COVID-19 Vaccination Rollout: How Individuals with Disabilities Were Failed

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Intro

Roughly 30% of COVID-19 related deaths occurred in people with intellectual and developmental disabilities, despite comprising only 3-5% of the population (IEC, 2020, np.; NCD, 2021, np.). More specifically, people with Down Syndrome were up to 10 times as likely to die from COVID-19 than people without Down Syndrome (Wiggins et al., 2021, pp. 185-189). These statistics in part are due to the lower vaccination rates for those with disabilities and suggest people with disabilities could have been better served during the pandemic. While many groups of individuals with pre-existing conditions were prioritized in the rolling out of the COVID-19 vaccines, people with intellectual or developmental disabilities were excluded from early vaccination. The exclusion of these people was a huge mistake because many people with disabilities have conditions that make it harder to fight off and recover from the virus. For the purpose of this paper, intellectual or developmental disabilities will be defined as differences that usually present at birth and uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development (NIH, 2021, np.). Vaccine accessibility will refer to the capability of the vaccine to be used by everyone regardless of socioeconomic status, race, ethnicity, geographic location, or other determinants (CDC, 2024a, np.). Through analyzing the built environment of the vaccination centers themselves and the intersectionality of the many identities of people with disabilities, I will expose the disparities in vaccination access for people with disabilities during the COVID-19 pandemic.

Built Environment Analysis

While access to vaccines for people with disabilities can be stymied by policy, access is also dependent on the environment of the vaccination clinic itself. If getting a vaccination is not comfortable for everyone, it will deter certain populations from even attempting to get vaccinated. These factors include physical space, volume, and privacy, among others. Sarah Rotenberg, a research fellow in the International Centre for Evidence in Disability, says it best, "accessibility also includes the environment where tests or vaccines are administered. Loud, bright, or otherwise sensory-heavy environments may be inaccessible to people with certain disabilities." (Rotenberg et al., 2021, p. 5728)

In order to assess whether a vaccination clinic is accessible based on the current environment, a built analysis assessment is required. In the 1960s, Roger G. Barker, an environmental psychologist, developed the behavioral setting theory, which suggests that all actions need to be placed in the context of the environment in which they occurred (Scott, 2012, pp. 151-170). This framework pulls on urban planning, architecture, environmental psychology, and sociology to determine the relationship between one's environment and behaviors. In this theory, the environment where the behavior occurs is considered the behavioral setting. For this built environment analysis, the behavioral setting is the vaccination clinic. While it may be obvious that the physical building itself, layout, and furniture inside defines the space, the social aspects of the setting including the people and their actions do as well.

First, the physical environment will be analyzed. It may seem like common sense to offer vaccines at locations that are wheelchair accessible and have sufficient seating in the waiting

room. However, during the COVID-19 pandemic, there were many stories from all over in which this was not the case. For example, there were reports in Virginia, California, and Florida of two hour wait times after the time of the appointment with nowhere to sit (Blalock, 2021, np.; Harrington, 2021, p. 1; Huriash, 2021, np.). In Waterloo, Canada, free ride services to clinics discriminated against those in wheelchairs, as they were not wheelchair accessible (Raycraft, 2021, np.). Additionally, the layout of the clinic may pose a challenge for those with disabilities. Clinics that lack easy instructions and navigation would make it almost impossible for some to successfully receive a vaccination (Leibson, 2021, p. 1). Furthermore, clinics that are sensory heavy, meaning they have loud or overlapping sounds, bright or flickering lights, strong smells, or physically stimulating surfaces or textures, are not inclusive environments and may limit vaccination access.

Next, the behavioral environment will be assessed. Certain expected behaviors pose challenges to those with intellectual or developmental disabilities. For example, it was common practice for vaccination appointments to be scheduled online. However, operating a smartphone or computer can be extremely difficult for these populations. Having strict and short time slots were also harmful to those with disabilities, as sometimes it could take longer for these individuals to check-in and receive the vaccination. Furthermore, the lack of sign language interpreters present at clinics poses yet another barrier, as some people with disabilities can only communicate using sign language. Across the U.S. this was reported as an issue (Novic, 2021, np.; Olmo, 2020, np.). Without aides present, there is much room for miscommunication or no communication at all.

Finally, we will consider current solutions and how they can be scaled. One solution to physical barriers has been the creation of mobile vaccination sites, which was the product of a collaborative effort between the Center for Disease Control and Prevention (CDC) and the Federal Emergency Management Agency (FEMA) (FEMA, 2021, np.). These sites are able to travel to harder to reach areas and target high-risk populations. They could be utilized to travel to group homes for those with disabilities, which would greatly expand accessibility to vaccines. Similarly, the healthcare team at the University of Iowa have curated a sensory friendly space to care for patients with intellectual and developmental disabilities (Vessel, 2023, np.). The “comfort room”, as they call it, does not resemble the traditional clinical setting. Instead of a cold, sterile examination room, it is equipped with blankets, pillows, fiber optic lights, and toys. This innovation is revolutionary as it completely changes the physical environment of the practice, and it has proven successful in being able to improve patient behavior. A potential solution to the time constraint on appointments would be to have at least one hour every day for a reduced number of appointments, allowing for a more relaxed experience for both the patient and professional healthcare provider. These examples where the compassion and care of the healthcare team resulted in tangible change and improved care for patients, show promise for the future of inclusive treatment. By minor alterations of the physical components of the clinics themselves, there can be significant positive impacts on the actions of the people in these spaces.

The argument for better vaccine accessibility is rooted in ethical thinking. Utilitarianism was developed in the late 18th and 19th centuries by Jeremy Bentham and John Stuart Mill (West, 2024, np.). It is a form of consequentialism that could be used to pose a counterargument to the need for vaccination centers to be fully inclusive. In utilitarianism, morality is math. As long as the end result is the greatest good for the greatest number of people, the right thing has been done. As of 2020, RISP reported that 3% of the U.S. population has an intellectual or developmental disability (RISP, 2020, p. 473). A utilitarian would argue that implementing all of these changes to the built environment of clinics is not necessary, as the majority of the general population is being served by the current set-up. This is dangerous logic because it removes the autonomy of the humans in the minority group. In only accounting for the benefit of the majority, utilitarians neglect to consider the harm imposed on the minority. A deontological approach to ethics would argue that it is important to remember the humanity of the minority. Calvin Cook, a self-advocate for the community with disabilities, takes this approach in saying, "We are not expendable. We are people first." (ACL, 2021, np.) Therefore, a more balanced ethical framework that respects both the needs of the majority and the rights of the minority is essential to ensure equitable access for all individuals.

In designing more comfortable and inviting clinics, patients will be more relaxed and trusting, resulting in improved patient-healthcare provider relationships. This can be accomplished by first analyzing the current vaccination settings and then implementing changes when altering existing or developing new clinics. It is our duty as the majority to protect all populations, especially those who may not be able to advocate for themselves. While aimed to help those with disabilities, these improvements also have the potential to improve the experience for every patient regardless of ability.

Intersectionality

In 1989, Kimberle Crenshaw coined the term, "intersectionality". This is a framework for understanding how the various aspects of an individual's identity, including race, gender, social class, and lived experience interact to shape their experiences of privilege, oppression, or exclusion (Samie, n.d., np.). Intersectionality is also a methodical tool for research, which allows for exploration into how existing systems in our culture combine and contribute to an individual's circumstance (Carrigan et al., 2023, pp. 12-13). In this framework, a person can have many social identities that affect how they navigate life. For the purpose of this paper, social identity will be defined as a group membership recognized by a person and perceived by others as such (Britton, 2008, pp. 107-121). Some social identities are known to advance life, while others can hinder one's success. In separately analyzing how each social identity contributes to one's oppression or privilege, it becomes clear how each social identity intersects with each other to sum to the lived experience of the person as a whole. When analyzing the accessibility of vaccines to people with disabilities, there are many social identities to explore. I have chosen to research how socioeconomic status (SES) and race play a role in accessibility to COVID-19 vaccinations for populations with disabilities.

Socioeconomic status can be determined by many factors that reflect their social and economic position within society, including income, education, occupation, wealth, living conditions, social class, family and social networks, geographic location, cultural capital, and access to resources and opportunities (APA, 2023, np.). In 2018, it was found that people with disabilities face poverty at rates that are more than double that of people without disabilities, at 29% (Guhlincozzi & Lotfata, 2021, p. 860). Data from the American Association of People with Disabilities supports the claim that two-thirds of individuals with disabilities seek work opportunities but are unable to find adequate employment, resulting in Americans with disabilities earning $10,000 less on average than their peers without disabilities (Fletcher, 2023, np.). Unfortunately, it is apparent that Americans with disabilities have lower SES than an average American.

An individual's SES can make it more difficult to have access to vaccines because of cost, geographic barriers, and reduced health literacy. In the United States, there are many options for private and public health insurance plans. Individuals with disabilities or lower income may qualify for programs such as Medicare and Medicaid, aimed to grant broader access to health insurance. Of the insured people with disabilities, 44% have private health insurance and 89% are covered by public health insurance, with some individuals having both private and public insurance (Guhlincozzi & Lotfata, 2021, p. 860). However, in 2024, there are still 2.3 million Americans with disabilities who are not insured. This is 5.6% of all Americans with disabilities (Hurst, 2024, np.). In the absence of health insurance, medical care can be extremely expensive. This can deter uninsured individuals from seeking the medical help that they need. During the COVID-19 pandemic, there were some federal programs in place to widely reduce the cost of the COVID-19 vaccine, even for uninsured individuals. For example, up until March 2022, the Department of Human and Health Services (HRSA) reimbursed clinics for testing, treating, and administering COVID-19 vaccines to uninsured individuals (HRSA, 2024, np.).

While the vaccine itself was not costly, there are other factors to take into account when determining the price of the vaccine. Some of these factors include the cost of transportation, time off work, and child care if needed. Furthermore, some individuals with disabilities would need to be assisted by an aide or interpreter at the vaccine clinic. These aides and interpreters can also be costly, with the average cost of an aide being 27 dollars per hour (Ultimate Care, 2025, np.). Any one of these costs may seem negligible in isolation, but for people with lower SES, these combined costs can be burdensome. Notably, 6.3% of low-income individuals live in rural areas (LSC, 2024, np.). This may seem low but is proportionally high, as only 20% of the entire American population live in rural areas (Pipa, 2024, np.). During the pandemic, it was found that 45.8% of people with disabilities lived greater than 1 mile away from a vaccination site, with rural Americans living an average of more than 10 miles from the nearest hospital (Jimenez, 2021, np.). Longer distances to vaccination sites, further the barrier for vaccination access. This impacts rural areas more, because the travel distances to the vaccines are longer in rural areas.

Furthermore, in areas with lower mean SES, there is a history of medical care hesitancy or resistance. Unfortunately, there can be a stigma around seeking medical attention (Stroud,

2023, np.). While untrue, it can be perceived as a weakness in some communities. This fear of judgement from others could prevent individuals from getting vaccinated. It is believed that this stigma could be rooted in decreased health literacy in these areas. Health literacy is, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." (Berkman et al., 2010, p. 13). In areas of low SES, health literacy could be lower for a range of reasons. First, people with lower SES tend to have less access to quality education. Traditionally, school systems in low-SES areas are found to be under-resourced (APA, n.d., np.). This can lead to poor cognitive development, language, and memory, which would make reading and understanding health care service information challenging. Additionally, low-SES individuals may not have full access to helpful resources where health information is shared, including online internet resources and books. In 2021, it was found that 40% of adults with lower incomes do not have home internet access (Vogels, 2021, np.). This can largely limit access to health care information, especially new advancements such as the COVID-19 vaccine. Finally, individuals with lower SES face more stress related to housing insecurity and financial instability (APA, 2018, np.). While facing significant life challenges or potentially juggling multiple jobs, they may have less energy or time to expend on processing complex health information. It is apparent that the lower SES of people with disabilities can greatly impact their access to vaccines due to increased financial burden, geographic barriers, and limited health literacy. Next we will determine how this social identity combined with different ethnicities can compound this accessibility problem.

Another important aspect of one's identity is their race. For the purpose of this paper, race can be defined as a social construct used to categorize people based on biological characteristics, including skin color, facial features, and hair texture (Takezawa, 2025, np.). While people of different races should experience the same standard of care and accessibility in the health care system, it has been proven that minorities often face obstacles in the healthcare system. It has also been reported by the CDC that prevalence of disabilities impact different racial groups at varying rates. For example, disabilities occur in 30% of American Indian Natives , 25% of African Americans, 20% of Caucasians, 17% of Hispanics, and 10% of Asians (CDC, 2024b, np). This is important to note as African Americans and Hispanics tend to face the most obstacles in the healthcare system. It was also found that COVID-related hospitalization rates for African American and Indigenous people were five times that of non-Hispanic Caucasians (NDI, 2020, pp. 1-11). This is attributed to the lower vaccination rates of these racial groups.

People with disabilities are also impacted by the racial identity of their caregivers. One report stated that, "Black and Hispanic direct service providers (DSPs) are more hesitant to receive a COVID-19 vaccine than White DSPs" (Lisa Wiggens et al., 2022, pp. 186-187). If a caregiver is not supporting vaccinations, it could lead to lower vaccination rates of the people for which they care for. This is mirrored in the statistic that the lowest increase in overall vaccination rates throughout the pandemic occurred in adults with disabilities that identified as Black, Non-Hispanic with a rate of 2.1% (Castro et al., 2023, pp. 3-5). This is contrasted with the increase in vaccination rates of 18% that occurred in adults with disabilities that identified as

Asian (Castro et al., 2023, pp. 3-5). This is not a surprising statistic because there has been a history of misuse of African American populations in healthcare, especially with the experimentation of new medical technologies, which the COVID-19 vaccination could be classified as. This is a logical reason that these populations may be more hesitant to receive the latest vaccination, and it is important to consider this when rolling out and advertising new treatments.

Having a disability is one identity that often adds to an individual's exclusion. However, when this is coupled with other identities that also are often mistreated in the healthcare world, it can have detrimental effects on that individual's experience. Each aspect of one's identity influences how they experience the world and interact with social systems, making their experience of exclusion different from individuals who only face one or none of these forms of marginalization. These overlapping identities of disability, race, and socioeconomic status create unique and compounded layers of exclusion that cannot be completely understood if looked at in isolation. It is critical to understand this intersectionality. If neglected, policies that address only one aspect of someone's identity may be created. For example, a policy that offers disability services may not account for how this affects individuals with disability that also have a low SES or belong to a marginalized race. These policies would limit access to certain groups of individuals who may not be able to improve their circumstance on their own. In fact, 47% of individuals with disabilities spend more than 30% of their income on housing costs, which is significantly higher than the 38% of people without disabilities (NDI, 2020, np.). This limits the amount of money they could use for programs that could improve access to vaccinations, including insurance and ride or aide services.

Just as important to creating inclusive policies, we must work to increase awareness of these issues. Because individuals with disabilities make up a minority of the population, many people who are not directly affected by disabilities may not be aware that these limitations exist. Even if they realize the limitations of racial or SES groups, they would not understand that those issues perpetuate barriers for individuals with disabilities. In order to ignite widespread change, social movements and advocacy efforts must demand inclusive policy and cultural acceptance. It is not enough to change policy without trying to remove the stigma around people with disabilities. These individuals deserve the same level of respect as those without disabilities, and we must bring more attention to these social injustices. We must stand in solidarity with this population to increase accessibility to vaccinations for the people who need it the most.

Conclusion:

While people with disabilities are more likely to have pre-existing conditions that make contracting COVID riskier, they were not prioritized enough during the COVID vaccination roll out. It is crucial that people who are most at risk are prioritized regardless of their ability. While policymakers need to study the shortcomings of the current built environment of vaccination centers and the intersectional identities that add to the overall exclusion individuals with disabilities face, the general public must also be educated on these disparities. This will hopefully lead to increased access to vaccinations and possibly other healthcare resources. Even

if it means extra steps or work, we as a society and country can not neglect those who need help most. We must continue to ask ourselves, are people with disabilities still being overlooked by the healthcare system? How can we make the world more inclusive? How can healthcare become more ethical?

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