COVID-19 HEALTH CARE BARRIERS AMONG PEOPLE WITH DISABILITIES

A Report to the Public
from the COVID-19 Health Disparities
Statewide Leadership Task Force
August 2022

PROJECT BACKGROUND

The COVID-19 pandemic has been difficult on everyone, but for some groups, including and especially the disability community, its impact has been staggering. This is even more the case for those in the disability community who live in rural areas and those belonging to racial and ethnic minorities.

The Arc of Pennsylvania received funding to investigate, educate, and report on problems that people with disabilities in Pennsylvania have accessing appropriate information and help during the COVID-19 pandemic.

Some issues people with disabilities face include:
- Barriers to accessible information (braille, plain language, multicultural, etc.),
- Reduced access to testing, vaccinations, and necessary accommodations
- Increased risk of severe illness or death due to COVID-19.

PROJECT OVERVIEW

Our project brings together disability and health care stakeholders to listen, talk, and learn about COVID-19 disparities in the disability community. We will assure that people with lived experience of disability have their voices heard as we establish state and regional partnerships. These partnerships will align public health, health care, disability, and non-health interventions on behalf of the disability community across diverse racial, ethnic, and geographic populations.

EXECUTIVE SUMMARY

With a grant from the PA Department of Health through the CDC's National Initiative to Address COVID-19 Health Disparities Among Populations at High-Risk and Underserved, The Arc of Pennsylvania is working to answer the following questions:

- To what extent have we used a disability-inclusive approach to combat COVID-19?
- To what extent will we use a disability-inclusive approach to prepare for future emergencies?

A disability inclusive approach means that the interests of people with disabilities were included every step along the way.

Through interviews, surveys, and meetings we collected responses and organized them into a list of barriers. We think of barriers as obstacles that make it more difficult for certain individuals to access and benefit from health care services.

We organized the information by what the federal government calls "Social Determinants of Health." Social Determinates of Health are how conditions like where people are born, grow, live, work, and get older affect someone's health.

Previous research shows that people with disabilities tend to have worsened health outcomes due to health care barriers. The figure on the next page shows our findings in terms of COVID-19 health care barriers for people with disabilities.

COVID-19 Health Care Barriers for People with Disabilities

HEALTH CARE ACCESS AND QUALITY	NEIGHBORHOOD AND BUILT ENVIRONMENT	SOCIAL AND COMMUNITY CONTEXT	ECONOMIC STABILITY	EDUCATION ACCESS AND QUALITY
Systemic • Health care system **Mental Health and Physical Health** • Mental health impacts • Trauma • Physical activity • Nutrition • Pre-existing conditions **Vaccinations and Testing** • Rollout and scheduling • Accessibility • Attitudes **Staffing** • Staff training and quality • Staff vacancies and retention **Technology** • Telehealth	**Local Conditions** • Local government • Rural areas • Local organizations • Family support **Transportation** • Public transportation • Accessible transportation **Accessibility** • Physical access • Plain language	**Information** • Misinformation • Changing information **Cultural, Linguistic** • Racial/ethnic • Discrimination • Language and cultural diversity	**Financial Security** • Employment • Income • Food security **Social Supports** • Funding • Direct support professional (DSP) wages	**Systemic** • Education system **Technology** • Access to devices • Internet access • Knowledge and ability to use Zoom

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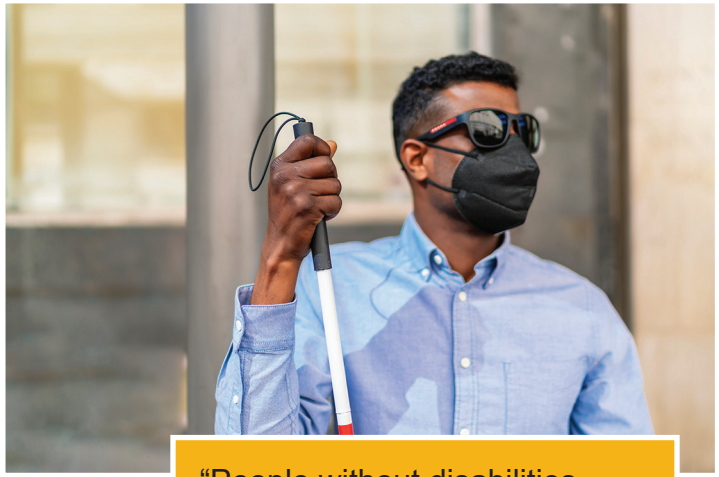
"People without disabilities were struggling but they had options and people with disabilities didn't have those same options and access to accurate information. We didn't get it."

"Vaccinations are less accessible for those with mobility issues/homebound."

INTRODUCTION

"COVID-19 Health Disparities among People with Disabilities" is the name of an important Arc of Pennsylvania project. In this project we ask these questions:

- In what ways are we using a disability-inclusive approach to combat COVID-19?

- In what ways will we use a disability-inclusive approach to prepare for future emergencies?

A disability-inclusive approach means that the interests and ideas of people with disabilities are included every step along the way. We received funds from the Pennsylvania Department of Health for the project. Our project started by learning about COVID-19 health care problems felt by people with all types of disabilities. In that group were people with different racial or ethnic backgrounds and people from rural areas. We studied what others have learned on this topic through a literature review. Then, we surveyed and talked with Pennsylvanians, including people with different racial or ethnic backgrounds and people from rural areas.

This report shares what we learned so far. We organized the information by what the U.S. Department of Health and Human Services calls "Social Determinants of Health." Social Determinants of Health are the conditions where people live, learn, and work that affect their health and quality of life.
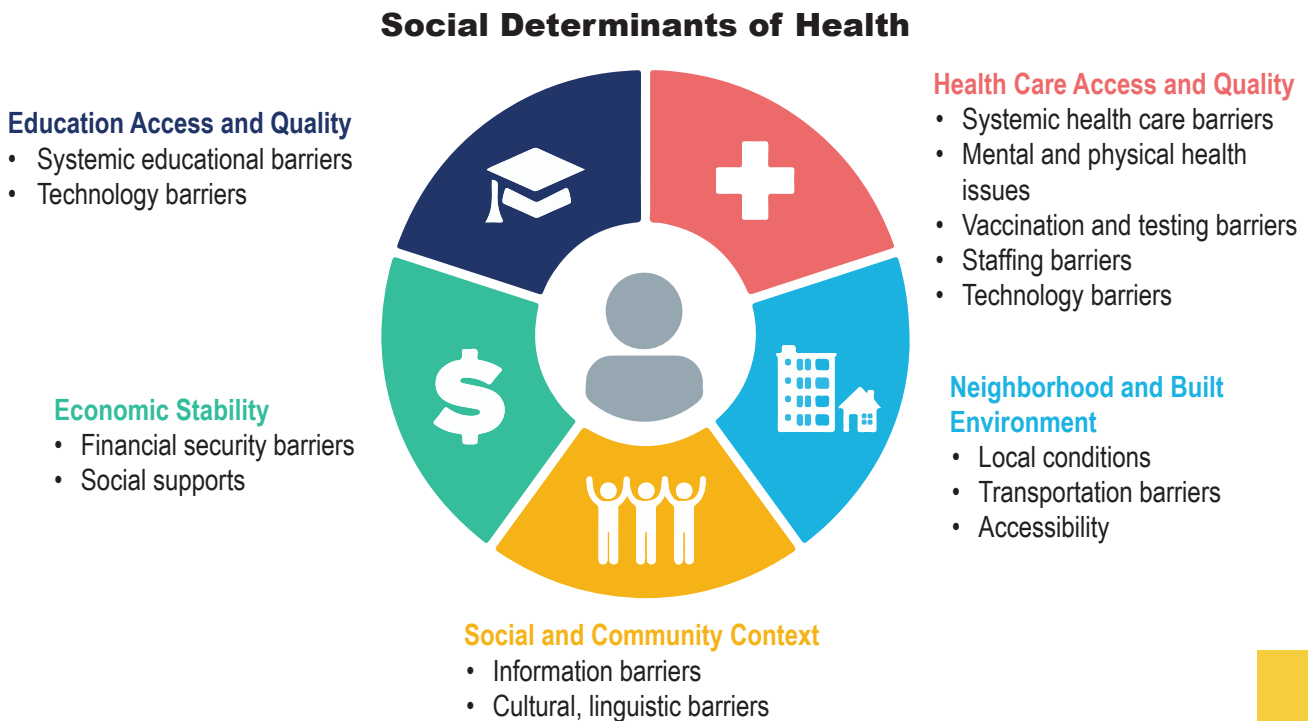
Figure 1. COVID-19 health care barriers for people with disabilities by Social Determinants of Health

Social Determinants of Health

Education Access and Quality
- Systemic educational barriers
- Technology barriers

Health Care Access and Quality
- Systemic health care barriers
- Mental and physical health issues
- Vaccination and testing barriers
- Staffing barriers
- Technology barriers

Economic Stability
- Financial security barriers
- Social supports

Neighborhood and Built Environment
- Local conditions
- Transportation barriers
- Accessibility

Social and Community Context
- Information barriers
- Cultural, linguistic barriers

OUR APPROACH AND SAMPLE

OUR APPROACH

We collected stories and experiences from people through an online survey, in meetings, and in interviews. In all methods we asked the same two questions:

- *"What in your area has made it easy for people with disabilities to stay healthy during the COVID-19 pandemic?"*

- *"What challenges in your area have made it difficult?"*

In the meetings, that we called "Listening Tours," people had a chance to talk with others about their answers. The Arc of Pennsylvania and regional Arc chapters held the meetings.

We examined all the information received and organized it by the patterns we saw. We checked to make sure that those reading the information and identifying patterns agreed with each other, to a large degree.
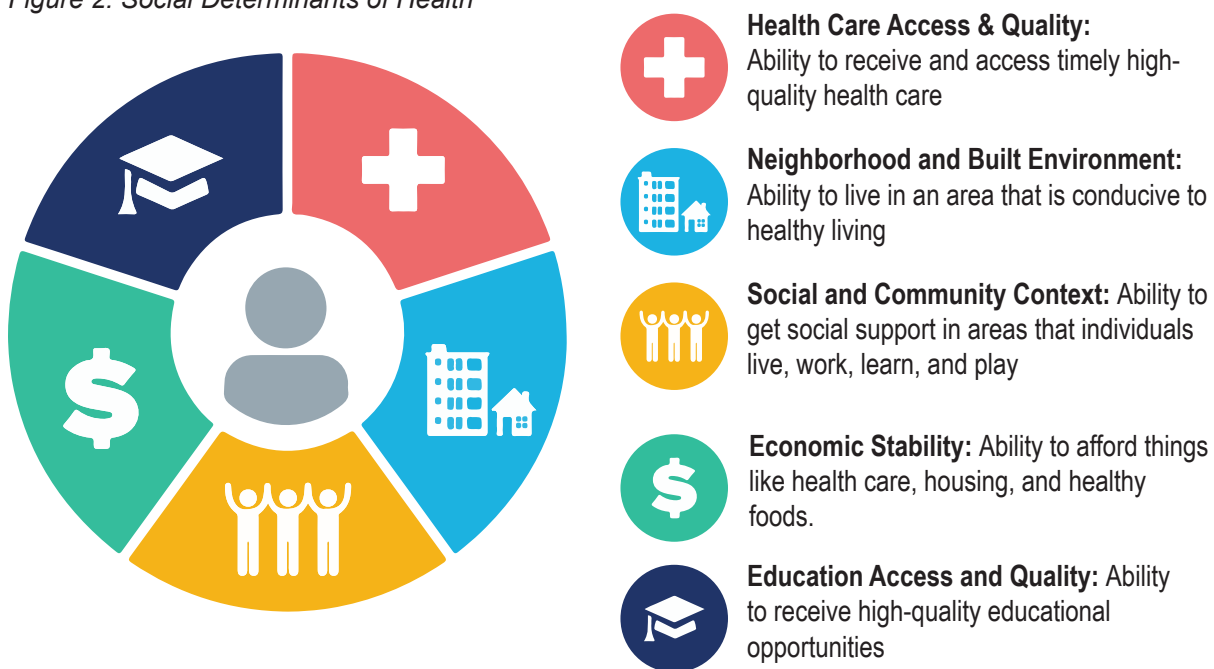
SAMPLE

We had 393 people who responded to surveys; attended a "listening tour" meeting; or were interviewed individually. They represented 33 counties of Pennsylvania. In this report we call the people we sampled - "participants."

Participants included people with disabilities, caretakers and family members, and professionals who work with people who have disabilities. Many different types of disabilities were represented in the participants. Also, we reached out to all groups of people in Pennsylvania, including those thought of as "underrepresented" groups and minorities. For example, the participants included people from Hispanic, Asian American, African American/Black, Indigenous, and LGBTQIA+ communities. We also recruited participants from several of the most rural counties of Pennsylvania and the most urban areas.[1]

HEALTH CARE BARRIERS FOR PEOPLE WITH DISABILITIES BY SOCIAL DETERMINANTS OF HEALTH FRAMEWORK

As explained earlier, we organized information by the "Social Determinants of Health." Social Determinates of Health are how conditions like where people are born, grow, live, work and get older affect someone's health and quality of life.[2] Below is Figure 2. Social Determinants of Health.

Figure 2. Social Determinants of Health

Health Care Access & Quality: Ability to receive and access timely high-quality health care

Neighborhood and Built Environment: Ability to live in an area that is conducive to healthy living

Social and Community Context: Ability to get social support in areas that individuals live, work, learn, and play

Economic Stability: Ability to afford things like health care, housing, and healthy foods.

Education Access and Quality: Ability to receive high-quality educational opportunities

These conditions – where people are born, grow, live, work, and get older - are influenced by money, power, and resources. These factors are responsible for health inequities. Health inequities are unfair and avoidable health differences. Inequities are connected to social, economic, and/or environmental disadvantages. For example, people with disabilities have lower rates of employment, education, and income than people without disabilities.[3]

A health care barrier is a challenge that makes it harder for some people to access and benefit from health care services. Even before the COVID-19 pandemic, people with disabilities experienced many health care barriers. For example, in 2019

because of cost, about 27 percent of people with disabilities were not able to access health care compared to about 10 percent of people without a disability.[4] Before the pandemic, documented barriers to the inclusion and integration of people with disabilities included attitudes (ableism, discrimination), accessibility (communication and physical mobility obstacles), policy, transportation, and programmatic (including lack of appropriate health care provider training).[5]

There are ableism and attitude barriers even in health care settings and doctors' perceptions. Ableism is discrimination and social prejudice against people with disabilities based on the belief that it is better to have typical abilities. Biases on the part of doctors might add to health care disparities. A report that looked at doctors' attitudes about people with disabilities found that 82 percent of U.S. doctors thought that people with disabilities have a worse quality of life than people without disabilities.[6] The same report said only 56 percent of doctors strongly agreed that they welcomed people with disabilities into their medical practices.[7]

For a long time, people with disabilities have experienced inequality in health care outcomes. For example, even before the COVID-19 pandemic, people with disabilities had much worse health when compared to those without disabilities when it comes to diabetes, stroke, chronic obstructive pulmonary disorder (COPD), cancer, and depression.[8]

One of the biggest examples of how COVID-19 unequally affected people with disabilities was a study by Jefferson Health in Philadelphia, Pennsylvania. Their study reported the devastating impact of COVID-19 on people with intellectual disabilities in the United States. People with intellectual disabilities were six times more likely to die from COVID-19 than other people. The study found that other than a person's age, having an intellectual disability put people at most risk of getting COVID-19 and dying of COVID-19.[9]

WHAT DID WE LEARN?

The figure below organizes the information we learned through our surveys, meetings, and interviews about COVID-19 health care barriers.

Figure 3. COVID-19 health care barriers for people with disabilities (barrier themes and sub-categories)

HEALTH CARE ACCESS AND QUALITY	NEIGHBORHOOD AND BUILT ENVIRONMENT	SOCIAL AND COMMUNITY CONTEXT	ECONOMIC STABILITY	EDUCATION ACCESS AND QUALITY
Systemic • Health care system **Mental Health and Physical Health** • Mental health impacts • Trauma • Physical activity • Nutrition • Pre-existing conditions **Vaccinations and Testing** • Rollout and scheduling • Accessibility • Attitudes **Staffing** • Staff training and quality • Staff vacancies and retention **Technology** • Telehealth	**Local Conditions** • Local government • Rural areas • Local organizations • Family support **Transportation** • Public transportation • Accessible transportation **Accessibility** • Physical access • Plain language	**Information** • Misinformation • Changing information **Cultural, Linguistic** • Racial/ethnic • Discrimination • Language and cultural diversity	**Financial Security** • Employment • Income • Food security **Social Supports** • Funding • Direct support professional (DSP) wages	**Systemic** • Education system **Technology** • Access to devices • Internet access • Knowledge and ability to use Zoom

GREATEST STRENGTHS

To understand what went well during COVID-19 for people with disabilities, we asked, "What in your area has made it easy for people with disabilities to stay healthy during the COVID-19 pandemic?" Responses fell in the areas of: Technology, Systemic, Mental and Physical Health, Vaccinations, Staffing, Local Conditions, Transportation, Accessibility, Communication, Cultural/Linguistic, and Economic. Participants identified four strengths as most important: Vaccination, Local Conditions, Communication, and Technology.

Vaccination and Testing Strengths	
Flexibility	Mobile vaccine clinics and home vaccine visits made it easier to get vaccinated. Some drive-through testing sites were especially disability friendly. These sites addressed physical accessibility barriers, masking requirements, sensory, behavioral, and anxiety challenges.
	One person shared, "I liked that they went to the neighborhoods, and the city had it so you could call and get a ride to a vaccination."

Local Conditions Strengths	
Partnerships	Community organizations came together to make sure that members were cared for. They made partnerships for the greater good of the community.
	A quote that captures this says, "Formed partnerships—small agencies helping each other and in so doing helping the community."
Environment	Some people with disabilities live in locations that help promote healthy habits.
	One participant stated that a strength in their area was, "The parks and natural outdoor activities—we knew the ropes, how to access, where to go; we already biked and kayaked—people got more familiar with the resources that were always there."

Communication Strengths	
Information	Throughout the pandemic, information changed over and over. Some participants felt like local and state organizations shared new information quickly. They kept people "in the loop" on ways to stay healthy and safe.
	One participant stated that, "Information available on steps to stay healthy (washing hands, mask wearing, etc.) was helpful."

Technology Strengths	
Telehealth	People with disabilities relied a lot on telehealth and teletherapy services.
	One participant stated that, "Telehealth worked as folks didn't need to worry about the long travel to get to appointments; and found they could attend more health appointments."
Online Meeting Tools	Online meeting tools (like Zoom) were very important in helping people with disabilities stay connected. Local organizations held online meetings. Members could connect and get social support.
	As one participant explained "I felt connected to humans, I can't imagine if I didn't have that because I did not see anyone for a year!"

GREATEST BARRIERS

Our Regional Community Work Groups and Statewide Leadership Task Force identified four barriers as most important for creating solutions for the Pennsylvania Department of Health. In ranked order, the greatest COVID-19 health care barriers for people with disabilities were Systemic Health Care, Mental and Physical Health, Staffing, and Accessibility. More detail is given in the section on Health Care Barriers for People with Disabilities.

Some barriers were also named as strengths. For example, telehealth was a strength to people who had high-quality, timely supports. But it was identified as a barrier for others. Some people that had trouble with telehealth were people with sensory or intellectual disabilities; those with internet challenges; and people needing interpretation or translation help.

HEALTH CARE BARRIERS SELDOM STAND ALONE

Health care barriers don't usually happen alone. Barriers complicate and relate to each other.

> **People with disabilities said that their families rely more on systems for service, care, support, and information than the natural community support that other people rely on. Many people said that unequal access to health care and system services during COVID-19 made their issues worse. For example, their health conditions became even worse. Unequal access to health care and support damaged the quality of life for the whole family.**

For example, a lack of school therapies or medical services caused a need for surgeries or more complicated medical help. Participants said they lost communication skills and a variety of daily living skills. They also reported more behavior problems and mental health crises. People had less ability to be in their community to access health and education services. Most felt the "return to normal" was further out of reach than before the pandemic.

One parent of a child with Intellectual Developmental Disabilities/Autism Spectrum Disorder (IDD/ASD); complex behavioral and medical needs said, "Once you set that behavior, you're not going to unset that behavior without intensive service."

Also, online learning and the lack of school helpers put families of children with disabilities in an overwhelmed position. This included families of adult-age children. A child's education, medical, and therapy needs affected parents' ability to work. Not all the parents' employers were flexible.

Participants felt that decision-makers didn't understand how policies affected people with disabilities. They also felt decision-makers didn't understand the impact of pandemic policies on participants' families.

Participants said that systems did not have a strong enough safety net. For example, COVID-19 safety needs for the public required gloves, masks, and medical equipment. That new need, because of the pandemic, got in the way of the existing, everyday need that people with disabilities already had for those materials. Not having access to gloves, masks, and special medical equipment put children with complex medical needs at great risk. The risk they faced was much greater than that of people without such complex medical needs.

HEALTH CARE BARRIERS FOR PEOPLE WITH DISABILITIES

In this section, we further explain the COVID-19 health care barriers for people with disabilities learned through our surveys, meetings, and interviews. We include examples of participant statements and findings from our literature review. The figure below organizes the information we learned.

Health Care Access and Quality Barriers for People with Disabilities

Systemic Barriers for People with Disabilities	
Health Care System	Health care barriers affect people with disabilities in a unique way. Research says that only about 57 percent of health care providers feel their practices welcome people with disabilities.[10] There is a lack of education in medical schools about how to treat people with disabilities. This leads to worry and confusion for patients and providers. Our participants reported similar experiences. "The medical community doesn't know how to work with people with disabilities."
Mental Health Impacts	The mental health of people with disabilities was negatively affected by COVID-19. One study found that over 90 percent of children and young adults with disabilities reported a negative impact. These effects included worse behavior, mood, and fitness. Also, the impacts included social and learning setbacks.[11] Our participants also felt these effects. Most said that isolation led to increased feelings of depression and fear. One participant said, "This whole thing made it difficult for persons with disabilities to be self-sufficient; it's like climbing a ladder, the further up you go, away from the familiar, the scarier it is and the more alone you feel." This quote captures how lonely this community felt during these times."

Mental Health and Physical Health Barriers for People with Disabilities	
Trauma	Real-life experiences during the pandemic caused many feelings of fear. These experiences left people with new and developing trauma. Deaths of family members and loved ones and dealing with grief added to trauma. People also were uneasy about political unrest and riots over societal issues. One participant stated, "I have children I know who lost every adult in their family; just lost every adult in a few weeks. No one is talking about that level of trauma."
Physical Activity	People with disabilities reported negative impacts from less physical activity during COVID-19. Programs and gyms closed. People had to quarantine. Each issue contributed to reduced physical activity.[12]
Nutrition	Access to healthy foods was a barrier that many people across the state experienced. Research shows that people with disabilities have a greater risk of food insecurity than those without disabilities. During COVID-19, it was even harder for people to access food. There was fear of catching the virus at stores, high food delivery prices, and lack of transportation.
Pre-Existing Conditions	Studies show that people with IDD have higher rates of "comorbidities." Comorbidities are two or more health problems happening at the same time. Having more health problems meant worse health outcomes from COVID-19.[13] One participant said that they were, "afraid to go anywhere because of an immunosuppressant medication."

Barriers to Vaccination and Testing for People with Disabilities	
Rollout and Scheduling	The release of vaccines created new challenges for people with disabilities. Some participants felt that people with disabilities got left behind in the process. Knowing how to schedule a vaccine appointment was very hard.
Attitudes	Misinformation about COVID-19 vaccinations was harmful. This was especially true for those with disabilities who need staff in their homes. Sometimes unvaccinated staff would not say if they were or weren't vaccinated, yet still entered homes. One participant said that his DSP knowingly came into the home after an exposure. The DSP spread the virus to the individual, leading to his hospitalization.
Accessibility	Vaccination sites were an accessibility barrier. One participant said that "Vaccinations are less accessible for those with mobility issues/homebound."

Staffing Barriers for People with Disabilities	
Staff Training and Quality	Because of the shortage of Direct Support Professionals, staff training happened more quickly. Some participants felt as though the quality of staff was not up to par. One person felt that, "Because of the direct support professional shortage, employers would hire anybody, even if they weren't qualified."
Staff Vacancies and Retention	Many staff quit during the pandemic. When support staff began quitting it raised a specific issue for people with disabilities. Many agencies said that staff was leaving for better-paying jobs, which ties back to the lack of funding for DSPs and other support services. One participant said, "I don't have family supporting me and there was no one coming to help me. Ninety percent of the support is paid to be there and that was hard."

Technology Barriers for People with Disabilities	
Telehealth	Increased telemedicine is a product of the pandemic but is not always accessible for people with disabilities. There are unique challenges for them. For example, communication can be a problem. Taking part in a physical assessment through telemedicine can be a problem. Types of accommodations needed adjusting so that telemedicine could be more accessible.[14]
	Many participants felt that online health services needed more adjustments. One person felt that, "Physical and occupational therapy services are not as effective online as they are in person."

Neighborhood and Built Environment Barriers for People with Disabilities

Local Conditions Impacting People with Disabilities	
Local Government	Some participants felt that local officials lacked awareness of the barriers and difficulties that people with disabilities faced during the pandemic.
	A participant also felt as though, "Local government made no effort to connect with community trust points such as churches, food banks, service providers."
Rural Areas	Rural communities face unique barriers to health care including the low number of health care providers. One study found that, "Individuals living in rural areas were 24 percent to 33 percent more likely to delay or forgo needed medical care due to cost than those in urban areas."[15]
	Our participants agreed, stating one barrier as, "Lack of medical care services in rural areas."

Local Conditions Impacting People with Disabilities (cont.)	
Local Organizations	Temporary shutdowns of local organizations were hard for people with disabilities who rely on those services. Organizations like food banks and nonprofits are crucial parts of a community. The closures affected people with disabilities.
Family Support	Quarantine and isolation meant few family visits when individuals with disabilities lived in a group home. This area includes support for family members. There was no respite for families. One family member remembered feeling like she had to be a teacher, caregiver, nurse, and mother all at once, with no outside support.

Transportation Barriers for People with Disabilities	
Public Transportation	Many participants, often from rural areas, reported a lack of public transportation. Also, people across the state feared catching the virus on public transit. Lack of public transportation can impact health. Research shows that having public transportation can improve health. It allows people to travel to healthy grocery stores and medical facilities.[16]
Accessible Transportation	Often, when there was public transit available, it was not accessible for people with disabilities. A participant with lived experience said, "Boarding in the middle part of the bus was not accessible to those with disabilities."

Accessibility Barriers for People with Disabilities	
Physical Access	Testing sites, vaccine sites, and health care facilities are not always accessible. This creates barriers for people with disabilities. Some said that drive-thru testing was not accessible or accommodating. In some cases, buildings, where vaccines were being given, did not have accessible ramps.
Plain Language	Throughout public information sharing about COVID-19, a lack of plain language was notable. Prepared information was not easily understood by all people. This created more confusion and worry. One participant said, "Information was never presented in a way that made sense to ALL persons, i.e., plain language."

Social and Community Context Barriers for People with Disabilities

Information Barriers for People with Disabilities	
Misinformation	Participants found that information was confusing during the pandemic. There was a lot of inaccurate information. Often this was from social media. For example, it wasn't easy to know when to wear a mask or knowing when someone should quarantine. One concerned participant said, "The media often dropped the ball with spreading correct information."
Changing Information	Many participants said the constantly changing information about the pandemic was confusing. It made them more anxious. Guidelines and rules from federal, state, and local government changed daily.

Cultural/Linguistic Barriers for People with Disabilities Who are Also a Part of a Minority Population	
Racial/Ethnic	Racial and ethnic minority groups experience health disparities. The disparities compound when the person also has a disability. If you were black or a member of an ethnic minority your health outcomes for COVID-19 were worse. People in these groups had higher hospitalization and death rates.[17] Participants also saw these effects citing, "a lack of focus on racial disparities and other disproportionately affected communities."
Discrimination	Discrimination occurs in minority populations even when there isn't a pandemic. But the pandemic made these experiences worse. One study found that a larger percentage of minority adults than white adults felt stress and worry that they would be discriminated against or blamed for spreading COVID-19.[18]
Language and Cultural Diversity	During the pandemic, there was a lack of interpreters. This made it hard for parents of children with disabilities and those with disabilities themselves. One participant said that, "translators are notorious for not translating medical and special education language accurately."

$ Economic Stability Barriers for People with Disabilities

Financial Security for People with Disabilities	
Employment	A barrier often mentioned by participants was the hardship felt by not having employment. In 2021, only 19 percent of persons with disabilities in the United States had jobs compared to almost 64 percent of people without disabilities. No matter the age or level of education, unemployment rates are much higher for people with disabilities than for those without a disability.[19] In the words of one participant, "Parents worried about losing their jobs and paying bills."
Income	People with disabilities and families told us how low income affected their housing and food security. They also reported low income harmed their physical and mental health. The Americans with Disabilities Act prohibits discrimination based on disability. The Act assures people with disabilities equal opportunity. But despite the protection of this law, a high number of people with disabilities are poor and undereducated.[20]
Food Security	The rising costs of food delivery services were a barrier named by many participants. People with disabilities and their families and caregivers wanted to be safe from COVID-19 by ordering groceries online. But the high fees were limiting.

Social Supports Barriers for People with Disabilities	
Funding	Lack of funding was another recurring topic. People with disabilities felt a great deal of isolation during the pandemic. A lack of funding for mental health services further worsened their situation.
Direct Support Professional (DSP) Wages	Participants worried about the ongoing direct support professional (DSP) crisis in Pennsylvania. Wages for DSPs are often too low. The low wages lead to problems hiring workers. One person said they were, "unable to hire staff due to only being able to offer low wages, especially compared to fast food and retail companies."

Education Access and Quality Barriers for People with Disabilities

Systemic Barriers for People with Disabilities	
Education System	Education systems in Pennsylvania created some barriers for people with disabilities during COVID-19. This was especially true when learning moved online. Virtual education was difficult for many children with disabilities. Before the pandemic, the children usually received extra services during the school day. Students lost services when schools closed, and learning moved online. Online education was not as effective. And less learning time led to many challenges for students with disabilities.[21]

Technology Barriers for People with Disabilities	
Access to Devices	Tools used for online education such as iPads and computers were not owned by or made available to all families. For many students, this caused them to miss out on essential class time and homework. One participant said, "I know there are a shockingly high number of kids who fell between the cracks and lost two years of learning."
Internet Access	Lack of reliable internet service, especially in rural areas, had an especially large effect during the pandemic. Many previously in-person services and activities moved online. Those without internet could not take part. It's estimated that 800,000 Pennsylvanians don't have access to high-speed internet. Of those, 520,000 people live in rural areas.[22] For school children, the lack of internet access kept them from attending their online classes.
Knowledge and Ability to Use Technology	The pandemic made many people rely more on the internet. People needed to use it for their work, socialization, education, and health care. For those people who didn't know how to use technology, especially older people, learning to use a computer was frustrating and hard. Also, people with disabilities may have lacked access to accessible technology.
Zoom	Zoom use was everywhere during COVID-19. Many participants said that online school and activities were not as effective on Zoom. For some students, this meant falling behind or receiving a substandard education. Making things worse, Zoom lacks accessibility features needed by people with disabilities.

Health Care System Barriers for People with Disabilities

Mental and Physical Health Barriers for People with Disabilities
- "This whole thing made it difficult for persons with disabilities to be self-sufficient; it's like climbing a ladder, the further up you go, away from the familiar, the scarier it is and the more alone you feel."
- "I have children I know who lost every adult in their family just in a few weeks. No one is talking about that level of trauma."
- "Not wanting to go out in public made getting food difficult."
- "You had to have a car to access the remaining open food banks because they became 'drive-through'."
- "Anxiety and depression and anger over the fear of the unknown concerning one's increased susceptibility to COVID due to existing disabilities."

Vaccination and Testing Barriers for People with Disabilities
- "People who had the most resources were able to do that [get vaccinated], but the ones that didn't, the have-nots . . . we just had to just wait, we'd wait and wait."
- "People with disabilities were the last for the vaccine and felt left behind."
- "Information on vaccine and booster was confusing, had to dig deep and click on multiple pages to get the answers sought."

Systemic Health Care Barriers for People with Disabilities
- "Assisted Living facility where I used to live being really short-staffed and the impact of that on my care; they even brought back an aide that had been fired due to poor performance because they were so short-staffed!"
- "Direct support professionals don't have a medical background and are not qualified to make the big health care decisions that are often put on them."
- "Had to juggle a lot to make up for staff shortage."
- "We are already people with complex care needs, to get even fewer medical supports that was really, really hard."
- "Politicians aren't focusing on what's actually important to citizens."
- "People are lacking patience now and don't care about ways to make everyone safe."

Neighborhood and Physical Environment Barriers for People with Disabilities

Transportation Barriers for People with Disabilities
- "Transportation is always a barrier here [rural], pandemic or not. This spills over to access to vaccines, testing, appointments, etc."
- "Scared to ride public transportation due to risk of getting virus."

Accessibility Barriers for People with Disabilities
- "Really need to up our efforts around accessibility - for example building and creating more accessible walking trails and parks."

Social and Community Context Barriers for People with Disabilities

- "Translators are notorious for not translating medical and special education language accurately."
- "People without disabilities were struggling but they had options and people with disabilities didn't have those same options and access to accurate information, we didn't get it."

Economic Stability Barriers for People with Disabilities

- "Parents worried about losing their jobs and paying bills."
- "Unable to hire staff due to only being able to offer low wages, especially compared to fast food and retail companies."

Education Barriers for People with Disabilities

- "Certainly, access to education is a primary concern which affects those with disabilities exponentially. When a child has a vision or hearing impairment, it is nearly impossible to get the appropriate education via Zoom and asynchronous activities."
- "[My daughter] lost access to her educational paraprofessional but was required to do asynchronous learning activities, which by definition, as a child requiring a 1:1 paraprofessional, she could not do. The lags that she faced due to lapse in appropriate education will take a long time to overcome."
- "Many group homes only had one computer and that had to be shared with staff."
- "Virtual education did not work for a lot of families and the school seemed both not to understand nor to care."

NEXT STEPS

We now have a deeper understanding of COVID-19 health care barriers for Pennsylvanians with disabilities. Next, our project will focus on recommendations for the Department of Health to address health disparities.

Our project is part of the Pennsylvania Office of Health Equity's 2022 focus on disability equity. It is an opportunity for learning, connecting, and joint action. The end result is to increase health equity for this important part of our community.

END NOTES

[1] SemiColonWeb. (n.d.). Rural urban definitions. Rural Urban Definitions - Center for Rural PA. Retrieved May 11, 2022, from https://www.rural.pa.gov/data/rural-urban-definitions (Accessed May 11, 2022).

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HUNE Self Advocate

"We are already people with complex care needs...to get even fewer medical supports, that was really, really hard."

- Individual with complex medical needs