AIMEDALLIANCE

March 17, 2025

Via Electronic Correspondence

Majority Leader Robyn Gabel
Illinois General Assembly
501 S 2nd St
Springfield, IL 62757

RE: SB 66, The Health Care Availability and Access Board Act

Dear Senator Robyn Gabel:

Aimed Alliance is a not-for-profit health policy organization that seeks to protect and enhance the rights of healthcare consumers and providers. We are writing to provide comment on Senate Bill 66, which proposes the establishment of the Health Care Availability and Access Board. Aimed Alliance urges members of the Assembly to carefully consider the potential consequences of this legislation and ensure consumers are at the center of these reforms.

I. UPL Alternatives Can Have a Direct Impact on Consumer Affordability

Senate Bill 66 seeks to address rising prescription drug costs by creating the Health Care Availability and Access Board, which would have the authority to set upper payment limits (UPLs) for certain medications. However, UPLs cap the amount that *payors* reimburse pharmacy benefit managers (PBM) for a prescription drugs. There is no requirement that these savings are passed down to consumers in meaningful ways such as lower prescription drug costs or lower premiums. Without clear provisions ensuring that cost savings are passed down, there is no guarantee that consumers will see reduced out-of-pocket costs and improved health care affordability.

Importantly, research has revealed that UPLs may increase patient access and affordability challenges. For example, a recent study published by *Avalere* found that health plan representatives anticipate greater implementation of utilization management tactics, such as step therapy and prior authorization, in response to UPLs being set on certain prescription drugs.[1] Plan representatives also anticipate adjustments to formularies, such as reassigning selected drugs and therapeutic alternatives to different tiers.[2] These changes have the potential to increase costs and hinder patients' access to essential medications, underscoring the need to use caution and explore alternative approaches to enhance prescription drug affordability.

The proposed Health Care Availability and Access Board is modeled after prescription drug affordability boards (PDABs), the first of which was established in 2019. Since then, several states have followed suit, however, no state PDAB has successfully completed the drug selection and UPL setting process. As a result, these boards remain experimental initiatives with significant upfront costs and no guarantee that any potential savings will lower costs for

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[1] Kate Sikora, et al., *Research Explores Health Plan Perceptions of PDABs and UPL*s, AVALERE (April 2, 2024), https://avalere.com/insights/research-explores-health-plan-perceptions-of-pdabs-and-upls.
[2] *Id*.

healthcare consumers. As stated above, the way these boards are structured, any savings accrued would likely only benefit payors, as UPLs restrict what *payors* reimburse PBMs, without any requirement these savings be passed down to the consumers through meaningfully reduced prescription drug costs or premiums.

II. The Board Must Prioritize Patient Access and Affordability

If the Assembly elects to move forward with SB 66, Aimed Alliance urges members to ensure that the Board is required to prioritize patient input by including a consumer or patient representative on the Board, mandating ongoing consumer engagement, and requiring that UPL-derived cost savings be passed on to patients.

A. Prioritize Patients' Perspectives and Lived Experiences

Research consistently highlights the benefits of actively involving patients in healthcare decisions. For example, studies have found that patient inclusion has created positive effects on improving health outcomes, enhancing satisfaction with the care experience, and lowering health care costs.[3] Including patients in health policy decisions can also improve the quality of healthcare delivery and improve accessibility.[4]

Moreover, given that patients are the intended beneficiaries of these medications, their perspectives are essential for accurately assessing the value of these medications. Involving patients in the decision-making process can also provide insights into disease management, access challenges, treatment preferences, and other pertinent considerations associated with various medications.[5] Their firsthand experiences can help ensure that healthcare policies address the needs of those they aim to serve.[6] It also enables the Board to access a wealth of firsthand knowledge that is essential for making well-informed and patient-centered decisions about prescription drug affordability and value.[7]

To ensure the patient, caregiver, and provider perspectives are appropriately valued and considered, Aimed Alliance urges the Assembly to ensure that the legislation mandates that both the both the Health Care Availability and Access Board and the Health Care Availability and Access Stakeholder Council have patient representatives. Providing permanent and formal positions for this perspective will ensure the development of surveys, questions, and processes are consumer-friendly and inclusive. Moreover, appropriately valuing the lived experiences of consumers with chronic conditions can help ensure that healthcare policies address the needs of those they aim to serve.[8]

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[3] Lisa Baumann, et al., *Public and patient involvement in health policy decision-making on the health system level – A scoping review*, 126 HEALTH POL. 1023-38 (Oct. 2022), https://www.sciencedirect.com/science/article/pii/S0168851022001919.

[4] *Id.*

[5] Alex Krist, et al., *Engaging patients in decision-making and behavior change to promote prevention*, 240 STUDENT HEALTH TECH. INFO. 284-302 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6996004/.

[6] *Id.*

[7] *Id.*

[8] *Id.*

Recently, the federal government has recognized the value of ensuring a permanent position for the patient perspective by requiring all Pharmacy & Therapeutics (P&T) Committees to include *at least* one patient representative as a Member of the Committee. In making this decision, the government recognized that consumer representatives can provide "insights into real consumer experiences unknown to P&T committees."[9] Thus, a similar permanent position could be equally as valuable and beneficial for the Health Care Availability and Access Board and the and the Health Care Availability and Access Stakeholder Council.

B. Mandate a Continuous Consumer Engagement and Oversight Process

The obligation to engage the patient, provider and caregiver community should not be satisfied by creating Board and Council positions for patient representative. Any drug selection and UPL-setting process should impose a continuous obligation to actively seek input from a broad range of stakeholders, including patients, caregivers, and community representatives. The continuous inclusion of these voices and perspectives can help ensure the development of a fair and comprehensive drug review framework.

Furthermore, it is imperative to acknowledge that the governmental entity responsible for developing the drug selection process has a shared responsibility in engaging these communities. Patients and caregivers must manage work and family commitments and their treatment regimens, while striving to navigate complex healthcare systems to ensure optimal care for themselves or their loved ones. Therefore, the responsibility to be aware of and engage in the drug selection and UPL-setting process cannot rest solely on consumers to advocate for their needs; the Board must have an affirmative obligation to engage these communities.

Additionally, the engagement process must extend beyond the initial review stage. Once the Board establishes a UPL, the Board should continuously monitor its impact on access and affordability. Establishing clear channels for consumers to voice concerns and grievances regarding any access barriers stemming from pricing policies is critical to ensuring equitable access to essential medications. By fostering a culture of transparency and responsiveness, the Board can effectively address emerging challenges following the adoption of UPLs.

C. Payors and PBMs Must Pass UPL Savings to Patients

As stated above, UPLs serve as a cap on what *payors* can reimburse for a drug. Without precise legislative language mandating that any savings are passed down to consumers, payors are likely to retain any potential benefits without alleviating the financial burden on patients. Therefore, Aimed Alliance urges the Assembly to modify the current bill language to include specific language that requires any UPL savings to be passed down to beneficiaries in the form of meaningful reductions to premiums or prescription drug costs.

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[9] Ctrs. For Medicare & Medicaid, Dep't of Health and Human Servs., and Dep't of Treasury, *Patient Protection and Affordable Care Act, HHS Notice of Benefit and Payment Parameters for 2025, 89 FR 26218* (Apr. 15, 2024); *See also,* Lisa Baumann, et al., *Public and patient involvement in health policy decision-making on the health system level – A scoping review*, 126 HEALTH POL. 1023-38 (Oct. 2022), https://www.sciencedirect.com/science/article/pii/S0168851022001919.

III. Conclusion

In conclusion, Aimed Alliance urges the Assembly to ensure that the legislation prioritizes patients' perspectives and lived experiences, establish a continuous consumer engagement and oversight process, and require payors and PBMs to pass UPL-derived cost savings to patients.

Please contact us at policy@aimedalliance.org if you have any questions or would like to further discuss our concerns.

Sincerely,

Olivia Backhaus
Staff Attorney