NCD letter to NGA re: vaccine allocation

February 9, 2021

The Hon. Governor Andrew Cuomo
Chair, National Governors Association
444 North Capitol Street, Suite 267
Washington, D.C. 20001

Dear Chairman Cuomo:

I write to you on behalf of the National Council on Disability (NCD), to address the often-inequitable allocation of the COVID-19 vaccination to people with disabilities by the States, and to provide recommendations NCD believes are paramount in addressing this important matter.

As you are aware, persons with disabilities are disproportionately affected by the COVID–19 virus, particularly persons with intellectual or developmental disabilities (IDD) and persons with disabilities with underlying health conditions (*e.g.,* chronic lung disease, diabetes, chronic kidney disease, a serious heart condition, or a weakened immune system), that place them at risk for contracting the virus, higher risk for hospitalization once the virus is contracted, and with a greater risk of dying from the virus. Complications from, and death rates due to, COVID-19 for people with IDD are disproportionately higher when compared to people without IDD. Mortality rates have been cited to be up to 15% in individuals with IDD.[1] Concerning individuals with Down syndrome specifically, there is an estimated four-fold increase in risk for COVID related hospitalization and ten-fold increase in COVID-19 related death.[2] Given the alarming rates of COVID-19 hospitalization and death, individuals with IDD must be prioritized explicitly along with other high-risk diagnoses. In addition, the Center for Disease Control and Prevention (CDC) has identified persons who have limited mobility who cannot avoid coming into contact with persons who may be infected, such as direct support providers and family members, as being at an increased risk of becoming infected or having unrecognized illness.

While the CDC and the National Academies of Science Engineering and Medicine framework proposed persons *of all ages* with comorbid and underlying conditions that put them at significantly higher risk be included in Phase 1b or Phase 1c, 29 states – Alabama, Alaska, California, Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Kansas, Kentucky, Maine, Massachusetts, Michigan, Minnesota, Nevada, New Mexico, North Dakota, Oklahoma, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Virginia, Washington, West Virginia – and Washington DC, have all de-prioritized persons with disabilities that fall into that category, including those with developmental disabilities.[3] Moreover, in Illinois, direct service providers including family caregivers are given priority to the vaccination, but not the persons with disabilities for whom they care. While we recognize that in virtually all states the number of vaccines is limited, decisions as to who receives the

vaccinations first must consider the most vulnerable in the disability community, as a matter of equity.

As per other CDC recommendations, many high-risk individuals have already been prioritized and have been offered vaccination, including older Americans and those living in congregate settings. Fortunately, individuals with IDD who happen to live in nursing homes and assisted living facilities have largely been included in these efforts. However, high-risk individuals with disabilities also live in their own homes as well as in other congregate settings such as acute psychiatric facilities and group homes for individuals with disabilities, including serious mental illness, developmental and intellectual disabilities, physical disabilities or substance use disorders. Colorado, Georgia, Hawaii, Indiana, Maine, Minnesota, Mississippi, Texas and Vermont have excluded those other congregate settings in their prioritization of the vaccination.[4]

While some may say that the issues we have identified will be resolved as more vaccines become available – and therefore, just wait – respectfully, that is an untenable position given the high mortality risk among persons with disabilities. As the distribution and allocations of the vaccine continues, we urge you to emphasize to governors and health departments that more equitable frameworks must be determined that incorporates persons with disabilities with IDD, those with limited mobility, and those with underlying health conditions in priority groups, regardless of their setting.

Finally, persons with disabilities have largely been ignored since the commencement of the pandemic in data surveillance, specifically rates of infection, hospitalizations, outcomes, and deaths. Data is critical to informing the public health response and can also assist in identifying which segments of the population with disabilities within a state to specifically target and prioritize for purposes of administration of the vaccine. Thus, NCD urges that states capture the number of their respective constituents receiving home and community-based services and/or developmental disability services because persons receiving those services are likely to have one or more comorbidities that enhance their risk for contracting the virus and enhances their risk for poorer outcomes. From

that data, local and national public health officials can generate evidence to support community-level advocacy and intervention efforts.

Thank you for the NGA's attention to this important matter. Please do not hesitate to contact me with any related questions or to discuss further as necessary.

Respectfully,

Andrés J. Gallegos
Chairman

cc: Mr. Tim Storey
Executive Director
National Conference of State Legislatures

Mr. David Adkins
Director and Chief Executive Officer
The Council of State Governments

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[1] Landes SD, Turk MA, Wong AWWA. COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. *Disability and Health Journal,* 2020,1-5. *See also*, Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*, 2020, 100942. *See also,* Landes SD, Turk MA, Formica MK, McDonald KE, Stevens JD. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal,* 2020, 100969.

[2] Clift AC, Coupland CAC, Keogh RH, Hemingway H, Hippisley-Cox J. COVID-19 mortality risk in Down syndrome: Results from a cohort study

of 8 million adults. *Annals of Internal Medicine,* 2020, 21 October 2020: Letters.

[3] Data obtained from the Jon Hopkins Disability Health Research Center and the Center for Dignity and Healthcare for People with Disabilities COVID – 19 Vaccine Prioritization Dashboard. Last Accessed: February 9, 2021. Available at: COVID-19 Vaccine Prioritization Dashboard – The Johns Hopkins Disability Health Research Center (jhu.edu)

[4] *Id.*

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