TESTIMONY OF

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ON

**BRIDGING HEALTH EQUITY GAPS FOR PEOPLE WITH
DISABILITIES AND CHRONIC CONDITIONS**

BEFORE THE

**THE COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON HEALTH**

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Introduction

Thank you for inviting me to submit this testimony. My name is Rupa Valdez, and I am an associate professor at the University of Virginia with affiliations in the School of Medicine, School of Engineering and Applied Sciences, and College of Arts and Sciences. I also serve on the Board of Directors for the American Association of People with Disabilities and as president of Blue Trunk Foundation, a nonprofit dedicated to accessible travel. However, the opinions expressed in this testimony are solely my own and do not necessarily reflect those of the University of Virginia, the American Association of People with Disabilities, or the Blue Trunk Foundation.

I have dedicated my career to studying and teaching about how people manage chronic health conditions and designing systems to support them in doing so. In particular, I have focused my work on historically marginalized communities including rural communities, communities of color, and the disability community. In writing this testimony, though, I draw not only on my professional expertise but also on over twenty years of living with multiple chronic health conditions and disabilities. I write to you as a disabled person who simultaneously experiences and seeks to address the many structural and attitudinal barriers to health equity faced by the disability community.

The barriers to health equity for the disability community are numerous and complex, spanning factors related to broader social inequities such as education, employment, socioeconomic status, and histories of institutionalization as well as factors more specifically related to healthcare delivery systems. Although all must be addressed for equitable care to be realized for the disability community, this testimony will focus predominately on six barriers that must be addressed at the level of healthcare delivery systems.

1. To address pervasive health disparities experienced by people with disabilities, the disability community must be formally recognized as a health disparity population.

Disability is not commonly included in conversations about health disparities despite people with disabilities experiencing significant and persistent disparities in both healthcare access and health outcomes. For example, the National Institute on Minority Health and Health Disparities (NIMHD), which is charged with leading research efforts to improve minority health and reduce health disparities, designates four health disparity populations: 1) racial/ethnic minorities, 2) socioeconomically disadvantaged populations, 3) underserved rural populations, and 4) sexual and gender minorities.[1] Although disability status is considered by NIMHD to be a "fundamental characteristic" that may interact with these health disparity populations, the disability community is not in and of itself recognized as a health disparity population. Consequently, disability is seldom the focus of research efforts aimed at reducing health disparities despite undeniable evidence that the disability community faces pervasive and persistent disparities.

The fact that the disability community constitutes a health disparity population that faces unique barriers to care is well-documented. One in three disabled working-age adults do not have an established primary health care provider[2] due to reasons such as physicians' lack of confidence in their ability to provide care to people with disabilities[3] as well as lack of accommodations like accessible exam tables[4] and telehealth systems.[5] Lack of access also results from broader social determinants of health such as significantly lower employment rates and socioeconomic status, resulting in financial difficulties in accessing care.[6–8] Limited access to health services results in disabled people being significantly more likely to develop poor health outcomes like the disproportionate acquisition of chronic health conditions including diabetes, obesity, and heart disease.[2] Thus, health disparities in the disability community are driven not by the original diagnosis alone but also by systemic barriers to healthcare access. The pandemic emphasized the devastating cumulative effects of these disparities: people with intellectual and

developmental disabilities are six times more likely to die from COVID-19 than other members of the population,[9] and people like me who live with more than four chronic health conditions comprise over 75% of COVID deaths in fully vaccinated populations.[10] Consequently, the specific health disparities faced by the disability community and the root causes of such disparities must be addressed explicitly.

It is only when the disability community is explicitly recognized as a health disparity population that resources can be directed to addressing its needs. For example, at the beginning of the pandemic, the University of Virginia (UVA) Health System assembled a steering committee focused on health equity. Although not originally conceptualized as a focus of the committee, when I brought the needs of the disability community to my colleagues' attention, they were eager to learn more and to work alongside community partners to co-design and implement changes. These efforts led to the organization of accessible vaccination clinics. They also led to the establishment of the Accessible Care Committee within the UVA Health System which in turn has led to multiple ongoing initiatives. While I was able to draw attention to the disability community as a health disparity population, we cannot rely on individuals within single health systems to bring about large-scale. We need systemic changes, and formally designating the disability community as health a disparity population is an essential first step.

2. Many healthcare services remain inaccessible to disabled individuals. We must enforce and expand existing legislation and regulation to be fully responsive to the needs of the disability community.

While the disability community as a whole is a health disparity population, the structural and attitudinal barriers to healthcare access are not uniformly experienced by all disabled individuals. The types of disability may be organized in many ways. The federal government typically collects information about six broad types of functional disability: mobility (13.7% of the US adult population), cognitive (10.8%), independent living (6.8%), hearing (5.9%), vision (4.6%), and self-care (3.6%).[2] Another way in which disability is often conceptualized is by type of diagnosis (e.g., autism spectrum disorder, spinal cord injury, down syndrome). People who are classified as having the same type of functional disability or the same diagnosis, however, may have different experiences of disability, resulting in different types of accommodation needs. At the same time, one design change can better accommodate the needs of people living with multiple conditions. For example, an adjustable exam table simultaneously accommodates people with mobility related disabilities, people of varying heights, and individuals who experience limited strength or dizziness. Thus, while multiple accommodations are needed to improve healthcare access for the disability community, many such accommodations would simultaneously address the needs of people living with different types of disabilities.

Although Section 504 of the Rehabilitation Act and Titles II and III of the Americans with Disabilities Act (ADA) require healthcare systems to be accessible for people with disabilities, such accessibility is rarely seen. Over 75% of individuals with disabilities report experiencing barriers that impede them from using healthcare and wellness services.[11] Moreover, one study showed that over 50% of clinical practices do not have exam tables accessible to wheelchair users and over 90% do not have fully accessible restrooms.[12] There are two reasons for these statistics: First, when the ADA does require spaces such as public restrooms to be accessible, such accessibility is rarely enforced. Second, there are many gaps in the areas covered by both the Rehabilitation Act and the ADA. For example, although the US Access Board finalized standards for accessible diagnostic medical equipment in 2017, healthcare providers are not required to purchase this equipment. All too frequently people with disabilities cannot engage in the most basic of diagnostic tests like getting weighed or getting medical imaging done. There is a clear need for expanded legislation and enforcement of existing requirements.

Given that existing standards do not address the full range of experiences of people with disabilities, there is a further need to extend regulations implementing the Rehabilitation Act and the

ADA. Individuals like myself who live with upper extremity-related disabilities continue to face physical barriers to healthcare access because of the absence of push buttons on doors used to enter clinical buildings and public restrooms inside these buildings. Similarly, few healthcare systems account for the needs of individuals with disabilities requiring low-sensory environments (e.g., low-light and low-noise in clinical waiting rooms). As such, there is a need to not only reinforce practice compliance but also to expand the notion of what compliance entails.

3. Telehealth solutions must be designed, implemented, and evaluated in ways that account for the specific needs of the disability community to avoid limited impacts or exacerbated disparities.

For some people with disabilities, the exponential rise of telehealth services has meaningfully reduced barriers to health care access and improved quality of care. However, for others telehealth presents new accessibility challenges. In discussing telehealth, it is important to note that, under Section 1557 of the Affordable Care Act, all covered entities (i.e., health programs and activities that receive federal funding) are prohibited from discrimination on the basis of disability, and therefore must ensure that all programs delivered through electronic and information technology are accessible. Were the promise of Section 1557 fully realized, telehealth would only be a benefit to those with disabilities seeking health care. Yet, to date, this promise has not been realized.

Some members of the disability community who face persistent barriers to in-person encounters with the health system fare better in a digital environment. Reduction of barriers includes those that exist both prior to entry of a health care facility and those that exist once an individual enters a health care facility. For example, some disabled individuals rely on public transportation to physically attend an appointment. Without telehealth as an option, these individuals may have had to either miss or delay appointments if these forms of transportation were not readily available. For others in the disability community, the barriers within clinical spaces themselves are onerous in nature and may be avoided through the use of a telehealth encounter that allows them to stay in home and community spaces that are better aligned with their physical, sensory, cognitive, and mental health related needs. Finally, current telehealth provisions also expand access to the range of providers with which a disabled individual may engage, allowing broadened access to appropriate specialists and to shorter wait times, improving both the quality and timeliness of care.[13] Given the ways in which telehealth has improved the experience of health care for some people with disabilities, it is essential to both extend and expand access to such services.

Despite the promise of telehealth for improving health care access for the disability community, benefits are not equally experienced; instead, many disabled individuals face real barriers to effectively engaging with telehealth services. For example, while I have significantly benefited from the availability of telehealth services as related to my mobility-related disability and my reliance on either public transportation or the assistance of a family member or friend to attend an appointment, other aspects of engaging with telehealth remain challenging. My upper extremity and vision-related disabilities make it nearly impossible to derive the full benefit from engagement with telehealth. This difficulty arises in part because telehealth platforms rarely enable multiple modes of inputting information into a system or work seamlessly with a screen reader (i.e., a technology that helps people with difficulties seeing to engage with digital content). The particular constellation of barriers that I experience with in-person and virtual care means that I often evaluate whether it is worth the effort and physical pain to access health care or whether it is best to forgo it. Improving accessibility not only of in-person services but also of telehealth services is therefore essential to fully removing access barriers for the disability community.

For telehealth to be fully accessible, the specific needs of the disability community must be accounted for in design implementation and evaluation efforts.[5,14] In particular, telehealth technologies must be designed in ways that are both usable and useful for all disabled individuals. Examples of

usability that must be improved include the need to consistently implement standards and plug-in solutions to enable sign language or the appropriate interpretation and closed captioning on the same screen as the services being provided, even for unscheduled appointments. Such a design change would meaningfully improve the accessibility of video-based telehealth services for individuals identifying as deaf, hard of hearing, and speech disabled, among others. Similarly, many telehealth services assume that engagement consists of an interaction between a health professional and patient without any other engaged parties. However, it is not uncommon for individuals with disabilities to engage others in their care, including family members and friends, personal care attendants, and individuals providing interpretation services. In such cases, there is a need for telehealth services to be designed to allow sophisticated proxy access as well as synchronous communication between multiple parties. These examples illustrate the need to strictly enforce existing standards (e.g., web content accessibility guidelines) and to extend the reach, clarity, and specificity of such standards in partnership that broadly engages the disability community.

Designing telehealth to meet the needs of the disability community is necessary but not sufficient to ensure that care provided through this modality is accessible. Like many other health disparity populations, disabled individuals experience the digital divide, with 15% (in comparison to 5% of nondisabled individuals) stating that they never go online. Moreover, people with disabilities are less likely than the general populations to own the hardware that they need to use telehealth.[15] The investments in broadband in the Infrastructure Investment and Jobs Act will work to close this connectivity gap. But the expansion and widespread use of telehealth will outpace the implementation of the programs in the IIJA, and this lack of digital access, coupled with a lack of hardware, can lead to canceled appointments, technical difficulties during appointments, and misinterpretation of the information exchanged. These all lead to reduced quality of care. Moreover, both health professionals and disabled patients must be provided with appropriate training on how to configure telehealth technology for accessibility. Finally, during telehealth encounters, health systems will need to provide timely access to personnel such as qualified readers, interpreters, and speech-to-speech translators to ensure full accessibility. Urgent action is needed to close the digital divide and provide necessary hardware, training, and other resources.

Given its long history of marginalization, the disability community is vulnerable to potential unintended consequences of telehealth expansion. Outcomes must be monitored, and any disparities addressed. For example, it is possible that telehealth may be found to be not only clinically effective but also cost effective and thus, it may be adopted as a measure of cost containment. Consequently, health care providers may discourage in-person visits. Such discouragement may have disproportionately negative consequences for people with disabilities for whom in-persons visits may be more clinically appropriate (e.g., challenges with appropriate positioning for telehealth visits) and more accessible (e.g., accessibility of telehealth remains poor). Another potential unintended consequence could arise from HIPAA flexibilities. During the pandemic, HHS put in place HIPAA flexibilities that allow health professionals to use a variety of platforms to deliver telehealth services. While such flexibilities may allow for greater access, they also have the potential negative, unintended consequence of breaches in cyber security. Such breaches may be particularly detrimental to members of the disability community, as disclosure of disability status may impact everything from employment to social relationships. It is therefore imperative that health care providers be required to observe, monitor, and report health service utilization outcomes, health outcomes, and a wide range of patient-centered outcomes.

Legislation currently under consideration to expand telehealth services would have the important effect of sustaining telehealth access for members of the disability community who have found such a mode of care to reduce barriers to healthcare access. At the same time, any temporary extension of waivers must be seen as an opportunity to rigorously track the outcomes listed above for the disability community. Any permanent legislation related to telehealth should then be informed by the results of this

analysis. Moreover, any temporary extension of waivers must be viewed as a period in which to advance requirements for the accessible design and implementation of telehealth services.

4. Clear and comprehensive requirements for data collection across health systems would allow for meaningful monitoring of and response to health disparities among the disability community.

During the pandemic, one persistent challenge experienced by UVA Health and other health systems was the inability to determine if there were differential experiences and outcomes for people with disabilities. A key reason for this challenge is the general lack of data collection about the disability status of patients. This gap is recognized by CMS in their efforts to revise quality programs in ways that improve data collection about health equity as related to race, ethnicity, and other sociodemographic factors shaping health outcomes, including disability.[16] Without such data, it is nearly impossible to systematically detect and address health disparities experienced by the disability community. As such, data collection efforts emphasizing people with disabilities should be prioritized.

It is possible for health systems to immediately begin collecting basic data related to disability, which parallels the data collected by the American Community Survey. At least one electronic health record system present across many health systems in the country already contains the capability to collect such data and consequently, the collection of such data from patients could be relatively quickly integrated into clinical workflow. Over time, more granular data elements about disability status should be developed in partnership with the disability community. More granular measures would allow for a deeper understanding of the differential health disparities experienced by and tailored solutions needed across people with a wide range of disabilities. This type of effort would parallel initiatives to collect more granular data about race and ethnicity based on similar rationales.[17]

While working with our local disability community in Charlottesville on how to most appropriately collect such data, we found that these efforts should take place in private clinical spaces and that data should be collected by a health professional. Our community partners, representing people with physical, cognitive, and sensory disabilities, expressed that collection during a clinical encounter, rather than at the time of registration or scheduling, was more appropriate and culturally competent, given the potential sensitivity of disability-related questions. Data related to disability should be collected in ways that are both comprehensive in their content and sensitive to the context of collection.

5. The (continuing) education of health professionals must explicitly encompass the needs and experiences of the disability community to combat persistent barriers to healthcare access and high-quality care.

It is well recognized that providing appropriate care to historically marginalized communities requires training specific to the needs and preferences of community members. While such training often falls under the umbrella of training in cultural competencies, cultural competency training for health professionals typically excludes the disability community.[18] The negative impacts of this exclusion are undeniable. Despite people with disabilities typically rating their quality of life as similar to that of people without disabilities,[19] 82.4% of physicians reported that people with significant disability have worse quality of life than their nondisabled counterparts. Similarly, lack of training on how to work with disabled individuals has led to only 40.7% of physicians reporting feeling "very confident" in their ability to provide the same quality of care to their patients with disabilities.[3] In addition to lack of knowledge related to providing appropriate care, many health professionals also have very little knowledge about their legal requirements when serving the disability community. Over one-third of physicians claimed to know little to nothing about their responsibilities under the ADA and two-thirds reported feeling at risk of an ADA lawsuit due to problems providing reasonable accommodations for their patients with disabilities.[20] Taken together, this lack of provider knowledge significantly compounds already persistent

structural barriers to equitable health care access and must be addressed through explicit efforts to enhance the training of health professionals in the needs and experiences of the disability community.

The work I am leading at the University of Virginia has begun to address this long-standing gap in education of health professionals. After forming a partnership with many members of the local disability community, we are in the process of creating learning modules which will be required training for all 7000+ health system employees. This training presents the disability community as a health disparity population which has experienced persistent structural and attitudinal barriers to equitable care and presents additional contextual information about the disability community, such as the history of the disability community, common misconceptions related to the disability community, and ways to appropriately engage with disabled patients, among other topics. Additionally, we have begun to invite a panel of patients with a wide range of experiences related to disability into a required class for first-year medical students so that they are introduced early on to the lived experiences of disabled individuals, both inside and outside of clinical settings. Such training must be more widely adopted as only 52% of 75 medical schools responding to a nation-wide survey reported providing any form of disability awareness education for medical students.[21] These are only first steps on a much longer journey to explicitly address the needs of the disability community in the education of health professionals. Larger scale efforts of this nature are needed at a national level to transform health professional's understandings of the needs of the disability community.

It is important to note that training of health professionals must address not only the wide range of disabilities, but also the ways in which experiences of health care access and quality for disabled individuals are shaped by their other identities. I have personally experienced the compounded bias in the healthcare system that people of color and women face when living with chronic pain.[22,23] I live with a condition called Enthesopathy and have widespread tendon damage, which impacts many of my activities of daily living. I first experienced the impact of this condition in my late twenties, and by my early thirties I was living with widespread chronic pain. Each day was an incredible challenge. I could no longer walk across a room, prepare a meal, bathe on my own, or care for my then one-year-old daughter. Trying to get an accurate diagnosis was both physically and emotionally exhausting, as many physicians dismissed my symptoms as stress or depression. After years of such encounters, I stopped seeking a diagnosis until a family friend took the initiative to schedule one more set of appointments for me at a clinic known to work collaboratively with patients experiencing chronic pain. After years of parenting and working with little relief or insight into what was happening to my body, I ended up with a team of physicians who assumed I had valuable knowledge about my own body and did not dismiss my symptoms. It was finally through this encounter, more than five years after my symptoms began, that I received an appropriate diagnosis and treatment plan, which has allowed me to engage in meaningful rehabilitation. Despite dedicating my life to field of healthcare, prior to this encounter, I had all but dismissed the possibility of engaging effectively with the health system for my own health care. Although my story has a hopeful resolution, disengaging with the health system is not an uncommon experience among individuals who experience systemic attitudinal barriers related to the intersection of their gender, racial/ethnic, and disability identities. As my personal story illustrates, people with disabilities not only face structural barriers to accessing care, but also barriers arising from health professionals' lack of knowledge and ability to treat them. The only way to ensure that health professionals have the knowledge, training, and experience to work with individuals with disabilities is to ensure that the (continuing) education of healthcare professionals integrates the needs and experiences of the disability community.

6. The underrepresentation of individuals with disabilities in health professions limits the ability of healthcare systems to provide appropriate care. We must eliminate barriers to entering and remaining in training programs as well as barriers to remaining in practice.

The extremely low number of health professionals who live with disabilities significantly hinders our ability to provide high quality care to the disability community. It has been established that across marginalized communities, such as racial and ethnic minorities, treatment adherence and health outcomes improve when patients and health professionals share characteristics such as race, ethnicity, and language.[24] Moreover, physicians who identify with racial and ethnic minorities are significantly more likely to welcome those with similar lived experiences, such as being uninsured, being a recipient of Medicaid, and being a non-English speaker into their practice. Despite being significantly underrepresented in medical professions, physicians who identify with racial and ethnic minorities provide care for 53.5% of minority patients and 70.4% of non-English speaking patients.[25] Given the unique histories and experiences of marginalization within the disability community, it is reasonable to expect that both access to and quality of care for disabled patients would be better when there is an option to receive care from a disabled health professional. Yet, the number of health professionals with disabilities remains very low. Although close to 25% of the U.S. population lives with a disability, only 3.1% of physicians[26] and 2.7% of medical students are disabled.[27] Minimizing health disparities faced by the disability community will therefore require purposeful action to increase this number.

The impact of representation is not only at the level of individual patient care, but also at the level of the health system. I have seen first-hand the impact of this representation for the disability community. Even when committed to ensuring health equity for all, my non-disabled faculty colleagues are often unaware of the specific needs of the disability community as they craft policies and programs. When I enter these conversations as both a colleague and a member of the disability community, I am able not only to articulate the needs of the community as I understand them but also to build on trusted relationships with other disabled individuals in our local community to inform actions to be taken by the health system. This representation is particularly essential, even lifesaving, when policies must be crafted quickly and before federal guidance is available, as in the case of the pandemic. For example, I was able to ensure that the needs of the disability community were represented in our health systems crisis standards of care at a time when many such policies nationally were written in ways that were discriminatory to the disability community. An increase in people with disabilities in spaces where health system policies are being created can significantly minimize the likelihood of developing policies that not only perpetuate but also exacerbate health disparities.

Increasing the number of health professionals with disabilities requires removing key barriers to entering training programs and remaining in practice. One key barrier to entry is financial in nature. Current provisions within the Build Back Better Act creating medical school scholarships for historically underserved communities, including the disability community, would be an important step to addressing such financial barriers. Additionally, prior to entering a training program, prospective students often must show that they meet a set of technical standards, which outline the required, essential functions that a prospective student must be able to perform. Although such standards are subject to Section 504 of the Rehabilitation Act and Titles II and III of the ADA, many do not comply with this legislation. In particular, noncompliant standards are written as organic rather than as functional. Organic technical standards are written in ways that specify the individual's ability to function without accommodation, while the more compliant functional technical standards simply specify the task that must be performed rather than the way in which such a task must be accomplished.[28] This latter form of standards allows people with disabilities to use accommodations such as emerging technologies and intermediaries to accomplish required tasks. They also allow people with disabilities to obtain waivers of tasks that would not be essential for the specialty that they intend to pursue. Taken together, compliant standards must be enforced as the norm as they allow people with disabilities to enter health professions and to provide the same level of care as their non-disabled peers.

Even if an individual with a disability is able to enter a training program, barriers to remaining in training and in practice persist. For example, students and practicing health professionals often struggle

with obtaining the accommodations they need given the stigma associated with accommodation requests as well as lack of clear processes for requesting and obtaining accommodations.[29] Another challenge for remaining in practice stems from the risk of licensure revocation for those who acquire a disability or experience changes to their disability in the course of their career. Current practices for licensure do not conform to the requirements set forth in Titles II and III of the ADA. Rather than focusing on an individual's ability to engage in their professional responsibilities, licensure questions often focus on the naming of a particular diagnosis.[30] This process has several unintended consequences including the inappropriate dismissal of disabled health professionals who would still be able to practice with appropriate accommodations. It also has the unintended consequence of discouraging reporting of diagnoses,[31] limiting medical treatment, and potentially attempting to practice without the accommodations needed to perform to their full ability. To improve the retention of health professionals with disabilities, it is essential to remedy ADA violations when a health professional acquires a disability and loses their license to practice despite being able to practice with reasonable accommodations.

Conclusion

Although the subject of this hearing is about the disability community, this discussion must be viewed as intrinsically linked to discussions about other communities including veterans, rural communities, older adults, and communities of color. While 25% of Americans nationwide are disabled, this number rises to 30% for veterans,[32] 33% for those living in rural settings,[33] and 40% for those age 65 years or older.[2] Similarly, disability is overrepresented among Black and indigenous communities.[34] Although the rate of disability for those identifying as Hispanic is lower overall, in part given the lower median age for Hispanics (29.8 vs 43.7),[35] the likelihood of acquiring a disability as one ages is significantly higher for those identifying as Hispanic.[36] Addressing disparities faced by the disability community therefore allows us to simultaneously address the needs of these other underserved and/or marginalized groups.

To end on a personal note, I have experienced the impact of acquiring disabilities multiple times over the past 20 years. The chronic conditions and disabilities with which I live have impacted everything from what I eat to how much I am able to use my arms and legs, to the length of time I can look at printed words or screens. Yet in the context of my work environment, such disabilities have not limited my ability to thrive. I work in ways that are atypical, yet with the appropriate attitudes and structures around me, such atypicality is not a barrier to good outcomes. For example, as I write this, I am speaking words aloud to an assistant and she is both typing them and reading them back to me for editing. When people say that I am inspiring, I understand that it is meant as a personal compliment. However, in this same body, without accommodations, such work would be impossible for me. What is inspiring, then, is when a system molds itself to fit the needs of an individual. At present, there remains a wide gap between what people with disabilities need to access high quality and equitable care in the current state of the health care system. Addressing these six barriers would be meaningful steps towards creating a healthcare system in which people with disabilities, like myself, can also thrive.

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