**Emailed to federal partners**

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**Sent:** Monday, January 25, 2021 1:03 PM
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**Subject:** COVID Vaccine disability issues

We are grateful for your continued work and recognize the challenges we face.  In support of our collective efforts I wanted to pass on some issues/questions we are getting:

* We are hearing that the CDC VAMS system is not accessible to those who are blind or whose disability requires screen readers.
* Folks are still confused about former Secretary Azar’s comments about vaccine access for those 65 and up and those at high risk. Clarification is needed as to what the current federal guidance is.
* We continue to hear how critical dissemination of plain language educational information (including translations) about vaccine distribution is.  It would be helpful to have this type of information clearly availability within federal and state websites.  Individuals need to find accessible information in these trusted websites.
* Following the CDC 1a definition of health care worker broadly defined to include paid and unpaid has created some significant challenges in the community living space where many PWD (of all ages) are receiving support from unpaid care givers. States seem to lack in getting the mechanisms in place to ensure the vaccines happen for unpaid. This is because the registration process requires going through an employer. With unpaid and consumer-directed caregivers, there is no employer. Guidance could suggest creating a registration category for unpaid/consumer-directed caregivers from the start in the registration system.
* Eligibility for the ID/DD community continues to be a patchwork.
	+ California, Ohio, Indiana, Wisconsin, and Illinois have officially prioritized the caregivers of people with intellectual and/or developmental disabilities for vaccines.
	+ Oregon, Ohio Missouri, Tennessee (sort of), and Texas have prioritized people with intellectual and/or developmental disabilities.

In the majority of states, people with ID/DD are not eligible for vaccination until Phase 1C, which leaves them with numerous additional months of exposure, hospitalizations, and deaths as the highest risk category.

* We are hearing a need for technical assistance and guidance about rights and assent. This critical need is elevated as we are aware that some are considering the use of restraints to administer vaccine. This is an area where plain language educational information is vital for people with ID/DD, particularly for adults in institutionalized settings who do not have family advocates.
* Because adults with disabilities, including those with developmental disabilities, have disproportionately low income and lack transportation, we are hearing needs for reasonable modifications to “drive-up only” sites or other testing facilities, such as establishing mobile vaccination programs or providing no-cost transportation, to ensure that vaccinations are accessible to people with  disabilities who do not drive and whose family members do not drive, or who reside in settings that do not provide transportation.
* We continue to hear that the mechanisms to register and receive the vaccine are extremely problematic. Folks are spending large amounts of time on hold and on websites to try to secure an appointment, a process that requires the privilege of time and access. Of note is the challenge of lack of clarity as to where to seek guidance and information and where to register (county health departments, state sites, pharmacy sites, etc.).
* Finally, while vaccine is not yet approved for most children, we are hearing growing concern about lack of planning for pediatric distribution, elevating the chance of a repeat of challenges in late summer or early fall.

Happy to talk more about any issue.  Looking forward to continued partnerships in this effort.

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