SUPPORTING THE EDUCATIONAL NEEDS OF YOUNG PEOPLE WITH ME/CFS

Dr. Faith Newton, Workgroup Chair
Professor of Education
Delaware State University
CFSAC JUNE 2018

Working Group Members

- Robin Curtis (CDC)
- Ken Friedman (Associate Professor of Pharmacology and Physiology, New Jersey Medical School, retired)
- Beth Mattey (National Association of School Nurses)
- Carmen Sanchez (US Dept. of Education)
- Beth Unger (CDC)
- Vicky Whittemore (NINDS)
- Leah Williams (MassCFIDS)

Update on January 2017 Recommendations

Recommendation from the January 2017 CFSAC meeting that the CDC and Department of Education work together to develop a landing page that connects the Center for Parent Information & Resources (CIPR) website to the CDC Pediatric ME/CFS website. The intent of the landing page is to highlight resources that parents and schools could access about ME/CFS.

Center for Parent and Information Resources (CPIR) Website – Carmen Sanchez – US Department of Education
Robin Curtis – Center for Disease Control

CPIR's role is to provide information and resources to the federally funded parent centers.

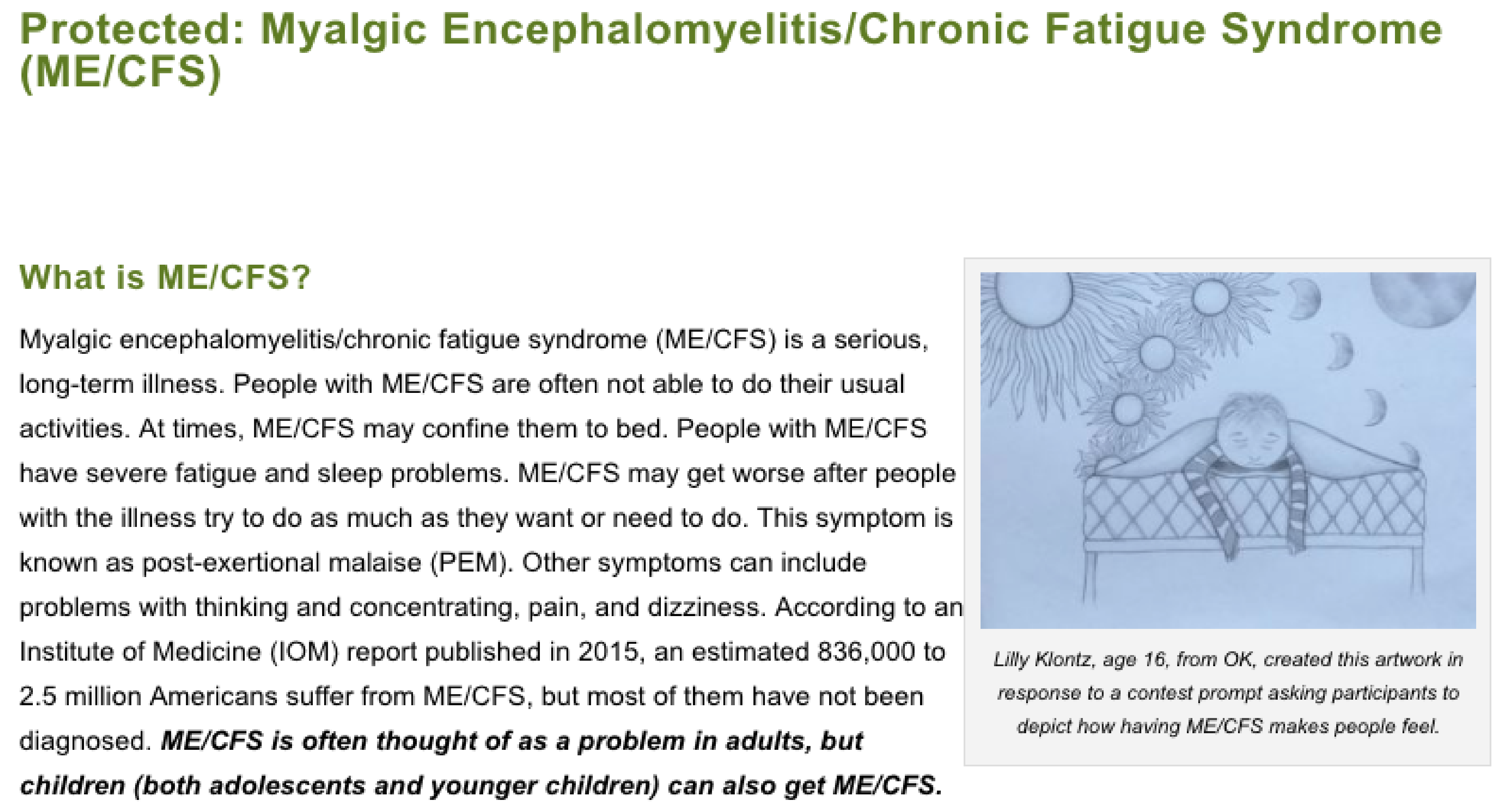
The goal is that when a parent calls a parent center, the staff members will have the links to access the ME/CFS materials.

This will be marketed to the staff of the parent centers in all 50 states.

Center for Parent and Information Resources (CPIR) Website –
Carmen Sanchez – US Department of Education
Robin Curtis – Center for Disease Control

A lot of parents also come to the CPIR website looking for help.

The information about ME/CFS has to be written in such a way that everyone who comes to the site can understand the information.

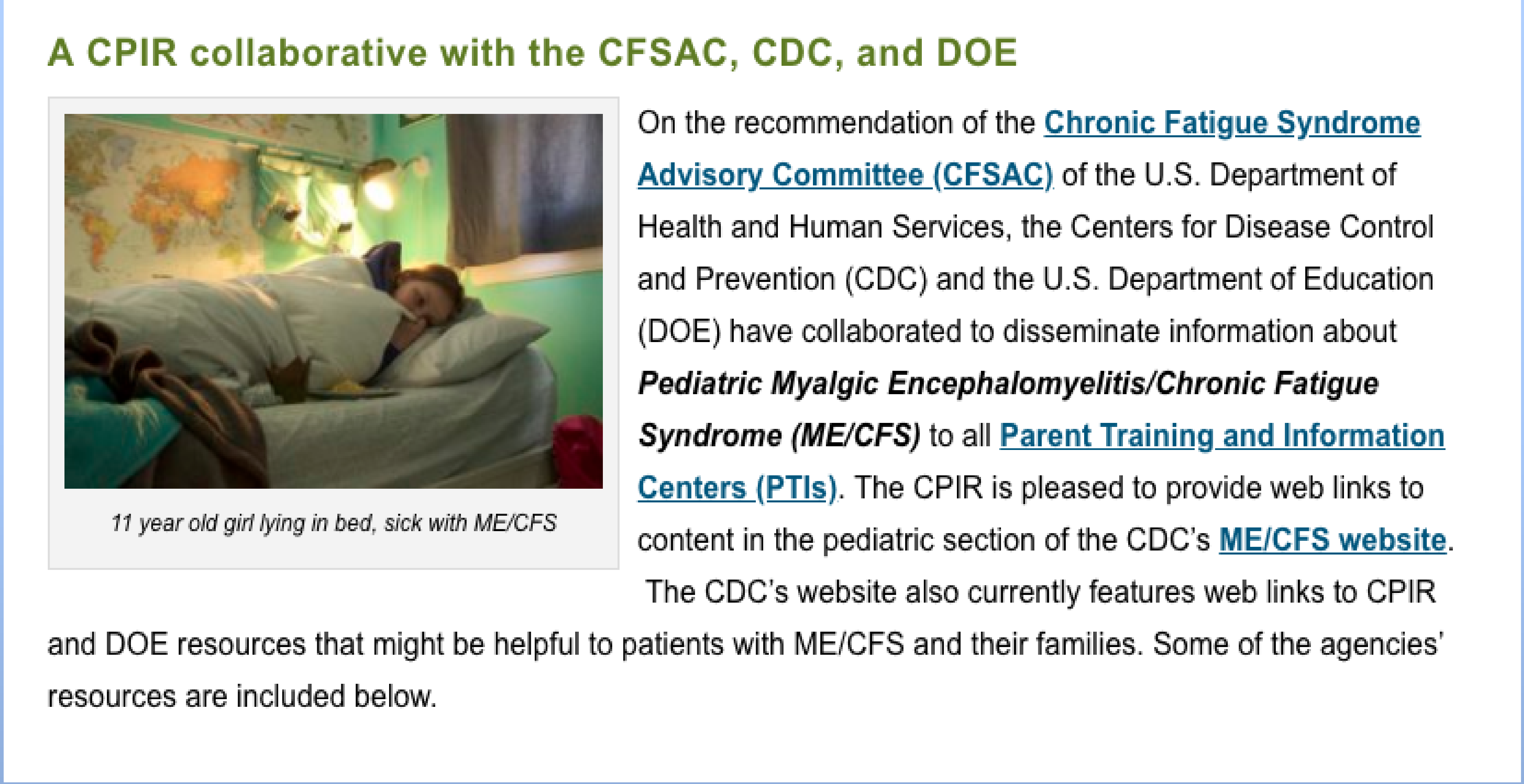


Protected: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

What is ME/CFS?

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious, long-term illness. People with ME/CFS are often not able to do their usual activities. At times, ME/CFS may confine them to bed. People with ME/CFS have severe fatigue and sleep problems. ME/CFS may get worse after people with the illness try to do as much as they want or need to do. This symptom is known as post-exertional malaise (PEM). Other symptoms can include problems with thinking and concentrating, pain, and dizziness. According to an Institute of Medicine (IOM) report published in 2015, an estimated 836,000 to 2.5 million Americans suffer from ME/CFS, but most of them have not been diagnosed. ***ME/CFS is often thought of as a problem in adults, but children (both adolescents and younger children) can also get ME/CFS.***

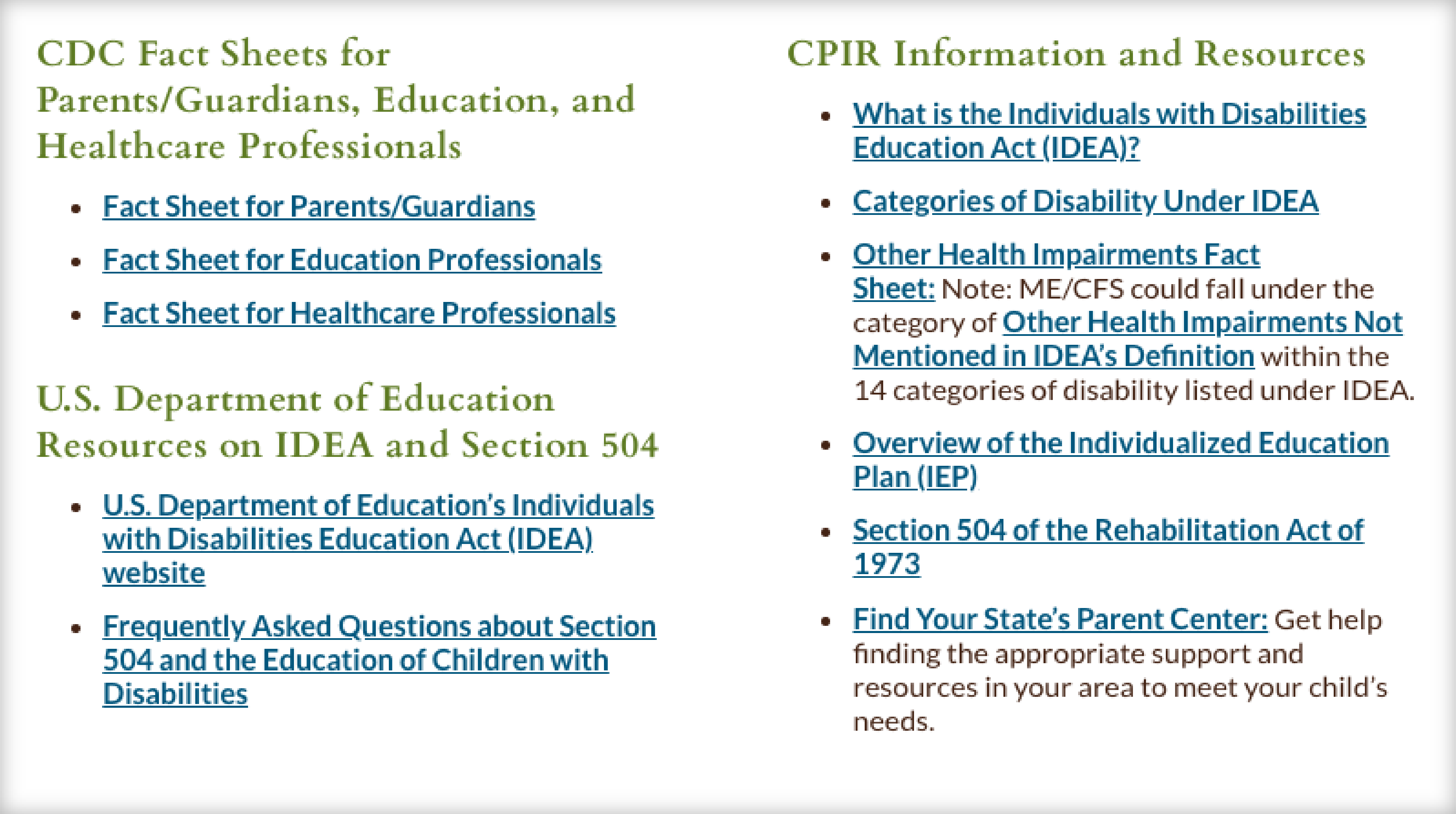
Lilly Klontz, age 16, from OK, created this artwork in response to a contest prompt asking participants to depict how having ME/CFS makes people feel.



A CPIR collaborative with the CFSAC, CDC, and DOE

11 year old girl lying in bed, sick with ME/CFS

On the recommendation of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) of the U.S. Department of Health and Human Services, the Centers for Disease Control and Prevention (CDC) and the U.S. Department of Education (DOE) have collaborated to disseminate information about ***Pediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)*** to all Parent Training and Information Centers (PTIs). The CPIR is pleased to provide web links to content in the pediatric section of the CDC's ME/CFS website. The CDC's website also currently features web links to CPIR and DOE resources that might be helpful to patients with ME/CFS and their families. Some of the agencies' resources are included below.



CDC Fact Sheets for Parents/Guardians, Education, and Healthcare Professionals

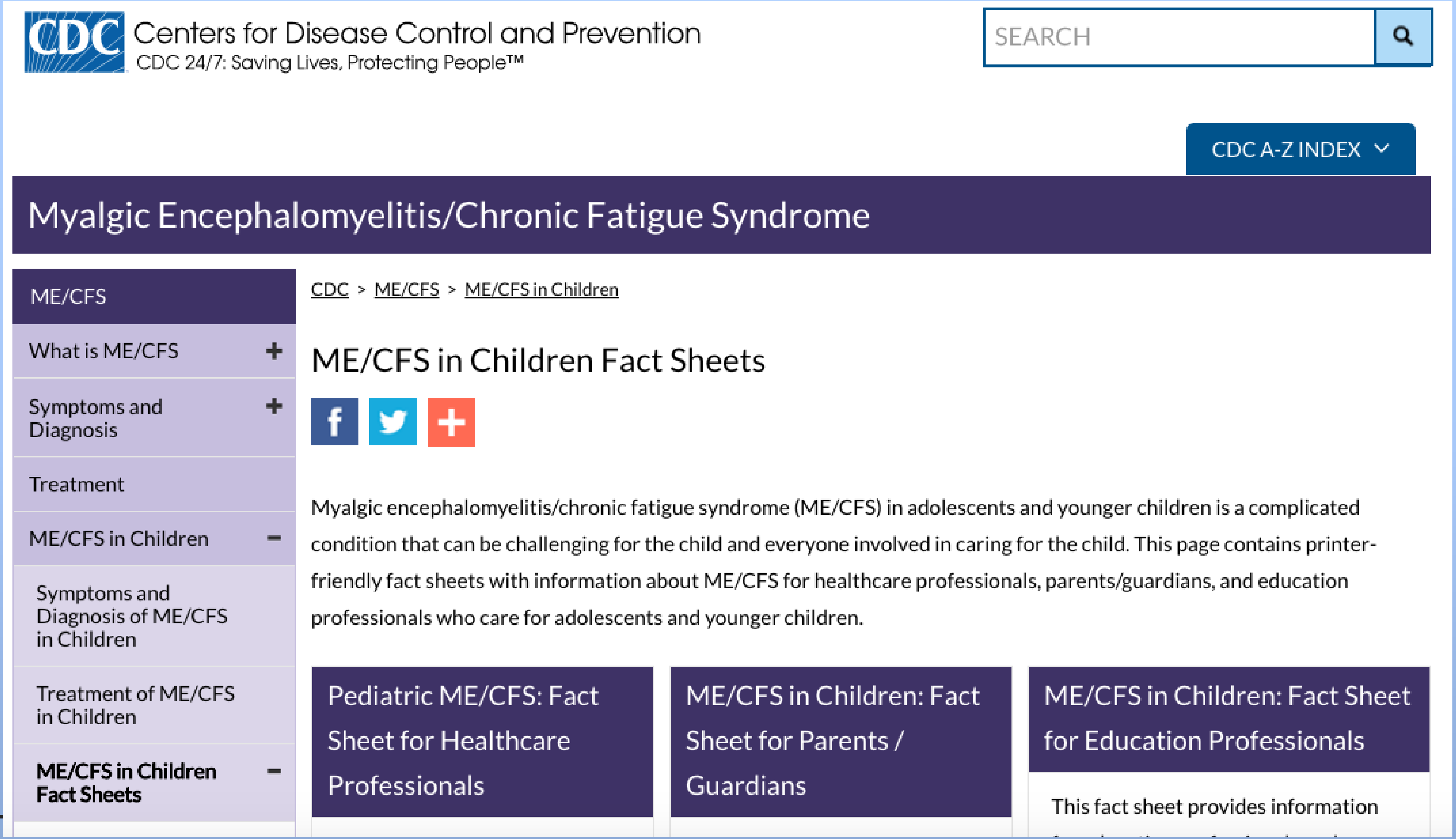
- Fact Sheet for Parents/Guardians
- Fact Sheet for Education Professionals
- Fact Sheet for Healthcare Professionals

U.S. Department of Education Resources on IDEA and Section 504

- U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) website
- Frequently Asked Questions about Section 504 and the Education of Children with Disabilities

CPIR Information and Resources

- What is the Individuals with Disabilities Education Act (IDEA)?
- Categories of Disability Under IDEA
- Other Health Impairments Fact Sheet: Note: ME/CFS could fall under the category of Other Health Impairments Not Mentioned in IDEA's Definition within the 14 categories of disability listed under IDEA.
- Overview of the Individualized Education Plan (IEP)
- Section 504 of the Rehabilitation Act of 1973
- Find Your State's Parent Center: Get help finding the appropriate support and resources in your area to meet your child's needs.



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

ME/CFS in Children Fact Sheets

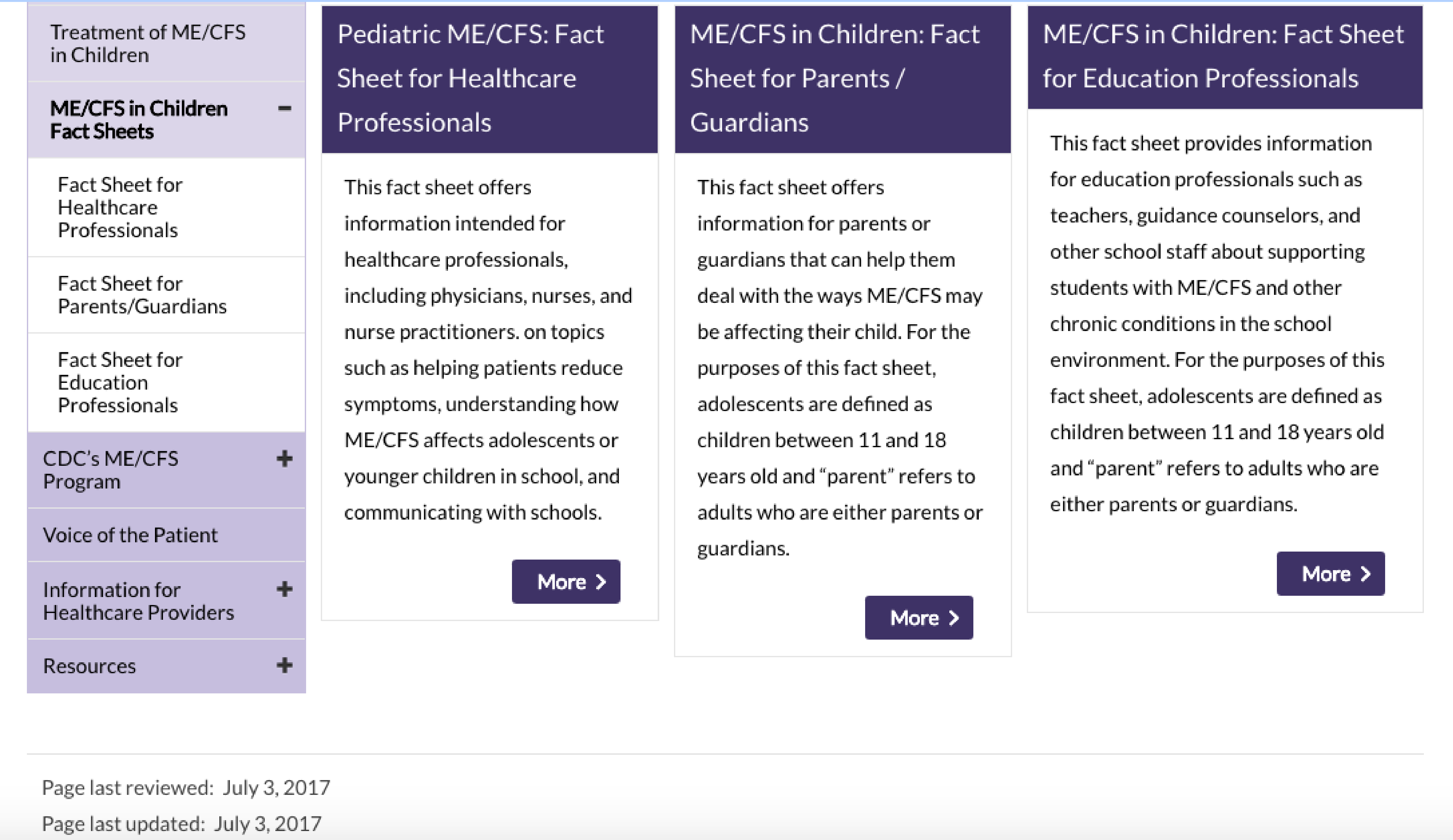
Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in adolescents and younger children is a complicated condition that can be challenging for the child and everyone involved in caring for the child. This page contains printer-friendly fact sheets with information about ME/CFS for healthcare professionals, parents/guardians, and education professionals who care for adolescents and younger children.

Pediatric ME/CFS: Fact Sheet for Healthcare Professionals

ME/CFS in Children: Fact Sheet for Parents / Guardians

ME/CFS in Children: Fact Sheet for Education Professionals

This fact sheet provides information



Pediatric ME/CFS: Fact Sheet for Healthcare Professionals

This fact sheet offers information intended for healthcare professionals, including physicians, nurses, and nurse practitioners. on topics such as helping patients reduce symptoms, understanding how ME/CFS affects adolescents or younger children in school, and communicating with schools.

ME/CFS in Children: Fact Sheet for Parents / Guardians

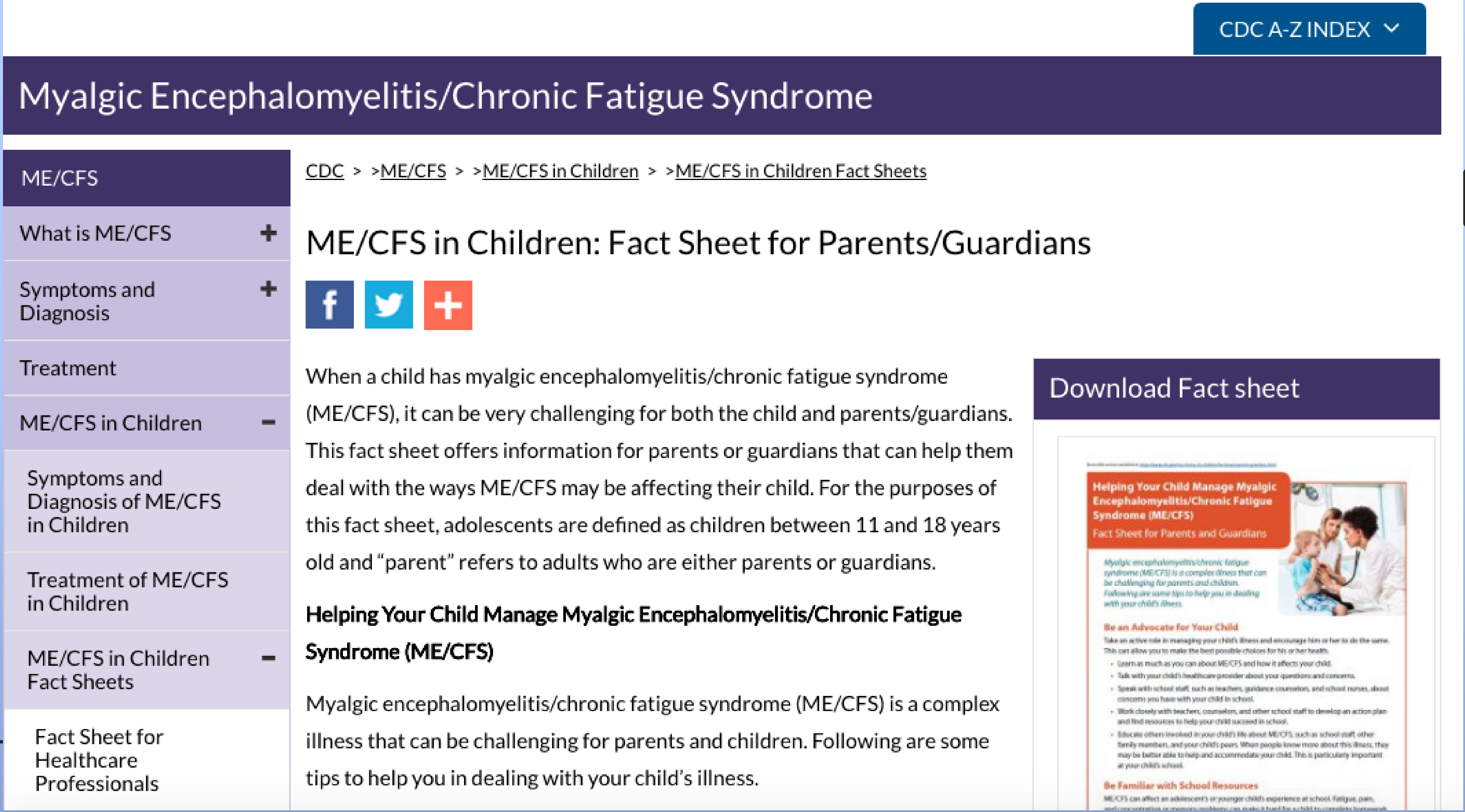
This fact sheet offers information for parents or guardians that can help them deal with the ways ME/CFS may be affecting their child. For the purposes of this fact sheet, adolescents are defined as children between 11 and 18 years old and "parent" refers to adults who are either parents or guardians.

ME/CFS in Children: Fact Sheet for Education Professionals

This fact sheet provides information for education professionals such as teachers, guidance counselors, and other school staff about supporting students with ME/CFS and other chronic conditions in the school environment. For the purposes of this fact sheet, adolescents are defined as children between 11 and 18 years old and "parent" refers to adults who are either parents or guardians.

Page last reviewed: July 3, 2017

Page last updated: July 3, 2017



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

ME/CFS in Children: Fact Sheet for Parents/Guardians

When a child has myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), it can be very challenging for both the child and parents/guardians. This fact sheet offers information for parents or guardians that can help them deal with the ways ME/CFS may be affecting their child. For the purposes of this fact sheet, adolescents are defined as children between 11 and 18 years old and "parent" refers to adults who are either parents or guardians.

Helping Your Child Manage Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex illness that can be challenging for parents and children. Following are some tips to help you in dealing with your child's illness.

Helping Your Child Manage Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Fact Sheet for Parents and Guardians

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex illness that can be challenging for parents and children. Following are some tips to help you in dealing with your child's illness.

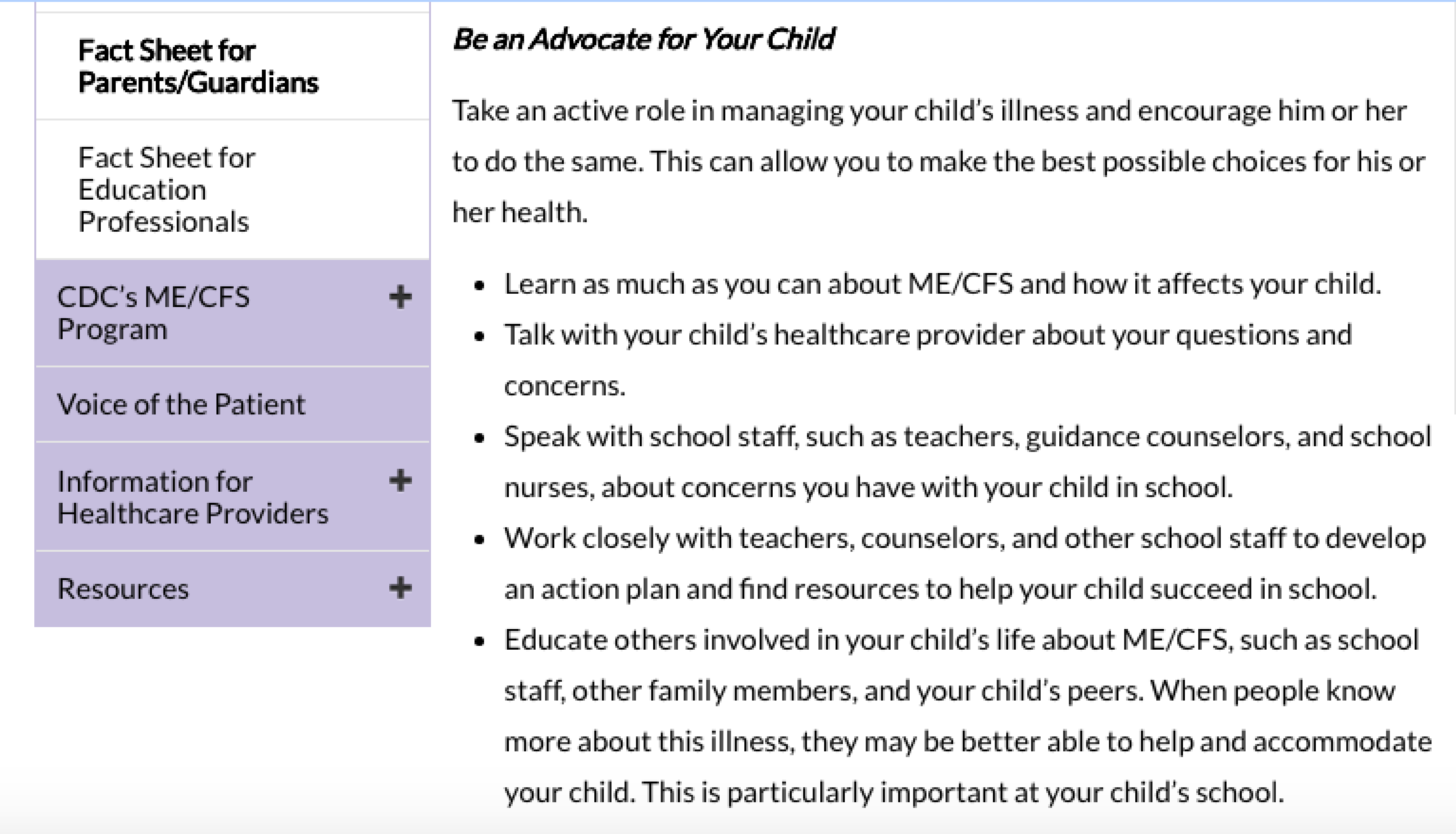
Be an Advocate for Your Child

Take an active role in managing your child's illness and encourage him or her to do the same. This can allow you to make the best possible choices for his or her health.

- Learn as much as you can about ME/CFS and how it affects your child.
- Talk with your child's healthcare provider about your questions and concerns.
- Speak with school staff, such as teachers, guidance counselors, and school nurses, about concerns you have with your child in school.
- Work closely with teachers, counselors, and other school staff to develop an action plan and find resources to help your child succeed in school.
- Educate others involved in your child's life about ME/CFS, such as school staff, other family members, and your child's peers. When people know more about this illness, they may be better able to help and accommodate your child. This is particularly important at your child's school.

Be Familiar with School Resources

ME/CFS can affect an adolescent's or younger child's experience at school. Fatigue, pain,



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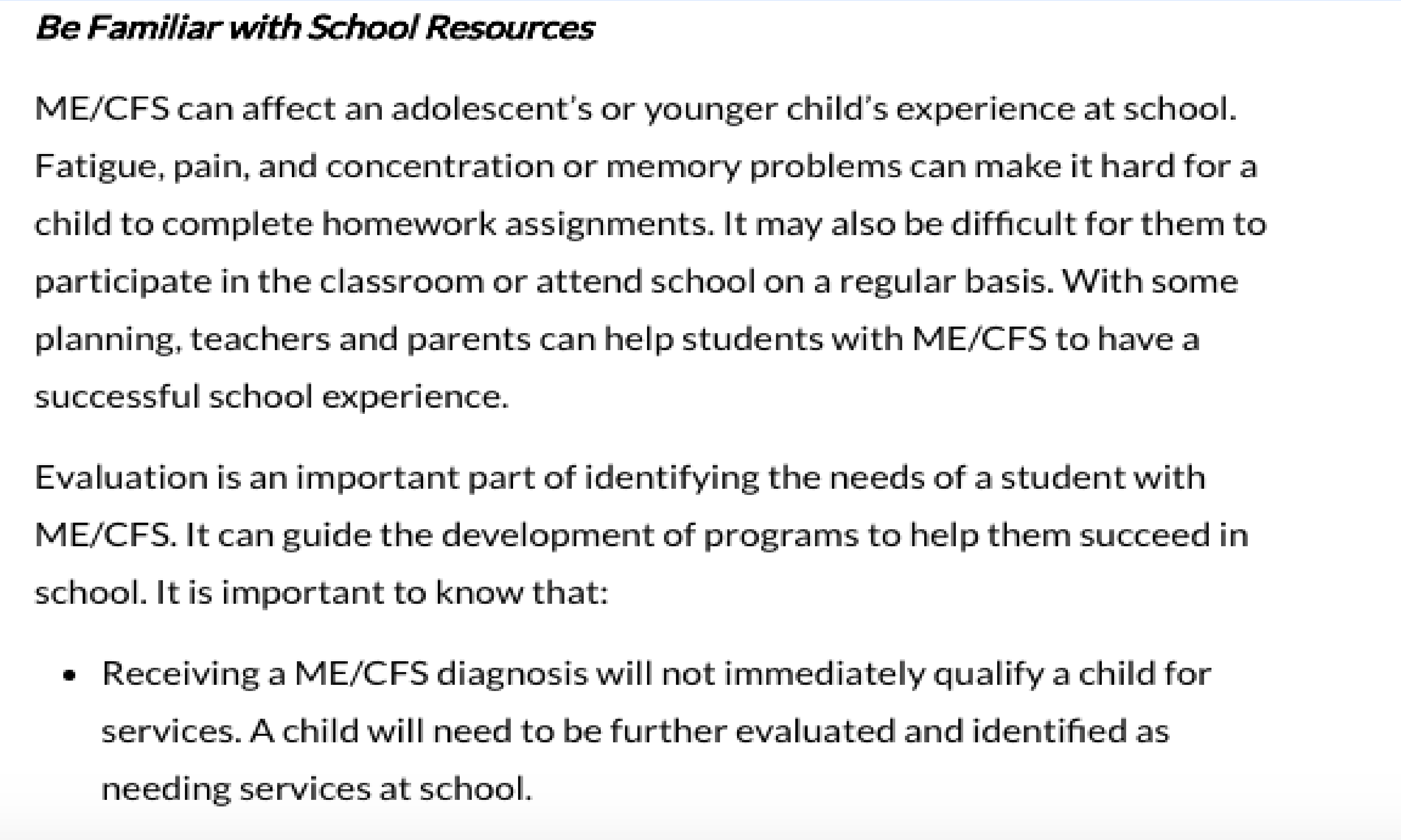
Fact Sheet for Parents/ Guardians



Be Familiar with School Resources

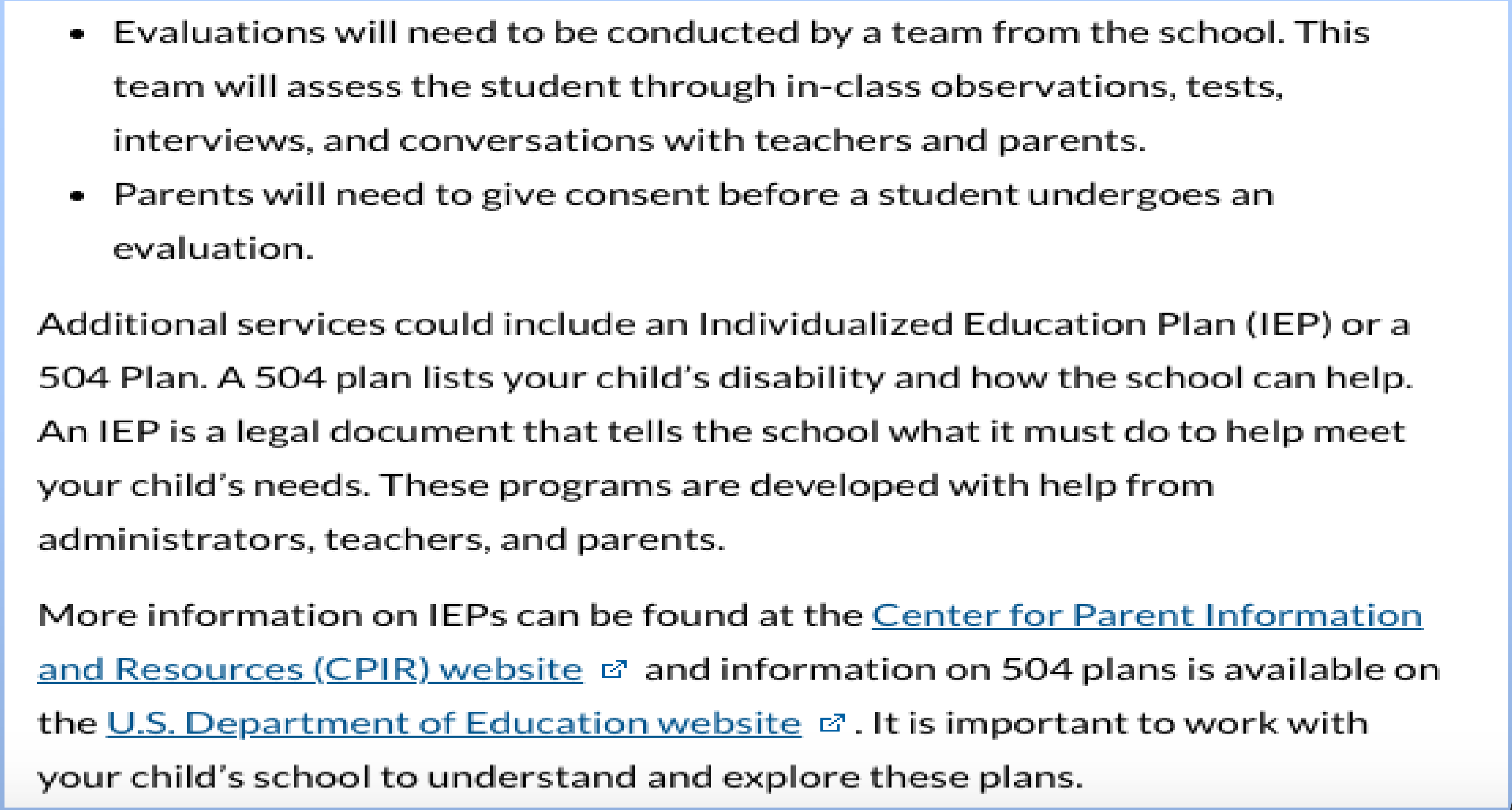
ME/CFS can affect an adolescent's or younger child's experience at school. Fatigue, pain, and concentration or memory problems can make it hard for a child to complete homework assignments. It may also be difficult for them to participate in the classroom or attend school on a regular basis. With some planning, teachers and parents can help students with ME/CFS to have a successful school experience.

Evaluation is an important part of identifying the needs of a student with ME/CFS. It can guide the development of programs to help them succeed in school. It is important to know that:

- Receiving a ME/CFS diagnosis will not immediately qualify a child for services. A child will need to be further evaluated and identified as needing services at school.

Fact Sheet for Parents/ Guardians

Be Familiar with School Resources continued….

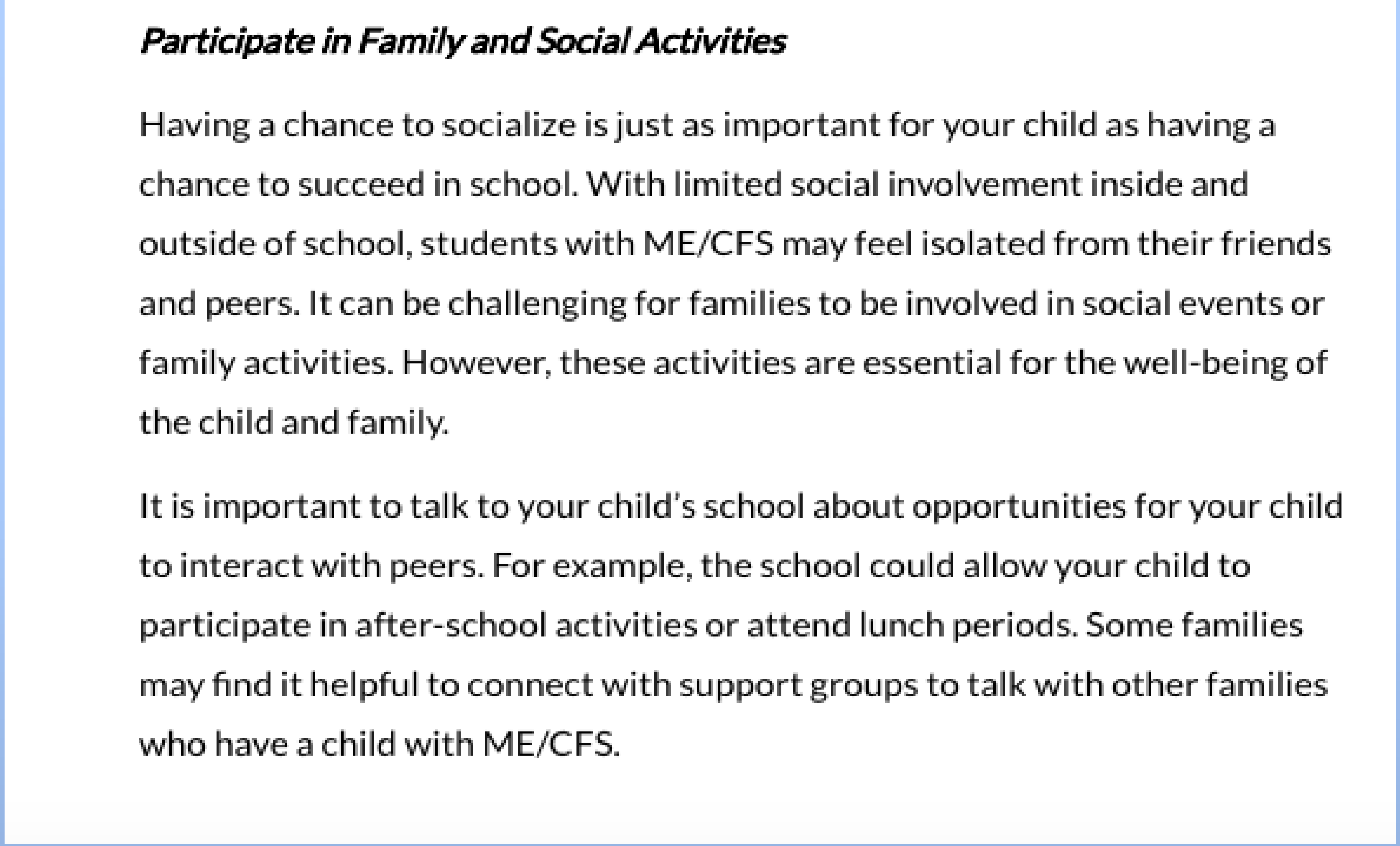


- Evaluations will need to be conducted by a team from the school. This team will assess the student through in-class observations, tests, interviews, and conversations with teachers and parents.
- Parents will need to give consent before a student undergoes an evaluation.

Additional services could include an Individualized Education Plan (IEP) or a 504 Plan. A 504 plan lists your child's disability and how the school can help. An IEP is a legal document that tells the school what it must do to help meet your child's needs. These programs are developed with help from administrators, teachers, and parents.

More information on IEPs can be found at the Center for Parent Information and Resources (CPIR) website and information on 504 plans is available on the U.S. Department of Education website. It is important to work with your child's school to understand and explore these plans.

Fact Sheet for Parents/ Guardians



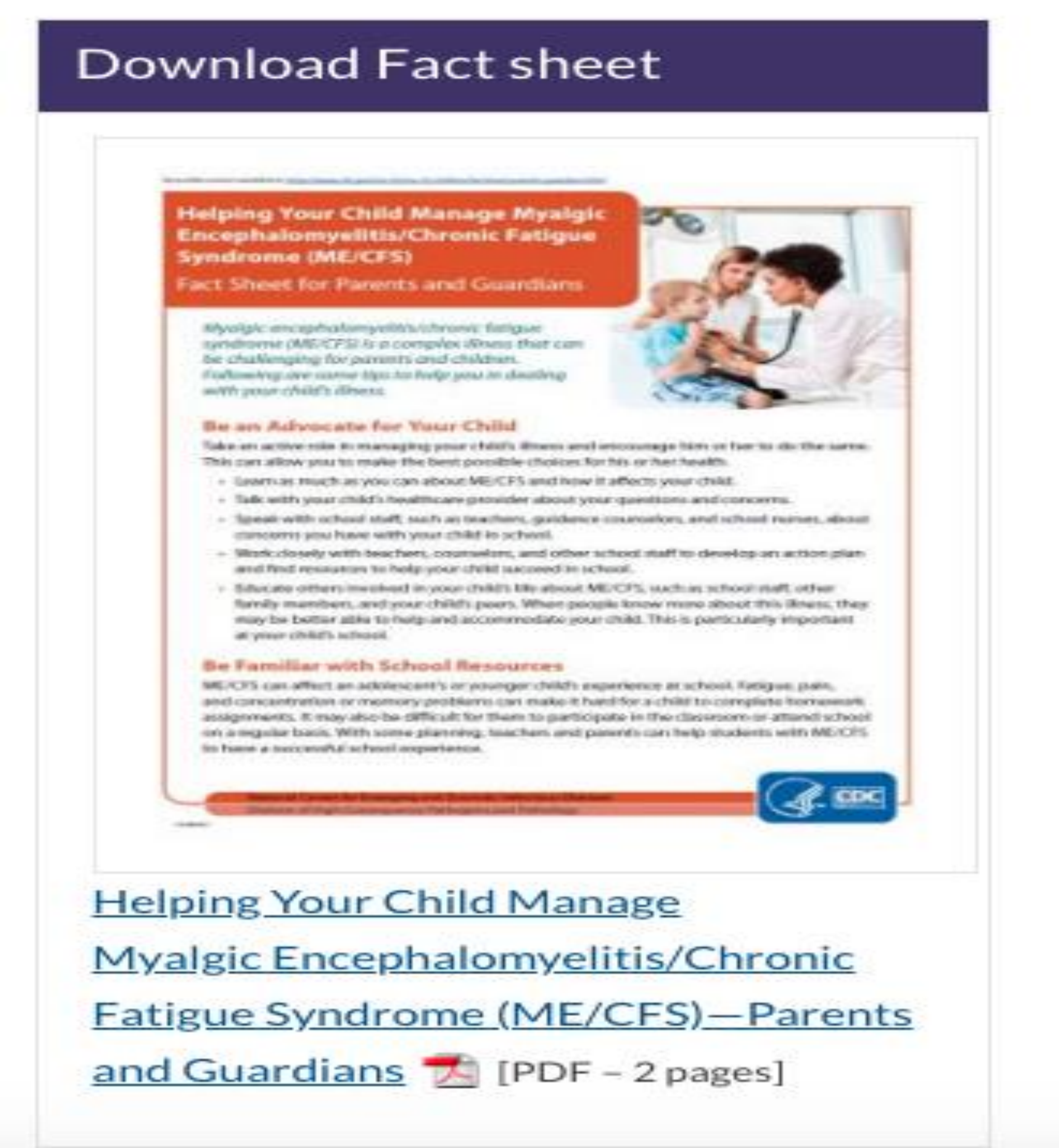
Participate in Family and Social Activities

Having a chance to socialize is just as important for your child as having a chance to succeed in school. With limited social involvement inside and outside of school, students with ME/CFS may feel isolated from their friends and peers. It can be challenging for families to be involved in social events or family activities. However, these activities are essential for the well-being of the child and family.

It is important to talk to your child's school about opportunities for your child to interact with peers. For example, the school could allow your child to participate in after-school activities or attend lunch periods. Some families may find it helpful to connect with support groups to talk with other families who have a child with ME/CFS.

Fact Sheet for Parents/ Guardians

https://www.cdc.gov/me-cfs/pdfs/me-cfs-children-parents.pdf



Download Fact sheet

Helping Your Child Manage Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

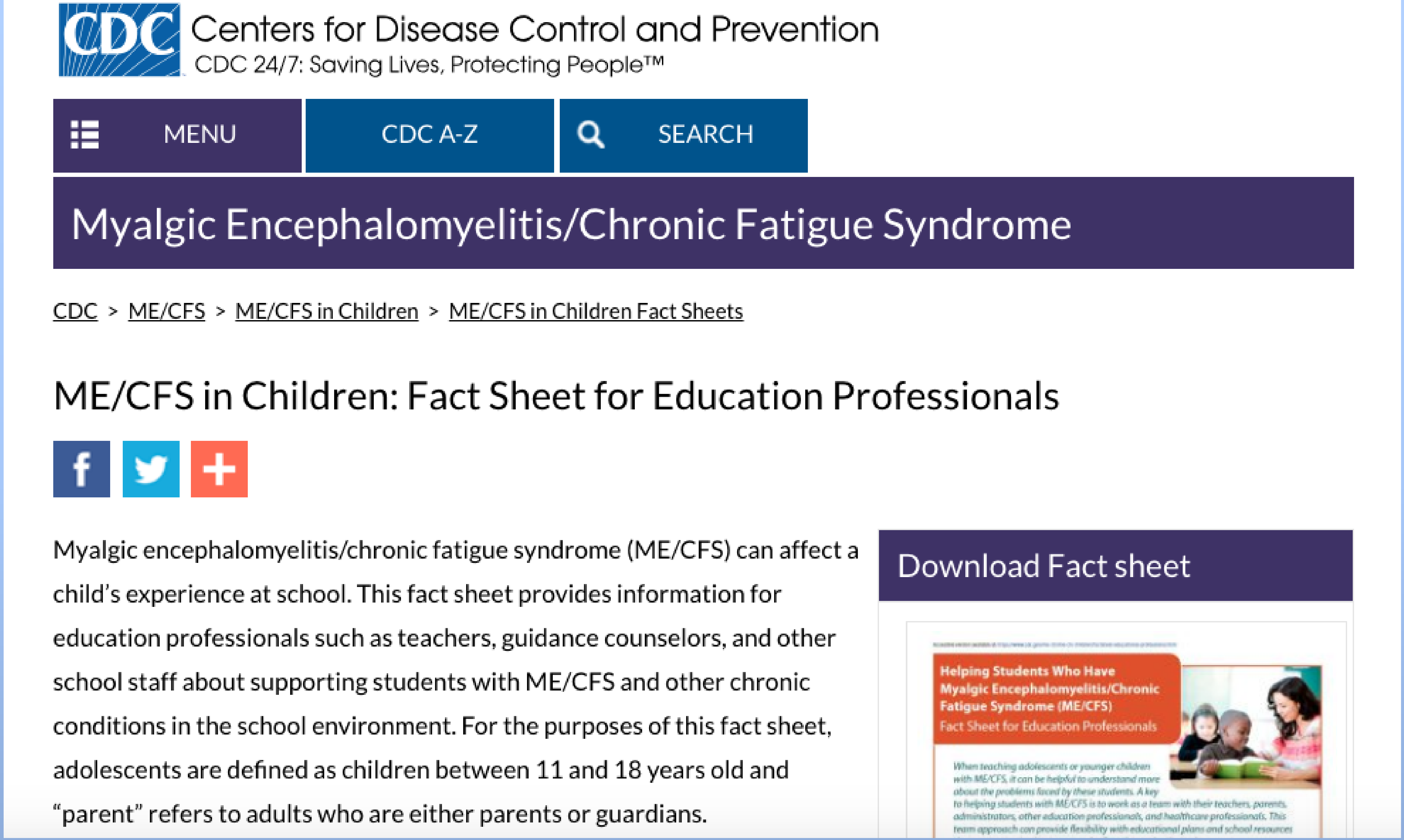
Fact Sheet for Parents and Guardians

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex illness that can be challenging for parents and children. Following are some tips to help you in dealing with your child's illness.

Be an Advocate for Your Child

Be Familiar with School Resources

Helping Your Child Manage Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)—Parents and Guardians [PDF – 2 pages]



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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

CDC > ME/CFS > ME/CFS in Children > ME/CFS in Children Fact Sheets

ME/CFS in Children: Fact Sheet for Education Professionals

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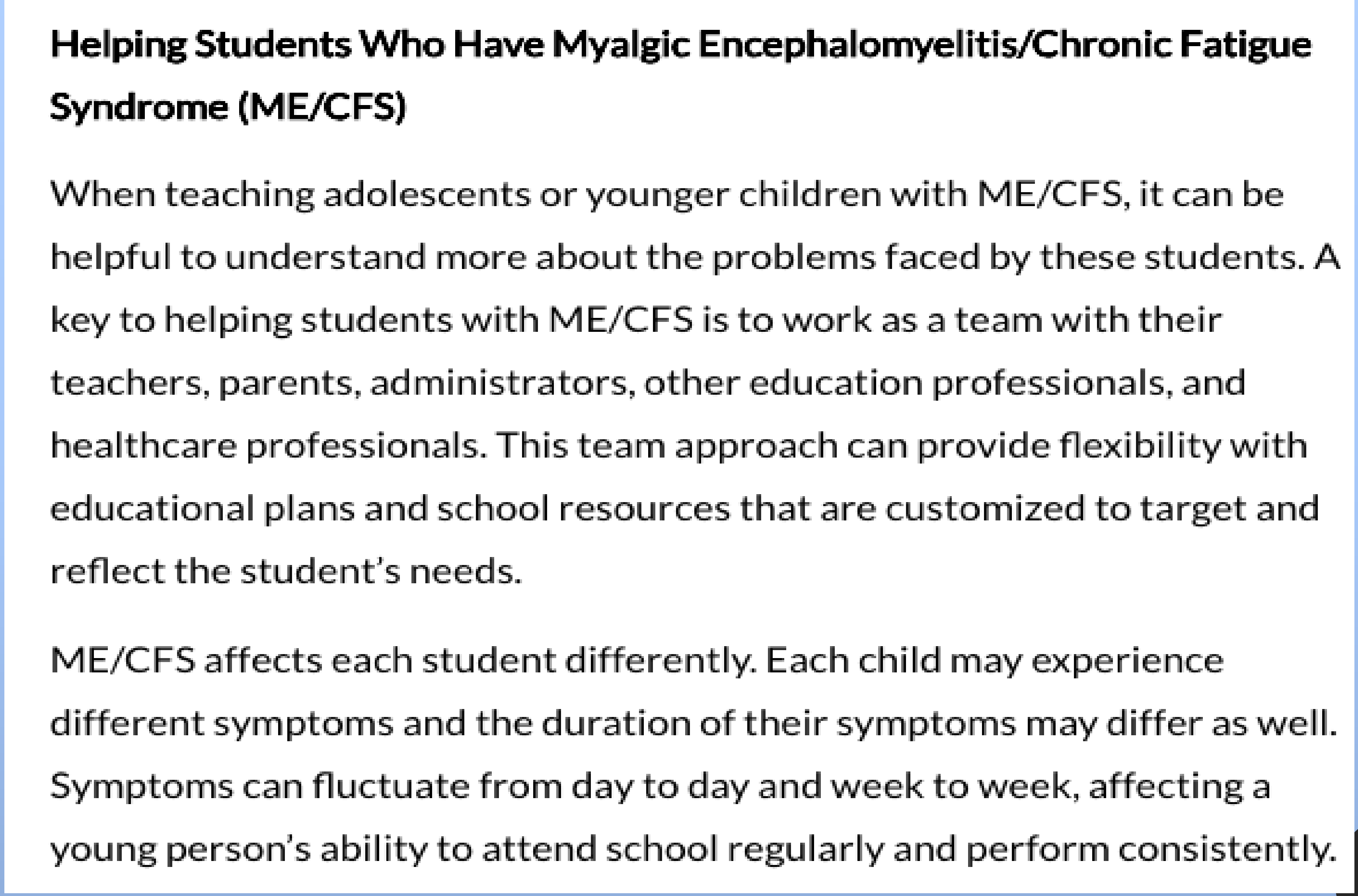
Download Fact sheet

Helping Students Who Have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
Fact Sheet for Education Professionals

When teaching adolescents or younger children with ME/CFS, it can be helpful to understand more about the problems faced by these students. A key to helping students with ME/CFS is to work as a team with their teachers, parents, administrators, other education professionals, and healthcare professionals. This team approach can provide flexibility with educational plans and school resources

ME/CFS Fact Sheet for Education Professionals



Helping Students Who Have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

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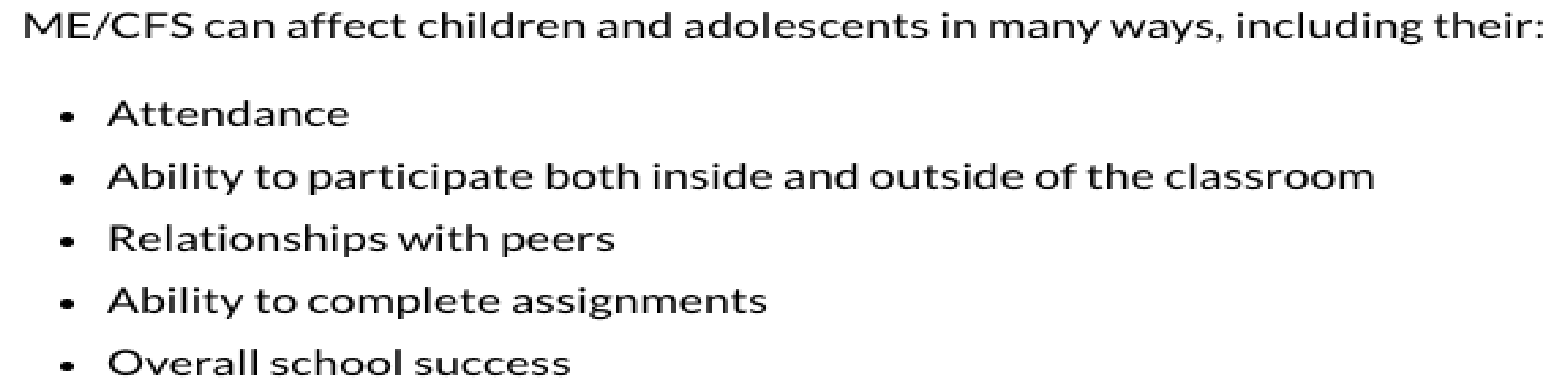
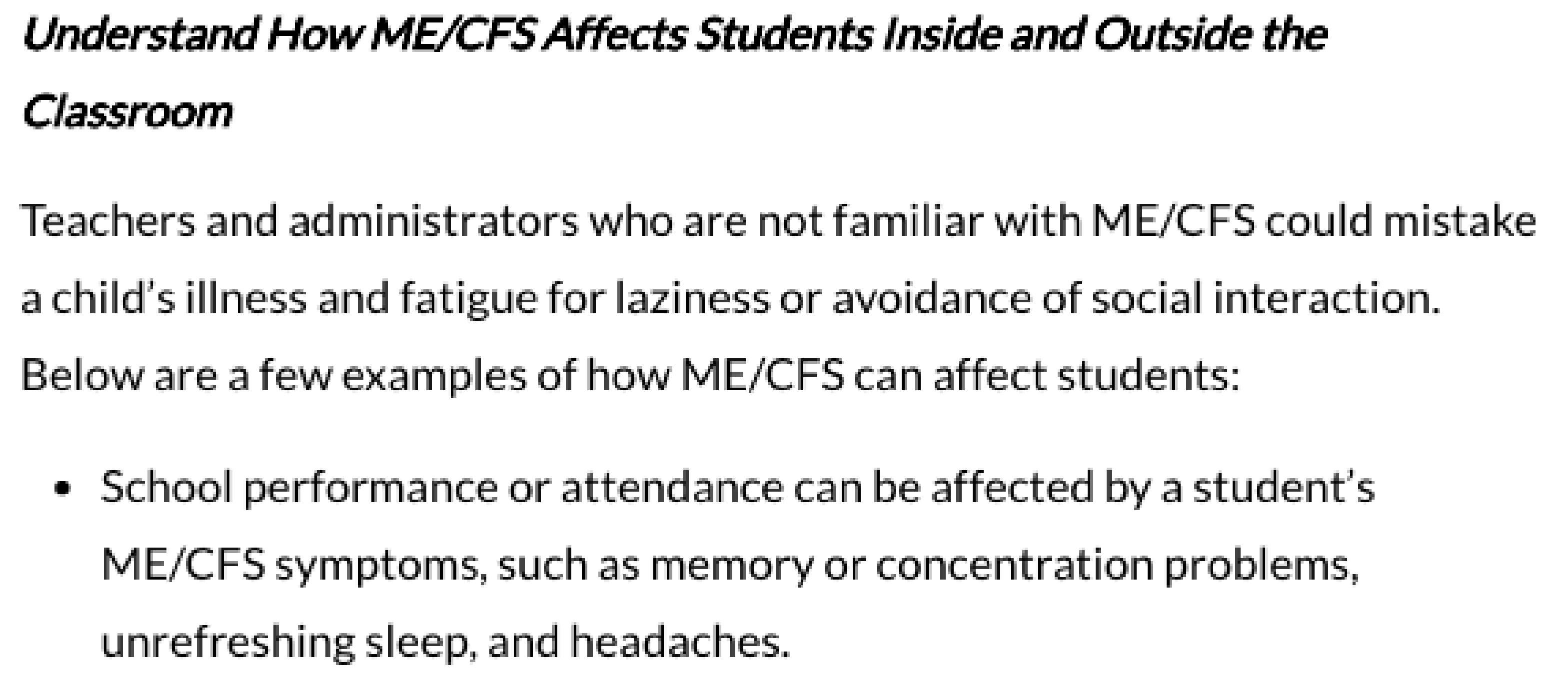
ME/CFS affects each student differently. Each child may experience different symptoms and the duration of their symptoms may differ as well. Symptoms can fluctuate from day to day and week to week, affecting a young person's ability to attend school regularly and perform consistently.

ME/CFS Fact Sheet for Education Professionals



ME/CFS can affect children and adolescents in many ways, including their:

- Attendance
- Ability to participate both inside and outside of the classroom
- Relationships with peers
- Ability to complete assignments
- Overall school success



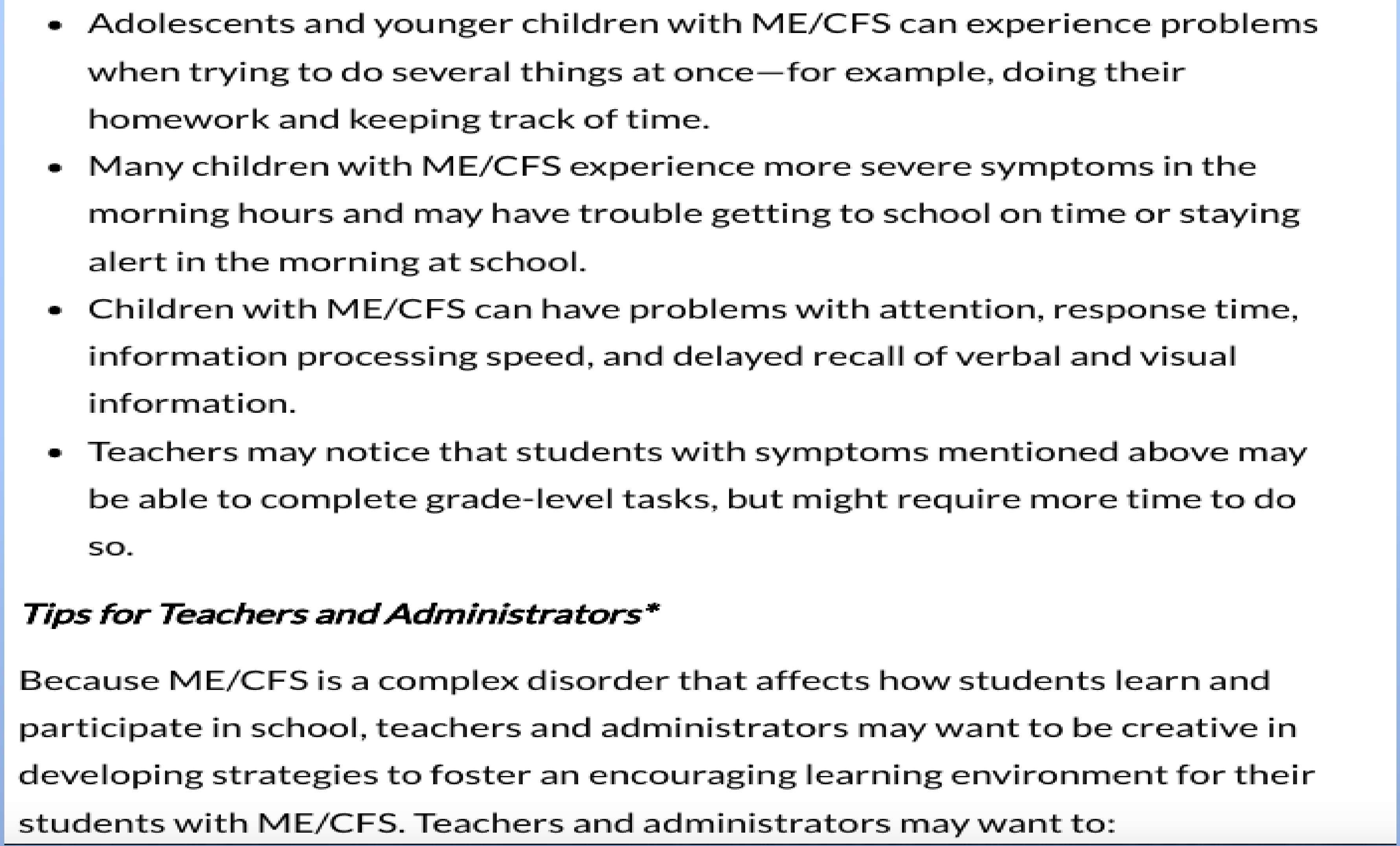
Understand How ME/CFS Affects Students Inside and Outside the Classroom

Teachers and administrators who are not familiar with ME/CFS could mistake a child's illness and fatigue for laziness or avoidance of social interaction. Below are a few examples of how ME/CFS can affect students:

- School performance or attendance can be affected by a student's ME/CFS symptoms, such as memory or concentration problems, unrefreshing sleep, and headaches.

ME/CFS Fact Sheet for Education Professionals

Understand How ME/CFS Affects Students Inside and Outside the Classroom continued...



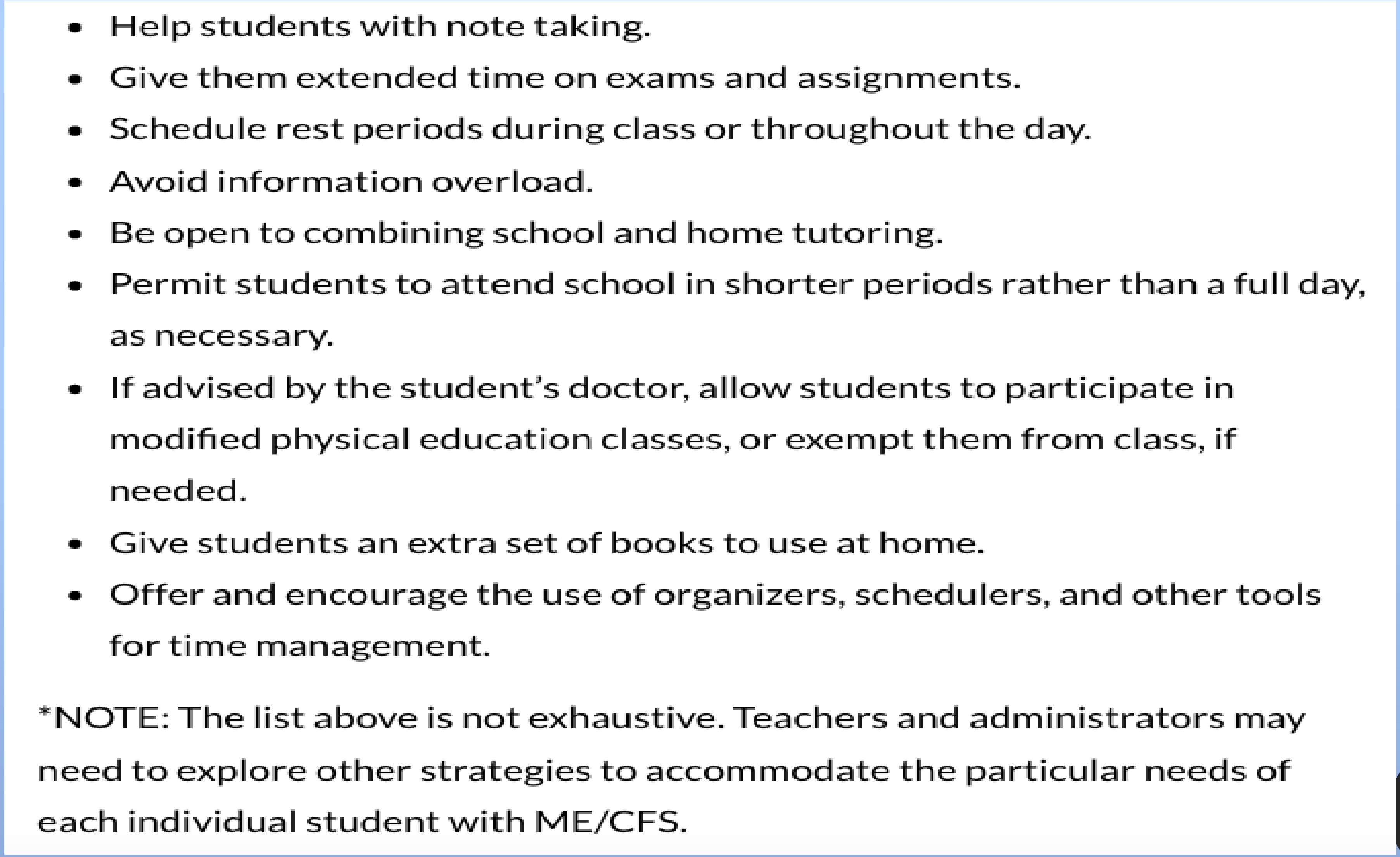
- Adolescents and younger children with ME/CFS can experience problems when trying to do several things at once—for example, doing their homework and keeping track of time.
- Many children with ME/CFS experience more severe symptoms in the morning hours and may have trouble getting to school on time or staying alert in the morning at school.
- Children with ME/CFS can have problems with attention, response time, information processing speed, and delayed recall of verbal and visual information.
- Teachers may notice that students with symptoms mentioned above may be able to complete grade-level tasks, but might require more time to do so.

Tips for Teachers and Administrators*

Because ME/CFS is a complex disorder that affects how students learn and participate in school, teachers and administrators may want to be creative in developing strategies to foster an encouraging learning environment for their students with ME/CFS. Teachers and administrators may want to:

Tips for Teachers and Administrators continued…

ME/CFS Fact Sheet for Education Professionals

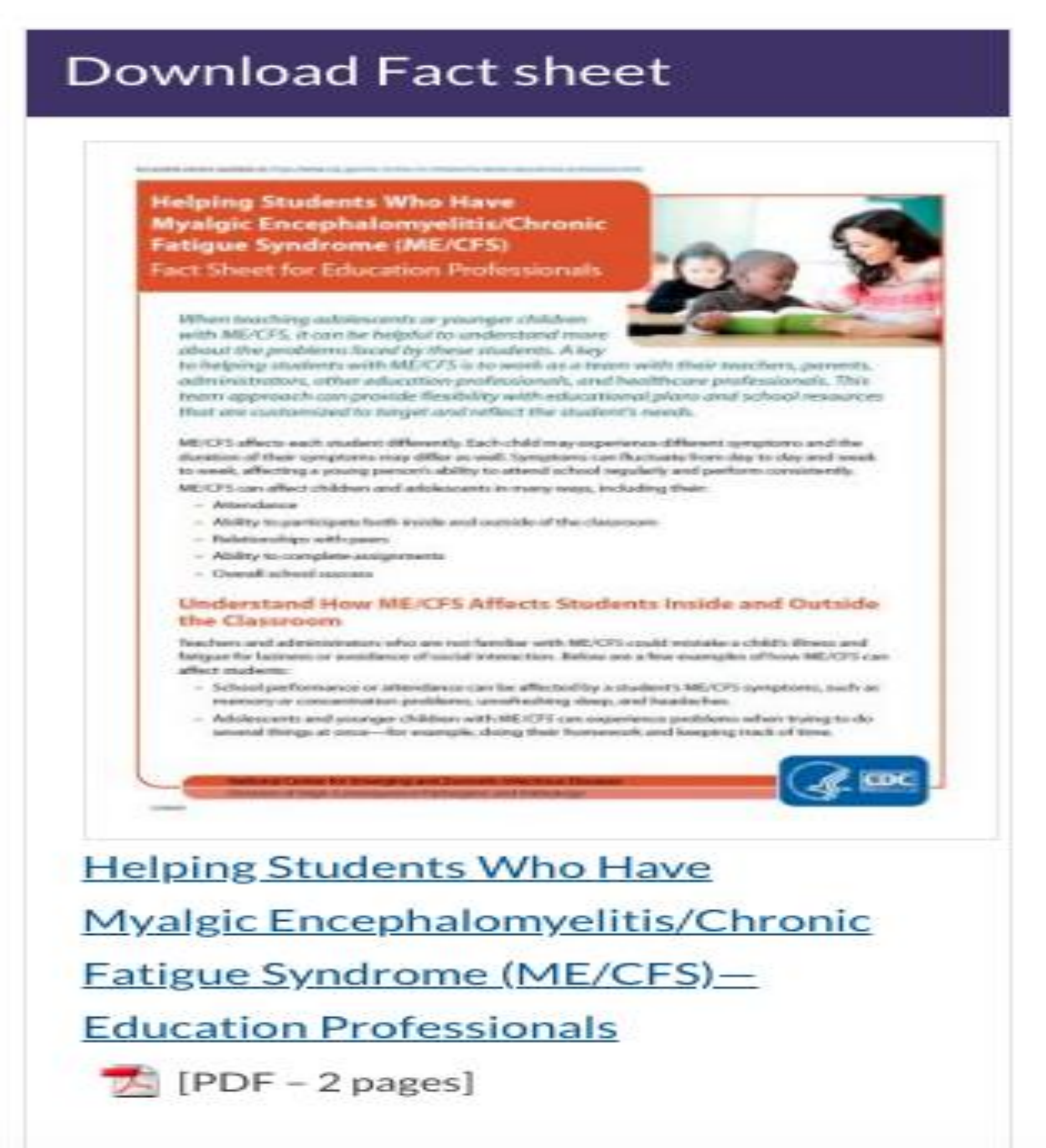


- Help students with note taking.
- Give them extended time on exams and assignments.
- Schedule rest periods during class or throughout the day.
- Avoid information overload.
- Be open to combining school and home tutoring.
- Permit students to attend school in shorter periods rather than a full day, as necessary.
- If advised by the student's doctor, allow students to participate in modified physical education classes, or exempt them from class, if needed.
- Give students an extra set of books to use at home.
- Offer and encourage the use of organizers, schedulers, and other tools for time management.

*NOTE: The list above is not exhaustive. Teachers and administrators may need to explore other strategies to accommodate the particular needs of each individual student with ME/CFS.

ME/CFS Fact Sheet for Education Professionals

https://www.cdc.gov/me-cfs/pdfs/me-cfs-children-educators.pdf



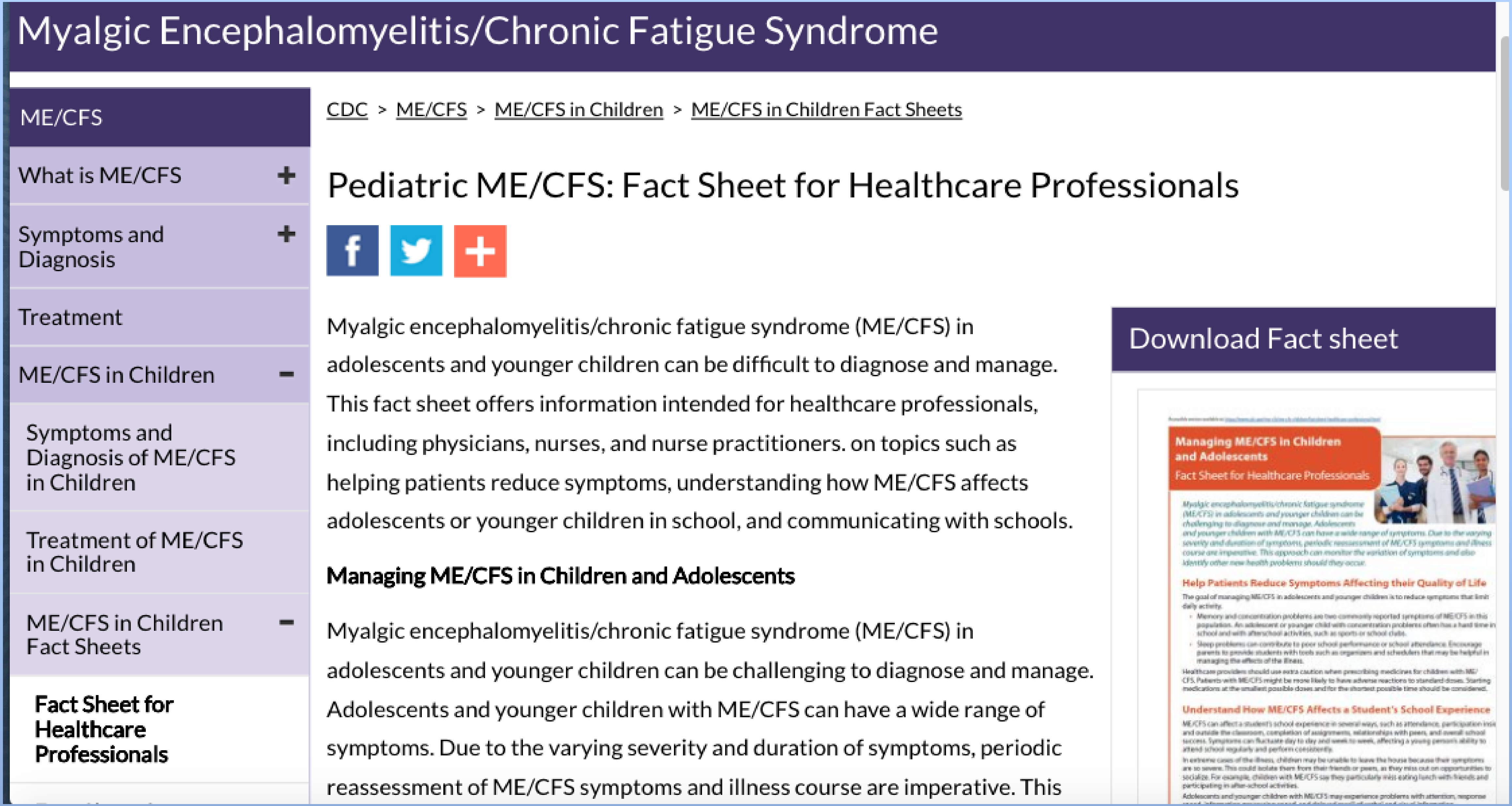
Download Fact sheet

Helping Students Who Have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
Fact Sheet for Education Professionals

Understand How ME/CFS Affects Students Inside and Outside the Classroom

Helping Students Who Have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)— Education Professionals

[PDF – 2 pages]



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

- ME/CFS
- What is ME/CFS +
- Symptoms and Diagnosis +
- Treatment
- ME/CFS in Children −
  - Symptoms and Diagnosis of ME/CFS in Children
  - Treatment of ME/CFS in Children
  - ME/CFS in Children Fact Sheets −
    - **Fact Sheet for Healthcare Professionals**

CDC > ME/CFS > ME/CFS in Children > ME/CFS in Children Fact Sheets

Pediatric ME/CFS: Fact Sheet for Healthcare Professionals

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in adolescents and younger children can be difficult to diagnose and manage. This fact sheet offers information intended for healthcare professionals, including physicians, nurses, and nurse practitioners. on topics such as helping patients reduce symptoms, understanding how ME/CFS affects adolescents or younger children in school, and communicating with schools.

Managing ME/CFS in Children and Adolescents

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in adolescents and younger children can be challenging to diagnose and manage. Adolescents and younger children with ME/CFS can have a wide range of symptoms. Due to the varying severity and duration of symptoms, periodic reassessment of ME/CFS symptoms and illness course are imperative. This

Download Fact sheet

Managing ME/CFS in Children and Adolescents

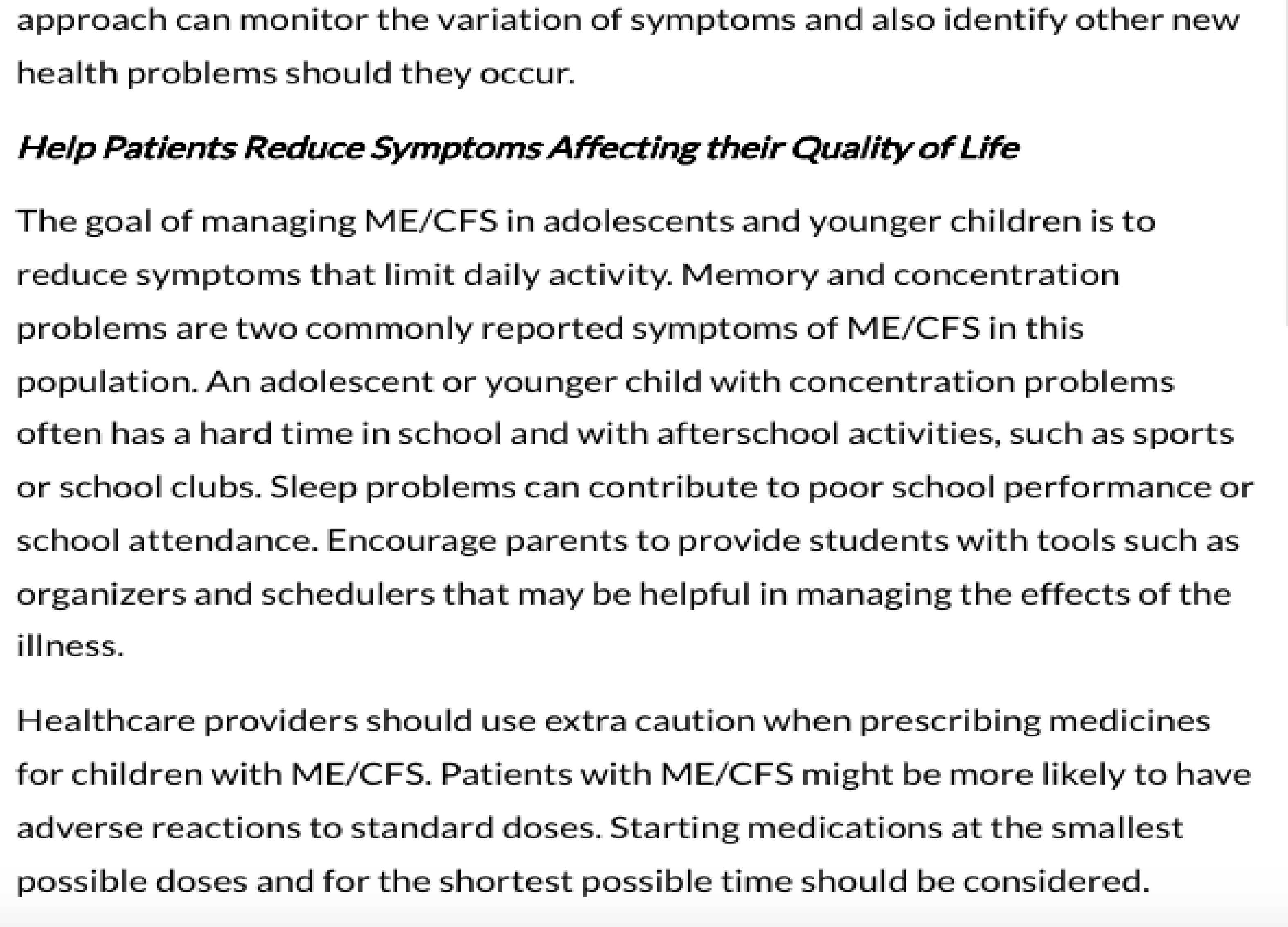
Fact Sheet for Healthcare Professionals

Help Patients Reduce Symptoms Affecting their Quality of Life

Understand How ME/CFS Affects a Student's School Experience

ME/CFS Fact Sheet for Healthcare Professionals

Managing ME/CFS in Children and Adolescents continued…



approach can monitor the variation of symptoms and also identify other new health problems should they occur.

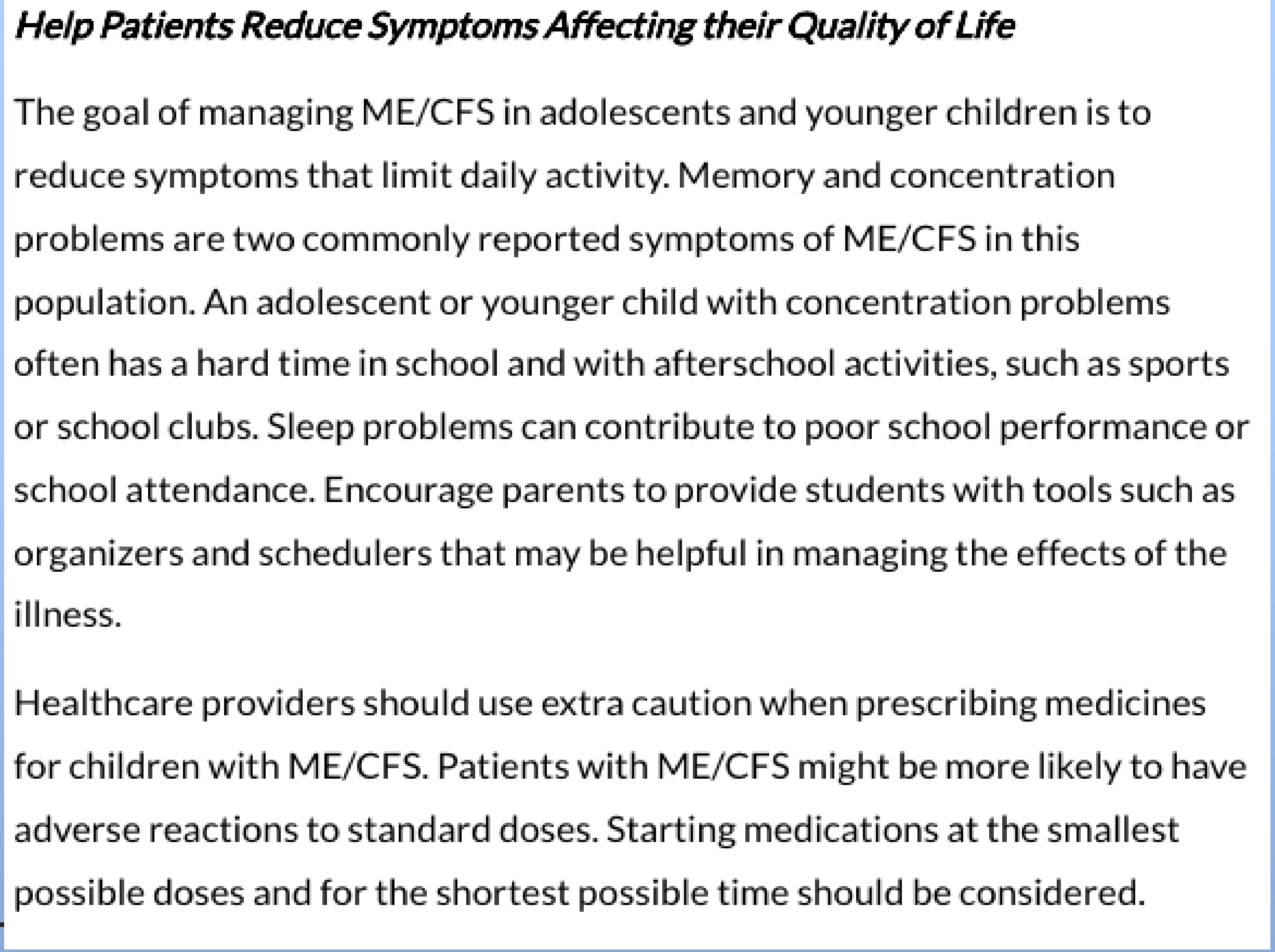
Help Patients Reduce Symptoms Affecting their Quality of Life

The goal of managing ME/CFS in adolescents and younger children is to reduce symptoms that limit daily activity. Memory and concentration problems are two commonly reported symptoms of ME/CFS in this population. An adolescent or younger child with concentration problems often has a hard time in school and with afterschool activities, such as sports or school clubs. Sleep problems can contribute to poor school performance or school attendance. Encourage parents to provide students with tools such as organizers and schedulers that may be helpful in managing the effects of the illness.

Healthcare providers should use extra caution when prescribing medicines for children with ME/CFS. Patients with ME/CFS might be more likely to have adverse reactions to standard doses. Starting medications at the smallest possible doses and for the shortest possible time should be considered.

ME/CFS Fact Sheet for Healthcare Professionals

Managing ME/CFS in Children and Adolescents continued…



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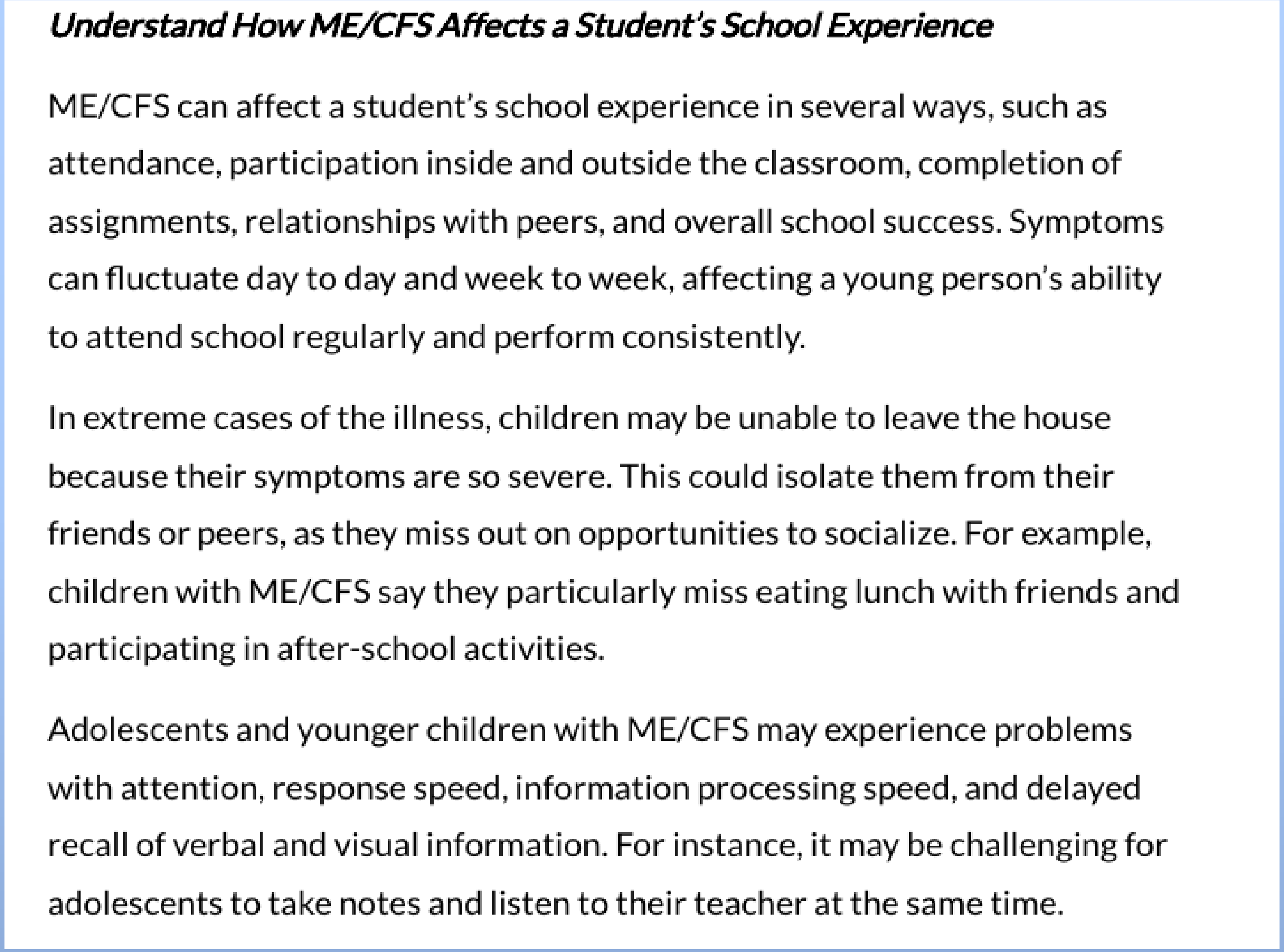
ME/CFS Fact Sheet for Healthcare Professionals



Understand How ME/CFS Affects a Student’s School Experience

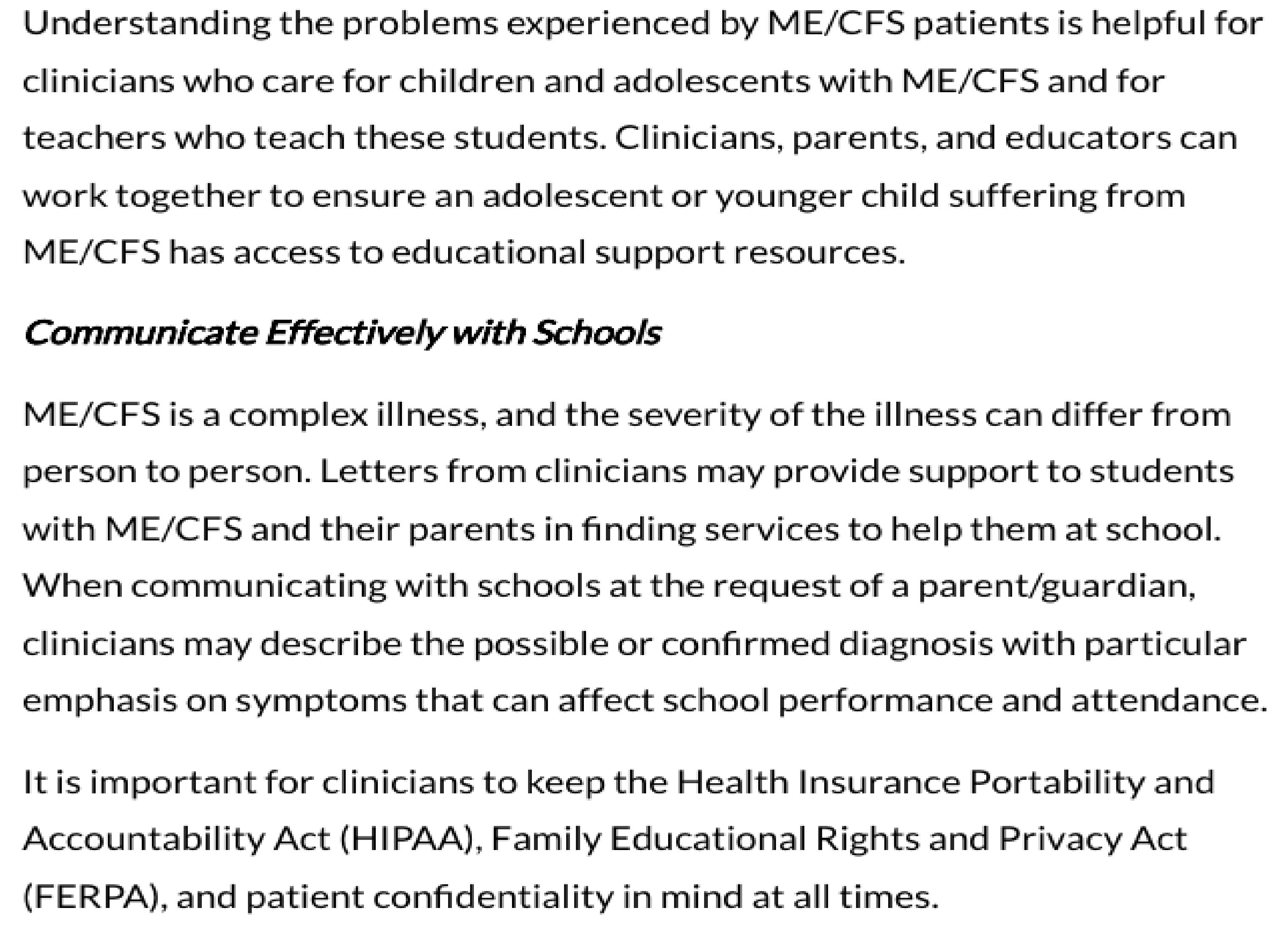
ME/CFS can affect a student’s school experience in several ways, such as attendance, participation inside and outside the classroom, completion of assignments, relationships with peers, and overall school success. Symptoms can fluctuate day to day and week to week, affecting a young person’s ability to attend school regularly and perform consistently.

In extreme cases of the illness, children may be unable to leave the house because their symptoms are so severe. This could isolate them from their friends or peers, as they miss out on opportunities to socialize. For example, children with ME/CFS say they particularly miss eating lunch with friends and participating in after-school activities.

Adolescents and younger children with ME/CFS may experience problems with attention, response speed, information processing speed, and delayed recall of verbal and visual information. For instance, it may be challenging for adolescents to take notes and listen to their teacher at the same time.

Understand How ME/CFS Affects a Student's School Experience continued...

ME/CFS Fact Sheet for Healthcare Professionals



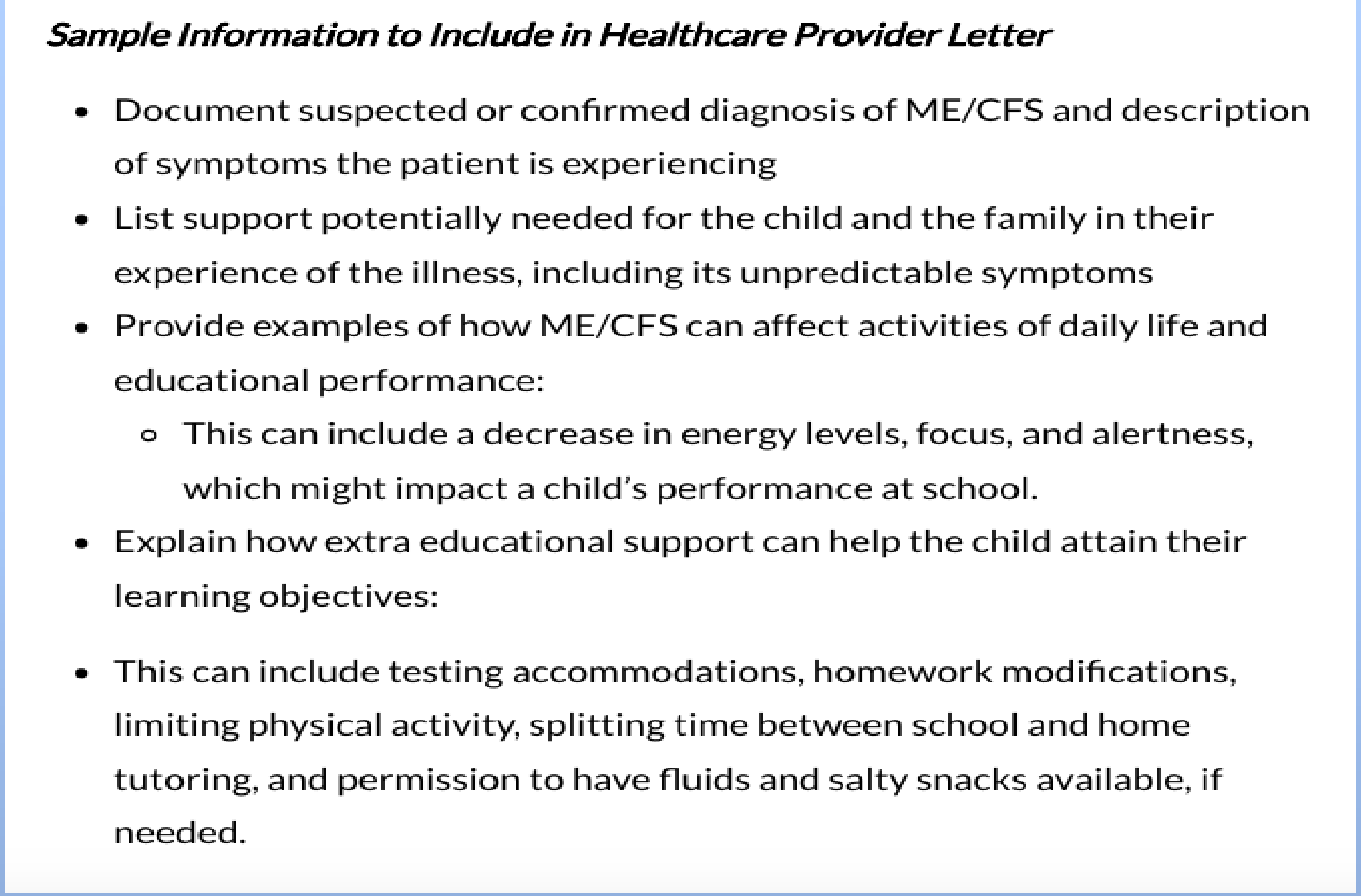
Understanding the problems experienced by ME/CFS patients is helpful for clinicians who care for children and adolescents with ME/CFS and for teachers who teach these students. Clinicians, parents, and educators can work together to ensure an adolescent or younger child suffering from ME/CFS has access to educational support resources.

Communicate Effectively with Schools

ME/CFS is a complex illness, and the severity of the illness can differ from person to person. Letters from clinicians may provide support to students with ME/CFS and their parents in finding services to help them at school. When communicating with schools at the request of a parent/guardian, clinicians may describe the possible or confirmed diagnosis with particular emphasis on symptoms that can affect school performance and attendance.

It is important for clinicians to keep the Health Insurance Portability and Accountability Act (HIPAA), Family Educational Rights and Privacy Act (FERPA), and patient confidentiality in mind at all times.

ME/CFS Fact Sheet for Healthcare Professionals



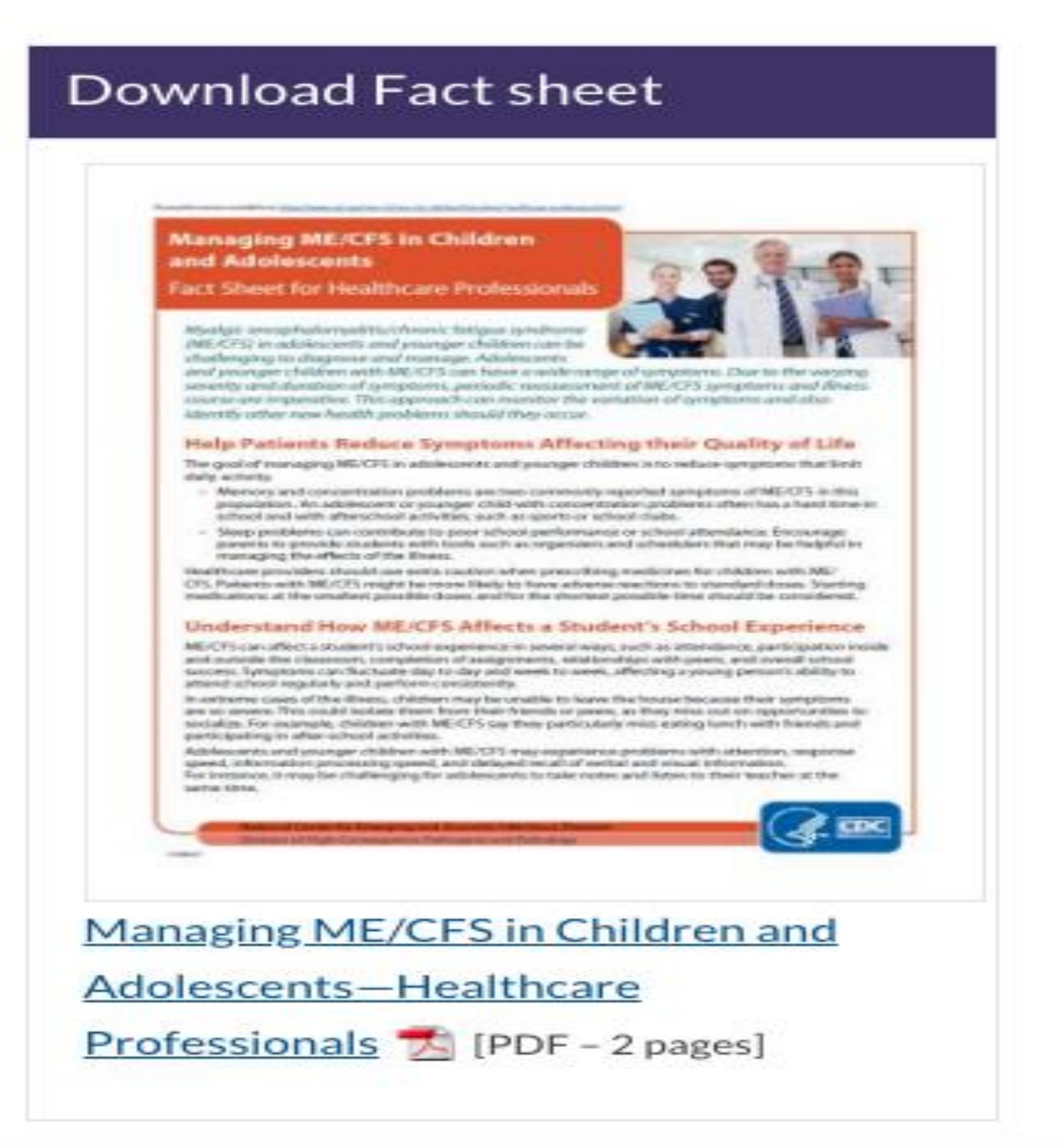
Sample Information to Include in Healthcare Provider Letter

- Document suspected or confirmed diagnosis of ME/CFS and description of symptoms the patient is experiencing
- List support potentially needed for the child and the family in their experience of the illness, including its unpredictable symptoms
- Provide examples of how ME/CFS can affect activities of daily life and educational performance:
  - This can include a decrease in energy levels, focus, and alertness, which might impact a child’s performance at school.
- Explain how extra educational support can help the child attain their learning objectives:

- This can include testing accommodations, homework modifications, limiting physical activity, splitting time between school and home tutoring, and permission to have fluids and salty snacks available, if needed.

ME/CFS Fact Sheet for Healthcare Professionals

https://www.cdc.gov/me-cfs/me-cfs-children/factsheet-healthcare-professional.html



Download Fact sheet

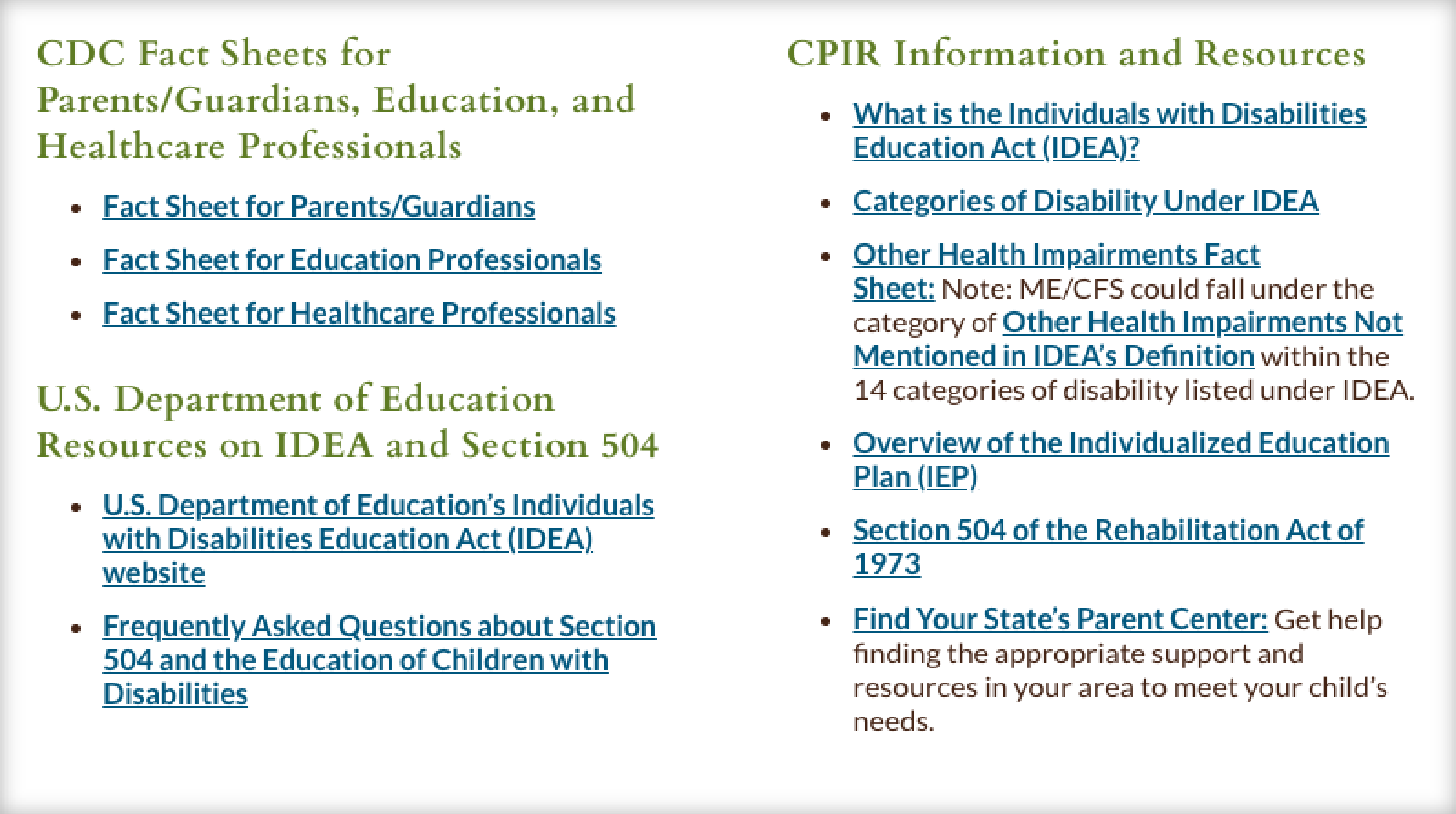
Managing ME/CFS in Children and Adolescents

Fact Sheet for Healthcare Professionals

Help Patients Reduce Symptoms Affecting their Quality of Life

Understand How ME/CFS Affects a Student's School Experience

Managing ME/CFS in Children and Adolescents—Healthcare Professionals [PDF – 2 pages]



CDC Fact Sheets for Parents/Guardians, Education, and Healthcare Professionals

- Fact Sheet for Parents/Guardians
- Fact Sheet for Education Professionals
- Fact Sheet for Healthcare Professionals

U.S. Department of Education Resources on IDEA and Section 504

- U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) website
- Frequently Asked Questions about Section 504 and the Education of Children with Disabilities

CPIR Information and Resources

- What is the Individuals with Disabilities Education Act (IDEA)?
- Categories of Disability Under IDEA
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- Find Your State's Parent Center: Get help finding the appropriate support and resources in your area to meet your child's needs.

U.S. Department of Education Resources on IDEA and Section 504
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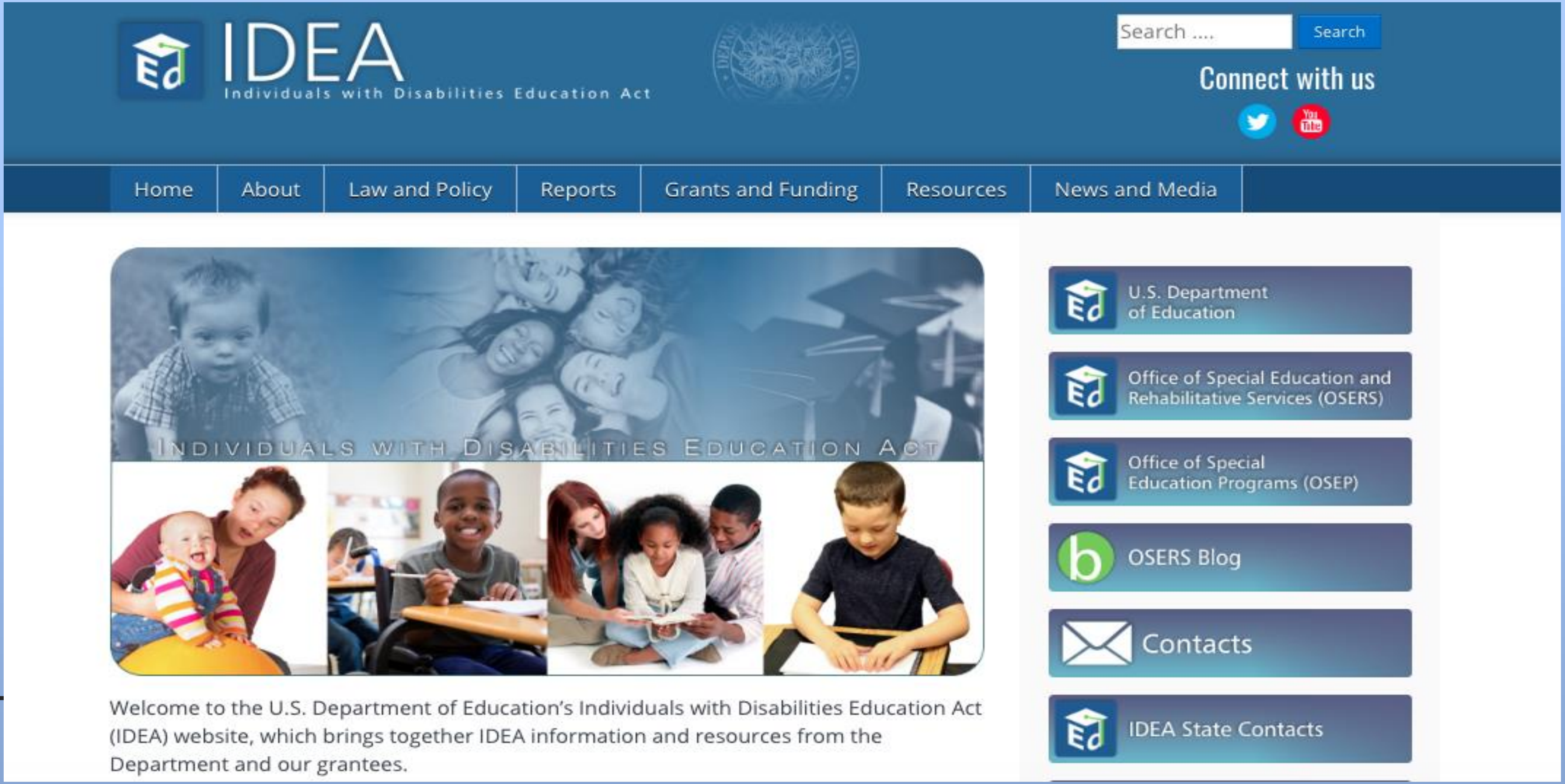
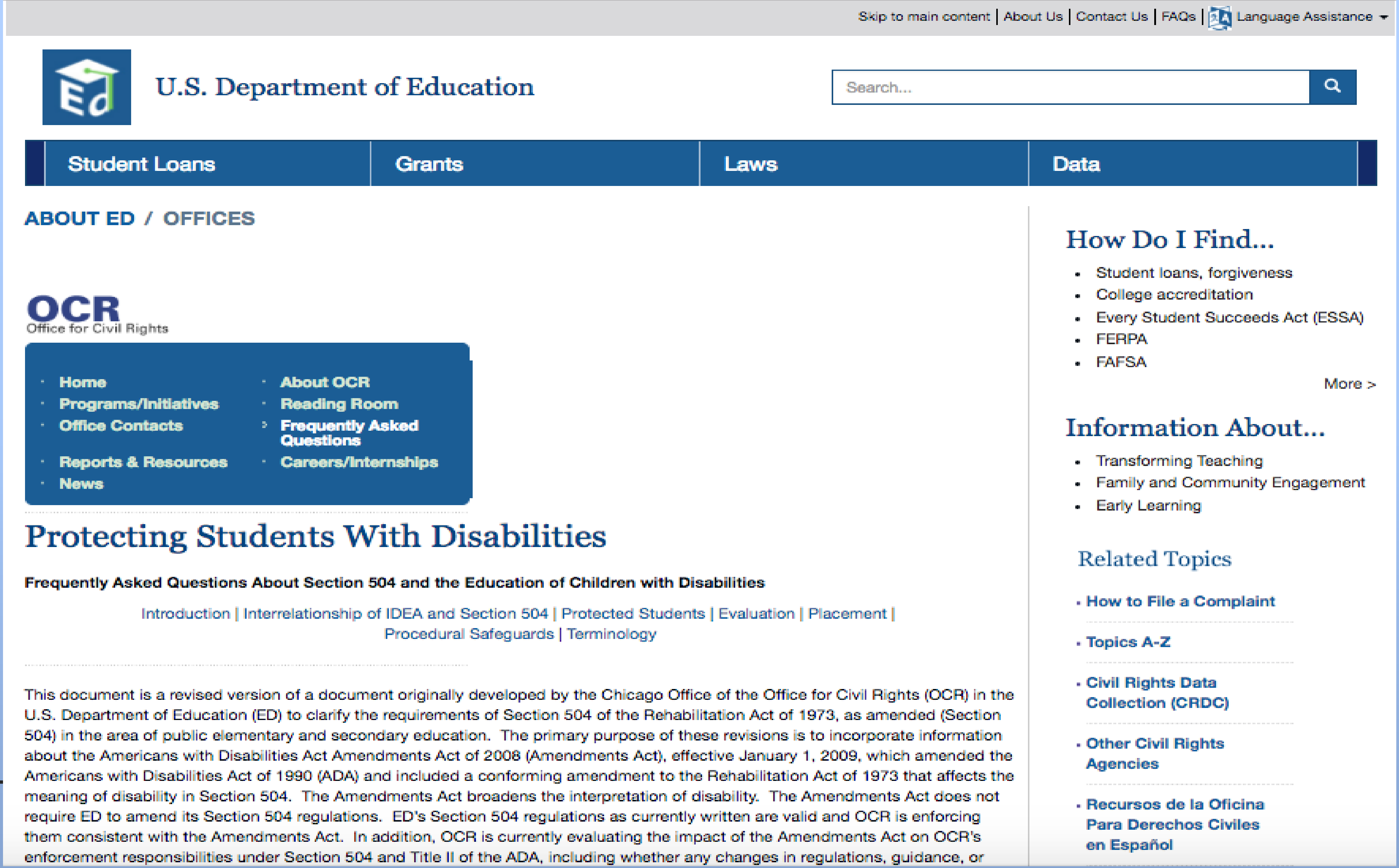


Welcome to the U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) website, which brings together IDEA information and resources from the Department and our grantees.



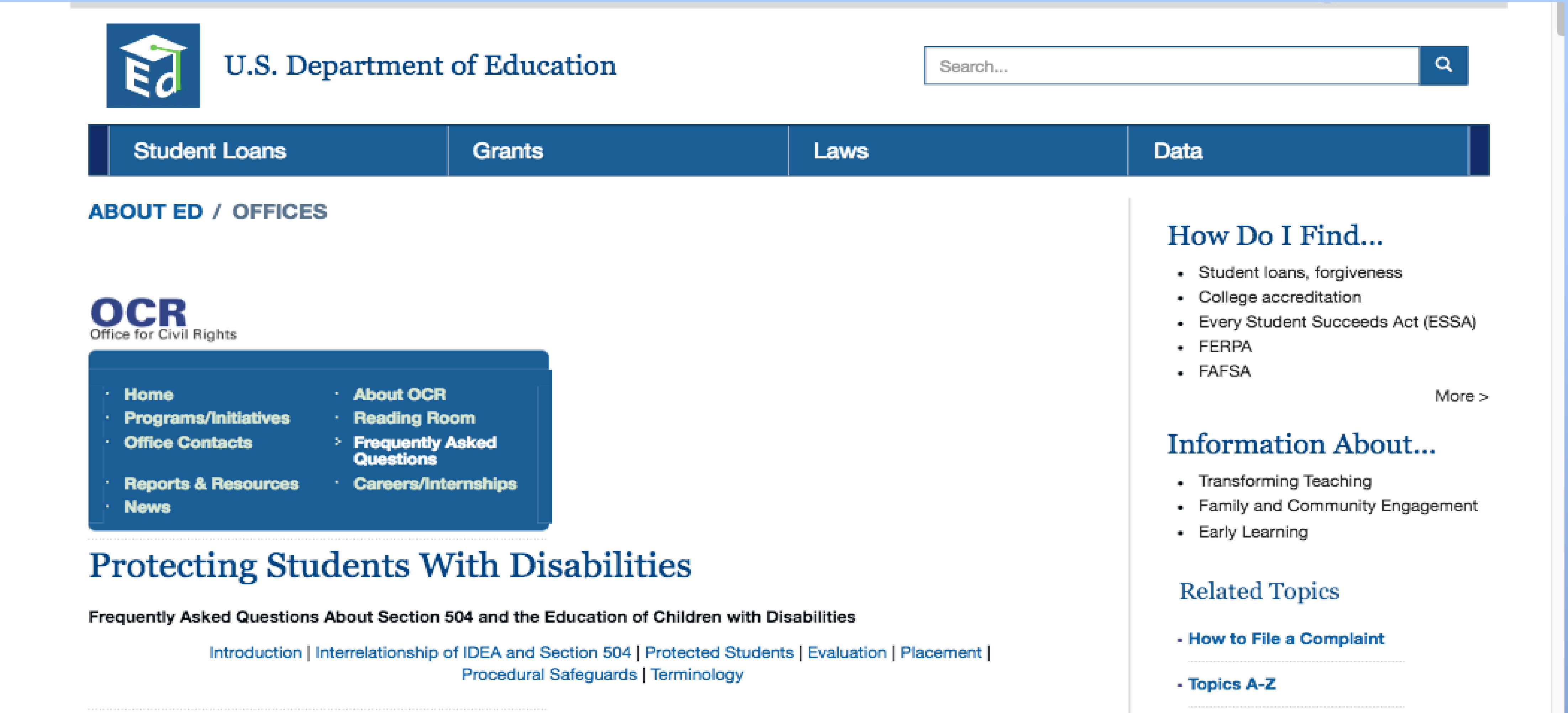
Protecting Students With Disabilities

Frequently Asked Questions About Section 504 and the Education of Children with Disabilities

Introduction | Interrelationship of IDEA and Section 504 | Protected Students | Evaluation | Placement | Procedural Safeguards | Terminology

This document is a revised version of a document originally developed by the Chicago Office of the Office for Civil Rights (OCR) in the U.S. Department of Education (ED) to clarify the requirements of Section 504 of the Rehabilitation Act of 1973, as amended (Section 504) in the area of public elementary and secondary education. The primary purpose of these revisions is to incorporate information about the Americans with Disabilities Act Amendments Act of 2008 (Amendments Act), effective January 1, 2009, which amended the Americans with Disabilities Act of 1990 (ADA) and included a conforming amendment to the Rehabilitation Act of 1973 that affects the meaning of disability in Section 504. The Amendments Act broadens the interpretation of disability. The Amendments Act does not require ED to amend its Section 504 regulations. ED's Section 504 regulations as currently written are valid and OCR is enforcing them consistent with the Amendments Act. In addition, OCR is currently evaluating the impact of the Amendments Act on OCR's enforcement responsibilities under Section 504 and Title II of the ADA, including whether any changes in regulations, guidance, or

U.S. Department of Education Resources on IDEA and Section 504 Frequently Asked Questions about Section 504 and the Education of Children with Disabilities



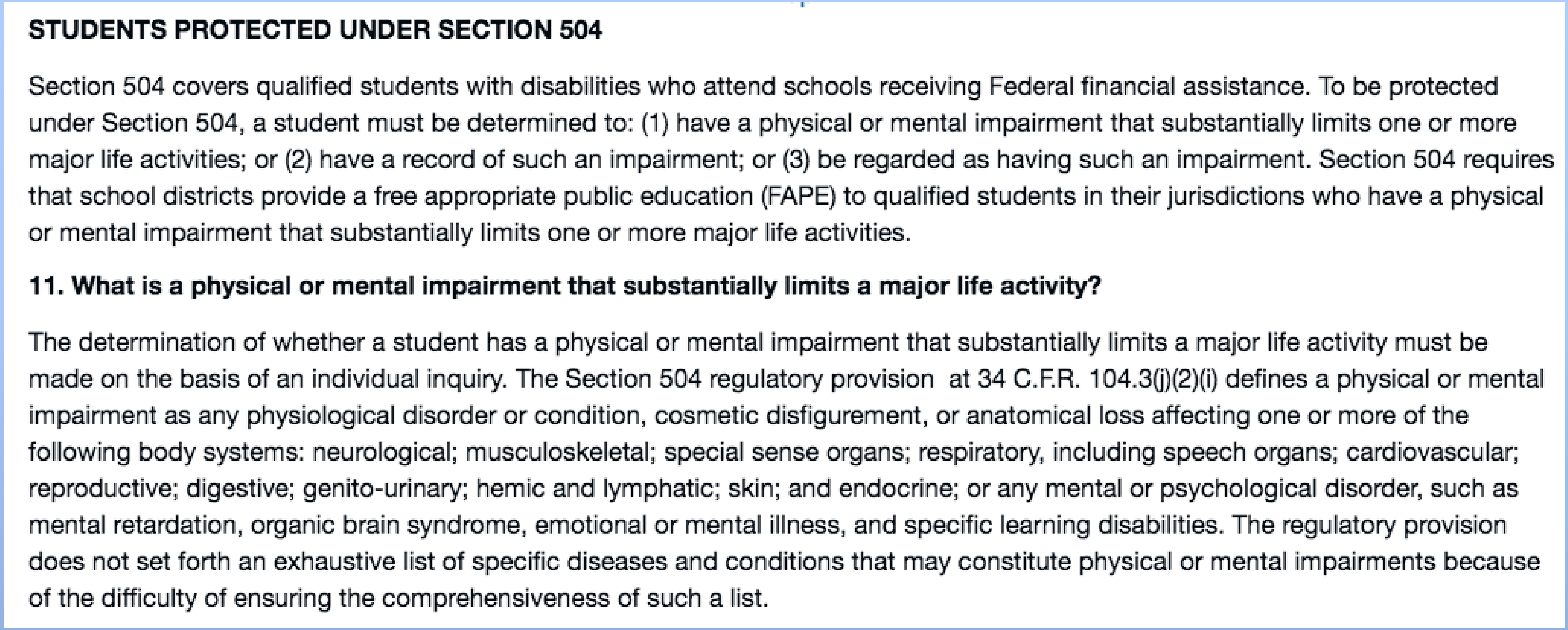
Protecting Students With Disabilities

Frequently Asked Questions About Section 504 and the Education of Children with Disabilities

Introduction | Interrelationship of IDEA and Section 504 | Protected Students | Evaluation | Placement | Procedural Safeguards | Terminology

U.S. Department of Education Resources on IDEA and Section 504

Frequently Asked Questions about Section 504 and the Education of Children with Disabilities



STUDENTS PROTECTED UNDER SECTION 504

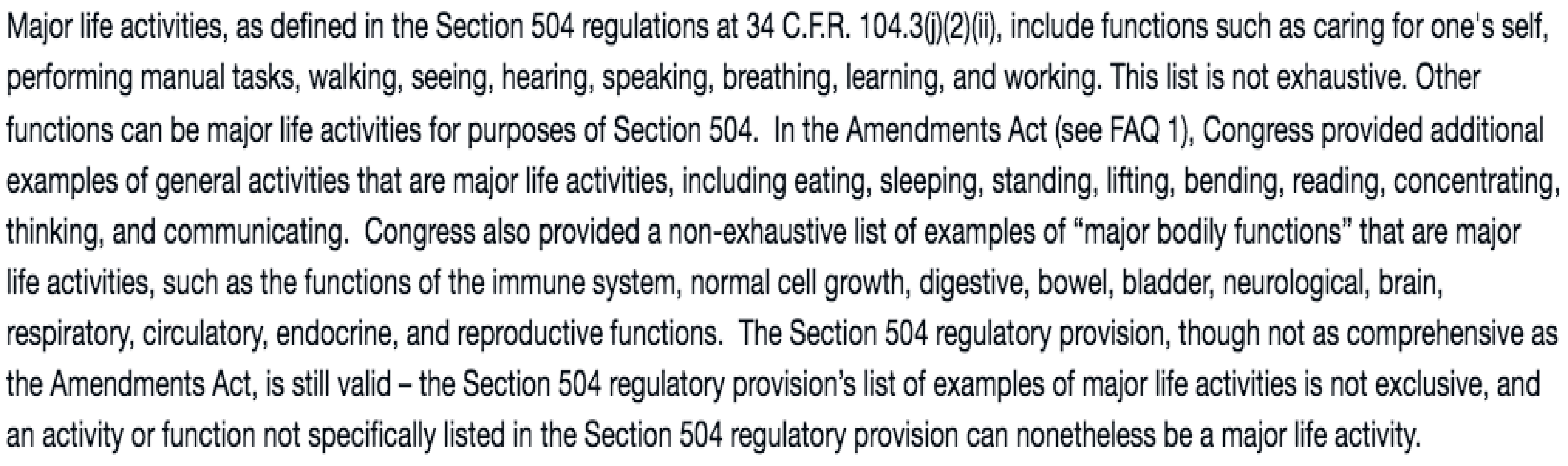
Section 504 covers qualified students with disabilities who attend schools receiving Federal financial assistance. To be protected under Section 504, a student must be determined to: (1) have a physical or mental impairment that substantially limits one or more major life activities; or (2) have a record of such an impairment; or (3) be regarded as having such an impairment. Section 504 requires that school districts provide a free appropriate public education (FAPE) to qualified students in their jurisdictions who have a physical or mental impairment that substantially limits one or more major life activities.

11. What is a physical or mental impairment that substantially limits a major life activity?

The determination of whether a student has a physical or mental impairment that substantially limits a major life activity must be made on the basis of an individual inquiry. The Section 504 regulatory provision at 34 C.F.R. 104.3(j)(2)(i) defines a physical or mental impairment as any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genito-urinary; hemic and lymphatic; skin; and endocrine; or any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities. The regulatory provision does not set forth an exhaustive list of specific diseases and conditions that may constitute physical or mental impairments because of the difficulty of ensuring the comprehensiveness of such a list.

https://www2.ed.gov/about/offices/list/ocr/504faq.html

U.S. Department of Education Resources on IDEA and Section 504
Frequently Asked Questions about Section 504 and the Education of Children with Disabilities continued….



Major life activities, as defined in the Section 504 regulations at 34 C.F.R. 104.3(j)(2)(ii), include functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. This list is not exhaustive. Other functions can be major life activities for purposes of Section 504. In the Amendments Act (see FAQ 1), Congress provided additional examples of general activities that are major life activities, including eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, and communicating. Congress also provided a non-exhaustive list of examples of "major bodily functions" that are major life activities, such as the functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions. The Section 504 regulatory provision, though not as comprehensive as the Amendments Act, is still valid – the Section 504 regulatory provision's list of examples of major life activities is not exclusive, and an activity or function not specifically listed in the Section 504 regulatory provision can nonetheless be a major life activity.

https://www2.ed.gov/about/offices/list/ocr/504faq.html

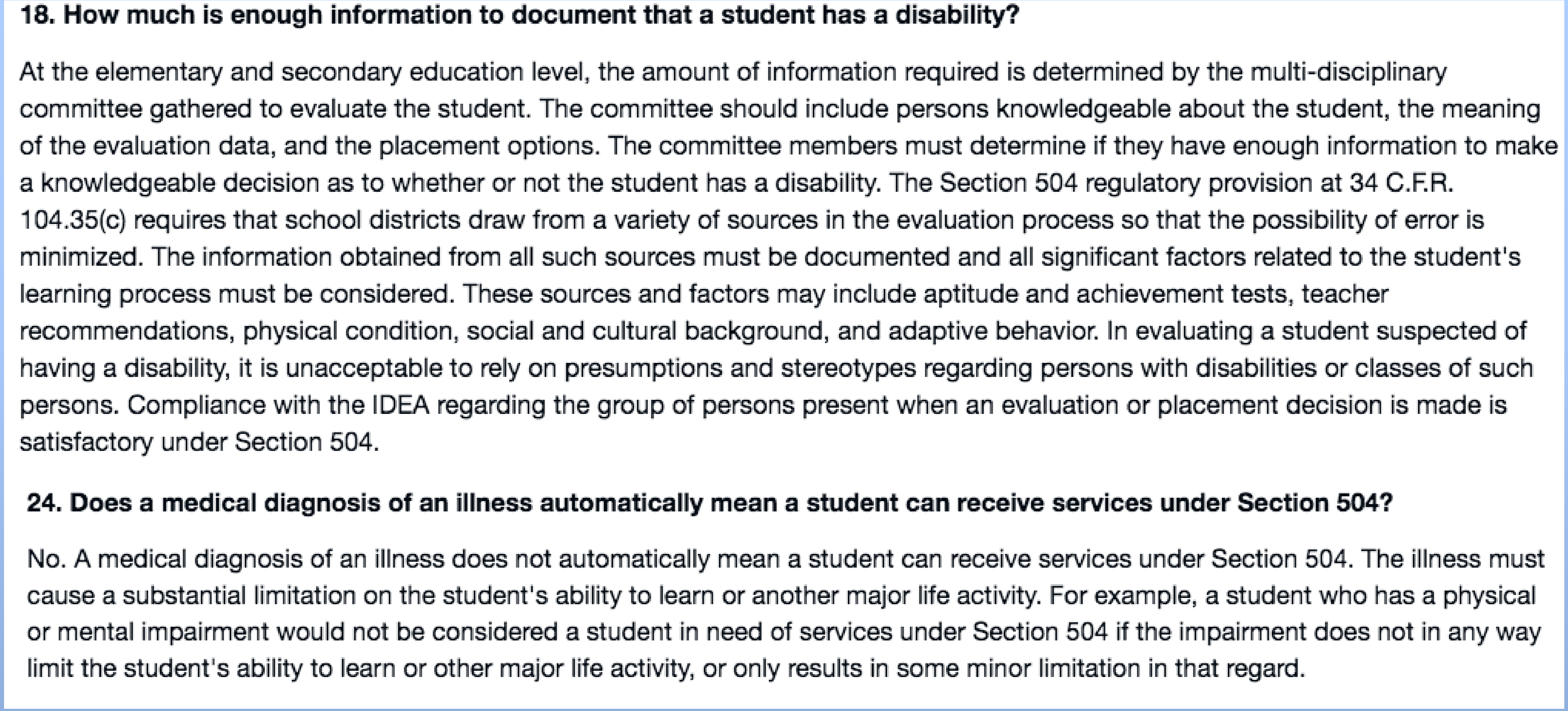
504 Plan – Definition and examples

1. ***504 Plans come under the Americans with Disabilities Act and allow only for accommodations, but they are put in place more easily than IEP's***
2. ***Students with mild to moderate cases of ME/CFS could qualify for a 504 plan, which provide accommodations only to a student's educational environment.***
3. ***Accommodations change the learning environment to allow students to meet the same standards or requirements as their peers.***
4. ***An example is alternative activities in PE class such as writing a paper in place of physical activity or extended time for tests and/or assignments.***

IEP's– Definition and examples

1. Individual Education Plans (IEP's) entitle students to special education services if their learning is impaired by the ME/CFS. "Other Health Impaired" is the category under which students qualify for an IEP.
2. Your child is entitled to accommodations and modifications to your learning on an IEP until they are 21.
3. Modifications are changes made in the learning environment that change the standards or requirements that a student must meet.
4. For example, eliminating PE class as a graduation requirement or reducing the number or length of tests and/or assignments are examples of modifications.
5. IEP's require a full assessment and federally compliant process but provide more options and protections for students.

U.S. Department of Education Resources on IDEA and Section 504 Frequently Asked Questions about Section 504 and the Education of Children with Disabilities continued….



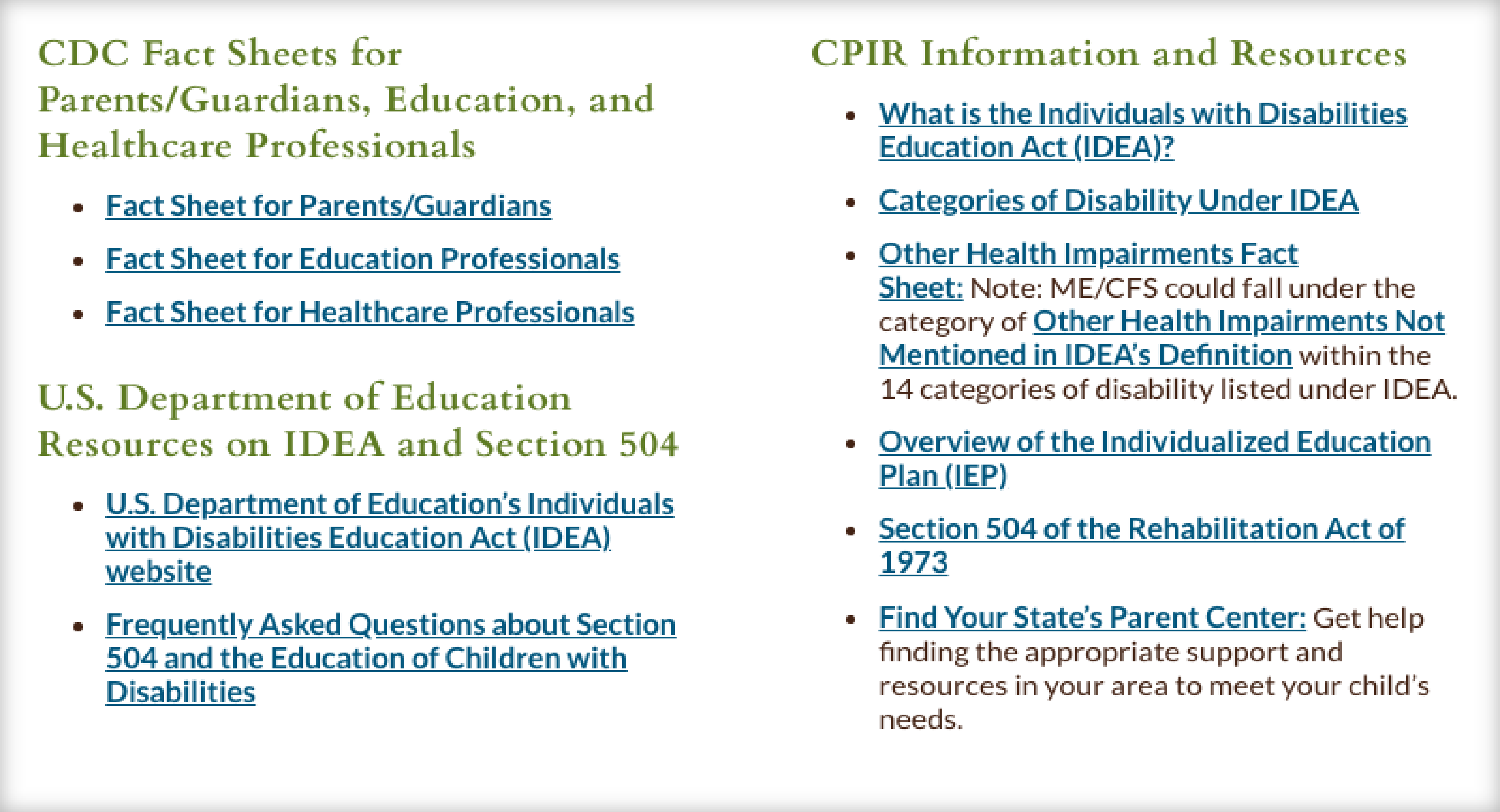
18. How much is enough information to document that a student has a disability?

At the elementary and secondary education level, the amount of information required is determined by the multi-disciplinary committee gathered to evaluate the student. The committee should include persons knowledgeable about the student, the meaning of the evaluation data, and the placement options. The committee members must determine if they have enough information to make a knowledgeable decision as to whether or not the student has a disability. The Section 504 regulatory provision at 34 C.F.R. 104.35(c) requires that school districts draw from a variety of sources in the evaluation process so that the possibility of error is minimized. The information obtained from all such sources must be documented and all significant factors related to the student's learning process must be considered. These sources and factors may include aptitude and achievement tests, teacher recommendations, physical condition, social and cultural background, and adaptive behavior. In evaluating a student suspected of having a disability, it is unacceptable to rely on presumptions and stereotypes regarding persons with disabilities or classes of such persons. Compliance with the IDEA regarding the group of persons present when an evaluation or placement decision is made is satisfactory under Section 504.

24. Does a medical diagnosis of an illness automatically mean a student can receive services under Section 504?

No. A medical diagnosis of an illness does not automatically mean a student can receive services under Section 504. The illness must cause a substantial limitation on the student's ability to learn or another major life activity. For example, a student who has a physical or mental impairment would not be considered a student in need of services under Section 504 if the impairment does not in any way limit the student's ability to learn or other major life activity, or only results in some minor limitation in that regard.

https://www2.ed.gov/about/offices/list/ocr/504faq.html



CDC Fact Sheets for Parents/Guardians, Education, and Healthcare Professionals

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- Section 504 of the Rehabilitation Act of 1973
- Find Your State's Parent Center: Get help finding the appropriate support and resources in your area to meet your child's needs.

What is the Individuals with Disabilities Education Act?

http://www.parentcenterhub.org/me-cfs

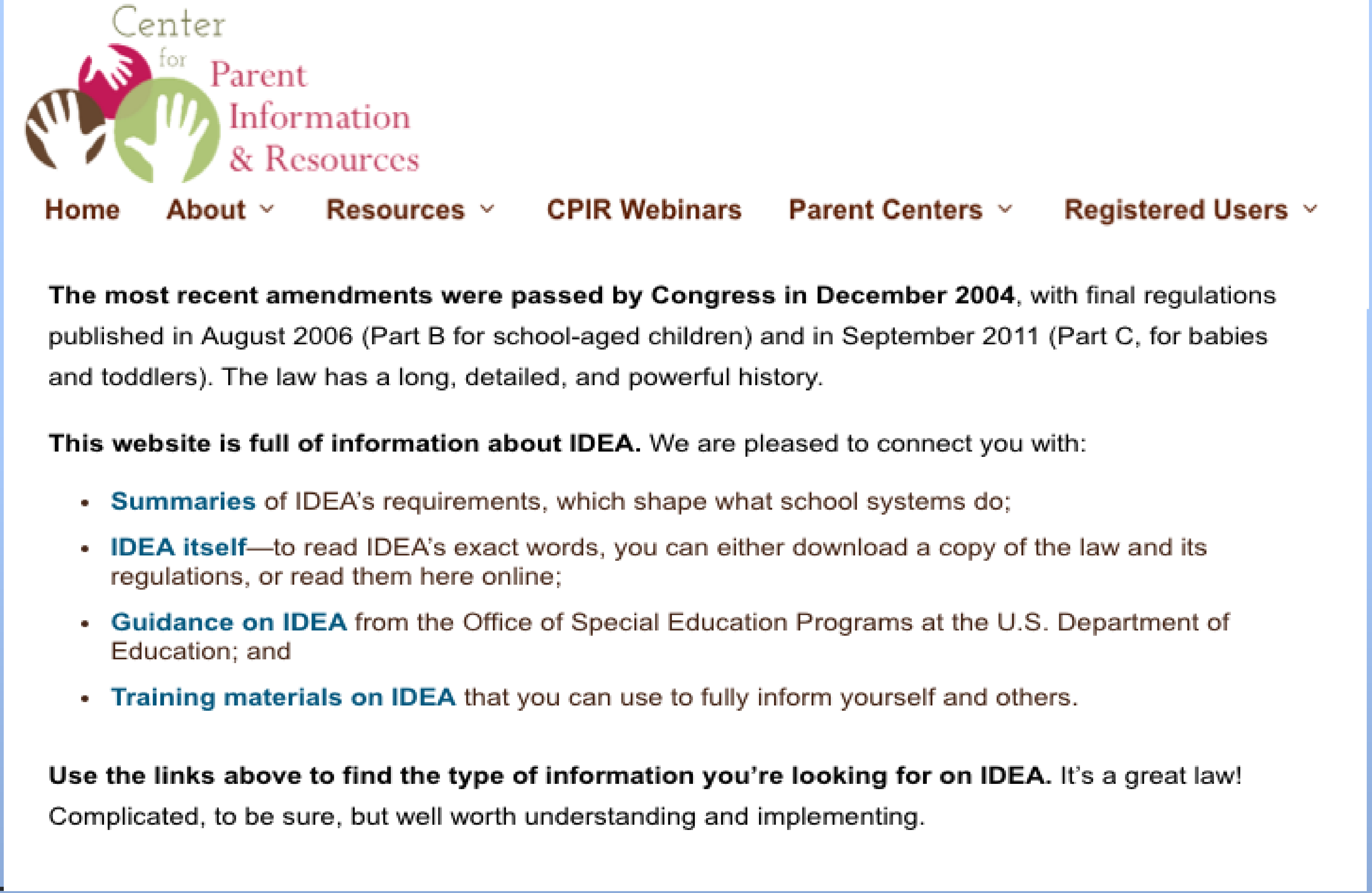
IDEA—the Individuals with Disabilities Education Act

Sep 24, 2017

Current as of September 2017

In Spanish | En español

IDEA was originally enacted by Congress in 1975 to ensure that children with disabilities have the opportunity to receive a free appropriate public education, just like other children. The law has been revised many times over the years.



The most recent amendments were passed by Congress in December 2004, with final regulations published in August 2006 (Part B for school-aged children) and in September 2011 (Part C, for babies and toddlers). The law has a long, detailed, and powerful history.

This website is full of information about IDEA. We are pleased to connect you with:

- **Summaries** of IDEA's requirements, which shape what school systems do;
- **IDEA itself**—to read IDEA's exact words, you can either download a copy of the law and its regulations, or read them here online;
- **Guidance on IDEA** from the Office of Special Education Programs at the U.S. Department of Education; and
- **Training materials on IDEA** that you can use to fully inform yourself and others.

Use the links above to find the type of information you're looking for on IDEA. It's a great law! Complicated, to be sure, but well worth understanding and implementing.

Categories of Disability Under IDEA

http://www.parentcenterhub.org/categories/

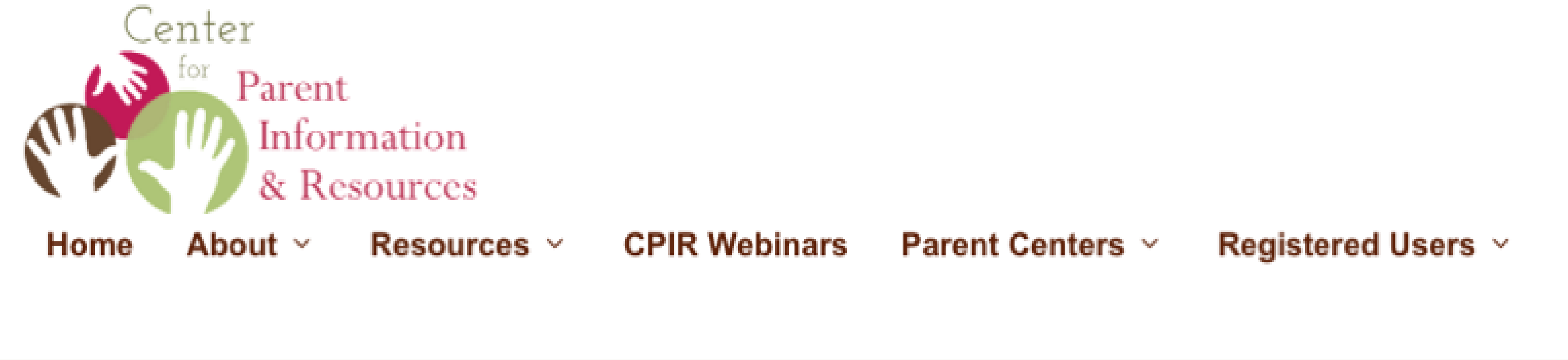
Categories of Disability Under IDEA

Quick-Jump Links

- Autism
- Deaf-blindness
- Deafness
- Developmental delay
- Emotional disturbance
- Hearing impairment
- Intellectual disability
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness

Other Health Impairment Fact Sheet

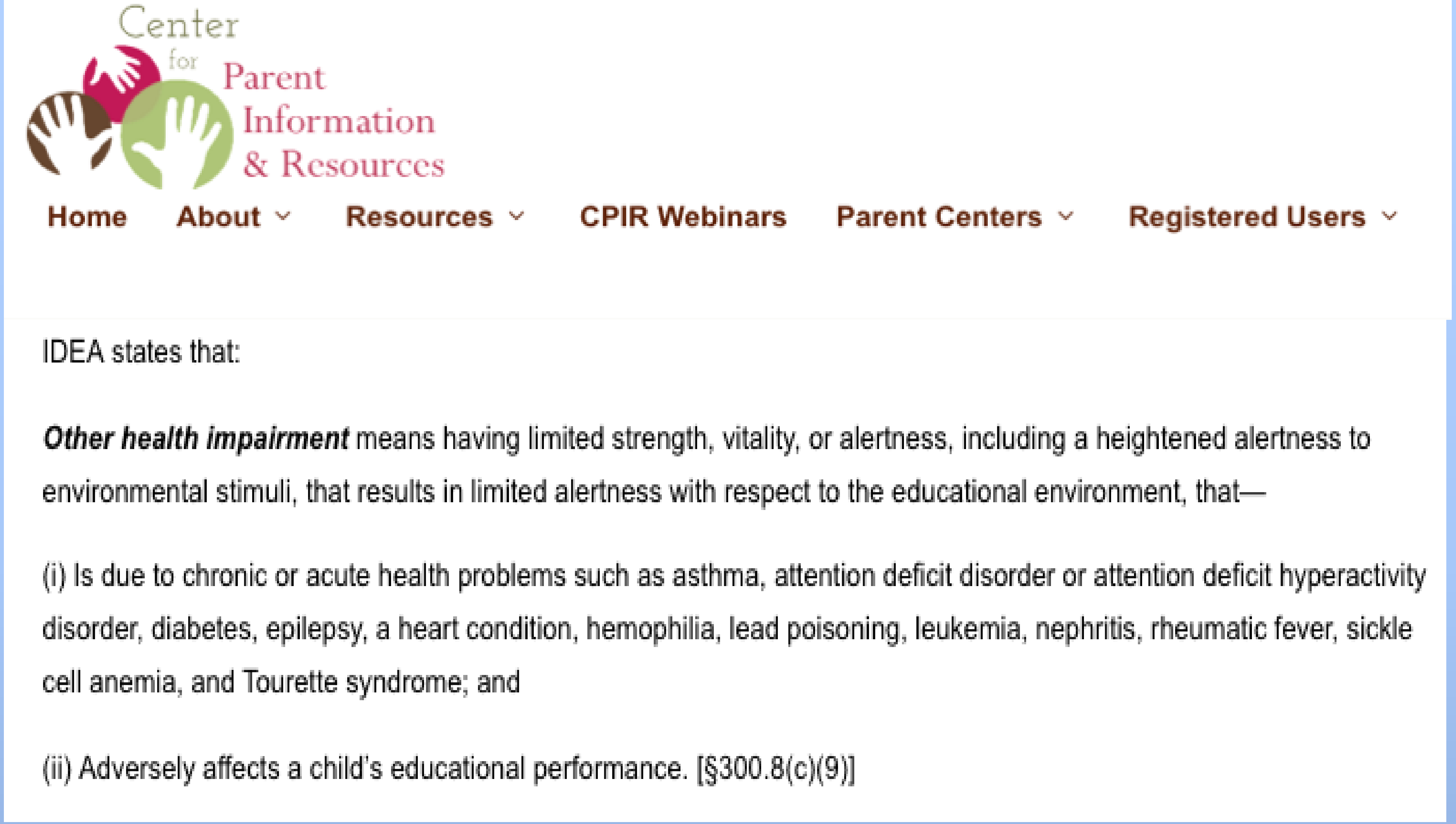
http://www.parentcenterhub.org/categories/



Note: ME/CFS could fall under the category of Other Health Impaired. Although it is Not mentioned in IDEA's Definition within the 14 categories of disability listed under IDEA those categories are not exclusive.

Other Health Impairment Fact Sheet

http://www.parentcenterhub.org/ohi/



IDEA states that:

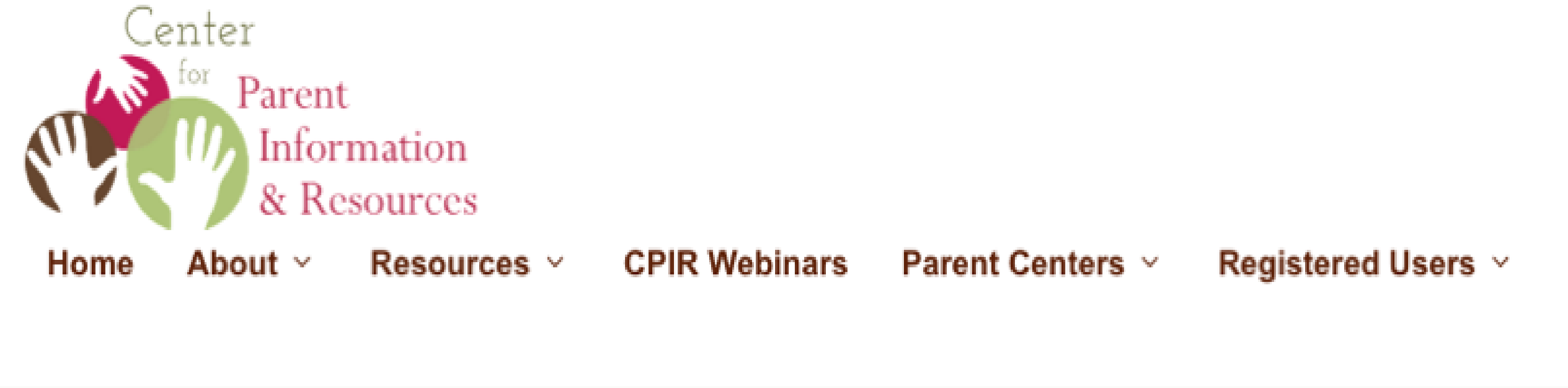
Other health impairment means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

(i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and

(ii) Adversely affects a child's educational performance. [§300.8(c)(9)]

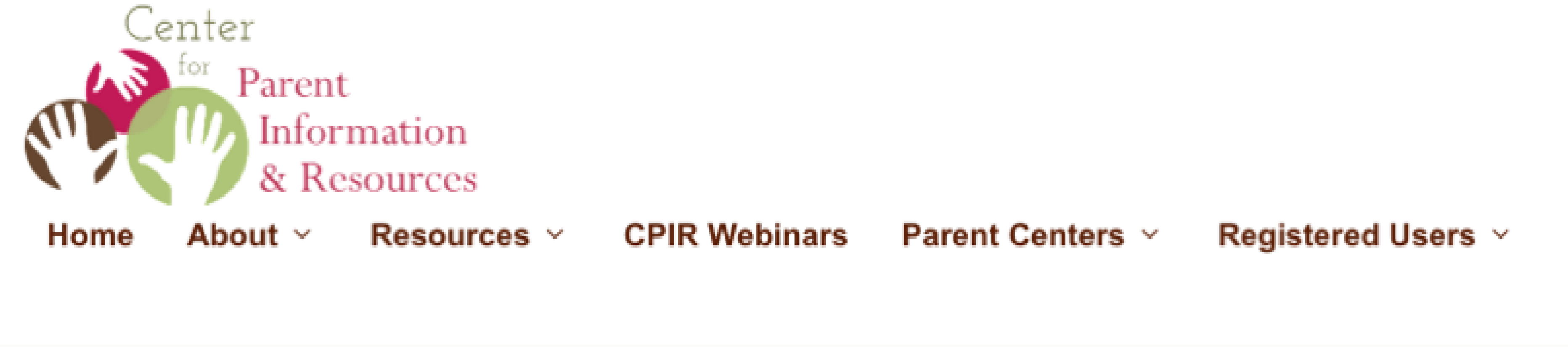
Other Health Impairment Fact Sheet

http://www.parentcenterhub.org/ohi/



What’s central to all the disabilities falling under “Other Health Impairment” is that the child must have limited strength, vitality, or alertness due to chronic health problems; and
an educational performance that is negatively affected as a result.

Other Health Impairment Fact Sheet

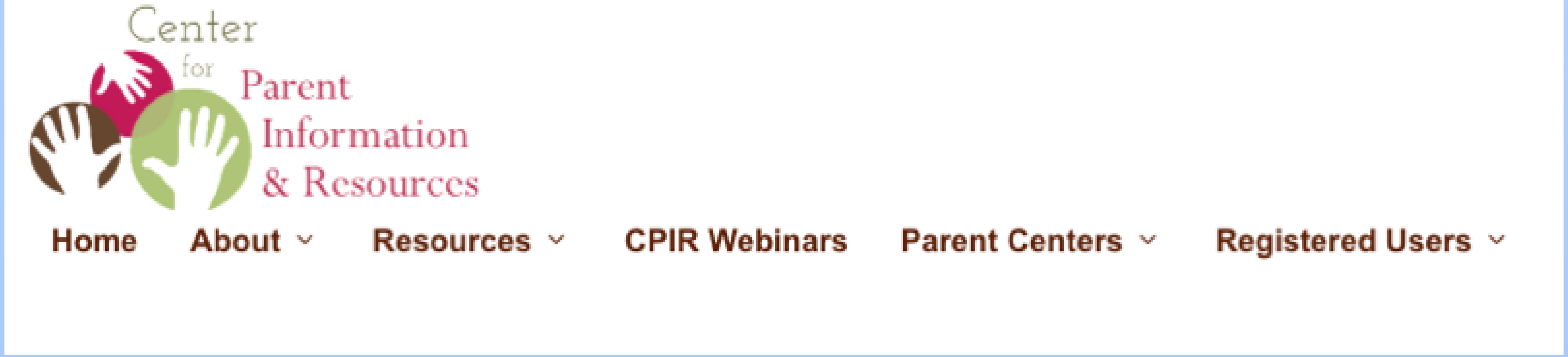


http://www.parentcenterhub.org/ohi/

When health affects school attendance

It's not uncommon for a child with an OHI to have periodic absences from school, sometimes even lengthy ones, especially if hospitalization is necessary for whatever reason. **During these times, the public school remains responsible for providing educational and related services to the eligible child with OHI.** Because IDEA specifically states that special education can be provided in a range of settings, including the home or the hospital, states and school districts will have policies and approaches for addressing children's individualized needs and circumstances.

Other Health Impairment Fact Sheet

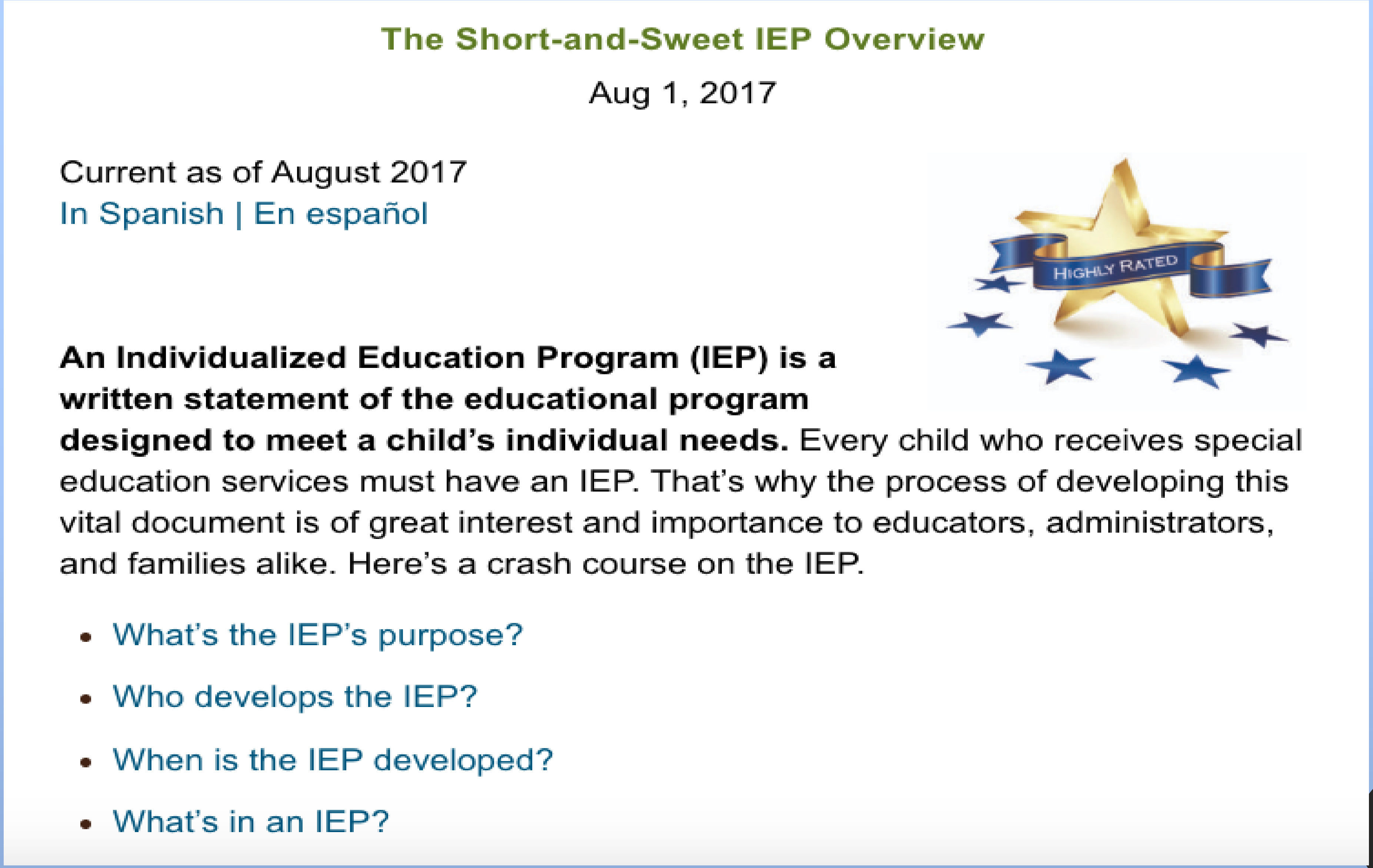


http://www.parentcenterhub.org/ohi/

When the child is at home, the school may arrange for a homebound instructor to bring assignments from school to home and help the student complete those assignments.

Overview of the Individualized Education Plan

http://www.parentcenterhub.org/iep-overview/



The Short-and-Sweet IEP Overview

Aug 1, 2017

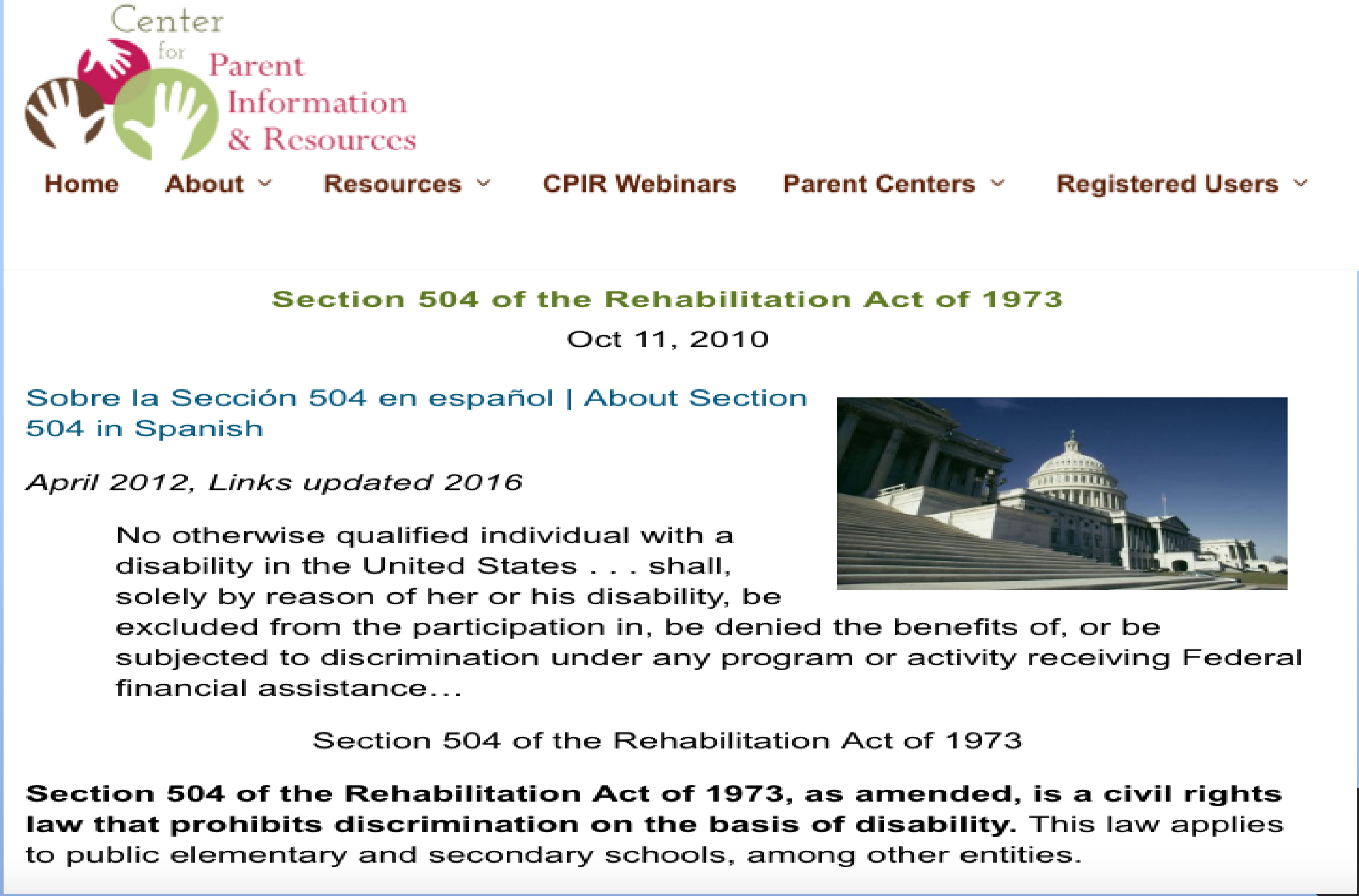
Current as of August 2017
In Spanish | En español

An Individualized Education Program (IEP) is a written statement of the educational program designed to meet a child's individual needs. Every child who receives special education services must have an IEP. That's why the process of developing this vital document is of great interest and importance to educators, administrators, and families alike. Here's a crash course on the IEP.

- What's the IEP's purpose?
- Who develops the IEP?
- When is the IEP developed?
- What's in an IEP?

Section 504 of the Rehabilitation Act

http://www.parentcenterhub.org/section504/



Section 504 of the Rehabilitation Act of 1973

Oct 11, 2010

Sobre la Sección 504 en español | About Section 504 in Spanish

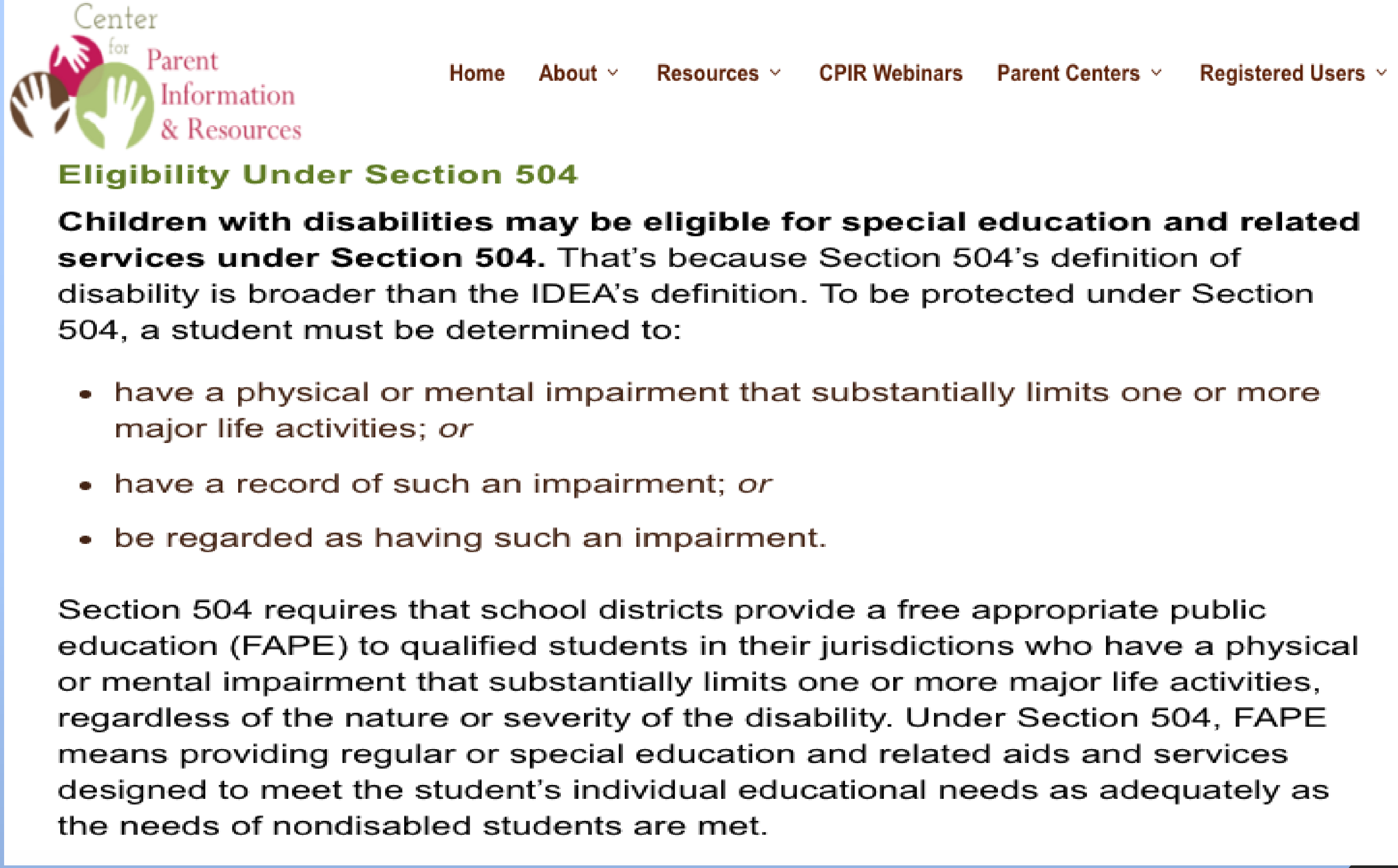
April 2012, Links updated 2016

> No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance…
>
> Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973, as amended, is a civil rights law that prohibits discrimination on the basis of disability. This law applies to public elementary and secondary schools, among other entities.

Eligibility under Section 504 of the Rehabilitation Act

http://www.parentcenterhub.org/section504/



Eligibility Under Section 504

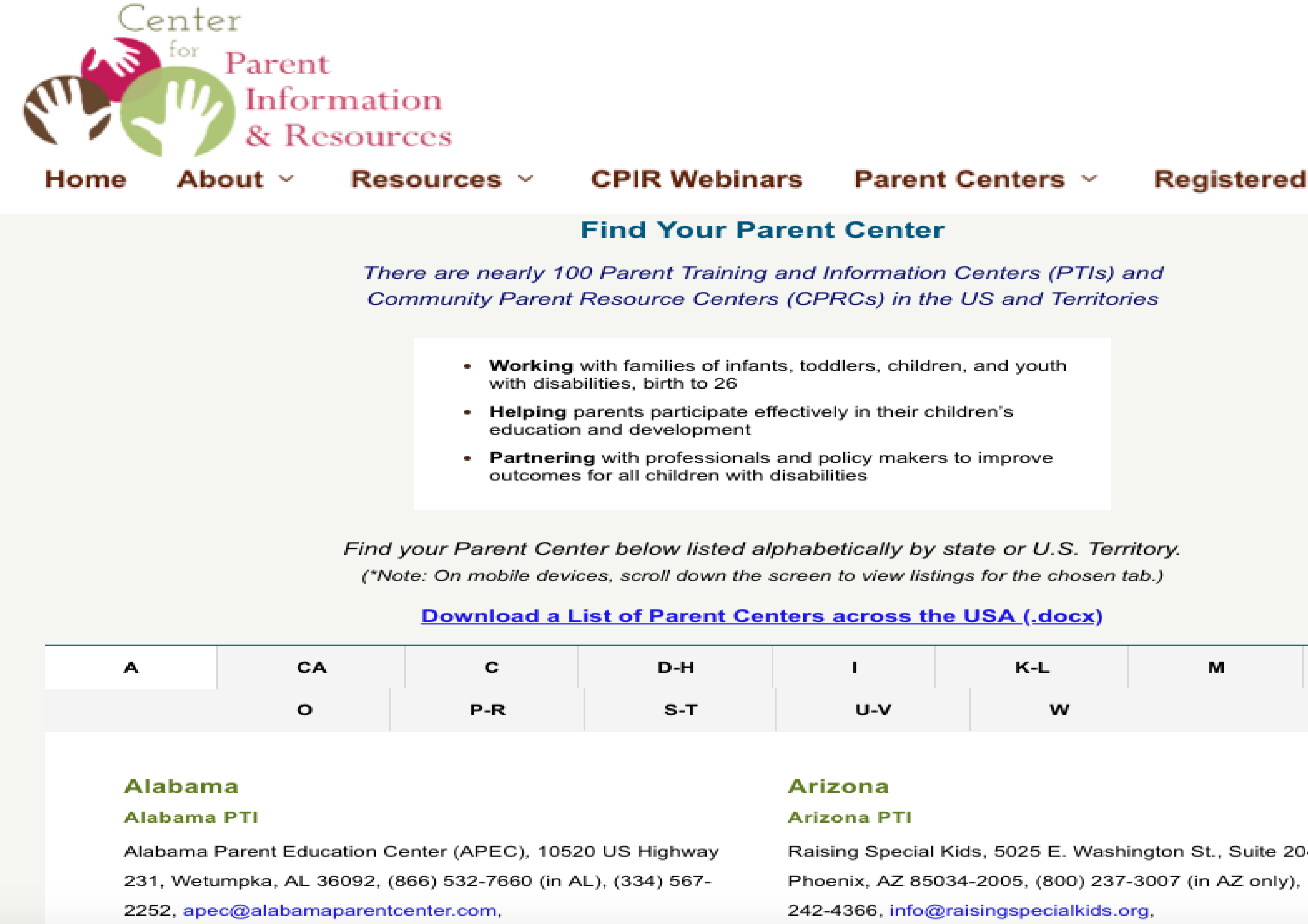
Children with disabilities may be eligible for special education and related services under Section 504. That's because Section 504's definition of disability is broader than the IDEA's definition. To be protected under Section 504, a student must be determined to:

- have a physical or mental impairment that substantially limits one or more major life activities; *or*
- have a record of such an impairment; *or*
- be regarded as having such an impairment.

Section 504 requires that school districts provide a free appropriate public education (FAPE) to qualified students in their jurisdictions who have a physical or mental impairment that substantially limits one or more major life activities, regardless of the nature or severity of the disability. Under Section 504, FAPE means providing regular or special education and related aids and services designed to meet the student's individual educational needs as adequately as the needs of nondisabled students are met.

Find Your State's Parent Center

http://www.parentcenterhub.org/find-your-center/



Find Your Parent Center

There are nearly 100 Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in the US and Territories

- **Working** with families of infants, toddlers, children, and youth with disabilities, birth to 26
- **Helping** parents participate effectively in their children's education and development
- **Partnering** with professionals and policy makers to improve outcomes for all children with disabilities

Find your Parent Center below listed alphabetically by state or U.S. Territory.

*(*Note: On mobile devices, scroll down the screen to view listings for the chosen tab.)*

Download a List of Parent Centers across the USA (.docx)

Alabama

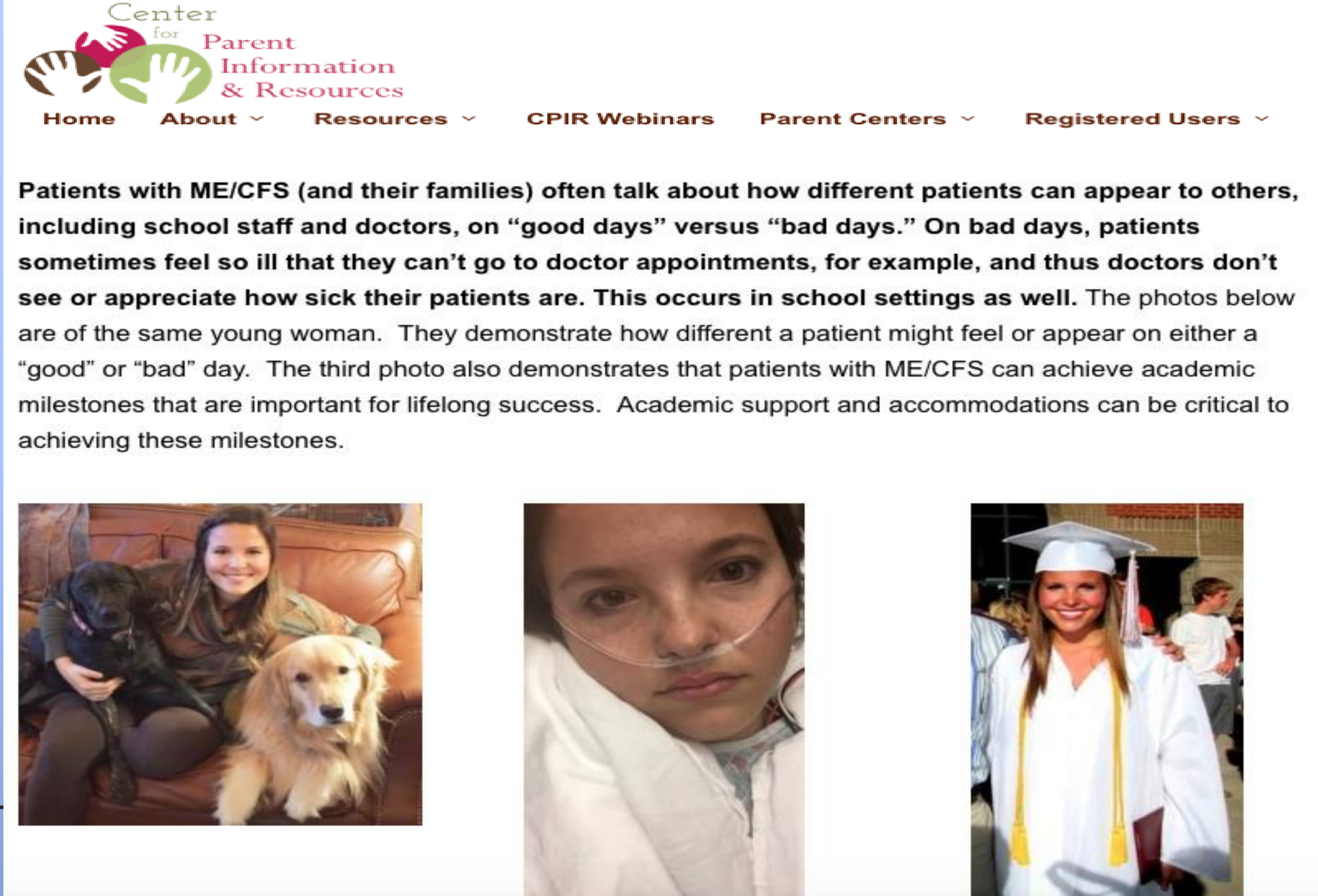
Alabama PTI

Alabama Parent Education Center (APEC), 10520 US Highway 231, Wetumpka, AL 36092, (866) 532-7660 (in AL), (334) 567-2252, apec@alabamaparentcenter.com,

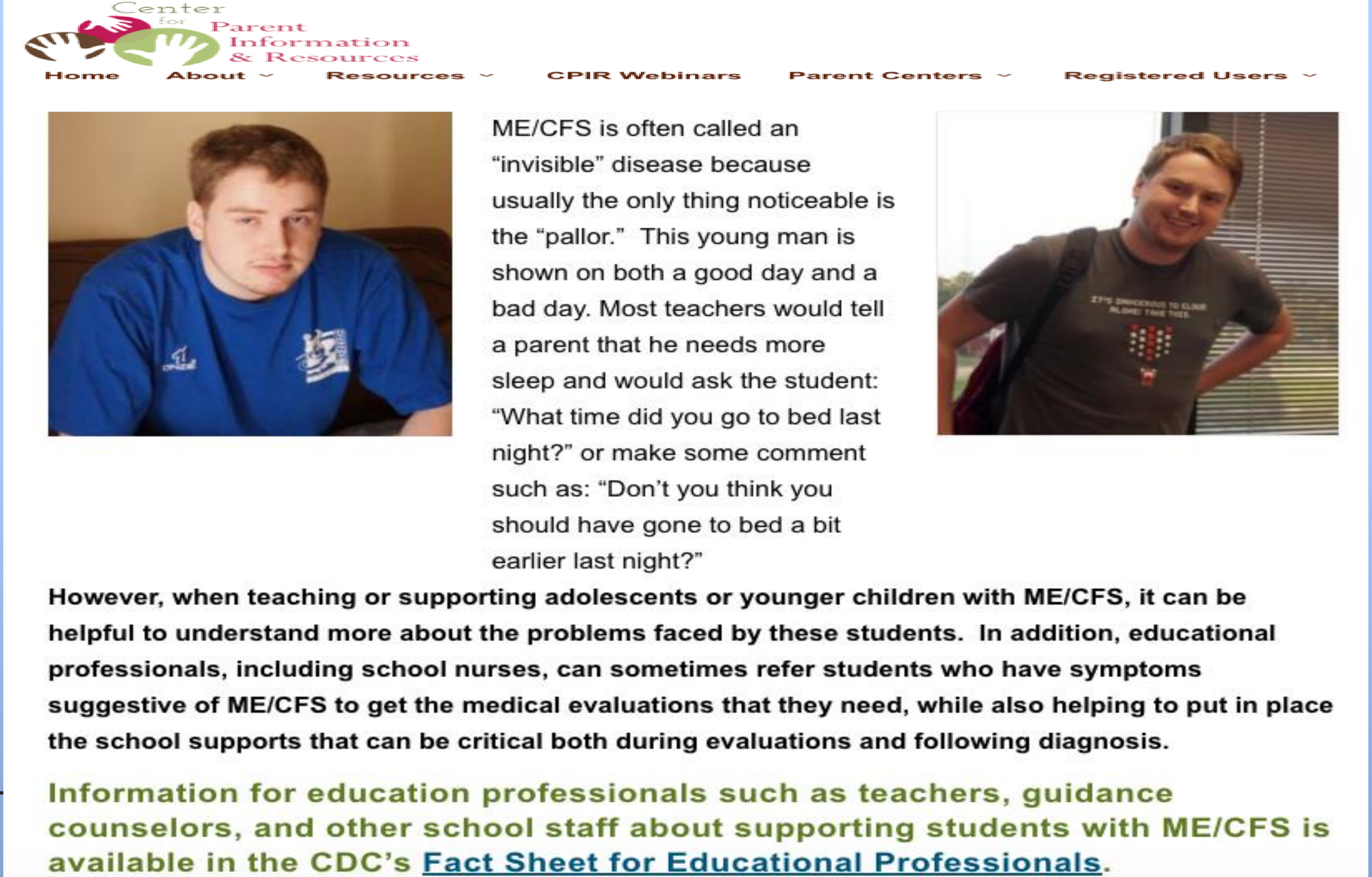
Arizona

Arizona PTI

Raising Special Kids, 5025 E. Washington St., Suite 20
Phoenix, AZ 85034-2005, (800) 237-3007 (in AZ only),
242-4366, info@raisingspecialkids.org,



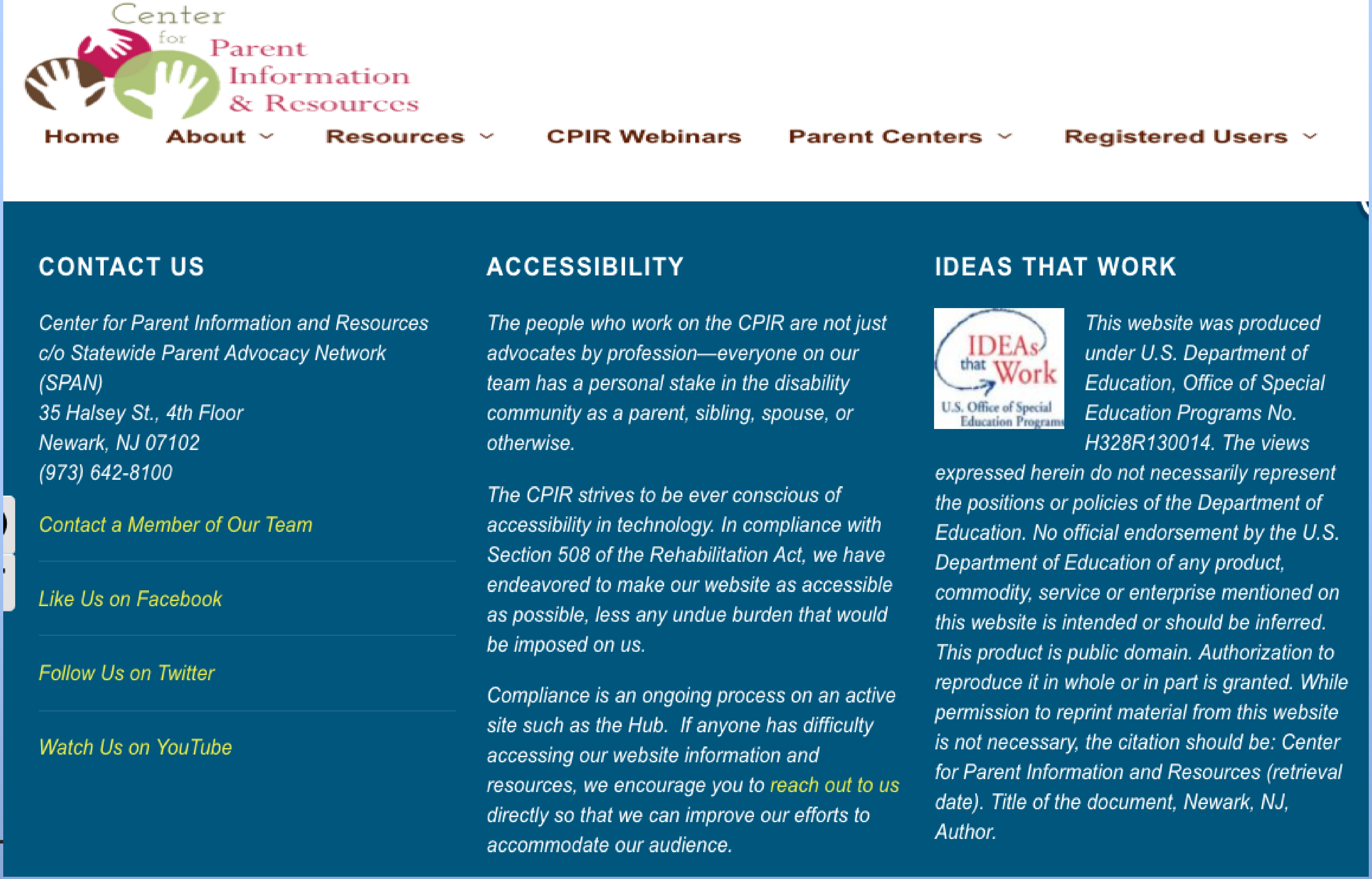
Patients with ME/CFS (and their families) often talk about how different patients can appear to others, including school staff and doctors, on "good days" versus "bad days." On bad days, patients sometimes feel so ill that they can't go to doctor appointments, for example, and thus doctors don't see or appreciate how sick their patients are. This occurs in school settings as well. The photos below are of the same young woman. They demonstrate how different a patient might feel or appear on either a "good" or "bad" day. The third photo also demonstrates that patients with ME/CFS can achieve academic milestones that are important for lifelong success. Academic support and accommodations can be critical to achieving these milestones.



ME/CFS is often called an "invisible" disease because usually the only thing noticeable is the "pallor." This young man is shown on both a good day and a bad day. Most teachers would tell a parent that he needs more sleep and would ask the student: "What time did you go to bed last night?" or make some comment such as: "Don't you think you should have gone to bed a bit earlier last night?"

However, when teaching or supporting adolescents or younger children with ME/CFS, it can be helpful to understand more about the problems faced by these students. In addition, educational professionals, including school nurses, can sometimes refer students who have symptoms suggestive of ME/CFS to get the medical evaluations that they need, while also helping to put in place the school supports that can be critical both during evaluations and following diagnosis.

Information for education professionals such as teachers, guidance counselors, and other school staff about supporting students with ME/CFS is available in the CDC's Fact Sheet for Educational Professionals.



CONTACT US

Center for Parent Information and Resources
c/o Statewide Parent Advocacy Network (SPAN)
35 Halsey St., 4th Floor
Newark, NJ 07102
(973) 642-8100

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Follow Us on Twitter

Watch Us on YouTube

ACCESSIBILITY

The people who work on the CPIR are not just advocates by profession—everyone on our team has a personal stake in the disability community as a parent, sibling, spouse, or otherwise.

The CPIR strives to be ever conscious of accessibility in technology. In compliance with Section 508 of the Rehabilitation Act, we have endeavored to make our website as accessible as possible, less any undue burden that would be imposed on us.

Compliance is an ongoing process on an active site such as the Hub. If anyone has difficulty accessing our website information and resources, we encourage you to reach out to us directly so that we can improve our efforts to accommodate our audience.

IDEAS THAT WORK

This website was produced under U.S. Department of Education, Office of Special Education Programs No. H328R130014. The views expressed herein do not necessarily represent the positions or policies of the Department of Education. No official endorsement by the U.S. Department of Education of any product, commodity, service or enterprise mentioned on this website is intended or should be inferred. This product is public domain. Authorization to reproduce it in whole or in part is granted. While permission to reprint material from this website is not necessary, the citation should be: Center for Parent Information and Resources (retrieval date). Title of the document, Newark, NJ, Author.

Working with School Nurses on ME/CFS

- **Massachusetts Department of Health screening of the of the award-winning film UNREST – March 27, 2018**
- **Presentations on ME/CFS to School Nurses – Next steps – Presenting at their annual conferences.**

National Association of School Nurses (NASN) Journal Article on ME/CFS

- Article on ME/CFS and educating children in schools is in the final edits. It has been informally reviewed by several school nurses including Sharon-rose Gargula (Delaware).
- Authors: Ken Friedman, Ph.D., Beth Mattey, Past President of NASN, Faith Newton, Ed.D.

School Nurses Can Improve the Lives of Students with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

- *Topics covered include:*
  - *Definition of ME/CFS*
  - *Erroneous belief that ME/CFS is a psychological disease*
  - *Prevalence in school-age children*
  - *Causes of ME/CFS*
  - *Distinguishing ME/CFS from Other Conditions*
  - *Implications for School Nurses (including symptom recognition)*
  - *How to support students who have ME/CFS (including accommodations and modifications to their educational program)*

Advances in ME Research and Patient Care Journal

An invited, themed issue of a new Journal Frontiers in Pediatrics.
Dr. Friedman is hoping to have the themed issue co-listed in several journals including Frontiers in Medicine and Frontier in Public Health.
Dr. Beth Unger, Dr. Vicky Whittemore, Dr. Faith Newton, and MassCFIDS have agreed to submit articles.
Articles will be peer-reviewed and are due on August 25th
If anyone is interested please contact Dr. Friedman

Recommendations to Health and Human Services

We have spent the last several months making sure that the landing page between CIPR and CDC are working and connected. Those of us that were not working on that project have been working on the NASN article.

We have no new recommendations at this time.

A special thank you goes to Robin Curtis (CDC), Jessica Wilson (CPR), and Carmen Sanchez (U.S. Department of Education) for all of their hard work on this Landing Page as well as to all the members of this working group for all of their hard work!