



Dear {County Health Department Official},

{Name} County has been working to ensure that vaccines are given first to those who most need them. Certainly, front line workers and the elderly are appropriately in your initial groups. There is another group of highly vulnerable individuals whom we ask you to consider for higher prioritization: people with a wide range of disabilities and chronic health conditions across the age spectrum.

Close to 300 members of the Arizona Developmental Disabilities Network and other concerned individuals and organizations participated in a forum on January 22, 2021 where we learned that current vaccine prioritizations have excluded many vulnerable groups, including those whom we represent. We believe these groups can and should be given higher priority tiers. We are asking your county health department to make the following changes:

1. Individuals with Down syndrome (DS), particularly those over 40 and/or those younger than 40 with significant comorbidities, be prioritized under 1B, as based upon the December 23, 2020 Centers for Disease Control & Prevention (CDC) [COVID high risk classification](#).
2. People with disabilities of any age who receive long-term services and supports (LTSS) through the Arizona Long Term Care System (ALTCS) waiver services and programs and/or the Division of Developmental Disabilities (DDD), ALTCS members, be included under 1C.
3. Members of the intellectual and developmental disabilities (IDD) community who currently live in Department of Economic Security (DES) group homes retain their 1A status and other members of the IDD community be included under 1C, with IDD considered as an underlying health condition.
4. All family members and informal caregivers of ALTCS members and the IDD community who are providing home health or are serving as a home aide/caregiver for a person with a disability should be prioritized under 1A with other health care workers. This is a similar prioritization to states like California and Illinois and to Arizona's ALTCS-funded paid family care attendants who are already prioritized under 1A.
5. The County should develop policies, procedures, and an outreach plan to account for the fact that many vulnerable adults in our community are homebound.
6. The County should reevaluate their communication plan with the disability community and other underserved groups and include disability rights organizations as key partners in this plan.
7. The County should recommend subpriorities within 1B and 1C based on who has been most impacted by the pandemic taking into account race, ethnicity, and geography.

Disparate Health Outcomes

People with IDD are at a higher risk than the general population for acquiring the coronavirus. Early data show that people with IDD face a higher risk of death and increased disability due to COVID-19. A recent [FAIR Health white paper](#) analyzed more than 467,000 insurance claims with a diagnosis of COVID-19 documented across all age groups. The analysis showed people with IDD have the third highest risk of COVID-19 death and are three times more likely to die than the general population; people with DS are [10 times more likely to die](#). Moreover, these data revealed that the risk of death for an individual with DS after age 40 is equivalent to the risk of death for an individual without DS after the age of 80.

Due to these alarming statistics, the CDC [added Down syndrome](#) to the list of medical conditions that increase a person's risk for severe illness from COVID-19, meaning they are more likely to be hospitalized, placed in the ICU, put on a ventilator, or die. Based on these outcomes, the CDC strongly recommended that individuals with DS, particularly those over 40 and/or those younger than 40 with significant comorbidities, be prioritized under 1B for COVID-19 vaccination programs.

Risk Factors

We ask that, in addition to considering the findings from these studies, you consider the fact that there are multiple risk factors for members of the IDD community and ALTCS that should be considered in the County prioritization plan, specifically:

1. Many members of the IDD community and ALTCS live in congregate settings. Congregate settings include licensed and unlicensed homes in Arizona, such as assisted living, 1-2 bed or 3-4 bed adult family homes, and community-based residential facilities. People in these settings are often unable to make decisions regarding who and how many outside people provide supports and services. Their service providers are often in intimate proximity, which does not allow for physical distancing. Many settings that are not formally licensed through the Arizona Department of Health Services (DHS) or DDD are still congregate in nature but have not been notified they are eligible for vaccines. As a result, many in this group have yet to be vaccinated.
2. Members of the IDD community and ALTCS disproportionately attend day services in congregate settings, including adult day care, day service centers, and sheltered workshops. They use congregate transportation, such as buses, to get to those settings. These situations bring together people with disabilities and providers from many different households, increasing the risk of contracting the virus. While many have policies in place to limit exposure, it is impossible to eliminate all risk.
3. Members of the IDD community and ALTCS who live in their own homes or supported apartments are still at greater risk of contracting COVID-19. Most have multiple caregivers providing hands on care to them. Paid caregivers may also be working with multiple individuals at multiple locations, increasing the risk of spreading the virus between individuals. Although technically covered under phase 1A, most of these informal and private care workers are not connected to any health care system and do not have ready access to the vaccine. Vaccination under phase 1A that was supposed to protect vulnerable members living in the community (by protecting its care force), has not been implemented at this time, leaving both the caregivers and the people they serve at risk of infection. Compounding this issue is the high rates of vaccine hesitancy among caregivers.

4. Some members of the IDD community and ALTCS have limited ability to follow CDC recommendations that reduce the potential for contracting and spreading the virus. Sensory issues, receptive and expressive language disorders, and inability to assess safety risks are all typical symptoms of intellectual disabilities that make it far more likely that this population will be unable to comply with basic preventative protocols. The largest national [survey](#) of Direct Support Professionals (DSPs) indicates that approximately 40% of the people supported by DSPs have either only fair or poor social distancing practices.
5. ALTCS members are eligible for a nursing home level of care but have been able to live in the community with supports and services. To qualify for Arizona's long-term care waiver services, an individual must be found eligible to need a nursing home level of care. This group of Arizonans would have fallen into 1A if they were not being cared for in the community under the home and community-based waivers.

Additional Data-Informed Recommendations

The Arizona Health Care Cost Containment System (AHCCCS) already has access to the location, health conditions, and the service systems that deliver the care to ALTCS members. Members have routine contact with a care manager who can help them gain information on how and where to receive the vaccine and can facilitate reminders when the second dose needs to be administered.

We recommend that the County develop policies, procedures, and an outreach plan to account for the fact that many vulnerable adults in our community are homebound and unable to leave their homes for various reasons. For example, other state health departments explicitly included language to have contracted nurses vaccinate homebound individuals. In Corpus Christie, Texas, paramedics phone and schedule vaccines for homebound individuals. Having policies in place would ensure those who are unable to travel will have equitable access to the COVID-19 vaccine once it becomes available. In Arizona, a model already exists in the congregate facilities contract between the State and both CVS and Walgreens, whereby pharmacy employees take the vaccine to group homes and other residential settings to administer injections to residents where they live.

We recommend that the County reevaluate their communication plan and include disability rights organizations as key partners in this plan. We have heard from individuals in the community that there have been consistent barriers to communication of key information to the IDD community. Vaccination details require effective communication in accessible formats (e.g., plain language, ASL, Braille, audio, large print, etc.). Disability organizations can help identify networks to communicate with the various communities. Information about the vaccine (efficacy, prioritization, side effects, clinical trials, Emergency Use Authorizations) can be overwhelming. In addition, information should be easily accessible in Spanish, as well as other languages.

Finally, we encourage the County to recommend subpriorities within 1B and 1C based on who has been most impacted by the pandemic. For example, not all older adults 75+ have been similarly situated, with death and infection rates disproportionately impacting older adults of color. Further subprioritization based on considerations such as race, ethnicity and geography is critical in ensuring a vaccine allocation grounded in equity.

We respectfully request that you adopt these seven recommendations and modify your current prioritization, communication, and dissemination plans based on this information. We again ask

that you include everyone with DS over the age of 40 and/or those under that age with existing comorbidities as well as the entire population in the Medicaid long-term waiver under home and community-based services (HCBS) in the 1B or 1C priority groups, as well as individuals who have IDD and their informal and family caregivers.

We believe this is in keeping with your existing priorities to make certain those most vulnerable receive the vaccine as quickly as possible. It is the logical, fact-based, and humane next step. If you have any questions or concerns about any of this information, please feel free to contact any of the organizations that have signed on below.

Sincerely,