POLICY PRIORITY:

Support and defend access to robust, stable coverage and high-quality care in the Medicaid program.

Medicaid provides essential access to treatment and care for many people with bleeding disorders.

BACKGROUND:

Medicaid is a public health insurance program for low-income individuals, families, seniors, and people with disabilities. States set up and run their own Medicaid programs, subject to federal guidelines and requirements; the federal government matches a specified percentage of the state's spending. Under the Affordable Care Act, states have the option to expand their Medicaid programs to cover adults earning up to 138% of the Federal Poverty Limit. Currently, 38 states and the District of Columbia have opted into (but, in some cases, not fully implemented) Medicaid expansion.

Medicaid is the single largest insurer in the US, covering 1 in 5 Americans. The National Hemophilia Foundation estimates that **about 30% of people with a bleeding disorder** are enrolled in Medicaid. This coverage provides essential access to medication, treatment, and care coordination for some of the most vulnerable members of the bleeding disorders community.

ISSUES:

MEDICAID EXPANSION

Medicaid expansion provides essential health insurance and care for low-income adults -- coverage that is especially important for individuals living with a bleeding disorder or other serious health condition. Studies show that Medicaid expansion increases coverage and access to care among populations with chronic disease and/or disabilities; improves families' financial security; narrows racial disparities in coverage and certain health outcomes; benefits state budgets, hospitals, and health care providers; and more. HFA supports the adoption and continuation of Medicaid expansion in all 50 states.

MEDICAID MANAGED CARE

More than two-thirds of Medicaid beneficiaries, nationally, receive most or all of their care from managed care organizations (MCOs) that contract with state Medicaid programs. But managed care can be problematic for enrollees with bleeding disorders. Most notably, **capitated managed care** reimbursement arrangements (where MCOs are paid a flat per-beneficiary rate) fall far short of covering the high, and highly-variable, pharmacy costs associated with bleeding disorders treatment. The inevitable reimbursement gap gives the MCO a financial incentive to limit or disallow necessary care – i.e., to restrict or deny access to medication. To avert such threats to patient health, HFA urges states using a Medicaid managed care model to "carve out" bleeding disorders care (wholly or, at a minimum, the pharmacy benefit) from their managed care plans.

People with bleeding disorders also rely on expert care from specialist hematology providers. If a state chooses to provide medical services for bleeding disorders under a managed care rubric, the state's MCO network(s) must allow access to the specialized treaters who can provide the requisite expert, comprehensive, patient-centered care.

PREFERRED DRUG LISTS

Clotting factor therapies (and newer, non-factor replacement treatments) are complex biological products with no generic equivalents. Patients' responses to and tolerability for specific treatments will vary from individual to individual. For these reasons, NHF's Medical and Scientific Advisory Committee recommends that patients retain access to the full range of FDA-approved bleeding disorders products.

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ELIGIBILITY RESTRICTIONS

From 2018-2020, almost 20 states sought federal approval to impose certain (previously-disallowed) restrictions on Medicaid eligibility. The U.S. Centers for Medicare and Medicaid Services (CMS) approved 12 state applications to establish **work reporting** programs: CMS said these states could cut coverage for Medicaid enrollees who failed to work enough hours, or to report their work. In other instances, CMS allowed states to impose premium payments for coverage; end retroactive Medicaid eligibility; and/or require frequent re-certification of eligibility.

Work reporting requirements were implemented in only one state – Arkansas, where they caused substantial coverage losses in just four months – before they were overturned by a federal court. Work reporting requirements are currently inoperative in every state, due to one or more of the following: adverse court rulings, litigation risk, electoral changes, and the COVID pandemic.[1] The Biden Administration has begun the process of formally reversing its predecessor's policies on work reporting requirements and has revoked previous CMS approvals of such programs.

HFA and coalition partners oppose work reporting requirements and similar restrictions on eligibility. Tying individuals' Medicaid coverage to work reporting requirements defies the purposes of the Medicaid statute, which is to provide access to health care. Moreover, most people on Medicaid who can work already do so; in fact, studies show that Medicaid coverage helps people to find and sustain employment. Creating extra red tape, and denying or suspending coverage for non-compliance, harms people who live with serious health conditions that require uninterrupted care and continuous coverage.

BLOCK GRANTS

In 2019, CMS overturned longstanding policy and invited states to apply for block grant funding for their Medicaid programs (in place of the open-ended federal matching arrangement that the Medicaid statute specifies). Tennessee accepted this invitation, asking CMS to approve lump sum funding together with additional "flexibility" for the state to manage its Medicaid program – including the ability to **limit or exclude coverage for certain high-cost drugs**. CMS approved a version of Tennessee's request on January 8, 2021. Three weeks later, the incoming Administration signaled it was reversing course. Via an Executive Order dated January 28, 2021, the President directed federal agencies to review prior CMS decisions restricting Medicaid, including the block grant waivers.

HFA and coalition allies oppose Medicaid block grants. Funding caps and block grants are designed to reduce federal spending on Medicaid, forcing states to either make up the difference with their own funds or make cuts to their programs. This potential implications for patient care are far-reaching. A state operating under a block grant such as Tennessee's, with authority to limit drug coverage, would have strong incentives to reduce benefits for people with bleeding disorders and other serious and expensive health needs.

[1] Since March 2020, state Medicaid programs have received extra federal matching funds – and in return, have agreed to maintain continuous eligibility and coverage for Medicaid enrollees as long as the COVID-19 public health emergency (PHE) continues. HFA and other advocates will closely monitor the redetermination policies and processes that will come into play when the PHE ends and state "maintenance of effort" obligations expire.

HFA'S ADVOCACY EFFORTS TO PROTECT MEDICAID COVERAGE:

HFA participates with other patient and consumer advocacy groups in the Partnership to Protect Care coalition, which opposes harmful Medicaid policies. In concert with the Partnership and with our member organizations, **HFA will continue to oppose work reporting requirements, block grants, and other Medicaid restrictions that threaten coverage and care for individuals with bleeding disorders.**

HFA will continue to assist member organizations in their efforts to advocate for the adoption, implementation, and/or continuation of Medicaid expansion in their states.

HFA will continue working with member organizations engaging in advocacy around state preferred drug lists, step therapy, burdensome prior authorization requirements, and other barriers to access.

WHAT CAN YOU DO?

- Help HFA tell the story of why Medicaid coverage is important to people with bleeding disorders.
- Build relationships with your state Medicaid agency. Remember that they may not be knowledgeable about bleeding disorders; you may be able to educate them about your disorder and the care you require.
- Stay informed about your state's Medicaid drug review process and scheduled meetings. HFA can help you prepare and submit comments defending enrollees' access to bleeding disorder treatments.

Resources:

- KFF Medicaid Expansion Tracker, https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/
- KFF Medicaid Waiver Tracker, https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/
- KFF Report, How State Medicaid Programs Are Managing Prescription Drug Costs (2020), https://www.kff.org/medicaid/report/how-state-medicaid-programs-are-managing-prescription-drug-costs-results-from-a-state-medicaid-pharmacy-survey-for-state-fiscal-years-2019-and-2020/
- KFF Medicaid Pharmacy Benefits State Fact Sheets, https://www.kff.org/statedata/medicaid-pharmacy-benefits-state-fact-sheets/
- Find your state Medicaid agency here: https://medicaiddirectors.org/about/medicaid-directors/