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December 11, 2020

Stephanie McCloud
Director of Health
Ohio Department of Health
246 North High St.
Columbus, Ohio 43215

Re: Comments to Ohio’s COVID-19 Vaccination Plan, including its recent interim draft plan


Director Stephanie McCloud:

Disability Rights Ohio (“DRO”) is a non-profit corporation that serves as Ohio’s protection and advocacy system for individuals with disabilities. In furtherance of our mission to advocate for the human, civil, and legal rights of people with disabilities in Ohio, DRO appreciates the opportunity to provide comments and recommendations to the Ohio COVID-19 Vaccination Plan.

The following undersigned organizations also join these comments: Ohio Brain Injury Program, University of Cincinnati Center for Excellence in Developmental Disabilities, Ohio Olmstead Task Force, Down Syndrome Association of Central Ohio, Coalition for Community Living – Ohio, Disability Law Society at Case Western Reserve University, Ohio Chapter of the National Association of Social Workers, and Columbus Chapter of the National Association of Black Social Workers.

We appreciate that Ohio has taken a thoughtful approach in determining critical populations by placing first responders, high-risk healthcare workers, people at significantly higher risk due to comorbid or underlying conditions, and older adults living in congregate or overcrowded settings amongst the earliest to receive the vaccine. DRO is also pleased to see the more recent developments as to the inclusion of people with intellectual disabilities, as well as those with mental illness, who live in group homes, as well as patients at psychiatric hospitals and residents of assisted living facilities into Phase 1A.

We also understand that the current plan serves only as a working framework in which leading health experts, key stakeholders and local leaders are able to offer input, as well as strategic planning. Therefore, as the Ohio COVID-19 Vaccination Plan will be updated over time while vaccines continue to be developed, DRO offers the recommendations listed below to ensure that



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the rights of people with disabilities are protected and that the allocation of the vaccine will occur in an equitable manner. These recommendations should be incorporated into a revised draft of Ohio’s COVID-19 Vaccination Plan:

- Prioritize people with disabilities in **all** types of congregate settings;
- Prioritize people with disabilities, regardless of age, in all congregate settings;
- Prioritize people with disabilities in home and community-based services settings;
- Prioritize individuals with intellectual and developmental disabilities, even if they do not fit within one of the existing categories; and
- Ensure that both the information and education about the administration of the vaccine are accessible to people with disabilities.

We also applaud the state for recognizing in its interim draft plan that racial and ethnic minority populations have a higher prevalence of comorbidities and risks of infection.¹ Systemic, institutional racism has led to this reality, and people with disabilities in these racial and ethnic minority groups encounter multiple barriers to health care and service systems. The pandemic has exacerbated these longstanding disparities. Along with our recommendations explained in further detail below, we encourage the state to continue to develop and implement its vaccine plan through this intersectional lens.

Explanation of Recommendations

1. Recommendation for a Broader and Comprehensive Characterization of Congregate Settings in Phase 1

The rate of COVID-19 infection is significantly higher in congregate settings, due to rotating staff and often the inability to comply with social distancing and other public health recommendations. In fact, less than one percent of people live in long-term care facilities, but residents of those facilities have comprised approximately forty percent of deaths nationally to date.² Moreover, the Centers for Medicare & Medicaid Services (“CMS”) reported, as of November 15, over 496,000 confirmed or suspected COVID-19 cases and 69,872 deaths in nursing homes.³ However, these figures only represent a fraction of the impact in congregate settings because CMS has only required testing and reporting of COVID-19 infections and deaths from nursing facilities, while leaving out other Medicaid-funded or certified congregate settings.

¹ In Ohio, per COVID-19 statistics released by the Ohio Department of Health, as of December 10, 2020 Black Ohioans account for 19.9% of COVID-related hospitalization and 13.9% of deaths. *COVID-19 Dashboard*, Ohio Department of Health, <https://coronavirus.ohio.gov/wps/portal/gov/covid-19/dashboards/demographics/case-demographics> (last visited Dec. 10, 2020).

² *State Data and Policy Actions to Address Coronavirus*, Kaiser Family Foundation, <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/> (last visited Dec. 10, 2020); *The Long-Term Care COVID Tracker*, The COVID Tracking Project, <https://covidtracking.com/data/longtermcare> (last visited Dec. 10, 2020).

³ *COVID-19 Nursing Home Data*, Centers for Medicare & Medicaid Services, (Nov. 29, 2020) <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>.

In the face of such staggering statistics, we strongly encourage that the interim draft plan be revised to effectively address risks to individuals with disabilities who live in **any** type of congregate setting. The Ohio Department of Health should revise the plan’s framework to include a broader characterization of the term “congregate settings,” so as to include all of the following: nursing facilities, assisted living facilities, intermediate care facilities for people with intellectual and developmental disabilities (including state-operated developmental centers), group homes, residential treatment centers, medical hospitals, publicly-operated and privately-run psychiatric facilities, homeless shelters and other similar congregate settings throughout the state in Phase 1. The state should include the staff who work in these congregate settings, too.

Similarly, Ohio should include prisons, jails, and detention centers as a high priority, as the incarcerated population disproportionately includes people with disabilities,⁴ who often face a higher risk of complication or death from COVID-19.⁵ And the same difficulties in complying with social distancing and other public health guidelines exist in these settings, too, as the high rates of infection and fatalities demonstrate. Staff of prisons, jails, and detention centers should be prioritized as well.

2. Recommendation to Prioritize Younger Individuals with Disabilities In Congregate Settings By Removing Age Distinction in Phase 1

Ohio’s interim vaccine allocation framework focuses only on vaccinating older adults in congregate or overcrowded settings in Phase 1B. The plan thus overlooks the fact that many young people with disabilities, who also live in long-term care facilities and other congregate settings, share similar medical risk factors and the inability to comply with public health guidelines, like social distancing. A recent study found that the virus poses a greater risk to people with intellectual and developmental disabilities, especially at younger ages.⁶ The study determined that “18 to 74 year-olds with developmental disabilities, mostly diagnosed with autism, who contracted the virus died at nearly twice the rate as others.”⁷ In addition, the state’s

⁴ Forty percent of jail inmates report having at least one disability. *Disabilities Among Prison and Jail Inmates, 2011-2012*, U.S. Department of Justice (Dec. 2015) <http://www.bjs.gov/content/pub/pdf/dpji1112.pdf>.

And, more than half of the individuals detained in jails (53%) with a disability reported a co-occurring chronic condition. *Id.*

⁵ According to the Centers for Disease Control and Prevention (“CDC”), persons with disabilities are at a higher risk for serious illness resulting from COVID-19. *People at Increased Risk And Other People Who Need to Take Extra Precautions*, Centers for Disease Control and Protection (Nov. 30, 2020) https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fhigh-risk%2Fhigh-risk-complications.html. This includes individuals with impaired lung function, immunocompromising disorders, including individuals taking immunocompromising drugs, high blood pressure, diabetes, and heart disease. Seth McBride, *Disability-Specific Recommendations for COVID-19*, *New Mobility Magazine* (Apr. 3, 2020), <https://www.newmobility.com/2020/03/disability-specific-recommendations-for-covid-19/>.

⁶ Margaret A. Turk, MD, et al., *Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis*, *Disability and Health Journal* (July 2020) <https://www.sciencedirect.com/science/article/abs/pii/S1936657420300674>.

⁷ *Id.*

plan fails to consider that adults ages 31 to 64 have been the fastest growing population in nursing facilities.⁸

To ensure that all high-risk groups who have an increased likelihood of contracting COVID-19 and an elevated risk of serious illness or fatality are included, it is imperative that the age distinctions outlined in Phase 1 be removed. DRO thus recommends that the Ohio COVID-19 Vaccination Plan specifically prioritize all people, regardless of age, who live in these congregate settings to be included in Phase 1.

3. Recommendation to Prioritize All Individuals with Disabilities Receiving Home and Community-Based Services

DRO acknowledges the efforts of the Ohio Department of Health to try to ensure evenhandedness throughout the framework of the vaccination plan. In keeping in line with this goal, DRO encourages the Ohio Department of Health to recognize that many individuals with disabilities do not reside in congregate settings, but rather often live within their own communities while receiving home and community-based services (“HCBS”). These services fund needed hands-on assistance with, for example, eating, bathing, ambulating, getting dressed, or medication administration, by providers who remain in direct contact with the person receiving services. This makes social distancing, isolating and quarantining from others outside their household difficult or impossible for individuals receiving HCBS services. Moreover, many HCBS providers live outside the home of the person they assist and often rotate with other providers, increasing exponentially the potential contacts for individuals receiving HCBS services.

DRO therefore urges the Ohio Department of Health to prioritize people with disabilities who reside within their own communities while receiving HCBS. This should include people enrolled in Medicaid waiver programs administered by the Ohio Departments of Medicaid, Developmental Disabilities, and Aging; people receiving Medicaid-funded state plan services, like nursing and home health aide services; and those who receive similar types of services through other funding sources. And like congregate facilities, HCBS providers should be given priority as well. The state could work with local entities (like county boards of developmental disabilities) to determine objective criteria for who is most at risk from COVID-19 (for example, people with developmental disabilities enrolled in the Individual Options waiver, have complex and serious underlying medical conditions).

4. Recommendation to Prioritize Individuals with Intellectual and Developmental Disabilities

DRO recognizes Governor DeWine’s recent announcement to prioritize individuals with intellectual disabilities and mental illness who reside in a group home or psychiatric hospitals. However, Ohio COVID-19 Vaccination Interim Draft Plan otherwise makes no mention of people with intellectual and developmental disabilities, despite them being at a

⁸ *The Younger Adult in the Long-Term Care Setting*, The Society for Post-Acute And Long-Term Care Medicine, <https://paltc.org/product-store/younger-adult-long-term-care-setting> (last visited Dec. 10, 2020).

disproportionately higher risk of COVID-related complications and death when compared to others.⁹ According to a recent NPR analysis, “people with intellectual disabilities and autism who contract COVID-19 die at higher rates than the rest of the population.”¹⁰

Moreover, recent studies have examined the COVID-19 mortality risk in people with Down syndrome. A report published in the *Annals of Internal Medicine* found that individuals with Down syndrome faced fivefold increased risk for COVID-related hospitalization and a tenfold increased risk for COVID-related death.¹¹ The researchers emphasized that people with Down syndrome are currently not “strategically protected,” as neither the United States nor the United Kingdom has identified Down syndrome as comorbidities that heighten the risk for serious complications or death from COVID-19.¹²

Therefore, despite facing such dismal outcomes when contracting COVID-19, this high-risk group is left disenfranchised by the existing vaccination plan. For instance, the Ohio Department of Health recently released a Down Syndrome Factsheet explaining that many people with Down syndrome are active and valued members of their community, while highlighting that many of the adults live independently or with some support.¹³ Under the current framework of the interim draft, an older individual with Down syndrome who resides within their community and is not identified as having comorbid or underlying conditions would automatically be placed in Phase 2 of the vaccination plan. However, if the individual is not an older adult, then they would not receive the vaccination until Phase 3 or Phase 4. Therefore, young individuals with Down syndrome who reside at home with their families will likely be placed amongst the last people to receive the vaccine, despite a tenfold risk of dying from COVID-19. This is especially troubling when, on average, persons with Down syndrome live to be about 47 years old and over 60% reside at home while receiving healthcare services.¹⁴

By incorporating people with developmental and intellectual disabilities into Phase 1, the Ohio COVID-19 Vaccination Plan will effectively account for their staggering heightened risk of COVID-19 complications and fatality. This inclusiveness will also address the evident disparities which exist within the current framework, allowing for a more equitable and fair allocation of the

⁹ Margaret A. Turk, MD, et al., *Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis*, *Disability and Health Journal* (July 2020)

<https://www.sciencedirect.com/science/article/abs/pii/S1936657420300674>.

¹⁰ Joseph Shapiro, *COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities*, NPR, (June 9, 2020) <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>.

¹¹ Ashley Kieran Clift, MA, MBBS, et al., *COVID-19 Mortality Risk in Down Syndrome: Results From a Cohort Study Of 8 Million Adults*, *Annals of Internal Medicine* (Oct. 21, 2020)

<https://www.acpjournals.org/doi/10.7326/M20-4986>.

¹² *Id.*

¹³ *Down Syndrome Fact Sheet for New and Expectant Parents*, Ohio Department of Health (Oct. 20, 2020).

<https://odh.ohio.gov/wps/wcm/connect/gov/58a55d9a-50bd-4911-b949-8a762ae9dcb9/DownSyndromeFactSheet-12-09->

[2015.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0N0JO00QO9DDDDM3000-58a55d9a-50bd-4911-b949-8a762ae9dcb9-mqDqdv1](https://odh.ohio.gov/wps/wcm/connect/gov/58a55d9a-50bd-4911-b949-8a762ae9dcb9-mqDqdv1_2015.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0N0JO00QO9DDDDM3000-58a55d9a-50bd-4911-b949-8a762ae9dcb9-mqDqdv1).

¹⁴ *Data and Statistics on Down Syndrome*, Centers for Disease Control and Prevention (Dec. 5, 2019)

<https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>.

COVID-19 vaccine. Though many people with intellectual and developmental disabilities would fall within one of the expanded categories we recommend above, some may not. This additional priority category, we feel, is therefore needed.

5. Recommendation to Ensure Vaccine Education and Information is Fully Accessible to Individuals with Disabilities

DRO appreciates that the Ohio COVID-19 Vaccination Plan provides that the state will “operate with equity and transparency to ensure equitable allocation of vaccines for the residents of Ohio to reduce COVID-19 infection and mortality among at-risk and vulnerable populations.”¹⁵ As DRO advocates that individuals with disabilities be prioritized in the vaccine allocation framework, it does so solely on the basis that the vaccine has been determined to be safe and beneficial to the health of people with disabilities. However, there may be unanticipated side effects and risks.

Therefore, in an effort to ensure informed choice, DRO recommends that the dissemination of vaccine information and all outreach be fully accessible and provided in multiple formats and using clear and easy-to-understand language, to people with disabilities and their families. This information should explain the benefits and risks involved. The administration of the vaccine must be based on informed consent. Ensuring that vaccine messaging will be fully accessible and that informed decisions are respected will help promote legitimacy, as well as build trust amongst one of Ohio’s most at-risk populations.

Conclusion

Thank you for the opportunity to provide input on this critical matter. We appreciate the urgency of the task facing the Ohio Department of Health, particularly as the number of COVID-19 cases are rising across the state. We would welcome the opportunity to be a resource to you to ensure that the needs of individuals with disabilities are addressed. Please do not hesitate to contact Kevin Truitt at ktruitt@disabilityrightsohio.org or (614) 466-7264 ext. 122 if you have any questions or need any additional information.

Respectfully,

/s/ Kerstin Sjoberg

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¹⁵ *Ohio Covid-19 Vaccination Plan Interim Draft*, Ohio Department of Health, 29 (Oct. 16, 2020) <https://coronavirus.ohio.gov/static/docs/Interim-Draft-COVID-Vaccination-Plan-10-16-20.pdf>.

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