



May 20, 2024

Cecile Erwin Young, Executive Commissioner
Texas Health and Human Services Commission
P.O. Box 13247
Austin, TX 78711-3247

Dear Commissioner Young,

On behalf of the approximately 2,300 Texans living with cystic fibrosis (CF), we write to urge the Texas Health and Human Services Commission (HHSC) to request full funding for Medicaid and the Children with Special Health Care Needs Program (CSHCN) in the FY 2026-2027 legislative appropriations request (LAR). Particularly given that the state is projected to have a budget surplus, funding for crucial Medicaid and CSHCN services for Texans with CF to stay healthy should be a priority.

About Cystic Fibrosis & the CF Foundation

Cystic fibrosis is a progressive, genetic disease that affects the lungs, pancreas, and other organs. There are close to 40,000 children and adults living with cystic fibrosis in the United States and CF can affect people of every racial and ethnic group. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. For those with CF, health care coverage is a necessity, and interruptions in coverage can lead to lapses in care, irreversible lung damage, and costly hospitalizations—compromising the health and well-being of those with the disease.

As the world's leader in the search for a cure for CF and an organization dedicated to ensuring access to high-quality, specialized CF care, the Cystic Fibrosis Foundation supports the development of CF clinical practice guidelines and accredits more than 130 care centers nationally—including 18 programs in Texas. As experts in CF care, the CF Foundation and our care centers understand the need for access to adequate, affordable health coverage, including through programs like Medicaid and CSHCN.

Children with Special Health Care Needs

As you begin negotiations for the 2026-2027 budget, we urge you to request full funding for the Children with Special Health Care Needs Program, which helps people with CF afford their care. For CSHCN enrollees with CF, the program is a crucial source of coverage—often filling gaps left by other plans or covering those without another source of insurance. By ensuring access to life-saving services, CSHCN helps people with CF maintain their health and well-being.

People with CF face a high-cost burden due to the intensive nature of their care and without adequate coverage, they are more likely to go without needed treatments. According to a survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care in 2019—including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns.ⁱ Because CF is a progressive disease, patients who delay or forgo treatment face an increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations. CSHCN serves a critical role in ensuring people with CF can afford the care and treatments they need.

Medicaid

Medicaid is also a crucial source of coverage for patients with serious and chronic health care needs, including CF, and we urge you to reject any proposed reductions to eligibility or benefits. Nearly half of children and approximately one in six adults living with CF in Texas depend on the program for some or all of their health care needs. For many with CF, Medicaid fills coverage gaps in private insurance that leave patients with unsustainable out-of-pocket costs. We hope that Texas is able to maintain Medicaid benefits and eligibility for those who rely on the program.

The CF Foundation urges HHSC to request full funding for Medicaid and CSHCN in the FY 2026-2027 budget to ensure that Texans living with CF have access to the critical health care they need. If you have any questions about cystic fibrosis or would like to discuss the importance of Medicaid and CSHCN to the CF community, please contact Amanda Attiya at aattiya@cff.org. Thank you for your attention to this important issue.

Sincerely,



Mary B. Dwight

Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation

ⁱ Seyoum, Semret; Regenstein, Marsha; and Nolan, Lea, "Cost, coverage, and the underuse of medications among people with CF" (2020). Health Policy and Management Issue Briefs. Paper 57. https://hsr.himmelfarb.gwu.edu/sphhs_policy_briefs/57