



MARYLAND DEVELOPMENTAL DISABILITIES COALITION

Dedicated to the rights and quality of life for people with developmental disabilities in Maryland

December 8, 2020

The Honorable Kirill Reznik
The Honorable Sandy Rosenberg
The Honorable Joseline Pena-Melnyk
VIA E-MAIL

Dear Chair Reznik, Chair Rosenberg, and Chair Pena-Melnyk, and members of the subcommittees:

As Maryland continues making plans for how to allocate COVID-19 vaccinations, we write to reiterate that vaccine distribution and allocation must be done in a safe and equitable manner, and people with intellectual and developmental disabilities (IDD) must be explicitly addressed in the Maryland COVID-19 Vaccination Plan.

- **People with intellectual and developmental disabilities are a high-risk population and should be prioritized for COVID-19 vaccines.**

It is well documented that people with IDD have long experienced structural health inequities, including social determinants that increase their overall health risk. Complications from and death rates due to COVID-19 for people with intellectual and developmental disabilities (IDD) are also disproportionately higher when compared to people without IDD (Turk, et al., 2020; Landes, et al., 2020). COVID-19-related fatality rates among people with IDD nationally who have tested positive for COVID-19 are 100% to 200% greater than the mortality rates among the general population who have tested positive for COVID-19. Therefore, individuals with IDD must be specifically considered and prioritized in the COVID-19 vaccine allocation efforts.

- **As essential healthcare personnel, direct support professionals working in all settings (residential congregate, day program, and individual homes) are on the frontlines supporting people with IDD to stay safe and healthy, and should be prioritized for COVID-19 vaccines.**

Many people with IDD rely on home health and personal support workers who travel between client homes for daily support. Numerous others live in congregate residential settings and/or receive services during the day at a provider location, supported by direct support professionals. Direct support professionals (DSP) play a critical role in the daily lives of the over 17,000 people with developmental disabilities who receive services and supports funded and licensed by the Developmental Disabilities Administration (DDA). In recognition of these critical services, Governor Hogan deemed the services as essential and the direct support professionals as essential employees (Executive Order NO. 20-03-31-02).

- **Prioritized access to COVID-19 vaccines is critical for people with intellectual and developmental disabilities and direct support professionals.**
- **When prioritized, people must still be afforded the option to receive the vaccine or not. No one should be required to be vaccinated.**

Maryland's draft vaccination plan acknowledges the need for equitable access to the vaccine. Many people with disabilities will face barriers to safe access of the vaccine, including significant challenges with transportation and concerns about exposure to the virus at vaccination sites. If possible, and in consideration of vaccine storage constraints we may face, home health and other direct support professionals with appropriate training should be allowed to vaccinate people in their homes.

We know that the pandemic has placed tremendous demands on limited resources. We appreciate that the State has continued to prioritize people with developmental disabilities and the direct support professional whom they rely on for vital services. We strongly recommend this prioritization continue related to access to the vaccine in order to save lives of people who are especially vulnerable to COVID-19, and their staff. A number of other states have included people with developmental disabilities and their staff in the highest priority category, and we hope that Maryland leaders will make the same decision.

Sincerely,



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People on the Go of Maryland



Ande Kolp, Executive Director
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Laura Howell, Executive Director
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Megan Rusciano, Interim Co-Managing Attorney
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cc: The Honorable Maggie McIntosh
The Honorable Shane Pendergrass

December 18, 2020

The Honorable Lawrence J. Hogan, Jr.
Governor
100 State Circle
Annapolis, MD 21401

Dear Governor Hogan:

Thank you for your continued efforts to ensure the health of Marylanders throughout the COVID-19 pandemic. Today, while the virus intensifies and our state marks its highest case numbers of COVID-19, the promise of a vaccine brings us hope. We applaud that Maryland's draft vaccine plan ("Plan") prioritizes frontline health care workers, first responders, and incarcerated people. As a cross-disability network of advocacy organizations that have witnessed firsthand the horrific impact of the virus on people with disabilities, we are writing to underscore that people with disabilities, and the professionals and caregivers that support them, should be prioritized in the first phases of vaccination. Our recommendation is based on the high risk of contracting and dying from COVID-19 for this group of individuals. We appreciate that the Plan will continue to evolve and in that spirit we offer the following comments.

1. Prioritize all residents in nursing homes and residential care facilities so people with disabilities who are at high risk in these facilities, not only older adults, have access to the vaccine in Phase 1.

Maryland's Plan prioritizes adults over the age of 65 who reside in nursing homes and residential care facilities in Phase 1 (p.45). Thus, it makes a distinction between older adults in these high-risk congregate settings and others with disabilities who live in the same facilities and are also at risk of contracting COVID-19 and experiencing severe adverse health consequences. The Plan should be amended to ensure that all people living in these facilities, which are at the epicenter of cases and deaths from COVID-19, are prioritized for a vaccine. At least 50% of Maryland deaths from COVID-19 occur inside nursing facilities.¹

Nursing homes and residential care facilities house people with disabilities of all ages who frequently, due to our institutional bias in health care, cannot obtain needed home health care in their communities. While some such individuals may receive priority Phase 1 status, based on having specific co-morbid or health conditions, others may have a disability that has yet to be linked to increased COVID-19 risk either because their condition is less well-known and may never reach the case numbers required for recognition as a statistically significantly risk factor for COVID-19 or because they have a different diagnosis from one of the conditions listed, even though they are at very high risk for adverse effects (e.g. persons with intellectual or developmental disabilities, *see* Number 4. below). We believe that people with disabilities who are under age 65 and who reside in congregate settings and therefore rely on personal care for

¹ New York Times, "More Than 100,000 U.S. Coronavirus Deaths Are Linked to Nursing Homes", last updated December 4, 2020, available at <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html>. (Citing that 50% of Maryland's COVID-19 deaths have occurred in nursing homes).

assistance with basic activities of daily living, including bathing, grooming, toileting, receiving medications and eating must be prioritized in Phase 1. All residents in these facilities face an unavoidable risk of infection and should be prioritized for the vaccine. In fact, this appears to be the approach used for people in prisons, jails and detention centers - all of whom are in Phase 1 priority status regardless of age or health conditions. Factors that create heightened risks in detention facilities: nature of the facility, the inability to socially distance, reliance on multiple staff, co-mingling of population in the facility, high risk populations –apply to nursing and residential facilities housing persons with disabilities. We ask that the age restriction for nursing and congregate facilities in Phase 1 be amended.

2. Clarify that the congregate and/or overcrowded settings in Phase 1 includes assisted living facilities, intermediate care facilities for people with developmental and/or intellectual disabilities, psychiatric hospitals and board and care homes.

Maryland’s Plan wisely recognizes the need to protect and prioritize people in congregate or overcrowded settings. However, the Plan does not define residential care facilities. The Plan should clarify that all individuals with disabilities in assisted living facilities, intermediate care facilities for people with I/DD, psychiatric hospitals, and board and care homes, are within Phase 1. We note that people residing in congregate settings: (1) are at higher risk of contracting COVID-19 due to their close proximity to and reliance on others for care and (2) generally have disabilities that disproportionately place them at moderate to high risk of severe effects or death from COVID-19.

The Center for Disease Control (CDC) has noted that people with disabilities are three times as likely as people without disabilities to have heart disease, stroke, diabetes, or cancer, which may make them more susceptible to serious effects from COVID-19.² The CDC has also found that people with disabilities may face heightened risk of becoming infected and having unrecognized illness, because they may have limited mobility; cannot avoid coming into close contact with others who may be infected; may have trouble understanding information or practicing prevention measures; and may not be able to communicate symptoms of illness.³

3. Advance the priority from Phase 2 to Phase 1 for people with disabilities in group homes.

For reasons stated in Recommendation 2, people with disabilities in group homes should also be prioritized in Phase 1. The number of people in this category is limited, but the health consequences are very significant to them and others in their shared space. People with disabilities, including people with intellectual and developmental disabilities, brain injuries, and behavioral health conditions may share bedrooms and bathrooms with others and have staff who come and go from the programs and who frequently provide hands on care to the individuals they support. Recognizing this heightened risk to this group of individuals, other states have

² The Centers for Disease Control, “COVID-19: People with Disabilities”, last updated Sept. 11, 2020, available at <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>.

³ Id.

prioritized people with disabilities in congregate settings, including group homes in the first phases of vaccination.⁴ Maryland should do the same.

4. Prioritize in Phase 1, people with intellectual and developmental disabilities as people with conditions that put them at significantly higher risk of contracting and dying from COVID-19.

People with intellectual and developmental disabilities (I/DD) must be recognized as a group who is at significantly higher risk of contracting and dying from COVID-19. Many studies have shown that people with I/DD are at a higher risk of complications and death if exposed to COVID-19.⁵ Indeed, a recent study further confirmed that “developmental disorders, as well as intellectual disabilities and related conditions, are important risk factors for COVID-19 mortality, as are lung cancer and leukemia and lymphomas.”⁶

The Developmental Disabilities Administration (DDA), which provides community-based services to people with intellectual and developmental disabilities reports a mortality rate from COVID-19 among participants receiving DDA services of 5%, which is more than double the mortality for Marylanders who have contracted COVID-19.⁷ Because of their well-documented vulnerability to complications and death from COVID-19 people with I/DD should be prioritized in Phase 1 of vaccine allocation as people with co-morbid and underlying condition that put them at significantly higher risk of contracting and dying from COVID-19.

⁴ See policies in: NJ, MA, DE, NC, NM, IL, CA, MN, NH, OH, LA, IN, IA, VA, WA, OR, and NE. Citations available on request. As examples, please see North Carolina, available at: <https://files.nc.gov/covid/documents/NC-COVID-19-Vaccine-Plan-with-Executive-Summary.pdf>. Ohio, available at: <https://coronavirus.ohio.gov/wps/portal/gov/covid-19/resources/news-releases-news-you-can-use/covid-19-update-12-04-20>, and Minnesota, available at:

<https://www.health.state.mn.us/diseases/coronavirus/vaccine/phase1aguide.pdf>.

⁵ See American Academy of Developmental Medicine & Dentistry, “COVID-19 Support Guidelines for Individuals with IDD During the Pandemic”, July 2020, available at

<https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5f16512e8f88d259900766f5/1595298102002/COVID-Support-Guidelines.pdf>. See also, Turk, et. al, “Intellectual and developmental disability and COVID-19 case-fatality trend: TriNetX analysis”, *Disabil Health J* 2020 Jul; 13(3), available at

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7245650/>; Landes, et. at. “COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State, *Disabil Health J* 2020 Oct 13(4), available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7311922/>.

⁶ White Paper: Risk Factors for COVID-19 Mortality among Privately Insured Patients: A Claims Data Analysis” A FAIR Health White Paper in Collaboration with the West Health Institute and Marty Makary, MD, MPH, from Johns Hopkins University School of Medicine, November 11, 2020, available at

<https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf>.

⁷ Compare, Developmental Disabilities Administration (DDA) Updates, Bernard Simons, December 4, 2020, available at:

<https://dda.health.maryland.gov/Documents/COVID%2019%20Documents/Dep%20Sec%20Webinars/Webinar%20DDA%20Deputy%20Secretary%20FINAL%20BS%2012.4.20.pdf> with Maryland Department of Health, Coronavirus Disease 2019 (COVID-19) Outbreak, available at: <https://coronavirus.maryland.gov/>.

5. Include within the definition of home health workers, direct support professionals and caregivers who provide care services to people with disabilities in community and group home settings in Phase 1.

The Plan prioritizes home health workers in Phase 1, but relegates similarly situated group home staff, including those who provide supports to people with intellectual disabilities, brain injuries, mental health conditions, and substance use disorders, to Phase 2 (pg. 45-46). The exclusion of direct support professionals, an already underfunded profession, only further burdens these workers who have put their lives at risk to support people with disabilities throughout this pandemic. Direct support professionals play a critical role in the daily lives of people with developmental and behavioral health disabilities and people with brain injuries who receive services and supports funded and licensed by the Maryland Department of Health. These support persons often work in the homes of multiple people with disabilities and may have their own families as well. They all have the same need for PPE and regular virus testing as other frontline healthcare workers, but likely have less access to both. Furthermore, the home care workforce also raises racial/ethnic equity concerns as “the care workforce is disproportionately composed of women of color, Black women and immigrant women.”⁸ Other states have prioritized direct support professionals and caregivers in Phase 1 of vaccination and Maryland should expand the definition of health care workers to include direct support professionals and unpaid caregivers of people with disabilities and seniors in Phase 1.⁹

6. Include people who are “chronically homeless” in Phase 1 as people at significantly higher risk of contracting and dying from COVID-19.

A chronically homeless person, by definition, is a homeless person with a disability “who lives either in a place not meant for human habitation, a safe haven, or in an emergency shelter, or in an institutional care facility if the individual has been living in the facility for fewer than 90 days and had been living in a place not meant for human habitation, a safe haven, or in an emergency shelter immediately before entering the institutional care facility.”¹⁰ People who are chronically homeless are at higher risk of contracting COVID-19 often due to underlying conditions and more likely to experience more severe illness and death because of lack of reliable health care.¹¹ They should be prioritized for vaccine allocation as people with comorbid and underlying

⁸ Josephine Kalipeni & Julie Kashen, BUILDING OUR CARE INFRASTRUCTURE FOR EQUITY, ECONOMIC RECOVERY, AND BEYOND (September 1, 2020), at 7, at https://caringacross.org/wp-content/uploads/2020/08/Building-Our-Care-infrastructure_Aug1_FINAL.pdf.

⁹ See policies in: NJ, MA, DE, NC, NM, IL, CA, MN, NH, OH, LA, IN, IA, VA, WA, OR, and NE. Citations available on request. As examples, please see North Carolina, available at: <https://files.nc.gov/covid/documents/NC-COVID-19-Vaccine-Plan-with-Executive-Summary.pdf>. Ohio, available at: <https://coronavirus.ohio.gov/wps/portal/gov/covid-19/resources/news-releases-news-you-can-use/covid-19-update-12-04-20>, and Minnesota, available at: <https://www.health.state.mn.us/diseases/coronavirus/vaccine/phase1guide.pdf>.

¹⁰ Federal Register Vol. 80 No. 233, Friday December 4, 2015, available at: <https://www.govinfo.gov/content/pkg/FR-2015-12-04/pdf/2015-30473.pdf>

¹¹ See New York Times, “Coronavirus Outbreak Has America’s Homeless at Risk of ‘Disaster’”, Thomas Fuller, Aug. 18, 2020, available at: <https://www.nytimes.com/2020/03/10/us/coronavirus-homeless.html>; See also, Benfer, et. al, “Eviction, Health Inequity, and the Spread of COVID-19: Housing Policy as a Primary Pandemic Mitigation Strategy”, Journal of Urban Health, Nov 25, 2020, available at: <https://bit.ly/COVID19HousingisHealth>.

conditions that put them a significantly higher risk of contracting and dying from COVID-19. Chronically homeless individuals are identified through various federal and local programs and can be located for purposes of receiving a vaccine.

7. Prioritize people with disabilities as a critical population

People with disabilities should receive priority for a vaccine when, due to their disability, they cannot distance themselves from others outside of their household. This includes people who receive personal care services from paid or unpaid caregivers. People with disabilities face multiple risks from COVID-19. As discussed, many people with disabilities have underlying conditions that place them at a higher risk of infection and death from COVID-19; they may be unable to keep social distance from caregivers who assist them with activities of daily living; and they may have trouble understanding information or practicing prevention measures.¹² Studies have also shown that people with mental disorders face a higher risk of infection and mortality from COVID-19.¹³ Other states have recognized that people with disabilities should be prioritized as a group at significantly higher risk of contracting and dying from COVID-19 in Phase 1 and Maryland should do the same.¹⁴

The COVID-19 pandemic has laid bare the longstanding inequities and injustices that people with disabilities face in accessing our health care system. Moreover, people with disabilities more generally continue to be disproportionately at-risk of contracting and dying from COVID-19. As a cross-disability group of advocates, we have come together to underscore the need for people with disabilities to be prioritized for this vaccine. The COVID-19 pandemic's impact on people with disabilities cannot be understated and we suggest that Maryland's Plan be amended to reflect this reality.

Please feel free to contact Megan Rusciano at meganr@disabilityrightsmd.org for questions or clarifications.

With appreciation for your efforts and actions on this matter,

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¹² The Centers for Disease Control, "COVID-19: People with Disabilities", last updated Sept. 11, 2020, available at <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>.

¹³ Increased risk of COVID-19 infection and mortality in people with mental disorders: analysis from electronic health records in the United States, QuanQui Wang, Rong Xu, and Nora D. Volkow, *World Psychology*, October 7, 2020.

¹⁴ NJ, MN, OH, IA, VA, WA, OR, and NE. Citations available on request. As examples, please see Ohio, available at: <https://coronavirus.ohio.gov/wps/portal/gov/covid-19/resources/news-releases-news-you-can-use/covid-19-update-12-04-20>, Minnesota, available at: <https://www.health.state.mn.us/diseases/coronavirus/vaccine/phase1guide.pdf>, and Oregon, available at: <https://www.oregon.gov/oha/covid19/Documents/COVID-19-Vaccination-Plan-Oregon.pdf>.

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