COVID-19 HEALTH CARE BARRIERS AMONG PEOPLE WITH DISABILITIES

A Report of the COVID-19 Health Disparities
Statewide Leadership Task Force
August 2022

The Arc™
Pennsylvania

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

"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."
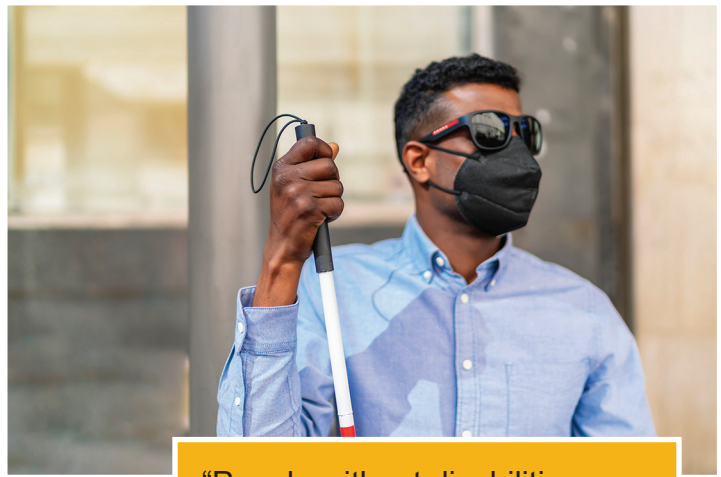
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"I don't have family supporting me and there was no one coming to help me. Ninety percent of the support was paid to be there and that was hard."

"Anxiety and depression and anger over the fear of the unknown concerning one's own increased susceptibility to COVID due to existing disabilities."

"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

The Arc of Pennsylvania's *Initiative to Address COVID-19 Health Disparities Among People with Disabilities* is actively exploring two questions:

1. To what extent have we used a disability-inclusive approach to combat COVID-19?

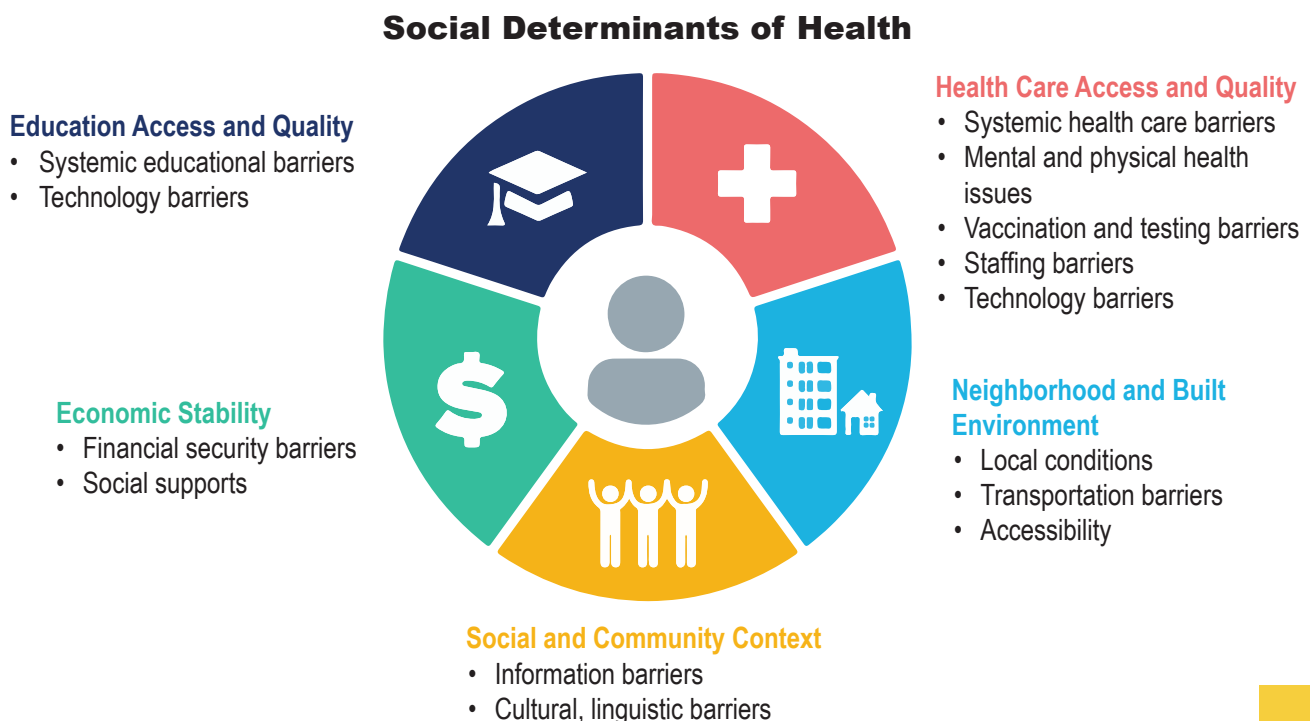2. To what extent will we use a disability-inclusive approach to prepare for future emergencies?

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

Funded by the Pennsylvania Department of Health, the initiative is convening health care and disability stakeholders from all over the Commonwealth to explore these questions. Our first phase of work has been to understand COVID-19 health care barriers experienced by Pennsylvanians with all types of disabilities including those from diverse racial, ethnic, and rural populations.

Based on literature review, surveys, and listening tours, this document highlights our preliminary findings displayed in Figure 1 by Social Determinants of Health (SDOH) from the Healthy People 2030 under the U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (ODPHP).

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

Economic Stability
- Financial security barriers
- Social supports

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

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

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

METHODOLOGY AND SAMPLE

METHODOLOGY

Qualitative data was collected from participants via an online survey, listening tours, and interviews. All methods 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 for people with disabilities to stay healthy during COVID-19?"*

The listening tours functioned as focus groups, where participants had the opportunity to discuss their answers. Listening tours were conducted by The Arc of Pennsylvania as well as by regional Arc chapters.

Data was analyzed using thematic analysis methodology – reading all responses, identifying patterns (themes/ codes and sub-categories), and checking inter-rater reliability.

SAMPLE

Throughout this report we use the phrase "participants from listening tour" or "participants" to refer to respondents from surveys, regional and local listening sessions, and interviews.

The sample consists of at least 393 respondents (n = 393) including survey respondents (n = 67) as well as participants from 17 regional listening tour conversations from 33 counties (n= 122), 29 local listening tour sessions (n= at least 188), and individual interviews (n = 16). The number of participants is actually greater than the number reflected here. In many local listening conversations, detailed demographics were not collected in order to ensure participant confidentiality.

Participants included people with lived experience of a disability, caretakers and family members of those with a disability, and professionals in the field. The

participants with disabilities, the caretakers, and family members represented diverse types of disability including physical, intellectual, developmental, behavioral, or emotional, sensory impairment, and complex medical disabilities.
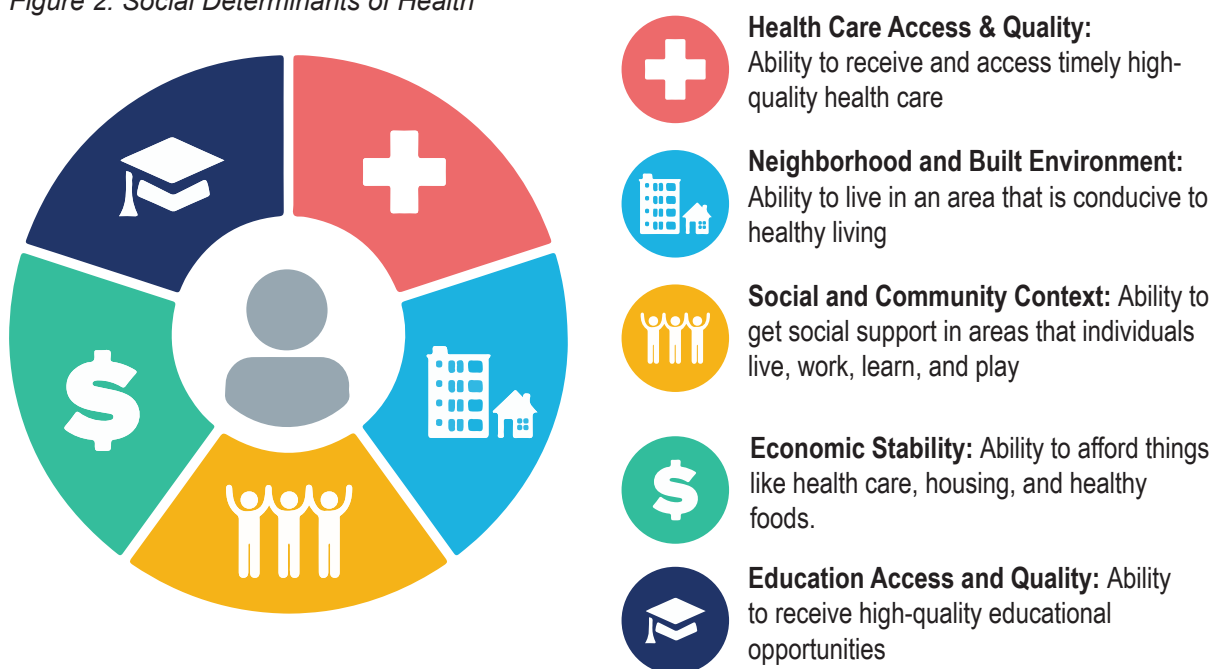
In order to understand the intersectionality of disability and racial/ethnic diversity, the sample included intentional outreach to all populations across Pennsylvania. The sample included representatives of all U.S. Census Bureau racial and ethnic categories. It included heightened attention to underserved/ underrepresented populations including: Hispanic, Asian American, African American/Black, Indigenous, and LTBTQIA+ communities. The sample included 4 of the 10 most rural counties and 9 of the 10 most urban counties in Pennsylvania.[1]

[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).

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

"Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."[2] See 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

As described by the World Health Organization, these social circumstances are shaped by the distribution of money, power, and resources and are responsible for health inequities. Health inequities are unfair and avoidable health differences linked with social, economic, and/or environmental disadvantage.

People with disabilities have long experienced significantly lower rates of employment, education and income. For example, in 2019 only 43.6 percent of people with disabilities were employed compared to 66.4 percent of people without a disability and 19.7 percent of people with a disability lived at an income level of less than $15,000 annually compared to 6.6 percent of people without a disability.[3]

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[2] The Office of Disease Prevention and Health Promotion, Office of the Assistant Secretary for Health, Office of the Secretary, U.S. Department of Health and Human Services. Healthy People 2030. https://health.gov/healthypeople/priority-areas/social-determinants-health (Accessed April 22, 2022).
[3] Employment & Income statistics: Centers for Disease Control and Prevention, Disability and Health Data System (DHDS), Demographics (2019).

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A health care barrier is a challenge or obstacle that makes it more difficult for certain individuals 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, 26.7 percent of people with a disability were reported as not being able to seek health care due to cost compared to 10.1 percent of people without a disability in the same twelve-month period.[4] Pre-pandemic, documented barriers to the inclusion and integration of people with disabilities include attitudinal (ableism, discrimination), accessibility (communication and physical mobility obstacles), policy, transportation, and programmatic (including lack of appropriate health care provider training).[5]

Ableism and attitudinal barriers are present, even in health care settings and physician perceptions. Biases on the part of physicians, the gate keepers to access to health care treatment, could perhaps contribute to persistent health care disparities. A report was conducted that looked at physicians' attitudes of people with disabilities and found that 82.4 percent of U.S. physicians thought that people with disabilities have a worse quality of life than people without disabilities.[6] The same paper went on to say that only 56.4 percent of physicians said they strongly agreed that they welcomed people with disabilities into their practices.[7]

It is also well documented that people with disabilities have long experienced great inequities in health care outcomes. For example, even before the COVID-19 pandemic, individuals with disabilities experienced significantly poorer health when compared to those without disabilities with respect to diabetes, stroke, chronic obstructive pulmonary disorder (COPD), cancer, and depression.[8]

One of the most striking studies examining how COVID-19 disproportionately impacted people with disabilities was conducted by Jefferson Health out of Philadelphia, Pennsylvania. Based on their research across 547 U.S. health care organizations, the study documented the devastating impact of COVID-19 on individuals with intellectual disabilities in the United States. People with intellectual disabilities were six (6) times more likely to die from COVID-19 than other members of the population. The study concluded that "having an intellectual disability was the

[4] Health care costs: Centers for Disease Control and Prevention, Disability and Health Data System (DHDS), Barriers & Costs of Health Care (2019).

[5] Common barriers: Centers for Disease Control and Prevention, Disability and Health Promotion, Common Barriers to Participation Experienced by People with Disabilities

[6] Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., Lagu, T., & Campbell, E. G. (2021). Physicians' Perceptions Of People With Disability And Their Health Care. Health affairs (Project Hope), 40(2), 297–306. https://doi.org/10.1377/hlthaff.2020.01452

[7] Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., Lagu, T., & Campbell, E. G. (2021). Physicians' Perceptions Of People With Disability And Their Health Care. Health affairs (Project Hope), 40(2), 297–306. https://doi.org/10.1377/hlthaff.2020.01452

[8] Poorer health outcomes bar chart: Centers for Disease Control and Prevention, Disability and Health Data System (DHDS), Chronic Conditions (2018) and Mental & Emotional Health (2019).

strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality."[9]

So, what have we learned from The Arc of Pennsylvania initiative through our surveys, regional and local listening sessions, and interviews about COVID-19 health care barriers? Figure 3 is organized under the SDOH (table headers). The table includes the COVID-19 health care barriers for people with disabilities displayed by barrier themes (bold statements) and sub-categories (bulleted statements).

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
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[9] Intellectual disabilities risk: Gleason J, Ross W, Fossi A, Blonsky H, Tobias J, Stephens M. The Devastating Impact of COVID-19 on Individuals with Intellectual Disabilities in the United States. NEJM Catalyst Innovations in Care Delivery. March 5, 2021.

To explore 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?" The responses fell under eleven codes: Technology, Systemic, Mental and Physical Health, Vaccinations, Staffing, Local Conditions, Transportation, Accessibility, Communication, Cultural/Linguistic, and Economic. Participants identified four strengths: Vaccination, Local Conditions, Communication, and Technology with much higher frequency than all other areas of strengths.

Vaccination and Testing Strengths	
Flexibility	Mobile vaccine clinics and home vaccine visits made getting the vaccine more accessible for people who could not enter vaccine sites. Some drive-through testing sites were described as especially disability friendly by addressing 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 ensure that members were being taken care of. This meant that partnerships had to be made 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 an environment that is conducive to promoting 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 was rapidly changing with emerging discoveries. Some participants felt as though local and state organizations dispersed new information quickly and 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 heavily 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 (such as Zoom) were crucial to staying connected for people with disabilities. Local organizations held meetings virtually, allowing members to connect with one another 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

The Regional Community Work Groups and Statewide Leadership Task Force prioritized four barriers as most salient for generating 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 provided in the section on Health Care Barriers for People with Disabilities.

Some barriers were also identified as strengths. For example, telehealth was identified as a strength by those who accessed high-quality, timely supports, but it was identified as a barrier with limited access for people with sensory impairments, intellectual disabilities, internet challenges, interpretation, and translation needs.

HEALTH CARE BARRIERS SELDOM STAND ALONE

While this report presents discrete barriers to health care access and health care outcomes experienced during the pandemic for people with disabilities, it is important to note that many of these barriers are highly inter-relational and complex.

> **People with disabilities reported that their families are often more reliant on systems for service, care, support, and information than the natural community supports that are available to others. Many participants described that inequitable access to health care and other social system supports during COVID-19 compounded issues, exacerbated health conditions, and led to a disintegration in quality of life for the whole family.**

For example, lack of access to educational therapies or medical services caused a need for surgeries or more complicated and extensive medical interventions. Participants reported loss of communication skills, functional skills, adaptive skills, and other skills needed for activities of daily living and increased behavioral difficulties, mental health crises and reduced ability to be within their community to access health and education services.

Most felt the "return to normalcy" was now further out of reach than before the pandemic. As described by one parent of a child with Intellectual Developmental Disabilities/Autism Spectrum Disorder (IDD/ASD) complex behavioral and medical needs, "Once you set that behavior, you're not going to unset that behavior without intensive service." Additionally, virtual learning and lack of paraprofessional access put families of children (including adult aged children) with disabilities in a precarious position, their ability to work competed with their child's education, medical and therapeutic needs, and employers were not all flexible.

Participants felt that decision makers did not understand the full ramifications of their agencies' policies and procedures on people with disabilities and their families, and that systems did not provide a sufficient safety net. For example, safety measures and care needed for the general population competed with critical materials and access that people with disabilities needed for their daily lives. For families of children with complex medical needs, restricted access to gloves, masks, ventilators, and specialized medical equipment created tremendous risk unparalleled by individuals without such complex medical preconditions.

The increased need for mental health support in the general population redirected resources - those in crisis could not get support and multiple participants reported suicide attempts by their child with a disability during the pandemic. The parent of a son with IDD/ASD that identifies as BIPOC shared, "both my son and I had COVID – so to have a health condition, know that you have a disability that supposedly makes that a worse condition, and you can't get doctor's care, that's really not a good thing."

Meanwhile, the lack of staff in all these areas compounded the issues. Another person with a disability that identifies as BIPOC shared that positive COVID test policy left him without needed personal assistance several times, and on those days, he could not leave his bed – he couldn't work, or have his basic needs met.

As we turn our attention to looking more deeply at health care barriers for people with disabilities, we also wish to acknowledge that participants also celebrated many strengths of communities, systems, and supports that strengthened their health care access during the COVID-19 pandemic. Many of the categories of barriers listed in this report were listed by others as strengths.

HEALTH CARE BARRIERS FOR PEOPLE WITH DISABILITIES

In this section, we further explain the COVID-19 health care barriers for people with disabilities that were common themes (headers of tables) and sub-categories (left hand columns) cited by listening tour participants. As explanations, we offer example participant statements and findings from our literature review.

Health Care Access and Quality Barriers for People with Disabilities

Systemic Barriers for People with Disabilities	
Health Care System	Health care barriers impact people with disabilities in a unique way. According to the literature, it is known that only 56.5 percent of health care providers feel as though they welcome people with disabilities into their practices.[10] There is a lack of education in medical schools about how to treat patients with disabilities, leading to confusion and worry for both patient and provider.
	Participants in the listening tours reported similar experiences, "Medical community doesn't know how to work with people with disabilities."

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[10] Iezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG (2021). Physicians Perceptions of People with Disability and Their Health Care. Health Affairs. 40(2). https://doi.org/10.1377/hlthaff.2020.01452

Mental Health and Physical Health Barriers for People with Disabilities	
Mental Health Impacts	People with disabilities were negatively impacted by COVID-19 especially with regards to mental health. A report published states, "over 90 percent [of children and young adults with disabilities] report a negative impact on mental health (including poorer behavior, mood, fitness and social and learning regression)."[11]
	The participants in the listening tours also felt these effects. Most cited that isolation led to increased feelings of depression and fear. A quote that captures how lonely this community felt during these times is as follows, "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."
Trauma	The pandemic caused a lot of feelings of fear, many of which were backed up from personal experiences that left people with new and developing trauma. Deaths of family members and loved ones and dealing with feelings of grief were present as well as political unrest and riots surrounding societal issues.
	One participant stated, "I have children I know who lost every adult in their family in a few weeks; just lost every adult in a few weeks. No one is talking about that level of trauma."
Physical Activity	Programs shutting down, gyms closing, and imposed quarantines all contributed to a reduction of physical activity levels. People with disabilities reported negative impacts on physical activity levels during COVID-19.[12]
Nutrition	Access to healthy foods was a barrier that many people across the state experienced. Literature shows that people with disabilities experience greater risk of food insecurities when compared to people without disabilities.
	During COVID-19, it was even harder for people to access food due to fear of catching the virus at the store, the high delivery prices, and lack of transportation to stores.

[11] Theis, N., Campbell, N., De Leeuw, J., Owen, M., & Schenke, K. C. (2021). The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. Disability and health journal, 14(3), 101064. https://doi-org.ezaccess.libraries.psu.edu/10.1016/j.dhjo.2021.101064

[12] de Boer, D. R., Hoekstra, F., Huetink, K., Hoekstra, T., Krops, L. A., & Hettinga, F. J. (2021). Physical Activity, Sedentary Behavior and Well-Being of Adults with Physical Disabilities and/or Chronic Diseases during the First Wave of the COVID-19 Pandemic: A Rapid Review. International journal of environmental research and public health, 18(12), 6342. https://doi.org/10.3390/ijerph18126342

Mental Health and Physical Health Barriers for People with Disabilities (Cont.)	
Pre-Existing Conditions	Literature shows that people with IDD experience higher rates of comorbidities, which lead to poorer health outcomes related to COVID.[13] A participant in one of the listening tours 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 advancement of the vaccine brought about new challenges for those with disabilities. Some felt as though people with disabilities were left behind in the rollout process and that trying to find information on scheduling the appointment was difficult.
Attitudes	Misinformation surrounding COVID-19 vaccinations proved to be harmful, especially for those with disabilities who need staff in their homes. Unvaccinated staff would not disclose their vaccination status and still enter homes, with one participant stating that his DSP knowingly came into the home after having been exposed and ended up giving the individual the virus. The individual was later hospitalized.
Accessibility	Vaccination and testing sites proved to be an accessibility barrier. One participant stated 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 DSPs, training often had to be expedited and some participants felt as though the quality of staff was not up to par. One felt as though, "Because of the direct support professional (DSP) shortage, employers would hire anybody, even if they weren't qualified."

[13] Turk, M., Landes, S., Formica, M., Goss, K., (2020). Intellectual and Developmental disability and COVID-19 Case-Fatality Trends: TriNetx Analysis, Disability and Health Journal, 13(3).

Staffing Barriers for People with Disabilities (Cont.)	
Staff Vacancies and Retention	Many staff quit during the pandemic, for a myriad of reasons. However, when support staff began quitting, it raised a specific issue for people with disabilities. Many agencies said that staff were leaving for more lucrative jobs, which is tied back to the lack of funding for DSPs and other support services. One participant stated, "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	Telemedicine appointments have been a great byproduct of the pandemic, but it doesn't always prove accessible for people with disabilities. There are unique challenges such as communication barriers, tele-physical assessment barriers, and overall accommodations that need to be adjusted so that telehealth can be more accessible for people with disabilities.[14] Many participants felt as though services offered online needed some adjustments, "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 felt as though local officials had a lack of awareness of barriers and difficulties that people with disabilities were facing 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."

[14] Annaswamy, T. M., Verduzco-Gutierrez, M., & Frieden, L. (2020). Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond. *Disability and Health Journal*, 13(4), 100973. https://doi.org/10.1016/j.dhjo.2020.100973

Local Conditions Impacting People with Disabilities (cont.)	
Rural Areas	Rural communities face unique barriers to health care including the low number of health care providers. In one study it was 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] Participants echoed these findings while stating a barrier as, "Lack of medical care services in rural areas."
Local Organizations	The temporary shutdowns of local organizations proved difficult for those with disabilities who rely on those services. Organizations such as food banks and nonprofits are crucial parts of a community, and the closure was felt by people with disabilities.
Family Support	Quarantine and isolation were met with decreased family visits for individuals with disabilities who live in a group home. Family members experienced minimal support and in many cases no respite from caregiving responsibilities. One family member remembered feeling like she had to act as a teacher, caregiver, nurse, and mother all at once with no outside support.

Transportation Barriers for People with Disabilities	
Public Transportation	Many participants, often located in rural areas, stated a lack of public transit options. There was also a fear of catching the virus on public transit across the Commonwealth. From the literature, it is known that access to public transportation can improve health by allowing for passage 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 stated, "Boarding in the middle part of the bus was not accessible to those with disabilities."

[15] Health Equity Report 2019-2020 (n.d.). U.S. Department of Health and Human Services, p. 20
[16] Dai, Z., et.al. (2020). Mobility, Accessibility, and Connectivity: Assessments and Recommendations Concerning Rural Transportation Equity in Pennsylvania. Heinz College of Information Systems and Public Policy Carnegie Mellon University. Retrieved from: https://mobility21.cmu.edu/wp-content/uploads/2020/07/Mobility-Accessibility-and-Connectivity-Assessments-and-Recommendations-Concerning-Rural-Transportation-Equity-in-PA.pdf

Accessibility Barriers for People with Disabilities	
Physical Access	Testing sites, vaccine sites, and health care facilities are not always accessible for those with disabilities, creating a barrier when trying to utilize these services. Some said that the drive through testing was not accessible or accommodating and there were not accessible ramps to buildings where vaccines were being administered.
Plain Language	The lack of plain language was evident throughout the dispersal of information process for all things COVID related. Information was presented in a way which was not easily understandable for all people, thus creating more confusion and worry. One participant in a listening tour stated, "Information 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 expressed concern over the amount of misinformation, often through social media, that circulated during the pandemic. From topics about quarantine and mask-wearing to vaccine hesitancy, navigating through this stream of information was difficult. A participant voiced their concern stating, "The media often dropped the ball with spreading correct information."
Changing Information	Many participants cited the constantly changing information about the pandemic as a source of confusion and anxiety. Guidelines and rules shifted daily, both from the federal government as well as local and state governments.

Cultural/Linguistic Barriers for People with Disabilities Who are Also a Part of a Minority Population	
Racial/Ethnic	Racial/ethnic minority groups experience health disparities that are compounded when the individual also has a disability. There are differences in comorbidities and health outcomes when looking at the intersection of these groups. Literature surrounding health outcomes for COVID-19 found that, "The hospitalization rates and death rates per 10,000, respectively, were 24.6 and 5.6 for Black patients, 30.4 and 5.6 for Hispanic patients, 15.9 and 4.3 for Asian patients, and 7.4 and 2.3 for White patients."[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 without the presence of a pandemic. However, the pandemic often exacerbated these experiences. One study found that, "A larger percentage of multi-racial and non-Hispanic adults of other races and ethnicities reported stress and worry about stigma or discrimination associated with being blamed for spreading COVID-19 in comparison to White adults."[18]
Language and Cultural Diversity	The lack of interpreters during this time proved a challenge for parents of children with disabilities and those with disabilities themselves. A participant felt as though, "translators are notorious for not translating medical and special education language accurately."

[17] Lopez, L., Hart, L., Katz, M., (2021). Racial and Ethnic Disparities Related to COVID-19, JAMA, 325(8): 719-720. doi:10.1001/jama.2020.26443

[18] The Impact of COVID-19 on Minority Mental Health (2021). Mental Health First Aid, https://www.mentalhealthfirstaid.org/2021/07/the-impact-of-covid-19-on-minority-mental-health

$ Economic Stability Barriers for People with Disabilities

Financial Security for People with Disabilities	
Employment	A recurrent barrier identified by listening tour participants was the economic hardship of not being employed. In 2021, only 19.1 percent of persons with disabilities were employed compared to 63.7 percent of people without disabilities nationally. Across all age groups and all educational attainment levels, unemployment rates for persons with a disability are significantly higher than those for persons without a disability.[19] In the words of one listening tour participant, "Parents worried about losing their jobs and paying bills."
Income	Caregivers and self-advocates in our listening tour talked about the impacts of low income on their housing security, food security, and on their physical and mental health. "Low SES and its correlates, such as lower educational achievement, poverty, and poor health, ultimately affect our society. Although the Americans with Disabilities Act (ADA) assures equal opportunities in education and employment for people with disabilities and prohibits discrimination on the basis of disability, people with disabilities remain overrepresented among America's poor and undereducated."[20]
Food Security	The rising costs of food delivery services was a barrier identified numerous times by participants. While people with disabilities and their families and caregivers were trying to reduce the risk of COVID-19 by ordering groceries online, the high fees were a barrier to this.

[19] Bureau of Labor Statistics, U.S. Department of Labor. (February 24, 2022.) Persons with a Disability: Labor Force Characteristics 2021. News Release USDL-22-0317.
[20] American Psychological Association. (2010.) Disability and Socioeconomic Status. (Accessed 4/22/22). https://www.apa.org/pi/ses/resources/publications/disability

Social Supports Barriers for People with Disabilities

Funding	Lack of funds was another recurring theme throughout data collection. Lack of funding for mental health services negatively impacted people with disabilities who were feeling the effects of prolonged isolation during the pandemic.
Direct Support Professional (DSP) Wages	Participants expressed concern over the ongoing direct support professional (DSP) crisis in Pennsylvania. Wages for DSPs are often too low, leading to shortages of DSPs. One participant described being "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	The educational system in Pennsylvania was the source of some barriers for people with disabilities during COVID-19, especially when learning got moved online. Virtual education proved difficult for children with disabilities who typically receive additional support during the school day. Less support, quality of education over zoom and loss of instructional time caused many problems for students with disabilities.[21]

[21] Williams, E., Musumeci, M. (2022). The Intersection of Medicaid, Special Education Service Delivery, and the COVID-19 Pandemic. Kaiser Family Foundation, Retrieved from: https://www.kff.org/medicaid/issue-brief/the-intersection-of-medicaid-special-education-service-delivery-and-the-covid-19-pandemic

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 families. For many students, this caused them to miss out on essential class time and homework. A participant stated that, "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, barring those without internet from participating. It's estimated that 800,000 Pennsylvanians lack access to high-speed internet, with 520,000 of those being residents of rural areas.[22] For children in school, the lack of internet access barred them from attending their online classes.
Knowledge and Ability to Use Technology	The pandemic forced many people to rely more heavily on the internet for their work, socialization, education, and health care. For those people who lack the knowledge of how to use technology, especially prevalent amongst older populations, learning to navigate a computer was frustrating and difficult. In addition, people with disabilities may have lacked access to accessible technology.
Zoom	Zoom use became almost ubiquitous during COVID-19. Many participants expressed that online school and activities were not as effective on Zoom as they would be in-person. For students, this meant potentially falling behind or receiving a substandard education. To compound this issue, Zoom lacks accessibility features necessary for people with disabilities to utilize it.

[22] GovTech. (2021, December 22). What Pennsylvania's Broadband Bill Means for one county. GovTech. Retrieved April 22, 2022, from https://www.govtech.com/network/what-pennsylvanias-broadband-bill-means-for-one-county

IN THE WORDS OF PARTICIPANTS

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 own 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

Informed by a deepened understanding of COVID-19 health care barriers among Pennsylvanians with disabilities, our Regional Community Work Groups and state level COVID-19 Health Disparities Statewide Task Force will focus on recommendations for the Department of Health to address health disparities.

As part of the Pennsylvania Office of Health Equity's 2022 focus on disability equity, this initiative is an opportunity for learning, connecting, and joint action to increase health equity for an important sector of our community.

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

- Individual with complex medical needs