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# Lessons learned: COVID-19 vaccinations and people with disabilities

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## Abstract

This manuscript is being submitted as a Commentary; Abstract not applicable.

### Keywords

COVID-19; Vaccination; People with disabilities

## 1. Introduction

People with disabilities comprise a large and heterogenous segment of the U.S. population; up to 26 % of adults report some functional disability (e.g., mobility, cognition, independent living, hearing, vision, self-care) and approximately 17 % of children have a developmental disability, based on parent report [1,2]. Numerous reports document that people with disabilities have been disproportionately affected by disasters and emergencies in the U.S. [3–6]. During the COVID-19 pandemic they experienced a higher proportion of severe illness, hospitalization, and death [7–9]. Unfortunately, people with disabilities have not been adequately considered in emergency readiness and response efforts and within the public health infrastructure. This has led to challenges in identifying, monitoring, and



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Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

CRediT authorship contribution statement

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addressing disparities – an example is the reported concern by partner organizations of less access to COVID-19 vaccinations by people with disabilities [10].

People with disabilities have experienced long standing health inequities, reflected in differences in quality of life; rates and severity of disease and co-occurring conditions; hospitalizations; and mortality. Achieving health equity requires focused and ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and healthcare; and eliminate preventable health disparities [11,12].

## 2. Lessons learned

Based on input from various sources, early in the response CDC identified areas where focused attention was needed for people with disabilities including data collection on infection, hospitalization, and mortality; accessible services such as testing and vaccination; accessible communication; and collaboration with partners to address vaccine confidence and access. Recognizing that people with different functional disabilities may have different needs, CDC funded several COVID-19 disability projects to increase awareness of COVID-19 information, identify barriers to vaccination, and support efforts to increase vaccine uptake. As examples, inaccessible vaccination facilities led to in-home vaccination; and standard communication materials were written in easy-to-read language, created in audio formats, and translated into American sign language. Although many of these projects have concluded, they built a solid foundation for future efforts. The following sections describe CDC's efforts to address gaps in readiness and response and lessons learned.

### 2.1 Data

The 2010 Affordable Care Act established data collection standards for five demographic categories, including disability status [13]. Despite these standards, data to monitor and evaluate the impact of COVID-19 and prevention and treatment efforts for individuals with disabilities were sparse, missing, or incomplete, resulting in the lack of real time data to support public health action [5]. Better data are necessary to understand what people with different functional disabilities need to support vaccination and to evaluate our public health efforts. Improved disability definitions, data collection and integration, and staff training are necessary to address these data gaps. Although progress has been made, there is still much to be done.

CDC initiated several projects to improve identification of people with disabilities in administrative and survey data to inform public health actions. For example, CDC is working with the Association of State and Territorial Health Officials to develop disability definitions for syndromic surveillance using electronic health record data included in the National Syndromic Surveillance Program. These data will provide public health officials with a timely system for assessing impacts of public health outbreaks on people with disabilities as collected from emergency department visits across the nation.

Public health partners at the local, state, and federal levels lacked granular data around vaccination rates for people with disabilities making it challenging to understand

implementation efforts in real-time. An analysis of the National Immunization Survey Adult COVID Module showed that individuals with disabilities were less likely to receive a COVID-19 vaccination, despite lower hesitancy about getting vaccinated. Adults with disabilities reported more difficulties obtaining a COVID-19 vaccine than persons without disabilities [14]. These data pointed to the importance of reducing barriers to scheduling appointments and increasing access to vaccines. This information helped shape CDC's efforts.

Data integration and sharing provides an opportunity to gain important information. Interagency data sharing can improve the timeliness of critical information during a public health emergency. During the COVID-19 pandemic, the Centers for Medicare & Medicaid Services (CMS) and CDC fostered an interagency partnership to share administrative claims data for public health analyses. These datasharing efforts augmented the ability to examine the incidence and severity of disease faced by persons with disabilities. Sustaining and expanding these efforts may further improve identifying barriers to optimal health for people with disabilities.

## 2.2 Accessibility

Accessibility is when the needs of people with disabilities are specifically considered, and products, services, and facilities are built or modified for use by people of all abilities. [15]. Accessibility is required under Title II of the Americans with Disabilities Act which prohibits state and local governments from discriminating on the basis of disability [16]. If public health services and facilities are inaccessible to people with disabilities, they will be unable to use critical services during an emergency.

Efforts to increase access to prevention and treatment, including vaccination, are critical to reducing severe COVID-19–associated outcomes among persons with disabilities. Federal, state, local governmental and organizational disability partners provided input throughout the vaccine roll-out, during virtual meetings, stakeholder interviews and via emails. This feedback supported concerns that people with disabilities were more likely to report difficulty obtaining COVID-19 vaccines and that accessible information, transportation, and vaccine events were vital to successful participation in COVID-19 vaccination efforts.

To ensure people with disabilities had access to vaccine and testing programs and services, CDC funded the Administration for Community Living to launch the Disability Information and Access Line (DIAL). DIAL helped individuals with disabilities get vaccinated and tested for COVID-19. Between June 2021 and February 2023, DIAL responded to more than 74,000 contacts (calls, chats, texts, and emails). The most frequently requested COVID-19 information included in-home vaccination, booster shots and free testing kits.

## 2.3 Communication

Communication barriers for people with disabilities were a concern to CDC and its many partners. This concern is not new. The 2014 National Council on Disabilities report*, Effective Communications for People with Disabilities Before, During, and After Emergencies*, examined facilitators and barriers to effective emergency-related communication, such as the lack of American Sign Language interpreters, and inaccessible

web sites, (e.g., not having screen readers for people with visual impairments) [3]. Yet, communication barriers remain, likely due in part to lack of enforcement and readily available resources.

To support communication needs for persons with disabilities, CDC created a COVID-19 Toolkit for People with Disabilities which includes accessible materials to communicate CDC guidance [17]. People with disabilities need messages, materials, and guidance developed in plain language using multiple formats, such as easy-to read materials, American Sign Language, and braille. The use of images with alternative text, infographics, and videos with captioning further improves accessibility. Toolkit documents have been downloaded over 1.4 million times.

Trusted messengers with disabilities play a vital role in emergency communication within the disability community – before, during, and after an emergency or disaster. These messengers are key to timely communication and dissemination of critical information throughout the disability community. For example, the South Dakota University Centers for Excellence in Development Disabilities, Education, Research and Service adapted and implemented the “Trusted Voices” campaign which featured Tribal leaders with disabilities sharing timely, science-based COVID vaccine information to Native American people.

### 2.4 Partnerships

Collaboration with trusted partners is critical to public health success during an emergency. CDC has expanded its partnerships to include additional disability partners and disability-led organizations such as the Partnership for Inclusive Disaster Strategies which hosted daily COVID-19 disability calls throughout the pandemic, including weekends and holidays.

It takes time and commitment to build and sustain trust among partners, reinforcing the need to develop strong relationships before an emergency. CDC’s partnerships during the pandemic and inclusion of people with lived experience in communication and programmatic efforts supported vaccination among people with disabilities, as exemplified below.

CDC partnered with the CDC Foundation to support 40 Centers for Independent Living (CILs) to increase vaccination for people with disabilities. The project improved vaccination by providing vaccine education and services to over 27,000 consumers with disabilities, scheduling over 6,000 vaccination appointments, including in-home vaccinations, coordinating 903 accessible transportation appointments, and providing 3,677 instances of technical assistance to state and local health departments (SLHD). Staff also developed a partnership guide for CILs and SLHDs to promote collaboration between disabilityled organizations and public health [18].

The Movimiento para el Alcance de Vida Independiente (MAVI) CIL developed critical partnerships to address barriers and ensure equal access to COVID-19 vaccinations among people with disabilities in Puerto Rico. Using vaccine coordinators and information from consumer focus groups, they identified local barriers and implemented strategies to improve vaccination uptake. Strategies included hosting 38 vaccination events, establishing 16 MOUs

with local agencies, providing disability training to over 900 emergency management personnel, and creating a vaccination directory to help identify accessible vaccination sites, all within 6-months.

CDC partnered with the Association of University Centers on Disabilities and their Direct Support Professional (DSP) partner organizations, National Alliance for Direct Support Professionals, National Association for Home Care & Hospice, and American Network of Community Options and Resources, to address vaccine confidence and promote COVID-19 vaccination among people with disabilities and DSPs. Materials in plain language supporting vaccination were distributed and translated into other languages. Preliminary evaluation indicates an increase in COVID-19 vaccinations among individuals with intellectual and developmental disabilities, their families, and DSPs.

## 3. Conclusion

The pandemic highlighted U.S. gaps in readiness and response efforts to ensure equitable access to vaccination for people with disabilities, many of whom were at higher risk of adverse impacts from COVID-19. Lessons were learned regarding data collection, vaccine accessibility, embedding disability within COVID-19 messaging, providing guidance in accessible formats, and fostering important partnerships. Future evaluation of these efforts is key to better understanding the most effective supports and processes for vaccinating people with disabilities. Building upon these lessons is critical to CDC's readiness efforts to promote equity for people with disabilities moving forward.

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## Data availability

No data was used for the research described in the article.

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