

Day-to-Day School and CF



Learning opens doors to new worlds and helps prepare young people for a bright future. Many people with cystic fibrosis (CF) have become doctors, lawyers, teachers, homemakers and engineers, or have pursued careers in other fields. Learning is a vital part of life at all ages. Schools help people to live, learn and enjoy each day, whether to prepare for a career or just to enjoy the process. When people with CF attend school, they may need special permissions, services or changes from the school to maintain their health. For instance, some people with CF may need to take medicines at school without going to the nurse's office. Others may need to have a single room in a college dorm or be permitted to park their car close to an entrance.

This pamphlet tells you about the laws that allow students to have their medical needs met when they attend day care, elementary and high school, college and university or get **vocational training**. This



pamphlet only applies to the **accommodations** students may need because of CF. In general, parents of a child with CF and adults with CF should try to work with their school to have their CF needs met.

Your CF care team can help you learn more about the rights of students with CF and how to work with your school.

Day Care

It may be hard for you to find day care for your child with CF, as some day-care providers may not feel confident in their ability to care for your child. The **Americans with Disabilities Act (ADA)** may help if you are having a hard time finding day care for your child or if you are experiencing **discrimination**. Under the ADA, a day-care provider cannot refuse to care for a child simply because the



**Words that appear in bold italic are defined at the end of this pamphlet.*

child has a *disability*, unless it is an *undue hardship* to bring the child into the day-care setting. This is determined on a case-by-case basis. To find out more about the ADA, see the "Private Schools" section of this pamphlet. You also can contact the ADA at (800) 514-0301 or visit their Web site at www.usdoj.gov/disabilities.htm. If the day-care center gets federal funding, you may have options under **Section 504** of the *Rehabilitation Act of 1973*, discussed in the next section.

Public Schools

Elementary School and High School

Many children with CF find that attending school with their friends prepares them for the future. If your child goes to school, it is vital to work with the school to help meet your child's daily health needs. To do this, you may need an *Individual Education Plan (IEP)* under the *Individuals with Disabilities Education Act (IDEA)* or a 504 plan under Section 504 of the Rehabilitation Act of 1973. The IDEA is a federal law that makes



Sample IEP accommodations

1. Give time during school day to take medicines or do airway clearance therapy.
2. Adjust school rules to allow child to take own medicines, like pancreatic enzymes.
3. Have plan to get homework or tutor when child is ill or in the hospital.
4. Give audio or video-tapes of missed classes.
5. Adjust or waive attendance rules.
6. Give access to private bathroom, perhaps in a nurse's office.
7. Don't limit access to bathroom or water.
8. Have a school medical emergency plan.

Are you disabled?

Many people with CF work hard to stay healthy and active. They may not wish to think of themselves as "*disabled*" to qualify for changes at school. Most laws are based on someone's health status or being identified as having a "disability." See what options you have, and consider identifying yourself as disabled to be eligible for changes you may need.

public elementary and secondary schools give free and appropriate education to children with disabilities. Section 504 is a federal law that prohibits discrimination against a person because of a disability by any group that gets federal funds. An IEP or 504 plan outlines how absences or medical treatments, like taking enzymes, will be managed by the school. An IEP or 504 plan can be requested for many reasons.

To get an IEP or 504 plan, or a review of your child in preparation for one, contact your child's school. It is best to do this at the start of each school year. Contact the teacher, administrator or school nurse, and ask for an evaluation of your child under the IDEA or Section 504 of the Rehabilitation Act. Your CF care center has a sample letter that your CF doctor can use to write to the school to explain how CF affects your child and to identify some school accommodations that may help. Your CF care team also may have ideas about how the school can help you meet

your child's learning and health care needs.

Not all parents want to have a written IEP or 504 plan. Instead, you may have a verbal agreement with the school so your child can take medicines at school. But, without a written plan, the school does not have to honor the agreement.

Under the IDEA, students **qualify for services** if their disability affects their ability to learn. Missing school is one way an illness can affect your child's ability to learn. This may qualify your child for services, like a tutor, when your child is absent from school due to an illness. But, you need to have an IEP or 504 plan in place *before* your child is absent because of an illness. If you do not, it may take weeks to get help from the school. If a plan is in place before your child gets sick, the school can start the plan and get a tutor in a few days when you tell the school that your child is absent due to illness and will need help.

Once a student qualifies for services, the school will hold a team meeting with the family to make an IEP or 504 plan. The plan says what the school will need to do to meet your child's needs. You, the school's IDEA coordinator, the teacher and people who know your child's needs should attend the team meeting. Students age 14 and older often are encouraged to attend. Bring a copy of the letter

from your CF doctor and any other records that show why your child needs certain accommodations. If the IEP or 504 plan does not meet your child's needs, do not sign it. You have the right to stop and reschedule the meeting if you need to learn more about your child's needs before a plan is done. Your CF care center has a copy of a sample plan if you would like help in making an IEP or 504 plan. The IEP or 504 plan should be reviewed at least once a year to see if changes are needed.

The school may not agree that your child is qualified for services under the IDEA. It may state that CF does not affect the child's ability to learn. Then, you can ask that your child be evaluated under Section 504 of the Rehabilitation Act of 1973. Section 504 requires the student to have a disability that **substantially limits a major life activity**. Many people with CF qualify for services because their ability to breathe or digest food is limited. So, Section 504 should give your child the changes needed to benefit from school.

Getting Changes When Denied:

Working with a school to get accommodations for your child can be challenging. Keep in mind that you will be dealing with the school for many years, and your final goal is to get the education that your child is allowed by law.

The IDEA provides help for parents who cannot get needed accommodations or services for their child. Your CF care team can help with the appeal. If the school will not make needed changes, you may file a complaint with your **State Education Agency**. You may need to



request **mediation** with the school and a **mediator** from your State Education Agency to solve the issue. If this does not work or is not offered in your state, ask the school to have your complaint heard by a **hearing officer** or **administrative law judge** or have the **United States Office for Civil Rights** look into the issue. If this does not work, you can file a lawsuit in federal court **alleging violations** of the IDEA; however, this can be complicated and expensive.

Section 504 allows each school to create its own way to **appeal a denial** for accommodations or services. But, some schools may use the same way outlined for the IDEA. At the least, parents should be told of a denial, have access to school records about the student and be allowed to work with the school to solve the issue. Parents also can use mediation or request a due process hearing. **Violations** of Section 504 can be reported to the U.S. Office for Civil Rights. A lawsuit can be filed; however, this can be difficult and costly.

Private Schools

If you or your child chooses to attend a private school, talk to school administrators, teachers and other students to learn how flexible the school is in meeting the needs of people with CF or with other health conditions.

Private schools that do not get federal funding do not have to follow the IDEA or Section 504. But, the

ADA may help students with CF get changes or accommodations at a private school. The ADA protects a person: who has a physical or mental **impairment** that substantially limits one or more major life activities; who has a record of impairment; or who is regarded as having an impairment. It applies to schools, day-care centers, public buildings and other places that are open to the public.

Most students with CF meet the ADA's definition of a person with a disability because they are substantially limited in major life activities such as breathing and digesting food. Your CF care center can help you document your or your child's needs in order to request school accommodations. You can request changes like those found in an IEP or 504 plan; however, the request will not necessarily be granted as private schools legally do not have to follow an IDEA or 504 plan.

A private school that does not get federal funding may decide not to accept a student because of the need for accommodations. It is against the law for a school that gets federal funds to refuse to accept someone because of requested health accommodations. But, it could happen. You do not have to disclose health needs unless and until you need or request accommodations.

Do what you feel works best for your situation. You can tell the school about your health concerns, or you can wait to tell them until you need accommodations made. Your CF care team can help.

Getting Changes When Denied: If you and the school cannot agree about the needed changes, you can



file a complaint with the **United States Department of Justice** (www.usdoj.gov). To learn more about education laws or scholarships, call the CF Foundation at (800) FIGHT CF or visit www.cff.org.

College, University and Vocational Training

After finishing high school, some students with CF may decide to get a college and/or university degree or learn a vocation. The joy and pursuit of learning should be encouraged. People with CF should seek new options to learn and plan for their future.

Colleges, universities, vocational training centers and other places of higher education that get federal funds are covered by Section 504 and cannot refuse to admit a qualified student solely because the student has a disability like CF. Most colleges and universities have an Office for Students with Disabilities that can help students get accommodations that are needed. If a school of higher education



Accommodations that may be requested when living at school

1. Provide student certain type of dorm room, like a private room, or room with private bathroom or air conditioning, if needed because of health.
2. Change the student's required number of class hours per semester. However, this change could affect the student's health insurance coverage.
3. Change class attendance rules, giving student other options like Internet, video, etc.
4. Change student's physical education requirements.
5. Plan to change project due dates or test dates if student is absent due to illness.
6. Plan to give student notes from class or class audiotape if absent due to illness.
7. Give student a chance to finish coursework after the course has ended, if much of the semester was missed due to illness.
8. Give on-campus housing or parking.

has no such office, there should be someone in the school's administration who helps students obtain accommodations because of a disability. Call the school to learn about the help available for students with disabilities. You also can meet with someone at the school to talk about your concerns.

You do not have to tell the school that you or your child has CF. But, you will need to tell them about CF if you request accommodations that you or your child needs because of CF. If asking for accommodations, get a written agreement with the school that lists the changes to be made. You may request an accommodation from the school at any time. If you or your child leaves home to attend school, contact the CF care center nearest to the school at the beginning of the school year so they can help you with any treatment for health problems during the year. Your CF care team can help you determine the needed accommodations and work with the school.

Getting Changes When Denied:

If you cannot get changes from a college, university or vocational school, you can file a complaint with the school. Your CF care team can help with this process. They can help with the forms and letters you may need from a doctor during the complaint process. You also can report violations of Section 504 to the U.S. Office for Civil Rights. If the school is still unwilling to meet your or your child's needs, you can file a lawsuit in federal court to try to get the needed changes; however, this can be difficult and expensive.

In summary, people with CF can enjoy learning at all ages. The laws described in this pamphlet can help you or your child obtain accommodations in the school system to meet your or your child's changing health care needs. Do not be shy about asking for these accommodations. They will help you enjoy learning—and life—more fully.

Getting Accommodations in School

- Goal is education for you or your child
- Request and work with the school to get a written IEP
- CF care team can help
- If changes are denied:
 - **Public school** – contact your state education agency and request mediation
 - **Private school** – contact U.S. Department of Justice and file a complaint
 - **College, university and vocational training** – contact the school and file a complaint or report a violation of Section 504 to the U.S. Office for Civil Rights

GLOSSARY

Accommodations: Changes that are needed for someone to participate in an activity, like “no smoking” rules

Administrative law judge: Administrative law judges, also called hearing officers or adjudicators, make decisions for government agencies. They hold hearings, decide eligibility for Social Security benefits, enforce health and safety rules and address discrimination

Alleging violations: When it is suggested that there is evidence that a person at an institution, such as a school authority, has broken the law

Americans with Disabilities Act (ADA): A federal law that prohibits discrimination in public settings against a qualified person because of their disability

Appeal a denial: A process to ask for a review of a request for accommodations that has been refused

Disability: A physical or mental impairment or problem that substantially limits one or more major life activities. This definition is for the ADA and Section 504. “Disability” may be defined differently under Social Security or other government assistance programs

Disabled: When a person has a disability (see *Disability*)

Discrimination: Excluding a person from a program or making a decision about them based on race, color, religion, sex, age, disability or country of origin

Hearing officer: See *Administrative law judge*

Impairment: A decreased ability to do something, such as a major life activity (see *Major life activities*)

Individual Education Plan (IEP): A plan between a child’s family and a school to help meet the child’s learning needs; the plan tells how the school will manage things like absences or medical treatments at school, such as taking enzymes

Individuals with Disabilities Education Act (IDEA): A federal law that makes public elementary and high schools give free and appropriate education to children with disabilities

Major life activity: Activities that a healthy person usually does and that are major or vital in life; these activities include, but are not limited to: breathing, walking, seeing, hearing, speaking, eating and learning

Mediation: The process of two parties solving a problem, using a third person as a guide who acts as a mediator

Mediator: Someone unbiased who helps two parties solve a problem

Qualify for services: To be eligible for services through a program

Rehabilitation Act of 1973, Section 504: A federal law that prohibits discrimination against a person because of a disability by any group that gets federal funds. This law applies to day care and to public and private schools that get federal funds. For the educational plan, which comes under Section 504 (see *Individual Education Plan*)

Section 504: See *Rehabilitation Act of 1973, Section 504*

State Education Agency: The government office that oversees education in a state

Substantially Limits: To decide if an impairment or illness affects or limits a person’s ability to do something, it depends on: the type or degree of impairment; the actual or expected length of time the impairment lasts; and the known or expected permanent or long-term impact of the impairment

Undue hardship: Under the ADA, a public agency does not have to make changes to a program or facility if doing so would be an undue hardship, which is defined as very costly

United States Department of Justice: A department of the federal government that examines complaints of discrimination under the ADA and other laws

United States Office of Civil Rights: A part of the Department of Education that ensures equal access to education

Violations: When someone breaks the law

Vocational training: An education program that trains people for a job position, like an electrician or mechanic

Resources

Besides your CF care team, there are many other resources to help you sort through the issues to get the best education for you or your child.

- The CF Foundation:
(800) FIGHT CF or info@cff.org
- Your CF care center has the *Advocacy Manual: A Clinician's Guide to the Legal Rights of People with Cystic Fibrosis* as a resource
- Americans with Disabilities Act (ADA): (800) 514-0301 or www.usdoj.gov/disabilities.htm
- CREON Family Scholarship Program from Solvay Pharmaceuticals, Inc.:
(800) 354-0026 ext. 5898 or jamie.oliver@solvay.com
- Cystic Fibrosis Scholarship Foundation: (847) 328-0127 or MKBCFSF@aol.com
- Colorado Department of Education: *Fast Facts: The Role and Responsibility of a School Nurse*: www.cde.state.co.us/cdesped/nurse.htm
- Federal Student Aid Information Center: (800) 4-FED-AID or www.fafsa.ed.gov
- To learn more about federal government programs and laws, visit www.firstgov.gov/
- HEATH Resource Center for financial aid for school: (800) 544-3284 or www.heath.gwu.edu

- National Association of School Nurses: www.nasn.org/positions/positions.htm
- National Information Center for Children and Youth with Disabilities: www.nichcy.org
- Neighborhood Legal Services – appeal process resources: www.nls.org
- Parent Advocacy Coalition for Educational Rights (PACER): (952) 838-9000 (in Minnesota, call (800) 537-2237) or visit www.pacer.org
- U.S. Department of Education: www.ed.gov/index.jsp
- U.S. Department of Justice www.usdoj.gov
- U.S. Office for Civil Rights: www.ed.gov/offices/OCR/

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...adding tomorrows every day.

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