

# **A FAR CRY FROM FAIR: Health-Care Access for People with Disabilities**

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## Dedication:

This report is dedicated to the many people with disabilities, allies, and advocates, who have taught us so much and who continue to catalyze change.

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## Introduction

Disability advocates have been organizing to improve access to health care for decades. More than twenty years ago, in the early years of our foundation but almost a decade after the passage of the Americans with Disabilities Act, FISA staff were guests in disability-centered spaces focused on the stunning failures of the health-care system to meet very basic access needs. We learned that few medical offices or hospitals had adjustable-height exam tables or any other means to allow safe transfer for patients who couldn't "hop up" to be examined. Many wheelchair users were not weighed and could not get mammograms or other diagnostic tests because equipment required standing. Forms, prescriptions, and patient teaching materials were available only in small print, making it impossible for Blind people or those with low vision to manage their own health care. In 2024, these barriers remain.

In the intervening decades, the National Council on Disability (NCD), Federation of the Blind, Access Board, ARC, and many other disabled-led groups have championed initiatives, issued recommendations, and called for changes to policy and practice (1–4). People with disabilities and their allies have invested in coalitions and fought tirelessly for systemic reforms. Passage of the Affordable Care Act and the expansion of Medicaid in some states have been critically important in expanding coverage for people with disabilities and eliminating

preexisting condition denials for the millions of Americans who live with chronic health conditions (5).

Still, after decades of concerted effort, people who live with all types of disabilities endure bias from health-care providers and encounter myriad barriers in seeking and receiving patient-centered accessible care, accessing health-related information, communicating with their providers, navigating physical environments, and affording the high cost of care. Singularly or cumulatively, these barriers negatively impact physical and mental health and well-being, economic stability, employment, independent living, and relationships with family and friends.

The pervasiveness and consistency of these experiences; the casual, routine violation of federal civil rights and obligations; and the callous indifference that people with disabilities regularly report in seeking health care are extensions of historic patterns of ableism built into the fabric of U.S. health care from its beginnings. This history was carefully documented by Mary Crossley, in her 2022 book, *Embodied Injustice: Race, Disability, and Health*, which chronicles the history of medicalized exploitation of disabled people, and the compounded discrimination experienced by people of color with disabilities (6). Her work spotlights repeated examples of the devaluing of people with disabilities, including involuntary and nonconsensual experimentation on residents of institutions, “selective nontreatment,” infanticide of babies born with disabilities, eugenics, and forced sterilization.

As a field, medicine has done little to counter ableist beliefs that characterize the lives of disabled people as less-than or burdensome. Nevertheless, some health-care providers, researchers, administrators, disability advocates, and legislators have advanced quality, accessible, patient-centered care within this flawed system. They have piloted model programs and clinics, rewritten curricula, trained health-care professionals, advocated with insurers, listened and made phone calls, and gone the extra mile to do what they thought was right. We acknowledge and lift up these exceptional examples while maintaining that, as a human right, health care should not depend on the extraordinary efforts of select individuals but should instead be reconstructed to serve everyone fairly and equitably.

This report highlights the barriers that people with disabilities must still contend with to successfully navigate the health-care system. It gathers and summarizes the published research and adds the voices of local people with disabilities to the broader national conversation. It is a call to action to remake our health-care system to center the humanity of patients, including those living with disabilities, so we can all live our best and healthiest lives.

Kristy Trautmann  
Executive Director, FISA Foundation

# **A Far Cry from Fair: Health-Care Access for People with Disabilities**

Everyone deserves health-care services that prevent and treat illness and promote health and well-being.

Unfortunately, the United States health-care system does not provide adequate access to these services and is not designed to provide all people with equitable care. This report explores the barriers and obstacles that people with disabilities report in seeking and receiving health care. By drawing on research literature in the U.S. and citing the experiences of disabled people and their caregivers gathered from interviews in southwestern Pennsylvania, we will explore numerous barriers to accessibility, pervasive bias on the part of health-care professionals, and financial barriers to care. These patterns of discrimination, whether conscious or unconscious, are disturbingly commonplace and are referred to as ableism, which is discrimination and prejudice against people with disabilities. Ableism is rooted in the belief that typical abilities are superior (7) and that people with disabilities are less valuable or useful, are less deserving of resources, and have a poor quality of life. Ableism is deeply embedded in our society and systems, including the health-care system. Examples can be seen throughout this report and include failure to provide complete care because adaptive equipment is unavailable or perceived as too difficult or time-consuming to use, withholding certain treatments from patients with disabilities, and attributing symptoms of a treatable illness to a known diagnosis without thorough investigation.

Bias in health care is not unique to people with disabilities. Racism, sexism, heterosexism, transphobia, and other forms of discrimination permeate the system and impact access to care. Because people with disabilities often need a variety of specialty and recurring services in addition to the routine and preventive health care needed by people without disabilities, they have greater exposure to the health-care system and are more likely to experience bias due not only to their disability status but also due to membership in other marginalized groups. As a result, health care for people with disabilities is woefully inadequate, and the care received is often of poor quality and potentially harmful. These unfair differences in care can and do lead to differences in health outcomes (known as health disparities), unnecessary complications, suffering that could have been avoided, and death. This report aims to provide a brief but comprehensive summary of the experience of accessing health care as reported by people with disabilities.

## **What We Did**

To describe the experience of accessing health care for people with disabilities in the United States, we conducted a systematic review of published research on access to health care from the perspective of people with disabilities or their primary caregivers from 2014 onward in the United States.



We also incorporated local voices and emphasized barriers to accessing healthcare by conducting semi-structured interviews with twenty-one people with a range of disabilities, identities, and backgrounds living in and utilizing health-care services in the Pittsburgh, Pennsylvania, area from September through December of 2022. See [Appendix 1: Methodology](#) for more details about the construction of this study.

<Text box 1>

**A note about language:** FISA Foundation recognizes the importance of language to affirm disability rights and justice and recognizes that the disability community has varied preferences on terminology. In this report, we alternate between person- first language (“person with a disability”) and identity-first language (“disabled person”). The terms are used interchangeably to acknowledge that these varying preferences exist.

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## **When Health Care Is Not Accessible, There Are Widespread Consequences for People with Disabilities**

The studies that we reviewed and the people we interviewed reaffirm that access to health care is limited and unjust for people who have disabilities and that restricted access has broad consequences. Notably, when accessing health care is difficult or the care inadequate, it

not only threatens physical health outcomes but also decreases mental and emotional well-being, drains individual and societal resources, and negatively impacts trust in health-care providers, careers, financial stability, and personal relationships (8–16). Here is what people with disabilities told us, in their own words, about how the barriers to care described in this report affect their lives.

### **Poorer Health**

“So, I have urinary supplies. I'm supposed to change them out once a week, but I only get two a month [...]. And then also, I have an ostomy, and I only get 20 changes a month, so [I've] got to be careful with that as well. [... It is] very frustrating. Because also, if I could change it once a week, that might also cut down on the infections.” Young white woman with physical disabilities

### **Distrust of Health-Care Systems and Providers**

“But I'm just so anxious because of the way I've seen my mom get treated in health-care facilities because she's Black and disabled. And I have seen the worst experiences. She's been in hospitals and had nurses just outright push her out or being really rejecting and rude.” Black nonbinary person with multiple disabilities

“I mean, there's so many things involved, that's really exhausting. And sometimes I have to think about, is it going to make my health worse to push myself [and] go to see this doctor who may or may not be helpful? And I mean, an appointment for me can just make me crash the rest of the day because [... of] the sensory overload and

just all of it is really exhausting.” White gender-nonconforming person with physical disabilities

## **Financial Strain**

“Financial barriers are number one. My husband and I are over-income and we have to [pay] out of our pockets to provide services to our son, and we can’t afford it. Insurance covers limited services, and we are at a deficiency in giving our son what he needs.” Parent of child with intellectual and developmental disability, as reported in the literature (15)

## **Relationship Complications**

“It was hard when his dad and I were divorced when [our child] was less than two, because [his father] couldn’t handle[having] a child with a disability, because it takes so much of your time.” Mother of a child with disabilities living in a rural area, as reported in the literature (16)

“My husband and I, we weren't married then at that point. But I really started to see how [my health-care experiences] started to affect him mentally and physically. And it's really hard [...]. Everything just went downhill. And it was [...] just like, ‘I can't give up. If he's not giving up on me, then I can't really give up on myself.’” Young multiracial woman with physical disabilities  
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## **Disability Is More than a Diagnosis**

Disabilities are a common and natural part of being human. As many as one in four adults in the United States has some type of disability (17). Disabilities may be present at birth or arise later in life, they may be temporary or lifelong, and they may be visible or invisible to others. There are many ways to think about and understand disabilities, and these views matter because they influence how a society values and treats disabled people. In turn, the way a society treats people with disabilities can create or eliminate barriers to participation in community life and access to health care.

The United States health-care system is built on a foundation that views disability as a problem with an individual's body or mind that needs to be fixed or cured. Known as the medical model of disability, this framework considers disability to be a poor health outcome or a treatment failure. Because most medical training still relies on this model, health-care providers are most likely to understand disability as the consequence of a medical problem that needs to be evaluated, diagnosed, treated, and, if possible, cured. Framing disabilities as problems often leads to treating people with disabilities as problematic and results in health-care systems and staff that are fundamentally unprepared to engage appropriately with disabled patients or to promote the health and well-being of people with disabilities.

There are other models that frame disability as a natural part of the human experience and emphasize the role of

society in the creation of barriers that prevent people with disabilities from fully participating in daily life. A person may have a condition or diagnosis, but the degree to which they can participate in the community may vary depending on its accessibility. For instance, use of a wheelchair and access to ramps, elevators, and curb cuts promotes community engagement and independence while uneven sidewalks, lack of accessible transportation, and steps create barriers that restrict independence and reduce the quality of life of people with disabilities. The International Classification of Functioning, Disability, and Health (ICF) is a model of disability developed by the World Health Organization that understands disability as an interaction of a person's health status and the physical, sensory, and social environment in which they live (18–20). Notably, the United Nations uses a similar model, defining people with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (21).

Familiarity with different models of disability can broaden the understanding of health-care professionals about what an individual needs to live a healthy life. Better awareness of the social and environmental context of living with a disability allows health-care providers to address the full range of factors affecting a patient's health, leading to more comprehensive, patient-centered care. When the medical model reaches its limits in treating a specific diagnosis, leaning on other models of disability

encourages providers to listen to patients' experiences, collaborate on solutions that address external barriers, and support individuals with disabilities to live healthy lives. See [Appendix 2: Models of Disability](#) for more information about the medical, social, minority, and biopsychosocial models of disability.

## **People with Disabilities Report Three Key Problems Accessing Health Care**

In both the published literature and the local interviews, people with disabilities report that health care is not accessible, that ableist bias and discrimination are pervasive among health-care providers, and that health care is too expensive.

### **Problem 1: Health-Care Services Are Rife with Accessibility Barriers**

Disabled people navigating the health-care system encounter multiple failures to meet their basic accessibility needs. Buildings and equipment are not designed to be accessible to everyone, care and services are not located conveniently to the people who need them, and transportation is inadequate. Many clinics are unprepared to make even the legally required accommodations for people with disabilities, health-care providers lack sufficient knowledge to comprehensively treat patients with disabilities, and all of this takes place within a health-care system that is complex and difficult to navigate. All of these factors merge to prevent people with disabilities from getting the health care that they need and deserve.

These experiences are explored in more depth below, with examples and quotes provided by people with disabilities.

## **Inaccessible Buildings, Equipment, and Services**

People with disabilities report that inaccessible buildings and physical environments are barriers to obtaining appropriate care. For example, health-care services are provided in spaces with inaccessible entrances, narrow hallways, and waiting areas too small or too crowded to maneuver mobility equipment. They may lack ramps and elevators or place these accommodations out of the way, requiring further travel (15,22).

“The chairs [in one waiting room] were too close the way it was arranged. And then they had an alternate waiting room, and the [wheel]chair didn't fit [through the door]. So we rescheduled the appointment.” Black woman who provides care to her sister who uses a wheelchair

Offices routinely lack such things as clear signage, large print or braille forms, interpreter services, or sound amplification equipment, and they use systems that do not accommodate sensory disabilities, such as door buzzers to get inside or calling names in the waiting room.

"I'm pretty independent. But unfortunately, when you're talking about even simple things, like say there's like 200 people in a crowded waiting room, and they call your name... I just wasn't getting it

because I couldn't lip-read through the mask. They tried to say, 'Well, you missed your appointment.' 'Well, I was sitting here. Nobody told me.'" White woman who is deaf

"I went to the ophthalmologist. I was given a short survey form while waiting. It was in a very small font, so I said, 'Why don't you put this in large print? You know, you are the ophthalmologist.' They said, 'No.' So, I feel like I could not survive anywhere." Woman with low vision, as reported in the literature (23)

Health-care spaces also frequently include unnecessarily overstimulating sensory components like crowded waiting rooms, bright lights, and loud televisions, which are difficult to anticipate and difficult to work around (15,22).

"[Physical barriers] are significant issues. But I feel like you can call and say, 'Do you have steps getting into your office?' Right? It's a little bit harder to call ahead and say, 'Am I going to be overstimulated in your waiting room because it's a disaster?'" White gender-nonconforming person with physical and neurological disabilities

Accessible equipment such as adjustable-height examination tables, wheelchair scales, and flexible diagnostic equipment are not routinely available, which leads to poor-quality care and unmet screening needs (24–27). A survey of 1,159 people with long-term physical



disabilities such as multiple sclerosis, muscular dystrophy, and spinal cord injuries identified the most common access issues as the absence of a lift or other equipment for safe transfer to the exam table (69%), no method for weighing people who use wheelchairs (67%), and no adjustable-height exam table (44%) (27). Similarly, in a survey of 118 women with cerebral palsy, 59% reported that wheelchair-accessible mammograms were not available to them (28).

“They don't have a wheelchair scale in preop. [...] You're a children's hospital. How do you not have a wheelchair scale in preop? [...] Even his pediatrician's office doesn't have a wheelchair scale. And we were there today, and he told his pediatrician, he said, ‘You need to get a wheelchair scale. I'm not a baby. I don't want to sit on the baby scale.’” White mother of a child who uses a wheelchair

Important information about health and health care is often not accessible (29–34). Even where legal requirements to provide information in accessible formats exist, they are often ignored. One of the people we interviewed shared that they need to use a screen-reader application when seeking information online, but websites and other resources that impact their health are often not designed to be compatible with these types of assistive technologies. Finally, even when appropriate accommodation tools are present, staff may not use them or use them inappropriately, suggesting that the

availability of accommodating equipment is not sufficient (24).

## **Inadequate Transportation**

In 2017, 5.8 million people in the United States did not get needed health care due to lack of transportation, and people with disabilities were 2.6 times more likely than those without disabilities to report this barrier (35).

Challenges with existing travel options were frequently reported by people with disabilities throughout the literature and in our local interviews (9,15,16,36). Standard personal vehicles are inaccessible to many people with disabilities and may require modifications that are not covered by insurance and are financially prohibitive (37). Public transportation systems, where they exist at all, may be too far from the individual's home, be difficult to use, or lack necessary accessibility features such as wheelchair ramps or lifts, designated seating, or accessible signage (9,38). Both public and specialized transportation services are frequently unreliable, require significant wait times, and may rely on staff unfamiliar with disability accommodation.

Notably, many of these problems are amplified by geographic location (10,37,39). Health-care resources and services tend to cluster in highly populated urban centers and may not be available in rural areas at all, leading to lengthy travel times or lack of care (40). In addition, few public transportation options are available in many rural areas.

“I mean there were days [local transportation] just did not come or if you went to your appointment, they leave you and it might be four [or] five hours before they get you and you [are] stuck at [the] health facility.” Parent of a child with disabilities, as reported in the literature (16)

Despite transportation being a very common and well-documented barrier for people with disabilities, the health-care system routinely fails to accommodate or even acknowledge the problem, compounding access issues. Providers only rarely employ mitigation measures that challenge health-care norms, such as grouping appointments, co-locating important services, providing care coordination and transportation assistance, or scheduling clinics in a way that provides some flexibility for arrival times (41,42). Rather, the very real difficulties inherent in the transportation situation are ignored, and patients with disabilities are blamed or even punished when providers are inconvenienced. Being late and rescheduling appointments are framed as character flaws or evidence of a lack of respect for the provider, and the patient’s commitment to their own health is questioned. Some health-care providers refuse to see patients who arrive late, and some deny future appointments if prior appointments have been missed.

### **Health-Care Professionals Unprepared to Provide Accommodations**

Many clinical settings have inadequate policies to guide accommodation, do not understand even basic

accessibility needs, and are not willing to adapt or make accommodations. Additionally, many are not fully prepared to collaborate with patients or to share decision-making about how best to meet their needs.

“For example, there was a new dentist in town, and I did call and ask if [they will] see a child with special needs. When you call, they say yes. So when we drove there with [child's name] with a wheelchair, at first [...], they seemed ok. But then [child's name] [was] getting nervous and start[ed] shaking, [and] they wouldn't see him.” Parent of a child who uses a wheelchair, as reported in the literature (16)

Providing high-quality care and accommodation to people with varied and complex needs often requires advanced planning and provider preparation. Scheduling extra time for an appointment, arranging an interpreter, and putting adaptive equipment in place are all standard accommodations that must be planned for in advance. However, most providers do not routinely ask patients if they need accommodation, do not prepare in advance to provide needed accommodation, and have no system in place that would allow them to do so. Typically, there is also no obvious way for patients to begin this conversation prior to an appointment and no centralized way to get answers to questions pertaining to access and accommodation. Instead of the health-care system being responsible for collecting and recording information about a patient and making appropriate accommodations, people with

disabilities are left to “get by” and “make it work” and manage the logistics of accommodation as best they can.

"You have to make an appointment and then you have to educate them and to remind them to start searching for an interpreter. [...] They have to locate an interpreter and coordinate schedules and all of that. So we can't really as Deaf people have any kind of emergency or any kind of last-second meetings because there's never an interpreter available." Deaf woman, as reported in the literature (37)

Rigid scheduling practices lead to rationing of care for people with disabilities as there is not sufficient time in a standard appointment to fully provide accommodation, address medical concerns, discuss treatment options, and answer questions. People with disabilities often report that they need more time with their health-care providers than is allotted. Many people we interviewed shared that their appointments often took more time than was scheduled due to factors such as the space being difficult to maneuver with a mobility device, accommodations requiring additional time, and staff not knowing how to use accessible equipment or communication tools. Challenges like these sometimes led to providers and staff becoming frustrated, allowing less time to discuss medical concerns, providing lower-quality care, or refusing to provide care at all. Unsurprisingly, 30% of people with intellectual and developmental disabilities report insufficient time with a provider as compared to 8% of people without disabilities

(43), and inadequate time with providers significantly detracts from the quality of care received (44,45).

“It’s like I feel like they’re pushing through. It’s the numbers game. They’re trying to see as many people as they can, as quickly as they can, and they want to get out of the room as soon as possible.” Black woman with physical disabilities

### **Doctors Without Basic Knowledge of Disability**

Health-care providers typically have limited knowledge about disabilities and how to provide care that meets the unique needs of patients with disabilities (26,44,46–50), and in turn people with disabilities are up to three times more likely to report dissatisfactory interactions with their provider than people without disabilities(51). For example, a survey of 432 adults who use wheelchairs found that 54% of participants reported not being provided complete care by a physician because of their disabilities. Among 126 pregnant women with physical disabilities, 40% believed that their prenatal care provider initially knew very little about the impacts of their disabilities on pregnancy (26). In a national survey of 1,551 families of youth and adults with autism spectrum disorder, 40% reported that their physician did not understand the diagnosis (46).

“I thought doctors knew everything at first. All doctors knew everything. But... they don’t know. They don’t know about disability.” Hispanic woman with physical disabilities, as reported in the literature (52)

Sometimes providers are reluctant to diagnose and treat routine illnesses when the patient has a disability. Ordinary problems like ear infections, typically easily treatable by an office or urgent care visit, become much more complicated.

“When he would get ear infections and stuff [...providers] would freak out about the fact that he had a transplant, ‘Oh, I don't know if we can do that. You might have to go to the ER.’ And I'm like, ‘Can you just check for the ear infection? It's just an ear infection.’ [...] And that was frustrating because he had so many ear infections and I did not want to go to the ER just for an ear infection. So that happened a few times until we finally found a PCP. I called around. [...] I said, ‘I need somebody [laughter] who is not scared of a child who's had a transplant and can see him for just normal everyday issues too.’” Middle Eastern mother of a child with physical disabilities

The significant burden of educating providers about disabilities, how to treat them, and how to navigate the complicated system of needed services often falls to the person with disabilities.

“I feel like I have to do so much of the legwork just [...] trying to figure out my symptoms and what might be going on with me or what kind of test I might need. A patient shouldn't have to do all that by themselves. That should be the doctor's work.” White woman with physical disabilities

Similarly, the caregivers of children with disabilities take on the role of information gathering and educating their child's provider, which impacts their peace of mind and ability to spend time on other things or with their child.

“It just takes over everything. I'm constantly in a fight-or-flight state, and I have no time to exercise or take care of myself or just not be angsty about...It's hard to find a balance. So yeah, if I had somebody that I could trust to be up to date on all of the science of it and the choices I have and who accepts insurance and who doesn't, that would take a huge part of my day off. I can actually focus on the child.” White mother of a child with physical disabilities

When doctors do not seem to be working together or to have background knowledge pertinent to their care, patients worry that they will not receive the care they need.

“I've had some [doctors] that [...] didn't even understand the test that I had had ordered by another provider. They were like, ‘Oh, I've never even seen these tests.’ That's scary for me because they're supposed to be the experts. Yeah, that's a little, that feels weird. And I don't have much confidence in their ability to actually help me if they're intimidated by how complex it is.” White gender-nonconforming person with physical disabilities



## **Coordination Challenges and Long Waits**

People with disabilities often require a broad range of health-care services to manage their health. In addition to primary care providers, they may see multiple specialists, utilize a range of therapies, and require various types of support. Due to our fragmented and siloed health-care system, accessing and organizing services can be exceedingly difficult and time-consuming. At the same time, very little coordination support is available, and the responsibility for coordinating communication across systems, sharing information, and planning for care has largely fallen to people with disabilities or their families (9,25,53–55).

All of this takes time, and long waits are a common occurrence for people with disabilities (15,22). The limited availability of high-quality, accessible care and the extra time and energy required to find, coordinate, and otherwise navigate a hostile system can be significant (38,56) and lead to incredibly long waits for care (10,57,58). A third of adults with disabilities report that the amount of time they have to wait for care across services and specialty types is a cause of stress and a barrier to achieving and maintaining good health (15,22). Patients wait for next available appointments, insurance authorizations, referrals to specialists, and prescriptions, and they report that the time required to reach a diagnosis and solidify a treatment plan is too great.

“The wait is too long, especially for the level of pain I am in. I need to be able to ask as many questions as I

want at my appointment. They need to actually help me rather than making me make numerous appointments which are hard to manage and get to.” Patient with public insurance, as reported in the literature (54)

“When I got out of the hospital, I didn’t have any meds and they said, ‘Go to your primary care, they’ll refill them.’ I went to my primary care, and she goes ‘We don’t refill prescriptions from other doctors.’ And I’m like what am I supposed to do? ‘Find a psychiatrist.’ There’s a four-week waiting list. Well, I can’t wait four weeks for my meds.” Person with mental health disabilities experiencing homelessness, as reported in the literature (13)

Waiting for needed medical equipment is especially frustrating.

“It takes forever to get your equipment, even for a repair. My son's battery pack on his power chair has been acting up and glitchy for weeks. We ordered him [...] a new battery pack. [...] ‘The power died. This is his legs. What do you mean that it's weeks that he has to be pushed around because his power dies?’ And he's upset about it too. He cries about it. He gets really upset. He's like, ‘My chair isn't working.’ And he's upset. Because how would you feel if you were stuck in one spot? [...] And you can't drive to where you want to [...] get to, and you're relying on somebody else to move you across the room because

your battery died, and it takes weeks and weeks and weeks to get a replacement battery. [...] This is their independence. This is just unacceptable.” White mother of a child who uses a wheelchair

## **Problem 2: Widespread Bias Compromises Care**

Health care is rife with bias and discrimination. Across many studies and interviews, people with disabilities report encountering providers who demonstrate ableist bias, making comments and sometimes clinical decisions based on assumptions about the capabilities, quality of life, or health-care needs of people with disabilities (23,24,37,45,48,52,55,59–62). New symptoms are attributed to a known diagnosis rather than investigated thoroughly, and providers may not follow standard treatment protocols, make appropriate referrals, recommend specific services, or order standard screening tests for patients with disabilities (26,53,63). For example, in a study of 432 adults who use wheelchairs, 40% reported they had not received age-appropriate bone density tests because their physician never recommended it (26). Being provided with less care or denied services altogether due to disabilities was frequently reported in the literature (25,26). In one particularly egregious example, 126 pregnant women with disabilities were surveyed; 46% reported having difficulty finding a prenatal provider due to their disabilities, and 35% received a negative reaction to their pregnancy from their health-care provider (25). People with disabilities report that such bias and discrimination are so common they are routine.

“[Being treated differently], it just made me not want to pursue help right away. I mean, that's already something that occurs within a Black community, right? It's already expensive. You're going to be there waiting. It's like you already know the staff are not going to be that pleasant to you. [...] And it's just like, ‘Okay. I've seen how this person has been treated. I've heard their story.’ And it's just like it also embeds a lot of fear.” Young multiracial woman with physical disabilities

Such attitudes impact the provider–patient relationship and the delivery of person-centered care, frequently leading to discriminatory practices and neglect of certain health-care concerns. People with disabilities frequently reported feeling “abandoned” and “brushed off” by their providers (23,45,52,64,65).

“Doctors would say everything from like, ‘You're faking it,’ or ‘This was caused by a psych med. So clearly, it's just in your head,’ whatever. And people would just refuse to actually do anything about it. And it was so incredibly painful, and I just kind of had to watch as they were like, ‘Yeah, okay.’” Young, queer white man with multiple disabilities

Experiencing discrimination and the resulting lack of care can lead to people with disabilities having difficulty trusting their care providers and the care they are given. They find

it challenging to advocate for themselves and the care they need while also worrying about alienating the providers whose sympathies they feel they need.

“We [people who are neurodivergent] have needs, and we need accommodations, and sometimes, [...] I'm too nervous to advocate for it sometimes unless somebody's like, ‘Do you need anything?’ And it's really nerve-wracking. Black nonbinary person with multiple disabilities

“I'm afraid of feeling completely powerless. There have been times where I've most definitely been discriminated against or mistreated or whatever by health-care providers. And I have, a few times, tried to file a grievance or whatever it's called, and it goes nowhere. And it just kind of cements that powerlessness. And I remember one time even being told by someone I should be really careful about filing grievances because that's going to go on my record, and then no one's going to want to treat me.” Young, queer white man with multiple disabilities

It can also lead to a lack of confidence in the person's own perceptions of their body, as provider after provider fails to take concerns seriously or implies that problems are not real (37).

“[The experience of being unable to get needed medical care was] very detrimental to my mental well-being in my 20s, 30s, and 40s for sure, because it

makes you question yourself, too. I mean, you're like [...], you're going to doctor after doctor and they're just dismissing you, then what's the common denominator here, right?" White woman with physical and mental health disabilities

Notably, because people with disabilities are often also members of other minoritized groups, ableism is frequently compounded by racism, heterosexism, transphobia, classism, and other forms of bias and oppression. Being multiply marginalized can increase exposure to discrimination and intensify the impact on health-care outcomes.

"So I wish things could be different for [my sister], but I don't think... I think, just like everything else, if you want to exclude somebody or make something hard, you can. Some doctors use [my sister]'s disability to make it hard for her, but those are the same people who will use [...] my color to make it different for me, or use you being [a] woman to make it difficult for you." Black woman who provides care to her sister who uses a mobility device

"And the problem is, with discrimination, you never know why. You don't know which thing it is. Do they not like other women? Do they not like Black people? Do they not like disabled people? Yesterday, [I] went to go get a procedure done. It turned out they didn't take my insurance. [...] So this lady proceeded to speak to the guy who was with me. And he was just

the guy who had driven me and he rolled me in there. He was the person who just helps from the facility. She proceeded to talk to him. And I'm like, 'Hello?' And she's like, 'Well, does she?' I'm like, 'I'm right here. I can answer your questions.' She's like, 'Oh, okay.' But why assume that I couldn't? I felt like he was white. He was male. So she was going to defer to him first because she saw him as the authority. And he was standing. He was able-bodied. So it could have been all three of those. He trumped me. [...] He trumped me on all three areas. Color, gender, and mobility. So she felt he was the person to talk to instead of me about my own appointment and my own body. What the heck?" Black woman who uses a wheelchair

Navigating this system drives many patients to take on extra preparatory work in an effort to be perceived as more worthy of care, more "likeable," or more sympathetic than they might be otherwise. Patients with disabilities and other marginalized identities report that they spend extra time and energy attempting to obtain the same quality, patient-centered care routinely given to others.

"If you go into a hospital on Medicaid, on disability... in something grubby or dirty, with my hair not done, and my jewelry not on, I'm going to get treated like shit, and I know that... So what I need to do before I go to any hospital is to make sure I've got my middle-class face on and my tattoos mostly covered and dress nice and go to a suburban hospital because if I go to the

hospital closest to my janky house, they're going to say I'm welfare and I've got the mental health diagnosis [...]. It's going to be problematic, and I'm going to get treated like a drug seeker, even if I was in there for diarrhea.” White autistic woman

## **Problem 3: Health Care Costs Too Much and Other Financial Barriers**

**<Bar chart>**

### **Annual Health-Care Expenditures (Medicare 2013-2015).**

A bar chart shows dollars spent annually on health-care services for people with and without disabilities, based on the 2013-2015 Medicare Expenditure Plan Survey in 2017 US Dollars (56). People without disabilities spent \$3,541, while people with disabilities spent \$16,491.

**<End of bar chart>**

While many societies consider health care to be a human right and provide it to all citizens, health care in the United States is a luxury to be purchased. Thus, the cost of care is a pervasive barrier for people with disabilities and people without disabilities alike. The reality of our capitalistic, for-profit, insurance-based system is that it seeks to increase profits and reward shareholders even when that means shifting the economic burden to patients and increasing the cost of care. As a result, patients are responsible for increasingly costly co-pays and deductibles and also for any services, medications, or



equipment that their insurance does not cover or deems out of network (54,64,66). Importantly, the costs of care are often greater and more significant for people with disabilities, who are 70% more likely than their peers without disabilities to report that they could not get health care that they needed because of the costs (67,68). This is not surprising, as half of all people with disabilities report not having enough income to cover basic needs such as food, housing, childcare, and transportation, yet must typically spend two to four times as much on out-of-pocket health-care costs than their peers without disabilities (8,66). This forces very difficult decisions about which needs to prioritize.

“When it comes to choosing groceries or co-pays, I have to choose food.” Woman with disabilities living on less than \$30,000 per year household income, as reported in the literature (23)

“Yeah, there's been situations where I just couldn't go to an appointment or get a test done that a doctor ordered because I couldn't afford it. I just straight up couldn't, and I had to skip it, and that's never good. It sucked being in that kind of situation.” White woman with physical disabilities

Health insurance plans often do not cover all needed care, and not all insurance types are accepted by all health-care providers. Across published research and participant interviews, people with disabilities frequently reported needing health care that was not covered by

their health insurance policy. This uncovered care included preventive care, hearing aids, portable oxygen, diabetic shoes, rehabilitation therapies, genetic screening, bed pans, contraceptives, and alternative brands of medications or equipment (27,50,54,69).

“In order for him to qualify for the adhesive pads that go over his back for bed sores, [he must already have bed sores...]. Because he has almost no meat back there anymore, he's in pain a lot. He's uncomfortable a lot. Those pads help [...] keep him from being uncomfortable, but they're really intended to heal bed sores. And they keep him from getting bed sores when we keep him protected that way. [...] And we keep saying if he could have those pads on him all the time, he doesn't develop bed sores. And so it's preventive. And they said, ‘We don't pay for preventive. We only pay if it's already a problem.’”  
Wife of a white man over age 60 with physical disabilities

In addition, insurance policies are not designed to be easy to understand, and information about what services are covered and how to access them is often not readily available. To take full advantage of their benefits, people with disabilities must have an in-depth understanding of their insurance policy coverage. This includes knowing their in-network providers, how and when to qualify or re-qualify for care, and what their co-pays and deductibles will be across different service types and in relation to the fiscal year (38,54). Quite often, they must also know their

rights as a patient and how to advocate for the provision of needed care. While people without disabilities can certainly relate to the difficulty of arranging care within a complex web of insurance coverage, this becomes a larger burden for people with disabilities, who typically require a broader array of services.

“And the nightmare of finding a supplier that not only took [insurance] but also medical assistance [...] and you end up with this very narrow little place... was difficult. I mean, we literally spent hours and hours and hours. [...] And then there were gaps in supplies getting there, and then it's a rush to try to figure out how you get supplies to tide you over when you're already on a limited income. I mean, it was such a nightmare. [...] It may seem like a little thing, but it was a huge, huge thing.” White mother of adult children with disabilities

Finally, the time required to navigate these challenges further increases the cost of care for people with disabilities by limiting their opportunity to engage in paid work (38,56).

“Well, this also goes into life with a disability. Since we had our son, who has spina bifida, only one of us has worked full-time specifically because there's only so much time you can take off. There's only so much that you can miss before it's just... If I was working full-time... it would be nearly impossible because you're always missing for something. [...] It's a

financial hit that people don't talk about.” White mother of a child with multiple disabilities

## **Barriers Compound and Intersect, Creating Additional Barriers to Care**

People with disabilities contend with health care that is inaccessible, fraught with ableism and other biases, and incredibly expensive. Among the access barriers they encounter are blatant failures to meet even their most basic accommodation needs, difficulty getting to where services are located, and providers who are unprepared or unwilling to treat patients with disabilities respectfully and comprehensively. While every one of the experiences described above creates an access issue that can lead to an avoidable medical complication and unfair outcome differences, they also have a cumulative impact. The experience of one barrier leads to additional barriers, which collect and magnify each other, making the process of accessing health care more difficult over time.

For example, many facilities that provide health care lack a wheelchair-accessible scale, which in itself is a barrier to appropriate care. A patient who uses a wheelchair and needs certain types of care now needs to travel farther to a different provider that does have the necessary equipment but is not accessible by public transportation, creating a transportation barrier. The patient may have to pay out of pocket for specialized transportation, which creates a financial burden. Travel time to the farther facility coupled with standard hours of operation also necessitates more time off from work, complicating

financial barriers and creating employment-related challenges. Traveling outside of their preferred neighborhood may increase the likelihood of racism, heterosexism, or other discrimination. All of these things cumulatively impact a patient's access to care and thereby endanger their health and well-being and their ability to participate in community life.

“And I think it is for all disabled people because we aren't just disabled. We're also disabled and women. We're also disabled and racially classed. We're also disabled and fat or disabled and very thin, disabled and visibly queer, disabled and trans, or combinations of all of those things. And you can't always separate them out. And if we are disabled officially and living on Social Security or SSI, then we're also disabled and poor. And that also has a huge impact on quality of care and ability even just to get to appointments sometimes because you don't have money for an Uber or whatever. So, it's always difficult for me. And we have these conversations within disability circles of how do you find culturally competent care for the disabled part of you, but also this part of you, the that part of you, and to put it all together. And it's an impossible puzzle.” Black nonbinary person who cares for their mother with disabilities

While compounding access barriers affect everyone, people with disabilities have broader contact with the health-care system and experience more barriers when accessing care and are thus disproportionately impacted.

## Barriers People with Disabilities Experience While Accessing Health Care

A flowchart outlines obstacles that people with disabilities face throughout the journey of receiving health care. There are 6 different touch points identified in the journey of receiving healthcare that are outlined below: Health management, Diagnosis, Finding Care, Getting to the Care, Receiving Care, and Outcomes.

### 1. Health Management

- Symptom/Problem
- Preventive Care
- After experiencing a symptom/problem or seeking preventive care, barriers that prevent a timely diagnosis include: access to information, inaccessible equipment, provider bias, lack of training, and costs.

### 2. Diagnosis

- Screening
- Evaluation
- After a diagnosis, barriers that interfere with finding care include: access to information, waiting lists, coverage/qualifying (insurance), and denial due to disability.

### 3. Finding Care

- After finding care, barriers that interfere with getting to the care: planning for access, time spent traveling, and transportation.

### 4. Getting to the care

- After getting to the care, barriers that interfere with receiving care: Provider bias, inexperience with disability, lack of accommodations, and inaccessible environment.

### 5. Receiving Care

### 6. Outcomes

- Access barriers outlined from point 1 to point 5 can lead to the following outcomes:
  - Unmet needs
  - deteriorated health
  - decreased mental and emotional well-being
  - loss of trust in the health-care system
  - increased costs
  - disrupted employment
  - financial strain and
  - relationship complications.

## In Conclusion

“[When my health care did not meet my needs, I felt] intimidated, uncomfortable, and I guess scared.”

Black nonbinary person with multiple disabilities

This report summarizes the experience of accessing health care for people with disabilities as reported both in the published literature and by individuals living in the Pittsburgh area. People with disabilities face numerous barriers when they try to access and engage with the health-care system. Ableism, racism, sexism, heterosexism, and other forms of discrimination combine with inaccessible environments and excessive costs to severely and disproportionately restrict access to care for people with disabilities. As a result, people with disabilities report worsened health, increased care requirements, distrust of providers, financial strain, and relationship complications. Inadequate access to health-care services over time inevitably leads to unfair differences in health outcomes, unnecessary complications, avoidable suffering, and even death (8–16).

Despite all this, many people with disabilities expressed optimism that conditions have improved over time and that with ongoing pressure they will continue to get better.

“I don't think perfection ever exists. I think that once this problem is resolved, there'll be something else. But I think that now it's not as hard to get the care that you need [and providers have] more experience with doing care for people like [my sister]. But I also know



that people like [my sister] [...] have dealt with it for so long. [...] I mean, like a drip of water on concrete. It's subtle, but sooner or later, not only does it leave a mark, it eats at the concrete. That's how I see it. But if that drip of water stops, then nothing changes. I mean, the concrete will still be there. But it can be broken through. It can be penetrated.” Black woman who provides care to her sister who uses a mobility device

The voices and wisdom collected here join others in the disability justice movement by pointing out injustices, describing the harm done, and calling for change. Health-care systems, insurers, administrators, practitioners, funders, and policymakers should listen to people with disabilities and take immediate action to create a health-care system that provides equitable care to all people and does not discriminate against people with disabilities.

## **Closing from FISA Foundation**

When harm has been done, an essential step toward repair is to begin with fearless and unflinching truth-telling. We are grateful for the disabled people and family members who shared their stories with us in the hope that real change is possible. They shared the same themes that people with disabilities have reported for decades: consistent physical, financial, attitudinal, and logistical barriers to accessing health care. The stories in this report highlight barriers to just and equitable care: myriad problems with accessibility, pervasive bias on the part of health-care workers, and financial hardship.

### **It's time for change.**

While transforming systems can feel daunting, we are heartened by the opportunity to use this report as part of an initiative to engage the disability community in partnership with health-care professionals, administrators, insurers, and policymakers in setting priorities for system change. It is on all of us to create a more equitable and just health-care system that meets the needs of people with disabilities.

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## APPENDIX 1: METHODOLOGY

To describe the experience of accessing health care for people with disabilities in the United States, we conducted a systematic review of published research reporting from the perspective of people with disabilities. Results were screened for inclusion based on the following criteria: original research data from 2014 onward, based in the United States, and describing access to health care from the perspective of people with disabilities or their primary caregivers. Studies were excluded if they contained only the perspectives of medical professionals. Forty-seven articles were included, and their data is summarized here.

We also incorporated local voices and emphasized access barriers most salient to our community by conducting semi-structured interviews with twenty-one people living in and utilizing health-care services in the Pittsburgh, Pennsylvania, area from September through December of 2022. We talked with fourteen adults with disabilities, four people who provide care to adult family members with disabilities, and three parents of children with disabilities. This study opportunity was advertised via targeted community organizations and social media groups. Participants were recruited based on their expertise and selected for a diversity of experiences, identities, and disability types. Interviews were conducted via Zoom and lasted 60–90 minutes. Each person was compensated with a prepaid gift card.

## The People We Interviewed

### Reason for Inclusion

Adults with Disabilities	14
People who Provide Support to Family Members with Disabilities	4
People who Parent Children with Disabilities	3

### Race

White	15
Not White	6

### Gender Identity

Female	16
Male	3
Other	2

### Age

Age 60 and Over	3
Age 40–59	12
Under 40	6

### Primary Disability Type

Physical	17
<i>Mobility Specific</i>	10
Intellectual & Developmental	9
Sensory	6
<i>Vision</i>	4
<i>Hearing</i>	2
Mental Health	5

## APPENDIX 2: MODELS OF DISABILITY

Several ways of understanding disabilities are briefly described below to provide crucial contextual information for the experiences people with disabilities have accessing health care: the medical model, the social model, the minority model, and the biopsychosocial model.

### **The Medical Model of Disability**

The medical model of disability considers disability to be the consequence of a medical problem with an individual's body or mind that needs to be fixed. In this model, the focus is on what is wrong, health-care interventions are focused on a cure, and disability is considered a poor outcome or a treatment failure (70). Social and environmental aspects of disability are generally ignored. Because our health-care system was built on this model and most medical training still relies on it, health-care providers are most likely to understand disability as the consequence of a medical problem that needs to be evaluated, diagnosed, treated, and, if possible, cured. As a result, the health-care system neglects to consider how social and environmental factors impact the experience of disability (71,72).

## **The Social Model of Disability**

In contrast, the social model of disability rejects the premise that disability is a characteristic of the individual. Instead, this model emphasizes the role of society in the creation of barriers that prevent people with disabilities from fully participating in daily life. The person is disabled not by their condition or their diagnoses but by physical or sensory environments that exclude them. This focus on the causal role of the environment is key because it emphasizes that if environments were designed to be accessible and if people were treated equitably, the experience of disability wouldn't exist in the same way that it does today because people with disabilities could participate as they desire in their communities (70,73,74).

## **Disability in the Environment**

Tyesha lives alone by a busy intersection. She does not drive, but she walks with a cane to nearby shops and bus stops. She has always been able to cross the road, assisted by the traffic signals, to complete errands and to socialize. When the city decreased the crossing time at her crosswalk by 7 seconds, she was suddenly no longer able to cross in time, restricting her activities to one side of the street. Tyesha's ability to walk did not change, but the shortened time allotted for crossing the street changed her environment and affected her independence and access to the community.

## **The Minority Model of Disability**

One variation on the social model is the minority model of disability, which emphasizes disability as an identity within a social context. It underscores the bias, discrimination, and negative attitudes that further marginalize people with disabilities. People with disabilities are seen as a marginalized minority group, and ableism is viewed as an oppressive force similar to racism, sexism, or heterosexism. Advocacy and empowerment within the disability community and a push for disability justice parallel the work of lifting other oppressed groups. It is important to note here that many people with disabilities are also members of other minority groups and that having more than one marginalized identity compounds the disabling impact of marginalization and further restricts access to the community (75–77).

## **The Biopsychosocial Model of Disability**

The International Classification of Functioning, Disability, and Health (ICF) is a biopsychosocial model of disability, developed by the World Health Organization that merges the medical and social models. In this framework, disability results from the interaction of a person's physical and mental health and their environment (18). The environment encompasses the physical, sensory, and social components, including social determinants of health (the social, economic, political, and cultural conditions in which people are born, live, learn, work, and play) (19,74). It seeks to approach disability more holistically than solely as a medical problem to be solved or a social injustice to be rectified (20,72).

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