

CFIDS Association of America

working to make CFS widely understood, diagnosable, curable and preventable

Educating Schools:

What Schools Need to Know About Chronic Fatigue Syndrome (CFS) , a.k.a. Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)

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Basic Information

1. According to the Centers for Disease Control and Prevention, chronic fatigue syndrome (CFS) "is an illness that is characterized by debilitating fatigue and a group of other related symptoms, including headache, sore throat, fever, weakness, lymph node pain, muscle and joint pain, memory loss, and difficulty in concentrating. By definition, the illness lasts at least six months and often for years."
2. CFS/CFIDS researchers have demonstrated that the physical and cognitive symptoms of the illness may affect the learning process. The impact on educational achievement depends on the severity of the symptoms and the time absent from school. Young persons with CFS/CFIDS (YPWCs) may require a modified full school day, half-day, or a total home tutoring program.
3. YPWCs may be inaccurately perceived as being lazy, school phobic, emotionally disturbed, or unmotivated.
4. YPWCs may experience academic failure, social isolation and resulting emotional distress, depression, and a loss of self-esteem.
5. YPWCs who are not achieving to their pre-illness state have the legal right to accommodations, related services, or special education, so they may participate on an equal basis with their peers. YPWCs have the right to achieve their full academic potential!

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How Schools Should Assist YPWCs

1. School is vital to a child's social, emotional, and academic development. The classroom environment helps teach children to be confident, productive members of society. YPWCs may miss these educational and social

opportunities.

2. A regular education program may not provide the best or most appropriate educational program for YPWCs. They may need accommodations or specialized educational support services.
3. Encourage parents to become active partners in the development, implementation, and evaluation of their child's educational program.
4. Notify parents of YPWCs' educational rights under the Individuals With Disabilities Education Act (IDEA) and The Federal Rehabilitation Act of 1973 (Section 504).
5. If YPWCs are frequently absent and are having difficulties with academics, conduct a special education evaluation to define strengths, weaknesses, and learning styles. Determine if either an Individualized Education Plan (IEP) or a 504 Plan is appropriate.

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How The "Individuals With Disabilities Education Act (IDEA)" Applies to YPWCs

1. The Individuals With Disabilities Education Act (IDEA) mandates a free appropriate public education for all children with disabilities, assures due process rights, and mandates education in the least restrictive environment possible.
2. YPWCs may fit IDEA's disability classification of "OTHER HEALTH IMPAIRED" which is defined as having "...limited strength, vitality or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, asthma, leukemia... or diabetes which adversely affects a child's educational performance."
3. The Committee on Special Education should do an evaluation to determine if the classification "other health impaired" and special education services are appropriate. The special education evaluation is conducted by a multi-disciplinary team that may consist of specialists in the areas of: psychology, special education, medicine, and physical/occupational therapy, etc.
4. The special education assessment should include: a health history and physical exam, individual psychological evaluation, social history, classroom/home observation, appropriate educational assessments to determine strengths, weaknesses, and learning styles with parental and physician input.
5. Some CFS/CFIDS researchers have been studying cognitive dysfunction in CFIDS looking for rehabilitation techniques. They have used many different assessment tools including the Wechsler Intelligence Scale (WISC) to measure the problems with: memory and comprehension, word transposition (putting the wrong word in), directional and spatial problems, acalculia (inability to do simple math), anomia (inability to match names and faces), dyslexic-type problems (letter reversals), inability to remain on task, fine/gross motor problems (difficulty walking or holding onto a pen), etc. An educational evaluation including the WISC or another intelligence test should identify YPWCs' cognitive problems and assist in remediation techniques.
6. The physical symptoms of headache, fatigue, sore throat, abdominal problems, dizziness, weakness, muscle/joint pain, lymph node pain, eye pain, etc., will fluctuate in severity and at times YPWCs may appear to be healthy. This presents the greatest challenge to educators. Academic and physical ability may change from week to week, sometimes hour to hour. The school must allow great flexibility in programming and scheduling to maximize the potential for success.
7. If YPWCs are classified as "OTHER HEALTH IMPAIRED," and this disability is adversely affecting educational performance, a special education program should be provided in the least restrictive environment possible. Most YPWCs' needs can be met in the regular classroom or by home instruction, with remedial support services such as a resource room program with testing modifications, related services, and adaptive equipment.

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If YPWCs Are Found Eligible for Special Education Services

1. IDEA requires that the parents and school meet to make decisions regarding the special education program for the "other health impaired" child. A written statement called an Individualized Education Program (IEP) is developed with parental input.
2. The IEP should include the YPWC's learning strengths, weaknesses, type of specially designed educational program, related services, adaptive aids, testing modifications, program initiation date, and annual review date.
3. There should be an annual meeting to review the IEP, but requests to amend or change the IEP may be initiated by parents, teachers, or the school. The Committee on Special Education must convene to discuss any changes.

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Special Education Services May Be Appropriate for YPWCs

1. Special education is defined as specially designed instruction to meet the unique needs of the Individualized Education Program (IEP). This includes classroom, hospital, or home instruction. This is vital for home-bound YPWCs.
2. Special education includes **Related Services** which are support services needed for the child to benefit from academic instruction. For YPWCs this may include: special transportation (door-to-door), physical therapy (to improve muscle strength, mobility, range of motion, posture, endurance), occupational therapy (to improve school skills - writing, managing books and papers), etc.
3. **Adaptive Aids** may be required to help YPWCs benefit from instruction and may include: calculator, tape recorder (note taking), computer/word processor, amanuensis (person who writes notes or test answers), books on tape (Recording for the Blind and Dyslexic, Inc. 800-221-4792), etc.
4. **Testing Modifications** allow YPWCs an equal opportunity to demonstrate their capabilities on tests and may include: flexible scheduling, extended time, flexible or alternate setting, revised test format/directions, use of aids, etc.

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Assisting Home-bound YPWCs

1. There are few regulations addressing home instruction unless it is a disciplinary matter. Some districts may have home/hospital instruction guidelines, but these are geared toward a short term absence. It is imperative that schools make every effort to provide a good home tutoring situation.
2. A good home tutoring situation exists when there is communication between the home tutor and the classroom teachers. The home tutor must have access to the academic lesson objectives and to the materials needed to present and evaluate those goals.
3. YPWCs identified as "OTHER HEALTH IMPAIRED" and receiving special education services are entitled to those services, accommodations, and/or adaptive aids as part of their home tutoring. This should be written into the IEP. For example, in New York State, resource room teachers have served as liaisons between the

school and the home tutors.

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If YPWCs Are Not Eligible for Services Under IDEA

1. If YPWCs are achieving to their pre-illness state, and their educational performance has not been adversely affected, then they are NOT eligible for services under the Individuals With Disabilities Education Act.
2. The Federal Rehabilitation Act of 1973 is a civil rights law. Section 504 assures equal opportunities for disabled youth in schools receiving federal funds.
3. With proper medical documentation, YPWCs qualify as "persons with a disability" under Section 504. A disability is having a physical or mental impairment which substantially limits a major life activity such as caring for oneself, walking, working, etc.
4. YPWCs need to be put in touch with the 504 contact person so that documented modifications, accommodations or aids may be put into a plan. This 504 "plan" will list what is needed for a YPWC to participate and benefit from the educational program.

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For Further Information: Contact NICHCY - National Information Center for Children and Youth with Disabilities 1-800-695-0285; web site: <http://www.nichcy.org>

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