



January 25, 2021

Governor's Medical Advisory Group (GMAG) Subcommittee
Governor's Expert Emergency Epidemic Response Committee
Colorado Governor's Office
202 East Colfax Avenue
Denver, CO 80203

Dear Mr. Bookman and GMAG members,

Thank you for your leadership and commitment to the people of Colorado, in particular people with intellectual and developmental disabilities, their families, and allies.

There is growing evidence regarding the increased risk of death from COVID-19 for people with intellectual and developmental disabilities (IDD) that urgently requires our attention.

The reasons people with IDD face increased risk from COVID-19 spans 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.

It is vital that vaccine allocation frameworks and other public health programs are based upon an accurate understanding of the lives of people with IDD. People with IDD enrolled in HCBS waivers are receiving an institutional level of care in the community and require these services in order to avoid institutionalization. But there are other aspects of their lives that also resemble institutional care in terms of COVID-19 risk such as the congregate nature of many community-based programs and the shared pool of caregivers serving multiple people across multiple HCBS settings.

In October 2020 The American Academy of Developmental Medicine (in partnership with other national advocacy organizations) released a [Joint Position Statement on Equity for People with Intellectual and Developmental Disabilities Regarding COVID-19 Vaccine Allocation and Safety \(attached\)](#). The position statement was updated December 9th 2020 and contains data and discussion regarding specific COVID-19 risk factors for people with IDD, and recommendations for vaccine allocation frameworks based upon these specific risk factors.

The excerpt below from the Joint Position Statement summarizes key data regarding death rates among people with IDD from COVID-19.

“There are an estimated 7.5 million Americans with IDDⁱ, and it is well documented that people with IDD have long experienced structural health inequities, including adverse social

American Academy of Developmental Medicine (2020). *On Equity for People with Intellectual and Developmental Disabilities (IDD) Regarding COVID-19 Vaccine Allocation and Safety*

Alliance (2018). *Aging Caregiver and DSP Campaign*. www.alliancecolorado.org/hb1407info

determinants of health, that put their health at far greater risk for poorer outcomes from COVID-19^{ii,iii,iv}. Complications from and death rates due to COVID-19 for people with IDD are disproportionately higher when compared to people without IDD.^{v,vi} Mortality rates have been cited to be up to 15% in individuals with IDD^{vii,viii,xi}. In 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. Therefore, individuals with IDD must be specifically considered and prioritized in the COVID-19 vaccine allocation efforts,” (American Academy of Developmental Medicine [AADM], 2020).

This excerpt also highlights the long-standing issue of structural health inequity which cannot be ignored in the process of designing and delivering public health programs that successfully protect and promote the health of people with IDD. This includes establishing COVID-19 vaccine allocation frameworks that reflect their elevated risk of death from COVID-19, as well as communicating about and executing vaccine programs that are accessible to people with IDD.

The Joint Position Statement makes several evidence based vaccine allocation recommendations which are not currently included in CO’s Vaccine Allocation Framework and they are summarized here:

1. Include IDD in list of high risk diagnoses
2. Specifically consider and prioritize people with IDD in vaccine allocation frameworks
3. 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

We are extremely concerned that people with IDD are not specifically included in CO’s vaccine allocation framework though they may receive a vaccine if they live in what is deemed a congregate setting or are age over 70 years. Meanwhile, the larger number of people who provide their care and support are included in Phase 1a or 1b. However, information about vaccine roll-out suggests that many providers of this care and support are declining COVID-19 vaccines. While it is every person’s right to decline a vaccine, it leaves the highly vulnerable people they serve unable to effectively manage the risk involved in receiving essential long term care services.

Public health experts have articulated two goals for vaccine programs, the first is to save lives and the second is to stop the spread of disease. There is still much to be learned, but recent information suggests that vaccines may reduce the likelihood of contracting COVID-19 and may also reduce the severity of symptoms and likelihood of dying from COVID-19.

However, relying on indirect vaccine programs and herd immunity will not save the lives of people with IDD given their elevated risk from COVID-19 and the reported low uptake of vaccines among direct support professionals (DSP). Specifically, The Alliance reports “Colorado currently has an average 39% DSP turnover rate, with some agencies experiencing up to 81% turnover,” (Alliance, 2018). In an effort to save lives, should a single shot vaccine prove to meet the efficacy guidelines for ultimate effectiveness, we propose that people with IDD be prioritized for single dose vaccine. This “one and done” tactic may help to offset challenges related to staffing resources and transportation associated with managing maximum administration.

Vaccine supply is very limited and unpredictable at this time and adding people with IDD to a vaccine phase may seem impractical since the vaccine is not available. However, it is important to separate American Academy of Developmental Medicine (2020). *On Equity for People with Intellectual and Developmental Disabilities (IDD) Regarding COVID-19 Vaccine Allocation and Safety*

Alliance (2018). *Aging Caregiver and DSP Campaign*. www.alliancecolorado.org/hb1407info

vaccine supply from evidence based decisions about vaccine prioritization in order to achieve equity. It makes sense to spend time now deciding who is in line and in what order so that the appropriate communication, accommodations, and support can be provided to people so they are ready and barrier free when their turn comes.

We urge you to review the data on COVID-19 outcomes for people with IDD and adjust CO's vaccine allocation framework to include people with IDD in Phase 1b of CO's vaccine allocation plan along with the people who provide their care and support.

Respectfully,

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Linda Skaflen, Executive Director, The Arc of Adams County

Darla Stuart, Executive Director, The Arc of Aurora

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