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Rep. Jeffrey Sánchez, House Chairman
Sen. James T. Welch, Senate Chairman
Joint Committee on Health Care Financing
Massachusetts State House

Dear Committee Members:

Thank you for allowing me to testify today. My name is Lydia Brown. Some of you may already know me, as I seem to have made Beacon Hill visits a dedicated hobby. I am a disabled advocate and community organizer; I am also an East Asian person of color, queer identified, and gender non-conforming. In Massachusetts, I am chairperson of a statewide disabilities council and co-president of TASH New England, the regional chapter of an international disability rights organization. Nationally, I serve on the board of the Autism Women's Network.

From both personal and professional experience, I am keenly aware that healthcare disparities are one of the most insidious and pervasive forms of discrimination impacting any underrepresented or minoritized group. These disparities are evident in quality of care, diagnostic accuracy, network adequacy, service delivery models, multicultural competency, and overall health outcomes. These disparities result in lower life expectancy, less access to any healthcare including mental health services, and other deleterious effects on well-being and social stability.

Today, your committee will hear testimony on a bill – **S-1114 (An Act to eliminate health disparities in the commonwealth)** – that seeks to address and remediate health disparities in the Commonwealth by establishing a dedicated state office on health equity. Such an office could serve as a critical starting point in identifying specific sources of inequity affecting Massachusetts residents, especially those impacting whole populations, and then addressing those systemic issues.

This bill should be reported favorably from committee, but **if and only if it is amended to be stronger than the existing bill (H-3969 / S-2143, An Act eliminating racial and ethnic health disparities in the Commonwealth) that has already been passed to be engrossed.**

The language of S-1114, the bill before you today, is much weaker and rather concerning compared to the other bill. Specifically, this bill identifies “race and ethnicity” and “disability status” as separate determinants (or people of color and people with disabilities as separate groups) associated with health disparities:

Ex. 1 (definitions)

“Health disparities”, differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions, in the access to or receipt of health care, or both, that disproportionately affects certain racial and ethnic groups, as determined by the office, and people with disabilities.

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Ex. 2 (statutory mandate)

The office [of health equity] shall also consider and make recommendations regarding subpopulations among racial and ethnic minorities and people with disabilities that experience the highest levels of disparity in health and health care.

The other bill (H-3969 / S-2143) that has already been passed to be engrossed, states instead:

Ex. 1 (definitions)

“Health disparities”, differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions, differences in the access to or receipt of health care or both such differences that disproportionately affect individuals based on race, ethnicity, gender and disability status.

Ex. 2 (statutory mandate)

The office [of health equity] shall also consider and make recommendations regarding individuals that experience the highest levels of disparity in health and health care based on race, ethnicity, gender and disability status.

That bill as amended is significantly stronger and more promising than S-1114 because it attempts, however potentially ineffectually, to acknowledge that a person may be impacted by membership in more than one minoritized group, and to attempt to focus the office’s resources on such people.

Nevertheless, both bills require substantial changes in order to fulfill their intended purpose of identifying and addressing healthcare disparities. Both bills can and should be strengthened by adding language that does not merely list various categories of minority identity, but that acknowledges the particularly pernicious effects of compounded systemic inequalities. (The new bill lists race, ethnicity, and disability as possible factors; the existing bill lists race, ethnicity, gender, and disability. Some possible additional characteristics might include limited English proficiency and sexual orientation.)

As a disabled and gender non-conforming person of color, I understand disability issues as neither separate from nor competing with racial or transgender issues. The healthcare outcomes of white disabled people differ from those of disabled people of color; those of transgender people of color with disabilities differ significantly from those of non-transgender white people with disabilities. This new bill, S-1114, speaks of people of color and people with disabilities as though we comprise two separate constituencies; this could not be farther from the reality that we face.

We must focus on race and ethnicity as sources of continued discrimination and systemic disenfranchisement in healthcare, because people of color continue to experience appallingly ordinary discrimination in healthcare settings. Look no further than the numerous studies showing that people of color, especially Black people, are taken less seriously when complaining of pain than white people. This does not in any way whatsoever undermine the reality that LGBTQ people and disabled people experience often severe discrimination in healthcare.

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We have research demonstrating that doctors are more likely to make more rapid life or death decisions on risky procedures if the patient has a developmental disability, including denying eligibility for organ transplants without any medical reason. We know that disabled people of colors and LGBTQ disabled people have been more likely than others to be denied sex education or worse, subjected to forcible sterilization. We know that the transgender people least likely to be able to access gender affirming healthcare are transgender people of color and transgender people with disabilities.

Thus, we cannot afford to conceptualize categories of difference as mutually exclusive. Disability cannot mean white disabled people only. Race cannot mean non-disabled people of color only. Gender cannot mean non-transgender women only. I cannot settle for a bill that not only seems to pit my communities against each other, but which could also lead to further disparities by focusing desperately needed resources only on the most privileged members of my communities.

An effective health equity office can only fulfill its mission of identifying and ameliorating healthcare disparities if it is equipped with an explicit statutory mandate to address those most impacted by multiple systemic inequalities. That mandate must be fulfilled through

- (1) ensuring that the office's administration, internal leadership, and community engagement activities are of, by, and with members of the directly impacted communities at all levels;
- (2) enumerating multiple categories of minoritized identities (*starting* with race, ethnicity, gender identity, and disability) as many possible bases for health disparities that do not exist in isolation and that compound one another, and explicitly creating a particular mandate to focus on health disparities affecting people impacted by multiple minority experiences, who are not *subpopulations* but *specific underrepresented populations*;
- (3) ongoing multicultural competency training for all of the office's leadership and staff on sexual orientation, gender identity, race, disability, and other minoritized identities; and
- (4) sustained partnership with organizations led by and for minoritized communities, especially those led by people with multiple minority experiences, that are already addressing healthcare disparities from the ground up.

These bills both contain much promise, and I urge this committee to work hard to ensure that, through all necessary amendments, those bills are in the best possible position to keep that promise for those of us most impacted by compounded inequalities. To that end, I am happy to work with interested members of this committee and others in the legislature on amendments to S-1114 or to H-3969 / S-2143. Thank you again for your time and consideration.

Sincerely,

Lydia X. Z. Brown