



Oregon Council on Developmental Disabilities

BETTER TOGETHER

Jan. 24, 2021

To: Sen. Gelser, Chair, Senate Committee on Human Services, Mental Health and Recovery

From: Leslie Sutton, Executive Director, Oregon Council on Developmental Disabilities

RE: Phase 1a COVID-19 Vaccine Roll Out to the Developmental Disability Population

Chair Gelser and Members of the Committee:

The Oregon Council on Developmental Disabilities works to create change so that people with intellectual and development disabilities (IDD) can live full lives as valued members of their communities. We take direction from people experiencing IDD and their families. Two out of three of our Council members are self-advocates or family members.

By including all people with intellectual and developmental disabilities (IDD) and their paid and unpaid support workers and direct support professionals in Phase 1a of the COVID Vaccine roll out, Oregon was one of only a few states in the nation to incorporate the scientific evidence proving that people with IDD need the vaccine now because they have three times higher mortality than other populations.¹ People with IDD are also at higher risk of contracting COVID because they need supports in their homes. When Oregon created the COVID vaccine prioritization plan, it centered on equity that included the DD Community as a Phase 1a population.

In the past week, I've asked people with IDD, their families and DD Community partners one word to describe what the COVID-19 vaccine means to them. Generally, people with IDD focused on words that describe what opportunities the vaccine can bring to their lives like work, connection, friends, peace and normalcy. But they also used words like "important but frustrating," and "no access." Families used words like relief, freedom, and values like inclusion and sentences like "the vaccine means my child matters." DD Community partners including case managers, Oregon Health Authority (OHA) and Oregon Department of Human Services staff focused on words that demonstrate they understand the importance of getting the vaccine to the DD community. Their words included responsibility, resilience, cautiously optimistic and continuous improvement.

¹ Oregon Health Authority Phase 1a Description, pages 6 and 8:

<https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le3527.pdf>

IDD population mortality data: New York Times, Nov. 10, 2020 (updated Nov. 11, 2020)

<https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html>, citing FAIR Health White Paper, Risk Factors for Covid-19 Mortality Among Privately Insured Patients. Nov. 11, 2020

<https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf>

Most compelling is that people with IDD, their families and DD Community partners all said the vaccine means hope and community.

In the first few weeks of the vaccine availability, the IDD community mobilized quickly to engage with local public health and gain access to the vaccine. Initially, there were very few opportunities for the DD Community to get a vaccine:

- coordination and response with local public health authorities was difficult in most areas (and non-existent in some areas),
- clinics were deemed for "healthcare workers only,"
- Many counties were confused about how the DD community fit in Phase 1a,
- registration forms were for organizations to register their staff for vaccination rather than allowing for individuals to register,
- people with IDD and their families are turned away and told they were not eligible when they were,
- clinic registration was online which was not accessible to the DD community,
- registration was only in English,
- the DD Community was informed of clinics after the clinics already happened or were already full,
- the federal pharmacy partnership went silent for DD providers delaying vaccines for people living in group or foster homes and creating confusion and local clinics, and
- families called their doctor, their public health authority and DD case manager for information about where to get the vaccine - but there was no information and very few vaccines for the DD Community.

Many partners in the DD Community have worked with the Oregon Health Authority and local public health officials for weeks to fix these problems and are grateful for their partnership. From this work, many people in the DD community have accessed the vaccine, however, our work is not done. We feel the urgency and fear that once new phases of vaccine eligibility open that this population will be left behind.

We have some lessons learned that have ensured that more people in the DD community can access the vaccine. We are working in partnership with Oregon Health Authority and local public health authorities to continue to implement these lessons on the ground in each community. These lessons include:

Continue IDD-specific reserved “slots” at clinics and enlist the DD Community to get the word out.

So far, most clinic events are exclusive to those who can access email or the internet and can register quickly before all the slots are taken. This eliminates access to clinics for people who do not have email, internet access or who speak a language other than English or who need to connect with a support person or case manager to help them register. By reserving slots for the DD community, people can get the support they need to register before slots are taken. Share the clinic information and registration with DD Case Management Entities who can then support people who may need additional time to register and ensure clinic information gets to people with IDD and their support workers.

A centralized, searchable list of vaccine opportunities.

This is the most requested tool from Oregonians. We understand OHA is working on this. However, as I mentioned, do not post all the DD-specific registration links to a centralized website meant for the general public. We have heard reports of people in groups not yet eligible to receive the vaccine registering as a member of the DD community in an effort to get the vaccine sooner when links are public.

We recommend that OHA publishes some opportunities with links and phone numbers to register, but reserve other opportunities just for the case management entities to directly register people or for them to send to individual customers.

Assign OHA Regional Coordinators to help remove barriers in Eastern Oregon and Multnomah County.

In order to make their work most effective, we recommend an up-front orientation to the IDD service system in Oregon, which we would be happy to provide. We understand this is happening now and we are seeing great progress in these areas.

Standard Accessibility for Clinic Registration

So far, most clinic events are exclusive to those who can access email or the internet and can register quickly before all the slots are taken. Currently, many clinics even require that you enter complex information within a short timeframe or lose your spot. This eliminates access to clinics for people who do not have email, internet access or who speak a language other than English.

Not all people with DD receive DD services and it is imperative that all vaccine clinic registrations are accessible and consider people who speak other languages, do not access or use the internet or use other communication methods. Clinics should also have phone registration with people answering the phones who speak languages other than English.

Require Accessibility Modifications and Procedures at Vaccination Clinics

Many people with disabilities cannot wait in line for vaccinations. DD Community partners crafted language that we have proposed to the Oregon Health Authority for each clinic moving forward that will support broader accessibility of each clinic site. The proposed language is in the attached appendix.

Set up vaccine clinics at DD Case Management offices, where feasible.

Look to DD case management entities to host smaller, targeted, and equipped events at their offices, in rural parts of the state. There are a number of folks who would be unable to attend a mass-vaccination event due to medical or behavioral support needs but could access a smaller event at a familiar setting.

Continue creative efforts to provide in-home vaccinations.

There is a pharmacy program that is supposed to vaccinate people who live in foster or group homes, however, that has been a spotty roll out, and many people with IDD do not live in group or foster homes. Some people's medical conditions, behavioral support needs or transportation needs mean they cannot access a mass clinic. Vaccinating them at home makes sense. We are grateful that several counties are moving in this direction this week.

Although the last few weeks have brought hope of a vaccine to the DD Community, the vaccine has only been a reality for some. Despite this, the vaccine continues to represent hope and opportunity that the Oregonians with IDD can and will survive COVID. With strong partnerships and commitment from the Oregon Health Authority, Local Public Health Authorities, Health Systems and the DD community, we can continue to make the vaccine a reality for thousands of Oregonians with IDD and their paid and unpaid support workers and direct support professionals.

Appendix: Proposed Vaccine Clinic Accessibility Requirements in Compliance with the Americans with Disabilities Act

Proposed: Federal and State law requires that all public spaces, such as public health buildings, convention centers, fairgrounds, doctors' and dentists; offices, pharmacies, and other businesses comply with the American's with Disabilities Act to protect people from discrimination based on their disabilities.

Vaccination Clinics authorized by a County Public Health Authority must comply with the Americans with Disability Act. Prior to operating a Vaccination Clinic authorized by the County Public Health Authority, the Entity must have policies and procedures in place that includes how it will serve people with disabilities, including steps to communicate effectively with customers with disabilities, and a process for receiving and responding to ADA complaints.

What these ADA accommodations may look like, particularly for vaccination clinics, may be different from place-to-place. Accommodations should consider that many people who are trying to access vaccinations may have multiple disabilities. They may be Deaf or Hard of Hearing. They may experience blindness or low vision. They may use a wheelchair or other mobility devices. They may have low stamina or experience fatigue, mental health conditions or behavioral support needs that prevent them from standing in line for long periods of time. Some examples of reasonable accommodation as it relates to vaccine sites include:

1. Choose a centrally-located site that is physically accessible and that people can reach by mass transit, if possible
2. Have simple, plain-language written materials on hand for people to review who may have cognitive challenges
3. Have some large print items available for people who have low vision.
4. Maintain pathways to and from the vaccine site with clear, level access for vaccine recipients who use wheelchairs and other mobility devices.
5. Have an "ADA/Special Needs" entrance to allow people to get in faster and avoid long lines.
6. Modify mask requirements for those individuals whose disabilities prevent them from wearing a face covering
7. Have staff wear clear face coverings so that those individuals who read lips can effectively communicate with vaccine staff
8. Be prepared to offer assistance to vaccine recipients who experience blindness or low vision who ask for someone to read forms to them.
9. Be prepared to offer language interpretation support such as American Sign Language or other languages.

