



Superintendent's Circular

School Year 2018-2019

NUMBER:
SHS-#25

DATE:
October 25, 2018

Sickle Cell Disease Policy and Implementation

1. I. Policy Background

The Boston Public Schools (BPS) entered into a voluntary Resolution Agreement with the US Department of Education's Office for Civil Rights (OCR) on January 30, 2018. As part of this Resolution Agreement, BPS agreed to develop this Policy to ensure that it meets its obligations under federal law with regard to students with sickle cell disease (SCD). Further, BPS agreed to develop this Policy with advice from a SCD Advisory Group, composed of community experts in SCD, parents, students, and BPS staff. BPS recognizes that a clear, comprehensive policy on SCD management in school can have an impact on academic achievement and support the general wellbeing of students with SCD.

2. II. Policy Statement

BPS acknowledges that SCD is a disability that substantially limits a major life activity, and qualifies students with SCD for a comprehensive evaluation and consideration of eligibility under Section 504 of the Rehabilitation Act of 1973 (Section 504) to determine the services and accommodations they may need to attain a free appropriate public education. As part of BPS' commitment to maintaining an educational environment that is welcoming, inclusive and encouraging, such that all students are able to flourish, all schools must follow established protocols and procedures for addressing the needs of children with SCD and regularly evaluate the implementation of these plans.

BPS acknowledges that the successful implementation of this Policy at the district and school levels relies on fostering and maintaining a culture of awareness and acceptance regarding SCD through acknowledging the history of SCD and the unique challenges students with SCD face. With this in mind, BPS recognizes that:

- People with SCD have long faced harmful stigmas, many with racially charged origins.
- People with SCD are often challenged about their disease's seriousness or even existence.
- Students with SCD have long experienced barriers to their health and success at school.

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3. III. Sickle Cell Disease Basics

SCD refers to a group of genetic blood disorders. It affects individuals of all races and ethnicities, but in the United States it is especially prevalent among African Americans and Hispanics. Complications include but are not limited to severe anemia, susceptibility to infections, insomnia, jaundice, frequent urination, dehydration, chronic pain, and episodes of extreme, debilitating pain. Pain episodes (also known as "crises") can cause tissue and organ damage, lead to hospitalizations, and have life-threatening consequences. People with SCD are also at heightened risk for anxiety, depression, post-traumatic stress

disorder, social isolation, delayed social development, visible strokes, and “silent strokes” that may go unnoticed but can affect learning abilities in the short and long terms. Pain episodes and other complications may be triggered by a wide variety of physical and psychological stressors.

As a result of these complications and the side effects of medications, many children with SCD experience frequent absences and difficulty focusing or engaging as they usually do at school, particularly with regard to physical activities. On days free from harsher symptoms and side effects, many students with SCD still experience baseline symptoms and health vulnerabilities that require modifications to standard participation requirements.

Additionally, the biology and history of SCD create the following unique challenges:

- SCD pain is often “invisible.” People with SCD learn coping mechanisms (such as staying still and quiet) that may seem counterintuitive. SCD pain therefore often goes undetected by others, leading to challenges about the seriousness or existence of the pain.
- Symptoms such as jaundice, short stature, and delayed social development, along with repeated absences, can make students with SCD targets of bullying and harassment.
- Medications used to treat people with SCD, such as opioid pain medications and hydroxyurea (a chemotherapy drug that can also help some people with SCD), can cause serious and disruptive side effects and carry stigmas of their own.
- Individuals with SCD have historically been stigmatized in the community, hospitals, schools, the armed services, and places of employment. Labeled a “Black disease,” SCD has historically been associated with claims of racial weakness and genetic inferiority.

4. IV. Overview – Addressing Needs of BPS Students with SCD

A. CHILD FIND: Identification, Location, Immediate Accommodations & Evaluation

1. Identification and Location

BPS acknowledges that, due to the stigmas noted above, many parents choose not to identify their child with SCD instead of seeking supportive services and accommodations for their children. To overcome this challenge, BPS utilizes multiple strategies as part of an outreach and public awareness campaign to raise awareness of SCD and its effects on learning to assure families that BPS is a willing partner to create a community of support, collaboration and understanding around students with SCD. These strategies include but are not limited to:

- Letter of notice to all parents describing SCD, establishing rights and protections under Section 504, including the school district’s affirmative duty to identify, locate and evaluate students who need or are believed to need special education or related aids and accommodations.
- Collaboration with local medical centers that treat children with SCD and leveraging these to develop strategies for identification and location. (e.g. sharing outreach materials with clinics, providing “know your rights” materials for families in clinics that see students with SCD, meeting with medical providers to develop additional strategies etc.).
- Providing information for parents at registration sites and Countdown to Kindergarten activities about: SCD and schooling, the rights of children with SCD, and the services and supports available to students with chronic diseases generally and to children with SCD specifically.
- Ensuring that all communications are available in multiple languages and/or modes in order to be accessible to all families.
- Ensuring that the outreach and public awareness campaign includes outreach to preschools, early intervention providers and community support providers, who are likely to have students that are or will enroll in BPS (i.e. located in Greater Boston).
- Posting information for parents about SCD and schooling and the rights of children with SCD in school on the main BPS website, the BPS health services website, the BPS equity site, and any other relevant BPS sites.
- Additional strategies developed with input from the SCD Advisory Group.

a. Specific considerations regarding enrollment:

BPS, upon identifying a child with SCD at enrollment, ensures proper placement in a school with appropriate health and related services. Given stigmas related to SCD, BPS gives special attention to ensuring the privacy of students with SCD. This includes appropriately limiting the scope of releases parents sign regarding disclosures of their child's SCD status.

Further, BPS ensures appropriate efforts are made to initiate and maintain connections between school health staff and students with SCD, their parents, and their medical teams upon enrollment of the student (or upon identification if after enrollment). This includes providing information to parents and school health staff and ensuring privacy rights are maintained.

2. Interim Services/Supports Pursuant to Section 504

BPS acknowledges that, because SCD is a physical disability that substantially limits major life activities, students with SCD are entitled to certain accommodations *upon identification and location* to ensure their health, safety, and equal educational opportunities, pending the completion of a comprehensive evaluation. All rights and protections pursuant to Section 504, including procedural safeguards, are ensured upon identifying and locating students with SCD. BPS ensures that the interim accommodations implemented pursuant to Section 504 include the following:

- Two sets of textbooks, one for school and the other for home.
- Unlimited bathroom access as needed.
- Unlimited access as needed to the school nurse or school health official.
- Unlimited access as needed to communicate with parent and/or physician if they are experiencing symptoms that are unfamiliar or are ones their physicians told them to contact them about if experienced.
- Unlimited water access as needed through access to a water bottle and water fountains
- Time/permission to access medication (including prescribed opioids), as needed.
- Permission to wear a coat indoors whenever feeling cold and to stay indoors or be exempt from outdoor activities whenever it is too hot, too cold, or when air quality is poor.
- Permission to move away from indoor AC or heating units.
- Consideration for door-to-door transportation, except in the very limited circumstances where it would be impractical (e.g. student resides next door or across the street from the school building he/she attends).
- Permission to access an elevator, if relevant, and to leave class early to get to the next one (or alternatively, extra time between classes).
- Modified participation in gym class, based on student needs.
- Proactive plans to address academic and social/emotional supports upon return to school from absences including supplemental instruction provided by qualified subject-area teachers and service providers in order to scaffold missed and ongoing instruction in the classroom and to enable students to catch up with and stay on pace with classmates.

3. Comprehensive Evaluation

BPS ensures that all students with SCD receive a timely, comprehensive evaluation of all areas of suspected disability in order to determine the nature and extent of a student's need, if any, for specialized instruction or related aids and services. BPS ensures that a neuropsychological evaluation is considered as part of a comprehensive evaluation for any student with SCD.

B. FREE APPROPRIATE PUBLIC EDUCATION

To address needs for students with SCD, BPS ensures that—as part of special education and related services that may be identified through comprehensive evaluations—any 504 plans and/or IEPs specifically address challenges students with SCD face related to health and safety needs, academic needs, social-emotional needs, resuming school after absences, and stagnations and/or declines in

academic progress or performance. BPS therefore ensures the utilization of a checklist of potential accommodations at each Section 504/IEP Team meeting for a student with SCD. The checklist is considered in addition to all other appropriate services and supports determined necessary for an individual student with SCD to receive a free appropriate public education. BPS ensures that documentation of each item's consideration by the 504 or IEP team is included in meeting minutes and provided to parents.

BPS ensures that neither Individual Health Plans (IHPs) nor Individual Collaborative Health Plans (ICHPs) are used in lieu of a 504 Plan, IEP or interim accommodation plan.

Additional points requiring particular attention:

1. Continually Updating Health and Safety Services/Supports

BPS ensures that the 504 Plans and/or IEPs of children with SCD reflect the up-to-date health and safety needs of the child, recognizing that these needs may change during the course of the year. BPS ensures that any new information received regarding changed needs for a student with SCD will be addressed in light of the student's 504 Plan or IEP.

2. Tracking Effects of Absences and Sudden Changes in Needs

BPS ensures that, when a child with SCD has had absences and there has been a lack of expected progress toward annual goals in an IEP and/or in the general curriculum, discussions are promptly held regarding how the absences are interfering with academic progress and how this interference can be overcome, including consideration of instruction in the summer. BPS also ensures that sudden drops in academic performance and sudden increases in social-emotional needs that are experienced by students with SCD are detected and responded to appropriately.

3. Designation of Office of Ombudsperson if and when Services or Supports are not Provided

BPS ensures that students with SCD, their parents, and (with proper consent/privacy precautions) their medical team have access to the Boston Public Schools Ombudsman Office (e.g., designated individuals) to escalate concerns they have about a child with SCD not receiving a free appropriate public education. This process is separate from and does not preclude due process and grievance rights available under Section 504 and IDEA. These mechanisms are necessary given the severity and swiftness of the health, academic, and social-emotional consequences that can occur for children with SCD.

C. ENSURING APPROPRIATE CULTURE WITHIN BPS REGARDING SCD -- BPS Ensures that the Culture Regarding SCD with BPS Includes:

- believing students with SCD when they communicate that they: are in pain, are having some other complication, or are unable to perform a certain task due to their symptoms;
- not blaming or shaming students with SCD or their parents for their challenges;
- identifying challenges quickly and working collaboratively to find appropriate solutions;
- facilitating awareness that children with SCD are members of school communities;
- facilitating an understanding of what SCD is and its implications for health and safety;
- facilitating an understanding of the services/supports that students with SCD may need to ensure their health and safety, as well as an understanding of the importance of adhering to these accommodations; and
- facilitating an understanding of the special education and related services a student with SCD may need to ensure their access to a free appropriate public education.

a. Awareness and Trainings

As part of ensuring an appropriate culture regarding SCD, BPS conducts ongoing outreach and public awareness campaigns that address each aspect of an appropriate culture described above. BPS also

conducts ongoing trainings for all teachers, administrators, nurses, and other relevant staff. Trainings cover all necessary topics to ensure that all BPS staff coming into contact with students with SCD have the necessary knowledge and awareness to properly implement all policies, protocols, and procedures regarding SCD and to appropriately support the student with SCD. School nurses receive additional periodic training in managing the medical needs of students with SCD.

b. Scope and Frequency of Awareness and Training Activities

BPS ensures that awareness and training efforts are wide enough in scope to reach all appropriate personnel and repeat with enough frequency to reach any new or temporary personnel who may enter over the course of a school year.

D. DATA MONITORING

BPS conducts sufficient data monitoring to track successes and failures in the implementation of its policies, protocols, and procedures regarding SCD. This monitoring includes documenting instances where students with SCD, their parents, and/or their medical team had to escalate concerns about health and safety services/supports being provided or followed and/or a free appropriate public education being properly provided. The data produced is regularly reported through summary statistics without personally identifiable information to the SCD Advisory Group and publicly via BPS website postings and press releases.

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