



**ACLU OF ILLINOIS GUIDANCE: ADDRESSING ILLINOIS' PLAN FOR  
PRIORITY ACCESS TO INITIAL COVID-19 VACCINE**

COVID-19 has had a disproportionately severe impact on many groups, including individuals living with disabilities; those living in neighborhoods suffering the adverse effects of institutional racism in policing, the prison system, the health care system, and other societal institutions; youth in state foster care; and individuals who are incarcerated or in detention. The ACLU of Illinois represents many of these communities through its advocacy and in litigation.

As Illinois prepares for initial distribution of limited supplies of COVID-19 vaccine, the manner in which particular groups of individuals are given priority access to vaccination must recognize and protect the rights and civil liberties of Illinois' citizens.<sup>1</sup> Below, we make specific requests for refinements to Illinois' current Plan for vaccine distribution.<sup>2</sup>

**Summary of Requests**

- 1. Within the first tier of distribution to healthcare workers within Phase 1a, Illinois must prioritize on-site staff (those who cannot work from home) first in hospitals, and then in congregate residential settings of all kinds. This distribution should *not* be driven by geographic location or county.**
- 2. The next tier of distribution to health care workers in Phase 1a must prioritize above all others (paid or unpaid) who are not on-site facility staff, but who provide direct, supportive care to individuals with disabilities and/or mental illness, whether those individuals live in institutions or in the community.**
- 3. DCFS workers who investigate alleged abuse and neglect or who provide direct casework service to children in State care or custody should be given the same Phase 1a priority as law enforcement, fire department, and other "first responders."**
- 4. When there is insufficient supply to vaccinate all members of a particular priority group, preference within that group should prioritize those who live in communities that have been most vulnerable to COVID-19 infection and death due to the impacts of longstanding institutional racism.**
- 5. Within Phase 1b and thereafter, Illinois should adopt the concept of "critical risk" workers, which gives priority to those employed in "essential" functions who *also* are unable to work from home.**

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<sup>1</sup> This communication focuses on the appropriate prioritizing groups for vaccination while vaccine supply is limited. That focus should not be construed as a suggestion that there are no other civil liberty concerns in respect to the vaccination plan (e.g., issues relating to data collection and privacy protections).

<sup>2</sup> The Illinois draft "SARS-CoV-2/COVID-19 Mass Vaccination Planning Guide V3," available at <https://dph.illinois.gov/sites/default/files/COVID19/IL%20COVID19%20Vaccination%20Plan%20V%203.0%2012.5.20%20.pdf>, is referred to herein as Illinois' "Plan."

6. **All individuals living in any form of institutional and other congregate residential facilities and who are at high risk for severe COVID-19 illness or death should be given equal Phase 1b priority, and the “high risk” group should be expanded to include a secondary group of individuals aged 50 and above.**
7. **It is essential for Illinois to ensure that those receiving vaccination do so through informed consent.**
8. **It is essential that Illinois ensure fair access for indigenous peoples residing within the State.**
9. **The vaccination system must be equally and fairly available to all, regardless of whether they are citizens or have current “documentation.”**
10. **Illinois must begin work immediately to ensure that comprehensive translations of public-facing information are available as the vaccination program expands.**

### **Explanation of the Requests**

In preparing our requests, we have carefully reviewed the newly-issued ACIP recommendation regarding initial allocation of vaccines (“ACIP” Recommendation),<sup>3</sup> the Illinois Plan for vaccine distribution, various guidance materials issued to date by the CDC and the US. Department of Health and Human Services (“DHS”) in respect to potential vaccine characteristics (including dosage, shipment and storage requirements that may impact vaccine administration) the ethical principles and practical considerations involved in initial distribution of a limited supply of one or more COVID-19 vaccines.<sup>4</sup> We have also reviewed various DHS Bulletins issued by the U.S. Department of Health and Human Services affirming that COVID-19 healthcare must be delivered in a non-discriminatory manner.<sup>5</sup>

Our requests further take into consideration the likelihood that more than one brand of vaccine may be available when the program begins, that initial vaccine brands likely will require two-doses (each of the same brand) administered several weeks apart, and that ultra-cold requirements for shipping and storing vaccine doses will impact the process of vaccine administration.

### **Requests 1 and 2 – Top priority for certain health care workers.**

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<sup>3</sup> On December 1, 2020, ACIP voted to adopt the recommendation outlined in “ACIP COVID-19 Vaccines Work Group, Phased Allocation of COVID-19 Vaccines,” Kathleen Dooling, Kathleen, MD, MPH, 12/1/2020, available at <https://www.cdc.gov/vaccines/acip/meetings/downloads/slides-2020-12/COVID-02-Dooling.pdf>. As we understand it, the recommendation has been submitted for approval.

<sup>4</sup> *COVID-19 Vaccination Program Interim Playbook for Jurisdiction Operations*, Centers for Disease Control and Prevention, Version 1 (September 16, 2020) and Version 2 (\_\_\_) (hereinafter the “Interim Playbook, V. \_\_\_”); *From the Factory to the Frontlines, The Operation Warp Speed Strategy for Distributing a COVID-19 Vaccine*, U.S. Dept. of Health and Human Services, September 16, 2020 (hereinafter the “OWS Report”); *Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine*, Committee on Equitable Allocation of Vaccine for the Novel Coronavirus, National Academies of Sciences, Engineering and Medicine, September 1, 2020 (hereinafter the “Draft Framework”); *COVID-19 Vaccine Prioritization: Work Group Considerations*, ACIP COVID-19 Vaccines Work Group, Kathleen Dooling, MD, MPH, August 20, 2020.

<sup>5</sup> Bulletin: *Civil Rights Protections Prohibiting Race, Color and National Origin Discrimination During COVID-19*, HHS Office for Civil Rights in Action, July 20, 2020 (“HHS Civil Rights Bulletin 7/20/2020”); Bulletin: *Ensuring the Rights of Persons with Limited English Proficiency in Health Care During COVID-19*, HHS Office for Civil Rights in Action, May 15, 2020 (“HHS Civil Rights Bulletin 5/15/2020”); Bulletin: *Civil Rights, HIPAA, and the Coronavirus Disease 2019*, HHS Office for Civil Rights in Action, March 28, 2020 (“HHS Civil Rights Bulletin 3/28/2020”).

Illinois' Plan indicates that "health care personnel" will be vaccinated during Phase 1a, and that these workers will have primacy above all others *within* Phase 1a.<sup>6</sup> That group is generally defined "as paid and unpaid persons serving in health care settings who have the potential for direct or indirect exposure to patients' infectious materials." *Id.* at p. 12.

We understand that Illinois' initial shipments of vaccine will not be nearly large enough to vaccinate all health care workers. We further have heard that because Illinois' initial shipment(s) will be very limited, Illinois intends to prioritize initial distribution within a select number of counties (aside from the City of Chicago), with first service given to counties that have had the worst death rates. An initial county-based focus will be inequitable, however, and it will not maximize the underlying goals of reducing mortality or spread.

A. *Hospital staff first.*

Medical personnel and other on-site staff in Illinois hospitals – *wherever* located – should be first in line. These individuals face exceedingly high risk of COVID-19 exposure, and they are of paramount importance to the health of *all* Illinois citizens. No matter where one lives, medical care is unavailable for COVID-19 patients *and* others requiring hospital care for other medical emergencies (heart attack, stroke, catastrophic injury and the like) if available area hospitals are overrun due to COVID-19. This workforce has borne the brunt of the pandemic, and COVID-19 infection-related shortages in this work force endanger the public at large.

A broad definition of "hospital staff" to include medical *and* non-medical personnel who cannot do their work from home is fully consistent with the CDC's extremely broad definition of "health care workers,"<sup>7</sup> and thus meets Illinois' commitment to comply with CDC guidance in respect to its Plan.<sup>8</sup> Vaccinating on-site non-medical staff recognizes that their work is essential to the operation of hospitals, that these workers also face heightened risk of being infected themselves, *and* that they present a further risk to others by transmitting COVID-19 both in the hospital setting and in the community.

Initial focus on hospital staff will also be easier from a logistical standpoint than a more diffuse, county-based strategy generally focused on all varieties of "health care workers." The number of individuals staffing hospitals likely will more closely match the batch sizes for initial shipments of vaccine, all of which apparently will require ultra-cold storage. Tracking which facilities have received a particular manufacturer's vaccine presumably will be simplified, which helps ensure timely delivery of second dose shipments of vaccine from the correct manufacturers when due. Hospital staff should be relatively easy to *accurately identify and to count*,<sup>9</sup> which should minimize the risk of wasted

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<sup>6</sup> Illinois Plan, p. 9.

<sup>7</sup> CDC guidance defines the term "health care personnel" as:

[A]ll *paid and unpaid* persons serving in healthcare settings who have the potential for direct or indirect exposure to patients or infectious materials, including body substances (e.g., blood, tissue, and specific body fluids); contaminated medical supplies, devices, and equipment; contaminated environmental surfaces; or contaminated air. HCP include, but are not limited to, emergency medical service personnel, nurses, nursing assistants, home healthcare personnel, physicians, technicians, therapists, phlebotomists, pharmacists, students and trainees, contractual staff not employed by the healthcare facility, *and persons not directly involved in patient care, but who could be exposed to infectious agents that can be transmitted in the healthcare setting (e.g., clerical, dietary, environmental services, laundry, security, engineering and facilities management, administrative, billing, and volunteer personnel).*

Available at: [https://www.cdc.gov/coronavirus/2019-ncov/hcp/infection-control-recommendations.html#anchor\\_1604360694408](https://www.cdc.gov/coronavirus/2019-ncov/hcp/infection-control-recommendations.html#anchor_1604360694408).

<sup>8</sup> See, e.g., Plan at p. 11, referencing Illinois' ongoing review of NASEM and ACIP guidance.

<sup>9</sup> We note that *no* information has been circulated to date explaining how people who believe they are part of a priority group will be expected to demonstrate that status when seeking vaccination. Unless Illinois intends to allow vaccination

vaccine and should facilitate issuance of reminders and prompts for second dose administration And, hopefully, a high percentage of hospital personnel will agree to be vaccinated – a point that could be extremely helpful as Illinois works to assure the general public that risks associated with vaccination outweigh the benefits. Finally, vaccination can be set up to occur on-site at the hospital facility, so that the hospitals can continue to serve longer-term as hubs for future vaccination phases (located either out-of-doors or in a separately accessible location on the hospital campus isolated from the emergency room and other patient care.

B. *Staff in all congregate residential settings with or immediately after hospital staff.*

Once there is sufficient vaccine available for a second sub-group of health care personnel beyond hospital staff, the next to receive top priority in Phase 1a should be medical *and* non-medical staff at *all* types of congregate residential settings. That stratification is appropriate because the people residing in these facilities literally depend on facility staff to survive.

Since significant vaccination planning began, there has been widespread support for giving priority to staff at “nursing facilities” or “long term care facilities.” That makes sense, for the infection and mortality rates in that specific setting have been horrific.<sup>10</sup> Illinois defines “long term care facilities” as those that “provide a variety of services, including medical and personal care, to persons who are unable to live independently.”<sup>11</sup> But nearly all of the factors that weigh in favor of vaccinating nursing facility staff apply to other congregate settings, including long-term care facilities, Specialized Mental Health Rehabilitation Facilities (“SMHRFS”), residential facilities for DCFS youth and other children, and jails, prisons, and detention centers. For each:

- Workers in these facilities are at very high risk for infection and are deemed part of the “essential” workforce that must show up even when they work in a place with a raging COVID-19 outbreak.
- Worker shortages related to COVID-19 have had significant, negative impact on the quality of care residents receive.
- The residents are confined to the facility with little (if any) freedom to leave.
- Residents cannot protect themselves by practicing social distancing.
- Residents rely entirely on facility staff for all of their basic needs, including food and medical care.
- Data show that COVID-19 infection generally is introduced into such facilities inadvertently *by staff*.<sup>12</sup>
- Once COVID-19 is introduced into a congregate residential facility, it generally spreads rapidly to residents and staff throughout the facility even when best efforts are made to follow CDC precautions and guidance.

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of individuals without requiring any verification from them regarding their claimed status for priority, the State should be preparing the public already for what they will encounter in terms of disclosures and process when it is their “turn” for vaccination.

<sup>10</sup> See, e.g., Draft Framework V. 1 at 1300-1305 (“Nursing home residents and staff have been at the center of the pandemic since the first reported cases. As of August 2, 2020, there were 286,382 confirmed or suspected COVID-19 cases and 456,958 deaths among nursing home residents, according to the Centers for Medicare and Medicaid Services, . . . and these numbers are likely to be underreported.” (citation omitted)).

<sup>11</sup> Illinois Plan, p. 13.

<sup>12</sup> This is particularly true where proper isolation practices are followed prior to an individual’s admission into a facility.

- Many of the facilities house people at high risk for severe symptoms or death due to COVID-19 (e.g., the elderly, and/or individuals with other pre-existing health conditions disabilities, or mental illness).
- Evidence shows staff serving in such facilities generally are responsible, however inadvertently, for introducing COVID-19 into facilities, which has led to high rates of severe illness, hospitalization and death.
- Infection of staff in such facilities contributes to community spread.<sup>13</sup>

Every one of these institutions fits within the CDC definition of “health care settings” because each necessarily has the capacity to address healthcare needs of residents.<sup>14</sup> And it bears emphasis that all on-site staff at congregate residential settings *for children* must be included even though children without preexisting medical conditions generally do not appear at high risk for severe symptoms or death due to COVID-19. Youth in residential institutions instead suffer a different, but still significant, harm when COVID-19 is introduced where they live. Like adults living in institutions, these children cannot practice social distancing. And *each* time they have contact with someone infected, these children are subject to weeks-long isolation periods during which they are confined to their tiny room, furnished only with a bed and a crate to hold their clothing and belongings, to eat and sleep and pass the hours alone. They cannot have family visits, cannot attend school, and cannot even socialize with other children at the facility. Some DCFS youth in residential settings have suffered through serial isolation periods throughout the summer and early fall, each interspersed by just a few days of relative freedom. That is, quite simply, terrible for the children’s well-being, particularly since many of these youth are living in institutions because they already suffer from significant mental or behavioral health issues that can be significantly exacerbated by periods of forced isolation.

We note that to date, Illinois has labeled “incarcerated / detained people and staff” as “TBD” in terms of prioritization, with that group roughly slotted between phases 2 and 3. Treating staff at such facilities differently than staff in other institutional settings is both misguided and dangerous. There is no such thing as social distancing in a prison, jail, or detention facility. So long as people are being held in these institutions, staff must be present to provide for their basic needs and safety. When COVID-19 is introduced to these environments, it has resulted in rapid and extensive infection rates among those detained and among staff. Research shows that infections in jails and detention centers under is all but inevitable, and when it occurs, mass contagion results.<sup>15</sup> For example, the number of confirmed cases in a Chicago area jail skyrocketed from 2 to 353 in just two weeks.<sup>16</sup> Similar mass infections have occurred in

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<sup>13</sup> This is true for nursing (and other long-term care) facilities and for jails, prisons, and detention centers. *See* nn. 15-17, *infra*.

<sup>14</sup> The CDC defines a “health care settings” as a place where “healthcare is delivered and includes, but is not limited to, acute care facilities, long term acute care facilities, inpatient rehabilitation facilities, nursing homes and assisted living facilities, home healthcare, vehicles where healthcare is delivered (e.g., mobile clinics), and outpatient facilities, such as dialysis centers, physician offices, and others. *See* n. 7, *supra*.

<sup>15</sup> A consortium of researchers (which included U.S. Department of Homeland Security medical experts) recently completed a study recognizing the “fast pace” of coronavirus transmission in detention settings and concluding that entry of the virus into ICE facilities is “inevitabl[e].” Daniel Coombs & Michael Irvine, *Modeling COVID-19 and Impacts on U.S. Immigration and Enforcement (ICE) Detention Facilities, 2020* (“ICE Facilities Study”), *J. Urb. Health* 2020, at 3, [https://whistleblower.org/wp-content/uploads/2020/04/Irvine\\_JUH\\_ICE\\_COVID19\\_model.pdf](https://whistleblower.org/wp-content/uploads/2020/04/Irvine_JUH_ICE_COVID19_model.pdf). The ICE Facilities Study found that after entering a detention facility, coronavirus will infect between 77% and 99% of detainees within months. *Id.* at 6 & Table 1 (reporting that a 500-person facility will have between 386 and 494 infected people in 90 days). Absent concerted efforts to address COVID-19 spread in facilities, negative health outcomes will occur not only for detainees, but in the communities that support detention facilities as large numbers of detainees, staff, and community spread victims swamp local providers and hospitals. *Id.* at 40.

<sup>16</sup> Timothy Williams & Danielle Ivory, *Chicago’s Jail is Top U.S. Hot Spot as Virus Spreads Behind Bars*, *N.Y. Times* (Apr. 8, 2020), <https://www.nytimes.com/2020/04/08/us/coronavirus-cook-county-jail-chicago.html>.

prisons.<sup>17</sup> Such rapid transmission rates drain and may even overwhelm local public health resources, and if staff are not vaccinated, they are at extremely high risk of contracting COVID-19 and contributing to extensive community spread. Given this past history, staff working in prisons, jails, and detention facilities should be included in Phase 1(b).

As for logistics, prioritizing all on-site staff at congregate residential facilities and institutions will be manageable from a logistical standpoint. These workers should be relatively easy to identify and count, they likely will be highly incentivized to accept vaccination and to follow through with a two-dose vaccine. They should be able to commute to a vaccination hub location, such as a hospital or other designated public health center for both doses. And these workers could be assigned to specific vaccination sites within reasonable geographic proximity to their homes in a manner that would accommodate the vaccine “batch” sizes and ultra-cold storage requirements for the Pfizer and Moderna vaccines.

C. *Health care personnel providing direct, supportive care to individuals with disabilities and/or mental illness must have next priority.*

The third priority tier within the health care personnel category should consist of workers who visit people in their homes, or in institutions, to provide essential supportive care. These workers help individuals with disabilities perform activities of daily living. They include ACT and CST team members and others who serve people who require ongoing mental health care. They are “essential” workers expected to serve their clients through direct contact as necessary despite the risk that COVID-19 presents both to the worker and to the client. And the care they provide to clients is essential to their clients’ well-being, health, and independence.

Illinois has already seen the devastating consequences that result when COVID-19 decimates the provider network of supportive care for individuals with disabilities and / or mental illness. The State’s efforts to comply with its *Olmstead* obligations and the *Olmstead*-related requirements imposed by several Consent Decrees (including those entered in *Williams*, *Colbert* and *Ligas*) have been significantly impaired due to staffing shortages at provider agencies that directly serve the needs of individuals with disabilities and those with significant mental illness.

Workers providing direct, supportive services to clients living in institutional or community settings again fit easily within the CDC’s definition of health care personnel who should receive top priority for vaccination. Through its Consent Decree compliance efforts the State already is highly familiar with many providers of such services, and again, identifying the remainder of Illinois’ supportive care workforce should be a relatively manageable task. Vaccination of this portion of Illinois’ healthcare workforce could then be handled in the same manner used for staff employed by congregate residential facilities, with workers directed to a vaccination hub within reasonable geographic proximity to their homes and with a readily managed process for follow-up communications and second dose administration.

**Request 3 - DCFS investigative and direct service staff are Phase 1b “first responders.”**

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<sup>17</sup> There were only three confirmed cases in the Stateville Correctional Facility in Illinois on March 25, 2020. *Coronavirus in Illinois Updates: Here’s What Happened March 25 With COVID-19 in the Chicago Area*, Chi. Trib. (Mar. 25, 2020, 7:48 PM), <https://www.chicagotribune.com/coronavirus/ct-coronavirus-pandemic-chicago-illinois-news-20200325-swgp5hlecrbabjqx52etj2rruq-story.html>. In less than two weeks, 49 inmates and 17 staff members at the facility had tested positive for coronavirus. Josh McGhee, *Stateville Prison Outbreak Signals COVID-19 Threat to Inmates, Surrounding Hospital Systems*, Chi. Reporter (Apr. 13, 2020), <https://www.chicagoreporter.com/stateville-prison-outbreak-signals-covid-19-threat-to-inmates-surrounding-hospital-systems/>. Within a few more weeks, 271 inmates and 207 staff had tested positive. See Ill. Dep’t of Corrections, *COVID-19 Response: Confirmed Cases*, <https://www2.illinois.gov/idoc/facilities/Pages/Covid19Response.aspx> (last visited May 12, 2020).

Illinois has slotted “First Responders” in Phase 1b of its Plan.<sup>18</sup> This group generally is defined to include EMTs, police, and fire department personnel.<sup>19</sup> Two sets of workers within the Department of Children and Family Services (“DCFS”) are often overlooked as having duties, and facing exposure risks, equivalent to those of the police and other traditionally recognized “first responders.” They are the Child Protection Service Investigators who respond when allegations of child abuse or neglect are made, and the direct service child welfare caseworkers responsible for the safety and well-being of children who are removed from their families and taken into Illinois custody.

We are well aware of strong criticism that state child protection workers *should not* serve functions akin to law enforcement, and that their service in that role is a vestige of institutional racism that should be eradicated. At present, however, Illinois continues to mandate that when an allegation of child abuse or neglect is reported, *it must be investigated in person*. So long as families are asked to open their doors to such investigations, we must at do all we can to ensure that the DCFS investigator is not bringing COVID-19 into the family’s home. Likewise, if such investigators are going to be required to engage in visits where they have no control over the environment they are entering, including them in the priority group for vaccination should reduce the danger that they will contract the virus and spread it from family to family in the course of their work.

Direct service DCFS staff, whether employed directly by the State or by private providers working on DCFS’ behalf, likewise are expected to serve as “first responders.” They are charged with responsibility for front-line safety and health protection for abused and neglected children while the children remain in the care and custody of Illinois. These caseworkers must conduct regular, in-person contacts with licensed and unlicensed foster care providers, they must respond in person when a youth in DCFS’ care requires emergency psychiatric or other healthcare, and in many instances they must be present to supervise critically important in-person contacts between children and their families of origin. DCFS caseworkers are expected to serve as a link between foster parents and all members of their households, the DCFS youth placed in those homes, and DCFS youths’ families of origin. Many direct service caseworkers have caseloads comprised of dozens of youth. For the safety of everyone attempting to serve the traumatized children in DCFS care, DCFS caseworkers providing direct service to youth merit the same priority access to vaccination that police, firefighters, and other community safety workers will be given under Illinois’ Plan.

As with the other priority groupings we have suggested, giving early access to DCFS investigators and direct service caseworkers should not present undue logistical problems or significantly delay access for other priority groups. The workforce for these two DCFS roles is readily identifiable and relatively small in size in comparison to many other groups (such as those with medical conditions placing them at serious risk of severe illness or death due to COVID-19).<sup>20</sup> Further, DCFS has well-established communication links with this set of workers, which will facilitate both the initial and second dose phases of vaccine administration. DCFS leadership should be able to materially assist in planning for vaccination of these two, limited components of its workforce.

#### **Request 4 - Acknowledging and addressing the impact of institutional racism.**

Federal and additional academic materials addressing the impact of COVID-19 have frankly acknowledged that minority communities have suffered disproportionate infection rates and more severe health outcomes because of widespread and historic institutional racism.<sup>21</sup> The impact of such racism includes reduced access to quality and timely

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<sup>18</sup> See Illinois Plan, p. 14.

<sup>19</sup> See, e.g., Draft Framework at lines 1345-47; Johns Hopkins Framework at p. 27.

<sup>20</sup> For example, we note that Illinois estimates the subgroup of “People with significant comorbid conditions” in this State to number 1,271,938. See Illinois Plan, p. 14.

<sup>21</sup> See, e.g., Draft Framework at 786-90 (“Fundamental health inequities in COVID-19 and in other health conditions are rooted in structural inequalities, racism, and residential segregation. Any vaccine allocation scheme . . . must explicitly address the higher burden of COVID-19 experienced by the populations affected most heavily, given their exposure and compounding health inequities.”); see also Johns Hopkins Framework at 1-2.

health care (and thus higher incidence of health conditions that make COVID-19 more deadly), poverty flowing from discrimination in employment, and redlining that has concentrated minority communities into areas characterized by their food deserts, pollution, and overcrowding.

The extremely high correlation between race and high incidence of COVID-19 and poor health outcomes is beyond dispute. A recent comparison between the communities hit hardest by the virus, and those beset by pollution, poverty, poor access to food and health care, damage from persistent flooding, and overcrowding in Chicago were nearly identical. And due to a “history of racist practices – from redlining to contract buying to the grossly unequal lending that persists today,” those impacted communities are communities of color.<sup>22</sup>

While the federal Draft Framework does not *directly* grapple with the impact of institutional racism,<sup>23</sup> it does suggest one strategy that could have some beneficial effect in giving priority access to people living in predominantly minority communities. The Draft Framework proposes that *if* there is insufficient available vaccine to treat all members of a particular prioritized group at the same time, then priority *within* that group should apply “some metric of social disadvantage, such as the CDC’s Social Vulnerability Index, into the prioritization of vaccine recipients by making it an additional consideration within the phases.”<sup>24</sup> The CDC’s Social Vulnerability Index (“SVI”) uses Census data to rank counties and Census tracts based on 15 factors that are grouped into four “themes” – Socioeconomic, Housing Composition and Disability, Minority Status and Language, and Housing and Transportation.<sup>25</sup> It is used in emergencies (such as floods, wildfires, and the like) to identify areas that most likely will need emergency support following a natural disaster or other hazardous event.

To our knowledge, Illinois to date has not announced an intent to add an overlay to its distribution plan, such that when supply for a prioritized group is insufficient, distribution is first focused in historically underserved areas of the State. We have seen reports, however, that the first shipments Illinois receives may be distributed to health care workers in 50 Illinois counties that have experienced the highest death rates due to COVID-19.<sup>26</sup> We urge the State to abandon that strategy as far too rough a measure, and instead to conduct a more refined analysis that looks instead to the individualized communities where residents have been hardest hit by COVID-19 due to the longstanding impact of historical, institutional racism.

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<sup>22</sup> See Deaton, J. and Olapido, G., “Mapping the Disparities That Bred an Unequal Pandemic,” Bloomberg CityLab, 9/30/2020, available at <https://www.bloomberg.com/news/articles/2020-09-30/mapping-the-disparities-of-chicago-s-unequal-pandemic>.

<sup>23</sup> See Draft Framework at lines 818-24, 830-33, 1065-71. For example, the Draft Framework anticipates that people of color will be more heavily concentrated in some groups with relatively high early priority, such as “critical workers who cannot work from home and people with serious underlying health conditions placing them at “high risk” for poor COVID-19 outcomes. *Id.* at 1161-63. By giving such individuals priority, the intended effect is to at least *indirectly* give earlier access to disproportionately larger percentages of people of color most likely at high risk of contracting COVID-19. *Id.* at p. 91, fn. 28; see also Johns Hopkins Framework at p. 4.

<sup>24</sup> Draft Framework, lines 830-33.

<sup>25</sup> Factors considered in the “Socioeconomic Status” grouping are below poverty, unemployed, income, and lack of high school diploma. Factors considered in the Household Composition and Disability “theme” are age 65+, age 17 or less, age 5+ living with a disability, and single-parent households. Factors considered in the Minority Status “theme” are minority status and speaking English “less than well.” The final “theme,” Housing Type and Transportation, considers multi-unit structures, mobile homes, “crowding,” no vehicle, and group quarters. Details regarding the Index can be found at CDC Social Vulnerability Index 2018 – USA, [https://svi.cdc.gov/Documents/Data/2018\\_SVI\\_Data/SVI2018Documentation.pdf](https://svi.cdc.gov/Documents/Data/2018_SVI_Data/SVI2018Documentation.pdf).

<sup>26</sup> See Capitol Fax, Monday, 12/7/2020,



## **Request 5 – Adopt the concept of “critical risk” workers.**

In its Plan, Illinois does not appear to distinguish between individuals who can work from home and those who cannot. That distinguishing feature is not applied to the broad categories of health care personnel, or to “workers in industries and occupations important to the functioning of society” who likely will be given Phase 2 priority.<sup>27</sup> We strongly urge Illinois to refine its Plan by adopting the concept of “critical risk workers.” That concept was outlined in the Draft Framework,<sup>28</sup> and it differentiates between “essential workers” – a category that includes *all* employees working in businesses considered “essential” for basic societal function – and “critical workers,” who are “essential workers” whose jobs make it impossible for them to “telework.” This is an extremely important distinction to draw during stages of limited vaccine availability, as it reserves prioritized access to those who truly face a high risk of COVID-19 infection and cannot protect their own or their families’ health and safety by working from home.

## **Request 6 - Residents of any type of institutional and other congregate residential facility who are at “high risk” for severe illness or death due to COVID-19 should be given Phase 1b priority, and people aged 50 and above should be considered at high risk.**

*All* individuals living in congregate residential or institutional settings who have conditions placing them at high risk of severe illness or death due to COVID-19 should be treated equally in Illinois’ Plan. At present, however, Illinois plans to prioritize all people living in long term care facilities in Phase 1a, and all other individuals who are over 65 years of age and /or have high risk medical conditions would be placed in Phase 1c.<sup>29</sup> That group is immense, *regardless* of their health condition, and also prioritizes people of *any* age who have underlying health conditions placing them at significantly higher risk of death or serious illness if they contract COVID-19.

We do not disagree that older adults living in congregate care or overcrowded conditions should be prioritized as part of Phase 1a. The data showing the horrific rates of serious illness and death for nursing facility residents<sup>30</sup> leave no question on that score. But we do want to make sure that *all* people living in institutions who are 65 or older and/or have significant underlying health conditions are given access to vaccine as part of Phase 1(b) *regardless* of the institution where they are housed – whether that is a group home for ID/DD, a facility providing substance abuse treatment, an institution caring for people with mental illness, or people housed in jails, prisons, or detention centers. There is ample data demonstrating that COVID-19 spread is rampant in jails and prisons *as well* as nursing facilities.<sup>31</sup> Priority is equitable when the focus is on an individual’s risk status, not the label applied to the institution in which they are housed.

We further ask that the State expand the group of individuals considered to be at “high risk” to include individuals who are age 50 and above. If necessary due to short supply of vaccine, this expansion of the “high risk” category could be placed “in line” behind those 65 and older. CDC guidelines recognize that *age alone* is a factor increasing the risk of serious or disease or death due to COVID-19.<sup>32</sup> Illinois would simply be “following the science” in making the expansion we request.

Finally, we note that youth with conditions placing them at high risk of COVID-19 who are living in congregate residential settings likewise should be prioritized for vaccination as CDC emergency approval for administration to those under 18 years of age is granted.

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<sup>27</sup> See Illinois Plan, p. 9.

<sup>28</sup> See Draft Framework at lines 1161-63.

<sup>29</sup> See Illinois Plan, pp. 13, 14.

<sup>30</sup> See n. 10, *supra*.

<sup>31</sup> See nn. 16 and 17, *supra*.

<sup>32</sup> See CDC posting at <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html>.

## **Request 7 - Ensuring informed consent is essential.**

Because initial vaccinations will be given through Emergency Use Authority (“EUA”), which suspends clinical testing and other requirements ordinarily required before a vaccine is authorized,<sup>33</sup> it will be critically important to ensure that individuals are fully informed of risk when offered access to vaccination.

There has been extensive media attention to the fact that many groups who previously have been victimized through government-led and/or government-sanctioned drug experimentation are likely to be highly mistrustful of COVID-19 vaccine. There is a reprehensible, documented history of drug manufacturers and government actors testing experimental treatments on people of color, prisoners, and people living with disabilities without their knowledge or informed consent, and without any aftercare to address the serious physical harm to those victimized in the course of this experimentation.<sup>34</sup> Ensuring that vaccine recipients receive meaningful information about the various vaccines available will be an essential component to building trust with the public. That disclosure must be full, balanced, and available in multiple languages.

Finally, it bears emphasis that when vaccine is provided to institutionalized persons, it must not be administered *absent real, properly obtained* informed consent. Priority *access* must not be confused with a purportedly beneficent motive of “doing what’s best” for an institutionalized person. These individuals are entitled to make their own decisions regarding the risk they choose to take – whether that is to take a vaccine that has not been fully tested and has undetermined efficacy, or to forego the vaccine until a more developed track record regarding safety has been developed.

## **Request 8 - Ensure fair access for Native American and Alaska Native peoples.**

The federal Draft Framework emphasizes that “any vaccine allocation plan implemented at the federal and state levels must respect the tribal sovereignty of American Indian and Alaska Native nations.”<sup>35</sup> The Interim Playbook further states that federal authorities have been “working directly” with the Indian Health Service at the federal levels, but that no finalized plans for delivering vaccine to tribal health facilities have been finalized.<sup>36</sup> States are urged to work with any tribal health facilities that are not “officially connected to IHS,” as these “non-federally recognized tribes ... will likely not be served by IHS.” *Id.* In other words, there is no clarity as to how the needs of American Indian and

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<sup>33</sup> See Interim Playbook at p. 40.

<sup>34</sup> See, e.g., Stobbe, M., “Ugly past of U.S. human experiments uncovered,” Associated Press, available at <https://road2justice.wordpress.com/2011/02/28/ugly-past-of-u-s-human-experiments-uncovered>. There is documentation suggesting as many as 40 such studies may have been conducted, with examples including: (i) a study that extended for decades, into the 1970’s, in which 600 Black men who had syphilis were studied (without their informed consent), but were never given treatment even after penicillin became available; (ii) a 1942 study in which male patients at a state “insane asylum” (many of whom were not capable of giving informed consent) were injected with an experimental flu vaccine and then exposed to flu; (iii) 1940s experiments in which men, some of whom were patients in mental health institutions, were exposed to hepatitis; (iv) a 1957 experiment in which groups of prison inmates, half of whom received an experimental vaccine, were purposefully infected with Asian flu; (v) a 1963 study in which debilitated patients at a chronic disease hospital in Brooklyn were injected with cancer cells, without their informed consent; and (vi) a study conducted from 1963 to 1966 in which children with developmental disabilities living at the Willowbrook State School, a facility in Staten Island were infected with hepatitis in order to test the efficacy of gamma globulin as a cure. *Id.*

<sup>35</sup> See Draft Framework, lines 792-93.

<sup>36</sup> See Interim Playbook, p. 8.

Alaska Native peoples will be met. Illinois has a significant population of Native American and Alaska Native people, and given the limited reach of the Indian Health Service, a targeted and specialized outreach to this community is necessary.

**Request 9 - The vaccination program must not consider citizenship or documented status.**

Most of the vaccine guidance materials estate that *all* people in a priority group, including non-citizens without documentation, are eligible for and should feel safe to participate in the vaccination program.<sup>37</sup> At the same time, because the vaccine that will be available in early stages of administration both will require two doses, federal guidance demands that States track who has received an initial dose and to take appropriate action to ensure that second doses are administered.<sup>38</sup> That raises significant questions regarding what information people will be required to provide when receiving their first dose, who will have access to that information, and how long the information will be stored. The guidance materials discuss anticipated privacy protections and the intent that individualized data will be closely restricted and used only for public health purposes,<sup>39</sup> but we remain very concerned about data usage and storage. Illinois should clearly communicate to the public that private information gathered during vaccine administration will not be shared with law enforcement or ICE and used for enforcement purposes.

We are aware that other States have either refused to sign the CDC data sharing agreement linked to COVID-19 vaccine distribution that would require States to share personal information in vaccine registry databases with the federal government. Other States have signed those agreements while specifying that the State nevertheless will not comply with provisions requiring disclosure of personal information.<sup>40</sup> We urge Illinois to adopt either of these two strategies for protecting the private information of vaccine recipients.

**Request 10 - Comprehensive translations of public-facing information regarding vaccination.**

The federal guidance materials recognize that to be successful, key messaging and communications about vaccine safety, who is eligible to receive early vaccination, where administration will occur, and the properly timed two-dose vaccine course must reach *everyone*.<sup>41</sup> The need for “plain language” and “culturally sensitive” messaging is emphasized, but to date, little attention has been paid to the need for translated materials. Indeed, when the Draft Framework was released on September 1, 2020, it was only made available in English, it spanned approximately 100 pages of text, and only four days were allowed for submission of public comment. As far as we can tell, subsequent guidance materials regarding the vaccination program likewise have only been released in English.

HHS has issued at least two Bulletins emphasizing that civil rights protections apply in the context of COVID-19 health care, and that “messaging about testing and treatment” should be provided “in plain language and in the non-English languages prevalent in the affected area through all forms of media, including online, television, or social media, and through targeted outreach to community and faith-based organizations that can reach individuals” with limited

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<sup>37</sup> The materials are not uniform in this regard. For example, the OWS Report at one point states that the intent of the national vaccination program is for all “*American[s]*” to be vaccinated without charge. See OWS Report at 7 (emphasis supplied).

<sup>38</sup> See Interim Playbook at 29-30.

<sup>39</sup> See Interim Playbook at p. 29-34.

<sup>40</sup> See <https://www.nytimes.com/2020/12/08/us/politics/cdc-vaccine-data-privacy.html?referringSource=articleShare>.

<sup>41</sup> Interim Playbook, pp. 15, 35-37.

English proficiency.<sup>42</sup> The HHS guidance suggests that States consult federal DOJ and Census resources as a starting point for identifying language for which translation is needed.<sup>43</sup> Developing appropriate materials in multiple languages plainly will be a critical, but time-intensive piece of each State’s program.

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<sup>42</sup> HHS Civil Rights Bulletin 5/15/2020 at p. 2; *see also* HHS Civil Rights Bulletin 7/20/2020 at 1-3 (specifically focusing on prohibition of discrimination based on race, color, and national origin); HHS Civil Rights Bulletin 3/28/2020 at pp. 1-2 (noting that “governmental officials [and] health care providers . . . should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served” during the COVID-19 crisis by, among other things, “[p]roviding meaningful access to programs and information to individuals with limited English proficiency.”)

<sup>43</sup> *See* HHS Civil Rights Bulletin 5/15/2020 at p. 2, fn. 4 (referencing the “DOJ Map App available at <https://www.lep.gov/maps> and the Census ACS website”); *see also id.* at pp. 3-4, listing additional guidance materials regarding accessible communications with individuals who have limited English proficiency.