Health Care in Motion

Timely, Substantive Updates on Policy Shifts · Actionable Advocacy to Protect Health Care

December 18, 2024

Gearing Up for 2025: Advocates Share Challenges and Opportunities

In the waning days of the Biden Administration, advocacy organizations are preparing for a very different political landscape starting in 2025. Along with the presidency, Republicans will have razor-thin majorities in both the House of Representatives and the Senate. In the days and weeks since the election, President-elect Trump has announced various Cabinet picks and Administration leadership, which telegraphs some of his potential health care priorities. However, the exact agenda, the scale and scope of what is achievable with such slim majorities in Congress and within the legal authority of the executive branch, and how quickly policy changes will move is very much unknown.

In this environment, new challenges will emerge, but the need for access to comprehensive, high-quality, and non-stigmatizing health care continues. CHLPI spoke to advocates from three national organizations focused on health law and policy to get a sense of how each is approaching these issues in 2025. Their responses are below.

Bethany Lilly, Leukemia & Lymphoma Society (LLS)

Bethany Lilly is the Executive Director of Public Policy at LLS

LLS works to cure blood cancers and improve quality of life for individuals and families affected by blood cancer. LLS's policy work has focused on ensuring that cancer care is accessible, affordable, and equitable.

In CHLPI's conversation with Lilly, she emphasized that LLS will continue to focus on the affordability of cancer care and the financial impact that rising health care costs have on people with cancer. According to Lilly, "there is a clear

The Leukemia & Lymphoma Society (LLS) is a non-profit dedicated to creating a world without blood cancers. The mission of LLS is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

mandate from the election that things are not affordable. People are spending too much money on everything, including health care." A primary and acute symptom of the unaffordability of health care is the growing medical debt crisis in this country. Lilly described four areas that will be important policy priorities to address:

 Invest in policies at the state and federal level that make medical debt less likely to occur in the first place. Lilly argues that these types of interventions are necessary to ensure that a cancer diagnosis does



not quickly translate into a financial crisis. Policy interventions that are top-of-mind for LLS include <u>extending the enhanced premium tax credits (PTCs)</u> that have made Affordable Care Act (ACA) marketplace coverage more affordable for millions of Americans and state-level reforms that improve access to high quality coverage. Lilly also pointed to the importance of ensuring that coverage is comprehensive, including tamping down on the availability of "junk plans" that might look like major medical coverage, but can leave unsuspecting consumers with <u>limited coverage when they need it most</u>.

- Ensure that Medicaid remains a vital safety net for low-income people with cancer. Ensuring that Medicaid remains a fully funded entitlement program is also critical to staving off medical debt for people with cancer, and Lilly emphasized the importance of protecting this program from potential funding changes or increased bureaucratic barriers.
- Lower provider prices and cost of care. Lilly emphasized the need to continue LLS's work to identify and address misaligned incentives that are driving up prices of care, including <u>rampant provider consolidation</u>. Tamping down prices, LLS has argued, will benefit consumers in the form of lower premiums, lower cost sharing, and the elimination of surprise or unfair fees.
- Mitigate financial harm for people who already have medical debt. This can include interventions like removing medical debt from credit scores, something the federal government has <u>already proposed</u>.

S. Mandisa Moore-O'Neal, The Center for HIV Law and Policy (CHLP)

Mandisa Moore-O'Neal is the Executive Director of CHLP

CHLP works at the intersection of public health and the criminal legal system. It takes a systems-wide approach, in which it works to separate the criminal legal system from our public health infrastructure.

Reflecting on the recent election and changing political environment, Moore-O'Neal emphasized: "Our work is the

"CHLP is an abolitionist legal and policy organization that envisions and works for a world where HIV and other stigmatized health conditions are no longer criminalized but met with compassion and the resources to thrive."

same, but the political terrain has shifted, and we will have to adopt strategies that respond to the current moment." For example, CHLP has been working closely with many federal stakeholders, and while the efficacy of those federal-level relationships evolve and are reassessed, CHLP anticipates deeper engagement with state and local officials and organizations. CHLP's priorities in 2025 include:

- Eliminating state laws that criminalize health, such as criminal HIV exposure laws. Through the <u>Positive Justice Project</u>, CHLP highlights the false assumptions about HIV and bias that underlie these laws. CHLP works to end them through state and federal advocacy, support for impacted communities and coalitions, and resources for public health agencies and individual defense attorneys.
- Ensuring data privacy for people with HIV and others at risk. HIPAA mandates a federal floor for protected health information, but there is more that states can do to ensure that sensitive information such as HIV



status is not compromised, particularly in an environment where HIV is still criminalized. For example, CHLP has developed a <u>model policy</u> for health departments and facilities to use to ensure respect for principles of privacy and consent.

Promoting LGBTQ+ and reproductive justice, especially where they intersect with decriminalization of health. For example, in the current political environment, concerns regarding legally sensitive health information also apply to aspects of reproductive justice, such as receipt of gender affirming care or pregnancy history.

Alissa Wassung, Food Is Medicine Coalition (FIMC)

Alissa Wassung is the Executive Director of FIMC

FIMC is a national coalition that envisions a future where anyone who needs medically tailored meals or groceries has access to the highest quality service, regardless of their ability to pay or where they live. FIMC advances its mission of increasing equitable access to nutrition services through developing and disseminating policy proposals, research and evaluation, and best practices.

The <u>Food Is Medicine Coalition (FIMC)</u> is a national coalition of nonprofit organizations that provide medically tailored meals and groceries, medical nutrition therapy, and nutrition counseling and education to people in communities across the country living with severe and chronic illnesses.

In CHLPI's conversation with Wassung and her team, Wassung emphasized that the food is medicine movement is "solidly bipartisan." Wassung noted that we are currently at a major inflection point for food policy (which includes food is medicine as well as other policy issues). Within this broader context, FIMC recognizes that "food is both harming us, and could help us." FIMC's policy agenda in 2025 includes the following priorities:

- Passing the Medically Tailored Home-Delivered Meals Demonstration Pilot Act in a 2024 end-of-year health care spending package or during the next Congress. FIMC has worked to garner bipartisan support in both chambers of Congress for a bill that would establish a Medicare pilot program to address the link between diet, chronic illness, and the health of older adults and people with disabilities. The pilot project would gather data assessing the effectiveness of well-defined nutrition services. This data would in turn help improve access to nutrition services in Original Medicare—where there currently isn't any—and in other health care programs.
- Funding food is medicine programs at the National Institutes of Health (NIH). The NIH Office of Nutrition Research has developed and received approval for a concept for "food is medicine centers of excellence" that would combine cutting-edge research support with innovative delivery of nutrition services through a network of providers throughout the country. FIMC, alongside partners in the field, is now calling on Congress to appropriate funding to allow NIH to stand up the centers and invest in the research necessary to expand the food is medicine model.
- Supporting funding for Ryan White CARE Act nutrition services. FIMC has long supported the Ryan White HIV/AIDS Program, which envisions the patient at the center surrounded by both medical care and social support services. Wassung views this as a "model for care for people living with other illnesses."



Building infrastructure and supporting implementation for food is medicine providers. Identifying sustainable funding sources, especially through insurance reimbursement, is critical to maintaining and increasing equitable access to nutrition services. FIMC, working with CHLPI, developed a <u>state Medicaid policy toolkit</u> earlier this year that provides a roadmap for expanding coverage, reimbursement, and data collection of food is medicine services in Medicaid, and intends to use that toolkit to work with state Medicaid programs throughout the country in the coming year.

Looking Ahead

The three organizations CHLPI spoke to all voiced a consistent priority: the work of their organizations to protect the people they serve and advance their vision for the future of health care will continue in 2025 and beyond. As new and unpredictable challenges and opportunities emerge in the year ahead, each organization expressed its commitment to finding creative ways to center the needs of their constituents.

Subscribe to all Health Care in Motion Updates

Health Care in Motion is written by Carmel Shachar, Health Law and Policy Clinic Faculty Director; Kevin Costello, Litigation Director; Elizabeth Kaplan, Director of Health Care Access; Maryanne Tomazic, Clinical Instructor; Rachel Landauer, Clinical Instructor; and Johnathon Card, Staff Attorney. This issue was written with the assistance of Amy Killelea of Killelea Consulting.

For further questions or inquiries please contact us at *chlpi@law.harvard.edu*.

