

CCFA Fact Sheet

NEWS FROM THE IBD HELP CENTER



SCHOOL ACCOMODATION (504) PLAN & INFLAMMATORY BOWEL DISEASES (IBD)

The symptoms of inflammatory bowel disease (IBD) can be unpredictable and may vary in severity. Students may need help to ensure they can be successful in school. IBD and treatments may affect school attendance or academic performance. Children may miss school for medical appointments, illness, disease flare-ups and side effects of treatment. However, students are still responsible for learning and completing their schoolwork. To help students with IBD achieve their academic goals, it is important to have a school accommodation plan in place. This accommodation plan is commonly known as a 504 Plan.

The Crohn's & Colitis Foundation of America (CCFA) recommend that all students with IBD have a plan in place at the beginning of the school year, even if they are feeling well. IBD is a disease in which symptoms change over time. Your child can be symptom free (in remission) and doing well at the beginning of the school year, but may experience active symptoms (flare up) later in the school year. Just because you have a plan in place, does not mean you must use all of the accommodations.

About IBD

Crohn's disease and ulcerative colitis belong to a group of conditions known as *inflammatory bowel disease*, or IBD. These disorders affect the gastrointestinal (GI) tract, the area of the body where digestion takes place. The disease causes inflammation of the gastrointestinal tract and may lead to ongoing symptoms and complications. There is no known cause or cure for IBD, but fortunately there are many effective treatments to help control the disease and symptoms.

- It is estimated that 1.6 million Americans suffer from IBD, with approximately 70,000 new cases diagnosed each year.
- Anyone can get IBD, but adolescents and young adults between the ages of 15 and 35 are more frequently diagnosed, (ten percent of those afflicted develop symptoms before the age of 18).

IBD often imposes a significant impact on quality of life through ongoing symptoms, school attendance disruptions, reduced ability to work, social stigma, and bathroom access.

- Symptoms range from mild to severe and even life-threatening, and include any or all of the following:
 - persistent diarrhea
 - abdominal pain or cramps
 - rectal bleeding
 - fever and weight loss

- fatigue
 - joint, skin, or eye inflammation
 - delayed growth in children
 - osteopenia (below normal bone mineral density)
- IBD is an unpredictable condition. Patients can look “well” on the outside but can have active disease symptoms. Some patients recover after a single attack or are in remission for years. Others require frequent hospitalizations and surgery. Symptoms may vary in nature, frequency, and intensity.

What is a 504 Plan?

Section 504 is the part of the Rehabilitation Act of 1973 which applies to persons with disabilities. Section 504 is a civil rights act which protects the civil and constitutional rights of persons with disabilities. A “504 Plan” is an action plan developed by the school, the parents/guardians and the student. The plan attempts to provide accommodations to and prohibit discrimination against students with disabilities, so that they may achieve their academic goals. It also contains a list of accommodations, or adjustments which may be required by a child with IBD to ensure that they are treated fairly and have the same access to education as other students. This law typically applies to public schools - but can also apply to private schools, if the school receives federal funding.

What is an IEP?

The Individualized Educational Plan (IEP) is a plan or program established for a child who has an intellectual or learning disability and requires specialized instruction and related services. For students who require specialized instruction, the Individuals with Disabilities Education Act (IDEA) controls the procedural requirements, and an IEP is developed. The IDEA process is more involved than Section 504 of the Rehabilitation Act and requires documentation of measurable growth.

What is the difference between an IEP and a 504 Plan?

If a student has an IEP for special education, AND the student also has IBD, the 504 accommodations for IBD will be incorporated into the IEP.

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

No. The illness must be chronic and cause a substantial limitation on the student's ability to achieve their academic goal and impact at least one major life activity.

What types of accommodation can be helpful for students with IBD?

- Unlimited restroom access
- stop-the-clock-testing
- Options to make up missed class time for medical appointments and illness without penalty
- Tutoring after a specific period of absence due to disease flare up
- Full participation in extracurricular activities even after classroom absences

What are some of the first steps in creating a 504 Plan?

Some important points to keep in mind when establishing a 504 Plan with your child's school are listed below:

- Contact the school about developing a 504 Plan for your child. The initial request for a 504 Plan can be verbal or in writing. It can come from the parents/guardians or the school.
- Get a letter/note from your child's doctor or medical report which confirms your child's diagnosis of IBD.
- Set up a meeting with the guidance counselor or referred point person with the school (i.e. Director of Special Services) to discuss the development of a 504 Plan.
- Ensure that all of your child's teachers are aware of, and understand, the Plan. The Plan is a shared responsibility, and clear communication about your child's health situation and education needs is important. Include anything you think your child may need for the year (even if he/she is currently in remission). A plan may be set up prior to the school year and changes can be made at the school's discretion and the parents request throughout the year.
- If the school tries to remove anything from the plan because they find that it is not currently necessary, emphasize that IBD symptoms change over time and may become active during the school year and therefore the accommodation should remain in the plan.
- You are able to make changes to the Plan. However it is important to keep open communication with the school about any health situations which do arise for your child.
- The Plan is only good for one year. Therefore, a Plan must be created or updated annually even if your child had no changes in their health.
- Establish with the school when your child is entitled to home tutoring. Each school district may have different guidelines for how many consecutive absences per week would entitle him/her to home tutoring. Your child is entitled to home tutoring at no cost.

Many schools have their own version of a 504 plan and it is perfectly appropriate to use the school's form. However, take care to review it to make sure that it includes the accommodations needed for your child.

Prior to meeting with your child's school, you may want to view our "*Guide for Parents*"

<http://www.ccfa.org/assets/pdfs/a-guide-for-parents-2014.pdf>

You will also want to share our brochure "*A Guide for Teachers and other School Personnel*" with your child's school district. You can print out copies at the following link:

http://www.ccfa.org/assets/pdfs/teachers_guide_brochure_final.pdf or contact the IBD Help Center to request free copies info@ccfa.org.

What are some of the Do's and Don'ts of creating a 504 Plan?

Do's	Don'ts
DO include your child in identifying accommodations that may help him/her succeed in school.	DON'T assume your child is aware of or using the accommodations available to him/her.
DO be specific about what accommodations are needed instead of saying "as needed."	Don't assume that the school is implementing your child's 504 plan
DO include why, what, where, when, who and how accommodations will be implemented.	DON'T assume every teacher, substitute, coach, staff or administrator knows your child's accommodation needs.
DO develop a plan even if your child is healthy and doing well at the beginning of the school year.	DON'T let your child talk you out of implementing a plan because they are "too embarrassed" or are doing well at the beginning of the school year.
DO continually check in with your child and their teachers to see if the plan is working. For example, does leaving the cafeteria five minutes before the end of the period give the student enough time to go to the restroom before going to class? Would ten minutes be better? Is the student accommodated to make up missed classwork during time out of the classroom? Should your child's locker be located next to the restroom or near the nurse's office?	DON'T play the blame game. It can be easy to blame the school for disappointments or a slow moving process. Blame can typically lead to an ill will situation. Avoid blame and keep calm. Learn the facts and use your energy to advocate for your child.

What if my child's school does not approve or follow the 504 Plan?

- Parents can request a due process hearing if they do not agree with the school district's evaluation decision. Parents should review "Notice of Parents and Student Rights" under Section 504 of the Rehabilitation Act of 1973 for more information.
- File a complaint with the school District's 504 Coordinator. This position may be called by another name in different school districts.

What if I disagree with the 504 plan or any of its components? What are my rights?

If you disagree with the 504 plan, you can express your views at the meeting and suggest alternatives. You may refuse to sign the plan until your concerns are addressed.

Is my child required to take physical education?

Children with IBD are not automatically excluded or excused from physical education. Physical education accommodations can be written into a 504 Plan.

Students with and without IBD may benefit from physical activity, which improves muscular strength, helps control body weight, and can enhance psychological well-being.

Does my child have to be struggling with classes or failing before he/she can get accommodations?

No. The law does not say a child must be failing or struggling with classes or subjects in order to qualify for accommodations. Even if a child is a straight "A" student he/she would still qualify for accommodations under the 504 plan.

Can my child get accommodations for taking college boards, (i.e. PSAT, SAT, ACT etc.?)

Yes, but application for accommodation for standardized tests outside of the school district's realm, such as [College Board accommodations](#), must be applied for well in advance of the test in order for the student to be provided accommodations. Your child's guidance counselor can provide further information about implementing accommodations outside of the 504 plan. Students can work with their school to submit a formal request for College Board accommodations if the following criteria can be met:

- The Student has a documented disability including medical impairments such as IBD.
- The Disability will impact the student's ability to participate in college boards in the usual manner and accommodation is needed. Students receiving school accommodations do not automatically qualify for College Board accommodations.

What is the difference between accommodations in college and elementary/high school?

Section 504 of the Rehabilitation Act of 1973 also protects students in higher education. However, unlike high school, the college student must seek out services and advocate on his/her own behalf. Colleges are not allowed to ask students if they have a disability or health issue. Students must voluntarily disclose that they have IBD, provide documentation, and request supports or accommodations. The college is not required to evaluate the student to determine which accommodation is needed.

Colleges offer an array of supports but your child must seek out these supports. It's best to seek them out at the beginning of the semester or before the student is at risk of failing or dropping out of a course.

Final thoughts

You are your child's best advocate. Take an active role early on in working with your school district and educating them about IBD and your child's needs. Be sure to involve your older child in the accommodation decision making because one day he/she will need to advocate for themselves.

Enlist the help of your child's health care provider -they have likely helped many pediatric patients with developing a 504 plan. They can give you guidance on what accommodations have been most helpful for other patients.

For more information on this topic, check out the resources below or contact CCFA's IBD Help Center at 1.888.MY.GUT.PAIN (888-694-8872) or at info@CCFA.org.

CCFA Resources

The Facts About Crohn's & Colitis: <http://www.ccfa.org/assets/pdfs/updatedibdfactbook.pdf>

Guide for Teachers: <http://www.ccfa.org/assets/pdfs/teachersguide.pdf>

Guide for Teens with IBD: <http://www.ccfa.org/assets/pdfs/teenguide.pdf>

Guide for Parents: <http://www.ccfa.org/assets/pdfs/a-guide-for-parents-2014.pdf>

IBD & Me Activity Book (for ages 8-12): <http://www.ccfa.org/assets/pdfs/ibd-me-ac.pdf>

Pete Learns All About Crohn's & Colitis (for ages 8 -12): <http://www.ccfa.org/assets/pdfs/pete-learns-all-about-crohns.pdf>

Camp Oasis: <http://www.ccfa.org/get-involved/camp-oasis/>

Campus Connection: Website for College Students: <http://www.ccfa.org/campus-connection/>

Just Like Me! Teen Website: <http://www.justlikemeibd.org/?referrer=http://www.ccfa.org/>

Additional Resources

American's with Disability Act www.ada.gov

[American Diabetes Association](http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/written-care-plans/section-504-plan.html) <http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/written-care-plans/section-504-plan.html>

College Boards <https://www.collegeboard.org/students-with-disabilities/eligibility>

Council of Parent Attorneys and Advocates: <http://www.copaa.org/>

Individuals with Disability Act www.idea.ed.gov

United States Department of Health and Human Services, Office for Civil Rights
<http://www.hhs.gov/ocr/office/about/rgn-hqaddresses.html>

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