIDS researchers have demonstrated that the physical and/or cognitive symptoms may affect the learning process. The physical symptoms may include: severe fatigue, sleep disturbance, muscle and/or joint pain, balance problems, dizziness, headaches, visual problems, abdominal pain etc. YPWCs may have cognitive problems in the areas of attention, concentration, short-term memory, word finding, spatial relationships, mathematical processes, etc.

WHAT CAN PARENTS DO IF THEY SUSPECT THAT CFIDS MAY BE INTERFERING WITH THEIR CHILD'S EDUCATION?

Parents have the right to request an "evaluation" of their child. Under Section 504 of the Federal Rehabilitation Act, the evaluation must assess all areas related to the suspected disability; but it is suggested that parents request a special education evaluation because there is a set time table, specific guidelines, and more due process rights.

The Individuals with Disabilities Education Act (IDEA) states that a request for an evaluation may come from the parents or the school. Parents should make a written

request to the building administrator and/or the administrator in charge of special education services. Including a note from your physician is important in the case of a chronic illness such as CFIDS.

Sample Special Education Evaluation Request

Date _____

Dear (Building Administrator or District Administrator):

I am writing concerning my child (include name, DOB, school and grade) to request that you conduct an individual evaluation to determine whether or not an educational disability is present that would make my child eligible for special education services.

I am concerned about my child's educational difficulties in the following areas: subject areas (math, reading, English, social studies, science) or grades.

Please contact me as soon as possible.

Sincerely,

Name, Address, Phone Number

If the school refuses to evaluate your child because it does not suspect a disability, you must be given written notice of refusal with a full explanation. This letter must also include the procedural due process safeguards available under IDEA which include your right to challenge the refusal by requesting an impartial due process hearing.

WHAT IS A SPECIAL EDUCATION EVALUATION?

A special education evaluation under the IDEA should assess the total child and his/her unique needs. With parental permission, formal tests, observations, and assessments are done to determine if there is an educational disability and the type of special education services needed. The regulations are very strict about how school districts must conduct evaluations of children who may have a disability, and due process guidelines apply to protect the child's rights. Parents must be informed of their rights, and each school district should have its own information packet.

By law, a "multi-disciplinary team" must be involved in this comprehensive, individualized assessment. The team may include a school psychologist, educational diagnostician, medical specialist, speech and language pathologist, occupational or physical therapist, physician, classroom teachers, etc. This team approach ensures that information can be gathered in several ways because the law requires that no single procedure or test be the sole criterion for determining the appropriate educational placement.

The evaluation process should include:

- 1) observations by professionals who have worked with the student;
- 2) a medical history (in the case of a YPWC);
- 3) input from the family and student about school;
- 4) tests that examine academic ability, intellectual functioning, and other factors as appropriate. (Ask that your child be evaluated by a physical therapist and/or an occupational therapist. For example, a YPWC may have difficulty holding on to a

pen, sitting up in a chair, or walking from class to class.)

If parents disagree with the results of the school evaluation, they have the right to obtain an "Independent Educational Evaluation" (IEE). This means that parents may request that a qualified professional examiner or a qualified clinic conduct another evaluation of the child. This person or clinic must not be employed by the school district. School districts usually maintain a list of qualified examiners. Parents may request an examiner not on the list if it can be demonstrated that there are some unique circumstances that justify it.

The cost of an independent educational evaluation may be paid for by the school district, depending on the circumstances. Parents may pay for their child's evaluation if they choose. Regardless of who pays for the IEE, the school district must consider the outside evaluation results when making any decisions about the educational program of the child.

The information gathered from the special education evaluation will be used to determine if the child is "eligible" for special education and related services. In most cases the school will hold a meeting to decide if the child meets the eligibility criteria of "other health impaired" and if this impairment adversely affects educational performance. Parents should inquire about attending the eligibility determination meeting. Then an "Individualized Education Program" or "IEP" will be developed. YPWCs not eligible under IDEA for special education would still qualify for a "504 Plan" as a "person with a disability" under Section 504 of the Federal Rehabilitation Act. The services under IDEA are preferable and most appropriate because of the instructional goals, transition services, and due process protection.

THE INDIVIDUALIZED EDUCATION PLAN (IEP)

An Individualized Education Plan (IEP) is developed following the determination that a child is eligible for services. The IEP is a written statement of the educational program designed to meet a child's special needs. The IEP's purpose is to establish learning goals and to state the services that will be provided by the school. It is important because it is the basis for instruction. The IEP is used to document and review progress toward those goals. It's important to note that the IEP is not a legally binding contract that will assure that every annual goal is met. It is more of a letter of intent to provide the services needed to meet those goals.

THE "IEP MEETING"

The Individualized Education Program (IEP) is developed in an "IEP Meeting." The IEP is not supposed to be completed prior to the meeting and presented for the parents to sign. Staff involved may come prepared with recommendations regarding the goals, but parents have much to offer in the development of the IEP because of their first hand knowledge of their child. They are an important part of the "team" and should speak freely.

The purpose of the IEP meeting is to develop short-term instructional objectives and the appropriate evaluation criteria to measure the achievement of the objectives. There should also be a schedule to review the IEP at least yearly.

The following people should participate in the development of the IEP:

- 1) parents of the student, to provide information;

- 2) the student, if appropriate, especially at the secondary level;
- 3) the child's regular education teacher, special education teacher, and/or home tutor;
- 4) a representative of the school system, other than the teacher;
- 5) others requested by the school or the parents: parent advocate, clergy, case worker, or friend;
- 6) other school personnel: physical therapist, guidance counselor, administrator, school nurse, etc.

CONTENT OF THE IEP

School districts develop their own IEP forms, but by law, the Individualized Education Program (IEP) must include statements with the following information:

- 1) present level of educational performance and individual needs in the areas of academic achievement, social and physical development, and management;
- 2) classification of the educational disability, which for YPWCs is "other health impaired";
- 3) continuum of services which describes the specific type of special education services and related services and who will provide them;
- 4) annual goals, which are objectives that may be reasonable for the child to attain in one year;
- 5) short term objectives, which are smaller, measurable steps that are needed to achieve annual goals;
- 6) projected date of initiation of services and frequency and duration of services;
- 7) specialized equipment and adaptive aids;
- 8) testing modifications;
- 9) recommended placement in the least restrictive environment, including home/hospital settings;
- 10) transition services, for employment, post- secondary education, etc. to begin no later than age 16.

The IEP document is a written record of the decisions reached at the IEP meeting. For YPWCs, the special education classification of "other health impaired" will be stated. Also listed will be the annual goals/objectives and the specialized services, modifications and/or aids that will be needed to achieve those goals. The type of placement (special class, resource room, or home/hospital instruction), a service initiation date, and review date will be given. Following is a more detailed explanation of annual goals/objectives, testing modifications, transition planning, and related services.

IEP ANNUAL GOALS AND SHORT-TERM OBJECTIVES

The Committee on Special Education uses the special education evaluation to determine the child's unique learning profile. This informational overview of a student's academic function, strengths, and weaknesses helps with the development of IEP goals/objectives which assist the child in achieving full academic potential.

This unique learning profile is used to write the IEP "annual goals." These goals are statements that describe what the student may reasonably expect to achieve within a 12-month period. The annual goals are related to the student's present level of academic function. For YPWCs, some annual IEP goals may be to improve word analysis and reading comprehension, mathematical calculations and applications, written language, organizational skills, etc.

The annual goals are then broken down into smaller, more easily measured tasks called "short term instructional goals" or "IEP objectives." The IEP objectives are used as milestones or benchmarks to measure the progress that has been made toward achieving the annual goals. Both the annual goals and the IEP objectives are concerned with meeting the special needs of the student by reducing the effects that the disability has on educational performance.

For example, an "other health impaired" YPWC might have an annual goal of improving math skills. One short term objective or IEP goal may be "Given seventh grade math word problems, the student will identify the correct operation and solve the problems." Another YPWC might be having problems with organization, and a short term IEP objective would be "Given seventh grade academic classes, the student will demonstrate good work habits by keeping well organized notebooks." An appropriate written language goal is: "Given a topic, the student will use a good writing model to pre-write, draft, revise, and edit a 500-word composition."

The IEP goals and objectives are related to the special education plans. They aren't detailed or specific enough for a daily lesson plan book, but they do serve as the basis for the general path that the special education teacher will take. In many cases, YPWCs will be in regular classes most of the time, with extra help through resource room service in addition to the regular classroom instruction. The IEP is designed to track a classified student's progress with the special education services, not with regular education. At any time, the parents or the school may make a request to review and to change these IEP goals; this would be done at another IEP meeting.

IEP TESTING MODIFICATIONS

Testing modifications are changes in testing procedures or formats which provide students with an equal opportunity to participate in test situations and to demonstrate their knowledge and abilities. This gives students with disabilities the chance to demonstrate their mastery of skills and attainment of knowledge without being limited or restricted due to the effects of their disabilities. The modifications will be based on each student's individual needs as determined by the special education evaluation and the IEP meeting.

These are some possible testing modifications:

- 1) Flexible scheduling: YPWCs may tire and need frequent breaks. A time extension, in which the test is administered before the specified time and/or continues after the specified time, over several sessions or several days may be necessary. Testing duration is the maximum time that a student should work without a break. For example, a 10-minute break for every 40-minute testing period.

2) Flexible setting: YPWCs may be easily distracted or have difficulty remaining on task, may require a reader or a writer (which may be distracting to others), may be on home or hospital instruction, and/or may need special lighting, acoustics or furniture. Tests may be given individually or in a small group in an alternate testing location.

3) Revised test format: YPWCs may have visual, perceptual, or motor problems which make it difficult for them to read regular-size print or maintain their place on a page. Transcription of the test to large print, increasing the spacing between the test items, changing the size, shape or location of the answer spaces, or placing fewer items on a page, are examples of revised formatting.

4) Revised test directions: YPWCs having visual, perceptual, or motor problems may need the entire test and/or just the test directions revised. Examples are: rewriting test directions in simple language, underlining key words, and reading and/or rereading directions.

5) Use of aids: YPWCs may need special equipment or assistance to interpret and/or to respond to test items. These may include: typewriters, word processors, tape recorders, amanuensis/secretary, or other aids.

IEP TRANSITION SERVICES

The IDEA requires that the IEP contain a statement of the "transition services." Transition services are what classified students need to prepare for what they do after high school. The IDEA defines transition services as:

"a coordinated set of activities for a student, designed within an outcome-oriented process that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation... the coordinated set of activities must... be based on the individual student's needs, taking into account the student's preferences and interests, and... include... instruction, community experiences,... development of employment and other post school objectives... beginning no later than age 16 (and younger if determined appropriate)..."

Transition services are intended to help identify those goals or services that are needed by "other health impaired" students as they move into adulthood. This is an opportunity for YPWCs to take control of their lives and to become their own advocates. The transition plan needs to address the impact a chronic illness like CFIDS has on employment, education, and daily living. Transition planners should locate resources that would assist YPWCs educationally, financially, or medically. They should educate YPWCs about their rights under the Family Education Rights and Privacy Act (FERPA), the Federal Rehabilitation Act-Section 504 and the Americans with Disabilities Act (ADA). It's important to think about what the YPWC is going to do after high school and what resources or accommodations will be needed to achieve those goals.

If the YPWC's goal is to continue education after high school, then the transition plan should reflect this. This is true if the goal is a vocational-technical type program or an academic college program. Some appropriate transition goals or objectives might be: to learn/improve good study habits, identify the schools that offer the desired vocational or academic programs, do vocational assessment, arrange for the necessary testing accommodations needed during SATs or other entrance exams, apply to the schools, etc. The most important goal is for the YPWC to learn the necessary skills to be his/her own educational advocate.

Transition planning is vital as YPWCs graduate from high school and leave the protection of the Individuals with Disabilities Education Act. The IDEA covers children/youth with disabilities until age 21 or high school graduation. After high school graduation, an IEP does not exist and YPWCs will have to look for their rights as "persons with disabilities" under Section 504 of the Federal Rehabilitation Act and the Americans with Disabilities Act. There is no transition plan required under 504 as there is under the IDEA.

RELATED SERVICES IN THE IEP

IDEA defines "related services" as:

"...transportation, and such developmental, corrective, and other support services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, including therapeutic recreation and social work services, and medical and counseling services including rehabilitation counseling, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist the child with a disability to benefit from special education..."

Related services are provided in conjunction with academic classes to assist classified students with their total education program. A related service is different from a special class or a resource room in that the person providing it has special knowledge and skills that aren't usually taught in an academic classroom. These special skills are needed by students to benefit from special education instruction. A common example of a related service is speech and language. A "speech" teacher is a specialist in speech pathology and generally works with eligible students for one to two sessions a week. These "speech or language" impaired students need to improve their communication skills in order to benefit fully in their regular classrooms.

The need for related services will be determined during the special education evaluation and written into the IEP. Some examples of related services are: speech therapy, physical therapy, occupational therapy, transportation services, psychological, social work, counseling, school health services, etc. The IEP will state the type of related service specialist needed and the frequency and duration of that support service. IDEA makes federal funds available to help states provide special education and related services for students with "disabilities." There is no cost to the parents for these specialists.

Some YPWCs classified as "other health impaired" have benefited from physical or occupational therapy. Following physician referrals, YPWCs were evaluated by physical and/or occupational therapists during the special education evaluation. The Committee on Special Education determined that these YPWCs needed physical and or occupational therapy support services in order to participate fully in their educational programs.

Physical therapy (PT) is provided to increase muscle strength, mobility, and endurance. PT focuses on gross motor skills that rely on the large muscles of the body involved in physical movement and range of motion. A physical therapist helps students improve posture, gait, and body awareness. In special education, physical therapy is concerned with developing full physical potential so that classified students can achieve maximum independence and function in all their educational activities.

YPWCs may be house-bound and have difficulty sitting up for an extended period of time. Due to joint and muscle pain, they may become deconditioned, losing flexibility and range of motion. Other YPWCs, able to attend school full or part time, may still have difficulty walking from class to class or even sitting at a desk for a full school day. IEP goals for physical therapy might be: "to improve strength, endurance and flexibility in learning and school activities."

Occupational therapy (OT) focuses on the way a disability like CFIDS impacts daily life functioning. Daily life functioning includes daily living skills such as eating and dressing, school and work skills such as writing, using scissors, sitting effectively in class, and managing books and papers. OT treats fine motor functions of the small muscles which affect eye-hand coordination and manual dexterity. One YPWC's OT goal was to "conserve energy throughout the school day." The occupational therapist assisted with energy conservation techniques such as taking the school elevator and having an extra set of books at home. The OT prescribed equipment like rubber grip pen holders, book stands, computer armrests, and wrist splints.

YPWCs who are not classified as "other health impaired" under IDEA may still be eligible for related services under Section 504 of the Federal Rehabilitation Act. YPWCs with proper medical documentation are considered to be "persons with disabilities" and are covered under 504. The law requires... "the provision of... free... and appropriate educational services and related services..." There is no IEP, but the student's needs are addressed in a 504 plan. 504 is a civil rights law, and the IDEA is a special education law.

IEP ACCOUNTABILITY

The IEP is not a guaranteed performance contract that imposes legal liability on the teachers or the school if the classified student does not achieve all the IEP objectives. By law, the special education and related services must be provided as stated in the IEP. The intent is that the school and teachers make a good faith effort to assist the student in achieving his/her IEP goals. The parents still have the right to ask for IEP revisions if they feel that these efforts are not being made.

DUE PROCESS UNDER IDEA

Due process describes procedures that are used to protect a child's right to a free, appropriate public education. Laws such as The Family Educational Rights and Privacy Act (FERPA), Federal Rehabilitation Act of 1973, The Americans with Disabilities Act and the Individuals with Disabilities Education Act all address due process issues concerning education and/or employment. IDEA has very specific due process procedures called "procedural safeguards" and requires that parents be given this information. These safeguards are designed to protect the rights of parents and their children with disabilities. This also gives families and schools a mechanism for resolving disputes. These are important rights to remember when a YPWC is receiving services under IDEA.

- 1) Parents have the right to confidentiality of information. With the exception of school personnel, no one may see a child's records without written permission from the parents.
- 2) Parents have the right to participate in every decision relating to the identification, evaluation, and placement of their child. This is accomplished by attending the meetings, asking questions and giving information from a parent's point of view.
- 3) Parents must give consent for any initial evaluation, assessment, or placement. They must be informed, knowledgeable, notified of any change in placement, and included in meetings to draw up IEP and must approve these plans before they go into effect for the first time.
- 4) Parents have the right to challenge and appeal any decision related to the identification, evaluation, and placement of their children by following clearly stated due process procedures.

An excellent resource is NICHCY (The National Information Center for Children and Youth with Disabilities). NICHCY can be reached by telephone at: 800/695-0285, by e-mail at nichcy@aed.org, and at their web site: <http://www.nichcy.org>

LOOKING AHEAD

The Individuals with Disabilities Education Act (IDEA) is viewed as the major resource and entitlement for children and youth with special education needs. This is due to the IDEA's federal funding, specific instructional goals, and detailed procedural guidelines. But as has been explained, there is a civil rights law called the Federal Rehabilitation Act that protects YPWCs as persons with disabilities. If an evaluation finds that CFIDS is not adversely affecting the YPWC's educational performance, then that YPWC may still be eligible for accommodations under Section 504 of the Federal Rehabilitation Act.

There is no requirement for a written "504 Plan," but many school districts have some type of 504 plan form. Eligible YPWCs may receive related services, testing modifications, special aids or equipment similar to those described in the Individualized Education Program (IEP). Unlike the IEP, a 504 plan does not address specific instructional goals or have transition services. 504 provides the necessary accommodations that will enable disabled YPWCs to participate in and to benefit from educational programs and activities.

Section 504 has had the greatest impact on post- secondary education because most colleges and universities (even private) receive federal funds. The Americans with Disabilities Act (ADA) extends these rights into the private sector. On campuses, "disability services coordinators" work with eligible students to identify what types of accommodations are needed. Examples of 504/ADA accommodations are:

- 1) providing course modifications, substitutions or waivers of courses, major fields of study, or degree requirements. (These accommodations would not have to be made if the college can demonstrate that the change would substantially alter the essential elements of the course program);
- 2) providing services such as readers, interpreters or note takers;
- 3) permitting testing modifications such as flexible scheduling, alternate setting, and revised test format;
- 4) permitting the use of computer programs or other assistive technological devices to assist in test taking and study skills.

A good resource is HEATH (National Clearinghouse on Post-secondary Education for Individuals with Disabilities). HEATH can be reached by telephone at 202-939-9320 or by e-mail at askheath@heath.gwu.edu, and at their [web site](#).

STATE LAW CONSIDERATIONS

Most federal laws passed by Congress establish minimum standards that states must follow in order to receive federal funds. Often federal laws give the states flexibility in the implementation and delivery of educational services. Most education regulations come from state and local governments, with the exception of special education which is strictly regulated under the Individuals with Disabilities Education Act (IDEA). Every three years, states must have approved plans to demonstrate how they provide a free, appropriate public education for children with disabilities. It's important to become familiar with the state and local laws regarding education. Write to the state department of education and ask for a copy of your state's special education law regulations, policies, and any recent judicial decisions that could affect educational services. For example,

there are state proposals to put a "cap" or a limit on what percentage of a school district's enrollment may be identified as needing special education services. Parents have the right to a copies of this important information so that they may be informed educational advocates.

YPWCs AND SCHOOL SUCCESS

YPWCs face many challenges in coping with CFIDS. Dealing with the school can be very frustrating because there isn't a specific educational plan for remediating the problems caused by CFIDS. Each YPWC needs to be evaluated on an individual basis to determine his/her own unique learning style. If YPWCs are not achieving to their pre-illness state, then they are eligible for services under the IDEA. Parents may be reluctant to classify their child as "other health impaired," but all that definition means is that CFIDS is adversely affecting their child's educational performance. The special education services, accommodations, and related services are to address the very special needs that YPWCs have. YPWCs are entitled to the same educational opportunities as any other child. Their educational success shouldn't be compromised by CFIDS. YPWCs should be at the starting line along with their healthy peers.

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