

Dear Representative or Senator \_\_\_\_\_,

Advocacy efforts to have adults with Down syndrome included in the equitable distribution of available COVID-19 vaccines have been denied. The response from the North Carolina Department of Health and Human Services (NC HHS) and the Office of Governor Roy Cooper has been consistent. The State maintains that adults with Down syndrome are included in NC HHS vaccine distribution in Groups 1, 2, and 3. I respectfully ask for your support advocating for adults with Down syndrome

The State's response:

- ACIP First group 1a is Health Care Workers and LTC staff and residents.
  - o That now aligns with NCDHHS's expanded Group 1- Deep Dive on this group is here <https://covid19.ncdhhs.gov/vaccines/find-your-spot-take-your-shot/deeper-dive-group-1>
  - o Health Care workers – This includes home health providers. Also, includes homecare givers providing regular medical care to children or adults with special needs as well as direct support professionals.
  - o LTC - This includes people with Down's Syndrome who may be at increased risk of exposure due to congregate care. This includes people in adult care homes, family care homes, group homes, mental health group homes, and shared housing with two or more individuals with intellectual and developmental disabilities receiving home and community-based services.
- ❖ Multiple "health care workers" may receive the limited number of vaccines for every one adult with Down syndrome who does not receive the vaccine. This includes family members and direct service providers.
- ❖ Long-term Care settings are limited and most adults with Down syndrome live in the family home of origin. Of the 4,098 licensed beds in group homes, less than half of the occupants receive Innovations Waiver services. <https://www.ncdsalliance.org/wp-content/uploads/2021/02/Group-Home-Data-Report.pdf>
- ❖ 11,000 people with Intellectual & Developmental Disabilities are on the Innovations Waiver Registry of Unmet Needs. Many adults with Down syndrome do not receive home and community-based services. <https://tinyurl.com/2pd8fhyj> Kaiser Family Foundation

The State's response:

- ACIP Second group 1b includes people over 75 and frontline essential workers.
  - This aligns with NCDHHS' groups 2 (older people)- <https://covid19.ncdhhs.gov/vaccines/find-your-spot-take-your-shot/deeper-dive-group-2> and group 3 (frontline essential workers) - <https://covid19.ncdhhs.gov/vaccines/find-your-spot-take-your-shot/deeper-dive-group-3> . We broke it out into 2 groups as it was a large group. In addition, we did decrease the age to people over 65 to align with updated federal recommendations, as a way to be more equitable as minority populations are underrepresented in older populations, as a way to include more people with chronic high risk conditions, and because people over 65 account for 85% of deaths from COVID19. In addition, frontline essential workers include a population with a high proportion of people with high risk chronic conditions who have a high risk of exposure and are disproportionately represented by Historically Marginalized Populations. This group includes anyone with Down's Syndrome who have a high risk of exposure due to their work.
- ❖ The average life expectancy for people with Down syndrome is 60 years of age. <https://med.emory.edu/qa/departments/human-genetics/patient-care/down-syndrome-clinic/down-syndrome-facts.html>



- ❖ The risk of death increases for patients with Down syndrome age 40 and older (similar to patients without Down syndrome age 80 and older). [COVID-19 and Down syndrome survey – T21RS](#)
- ❖ Unemployment rate for people with disabilities is nearly 80% - most adults with Down syndrome are not actively employed. <https://www.bls.gov/news.release/disabl.nr0.htm>

Adults with Down syndrome are included in Groups 1, 2, and 3 in theory only. Please consider contacting Dr. Mandy Cohen and Governor Roy Cooper about the placement of individuals with Down syndrome on the list of priority for vaccines for COVID-19. **Add a short, personal note about the impact the pandemic has on the life of the individual with Down syndrome.**

Sincerely,

**First Name Last Name**  
**City, NC**