



Center for Public
Representation

Governor Charles Baker
Lt. Gov. Karyn Polito
Secretary Marylou Sudders
Acting Secretary Daniel Tsai
DPH Commissioner Monica Bharel
Attorney General Maura Healy
Senate President Karen Spilka
Speaker of the House Ronald Mariano

January 28, 2021

Dear Governor Baker and other distinguished State officials:

We want to take this opportunity to thank the Administration, and the members of the Vaccine Advisory Group, for their work in developing and rolling out the Commonwealth's vaccine allocation and distribution plan. We appreciate the plans' response to concerns raised by members of this coalition in December 2020,¹ and specifically our requests to prioritize individuals in a range of criminal justice, institutional, and congregate care settings, providers of home and community-based services, and communities of color hard hit by the pandemic.

Our coalition members are actively monitoring vaccine distribution in our respective communities. We are talking with affected individuals about the specific information they need to make an informed choice about vaccination, and the accommodations necessary to ensure they are afforded equal access to this opportunity. We remain open and willing to collaborate with the Administration and other State officials to develop resources and educational materials consistent with these needs.

With regard to current and upcoming phases of vaccine distribution, our members offer specific recommendations for further action by the Administration in the following areas: providing accessible information and resources to individuals in congregate settings; reaching individuals with multiple comorbidities; accessible vaccination sites and procedures; missing priority populations; and data collection and reporting. Each of these recommendations is discussed below.

¹ See <https://www.centerforpublicrep.org/news/cpr-and-partners-weigh-in-on-massachusetts-vaccine-allocation-plans/>.

Supporting informed choice in psychiatric hospitals and congregate settings

Vaccinations are either planned or already underway in many state operated psychiatric hospitals and state licensed and operated congregate care settings, including those overseen by the Department of Developmental Disability Services, the Department of Mental Health, and the Department of Correction. Because of the risks associated with these settings, and the likelihood that individuals in these settings have multiple, co-morbid conditions that place them at higher risk should they contract COVID-19, it is critical that individuals and staff receive accessible information about the vaccine, and the opportunity to ask and receive answers to questions that may be contributing to their vaccine hesitancy.

Rather than rely exclusively on informed consent materials provided at local vaccination sites, we encourage the Commonwealth to: 1) develop toolkits and guidance for State agency staff who are engaging individuals around the vaccination process; 2) encourage the use of accessible, plain language materials in multiple formats,² including videos; 3) provide written resources that point to reliable sources of information on vaccine safety, and 4) develop scripts that might help medical professionals, including PCPs, communicate effectively with individuals with disabilities. Members of this coalition are very willing to help with the identification and development of such materials.

In order to improve vaccine intake in prisons and jails, we recommend a process that allows for medical providers to confidentially answer individual questions from those who are incarcerated, and from corrections staff that may be unsure about taking the vaccine. Because there is sometimes significant distrust of DOC and HOC contracted medical providers by those who are incarcerated, we recommend using external medical providers and public health professionals to confidentially answer questions. The oversight of DPH personnel could also greatly improve vaccine acceptance rates across facilities.

Reaching individuals with multiple comorbidities

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

² 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>.

persons with disabilities for whom such comorbidities are common.³ However, important questions remain regarding how this aspect of the Commonwealth’s plan will be implemented:

- 1) What co-morbid conditions will be considered to increase an individual’s risk for COVID-19 complications, above and beyond those enumerated by the CDC?
- 2) How will the State provide education and outreach to individuals with conditions that place them at higher risk of complications from COVID-19?
- 3) How will individuals with multiple disabilities or co-occurring conditions be accommodated at mass vaccination sites, or in other community provider locations approved to administer the vaccine?

There is no one strategy sufficient to reach all individuals who may be eligible for, and benefit from this prioritization. For that reason, we encourage the Commonwealth to adopt multiple strategies designed to work in concert. We make three specific suggestions below.

First, the Commonwealth should supplement the CDC’s list of health conditions known to significantly increase risk of severe illness from COVID-19.⁴ 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-19.⁵ At a minimum, these conditions should be added to the State’s list of co-morbid conditions eligible for vaccination in Phase II.

Second, we encourage the Commonwealth to adopt pathways that allows for other combinations of co-morbid conditions to be identified and considered in individual cases. For instance, additional conditions could be identified by individuals when completing the proposed self-attestation form. In addition, the Commonwealth could develop a process for individualized

³ 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](https://www.samsha.gov/covid19-behavioral-health-disparities-black-latino-communities.pdf).

⁴ See <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>.

⁵ See, e.g., [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 Psychology, 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.

assessments of unique conditions and circumstances⁶ that justify prioritization for vaccine allocation.⁷ One approach to documenting these assessments would be for the Department of Public Health to develop and make available an electronic COVID-19 vaccination referral form, which can be signed by the responsible physician or other medical professional and shared as part of scheduling a vaccination appointment. This form also could provide one way of indicating whether the individual requires specific reasonable accommodations from the provider site in order to access the vaccine.

However, this approach cannot be the only strategy for identification and referral of persons with conditions that place them at significant risk from the virus. Low income individuals and people from communities of color often do not have ongoing patient relationships with physicians and health care providers who know their individual circumstances and who will suggest they be prioritized based on co-morbid conditions. Other members of our communities have faced disability discrimination, language, and insurance barriers that similarly impede their access to care.

For these reasons, we strongly recommend additional, targeted outreach as a third strategy in this phase of vaccine roll-out. This outreach should include forging partnerships with community leaders in cities and towns hardest hit by the virus, and whose members are at higher risk based by the CDC's Social Vulnerability Index. Through these partnerships, the Commonwealth can develop and share relevant information about vaccine distribution, including alternative ways for individuals with multiple medical conditions to demonstrate their eligibility for vaccination and to secure appointments at local administration sites. Essential to the success of this strategy is the intentional recruiting and registration of provider vaccination sites that are located within hard hit communities and regions, including Suffolk County.⁸

Accountable Care Organizations, Managed Care Organizations, Senior Care Options plans and One Care plans also are well-positioned to be a trusted source of information on COVID 19 and, 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

⁶ For instance, some individuals with autism, developmental or cognitive disabilities may also have sensory issues or behavioral challenges which make it difficult to tolerate masking protocols, or follow social distancing expectations, thus increasing their risk.

⁷ For example, New Hampshire's Vaccination Allocation Plan Summary includes the following statement with regard to identification of persons with two or more comorbid conditions: "[f]lexibility is provided for a health care provider to vaccinate any patient whose primary care provider assesses a significant risk for severe illness due to any multiple co-occurring co-morbidities." Division of Public Health Services, Covid-19 Vaccination Allocation Plan Summary, January 14, 2021, available at <https://www.dhhs.nh.gov/dphs/cdcs/covid19/documents/covid19-vaccine-allocation-plan-summary.pdf>.

⁸ *In Suffolk County, Black and Latino residents face stark disparities in vaccine access*, The Boston Globe, Deanna Pan and John Hancock, available at <https://www.bostonglobe.com/2021/01/23/nation/suffolk-county-black-latino-residents-face-stark-disparities-vaccine-access/>.

their needs. This includes providing vaccines to home-bound individuals, and coordinating accessible transportation to vaccination centers.

Accessible vaccination sites / appointment procedures

We understand that the Commonwealth is moving quickly to approve vaccination sites, and to ensure their qualifications to safely administer the vaccine. As discussed above, it is essential that there be more locations in and near low-income communities and communities most adversely impacted by the virus. It is also important that notice of such sites not only be through the state website or other electronic systems, since these may be less accessible to people with disabilities and low-income communities.

As part of the site approval process, all locations should be expected to 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 equal access by persons with disabilities.⁹ 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 websites, or alternative methods for scheduling appointments, require interpreter services, or rely on adaptive equipment/assistive technology to communicate with staff sharing information about administration of the vaccine. Individuals who are experiencing difficulties accessing the appointment process or vaccination locations due to a lack of accommodations, should be provided a mechanism for reporting and resolving these access issues, and for filing complaints with responsible state agencies, including the Massachusetts Attorney General's Civil Rights Division.

Overlooked populations/settings in vaccine allocation

⁹ 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.

In addition to the vulnerable populations already identified in phase 2, we urge the Commonwealth to include caregivers of medically fragile adults and youth under 16 years of age. Many youth with multiple, comorbid conditions depend upon a family caregiver to provide hands-on personal care, feeding, and even delegated nursing tasks. Since these youth are not eligible for vaccination under the Emergency Use Authorization, vaccination of family caregivers provides them with some additional protection from infection and, more importantly, protects the individuals they rely upon to remain in their homes and communities and out of more restrictive hospital or nursing home placements. The same risk of unnecessary institutionalization is present for adults with complex disabilities who cannot maintain social distancing because of their personal care needs, and who depend upon family caregivers to remain in the community.

Also, in keeping with the joint letter sent to Secretary Sudders on December 22, 2020, we ask that the Commonwealth add site-based day and adult day health settings, and those who staff and attend those programs, to the ongoing administration of vaccine to congregate care settings.¹⁰ Many individuals with disabilities have experienced extreme isolation and lack of access to services during the pandemic. Targeting vaccines to these individuals, their caregivers, and site-based day programs will afford them greater access to necessary services and supports in the community.

Data collection and reporting

Finally, we urge the Commonwealth to utilize data collection strategies to inform its ongoing vaccine distribution efforts. Throughout the pandemic, public health data and analysis has helped the State to understand how different communities are affected by the virus. This information is critical to targeting and tailoring outreach strategies, and necessary to rectify disparities in our health care delivery system and ensure equitable access to the vaccine.¹¹

Thank you for your consideration of these time sensitive recommendations. Any questions can be directed to Kathryn Rucker at krucker@cpr-ma.org.

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¹⁰ Advocates letter on MA Vaccine Prioritization and DDS Funded Congregate Day Settings, available at <https://thearcofmass.org/wp-content/uploads/2021/01/IDD-Vaccine-Letter-12-22-20.PwDRequest.pdf>.

¹¹ 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>.

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