



980 9th Street, Suite 1450, Sacramento, California 95814 • 916.446.7961 • www.arcanet.org

November 29, 2020

Dr. Nadine Burke Harris, Chair, Community Vaccine Advisory Committee
Dr. Oliver Brooks, Co-Chair, COVID-19 Vaccine Drafting Guidelines Workgroup
Dr. Robert Schechter, Co-Chair, COVID-19 Vaccine Drafting Guidelines Workgroup

RE: COVID-19 Vaccine Prioritization And Californians With Developmental Disabilities

Honorable Drs. Burke Harris, Brooks, and Schechter:

The Association of Regional Center Agencies (ARCA) represents the network of 21 community-based non-profit regional centers that coordinate services for, and advocate on behalf of, well over 350,000 Californians with developmental disabilities.

We urge the inclusion of people with developmental disabilities, as well as direct support professionals (DSPs) and families in the priority list of those who will first access a COVID-19 vaccine.

COVID-19 has profoundly impacted life for Californians. People with developmental disabilities are particularly vulnerable to its impacts. Additionally, the DSPs who make integrated community life possible are **one of the most important** elements of ensuring daily life can continue. Similarly, for the many people with developmental disabilities who live at home, particularly those with aging caregivers, their parents are often in high-risk groups.

ARCA urges the Department of Public Health to prioritize people with developmental disabilities in accessing COVID-19 vaccines. We are fortunate to have had a robust, collaborative response by regional centers, service providers, and families in adapting to this temporary “new normal.” Because of this diligence, those served by regional centers are reporting lower morbidity and mortality rates than congregate settings that support many other vulnerable populations.

As of November 13, 2020, the California Department of Developmental Disabilities (DDS) reported¹ 179 deaths of the 3,600 COVID-19 confirmed positive cases, which compares favorably to the statistics from Skilled Nursing Facilities (SNFs) and assisted living facilities. Those facilities have recently reported 6,364 deaths amongst the 67,551 confirmed positive COVID-19 cases,² which makes up 34% of the state total. In short, California’s system of services and supports for people with developmental disabilities that keeps them out of institutional settings keeps them safer and healthier.

¹ https://www.dds.ca.gov/wp-content/uploads/2020/11/DDS_COVID-19_demographics-and-residence_10302020.pdf

² <https://www.latimes.com/projects/california-coronavirus-cases-tracking-outbreak/nursing-homes/>

However, this success is not a reason to overlook our community. The following findings highlight that COVID-19 patients with developmental disabilities are far more likely than developmentally typical individuals to die from it:

- A recent journal article noted that “people with IDD had higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes.”³
- The death rate among all patients with COVID-19 is 0.6%, but for people with developmental disorders the percentage is 1.22%, and for those with intellectual disabilities the reported percentage is 3.37%.⁴
- Researchers concluded that for every 100,000 confirmed COVID-19 cases in people with developmental disabilities there would be an estimated 4,500 deaths.⁵ Comparatively, the findings suggest approximately 2,700 out of 100,000 people without developmental disabilities within the same age range would expire from complications associated with COVID-19.

Because of this, those with developmental disabilities and those who support them should be among those prioritized for vaccination. This priority should also be extended to two other groups, DSPs and family members who live with and support people with developmental disabilities. First, DSPs provide constant support, including communication, mobility, personal hygiene, and other elements of self-care. Their close and extended proximity to those they serve means they are at exceptional risk of being infected by, or transmitting, COVID-19. We cannot overstate the need to ensure DSPs can be an ongoing part of the lives of those they support.

Second are the family members people with developmental disabilities live with. Like DSPs, families provide critical daily support to people served by the regional centers. As of September 2020, nearly 80% of people with developmental disabilities lived in the home of a parent/guardian⁶. For these individuals, family members are critical support workers. Their health and safety must also be prioritized. Additionally, by virtue of age, many parents of adults with developmental disabilities are often in one or more high-risk groups. Any illness – let alone mortality – would be both tragic and unspeakably disruptive. They, too, must be early candidates for any vaccine.

We thank you for considering the health and safety of people with developmental disabilities, the committed professionals who serve them, and the families that are integral parts of their lives. If you have any questions regarding our position, please do not hesitate to contact Daniel Savino in our office at dsavino@arcenet.org or (916) 446-7961.

Sincerely,

/s/Amy Westling
Executive Director

Cc: Nancy Bargmann, Director, Department of Developmental Services
Dr. Mark Ghaly, Secretary, Health and Human Services Agency

³ <https://www.sciencedirect.com/science/article/abs/pii/S1936657420300674?via%3Dihub>

⁴ <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>

⁵ <https://www.upstate.edu/hloa/2020/060520-turk-landes-interview.php>

⁶ <https://www.dds.ca.gov/transparency/facts-stats/quarterly-client-characteristics-reports/>