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Subcommittee on Health
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Bridging Health Equity Gaps for People with Disabilities and Chronic Conditions
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Thank you, Chairman Doggett, Ranking Member Buchanan, and members of the Subcommittee, for the opportunity to testify today. My name is Bethany Lilly and I am the Senior Director of Income Policy at The Arc of the United States. The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. We have almost 600 chapters across the United States and we bring that on-the-ground experience to our policy work here in DC. Put simply, I am here today representing people with intellectual and developmental disabilities, their families and friends, and the essential frontline disability service providers who support them; all of whom have directly experienced the barriers that people with disabilities face in accessing health care.

As a person with a disability, I want to acknowledge exactly how devastating the past two years of pandemic have been to my community. Millions of people with disabilities and our loved ones have lost their lives or faced two years of isolation and lockdown to protect ourselves. The death rates for people with disabilities in congregate settings have been deeply disturbing. The death rates for people with pre-existing conditions and disabilities in all settings have been equally concerning. We are those who are most likely to lose our lives in this pandemic, alongside direct support professionals and other frontline health care workers serving people with disabilities. The majority of those workers are women of color, who have also borne the brunt of the pandemic, including many workers, like Angie Reaves of Virginia, who lost their lives.¹ We mourn all of these lost lives. And our hearts and thoughts are with their families and friends.

The pandemic also resulted in great disruptions to the American health care system, with hospitals being forced to ration care and necessary health care services being delayed because of staff and supply shortages. As these health care crises occurred, people with disabilities were put in the position of not only having to survive COVID, but also fight discrimination. We are currently seeing a similar crisis to that of mid-2020 play out across different parts of this country as each community responds to the Omicron variant. These care delays also disproportionately harm people with disabilities who often require regular health care to maintain existing levels of function. These and other repercussions of the pandemic are not only devastating on their own, but have highlighted long-standing problems within the programs on which people with disabilities and others with intensive health care needs rely.

Sometimes, one's disability is a communication access need, such as needing an American Sign Language (ASL) interpreter, or a physical access need, such as needing an accessible exam table. Other times, it is a need for cognitive processing access, such as having a support person to help process and make decisions about health care. People of color with disabilities face compounded barriers to accessing health care and in all other spaces. I am here speaking on behalf of one part of a diverse community and speaking specifically about access to health care.

My testimony today will touch on the common challenges and barriers that people with disabilities experience when accessing health care, the impact of the pandemic has had on all of this, and how we can move forward to build a more equitable system. There are important reforms that would improve access to health care insurance coverage, including Chairman Doggett's bill to ensure that people with disabilities eligible for Social Security Disability Insurance (SSDI) have access to health insurance. There are other reforms that would improve access to health care services such as investments in telehealth and scholarships for people with disabilities and others from marginalized communities to become doctors.

I am going to structure my remarks today by first looking at the systemic gaps in health insurance coverage, since that is often the first step towards accessing health care. Second, I will touch on the many disparities in access to services and quality of care for people with disabilities. I know many of my co-panelists will speak on the same things and that the Committee has worked on these issues from many angles and I look forward to the discussion we will have.

At a base level, all people with disabilities need health insurance. Here in the United States, we have a very haphazard system of multiple private and public options that leaves many gaps. We have Medicaid for the lowest income people, Medicare for older adults, and Affordable Care Act (ACA) coverage via the exchanges for others, in addition to the Veterans Health

Administration, the Indian Health Service, and employer-sponsored coverage and other private options.² For many people with disabilities and older adults, access to home and community-based services (HCBS) is necessary, and Medicaid is effectively the only health insurance coverage that provides those services.³

People with disabilities often rely on multiple forms of health insurance, especially those eligible for Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI). SSDI provides eligibility to Medicare and SSI usually provides eligibility for Medicaid—and there are millions of beneficiaries eligible for both kinds of health insurance.⁴ Many of The Arc's state chapters help people with disabilities and their families navigate this incredibly complex system.

And there remain gaps in access to health insurance. One I know is frequently on the Chairman's mind is the 2-year waiting period for access to Medicare for SSDI beneficiaries. Even once a person with a disability has met the incredibly strict Social Security disability standard, they must wait 5 months for their benefits and then another 2 years to access Medicare.⁵ This Medicare waiting period is particularly concerning to my organization and many other disability organizations because, by definition, these are people with disabilities who need access to affordable health care. Since the passage of the ACA, we have not had a comprehensive study of this population and their access to health insurance, but we know these individuals have very limited work capacity and cannot access employer-based coverage. We know that some live in states where Medicaid has not been extended to all individuals with an income below 138% of the federal poverty level, leaving those in poverty without affordable health insurance. Others may be eligible for the subsidies that help to cover the costs of health insurance through the ACA exchanges. But these subsidies were not always affordable—a problem addressed in the American Rescue Plan, but these improvements to the Advanced Premium Tax Credits need to be made permanent. Unfortunately, for many others, Continuation of Health Coverage (COBRA) coverage is unaffordable, an issue I know one of my co-panelists is personally experiencing right now.

While some SSDI beneficiaries will figure out alternative coverage, those who are low-income in non-expansion states and who are otherwise unable to access health coverage face serious harm. As discussed earlier, lack of access to care can result in faster functional decline, but lack of access to any health insurance can result in serious health conditions or complications being undiagnosed and death.⁶ With the pandemic, there is the additional concern about accessing testing and care for COVID, even with health insurance coverage improvements passed by Congress specifically for treatment received because of COVID.

The pandemic is also a mass disabling event, with millions of people developing post viral complications, called Long COVID. All post viral illnesses are poorly understood and desperately need additional research, especially their impact on people with existing disabilities. Ensuring that all people with disabilities have access to comprehensive health care right now has never been more crucial.

For all these reasons, we have historically supported Chairman Doggett's Stop the Wait Act. I am aware there are a few changes to the bill this Congress and we have not seen final legislative language, but we expect to support the bill this Congress as well. By providing health insurance to uninsured or underinsured people with disabilities in the Medicare waiting period, the bill would prevent deaths and functional declines and improve quality of life for people with disabilities. Not only must we end the Medicare waiting period, we also must close other coverage gaps and ensure coverage is affordable. In particular, my organization strongly supports closing the Medicaid coverage gap and making the improvements to the ACA subsidies permanent.⁷ Closing the Medicaid coverage gap is important not only to the millions of people with disabilities who would become eligible, but also as a matter of racial equity—those currently left uninsured are disproportionately people of color.⁸

I will now turn my attention to the services and quality of care that people with disabilities receive once they have access to that basic health insurance. While health insurance coverage is an important first step, many people with disabilities face substantial additional barriers in accessing health care services once they obtain coverage—from access to the services and specialized providers they need to accessibility of basic medical equipment.

For people with disabilities, access to the right health care services is also a matter of independence and equality. Many people with disabilities rely on home and community-based services (HCBS) not only to keep themselves healthy, but to allow them to fully participate in their communities. HCBS helps people with disabilities with essential daily activities, such as getting in and out of bed, making food, getting dressed, managing medications, and other essential daily activities.⁹ Many people with intellectual and developmental disabilities rely on direct support professionals to help with employment and other activities in the community. Medicaid is effectively the only health insurance program that provides access to HCBS and since Medicaid is a means-tested program, many people with disabilities must spend down all of their resources and remain in poverty to access these services.¹⁰ There are also laws that allow for recovery against families who rely on these home and community based services and other long term services and supports, contributing to intergenerational poverty, especially for families of color.¹¹

Access to HCBS is also a crucial issue for older adults who want to age in place, rather than entering a nursing home or other congregate setting.¹² Congregate settings for people with disabilities and older adults have been extremely dangerous during the pandemic, with approximately 23% of all COVID deaths taking place in these settings.¹³ This is why over 800,000 people across the United States are on waiting lists for HCBS.¹⁴ There are many others in need who have yet to even get on the waiting list. We desperately need comprehensive investment in HCBS so that people with disabilities and older adults can access the services they need.

In order to clear those waiting lists and to expand HCBS, we must address the direct support workforce crisis. Currently, direct support professionals and other direct care workers are not paid a living wage and turnover rates are extremely high. Because the wages are set by Medicaid, these wages can be below the minimum wage rate in the region or locality. These essential, frontline workers have been working throughout the pandemic to ensure that people with disabilities maintain as much access to their communities and to their normal lives as possible. Some have died and many others have made impossible choices to ensure that the people they are caring for were safe.

While these problems have existed for decades, the pandemic has brought the HCBS service system to an even greater point of crisis, leading some providers to shut down. The American Rescue Plan Act included a 10% federal matching percentage bump specifically targeted at these services to try and stabilize the system, but that will expire and must be extended. Several members of this Committee are co-sponsors of the Better Care Better Jobs Act which provides the necessary investment to stabilize this system and improve wages for direct care workers. I hope, and I know millions of people with disabilities, older adults, and their families across this country also hope, that we will see this investment pass through Congress as soon as possible.

While vital and urgent, HCBS services are not the only services that people with disabilities may have trouble accessing. There are many barriers to accessing comprehensive service—narrow networks preventing people from accessing specialists, discriminatory benefit design, parity violations, and many others. With limited time, I will address a few that I know the Committee has focused on before and that I think particularly highlight the issues that people with disabilities have faced over the past few years.

Many people with disabilities rely on prescription drugs and we are all aware of the unaffordability of many of these drugs. In Medicare, there is no out-of-pocket cap in Part D, leaving beneficiaries, especially with high-cost life-saving drugs, on the hook for thousands of dollars in out-of-pocket costs.¹⁵ Exchange plans often have completely unaffordable costs for

people with disabilities who are often required to pay out-of-pocket for the drug they need if it is not covered.¹⁶ In addition, anecdotal reports show that some people are unable to find any plan on the Marketplace that covers their current medications. We were pleased to see provisions in the Build Back Better Act to address some of these issues and generally maintain and improve affordability of prescription drugs for people with disabilities.

Millions of individuals with disabilities rely on Medicare to access the services and devices they need to remain healthy, functional, and live independently in their homes and communities. Yet there are significant gaps in Medicare's coverage of basic health care services—especially since Part B excludes dental, vision, and hearing benefits. The lack of dental coverage disproportionately impacts individuals with disabilities' access to oral health services. For example, 62% of individuals with disabilities under 65 report that they have not seen a dentist in the last year compared to 49% of Medicare enrollees overall.¹⁷ Further, they are more than twice as likely to forgo needed dental care due to cost compared to Medicare enrollees overall, a result consistent with their lower average income and resources. Lack of coverage for these critical services often contributes to complications and poorer overall health, especially for people who cannot afford to pay for these services out of pocket.

The idea that people with disabilities are living less valuable lives because of their disabilities, is also a problem across health care systems. The pandemic once again highlighted exactly this issue and one of the clearest examples of this discrimination occurred during the early months of this pandemic when hospital systems were attempting to make decisions about how to prioritize care in circumstances of limited resources. Many of the initial “crisis standard of care” developed by hospitals and states devalued the lives of people with disabilities and deprioritized them for treatment.¹⁸ Many daily home ventilator users in my network were terrified about going to a hospital, concerned that their personal ventilators might be seized and used for “healthier” people as some standards suggested they might be.

The Arc and other disability rights organizations filed multiple complaints with the Department of Health and Human Services Office for Civil Rights (OCR), leading to the revision of standards in seven states.¹⁹ But we are still waiting on comprehensive guidance from the federal government providing guidelines on how to ensure these standards do not discriminate—in addition to other guidance on Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act. Unfortunately, this kind of discrimination is not new. Research makes it clear that many in the medical profession do not see people with disabilities having the same quality of life as people without disabilities and their actions reflect this.²⁰ These civil rights protections are absolutely crucial to protecting people with disabilities, especially people of color with disabilities.²¹

Another way we saw this disregard for the lives of people with disabilities demonstrated during the pandemic was in the structure of new visitor policies created to limit the spread of COVID in hospitals.²² Many people with disabilities who rely on support staff for assistance in communicating, making decisions, and in accessing health care encountered barriers to bringing that support staff into hospitals. Oftentimes, lawyers were needed to sort out something that should have been a part of the initial plan, especially given the similar issues for people with language access needs have, either because they speak ASL or because they speak in a language that is not English. The Arc filed several complaints with OCR challenging these discriminatory policies and reached resolutions with states and hospital systems ensuring the policies allowed the supporters of people with disabilities to come to the hospital when needed as a reasonable modification.

Physical access to COVID testing and vaccines also has been and is haphazard. Many testing locations did not initially provide accommodations, such as not providing chairs for those waiting in line, drive-up only testing (leaving out those who cannot drive or who cannot afford a car), and inaccessible testing sites. Many states and localities do not provide at-home vaccination for those who are unable to leave their homes. The tests themselves are inaccessible for people who are blind or visually impaired or who may need support to take the test or interpret the results.²³ Again, none of this is surprising for people with disabilities who have constantly experienced doctors' offices without wheelchair accessible scales, waiting rooms that are not accommodating for people with sensory disabilities, and inaccessible exam tables.

The deep-seeded bias against people with disabilities within health care is all the more concerning when we consider the growing number of patients becoming permanently disabled as a result of Long COVID. I know members of this Committee have done some work to address the needs of people experiencing post-viral conditions and more work is needed. Post-viral conditions such as myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) are poorly understood and some people with Long COVID have symptoms consistent with those conditions as well. Ensuring that efforts to understand Long COVID also include research into these other, similar conditions will help expand our understanding of all post viral conditions.²⁴

Similarly, public health data has also failed to capture the experiences of people with disabilities and people of color with disabilities in particular—over the course of the pandemic, we have frequently raised our concerns about data requirements for nursing homes failing to take into account other, disability-specific congregate care settings.²⁵ Similarly, it is crucial that data is collected with full stratification of reporting by key demographic groups, including disability status, age, sex, sexual orientation, gender identity, race, ethnicity, primary language,

residential setting, and treatment setting.²⁶ Without this data we cannot track the systemic inequities in our health care system for people with disabilities and people of color with disabilities.

One policy solution that will help to remedy these inequities is to ensure that the medical profession includes people with disabilities themselves. This is another thing the Committee has examined, marking up the Pathway to Practice Training Programs as part of the Build Back Better Act. We are very supportive of legislation to expand scholarships to medical students with disabilities.

Finally, and on a positive note, there have been innovations stemming from the pandemic of which we are very promising. The massive expansion of telehealth services has been incredibly helpful in ensuring that people with disabilities who cannot safely venture into a doctor's office can still access the health care services they need. Even in non-pandemic times, telehealth can be the most accessible option for some people with disabilities who may have limited access to transportation or become anxious in new environments. The flexibilities related to telehealth established during the pandemic should remain available across Medicare, Medicaid, and private insurance.

There are also guardrails and protections that we know must be included in any expansion. We have endorsed the Consortium for Citizens with Disabilities' telehealth principles, which highlight the importance of ensuring disability and language access, privacy protections, network adequacy, and other crucial factors.²⁷ In addition to these factors, people with disabilities experience many of the same challenges accessing broadband as many low-income and rural areas.²⁸ This can be compounded by a lack of access to specific types of technology (such as access to the internet only on a smartphone which may or may not be usable for the particular telehealth system). We applaud the Committee for its bipartisan work in this space and the care with which they have put together thoughtful legislation recognizing that this new access should not go away and look forward to working on these solutions.

Working on solutions is how people with disabilities and organizations representing people with disabilities have responded to the pandemic--we have come together and explained our needs and asked to be included in the development of responsive policy. That is also partially why I'm here today--to reiterate things we have been saying throughout this pandemic and prior to it concerning the health care access needs of people with disabilities. If policy works for people with disabilities, it will work for everyone. I look forward to answering the Committee's questions and continuing to work with the Committee on these issues going forward.

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