



December 7, 2020

VIA EMAIL

The Honorable John Carney, Governor
Molly Magarik, Secretary, DHSS
Dr. Karyl Rattay, Director, DPH

Dear Governor Carney, Secretary Magarik, and Dr. Rattay:

We, the undersigned, represent the major organizations in the state charged with advocating on behalf of people with intellectual and other developmental disabilities¹ (IDD), as well as other entities interested in their well-being. As such, and in conjunction with the Delaware Division of Developmental Disabilities Services, we are writing to request that the Delaware COVID Vaccination Allocation Phased Groups draft currently under discussion and development by the State's Division of Public Health and COVID Vaccine Task Force list individuals with IDD who live in congregate living arrangements other than nursing facilities and ICF/IIDs in Group 1B1, and list IDD as a high risk diagnosis under 1B2. Under the current draft, these individuals would not receive vaccination until Group 2D, which is unacceptable.²

A growing body of research and data supports the conclusion that individuals with IDD are at high risk of infection and are more likely to experience severe outcomes or death associated with this virus.³ In Delaware, for instance, individuals with IDD living in residential provider settings have

¹ For a definition of IDD, please see here: <https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default>.

² Please read letters from the American Academy of Developmental Medicine and Dentistry, endorsed by ANCOR, NASDDDS, NADSP and DDNA and ANCOR, which highlight heightened risks for individuals with IDD and the individuals who care for them. <https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5f99bd13f9d8c02a1e558c89/1603910932293/Covid-19-Vaccine-Statement.pdf>; <https://www.ancor.org/newsroom/news/ancor-issues-statement-need-prioritize-people-intellectual-developmental-disabilities>. Also note the recent letter from the Consortium for Citizens with Disabilities letter to President Elect Biden's COVID task force that addresses this issue. <http://www.c-c-d.org/fichiers/CCD-Letter-to-COVID19-taskforce-final-11-20-20.pdf>.

³ Delaware does not track disability as part of its COVID data collection, which is unfortunate. However, national and international studies, some of them very recent, establish the heightened risk that individuals with IDD face from COVID. Please see, White Paper on Risk Factors for COVID19 Mortality in Private Insurance Claims, <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>; showing that individuals across all age groups with developmental

experienced a 7% infection rate and a 13% mortality rate from COVID-19 compared to state-wide numbers of 4% of the population contracting the virus and 2% succumbing to it.⁴ The unique risks faced by individuals with IDD stem from two critical characteristics of this population: the frequent presence of multiple, co-morbid health conditions that place these individuals at an elevated risk; and the inability of many of these individuals to use the current public health strategies recommended including mask wearing, social distancing, or consistent enhanced hand hygiene.

For individuals with IDD, a vaccine will be the most critical – and accessible – public health measure available to keep them safe. Their inability to utilize current strategies for mitigation the same way that other populations are able to do increases risk and makes access to the tool of vaccines even more compelling.⁵

As many of the signatories to this letter have stated during multiple DPH Ethics Advisory Committee meetings: when a vaccine becomes available in our state, we want to make certain the unique vulnerabilities and needs of people with intellectual and developmental disabilities cannot be overlooked when determining allocation. Assuming that the vaccines are established as safe and effective based on adequate clinical trials and prevailing science, we recommend the following:

1. Individuals who live in group homes, supervised shared living arrangements, or other congregate residential settings should be considered at equivalent risk to older adults who live in congregate settings such as nursing homes and thus be included in phase 1B1 of vaccine allocation;
2. IDD should be *explicitly* included in the list of high-risk diagnoses that are used to determine if an individual is included in phase 1B2 high risk diagnosis; and
3. Confirm that all direct support professionals (DSPs) and other staff who work with and/or care for people with IDD, including group home staff and personal care assistants, should be considered essential health care workers and should be included in Phase 1A2 of vaccine allocation.⁶

Additionally, we request that the Delaware Vaccination Task Force include representation from advocates, providers and others who can assist the state in understanding the needs of Delawareans with disabilities. Currently there is no representation for these populations on the Task Force, which is a glaring omission. Representatives from the disability community should also be included in any substantive subcommittees, and the entire planning process should be transparent.

disabilities had the highest odds of dying from COVID-19; Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disabil Health J* 2020; 13: 100942. [PMC free article] [PubMed] confirming higher morbidity for individuals with IDD; COVID-19 Mortality Risk in Down Syndrome: Results From a Cohort Study Of 8 Million Adults, <https://www.acpjournals.org/doi/10.7326/M20-4986>.

⁴ DDDS Family Letter, 11/6/2020; <https://dhss.delaware.gov/dhss/ddds/files/letter11062020.pdf>.

⁵ It is also worth noting the extreme disruption in day, educational and vocational services to those with IDD that has had a negative impact on functioning and quality of life, and which will be alleviated by reduction in infection through vaccines. <https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html#:~:text=the%20main%20story-.Developmental%20Disabilities%20Heighten%20Risk%20of%20Covid%20Death,conditions%2C%20a%20new%20analysis%20found>; <https://www.cambridge.org/core/journals/bjpsych-open/article/priority-concerns-for-people-with-intellectual-and-developmental-disabilities-during-the-covid19-pandemic/0957E0D8EB4208171F5C4F7E06A475F9>;

⁶ CDC Guidance on vaccine distribution and its list of high risk and medium risk co-morbidities is not binding on the states, who maintain discretion regarding prioritization. Some states, such as North Carolina and Oregon, have already modified their plans to incorporate these suggested changes. See in particular, North Carolina's plan, pages 59-67. <https://files.nc.gov/covid/documents/NC-COVID-19-Vaccine-Plan-with-Executive-Summary.pdf>;

Finally, and relatedly, DPH, and DHSS more broadly, must begin to consider and plan for the accessibility of vaccination distribution programs, immediately for the higher risk groups, and then over time for the rest. *Many, if not most individuals with disabilities, including medically complex and technologically dependent individuals, live in the community and not in nursing facilities.* Many live with their extended families, including aging parents. The perennial difficulties that people with disabilities in the community face with communication, transportation, and access to outreach must be addressed now before the vaccine is available. Particular focus will be required on providing accessible and detailed information about the benefits and risks of vaccination and of specific vaccines. This requires the coordination of many entities, including DMMA, DSAAPD, DDDS, DSAMH, DeIDOT, Medicaid managed care organizations, and providers.

We would ask that you carefully review this letter and referenced materials. There are compelling reasons, with supporting data, to prioritize individuals with intellectual and developmental disabilities and their caregivers/staff for receipt of vaccine. These reasons extend to individuals who live and receive supports through self-directed and other home and community-based services, those who live in provider-managed settings such as group homes and those in congregate care settings such as nursing homes. Prioritization of this vulnerable population and their caregivers/staff is also a practical measure to mitigate the spread of COVID-19. We the undersigned stand ready to provide our collective subject matter expertise and guidance to the Division of Public Health. We look forward to partnering with you to ensure the equitable distribution of the COVID-19 vaccine based on the revised priorities placing individuals with IDD at levels 1B1 and 1B2.

Respectfully,

Delaware Developmental Disabilities Council
Disabilities Law Program of CLASI
Center for Disabilities Studies
Statewide Council for Persons with Disabilities
Governor's Advisory Council for Exceptional Citizens
Ability Network of Delaware
Easterseals Delaware and Maryland's Eastern Shore
The Arc of Delaware
United Cerebral Palsy of Delaware
Point of Hope
Community Systems, Inc.
Freedom Center for Independent Living
EPIC- Endless Possibilities in the Community
We Stand 4 Something