The COVID-19 Vaccine Experiences
of People with Intellectual and Developmental Disabilities & Direct Support Professionals

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Executive Summary

Across the country, we're seeing signs that the situation regarding access to COVID-19 vaccines is changing dramatically. Compared to the earliest months following FDA approval of the first COVID-19 vaccines when demand for the shots far outpaced supply, there are now reports that in many states and communities, there are far more appointments available than there are people able or willing to take them. By the time of this writing, everyone in the United States 12 years of age or older has become eligible to receive the shot, ending a months-long patchwork of state systems in which only those in particular priority tiers were eligible.

This significant shift in the national COVID-19 vaccine situation led ANCOR to wonder whether the uptick in vaccine accessibility happening at the national level was also being experienced by people with intellectual and developmental disabilities (I/DD) and the direct support professionals (DSPs) who support them.

This curiosity led us to field a survey of our members in April 2021 to understand the situation regarding access to and uptake of COVID-19 vaccines within our community. In the context of the situation facing people supported by the provider organizations that responded, the questionnaire sought to assess what percentage of people supported had received at least one shot, the primary modes by which people supported were receiving vaccines, and the barriers preventing vaccination rates from being higher. The questionnaire asked similar questions about the DSPs employed by respondents' organizations, although in this context, we asked what provider organizations were doing to support their employees' ability to become vaccinated.

In all, the survey garnered 164 responses from provider organizations that deliver I/DD services in 25 states. Together, these organizations serve 73,840 adults and children with I/DD, with the average respondent supporting 456 families. The remainder of this article summarizes our key findings and concludes with our observations about the next chapter in our broader efforts to ensure people with I/DD and the DSPs on which they rely remain safe from the worst effects of COVID-19.

Key Finding: Vaccination rates among people with I/DD are higher than that of the general population, but remain inconsistent.

In our survey, which was fielded between April 14-27, 2021, 73.2% of respondents reported that at least 60% of the people with I/DD they supported were at least partially vaccinated. By comparison, the U.S. Centers for Disease Control & Prevention (CDC) reported that only 44.4% of Americans were at least partially vaccinated as of May 3, 2021.

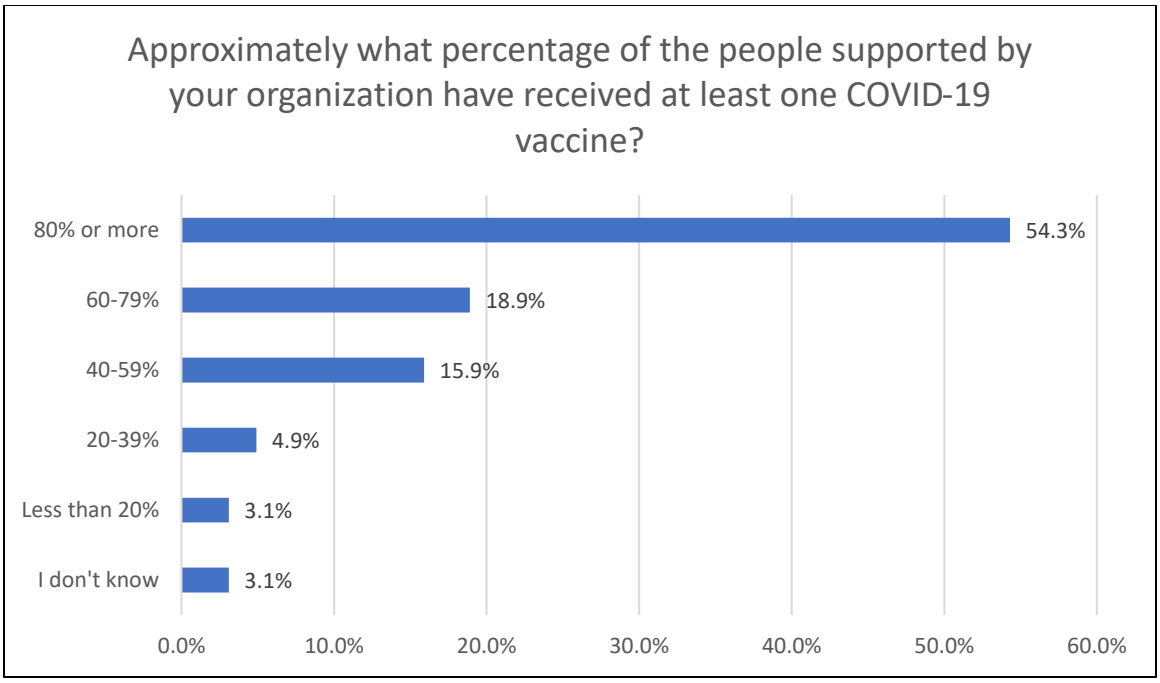

Figure 1. Vaccination rates among people supported by provider agencies.

Given that people with I/DD in most states were eligible to be vaccinated earlier than the general population (thanks in part to advocacy by ANCOR and our members), it is unsurprising that vaccination rates among people with I/DD exceed those of the general population. However, this is still a promising finding, especially considered in the context of evidence that people with I/DD are significantly more likely than people in the general population to die from COVID-19 if they contract the coronavirus.

On the other hand, the data also reveal that there are barriers to getting people with I/DD vaccinated, with three percent of respondents indicating that less than 20% of the people they support were at least partially vaccinated, and another 4.9% indicating that more than 20% but less than 40% of the people they support were at least partially vaccinated.

Key Finding: When it comes to barriers preventing people with I/DD from being vaccinated, refusal and hesitance emerge as significant problems.

We asked respondents to the survey to identify the primary barrier(s) to vaccination among those individuals with I/DD who had not yet received at least one shot. Respondents could select from a list of stock responses, such as difficulty getting an appointment, and/or they could provide an open-ended response. Respondents were able to select as many barriers as were applicable.

Among the full suite of options presented to respondents, two emerged as the primary barriers to vaccination: vaccine hesitancy and vaccine refusal.

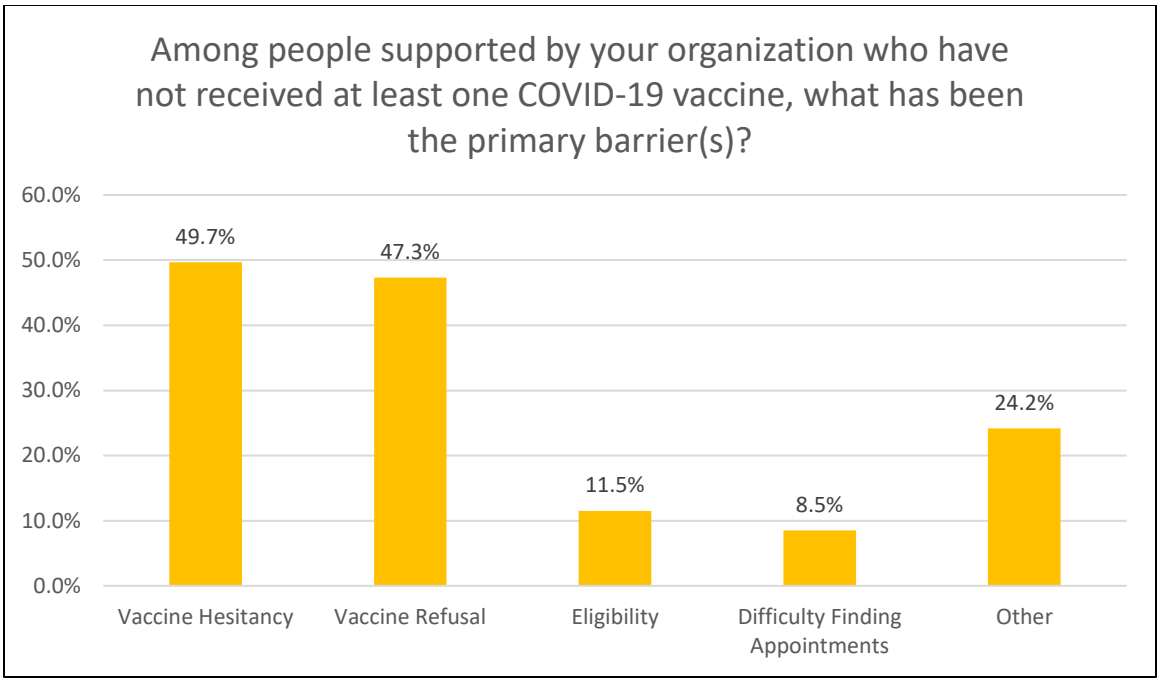

Figure 2. Top barriers to vaccination among people supported by provider agencies.

Fully half of respondents (*n* = 82) indicated that vaccine hesitancy was a significant barrier to uptake of the COVID-19 vaccine, although a closer examination of the open-ended responses calls into question *who* is hesitant. In some cases, people with I/DD reported being hesitant, such as because they were scared of the side effects of the shot or they didn't know what was in the vaccine. In other cases, however, it was the hesitancy of an individual's parent, family member or legal guardian that prevented them from getting vaccinated.

Although vaccine hesitancy is not the same as vaccine refusal, nearly as many respondents (78, or 47.6%) indicated vaccine uptake rates weren't higher due to vaccine refusal. Here again, we see that the refusal is sometimes that of the individual and sometimes that of their parent, family member or legal guardian.

Key Finding: DSPs were less likely than the people they support to have been at least partially vaccinated.

One strategy for ensuring that unvaccinated people with I/DD remain isolated from COVID-19 is to ensure high vaccine acceptance among the DSPs who support them. However, whereas vaccination rates among people supported by respondents' organizations was relatively high, the same could not be said about DSPs. As Figure 3 below illustrates, more than two-thirds (36.3%) of respondents indicated that more than 60% of the DSPs they employ were at least partially vaccinated, but nearly three in 10 (29.4%) reported that less than 40% had received one or both shots.

As with people supported, the primary barriers to improved vaccination rates among DSPs were hesitancy and refusal, but among DSPs, these barriers were reported with significantly higher frequency. Of the 159 responses to the question about barriers to vaccination among DSPs, 127 (79.%) identified vaccine hesitancy while 116 (73%) identified vaccine refusal.

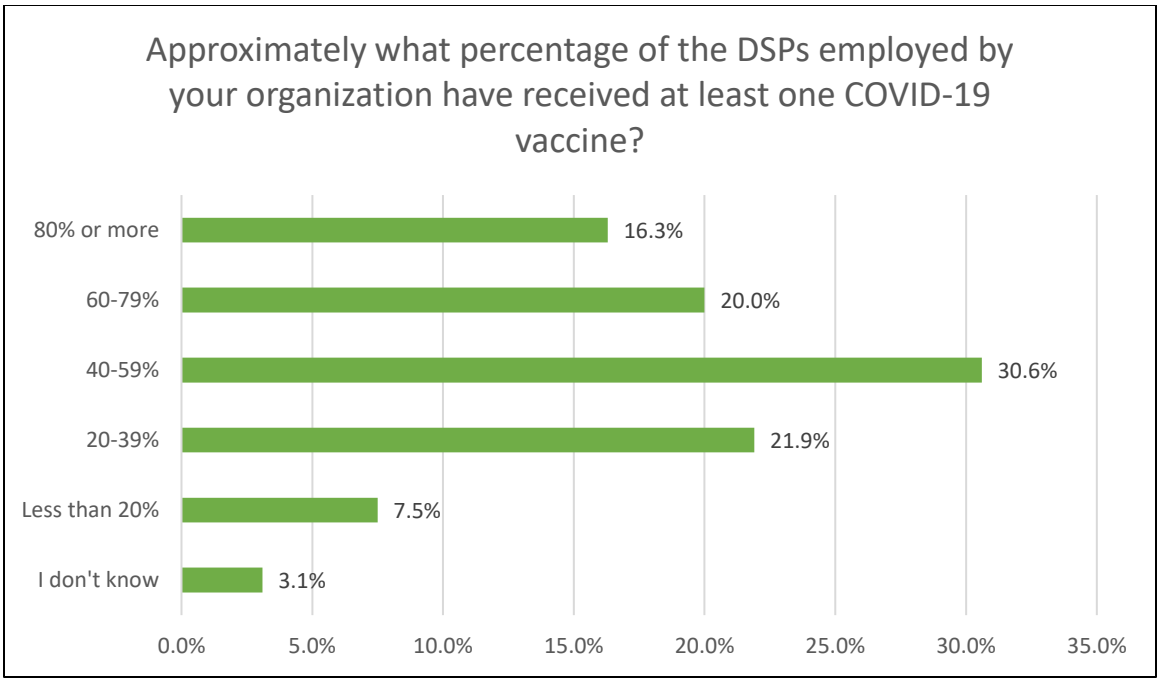

Figure 3. Vaccination rates among direct support professionals employed by provider agencies

Key Finding: There remains a significant need to equip providers with resources to improve vaccine uptake among the direct support workforce.

Open-ended comments furnished by respondents that identified hesitancy and refusal as significant barriers reveal some of the underlying drivers of low vaccine acceptance rates among DSPs. Many of the reasons provided align with what one might expect: some indicated DSPs they employ had medical or religious reasons for not accepting the vaccine, for example, while others indicated DSPs feared the vaccine's side effects or were uncertain about its ingredients.

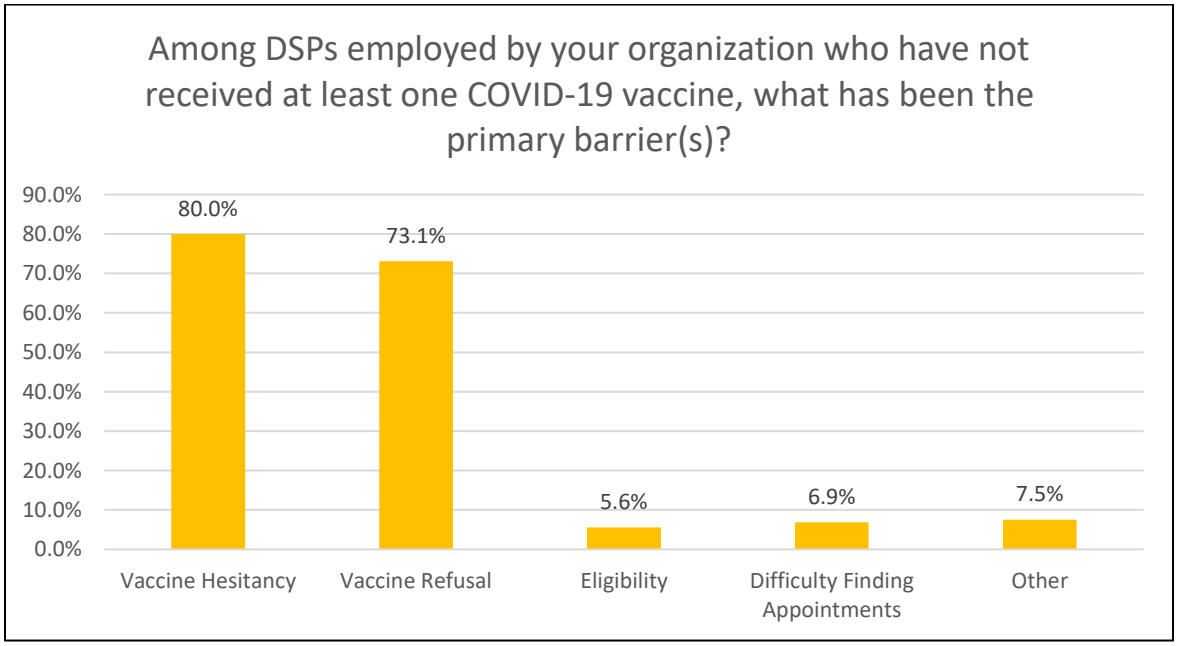

Figure 4. Top barriers to vaccination among DSPs employed by provider agencies

However, there were a number of responses that indicate reasons for hesitancy or refusal that may not be rooted in scientific fact. For example, several respondents indicated that the DSPs working in their organizations refused to be vaccinated because they are of child-bearing age, suggesting a fear that the vaccines could interfere with fertility. However, there is no evidence to suggest that the vaccine impacts fertility or a person's future prospects of conceiving a child in any way. Likewise, several respondents indicated they employed DSPs who were forgoing vaccination because they had already contracted COVID-19 and thus were immune. Although evidence does suggest that people who have recently recovered from COVID-19 are immune for a period of time following infection, likely 3-6 months, the CDC still recommends getting vaccinated as soon as possible, even if they have recently recovered from COVID-19.

The prevalence of concerns like these being cited as reasons why DSPs are hesitant or refusing to receive the vaccine suggests a difficult information environment with which all of us—provider organizations included—are working to navigate. With so much information out there and with guidelines changing regularly, it can be difficult to discern which sources are most credible. As a result, it's unsurprising that people are hesitant about receiving the vaccine.

Given our findings that hesitancy among the direct support workforce is more prevalent than in the general population, as well as the important role DSPs play in keeping people with I/DD safe, provider organizations can be a valuable source of credible information for their employees. To aid providers' efforts, community-based disability providers should be equipped with information and resources to help better inform DSPs, as well as with guidance on how to increase confidence in COVID-19 vaccines as a strategy for reducing hesitancy and refusal and, ultimately, driving up vaccination rates.

Takeaways for Providers

With the findings of ANCOR's recent survey on the state of vaccine access and uptake as our backdrop, we conclude that by and large, provider organizations are continuing to move mountains in the effort to sustain the safety and well-being of the people with I/DD they support. At the same time, that so many people with I/DD remain unvaccinated nearly six months after the FDA's first emergency use authorization in early December confirms that more work remains ahead.

Some of that work involves doing what community providers have been doing all along: educating people about the necessity of vaccination, hosting onsite clinics where high volumes of people can be vaccinated in a single day, supporting people to make their own informed decisions about the vaccine, helping people navigate online appointment booking systems, providing transportation to vaccination sites and more. But if we are to take seriously the need to build on the important work providers have been doing during the pandemic, it will be important for them to be equipped with resources that can increase vaccine acceptance not only among the people they support, but also among their family members and direct support professionals.

We found that family members or legal guardians can be barriers to vaccination, as their own predispositions may influence them to disallow their loved ones from accepting the vaccine. For these members of our community, it may be prudent to educate them about the possibility that intellectual and developmental disabilities are considered comorbidities, meaning their loved

ones are more likely to die if they contract COVID-19 compared to someone with a similar health profile who doesn't live with a disability.

DSPs, on the other hand, may perceive themselves to be at no higher risk of hospitalization or death due to COVID-19 when compared to people in the general population. For these professionals, provider organizations can engage in outreach that reminds DSPs that although they may not experience heightened risk themselves, their work cannot be done while maintaining physical distance, meaning they present a significant risk to the people they support should they become infected. It may be helpful to remind DSPs working in group homes or other congregate residential settings that the risk of transmission between unvaccinated individuals is especially high in these settings.

Providers should also keep in mind that the unique demands of DSPs' jobs may present barriers, and thus steps should be taken to mitigate the impact of these demands on their employees' ability to get vaccinated. For instance, offering schedule flexibility or paid leave so DSPs can attend their vaccine appointments or take time off in the event of significant side effects may be appropriate, as may be the hosting of onsite or mobile vaccine clinics tailored specifically to the scheduling needs of DSPs who might otherwise be on the fence about getting their shots.

If the past 15 months have been any indication, providers will continually rise to meet the demands of the moment, which makes ANCOR confident that the threat of COVID-19 will continue to lessen over time. Nevertheless, we applaud all that community providers are doing to keep people safe, and look forward to continuing our advocacy on your behalf.

Get in Touch

Have questions or want to learn more? Contact Sean Luechtefeld, Ph.D., ANCOR's Senior Director for Communications, at sluechtefeld@ancor.org.