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**Testimony of Allie Bohm
On Behalf of the New York Civil Liberties Union
Before the New York City Council Committees on Health and Hospitals
Regarding Oversight - COVID-19 Vaccine Distribution & Accessibility in
NYC**

January 12, 2021

The New York Civil Liberties Union (NYCLU) is grateful for the opportunity to submit the following testimony regarding oversight of COVID-19 vaccine distribution and accessibility in New York City. The NYCLU, the New York state affiliate of the American Civil Liberties Union, is a not-for-profit, nonpartisan organization with eight offices across the state and over 180,000 members and supporters. The NYCLU defends and promotes the fundamental principles and values embodied in the Bill of Rights, the U.S. Constitution, and the New York Constitution through an integrated program of litigation, legislative advocacy, public education, and community organizing.

The U.S. has long pinned its hopes of emerging from the coronavirus pandemic on the development and distribution of an effective vaccine.¹ And yet, New York City's initial vaccine rollout has been slow. As of last week, the City had distributed just 25% of the COVID vaccines it had received since mid-December, and only around 110,000 New Yorkers have received their first dose of the vaccine.² The City Council must do everything in its power to ensure that all New Yorkers who want to be vaccinated can get the COVID-19 vaccine and that all New Yorkers both are and feel safe doing so. This testimony will focus on three areas where the need for timely, equitable vaccine is particularly acute – congregate care, public schools, and carceral settings – and articulate three challenges the City Council must keep front of mind: vaccine distribution mechanisms; equitable, culturally competent vaccine distribution; and vaccine confidentiality.

¹ *E.g.* David Paul, *Wall Street's Rosy Scenario is About to Come Crashing Down*, MEDIUM, July 21, 2020, <https://davidapaul.medium.com/wall-streets-rosy-scenario-is-about-to-come-crashin-46d96880dfca>; *cf.* *Waiting for a vaccine fairy is for children, not leaders*, SUNDAY INDEPENDENT, Oct. 18, 2020, <https://www.pressreader.com/ireland/sunday-independent-ireland/20201018/282282437780731>.

² Kay Dervishi, *Why can't NYC vaccinate like it's 1947?*, CITY & STATE, Jan. 5, 2021, <https://www.cityandstateny.com/articles/policy/health-care/why-cant-nyc-vaccinate-its-1947.html>.

Vaccine Rollout in Congregate Care Settings

Although individuals living in congregate care settings, including the disabled, were rightly prioritized to receive vaccines, there has been a complete failure to exercise centralized and uniform control over the rollout of the available vaccines to these priority populations. The state appears to have left it to the various Office for People with Developmental Disabilities (OPWDD), Office of Mental Health (OMH), and Office of Addiction Services and Supports (OASAS) congregate care providers in the 1a priority pool to make their own arrangements for their residents and staff to be vaccinated.³

Where nursing home residents are not vaccinated “at home” and workers are not vaccinated at work, they are left to navigate a confusing array of barriers to determine whether they are eligible for the vaccine and, if they are eligible, they must traverse the internet to identify a vaccine location and make an appointment. This is true despite the fact that individuals with developmental disabilities are traditionally the group least likely to be digitally literate.⁴ And, 46% of New York City households living below the poverty line – a category that both home health aides and people with developmental disabilities disproportionately fall into – do not have home internet access.⁵

The challenges these individuals face obtaining vaccines are only likely to increase as New York opens vaccine eligibility to the 1b population without any concomitant increase in the number of doses allocated to the state.⁶ Although Governor Cuomo insists that the 1a populations will remain top priority for vaccination,⁷ in practice the developmentally disabled and others in congregate care settings are likely to lose vaccination slots to the more able and digitally literate individuals in category 1b who will be better able to navigate the online appointment scheduling system, more likely to have the ability to travel to far flung vaccination sites,⁸ or who may be vaccinated at their workplaces.⁹

³ Guidance for the NYS Office for People with Developmental Disabilities (OPWDD), Office of Mental Health (OMH), and Office of Addiction Services and Supports (OASAS) Prioritization of Essential Healthcare and Direct Support Personnel as well as High-Risk Populations for the COVID-19 Vaccination, New York Dep’t of Health 2 (Jan. 2021).

⁴ Darren Chadwick, Caroline Wesson, & Chris Fullwood, *Internet Access by People with Intellectual Disabilities: Inequalities and Opportunities* 5 FUTURE INTERNET 376, 379 (2013).

⁵ *Mayor de Blasio and Taskforce on Racial Inclusion and Equity Announce Accelerated Internet Master Plan to Support Communities Hardest-Hit by COVID-19*, NYC, July 7, 2020, <https://www1.nyc.gov/office-of-the-mayor/news/499-20/mayor-de-blasio-taskforce-racial-inclusion-equity-accelerated-internet-master>.

⁶ See Jeanmarie Evelly, *City Pushes Feds to Deliver More Vaccines to NYC*, CITY LIMITS, Jan. 5, 2021, <https://citylimits.org/2021/01/05/city-pushes-feds-to-deliver-more-vaccines-to-nyc/>.

⁷ Matt Troutman, *Coronavirus Vaccine Expands to NY Elderly, Teachers*, PATCH, Jan. 8, 2021, <https://patch.com/new-york/new-york-city/cuomo-expands-coronavirus-vaccine-eligibility-1-5m-nyc>.

⁸ See *infra* pp. 6 – 7.

⁹ See Press Release, Gov. Andrew Cuomo, Governor Cuomo Updates New Yorkers on COVID-19 Vaccine Distribution Efforts (January 5, 2021) (<https://www.governor.ny.gov/news/governor-cuomo-updates-new-yorkers-covid-19-vaccine-distribution-efforts>) (“To prepare for the next phase of eligibility, the Governor is encouraging essential worker groups such as police departments, fire

Compounding these challenges, there is no public tracking of how many people living in congregate care settings and how many of the staff supporting them have received vaccines, refused vaccination, or are medically counter-indicated. This tracking is necessary to ensure that everyone in these highly vulnerable populations who can tolerate the vaccine and wants to receive a vaccine is able to do so expediently. Governor Cuomo has indicated that all nursing home residents and staff will be vaccinated by the end of the week,¹⁰ and transparent nursing home data is integral to ensure for accountability for meeting this milestone.

The Impact of Vaccines on Public Schools

We are grateful that teachers and education workers are included in Phase 1b of vaccine rollout, which began yesterday.¹¹ The vast majority of New York City public school students (approximately 700,000) still attend classes remotely, and even those who participate in hybrid learning only spend two or three days per week in the classroom. These students also face frequent school closures because of COVID rates in school buildings. For these reasons, the plan for vaccine distribution across New York City must include a thoughtful focus on the needs of public school communities, and vaccination in school communities must be timely and equitable.

The vaccination plan must be crafted to ensure vaccine distribution is used as a tool to bring students back *into* learning environments, not to exclude them unfairly. For example, students should be able to move from virtual to in-person instruction with *reasonable* notice to the school. The current system of one-chance deadlines puts undue pressure on parents to “opt in” to in-person learning even when they are not sure it is safe.¹²

Additionally, the Department of Education (DOE) must improve its school-related COVID data so teachers and families can make smart decisions and vaccines can be directed where they are most needed. Right now, the data available through the DOE’s COVID “situation room” are not reliable or granular enough to be useful, are updated at different times on different days, and do not give complete information.¹³

departments, educators, and public transit organizations to begin developing plans to vaccinate their workforce.”).

¹⁰ Press Release, Gov. Andrew Cuomo, Governor Cuomo Updates New Yorkers on COVID-19 Vaccine Distribution Efforts (January 5, 2021).

¹¹ *Phased Distribution of the Vaccine*, NEW YORK STATE DEP’T OF HEALTH, <https://covid19vaccine.health.ny.gov/phased-distribution-vaccine> (last visited Jan. 11, 2021).

¹² See Elizabeth Kim, *In Major Shift, NYC Will Offer Public School Families Only One More Chance To Opt Into In-Person Learning*, GOTHAMIST, Oct. 26, 2020, <https://gothamist.com/news/major-shift-nyc-will-offer-public-school-families-only-one-more-chance-opt-person-learning>.

¹³ *Daily COVID Case Map*, NYC DOE, <https://www.schools.nyc.gov/school-year-20-21/return-to-school-2020/health-and-safety/daily-covid-case-map> (last visited Jan. 14, 2021); See also, Jillian Jorgenson Twitter post, Jan. 6, 2021, 11:33 a.m.,

https://twitter.com/Jill_Jorgensen/status/1346857310019325954?s=20 (The “situation room” provides the current day’s citywide totals, as well as a cumulative total since the first day of school).

Importantly, the school vaccine plan must ensure that students who not vaccinated are not unfairly and pointlessly excluded from virtual education. At the beginning of this school year, we were contacted by parents whose children were shut out of remote learning because they did not have updated vaccination records on file. Vaccines are an essential public health tool, but in a year when families were advised to avoid leaving the home (including for non-urgent visits to the family doctor) and classes were available online, this denial was pointless and cruel. We urge the City to utilize remote learning capabilities as a tool to make educational opportunities more widely available, not less. While we do not object to traditional mandatory vaccination requirements for school children, we hope that the existence of online learning could at least grant families more leeway to meet deadlines. In the state of New York, education is a right, not a reward for filing the proper paperwork.

Finally, creating an environment where all students feel safe to return to school is essential, but at the same time, it would be a mistake to ignore or deprioritize remote learning simply because a vaccine exists. For some students (who have a space to work, access to high-speed internet, and adequate devices) online learning can be as good or even better than the traditional classroom,¹⁴ and even for students who return to physical classrooms, the need to complete work online and maintain email communication with teachers will only grow. For these reasons, New York City must improve remote learning capabilities and close the digital divide.¹⁵

Vaccine Distribution in Carceral Settings

There is substantial confusion over whether individuals who are incarcerated are included in vaccine priority tier 1b. Zack Fink of NY1 reported on January 5th that Governor Cuomo, Dr. Howard Zucker, and Larry Schwartz told “legislators that inmates . . . are in the next tranche of vaccinations, listed as 1B, along with Corrections Officers,”¹⁶ but Senate Minority Leader Robert Ortton refuted this report, saying that “no decision had been made.”¹⁷ New

¹⁴ See Elizabeth Harris, *Not Everyone Hates Remote Learning. For These Students, It's a Blessing*, N.Y. TIMES, May 2020, <https://www.nytimes.com/2020/05/20/nyregion/coronavirus-students-schools.html>.

¹⁵ There is promise in high-quality virtual education for reaching certain student populations (for example, those with serious health challenges) and delivering education more equitably (for example, allowing students to take advanced courses that are not provided in their home school). The City must invest in building a permanent, 21st-century virtual learning infrastructure to make education more flexible, more meaningful, and to close the homework gap. This means not only putting devices in students' hands, but actually closing the digital divide, adapting curriculum and graduation requirements for virtual learning, and ensuring that student privacy is protected when learning virtually.

¹⁶ Zack Fink (@ZachFinkNews), Twitter (Jan. 5, 2021), <https://twitter.com/ZachFinkNews/status/1346560285428113410?s=20>.

¹⁷ Morgan McKay, SPECTRUM NEWS NY1, Jan. 6, 2021, <https://www.ny1.com/nyc/all-boroughs/ny-state-of-politics/2021/01/06/confusion-over-when-new-york-inmates-will-be-vaccinated>.

York's Phased Distribution website is ambiguous at best on this point.¹⁸ Both Brooklyn Defender Services and New York County Defender Services testified at this hearing that they have been informed that the City will vaccinate high-risk individuals who are incarcerated.¹⁹

Because social distancing is impossible in prisons and jails, the COVID-19 infection and death rates on City jails have been staggering.²⁰ While New York City should work to decarcerate as an important pandemic mitigation measure, it must also prioritize those who are incarcerated in the city jails for informed, consensual vaccination, and their counsel should be involved in conversations about vaccination and vaccine prioritization within the City jails.²¹

At the same time, many questions remain about how vaccination in City jails will function, and the City Council should seek answers to these questions: how is Correctional Health Services (CHS) determining who is high-risk? If the number of high-risk individuals exceeds CHS's allotment, how will vaccines be rationed? When will the vaccine be available to everyone in custody? How will the City ensure that individuals receive both doses of the vaccine if they are released between doses? How are the Department of Correction and CHS educating individuals who are incarcerated about the vaccine and alleviating any fears they may have about it?²² This is particularly important given the U.S.'s long history of medical experimentation on incarcerated populations.²³

¹⁸ *Phased Distribution of the Vaccine*, NEW YORK STATE DEP'T OF HEALTH, <https://covid19vaccine.health.ny.gov/phased-distribution-vaccine> (last visited Jan. 11, 2021). ("describing category 1b as including "Local Correctional Facilities, including correction officers.").

¹⁹ TESTIMONY OF KATHLEEN MCKENNA, BROOKLYN DEFENDER SERVICES, NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS ON OVERSIGHT - COVID-19 VACCINE DISTRIBUTION & ACCESSIBILITY IN NYC (2021); TESTIMONY OF CHRISTOPHER BOYLE, New York County Defender Services, NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS ON OVERSIGHT - COVID-19 VACCINE DISTRIBUTION & ACCESSIBILITY IN NYC (2021).

²⁰ See generally MICHAEL REMPEL, COVID-19 AND THE NEW YORK CITY JAIL POPULATION (Center for Court Innovation, Nov. 2020).

²¹ It is not clear that consent can ever be truly voluntary when an individual is incarcerated, though incarcerated populations are among both the highest risk and the least likely to have access to adequate medical care. Cf. Camila Strassle, E. Jardas, Jorge Ochoa, Benjamin E. Berkman, Marion Danis, Annette Rid, & Holly A. Taylor, *Covid-19 Vaccine Trials and Incarcerated People – The Ethics of Inclusion*, 383 N. ENGL. J. MED. 1897 (2020).

²² See, e.g., *infra* pp. 10 – 12.

²³ See generally Greg Dober, *Cheaper than Chimpanzees: Expanding the Use of Prisoners in Medical Experiments*, PRISON LEGAL NEWS, Mar. 15, 2008, <https://www.prisonlegalnews.org/news/2008/mar/15/cheaper-than-chimpanzees-expanding-the-use-of-prisoners-in-medical-experiments/>.

Vaccine Distribution Mechanisms

Both for prioritized populations and as vaccines become more widely available, New York must focus on ensuring that its vaccine distribution mechanisms are robust and reach all of our communities.

The federal government has announced that it will use the traditional private health infrastructure that delivers the flu vaccine (major pharmacy chains, doctors' offices, and hospitals) to distribute COVID-19 vaccines.²⁴ Unfortunately, the traditional private health infrastructure does not serve all communities equally. In fact, this network is woefully inadequate in the neighborhoods hardest hit by COVID-19. This is unsurprising, given that the pandemic has disproportionately impacted New York City's lower income neighborhoods that are home to a high percentage of essential workers and individuals who cannot work from home.²⁵ For example, Manhattan has nearly *four times* as many traditional vaccination sites as the Bronx – despite comparable borough populations.²⁶ Particularly galling, there is only *one* lonely vaccination site in East Elmhurst, Queens,²⁷ which is home to more than 23,000 people.²⁸

New York City's newly released COVID-19 vaccine finder paints an even starker picture than the traditional vaccine network map.²⁹ Entire neighborhoods – like Woodside, Corona, Fresh Meadows, Bayside, Queens Village, South Richmond Hill, and Ozone Park in Queens; Brownsville and Fort Hamilton in Brooklyn; Parkchester, Throgs Neck, and Hunts Point in the Bronx; Washington Heights and Inwood in Manhattan; and Willowbrook and Woodrow on Staten Island – lack a single COVID-19 vaccination site.³⁰

The paucity of traditional vaccination sites in lower income communities that have been devastated by the pandemic is likely to be exacerbated by the extremely cold storage required for the two vaccines that have so far been granted emergency use authorization (EUA). Pfizer's vaccine must be stored at -70 degrees Celsius and will go bad if not injected within five days of thawing.³¹ Moderna's vaccine must be stored at -20 degrees Celsius,

²⁴ Press Release, Gov. Andrew Cuomo, Audio & Rush Transcript: Governor Cuomo Updates New Yorkers on State's Progress During COVID-19 Pandemic (Nov. 2, 2020) (<https://www.governor.ny.gov/news/audio-rush-transcript-governor-cuomo-updates-new-yorkers-states-progress-during-covid-19-18>).

²⁵ See Joseph Goldstein, *1.5 Million Antibody Tests Show What Parts of N.Y.C. Were Hit Hardest*, N.Y. TIMES, Aug. 19, 2020, <https://www.nytimes.com/2020/08/19/nyregion/new-york-city-antibody-test.html>.

²⁶ *Flu Vaccine*, NYC, <https://a816-healthpsi.nyc.gov/NYHealthMap/> (last visited Dec. 2, 2020).

²⁷ *Id.*

²⁸ U.S. Census Bureau, Census 2010, Table PL-P5 NTA: Total Population Per Acre New York City Neighborhood Tabulation Areas.

²⁹ See *COVID Vaccine Finder*, NYC, <https://vaccinefinder.nyc.gov/locations> (last visited Jan. 12, 2021).

³⁰ *Id.*

³¹ *Deep-Freeze Challenge Makes Pfizer's Shot a Vaccine for the Rich*, BLOOMBERG, Nov. 10, 2020, <https://www.bloomberg.com/news/articles/2020-11-10/deep-freeze-challenge-makes-pfizer-s-shot-a-vaccine-for-the-rich>.

although it remains stable for 30 days at 2 – 8 degrees Celsius.³² Extreme cold storage and transport procedures (“cold chains”) are expensive, and to ensure that the vaccines that are now available via EUA are not solely options for the rich, appropriate cold chains will need to be established throughout the City.³³

While we are grateful that the City and state have supplemented the traditional private health infrastructure by enlisting community-based providers to serve as vaccination sites, we have learned that these providers face myriad bureaucratic hurdles to effectively and efficiently distributing vaccines. In fact, the bureaucratic hurdles are so high – and the penalties for a mistake are so steep – that some medical providers were forced to throw out vaccine doses, because they simply could not find people to vaccinate who met all of the state’s vaccination criteria.³⁴ In addition, we understand that community-based providers were told on January 3rd that they may be stripped of their vaccine supply³⁵ or denied subsequent vaccine allocations³⁶ if they did not distribute their entire initial supply of vaccines by Thursday, January 7th. Those that have used their entire vaccine supply do not know whether or when their doses will be replenished. Community-based providers are deeply integrated into their communities and are trusted sources of care for the populations they serve. They therefore have an integral role to play in ensuring that the vaccine reaches everyone.

The City Council must do everything in its power to ensure that the vaccine reaches all of our communities and to make sure that individuals do not have to traverse the city to receive vaccines, but rather can be vaccinated – without substantial wait times – within their neighborhoods. In addition to supporting vaccination programs within the existing community-based health care providers, this should include partnering with community-based organizations to establish additional vaccination sites that are local, culturally competent, and linguistically inclusive. The City should also ensure free and accessible transportation to existing vaccination sites, as well as guarantee job-protected time off work to get vaccinated, where necessary. And, the City should engage in a culturally competent and linguistically inclusive public education campaign to ensure that all of our communities know where they can receive vaccines.

³² Press Release, Moderna, Moderna Announces Longer Shelf Life for its COVID-19 Vaccine Candidate at Refrigerated Temperatures (Nov. 16, 2020) (<https://investors.modernatx.com/news-releases/news-release-details/moderna-announces-longer-shelf-life-its-covid-19-vaccine>).

³³ *Deep-Freeze Challenge Makes Pfizer’s Shot a Vaccine for the Rich*, BLOOMBERG, Nov. 10, 2020, <https://www.bloomberg.com/news/articles/2020-11-10/deep-freeze-challenge-makes-pfizer-s-shot-a-vaccine-for-the-rich>.

³⁴ Dana Rubinstein, *After Unused Vaccines Are Thrown in Trash, Cuomo Loosens Rules*, N.Y. TIMES, Jan. 10, 2021, <https://www.nytimes.com/2021/01/10/nyregion/new-york-vaccine-guidelines.html>.

³⁵ Letter from Howard A. Zucker, M.D., J.D., Commissioner of Health, New York State Dep’t of Health, to COVID-19 Vaccine Provider (Jan. 3, 2021) (on file with the author).

³⁶ Press Conference, Gov. Andrew Cuomo, (Jan. 8, 2021).

Equitable, Culturally Competent Vaccine Distribution

New York has articulated its first priority groups for vaccination.³⁷ In addition to the health care workers; those working at and those living in congregate settings, including the elderly and the disabled; teachers and other school staff; public transit workers; and pharmacy and grocery store workers; individuals living or working in homeless shelters with shared “sleeping, bathing or eating accommodations” who are already prioritized, New York must also prioritize those working at and those detained in prisons and jails; essential workers of all stripes; those with pre-existing medical conditions; and those whose racial, ethnic, and socioeconomic circumstances heighten their vulnerability; among others.

It is imperative that New York focus on those with the most need and that, within the prioritized groups, vaccines be distributed on an equitable basis. The City must also develop efficient, easily accessible, simple-to-use ways for New Yorkers to sign-up to be vaccinated. At present, while the City hosts a centralized vaccine finder website,³⁸ individuals must navigate to each provider’s website to try to register for one of precious few vaccination slots, often filling out the same intake materials over and over again with each new attempt to obtain an appointment.³⁹ Comptroller Scott Stringer reports that “[t]hose seeking appointments [at DOHMH locations] must fill out a multi-step verification process to set up an account and face about 51 questions or fields to check off.”⁴⁰ Although the City has developed a hotline for New Yorkers to make appointments, that phone line is often overwhelmed and, moreover, only accommodates English and Spanish speakers.⁴¹ This is unacceptable. The City must ensure that all of our communities – particularly those who endure multiple burdens, including limited English language proficiency, digital illiteracy, and lack of connectivity – are able to easily schedule vaccination appointments.

And, the City must accommodate those who, whether for fear of deportation, criminalization, losing custody of their children, or any other reason, may be afraid to share intimate information with the government. This is particularly true when it comes to intake forms, like CVS’s, that ask for a social security number, state identification number, or driver’s license number for individuals who are uninsured;⁴² there is no reason that vaccine providers should be soliciting this information.⁴³

³⁷ *Phased Distribution of the Vaccine*, NEW YORK STATE DEP’T OF HEALTH, <https://covid19vaccine.health.ny.gov/phased-distribution-vaccine> (last visited Jan. 8, 2021).

³⁸ *COVID Vaccine Finder*, NYC, <https://vaccinefinder.nyc.gov/locations> (last visited Jan. 12, 2021).

³⁹ Sydney Pereia, *New Yorkers Eligible for COVID Vaccine Report Frustrations With City Registration Websites*, GOTHAMIST, Jan. 11, 2021, <https://gothamist.com/news/new-yorkers-eligible-vaccine-report-frustrations-city-registration-websites>.

⁴⁰ *Id.*

⁴¹ COUNCILMEMBER MENCHACA, NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS ON OVERSIGHT - COVID-19 VACCINE DISTRIBUTION & ACCESSIBILITY IN NYC (2021).

⁴² *COVID Vaccine Intake Consent Form*, CVS, [https://info.omnicare.com/rs/095-VIX-](https://info.omnicare.com/rs/095-VIX-581/images/COVID%2019%20Vaccine%20Intake%20Consent%20Form.pdf)

581/images/COVID%2019%20Vaccine%20Intake%20Consent%20Form.pdf (last visited Jan. 12, 2021).

⁴³ See *infra* pp. 12 – 14.

In addition, the options on these vaccine sign-up forms must include individuals whose gender does not align with the gender binary and transgender people. We have heard reports that some intake forms inquire about a potential vaccine recipient's sex assigned at birth. We are aware of no reason these forms should include a question that is so likely to provoke fear and othering.

The City must also develop a mechanism for distributing vaccines to those for whom traditional identification documents present a problem, including undocumented individuals.⁴⁴ At a minimum, vaccination sites must accept a broad range of identity documents, including foreign IDs and documents besides photo identification, such as utility bills. The City must also establish ways for individuals who lack such documents to receive vaccines, because many low-income individuals and people experiencing homelessness do not have identification documents.⁴⁵

In addition, we have heard reports of individuals who were denied vaccines because they are pregnant even though the EUA explicitly contemplates vaccination of pregnant people⁴⁶ and despite the fact that New York law proscribes medical providers from overriding a pregnant person's informed consent to receive a vaccine.⁴⁷ The City must ensure that pregnant people are in the position to decide whether to be vaccinated – which includes having access to the information they need to make the best decision for themselves⁴⁸ – without interference from paternalistic medical providers or paternalistic government actors.

⁴⁴ Despite IDNYC and the state's Green Light law, which make identity documents available to undocumented New Yorkers, ID requirements continue to present unique challenges for undocumented people.

⁴⁵ See BRENNAN CTR. FOR JUSTICE, *CITIZENS WITHOUT PROOF: A SURVEY OF AMERICANS' POSSESSION OF DOCUMENTARY PROOF OF CITIZENSHIP AND PHOTO IDENTIFICATION* 3 (Nov. 2006), https://www.brennancenter.org/sites/default/files/legacy/d/download_file_39242.pdf (“At least 15 percent of voting-age American citizens earning less than \$35,000 per year do not have a valid government-issued photo ID.”); NAT'L LAW CTR. ON HOMELESSNESS & POVERTY, *PHOTO IDENTIFICATION BARRIERS FACED BY HOMELESS PERSONS: THE IMPACT OF SEPTEMBER 11* 13 (Apr. 2004) (“A total of 10.7% of clients lacked photo identification.”).

⁴⁶ *E.g.* Letter to Elisa Harkins, Pfizer Inc., from Denise M. Hinton, Chief Scientist, Food & Drug Admin. (Dec. 23, 2020, <https://www.fda.gov/media/144412/download>) (“Each periodic safety report is required to contain descriptive information which includes: . . . A narrative summary and analysis of adverse events submitted during the reporting interval, including interval and cumulative counts by age groups, special populations (e.g., pregnant women) . . .”); FACTSHEET FOR HEALTHCARE PROVIDERS ADMINISTERING VACCINE (VACCINATION PROVIDERS) EMERGENCY USE AUTHORIZATION (EUA) OF THE MODERNA COVID-19 VACCINE TO PREVENT CORONAVIRUS DISEASE 2019 (COVID-19), FOOD & DRUG ADMIN. (Dec. 2020) (“There is a pregnancy exposure registry that monitors pregnancy outcomes in women exposed to Moderna COVID-19 Vaccine during pregnancy. Women who are vaccinated with Moderna COVID-19 Vaccine during pregnancy are encouraged to enroll in the registry . . .”).

⁴⁷ See *Schloendorff v. Soc'y. of New York Hosp.*, 211 N.Y. 125, 129 (1914); *Rivers v. Katz*, 67 N.Y.2d 485, 493 (1986).

⁴⁸ N.Y. Pub. Health Law § 2805-d (McKinney 2017).

Moreover, it is imperative that everyone who receives a vaccine has first given voluntary, informed consent.⁴⁹ The initial vaccines are distributed under an EUA, which means that the FDA released the vaccine “without all of the evidence that would fully establish its effectiveness and safety” and without reviewing – or having access to – all of the information and evidence that it typically would before approving a drug, device, or test in the normal course.⁵⁰

Many, particularly in the Black community, remember the Tuskegee syphilis study – when, in the 1930s, the U.S. government studied the trajectory of untreated syphilis in hundreds of Black men, both concealing the nature of their research and withholding effective treatment after one had been identified – as well as surgical experimentation on enslaved people.⁵¹ To individuals who still face stark disparities in the U.S. health care system,⁵² Tuskegee feels ever-present. Black patients suffering from appendicitis, broken bones, and other serious conditions are less likely to be offered painkillers than white patients,⁵³ and in 2016 researchers found that half of white medical students surveyed “were willing to entertain one or more false statements about biological differences based on race, such as the notion that African Americans have less-sensitive nerve endings than whites.”⁵⁴ In fact, COVID-19 researchers are using a cell line that originated from Henrietta Lacks, a Black woman whose cells were harvested without her knowledge and consent. And, although research done with so-called HeLa cells “underpin[] much of modern medicine . . . [n]one of the biotechnology or other companies that profited from her cells passed any money back to her family.”⁵⁵

⁴⁹ It is not clear that consent can ever be truly voluntary when an individual is incarcerated, though incarcerated populations are among both the highest risk and the least likely to have access to adequate medical care. Cf. Camila Strassle, E. Jardas, Jorge Ochoa, Benjamin E. Berkman, Marion Danis, Annette Rid, & Holly A. Taylor, *Covid-19 Vaccine Trials and Incarcerated People – The Ethics of Inclusion*, 383 N. ENGL. J. MED. 1897 (2020).

⁵⁰ Joshua Sharfstein, MD, *What Is Emergency Use Authorization?*, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH, Oct. 20, 2020, <https://www.jhsph.edu/covid-19/articles/what-is-emergency-use-authorization.html>.

⁵¹ Peter Jamison, *Anti-vaccination leaders fuel [B]lack mistrust of medical establishment as covid-19 kills people of color*, WASH. PO., July 17, 2020, https://www.washingtonpost.com/dc-md-va/2020/07/17/black-anti-vaccine-coronavirus-tuskegee-syphilis/?hpid=hp_hp-banner-main_black-antivax-940am%3Ahomepage%2Fstory-ans.

⁵² Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018).

⁵³ Peter Jamison, *Anti-vaccination leaders fuel [B]lack mistrust of medical establishment as covid-19 kills people of color*, WASH. PO., July 17, 2020, https://www.washingtonpost.com/dc-md-va/2020/07/17/black-anti-vaccine-coronavirus-tuskegee-syphilis/?hpid=hp_hp-banner-main_black-antivax-940am%3Ahomepage%2Fstory-ans.

⁵⁴ *Id.*; Sandhya Somashekhar, *The disturbing reason some African American patients may be undertreated for pain*, WASH. PO., Apr. 5, 2016, <https://www.washingtonpost.com/news/to-your-health/wp/2016/04/04/do-blacks-feel-less-pain-than-whites-their-doctors-may-think-so/>.

⁵⁵ *Henrietta Lacks: science must right a historical wrong*, NATURE, Sept. 1, 2020, <https://www.nature.com/articles/d41586-020-02494-z>.

Indigenous Americans, too, have survived “significant unethical research and medical care” since colonization.⁵⁶ Latinx New Yorkers remember that between the 1930s and the 1970s, approximately one-third of Puerto Rican women and girls were forcibly sterilized.⁵⁷ This history feels strikingly present as immigrants detained in ICE facilities in Georgia this year report forced hysterectomies.⁵⁸ Against this backdrop, it is no wonder that some communities are skeptical of vaccines, particularly if pushed too forcefully upon them when the vaccine is experimental and new.⁵⁹ Getting New Yorkers to take this vaccine will require planning, care, and sensitivity to these concerns.

Unfortunately, throughout the pandemic response, both the City and state have failed to prioritize cultural and linguistic competence and meaningful community engagement – to all of our detriments.⁶⁰ Given the City’s high vaccine refusal rate,⁶¹ it appears to be making the same mistakes once again. These community engagement failures are public health failures. The City must work with community members and community-based organizations to engage all New Yorkers in the vaccination effort. Just as community members have been more effective at convincing their neighbors to wear masks and adhere to social distancing,⁶² community members and organizations are more likely than outsiders to know how to convince their neighbors to get vaccinated.

⁵⁶ See Felicia Schanche Hodge, *No Meaningful Apology for American Indian Unethical Research Abuses*, 22 ETHICS & BEHAVIOR 431 (2012).

⁵⁷ Katherine Andrews, *The Dark History of Forced Sterilization of Latina Women*, UNIV. OF PITTSBURGH, Oct. 30, 2017, <https://www.panoramas.pitt.edu/health-and-society/dark-history-forced-sterilization-latina-women>.

⁵⁸ Caitlin Dickerson, Seth Freed Wessler, & Miriam Jordan, *Immigrants Say They Were Pressured Into Unneeded Surgeries*, N.Y. TIMES, Sept. 29, 2020, <https://www.nytimes.com/2020/09/29/us/ice-hysterectomies-surgeries-georgia.html>.

⁵⁹ E.g. Desi Rodriguez-Lonebear, PhD (@native4data), Twitter (Nov. 25, 2020), <https://twitter.com/native4data/status/1331818437211955204>. Nearly half of Black people in the U.S. say they will avoid a vaccine “even if scientists deem it safe and it is available for free,” and 40% of Hispanic adults expressed skepticism about getting vaccinated while “two-thirds of white people said they would definitely or probably get vaccinated.” Press Release, Kaiser Family Foundation & The Undeclared, New Nationwide Poll by the Kaiser Family Foundation and The Undeclared Reveals Distrust of the Health Care System Among Black Americans (Oct. 13, 2020) (<https://www.kff.org/racial-equity-and-health-policy/press-release/new-nationwide-poll-by-the-kaiser-family-foundation-and-the-undeclared-reveals-distrust-of-the-health-care-system-among-black-americans/>).

⁶⁰ See generally NYCLU, TESTIMONY BEFORE THE NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS REGARDING OVERSIGHT OF NYC’S COVID-19 TESTING AND CONTACT TRACING PROGRAM, PART II (2020).

⁶¹ See Henry Goldman & Keshia Clukey, *N.Y. Front-Line Workers to Lose Place in Line If Skip Shot*, BLOOMBERG, Jan. 7, 2021, <https://www.bloomberg.com/news/articles/2021-01-07/nyc-s-de-blasio-blames-state-for-thousands-of-unused-vaccines> (“More than 30% of health workers resist jabs, causing surplus.”).

⁶² Ashley Southall, *Police Face Backlash Over Virus Rules. Enter ‘Violence Interrupters.’*, N.Y. TIMES, May 22, 2020, <https://www.nytimes.com/2020/05/22/nyregion/Coronavirus-social-distancing-violence-interrupters.html>.

In addition, as long as there are not enough vaccines to go around, New York City must eschew any temptation to make vaccination a pre-requisite for employment, education,⁶³ housing, or public accommodations. Such a requirement could worsen New York's existing racial, disability, and economic disparities.⁶⁴ In addition, some individuals may never be able to be vaccinated because of medical counterindications. These individuals must be able to continue to participate in society. As New York City adapts its policies to the changing realities of the pandemic, it must maximize adherence to the best public health practices and to equity.

Vaccine Confidentiality

In November, the federal government informed states that it was conditioning distribution of any COVID-19 vaccine to a state on that state's signing a data use agreement (DUA)⁶⁵ that committed to provide the federal government with a wealth of personal information about each vaccine recipient, including, but not limited to, name, address, date of birth, and identification number.⁶⁶ The sweeping nature of this data sharing agreement was unprecedented.

Although the federal Centers for Disease Control (CDC) run other vaccination programs and infectious disease surveillance programs, patients' personally identifiable information typically remains with state or local departments of health.⁶⁷ This is true, for example, when it comes to information collected to inform the federal government's response to the other pandemic we have faced in our lifetimes: the national HIV surveillance program.⁶⁸

What is more, that data sharing agreement was explicit that the CDC and the federal Department of Health and Human Services (HHS) could share vaccine recipients'

⁶³ COVID-19 vaccines have not yet even been tested on young people. Denise Grady, *Moderna Plans to Begin Testing Its Coronavirus Vaccine in Children*, N.Y. TIMES, Dec. 2, 2020, <https://www.nytimes.com/2020/12/02/health/Covid-Moderna-vaccine-children.html>.

⁶⁴ Cf. Esha Bhandari & ReNika Moore, *Coronavirus Immunity Passports' are not the Answer*, ACLU, May 18, 2020, <https://www.aclu.org/news/privacy-technology/coronavirus-immunity-passports-are-not-the-answer/>.

⁶⁵ Data Use and Sharing Agreement to Support the United States Government's COVID-19 Emergency Response Jurisdiction Immunization and Vaccine Administration Data Agreement (Nov. 9, 2020) (on file with the author).

⁶⁶ See CENTERS FOR DISEASE CONTROL AND PREVENTION, COVID-19 VACCINATION PROGRAM INTERIM PLAYBOOK FOR OPERATIONS 63 – 64 (Oc. 29, 2020).

⁶⁷ E.g. *Statistics Center*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/hiv/statistics/index.html> (last visited Dec. 2, 2020) (“CDC'S National HIV Surveillance System is the primary source for monitoring HIV trends in the United States. CDC funds and assists state and local health departments to collect the information. Health departments report de-identified data to CDC so that information from around the country can be analyzed to determine who is being affected and why.”).

⁶⁸ *Id.*

information with “other federal partners,”⁶⁹ which could include Immigration and Customs Enforcement (ICE), the FBI, or the Department of Homeland Security (DHS). This too was without precedent.⁷⁰ Any number of people are likely to be chilled from receiving vaccines if they believe their personal information will be shared broadly within the federal government. This is particularly true for Black, brown, and immigrant communities, who, due to a toxic cocktail of socioeconomic factors, physical environment, and inferior access to health care,⁷¹ are disproportionately likely to suffer from COVID-19.⁷² They are also disproportionately likely to be alienated from and distrustful of our health care system because of the racial biases that pervade that system.⁷³ This is also true of religious enclaves, such as New York City’s Hasidic community, which has also been ravaged by COVID-19,⁷⁴ still harbors deep distrust of the public health system and government after 2019’s bruising battle over the repeal of religious exemptions for vaccines,⁷⁵ and feels singled out for pandemic-related enforcement.⁷⁶

⁶⁹ Data Use and Sharing Agreement to Support the United States Government’s COVID-19 Emergency Response Jurisdiction Immunization and Vaccine Administration Data Agreement (Nov. 9, 2020) (on file with the author).

⁷⁰ *E.g.* *National Immunization Surveys*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/vaccines/imz-managers/nis/confidentiality.html> (last visited Dec. 2, 2020) (“It is against federal law for us to give your name or any other information that could identify you to anyone, including the President, Congress, National Security Agency, Department of Homeland Security, Internal Revenue Service, Immigration and Naturalization Service, or welfare agencies for any reason.”)

⁷¹ *NCHHSTP Social Determinants of Health*, CENTERS FOR DISEASE CONTROL, <https://www.cdc.gov/nchhstp/socialdeterminants/index.html> (last visited May 14, 2020); *see also* Ibram X. Kendi, *Stop Blaming Black People for Dying of the CoronaVirus*, ATLANTIC, Apr. 14, 2020, <https://www.theatlantic.com/ideas/archive/2020/04/race-and-blame/609946/>.

⁷² *Fatalities*, NYS DEP’T OF HEALTH, <https://covid19tracker.health.ny.gov/views/NYS-COVID19-Tracker/NYSDOHCOVID-19Tracker-Fatalities?%3Aembed=yes&%3Atoolbar=no&%3Atabs=n> (last visited May 26, 2020); *see also* *The Color of Coronavirus: COVID-19 Deaths By Race And Ethnicity in the U.S.*, AMP RESEARCH LAB, May 20, 2020, <https://www.apmresearchlab.org/covid/deaths-by-race>; John Eligon, Audra D.S. Burch, Dionne Searcey, & Richard A. Oppel Jr., *Black Americans Face Alarming Rates of Coronavirus Infection in Some States*, N.Y. TIMES, Apr. 14, 2020, <https://www.nytimes.com/2020/04/07/us/coronavirus-race.html>.

⁷³ Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018).

⁷⁴ Joseph Goldstein, *N.Y.C. Warns About Rising Virus Cases in Hasidic Neighborhoods*, N.Y. TIMES, Sept. 22, 2020, <https://www.nytimes.com/2020/09/22/nyregion/coronavirus-Orthodox-Jewish-neighborhoods.html> (“In late April, roughly 700 members of New York City’s Hasidic community were believed to have been killed by the disease, and few families have been spared . . . In some areas with significant Hasidic populations, more than 40 percent of people being tested were found to have antibodies.”).

⁷⁵ *See* Bobby Allyn, *New York Ends Religious Exemptions For Required Vaccines*, NPR, June 13, 2019, <https://www.npr.org/2019/06/13/732501865/new-york-advances-bill-ending-religious-exemptions-for-vaccines-amid-health-cris>.

⁷⁶ Liam Stack & Joseph Goldstein, *New York Threatens Orthodox Jewish Areas With Lockdown Over Virus*, N.Y. TIMES, Sept. 25, 2020, <https://www.nytimes.com/2020/09/25/nyregion/coronavirus-orthodox-jewish-communities.html>.

Fortunately, in early December, as a result of advocacy from many organizations and several states, including New York, the CDC did roll back the most egregious parts of the DUA. The new DUA states explicitly in Appendix G that vaccine recipient information will not be used “for any civil or criminal prosecution or enforcement, including, but not limited to, immigration enforcement, against such individuals whose information is shared pursuant to this DUA.”⁷⁷ It is also explicit that the federal government “will not seek social security numbers, driver’s license numbers, or passport numbers.”⁷⁸ But, the DUA itself continues to insist that only states with a state law or regulation prohibiting them from sharing identifiable information about vaccine recipients may send de-identified information to the federal government; all other states are still required to share vaccine recipients’ identifiable information.⁷⁹ New York has no such law, which means that New York will still be required to share vaccine recipients’ names, addresses, dates of birth, and other personal information with the federal government, unless or until we pass such a law. Moreover, the latest DUA continues to permit the federal government to unilaterally change its appendices with only notice to the states – that is, without the opportunity to agree or disagree to the changes.⁸⁰ This means that the protections in Appendix G could disappear at any time. New York must remain vigilant.

At the same time, councilmembers must be careful to avoid spreading confusion and fear about the risks of information sharing so as not to exacerbate a chilling effect. And, City Council must do everything it can to ensure that New York does not share troves of vaccine recipients’ personal information with the federal government and that, where information is shared, it remains entirely within federal health agencies. This advocacy should include re-evaluating and strengthening, where necessary, the protections for the Citywide Immunization Registry, as well as pressuring state and federal lawmakers to adopt policies that protect vaccine recipients’ personal information, because no one should have to worry that information shared to respond to a public health crisis will be used to criminalize or deport them or to take their children away.

The NYCLU thanks the Committees for the opportunity to provide testimony and for their consideration of this critically important issue.

⁷⁷ Data Use and Sharing Agreement to Support the United States Government’s COVID-19 Emergency Response Jurisdiction Immunization and Vaccine Administration Data Agreement 24 (Dec. 1, 2020) (<https://www.cdc.gov/vaccines/covid-19/reporting/downloads/vaccine-administration-data-agreement.pdf>)

⁷⁸ *Id.*

⁷⁹ *Id.* at 2.

⁸⁰ *Id.* at 9. Appendix G does permit states to refuse changes to the data elements required under the DUA, presumably because the federal government requires state cooperation to receive additional data elements information. *Id.* at 24.