



Center for Public  
Representation

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Re: Written Testimony for Health Equity Taskforce Hearing

Dear Taskforce Members:

We are grateful for this opportunity to inform the work of the Health Equity Taskforce, and its upcoming report and recommendations on responding to health care inequality in Massachusetts.

The COVID-19 pandemic has brought into sharp relief a range of barriers – both historical and ongoing – which undermine equal access to health care in Massachusetts. Among these is the ableism that leads to the devaluing and discriminatory exclusion of people with disabilities, and the structural racism that continues to disenfranchise communities of color. The events of the past year have elevated our collective awareness of these issues, and created a much needed sense of urgency in working to dismantle barriers to health care and to redress these harms going forward. With these objectives in mind, and with a focus on vulnerable, high risk communities, we offer the following short and long term recommendations:

### **Nondiscriminatory Crisis Standards and Training on Implicit Bias**

The prevalence of discriminatory Crisis Standards of Care (CSC) laid bare a health care system long plagued by inequality and bias towards people with disabilities, older adults, and communities of color. Around the country, States began publishing CSC that discriminated against disabled individuals, as well as those with pre-existing conditions or comorbidities, including older adults and people of color. Individuals with certain diagnoses, who needed hands-on assistance for activities of daily living, or who faced shorter life expectancies due to health care inequities and underlying disability, found themselves excluded from or deprioritized for lifesaving treatment, or subjected to unconscious bias based on misinformed assumptions about the value and quality their lives.<sup>1</sup> Most State CSCs also failed to consider what reasonable accommodations would be required to ensure disabled individuals could communicate their symptoms, provide informed consent, and participate in their care and treatment.<sup>2</sup> Massachusetts was no exception. After months of engagement with stakeholders, Massachusetts twice revised

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<sup>1</sup> See, e.g., OCR Complaints filed in Washington State, Alabama, and Tennessee, available at <https://www.centerforpublicrep.org/covid-19-medical-rationing/>

<sup>2</sup> More than 35 state advocacy organizations sent letters to their Governors and responsible public health agencies regarding the need for nondiscriminatory crisis standards of care, including the provision of reasonable accommodations to the triage process. These letters can be found at <https://www.centerforpublicrep.org/covid-19-medical-rationing/>.

its CSC to provide reasonable accommodations for patients with disabilities, avoid reliance on long term prognosis, and limit the potential for explicit and implicit bias in health care rationing decisions.

However, improved Statewide CSC guidelines will not translate into equitable care or consistent allocation of scarce resources unless individual hospitals adopt standards that adhere to these guidelines, and are prepared to implement them should the need arise. For this reason, the Department of Public Health should be charged with ensuring individual hospitals have nondiscriminatory CSC in place that conform to the October 2020 revisions, with triage teams and oversight committees trained to implement those standards, and an appeal process for patients and families who may be deprioritized for, or subject to withdrawal of, life-saving care. The Massachusetts CSC requires all facilities crisis standards be publicly available on their websites, and for triage teams to have competency-based trainings in implicit bias. Enforcement of this expectation, paired with a robust system of State oversight and accountability, is crucial to preventing discrimination in the event crisis standards ever need to be invoked in the future.

### **Support Informed Choice Through Effective Vaccine Education and Outreach**

Accessible information from trusted sources is key to overcoming vaccine hesitancy. Rather than rely exclusively on boiler plate informed consent materials provided at local vaccination sites, we encourage the Commonwealth to: 1) develop toolkits, written materials, and guidance for State agency staff, public health workers, and other community organizations who are engaging individuals around the vaccination process; 2) encourage the use of plain language materials provided in various formats, including videos;<sup>3</sup> 3) create content that can be disseminated in PSAs, radio broadcasts, and social media platforms, and 4) develop scripts to assist medical professionals in communicating effectively with individuals with disabilities.

The Commonwealth also should consider interactive ways to disseminate this information, including opportunities for medical and public health professionals to confidentially answer questions about the vaccines. This is especially important for residents who are not connected to primary care doctors or other trusted medical providers. Outreach strategies should also incorporate testimony from individuals with shared experiences and credibility within communities where hesitancy exists.

Many of the communities most vulnerable to COVID-19 have faced discrimination, language, and insurance barriers that impede their access to care. As a result, they are less likely to access the health care and services they need, including COVID-19 testing and vaccination. For these reasons, we strongly recommend targeted outreach to populations and communities hardest hit by the virus. This work should include forging partnerships with disability organizations, self-advocates, and leaders in cities and towns whose members are at higher risk based by the CDC's

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<sup>3</sup> Many State Developmental Disability Councils have developed explanations of the vaccine in plain language. The NY Office for People with Developmental Disabilities website has resources in multiple languages, available at <https://opwdd.ny.gov/coronavirus-guidance/covid-19-vaccine-plain-language-flyer>. The Wisconsin Board for People with Developmental Disabilities has a COVID-19 resource tool kit available at <https://wi-bpdd.org/index.php/covid-19/>. The Self Advocacy Resource and Technical Assistance Center's COVID-19 Vaccine Information is available at <https://selfadvocacyinfo.org/resource/covid-19-vaccine-information-in-plain-language/>. See also, Information for Residents of Correctional Facilities: Frequently Asked Questions about the COVID-19 Vaccine, available at <https://amend.us/wp-content/uploads/2021/01/COVID-Vaccine-FAQ-Non-CA-v1.pdf>.

[Social Vulnerability Index](#). Through these partnerships with ‘hotspot’ communities, the Commonwealth can develop and share relevant information about testing, surveillance, and vaccine distribution. Essential to the success of this strategy is the intentional recruiting and registration of testing providers and vaccination sites within impacted communities.

Accountable Care Organizations, Managed Care Organizations, Senior Care Options, and One Care plans are also well-positioned to offer information on COVID 19 and support in accessing the COVID 19 vaccine. ACOs and MCOs have care coordinators who can be a resource to members navigating the vaccination process. They have encounter and other data needed to partner with MassHealth in disseminating the vaccine across high risk populations in a manner appropriate to their needs. This includes providing vaccines to home-bound individuals, and coordinating accessible transportation to vaccination centers.

### **Ensure Accessible Testing and Vaccination Programs**

The Commonwealth is moving quickly to approve vaccination sites, and to ensure their qualifications to safely administer the vaccine. It is essential that there be more locations in and near low-income communities and communities hardest hit by the virus. It is also important that appointment scheduling not be limited to state or provider websites, since these platforms may be less accessible to people with disabilities and low-income communities.

As part of the site approval process, it is essential that all locations verify that they understand their obligations under State and federal law to provide physically accessible vaccine administration, and to make reasonable accommodations when necessary to ensure access by persons with disabilities.<sup>4</sup> For instance, individuals with multiple, co-occurring conditions may be unable to stand in long lines, or need the support of a family member or other designed support person when the vaccine is administered. They may need accessible forms, require interpreter services, or rely on adaptive equipment/assistive technology to communicate with staff sharing information about administration of the vaccine. As part of its ongoing oversight of vaccine distribution, the Commonwealth should provide a mechanism for reporting and resolving access issues with responsible State agencies, including the denial of responsible accommodation requests.

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<sup>4</sup> Title II of the ADA prohibits public entities from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Implementing regulations promulgated by the United States Department of Justice (DOJ) define unlawful discrimination under Title II to include, inter alia: using eligibility criteria that screen out or tend to screen out individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8). Title III of the ADA prohibits places of public accommodation from denying qualified individuals the equal enjoyment of their goods, services and facilities, providing separate or unequal benefits, or failing to make reasonable modifications in policies, practices, or procedures, unless such modifications would result in a fundamental alteration. Under Section 504 of the Rehabilitation Act, individuals may not be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance, including those principally involved in the business of health care. Section 1557 of the ACA also provides that no health program or activity that receives federal funds, nor any program or activity administered or established under Title I of the ACA, may discriminate against a person protected by Section 504. Finally, Massachusetts’ Public Accommodation Law prohibits discrimination based on physical or mental disability, including restricting admission to and treatment by health care facilities. *See*, M.G.L. c. 272, §98.

## **Continue to Prioritize Vulnerable Populations and Communities**

By the middle of February, 2021, vaccines should become available for individuals with two or more co-morbid conditions who are at high risk for COVID-19 complications. This stage of the Commonwealth's vaccination plan will be critical to protecting communities of color and persons with disabilities for whom such comorbidities are common. Over the last year, medical professionals and research studies have recognized that serious mental illness, autism, neurological conditions, acquired brain injury, and intellectual and developmental disabilities increase individuals' risk of serious complications and death from COVID-19.<sup>5</sup> To ensure these communities are appropriately protected, the Commonwealth should supplement the CDC's list of health conditions that significantly increase risk of severe illness from COVID-19.<sup>6</sup> We also encourage the Commonwealth to adopt pathways that allows for other co-morbid conditions to be identified and considered in individual cases, keeping in mind that many low income individuals and people from communities of color may not have consistent, ongoing patient relationships with health care providers who know their conditions and can refer them for vaccination.

Our Black and Latino neighbors have been among the hardest hit by the pandemic, and thus far we have failed to implement sufficient measures to protect them. Viral transmission rates remain high in low income communities and among frontline workers. In Massachusetts, 20% of doses in the second wave of vaccinations are purportedly set aside for residents of COVID-19 hotspots, but no plan for delivering these vaccines is in place. Simply setting aside doses is insufficient to ensure that they actually reach marginalized communities, especially when vaccine availability remains a challenge.

## **Enhance Statewide Data Collection, Reporting, and Analysis**

The collection and reporting of public health data, including demographic information, surveillance in the institutional and congregate settings, and tracking of community infection rates has helped the State to better understand how different populations are affected by the virus. This information is critical to identifying disparities in access to and delivery of health care services, and should be used to target resources in a wide variety of areas, from ongoing COVID-

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<sup>5</sup> See, e.g., Double Jeopardy: COVID-19 and Behavioral Health Disparities for Black and Latino Communities in the U.S., SAMSHA (Submitted by OBHE), available at [covid19-behavioral-health-disparities-black-latino-communities.pdf](#); [Risk Factors for COVID-19 Mortality among Privately Insured Patients - A Claims Data Analysis - A FAIR Health White Paper.pdf](#), in Collaboration with the West Health Institute and Marty Makary, MD, MPH, November 11, 2020; [Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis - ScienceDirect](#), Margaret A. Turk, MD, Scott D. Landes, PhD, Margaret K. Formica, MSPH, PhD, Katherine D. Goss, MPH, Disability and Health Journal, July 2020; [Increased risk of COVID-19 infection and mortality in people with mental disorders: analysis from electronic health records in the United States - Wang - 2021 - World Psychiatry - Wiley Online Library](#), QuanQui Wang, Rong Xu, and Nora D. Volkow, World Psychiatry, October 7, 2020; See also, [American Academy of Neurology](#) (“anyone with a neurologic disorder such as brain injury is particularly vulnerable to diseases like influenza and COVID-19”); Open-Letter-from-BIAA-Medical-Directors, January 25, 2021, available at [https://www.biausa.org/wp-content/uploads/dlm\\_uploads/Open-Letter-from-BIAA-Medical-Directors-01.25.21.pdf](https://www.biausa.org/wp-content/uploads/dlm_uploads/Open-Letter-from-BIAA-Medical-Directors-01.25.21.pdf).

<sup>6</sup> See <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>.

19 testing to vaccine distribution efforts.<sup>7</sup> Looking beyond the pandemic, this data should be analyzed and used to disseminate public health funding, inform health care reform strategies, and set objective, measurable benchmarks for progress towards greater health equity.

### **Invest in Programs That Addressing Social Determinants of Health (SDOH)**

The root causes of health inequality begin outside of the health care system. Lack of access to stable, safe and healthy housing, food insecurity, pollutants and environmental hazards, limited access to education, and underemployment all contribute to poor health outcomes for adults and children, further taxing the health care system in Massachusetts. Compounding these barriers are the psychological and physiological impacts of disability and race discrimination on the overall health and well-being of our communities.

Healthcare providers must address SDOH on both a systemic and individual level. Improving health outcomes requires addressing structural barriers to good health and increasing equitable access to education and employment, food and nutrition, stable housing, and economic opportunity. The Commonwealth should invest in, and expand upon State, hospital, and community-based programs with established track records in addressing the root causes of health inequality: Medical Legal Partnerships and health equity programs;<sup>8</sup> the Massachusetts Food Trust;<sup>9</sup> the SNAP benefit program; accessible transportation and paratransit services; crisis intervention and behavioral health services; supported housing, and subsidized 811 and Housing Choice Voucher programs.

Additional recommendations on the equitable distribution of health care resources, and strategies to address SDOH, can be found in the November, 2020 Health Equity Report issued by the Massachusetts Attorney General's Office.<sup>10</sup>

### **Develop Inclusive Strategies and Community Partnerships**

Throughout the pandemic, individuals with disabilities and their allies have fought to make their voices heard on range of public health decisions: the provision of PPE for home and community based service providers; safety precautions and access to testing in institutional and congregate settings; discriminatory policies on health care rationing and hospital visitor restrictions; and vaccine allocation priorities. Although their lives were directly and profoundly impacted by these decisions, people with disabilities were not included in the planning and implementation process. Nor were they tapped to participate in advisory groups and taskforces charged with developing the Commonwealth's pandemic response.

This oversight meant that the unique needs, concerns, and vulnerabilities of the disability community were not properly considered when formulating important health policy decisions,

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<sup>7</sup> See, The Leadership Conference: CIVIL RIGHTS PRINCIPLES FOR COVID-19 VACCINE DEVELOPMENT AND DISTRIBUTION, available at <http://civilrightsdocs.info/pdf/policy/letters/2020/covid-19vaccineprinciples12920.pdf>.

<sup>8</sup> See, e.g., <https://www.bmc.org/mission/social-determinants-health>

<sup>9</sup> See, <https://mapublichealth.org/priorities/access-to-healthy-affordable-food/>.

<sup>10</sup> *Building Toward Racial Justice and Equity in Health: A Call to Action*, Office of the Massachusetts Attorney General, November 2020, available at <https://www.mass.gov/info-details/building-toward-racial-justice-and-equity-in-health-a-call-to-action>.

despite outreach and offers of assistance from disability organizations and self-advocates around the State. In order to meaningfully address health care inequality in the future, people with disabilities must be included in all levels of public health decision-making within the Commonwealth.

### **Equitable Distribution of Health Care Resources**

The Commonwealth's public health system, which was the primary point of responsibility for responding to COVID-19, is both alarmingly decentralized and largely determined by wealth. Each of the 351 local towns has its own department of health, resulting in a fragmented system with significant regional disparities in resources and staffing.<sup>11</sup> Each department is responsible for taking all public health actions in that locality, from collecting COVID-19 data to conducting health inspections of rental units. Each town's department is funded by property taxes. The resulting discrepancy in overall resources is reflected in public health actions, treatment opportunities, infrastructure, and outcomes. The lessons of this pandemic, and the vulnerabilities it exposed, should prompt further research, legislation and investment into the Commonwealth's public health infrastructure. Reform efforts should focus on more equitable funding approaches which preserve local control, but significantly expand the resources and effectiveness of these public health agencies.<sup>12</sup>

Thank you for your consideration of these recommendations, and for the important work undertaken by the Health Equity Taskforce.

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<sup>11</sup> *Building Toward Racial Justice and Equity in Health: A Call to Action*, Office of the Massachusetts Attorney General, November 2020, at p. 50.

<sup>12</sup> See, e.g., the Statewide Accelerated Public Health for Every Community Act (SAPHE 2.0)(S1294/H1935). Sponsored by Senator Jason Lewis and Representatives Kane and Garlick, S1294/H1935 seeks to advance the goals identified by the Special Commission on Local and Regional Public Health, including greater access to training, the promotion of best practices, workforce standards, data reporting, and the sharing of services across municipalities to increase regional service capacity. For more information, see the Massachusetts Public Health Association, legislation fact sheet at [https://mapublichealth.org/wp-content/uploads/2019/09/SAPHE\\_Fact\\_Sheet.pdf](https://mapublichealth.org/wp-content/uploads/2019/09/SAPHE_Fact_Sheet.pdf).