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Testimony to the United States Senate Special Committee on Aging

## **COVID-19 One Year Later: Addressing Health Care Needs for At-Risk Americans**

March 18, 2021

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### Oral Testimony

Chairman Casey, Ranking Member Scott and honorable Committee Members, thank you for inviting me to speak today. My name is Amy Houtrow, MD, PhD, MPH. I am the chief of rehabilitation medicine at UPMC Children's Hospital of Pittsburgh and professor and endowed chair at the University of Pittsburgh.

I am approaching my testimony from the perspective of a person with disabilities, as a physician who cares for people with disabilities, as an advocate for health equity, and as an academic with training and research expertise in health services and policy. As they say, 'we are all weathering the storm together, but we are not all in the same boat.' My boat is small and scarred. I was born with an exceptionally rare genetic disorder that shaped my body in dysmorphic atypical ways and has shaped me into the person I am today. I know of limitations; I live with them. I also know of perseverance and circumstance. In late February 2020, before most of America knew what was happening, I was preparing to isolate myself. My spine is twisted, my lungs cramped, the lower lobe of my right lung always vulnerable to infection because of the deformities of my chest. I take immunosuppressive medications. I knew right away that getting COVID-19 could easily kill me. I am an at-risk American.

My work here on this planet is not done, so I set about protecting myself and my patients. I am lucky that I could move the entirety of my work to the virtual space, all my meetings, all of the planning I was doing for our pandemic response, all my research, and all of my patient care went virtual. Thankfully with emergency waivers we have been able to successfully deliver telehealth care. Recent telehealth innovations and expansions have benefited many patients with disabilities during the pandemic and will beyond if they are promoted and supported.

For the past year, we have all watched, in horror and with sadness, as COVID-19 ravaged congregate care facilities. But for every dark cloud, we must find the silver lining. As we plan for the future, we must assure the health and safety of people living in congregate settings, but we should also develop and promote strategies to keep older adults and people with disabilities living in their homes with the supports and services they need. To do this we need to strengthen home and community-based services and develop a more robust home care workforce. It behooves us to improve these services because most people desire staying in their homes and according to CMS [home care is less costly than residential care](#). The \$12.7 billion fought for by Senator Casey in the American Rescue Plan for expansion of Medicaid home and community-based services is an excellent step toward realizing the [promise of Olmstead](#).

Perhaps the biggest triumph of the pandemic is the speed of which vaccines were developed. Unfortunately, equitably distributing these vaccines has proven challenging. As a starting point, vaccine registration systems and administration sites must meet the standards of the ADA and

Section 504 of the Rehabilitation Act. Monies in the American Rescue Plan are much needed to address this urgent problem. Active outreach in communities is also necessary to help reduce existing disparities in vaccine access that exist today. Strategies to reach those in need such as [mobile vaccination units](#) that can administer vaccines in people's homes should be expanded to vaccinate semi- or completely-homebound individuals and people for whom home administration would be safer and easier than administration at a vaccine site. We should [empower trusted community](#) leaders to help reach people, whether in [churches](#) or barbershops, to improve vaccine distribution to those hardest hit by disparities. We need this now and we need to have plans in place for the next pandemic.

This pandemic is an inflection point for the United States. Do not let it go to waste. We need to address the structural problems that make certain members of our communities more vulnerable to COVID-19 and other disease. We need to make changes to our public health infrastructure and health care systems so that we are better prepared for the next crisis. We need to make it possible for all of us to thrive -today, tomorrow and beyond. Thank you for the opportunity to present to the committee and I would be pleased to answer your questions. As I close my oral testimony, I offer you this quote from Maya Angelou: [“Do the best you can until you know better. Then, when you know better, do better.”](#)

### **Written Testimony**

The charge of the Special Committee on Aging is to study matters pertaining to problems and opportunities of older people including maintaining health, assuring adequate income, finding employment, engaging in productive and rewarding activity, securing proper housing and obtaining care or assistance. We should note that older Americans are not living their lives in a vacuum, although this past year, many have been living in isolation. Experiences over one's life affect the ability to address challenges as one ages. The life course health development model demonstrates how early events and circumstances shape our futures. The health that an older American experiences today is the result of their health trajectory- the product of cumulative risk and protective factors, the multiple determinants that interact over time throughout their life.<sup>1</sup> Further, many of the issues faced by seniors in the pandemic are also experienced by people with disabilities and the solutions are often similar or at least complementary. It is fitting then, that the Special Committee take up the issue of addressing the health care needs for at-risk Americans; those who are older and those with disabilities.

### **Life-Course Health Equity**

My written testimony is framed with a life-course health equity lens. The poor health status of the US population compared to other high-income countries, the existence of avoidable health inequalities, and the policy-driven changes in social conditions underscore the importance of enacting policies addressing social and political determinants of health.<sup>2</sup> We know that socioeconomic conditions underlie many health inequities, therefore we should be compelled to find policy solutions to improve health across the life span. A good example is the child tax credit that was part of the recent American Rescue Plan (see below). Lifting hundreds of thousands of children out of poverty will have long-term benefits, including better physical and

emotional health throughout their lives. It is a game changer when it comes to the well-being of children and will be a game changer when they are seniors.

The pandemic has accelerated inequities already pervasive in health care.<sup>3</sup> Older adults and people with disabilities have been hardest hit by the pandemic. People with disabilities who are poor and/or minorities have been even harder hit by COVID-19,<sup>4</sup> as have minorities in general (especially Blacks).<sup>5</sup> Early in the pandemic, it was clear that individuals with intellectual and developmental disabilities (IDD) living in residential group homes were more likely to die if they were infected than the general population (15% case fatality rate for New Yorkers with IDD versus 7.9% for the general New York population).<sup>6</sup> Using a large private health insurance claims database which included 467,773 individuals with COVID-19 between April 1, 2020 and August 31, 2020, researchers found that across all age groups, patients with [developmental disorders had the highest odds of dying from COVID-19](#). Similarly, older Americans aged 70+ were at high risk accounted for 42.4% of deaths in the cohort.

These terrible statistics come as no surprise to those of us familiar with the impacts of racism, classism and ableism on health outcomes.

The Health Resources and Services Administration (HRSA) [defines health equity](#) as “the absence of disparities or avoidable differences among socioeconomic and demographic groups or geographical areas in health status and health outcomes such as disease, disability, or mortality.” In this definition, health equity is an outcome that will be achieved when disparities based on membership of a disadvantaged group or under-resourced group are eliminated. The process to achieve health equity requires the removal of obstacles and barriers to health which includes transforming the structures, policies and beliefs that systematically benefit certain groups of people over others. The [basic tenet of health equity](#) is that all people, regardless of their circumstances, have a fair and just opportunity to be as healthy as possible. The life course health equity frame places emphasis on how systems, policies, programs, services and practices enable people to be healthy throughout their lives. The opposite side of that coin is how these systems, policies, program, services and practices do not enable or restrict individuals’ ability to be as healthy as possible and how health disparities are created and perpetuated.

“Structural inequities encompass policy, law, governance, and culture and refer to race, ethnicity, gender or gender identity, class, sexual orientation, and other domains. These inequities produce systematic disadvantages, which lead to inequitable experiences of the social determinants of health... and ultimately shape health outcomes.”<sup>7</sup> To dismantle these structural inequities, we must first acknowledge that they exist. For example, people with disabilities face systemic long-standing barriers to equitable health care.<sup>8</sup> A [third](#) of working-age adults with disabilities do not have a usual health care provider and a [third](#) have unmet health care needs. It should go without saying, the lives of people with disabilities are equally valuable to people without disabilities and people with disabilities are equally deserving of health care. Yet inequitable treatment is pervasive and worsened in times of crises (see below).<sup>9</sup>

According to the CDC, [26% of adults have a disability](#) of some type. The experience of disability is more common among blacks and native adults, furthermore, disability is highly correlated with age as well as socioeconomic disadvantages.<sup>10</sup> Disability is a part of the human experience, but disability is disproportionately experienced by individuals living in or near poverty, minorities, those with lower educational attainment and individuals living in rural areas.<sup>11,12</sup> Children with disabilities are also more likely to be minorities and live in poverty.<sup>13</sup> Disability is both a [cause and result](#) of poverty. As such, people with disabilities frequently have intersecting identities of categorical disadvantage.<sup>14,15</sup>

The United States has been plagued by widening income inequality for decades, fueled by tax cuts for the wealthy and the false belief that [trickle-down economics](#) meaningfully impact employment or economic growth. After visiting the United States in 2017, Phillip Alston provided numerous recommendations in his [Report of the Special Rapporteur on extreme poverty and human rights on his mission to the United States of America](#). Specifically, he recommended the decriminalization of being poor, acknowledging the damaging consequences of extreme inequality, recognize a right to health care, and to ‘get real about taxes.’ The changes to the Child Tax Credit and the Earned Income Tax Credit in the American Rescue Plan Act which will [cut child poverty by an estimated 40%](#) are an important step in addressing equity for all Americans. This change in policy will provide much needed support for millions of low-income Americans. There are additional opportunities to reduce child poverty as detailed in [A Roadmap to Reducing Child Poverty](#) including making the tax credits permanent. Recognizing the long-term health benefit of poverty reduction for children, Congress should consider these options. Additionally, revamping Medicaid to cover all children and fully funding it federally (as Medicare is) are options for Congress to consider.<sup>16</sup> Efforts to advance health equity in childhood have long-lasting societal benefits.<sup>17</sup>

Racial and other forms of discrimination are major drivers of health inequities.<sup>7</sup> Groups traditionally discriminated against face [major barriers to accessing the upstream resources](#) that positively influence health and well-being such as good jobs with fair pay, stable, safe and affordable housing and quality education.<sup>18</sup> Discrimination in policing and the criminal justice system further limit future opportunities racial minorities. [Racial discrimination](#) is both a direct and indirect (such as through [wealth](#) and resource inequality) cause of poor health outcomes.<sup>19</sup> Therefore, Congress should work to dismantle the legalization of racial discrimination to support the health and well-being of those affected by racism.

### **A Year of the Pandemic**

On March 11, 2020 the World Health Organization officially identified the COVID-19 outbreak as a [global pandemic](#). On that same day, the National Basketball Association’s commissioner, Adam Silver, [suspended the season](#). I distinctly remember hearing that announcement. I was in my kitchen and took a moment to be grateful that the leader of an association that would lose millions of dollars by canceling games recognized that saving lives was more important than profits. His announcement was followed by many others: [Broadway](#), the [National Hockey League](#) and [Major League Baseball](#). These announcements, followed by stay-at-home orders,

alerted Americans to the seriousness of the pandemic. Exactly one year later the [US reported 542,191 deaths and 29,862,124 cases](#) of COVID-19; more than any other country. This translates to approximately [160 individuals dying of COVID-19 per 100,000](#) people in the US.

In the spring of 2020, I, like most Americans, watched in horror as the virus spread and people died. I spoke with friends and colleagues about the case doubling rate and how easily the virus seemed to spread undetected. We saw what was happening in Italy as the virus swept through and overwhelmed their medical system. We knew the same problem would soon reach our shores. We got on planning calls, shared information, hoped for the best and prepared for it not to be the case. We saw our own hospitals and health systems stressed and strained, some beyond the breaking point. Hospitals counted the amount of PPE they had on hand in hours and minutes. There wasn't enough, in some places there still isn't. We saw the deceased, our loved ones, our friends, our colleagues, our community members, stored in refrigerated trucks because the morgues were full. States were outbidding neighboring states for supplies. We tracked the availability of ventilators. Medical care providers, my friends and colleagues, pushed past fear and fatigue to provide care and innovate to save lives. I worked with other leaders in my organization to quickly change how we delivered health care. Health systems, state and local governments, territories, public health authorities and communities scrambled to figure out what to do. We were building the plane as it was flying and it felt like we didn't have the right tools. We needed a coordinated organized response based on science, guided by public health goals. We needed the Federal Government to lead instead of impede.

Pandemic simulations take into account a number of factors such as how easily the virus spreads, how quickly governments respond and the resources available in the short, medium and long-term to manage the pandemic. In 2019, the United States was rated at the top of the [Global Health Security Index with a score of 83.5](#). Despite our strengths, the US was noted to have weaknesses, such as systemic deficiencies in the public health infrastructure, indicating a clear need for improvements. The basic tenets of public health strategies to control virus spread failed us early. Severe shortages in the supply of PPE were worsened by the lack of action by the federal government to maintain and distribute supplies.<sup>20</sup> Contract tracing was inadequate.<sup>21</sup> Reliable and accurate testing was in short supply.<sup>22</sup> Mask wearing, which has been demonstrated to substantially reduce SARS-CoV-2 transmission by limiting both exhaled virus reaching others and by limiting virus inhalation,<sup>23</sup> has been met with substantial societal resistance. Mandating masking in public was shown to be associated with declines in COVID-19 infection growth rates.<sup>24</sup> Modeling on data from earlier in the pandemic, researchers estimated that between September 22, 2020 and February 28, 2021 129,574 lives could have been saved if the US had achieved 95% mask use in public.<sup>25</sup> Unfortunately, those lives were not saved. Engaging science and reputable research is to our advantage in future pandemics.

But from our failures, we see more clearly our opportunities. States should be incentivized to coalesce around proven public health strategies, funding should be appropriated to build our public health infrastructure at the state, tribal and local levels with an adequate workforce to test, trace and vaccinate.<sup>3</sup> We have the opportunity to rethink our health care delivery and

payment systems to better align with the goals of health equity. As described above, we have opportunity to address structural barriers to equity.

### **Disability from “Long” COVID-19**

Post-infection syndromes occur with a number of viruses, SARS-CoV-2 among them. The symptoms can include fatigue, ongoing shortness of breath, brain fog, sleep difficulties, fevers, abdominal symptoms, depression, anxiety, decreased endurance, weakness, muscle aches, and pain. These symptoms can persist for weeks to at least months and may last much longer.<sup>26</sup> For some people the symptoms are quite debilitating. Some people with post-acute sequelae of COVID-19 (PASC) have new disabilities, some with a history of limitations are now even more limited. “Long-haulers” can be any age and the severity of the original COVID-19 disease doesn’t necessarily predict if the person will have long-term symptoms. The NIH has a large initiative to study “long COVID” and clinicians and hospitals are trying to figure out how to provide the best care for individuals with PASC. The constellation of symptoms and our current lack of understanding how to treat PASC have been a source of frustration for patients and physicians alike. A potential bright spot are the new multidisciplinary clinics that bring together physicians from multiple specialties as well as psychologists, physical therapists and others. While these types of clinics are relatively common in pediatrics (such as for sickle cell disease, spina bifida and cerebral palsy), they are rare in adult settings. Physiatrists, physicians who are trained in the interdisciplinary leadership and management of disability, are helping spearhead the efforts to organize long-hauler clinics mostly at major academic medical centers. We are finding that some of these ‘long-haulers’ may end up qualifying for SSDI and need supports and services that they didn’t require before. This means that federal agencies need to be prepared for this portion of the population of ‘long-haulers.’ As a society, we need to be prepared for the workforce to be partially depleted. In general, we should expect a rise in disability from COVID-19.

### **Ableism and Crisis Standards of Care**

Throughout the pandemic, those of us in the disability community have been concerned about discrimination against people with disabilities. Our concerns were warranted as news organizations reported how ableist quality of life assessments were influencing care decisions.<sup>27</sup> Biases and inappropriate assumptions about the quality of life of people with disabilities are pervasive and can result in the devaluation and disparate assessments and subsequent treatment of people with disabilities.<sup>28,29</sup> Health care providers are not exempt from deficit-based perspectives about people with disabilities,<sup>29</sup> and when health care providers make critical care decisions, the results can be a deadly form of discrimination.<sup>28</sup> Although implicit biases are underrecognized they are well documented. Many physicians misperceive quality of life for people with disabilities and medical judgments can be biased accordingly.<sup>28-31</sup> Value judgments are routinely being made about what it means to have quality of life, which in emergency pandemic situations can translate into -a life worth saving.<sup>32</sup> Consequently, necessary care can be withheld or withdrawn inappropriately from people with disabilities.<sup>28</sup>

Numerous organizations have filed complaints with states and the US Department of Health and Human Services over the crisis triage protocols in several states that discriminated against



people with disabilities.<sup>33</sup> A real concern was that biases against people with disabilities will lead to [under treatment of people with disabilities](#) during this crisis. Several states created policies that would do just that, according to the [Disability Rights Education & Defense Fund](#). In response to widespread concerns, the Health and Human Services Office for Civil Rights in Action released [a bulletin](#) which stated, in part, “In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.” Yet resource allocation protocols that several states utilized during the early months of the pandemic have explicit disability-based distinctions which have been identified as in violation of the law.<sup>32</sup> The three major federal statutes that prohibit disability discrimination in medical treatment are the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.<sup>32</sup> Using the presence of a disability to assign a person with a disability a lower relative priority score in accessing scarce resources constitutes a clear violation of disability nondiscrimination law.<sup>34</sup>

When public health officials and hospitals develop crisis standards of care or triage protocols for the allocation of scarce resources (such as ventilators), the risk of ableist discrimination is high.<sup>8</sup> Biases easily permeate triage processes especially when not implemented well.<sup>8</sup> Even when purportedly ‘objective’ criteria are used to allocate health care resources, subjective notions and ideas about the desirability of life with disabilities can play an influential role.<sup>35</sup> The challenge is to create protocols that minimize instead of magnify the structural discrimination and the impacts of implicit biases that already in operation.<sup>8</sup> Having disability community engagement in the creation of these policies is an important step in helping to address structural biases.<sup>27</sup>

In 2009, the Institute of Medicine published [a report](#) with a framework for establishing crisis standards of care that ensure that the response results in the best care possible given the resources at hand, that decisions are both fair and transparent, that there is consistency within and across states for policies and protocols and that citizens and stakeholders are included and heard.<sup>36</sup> To ensure best possible care, the crisis standards should adhere to fairness; have equitable processes of transparency, consistency, proportionality and accountability; engage communities and be legally sound.<sup>36</sup>

Resource allocations should be based on need, prognosis and effectiveness and not based on prejudicial criteria.<sup>37</sup> “Any recommendations for training of triage staff should include the principles of disability nondiscrimination, the need for accessibility, reasonable accommodations, and policy modifications.”<sup>38</sup> Consistent with the public health norms of using the least restrictive policy possible to achieve a fundamental goal and [avoiding discrimination against persons with disabilities](#), optimal critical care resource allocation should be achieved without using categorical exclusions.<sup>27</sup> Having a human rights-based strategy in place before catastrophic events happen is key for a disability inclusive response.<sup>39</sup> The core principles of dignity, nondiscrimination, equality of opportunity, and accessibility should be central during resource allocation protocol development.<sup>35</sup> To create successful disability inclusive



community-based responses, administrators and public health planners need to ensure that people with disabilities have roles and responsibilities in the design and implementation of the responses.<sup>39</sup> While required in the [2019 PAHPA legislation](#), the National Advisory Committee on Individuals with Disabilities and Disasters has not yet been formed. It is my recommendation that that committee includes members with disabilities and experts in health equity and consider the [evaluation framework](#) developed by disability experts.

### **The Caregiving Workforce**

In 2008, when the Americans with Disabilities Act was amended, [Congress wrote](#), “historically society has tended to isolate and segregate individuals with disabilities and despite some improvements such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” The issue of *isolating and segregating* people with disabilities should be front and center in our minds as we think how we can prepare for the next crisis and how we can better care for older adults and people with disabilities in general. We have the opportunity to fund services that help people stay in their homes as they desire, an opportunity to realize the full promise of the [1999 Olmstead](#) decision.

During the pandemic, families have been forced to scramble and scrape together supports for their loved ones with disabilities. I share the words of one of my colleagues, a mother of a child with severe disabilities who describes how they navigated the early days of the pandemic. Written in June by [Debbi Harris in the Journal of Pediatric Rehabilitation Medicine](#): “We have two full-time licensed nurses who work in our home – one four days per week and one four nights per week. In our area, this is remarkable staffing, given the nursing shortage. Immediate and extended family members fill in all other shifts, as our son requires 24-hour awake, hands-on care. We had just trained in a third nurse who was to start a mixture of day and night shifts on March 29, 2020. However, the full-time nurses expressed concern because the new part-time nurse also worked at a major hospital (with a newly established COVID unit), as well as at a long-term care facility. At the last moment, I asked him to hold off on his start date and assuaged the situation by paying him a bonus and promising to hold his hours until after the apocalypse... We have already asked all but immediate family to stop coming to the home, so my husband is doing about two night shifts a week, and I have about two 12- to 14-hour day shifts. We typically have no nursing on the weekends, so those are like marathons. We have been told by our DME [durable medical equipment company] that we may receive only 3 boxes of gloves per month for 24/7 care – trach, peri care, gastrostomy – everything. The respiratory therapist’s monthly visit has been replaced by a modem that sends information about vent settings to the company. Vent circuitry, tubing, connectors, humidification chambers, and temp probes are being rationed. We were told that home care is not a priority. Our home care agency has sent us nothing at all in the way of protocols or practical support. There has been no information about safety of staff, PPE, or safety for families and instead we have written our own COVID support plan.”<sup>40</sup>

Having to scramble to meet the needs of a loved one living at home with disabilities is not a new phenomenon. Many older individuals and people with disabilities rely on direct services in their homes to maintain their health. Prior to the pandemic, there was a critical shortage of

direct service workers [due to low wages, limited benefits and high turnover](#). Limited access to PPE, risk of exposure to SARS-CoV-2, lack of accessible childcare, long work hours, and limited availability of safe transportation have all been [identified as reasons](#) why the workforce crisis has worsened during the pandemic. Most of the funding for direct services is provided by the CMS (Medicare Home Health and Medicaid Home and Community-Based Services) and the HHS Administration for Community Living, some funding is provided through private insurance, and some is out-of-pocket. There are [4.5 million home health clients](#) and a direct and home health workforce of [nearly 6 million](#). Over [20% of Americans are caregivers](#) and mostly this work is unpaid. Some of the consequences of providing unpaid caregiving include work loss and economic instability which contribute to a cycle of poverty for many families.<sup>41,42</sup> Opportunities to improve the lives of families caring for people with disabilities in their homes include paying family caregivers, strengthening the Family Medical Leave Act and creating an adequate direct service workforce that is better paid with benefits. The RAISE Family Caregiving Act's Advisory Council will be developing a [national strategy](#) that will hopefully address many of the issues family caregivers currently face.

To address the workforce deficits for direct service providers, it is important to understand the lived experience of direct service workers. These individuals provide a vital service to older Americans and people with disabilities of all ages. The work they do is hard but rewarding. Financially though, they are undercompensated and struggle to make ends meet. Such is the tale of [Joyce Bumbray-Graves](#) highlighted in a recent NPR story.

According to the US Bureau of Labor Statistics, in 2019, home health and personal care aides earned a [median wages of \\$12.15/hour](#). This is far from a living wage. In my home county, Alleghany, Pennsylvania, a [living wage for a single mom of two children is \\$33.83/hour](#), nearly 3 times as high as Pennsylvania's [average wage of \\$12.41/hour](#) for a home care worker.

It is no wonder that there is [high turnover \(26.5% in 2020\)](#) for home care aides. If we want to realize the goal of having people with disabilities living in their homes, the supports and services needed must be available -this means paying a living wage and making systemic changes to problems that lead to burnout and turnover. Further, entry into programs to serve people with disabilities should be simplified, across sector collaborations should be supported and promoted, waiting lists eliminated, and emphasis placed on autonomy and self-direction.

### **Vaccine Access**

As mentioned in my oral testimony, there have been substantial problems administering vaccines to eligible individuals. While the CDC appropriately prioritized appropriately older people living in long-term care facilities for vaccination, older adults and people with disabilities who are homebound did not receive the attention they needed to ensure their rapid vaccination. Additionally, while direct service providers are considered health care providers in some states and essential workers in others, many direct service workers have struggled to secure vaccinations. [Millions of homebound older adults await vaccinations](#) because there is no reasonable way for them to access the vaccines. While the CDC has provided [guidance](#) for vaccinating homebound individuals, our public health infrastructure and our health care delivery systems are ill-equipped to administer vaccines in people's homes. Coordination,

training and resources are needed to quickly implement home vaccinations at scale. Rapid determination of how FEMA and other governmental agencies can assist in the identification of people needing home vaccination and how to operationalize the delivery of home vaccines could reduce virus transmission to this vulnerable population and save lives.

Mass vaccination sites offer a logical solution to address the challenges of vaccinating the majority of the population quickly and efficiently.<sup>43</sup> As with any effective public health strategy, community acceptance, accessibility and equity should be addressed from the outset.<sup>43</sup> Unfortunately, older adults and people with disabilities have found accessibility of vaccination sites problematic. Our piecemeal, confusing and malfunctioning distribution strategy is the result of inadequate coordination between stakeholders. We must create a comprehensive vaccine infrastructure that is truly equitable -we should work to improve our current infrastructure and create a strategy for the future based on a framework of equitable distribution.<sup>44</sup> This requires human capital, data systems, supply chains and public health messaging from trusted reliable sources.<sup>3</sup> Publicity campaigns with trust brokers may help overcome vaccine hesitancy in higher risk communities.<sup>43</sup> Overcoming [vaccine hesitancy](#) is especially important in the long-term care workforce among whom early vaccine acceptance was below 40%.<sup>45</sup>

While the CDC has provided [prioritization guidance](#) for offering COVID-19 vaccines, [states](#) are [taking different approaches](#) and have had [varying success](#) immunizing the population quickly. Disability advocates from around the country have helped inform prioritization by highlighting data that demonstrate the risk of death from COVID-19 among people with disabilities. People with disabilities face an [uphill battle](#) qualifying for, signing up for and actually getting a COVID-19 vaccine. While using existing platforms or building new websites for vaccine sign-up allowed for their quick roll-out, seniors and people with disabilities are often frustrated because the websites are confusing and inaccessible. Digital literacy varies between individuals, but is influenced by age and other sociodemographic factors (older Americans and those with a high school degree or less were the most likely to report that they [didn't find the internet essential](#) during the pandemic).<sup>46</sup> Contributors to the 'digital divide' include lack of access to broadband internet, overall literacy and digital literacy, lack of access to devices such as computers or smart phones, cultural expectations regarding digital use and the physical and cognitive capabilities required to navigate the digital space.<sup>47</sup>

The [challenge of getting vaccinated](#) is heartbreakingly articulated by Emily Ackermann in a blog post for the [Disability Visibility Project](#) last week. Ms. Ackermann, a young adult with disabilities, states: "While the state of Pennsylvania recognizes my need for early vaccination on paper, the effort largely ends there. With no uniformity or accountability, county clinics have tiered phase 1A itself, refusing to vaccinate anyone under 65 regardless of high-risk status and devaluing the lives of those living with co-morbidities. Appointments at pharmacies are difficult to come by, occur at one day's notice (the disabled nightmare: "No time to plan?!") and demand constant monitoring combined with a quick draw at entering your information in a race against the local contingency of the estimated 3.5-4 million Pennsylvanians eligible for phase 1A." Unfortunately, her story is not unique. Seniors and people with disabilities struggle

to sign up for a vaccine and once scheduled often experience [accessibility barriers](#) at vaccine administration sites. These barriers are even more substantial for poor and minorities with disabilities.

## **Telehealth**

Maintaining and expanding telehealth has great promise to improve access to services especially for those who struggle with transportation, have difficulty leaving their homes or have limited time away from other responsibilities such as work and maintaining the household. While many physicians and other health care providers note the limitation of not being able to physically examine a patient by the laying on of hands, we should recognize that telehealth has great benefits. Certainly, an examination solely conducted by observation is different, but in some ways it is better. This is especially true for people with disabilities of all ages. I wrote an editorial recently published in [Archives of Physical Medicine and Rehabilitation](#) regarding my telehealth experiences that I will quote from here: “All of the children I care for have disabilities, so it is incredibly valuable for me to be able to see them perform activities in their own environments.<sup>48</sup> I can actually see the barriers that might be present or how a simple adaptation to their kitchen table set up might make things easier for the child...I am honored that families trust me enough to having me come into their homes on video, especially the ones who don’t have a lot of resources. Occasionally I see the chaos of a large number of people living in a small space. Sometimes it becomes apparent to me that the family is food insecure and that I could help by connecting them with resources or prescribing nutritional supplementation for their child with a history of dysphagia from their Chiari malformation. Seeing children in their homes provides me a window into their lives.<sup>49</sup> The children tend to be more comfortable than at the clinic so are more participatory, especially the little ones. The exam I do fully by observation is not the same as the one I would do if we were conducting the visit in person,<sup>50</sup> but in some ways it is better, providing me with different information. As a physician who focuses on functioning, being able to evaluate functioning in a child’s home, even if only by video, is amazing.”<sup>51</sup>

The [Telehealth Modernization Act of 2020 \(S. 4375\)](#), [supported by the American Medical Association](#), would remove many regulatory restrictions on telehealth and expand provider eligibility. But, telehealth also has the potential to worsen disparities.<sup>52</sup> This is especially true for seniors because [approximately 40%](#) of them do not have home broadband access. The Department of Veterans Affairs has been addressing digital access by providing veterans with cellular Wi-Fi enabled iPads. This program served over [50,000 veterans](#) prior to the pandemic and has been expanded. Moving forward, innovations in delivering telehealth care, assuring equitable access and maintaining reimbursement will be necessary to reap the full benefits of this technology.

## **Conclusion**

As we envision a more equitable future for seniors and people with disabilities where everyone has the opportunity to live their lives to the fullest, I remind us of where we’ve been and opportunities before us. I quote our most recent inaugural poet, [Amanda Gorman](#), “There will always be light, if only we’re brave enough to see it, if only we’re brave enough to be it.”

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