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February 11, 2021

Honorable Governor Andrew M. Cuomo
Governor, New York State
NYS State Capitol
Albany, NY 12224
Sent via email

Dear Governor Cuomo:

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL leads statewide ILC efforts to eliminate physical, communications, attitudinal, and other barriers to all aspects of life. We are writing to request information on how the vaccine will be delivered to people with disabilities in an accessible and equitable manner. Most people with disabilities are at increased risk of contracting and dying from COVID-19. We are happy that the State has broadened eligibility to a number of additional categories and largely following CDC guidelines. We have several questions and concerns however which the State must address to ensure people with disabilities can access the vaccine.

Eligibility

NYAIL and its members are concerned that the eligibility list is poorly worded so that, in different sections, it is overly restrictive while in other sections it is overly broad.

- 1) We noted that the Centers for Disease Control (CDC) had listed Downs Syndrome on their list, but New York State has expanded the list to include “developmental disabilities.” It is our understanding that Downs Syndrome was included on the CDC list because researchers believe that background immune abnormalities, combined with extra copies of key genes in people with Downs Syndrome – who have three copies of chromosome 21 rather than the usual two – make them more vulnerable to severe COVID-19. The inclusion of “developmental disabilities” as a category seems to expand eligibility for the vaccine to people who may not be at greater risk, such as individuals with learning disabilities. Conversely, because the state is heavily relying on the Office of People with Developmental Disabilities (OPWDD) to meet the needs of this community and OPWDD does not serve individuals with Muscular Dystrophy (MD), we may also be inadvertently failing to address the needs of some individuals who have serious risks associated with COVID-19 infection.
- 2) Another category listed as eligible as of February 15 is neurological conditions, including dementia. Again, this broad category includes a wide range of conditions which may or may not have greater risks related to COVID-19. It is our understanding that no guidance has been given by the state and consequently individual providers will have their own interpretations potentially leading to disparities in the availability of the vaccine.

- 3) While it is recognized that “pulmonary disease” is a risk factor, there are individuals who have breathing difficulties – including the need for a ventilator – which is not based in a “disease” per se. We are concerned that such individuals may be inadvertently screened out.

Additionally, some conditions are not included in the list.

- 4) Despite studies showing Schizophrenia being the second highest risk factor for dying of COVID-19, they are not currently listed as an eligible population. This must be addressed and people with a schizophrenia diagnosis must be included as eligible for the vaccine.
- 5) We are concerned that some disabilities which are less common have been excluded from the list simply because there are not enough individuals with those conditions to create the statistical data to substantiate their inclusion in this list. For example, although Osteogenesis Imperfecta (OI) is primarily known as a bone disease leading to frequent fractures, at its core is a genetic defect in collagen manufacture, assembly, and/or quantity which makes up a large portion of the connective tissue of the lungs. Even though this appears to be a high risk group, like other less common conditions, there are not enough individuals with OI to create the statistical data needed for inclusion.

Finally, with regard to eligibility, individual counties may be releasing screening tools that differ from the state’s list.

- 6) As an example, advocates have provided the state with screenshots of the screening tool in Albany County and noted significant differences with the state’s list. Notably, that list includes “smoking” and although a history of being a smoker may correlate to poorer outcomes with COVID-19, it was not included on the state’s list.

We are gravely concerned that the confusion and uneven rollout of this phase of vaccination is failing to address the needs of individuals at significant risk while creating confusion, loopholes and false expectations.

Process

There are significant concerns about the process the state is using.

- 1) There are serious access issues with the state vaccination sites. For example, even though the Dome Arena is in a suburb of Rochester, it is essentially inaccessible by public transportation. Riders need to do a “ten-minute walk” on a busy road that has no sidewalks in order to get to the vaccination site. This is particularly dangerous in winter months when snow and inadequate light make such efforts truly treacherous.
- 2) The rollout of the vaccine to 1a-eligible healthcare workers has been deeply problematic. Although the hubs indicate that virtually all 1a-eligible individuals have been vaccinated, home care workers – particularly consumer-directed personal assistants – have struggled to get access to the vaccine. In some cases, they have been turned away from the healthcare sites charged with vaccinating this group and sent to the state sites where there is extremely limited vaccine.
- 3) There does not appear to be a plan to reach individuals with disabilities who have accessibility and transportation barriers to securing the vaccine, often referred to as “homebound” or “shut

ins". Effort needs to be made to target buildings that are built for seniors and/or people with disabilities for co-location of vaccination sites for those who cannot go out. Alternatively, canvassing could be used as is done in an emergency to identify individuals needing a vaccination and getting them vaccinated. Such efforts will be particularly important in more rural parts of our state where transportation can be an insurmountable barrier.

- 4) No information for the public has been posted about accessibility of sites and availability of reasonable accommodations (large print forms, ASL, reduced wait time, seating for those in line who cannot stand for periods of time, etc.) No site includes signage about rights to reasonable accommodations or how to request them.
- 5) Websites are primarily being used to schedule vaccines. Each county should also have a phone number available for those without computer access. Many people with disabilities and older New Yorkers do not have computers or an email address. The process seems to vary from county to county, making it even more confusing to navigate. In some counties, the ILCs are creating email addresses for people to help them just to sign up for the vaccine because there is no way to sign up without an email address.
- 6) There are also many pages and documents to fill out, more once on site. This could be difficult for someone to do independently with certain conditions, including fatigue, limited dexterity, or visual impairments, to name a few. Assistance needs to be provided to assist these individuals.

Generally speaking, the Disability Community has not been effectively engaged in the rollout of the vaccine and the fight against this virus. Although local vaccine hubs are describing themselves as "diverse" there is limited representation from disability-led organizations. Failing to engage us in a thoughtful manner has undermined the state's stated goal of an equitable distribution of the vaccine in the Disability Community and particularly impacted BIPOC with disabilities.

We would very much appreciate a response to our questions and concerns.

Sincerely,

Lindsay Miller

Executive Director

CC: Tina Kim, Assistant Secretary for Health
Rachel Baker, Excelsior Fellow for Health
Kerri Neifeld, Assistant Secretary for Human Services
Jihoon Kim, Senior Policy Advisor for Human Services