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(HEAL) Group
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National ADAP Working Group (NAWG)

Written Testimony, RE: S98
Vermont Legislature
Senate Committee on Health and Welfare
Committee Meeting 9/20/23

January 25, 2024

VIA Electronic Mail

Vermont Legislature
Senate Committee on Health and Welfare
115 State Street
Montpelier, VT 05633

**RE: S98 Granting New Authority to the Green Mountain Care Board
neglects ensure priority on patient voices and experiences and risks harming
access to care; In opposition.**

Honorable Chairwoman, Senator Lyons, Vice Chairman, Senator Weeks, and
Members of the Vermont Senate Committee on Health and Welfare,

About Community Access National Network (CANN): CANN is a 27-year-old
national nonprofit organization focusing on public policy issues relating to
HIV/AIDS and viral hepatitis from the patient perspective. CANN's mission is to
define, promote, and improve access to healthcare services and supports for
people living with HIV/AIDS and/or viral hepatitis through advocacy, education,
and networking.

**S98 Does not prioritize patient input, experiences, or outcomes above other
interests and poses potential for meaningful harms to patient access, public
health programs continuity, and provider entity financial stability.**

CANN is gravely concerned about S98 and, more generally, the speed in which
several states are adopting “Prescription Drug Affordability Boards”, often
neglecting to require patient input on each board, patient experience in required
evaluative and monitoring measures, and failing to consider the unintended, but
quite predictable, consequences of these boards.

Prescription Drug Affordability Boards or any other board empowered as same,
regardless of name, as described in S98, do not consider patient experiences with
payor (health insurer and pharmacy benefit manager) practices, like prior
authorizations or step-therapy or other benefit design concerns patients face
(including but not limited to insufficient provider and pharmacy networks or
patient steering amounting to self-dealing by “vertically integrated” companies
and their associated subsidiaries).

We appreciate the intent of the bill in trying to help families, people with
disabilities and chronic conditions, and those with limited incomes from feeling
like they’re “forced to choose between the medicine they need and basic



necessities.” As patients ourselves, we agree with this noble effort and the necessity of reducing cost and administrative burdens on patients and our healthcare providers.

In order to achieve this goal, the means and process of getting there must center those who are supposed to benefit – patients and our families. S98, as currently designed, fails to consider the most direct costs to patients and healthcare providers and, ultimately proves a focus on choosing favored industry interests versus other industry interests, rather than focusing on patient experiences.

For these reasons, we urge members of the Senate Finance, Insurance, and Consumer Protection Committee to oppose S98 in its current form.

CANN has worked in support of patient advocates and people living with HIV (PLWH) in several other states which have passed similarly situated legislation. Colorado, for example, is a state which has advanced quite swiftly in selecting medications for “affordability” review and continues in that process today. Indeed, Colorado is the most often referenced state for legislatures considering a PDAB or similarly situated board to take up authority to establish an upper payment limit. Despite touting Colorado as a “success”, [documentation of public comment](#) shows a routine and regular frustration from patients as the Board fails to address concerns and legitimate questions about implementation and potential impacts.

Speaking directly to patient experiences with these boards and their processes, those patients engaged in Colorado are regularly and routinely frustrated at the Board’s failure to adhere to the recommendations of the Advisory Council, failure to adequately and substantially engage with patients affected by “affordability” review selection and the potential impacts of imposing an upper price limit, and the failure to coordinate with state agencies with more substantial community connections – be it with patients or providers themselves. Extraordinarily, legislators in states considering a PDAB or granting upper payment limit powers to another board fail to mention or consider these frustrations. CANN is certain the Vermont legislature does not wish to have its good works undermined but a similar process. Safeguards must be included in any legislation impacting the public to ensure the public is truly heard and served. S98 as written does not achieve this end.

“Affordability” as Framed by S98 Does Not Speak to Patient Experiences

The issue of “affordability” strictly from the end-user, or patient, perspective does not start or end with list prices or reimbursement rates of medications. Rather, these are issues related to industry stakeholder interests, particularly those of pharmacy benefit managers (PBMs), and their profit margins; “Affordability” especially within the frame of various rebate structures, most directly translates to how much profit a PBM makes off of any particular medication. PBMs “get compensated” by a combination of spread pricing – or charging more than what they pay for particular medications, retaining rebates, and administrative fees. However, those rebates offered by pharmaceutical manufacturers are designed to reduce the costs of medication to patients, not pad the profit margins of PBMs or their vertically integrated mail-order or physical pharmacy locations.

Rather, patient experiences in accessible healthcare and treatment, particularly medication access, is far more complicated. Barriers to care begin with high deductible and high premium health plans and are complicated by issues of insufficient provider networks, patient steering in pharmacy selection, and utilization management practices which operate to allow health plans to disrupt the provider-patient relationship by way of

administrative burdens. Compounding these concerns, consolidation in the provider, hospital, and pharmacy markets reduce the number of access points of care, with particular harm toward rural communities wherein accessing even an emergency room might leave patients in rural communities hours away from life-saving care.

Actions to Protect Patients and Improve Access to Care and Treatments

The Vermont legislature is well positioned to address these barriers to care and meaningfully making care and treatment more meaningfully accessible to Vermonters by examining and addressing the role of these interests by any of the following actions, all of which work to provide protections to patient interests:

- Prohibiting unfair trade practices (particularly with regard to hospital consolidation and patient steering)
- Prohibiting spread pricing (wherein PBMs may not charge a patient or plan sponsor more than the cost of acquiring a medication)
- Prohibiting so-called “co-pay accumulator” or “co-pay maximizer” programs (wherein financial support from manufacturer patient assistance programs must be applied directly to a patient’s deductible and/or maximum-out-of-pocket limit)
- Prohibiting certain utilization management practices (such as prior authorizations or step therapy – adopting “provider prevails” program)
- Prohibiting patient steering (wherein patient choice of pharmacy is equally reimbursed and protected from vertically integrated entities which profit from the self-dealing nature of PBMs requiring patients to utilize mail-order or physical pharmacies owned by or associated with the PBM)

Questions Remain, Vermonters Should Not Answer by way of Experimentation

Many questions remain regarding the potential negative impacts of an upper reimbursement limit on programs and providers dependent upon revenues and savings generated from the 340B Drug Discount Program in order to provide life-saving and life-improving care for marginalized populations, particularly people living with HIV, rare diseases, disabilities, and chronic conditions. Ensuring safety-net providers are well supported in providing reduced cost and/or no cost care and treatment to the patients who need it most is critical to ensuring Vermont meets its highest ideals in caring for its residents. A UPL undermines these essential funding mechanisms.

Similarly, no state has yet to answer the question of what happens when a UPL is imposed and the cost to acquire a particular medication is higher than the allowable reimbursement rate? Who pays? Will it be patients? If an exemption is allowed, what process burdens will patients face to get the treatments our providers have identified best suit our individual care needs? Social media feeds are filled with pharmacists complaining about how low reimbursement rates are already harming patients’ access to care because those same pharmacies cannot afford to distribute certain medications to patients. Along the same lines, those pharmacists and providers administering medications are sharing that PBMs no longer making sufficient revenues from particular medications have removed those same lower-cost medications from formularies, leaving patients in the lurch. Something is rotten in this henhouse.

Will the Vermont legislature need to appropriate additional public health dollars to make up for reduced rebate savings for hospitals and federally qualified health centers serving poor and indigent patients? Will the state’s AIDS Drug Assistance Program find itself in a budget shortfall as a result of reduced reimbursements? What about the Medicaid program?



Evidence is already mounting that reimbursement limits are harmful to these programs, even if, admittedly, this seems “counterintuitive to a straightforward answer to drug price concerns and patient access. In a recent article in the publication 340B Report, Colleen Meiman, a national policy advisor for the State & Regional Associations of Community Health Centers, shared a “neat” allegory to an upper reimbursement limit as manufacturers reduced insulin costs to \$35; “Before 2024, most insulins had list prices of \$300-\$500 or more and were 340B penny-priced, so 340B providers earned savings of \$300-\$500 per prescription, Meiman said. However, now that many insulin list prices are \$35, the 340B savings could drop to around \$8 per prescription, she said. Historically, 340B savings on insulin have accounted for around 10% of community health system 340B revenue, she said.”

Lastly, what are the costs to the “system” of care of ultimately denying access to the personalized care patients require to meet our health outcome goals? As one patient in Colorado recently stated during a stakeholder meeting, “Is it more costly to give me the medication I need now or is it more costly for me to end up in the hospital for three weeks, attempting to be stabilized?” These questions are very, very real, especially in the frame of medications selected for review by the Colorado PDAB – rare disease and antiretroviral medications are among those selected. PLWH and cystic fibrosis patients are quite familiar with what happens to us, our friends, and our families when our treatment access is disrupted – people die, families struggle through transplant waitlists, and higher viral loads due to disruptions in care mean new HIV diagnoses. That’s not an exaggeration. But is our fear.

Conclusion

Ultimately, CANN respects the work and effort the Vermont Legislature is trying to achieve here. We well know you care about your constituents, your neighbors, and even your own families. And we know you want to address the complexities of our healthcare system which leave far too many patients behind. In these issues, we agree. A PDAB by any other name, especially one with the power to impose an upper price limit, is simply not the way to get there.

I am readily available to answer any questions you may have and look forward to future discussion on improving access to care for Vermonters. I can be reached at 313-333-8534 or by email at Jen@tiicann.org.

Ever yours in service,

A handwritten signature in black ink, appearing to read "Jen Laws", with a stylized flourish at the end.

Jen Laws
President & CEO
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