



November 16, 2023

Judy Mohr Peterson, Ph.D.
Medicaid Director, Med-QUEST Division Administrator
Med-QUEST Division, Attn: PPDO
P.O. Box 700190
Kapolei, HI 96709

Dear Director Peterson:

The Cystic Fibrosis Foundation appreciates the opportunity to submit comments on Hawaii's QUEST Integration 1115 Demonstration Extension. On behalf of people with cystic fibrosis (CF) living in Hawaii, we commend the state for prioritizing its Medicaid population. The CF Foundation is committed to ensuring that Hawaii's Medicaid program provides quality and affordable healthcare coverage. This demonstration is consistent with Hawaii's efforts to support healthy families and improve equitable access to care, and our organization supports the inclusion of continuous eligibility for children.

About Cystic Fibrosis and the Cystic Fibrosis Foundation

Cystic fibrosis is a rare genetic disease that affects close to 40,000 children and adults in the United States. 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 accredits more than 130 care centers nationally, including 1 in Hawaii, that provide multidisciplinary, specialized care in accordance with clinical practice guidelines. 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.

Continuous Eligibility for Children

The CF Foundation supports the proposal to provide multi-year continuous coverage for children under 6, as well as two-year continuous eligibility for older children. Continuous eligibility protects patients and families from gaps in care and promotes health equity.¹ Research has shown that individuals with disruptions in coverage during a year are more likely to delay care, receive less preventive care, refill prescriptions less often, and have more emergency department visits.² Gaps in Medicaid coverage have also been shown to increase hospitalizations and negative health outcomes for ambulatory care-sensitive conditions like respiratory diseases and heart disease.³ Additionally, continuous coverage can

¹ Chomilo, Nathan. Building Racial Equity into the Walls of Minnesota Medicaid. Minnesota Department of Human Services. February 2022. Available at: <https://edocs.dhs.state.mn.us/lfsrver/Public/DHS-8209A-ENG>

² Sugar S, Peters C, De Lew N, Sommers BD. Medicaid Churning and Continuity of Care: Evidence and Policy Considerations Before and After the Covid-19 Pandemic. Assistant Secretary for Planning and Evaluation, Office of Healthy Policy. April 12, 2021. Available at: <https://aspe.hhs.gov/sites/default/files/private/pdf/265366/medicaid-churning-ib.pdf>

³ "Effects of Churn on Potentially Preventable Hospital Use." Medicaid and CHIP Payment Access Commission, July 2022. Available at: https://www.macpac.gov/wp-content/uploads/2022/07/Effects-of-churn-on-hospital-use_issue-brief.pdf

help avoid higher healthcare costs resulting in delayed care. These policy proposals are designed to minimize “churn,” which elevates the risks of uninsurance and the loss of regular health care.⁴

Consistent care and access to specialized therapies are necessary for people with cystic fibrosis, and any loss or gap in coverage—even for as little as one month—may put people with CF at risk of declining health by forcing them to forgo daily therapies due to cost. For example, 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—including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns.⁵ 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.

Hawaii estimates that a quarter of all children in Hawaii experience gaps in coverage each year. Furthermore, studies show that children of color are more likely to be affected by gaps in coverage that continuous eligibility would address, rendering it crucial for increasing equitable access to care.⁶ Overall, multi-year continuous eligibility would improve access to and continuity of care for children during the critical early years of life⁷ while promoting health equity. The COVID-19 continuous coverage requirements have highlighted how important continuous eligibility is for maintaining access to care, and the Cystic Fibrosis Foundation supports Hawaii’s plans to implement these policies as soon as system infrastructure allows.

Thank you for the opportunity to provide comments on Hawaii’s QUEST Integration 1115 Demonstration Extension. If you have any questions about cystic fibrosis or need additional information on the program's value for our community, please contact Amanda Attiya, State Policy Specialist 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

⁴ Alker, Joan, et al. “The Biden Administration Should Approve Oregon’s Request To Cover Children Until Their Sixth Birthday.” Health Affairs Forefront. www.healthaffairs.org, <https://doi.org/10.1377/forefront.20220711.14370>. Accessed 8 Sept. 2022.

⁵ https://hsr.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs

⁶ Osorio, Aubrianna. Alker, Joan, “Gaps in Coverage: A Look at Child Health Insurance Trends”, Center for Children & Families (CCF) of the Georgetown University Health Policy Institute, November 21, 2021. Available at:

<https://ccf.georgetown.edu/2021/11/22/gaps-in-coverage-a-look-at-child-health-insurance-trends/>

⁷ Burak, Elisabeth Wright. “Promoting Young Children’s Healthy Development in Medicaid and the Children’s Health Insurance Program (CHIP).” Center for Children and Families, Georgetown University Health Policy Institute. October 2018. Available at: <https://ccf.georgetown.edu/wp-content/uploads/2018/10/Promoting-Healthy-Development-v5-1.pdf>