



Substance Abuse and Mental Health  
Services Administration

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September 23, 2024

Dear Colleague:

The Substance Abuse and Mental Health Services Administration (SAMHSA) would like to highlight to our partners and medical providers the significant behavioral health components of sickle cell disease (SCD). SCD is an inherited group of red blood cell (RBC) disorders that causes abnormal hemoglobin, the protein in RBCs that carry oxygen from the lungs to organs and tissues before returning carbon dioxide to the lungs. Abnormal hemoglobin caused by SCD can result in the blocking of small blood vessels. This reduces blood flow and can damage tissue in all major organ systems, causing severe pain. It is estimated that sickle cell disease affects approximately 100,000 people in the United States and three million worldwide. Black individuals are disproportionately affected by SCD with one in twelve carrying a sickle cell gene. All infants in the United States are screened at birth and the average life expectancy worldwide is 40 to 60 years<sup>1</sup>.

SAMHSA is aware of, and concerned about, the chronic behavioral health conditions that can arise from sickle cell disease. Behavioral health conditions that arise from the disease include chronic pain syndrome, depression, anxiety, sleep disorders, and fatigue. Additionally, the reliance on opioids to treat sickle cell crises can result in the development of substance use disorders. The fear and uncertainty of a sickle cell crisis causes anxiety and depression, especially in children. Its impact on families and caregivers is significant and a life-long component of the disease. Unfortunately, as busy emergency rooms are often the first healthcare system touchpoint for individuals with SCD, one can potentially encounter barriers to person-centered holistic care due to lack of resources, training, and staff. At doctor's offices, patients may face accusations that they are "drug-seeking" and have difficulty filling prescriptions for adequate pain relief.

SAMHSA joins our federal partners in raising awareness of the behavioral health impact of SCD. Among SAMHSA's resources are the 988 Suicide and Crisis Lifeline, <https://988lifeline.org/>, available 24 hours a day for individuals experiencing urgent mental health or substance use disorder symptoms. Moreover, Screening, Brief Intervention, and Referral to Treatment (SBIRT), is a rapid and reimbursable intervention to effectively screen and refer patients who may have substance use disorders. SAMHSA also offers assistance through

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<sup>1</sup> The Opioid Crisis and the Black/African American Population: An Urgent Issue | SAMHSA Publications and Digital Products. Samhsa.gov. Published April 2020. <https://store.samhsa.gov/product/opioid-crisis-and-blackafrican-american-population-urgent-issue/pep20-05-02-001>

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the Technology Transfer Centers, <https://www.samhsa.gov/technology-transfer-centers-ttc>, which can help strengthen the healthcare workforce through training in prevention and management of behavioral health conditions. SAMHSA is joining the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Health to coordinate federal SCD initiatives to increase life expectancy and access to care and new therapies, as well as improve quality of life and well-being. Additionally, the Biden-Harris Administration's [press release](#) on January 30<sup>th</sup> of this year announced action to increase access to SCD treatments. SAMHSA thanks you for your partnership to increase awareness and strengthen programs that address the significant behavioral health issues related to SCD.

Sincerely,

/Miriam E. Delphin-Rittmon/

Miriam E. Delphin-Rittmon, PhD.

Assistant Secretary for Mental Health and Substance Use