Section 504 Protections for Students with Sickle Cell Disease (SCD)

Section 504 of the Rehabilitation Act of 1973 is a Federal civil rights law that protects students from disability-based discrimination in schools (including preschools, K-12 schools, colleges, universities, and other postsecondary institutions) that receive Federal financial assistance.

Under Section 504, a student with sickle cell disease (SCD) can be a student with a disability for purposes of Section 504 if the student’s SCD substantially limits one or more of the student’s major life activities. 34 C.F.R. § 104.3(j)(1)(i).

What is SCD?

According to the Centers for Disease Control and Prevention, SCD is a group of inherited red blood cell disorders, including sickle cell anemia. Symptoms and complications of SCD are different for each person and can range from mild to severe. In addition to chronic pain and acute pain crises that may be so severe that hospitalization is necessary, persons with SCD may experience: frequent urination; fatigue; dizziness; light-headedness; fainting; fever; infections; nausea; vomiting; anemia; very low blood pressure; high blood pressure; fast or irregular heartbeat; swelling of body parts; coughing; breathing problems; sleeping problems; and, jaundice (yellowing of skin and white part of eyes).

Can a student with SCD have a disability under Section 504?

Yes. A student with SCD has a disability if their SCD substantially limits one or more of their major life activities.

SCD can substantially limit the operation of the circulatory system, which is a major bodily function and therefore a major life activity under Section 504. 29 U.S.C. § 705(20)(B) (incorporating 42 U.S.C. § 12102(2)(B)).

SCD and its complications can also substantially limit other major bodily functions, including the brain, and the neurological, immune, respiratory, cardiovascular, hemic, genitourinary, and digestive systems. SCD can also affect an individual’s breathing, learning, concentrating, thinking, seeing, reading, sleeping, walking, and standing, which are also major life activities under Section 504. 29 U.S.C. § 705(20)(B) (incorporating 42 U.S.C. § 12102(2)(A)-(B)).
Whether a student has SCD can be established by blood testing, which is generally performed at birth in the United States. Diagnosis of complications, such as organ damage, can require additional medical examination and testing. But medical tests are often not required to determine that a student is substantially limited in a major life activity. For example, a history of medical emergencies may provide sufficient information to determine that a student’s SCD substantially limits a major life activity. A school may always accept that a student has a disability without any documentation or medical tests.

Under Section 504, the issue of whether an impairment substantially limits a major life activity should not demand extensive analysis. 29 U.S.C. § 705(20)(B) (incorporating 42 U.S.C. § 12102(4)(B), which incorporates § 2(b)(5) of the findings and purposes of the ADA Amendments Act of 2008).

The term substantially limits must be construed broadly in favor of expansive coverage, to the maximum extent permitted by the statutory language. 29 U.S.C. § 705(20)(B) (incorporating 42 U.S.C. § 12102(4)(A)).

An impairment does not need to prevent, or significantly or severely restrict, an individual from performing a major life activity in order to be considered substantially limiting. It is enough that an impairment substantially limits the ability of an individual to perform a major life activity as compared to most people in the general population. Additionally, an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active. 29 U.S.C. § 705(20)(B) (incorporating 42 U.S.C. § 12102(4)(B), which incorporates § 2(a)(7)-(8), (b)(5)-(6) of the findings and purposes of the ADA Amendments Act of 2008, and § 12102(4)(D)).

The beneficial effects of mitigating measures, such as medication, used by an individual, must be disregarded in determining whether an impairment substantially limits a major life activity of an individual. 29 U.S.C. § 705(20)(B) (incorporating 42 U.S.C. § 12102(4)(E)).

**How can SCD affect a student’s experience in school?**

Students with SCD may:

- be absent from school due to medical appointments, severe pain, other complications of SCD, hospitalization, or care at home;
- have an ongoing sense of fear or stress about a painful sickle cell crisis; and/or
- need to take medication; or drink during classroom instruction.
What might a school need to do to address a student’s SCD?

If the student’s SCD has resulted in the student having a disability under Section 504, that student may require certain modifications (sometimes referred to as accommodations) to meaningfully access or benefit from the school’s educational opportunities. 34 C.F.R. §§ 104.4, 104.44. This is true even if the student is not substantially limited in the major life activity of learning.

Section 504 may require a school to provide modifications. For example:

- allowing the student to make up work, without penalty, and excusing late arrivals and absences when they miss class due to a medical appointment or when SCD-related symptoms hinder a student’s ability to complete their work;
- providing preferred seating to avoid exposure to cold or damp conditions or drafts to avoid triggering a pain crisis or other complications;
- allowing periodic rest breaks or as-needed rest periods;
- allowing the student to consume water during instruction;
- allowing the student to use the restroom as needed;
- modifying participation requirements in outdoor activities to avoid sudden changes in temperature or exposure to extreme hot and cold temperatures;
- adapting requirements for the required level of activity for participation in strenuous physical activities, such as in physical education and recess activities;
- implementing appropriate sanitation practices, e.g., wiping down desk, to prevent infections;
- providing prompt notification in a non-personally identifiable form when another student in class has a contagious illness, such as the flu, COVID-19, chicken pox, or measles; and/or
- granting periodic requests by students or parents for distance learning or the provision of necessary instructional materials for use at home when SCD-related pain or other symptoms intensify, making it difficult for a student to leave home.

Furthermore, even if a student with SCD has a disability but does not need modifications, they would still be protected from discrimination, such as disability-based harassment. For example, Section 504 may require a school to respond to bullying or harassment targeted at students because of their medical condition, or because they are regarded as or have a record of having a disability. 34 C.F.R. § 104.3(j)(1)(ii) & (iii). Such bullying or harassment, for example, could be related to a student’s absences, physical appearance due to jaundice, frequent trips to the restroom, or inability to participate in certain activities.

This fact sheet does not comprehensively address the assistance with SCD-related medical issues a school may be required to provide. In the elementary and secondary setting, students with SCD may also require some additional level of assistance with medication or symptoms, such as pain or complications, related to their condition. This could range from assistance only in an emergency to a trained school staff member providing ongoing assistance.

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What remedies might a school need to provide if the school does not appropriately address a student's SCD?

If a school violates the Section 504 rights of a student with SCD, the school may be required to, among other things:

→ offer the student an opportunity to re-take classes, tests, or assignments with appropriate modifications if needed, and without penalty or negative consequence to the student;

→ excuse absences incurred due to SCD and correct student records regarding unexcused absences; and/or

→ train faculty and staff on how SCD may manifest; in the elementary or secondary school setting, on students' SCD-related care/emergency plans; on addressing peer-to-peer bullying and harassment; and on how living with SCD may impact a student physically, psychologically, socially, and academically.

What can be done if a student or parent believes a school is not meeting its obligations under Section 504?

→ Section 504 requires schools to develop and implement a system of policies and procedures to address concerns and disagreements that may develop between schools and students. 34 C.F.R. §§ 104.7, 104.36. Parents and students may choose to initiate proceedings in keeping with these policies and procedures.

→ Students, parents, or others who would like to request technical assistance from the Office for Civil Rights (OCR), or who would like to file a complaint, may do so by contacting the OCR enforcement office that serves their State.

For more information on disability-related issues, please visit OCR’s Disability Discrimination webpage.

To request language access services or resources, which may include oral technical assistance or written translation of Department information, free of charge, contact OCR@ed.gov.

If you need more information about interpretation or translation services, call 1-800-USA-LEARN (1-800-872-5327) (TTY: 1-800-877-8339). To request documents in alternate formats such as Braille or large print, contact the Department at 202-260-0818 or ofo_eeos@ed.gov.

This fact sheet does not have the force and effect of law and is not meant to be binding, beyond what is required by statutory and regulatory requirements. All enforcement determinations made by OCR are based on the particular factual circumstances presented in each individual case.

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