

Insights

Recent Legislation that Supports Better Children's Health Outcomes

In recent months, there has been a surge of legislative actions for children's health advocates. New laws have been passed that provide funding for programs and research initiatives essential for improving the health and well-being of children and families across the country. Here, NICHQ provides an update on the legislation, as well as a brief analysis of the impact on children's health.

We share this update to help our readers stay informed about policies that influence children's health improvement work, and to find inspiration in the stories about the impact these policies will have—stories about the state programs, communities and families we're working with to drive change in children's health outcomes.

Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2018

More than [1,000 babies are born every year](#) in the U.S. with sickle cell disease (SCD), a blood disorder that can result in severe pain episodes, stroke, and life threatening health complications. Although outcomes have improved, children are still dying from this disease, and affected adults often struggle to access quality care. Many families live hundreds of miles from a treatment center or a provider specializing in SCD care; and many providers may not have the most up-to-date training on quality treatment. SCD primarily affects Black and African-American adults and children, which means improving care can help address significant health disparities.

In 2004, congress funded the Sickle Cell Disease Treatment Demonstration Program (SCDTDP), which sought to improve SCD care and outcomes for families across the country. Now, the **Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act of 2018** has:

- Provided funding for research and public health initiatives;
- Authorized a national SCD surveillance program with the goal of improving data collection on patients in states with a higher prevalence of the disease; and
- Reauthorized the SCDTDP with funding from 2019-2023.

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Along with 50 other organizations, NICHQ signed onto a letter initiated by the American Society of Hematology to Congress urging the swift passage of this important legislation. Reauthorizing the SCDTDP is an important step in ensuring that all patients with SCD, regardless of where they live, have access to high quality care. Building on the successes of the most recent iteration—which led to a nearly [30-percent increase in patients receiving care](#)—this latest program seeks to improve coordination and service delivery for individuals living with SCD, enhance access to services, and improve and expand patient and provider education.

Learn more about NICHQ's most [recent work](#) to improve sickle cell disease or read [this story](#) about the families this work affects.

Preventing Maternal Deaths Act

Maternal mortality rates in the U.S. have [drastically increased](#) in recent years, and are now the [highest in the developed world](#). These deaths are accompanied by significant racial disparities, with Black, non-Hispanic mothers dying at more [than three times the rate](#) of white mothers.

The **Preventing Maternal Deaths Act** responds to the urgent need to change these numbers. [Over 60 percent](#) of these deaths are preventable, which means increasing safer deliveries can save the lives of hundreds of women in the U.S. The law establishes a program to help states and tribal nations across the country review maternal deaths and causes, and develop a plan for improvement. Specifically, the federal program provides funding for new and existing maternal mortality review committees (MMRCs) that will annually identify pregnancy-associated deaths and pregnancy-related deaths, regardless of the outcome of the pregnancy. As [stated in the bill](#), the MMRCs will be charged to:

- Review data and information to identify adverse outcomes that may contribute to maternal deaths;
- Identify trends, patterns, and disparities in adverse outcomes;
- Make recommendations for improvement based off the identified findings.

In trying to understand the factors influencing maternal mortality, all MMRCs will collect information by examining maternal death cases and identifying ways to prevent future deaths. With this information, policymakers and improvement organizations will be better able to direct policies and programs toward addressing structural factors contributing to maternal mortality disparities.

Read a story about efforts to take on one of the leading causes of maternal death, [here](#).

SUPPORT for Patients and Communities Act

Opioids are [the main cause](#) of overdose deaths in the U.S., which rose 10 percent between 2016 and 2017 alone. In the wake of rising opioid misuse and death rates, foster care placements [have increased](#), opioid-related neonatal abstinence syndrome [has skyrocketed](#), and cycles of poverty and abuse have become all too common for American families.

The **Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act**, or SUPPORT for Patients and Communities Act, is a federal effort to combat the opioid crisis facing our country. Changes to Medicaid, Medicare, Children's Health Insurance Program (CHIP), and other health programs were included in this legislation to expand access to treatment and strengthen prevention and recovery. The new law also includes a targeted focus on the health and well-being of children and families.

Specifically, the law creates a demonstration program to expand substance use disorder treatment, and specifies treatment for infants born with neonatal abstinence disorder, pregnant and postpartum women, and adolescents. To increase access, the bill:

- Provides clarification around Medicaid payment for services provided to infants suffering from neonatal abstinence syndrome in residential pediatric recovery facilities, including parent counseling;
- Requires reporting on gaps in coverage for pregnant women and postpartum women with substance abuse disorder under the Medicaid program; and
- Expands mental health services coverage under all state CHIPs. It is important to note that these services are also applicable to pregnant women.

For more comprehensive information on the Act and how it will affect the health of children and families, review [this summary](#) from the National Advocacy for State Health Policy (NASHP).

Read a story about the opioid epidemic as a children's health crisis, [here](#).