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Findings and Recommendations: Barriers to Healthcare for People with Disabilities

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Abstract

The COVID-19 pandemic has been difficult for everyone. But for some groups, including and especially the disability community, its impact has been staggering. The Arc of Pennsylvania received funding through the Pennsylvania Department of Health to investigate, educate, and report on problems that people with disabilities in Pennsylvania have accessing appropriate information and help during the COVID-19 pandemic. With a deepened understanding of the unique health barriers that the disability community faces, The Arc of Pennsylvania has compiled a list of 10 recommended solutions to combat these very barriers and advance health equity for people with disabilities.

Executive Summary

The Arc of Pennsylvania received funding through the Pennsylvania Department of Health to examine the impacts of COVID-19 on the disability community and provide a robust set of solutions. By using a disability-inclusive approach and including people with disabilities at every step in the process, the Arc of PA reported the causes of the health disparities faced by the disability community. Heightened by the COVID-19 pandemic, factors such as the lack of education of medical professionals, inaccessibility of healthcare establishments, and inconsistent communication caused worsened healthcare outcomes for people with disabilities and compounded feelings of anxiety. With a deepened understanding of these barriers, The Arc of PA then compiled a list of solutions that are aimed to combat these very barriers to ensure that the disability community becomes a healthcare priority across the Commonwealth. Decisions regarding the health care needs of people with disabilities are often made without any input from the disability community, despite the community being among the country's largest health disparity groups. Identified solutions range from the involvement of the disability community at all levels of decision-making to broader policy changes that would benefit people with disabilities.

Introduction

People with disabilities have been experiencing health disparities for quite some time, and with the onset of the COVID-19 pandemic, these disparities were heightened. The Arc of Pennsylvania's Initiative to Address COVID-19 Health Disparities Among People with Disabilities has been actively exploring two questions to gain a deeper insight into these disparities: (1) To what extent have we used a disability-inclusive approach to combat COVID-19, and (2) To what extent will we use a disability-inclusive approach to prepare for future health care emergencies. The initiative convened health care and disability stakeholders from across the Commonwealth to explore these questions in depth. The first phase of work was to understand COVID-19 healthcare barriers experienced by Pennsylvanians with all types of disabilities, with heightened attention to those from diverse racial, ethnic, and rural populations. The second phase of work shifted focus to developing solutions to those very barriers that are aimed at increasing access to health care services and improving health outcomes for people with disabilities.

Literature Review

As stated above, people with disabilities have been experiencing healthcare barriers long before the COVID-19 pandemic. For example, in 2019, 26.7% of people with a disability were reported as not being able to seek health care due to cost, compared to 10.1% of people without a disability (Barriers & Costs of Health Care, 2019). 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) (Common Barriers, 2020).

Ableism and attitudinal barriers are present, even in healthcare settings and physician perceptions. Biases on the part of physicians, the gatekeepers to accessing health care treatment, could perhaps contribute to persistent health care disparities. A report was conducted that looked at physicians' attitudes toward people with disabilities and found that 82.4% of U.S. physicians thought that people with disabilities have a worse quality of life than people without disabilities (Iezzoni et al., 2021). 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 (Iezzoni et al., 2021).

It is also well documented that people with disabilities have long experienced inequities in health care outcomes. 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 (Adults with Disabilities, 2014). One of the most striking studies examining how COVID-19 disproportionately impacted people with disabilities was conducted by Philadelphia-based Jefferson Health out of Philadelphia, Pennsylvania. Based on their research across 547 U.S. healthcare 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 times more likely to die from COVID-19 than other members of the population. The study concluded that "having an intellectual disability was the strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality" (Gleason et al., 2021).

With previous research on this matter painting a clear picture of the devasting facts on health disparities and outcomes for people with disabilities, many organizations have gone on to present solutions to combat these barriers. Policy recommendations have been produced by disability advocacy organizations, academic institutions, and government entities. The National Council on

Disabilities produced a set of policy recommendations that detail federal action to improve health for people with disabilities. These recommendations included designating people with disabilities as a Special Medically Underserved Population, developing disability clinical care curricula, and guaranteeing accessible medical equipment (Framework to End Health Disparities, 2022). The Centers for Medicare and Medicaid also released their own set of recommendations to improve health equity, with certain recommendations aimed specifically at the disabled population. Increasing forms of accessibility, building the capacity of the healthcare workforce, and expanding the collection of data are among the policy recommendations that are listed (CMS Framework, 2022). With entities describing similar policy recommendations, The Arc of PA wanted to look specifically at Pennsylvania and see what went wrong during COVID-19 for people with disabilities locally and if policy recommendations could be given to the state.

Methodology

In order to get a sense of the barriers that people with disabilities faced during the pandemic, The Arc of PA focused specifically on connecting with the disability community. However, the input from the healthcare perspective was also critical in painting the full picture of the intricate barriers that lead to differences in health outcomes. During the first year of this project, groups were convened called “Regional Community Work Groups” (RCWG) that consisted of are not limited to individuals from Arc chapters across the state, disability advocates, people with lived experience of disability, family members of individuals with disabilities, caregivers of individuals with disabilities, and health care professionals. The project was also spearheaded by a group of professionals who were a part of the “Statewide Leadership Task Force.” The purpose of this group was to guide The Arc of PA’s research and evaluation process while providing critical insight into the research conversation itself.

The first year of this project focused exclusively on barriers to healthcare. Therefore, the main qualitative data collected from hundreds of respondents (n=393) answered the following question, “What challenges in your area have made it difficult for people with disabilities to stay healthy during COVID-19?”. This question was asked to the members of the RCWGs, the Statewide Leader Task Force, and in local listening tour sessions and individual interviews. Participants in these conversations included people with lived experience of a disability, caretakers, family members of those with a disability, and professionals in the field. The participants also 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.

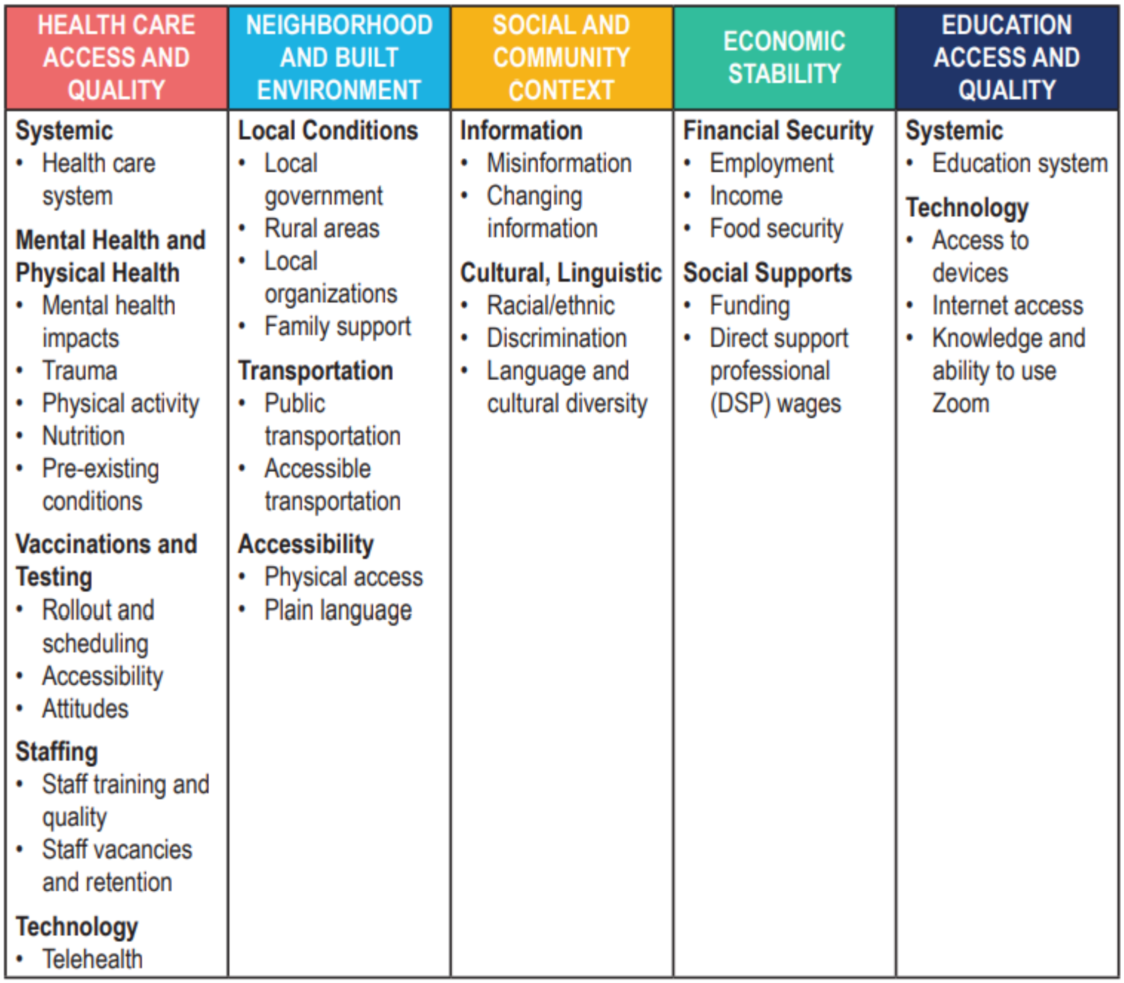
The second year of the project focused exclusively on collecting data about possible solutions and recommendations to combat the identified barriers. The same individuals who participated in the data collection process of the first phase of work were asked to participate once more. Two questions were asked to the participants, “What are core recommendations for using a disability-inclusive approach to combat COVID-19 and future health care emergencies?” and “What are additional recommendations for using a disability-inclusive approach to combat COVID-19 and future health care emergencies?”. As shown in the questions themselves, the policy recommendations are broken up into two categories, “core solutions,” which are offered directly to the Pennsylvania Department of Health and are tailored specially to encompass tangible changes within the department itself, and “additional solutions” which may require action by state agencies other than the PA Department of Health and/or collaboration across state agencies.

All qualitative data collected was analyzed using thematic analysis methodology – reading all responses, identifying patterns (themes, codes, sub-codes), and checking inter-rater reliability.

Findings

Based on the data collection during the first phase of the project, many barriers were identified. The barriers were placed into themes of Health Care Access and Quality, Neighborhood and Build Environment, Social and Community Context, and Education Access and Quality. These themes align with Healthy People 2030’s model of Social Determinants of Health (SDOH).

Figure 1. COVID-19 healthcare barriers for people with disabilities (barrier themes and subcategories)



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

Discussion

Figure 1 shows the various COVID-19 healthcare barriers for people with disabilities broken up by SDOH category. To begin, healthcare access and quality show barriers that have systemic routes or problems with the healthcare system itself. Participants in this study cited that “the medical community doesn’t know how to work with people with disabilities,” which in turn leads to confusion and worry for both the patient and the provider. People with disabilities and their families also face negative mental health impacts. 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.” The pandemic also caused a lot of feelings of fear, many of which were backed up by personal experiences that left people with new and developing trauma. Not only was mental health impacted, but the physical health of people with disabilities was also affected. Day programs shut down, gyms closed and imposed quarantines all contributed to a reduction in physical activity. Access to healthy foods was a barrier that many people across the state experienced. 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 the lack of transportation to stores. The vaccination process also presented unique barriers for people with disabilities. Participants cited feeling like the disability population was left behind in the beginning stages of the vaccine rollout, even though many have pre-existing conditions that make a COVID-19 diagnosis more severe. The accessibility of the vaccine locations was also a cause for concern. Inaccessibility of vaccine sites proved difficult for those with mobility issues or those who are homebound. There is also the issue of staffing, which caused additional barriers. Direct Support Professionals (DSPs) provide people with disabilities with essential services and help with everyday life. However, even though this position is essential for people with disabilities, the state did not qualify DSPs as essential workers early in the pandemic. Many staff ended up leaving the profession to receive better pay elsewhere and go to a career with less exposure to COVID-19. Lastly, as helpful as telehealth has been for the community, certain accessibility barriers were identified, which led to communication difficulties.

Looking at the Neighborhood and Built Environment Barriers, it is apparent that many participants from rural areas across Pennsylvania had unique experiences. Many stated that there is a lack of medical professionals and specialists in their community, and traveling far was not feasible during the height of the pandemic. In this SDOH category, the impact of local organizations shutting down and local governments not grasping the complexities of the impact of COVID-19 on disabilities was also identified. Transportation barriers were highlighted in every area across the state. Lack of accessible public transportation proved a large challenge for people with disabilities and their families as getting to health care appointments or vaccine appointments was hindered. Lack of accessibility in the form of communication was also cited, as one participant explained, “Information never presented in a way that made sense to ALL persons, i.e., plain language.”

Social and Community Context describes misinformation as a barrier for people with disabilities as well. Participants expressed concern over the amount of misinformation, often through social media, which circulated during the pandemic. From topics about quarantine and mask-wearing to vaccine hesitancy, navigating through this stream of information was difficult. To complicate this further, correct information was constantly changing. From masking guidelines to social distancing and correct quarantine information, the ever-changing information was not always provided in plain language, and made it even more challenging for people with disabilities. The presence of intersectionality of disability and race/ethnicity was also apparent in the data collection and analysis. Participants of color felt as though there was “a lack of focus on racial disparities and other disproportionately affected communities.” Language and cultural diversity proved challenging because of the lack of interpreters and lack of translated medical communication.

The SDOH of Economic Stability was a unique barrier for people with disabilities. Because of the staffing shortage, many parents had to quit their jobs to become full-time caregivers of their loved one with a disability. The loss of wages added to stress about paying bills, providing food for their family, and housing security.

The final SDOH category, Education Access and Quality, presented additional barriers. Virtual learning was an essential part of keeping communities safe from exposure. However, without the necessary support for students with disabilities, virtual learning proved difficult. 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 educational, medical, and therapeutic needs, and employers were not all flexible. Lack of access to devices and adequate internet access was also cited as being an educational barrier.

While this report presents discrete barriers to healthcare access and healthcare 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. 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. 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 conditions. 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 who 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 who identifies as BIPOC shared that the positive COVID test policy left him without needing personal assistance several times, and on those days, he could not leave his bed – he couldn't work or have his basic needs met.

The barriers identified are complex. Pennsylvania needs to alter the way services are provided, the way that the state communicates complex medical information, and make sure that disability is a priority moving forward. Without change, people with disabilities and their families are going to continue facing healthcare barriers.

Policy Action Solutions

Health equity is dependent on our ability to transform our generational injustices into disability-inclusive healthcare systems, policies, and practices. People with disabilities have long experienced health inequities. The COVID-19 pandemic illuminated these disparities and brought much-needed attention to the unique health challenges faced by the disability community. Based on the second phase of the project, the phase that focused on developing solutions, there are 10 core recommendations that the Pennsylvania Department of Health can either directly implement or work to advocate for that could greatly help people with disabilities and their families.

Solution 1) Create and promote new opportunities for people with lived experience of disability, their families, and caregivers to provide critical input into policy-making and implementation of the healthcare delivery system.

Barriers to health care for people with disabilities are complex and nuanced. Personal knowledge is critical to identifying barriers not recognized by those without lived experience, understanding the full scope of the impact of policies, and providing feasible solutions to barriers. While people with disabilities comprise one of the largest health disparity groups in the United States, most decisions regarding their health care are made without this insight or involvement. Without the involvement, knowledge, and perspective of people with disabilities and their families and caregivers at all decision points, health inequities will continue to persist.

Examples of including people with disabilities and families and caregivers in policy making and decisions might include equitable employment of people with disabilities in leadership positions in the Department of Health or reactivation of the Governor's Cabinet for People with Disabilities. Other examples might include listening sessions, panel discussions, participant forums, and interaction with advocacy groups. A key focus should be on ensuring that healthcare professionals honor the voices of individuals with disabilities driving healthcare decisions during healthcare emergencies.

Solution 2) Immediately reactivate all aspects of the Executive Order, 2006-09. Reinstate the Pennsylvania Governor's Cabinet for People with Disabilities and the Governor's Advisory Committee for People with Disabilities. Ensure coordination among agencies to ensure a disability-inclusive approach in decision-making, oversight of disability rights, and health care access.

People with disabilities should be centrally involved in policy and planning responsibilities, leading and ensuring coordination among agencies to ensure a disability-inclusive approach in decision-making, oversight of disability rights, and health care access across state agencies. It is recommended that the Department of Health champion the reactivation of all aspects of the Executive Order 2006-09 to ensure the needs of people with disabilities are considered at all levels of decision-making. The Governor's Cabinet for People with Disabilities and the Governor's Advisory Committee should be re-envisioned beyond just an advisory role. The needs of people with disabilities must be fully considered, understood, and addressed. It is essential to embed the lived experience of disability in all levels of decision-making, including at the highest level of the Commonwealth.

In 2006, the Governor's Cabinet for People with Disabilities and Governor's Advisory Committee was established under the Rendell administration. This Cabinet and Committee aimed to serve as an advising role to the Pennsylvania Governor on matters that affected people with disabilities. The establishment of this cabinet provided a great step in the right direction. However, the role of Executive Director of the Cabinet is not currently filled, and the Governor's Cabinet for People with Disabilities and Governor's Advisory Committee is inactive. People with all types of disabilities deserve to be represented in the Governor's Cabinet for People with Disabilities and the Governor's Advisory Committee so that the unique challenges facing the disability population receive adequate attention. The membership should be reviewed, and additional organization and membership roles added to reflect the current scope of state agencies, disability organizations, and range of disabilities needed to make informed decisions.

Solution 3) Identify and maintain tangible policy changes, federal and state waivers, and flexibilities that were implemented during the COVID-19 pandemic to ensure access to care and services and continue planning efforts to support health systems and health professionals to be more inclusive of the disability community.

The COVID-19 pandemic brought about various changes to how health care in Pennsylvania is given and received. Many of these changes were very beneficial to the lives and well-being of people with disabilities and their families. For example, telehealth was a monumental change to the delivery of health care and provided people who could not access a doctor due to distance, lack of transportation, and inaccessible facilities the means to speak with their healthcare professionals from the comfort and safety of their homes. Another prime example of a change in health care was the allowance of support staff and families to follow the individual into the hospital setting to provide support during the COVID-19 emergency, regardless of quarantine protocols. This allowance has been enshrined in the Office of Developmental Programs (ODP) waivers and is a great example of a tangible policy change that benefited the health and well-being of people with disabilities. Listening tour participants reported this practice eased anxieties and fears, and decreased challenging behaviors of the individual while ensuring the appropriate care was provided.

Direct Support Professionals (DSPs) were also classified as essential workers during the pandemic, a designation that made it possible for the staff to continue to provide essential services to people with disabilities. However, during the early portions of the pandemic, there was a lack of clarity on the term "essential workers." This led to DSPs not being provided with adequate Personal Protective Equipment (PPE) and not being assigned as a priority group in the COVID-19 vaccine rollout. Without federal standard occupational classifications for key personnel, such as DSPs, it is essential that the Department of Health coordinate with other agencies, such as the Department of Human Services, in making determinations of who should be identified as "essential workers" in health emergencies.

Solution 4) Expand the Community-Based Health Care Program in the Department of Health to include:

(a) Expansion and protection of accessible telehealth services; and

(b) Development of accessible mobile health care clinics.

People with disabilities often have difficulties accessing certain healthcare services. This can be attributed to conditions such as physical inaccessibility of facilities (i.e., wheelchair ramps, height-adjustable examination tables), inaccessibility of transportation services, and a non-sensory friendly environment of the facility. The inaccessible nature of current healthcare delivery perpetuates numerous health disparities facing the disability population. Services such as telehealth and mobile healthcare clinics allow people with disabilities to receive necessary healthcare services in a more accessible delivery system. During the health care barriers listening tour, many participants felt that their health care experiences, or their family member's health care experiences, would have benefited from the option of teleservices. Teleservices eliminate the need for transportation, allow for a more sensory-friendly environment, and eliminate issues around the inaccessibility of the facility. Additionally, mobile healthcare clinics allow for the provision of health services in rural and urban areas, tailoring services to specific communities, greater accessibility, and lower costs for patients and providers.

Accessible health care looks different based on the individual's needs, and not all services can be adequately delivered through teleservices and mobile health care clinics. In-person health care options must continue to be offered and available at traditional sites while being accessible. It is essential that there is enforcement of the Americans with Disabilities Act (ADA) and Affordable Care Act (ACA) requirements for accessible and affordable healthcare across all options (including telehealth, mobile health, and in-person) so that healthcare is accessible, including physical accessibility as well as access to language and communication services.

Solution 5) Appoint disability representatives to the Department of Health's Office of Health Equity Advisory Committee.

People with disabilities are disproportionately impacted by health inequities and yet are often overlooked in Diversity, Equity, and Inclusion (DEI) efforts. It is recommended that a disability representative be added to the Department of Health's Office of Health Equity Advisory Committee. Currently, the Office of Health Equity Advisory Committee works to advise the Secretary of Health on subjects pertaining to various health inequities. Even though this Office is making strides towards more equitable health care for many Pennsylvanians, there is no one currently on the Committee with direct knowledge pertaining to the health inequities that people with disabilities face. This person must have both experience of a disability and knowledge of the healthcare system. While this role would improve disability representation, there is acknowledgement that one singular person cannot represent the diverse needs of everyone in the disability community. It is also recommended that each regional Department of Health office has a point(s) of contact in that area who can provide critical insight into the needs of people with disabilities in that region. The point(s) of contact needs to be someone with lived experience of disability, a family member, or a caregiver. Input from people of different racial, ethnic, and cultural groups should be included to ensure the inclusion of intersectional perspectives. The point(s) of contact will then provide insight to the disability representative sitting on the Health Equity Advisory Committee.

Solution 6) Provide disability-specific whole person-centered health care training for healthcare providers.

Fronts of action for advancing disability-specific training might include requiring training during new member orientation, tying disability training to license renewal (like Act 31), coordinating with professional societies or organizations, and raising awareness of and promoting existing curricula. Healthcare professionals and community members include medical professionals, mental health professionals, support staff, government officials, employers, law enforcement, community organizations, caregivers, and family members. Training should include the intersectionality of disability, culture and ethnicity, and mental health.

During the barriers listening tour, people with lived experience of disability shared that they felt their healthcare provider did not know how to work with them because of their disability. This shortage of competent providers compounds existing health disparities and creates even more of a barrier when trying to access and utilize services. We need to ensure that education that aims to combat biases and stigmas is mandated while training these professionals. The respondents in the health care barriers listening tour described that the discomfort of providers when providing care to people with disabilities is evident and causes additional challenges when seeking health care services. This discomfort and lack of knowledge by healthcare professionals can result in refusal of care, misdiagnosis, inaccurate treatment plans, dismissal of pain, and devaluation of the patient's ability to self-report symptoms. Standardized curricula should include but are not limited to plain language importance and terminology basics, information about the history of medical mistreatment of people with disabilities, legal obligations and responsibilities for caring for patients with disabilities, whole person-centered health care approach which focuses on the individual being treated outside of the context of diagnosis, behavior as communication, trauma-informed care, and effective communication with the individual with a disability.

Solution 7) Collaborate with the Governor's Office and/or the General Assembly to request the Health Resources and Services Administration (HRSA) to waive the geographic barrier requirement to designate people with disabilities as a Medically Underserved Population.

A Medically Underserved Population designation could lead to such improvements as incentivizing health professionals to learn more about this population, health institutions reducing financial barriers to healthcare access, and incentivizing professionals who serve people with disabilities through loan forgiveness.

A Medically Underserved Population can be defined as a given community or population that has a proven shortage of health professionals (Federally Designated Underserved Areas, n.d.). People with disabilities clearly fall under this category, as shown in numerous studies conducted across the nation. In a survey completed by 714 practicing physicians, only 56.5% of surveyed physicians felt as though they strongly welcomed people with disabilities into their healthcare practice. Furthermore, even fewer (40.7%) said they were confident in their ability as a physician to provide proper care to a patient with a disability (Iezzoni et al., 2021). Additionally, in a study that conducted focus groups containing physicians, a multitude of questions pertaining to barriers to caring for patients with disabilities were asked. When asked about taking the weight of an individual in a wheelchair, some physicians responded that their offices cannot accommodate them and the patient would be sent to a supermarket, grain elevator, zoo, or cattle processing plant to be weighed (Lagu et al., 2022). People with disabilities already experience biases and stigmas when attempting to gain access to medical appointments, which can exacerbate feelings of anxiety when speaking to a physician. It can only be imagined that hearing that your physician is proposing to send you to a zoo to be weighed would only make these feelings worse. Based on these two studies alone, it is evident that people with disabilities have a proven shortage of competent healthcare professionals. This Medically Underserved Population designation would be a first critical step in making sure that this population is prioritized and that there are sufficient layers of support within systems to focus on eliminating disparities.

Solution 8) Establish and expand standardized data collection and develop statistics regarding the health and health care needs of people with disabilities.

The sentiment of "those who are counted, count" is a phrase that exemplifies the necessity of data collection regarding the health of people with disabilities. Currently, there is no systematic method that data and information regarding disability are integrated into electronic health records or other ways of capturing disability as a category. Data is essential for health systems to understand the needs of people with disabilities so they can address the health barriers faced and increase access. Standard disability demographic questions across the field should be determined to create a shared definition. This will lead to a complete data source that will provide insight into the experiences of people with diverse disabilities, needs, and other factors, including geographic location and the intersection of race, ethnicity, and socio-economic status. The Pennsylvania Department of Health is uniquely situated to require this demographic data to be collected in all its programs and services and to influence other organizations/agencies to do the same. With this data source, ethical data collection is essential, as well as accurate reporting. Death and other outcomes need to capture actual causes beyond an underlying disability when that is the case. This data is also essential to achieve the other recommendations and is important to provide an evidence base for advocacy.

Additionally, regarding the current data displayed on the Pennsylvania Department of Health's website, steps must be taken to remedy out-of-date language. Under the current web page detailing "Health Statistics A to Z," the term "mental retardation" is listed. The Task Force urges the Department of Health to correct this language. Lastly, The Office of Health Equity (OHE), which is integrated into the Pennsylvania Department of Health, "works to address the needs of the most vulnerable communities throughout Pennsylvania." However, in 2019, OHE released The State of Health Equity in Pennsylvania, and the word "disability" is mentioned twice. The Taskforce recommends the Pennsylvania Department of Health and the OHE establish a focus and intentionally include the disability community within their state and regional work so that the needs of *all* of Pennsylvania's most vulnerable communities are addressed.

Solution 9) Provide accessible, plain, and multi-language resources.

Information pertaining to COVID-19 was not released in formats that were accessible to all. All information being released by the State or healthcare agencies needs to be presented in various formats so that people from all walks of life have the opportunity to be informed on emerging news. Information must be distributed in a timely manner in both digital and print formats. This includes but is not limited to braille, large print, American Sign Language, closed captioning, qualified, accurate language interpreters, and bilingual consultants in healthcare settings.

Plain language provides information in a clear and concise manner, enabling readers to understand the content through accessible literacy levels, meaningful graphs and images, alternate text descriptions of images, and embedded definitions. It is recommended that the Pennsylvania Department of Health lead by example and provide strategies to support individuals to make meaning of complicated information while also promoting tools such as social stories to prepare individuals for medical appointments and vaccinations. Social stories often help to ease feelings of nervousness and anxiety that those with anxiety or executive functioning challenges may experience, as well as individuals who require preparation and planning before visiting a healthcare facility. Along with the use of accessible communication, The Task Force recommends that all Pennsylvania Department of Health information be translated into multiple languages before dissemination so that those whose primary language is not English are able to receive the material at the same time. During the health care barriers listening tour, The Arc of PA spoke with numerous individuals whose primary languages were Spanish and Mandarin to get a sense of the unique challenges faced by those populations. Many cited that the lack of translated information caused panic and confusion over the changing information related to the COVID-19 virus and vaccinations. These delays threatened their family's safety and health. Accessible and multi-language information needs to be released in a timely manner by the Pennsylvania Department of Health so that all Pennsylvanians have access to important information pertaining to their health and well-being.

Solution 10) Remove disability as a metric in determining Quality-Adjusted Life Years (QALYs) during times of health care rationing decision-making to ensure equitable triage of care.

With the sudden onset and escalation of the COVID-19 pandemic, many health systems in the US found themselves overwhelmed and unprepared for the sheer number of patients needing care. Furthermore, many of these patients had a severe case of the virus and needed life-saving measures, such as ventilators, to help keep them alive. With the sudden number of patients, hospital systems needed to ration their ventilators. Many hospitals relied on a metric called Quality-Adjusted Life Years (QALYs) to determine which individuals would be receiving lifesaving support. QALYs routinely assign a lower utility to people with disabilities based on inaccurate notions that people with disabilities live a lower quality of life than those without disabilities.

Conclusion

Based on information collected over this project, it is evident that policy changes must occur so that people with disabilities have access to adequate and accessible health care. Without these necessary changes, health inequities will continue to persist for years to come. Learning from the experiences faced by people with disabilities and their families during the COVID-19 pandemic is essential when developing and implementing policy change. The achievement of health equity and the focus on improving health outcomes in the disability community must be at the forefront of Pennsylvania's priorities.

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