Questions for the Record from
Representative Robert C. "Bobby" Scott (D-VA)

Committee on Education and the Workforce HELP Subcommittee hearing titled: "A Healthy Workforce: Expanding Access and Affordability in Employer-Sponsored Health Care"

Wednesday, April 2, 2025
10:15 A.M.

Answers to Questions from Robert C. "Bobby" Scott (D-VA) for Bethany Lilly, Executive Director, Public Policy, Leukemia and Lymphoma Society.

1. *In February, House Republicans voted to approve a budget resolution that aims to cut over $800 billion from Medicaid in order to give $4.5 trillion in tax breaks to large corporations and billionaires. Not only will the Republican's draconian budget plan explode the federal deficit, but it is also threatening the health coverage of over 154,000 people in Virginia's Third Congressional District, including nearly 40,000 children in my district. Take for example, the story of one of my constituents from Norfolk, Virginia, named Angel Pye. Medicaid enabled Angel's son, who had Sickle Cell Disease, to afford the health care he needed to live for 10 years. He was in and out of the hospital with blood transfusions, which Medicaid covered. Medicaid also provided some funding when Angel left her job to work as a home care provider for her son. Sadly, Angel's son passed away a month ago. Angel is now sharing her story to highlight the importance of protecting Medicaid.*
    a. *What impact would the cuts proposed in the House Republican budget resolution have on people who rely on Medicaid?*

As you highlighted in your question, we anticipate significant coverage losses. The Congressional Budget Office estimates that the proposals in the Budget Reconciliation bill, when combined with the expiry of the enhanced advance premium tax credits, would increase the number of people without health insurance by at least 13.7 million people. Medicaid provides a crucial safety net when people with blood cancer, as it did with DeAnne in North Carolina, mentioned in my written testimony, and for millions of others across the United States. The proposals would harm low-income working adults, Medicare beneficiaries, children, people with disabilities, and patients with complex health conditions. We urge Congress to reject these cruel and reckless policies.

2. *Medicaid plays an outsized role when it comes to long-term care. Medicaid accounts for 61 percent of all long-term care spending in this country. This includes things like nursing home care, but it also includes home and community-based services that provide support to disabled individuals, including older individuals, to continue to live and work in their communities.*
    a. *If not for Medicaid, who would pick up the bill for long-term care in this country?*

Long term services and supports (LTSS), also called long term care, are extremely expensive—"[o]n average, an American turning 65 today will incur $120,900 in future LTSS costs, measured in today's dollars."[i] Unfortunately, private insurance and Medicare generally do not cover LTSS, which leaves Medicaid as the only available insurance for these services.[ii] In 2022, Medicaid paid for 61% of the total $415 billion that was spent on LTSS and families paid for an additional 17% out of pocket.[iii]

Many people with blood cancer require access to LTSS because of the toll that cancer treatment can have on the body.[iv] If Medicaid stopped covering LTSS, suddenly millions of families would be unable to access the care they need. Private LTC insurance is unaffordable or unworkable for many, offering limited coverage.[v] This means even more families will not get the support they need.

An additional dynamic is the difference between more cost-effective home- and community-based services (HCBS) and institutional services.[vi] HCBS are "optional" Medicaid services, meaning that states are not required to cover them, while more expensive institutional services are mandatory.[vii] Unfortunately, this means that they are often targeted for reductions when state must balance Medicaid budgets, as happened following the early 2000s recession.[viii] Cutting at least $715 billion from Medicaid as the Budget Resolution proposes will force states to absorb costs or cut services and leaves people with LTSS needs facing an impossible choice—either institutionalization or loss of home care services.

3. *For 15 years, the Republican Party has waged a war on the Affordable Care Act and the landmark consumer protections it enshrined into law for millions of working people in this country. These consumer protections include protecting over 130 million Americans with pre-existing conditions, allowing young people to stay on their parents' insurance until age 26, prohibiting charging women higher premiums than men for the same coverage, and much more. In January 2025, 64 percent of the public had a favorable opinion of the ACA. Despite its sky-high approval and historic progress in decreasing the uninsured rate, Republicans continue to push for the repeal of the ACA and expansion of "junk" health insurance plans that evade vital consumer protections.*
    a. *Ms. Lilly, can you speak to the deficiencies of these substandard health plans— such as association health plans and short-term, limited duration insurance—for Americans? What benefits do these plans cover (or not cover)?*

While insurance issues exist regardless of the source of coverage, LLS knows firsthand that there are categories of insurance and "insurance-like products" that put not only our patients – but everyone who enrolls in them – at significant risk, both financially and in terms of their health. This category of products can often openly discriminate against patients, charge more to people with pre-existing conditions, retroactively refuse to pay for

care that has already been provided, and charge women more just for being women. This includes association health plans (AHPs); short-term limited-duration insurance (STLDI); and a variety of other products. While the rules of each differ, all lack some part of comprehensive coverage that the Affordable Care Act mandated. Importantly, because of the skimpy coverage offered by some of these products, patients and consumers can be disproportionately harmed financially when their coverage fails to meet their medical needs. LLS urges the committee to find solutions to address healthcare costs that do not promote low-quality coverage.

4. *In March, the Trump Administration proposed a new regulation governing the ACA Marketplaces that would make it harder for people to get health coverage. Among many changes, the regulation would reduce the Open Enrollment period, end a monthly special enrollment period for Americans and allow insurance companies to offer health plans that cover less medical care. The Administration's own estimate is that 750,000 to two million Americans would lose their ACA health insurance in 2026 as a result of these changes.*
    a. *Ms. Lilly, how does the Trump Administration's proposal hurt Americans' ability to get quality health coverage?*

LLS opposed several components of the rule and we are concerned to see several of the proposals from the rule incorporated into the Budget Resolution text. In addition to shortening the Open Enrollment period, eliminating the special enrollment period (SEP) for low-income people, and reducing the actuarial value of plans, the rule proposes implementing a premium for people who like their plan and stay enrolled in it, increasing the paperwork burden on those attempting to use an SEP, allowing insurers to deny coverage to those who the insurer says owe it or a related entity premiums, preventing the autoenrollment of some people into cheaper coverage, and several other harmful changes. We are extremely concerned that these changes would erode blood cancer patients' access to meaningful coverage. Our full comments to the agency are available on Regulations.gov.[ix]

In addition, we note that <u>the best way of ensuring access to affordable premiums for comprehensive coverage would be to retain the enhanced premium tax credit. Congress needs to act and ensure that Marketplace coverage remains affordable.</u>

5. *The Trump Administration and DOGE have been carrying out mass firings of federal employees, including those at federal health care agencies, and have made cuts to federal funding and research grants.*
    a. *How do you expect these cuts will impact Americans' health?*

LLS is deeply concerned about the cuts to already-committed funding from the NIH and to federal agency staffing that have happened at lighting speed and without full understanding of the implications. We recognize the need for efficiency and to ensure taxpayer money is spent wisely, but these decisions must be thoughtfully made and cannot jeopardize critical

government functions, like basic research and the operations of health and safety net programs on which some people with chronic conditions rely. NIH funding has contributed to 354 of the 356 drugs approved from 2010 to 2019 and every dollar in NIH funding generates $2.46 in economic activity, ranging from $47.6 million to $13.8 billion per state.[x] Most importantly, half of all cancer treatments used today were discovered or developed at NCI.[xi] We urge Congress to consider the long-term impacts and lasting harm to patients that could come from these cuts.

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[i] https://aspe.hhs.gov/sites/default/files/documents/08b8b7825f7bc12d2c79261fd7641c88/ltss-risks-financing-2022.pdf.
[ii] https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/.
[iii] https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/.
[iv] https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/living-with-a-blood-cancer-in-later-life-the-complex-challenges-and-related-support-needs-of-adults-aged-75-and-older/19F78ABEE27081D425661C1C9EEE4662.
[v] https://kffhealthnews.org/news/article/dying-broke-why-long-term-care-insurance-falls-short/.
[vi] https://www.kff.org/medicaid/issue-brief/what-is-medicaid-home-care-hcbs/.
[vii] https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled.
[viii] https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled.
[ix] https://www.regulations.gov/comment/CMS-2025-0020-23132.
[x] https://www.lls.org/blog/balancing-fiscal-responsibility-saving-and-improving-lives.
[xi] https://www.lls.org/blog/balancing-fiscal-responsibility-saving-and-improving-lives.