EXCERPT FROM UPCOMING WHITE PAPER ON EMERGENCY RELOCATIONS FOR LONG-TERM CARE FACILITY RESIDENTS

AS TESTIMONY FOR SENATE HEARING ON ACCESS TO HEALTHCARE, OCTOBER 19, 2020

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Introduction

On July 15, 2020, a resident of Chalet Living and Rehab, a long-term care facility in Chicago, tested positive for the potentially fatal Legionnaire's Disease. Chalet responded by prohibiting showering or bathing and restricted hand washing to less than 20 seconds. With each passing day, the facility's near 200 residents faced increasingly inhospitable conditions in a facility that was already a crucible for infection. Before the Legionnaire's outbreak, COVID-19 had infected half and killed a tenth of Chalet's residents. Some asked, to no avail, to temporarily evacuate. Despite deteriorating hygiene among residents, they received no personal hand sanitizers and faced involuntary discharge if they left without permission. They begged staff for gallon jugs of water so they could crouch on their bathroom floors and pour cups of cold water over themselves. The ombudsman and a handful of state legislators engaged in a series of heated communications with the Illinois Department of Public Health (IDPH), the entity charged with regulating long-term care facilities. Beyond sending Chalet administrators mitigation guidelines, IDPH took no substantive action. On August 3, the ombudsman wrote IDPH: "I will need to push this request harder if the water restrictions are not lifted very soon." On August 7th, the ombudsman pleaded with facility administrators to purchase hanging shower bags and noted that hotels were offering accommodations. These suggestions elicited no response, and IDPH supported Chalet's course. "IDPH typically permits the facility and their water management team to determine what option or combination of options will work best for their facility's needs," emailed an IDPH liaison. Eventually a mobile shower unit arrived outside the facility but proved inaccessible to residents in wheelchairs. Seeking to apply public pressure to IDPH and the facility, residents and advocates reached out to over a dozen media outlets. None published the story. The fate of 200 Illinoisans living 38 days without water for bathing during a pandemic came and went like an unremarkable glitch in Illinois' institutional machinery.

How Chalet's crisis unfolded brings into stark relief several long-standing concerns with institutional care:

* **State and federal governments chronically fall short in regulating these settings.** Oversight agencies have long lacked the capacity to ensure the well-being of institutionalized residents.[1] The travesty Chalet residents endured is no surprise to individuals and organizations tracking long-term

care facilities, many calling them as early as March "petri dishes" for infection. At least two national petitions were published this spring demanding greater protections for residents and that facilities be depopulated to safer levels.[2]

* **State emergency operation plans do not provide as a matter of policy any robust option for relocating people in institutions during crises.** The Chalet case merely illustrates a broad, standard shelter-in-place approach to crises in institutions, regardless of the severity of consequences. Evacuation and relocation options are commonly in place for other populations, such as people experiencing homelessness, hospital patients, in-home-care recipients, and, to a degree, prisoners. The fact of institutionalization itself brands individuals with a set of restricted options regardless of whether they share the same medical, economic, or historic profiles as those not in institutions. The shelter-in-place restriction on residents of congregate care settings during natural disasters has proven catastrophic in response to today's pandemic and, historically, in response to floods, hurricanes, fires, and other calamities.[3]

* **Practices of social segregation have embedded stigma and stereotype within policies and perspectives on how to best support people who have been institutionalized.** Marginalizing through institutionalization perpetuates even greater disenfranchisement, a vicious and deadly cycle.

For a moment, it seemed the failings of institutional care had reached their inflection point. Reports early in the year of COVID-related die-offs in nursing facilities occupied daily headlines. The viral flare-up in Life Care Center in Kirkland, Washington, introduced the country to the devastation COVID-19 potentially held for the nation at large. The derelictions of nursing home care briefly became emblematic of the horrors we all might face. But as the nation acclimated to the daily tolls of the pandemic those most impacted, those institutionalized, were again relegated to the margins of the popular narrative, and those charged with ensuring their well-being implemented measures insufficient for the scale of the crisis. After a few political shake-ups in Illinois (IDPH fired two low-level administrators for the department's decisions not to investigate allegations of abuse and neglect for a period of four months), bureaucratic and social routines once again subordinated the historically deadly failings of policies and practices that support congregate care.

In this white paper, we address the second of the three issues above – the absence of, and indeed resistance to implement, relocation strategies in emergency operation plans for institutionalized people. Resolving this issue will likely impact the other two. Relocations may open up the industries of congregate care to alternate supports that in turn may introduce more consumer supportive strategies for affected populations. Relocated residents will likely interact with services and community support agencies that are not steeped in congregate setting cultures, especially those of private enterprises whose profit-seeking strategies have accumulated an ignominious record of undermining best practices for consumer well-being. Establishing relocation policies for those in institutions may also dissolve some of the institutional stereotypes of fragility and incapacity that these industries promote to justify segregationist models of custody and care. Until such discriminatory biases are removed from

congregate care policies, we will continue to fail over 100,000 Illinoisans living in these segregated settings.

Besides merely appearing to be the right thing to do, equitable relocation policies may be enforceable by law. Section 504 of the Rehabilitation Act states that "no otherwise qualified individual with a disability in the united States, as defined in section 7(20) shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the united States Postal Service."

Why Are So Many People Dying in Congregate Care Settings?

> …these deaths are far from inevitable. They arise from decades of indifference, invisibility, and deadly discrimination against the people who live and work in these settings. They also arise from our government's abdication of its responsibility to regulate and monitor these segregated institutions. - *ACLU, June 23, 2020*[4]

The rates of COVID-19 infection and deaths in congregate care settings are well known to most readers. In some states, as high as 80% of reported deaths have occurred in nursing facilities.[5] In Illinois, the figure surpasses 50%. We estimate that the infection rate of residents and staff in long-term care settings in Illinois is 70% greater than that of the general population. States do not track Covid rates in all congregate settings, which is one of the reasons this paper emphasizes long-term care facilities whose infection and death rates are relatively well documented. But there are data from another setting with a similarly tragic profile: prisons. As of September 18, the infection rate among the state's incarcerated is 107% higher than the general population. (The infection rate of staff in Illinois prisons is 171% higher than the general population.)[6] One study estimates that the Covid-related death rates in U.S. prisons is twice that of the general population.[7] Another study found that over 15% of infections in Illinois could be traced to Cook County Jail.[8] These high infection and death rates across population types should disabuse reasonable critics of the idea that being disabled accounts for rate disparities. In other words, above all, we should consider the place before the population.

In terms of pandemic response, this is precisely what many states have done with regards to incarcerated populations. At least twenty-one states have released prisoners to help mitigate the impact of COVID-19.[9] [10] California briefly enacted a zero-bail policy to allow suspects of misdemeanors and low-level felonies to avoid jail,[11] while other initiatives in the state expect to reduce its incarcerated population by about 18,000.[12] Illinois released between 1,300 and 4,000 prisoners in its state system,[13] and Cook County jail reduced its population by 25% in response to the pandemic.[14] In all of these cases, state and local administrators recognized that high-density carceral settings were driving viral spread. They responded by assessing the factors of each individual for commutation, temporary relocation or

diversion. (Although critics point to racial bias in Illinois' response *vis a vis* prison populations.[15]) Why, we ask, are there no analogous policies or processes in place for residents of congregate care settings?

While released prisoners may filter back into their communities, dispersing to apartments and family homes, depopulating congregate settings in which residents have few or no living options of their own requires the provision of safe temporary settings. Many long-term care facility residents are similar in this respect to those using homeless shelters. (And these populations frequently intersect, as discharged care residents end up in shelters and shelter users get admitted to nursing facilities.) Like long-term care facilities, homeless shelters were quickly overrun by COVID-19 cases this spring. The Chicago Department of Public Health indicated that some shelters surpassed 50% test positivity rates in April, and Heartland Alliance saw infection rates between 15-65% in shelters.[16] By August, the positivity rate in shelters, CDPH claims, had dropped to around 2%.[17] Why? Chicago's Family & Support Services (CFSS) states that, since the end of March, 1,784 clients of shelters have been placed in alternate temporary housing.[18] "Teams mobilized to reduce crowding in shelters and provide services to residents. [CFSS] decompressed shelters, adding new facilities so people could sleep six feet apart."[19] The overwhelming success in reducing infections by depopulating crowded homeless shelters, unfortunately, has not inspired similar strategies for long-term care facilities.

In comparison to the estimated 10% reduction in prison populations statewide, and the 1,784 people diverted from homeless shelters in Chicago, **there is virtually no record of Illinoisans who reside in congregate care settings being relocated in response to the pandemic.** Cook County's Bureau of Administration has identified only one individual from a long-term care setting who was temporarily relocated to mitigate the impact of COVID-19.[20] While state and local administrators overseeing carceral settings have made emergency response decisions by reviewing individual inmate histories, their colleagues in IDPH and other departments overseeing congregate care settings have taken no such approach. Public statements from Illinois administrators have applied a blanket assessment of residents of long-term care facilities as being too "medically fragile" to be provided safe refuge from high-density viral hotspots. We know from those who have transitioned out of facilities through standard channels that this response is inaccurate, inadequate, and all too many times fatal. While cities such as Chicago marshal alternate housing resources, such as hotels and vacant hospitals, for clients of overpopulated homeless shelters, no such corresponding effort has been made for crowded, deadly nursing facilities.

Again, the superficial and often deceptive characterization of facility residents as "medically fragile" should not dissuade development of relocation policies; conversely, the institutional setting should certainly compel evacuation preparedness. The structural and operational design of long-term care facilities is essentially a prescription for devastating viral spread. Even when within full regulatory compliance (a rare occurrence for most facilities), these settings necessarily fall short of key CDC guidelines for virus mitigation. Residents of most facilities share living quarters, sometimes as many as four to a room. The regulation size of a two-person living quarter is 245 square feet, less than the size of an accessible parking space. After accounting for beds, dressers, closets and other basic items, the ability to maintain the minimally recommended six-foot distance from other individuals is near impossible. Health experts now believe that closed quarters and aerosolized virus particles expand that

minimal perimeter significantly. The daily functions of staff require most to travel from one resident to the next in quick succession, potentially turning infected members into super-spreaders. Many staff work in multiple facilities, and there are recent accounts of travelling nurses, drawn by high compensation rates, going from one hotspot to the next.[21] Typically, long-term care facility mitigations include a no-touch thermometer read for incoming people, an unreliable protection as asymptomatic carriers, who have no fever, are capable of spreading the virus. And, as one resident pointed out, accurate skin temperature reads from someone coming in from the cold outdoors are unlikely. Congregate settings are chronically undersupplied with PPE,[22] and while state guidelines have somewhat improved protocol, incidents of breaches by residents and staff continue.[23] To make matters more precarious, oversight agencies such as ombudsman programs had been restricted from visitations, and over 20 governors, including Governor Pritzker, have enacted orders that protect facility staff and administrators from liability should residents fall victim to harm during the pandemic.

As of this report, over 30,000 long-term care residents of Illinois facilities have been infected by COVID-19 and over 4,500 have died. Some facilities, such as Chalet, have had over 10% of their residents killed by the Coronavirus, while the infected population represents approximately a third of nursing home residents in the state. Earlier this year, the state's Division of Rehabilitation Services (DRS), which oversees home support services for approximately 30,000 Illinoisans with similar health profiles and support needs as nursing facility residents reported to this paper's author that about 50 consumers had been impacted by COVID-19. That represents about a .2% rate, an astounding 11,000% lower infection rate than their cohorts in institutions. This differential should speak for itself, stating loud and clear that removing at-risk facility residents from their congregate settings must be a priority in emergency response plans.

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[1] The Centers for Disease Control points out that before the Coronavirus pandemic about 380,000 people in nursing facilities died annually of avoidable infections. More than 80% of nursing facilities are cited each year for infection control deficiences. It's likely to be even higher: 70% of state reviews miss at least one deficiency and 15% miss actual harm and immediate jeopardy to a nursing facility resident, according to the U.S. Government Accountability Office. A 2017 Kaiser Health study found that only about 1% of facilities deficient in infection control receive citations with financial penalties. Chronic staff shortages, cost-cutting strategies by profit-seeking owners, and inadequate oversight have made nursing facilities particularly dangerous settings for residents.

2019 CDC page on long-term care facilities: https://web.archive.org/web/20150403193558/http://www.cdc.gov/longtermcare/index.html

GAO Report on deficiencies: https://www.gao.gov/products/GAO-20-576R

Kaiser report on penalties for deficiencies: https://khn.org/news/infection-lapses-rampant-in-nursing-homes-but-punishment-is-rare/

[2] "PETITION OF AMERICAN CIVIL LIBERTIES UNION, SERVICE EMPLOYEES INTERNATIONAL UNION, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, AUTISTIC SELF-ADVOCACY NETWORK, DISABILITY RIGHTS EDUCATION AND DEFENSE FUND, NATIONAL COUNCIL ON INDEPENDENT LIVING, PARTNERSHIP FOR INCLUSIVE DISASTER STRATEGIES AND WORLD INSTITUTE ON DISABILITY," (ACLU, 6/23/2020) https://www.aclu.org/petition-covid-19-response-nursing-homes-and-other-congregate-settings-where-people-disabilities

"NATIONAL GOVERNORS ASSOCIATION NATIONAL CALL TO ACTION: EMERGENCY RELOCATION OF CONGREGATE SETTING RESIDENTS; SAVE LIVES NOW!," (Association of Programs for Rural Independent Living, 07/06/2020) https://www.april-rural.org/

[3] "Are Nursing Homes Ready for the Next Natural Disaster?," (AARP, 10/30/2017) https://www.aarp.org/caregiving/local/info-2017/nursing-homes-natural-disasters.html

[4] https://www.aclu.org/news/disability-rights/covid-19-deaths-in-nursing-homes-are-not-unavoidable-they-are-the-result-of-deadly-discrimination/

[5] "Minnesota's long-term care homes are dangerous," StarTribune, 05/25/2020 https://www.startribune.com/minnesota-s-long-term-care-homes-are-dangerous/570783782/

[6] "A State-by-State Look at Coronavirus in Prisons," The Marshall Project, https://www.themarshallproject.org/2020/05/01/a-state-by-state-look-at-coronavirus-in-prisons

7 "COVID-19 in U.S. State and Federal Prisons" https://cdn.ymaws.com/counciloncj.org/resource/resmgr/covid_commission/FINAL_Schnepel_Design.pdf

[8] Eric Reinhart and Daniel L. Chen "Incarceration And Its Disseminations: COVID-19 Pandemic Lessons From Chicago's Cook County Jail," (Health Affairs, June 4, 2020) https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2020.00652

[9] "Prison inmate release responses in response to the coronavirus (COVID-19) pandemic, 2020" (Ballotpedia, July 1, 2020) https://ballotpedia.org/Prison_inmate_release_responses_in_response_to_the_coronavirus_(COVID-19)_pandemic,_2020

[10] "Responses to the COVID-19 pandemic," (Prison Policy Initiative, 09/11/2020) https://www.prisonpolicy.org/virus/virusresponse.html

[11] "Editorial: A $0 bail for Californians accused of nonviolent crimes? That's exactly the right amount," (LA Times, 04/20/2020) https://www.latimes.com/opinion/story/2020-04-20/no-bail-california-emergency

[12] "California Ups COVID-19 Early Inmate Release Estimate Amid Objections, (CBS/AP, 08/05/2020) https://sanfrancisco.cbslocal.com/2020/08/05/california-inmate-early-release-estimate-up-covid-19-coronavirus-cdcr/

[13] Chuck Goudie and Barb Markoff, "Coronavirus: New questions about how many Illinois state prison inmates are being released due to COVID-19," (ABC7, 04/28/2020) https://abc7chicago.com/coronavirus-update-cases-illinois/6135977/

[14] Omar Jimenez, "Chicago's biggest jail has released almost a fourth of its population over coronavirus fears," (CNN, 04/17/2020) https://www.cnn.com/2020/04/17/us/cook-county-jail-coronavirius/index.html

[15] Emily Hoerner and Carlos Ballesteros, "Illinois Released White Inmates at Higher Rates in Coronavirus Pandemic," (NBC5, 06/23/2020) https://www.nbcchicago.com/news/local/illinois-released-white-inmates-at-higher-rates-in-coronavirus-pandemic/2294042/

[16] Katie Brandt, "Protecting Chicago's Homeless Population During Covid-19," (Chicago Health, 08/18/2020) https://chicagohealthonline.com/protecting-chicagos-homeless-population-during-covid-19/

[17] Mariah Woelfel, "Chicago's Homeless Add COVID-19 To Their Winter Worries," (WBEZ, 09/24/2020) https://www.wbez.org/stories/chicagos-homeless-add-covid-19-to-their-winter-worries/90a4a05f-c8a3-4ef0-9b44-be274cc29ad4

[18] FSS response to FOIAd request, 9/25/2020

[19] "Protecting Chicago's Homeless Population During Covid-19," (Chicago Health, 08/18/2020)

[20] Based on response to FOIA request, 9/17/2020

[21] Chaunie Brusie, "Travel Nurse Pay Triples Amid COVID-19 and Hospitals Use These 6 Extreme Hiring Tactics," (nurse.org, 4/29/2020) https://nurse.org/articles/hospitals-hire-travel-retired-army-nurses-covid19/

[22] Maggie Flynn, "At Least 1 in 5 Nursing Homes Report 'Severe Shortage' of Staff and PPE, with No Progress Since May," (Skilled Nursing News, 08/20/2020) https://skillednursingnews.com/2020/08/at-least-1-in-5-nursing-homes-report-severe-shortage-of-staff-and-ppe-with-no-progress-since-may/

[23] Culled from accounts by Chicago ombudsmen and facility residents.