

Racial Disparities in Access to Supplemental Security Income Benefits for Children

Community Legal Services of Philadelphia

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Executive Summary

SSI for children is crucial support for families in need. Supplemental Security Income (SSI) provides critical financial support to people with disabilities who experience economic hardship, including [1.1 million children](#). SSI income is crucial not only because it can [boost families out of poverty](#), but also because in many states, SSI recipients are [automatically eligible for Medicaid](#) and other programs that provide much needed resources. However, racial and ethnic disparities in Social Security Administration (SSA) policies, and in systems underlying SSI applications, create inequities in accessing and maintaining SSI benefits.

To establish a child's eligibility for SSI benefits, a family must present mental health, physical health, and education records to prove disability. If a child is eligible, they must periodically present new evidence to prove they still qualify. Children face possible suspension or termination of benefits if they become involved in the criminal justice or child welfare systems.

Black children are disproportionately impacted by SSA's policy choices, like heightened standards for asthma and sickle cell disease. SSA heightened its rules to qualify for benefits based on asthma and sickle cell to be incredibly challenging to meet, despite the disparate impact of these serious health issues on Black children.

Black children and non-Black children of color are disproportionately impacted by racism in the systems SSA relies upon for evidence. SSA must rely on information from medical providers, schools, and other systems to decide who is eligible to receive and maintain SSI benefits. Therefore, where racism and inequity exist in education, medicine, behavioral health, criminal justice, and child welfare systems, racism and inequity are perpetuated in the administration of SSI benefits.

SSA knows racial inequities persist in its programs. The United States General Accounting Office (GAO) identified racial and ethnic disparities with SSA's programs and [called on SSA to take appropriate action](#) to investigate and prevent racial disparities in its programs. However, because SSA [no longer reports data about race and ethnicity](#), progress is difficult to assess.

SSA must make internal changes and establish external collaborative partnerships to improve equity in access to crucial benefits.

To that end, Community Legal Services of Philadelphia recommends that SSA:

- address the GAO recommendations to improve its decision-making practices and [“more readily identify patterns of misconduct, including racial bias”](#) in its decision-makers by collecting and releasing data on race and ethnicity within its programs;
- provide training to SSI adjudicators on systemic inequities to inform holistic review of evidence in light of marginalized clients' barriers to care to accumulate evidence;
- eliminate suspension or termination of SSI for custodial juvenile justice placements;
- provide youth leaving institutional settings who previously received benefits with default eligibility and emergency funds for at least six months, so that the youth has time and resources to build a record with the evidence needed to continue benefits;
- amend its regulations for proving severe disability relating to asthma and sickle cell to eliminate unreasonable burdens which disproportionately affect Black children;
- solicit comments specifically addressing racial disparities when proposing rule changes;



- facilitate development of an accurate record by being lenient with deadlines to submit records and sending applicants to comprehensive evaluations when an applicant is affected by disparate access to care;
- implement a national outreach program to find and enroll all SSI eligible children;
- create an Office of Equitable Outcomes for the childhood disability program.

Racial Disparities in Access to Supplemental Security Income Benefits for Children

Introduction

Community Legal Services (CLS) has provided free civil legal assistance to more than one million low-income Philadelphians since its founding in 1966. CLS assists clients who face legal issues in a range of practice areas, including housing, employment, and public benefits. CLS is nationally recognized as a model legal services program, engaging in community education and policy change work in addition to direct representation of clients. The SSI Unit provides holistic support, including legal representation and social work, to people with serious disabilities who run into legal problems obtaining or maintaining benefits. The SSI Unit advocates for improvement of policies and practices at local, state, and national levels to make systems better for people with disabilities, with a particular focus on children and youth.

The Social Security Administration (SSA) administers the Supplemental Security Income (SSI) program, which provides critical financial support and health insurance to people with disabilities and seniors. For many families, SSI benefits provide a majority or the entirety of a family's income. However, racially disparate access to SSI benefits detrimentally affects many children and families, particularly in Black and Latinx populations. SSA should take steps to address racial disparities within its own programs and in the systems it relies on to determine eligibility for benefits to provide equal access to benefits for all.

This paper contextualizes racial disparities in SSI benefits for children by examining (1) a historical overview of Social Security's racist origins that continue to impact the program today, (2) the process for applying for SSI benefits, (3) the policies that determine whether a child qualifies for SSI, and (4) the current inequities in the systems upon which Social Security relies to determine whether an applicant is eligible for benefits.

SSA practices can produce racially disparate impacts on children in need of SSI benefits in two ways: (1) SSA's own policies affect Black children and non-Black children of color differently than white children, and (2) SSA gathers evidence from systems that treat Black and non-Black children of color differently. This paper addresses SSA policies that produce a racially disparate impact by discussing the changes made to rules regarding asthma and sickle cell disease. This paper addresses the systems underlying SSI applications and eligibility by discussing systemic racism in healthcare, education, juvenile justice, and child welfare systems.



The impact of systemic inequities on SSI benefits is twofold: affected families face more obstacles in gathering evidence, and affected children face more obstacles that disqualify them from receiving benefits, even after they have been found eligible. For example, under-diagnosis of children of color leads to less medical proof, while over-criminalization results in children of color being placed in forms of custody where they are not eligible to receive SSI.

This paper concludes by calling on SSA to make internal changes and establish external collaborative partnerships to improve equity in access to crucial benefits. Critically, SSA must release data on the race and ethnicity of SSI recipients and take tangible steps to mitigate racially disparate access to benefits.

Background on the Crisis of Equity in Administration of Social Security Benefits

Racial inequities in access to and eligibility for Social Security benefits have persisted since the program's inception. The Social Security Act of 1935 established a social insurance program [designed to pay retired workers age 65 or older a continuing income after retirement](#).¹ The Act also included unemployment insurance, old-age assistance, aid to dependent children and grants to the states to provide various forms of medical care.² Notably, however, the Act excluded domestic and agricultural workers, among other occupations.³ This [prohibited approximately two-thirds](#) of the Black workforce from eligibility for benefits until the program was expanded in the 1950s.⁴ This initial exclusion, as well as subsequent structuring of Social Security programs, forced many Black Social Security recipients into inferior and differentiated programs. Despite reforms, including the creation of additional types of insurance coverage and the expansion of already-existing coverage,⁵ [racial inequities persist](#).⁶

SSA is responsible for providing financial assistance to the elderly and people who are blind or disabled. Though the United States General Accounting Office (GAO) [identified racial disparities in SSA programs](#) and [called on SSA to take appropriate action](#) to investigate and prevent racial disparities in the administration of benefits, SSA has failed to adequately implement necessary measures or collect or publish the information necessary for a full investigation.⁷ While SSA

¹ Social Security Administration. *Historical Background and Development of Social Security*. <https://www.ssa.gov/history/briefhistory3.html>

² *Id.*

³ Kilolo Kijakazi, Karen Smith, and Charmaine Runes, *African American Economic Security and the Role of Social Security*, pg. 1, Urban Institute (July 2019), <https://www.urban.org/sites/default/files/publication/100697/african-american-economic-security-and-the-role-of-social-security.pdf>.

⁴ *Id.* at pgs. 2-3.

⁵ See *id.* at pg. 2 (noting, for example, that Social Security benefits were provided to dependents and survivors of qualified workers in 1939 and that disability insurance for children of retired workers was established in 1956).

⁶ See *id.* at pgs. 5-6 (highlighting that African American senior citizens hold fewer assets and receive less Social Security income on average compared to their white counterparts).

⁷ United States General Accounting Office (GAO), *Report to Congressional Requesters: SSA Disability Decision Making - Additional Measures Would Enhance Agency's Ability to Determine Whether Racial Bias Exists*, pg. 6, (Sept. 2002). Available at: <https://www.gao.gov/assets/240/235303.pdf>. See also GAO,



provides [annual reports pertaining to other demographic data](#),⁸ the agency [stopped reporting data about race and ethnicity](#) for the SSI program in 2002, and for the Old-Age, Survivors, and Disability Insurance (OASDI) program in 2009.⁹ The lack of data on race and ethnicity prevents SSA from investigating or addressing existing racial disparities within its programs.

Supplemental Security Income for Children and the Application to Prove Disability

SSA administers the SSI program, which provides essential financial support to the elderly and to people with disabilities experiencing economic hardship, including children with disabilities. About 1.1 million children (under age 18) receive SSI benefits [every year](#).¹⁰ For a child to receive SSI benefits, they must go through a rigorous application process, which requires submitting medical and educational records. They must establish that they meet or equal a listing (i.e. the child's documented impairment meets or equals SSA's description of a severe impairment) or that they have marked or extreme limitations in functioning. This is a high and difficult threshold to meet, and far less than half of children who apply are approved for SSI benefits.¹¹

Children must prove that the symptoms they experience are significant and make mental or physical functioning very difficult. Records from an "[acceptable medical source](#)" must verify their diagnoses.¹² For example, if a child has a mental health disorder, they and their family need to produce medical documentation of the diagnosis, supplemented by other records--like extensive therapy notes and individualized education plans--to demonstrate the child's symptoms and how they are impacted by treatment and interventions. If the child is granted SSI, they must undergo periodic reviews to prove that their existing symptoms or additional impairments continue to cause a serious disability, which requires ongoing medical and educational records.¹³ These records are [reviewed every three to seven years](#), and benefits are terminated if the new evidence provided is insufficient by SSA's standards.¹⁴

SSA Disability Decision Making: Additional Steps Needed to Ensure Accuracy and Fairness of Decisions at the Hearings Level, pgs. 5-6, 10-12, (Nov. 2003).

⁸ Social Security Administration. *SSI Annual Statistical Report 2018*. Research Statistics, and Policy Analysis, (Sept. 2019).

⁹ Patricia P. Martin, *Why Researchers Now Rely on Surveys for Race Data on OASDI and SSI Programs: A Comparison of Four Major Surveys*, SSA (Jan. 2016).

¹⁰ Social Security Administration. *Fast Facts and Figures about Social Security, 2020*, pg. 31. SSA Publication No. 13-11785 (July 2020). Available at: https://www.ssa.gov/policy/docs/chartbooks/fast_facts/2020/fast_facts20.pdf.

¹¹ SSA, "Table 70: Medical decisions at the initial adjudicative level, by age, year of application, and program, 1992–2017," *SSI Annual Statistical Report* (2018). Available at: https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2018/sect10.html#table70

¹² <https://www.ssa.gov/disability/professionals/childhoodssi-pub048.htm>

¹³ Social Security Administration. *Understanding Supplemental Security Income Continuing Disability Reviews -- 2020 Edition: Continuing Disability Reviews*. (2020).

¹⁴ *Id.*



SSI benefits are crucial for families experiencing financial hardship, particularly families harmed by the long-lasting and generational effects of slavery, systemic racism, and poverty.¹⁵ A study analyzing an SSA annual report and the Survey of Income and Program Participation (SIPP) found, “[t]he percentage of child SSI recipients with family income below the poverty line falls from 58 percent to 34 percent when SSI is counted. Thus, of children whose family income without SSI would be below the poverty line, about 41 percent are not in poverty when SSI payments are included in family income.”¹⁶ Though SSI payments help bring some families out of poverty, the majority stay within 150% of the federal poverty line.¹⁷

Of Black families who receive SSI, 45% remain below the poverty level, compared to 42% for white recipients and 32% of recipients in the “other” racial category.¹⁸ Despite the fact that Black families and recipients disproportionately live at or near the poverty level, Black recipients generally receive [lower benefit amounts than White recipients](#).¹⁹

In addition to experiencing poverty at a greater rate while receiving SSI benefits, Black families face challenges proving to SSA that they qualify for benefits and struggle to maintain benefits once they are granted. This stems from systemic racial inequities within SSA; in systems like healthcare and education, which impact gathering evidence of disability; and contact with systems such as the juvenile justice and child welfare systems, which impact eligibility to receive benefits.

Children in Need of SSI Face Compounding Challenges in Access to Benefits

In most states, SSI recipients are automatically eligible for Medicaid, allowing them to access vital healthcare. Families in need of SSI income, however, are burdened by a circular issue: eligible children need SSI benefits to access care, but without access to care, cannot prove that they are eligible for SSI benefits. An estimated [20.3 million children](#) (28% of all children) are either (a) uninsured, (b) do not receive routine primary care, or (c) are publicly insured children and connected to primary care, but have unmet needs for pediatric subspecialty care when

¹⁵ Calvin Schermerhorn, *Why the racial wealth gap persists, more than 150 years after emancipation*, Washington Post (June 19, 2019) <https://www.washingtonpost.com/outlook/2019/06/19/why-racial-wealth-gap-persists-more-than-years-after-emancipation/> (“The typical black family has just 1/10th the wealth of the typical white one. . . . It’s a common misperception that the racial wealth gap is an unfortunate legacy of a bygone era.”)

¹⁶ Michelle Stegman Bailey and Jeffrey Hemmeter. *Characteristics of Noninstitutionalized DI and SSI Program Participants, 2013 update*. Social Security Administration: Office of Retirement and Disability Policy. Research and Statistics Note No. 2015-02 (released September 2015). Available at: <https://www.ssa.gov/policy/docs/rsnotes/rsn2015-02.html>.

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ Patricia P. Martin and John L. Murphy. *African Americans: Description of Social Security and Supplemental Security Income Participation and Benefit Levels Using the American Community Survey*. Social Security Administration: Office of Retirement and Disability Policy. Research and Statistics Note No. 2014-01 (released January 2014). Available at: <https://www.ssa.gov/policy/docs/rsnotes/rsn2014-01.html>.



needed.²⁰ Despite programs like Medicaid and the Children's Health Insurance Program (CHIP), which exist to provide health insurance coverage for children in poverty until age 18 or 19, [around ten percent of children are uninsured](#).²¹ Hispanic children lack insurance coverage at the highest rate;²² despite expansions of health coverage under the Affordable Care Act, the prevalence of uninsurance for Hispanic children [rose between 2016 and 2018](#).²³

Access to resources and care for children who experience poverty is especially critical because the [experience of poverty itself is traumatic](#) and has negative physical and psychological health consequences.²⁴ This is compounded for children of color, who are also more likely to suffer Adverse Childhood Experiences (ACEs). ACEs are experiences of trauma that impose toxic stress on children, often leading to lifelong health consequences. Public health experts note that "Black children are [disproportionately represented among children with ACEs](#). Over 6 in 10 have ACEs, representing 17.4% of all children in the US with ACEs."²⁵ Additionally, experiencing racial oppression is, in and of itself, an experience of trauma. Directly experiencing and witnessing racism is associated with [prolonged exposure to stress hormones](#), which in turn predispose children of color to chronic disease.²⁶

[Racism, segregation, and inequality](#) contribute to disparately poor health outcomes in three main ways: (1) increased risk, (2) lower-quality care, (3) and persistent socioeconomic disadvantages.²⁷ Due to environmental racism, Black children and non-Black children of color are disproportionately to pollution and toxins.²⁸ For example, because of factors including average closer proximity to hazardous facilities and greater exposure to unsafe living conditions,

²⁰ Children's Health Fund, *Unfinished Business: More than 20 million children lack sufficient access to health care*, pg. 4, (Nov. 2016). Available at: <https://www.childrenshealthfund.org/wp-content/uploads/2016/11/Unfinished-Business-Final.pdf>.

²¹ Heeju Sohn, *Racial and Ethnic Disparities in Health Insurance Coverage: Dynamics of Gaining and Losing Coverage over the Life-Course*, Population Research and Policy Review, Vol. 36,2 (2017): 181-201. doi:10.1007/s11113-016-9416-y

²² *Id.* ("The prevalence of uninsurance is the highest among Hispanics at all ages.")

²³ Samantha Artiga, Kendal Orgera, and Anthony Damico. *Changes in Health Coverage by Race and Ethnicity since the ACA, 2010-2018*. Kaiser Family Foundation (March 2020).

²⁴ Clancy Blair, PhD, MPH and C. Cybele Raver, PhD. *Poverty, Stress, and Brain Development: New Directions for Prevention and Intervention*. US National Library of Medicine - National Institutes of Health (April 2016).

²⁵ Bethell, CD, Davis, MB, Gombojav, N, Stumbo, S, Powers, K. *Issue Brief: Adverse Childhood Experiences Among US Children, Child and Adolescent Health Measurement Initiative*, Johns Hopkins Bloomberg School of Public Health (October 2017). Available at: https://www.cahmi.org/wp-content/uploads/2018/05/aces_fact_sheet.pdf.

²⁶ Maria Trent, Danielle G. Dooley, Jacqueline Dougé. *The Impact of Racism on Child and Adolescent Health*. American Academy of Pediatrics (Aug 2019). Available at: <https://pediatrics.aappublications.org/content/144/2/e20191765>.

²⁷ Andrew F. Beck, et al, *The color of health: how racism, segregation, and inequality affect the health and well-being of preterm infants and their families* (July 29, 2019). Available at: <https://www.nature.com/articles/s41390-019-0513-6#rightslink>.

²⁸ Robert Bullard, *Dumping In Dixie: Race, Class, And Environmental Quality* (3d Ed. March 31, 2008) ("Environmental racism refers to any policy, practice, or directive that differentially affects or disadvantages (whether intended or unintended) individuals, groups, or communities based on race or color.").



“[m]ore than twice the number of black children had [elevated blood lead levels](#) as white children of the same age” as well as higher levels of mercury.²⁹ This exposure disproportionately leads to negative health outcomes, including disproportionate development of asthma.³⁰

SSA made rules stricter for proving disability based on asthma and sickle cell disease—two health issues disproportionately affecting children of color

The upshot of all these factors is another circular issue: poverty creates more health issues, but poverty makes it harder to get proof that those health issues exist; and without proof, children cannot access the benefits that could treat their health issues and help boost their families out of poverty. This hardship is further exacerbated by the high bar that SSA sets for certain health conditions that disparately impact Black children.

For example, SSA changed its threshold for asthma, a condition that disparately impacts Black children. Black children are four times more likely to be hospitalized for asthma and 10 times more likely to die of asthma than white children.³¹ Asthma attacks can cause permanent lung damage, and children with asthma are more prone to develop respiratory infections, which can in turn trigger and exacerbate asthma attacks.³² Children with asthma also experience serious disruption to their education and may miss three times more school as their peers—developing asthma may increase absenteeism by as much as 50% by early adulthood.³³

Managing asthma is a substantial burden for families. Financial costs include: “time lost from work, transport to surgeries and hospitals, babysitter costs for other children (while the asthmatic child is at the hospital or in surgery), and special purchases such as air cleaners, humidifiers, or special bedding.”³⁴ Families already struggling to make ends meet simply cannot afford these costly necessities, and they cannot risk missing work or, worse, losing their jobs. Low income families are more likely to face prolonged exposure to environmental toxins and pollution and they are more often stuck in substandard living conditions with exposure to mold and vermin, which trigger asthma.³⁵

Still, SSA has made it harder for children with asthma to receive crucial income to aid in management of the disease or to alleviate the financial strife facing these families. Under SSA’s

²⁹ Children’s Environmental Health Network, *Children and Health Disparities*, (Feb. 2018). Available at: https://cehn.org/wp-content/uploads/2019/09/EJ-Factsheet_2018_FINAL_revised.pdf.

³⁰ *Id.*

³¹ *Id.*

³² Jason M. Fletcher, Jeremy C. Green, Matthew J. Neidell, *Long term effects of childhood asthma on adult health*, *Journal of Health Economics* (March 19, 2010) via <https://scholar.princeton.edu/sites/default/files/jcgreen/files/1-s2.0-s0167629610000482-main.pdf>;

³³ Jason M. Fletcher, Jeremy C. Green, Matthew J. Neidell, *Long term effects of childhood asthma on adult health*, *Journal of Health Economics* (March 19, 2010) via <https://scholar.princeton.edu/sites/default/files/jcgreen/files/1-s2.0-s0167629610000482-main.pdf>; A. Nocon, *Social and emotional impact of childhood asthma*, *Archives of Disease in Childhood* (April 1991) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1792988/pdf/archdisch00651-0006.pdf>.

³⁴ Nocon, *supra* note 34.

³⁵ Children’s Environmental Health Network, *Children and Health Disparities*, (Feb. 2018). Available at: https://cehn.org/wp-content/uploads/2019/09/EJ-Factsheet_2018_FINAL_revised.pdf.



previous standard, a child could qualify for benefits if, in a year, they experienced asthma attacks requiring physician intervention every two months or at least six times in the year.³⁶ Under the new standard, promulgated in 2016, a child may qualify if, in a year, complications from asthma require three hospitalizations—these hospitalizations must last at least 48 hours, and must be at least 30 days apart from each other.³⁷ SSA implemented this drastic change despite receiving only 212 comments from the public,³⁸ only six of which directly addressed asthma,³⁹ and none making specific note of potential racial disparity considering the greater prevalence of asthma in children of color.⁴⁰

This disproportionate burden demonstrates what Black civil rights leaders have long criticized: structural violence in our country's healthcare systems.⁴¹ The impact of structural violence in healthcare—i.e. systemic racism that simultaneously increases risk factors for poor health and reducing access to adequate and affordable healthcare or unbiased treatment—most recently has been demonstrated by the disproportionate burden of COVID-19 on communities of color.⁴² Likewise, for decades, leaders in the movement for racially just healthcare have focused on Sickle Cell Disease.⁴³ Sickle cell disease stems from a genetic blood disorder that is prevalent in the U.S., largely in populations that trace back to regions with high rates of malaria, as well as

³⁶ See Revised Medical Criteria for Evaluating Respiratory System Disorders – Notice of Proposed Rulemaking via <https://beta.regulations.gov/document/SSA-2006-0149-0024>.

³⁷ Disability Evaluation Under Social Security, 103.00 Respiratory Disorders – Childhood, 103.03 Asthma via https://www.ssa.gov/disability/professionals/bluebook/103.00-Respiratory-Childhood.htm#103_03.

³⁸ Revised Medical Criteria for Evaluating Respiratory System Disorders via <https://beta.regulations.gov/document/SSA-2006-0149-0024>.

³⁹ Search results for comments including “asthma” on Revised Medical Criteria for Evaluating Respiratory System Disorders – Notice of Proposed Rulemaking via <https://beta.regulations.gov/document/SSA-2006-0149-0024/comment?filter=asthma&sortBy=postedDate>.

⁴⁰ See Tyra Bryant-Stephens, *Asthma disparities in urban environments*, Journal of Allergy and Clinical Immunology (June 1, 2009) via [https://www.jacionline.org/article/S0091-6749\(09\)00689-7/fulltext](https://www.jacionline.org/article/S0091-6749(09)00689-7/fulltext) (“Asthma continues to disproportionately affect minority and low-income groups, with African American and Latino children who live in low-socioeconomic-status urban environments experiencing higher asthma morbidity and mortality than white children. This uneven burden in asthma morbidity has been ever increasing despite medical advancement.”).

⁴¹ See Mary T. Bassett, *No Justice, No Health: The Black Panther Party's Fight for Health in Boston and Beyond*, Journal of African American Studies (November 15, 2019) via <https://link.springer.com/article/10.1007/s12111-019-09450-w>. “Structural violence is a phrase that reflects the ways in which society's structures, systems, and policies affect the well being of individuals and groups in a negative and unjust manner.” Nathan C. Bahr, John Song, *The Effect of Structural Violence on Patients with Sickle Cell Disease*, Journal of Health Care for the Poor and Underserved (August 2015) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6346732/>.

⁴² Leonard E. Egede & Rebekah J. Walker, *Structural Racism, Social Risk Factors, and Covid-19—A Dangerous Convergence for Black Americans*, New England Journal of Medicine (Sept. 17, 2020) (arguing that higher infection and mortality rates from Covid-19 in Black American communities are indicative of structural racism because, due to systemic inequities, Black Americans are more likely to be put at risk and less likely to be able to access care).

⁴³ See Momo Chang, *Sickle Cell: The Last Health Care Frontier for Black Lives*, Center for Health Journalism (Sept. 12, 2018) <https://centerforhealthjournalism.org/fellowships/projects/sickle-cell-last-health-care-frontier-black-lives>.



among groups that have a low socioeconomic status.⁴⁴ SCD can lead to neurological impairment, renal failure, bone disease, and severe, chronic pain.⁴⁵ Children with sickle cell disease are at greater risk from infections, experience delayed puberty, and can suffer sudden pain episodes that create both extreme discomfort and anticipatory anxiety.⁴⁶ Rapid enlargement of the spleen and circulatory collapse (acute splenic sequestration resulting from SCD) can cause life threatening major episodes.⁴⁷

Malaria and sickle cell are prominent in regions such as parts of Africa, Southeast Asia, the Middle East, and Greece.⁴⁸ Despite the various groups impacted by sickle cell, a misconception persists that this condition is a “black disease”.⁴⁹ To be clear, racial categories are a political concept and have no basis in biology. In other words, there is no genetic basis to assigned racial categories. As Dorothy Roberts explains in *Fatal Invention*, European landowners and colonists created racial categories in America during the colonial period to prevent solidarity among European laborers and African enslaved people—and to legitimize the capture, bondage, and perpetual enslavement people from Africa.⁵⁰ Racial distinctions later served during the Jim Crow era to bolster a caste system and to determine which groups were “deemed qualified for citizenship.”⁵¹ “Making race revolve around biology constructed it as an innate, permanent, and inescapable status,” Dr. Roberts writes.⁵² Yet, in medicine and science, race is often used as a crude proxy to assess differentiated health outcomes that are caused by other factors, such as a person’s genetics, the environment they live in, or the stress and other experiences they have endured. When it comes to genetics, “[a] person from the Congo, a

⁴⁴ *Id.* (“Sickle cell has its origins in countries that have malaria. The sickle cell gene mutation was a genetic adaptation that has helped people naturally fight malaria. Children who have the trait are more likely to survive malaria infection.”); Nathan C. Bahr, John Song, *The Effect of Structural Violence on Patients with Sickle Cell Disease*, *Journal of Health Care for the Poor and Underserved* (August 2015) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6346732/>.

⁴⁵ Nathan C. Bahr, John Song, *The Effect of Structural Violence on Patients with Sickle Cell Disease*, *Journal of Health Care for the Poor and Underserved* (August 2015) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6346732/>.

⁴⁶ *Home Care for Children with Sickle Cell Disease*, Stanford Children’s Health via <https://www.stanfordchildrens.org/en/topic/default?id=home-care-for-children-with-sickle-cell-disease-160-8>.

⁴⁷ Emily Riehm Meier and Jeffrey L. Miller, *Sickle Cell Disease in Children*, *Drugs* (Jan. 23, 2014) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3899685/>.

⁴⁸ Mohsen A. F. El-Hazmi, Ali M. Al-Hazmi, & Arjumand S. Warsy, *Sickle cell disease in Middle East Arab countries*, *Indian Journal of Medical Research* (Nov. 2011) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3249957/>.

⁴⁹ Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Recreate Race in the Twenty-First Century* (2011) [hereinafter Roberts, *Fatal Invention*] (noting that “[h]igh frequencies of the trait also occur in parts of Europe, Oceania, India, and the Middle East, all places where there is malaria,” and that it is inaccurate and incorrect to define SCD as being a “black genetic disease”); see also Dorothy Roberts, *What’s Race Got to Do with Medicine?*, WPSU (Feb. 10, 2017) via <https://radio.wpsu.org/post/whats-race-got-do-medicine> (“Race is not a biological category that naturally produces these health disparities because of genetic difference. Race is a social category that has staggering biological consequences but because of the impact of social inequality on people’s health.”).

⁵⁰ Roberts, *Fatal Invention*, supra note 48, at 8.

⁵¹ *Id.* at 16, 18-19.

⁵² *Id.* at 23.



person from South Africa, and a person from Ethiopia are more genetically different from each other than from a person from France.”⁵³ Yet, the Congolese, South African, and Ethiopian people may be considered Black, whereas the person from France may be considered white.⁵⁴

Although Sickle Cell is a genetic disease, many still mistakenly connect the condition as endemic to an entire racial category. Even the Center for Disease Control highlights the occurrence of SCD based on race: “SCD occurs among about 1 out of every 365 Black or African-American births. SCD occurs among about 1 out of every 16,300 Hispanic-American births.”⁵⁵ Civil rights leaders contend that because SCD is linked to oppressed groups, particularly to Black Americans, it is a “neglected disease”—a disease that is underfunded and under-researched.⁵⁶ Simply put, the deficit of resources devoted to SCD is inherently due to racism.⁵⁷ For example, after decades of advocacy for sickle cell awareness and establishment of free clinics with sickle cell screenings by the Black Panthers, the federal government allocated funding for ten comprehensive sickle cell centers across the country; by 2005, all ten centers lost funding and “the disease essentially was forgotten.”⁵⁸ Notably, in 2013, SSA targeted sickle cell disease when it proposed revised requirements to prove disability to obtain SSI for children. These changes went into effect in 2015 over the objections of medical professionals who believed the rules were unnecessarily demanding.⁵⁹

Prior SSA rules would grant SSI for children who (1) experienced documented painful thrombotic crises occurring at least three times during the five months prior to their SSI decision, or (2) experienced extended hospitalization beyond emergency care at least three times during the twelve months prior to their SSI decision.⁶⁰ SSA then raised the bar: children must now show (1) documented painful (vaso-occlusive) crises requiring narcotic medication occurring at least six times within a twelve month period with at least 30 days between crises, or (2) three hospitalizations within twelve months that are at least 48 hours long and 30 days apart.⁶¹

When SSA proposed the change, the American Society of Pediatric Hematology Oncology (ASPHO) wrote to alert SSA that the higher bars contradicted the expertise of medical providers

⁵³ *Id.* at 52.

⁵⁴ *Id.*

⁵⁵ CDC, *Data & Statistics on Sickle Cell Disease*, via [https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20affects%20approximately%20100%2C00%20Americans,sickle%20cell%20trait%20\(SCT\).](https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20affects%20approximately%20100%2C00%20Americans,sickle%20cell%20trait%20(SCT).)

⁵⁶ Nathan C. Bahr, John Song, *The Effect of Structural Violence on Patients with Sickle Cell Disease*, *Journal of Health Care for the Poor and Underserved* (August 2015) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6346732/>.

⁵⁷ *Id.*

⁵⁸ Momo Chang, *Sickle Cell: The Last Health Care Frontier for Black Lives*, *Center for Health Journalism* (Sept. 12, 2018) <https://centerforhealthjournalism.org/fellowships/projects/sickle-cell-last-health-care-frontier-black-lives>.

⁵⁹ See Revised Medical Criteria for Evaluating Hematological Disorders via <https://beta.regulations.gov/document/SSA-2010-0055-0035>.

⁶⁰ Obsolete listing for hematological disorders via <https://secure.ssa.gov/apps10/poms.nsf/lnx/0434127007>.

⁶¹ Hematological Disorders – Childhood via https://www.ssa.gov/disability/professionals/bluebook/107.00-HematologicalDisorders-Childhood.htm#107_08.



for hematological disorders in the pediatric population.⁶² For example, the requirement of six pain crises requiring narcotic intervention was significantly greater than the well-established understanding that “patients experiencing three or more crises in a year fall into the severe category.”⁶³ ASPHO criticized SSA’s crediting of only in-patient care, because “[t]he patient may receive a similar intensity of care as in an emergency department in an outpatient hematology/sickle cell clinic for several hours immediately before hospitalization.”⁶⁴ On the hospitalization requirement, ASPHO wrote that a threshold of three hospitalizations is an excessively high requirement, “since impairment can be severe in a child following a single hospitalization.”⁶⁵

Dr. Caitlin Neri of Boston Medical Center critiqued SSA’s decision to credit only those pain crises treated with narcotics, because “[w]hether a patient requires parenteral narcotics or not is not a primary indicator of the severity of a painful crisis. Patients with severe SCD will often experience painful episodes that may only require oral analgesia but still cause serious disruption to their lives for days or weeks at a time.”⁶⁶ Likewise, the American Society of Hematology (ASH) wrote to caution SSA that its new standards were overly burdensome and alert SSA that “[m]ore and more patients are being treated on an outpatient basis. This is due to both changes in the standard of care . . . as well as pressures from public and private insurers to reduce hospital admissions.”⁶⁷ Notably, even in severe cases, experts push for outpatient treatment, which benefits care providers because of substantial reductions in cost.⁶⁸ Thus, SSA’s higher bar puts crucial benefits out of reach, particularly because “[m]ost children with SCD do not have frequent hospitalizations for pain (on average <1 per year).”⁶⁹

Challenges in Accessing Care and Gathering Evidence to Prove Disability

Applications for SSI are often denied because the decision maker finds the evidence insufficient to prove serious disability. In addition to the barriers to treatment mentioned above, for Black children and non-Black children of color, insufficient records are often a symptom of systemic

⁶² See Comment from American Society of Pediatric Hematology Oncology via <https://beta.regulations.gov/comment/SSA-2010-0055-0029>.

⁶³ *Id.*

⁶⁴ *Id.*

⁶⁵ *Id.*

⁶⁶ Comment from Boston Medical Center via <https://beta.regulations.gov/comment/SSA-2010-0055-0027>.

⁶⁷ See Comment from American Society of Hematology via <https://beta.regulations.gov/comment/SSA-2010-0055-0033>. The Comment from ASH primarily critiqued the overly stringent requirements for adults, which failed to account for the impact of chronic pain on ability to work. *Id.*

⁶⁸ See Judith A. Williams et. al, *A Randomized Study of Outpatient Treatment with Ceftriaxone for Selected Febrile Children with Sickle Cell Disease*, N. Engl. J. Med. (1993) via <https://www.nejm.org/doi/full/10.1056/NEJM199308123290705>.

⁶⁹ Charles T. Quinn, *Sickle Cell Disease in Childhood: From Newborn Screening Through Transition to Adult Medical Care*, Pediatric Clin. North. Am. (Dec. 2013) via <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4262831/pdf/nihms646297.pdf>.



issues like [underdiagnosis](#)⁷⁰ and [overcriminalization](#).⁷¹ While [Black and Latinx children are more likely to have food allergies](#),⁷² they are also less likely to be diagnosed.⁷³ Without proper diagnosis, these children are [not getting access to medical care](#), so the medical records they are able to provide cannot paint a complete picture of actual lived experiences.⁷⁴ Likewise, a Black child with autism may not be able to provide extensive evidence because Black children are [more likely to be misdiagnosed](#).⁷⁵ Black and Latinx children are more likely to be diagnosed at an older age and thus have [“less of an opportunity for proper intervention,”](#)⁷⁶ and in some areas are [less likely to be provided state-funded therapy](#).⁷⁷

Although schools are obligated to identify children with disabilities and refer them for testing and services,⁷⁸ “the limited data available on school system referrals have suggested that ethnic minority children with psychiatric disorders are often under-identified for mental health services.”⁷⁹ When behavioral issues are observed in school settings, Black children are [more likely to be punished](#) and face harsher discipline, compared to their white peers, who are punished less frequently and referred to behavioral health evaluations more frequently.⁸⁰ Even when a Black or Latinx child with autism obtains a diagnosis and can access treatment, the provider may [devote less money and fewer resources to that child](#) compared to their white

⁷⁰ Nora Gordon. *Race, poverty, and interpreting overrepresentation in special education*. Brookings (Sept 2017). Available at: <https://www.brookings.edu/research/race-poverty-and-interpreting-overrepresentation-in-special-education/>.

⁷¹ Joshua Rovner. *Racial Disparities in Youth Commitments and Arrests*. The Sentencing Project (April 2016). Available at: <https://www.sentencingproject.org/publications/racial-disparities-in-youth-commitments-and-arrests/>.

⁷² Ruchi S Gupta, et al. “The Public Health Impact of Parent-Reported Childhood Food Allergies in the United States.” *Pediatrics* vol. 142,6 (2018): e20181235. doi:10.1542/peds.2018-1235

⁷³ Perri Klass, M.D. *The Impact of Disparities on Children’s Health*. The New York Times. (June 2020). Available at: <https://www.nytimes.com/2020/06/15/well/family/the-impact-of-disparities-on-childrens-health.html>.

⁷⁴ *Id.*

⁷⁵ David S Mandell, et al. *Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder*. Journal of Autism and Developmental Disorders, Vol. 37,9 (2007): 1795-802. doi:10.1007/s10803-006-0314-8. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2861330/>.

⁷⁶ Casey Rentz. *Black And Latino Children Are Often Overlooked When It Comes To Autism*. NPR Why (March 2018). Available at: <https://www.npr.org/sections/health-shots/2018/03/19/587249339/black-and-latino-children-are-often-overlooked-when-it-comes-to-autism>.

⁷⁷ Sandy Magaña, Molly Stapleton, Alex Garcia. *Racial and Ethnic Disparities in Intensive Autism Services in the State of Wisconsin*. Robert M. La Follette School of Public Affairs at the University of Wisconsin-Madison (2006). Available at: <https://minds.wisconsin.edu/bitstream/handle/1793/38292/magana2009-027.pdf?sequence=1&isAllowed=y>.

⁷⁸ See generally 20 U.S.C. § 1400.

⁷⁹ Margarita Algeria et al., *Role of Referrals in Mental Health Service Disparities for Racial and Ethnic Minority Youth*, J Am Acad Child Adolesc Psychiatry (July 2013). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3652396/>.

⁸⁰ Travis Riddle and Stacey Sinclair, *Racial disparities in school-based disciplinary actions are associated with county-level rates of racial bias*, PNAS (Apr. 2019). Available at: <https://www.pnas.org/content/116/17/8255>.



counterparts.⁸¹ As a result, their SSI applications have limited proof of marked or extreme limitations in functioning.

Barriers to SSI Access from Disproportionate System Involvement

Black, Latinx, and Native American children are overly funneled into the child welfare and juvenile justice systems despite similar levels of committing crimes compared to white peers⁸² and instances of abuse or neglect among families.⁸³ Youth involved in the juvenile justice or child welfare system are often placed in institutions or settings that fail to screen for disability,⁸⁴ and provide inadequate services,⁸⁵ and thus limit the type of information available to prove eligibility for SSI benefits.

Disciplinary schools and juvenile placements [provide subpar educational services](#) and fail to provide adequate accommodations for youth who require special education.⁸⁶ In addition, many facilities [do not screen all youth for mental health and substance use issues or provide adequate services](#) for those with mental health and substance abuse needs.⁸⁷ [Girls in particular experience](#) higher rates of mental health and substance use disorders, and are less likely to have their medical needs identified or treated.⁸⁸ As many youth in the child welfare system experience high levels of transience and instability, they [often do not receive consistent access to education, healthcare and mental health resources](#).⁸⁹ Lack of information sharing between education systems, child welfare and juvenile justice systems further prevent youth from accessing medical treatment, quality education, or even their own records.

⁸¹ Lucile Packard Foundation for Children's Health and Public Counsel. *Assuring Equitable Funding of Services for Children with Developmental Disabilities*. (May 2017). Available at: https://issuu.com/publiccounsel/docs/assuring_equitable_funding_of_servi.

⁸² Joshua Rovner. *Racial Disparities in Youth Commitments and Arrests*. The Sentencing Project (April 2016).

⁸³ Casey Family Programs. *Disproportionality in the Child Welfare System: The Disproportionate Representation of Children of Color in Foster Care*. (June 2006). Available at: <https://www.ncsl.org/print/cyf/fostercarecolor.pdf>.

⁸⁴ Alexandra A. Miller, *Navigating Barriers to Special Education in a Juvenile Detention Center*, Journal of Correctional Education (Aug. 2019). Available at: <https://www.jstor.org/stable/26864180>.

⁸⁵ *Id.* (noting that "less than half (46%) of youth who qualify for disability services in secure custody actually receive them").

⁸⁶ Juvenile Law Center. *Broken Bridges: How Juvenile Placements Cut Off Youth From Communities and Successful Futures*, pgs. 19-21, (Dec 2018). Available at: <https://jlc.org/resources/broken-bridges-how-juvenile-placements-cut-youth-communities-and-successful-futures>.

⁸⁷ David Gottesman and Susan Wile Schwarz. *Juvenile Justice in the U.S.: Facts for Policymakers*. National Center for Children in Poverty (July 2011). Available at: http://www.nccp.org/publications/pub_1038.html.

⁸⁸ Leslie Acoca, Jessica Stephens, and Amanda Van Vleet. *Health Coverage and Care for Youth in the Juvenile Justice System: The Role of Medicaid and CHIP*. The Kaiser Commission on Medicaid and the Uninsured. Issue Brief (May 2014). Available at: <https://www.kff.org/wp-content/uploads/2014/05/8591-health-coverage-and-care-for-youth-in-the-juvenile-justice-system.pdf>.

⁸⁹ American Academy of Pediatrics (Policy Statement). *Health Care Issues for Children and Adolescents in Foster Care and Kinship Care*. Council on Foster Care, Adoption, and Kinship Care, Committee on Adolescence, and Council on Early Childhood. Pediatrics Oct 2015, 136 (4) e1131-e1140; DOI: 10.1542/peds.2015-2655. Available at: <https://pediatrics.aappublications.org/content/136/4/e1131>.



Barriers to SSI Eligibility in the Education System

In order to qualify for SSI, SSA requires applicants to provide official documentation of disabilities. School records and appropriate educational personnel are [important sources of evidence](#) documenting how a school-age child is functioning because children spend so much time in school.⁹⁰ When youth apply for SSI, [SSA asks schools to provide the following](#): copies of a child's school records, including records of academic performance, psychological evaluation, attendance and behavior; standardized and other specialized testing; school-based therapeutic interventions (e.g., speech and language therapy) and the use of other special services, including placement in special education classes or other specially adapted settings; individualized education programs (IEP); and other periodic assessments of the child; e.g., comprehensive triennial assessments.⁹¹

Poor quality of education for special education students typically [starts in elementary school](#), beginning with a student not receiving the services to which they are entitled or not being properly diagnosed.⁹² Substantial research shows that racial and ethnic minority students are [less likely to be identified](#) as eligible for special education than white students.⁹³ Underdiagnosis causes racially disparate access to special education services, which in turn reduces the amount and type of evidence of the child's disability in a school setting. If there is no official documentation of the physical, emotional, and intellectual challenges a child faces at school, proving a disability claim is significantly more challenging.

Race-based allocation of public school funding exacerbates the problem. Public schools are systematically underfunded along lines of race. For example, in Pennsylvania, [for every 10 percent increase in the white portion of the population, a district gets \\$447 more per student](#) on average.⁹⁴ Race and class intersect to pose particular challenges in accessing special education services for low income, Black youth.

Additionally, across the country, schools suspend students of color at [disproportionately higher rates](#) than they suspend white students, leading to stigma, more time out of the classroom, and

⁹⁰ Social Security Administration. *Childhood Disability: Supplemental Security Income Program*. Medical/Professional Relations. Available at: <https://www.ssa.gov/disability/professionals/childhoodssi-pub049.htm>.

⁹¹ *Id.*

⁹² Sarah Butrymowicz and Jackie Mader. *Low academic expectations and poor support for special education students are 'hurting their future.'* The Hechinger Report (Nov 2017). Available at: <https://hechingerreport.org/low-academic-expectations-poor-support-special-education-students-hurting-future/>.

⁹³ Nora Gordon. *Race, poverty, and interpreting overrepresentation in special education*. Brookings (Sept 2017).

⁹⁴ Evan Brandt. *Studies Show Racial Bias in Pennsylvania School Funding*. The Times Herald (April 2017). Available at: https://www.timesherald.com/news/studies-show-racial-bias-in-pennsylvania-school-funding/article_903428ec-c472-5886-b3d6-621f21b3edfe.html.



less opportunity for academic improvement.⁹⁵ Discipline, instead of treatment, services, or accommodations, leads to misdiagnosis or erasure of a student's disability. If a student is repeatedly disciplined because the child's disability needs are not being met, then the education records only show discipline, not disability. When schools fail to evaluate or serve students with disabilities, [they not only violate their civil rights and impede their ability to learn](#),⁹⁶ but they also jeopardize the child's ability to obtain critical SSI benefits because there is no documentation of the child's disability. Systemic racial inequities in education and racial stereotypes disproportionately affect Black children through misdiagnosis and/or failure to identify special needs. It logically follows, then, that inaccurate education records also disproportionately affect Black children's ability to succeed on SSI claims.

Challenges in Maintaining Benefits

Even if a child with disabilities has overcome the systemic hurdles needed to establish eligibility, children of color face additional barriers to *remain* eligible for benefits.

Children of color with disabilities who may qualify for SSI benefits are [disproportionately represented](#) in the juvenile justice and child welfare systems.⁹⁷ Children in those systems are often [ineligible for SSI](#).⁹⁸ Social Security benefits are suspended if an otherwise eligible person is [confined in a jail, prison, or other penal institution for more than 30 continuous days](#).⁹⁹ If a child is incarcerated for more than 12 months, their SSI benefits will be terminated and they will have to reapply upon re-entry.¹⁰⁰ Additionally, most children in foster care are [not eligible for SSI payments](#), even if they meet the disability criteria, because their federal foster care payments often exceed the income limit for SSI eligibility.¹⁰¹ The disproportionate presence of

⁹⁵ Carrie Spector. *Racial disparities in school discipline are linked to the achievement gap between black and white students nationwide, according to Stanford-led study*. Stanford Graduate School of Education (Oct 2019). Available at: <https://ed.stanford.edu/news/racial-disparities-school-discipline-are-linked-achievement-gap-between-black-and-white>.

⁹⁶ Individuals with Disabilities Education Act of 1975, 20 U.S.C. §§ 1400–1409.

⁹⁷ Literature Review: A Product of the Model Programs Guide. *Youths with Intellectual and Developmental Disabilities in the Juvenile Justice System* (May 2017). Available at: <https://www.ojjdp.gov/mpg/litreviews/Intellectual-Developmental-Disabilities.pdf>

⁹⁸ Social Security Administration, *Understanding Supplemental Security Income—2020 Ed*, at 14, 108. <https://www.ssa.gov/pubs/EN-17-008.pdf>; see also Laura King and Aneer Rukh-Kamaa. *Youth Transitioning out of Foster Care: An Evaluation of a Supplemental Security Income Policy Change*. Social Security Administration Office of Retirement and Disability Policy. Social Security Bulletin, Vol. 73, No. 3 (2013).

⁹⁹ Social Security Administration, *Benefits after Incarceration: What You Need To Know*. Available at: <https://www.ssa.gov/reentry/benefits.htm>. See also Social Security Administration. *What Prisoners Need to Know*. <https://www.ssa.gov/pubs/EN-05-10133.pdf>.

¹⁰⁰ 20 CFR § 416.1335.

¹⁰¹ Social Security Administration. *Spotlight on SSI Benefits for Disabled or Blind Youth in Foster Care*. Links to SSI Spotlights Home (2020 Edition). Available at: <https://www.ssa.gov/ssi/spotlights/spot-disabled-youth.htm>. See also Laura King and Aneer Rukh-Kamaa. *Youth Transitioning out of Foster Care: An Evaluation of a Supplemental Security Income Policy Change*. Social Security Administration. Social Security Bulletin: Vol. 73, No. 3 (2013).



Black, Native American, and Latinx youth with disabilities in the criminal justice and child welfare systems creates systematic racial disparities in ability to access and maintain SSI benefits.

Youth transitioning out of the child welfare and juvenile systems are more likely to experience youth homelessness.¹⁰² Many homeless children especially face difficulties receiving education and medical care.¹⁰³ Youth in and transitioning out of foster care or placement are often unable to access and provide necessary documents to establish a disability; and as a result, many youth with disabilities struggle to receive the resources they need.

Children confined in facilities away from home disproportionately [experience trauma, and are often subjected to isolation, physical restraints](#).¹⁰⁴ Youth who have been in foster care have a [greater likelihood of having mental and physical health problems](#), including ADD/ADHD, asthma, depression, anxiety, and behavioral or conduct problems.¹⁰⁵ Poverty, along with Black and Brown youth's disproportionate contact with the juvenile justice and foster care systems, prevent youth of color from receiving critical financial support through SSI.

Conclusion and Recommendations

Systemic inequities in the systems upon which SSI applicants must rely to prove their eligibility result in compounding and circular challenges: affected families face more barriers to access treatment and gather evidence, affected children face more obstacles that may later disqualify them from receiving benefits after they have qualified, and those most marginalized are most in need of benefits. While the Social Security Administration alone cannot rectify systemic issues in all sectors of education, healthcare access, and juvenile justice, SSA can take steps to improve its own processes, raise awareness about the racial disparities that influence their eligibility determinations, and build coalitions to improve outcomes for children with disabilities.

Community Legal Services of Philadelphia urges SSA to consider the following recommendations:

- SSA must start reporting information on race and ethnicity, addressing the GAO recommendations, and improving policies that limit access to benefits for youth of color.
- SSA must address the GAO recommendations to improve its decision-making practices and [“more readily identify patterns of misconduct, including racial bias”](#) in its decision-makers by collecting and releasing data on race and ethnicity within its programs.

¹⁰² Coalition for Juvenile Justice, *Youth Homelessness and Juvenile Justice: Opportunities for Collaboration and Impact*, Vol. 1, Issue 1 (June 2016). Available at: https://www.juvjustice.org/sites/default/files/resource-files/policy%20brief_FINAL.compressed.pdf; Youth.Gov, *Child Welfare*. Available at: <https://youth.gov/youth-topics/runaway-and-homeless-youth/child-welfare-system>.

¹⁰³ *Id.*

¹⁰⁴ Wendy Sawyer. Youth Confinement: The Whole Pie 2019. *Prison Policy Initiative*. Reports (Dec 2019). Available at: <https://www.prisonpolicy.org/reports/youth2019.html>.

¹⁰⁵ Kristin Turney and Christopher Wildeman. *Mental and Physical Health of Children in Foster Care*. Journal of the American Academy of Pediatrics. Vol. 138, Issue 5 (Nov 2016). Available at: <https://pediatrics.aappublications.org/content/pediatrics/138/5/e20161118.full.pdf>



- SSA adjudicators must be trained on systemic inequities to inform holistic review of evidence in light of marginalized clients' barriers to care to accumulate evidence.
- SSA must eliminate suspension or termination of SSI for custodial juvenile justice placements.
- SSA must provide youth leaving institutional settings who previously received benefits with default eligibility and emergency funds for at least six months, so that the young people have time and resources to build a record with the evidence needed to continue benefits.
- SSA must amend its regulations for proving severe disability relating to asthma and sickle cell to eliminate unreasonable burdens which disproportionately affect Black children.
- SSA must solicit comments specifically addressing racial disparities when proposing rule changes.
- SSA adjudicators must facilitate development of an accurate record by being lenient with deadlines to submit records and sending applicants to comprehensive evaluations when an applicant is affected by disparate access to care.
- SSA must implement a national outreach program to find and enroll all SSI eligible children.
- SSA must make a long- term commitment to improving outreach and increasing enrollment for children in SSI to implement the law that makes clear that SSA "shall...conduct an ongoing program of outreach to children who are potentially eligible for benefits under this subchapter by reason of disability or blindness." 42 U.S.C. § 1383d(a). SSA should study how to target outreach most effectively and evaluate its outreach efforts for efficiency and effectiveness.
- SSA should create an Office of Equitable Outcomes for the childhood disability program.

