

# Protecting Children with Sickle Cell Disease

## Helping your Child in School

### Every child has the right to an education.

Children with Sickle Cell disease must have the same opportunities and experiences in school as children who do not have the diagnosis.

If your child needs extra help or support because of Sickle Cell Disease, the school must provide it.

### The Law

The Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 are the laws that require schools to give special help to children with Sickle Cell Disease.

### Getting Help

Ask for a meeting at school to talk about your child's medical issues and educational needs.

The meeting should include you and school staff who will be working with your child – administrators, teachers, nurse, etc.

Your doctor may be willing to provide useful information about your child's medical condition.

### Making a Plan

The meeting results in a "504 Plan". This plan lists the help or "accommodations" that your child will get at school.

The plan covers all of your child's school day – getting to school, being absent, homework, tests, going to the nurse, physical education, etc.

See the other side of this flyer for suggested "504 Accommodations" for your child.

### Everyone at school must follow the 504 Plan.

This includes the classroom teacher, substitutes, cafeteria staff, gym teacher, recess staff, etc.

### Plans for Children with Learning Problems

Special education services help children with learning problems. If your child is receiving special education services, s/he does not need a separate "504 Plan". The accommodations your child needs because of Sickle Cell Disease will be part of his or her special education plan.



### Ensuring Participation

Children with Sickle Cell Disease have the right to participate in all school activities. This includes trips, field days, etc.

If necessary, the school must make special plans so that your child can participate.

### Addressing Problems with School Staff

Not all schools understand the educational impact of Sickle Cell Disease. Similarly, not all schools understand that children with Sickle Cell Disease cannot be left out of school activities.

If you have concerns, call us. Contact information is below.

#### Center for Children's Advocacy Medical-Legal Partnership Project [kidscounsel.org/mlpp](http://kidscounsel.org/mlpp)

Attorney Bonnie Roswig 860-545-8581  
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## Sample 504 Accommodations

Children with Sickle Cell Disease may need special services in school. Services are listed in a "504 Plan" that must be agreed to in writing.

Not all children have the same 504 Plan. Here are options that you may wish to include:

**1. Unlimited Access to School Nurse**

MAKE IT CLEAR: How will your child leave the class – asks permission, is just able to leave, needs a buddy if really sick, etc.

**2. Access to Extra Fluids**

MAKE IT CLEAR: How will your child get his or her fluids – water bottle on desk, unlimited trips to the water fountain, etc.

**3. Unlimited Access to Bathroom**

MAKE IT CLEAR: Does your child need to tell the teacher? Does your child need a note if the bathroom is in another part of the building?

**4. Extra Set of Books**

**5. Special Transportation**

**6. Modified Recess**

MAKE IT CLEAR: When will the child's recess be modified (too cold, too hot, your child has been sick)? What will the activity be when your child cannot go outside?

**7. Emergency Plan for Fire Drill or Other School Emergencies**

MAKE IT CLEAR: What is the plan if there is an emergency "drill"? Where will your child go if everyone needs to leave the school building?

**8. Approved Absences from School Based on Disability**

MAKE IT CLEAR: Do you have to call? Do you have to send a note? Do you need a note from the doctor? Do you need to call or write a note every day if your child is in the hospital?

**9. Support for Missed Academic Work Due to Disability**

MAKE IT CLEAR: What will the school do to help your child with missed work because s/he was too ill to complete the assignment? Under what circumstances will your child receive a tutor at home or at school? What assignments will have to be completed? What tests have to be completed? How much time will your child have to complete missed work once she is well enough to do school work? What is the plan for getting the work to your child? If your child is in the hospital for an extended period of time and requires tutoring while inpatient, how will the school communicate with the hospital tutor?

**10. Accommodations for Test Taking**

MAKE IT CLEAR: Does this apply to classroom tests, Connecticut tests, college entrance tests? Can your child take the test on a computer? Can your child take the test in a room that is not too hot or too cold?

**11. Access to Assisted Technology (Computers, etc).**

MAKE IT CLEAR: Who provides the computer, etc? Can your child bring the computer to school? Will there be a separate computer for home?



**12. Modified School Day**

MAKE IT CLEAR: When does your child's school day start and finish? How will your child be transported to school? What is the procedure for integrating your child back into a standard school schedule?

**13. Modified Course Work**

MAKE IT CLEAR: What is the procedure if your child needs to complete one or more courses on the computer? Will this occur in school or at home?

NOTE: Some schools would rather have a child with disabilities have all of their schooling at home. If a child is well enough, it is always better for the child to learn in a place where s/he can be with other children.

**14. Modified Physical Activity**

MAKE IT CLEAR: What will your child's gym programming be? Will s/he be excused from standardized fitness tests?

**15. Extended Year Programming**

MAKE IT CLEAR: Under what circumstances will your child go to summer school? What is the programming if there is no air conditioning at the designated summer program?

### This is just a sample list.

Your child's "504 Plan" will depend on your child's educational and medical needs.

If you have questions or concerns about the accommodations that your child is receiving, please call us. Contact information is on the other side of this flyer.