

CENTER FOR LAW AND EDUCATION

www.cleweb.org

reply to:
99 Chauncy Street
Suite 716
Boston, MA 02111
617-451-0855

7101 Holly Avenue
Takoma Park
MD, 20912
202-986-3000

Sent via electronic mail

January 12, 2015

Joel J. Berner, Regional Director
Office for Civil Rights
US Department of Education
8th Floor
5 Post Office Square
Boston, MA 02109-3921

Re: Complaint regarding the Boston Public School District's Ongoing Violations of Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act, and Title VI of the Civil Rights Act of 1964.

Dear Mr. Berner:

This Complaint filed by the Center for Law and Education and Massachusetts Law Reform Institute, alleges that the Boston Public School District's policies and practices regarding the identification and evaluation of students with a disability have resulted in the discriminatory exclusion of eligible students with Sickle Cell Disease (SCD) who are disproportionately African American and Hispanic students. CLE and MLRI and Complainant students and parents assert that BPS, by failing to meet its obligation to identify and evaluate this particular subset of students, i.e., those with SCD, who because of disability, need or are believed to need special education or related services, denies eligible students with disabilities access to instructional programs, supportive and related services, and the range of accommodations they need to enjoy the same opportunities to succeed as students without disabilities in violation of Section 504 of the Rehabilitation Act and Title II of the ADA, and their respective regulations. Because SCD is a genetic disorder affecting multiple bodily functions that almost exclusively affects African American and Hispanic students, the Complaint further alleges that BPS's policies and practices denying these students their rights as qualified individuals with disabilities, have a disparate impact on the basis of their race, color and national origin under Title VI of the Civil Rights Act of 1964. CLE and MLRI bring this Complaint against BPS on behalf of Complainant students and their parents as well as on behalf of all enrolled BPS students with SCD, who are virtually exclusively African American and Hispanic.

Introduction

Each school year, there are approximately 250 elementary and secondary school students enrolled in the Boston Public Schools (BPS) who have sickle cell disease (SCD), a serious genetic blood disorder affecting a major bodily function – the circulatory system. Children with SCD experience an array of complications from minimal to severe that “substantially limit” their participation in such other major activities as walking, concentrating, thinking and learning. Students with SCD typically miss days of schooling when they experience bouts of periodic pain and other complications associated with their disease. BPS has denied and continues to deny the vast majority of the enrolled students with SCD their rights to the protection and services under Section 504 of the Rehabilitation Act of 1973,¹ as amended by the Americans with Disabilities Act Amendments Act of 2008², by failing to identify and refer them for a comprehensive evaluation to determine their eligibility as qualified students with a disability.

By failing to meet its obligation to evaluate these particular students, BPS denies eligible students with disabilities access to instructional programs, supportive and related services, and the range of accommodations they need to enjoy the same opportunities to succeed as students without disabilities in violation of Section 504. BPS fails to consider the educational needs of students with SCD for related aids and services, which can be expected to include supplemental direct instruction of the core curriculum with tutoring, and possible extended school year services, to enable them to receive the teaching and instruction they miss when they are absent from school for reasons related to their disability. Moreover, the needs of qualified BPS students with SCD for accommodations, such as modifying/reducing assignments to be made up, or obtaining extra time to make up work missed during absences, are not considered.

Because SCD is a genetic disorder of the circulatory system that almost exclusively affects African-American and Hispanic students, BPS students with SCD, who are denied access to consideration for eligibility for Section 504’s protections, benefits and services, are disproportionately African American and Hispanic children and youth. Therefore, Complainants also allege that BPS’s policies and practices that deprive students with SCD, who are qualified individuals with disabilities from an eligibility determination necessary to receive aids, benefits, services and accommodations under Section 504, also have the effect of discriminating against these students with SCD on the basis of their race, color and national origin under Title VI of the Civil Rights Act of 1964.³ The disparate impact of depriving students with SCD, who are virtually exclusively African American and Hispanic students, consideration of their eligibility and their rights under Section 504 cannot be justified as educationally necessary under Section 504 or Title VI. The Office for Civil Rights survey data (2011-12) also shows that of the BPS K-12 students, white students are more than three times as likely to have a 504 plan than their African American and Hispanic classmates.⁴

¹ 29 U.S.C. § 794; 34 C.F.R. part 104.

² (ADAAA), P.L. 110-325.

³ 42 U.S.C. § 2000d, 34 C.F.R. part 100.

⁴ <http://ocrdata.ed.gov/Page?t=d&eid=30902&syk=6&pid=919> [504 only by race/ethnicity]; see *infra*, n.39. Also, note that the OCR CRDC data (2011) indicates that BPS serves only .3 percent (.3%) of its enrollment on Section 504 plans, an increase from .1 percent (.1%) in 2009, compared to 3 percent (3%) of students statewide based on estimated values for Massachusetts (2009). <http://ocrdata.ed.gov/DistrictSchoolSearch#districtSearch>.

I. PARTIES

Complainant students are among approximately 250 students with SCD enrolled in the Boston Public Schools,⁵ who are not receiving the benefits, supportive services and accommodations they need to participate meaningfully in their school's regular education program. The Complainant students all experience serious manifestations of the disease which will likely continue throughout their schooling. They bring this Complaint on behalf of themselves and all other BPS students diagnosed with SCD.

Student A is an African American 8th grade student diagnosed with SCD who attends the Rogers Middle School. She experiences serious SCD related pain episodes that necessitate visits to the nurse, multiple hospitalizations and repeated school absences. As a result of her absences, Student A was retained a grade during elementary school. Her teachers and principal have knowledge of her disease, as her parent submits a letter at the start of each school year from Student A's pediatrician.

Student B is an African American student with SCD who is enrolled in 6th grade at the Orchard Gardens K-8 school. She has sleep apnea associated with her SCD that results in chronic tardiness and absences. At the beginning of each school year, her mother also provides school personnel with a letter from her daughter's pediatrician describing her condition.

Student C is an African American 12th grade student at Urban Science Academy, whose SCD diagnosis is known to some BPS school personnel because of his history of chronic and sometimes debilitating pain episodes, multiple hospitalizations, repeated school absences, and physical symptoms such as jaundiced eyes.

Student D is an exemplar⁶ student who represents a composite of multiple Hispanic students and African American students with SCD who have received medical assistance from Boston-area pediatric hematologists. His mother has limited English proficiency. Student D experiences serious adverse effects, specifically, severe episodic pain that, in his case, is sometimes triggered by exposure to very cold and very hot temperatures. His medical providers have expressed concern to school personnel that his academic struggles and poor grades may relate to loss of cognitive functioning from SCD related silent and overt strokes for which he has been hospitalized multiple times. Because Student D missed so many days of schooling, BPS considered retaining him in grade.

Student E is also an exemplar⁷ student, and one of many BPS students with SCD who is being

⁵ This number is based on record reviews by Boston-area pediatric hematologists.

⁶ Unlike Students A-C whose names are known to BPS and who are represented by CLE and MLRI in seeking to address the issues raised by this Complaint, the students whose stories are contained in the composite descriptions of Student D and Student E to help illustrate the discrimination detailed in the Complaint, seek to maintain their privacy and do not wish to disclose their names and the schools which they attend. They are Hispanic and African American students who shared their stories with members of the Boston medical community treating their SCD and its manifestations, who tried to assist these BPS students who were not identified as 'otherwise qualified individuals with a disability to obtain a Section 504 Plan that would help them stay in school and to overcome SCD related barriers to participation in the school program. The examples described by the composite description underscore the adverse impact experienced by this category of 'other health impaired' students with SCD, who are virtually exclusively and thus disproportionately racial and ethnic minority students compared to all other disability categories, who are being denied access to services made available to and provided other eligible students with disabilities who are not exclusively or disproportionately African American and Hispanic.

⁷ See note 6; here Student E represents the stories of multiple African American students who as a result of the

treated by Boston-area pediatric hematologists. She is an African American, 9th grade female student whose academic grades have noticeably declined; she experiences difficulty concentrating in class because of episodic pain and fatigue, especially later in the school day. This SCD related pain and fatigue interfere with her learning and sometimes result in her being reprimanded for having her head on the desk and falling asleep. She has been called ‘lazy’ by one of her teachers which resulted in her being mocked by her peers. Neither she nor her parents have revealed her illness to school personnel because they fear that notifying the school will make her a target of further teasing and discrimination.

This case is also brought on behalf of two organizational complainants, the Center for Law and Education, a non-profit national advocacy organization located in Boston, and the Massachusetts Law Reform Institute, a non-profit, statewide poverty law and policy center. CLE’s mission is to make the right of all students to quality education a reality and to help enable communities to address their own education problems effectively, with an emphasis on assistance to low-income students. For more than 40 years, CLE has through individual advocacy, administrative and legislative advocacy, and litigation, worked to ensure meaningful and effective participation of all students, in particular, children of color, those with disabilities, and those who are English language learners in high quality public education programs and schools that provide them opportunities to attain the same educational outcomes and benefits expected for all other students. MLRI, as the statewide support center for the Massachusetts civil legal services delivery system, provides expertise and support to local legal aid programs and also to social service, health care and human service providers, and other community organizations that serve clients of low income. During the past year, MLRI has hosted an Equal Justice Works fellow who has worked closely with Boston pediatric hematologists treating children with SCD and assisted the families to obtain access to housing, income supports and educational services.

Together CLE and MLRI bring this complaint on behalf of individual student Complainants with SCD who are enrolled in BPS (described above), their parents, and all other BPS students with SCD -- some who are known by BPS to have a SCD diagnosis, and others, who are not yet identified, in part, because of their own and their parents’ fears of possible stigmatization. The Complainants contend that BPS’s failure to consider SCD as a disability and to engage in actively identifying, locating and evaluating children with SCD, discriminates against these students on the basis of their specific type of disability – a disability that disproportionately affects African American and Hispanic children – and, therefore, has a disparate impact on the basis of race and national origin. As a result of BPS’s policies and practices, these students with SCD are not properly identified and evaluated to determine their eligibility as qualified students with a disability. They are denied supportive services that would enable them to receive an appropriate public education, to participate meaningfully in the regular education curriculum, and to attain the benefits available to students without disabilities in violation of Section 504 and Title II of the ADA. Because the students with SCD who are discriminated against by BPS’s policies and practices are disproportionately African American students and Hispanic students,

manifestations of SCD –e.g., fatigue, inattention, episodic pain, recurring absences, experience ridicule and reprimands from teachers, and declining grades as a result of missed instruction. To protect the students’ privacy, their names and school attended are not identified. This is especially important because Student E and those African American students whose stories she describes have not been identified as having a disability that would qualify for related services, supports, and accommodations under Section 504. Nor have they or their parents disclosed their SCD diagnosis for fear of being subjected to further ridicule, isolation and stigma. See notes 18-23, *infra*. This student’s story underscores the adverse impact on student learning as a result of BPS’s failure to identify and refer students with SCD, who are known to be disproportionately African American students, for an evaluation for a determination of eligibility for necessary services and accommodations.

they are also discriminated against under Title VI on the basis of race or national origin.

The Respondent Boston Public School District (BPS) is a local educational agency in the Commonwealth of Massachusetts that is a recipient of federal funding from the U.S. Department of Education.⁸ According to data reported to the Massachusetts Department of Elementary and Secondary Education for the 2014-15 school year, BPS enrolls approximately 54,312⁹ students, a vast majority of whom are students of color (87%), including 34.5% African American and 40.4% Hispanic students. More than 85% of BPS students qualify for Free/Reduced Lunch. Thirty percent (30%) of BPS students are identified as having limited English proficiency (LEP); English is not the first language for 47.4% of BPS enrollees who speak more than 85 different languages. More than nineteen percent of BPS students are classified as students with disabilities who receive specialized instruction under an IEP consistent with IDEA, compared to the state average of 17%; BPS identifies only .3 percent of its students as receiving services only under a Section 504 plan.

John McDonough is the Interim Superintendent of Schools, who, under the guidance of a five member School Committee appointed by the Mayor of the City of Boston, is responsible for the administration and oversight of all operations of the Boston, MA public school district.

II. JURISDICTION

The Boston Public School District (BPS), a local educational agency, receives federal funding from the U.S. Department of Education under, *inter alia*, Title I of the Elementary and Secondary Education Act of 2001 (Title I), 20 U.S.C. § 6301, §6311, the Individuals with Disabilities Education Act Amendments (IDEA), 20 U.S.C. § 1401, §1411, § 1413, the Carl D. Perkins Vocational Technology Act, 20 U.S.C. § 2301, § 2307, the School Lunch Act, and the McKinney-Vento Homeless Education Act, 20 U.S.C. §1031. As a recipient of such funds from the U.S. Department of Education, BPS is subject to the antidiscrimination prohibitions of Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000 and Section 504 of the Rehabilitation Act of 1973 (Section 504), 29 U.S.C. § 794. The U.S. Department of Education, the Department's Office for Civil Rights (OCR) is responsible for enforcing Title VI and its implementing regulations 34 C.F.R. Part 100, which prohibit discrimination on the basis of race and national origin, and Section 504 and its implementing regulations at 34 C.F.R. Part 104, which prohibit discrimination on the basis of disability in programs and activities that receive financial assistance from the U.S. Department of Education.

Consequently OCR has jurisdiction to investigate Complainants' allegations that BPS's criteria or methods of administration violate Section 504 and Title VI, and their respective regulations, including those that allege they have a discriminatory effect on students with disabilities, 34 C.F.R. § 104.4(b)(4), - here those diagnosed with SCD - and within that population, African American and Hispanic students. 34 C.F.R. § 100.3(b)(2). OCR also has jurisdiction to investigate claims alleging violations of Title II of the Americans with Disabilities Act of 1990 (Title II), 42 U.S.C. § 12131, *et seq.*, and its implementing regulations at 28 C.F.R. Part 35, which prohibit discrimination on the basis of disability by state and local government agencies, including public education systems without regard to whether they receive federal assistance

⁸ "BPS Source of Funds, FY2012 - FY2013,"

http://www.bostonpublicschools.org/files/fy13_source_of_funds_04242012.xls.

⁹ An additional 3539 students are enrolled in eight charter schools located within the district. See <http://profiles.doe.mass.edu/search/search.aspx?leftNavId>.

from the U.S. Department of Education.

The Complaint is timely because the policies and practices of BPS –i.e., ongoing failure to identify, locate and evaluate eligible students with a disability, resulting in a failure to provide FAPE and to consider related services and accommodations necessary for such students to receive an education comparable to that provided by their non-disabled peers ---have a disparate impact on a particular group of students based on disability, here SCD, and on African American and Hispanic students who disproportionately comprise the majority of children and youth with this disability, namely SCD, and these policies and practices cannot be justified as educationally necessary.

III.BACKGROUND ABOUT SICKLE CELL DISEASE

Sickle cell disease (SCD) refers to a group of genetic blood disorders. Individuals with SCD experience a number of complications, including severe anemia, susceptibility to infections, insomnia, depression, jaundice, frequent urination, dehydration, chronic pain, and episodes of extreme debilitating pain. These latter pain episodes (also known as pain “crises”) can cause tissue and organ damage, lead to hospitalization, and have life-threatening consequences. People with SCD are also at heightened risk for strokes, including “silent strokes” that may go unnoticed but can affect learning abilities in the short and long terms.¹⁰

Red blood cells are crucial components of the circulatory system because they deliver oxygen molecules throughout the body.¹¹ When a person with SCD experiences various physical or emotional stressors, his or her blood cells can deform from a flexible doughnut shape into a crescent or “sickle” shape and become both rigid and sticky. When enough cells have sickled, the deformed cells can collectively block small blood vessels, depriving the surrounding tissue of oxygen. This causes tissue death and organ damage, which may lead to extreme levels of pain.

Anything that makes sickling of the cells more likely, constricts blood vessels, or increases the concentration of blood can make a pain episode more likely.¹² As a result, pain episodes can be triggered by, among other things, overexertion, exposure to sudden temperature changes, exposure to temperature extremes (heat or cold), dehydration, delayed medical management, psychological stressors, and infection.

SCD affects an estimated 90,000 to 100,000 Americans and about 30,000 students.¹³ While the disease affects individuals of all races¹⁴, it is especially prevalent among African Americans and Hispanics.¹⁵ Sickle cell disease occurs among about 1 out of every 500 African American births and among about 1 out of every 36,000 Hispanic American births.¹⁶ SCD is particularly common

¹⁰ John Hopkins Children’s Center, High Blood Pressure, Anemia Put Children with Sickle Cell Disease At Risk For Silent Strokes (2011) at <http://www.hopkinschildrens.org/high-blood-pressure-anemia-put-children-with-sickle-cell-disease-at-risk-for-silent-strokes.aspx>; see also The Internet Stroke Center, Stroke as a Complication of Sickle Cell Disease at <http://www.strokecenter.org/patients/about-stroke/pediatric-stroke/stroke-as-a-complication-of-sickle-cell-disease/> (2014); Gold et al., Detection and assessment of stroke in patients with sickle cell disease: neuropsychological functioning and magnetic resonance imaging, 25 *Pediatric Hematology and Oncology* 5 (2008).

¹¹ See Centers for Disease Control and Prevention website, Facts about Sickle Cell Disease at <http://www.cdc.gov/ncbddd/sicklecell/facts.html>.

¹² Id.

¹³ Sara Day and Elisabeth Chismark, The Cognitive and Academic Impact of Sickle Cell Disease, 22 *The J. of Sch. Nursing* 330, 330 (2006).

¹⁴ Facts about Sickle Cell Disease, *supra*.

¹⁵ Id.

¹⁶ Id.

among people whose ancestors originated from sub-Saharan Africa, South and Central America, the Caribbean, Saudi Arabia, India, and Turkey, Greece and Italy.¹⁷

Individuals with SCD have historically been stigmatized in the community (being said to have “bad blood”), hospitals, schools, the armed services, and places of employment. Thought of as a “Black disease,” SCD has historically been associated with claims of racial weakness and genetic inferiority.¹⁸ Additionally, scientific research and public knowledge of the disease is limited, especially in comparison to the knowledge and awareness of genetic disorders primarily affecting white Americans.¹⁹ People with SCD are routinely challenged about the seriousness or even existence of their disease²⁰ and ‘hidden’ disability. This reaction contributes to a distrust of institutions by students and their parents, which helps to explain why some BPS parents of school-age children with SCD choose to remain silent²¹ instead of seeking supportive services and accommodations for their “qualified” children with a disability under the ADA and Section 504.²² For example, a study looking at potential interventions for children with SCD at school found that teachers “erroneously attributed the fatigue and chronic absences [of children with SCD] to low motivation, a chaotic family, drug problems, or human immunodeficiency virus [HIV]. None attributed these problems to [SCD].”²³

IV. FACTUAL ALLEGATIONS

BPS Discriminates against Complainant BPS Students with SCD Based on the Nature of Their Disability

There are approximately 250 BPS students currently diagnosed with sickle cell disease (SCD).²⁴ SCD disproportionately affects persons of African and Hispanic origin.²⁵ Virtually all of the 250 BPS enrolled children with SCD are African American and Hispanic. A large percentage of the BPS students diagnosed with SCD experience repeated infections and episodic bouts of severe to extreme physical pain, which result in frequent absences. Many of these students have difficulty thinking normally and concentrating when experiencing moderate levels of pain or anemia

¹⁷ Id.

¹⁸ Melbourne Tapper, *In the Blood: Sickle Cell Anemia and the Politics of Race* (1999) p. 2.

¹⁹ Lauren A. Smith, Suzette O. Oyeku, Charles Homer & Barry Zuckerman, Sickle Cell Disease: A Question of Equity and Quality, 117 *Pediatrics* 1763, 1764-65 (2006); Hill, *supra* note 1, at 67; Keith Wailoo, Dying in the City of Blues: Sickle Cell Anemia and the Politics of Race and Health (2004) p. 79.

²⁰ Simon M. Dyson et al., Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school, 70 *Soc. Sci. & Med.* 2036, 2039-40 (2004).

²¹ Given the particular sensitivities of a SCD diagnosis, it is important to note that schools have a legal duty to protect the private health information of all students. If schools provide health services to students with SCD and/or engage in electronic transactions involving the health information of such students, they may qualify as health care providers under HIPAA, subjecting them to specific privacy restrictions. Though many elementary and secondary schools are considered HIPAA entities, they may not be subject to HIPAA regulations because the health information they keep on students is considered part of the student’s “education record” and not “protected health information.” All public schools are required to comply with the Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. § 1232g, which prohibits with limited, expressed exceptions, disclosure of a student’s personally identifiable information without prior written consent from the eligible student (18 years old) or his/her parent. 34 C.F.R. §§ 99.30-99.31.

²² 34 C.F.R. § 104.3(j) (1)(i), (ii) and (iii).

²³ Kristine Koontz, Amy D. Short, Karen Kalinyak, and Robert Noll. *A randomized, controlled pilot trial of a school intervention for children with sickle cell anemia*. *J Pediatr Psychol.* 2004 Jan-Feb;29(1):7-17. At page 8.

²⁴ Based on record reviews by Boston-area pediatric hematologists.

²⁵ See supra nn. 13, 14.

fatigue, or when they are experiencing side effects from pain medications (especially when attending school at the tail end of a pain episode). These students miss significant blocks of teaching and instruction as a result of regular, periodic absences from school and difficulties with concentration even while in school. The effect of missed instruction can snowball rapidly, as new material builds on prior teaching causing students with SCD to fall behind. This can lead to anxiety that may trigger SCD complications.

For BPS children with SCD, the school environment can also be unsafe physically and emotionally because they are vulnerable to teasing and harassment from peers and questioning from teachers, staff and administrators. The external markers of SCD, such as, yellowing of the eyes caused by jaundice, small stature caused by delayed growth, and delayed social development caused by frequent and socially isolating absences, can make children with SCD targets of negative peer interactions. Teachers sometimes see these students as malingerers because of the side effects of SCD, such as the need to hydrate and urinate frequently, to wear coats or extra clothing inside because of sensitivity to temperature change, to take breaks during physical activities (even from standing for long periods during science lab), to take extra time moving between classes or use an elevator, to have timely access to health related services, medication and the school nurse, and to miss school. What is not acknowledged or apparently understood by teachers and school staff is that pain episodes and other complications can be triggered if students with SCD are not permitted to respond to their needs.

There is no evidence of institutional leadership, awareness, and support for BPS children with SCD based on the lack of any outreach information and materials, policies, procedures, or data showing that students with SCD may be eligible for protection and services under Section 504. BPS has reason to believe that students with SCD may qualify as individuals with a disability under Section 504—given the number of students known to BPS with Individual Collaborative Health Plan (IChP), and/or whose parents and/or physicians provide documentation of their SCD related needs each school year. In addition, school staff daily witness manifestations of the disease —e.g., children’s need for hydration, frequent urination, fatigue, slowness, distractibility and inattentiveness, physical discomfort, episodic pain crises and chronic absences from school. However, the data does not show that BPS treats SCD as a disability.²⁶ The OCR CRDC survey data from the 2011-2012 school year indicates that BPS identified a mere .3 percent (.3%) of its students who receive services and accommodations only under a Section 504 plan compared to 3 percent (3%) of students statewide who received services only under 504 in MA.²⁷ Although white students comprise approximately 12% of BPS students, they represented almost 33% of the students identified as receiving services only under 504 based on the OCR CRDC survey data for the 2011-12 school year; African American and Hispanic students who comprise about 77% of the BPS enrollment and 100% of those students with SCD, together represented less than 61% of students identified as ‘only 504’ students.²⁸ Based on this data, of the BPS K-12 enrolled students, white students are more than three times as likely (.93%) to have a 504 plan than their African American (.30%) and Hispanic (.28%) classmates—a difference that is statistically significant.

BPS does not provide information and outreach to parents or school staff about SCD as a physical impairment that substantially limits one or more major life activities, its possible impact on learning, and the rights of children with a major bodily function that is seriously compromised

²⁶ Data of students with disabilities who need special education under IDEA are collected by disability type, but data collected by OCR of qualified students with a disability under Section 504 and the ADAA are not.

²⁷ See supra, note 4.

²⁸ Id.; see <http://ocrdata.ed.gov/Page?t=d&eid=30902&syk=6&pid=919> [504 only by race/ethnicity].

to receive a comprehensive evaluation to determine eligibility for possible special education or related services and accommodations tailored to meet their individual needs. This is in contrast to BPS's treatment of diabetes, asthma, and concussions, for example, which are the subject of separate BPS policies and procedures about their management in school.

With respect to diabetes, BPS expressly states that “[c]hildren with Type I or II Diabetes may need extra provisions during the school day. They often need to have their blood sugar measured multiple times, and carbohydrates counted from meals to make sure the correct amount of insulin medication is given.” Parents are told to be “sure to talk with the student’s primary health care provider and your school nurse to complete an Individual Collaborative Health Plan to address the child’s needs and a 504 plan if necessary.”²⁹ (emphasis added). BPS’s policy on “Student Health Information” set forth in Superintendent Circular, LGL-16 (9/1/2011), describes “routine medical information” appropriate for certain school staff to know “to maximize the safety for children” by offering an example of a child with diabetes who “needs to have teachers who are knowledgeable about the illness, in order for the child to have a safe learning environment.” It further acknowledges a link between the disease and an affected child’s academic performance or functioning in school: “Low blood sugar can also affect the child’s ability to concentrate” and notes that “[i]n this circumstance it would be appropriate to notify all of the child’s teachers...”³⁰

As further discussed below, BPS systemically discriminates against students with SCD through policies and practices that:

- fail to consider and recognize SCD as a disability that substantially limits a major life activity, warranting referral for evaluation and consideration of eligibility under Section 504, even if the student’s impairment does not substantially impact academic performance;
- misuse ICHPs to circumscribe the rights of those students with SCD, who are qualified students with a disability entitled to the protections and services under Section 504 and to receive those services under a properly developed Section 504 plan;
- do not identify a process and procedures for school staff, parents, physicians, clinicians, other concerned individuals to initiate referral of students with SCD in need or suspected of being in need of special education or related services and accommodations;
- fail to refer for evaluation of eligibility those students with SCD, despite having documentation of diagnosis and need for services and accommodations from parents and physicians;
- fail to provide eligible students with SCD, who do not require special education, a FAPE under a Section 504 plan developed by persons with knowledge of SCD, which is individualized and draws upon the child’s comprehensive evaluation to identify and address his or her disability related needs so as to be able to access the benefits and services available to their age and grade appropriate peers without disabilities.

As a result, eligible individuals with disabilities with SCD, including Complainant Students A-C, and those represented by the exemplars Students D and E, are not provided Section 504 plans, and are denied related and supportive services and accommodations necessary for them to access and meaningfully participate in the general curriculum, and to be provided instruction from qualified teachers that will enable them to learn what they have missed as a result of absences occasioned by the effects of their SCD and to have an equal opportunity to attain the same benefits and outcomes as their non-disabled peers. For example, Student A has a history of

²⁹ <http://bpshealthservices.org/>

³⁰ *Id.*

repeated absences and multiple hospitalizations. She regularly falls behind and has a difficult time learning what she has missed and catching up on her missed assignments. BPS has not referred her for a comprehensive evaluation essential to determining her need for regular or special education, related services, and accommodations that would enable her to keep pace with her non-disabled classmates.

Student B has been repeatedly scolded for her disability related needs that result in chronic tardiness and absences. She has never been referred for an evaluation and is deprived of an appropriate education, related services and accommodations that would enable her to obtain the teaching and instruction she ‘misses’ because of her disability and, consideration, if needed, for extra time to make up missed assignments.

Student C, a senior in high school, struggles academically. He has experienced serious episodic pain and multiple hospitalizations from SCD complications, but without an evaluation and determination of eligibility, he does not have a Section 504 plan and is denied instruction, necessary services and accommodations by BPS, specifically related to being taught the curriculum he has missed and provided the opportunity to hand in missed assignments under an extended deadline.

Student D experiences serious adverse SCD related effects when exposed to extreme hot and cold temperatures, in particular, serious episodic pain, fatigue and weakness, that make it difficult to remain in school to learn. He has not been evaluated and does not have a Section 504 plan, and is denied accommodations, for example, to wear his coat in the classroom to protect from the cold that triggers episodic pain, possible stroke and hospitalization. Student D has had several known strokes stemming from his SCD resulting in hospitalization. Despite notice of possible grade retention, and a request from his concerned medical providers, BPS has not provided Student D a timely comprehensive evaluation, including a neuropsychological evaluation, necessary for him to receive an education designed to meet his needs as adequately as the needs of students without disabilities.

Finally, Student E, as the other Complainants, experiences significant absences related to SCD that affect her learning and has become increasingly anxious and socially withdrawn. BPS has failed to refer her for an evaluation, and thereby ensured that she is denied FAPE, that might include a range of related and supportive services from structured make up instruction to counseling and accommodations under a Section 504 plan. For Student E and all other Complainant students, A-D, BPS discriminates against them by denying comprehensive evaluations that might target areas in need of immediate intervention and academic assistance, other in-school accommodations and services that would help them remain engaged in the curriculum with their non-disabled peers, and opportunities to attain comparable benefits.

- **BPS Students with SCD and Their Parents Are Not Notified of Their Rights under Section 504.**

BPS does not reach out and target parents of school-age children with SCD to inform them of the school district’s affirmative duty to identify, locate and evaluate their children who may be suspected of having a disability and need special education and/or related services. None of the parents of the above-described Complainant students received notice or other information explaining that children diagnosed with SCD may be children with disabilities who are eligible to receive special education and/or related and supportive services and accommodations to help them learn and to fully participate in school.

BPS does not provide outreach to parents for whom English is not their first language who have children diagnosed with SCD. Complainant student D's parent, who is not proficient in English and speaks only Spanish, did not receive any information from BPS in her native language.

The parents of Complainant Students A, B, C, and those representing the composite exemplar, Student D informed school personnel of their children's SCD status by providing notes from their children's physicians, bringing accompanied to meeting by their child's physician, or either informing them orally or having their children disclose their SCD status to their teachers or other administrative personnel. Although BPS was on notice that these students are diagnosed with SCD, experience serious manifestations of the disease --even requiring regular transfusions-- and could benefit from an array of supportive services and/or accommodations to help cope with the effects of SCD during school hours, not one of these students (A-C), nor D and E or the students diagnosed with SCD whom they represent, was referred for an evaluation for consideration of eligibility under Section 504.

None of the parents of the Complainant students knew to request that their children be evaluated by BPS for consideration of eligibility for related or supportive services and accommodations. Even when they disclosed their child's SCD each school year to school authorities, BPS did not explain that their children might be eligible for FAPE consisting of "regular or special education and related aids and services ... designed to meet individual educational needs of ... persons [with disabilities] as adequately as the needs of non-handicapped persons are met..."[34 C.F.R. § 104.33(b)]. Complainant students' parents were not told by BPS that children with SCD might be eligible to receive related services independent of special education, because SCD is a disability that can interfere with their walking, standing, thinking, concentrating, learning and other life activities, including bodily functions that inhibit their attending school. Most BPS parents of children with SCD are simply unaware of what they can ask for; some are coaxed or assisted by their children's medical providers, and many others remain silent, for they are fearful for their children because of the stigma surrounding the illness.

- **BPS Students with SCD Are Not Identified or Referred for a Timely Comprehensive Evaluation**

BPS fails to identify and refer students with SCD for whom an evaluation for special education or related services may be warranted. None of the Complainant students A-C, or those represented by the exemplar students D and E were identified for referral for a comprehensive evaluation by BPS.

Parents of Complainant students A and B informed school personnel of their SCD because they were concerned about their health and education. Complainant students C and D informed school personnel of their SCD when they asked for assistance related to SCD needs (lengthy, frequent absences, and need to wear a coat in the classroom because of sensitivity to cold). Even after teachers and other school staff had actual knowledge of a student's SCD diagnosis, and witnessed daily manifestations of SCD (e.g., regular periodic absences, fatigue, need for hydration and bathroom breaks, pain and discomfort) interfere with a student's performance of major life activities, BPS students with SCD were not referred for an evaluation.

Complainant students B, C, D, and E despite their SCD and its substantially limiting effect on their learning and other major life activities, including multiple bodily functions, still have not been *referred* for an evaluation by BPS to determine their eligibility under Section 504. One of the undisclosed students comprising the composite description for Student E was forewarned, as

he was told by his guidance counselor last winter that a 504 plan is “in the works, but it is a slow process.” As of June 2014, he still had not been evaluated.

BPS teachers and other school staff are not informed about SCD or trained to identify manifestations of SCD and the possible adverse effects on students’ learning that warrant referral for evaluations under Section 504 and/or IDEA. Nor has BPS provided information to teachers and other key school personnel about the stigma and social and emotional angst associated with SCD that makes parents of children, and the students themselves, distrustful and fearful of disclosing their SCD status.

Even when parents disclose their children’s SCD status to school officials, they are not told that parents may request an evaluation to determine if their children are eligible for related services and accommodations to cope with the effects of SCD. BPS did not inform Student B’s parent, who annually provides BPS with a letter from her daughter’s pediatrician describing SCD and its side effects, of her right to request a comprehensive evaluation to determine her daughter’s eligibility for services under Section 504. Instead, BPS threatened Student B’s parent with court intervention because her daughter, who has sleep apnea associated with SCD, is chronically tardy.

- **BPS Students with SCD Do Not Receive a Comprehensive Evaluation**

None of the Complainant students have been evaluated for eligibility for services and accommodations under Section 504. Through its policies and practices BPS does not ensure that students with SCD receive a comprehensive evaluation. Although Student A has a Section 504 plan, she was not provided a comprehensive evaluation; rather, BPS relied only upon a medical diagnosis by her pediatrician to develop her Section 504 Plan. Without a comprehensive evaluation in all areas of suspected disability, including cognition for students with SCD who are susceptible to strokes, Student A is not receiving the full array of comparable aids and benefits, related and supportive services and accommodations which she may need and is entitled to receive under a Section 504 plan. Such an evaluation is essential to ensure that eligible students with SCD receive the range of aids, related services and accommodations necessary for them to access the general education curriculum, stay in school to the extent possible, and through direct instruction, make up opportunities and other accommodations to attain the benefits of education available to students without disabilities.

BPS does not have a policy or practice of referring students with SCD who are known or suspected of having experienced silent strokes for neuropsychological evaluations to establish a baseline of neuro-cognitive functioning (so that cognitive declines can be detected and addressed through academic interventions³¹); nor does BPS, either as a matter of policy or practice, refer students who have had strokes for possible re-evaluation to determine whether they may require additional and/or different services, including immediate academic interventions, and accommodations. It is widely recognized that a neuropsychological evaluation is important for early detection of cognitive decline to mitigate the adverse impact on learning.³²

Based on research, BPS students with SCD are at heightened risk for undetected silent strokes³³

³¹ See Hebben, Nancy & Milberg, William, Essentials of Neuropsychological Assessment. (2002) p. 6-7.

³² See Brown et al., Neurocognitive Functioning and Magnetic Resonance Imaging in Children With Sickle Cell Disease. 25 *Journal of Pediatric Psychiatry* 7 (1999) available at <http://jpepsy.oxfordjournals.org/content/25/7/503.short>.

³³ Health Day, Sickle Cell Disease ties to silent strokes in children at <http://consumer.healthday.com/circulatory-system-information-7/anemia-news-25/sickle-cell-disease-tied-to-silent-strokes-in-children-659333.html> (2011);

that may affect executive and cognitive functioning, and adversely affect intellectual and academic abilities, attentiveness, visual-spatial skills, language, and long-term memory.³⁴ Approximately 11-17% of children with SCD have had silent strokes, including exemplar Student D.³⁵ Moreover, once having experienced a silent stroke, children with SCD are at an increased risk for more debilitating overt strokes as well as significant learning disabilities.³⁶ Children with SCD, who have had silent strokes, perform significantly worse on tests of arithmetic, vocabulary, visual motor speed and coordination, memory, attention, and executive skills, as detected through neuropsychological testing.³⁷

- **BPS Students with SCD Are Not Provided An Opportunity To Receive a Free Appropriate Public Education, including Related Services**

Student A is denied FAPE. Her Section 504 Plan is not based upon a comprehensive evaluation of her needs; it does not, for example, indicate how she would receive supplemental before/after school direct instruction and/or extended school year education provided by qualified teachers that she needs and to make up for the instruction she regularly misses as a result of SCD related absences. Nor does it reflect consideration of accommodations to reduce the number and volume of assignments and/or allow her additional time to make up tests, complete homework and projects. Instead Student A's Section 504 Plan, which was not developed consistent with the process set forth in the section 504 regulations, provides only limited tutoring through MA DESE and BPS's non-individualized home/hospital instruction support upon receipt of documentation from her pediatrician. The latter is not individualized or tailored to address her individual needs as a student who experiences frequent SCD related absences, stress and anxiety, so she may receive an education comparable to that provided her non-disabled peers who are educated in the classroom.

see also High Blood Pressure, Anemia Put Children with Sickle Cell Disease At Risk For Silent Strokes, *supra*.

³⁴ See The Internet Stroke Center, Stroke as a complication of sickle cell disease at <http://www.strokecenter.org/patients/about-stroke/pediatric-stroke/stroke-as-a-complication-of-sickle-cell-disease/>; Harvard Health Publications: Harvard Medical School, Silent strokes can jeopardize memory at <http://www.health.harvard.edu/blog/silent-strokes-can-jeopardize-memory-201206044846>.

³⁵ F. Bernaudin, S. Verlhac, F. Freard, F. Roudot-Thoraval, et al. *Multicenter prospective study of children with sickle cell disease: radiographic and psychometric correlation*. J Child Neurol. 2000 May;15(5):333-43. At 337.; Franklin G. Moser, Scott T. Miller, Jacqueline A. Bello, Charles H. Pegelow, Robert A. Zimmerman, Winfred C. Wang, Kwaku Ohene-Frempong, Alan Schwartz, Elliott P. Vichinsky, Dianne Gallagher, and Thomas R. Kinney. *The Spectrum of Brain MR Abnormalities in Sickle-Cell Disease: A Report from the Cooperative Study of Sickle Cell Disease*. AJNR Am J Neuroradiol. 1996 May;17(5):965-72. At 968.; Pavlakis SG1, Bello J, Prohovnik I, Sutton M, Ince C, Mohr JP, Piomelli S, Hilal S, De Vivo DC. *Brain infarction in sickle cell anemia: magnetic resonance imaging correlates*. Ann Neurol. 1988 Feb;23(2):125-30. At 125.

See Medical News, Anemia, high blood pressure linked to risk of risk of silent strokes in children with SCD at <http://www.news-medical.net/news/20111130/Anemia-high-blood-pressure-linked-to-risk-of-silent-strokes-in-children-with-SCD.aspx> (2011).

³⁷ F. Daniel Armstrong, Robert J. Thompson, Winfred Wang, Robert Zimmerman, Charles Pegelow, Scott Miller, Franklin Moser, Jacqueline Bellow, Anita Hurtig, and Kerstin Vass. *Cognitive functioning and brain magnetic resonance imaging in children with sickle Cell disease*. Neuropsychology Committee of the Cooperative Study of Sickle Cell Disease. Pediatrics. 1996 Jun;97(6 Pt 1):864-70. At 864; Leslie D. Berkelhammer, Adrienne L. Williamson, Stacy D. Sanford, Courtney L. Dirksen, William G. Sharp, Allison S. Margulies & Rebecca A. Prengler. *Neurocognitive sequelae of pediatric sickle cell disease: a review of the literature*. Child Neuropsychol. 2007 Mar;13(2):120-31.; Channa T. Hijmans, Karin Fijnvandraat, Martha A. Grootenhuys, Nan van Geloven, Harriët Heijboer, Marjolein Peters MD, and Jaap Oosterlaan. *Neurocognitive deficits in children with sickle cell disease: a comprehensive profile*. Pediatr Blood Cancer. 2011 May;56(5):783-8.; Carmen E. Sanchez, Jeffrey Schatz, and Carla W. Roberts. *Cerebral blood flow velocity and language functioning in pediatric sickle cell disease*. J Int Neuropsychol Soc. 2010 Mar;16(2):326-34.; Channa T. Hijmans, Martha A. Grootenhuys, Jaap Oosterlaan, Harriët Heijboer, Marjolein Peters MD, and Karin Fijnvandraat. *Neurocognitive deficits in children with sickle cell disease are associated with the severity of anemia*. Pediatr Blood Cancer. 2011 Aug;57(2):297-302.

Without having been evaluated, Complainant Students B, C, D, and E, and other BPS students with SCD for whom they seek to speak, are denied consideration of eligibility under Section 504; and thus, are similarly denied FAPE individualized to meet their needs, including instruction and supportive services they need to secure meaningful access to the educational benefits available to all other students without disabilities. Such services would likely reflect consideration of supplemental instruction and ongoing tutoring before and/or after school, and/or a modified schedule with provision for extended school year instruction from qualified teachers to compensate for the instruction each of these students regularly loses as a result of SCD related absences for multiple, serial days. Student C, for example, is not provided with make-up instruction from qualified subject matter teachers when he is absent -- because his SCD is not considered a disability that entitles him to receive FAPE, related service and accommodations under a properly developed Section 504 plan. Some of Student C's teachers have said that they thought his absences were due to skipping school or not wanting to attend, rather than from SCD-related complications. Without a Section 504 plan designed to address his specific needs, he is expected to make up homework assignments and class work missed as a result of SCD related absences without being provided the instruction upon which they are based or an alternative meaningful opportunity to learn (e.g., listening to tapes of classroom instruction).

Students with SCD, including those Complainant students who meet the definition of a "qualified individual with a disability" but remain unidentified (i.e., those represented by exemplar Student E), and thus, ineligible for services under Section 504, are also denied consideration of the range of related services to meet their respective individual needs, such as social work and counseling services to help them cope with all aspects of the disease, anxiety, fear of stigma, depression, bullying, and social isolation; school health related services (e.g., access to a school nurse and pain medications); special transportation because of fatigue, physical weakness, and susceptibility to temperature extremes; training for their parents, teachers and other school staff; and other mental and physical health related support services.

For example, Student E is called "lazy" by one of her teachers and told she is "not trying hard enough" in class when she exhibits chronic fatigue associated with her SCD. These comments have made her the victim of jokes from her peers, resulting in feelings of depression and anxiety regarding her ability to succeed in class. Student E's parents have not revealed her illness to school personnel because they fear that notifying the school will make her a target of further teasing and discrimination. She is not receiving supportive services, counseling, tutoring or accommodations, including rest breaks that might help her to overcome barriers to effective learning and participation.

Nor does BPS with respect to students with SCD, effectively monitor and oversee the delivery of the education, aids and supportive services that are individualized and essential to any 'qualified individual with a disability' if he or she is to make meaningful academic progress consistent with his or her age appropriate peers, benefit from the educational program and learn effectively.

- **Eligible Students with SCD, a Disability that Impedes Major Life Activities, Are Not Provided the Type and Range of Accommodations They Need to Participate As Effectively in the School Program As Students without Disabilities**

Complainant students A – E and the students with SCD whom they represent need an array of accommodations to enable them to participate meaningfully in the regular education curriculum. Because these students are not referred for evaluation, they continue to be denied the opportunity

to be determined eligible for protection, services, and such accommodations under Section 504 that would give them an opportunity to receive comparable benefits and to keep up academically with their non-disabled peers.

The needs of each student as determined by his/her evaluation may differ with respect to the type, scope and scale of accommodations required. However, because of the nature of the disease and its typical manifestations, many students with SCD will need unlimited water access, unlimited bathroom access, an extra set of textbooks (one for home and one for school), and extra time to move between classes. For others, such as Complainant Student D, it will be necessary to consider whether participation in certain activities should be modified, if they should be allowed to wear their coats in school, or to stay inside when it is unusually cold or hot outside. For other students with SCD, it may be necessary to consider if they need to use a restricted school elevator, as in the case of Student C, who experienced pain episodes, hospitalization, and absences after walking up multiple flights of stairs to get from one class to another, or, as Student E, need 'rest breaks' during class because of anemia fatigue. Additional accommodations may be needed to help them meaningfully participate in the regular education classroom with their peers on a daily basis.

- **BPS Policies and Practices Deprive Students with SCD Access to Benefits and Services Based on Their Disability, and Because Students with SCD Are Disproportionately African American and Hispanic, These Students Are Also Discriminated Against Based on Their Race and National Origin**

Complainants allege that BPS is engaging in a systemic and ongoing pattern of discrimination against approximately 250 students with SCD, virtually all of whom are African American and Hispanic children enrolled in the BPS district, based on the nature of their genetically-based disability under Section 504 and their race and national origin under Title VI. Through its policies and practices of failing to identify, refer for evaluation, and appropriately evaluate children with SCD, and thus denial of consideration of eligibility as children with disabilities in need of regular and special education, related services and accommodations, BPS is discriminating against this subset of children with SCD who are primarily African American and Hispanic based on their disability, race and national origin. BPS's misuse of the ICHP further contributes to discrimination against students with SCD. Instead of ensuring that qualified students with disabilities receive the related services and accommodations they are entitled to receive after a determination of eligibility based on a comprehensive evaluation of each student's individual needs, BPS merely uses an ICHP, which is no substitute for a Section 504 plan, to document mitigating measures for students with SCD.

The impact of BPS's cumulative failures is to deprive this cohort of BPS children with SCD comparable educational benefits and services to those provided students without disabilities and such supportive services and accommodations as needed to enable each eligible child with a disability to access the general education curriculum. Because the effect of this wholesale denial of access to comparable learning opportunities, specifically through failure to provide necessary related services and accommodations that allow access to the same academic program, instruction, and high expectations, has a disparate impact on African American and Hispanic students who comprise virtually all BPS's students diagnosed with SCD, BPS is discriminating against this group of students on the basis of race and national origin. Furthermore, BPS can offer no educational justification for this deprivation. Additional evidence of a statistically significant disparity based on race/ethnicity is provided by BPS data collected by OCR's CRDC survey referenced above. This data allows one to determine the relative likelihood of receiving a 504 plan in BPS's K-12 program by race/ethnicity. Based on the data, white students are more

than three times as likely (.93%) to have a 504 plan than their African American (.30%) and Hispanic (.28%) classmates.³⁸

V. LEGAL STANDARDS AS APPLIED TO STUDENTS WITH SICKLE CELL DISEASE AND DISCUSSION

A. Complainant Students Are Eligible Students with a Disability Who Can Bring Claims under Section 504

Section 504 protects an “individual with a disability” from discrimination, denial of benefits, and exclusion from participation solely by reason of disability in any program or activity receiving federal financial assistance.³⁹ A disability with respect to an individual under the Americans with Disabilities Act Amendments Act is defined as “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment...”⁴⁰ In 2008, the ADA Amendments Act amended the definition of disability in the ADA and the definition of disability as applied to Section 504 so that the two statutes “will generally operate under one consistent standard, and the civil rights of individuals with disabilities will be protected in all settings.”⁴¹

The ADA Amendments Act includes some rules of construction that are especially relevant to this case, e.g., that: the definition of disability under Title II and Section 504 is to be broadly construed to the maximum extent permitted by the Act⁴²; the term “substantially limits” must be interpreted in a manner consistent with the findings and purpose of the ADA Amendments Act; an impairment that substantially limits one major life activity does not have to limit other major life activities to be a disability⁴³; an impairment that is episodic or in remission is a disability if it would have substantially limited a major life activity when active⁴⁴; and whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures, except eyeglasses and contact lenses shall be considered.⁴⁵

In addition, the ADA Amendments Act now considers “the operation of a major bodily function, including but not limited to, the function of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions”⁴⁶ as a major life activity. As described above, SCD affects “normal cell growth,” and may also affect digestive, bowel, bladder, neurological, brain, and circulatory functions. The Amendments Act also expanded “major life activities” set forth in the ADA regulation and Section 504 regulation to include, but not be limited to: caring for oneself, bending, performing manual tasks, speaking, seeing, breathing, hearing, learning, eating, reading, sleeping,

³⁸ <http://ocrdata.ed.gov/Page/PrintPage?t=d&eid=30902&syk=6&pid=919&print=1&ct=t&pc=C> [Chart view: Students w. disabilities served under 504 only not IDEA, by race/ethnicity]; Toggle to Table view: <http://ocrdata.ed.gov/Page?t=d&eid=30902&syk=6&pid=919> [Students w disabilities served under 504 only (not IDEA), by race/ethnicity].

³⁹ 29 U.S.C. § 794(a).

⁴⁰ 42 U.S.C. § 12102(1).

⁴¹ 153 CONG. REC. S. 8347 (Sept. 11, 2008)(Statement of the Managers to Accompany S. 3406, the Americans with Disabilities Act Amendments Act of 2008); 29 U.S.C. § 705(20)(B).

⁴² *Dear Colleague Letter*, Q4, A, Q5,A; 58 IDELR 79 (OCR January 19, 2012).

⁴³ 42 U.S.C. § 12102(4)(C). See also *Dear Colleague Letter*, *supra*, n. 42, Q4, A.

⁴⁴ 42 U.S.C. § 12102(4)(D). See also *Dear Colleague Letter*, *supra*, n. 42, Q4, A.

⁴⁵ 42 U.S.C. § 12102(4)(E)(i). See also *Dear Colleague Letter*, *supra*, n. 42, Q4, A.

⁴⁶ 42 U.S.C. § 12102(2)(B).

concentrating, walking, thinking, standing, communicating, lifting, working.⁴⁷

Complainants recognize that there is no *per se* disability based on a medical diagnosis under Section 504 and Title II,⁴⁸ and the illness must cause a substantial limitation on the student's ability to learn or another major life activity, including a bodily function. Here, however, given the nature of SCD, a genetic disorder that is characterized by its effect on major bodily functions, including, but not limited to, normal cell growth, neurological, brain, and circulatory functions, the Complainant students (A-E) and virtually all BPS enrolled students with SCD, have a physical impairment that is a disability because that impairment would substantially limit a major life activity (i.e., bodily function) if active. An impairment that is episodic or in remission is a disability if, when in the active phase, it would substantially limit a major life activity.⁴⁹

Moreover, each of the Complainant Students A-E, based upon the facts described above, also meets the definition of a qualified student with a disability because each has a diagnosed physical impairment that through its multiple manifestations (e.g., chronic pain, pain crises, fatigue, sensitivity to temperature change, dehydration, diarrhea, limited strength, inattentiveness, lack of concentration) substantially limits one or more life activity, e.g., learning, concentrating, thinking, walking, standing, and/or has a record of such an impairment.⁵⁰

The Complainant students and those other BPS students with SCD whose interests they represent, qualify as individuals with disabilities who are protected from discrimination, retaliation and harassment.⁵¹ Whether or not each Complainant student (A-E) and other BPS students with SCD are, because of that disability, also in need of special education or related services must be determined on the basis of a comprehensive evaluation by knowledgeable persons.⁵² To date, none of the Complainant students have been referred for evaluation under Section 504⁵³ for a determination of eligibility as qualified individuals with a disability in need of special education or related services. The Complainant students, as well as many, if not all of the other BPS enrolled students with SCD, are being denied consideration of eligibility for possible special education or related services that they may need and have a right to receive under Section 504 and Title II of the ADA because they have not been referred for a comprehensive evaluation.⁵⁴ BPS's continued and inappropriate use of ICHPs that may deign to identify mitigation measures for certain students with SCD cannot substitute for its obligation to provide Section 504 plans based on a comprehensive evaluation of each BPS student with SCD who may need or benefit from special education or related services.

B. As a Recipient of Federal Financial Assistance BPS Cannot Discriminate Against Eligible Students with Disabilities under Section 504

Section 504 applies to “any program or activity receiving Federal financial assistance.”⁵⁵ The term “program or activity” is defined to include any public education institution, agency or

⁴⁷ 42 U.S.C. § 12102(2)(A); See also, 34 C.F.R. § 104.3(j)(2)(ii).

⁴⁸ See *Dear Colleague Letter*, supra, n. 41.

⁴⁹ 42 U.S.C. § 12102; See also *Dear Colleague Letter*, supra, n. 42, Q4, A.

⁵⁰ 34 C.F.R. §§ 104.3(j)(1) (i)-(iii).

⁵¹ 34 C.F.R. §§104.4, 104.21-23, 104.61.

⁵² 34 C.F.R. § 104.35(b), (c).

⁵³ 34 C.F.R. § 104.35(a), (b); See *Dear Colleague Letter*, supra n. 42.

⁵⁴ 29 U.S.C. § 705(20)(B); 34 C.F.R. § 104.3(j)(1)(i), (2)(i), (ii).

⁵⁵ 29 U.S.C. § 794(a).

school district⁵⁶, and makes clear that discrimination is prohibited throughout the entire institution if any part of the institution receives federal financial assistance. As described above, BPS is a “program or activity” subject to Section 504 as it receives federal financial assistance from the U.S. Department of Education under multiple federal grants in aid, including, *inter alia*, Title I of the Elementary and Secondary Education Act, Individuals with Disabilities Education Act, School Lunch and Nutrition Act, Carl D. Perkins Vocational and Technology Act.

1. Discrimination by Denying Comparable Aids, Benefits and Services to Students with SCD, 34 C.F.R. § 104.4(b)

Under Section 504 and implementing regulations, 34 C.F.R. § 104.4 (a), BPS, a recipient of federal financial assistance, may not discriminate against a qualified student with a disability or exclude them from participation in or benefiting from an aid, benefit or service provided by or on behalf of the school program.⁵⁷ This obligation to provide comparable opportunities to a qualified student with a disability applies equally to all aspects of a recipient school district’s operation, including nonacademic and extracurricular activities.⁵⁸ Yet as described above, BPS treats differently students with SCD who are ‘qualified’ individuals with a disability and affords them an opportunity to participate in or benefit from an aid, benefit or service that is not equal to that afforded others⁵⁹ or that is not as effective as that provided to others.⁶⁰ Such differential treatment cannot be justified by BPS.

As described above, BPS violates Section 504 and 34 C.F.R. § 104.4 (b) (1)(i) by failing to identify and notify students with SCD and their parents⁶¹ that the nature of SCD and its impact on major life activities, including bodily functions, potentially makes them eligible for related services and accommodations under Section 504. BPS’s practice of limiting child find, evaluations and other services to students, e.g., those with asthma, diabetes, Asperger’s syndrome, severe food allergies, who do not include those with SCD, violates Section 504. See *North Royalton (OH) City Sch. Dist.*, 52 IDELR 203 (OCR 2009)(policy limiting child find to poor attendance, academic performance, and students with seriously adverse social-emotional disorders is contrary to Section 504).

Through its failure to exercise oversight and engage in child find activities for students with SCD, including by ensuring that any student with SCD, who needs or is believed to need special education or related services because of disability, is referred for a comprehensive evaluation to make a determination of eligibility⁶², BPS denies these students the opportunity to access, to participate in, or benefit from the classroom instruction, regular education curriculum, and other education services that are equal to that provided nondisabled students.⁶³

Without access to related services and accommodations individually designed to enable them to participate fully and effectively in the school program, students with SCD are denied access to teaching and instruction, socialization opportunities and other educational benefits that are as effective as those provided to nondisabled students, who are not affected by fatigue, dehydration,

⁵⁶ 29 U.S.C. § 794(b).

⁵⁷ 34 C.F.R. § 104.4(b)(1)(i).

⁵⁸ 34 C.F.R. § 104.37(a)(1).

⁵⁹ 34 C.F.R. § 104.4(b)(1)(ii).

⁶⁰ 34 C.F.R. § 104.4(b)(1)(iii).

⁶¹ 34 C.F.R. §104.32(a), (b).

⁶² 34 C.F.R. §§ 104.35, 104.36.

⁶³ 34 C.F.R. §104.4(b) (1)(ii).

episodic pain necessitating their leaving the classroom during school hours and missing critical instruction, or accumulating multiple, and often frequent, serial days of absences from the school program.⁶⁴

BPS fails to ensure that its educational programs are as accessible and equally effective for students with SCD as they are for nondisabled students.⁶⁵ BPS's use of ICHPs to identify mitigating measures for students with SCD, who, e.g., may require hydration in class, additional time to walk between classes, limits placed on physical activities, breaks for rest or urination, access to the school nurse because of severe episodic pain and medication, is not sufficient to ensure that these students receive FAPE. For each eligible child, FAPE must be individually determined based on a comprehensive evaluation of the student's respective needs, and include such related services and accommodations necessary to enable the student to access equally the aids, benefits and services provided by BPS to all other BPS students.⁶⁶ BPS's use of ISHPs for students with SCD circumscribes the rights and protections of those students who are qualified individuals with a disability who are protected by Section 504 and the ADA; this practice is discriminatory toward this particular class of students with a disability under 34 C.F.R. §104.4(b)(4)(i).

2. Failure to Identify, Locate and Evaluate Students Who Are/May Be Qualified Individuals with a Disability, 34 C.F.R. §104.32, §104.35

BPS is failing to comply with Section 504 regulations requiring recipients of federal financial assistance to identify, locate,⁶⁷ and evaluate students who are suspected of needing special education or related services because of a disability.⁶⁸ Based on the facts above, none of the Complainant Students A –E or their parents were notified that students with SCD might be expected to qualify for necessary protections and supports under Section 504 and the ADA. BPS has not met its child find obligations with respect to BPS enrolled children with SCD.⁶⁹

BPS has not met its affirmative duty to ensure that parents of school-age children with SCD, as parents of children who are diagnosed with asthma, autism, diabetes or epilepsy, and/or who are in need of special education, are notified by BPS in writing,⁷⁰ and in their native language, of their children's rights and protections under Section 504,⁷¹ including to be evaluated under 34 C.F.R. §104.35. Before taking any action with respect to the initial placement of a student in regular or special education, a recipient must under §104.35(a) conduct an evaluation of any person, who, because of disability, needs or is believed to need special education or related services, in accordance with 34 C.F.R. § 104.35(b). With respect to the Complainant students (A-C), and the cohort of 250 enrolled students with SCD whose interests they seek to represent, BPS has not acted consistent with its obligation under 34 C.F.R. §104.35(a) to refer and to conduct an evaluation "of any person who, because of [disability], *needs or is believed to need special education or related services . . .*" (emphasis added).

⁶⁴ 34 C.F.R. §§ 104.4(b)(1)(i)-(iv), (vii); (b)(4).

⁶⁵ 34 C.F.R. § 104.4(b), (b)(2).

⁶⁶ 34 C.F.R. § 104.33(b).

⁶⁷ 34 C.F.R. § 104.32.

⁶⁸ 34 C.F.R. § 104.35(a).

⁶⁹ 34 C.F.R. § 104.32(b).

⁷⁰ Complainants do not suggest that the information sheets posted on BPS's website for parents of children with these health conditions are necessarily sufficient to comply with the requirements of Section 504.

⁷¹ 34 C.F.R. §104.36.

Significantly, this duty to evaluate exists regardless of whether a parent requests an evaluation. OCR has ruled that a district's practice of addressing the needs of students with diabetes strictly through health plans and conducting 504 evaluations only when parents specifically requested them violated Section 504. See *Forest Hills (OH) Local Sch. Dist.*, 58 IDELR 114 (OCR 2011). The key question is whether the district has reason to believe that the student has a disability and “needs or is believed to need special education or related services...” [34 C.F.R. § 104.35(a)] As OCR has recognized, a school district “is not obligated to evaluate and provide services just to students who it knows may have disabilities. Under the Section 504 regulation, at §§ 104.32 and 104.35(a), *it is not the parents’ responsibility*, but rather the [District’s] to identify and evaluate any student who needs or is believed to need special education or related services because of disability.” *Isle of Wight County (VA) Public Schools*, 56 IDELR 111 (OCR 2010)(emphasis added). In the case in point parents of Complainant Students A-C, and of the students represented by the exemplar Student D, have notified school personnel of their children’s SCD; in some instances, the children’s physicians have met with school personnel to discuss their needs for related services and accommodations that will reduce the children’s anxiety about being retained or receiving poor grades because of their absences and inability to catch up without targeted instruction and extra time to make up classwork and assignments. BPS has sufficient “reason to believe...” that students with SCD have a disability and must be evaluated for consideration of eligibility for services under Section 504. See *Aurora (CO) Pub. Schs.*, 1 IDELR 83 (OCR 2013) (the fact that a student with cerebral palsy suddenly began relying on a wheelchair to get around should have caused her charter school to evaluate her).

The Section 504 regulation at § 104.35(b) requires that a recipient establish standards and procedures for the evaluation and placement of any such students who, because of disability, need or are believed to need special education or related services, and the evaluation must be comprehensive and consistent with that provided under the IDEA.⁷² In the case in point, BPS has sufficient information that the approximately 250 BPS enrollees with SCD, including Complainant Students A-D and those who have not disclosed their SCD status and are represented by exemplar Student E, because of disability, need or are believed to need special education or related services. By failing to take such affirmative steps to evaluate these students who are known or suspected to have a disability –i.e., SCD that impedes a major life activity, including multiple bodily functions, BPS has violated and continues to violate their rights under 34 C.F.R. § 104.35(a) and (b). Moreover, given the nature of this endemic disease and the stigma that prevents some African American and Hispanic parents from disclosing their children’s diagnosis, BPS’s failure to modify ineffective policies and to establish policies and practices to improve outreach and training of members of the school staff and broader community so as to help identify, locate and refer for evaluation children with SCD violates the procedural requirements set forth in 34 C.F.R. § 104.36.

3. Failure to Provide FAPE and Related Services to Students with SCD Who Are Eligible Individuals with Disabilities under Section 504, 34 C.F.R. § 104.33

As described above, BPS is denying Complainant students and the other enrolled BPS students with SCD their right to a free appropriate public education, in particular through the failure to provide related services. Section 504 requires that a public school district “shall provide a free appropriate public education to each qualified...person [with a disability]...[in the district]... regardless of the nature or severity of the person’s [disability].” 34 C.F.R. § 104.33(a). FAPE consists of “the provision of regular or special education and related aids and services ... designed to meet individual educational needs of handicapped persons *as adequately as the*

⁷² 34 C.F.R §104.35(b)(1)-(3).

*needs of non-handicapped persons are met and ... are based upon adherence to procedures [of Section 504].*⁷³

As described above, Complainant students, A, B, C, D, and E and other enrolled BPS students with SCD are treated differently in violation of 34 C.F.R. § 104.4(a), because BPS does not treat SCD as a disability, and these students are not referred for evaluation despite their need, at a minimum, for related services, and in some cases, possibly special education.⁷⁴ Because BPS has failed and continues to fail to conduct evaluations of these students with SCD, who are suspected or known to have a physical disability that interferes with a major life activity, which includes a bodily function, BPS has not met and cannot meet its obligation to provide those who are eligible students with disabilities⁷⁵ an appropriate education consisting of “the provision of regular or special education and *related aids and services* ... that (i) are designed to meet the individual educational needs of [disabled] persons as adequately as the needs of [nondisabled persons] are met and (ii) are based upon adherence to procedures that satisfy the requirements of §§ 104.34, 104.35, and 104.36.”⁷⁶ BPS continues to deprive Complainant students and other enrolled students with SCD access to an appropriate education with such related aids and services⁷⁷ necessary to enable them to benefit fully from their regular education program. These aids and services, which may include supplemental direct instruction and/or tutoring provided by qualified subject matter teachers, transportation, counseling and training, and school health services for eligible students with SCD, are intended to be determined by a group of persons, including a person with knowledge of the student’s impairment,⁷⁸ drawing from results of a comprehensive evaluation of the student’s needs.⁷⁹

4. Failure to Provide Accommodations to Help Enable Students with SCD Overcome Barriers Related to Their Disability

BPS’s failure to provide students with SCD necessary accommodations is primarily the cumulative result of its policies and practices of failing to notify parents of students with SCD of their rights and to meet its obligation to identify, locate and evaluate students with SCD to determine their eligibility as individuals with a disability. Even for the student with SCD who is known to have a Section 504 plan, e.g., Complainant student A, BPS did not comply with the regulatory mandates and did not develop Section 504 plan that was based on a comprehensive evaluation of the student’s individual needs consistent with 34 C.F.R. §104.35 so as to provide her with such supportive services and accommodations under the ADA, at regulation 28 CFR § 35.130 (b)(7), necessary to effectively access the regular curriculum, remain in school and have a meaningful opportunity to attain comparable benefits available to students without disabilities.⁸⁰

Without an evaluation and determination of eligibility as a qualified individual with a disability

⁷³ 34 C.F.R. § 104.33(b) (emphasis added).

⁷⁴ See 34 C.F.R. § 104.35.

⁷⁵ As described above, SCD compromises a person’s cell growth, circulatory, hematic, digestive systems –bodily functions that fall within the definition of a major life activity under 42 U.S.C. § 12102(2)(B). Even without examining the manifestations of SCD that may vary in intensity and kind for different individuals at different times, virtually all of BPS’s estimated 250 enrollees diagnosed with SCD meet the definition of a qualified individual with a disability under Section 504.

⁷⁶ See 34 C.F.R. § 104.33(b) (emphasis added).

⁷⁷ Related aids and services under Section 504 are considered to mean the same as related services under the IDEA. See 34 C.F.R. § 104.33 (b)(2).

⁷⁸ 34 C.F.R. § 104.35(c)(3).

⁷⁹ 34 C.F.R. § 104.35(c)(1), (2).

⁸⁰ 34 C.F.R. §104.4(b).

other BPS students with SCD, who, for example, experience frequent and sometimes long-term absences related to their SCD and have other needs that require accommodations in order to receive comparable benefit.⁸¹ These accommodations may include: recognition of the importance of communication between parents, school staff, and school health personnel regarding the students' medical condition; requiring each student's teachers be informed of his/her SCD; provision of certain adjustments when a student becomes fatigued or needs to leave the classroom for health related reasons (management of pain episodes, need for additional hydration or use of the bathroom, requires access to the nurse/health related personnel); noting the importance of teachers' eliminating stress for a student with SCD when possible.

BPS's continued failure to provide accommodations to these unidentified, yet qualified students with a disability –SCD -through a properly developed Section 504 plan that will help ensure meaningful access to the same education provided non-disabled students, violates their rights under Section 504 and Title II of the ADA.

5. BPS' Failure to Recognize SCD as a Disability Has the Effect of Discriminating Against Students with Disabilities

Regulations promulgated under Section 504 expressly state:

A recipient may not directly or through contractual or other arrangements, utilize criteria or methods of administration (i) that have the effect of subjecting qualified...persons [with a disability] to discrimination on the basis of [disability], (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to ...persons [with a disability], or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common control or are agencies of the same state."⁸²

BPS discriminates against the subset of BPS enrolled students who are diagnosed with SCD specifically on the basis of the nature of their disability in violation of Section 504 and Title II of the ADA. BPS, through its policies and practices, as described above, fails to consider this limited group of students as having a disability that may qualify them for protection under Section 504 and Title II. Its policies and practices, including the inappropriate use of the ICHP, which may purport to identify mitigating measures, cannot be used to circumscribe the school district's obligations pursuant to Section 504 to identify, locate and evaluate any student who needs or is believed to need special education or related services because of a disability. BPS's methods of administration, acts and omissions have the effect of discriminating against this subset of approximately 250 students diagnosed with SCD, and depriving them of their rights under Section 504 to be evaluated for consideration of eligibility as students with a disability, and, those who are qualified individuals with a disability, to be provided the full range of related services and accommodations needed to receive comparable instruction and to participate as effectively in the regular curriculum as students without disabilities.⁸³

C. BPS Policies and Practices That Discriminate Against Students with SCD Have a Disproportionate Impact on the Basis of Race and National Origin That Cannot Be Educationally Justified

⁸¹ 34 C.F.R. §§ 104.49a), (b); 104.12; 28 CFR § 35.130 (b)(7).

⁸² 34 C.F.R. § 104.4(b).

⁸³ 34 C.F.R. § 104.4(b).

As described previously, BPS through its methods of administration, policies and practices fails to consider students with SCD as having a disability, and consequently fails to notify their parents of their rights under Section 504 and Title II; to provide children with SCD a comprehensive evaluation of their individual needs; and to provide related services and accommodations for eligible children with SCD so they may receive an appropriate public education, have equal access to the regular education curriculum, school's academic and non-academic programs, services, and activities and participate as effectively in the instructional and social opportunities offered by BPS as their non-disabled peers --- in violation of the Act and its regulations, and specifically its regulation at 34 C.F.R. § 104.4(b). Because students with SCD are virtually exclusively individuals of African American and Hispanic origin, these policies and practices have a disproportionate adverse effect on African American and Hispanic students in violation of Title VI of the Civil Rights of 1964.⁸⁴

Under Title VI of the Civil Rights Act, “no person in the United States shall, on the ground of race, color or national origin be excluded from participation in, be denied the benefits of, or be otherwise subject to discrimination under any program receiving federal financial assistance.”⁸⁵ The purpose of Title VI is to ensure that public funds are not spent in a manner to encourage, subsidize, or result in racial discrimination. The United States Supreme Court has ruled that regulations promulgated under Title VI may prohibit policies and practices that have a disparate impact on protected groups, even if the actions or practices are not intentionally discriminatory.⁸⁶ Hence, Title VI prohibits a recipient from using “criteria or methods of administration” [policies or practices] which have the effect [even if not the intent] of subjecting individuals to discrimination because of their race, color, or national origin.”⁸⁷ Under this ‘disparate impact’ theory, if BPS, a recipient of federal funding, disparately harms students –here those with SCD, who are disproportionately African American and Hispanic -- through its policies and practices, then those policies and practices are unlawful unless they can be justified by educational necessity *and* there is no less discriminatory means of achieving the same educational goals.

Complainants contend that BPS’s failure to identify, refer and comprehensively evaluate and provide effective related services and accommodations to eligible students with disabilities, in particular, students with SCD, who are disproportionately African American and Hispanic students, is discriminatory under Title VI [as well as Section 504 of the Rehabilitation Act and Title II], exacerbates the plight of BPS African American and Hispanic students, who with and without disabilities are already at a substantial disadvantage within the BPS system,⁸⁸ and cannot be justified. Complainants need not show that this discrimination is intentional;⁸⁹ its effects on African American and Hispanic students with SCD are clear and actionable under Title VI. Because Complainants have made a prima facie showing of the disparate impact of BPS’ policies and practices of not addressing the disability related needs of the BPS enrollees with SCD who are disproportionately African American and Hispanic students entitled to protection under Title VI, BPS bears the burden of demonstrating that its practices regarding students with SCD are

⁸⁴ 42 U.S.C. § 2000d; 34 C.F.R. § 100.3(b)(2).

⁸⁵ 42 U.S.C § 2000d; 34 C.F.R. § 100.3.

⁸⁶ See Alexander v. Choate 469 U.S. 287, 105 S. Ct. 712 (1985) (noting that disparate impact discrimination applies to Section 504 of the Rehabilitation Act).

⁸⁷ 34 C.F.R. §100.3(b)(2).

⁸⁸ <http://profiles.doe.mass.edu/accountability/report/district.aspx?linkid=30&orgcode=00350000&orgtypecode=5&>

⁸⁹ See Prewitt v. United States Postal Service 662 F.2d 221, 307 (5th Cir. 1981) (noting that in arguing disparate impact, employee does not have to prove that an employer policy was intended to be discriminatory but only make a prima facie showing of disparate impact).

supported by a “substantial legitimate justification”⁹⁰ or in other words, that they are required by “educational necessity.”⁹¹ BPS, which strives as its goal to “transform the lives of *all* children through exemplary teaching . . . and develop in *every* learner the knowledge, skill, and character to excel in college, career, and life,”⁹² cannot justify the above described discriminatory practices on the basis that they are educationally necessary. Even if BPS’s policies and practices that result in African American and Hispanic students with SCD being disproportionately denied consideration of eligibility for possible special education and related services and accommodation on the basis of their race and national origin, could somehow be framed as educationally necessary, there are clearly less discriminatory alternatives, e.g., starting with BPS complying with the requirements of §504 and Title II. Treating students with SCD, as all other students with disabilities who may qualify for special education or more likely related services under Section 504, would significantly reduce the discriminatory effect on African American and Hispanic students who almost exclusively are diagnosed with SCD; and the discriminatory denial of related services to these students would be further reduced, if BPS eliminated its inappropriate use of ICHPs which neither protect these students from discrimination, harassment or retaliation or provide them entitlements to services and accommodations to meet their needs as students with SCD.

VI. PROPOSED FINDINGS AND REMEDIES

Based on the above, the Complainants request that the United States Department of Education, Office for Civil Rights: 1) Accept jurisdiction of this Complaint; 2) Consider and fully investigate these claims of discrimination on behalf of Complainants and other students with SCD who challenge BPS policies and practices as violating their rights under Section 504, Title II of the ADA, and Title VI ; 3) Review BPS districtwide data, including longitudinal data pertaining to students identified with SCD compared to other physical conditions (e.g., diabetes, Crohn’s disease, IBD, asthma, etc.) by race, ethnicity, and status (served under an Individual Collaborative Health Plan, an IEP, a Section 504 Plan); 4) Review the education records of students with SCD who have an Individual Collaborative Health Plan, a Section 504 Plan, or an IEP for compliance with requirements of Section 504 regarding referral for evaluation, FAPE, related services and accommodations; 5) Review BPS policies and procedures and training materials, if any, pertaining to identification, evaluation and provision of FAPE and related services and accommodations for students with SCD, and compare them with those for other students with e.g., diabetes, asthma, allergies, Crohn’s disease, IBD, that also have manifestations that may interfere with students’ life activities.

We ask the Office for Civil Rights to find that BPS has violated Section 504 and Title II of the ADA by failing to ensure that students with SCD and their parents are notified of their potential eligibility for protection from discrimination, provision of special education or related services and accommodations that improve their access to programs and facilitate learning in the classroom; that BPS has failed to ensure that all students with SCD who are eligible under Section 504 and Title II of the ADA, are properly identified and evaluated so they may receive necessary accommodations and related services so as to meaningfully and effectively participate in the BPS curriculum and enjoy comparable benefits to those provided other students

⁹⁰ Elston v. Talladega Cty. Bd. of Ed., 997 F.2d 1394, 1412 (11th Cir. 1993).

⁹¹ Id.

⁹² Boston Public Schools website, Academic Excellence for Every Child at <http://www.bostonpublicschools.org/domain/24> (2008).

with and without disabilities.

We ask that OCR make findings that BPS, in circumscribing its obligations under Section 504 and Title II of the ADA specifically to students with SCD, who are known to be disproportionately African American and Hispanic students, systemically discriminates against these students with SCD on the basis of race and national origin under Title VI of the Civil Rights Act. We urge that this office mandate that BPS expedite referrals for comprehensive evaluations of students whose manifestations of SCD are interfering with their performance of major life activities and take immediate steps to remediate these wrongs and to make these students whole.

In addition, Complainants ask that BPS shall develop policies and guidance reflecting OCR's findings and consistent with ensuring that students with SCD, who are predominantly African American and Hispanic, are properly identified, referred for evaluation, and provided a comprehensive evaluation, including a neuropsychological evaluation, if warranted and consistent with the recommendations of the student's pediatrician or other medical practitioner involved in the oversight and treatment of student's SCD. We request that BPS further be required to design with consultation and input of the Complainants a plan that will help prepare parents, teachers, other school officials, and members of the broader BPS learning community with the knowledge and skills to support children with SCD in school and in their community. Such collaborative plan shall include:

- A Comprehensive Letter from BPS to All Parents Describing the Nature of SCD, Manifestations and Possible Impact on Student Performance and Participation and BPS's Obligation to Implement the Rights and Protections of Students

Complainants urge that BPS, with input from Complainants and medical and other community members, craft and disseminate a letter of notice to all parents,⁹³ describing SCD,⁹⁴ its common manifestations and possible adverse effects on the education and educational performance of a student diagnosed with SCD. The letter shall set forth the rights and protections a student with SCD experiencing manifestations that are interfering with major life activities has under Section 504: it shall state in plain language understood by lay persons that it is the school's duty to conduct comprehensive evaluations of students who need or are believed to need both special education or related aids and supportive services to determine their eligibility under IDEA and Section 504, and shall clarify that students who do not need specialized instruction under IDEA, but are found eligible for protection and services under Section 504, are entitled to receive related services and accommodations specific to their individual needs related to their SCD and its manifestations.⁹⁵

This letter should substantially lessen the advocacy burden on parents with affected children;

⁹³ This letter does not necessarily have to be a separate publication but can be made a part of any district prepared materials that BPS already distributes to children and their parents. Because 504 regulations do not prescribe the manner in which schools must undertake their notification activities, examples of appropriate activities might also include posting notices through the internet, publishing notices in the newspaper, disseminating information through health and social services agencies, early intervention providers and parent organizations, etc. If BPS chooses to employ the letter method, its content should be made accessible to parents who are not literate or that have disabilities themselves.

⁹⁴ The letter should also clarify the difference between SCD and the non-disease carrier state sickle cell trait, especially given historical confusion between the two, the general lack of awareness about SCD and sickle cell trait, and the far larger number of students who will have the trait but not the disease.

⁹⁵ Sending this letter of notice is consistent with a school district's duty under 34 C.F.R. § 104.32(b), see *supra* pp. 19-20.

parents will no longer solely bear the difficult responsibility of coming forward to explain the exigencies of the disease to school officials, of justifying or defending their child's need to miss school or of requesting services to enable their children to benefit from their education. In this way, it will also help to remove some of the stigma surrounding the disease and partially quell the fear of "outing" children with SCD because parents will understand that schools do not intend to discriminate against them but rather enable them to succeed in school. Furthermore, it will raise awareness about the disease and its effects on learning among parents so that they have a better understanding of how to assist their children in school. Moreover, it will assure parents that BPS is willing to partner with them on this issue, creating a wider community of support, collaboration and understanding around children with SCD.

- A SCD Training Curriculum and the Training of All Teachers, Interested Parents and Other Relevant Persons in the BPS community on the Nature of SCD, its Effects on Students' Participation in School, and Strategies for Identifying Students Experiencing Sickle Pain Episodes, Providing Support and Implementing Accommodations for Them in the Classroom.

Complainants urge BPS with input from Complainants to design, develop and implement training sessions for teachers, parents and other educational stakeholders in the school community to educate them on the nature of SCD and its effects on students' experiences and ability to succeed in school. Parents, school administrators and non-teaching school staff should be trained on the various physical manifestations of sickle cell disease as well as its social and emotional impacts on affected children so that parents and school staff can support teachers in ensuring that students get all the help they need to access school programs. Training sessions should also be geared to increasing awareness about the disease and diffusing some of the continuing racial stigma that surrounds it such that more parents will be willing to speak up and work with BPS in identifying, evaluating and providing the necessary services to their children.

Teachers should be prepared to implement classroom accommodations and to provide general support to students with SCD by showing concern and understanding for their difficulties rather than disparaging them. They should especially be trained on the nature of the pain associated with SCD and the array of student responses to this pain. Then teachers equipped with this knowledge should be present at all meetings discussing potential disciplinary action for students with SCD.⁹⁶ Furthermore, teachers, staff and administrators should be taught to be responsive to indicia of need for students in the classroom so, if possible, they can provide certain SCD-related services or contact parents or school health officials for assistance;⁹⁷ in particular they should be trained to look for potential signs that a child is not feeling well: irritability, social isolation and increased fatigue.⁹⁸ This will enable them to seek appropriate help for students in a timely manner. Additionally, teachers should be trained to look for cognitive declines or changes in students with SCD by closely monitoring their academic performance. Declines in a student's academic performance could mean that he or she has suffered a silent stroke. Lastly, teachers should be trained to work with parents and other school officials to develop a holistic understanding of the effects of SCD and to build a community of support around children with the disease so they do not feel ashamed, isolated or overwhelmed.

⁹⁶ See Virginia Beach (VA) City Public Schools 110 LRP 30208 (finding that manifestation determination meetings must be conducted by people who have an understanding of the relationship between the disease and related behaviors).

⁹⁷ See Lee County (FL) Sch. Dist., 46 IDELR 228 (OCR 2006) (district agreed to train its staff to provide diabetes-related services).

⁹⁸ Meyers, supra n. 82.

Complainants believe that the remedies described above will pose little burden to BPS.

- Timely Comprehensive Evaluations of BPS Students Diagnosed with SCD

BPS shall immediately, with the consent of parents and eligible students 18 years of age and older, conduct a comprehensive evaluation of students with SCD, whose manifestations are interfering with the affected student's major life activities, e.g., attending school, walking between classes, concentrating, remaining in the classroom, carrying books. This evaluation must be done to (i) determine whether the particular student with SCD qualifies as disabled under Section 504; (ii) identify and understand what his or her educational needs may be; and (iii) determine what strategies can be employed or interventions, services, and accommodations, provided to meet these needs as adequately as the needs of students without disabilities.⁹⁹ Furthermore, since children and youth with SCD are at risk for silent strokes which can lead to cognitive declines with strong educational implications, Section 504 Teams should consider use of neuropsychological testing as part of the comprehensive evaluation for each student with SCD. Initial neuropsychological tests will help establish a cognitive baseline for individual students with SCD. Then, reevaluations conducted at predetermined intervals will enable schools to track changes in students' neuropsychological functioning which could signal learning deficits that might adversely affect a child's educational performance.¹⁰⁰ This cognitive information will enable BPS to develop and provide specific educational interventions to those students who need them, including related aids and services and accommodations.¹⁰¹

- Timely Development of a Section 504 Plan for Each Eligible BPS Student with SCD that Is Designed to Meet Individual Educational Needs of a Student with SCD as Adequately as the Needs of Students Without Disabilities Are Met Consistent with 34 C.F.R. § 104.33(b).

After evaluating students with sickle cell disease, BPS shall convene the members of the student's Section 504 Team to ensure that eligible students with SCD are provided FAPE through provision of regular or special education, and such related aids and services, assistive technology,¹⁰² and accommodations so that their individual educational needs are met as adequately as those of students without disabilities. 34 C.F.R. § 104.33(b).

Students with SCD miss an average of 20 to 40 days of school per year, with pain frequency and clinic appointments being primary drivers of absences. For students with SCD who experience silent and overt strokes and other complications related to SCD that require hospitalization and transfusions, the lengths of absences may be double and even treble. Complainants believe that because of their multiple and usually unplanned absences from school, it is critical that BPS set up a mechanism that will ensure individual students with SCD obtain the teaching and instruction they missed during their absences – teaching and instruction that is comparable to that received by their non-disabled classmates. Such teaching and instruction must be provided by qualified subject matter personnel who provide instruction aligned with the state standards and comparable to what is provided in the classroom by the students' regular teachers.¹⁰³ The goal

⁹⁹ 34 C.F.R. §104.33(b).

¹⁰⁰ See Stroke as a complication of sickle cell disease, *supra*.

¹⁰¹ See Essential of Neuropsychological Assessment, *supra* at p. 6-7; see also Detection and assessment of stroke in patients with sickle cell disease: neuropsychological functioning and magnetic resonance imaging, *supra*.

¹⁰² Technology or devices that assist students in their movement and with their vision are recommended.

¹⁰³ “. . . a school district must provide, at a minimum, the instruction necessary to enable the student to keep up in his/her courses of study and minimize the educational loss that might occur during the period the student is confined at home or in a hospital.” MA DESE Program Quality Assurance Services, Question and Answer Guide on the

will be to keep the student with SCD, who because of his/her SCD-related needs is unable to attend school, on pace with his/her classmates.

While complainants acknowledge that 603 CMR 28.03(3)(c)¹⁰⁴ provides a pathway for some students, including those with disabilities who miss school for medical reasons to receive temporary in-home or in-hospital educational services,¹⁰⁵ this site-based instruction, in general, cannot meet the needs of students with SCD, who miss school typically because of debilitating pain and other severe manifestations of SCD. It is not generally feasible or practical for children with SCD to receive teaching and instruction while they are at home or hospitalized for dehydration, severe pain or overt strokes.

For students with SCD to receive instruction comparable to non-disabled peers under Section 504, BPS should be required to consider for any student who experiences repeated absences related to SCD, provision of supplemental instruction before and/or after school or extended school year to make up the instruction missed as a result of their SCD related absences. They likely will also require extra time to complete assignments and other work they have missed.

Given the nature of SCD, it can be expected that many students will require professional counseling as part of their Section 504 plan to help them to understand and cope with their illness; to help address the social and emotional impacts of being away from school, feelings of isolation, lack of confidence, fear, and learning how to live with the disease; and to help them learn how to talk about it with peers and family members, particularly those not affected by the disease.

BPS's Section 504 teams shall provide eligible students with such accommodations that effectively remove all SCD-related barriers to academic access and participation. The following accommodations may be helpful in directly addressing these barriers:¹⁰⁶

- **Two sets of textbooks: one for school and the other for home.** This will spare children with SCD the burden of having to carry heavy textbooks to and from school which can trigger pain episodes

Implementation of Educational Services in the Home or Hospital 603 CMR 28.03(3)(c) and 28.04(4) available at http://www.doe.mass.edu/pqa/ta/hhep_qa.html.

¹⁰⁴ Under 603 CMR 28.03(3)(c), “upon receipt of a physician's written order verifying that any student enrolled in a public school or placed by the public school in a private setting must remain at home or in a hospital on a day or overnight basis, or any combination of both, for medical reasons and for a period of not less than fourteen school days in any school year, the principal shall arrange for provision of educational services in the home or hospital. Such services shall be provided with sufficient frequency to allow the student to continue his or her educational program, as long as such services do not interfere with the medical needs of the student.”

¹⁰⁵ On the issue of the legally required sufficiency of a physician's statement under 603 CMR 28.03(3)(c), see In re Student v. Lowell Public Sch. District, #02-1497 (Figueroa, Oct. 24, 2001) (noting that the language of [the regulation] is unequivocal and does not leave the provision of educational services in the home to the school principal or the special education administrator where the requisite medical order is issued for medical reasons and the home placement is required to last at least 14 days). 603 CMR 28.03(3)(c) requires that a physician merely *verify*, not *explain*, that the student must remain at home for legal reasons. To require anything more is to place a higher burden on students and physicians than is legally mandated.

¹⁰⁶ List adapted from New England Pediatric Sickle Cell Disease, supra n. 2; Virginia Department of Health, Understanding the Child with Sickle Cell Disease: A Handbook for School Personnel; Mayes et Al, Psychoeducational Screening in Pediatric Sickle Cell Disease: An Evaluation of Academic and Health Concerns in the School Environment, supra. Appendix Handout Recommended School Accommodations for Children and Adolescents for Sickle Cell and Connecticut Children's Medical Center; and Children / Adolescents with Sickle Cell Disease School Planning Recommended Accommodations Modifications available at <http://www.childlife.org/files/SickleCellSchoolModifications.pdf>.

- **Bathroom passes.** This will grant children unlimited access to the bathroom and spare them the embarrassment of having to constantly request and justify their frequent bathroom visits to their teachers.¹⁰⁷
- **Unlimited access to the school nurse or school health official.** Complainants urge OCR to require BPS to develop mechanisms for allowing students with SCD to access the school nurse or other health official in order to be able to take prescribed pain management medication when needed.¹⁰⁸ Accessing narcotics when recommended by physicians has been a particular challenge, and complainants urge OCR to require BPS to develop mechanisms for allowing students with SCD to take these medications when needed and instructed by their physician. Children with SCD may need to be able to communicate with their parent and physician if they are experiencing symptoms that are unfamiliar or are ones their physicians told them to contact them about if experienced. Depending on the child and physician, this may be through a phone call from the nurse’s office, texting from a cell phone kept in the nurse’s office, or some other mechanism.
- **Permission to carry a water bottle at all times.** This will enable students with SCD to stay hydrated which is necessary to alleviate some of the symptoms of the disease.
- **Time to access water and medication.**¹⁰⁹
- **Training of health personnel and teachers on symptoms that warrant a call to parents or to emergency services.** Children with SCD can experience severe pain episodes or sickle crises that may need to be addressed immediately by parents or by experienced physicians. Teachers and school health officials should be trained to watch for symptoms that indicate a need to refer the child for advanced medical attention. These could include a fever of 101F or greater, swelling, pain, sudden or persistent headache, rapid heartbeat, and changes or difficulty in breathing.¹¹⁰
- **Permission to stay indoors or be exempt from outdoor activities when it is too hot (above 85-90 degrees depending on humidity) or cold (below 40-50 degrees depending on wind) outside, or when air quality is poor. Door-to-door transportation may also be necessary to prevent children with the disease from standing too long in the heat or cold (or when mobility is impaired from hip or other complications).**¹¹¹ Children with SCD are sensitive to extreme outdoor temperatures and to airway irritants such as pollution. They should also be allowed to wear a coat indoors when it is cold and to move away from indoor air conditioning or heating units if they are seated too close to them.

¹⁰⁷ Section 504 requires schools to provide health-related services to a student found to have a disability, here SCD, when the services must be performed during the school day in order for the student to attend school or if the student requires the services to meaningfully benefit from a full education. Bathroom passes are a health-related service under 504 because SCD causes affected students to need the bathroom frequently; without them, they will be unable to function properly at school; see Springboro (OH) Cmty. City Sch. Dist., 39 IDELR 41 (OCR 2003) (blood glucose monitoring, administration of medication and relaxation of snack policy were “related aids and services” under Section 504).

¹⁰⁸ See San Roman Valley (CA) Unified Sch. Dist., 18 IDELR 465 (OCR 1991) (noting that Section 504 requires districts to provide students with disabilities with health-related services, such as the *administration of medication*, that must be performed during the school day to enable these students benefit from their education.); see also Prince George’s (MD) County Schs., 39 IDELR 103 (OCR 2003) (certified nursing and licensed health aid services to monitor student’s medical needs and administer insulin were valid accommodations).

¹⁰⁹ Under 504, districts may allow additional time when necessary for students so that they can obtain what is necessary to them, such as snacks. Because students with SCD need to stay hydrated to avoid triggering pain crises, schools should allow them time to obtain water to drink as part of an accommodation plan. See Springboro (OH) Cmty. City Sch. Dist., 39 IDELR 41 (OCR 2003); see also Eureka (CA) City Sch., 23 IDELR 238 (OCR 1995).

¹¹⁰ Mayes et Al, Psychoeducational Screening in Pediatric Sickle Cell Disease: An Evaluation of Academic and Health Concerns in the School Environment, *supra*. Appendix Handout Recommended School Accommodations for Children and Adolescents for Sickle Cell.

¹¹¹ Id.

- **Permission to access an elevator if relevant and to leave class early to get the next one (or alternatively, extra time between classes).** As already discussed, children with SCD experience chronic pain and fatigue that can make it difficult for them to walk, run, and climb stairs. Allowing them to leave class early and to use an elevator will make it possible for them to get to classes on time.
- **Modified participation in gym class.** Gym class requires a large amount of physical exertion which children with SCD often cannot handle. Modified gym participation standards will ensure children are getting required physical education without exacerbating the symptoms of the disease.

Respectfully submitted,



Jenny Chou, Esq.
jchou@cleweb.org
Kathleen B. Boundy, Esq.
kboundy@cleweb.org
Center for Law and Education
99 Chauncy Street, Suite 716
Boston, MA 02111
617 451-0855

Rajan Sonik, Esq
rsonik@mlri.org
Massachusetts Law Reform Institute
99 Chauncy Street, Suite 500
Boston, MA 02111
617 357-0700

cc:
John McDonough, Interim Superintendent
Boston Public Schools
Office of the Superintendent
26 Court Street, 7th Floor
Boston, MA 02108
superintendent@bostonpublicschools.org

Michael O'Neil, Chairperson
Boston School Committee
26 Court Street, 4th Floor
Boston, MA 02108
moneill2@bostonpublicschools.org