



December 15, 2020

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Governor DeSantis:

As Florida begins its long-awaited initial phased distribution of COVID-19 vaccines across the state, Disability Rights Florida again writes to your Office to underscore several relevant considerations for ensuring that Florida’s disability populations remain safe and adequately informed in the coming months. Since 1977, our organization has served as the state’s federally designated Protection and Advocacy (P&A) system benefitting all persons with disabilities in the state through the provision of an array of client-directed and systemic intervention strategies authorized across a range of nine separate federal grants.

**Equitable Treatment of Disability-Specific Congregate Living Settings**

First, we again stress the importance of including all congregate residential settings serving individuals with disabilities within the state’s definition and understanding of “long-term care” (LTC) facilities.<sup>1</sup> As you know,

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<sup>1</sup> This includes ensuring the equitable characterization and treatment of staff and residents of congregate settings licensed and regulated by the state’s Agency for Persons with Disabilities (such as group homes, adult foster care facilities, residential habilitation centers, and intermediate care facilities) as well as the state’s Developmental Disability Centers – the Developmental Disabilities Defendant Program (DDDP), Sunland Center and Tacachale Center. This should also include all staff and residents of congregate settings licensed and regulated by the state’s Department of Children and Families (such as psychiatric hospitals and psychiatric units, short term residential treatment and group home facilities, forensic facilities, and Baker or Marchman Act receiving facilities and crisis stabilization units), as well as other settings in the state such as jails, prisons, detention centers, and homeless shelters.

many persons with disabilities have underlying health conditions that render them high-risk for experiencing complications and even death if exposed to COVID-19. For example, those with intellectual and developmental disabilities are almost three times as likely to die from COVID-19 as others who are infected, and people with chronic kidney or heart disease, cancer, and other comorbidities have a significantly elevated risk of death.<sup>2</sup> Many of these high-risk individuals live in congregate settings other than nursing homes or assisted living facilities, and according to the Kaiser Family Foundation, while those in long-term care facilities account for 6% of total COVID cases in the US, they simultaneously account for 40% of total COVID-related deaths.<sup>3</sup>

Past failures to identify and prioritize LTC settings other than nursing homes and assisted living facilities have resulted in coverage or protection gaps for many individuals with disabilities living in these populations. For example, when the state's mandatory facility testing protocols expired several months ago, the state argued that federal law requiring testing in nursing homes would sufficiently fill the void created by allowing these standards to lapse. However, the decision to jettison these testing requirements in this manner has left staff and providers of LTC settings other than nursing homes (as well as individuals with disabilities residing in these facilities) without equitable access to essential testing for months.<sup>4</sup>

Persons with disabilities and underlying health conditions that make them high-risk for infection should be prioritized within the state's response framework and understanding if they live in *any* type of congregate or shared residential setting – whether it be nursing homes, group homes, intermediate care facilities, psychiatric facilities, jails, or prisons. The risks to people living in congregate facilities – of all types – is well documented, and the state's planning for vaccine distribution and administration must properly encompass all such settings accordingly on an equitable basis as this planning commences.

### **The Importance of Informed Consent for Vaccinations Administered to Disability Populations**

While it is important for Florida to grasp the full range of vulnerable populations residing statewide in its congregate facilities, it is just as important for the state to understand and contextualize the legitimate fears and natural aversions that many individuals with disabilities and their advocates maintain towards the prospect of forced or coerced vaccinations and other medical experimentation.<sup>5</sup> Not unlike similar well-founded and well-publicized aversions held by other socially marginalized groups<sup>6</sup> in this country, the reluctance of those with disabilities in the state to being among the first to receive COVID-19 vaccines

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<sup>2</sup> "Risk Factors for COVID-19 Mortality among Privately Insured Patients" (November 2020), A FAIR Health White Paper in Collaboration with the West Health Institute and Marty Makary, MD, MPH, from Johns Hopkins University School of Medicine. Available electronically at [www.fairhealth.org](http://www.fairhealth.org). See also, Roni Caryn Rabin "Developmental Disabilities Heighten Risk of Covid Death", *New York Times* (November 10, 2020).

<sup>3</sup> "State Data and Policy Actions to Address Coronavirus" (December 11, 2020), Kaiser Family Foundation. Available electronically at <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/>.

<sup>4</sup> During this time, although the state began directing its federal allotment of "rapid test" kits to nursing homes when these requirements expired, such "point of care" testing could not be administered to staff or providers of group homes in the state without first obtaining a federal testing waiver to permit administration.

<sup>5</sup> See generally, Leah Rosenbaum "The Hideous Truths of Testing Vaccines on Humans", *Forbes* (June 12, 2020), detailing a 15-year long hepatitis vaccine experimentation program conducted upon children and adults with severe developmental challenges at the Willowbrook State School in Staten Island, NY.

<sup>6</sup> See generally, Joseph P. Williams "From Tuskegee to a COVID Vaccine: Diversity and Racism are Hurdles in Drug Trials", *U.S. News and World Report* (November 19, 2020); P.R. Lockhart "Experts Warn of Low COVID Vaccine Trust Among Black Americans", *NBC News* (December 11, 2020); Christopher Booker and Connie Kargbo "Inside the Attempt to Build Trust About the COVID-19 Vaccine in Black Communities", *PBS News Hour Weekend* (December 12, 2020).

following the FDA’s initial emergency authorization needs to be considered in good faith by public health officials in the state at this juncture. This is true despite substantial anecdotal and clinical support for the safety and efficacy of these vaccines.

While it is encouraging that your Office has routinely stressed its intention to administer these vaccines on a voluntary basis, the precise dimensions for how this voluntariness is to be cultivated across the state’s interactions with disability populations is yet unknown. What efforts will be made to receive the informed consent of individuals who rely upon court-ordered guardians or similar surrogate decisionmakers to coordinate their medical care? How will individuals who are voluntarily or involuntarily residing in state hospitals or treatment centers be appropriately advised of the risks and benefits of vaccination?

### **Ensuring the Accessibility of Information Related to Vaccine Administration**

Given the importance of hinging Florida’s vaccine distribution and allocation planning on appropriately obtained informed consent, it is somewhat distressing to note that the state’s “COVID-19 Vaccination Plan” contains no discussion or apparent consideration of the accessibility of information that it intends to communicate and disseminate to populations it will seek to vaccinate.<sup>7</sup> Ample portions of this planning reference various aspects of safety, awareness, and informational campaigns that the state intends to coordinate – including second-dose reminders, general program communication, vaccine safety monitoring, vaccination program monitoring, pre-vaccine communication strategies, limited vaccine availability communication strategies, and widespread vaccine availability communication strategies. It is imperative that Florida places an emphasis on targeted, accessible outreach to its disability populations for each of these communication strategies.

To facilitate both the efficacy of this vaccine planning as well as the requisite informed consent for its voluntary administration as your Office has regularly stated, Florida must ensure that materials regarding the vaccination protocol are accessible to all members of the public, including to people with disabilities and those with limited English proficiency. This includes – but is not limited to – providing such information in plain language, in screen-reader accessible formats, in other alternative formats needed by people with disabilities (including American Sign Language and graphic formats that are understandable by people who may not be able to read), and in the top 15 non-English languages spoken in the state.

### **Promoting Inclusive, Accessible Means and Modes of Vaccine Distribution and Administration**

Finally, the state must once again ensure that reasonable modifications are ultimately available to its distribution and administration planning efforts for individuals with mobility impairments or who are otherwise transportation disadvantaged. Although it appears that a central feature of the federal-state “LTC pharmacy partnership” will involve pharmacists traveling to long-term care facilities to administer doses of the vaccines to residents directly, Florida should begin coordinating mobile vaccination programs and other no-cost transportation options to ensure that vaccinations are accessible to people with disabilities and older adults who do not drive or who are in settings that do not provide transportation. As was the case earlier in the pandemic when county health departments initially began offering testing programs on a widescale basis, vaccination programs likewise cannot be restricted to facility-based or “drive-up only” sites.

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<sup>7</sup> Florida Department of Health “COVID-19 Vaccination Plan” (October 16, 2020). Available electronically at [http://ww11.doh.state.fl.us/comm/partners/covid19\\_report\\_archive/vaccination-plan/vaccination\\_plan\\_latest.pdf](http://ww11.doh.state.fl.us/comm/partners/covid19_report_archive/vaccination-plan/vaccination_plan_latest.pdf).

Disability Rights Florida appreciates your Office’s attention to the above considerations, and your commitment to ensuring the safety and well-being of all Floridians including those with disabilities during this time and throughout the duration of the COVID-19 pandemic. As you are aware, federal law<sup>8</sup> prohibits discrimination against individuals with disabilities in the provision of medical care and treatment. In March of this year, the US Department of Health and Human Services’ Office for Civil Rights (OCR) issued a bulletin<sup>9</sup> affirming that these protections remain in place throughout the COVID-19 pandemic, noting that “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best objective medical evidence.”

Although the state has structured and promised an ostensibly elective or voluntary approach to statewide administration of its COVID-19 vaccines, all components of Florida’s vaccine allocation framework must comply with federal civil rights laws and related directives from OCR. If there is anything that Disability Rights Florida may do to clarify these requirements – or to assist or collaborate on the above considerations and objectives – please do not hesitate to let our office know.

Very Sincerely,

/s/  
Peter P. Sleasman  
Executive Director  
Disability Rights Florida

/s/  
Tony DePalma  
Director of Public Policy  
Disability Rights Florida

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<sup>8</sup> To wit, the Americans with Disabilities Act of 1990, as amended (42 U.S.C. § 12101, et seq.), Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. § 794), and Section 1557 of the Affordable Care Act (42 U.S.C. § 18116).

<sup>9</sup> Office for Civil Rights, US Department of Health and Human Services “BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)” (March 28, 2020). Available electronically at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.