

# CENTER FOR LAW AND EDUCATION

[www.cleweb.org](http://www.cleweb.org)

105 Chauncy Street, 6<sup>th</sup> FL, Boston, MA 02111

617-461-0855

## **Boston Public Schools to Protect and Accommodate Students with Sickle Cell Disease**

BOSTON (February 7, 2018) – In response to an investigation by the US Department of Education’s Office for Civil Rights (OCR), Boston Public Schools (BPS) has agreed to recognize sickle cell disease (SCD) as a disability that interferes with a student’s education, and to implement policy changes to ensure that students with SCD receive the quality education they have long been denied due to health problems.

Under a voluntary agreement signed Jan. 30 by Boston Superintendent Tommy Chang, district policy now acknowledges that SCD is a disability that qualifies students for services and legal protections under federal education and civil rights statutes. These services include supplemental instruction to make up for missed classroom time because of SCD. “This means instruction by qualified subject-matter teachers to scaffold missed and ongoing coursework with the goal of keeping the student with SCD on pace with classmates upon return,” explained Jenny Chou, senior attorney at the Center for Law and Education (CLE).

The agreement resolves a complaint filed with the OCR more than three years ago by CLE and the Massachusetts Law Reform Institute on behalf of a group of BPS parents and students. According to the complaint, students with SCD—nearly all of whom are African American or Hispanic— were penalized when manifestations of their illness interfered with their ability to participate fully in class. These include chronic physical pain, infections, anemia, and fatigue as well as side effects from medication used to treat SCD that can result in difficulty concentrating and absences.

Because the school district failed to recognize SCD as a disability, it did not seek to identify students with SCD and to refer them for a comprehensive evaluation, and as a result, denied an alleged 250 students with SCD a free and appropriate education as required by law.

All qualified BPS students with SCD will have a 504 plan (named for section 504 of the 1973 Rehabilitation Act, which prohibits discrimination on the basis of disability in federally funded programs). A 504 plan requires a comprehensive evaluation of the ways a student’s disability interferes with learning, and identifies supportive services and accommodations to address the student’s needs. For students with SCD, accommodations may include modifying the requirements for participation in gym class, exemptions from certain activities, door-to-door transportation, and supplemental instruction.

“This agreement is an important step in recognizing the rights of children and youth with sickle cell disease,” said Dr. Rajan Sonik, who worked with the students when he was at MLRI. “These are highly vulnerable kids who are often stigmatized and left feeling invisible.”

Under the agreement, BPS will also:

- Establish by February 15 a Sickle Cell Disease Advisory Group comprised of parents, district administrators, Section 504 Coordinators, school health personnel, and representatives from local SCD advocacy groups.
- Develop a policy to identify and serve BPS children with SCD who will be referred for a comprehensive evaluation to determine the extent of the student's needs, if any, for services. The policy must be sent to OCR for review by May 1.
- Develop a checklist of potential accommodations to be used during Section 504 and/or Individual Education Plan meetings involving students with SCD. The checklist will include suggestions such as providing two sets of textbooks, permission to carry a water bottle at all times, and permission to stay indoors when temperatures are so hot or cold that they could aggravate SCD symptoms. The checklist must be sent to the Office of Civil Rights for review by December 1 with evidence that it has been distributed to all Section 504 coordinators, administrators, and teachers.
- Develop an outreach and public awareness campaign about accommodations for students with SCD. This will include publishing information on the BPS website and sending a letter to all BPS students' parents and guardians with information about SCD and student and parental rights. BPS must update OCR on its public awareness campaign plans by October 31.
- Provide training in person or online to all Section 504 coordinators, administrators, and teachers on SCD and the new SCD policy. The training must include BPS's obligations under Section 504 to evaluate all students with a suspected disability, an overview of SCD and its manifestations.

"This agreement sends the clear message that students and their families are not to blame for sickle cell disease-related absences, and that public schools must provide these children with supportive services and accommodations necessary to attain the educational benefits provided to other students," said Kathleen B. Boundy, co-director of the Center for Law and Education.

**Contact:** Jenny Chou, Center for Law and Education [jchou@cleweb.org](mailto:jchou@cleweb.org) 617-451-0855  
Rajan Sonik, J.D., Ph.D., [rajan.sonik@gmail.com](mailto:rajan.sonik@gmail.com) 916-233-8337

\*\*\*

**About the Center for Law and Education** - The Center for Law and Education (CLE) is a nonprofit national resource and advocacy organization, providing assistance to educators, parents, students, and advocates experiencing difficulty in the implementation of key education programs and initiatives at local and state levels. CLE strives to make the right of all students to quality education a reality and to help enable communities to address their own public education problems effectively, with an emphasis on assistance to low-income communities. [www.cleweb.org](http://www.cleweb.org).

**About Massachusetts Law Reform Institute** - Massachusetts Law Reform Institute (MLRI) is a statewide nonprofit poverty law and policy center. It provides statewide advocacy and leadership in advancing laws, policies, and practices that secure economic, racial, and social justice for low-income people and communities. As a law reform center, MLRI's focus is on systems change and high impact advocacy that addresses widespread problems and institutional inequities that affect low income, vulnerable and underserved people. [www.mlri.org](http://www.mlri.org)