VIA EMAIL

January 19, 2021

The Honorable Tom Wolf  
Office of the Governor  
508 Main Capitol Building  
Harrisburg, PA 17120

Dr. Rachel Levine, Secretary  
Department of Health  
625 Forster Street, 8th Floor West  
Harrisburg, PA 17120

Secretary Teresa D. Miller  
Department of Human Services  
333 Health and Welfare Building  
Harrisburg, PA 17105

RE: Concerns re Implementation of COVID-19 Vaccination Plan

Dear Governor Wolf, Secretary Levine, and Secretary Miller:

We write with concerns regarding how Pennsylvania is implementing its COVID-19 vaccination plan. These concerns are shared by both Disability Rights Pennsylvania and The Arc of Pennsylvania, as well as members of the larger disability community. Specifically, we question whether the current Department of Health (DOH) plan adequately accounts for the needs of people with disabilities and their caregivers. We understand that the COVID-19 vaccination plan is fluid, and DOH is responding as quickly as possible to ever-changing circumstances.

However, we are concerned that there is a lack of communication from DOH to the disability community, specifically regarding how, when, and where individuals
with disabilities and their caregivers can expect to be vaccinated. We are also concerned that DOH’s plan, which includes direct support professionals (DSPs) in phase 1A, does not define unpaid family caregivers as DSPs. Similarly, while phase 1B includes people enrolled in HCBS waivers, it does not mention people who are currently on a waiting list or receiving base services. Lastly, we are concerned that DOH and its local partners may not be considering accessibility and access to public transportation when selecting vaccination sites. Therefore, we request the following changes and additions to the plan:

**Communication:** More communication is needed around the plan. As the Commonwealth prepares to transition to vaccinating different subgroups within phase 1A, as well as populations within phase 1B, people who will be “next” on the list need information about their options for vaccination in advance of when it is their turn. In addition, people need to have a clear understanding of *where* they fall in the distribution plan (i.e. there should be a straightforward, easy to understand document that people can consult to learn what phase they are in).

We have heard that members of the disability community and their caregivers are confused about the plan, and its subsequent rollout. A concise summary of the COVID-19 vaccination plan is imperative as it will enable individuals and families to understand where they fall under the plan. In addition, many people need information in alternative formats in order to effectively process it; DOH needs to create materials that are accessible to *all people at all comprehension levels*.

At this point, some people may know which phase they fall into, but they lack specifics about when and where people in their phase can get vaccinated. Therefore, we suggest DOH create a webinar and fact sheet about who will be vaccinated in each phase of the plan. These materials should be shared across DHS platforms to ensure the broadest possible distribution. These resources should be specific, so that they make it readily apparent who does and does not qualify for each phase of the plan. They should also use plain, easy to understand language, so that they are accessible to people with a variety of disabilities. In addition, the resources should be in screen-reader accessible formats, and in other alternative formats needed by people with disabilities, including a graphic format that is understandable by people who may not be able to read. We would also encourage DOH to promote these resources on social media, on its own pages, but also by investing in paid promotions which “push” the resources out and directly on to people’s Facebook, Instagram, and Twitter “feeds.”
To help get these resources directly to the people with disabilities they serve, we would encourage DHS to include printed information about the vaccine plan in all physical mailings, and links to the fact sheet and webinar in all email communications. We would also encourage DHS to partner with service providers and use them as a means of disseminating the information (e.g. service coordinators could share fact sheets or graphics about vaccination with their clients). By using a multi-pronged approach to sharing information about the vaccination plan, DOH increases the likelihood that they will reach people with I/DD and their caregivers, especially unpaid family caregivers.

We strongly believe that people who are eligible for vaccinations in phase 1B need information about where they will be able to get the vaccine now. For all people, but particularly those with disabilities, who may need to rely on others for transportation to, or scheduling of the vaccine, it is important to know in advance where they will be able to get it. While Sections 5 and 6 of DOH’s plan give general information about the types of entities that will serve as vaccination providers, there is not yet specific information about locations that will be used, or the populations who will be eligible to receive the vaccine at said locations.

Understanding that information is fluid and ever-changing, we nonetheless urge DOH to push out this information as soon as it is reasonably able. We believe that even a tentative list, with a clear disclaimer that information is subject to change based on vaccine availability, would be useful and help people begin to plan.

**DSP Definition:** As written, the current version of the vaccination plan lists DSPs as falling into phase 1A, but does not provide guidance about who qualifies as a DSP. Given this, we are concerned that unpaid family caregivers would be denied the vaccine if they attempted to get vaccinated as part of phase 1A. Therefore, we request that DOH provide clarity and guidance to ensure that family caregivers are included in phase 1A, just as paid caregivers are.

Given that family caregivers, much like paid caregivers, cannot serve in their roles and adhere to social distancing, both they and the people with disabilities that they assist are more likely to spread COVID-19 if either party becomes infected. For this reason, we believe unpaid family caregivers should qualify as DSPs, and the plan should make their eligibility explicit.
We would also urge DOH to issue guidance about how unpaid family caregivers should establish their status as a DSP so that vaccine providers will vaccinate them without issue.

**Expanding Populations Included in Phase 1B:**

**Clarify Plan to Ensure Inclusive Definition of People with Intellectual and Developmental Disabilities:** As it is currently written, phase 1B of the vaccination plan includes people enrolled in HCBS waivers but does not mention people who are on the ODP waiting list or receiving base services. DOH must issue a clarification so that it is apparent that both of those populations are included in phase 1B, and may be vaccinated when this phase opens.

Given that there are no distinguishing characteristics or less risk between the people who are on a ODP waitlist or who receive base services and those who are enrolled in a HCBS waiver, and that these are, for all intents and purposes the same populations, we do not feel that DOH should make a distinction based on waiver status. Thus, we urge DOH to clarify who qualifies as “persons receiving home and community-based services.”

**Include Individuals Who are Deaf or Blind:** Given that individuals who are blind may rely on touching their surroundings to navigate through the community, this poses a higher risk to their health and safety. In addition, blind individuals are often supported by people who cannot socially distance from them to have assistance in navigating through the community. Individuals who are deaf may not be able to communicate with others if masks are used because it blocks the ability to read lips. We ask that individuals who are blind and individuals who are deaf be added to category 1B for prioritization.

**Locations of Vaccination Sites:** While DOH has publicized some locations it plans to use for vaccination sites, it has not yet released a comprehensive plan wherein all providers are listed. We imagine part of this lack of information is due to uncertainties about when and in what quantities more vaccine doses will be made available to the Commonwealth. As DOH learns more and is able to finalize vaccination providers, we urge it to choose locations that are accessible to people with disabilities, as well as close to public transportation.
When thinking about accessibility, we would encourage DOH to look beyond mere physical accessibility (e.g. compliance with the ADA) and also consider whether locations would raise concerns for people with sensory or mental disabilities (e.g. noise level, crowds etc.) We would suggest that DOH choose a variety of locations, and consider that some people may be weary to go inside buildings given the current state of the pandemic.

Drive-through vaccination clinics, as mentioned in Appendix 5 of the current plan, where people can stay in their cars and be vaccinated through an open window, may be a good option for people with a variety of different disabilities. However, a drive-through clinic also excludes people who do not own a car or know someone who does and could transport them.

Thus, we would remind DOH that is also important to choose locations that are easily accessed via public transportation. Such locations might include government buildings, public schools, and grocery stores. In areas where public transportation is lacking or nonexistent, we would urge DOH to establish a plan for mobile vaccination, as mentioned in Appendix 5. In this way, DOH will ensure that people without their own means of transportation can still get vaccinated.

We would also remind DOH of the possibility that some people with disabilities will need to bring a support person with them when they get vaccinated. Thus, we would urge DOH to issue guidance to vaccination providers, reminding them of the need to make reasonable accommodations to established procedures to allow for people with disabilities to have a support person with them.

We thank you for your consideration of our concerns. We welcome the opportunity to discuss these concerns.

Respectfully,

Sherri Landis          Peri Jude Radecic
Executive Director    Chief Executive Officer
The ARC of Pennsylvania Disability Rights Pennsylvania