The Implications of State COVID-19 Vaccine Distribution Plans for People with Intellectual & Developmental Disabilities

A report published by the American Network of Community Options and Resources
December 2020

ANCOR

Background

In light of the global COVID-19 pandemic, governments across the world worked with pharmaceutical companies to develop coronavirus vaccine candidates at a record pace. Here in the United States, the breakneck speed of vaccine development has left state and federal health authorities racing against the clock to devise frameworks for how to distribute vaccines as efficiently as possible to hasten the end of the COVID-19 pandemic.

Most federal and states' vaccine allocation frameworks have rightly prioritized frontline health care workers, residents of long-term care facilities and aging Americans as among the first to receive any vaccine approved by the U.S. Food & Drug Administration (FDA). At the same time, these frameworks have largely overlooked an important segment of the population: people with intellectual and developmental disabilities (I/DD), and the direct support professionals (DSPs) that are essential to their health and well-being.

This oversight has the potential for damning effects on the safety and well-being of people with I/DD given the precarious situation in which they find themselves during this pandemic. On the one hand, community-based providers of disability services have done a remarkable job of keeping the people they support isolated from the coronavirus. However, mounting evidence finds that people with I/DD who contract the virus are significantly more likely to die from it.[1] Although these early studies speculate that higher mortality rates can be attributed to physical health challenges such as preexisting comorbidities, as well as social determinants of health such as access to affordable care, the reality is that we simply do not yet know enough about the unique ways in which COVID-19 affects people with I/DD.

We do know, however, that preventing people with I/DD from contracting the coronavirus is the best way to ensure they don't succumb to its worst effects—hence why it's absolutely critical to vaccinate as early as possible people with I/DD and the frontline professionals that support them.

To aid in the effort to ensure these most vulnerable populations are appropriately prioritized for vaccination, ANCOR analyzed states' vaccine allocation frameworks to identify the extent to which people with I/DD have been included.[2] The following is a summary of our analysis.

States' Vaccine Allocation Plans: General Trends

Most of the state plans reviewed here were developed using a standard template furnished by the federal government, thereby facilitating even comparisons between states. For the purposes of our analysis, the following five key sections of the states' plans were compared:

---

[1] For instance, a recent analysis of case and mortality data from eight states representing approximately one-third of the U.S. population found that people with I/DD were twice as likely as the general population to die from COVID-19, even though they were not significantly more likely than the general population to contract COVID-19. See Scott Spreat, Ryan Cox & Mark Davis, *COVID-19 Case & Mortality Report: Intellectual & Developmental Disabilities*.

[2] Most states' vaccine allocation plans reviewed in this analysis were accessed from the Kaiser Family Foundation's website. In limited instances, the plans reviewed were accessed from the Center for Public Representation's website. Readers should note that at the time of analysis, three states (Hawaii, Minnesota, Pennsylvania) had only furnished an executive summary, while the District of Columbia and Virginia had published neither a plan nor an executive summary.

- Organizational Structure & Partner Involvement
- Phased Approach
- Critical Populations
- Second-Dose Reminders
- Program Communication

Other sections of the plans included information on matters such as vaccine distribution channels, vaccine storage capacities, ongoing safety monitoring and emergency preparedness exercises. These components, though generally important to fight the spread of COVID-19, were not analyzed for the purposes of this publication.

Key Finding: States with Earlier COVID-19 Outbreaks Tended to Offer More Detailed Plans

States that experienced early spikes in the incidence of COVID-19 tended to offer more fully developed plans, including detailed references and acknowledgment of lessons learned from earlier in the pandemic. For example, Washington, Oregon, New Jersey and Massachusetts—all of which were hit hard by the pandemic in the late winter and early spring months of 2020—had thorough plans with detailed action steps that have been taken to date.

By comparison, other states like Hawaii, Minnesota, Texas and Vermont offered less detail and more references to elements of the plan being "in development" or "in progress," presumably because certain details remained to be finalized.

Key Finding: Most States Have Thoroughly Developed Communication & Outreach Plans

Many states' plans included detailed communication and outreach strategies structured according to phases of vaccine distribution. In many instances, states even offered communication plans tailored to specific target populations. These states generally identified trusted community partners to be engaged to assist with communications, and many referenced cultural competence, linguistic sensitivities, disenfranchised communities and the need to overcome general skepticism as particular areas of consideration and focus. State plans that stood out as having particularly strong communications and outreach strategies include California, North Carolina (where the disability community was specifically identified as a target population), Oklahoma (which organized its plan by "Attitude Segment," such as pre-consideration, consideration, action and maintenance) and Oregon (whose plan offered significant depth regarding the incidence of COVID-19 among people with I/DD).

Prioritizing People with I/DD & Direct Support Professionals

One of the key challenges our analysis revealed was that states' plans included vague language that made it unclear whether people with I/DD were part of the intended priority tier.

Key Finding: Vague Language is as Harmful as the Exclusion of People with I/DD

Often, states' plans included groups in their highest priority tiers such as those living in "long-term care facilities," those living in "other congregate settings" and/or "people with severe risk of illness or death." However, states' plans just as often failed to specify whether these labels were intended to include people with I/DD—even though people with I/DD often live in congregate care settings and are at severe risk of illness or death.

ANCOR

Further complicating this challenge was that plans frequently deferred either (1) to NASEM's "Framework for Equitable Allocation,"[3] which does make reference to group homes but does not offer significant additional clarity beyond that reference, or (2) to guidance from the U.S. Centers for Disease Control & Prevention's Advisory Committee on Immunization Practices (ACIP), which was still forthcoming at the time these plans were reviewed.

Key Finding: Few State Plans Explicitly Address People with I/DD

Albeit to varying extents, 10 states explicitly addressed people with I/DD in their vaccine allocation plans. The table below indicates which states did so, along with notes about how they defined the population and the phase during which the population would be vaccinated.

STATE	PHASE	DEFINITIONS & NOTES
Colorado	2	Specifically, people living in group homes
Florida	1	People living in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs)
Georgia	2	People living in group homes
Hawaii	2	People living in group homes for persons with disabilities
Indiana	1b	People with intellectual and developmental disabilities
Louisiana	1b	People living in Adult Residential Care facilities and ICF/IIDs
North Carolina	1b	People living in family care homes and group homes
North Dakota	2	People living in ICF/IIDs and congregate settings; people at high risk of severe outcomes
Tennessee	1c[4]	People with intellectual and developmental disabilities
Washington	1a	People receiving Supported Living services

Key Finding: States Have Largely Failed to Define "Essential Workers" to Include DSPs

Just as states' language has been vague about whether people with I/DD are intended for inclusion in the highest priority tiers, so too have states been vague in defining who counts as an essential worker.

Almost all states identified groups with labels such as "essential workers" or "health care workers" as high-priority populations, but neglected to define whether that extends beyond workers in clinical settings such as hospitals' emergency departments. While the NASEM framework cited by several states specifically identifies "group home staff and home care givers" as "High-Risk Health Workers" to be vaccinated during Phase 1a, states infrequently specified that DSPs who deliver I/DD services were intended to be included in these groups.

The table at the top of the page that follows identifies the 11 states that made some reference to the DSP workforce, along with notes about how they defined the population and the phase during which the population would be vaccinated.

---

[3] National Academy of Science, Engineering and Medicine, "Framework for Equitable Allocation."

[4] Tennessee's plan currently identifies people with I/DD to vaccinated during Phase 1c, but acknowledges the population may be moved to Phase 1a.

ANCOR

STATE	PHASE	DEFINITIONS & NOTES
Arizona	1a	Personal care aides
Colorado	N/A	"Human service provider of direct care of 'patients' in state-licensed or voluntary funded programs
Delaware	1c	Group home staff
Hawaii	2	Staff who work in group homes
Indiana	1a	Group home employees
Louisiana	1a	Staff of adult residential facilities, ICF/IIDs, developmental disabilities facilities, home- and community-based care
New Mexico	1b	Developmental disabilities providers in group home settings
North Carolina	1a	Staff in congregate living settings
Ohio	2	Critical risk workers in human services operations
Tennessee	1a	Staff in group homes
Washington	1a	Supported living staff

Inclusive Planning

A key element beyond vaccine prioritization that was considered for this overview was the state's work to include offices or departments that administer disability-related programs and/or other stakeholders from the disabilities sector in the planning process. Upon review it was found that several states specifically referenced these stakeholders as having been part of the process, though we do not mean to suggest that these are the *only* states to have done so. Rather, highlighted here are the states that documented these efforts explicitly in their plans.

The table below shows states that specifically identified departments or divisions of I/DD services and/or other external stakeholders that participated in the process of developing vaccine allocation plans.

STATE	STAKEHOLDER(S) IDENTIFIED
California	Department of Developmental Services
Colorado	Disability advocacy groups and Cross-Disability Coalition
Indiana	Division of Disability and Rehabilitation Services
Kansas	Alliance for Kansans with Disabilities; InterHab (a state provider association)
Montana	Organizations serving people with disabilities
New Mexico	Monthly meeting of Disabilities Access & Functional Needs group
North Carolina	Disability Rights North Carolina (the state's Protection & Advocacy organization)
Ohio	Department of Developmental Disabilities
Oregon	Representatives from long-term care facilities; representatives of community-based care organizations; disability support staff
South Carolina	Advocates for special needs populations; the states Developmental Disabilities Council
South Dakota	Department of Social Services; Department of Human Services
Tennessee	Commission on Aging & Disabilities; Department of Intellectual & Developmental Disabilities
Vermont	Developmental Disabilities Council; Disability Rights Vermont; Developmental Disabilities Services Division

ANCOR

Conclusion

As is often the case, states are in varied phases of readiness to manage the prioritization, distribution, communication and monitoring of an initiative of this magnitude. Although we have every confidence that states will do everything they can to ensure a smooth distribution of the COVID-19 vaccine, the process is certain to elicit some confusion and disarray. It will be important that states take steps to avoid these potential outcomes to the best of their ability, particularly as we enter Phase 2 of distribution, during which the process will receive less attention compared to the very beginning of the vaccine distribution process.

Additionally, despite federal recommendations from ACIP, NASEM and others, it will be up to states to determine how and when various segments of their populations will be prioritized for vaccination. It is therefore incumbent upon individuals and advocates alike to convey the need for people with I/DD and the DSPs that support them to be among the first to have access to any FDA-approved COVID-19 vaccine.

To this end, ANCOR has partnered with American Academy of Developmental Medicine and Dentistry in a statement detailing the heightened severity of outcomes of the virus for people with I/DD. This statement complements ANCOR's own statement on the need to prioritize people with I/DD in the distribution of COVID-19 vaccines, as well as the letters ANCOR has sent to the National Governors Association, the Republican & Democratic Governors Associations, and each governor individually.

Ultimately, we know that widespread vaccination against COVID-19 will be the surest and quickest way to end this global pandemic, and we're grateful for the unprecedented speed with which vaccine candidates were developed and approved.

However, now is our moment to ensure those vaccines reach the right people at the right times. And no matter how long the pandemic lasts, ANCOR dedicates itself to ensuring that people with I/DD and the DSPs on which they rely have a strong voice in the process.

About ANCOR

For 50 years, the American Network of Community Options and Resources has been a leading advocate for the critical role service providers play in enriching the lives of people with intellectual and developmental disabilities (I/DD). As a national nonprofit trade association, ANCOR represents 1,600+ organizations employing more than a half-million professionals who together serve more than a million individuals with I/DD. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities. To learn more, visit ancor.org.