



The Case for COVID-19 vaccine prioritization for Coloradans with Intellectual and Developmental Disabilities

February 12, 2021

Introduction

The Colorado Developmental Disabilities Council has led the effort to prioritize COVID-19 vaccines for Coloradans with intellectual and developmental disabilities (IDD). In early December 2020, the Council contacted disability advocacy groups from around Colorado to determine support for prioritizing people with disabilities and other disabilities based on FAIR Health study results which found that people with IDD and those with certain other disabilities have significantly higher COVID-related mortality rates than the general public. In addition, a number of informational action alerts have been published by the Council urging community members to advise, educate and inform their Colorado public policy-makers.

State-Level Advocacy Recommending Vaccine Prioritization for People with IDD

Twenty-six Colorado-based disability advocacy organizations subsequently signed on to recommend specific vaccine prioritization for people with IDD and other disabilities found to be associated with these higher mortality rates. The letter dated December 22nd featured the FAIR Health study which found that people with IDD under the age of 70 were 4 to 5 times more likely to die following COVID-19 infection than the general population. This collaborative research effort between FAIR Health, West Health and John Hopkins University School of Medicine, *Risk Factors for COVID-19 Mortality Among Privately Insured Patients*¹ published November 11, 2020, is intended to “inform public health recommendations and policies, particularly those related to protocols for distribution of first-line vaccines...”² The letter which was directed to the Governor, Lieutenant Governor and Colorado’s vaccine planning committee recommended that people with IDD be specifically identified for vaccine prioritization. An analysis of the study appears in an Association of University Centers on Disability (AUCD)

¹ Risk Factors for COVID-19 Mortality among Privately Insured Patients. Accessed 2.3.21 from: <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>

² Ibid. (page 22)

publication entitled, *First to Die, Last to be Recognized: Will Vaccine Allocation be Equitable?*³ stating, “people with IDD face increased odds of dying from the (COVID-19) virus.” Further, a New York Times article on the same study quotes NYU’s Director of Medical Ethics, Arthur Caplan, as saying, “There is no question these people (with IDD) are high risk and must be given (vaccine) prioritization,” and that to not do so would be “on grounds (that would be) discriminatory.”⁴ While the Council is not accusing the State of Colorado of discriminatory practices, the State has mounted arguments against using the results of the FAIR study.

The Council has requested that the State consider the FAIR Health research because Colorado has not kept discrete records of disability status of Coloradans dying from COVID-19. The State has referred to Colorado data indicating that people with IDD utilizing Colorado’s Home and Community Based Services (HCBS) have not apparently experienced COVID-related mortality at levels greater than the general public. However, this most probably accounts for less than 17%⁵ of the total population of Coloradans with IDD. Thus, Colorado appears to ignore the vaccine prioritization needs of this high-risk population on the basis of data that captures COVID mortality rates for less than 1 in 5 Coloradoans with IDD.

The Arc of Colorado joined several local Arc chapters in recommending vaccine prioritization for people with IDD on January 25th. In making their case the letter states, “The reasons people with IDD face increased risk from COVID-19 span many aspects of human experience, including individual behavioral and physical health factors that can increase vulnerability. This individual risk is compounded by structural risks such as congregate settings and shared pools of caregivers, and structural barriers such as lack of accessible and accurate information about COVID-19 that gets in the way of managing the associated risks.”

The Arc letter also points to the December 9th Joint Position Statement of the American Academy of Developmental Medicine⁶ which states, “Given increased rates of serious illness and death from COVID-19 in people with intellectual and developmental disabilities, persons with this diagnosis or condition should be explicitly included in the list of high-risk diagnoses that are used to determine vaccine priority.” The Joint Position Statement (which is signed by a variety of national organizations) makes several evidence-based vaccine allocation recommendations which are not currently included in CO’s Vaccine Allocation Framework

³ First to Die, Last to be Recognized: Will Vaccine Allocation be Equitable? Accessed 2.3.21 from: <https://aucdpolicytalk.org/2020/12/17/first-to-die-last-to-be-recognized-will-vaccine-allocation-be-equitable/>

⁴ Developmental Disabilities Heighten Risk of COVID Death. Accessed 2.3.21 from: <https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html>

⁵ How Many People with IDD Live in the US? Accessed 2.3.21 at: <https://publications.ici.umn.edu/risp/2017/infographics/people-with-idd-in-the-united-states-and-the-proportion-who-receive-services>

⁶ Joint Position Statement of the American Academy of Developmental Medicine. Accessed 2.5.21 from: <https://www.aadmd.org/vaccine>

summarized here:

- Include IDD in list of high-risk diagnoses;
- Specifically consider and prioritize people with IDD in vaccine allocation frameworks;
- Include people with IDD in the same vaccine allocation phase as the people who live with, and/or provide support to them regardless of what setting they receive services in.

How other states are responding

According to the Kaiser Family Foundation (KFF) analysis⁷ of state COVID-19 vaccine distribution plans dated February 1st, there are twenty-one states with greater consideration for people with disabilities and/or others with high-risk conditions than Colorado. This analysis is based upon Colorado's January 29th distribution plan has placed "people with 2 or more high-risk conditions" into phase 1b. To its credit, Colorado has recently included Down syndrome on its "high-risk conditions" list, consistent with CDC guidance released December 23rd. Additionally, Colorado has added "people with disabilities that prevent them from wearing masks" to the high-risk conditions list. However, because Colorado requires two high-risk conditions to qualify for tier 1 prioritization, people with disabilities and those with other high-risk conditions have been pushed behind many other Coloradans who experience significantly less risk of severe medical complications or death from COVID-19.

Tennessee's vaccine distribution plan prioritizes "people with intellectual and developmental disabilities who cannot live independently due to a serious chronic medical condition or intellectual or developmental disability" into phase 1a1.⁸ According to KFF⁹, two states (Maryland and Ohio) specifically name people with intellectual and developmental disabilities as a prioritized group within vaccination distribution phase 1. Other recent state COVID-19 vaccination prioritization actions include, Iowa for "people with disabilities in home settings," Nevada for "people with disabilities," and Pennsylvania for "people receiving Home and Community Based Services (HCBS)," which for Colorado would include approximately 11,000 adults with IDD. On February 10th Illinois announced that it would be prioritizing all "people

⁷ State COVID-19 Vaccine Priority Populations, KFF. Accessed 2.3.21 from: <https://www.kff.org/other/state-indicator/state-covid-19-vaccine-priority-populations/?currentTimeframe=0&print=true&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

⁸ TN Notice of Update to Vaccination Plan. Accessed 2.3.21 from: <https://www.tn.gov/content/dam/tn/cdd/documents/covid-tncdd/1a1%20Vaccine%20Distribution%20to%20IDD%20Population.pdf>

⁹ The COVID-19 "Vaccination Line": An Update on State Prioritization Plans accessed 2.3.21 from: <https://www.kff.org/coronavirus-covid-19/issue-brief/the-covid-19-vaccination-line-an-update-on-state-prioritization-plans/>

with disabilities.”¹⁰ Additionally, it appears that 14 states prioritize people with only one high-risk condition, while Colorado requires two of these conditions for prioritization.¹¹

Expanded National and Local Attention on this Issue

On December 15th the National Council on Disability (NCD), which is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities, stated the need to extend COVID-19 vaccine prioritization to people with IDD.¹² The NCD recommendation states **“Compared to individuals without I/DD, individuals with I/DD face alarmingly higher complication and mortality rates from COVID-19, with mortality rates up to 15 percent. Current vaccine allocation frameworks prioritize groups at similar risk for severe complications and death, but prioritizing individuals with I/DD should be made explicit throughout all relevant guidance and state executive orders.”**

Early February news outlets are providing the public with additional information about this issue. On February 4th the New York Times published an opinion piece entitled, *Where’s the Vaccine for Ableism?*¹³ This article ends with the admonishment, “Until we recognize that we need one another, none of us will be safe.” On February 9th, the Democracy Now! broadcast: *Disabled Advocates Demand Better Vaccine Access as They Face Greater Risks of Dying from COVID-19*¹⁴ laid out the disability rights perspective on the issue. Also on February 9th, Denver’s CBS television affiliate examined the plight of two local households with sons who experience intellectual and developmental disabilities and who feel that the state is ignoring the significantly higher risk of COVID-related death for these individuals.¹⁵ This [newscast](#) provides a view of the impact of these decisions on local families.

¹⁰ <https://capitolfax.com/2021/02/10/pritzker-expands-phase-1b-eligibility-will-prioritize-those-with-disabilities/>

¹¹ <https://www.kff.org/coronavirus-covid-19/issue-brief/the-covid-19-vaccination-line-an-update-on-state-prioritization-plans/>

¹² NCD Recommends COVID-19 Vaccination Allocation Equity for Individuals with IDD. Accessed 2.3.21 from: <https://ncd.gov/newsroom/2021/ncd-recommends-covid-19-vaccine-allocation-equity-individuals-idd>

¹³ Where’s the Vaccine for Ableism? Accessed 2.10.21 from: <https://www.nytimes.com/2021/02/04/opinion/covid-vaccine-ableism.html?smid=em-share>

¹⁴ Disabled Advocates Demand Better Vaccine Access as They Face Greater Risks of Dying from COVID-19. Accessed 2.10.21 from: https://www.democracynow.org/2021/2/9/advocates_demand_vaccine_access_disabled_people

¹⁵ Denver Families of People with Disabilities Sounding the Alarm on Vaccine Inequity. Accessed 2.10.21 from: <https://denver.cbslocal.com/video/5284721-colorado-families-of-people-with-disabilities-sounding-alarm-on-vaccine-inequity/>

Summary

Three states (OH, MD, and TN) have explicitly prioritized people with IDD within their COVID-19 distribution frameworks within the 1A or 1B prioritization level. As many as twenty-one states have implemented stronger prioritization of people with disabilities and/or those with high-risk medical conditions than Colorado (as they require one, not two, high-risk conditions for priority status). While the state's January 29th iteration of the vaccine distribution plan caught up with the CDC's December 23rd addition of Down syndrome to high-risk conditions, Colorado continues to refuse to implement changes consistent with the FAIR Health study, the National Council on Disability and the Joint Position Statement of numerous national associations. The state's apparent dependence on Colorado data presumably representing less than 17% of the Colorado population of people with developmental disabilities is counter to evidence-based public policy decision-making.

The Colorado Developmental Disabilities Council urges the Governor to reconsider and include people with intellectual and developmental disabilities as an explicit high-risk medical condition prioritized within Phase 1B.