



June 2023

INDIANA INSTITUTE ON DISABILITY AND COMMUNITY
CENTER FOR HEALTH EQUITY

ISSUE BRIEF

Perceptions and Experience of Vaccination and Vaccination Outreach: Findings From an Online Survey of Adults With Disabilities and Caregivers in FEMA Region 5

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BACKGROUND

The Center for Health Equity (CHE) at the Indiana Institute on Disability and Community at Indiana University Bloomington serves as a Regional Hub for the Federal Emergency Management Agency (FEMA) Region 5 (Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin), to promote vaccinations among individuals with disabilities and their family and paid caregivers. This project aims to increase vaccinations recommended by the Centers for Disease Control and Prevention (CDC) among the disability community, to protect them against infectious diseases including COVID-19. CHE conducted an online survey to better understand the experience and thoughts of the disability community about getting CDC-recommended vaccines (e.g., flu, COVID-19, measles). For conducting effective vaccination outreach, the online survey was designed to identify the following: identify barriers and facilitators to vaccine access and accessibility; where people with disabilities and caregivers receive vaccine information; their preference for how they want to receive information; and their needs in getting a CDC-recommended vaccines.

METHOD

The online survey was conducted using the Qualtrics survey tool, from March 27 to April 25, 2023. Adults with disabilities and family and paid caregivers of individuals (minor or adult) with disabilities were eligible for the survey, if they were a) 18 years old and over, and b) living in the FEMA Region 5. To promote the survey, CHE collaborated with a wide variety of disability organizations in the five states, as well as the Association of University Centers on Disabilities (AUCD), and the advisory committee for this project. CHE requested their assistance in promoting the survey to disability advocates and disability organizations in the Region 5 states. CHE provided organizations with social media and newsletter templates that they could use to promote the survey. Below are the types of disability organizations with which CHE collaborated on the promotion in the FEMA Region 5 states:

- Centers for Independent Living

- Disability and advocacy organizations (e.g., Indiana Disability Rights, Self-Advocates of Michigan)
- 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

A total of 166 eligible participants were included in the analysis. The following is the breakdown of the participants by state: Illinois ($n = 25$), Indiana ($n = 59$), Michigan ($n = 48$), Minnesota ($n = 24$), Ohio ($n = 6$), and Wisconsin ($n = 4$). Regarding type of participants, they consisted of adults with disabilities ($n = 65$; 39.2%), family caregivers ($n = 76$; 45.8%), and paid caregivers ($n = 25$; 15.1%). The majority of survey participants were white (87.9%), female (76.0%), had a bachelor's degree or higher (59.4%), spoke English most often at home (99.4%), and had an annual family income of \$50,000 or higher (58.3%). The participants also reported living in suburban and urban areas (49% and 23.9%, respectively). The average age of the survey participants was 47.8 years old.

Many of the participants who identified as adults with disabilities reported that they had multiple disabilities. Their types of disabilities included vision disability (15.4%), hearing disability (17.2%), cognitive disability (37.5%), mobility disability (45.3%), self-care disability (23.4%), and independent living disability (36.9%).

The caregiver participants reported that the average age of the persons with disabilities they were caring for was 34 years old. The majority of those with disabilities were 15 years and older (83.2%). Many of individuals with disabilities they attended had multiple types of conditions. Their types of disabilities included vision disability (17.8%), hearing disability (17.8%), cognitive disability (78.2%), mobility disability (51.5%), self-care disability (62.4%), and independent living disability (92.9%).

Key Findings

The primary findings of the online survey are as follows:

- The majority of participants were vaccinated for COVID-19 (94.5%). Most of them received a booster shot for the virus (84.3%). More than one fourth of the participants reported that they had received a booster shot, but not the bivalent shot (27.1%). One in ten participants did not receive any booster shots (10.2%).
- The majority of participants reported that they had received their flu shot between fall 2022 and winter 2023 (78.3%).
- Regarding why participants received their COVID-19 vaccines (including boosters) and why they received their flu shots, top three reasons for getting the vaccines were the same: 1) they did not want to get sick from the virus, 2) they wanted to protect family/friends, and 3) they wanted to prevent the spread of virus.

- The primary concern about receiving either the COVID-19 vaccine/booster or the flu vaccine was worry about side effects.
- One in four participants reported having challenges receiving CDC-recommended vaccines (26.5%). Younger participants, particularly those ages 20-29, reported more challenge in receiving vaccines. Participants without a high school degree or GED also reported more challenge getting vaccinated.
- Participants reported the following top three reasons as to why it was difficult to remain up-to-date with vaccinations: 1) scheduling appointments with healthcare provider or pharmacy was confusing or difficult (20.3%), 2) sensory overload at vaccine site (19.0%), and 3) information about vaccine was confusing (11.4%), and difficult to leave home because of health condition/disability (11.4%).
- There are many available sources of information for CDC-recommended vaccines. Participants reported that they were ‘very likely’ to turn to their health care provider (75.8%), the CDC (70.4%), state or local health department (64.7%), disability organization (35.9%), family (30.5%), television news (25.0%), online and print news (21.3%), and friends (18.4%). The majority of the participants also reported that they were ‘not at all’ likely to turn to the following: church or place of worship (69.0%), videos such as YouTube or TikTok (66.4%), podcasts (58.9%), schools (55.6%), radio (55.6%), and social media such as Facebook, Instagram, or Twitter (54.5%).
- Participants stated that the following top five resources would be ‘very’ useful for staying up-to-date with information about CDC-recommended vaccines: vaccine resources websites (56.2%), plain language materials (47.1%), online news or newspapers (35.7%), broadcast news online or on television (30.7%), and online newsletters (27.1%). In contrast, they reported that the following top five resources would be ‘not at all’ useful: Informational/educational materials translated into language other than English (59.7%), American Sign Language (ASL) versions of informational/educational materials (52.3%), targeted advertisements on social media websites (46.4%), social media posts (39.0%), and radio public service announcements (35.0%). However, it must be noted that almost all participants reported that English is the language they spoke most often at home (99.4%), and that no one reported ASL as the language spoken most often at home.
- The majority of participants did not use information and referral phone services (e.g., 2-1-1) for help with scheduling appointments or getting information about CDC-recommended vaccines (71.7%).
- Participants were asked what information regarding CDC-recommended vaccines (including COVID-19 boosters) would be useful for them. Their responses were summarized into the following four needs with comments from participants:
 - Materials about vaccines have to be clear and in plain language.
 - *“An easy to read/understand publication for our field.”*

- *“clearer information about timelines for when vaccines are available for my specific age group would be helpful... It wasn’t easy parsing through a page of information to figure out when or whether I would be eligible.”*
 - There should be information about side effects from vaccines.
 - *“Information for specific vaccines and explain what is side of effects.”*
 - There needs to be information about the efficacy of vaccines.
 - *“It would be useful to know about the protection that the new vaccines have against the newest variants.”*
- When it came to vaccines, some participants noted that there was an ongoing distrust and skepticism of the health resources and information that needed to be addressed.
 - *“I think it can be difficult to combat disinformation when people affiliate with ideologies that discourage vaccination in the wider community, and in the disability community, especially when skeptics just say everything is lies without being expected to provide evidence.”*
- Participants recommended that promotional efforts should engage with local resources such as community centers and disability advocates in order to improve their reach.
 - *“I think it is most effective when providers (case managers, doctors, etc) talk to people about the benefits of vaccines”*
 - *“Our organization hosted several sensory friendly vaccine events specifically for autistic children. These events were very successful in reaching a population for whom vaccination is often a traumatic and difficult experience.”*
- Vaccinations efforts must consider how to have more convenient locations to receive vaccines and easier ways to get information about vaccines.
 - *“Additional resources that actually “make it” to care providers and their disabled family members. Perhaps through phone calls or direct mail.”*
 - *“provide transportation support for these appointments”*
 - *“[provide vaccinations] at area pharmacies (Walgreens, Target, Walmart) as I walk in the door as I am there shopping anyway”*

Limitations

This brief provides important information about the perspectives and experiences of vaccinations among the disability community in the FEMA Region 5. However, several limitations need to be considered when reviewing the findings. First, the survey did not recruit participants using a probability sampling technique. It is possible that there was selection bias because the sample was not randomly selected. The sample was primarily white, female, college-educated, spoke English most often at home, and reported high annual family incomes. Second, we were not able to recruit a large number of participants from each of the FEMA Region 5 states. There were only 10 participants in total from Ohio and Wisconsin. The survey participants may not well represent the target groups in the states. Third, this survey was intended to cover perspectives and experiences

with CDC-recommended vaccines. However, this survey was conducted during the COVID-19 pandemic. This may explain why many of the opinions regarding vaccines were dominated by the COVID-19 vaccines and boosters. These vaccines can elicit stronger opinions compared to other types of vaccines. Survey participants may have responded to questions on CDC-recommended vaccines, with COVID-19 as their primary reference for vaccines, rather than considering all types of vaccines.

Despite these limitations, the results of the survey can help us understand how to improve vaccination efforts for different types of vaccines among the disability community. Survey participants provided useful information about factors that made it difficult for them to remain up-to-date with vaccines and about the types of resources that should be used during vaccine promotions. The survey also serves as a comparison between COVID-19 vaccines and the flu vaccine. The participants had similar motivations for receiving those vaccines.

RECOMMENDATIONS

Vaccines remain one of the most effective tools to prevent the spread of viruses and are especially important in the disability community. People with disabilities are more likely to have chronic health conditions and weakened immune systems, which puts them at higher risk of infection and more severe outcomes, if infected. The COVID-19 pandemic provided important lessons about the necessity of vaccines in protecting people with disabilities and their caregivers. The results of the survey can serve as a tool for public health professionals and policymakers on possible strategies that could be used encourage vaccines in disability communities.

- The survey findings show that while responding to CDC-recommended vaccines (i.e., not just COVID-19 vaccines and boosters), many participants' responses were centered on COVID-19 vaccines. Health advocates have to consider how their promotion of other vaccines may be affected by people's perceptions of COVID-19. Advocates must make sure that vaccine promotions are not dominated by people's perceptions of COVID-19. Target populations need to understand the purpose of the different kinds of vaccines available to increase the likelihood of effective promotional activities.
- One fourth of the survey participants reported having challenges getting CDC-recommended vaccines. In particular, certain groups (e.g., young adults ages 20-29 and those with no high school diploma or GED) experienced more challenges than others. While programs need to ensure that all individuals in the disability community are able to access vaccines and information, a closer attention should be given to groups experiencing greater challenge in receiving their CDC-recommended vaccines. Health advocates should tailor promotional activities based on addressing the issues of access for these groups.
- Public health agencies, such as the CDC and state/local health departments, are still viewed as trusted sources for vaccine information. Other sources such as disability organizations and news (broadcast, online, and print) were also commonly used for vaccine information. Vaccine promotions should use trusted health resources to gather information about vaccines and disseminate the information through commonly used formats like broadcast and print news and through disability organizations.
- Vaccination efforts need to make sure that vaccination information is presented in clear and accessible formats for the disability community. Also, vaccine promotion has to

consider how it applies to the needs of the disability community. This may help develop greater trust in vaccines.

Acknowledgement

The “Local Vaccine Outreach with the Disability Community: Regional Hub for the Federal Emergency Management Agency (FEMA) Region 5” Project is funded by the Association of University Centers on Disabilities (AUCD). The content of this report does not necessarily represent the views of AUCD.

