

COVID-19 Vaccination Experience Among Adults with Disabilities and Caregivers in FEMA Region 5 (Illinois, Michigan, Minnesota, Ohio, and Wisconsin)

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BACKGROUND

To improve COVID-19 vaccination among the disability community in the Federal Emergency Management Agency (FEMA) Region 5, the Center for Health Equity (CHE) at the Indiana Institute on Disability and Community (IIDC) at Indiana University Bloomington conducted an online survey from March 25 to April 29, 2022. FEMA Region 5 covers the following six states: Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. However, this survey did not include Indiana because a separate COVID-19 vaccination survey was already conducted in Indiana. The online survey was designed to identify the following: COVID-19 vaccination status of adults with disabilities, family caregivers, and paid caregivers (e.g., direct support professional, personal care attendant/aide, and home care worker) of individuals with disabilities in FEMA Region 5 states (excluding Indiana); barriers and facilitators to COVID-19 vaccine access; where adults with disabilities and the caregivers receive information about COVID-19 vaccines; their preference for methods of receiving COVID-19 vaccine information; and their needs when getting a COVID-19 vaccine.

METHOD

The online survey was conducted using the Qualtrics survey tool. To promote the survey, CHE collaborated and communicated with a wide variety of disability organizations in the five states, as well as the Association of University Centers on Disabilities. CHE provided those organizations with social media and newsletter templates, requesting their assistance in promoting the survey to disability advocates and disability organizations in the states. Below are the types of disability organizations with which CHE collaborated on the promotion in the five states:

- Centers for Independent Living
- Disability and advocacy organizations (e.g., Autism Society; State and Protection Advocacy Systems)
- Great Lakes ADA Center serving Region 5 (Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin)
- Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs
- University Centers for Excellence in Developmental Disabilities (UCEDDs) programs

RESULTS

Participants

There were 90 eligible participants included in the analysis. The following is the breakdown of the participants by state: Illinois ($n = 9$), Michigan ($n = 34$), Minnesota ($n = 15$), Ohio ($n = 10$), and Wisconsin ($n = 22$). Approximately half of the participants (47.8%) identified as caregivers ($n = 43$), and 13 percent of the participants identified as direct support professionals ($n = 12$).

Also, about 40 percent of the participants (38.9%) reported as a person with disability ($n = 35$). Their types of disabilities included vision disability ($n = 6$), hearing disability ($n = 1$), cognitive disability ($n = 16$), mobility disability ($n = 21$), self-care disability ($n = 12$), and independent living disability ($n = 15$). It should be noted that some participants reported multiple disabilities.

The majority of the survey participants were white (89%), female (75.6%), and had bachelor's degree or higher (70.7%). They also lived primarily in suburban and urban areas (45.1% and 36.6%, respectively). The age groups of the respondents varied, but the most represented group was those between 50 – 64 years old (46.7%), followed by those ages 40 – 49 (18.9%) and those ages 30 – 39 (12.2%). Regarding income, the majority of participants reported '\$50,000 and more' for total family income in the last year before taxes: '\$50,000 to less than \$75,000' (29.1%), '\$75,000 to less than \$100,000' (12.7%) and '\$100,000 or more' (31.6%).

Key Findings

The primary findings of the online survey are as follows:

- The majority of the participants were fully vaccinated (93.3%) and also received a booster or additional dose after being fully vaccinated (88.1%).
- The top three reasons why participants received COVID-19 vaccines were as follows: 1) they wanted to protect their family/friends from possible infection (27.1%); 2) they did not want to get COVID-19 (24.7%); and 3) they wanted to prevent the spread of COVID-19 (23.9%).
- The top reasons why participants did not get the COVID-19 vaccine or booster were as follows: 1) they were worried about the long-term side effects (19.1%); 2) they were worried the vaccine came out too fast (12.8%); and 3) they already had been infected with COVID-19 (10.6%).
- When asked about the most likely sources for COVID-19 information, the following were the sources they were 'somewhat likely' or 'very likely' to turn to:
 - Healthcare provider (97.6%)
 - Centers for Disease Control and Prevention (CDC)/governmental agencies (91.7%)
 - State or local health departments (91.7%)
 - Disability organizations (68.7%)
 - News (online or print) (65.5%)
- Regarding useful resources for staying up-to-date with information about COVID-19 and vaccines, participants reported that the following resources would be 'somewhat' or 'very useful':
 - COVID-19 resources websites (89%)
 - Plain language materials (84.4%)
 - Webinars (69.1%)
 - Online newsletters (69%)
 - Radio public service announcements (57.3%)

- Most of the survey participants reported that they did not use information and phone services, like 2-1-1, for help with scheduling a vaccine appointment or for obtaining COVID-19 information (78.8%).
- The majority of participants used their state’s department of health website to schedule a vaccine appointment or get information about COVID-19 and vaccines (65.9%). When asked about their experiences with their department of health’s website for COVID-19, the respondents provided the following:
 - Experiences with COVID-19 vaccinations websites were inconsistent and could be dependent on what state a person lived in.
 - Some people found COVID-19 vaccination appointment websites helpful.
 - *“Everything has worked well in the past.”*
 - *“The Minnesota Department of Health has a great suite of COVID-19 websites.”*
 - In contrast, others thought the websites were not user-friendly.
 - *“I wish the website layout was more accessible (less text that's all one color, some hierarchy with the links like a link tree)”*
 - *“It was not a user friendly website/online registration for vaccine.”*
 - *“Website info not up to date, links did not work, website down at times they do not call back.”*
- When asked what information about COVID-19 or vaccines including a booster would be useful to participants, the following four needs were revealed:
 - People need to know when to get their COVID-19 vaccination boosters.
 - *“When to get boosters, and which vaccine to get.”*
 - *“Info about timelines for boosters”*
 - Information is needed on the efficacy of COVID-19 vaccines and the length of their efficacy.
 - *“...what amount of protection the vaccine actually provides.”*
 - *“Statistics on waning vaccine effectiveness and numbers after a booster on cases, hospitalizations, and deaths”*
 - People need to be informed on the side-effects of the COVID-19 vaccines.
 - *“Side effects and what things one can do to feel better from getting sick from the shot (I got very sick and it exacerbated my mental illness)”*
 - *“more info on side effects related to... the different shots so can make better decisions”*
 - Information about COVID-19 and vaccines need to be accurate and reliable.
 - *“Accurate information from reliable sources.”*
 - *“Reliable sources - no flip flop of message - consistent. CDC did a horrible job at the message.”*

- Regarding comments or suggestions for improving COVID-19 vaccinations for people with disabilities and caregivers in FEMA Region 5, responses were summarized into the following five needs:
 - There needs to be more accessible transportations available to vaccination sites.
 - *“Resources for transportation to and from the vaccine site if needed”*
 - *“My first shot was very hard to get due to me needing wheelchair transportation”*
 - *“How to get a free wheelchair transport to get a booster shot.”*
 - There needs to be options to get vaccinated at home for individuals who cannot easily leave their home.
 - *“In-home vaccination could be extremely useful for people with disabilities.”*
 - *“A way to get vaccines to people who are home- or bed-bound. We are at a very high risk because a) we are often in poor health and b) we have caretakers (home health care, PCAs, etc) coming in and out so we get exposed.”*
 - *“Also, many people are home bound. Scheduling home vaccinations would be very helpful.”*
 - There needs to be more accessible vaccination sites.
 - *“More drive thru or curbside vaccination sites.”*
 - *“Plus there are people who may need drive thru/curbside due to mobility issues or other disabilities. BOTH drive thru and not need to be offered, but changing a drive thru clinic to a “just come inside!” clinic is a huge accessibility issue and presents a barrier for people counting on drive thru access”*
 - *“Distance for Parking and walking for those with mobility issues was challenging for my family”*
 - There needs to be accessible and user-friendly options for scheduling COVID-19 vaccinations online.
 - *“Making information readily available in plain language and websites built for people with difficulties.”*
 - *“Helping older caregivers know how to maneuver the online scheduling.”*
 - *“Advocacy organizations should provide hot links to places where vaccinations, booster and tests are available.”*
 - People with disabilities and those who are caregivers of people with disabilities should be prioritized for COVID-19 vaccinations.
 - *“...caregivers should have been able to get the shots earlier so that they could limit exposure to their family.”*
 - *“placing individuals [sic] in the first to get vaccinated.”*
- Participants were asked to provide advice on what would help unvaccinated individuals or those who have not received their vaccination boosters to become fully vaccinated.

Their responses are summarized as follows:

- COVID-19 vaccinations should be mandated.
 - *“Maybe if their job mandated them. That would be good for in home care providers and mental health peer support”*
 - *“I think that for any and all medical appointments and surgeries it should be mandatory to receive the vaccine.”*
- Public health agencies need to provide accurate and reliable sources of information about the side effects and efficacy of the vaccines.
 - *“I think more transparency about potential [sic] side effects and how to cope with them would help build trust.”*
 - *“Information on likelihood of adverse side-effects and what they might be (including long-term ones)”*
 - *“Honest communication about the efficacy of vaccines and what vaccines can and CAN'T do...”*
- Healthcare providers and public health agencies should conduct outreach.
 - *“outreach from doctor or local health dept”*
 - *“Having a conversation with an MD”*
- It is important to personalize the COVID-19 and vaccination experiences.
 - *“Seeing someone they care about struggling to survive”*
 - *“Sadly, I think only direct confrontation with the disease and its deadly consequence will move the remaining holdouts.”*
- People need to make their own decisions about getting the COVID-19 vaccines.
 - *“If feels forced and like people don't have another choice. people should get to make decisions about their medical care, and not be considered "bad people" if they choose to wait to be vaccinated.”*
 - *“Nothing, it's a personal choice.”*
- It is unlikely that people who have not received their vaccinations will change their minds.
 - *“I live in area with high vaccination rates. The people who haven't received the vaccinations are not going to get them. It's become a matter of personal identity. Wasting resources on changing their minds is pointless.”*
 - *“If someone hasn't had the vaccine by now, they're probably not going to get it.”*
 - *“At this point, most people's minds are made up. The few that can be persuaded need information on how the long term effects are, if any.”*

Limitations

Our findings reveal important information about perspectives on COVID-19 vaccinations among people with disabilities and caregivers in FEMA Region 5. However, our findings need to be

considered in light of several limitations. First, we did not recruit the participants using a probability sampling technique. Given that our sample was not randomly selected, it is possible that selection bias occurred. The survey participants were primarily well-educated, female, white, and urban and suburban residents, and they reported high annual incomes. Second, we were not able to recruit a large sample despite our considerable promotional efforts and collaboration with various disability organizations across FEMA Region 5. The small sample size does not allow us to examine the findings by state (e.g., n=9 for Illinois, n=15 for Minnesota, n=10 for Ohio). Third, it should be noted that the survey was conducted between March and April 2022. The COVID-19 pandemic has constantly evolved, and policies and recommendations for safety have changed since April 2022. New COVID-19 variants have changed the efficacy of current vaccines, and many local and state governments have opted to remove or relax COVID-19 restrictions. Although the risk for infection remains high, many individuals' willingness to comply with preventive efforts and their perceptions about their risks of infection have changed. Given that the ongoing changes in the pandemic were not captured in the findings, they may not necessarily reflect how respondents currently perceive the pandemic or how they navigate COVID-19 guidelines. Finally, although the survey was written in plain language, an American Sign Language version was not available, which could serve as a barrier to participation for Deaf people.

Despite these limitations, the information gathered through this survey can be beneficial in understanding how to move forward with improving vaccination efforts. Survey participants noted multiple factors that prevent people with disabilities from appropriately accessing vaccines (e.g., transportation to vaccination sites and need for at-home vaccination services). It can be assumed that people with disabilities from harder-to-reach areas and groups with lower vaccination rates deal with these issues at higher rates. The survey results indicate that COVID-19 preventive measures could be improved through efforts like providing plain language materials and using reliable public health agencies to disseminate information.

Recommendations

For the foreseeable future, COVID-19 will remain a public health threat. With ever-evolving COVID-19 situations and related changes, people with disabilities will continue to experience new challenges that put them at risk for infection and related severe outcomes. People need to keep taking precautions to reduce their risk of infection, including receiving vaccine boosters. The results of this survey should serve as an ongoing guidance for public health professionals and policymakers on what is needed to ensure that all groups, especially those with disabilities, are able to access COVID-19 information and vaccines equitably. Regardless of how often the health information and preventive measures evolves and changes, these resources must be accessible to people with disabilities and accommodate their needs. Vaccination sites have to be physically accessible for people who use wheelchairs, and health care providers need to provide competent assistance to those with intellectual and developmental disabilities who want to be vaccinated. Programs will need to consider how to better serve people who need transportation to vaccination sites or cannot easily leave their homes. The COVID-19 pandemic has served as a stark reminder of the limitations on the current public health system in addressing the needs of individuals with disabilities, but it has also provided opportunities to improve the system for future crises.

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