

## **Health Care and the ADA-Inclusion of Persons with Disabilities**

Pacific ADA Center

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>> LEWIS KRAUS: Welcome to the healthcare and the ADA: Inclusion of persons with disabilities Webinar Series. I'm Lewis Kraus from the Pacific ADA Center, your moderator for this series. This series of webinars is brought to you by the Pacific ADA Center on behalf of the ADA National Network. The ADA National Network is made up of 10 regional centers federally funded to provide training, technical assistance, and other information as needed on the Americans with Disabilities Act. You can reach your regional ADA Center by dialing 1-800-949-4232. And that number is in the chat for you as well.

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And those numbers are in the chat as well. I want to also remind you all that this webinar is being recorded and will be able to access a copy in the ADAPresentations.org in the archives section of healthcare next week.

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Today's ADA National Network Learning Session is titled "Increasing Equitable Healthcare for People with Disabilities: Lessons Learned During the COVID-19 Pandemic." And an overview of NCD's Health Equity Framework. People with disabilities have long experienced barriers in accessing equitable healthcare, and the COVID-19 pandemic served to starkly highlight the barriers in discrimination that continue for this population. Changes are needed in the U.S. healthcare system to address and eliminate these persistent problems to lessen the significant health disparities and poorer health outcomes of people with disabilities. This webinar will present findings and recommendations from the National Council on Disability 2001 report: "The Impact of COVID-19 On People with Disabilities." Today's speakers are Ana Torres-Davis. Ana is a Senior Attorney Adviser at the National Council on Disability and oversaw the development of this report. She also oversaw the development of NCD's Bioethics Report Series in 2019, which raised awareness of five areas for people with disabilities continue to face discrimination in receiving life-saving and equitable care. And NCD's recent report on Accessible Medical Equipment back in 2021. Amged Soliman is a Senior Attorney Adviser at the National Council on Disability and serves as a staff lead on NCD's health equity initiative for people with disabilities. Amged oversaw the development of NCD's just released report "Medicaid O Health Coverage for Adults with Intellectual and Developmental Disabilities - A Fiscal Analysis." Which finds that the provision of preventive dental care to people with intellectual and developmental disabilities were absent through Medicaid and would create where absence through Medicaid would create a return on investment fiscally as well as a manner of health equity. All right, Ana and Amged, I'm going to turn it over to you now.

>> ANA TORRES-DAVIS: Hello, everybody! This is Ana. I'm very pleased to be here with you today on behalf of the National Council on Disability. You can move the slide, please. NCD is an independent nonpartisan federal agency responsible for advising the president, Congress, and federal agencies on matters affecting the lives of people with disabilities. It is comprised of nine presidential and congressional appointees who serve for limited terms.

NCD advises on a broad spectrum of issues. Including healthcare, employment, public accommodations, government services, transportation, education, emergency planning and response, and long-term services and supports. NCD drafted the first version of the Americans with Disabilities Act that was introduced into the House and Senate in 1988. As part of the statutory mandate, NCD evaluates on a continuing basis policies and programs concerning individuals with disabilities that are conducted or assisted by federal agencies in order to assess their effectiveness. NCD also evaluates new and

emerging disability policy issues at all levels of government and in the private sector. In conducting its duties as an evaluator and adviser, NCD's lens is the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act. Assessing the extent to which policies and programs facilitate or impede these hallmark federal laws. Next slide, please.

For a number of years NCD has embarked on an appraisal of healthcare access, treatment and outcomes for people with disabilities. And made recommendations to improve access to care. NCD's report, "The Current State of Healthcare for People with Disabilities" was released 19 years after the enactment of the ADA, and pointed out that there were disproportionately affected by barriers to care, including healthcare provider stereotypes, a lack of accessible medical facilities, a lack of accessible exam equipment, a lack of effective communication, and a lack of individualized accommodations and healthcare settings. In 2019, NCD published a five-report series on biomedical ethics, describing how longstanding stereotypes and disability bias had resulted in healthcare discrimination. Including denial of life-saving care in five areas. Those areas include organ transplants, where people with certain types of disabilities are denied access to life-saving organs even when those disabilities would not impact the patient's ability to accept that organ. And in medical futility decisions, which highlights how bias about life lived with a disability affects decisions about whether to provide life-saving medical interventions to people with preexisting disabilities. Much of the biases and discrimination discussed in this series were highlighted in the medical establishments and societal response to people with disabilities during the COVID-19 pandemic. NCD's report on medical diagnostic equipment calls for an end to a continuing physical barrier to healthcare for approximately 20 million people with mobility disabilities in the United States. The absence of height-adjustable exam tables and the absence of lift or transfer equipment means that people with mobility disabilities receive unequal access to healthcare, contrary to Section 504 and the ADA. The progress report on COVID-19's impacts on people with disabilities was released five months ago and is what I will be sharing with you today. Next slide, please.

NCD's progress report is an annual report required by statute that focuses on an issue of current or longstanding concern for the disability community. The 2021 report "COVID-19'S Impact On People with Disabilities" was absolutely necessary, because when the pandemic began, it was immediately noticeable that people with disabilities were experiencing broad scale impacts in a way that was more burdensome than their non-disabled peers. And issues of covert and overt discrimination were occurring across all areas of their lives. While no one had the benefit of preparation for what would become first of its kind public health emergency, shutting down our communities while simultaneously struggling to quickly find solutions for maintaining health and ensuring communication, the challenges were pronounced for people with disabilities. And their needs were left unmet. And others had to go to battle to receive equitable care. The nation's healthcare system was still unprepared to equitably meet the needs of people with disabilities in a time of resource scarcity. Today I'm going to focus on the findings on accessing healthcare, congregate care settings and effective communication, and the recommendations aimed at actions that we need to take now to

prepare the nation for any future public health emergency, for which we are long overdue. Next slide, please.

Prior to the pandemic, the U.S. healthcare system had widespread physical communication, programmatic and attitudinal barriers for people with disabilities. People with disabilities were simply not at the same starting line in healthcare when the pandemic hit. The public health emergency led to a few healthcare delivery changes that may benefit some people with disabilities, such as broader coverage, and availability of telehealth. For the most part, however, COVID-19 worsened the existing barriers. People with disabilities experienced multiple overlapping layers of healthcare discrimination during the pandemic. In the following specific areas, access to personal protective equipment, COVID-19 testing, and the capacity to shelter in place and isolate, medical rationing, Crisis Standards of Care and DNR orders, visitation policies and other healthcare policy modifications and accommodations, accessible vaccination and vaccine prioritization. Data collection on infection, hospitalization, and death rates of people with disabilities was lacking, and a decades-long dark of disability and functional status information left people with disabilities with the burden of being overlooked and the inability to prove their capacity to respond to treatment or their higher susceptibility to COVID-19 before full treatment and vaccination prioritization would be extended to them. At worst, these and other barriers during the pandemic led to people with disabilities losing their lives. For people with disabilities who have long endured healthcare discrimination and barriers to equally effective healthcare, COVID-19 was not only a healthcare crisis, but it was an extended test of the nation's recognition of their human and civil rights. It's important to point out the fact that civil rights laws protecting people with disabilities apply broadly to the healthcare industry. Federal and state disability nondiscrimination laws have included healthcare entities for decades. Virtually every hospital or healthcare facility is subject to disability rights law because they receive federal financial assistance through, for example, treating Medicaid or Medicare patients. They are the programs or activities of a state or local government, or because they are a private healthcare entity that is subject to Title III of the ADA. At the point that the pandemic hit, healthcare entities had to have recognized that they had nondiscrimination obligations that included requirements for physical accessibility, effective communication, and the obligation to make reasonable modifications in policies, practices or procedures for people with disabilities. NCD found that during the pandemic people with intellectual or developmental disabilities and medical fragile and technology-dependent individuals faced a high risk of being triaged out of COVID-19 treatment when hospital beds, supplies and personnel were scarce. People with disabilities were denied the use of their own ventilator devices after admission to a hospital. And at times they were denied the assistance of critical support persons during their hospital stays. Many of the Crisis of Care policies established or used by states and hospitals to govern healthcare services during periods where medical beds, equipment and personnel were strained, high levels of coronavirus infection and hospitalization discriminated explicitly and implicitly against people with disabilities. Some stating that certain people with disabilities would be put at the end of the line for care. Life-saving care. Or denied such care. This led to multiple lawsuits filed on behalf of people with disabilities alleging discrimination under Section 504 and

the ADA, and several settlements with the HHS Office for Civil Rights. The roll-out of COVID-19 vaccines in the United States raised competing priorities for achieving equitable distribution and achieving speedy and efficient vaccination, which left out people with disabilities who were at high risk from COVID-19. Especially those in group homes with intellectual and developmental disabilities. Based on the report findings and with the purpose of igniting government action to prepare for a future public health emergency, NCD recommended that Congress or HHS's Office for Civil Rights, OCR, should require hospitals and managed care plans that receive federal financial aid to increase public transparency of and nondiscrimination and due process within Crisis Standards of Care and medical rationing policies adopted during public health emergencies and emergency surge situations. We recommended that OCR should issue a Patient Bill of Rights addressing effective communication, policy modifications, treatment without discrimination, access to personal support persons, use of personal medical equipment, advanced directives, and more.

We recommended that OCR and the Department of Justice work with state civil rights counterparts to issue early general guidance, clarifying that there is nothing in federal or state law that automatically relieves them from their nondiscrimination obligations, including the obligation to provide reasonable modifications and accommodations in the event of an epidemic, pandemic, natural disaster, climate disaster, or in another public health emergency. We also recommended that HHS and the Department of Justice jointly established a healthcare technical assistance project to inform a range of healthcare providers on civil rights issues regarding patients with disabilities. Next slide, please.

I think I'm one slide behind.

Next slide, please. No demographic in the United States experienced COVID-19 more dramatically than people living in congregate care facilities. The way people in congregate settings live and receive care made the pandemic especially difficult to contain. And as a result greatly increased the risk of exposure for residents and staff. The institutional model was once again shown to be detrimental to people with disabilities. CCFs, including long-term care facilities, like nursing homes and assisted living facilities and other congregate settings, like state psychiatric hospitals, intermediate care facilities for people with intellectual and developmental disabilities, board and care homes and group homes, on the frontlines of a fast-changing pandemic, CCF reported severe staff shortages, inadequate personal protective equipment or PPE, and inconsistent and slow testing, and limited space for resident isolation and quarantine. Residents of CCFs also experienced extreme isolation due to COVID-related restrictions on visitors and many died alone. Most significantly, due to the difficulty of ensuring physical distancing, isolation and quarantine in CCFs, rates of transmission and death from COVID-19 in these facilities were extraordinary. As of March 2021, a year into the pandemic, over one-third of all COVID-19 deaths in the U.S. occurred in these facilities. Including nursing homes and assisted living facilities. 181,000 people in long-term care facilities died from COVID-19 up to that point. Accounting for more than a third of all the deaths in the United States. And this was from a group of individuals that constituted less than 3% of the nation's population.

However, the federal government was not counting for cases and deaths in other types of CCFs. For people with disabilities that were living in state psychiatric hospitals, intermediate care facilities and board and care homes, one 2020 study of New York State residents, for example, found that the mortality rate of those with intellectual disabilities, developmental disabilities who resided in group homes was nearly 8 times higher than the general population.

COVID-19 exposed many of the worst vulnerabilities of congregate care systems and emphasized the weaknesses and existing efforts to move individuals out of these settings in the face of the century's worst public health crisis, states had dramatically less capacity to fund and implement legally required diversion and transition initiatives. When reports of rapid infection and high death rates exploded across the country and within long-term care facilities, the primary discussion was about susceptibility to the virus because of age. But they rarely acknowledged that more than 14% of the residents in those facilities are people with disabilities younger than 65.

The idea that disabilities, that COVID-19 death rates could be diminished by rapidly diverting and de-institutionalizing people with disabilities from nursing homes was not widely considered, explicitly included or funded in federal or state emergency measures. Some states, in fact, adopted the reverse policy. They ordered nursing homes in the states to admit residents even if they were COVID-19 positive, and irrespective of insufficient coronavirus testing, PPE and infection control procedures in those facilities, putting vulnerable people in more danger. When the dangers imposed by the pandemic and CCFs created an emergency to transition residents to their own homes, or other non-congregate community settings to keep people safe, and to allow for distancing within facilities, the opposite actually occurred. Due to the pandemic's impact on direct care workers, case managers and other peer support workers, and what I mean by that is that so many of them also contracted COVID that they could not be there to do their work. The transitions and diversions in most of these places simply ground to a halt. And adding to the problems, many of the CCFs were not allowing transition staff to enter facilities to meet with clients about transitioning to the community. Deeming them visitors and delaying or stopping transition efforts that might have saved lives. It's important to note that despite the ADA's integration mandate and the Supreme Court's 1999 Olmstead decision, a severe shortage of community living opportunities or HCBS continues to be the norm. And this resulted in keeping many people with disabilities who wanted to and could have lived in a home or community-based setting, in an institutionalized setting, where the worst death toll took place.

About 600,000 people with disabilities who were living in congregate care settings were on the wait list for community living transition when the pandemic hit. And the lockdowns forced them to remain in these highly dangerous settings. Staffing shortages further exacerbated the vulnerabilities of CCF residents and staff. All types of CCFs reported experiencing the same unprecedented staff shortages due to COVID-19. One state-run facility that we spoke with in Pennsylvania was so short-staffed that even after closing an entire patient ward, the hospital still could not meet a 1:4 aid-to-patient ratio,

which is the professional recommendation. Some states looked to staffing agencies to recruit emergency workers. Others have called in the National Guard as a last resort.

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Based on our findings, NCD recommended that the Centers for Medicare and Medicaid Services, the Administration for Community Living, the Substance Abuse and Mental Health Services Administration, the Department of Housing and Urban Development, the Federal Emergency Management Agency, and DOJ jointly should develop and implement a strategy to mitigate the risks of infectious disease transmission in CCFs, and address the civil rights concerns that impact the lives of people with disabilities that live in those settings. We recommended that the CDC emphasize that congregate care facilities reduced the amount of people that live within them as an infection control strategy, and by expanding its guidance beyond long-term care facilities to include all CCFs. We recommended that CMS prioritize all CCFs for infection control purposes, ensuring they all receive equipment, such as test kits and proper PPE necessary to follow the CDC guidelines if there were a similar health emergency in the future. And that CMS should clarify the community providers that conduct in-reach transition support to facility residents or essential care providers, not visitors, and should not be restricted from entering facilities during a future pandemic or crisis. And, lastly, that DOJ should issue guidance concerning public entity's Olmstead obligation and they should clarify that Olmstead and the mandate requires transitions and diversions from CCFs continue, even during pandemics and other emergencies. Next slide, please.

The COVID-19 pandemic has uniquely impacted deaf and hard of hearing communities, people who are blind, and people who cannot rely on speech to be heard and understood. Today there are over 37.5 million people with difficulty hearing, and an additional 5 million people who cannot rely on speech to communicate in the United States. Prior to the pandemic they faced communication barriers in healthcare. The provision of disability-related accommodations and proper auxiliary aids and services by public entities and public accommodations, as are required by the ADA, in Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act was inconsistent and was often a barrier to access.

With the pandemic, disparities in effective communication deepened. Widespread mask use and social distancing protocol, as well as increased reliance on virtual forms of communication created new challenges for people with hearing, vision, speech and/or intellectual or developmental disabilities to interact with their communities and equally access healthcare. These new communication barriers also hindered the dissemination of public health information critical to slowing the spread of COVID-19. And exacerbated the difficulties that people with disabilities already faced in accessing essential services. During the pandemic written and oral communications related to the provision of medical care and public health precaution are of the utmost importance. It is critical that public entities, places of public accommodation ensure that communications are fully accessible to people with disabilities.

With regard to effective communications in healthcare settings, there were three areas of widespread problems. First, the use of opaque face masks served as a communication barrier to people with disabilities who rely on lipreading and facial cues for effective communication. The mask requirements were important to protecting individuals from contracting COVID-19, at the same time the common use of opaque masks created new challenges for people who are deaf and others with deaf disabilities that impact their hearing or speech. The use of face masks muffle sound, making it more difficult for people with hearing loss to understand speech and higher pitched voices. It also can take away an individual's ability to lipread and to contextualize communications through the observation of facial expressions.

People with hearing loss reported widespread difficulty in understanding healthcare providers who were wearing face masks during the pandemic. The use of clear masks was widely endorsed as an alternative that accommodates people who lipread. However, while some clear masks were approved by the FDA, they were not N95 rated and therefore were inappropriate in certain healthcare settings such as when a provider is interacting with COVID-19 patients. Also, they do not alleviate communication barriers created by muffled sound and certainly can't be a substitute for an ASL interpreter when that is the patient's primary language. Alternative communications for effective communication should also be considered by healthcare providers, depending on the needs and preferences of the individual, the use of a sign language interpreter, assistive technology, such as video remote interpreting, transcription services, Communication Access Realtime Translation, or CART, and assistive listening devices, or even low-tech solutions, like communication boards can be appropriate. It is essential that healthcare providers and administrators listen to the needs of people with communication disabilities and devise effective solutions to be sure they can learn and communicate about their health conditions.

In addition to the challenges that face mask mandates created in the receipt of information, from healthcare providers, they also created barriers for people with disabilities to provide information to their healthcare providers. There are individuals who by virtue of their disability cannot wear a face mask either at all or extended periods of time. Including individuals with developmental or intellectual disabilities who can't tolerate face mask. People with mobility impairments who cannot independently put on or take off a mask. People who use ventilators to support their breathing. People with sensory disorders who may experience while wearing a mask. People with lung diseases or breathing difficulties and people experience panic attacks while wearing a mask. These groups should be explored to increase their safety during a similar health emergency in the future. Secondly, prior to the COVID-19 pandemic in-person interpretation in the hospital setting was the highest standard of care for people who communicate through sign language. Healthcare experiences can be fast-paced and dynamic, especially in emergency situations. And they are often multiple healthcare providers in a room at once performing several tasks and attempting to communicate multiple pieces of information all while the patient is in a potentially supine or prone position and in pain. In such situations, it's critical that the auxiliary aids and services provided to that individual be built for this environment. The dual

interpretation services, such as VRI, have limited effectiveness in a crisis care situation, and they are inferior to an in-person interpreter.

But at the onset of the pandemic and throughout, sign language interpreters did express concern for their lives and safety, given the increased chance of contracting COVID-19 in the hospital setting. Likewise, patients expressed concern that interpreters could spread COVID-19 to the people who used the services. Other patients in the facility and hospital staff. These safety concerns were amplified by national shortages in PPE. Not only must our healthcare system have a stockpile of PPE ready for the next crisis, but the PPE should address the needs of patients with various communication disabilities. Additionally, most HIPAA compliant telemedicine platforms continue not to have built-in accessibility features to facilitate communications with patients with disabilities. Features like live captioning and three-way video visits, which allow an interpreter to join the meeting and facilitate communication are not yet commonplace. This means that telemedicine visits can be useless to the deaf and hard of hearing community who may be able to see but not communicate with their healthcare providers. While a telephone visit, when coupled with a relay service operator, such as Text Telephone, or TTY, may be more viable, the quality of care is questionable when the only means of communication is through text.

Likewise, telemedicine platforms and the patient education materials posted on them are often not accessible to people with vision loss. Websites, software programs, electronic documents are often not designed and formatted to be accessible with a screen reader. Compliance with World Wide Web Consortium Web Content Accessibility Guidelines is not widespread. And, lastly, despite clear legal requirements, people with disabilities were overlooked on multiple government levels during the COVID-19 pandemic. State Public Health Departments and local municipalities failed to make critical information accessible to people with communication disabilities, and so did the federal government. For example, while the pandemic was still in its infancy, arguably at its most critical stage in relation to stopping or at least slowing the spread of the deadly virus, the Trump administration's White House would not provide sign language interpreters during its COVID-19 briefings. And this left millions of U.S. residents to communicate using ASL without access to critical up-to-date information related to the pandemic. Federal, state and local governments must ensure that their programs and activities during a pandemic, and communications related to the pandemic are fully accessible for people with disabilities. In a national crisis, it is essential that people with disability have access to the same information that any other individual does.

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Based on these findings, NCD has recommended that HHS Office for Civil Rights and the Department of Justice should direct hospitals and other healthcare entities to include in their nondiscrimination notices and staff training a recognition of policy modifications as part of a patient's right to effective communication. In addition to the provision of auxiliary aids and services when needed by patients with disabilities. Also,

that all federal agencies involved in public health, emergency management and the provision of public announcements or briefings or broad public importance should prepare and disseminate information related to any public health emergency in accessible formats. Including providing sign language interpretation, or captions during live and pre-recorded video briefings and making all written materials available in alternative formats, and making all online materials accessible as well. And lastly, that state hospital associations should develop guidance and best practices for insuring effective communication in hospitals and associated urgent care clinics during public health emergencies, including the provision of qualified in-person interpretation, and fully accessible telemedicine platform. Next slide, please.

This slide is a picture of a healthcare worker giving a COVID test to a woman that is in a long-term care facility. I want to say in closing that I encourage you to please obtain a copy of the full report at the NCD website at [www.NCD.gov](http://www.NCD.gov). For complete information on all seven areas examined the report. Dr. Martin Luther King once said that of all the forms of inequality, injustice in health is one of the most shocking and inhumane. The lessons learned from this pandemic are very many. I only touched on some of them here. Some new and unique to this pandemic. Some long-standing that the country had not addressed appropriately before the pandemic, and which were highlighted by it. We shouldn't wait any longer to take actions to ensure compliance with the ADA and 504. The nation learned lessons from natural disasters prior to the pandemic, where people with disabilities were left behind. They were left out of life-saving efforts, and this pandemic shone the light once more on the many ways that this continues to occur. No one should be left behind. No one should be put in unnecessary danger. And we can ensure this by taking necessary actions to prevent discrimination and inequitable care. As NCD's chairman, an Dr. Gallegos says, "We can make these changes. We just need to will to do it." Now I will turn it over to my good friend and esteemed colleague, Amged Soliman, who will share the Health Equity Framework, another initiative by NCD to address healthcare disparities. Thank you so much for listening today.

>> AMGED SOLIMAN: Thank you for that report and the crucial points you have made. We greatly appreciate it. I would like to turn our attention, Ana was speaking about the Health Equity Framework for policy workers. NCD has been focused on the issue of health equity for people with disabilities on some level for several years now, but regard to this specific framework, about a little over a year ago, when President Biden appointed Chairman Gallegos to his chairmanship, it was a priority that NCD focus even more on the issue of health equity for people with disabilities. And to that end and for the sake of the purpose and general compliance with the ADA, NCD did begin its research, its deep dive into the issue of health equity for people with disabilities. We began putting together this framework a year ago in the sense that we reached out to community members and experts in what we have deemed our Dream Team, to collect the information we needed to put together this framework that makes up our recommendations. Next slide, please.

So I already touched a bit on the purpose and Ana certainly touched upon the need for our Health Equity Frameworks. I would like to go over what we deem our core components of the Health Equity Framework, and then I'm going over next steps, and then we will welcome questions and feedback. Next slide, please. So here again, the purpose or the need for this is address the decades-long health disparities that people with disabilities face. To address ableism, physical and other systemic barriers. And to achieve health equity for all categories of persons with disabilities. Next slide, please.

So, I quickly mentioned that we have what we call our Dream Team, our Multidisciplinary Dream Team of advisers. Here is a list of some of them. We have doctor -- I'm sure you will be familiar with many names, Dr. Lisa Iezzoni, professor of medicine at Harvard Medical School. Kristi Kirschner, clinical professor University of Illinois, Margaret Turk, at SUNY, Priya Chandan, from University of Louisville. And the list goes on, Barbara Kornblau and other very, very impressive people who really know what they're talking about. Next slide, please. Here are a few others. Susan Haverkamp, I'm sure you are familiar with her, she's done a lot of great work on the issue of clinical care and competency training of medical professionals, and medical students. And many others, as you can see, including our very own Dr. Rick Rader, who is a council member at NCD and director of the habilitation center Orange Grove center and president of the American association Health and Disability. We approached them and asked them, is there anything you wish to address first and foremost regarding the issue of health equity for people with disabilities, what would you address, how would you address it, what should we focus on? And I must credit everybody, including the ones I wasn't able to list in interest of time today, but really helping us put together this framework. Next slide, please.

So as I mentioned earlier, the framework has a list of over 30 things that we think should happen to help move forward health equity for people with disabilities. But we did put together what we deemed the core components of our framework. These are the four things identified by NCD with the help of our Dream Team that we believe, if achieved, would really truly -- I mean, these are the essential things that would really truly go very far in helping to achieve health equity for people with disabilities. I'm going to go through them briefly here.

Top of the list, designation of people with disabilities as a special medically underserved population please excuse the word "special." That is the term that is used in law. Essentially what would have to happen is people with disabilities would have to be legally identified as what they call a special medically underserved population through revision of the Public Health Service Act. And with that designation comes many benefit that would push forward health equity for people with disabilities. And I can do into a little bit of that -- a little more of that a little later. The second thing, comprehensive disability clinical care curricula. So one of the main problems is that there aren't health professionals or enough health professionals, I should say, that are trained to provide proper healthcare to people with disabilities. I mean, it's just not something that most medical students address. It's not something that is required of most if not all residency programs. It's not something that is enough of a focus in nursing programs. It's a real

problem. So that is the second component that absolutely must be addressed. Because as I was indicating earlier, you can't get quality healthcare if your provider isn't trained to deal with your needs and provide the reasonable care that you require.

That brings us to our third bullet point of the four components. Accessible medical diagnostic equipment. And this is something that my esteemed colleague, Ana, has certainly been a leader on among the staff at NCD. Certainly if medical and dental equipment are not accessible, that is surely a problem. We have heard many, many -- too many horror stories of people who could not get a proper checkup because the equipment necessary simply was not there. And we'll get into a bit more of that in a bit too.

And then the fourth, improved data capturing. Much needs to be done to help collect the data that is necessary to provide equitable healthcare for people with disabilities. There are 35 additional components that we outlined in our framework and I welcome everybody to log on to [NCD.gov](http://NCD.gov) and take a look at our framework. Please familiarize yourself with these four components. But also the 35 additional components that we have. All of them are very important in achieving health equity. But getting back to the four core components... next slide, please.

Core component number one. Special medically underserved population designation. This is something that would have to happen legislatively, as I was indicating earlier. Congress would need to direct the Health Resources and Services Administration, otherwise known as HRSA, to designate all people with disabilities as a medically underserved population, as I said before, under the Public Health Service. Typically MUP designations require population groupings. I don't mean special medical needs population, I just mean medically underserved population. I'll get to the difference in a little bit. MUP designations require population groupings based on geography. There's a section geographically of the United States where population within that geographic location should be deemed medically underserved and then once they get that designation, they get the benefits and services they require. Now, obviously that is not an applicable means of providing equitable healthcare to the national community of people with disabilities. People with disabilities live across the U.S., and thank God, thanks to the Olmstead case, people with disabilities aren't located in specific geographical locations in the sense that they're not institutionalized. And that is a good thing. We're spread all across the country. So as such, this geographic location requirement is problematic. Next slide, please.

So that is why you would have to have the special medically underserved population designation occur legislatively through the public health service act. And that has been done for other communities. Homeless population, residents of public housing, and farmworkers. These were groups that were given the designation through the revision of the public health service. And those benefits, if this is achieved for people with disabilities, some of the benefits through that designation would include the following: Federal funding for federally qualified health centers and other health centers.

Loan repayment and HRSA training programs. So, in other words, medical professional decides he's going to -- or she is going to focus on providing treatment to the designated population, in this case it would be people with disabilities. In exchange they have their student loans repaid as an incentive. Some other benefits include higher Medicare and Medicaid reimbursement. And that is important. Because one of the problems in achieving health equity for people with disabilities is that a lot of people with disabilities are on Medicaid or Medicare and those reimbursement rates don't always quite suffice to the liking of the healthcare provider. So higher Medicaid and Medicare reimbursement rates would go a long way in incentivizing healthcare providers to treat the population. Another benefit. Federal research preference and funding. So obviously research is very important. And with this designation a lot more research would be conducted to the benefit of the designated in the population, this case people with disabilities, among many other benefits that come with this. Next slide, please.

Now, as I mentioned, SMUP designations have to happen legislatively. And sometimes that can be a challenge. Not that it's a challenge not to be a reason for it to happen having said that, there is an alternative. Well, maybe "alternative" is not the best word because they achieve different things. But something that should happen if MUP designation was to happen, but also certainly if it doesn't happen, either way, something that would go a long way to benefit people with disabilities in achieving health equity would be what is called the Health Disparity Population designation under the minority health and health disparities research and education act of 2000. Health disparity population exists if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population compared to the health status of the general population. And I'm sure that will sound to many to apply to people with disabilities. So, again, SMUP designation is important. Health disparity population is separately important. But if SMUP designation cannot happen, then at least Health Disparity Population designation should happen and it should happen regardless, because it really would go a long way in helping to achieve health equity for people with disabilities. Next slide, please.

I should note before I go to this particular slide that many, if not most, are of the opinion that Health Disparity Population is something that can happen administratively and potentially easier than getting something done legislatively. Not that either should be a reason or the right thing not to happen to advance health equity for people with disabilities in consideration of the ADA and other disability rights laws.

Here we have some information on the second core component, which is comprehensive disability clinical care and competency curricula and training for medical students and other healthcare professionals. All of these issues are close to my heart, including designation of Health Disparity Population, but this one is maybe just a step more closer to my heart. NCD has done a lot of work in this area. And it truly is very, very important. Because healthcare providers, they just simply have to be trained to

treat people with disabilities. So I wanted to discuss a little bit Section 5307 of the Patient Protection and Affordable Care Act. It's applicable to U.S. undergraduate medical, nurse, healthcare professional and allied-health programs. Graduate residency and fellowship programs and international medical schools. Excuse me one second.

Sorry about that. Okay, so Section 5307 says that it welcomes at its discretion the Secretary of Health and Human Services to put together model curricula for medical schools to follow whereby the developed curricula would train their students in disability clinical care and competency training. And then that curricula could be shared with medical schools who would hopefully adopt it. At present, it's -- that section is not written as forcefully using terms such as "must" and "shall" as many would like, but there is a mechanism there and it should be considered because this is something that has to happen. NCD, I'm happy to report, had some success regarding this issue on the dental side. NCD worked and advised that U.S. dental schools should train their students to manage the treatment of patients with disabilities. And a lot of schools have adjusted -- have begun adjusting their curricular requirements accordingly. In fact, it's required of all student. And this took effect in July 2020. NCD was successful in recommending to the American Dental Association that it revise its model rules of professional responsibility, its code of conduct, to state that a provider cannot turn away a patient based solely on their disability. And because many states out there adopt those model rules as their own state law of professional conduct, several states actually changed their own laws to say that a dentist cannot turn away a patient based on their disability. So it was actually very wise to require all dental schools to train their students in the treatment and management of patients with disabilities, because that way you're not graduating students who, A, don't know how to treat patients with disabilities, but also you're not graduating students that in some states would be essentially not as in compliant with the law as they should.

But on the medical side, more needs to happen. I wouldn't say a good amount, but there are certain schools out there that have disability care curricula in place. The majority, again, do not. And that's something that has to be rectified.

Next slide, please.

That brings us to core component number 3, accessible medical and dental equipment. So, NCD is recommending adoption of the U.S. Access Board's 2017 voluntary standards. And we believe this is an issue pertinent to the Department of Justice and HHS Office of Civil Rights, Section 504 of the Rehabilitation Act of 1973. Relevant as well. Next slide, please.

And before I go into this slide, I would just say that NCD has done a lot of work, and again, my colleague, Ana was on the staff regarding that work. Please go to [NCD.gov](http://NCD.gov) to look up NCD's reports and other information put out concerning that important issue. Because as I said at the outset, we've heard some horror stories. We have heard some -- and we've been aware of this for quite some time, obviously, but it

does help to drive a point home. And here people are telling you how they went into the doctor's office and, you know, the doctor might look in their eyes, their ears. They don't really examine the patient from the waist down because they don't have the equipment to do it. Perhaps someone who is a paraplegic. You just have to have an accessible medical equipment. And to that effect we have made it.

And we have number 4 of our core components, and that is improved data collection regarding public health surveillance systems, electronic health records and also relation to the National Academy of Sciences comprehensive study of HHS' data collection systems and practices, that is something that has to happen. You cannot provide quality healthcare unless you have the data you need to do the job. So that's our fourth component as well. The federal government currently is doing some stuff to help achieve better data collection for this issue, and NCD certainly applauds them. Next slide, please.

So those are the four fundamental core components of our framework. But as I indicated earlier, there's 35 additional recommendations that NCD makes. Please, again, feel free, log on to [NCD.gov](http://NCD.gov), download the framework. It's a quick read, very quick read, and familiarize yourself with our framework and with that I would just like to say we appreciate you having us here to talk about this, health equity for people with disabilities is certainly an important part of the ADA and an important part of what NCD has built its recommendations around and fulfilled our statutory obligations. And with that I would welcome questions and feedback. And I thank you in advance.

>> LEWIS KRAUS: Thank you so much, Ana and Amged. All right, everyone, this is a good time for you to submit your questions in the chat window. And we can get to the questions for the speakers.

>> AMGED SOLIMAN: In the meantime can we go to the next slide?

Just wanted to put it out there while we wait for questions that anybody who has any questions or comments or anything related to NCD's Health Equity Framework, please feel free to contact NCD. You will see at the bottom of the screen there my email address.

>> LEWIS KRAUS: Okay. Let's begin. There's a couple of questions coming in now.

Is there a tax credit or some type of incentive for medical providers to purchase accessible medical equipment?

>> AMGED SOLIMAN: Ana, would you like to take that one? As I mentioned before, Ana has been a leader on the issue of accessible medical equipment among NCD staff members.

>> ANA TORRES-DAVIS: We may have addressed that in the report, and I can pull that and scan it really quickly while we're on here.

>> LEWIS KRAUS: Okay. I'll tell you what, Ana, why don't we just do another question while you're looking for that, okay?

>> ANA TORRES-DAVIS: Okay.

>> LEWIS KRAUS: Next question... will there be a call for entities to support or comment on the framework at some point?

>> AMGED SOLIMAN: We at NCD consider this to be -- the quick answer is yes, we welcome feedback on the framework. You know, certainly would be up to the council to determine if anything in it might change or not. That is to say we do welcome feedback. I don't want to say it's a living document, because the recommendations we made in it, I think the council certainly believes in. But at the same time, yes, NCD welcomes feedback and comments regarding the framework and anything that might have to be tweaked or changed, the council I'm sure would welcome that input and consider it. So, yes.

>> LEWIS KRAUS: Thank you.

Next question: Did we learn from these experiences? Are we ready for -- coming in fast -- are we ready for future issues like COVID or other risks?

>> AMGED SOLIMAN: Certainly I would defer to my esteemed colleague Ana, but if I made, because I think Ana might be looking up something. If I may, we certainly learned a lot. Now it's a matter of applying what we have learned. It's a matter of applying what we have learned. I think a lot during the pandemic -- or the height of the pandemic, and hopefully we're past that, you never know, but to 20, you know, you would see some problems, many of which Ana eloquently described. One quick example... patients with disabilities in hospitals, sometimes their caregivers weren't allowed into the hospital to tend to them because the hospital had a policy of not letting people in because they didn't want the COVID-19 disease to spread. But at the same time, there are, you know, accommodations that have to be made. And I recall, as that year progressed, different healthcare systems, different hospital systems caught on and learned from their mistakes and started letting in caregivers for people that absolutely needed them. Now, as a matter of policy and law, again, I would just reiterate what I said before, and that is that we learned a lot. Now it's just a matter of applying what we learned.

>> ANA TORRES-DAVIS: And I think too that certain policies stopped because of the -- certain discriminatory policies stopped when the U.S. Department of Health and Human Services Office for Civil Rights reached out to different hospital systems and states

about their discriminatory policies. Some of these were about Crisis Standards of Care, which for those of you that are not familiar with those, those are documents that go into effect when -- in a surge situation, like we saw with the pandemic. When you would see more patients than you would beds, for example. And states and hospital systems have developed these Crisis Standards of Care to decide who gets treated first and what is the order. And some of those, like I referenced in my talk, were explicitly said that, for example, people with certain types of developmental disabilities or intellectual disabilities would not be treated first. They would be put at the end of the line. And there was no other reason except for disability on the face of this document. They were just -- they decided that the value of their life was lesser than a person without a disability. And so HHS was able to work with some states and hospital systems on those, and those are also posted on their website. I'm not sure what the website is, but it's the Office for Civil Rights at HHS. So we saw some progress there.

We did see some progress on visitation. We did not see a lot of progress in other areas. I think there's still going to be some problems with making sure that people with disabilities have the ability to access healthcare. The telemedicine platforms, from what I understand, remain inaccessible to some people with disabilities, and until that is fixed, that is going to continue to be a source for inequitable healthcare. What else happened? What else has been done that has been improved? We need to make sure that before anything happens again that people with disabilities of all kinds will have access to the vaccination sites or any other access to equipment, personal protective gear, things that they were not able to access this time. And I don't know if that problem has been addressed thus far.

And I'm seeing here that there is an IRS tax benefit for businesses who have -- who make adjustments to their businesses -- let me see what it is. I will put the link to that in the chat box.

>> LEWIS KRAUS: Great. Thank you, Ana.

>> ANA TORRES-DAVIS: And keep in mind, though... I'm sorry, Lewis.

>> LEWIS KRAUS: It's okay.

>> ANA TORRES-DAVIS: Keep in mind that this all goes back to the ADA requirement and the Section 504 requirement that healthcare has to be provided in a way that is fair and equitable. And I -- and so providing accessible medical equipment is part of that. What we don't have right now is a document saying each doctor's office has to have, let's say, for example, one table for every five offices. We don't have that right now. We have the Access Board standards, which describe what it could be. And please note, too, that in the fall, the United States Department of Justice is planning to release a Notice of Proposed Rulemaking on this type of furniture and they will be requesting comments on that NPRM. So please look that up at the time and see if you can provide comments, questions, I am sure, that hospital systems will, you know, raise the issue of cost, and cost is something that is a barrier, but it is also just a civil rights issue. And so

we don't look at it from NCD's point of view. We take the position that, yes, cost is an issue, but it can't be the reason not to provide something that is guaranteed, a guaranteed civil right.

>> LEWIS KRAUS: Thank you. I want to remind everyone that many of the topics that our speakers have raised, like the vaccines sites, those have been gone in depth on our Webinar Series previously and you can find them in the archive section if you have a particular interest in those areas.

All right, next question... and this person apologizes that they have not yet reviewed the report, but is asking... are there any practices that are highlighted as progressive or positive that occurred during the pandemic response?

>> ANA TORRES-DAVIS: Good question. I do think that the development of telehealth did help a lot of people with disabilities. It didn't help everybody, but it certainly helped a lot of people who could not leave their house and that needed access to their doctor, and that were not able to have that before. And I think that it really has changed the face of that. And I think that it has the potential to really further change the face of that. Beyond that... go ahead.

>> AMGED SOLIMAN: I was going to say, that's a very good point, Ana. And I think there was a flipside to that coin, in the sense that with the increased use of telehealth, you had individuals with disabilities who could not access that approach the way others might be able to. And that was a new problem that developed. Because, unfortunately, technology isn't always accessible, and the shift towards telehealth and, you know, talking to your doctor using FaceTime, that is not something -- you know, using whatever similar technical program that may not be accessible, that was a problem that also developed. So we're seeing things getting better in some ways, but making things harder in others, and that's something everybody should be cognizant of.

>> ANA TORRES-DAVIS: I can say something, too, that I think has helped overall. Societally, and also with healthcare systems. Even though these barrier have existed for a long time, with this pandemic, there were so many news articles. There were so many news stories pointing out the disparities, the discrimination, the danger that people with disabilities were being put in, that people were being refused care, that people were being pushed aside. The barriers that were occurring, and there was so much activity by the department of HHS office for civil right, they were very active in this. They moved swiftly. They issued guidance to hospitals and healthcare providers, reminding them that they had duties under the ADA and Section 504 and under the Affordable Care Act to provide equitable care, and that that did not allow them to discriminate against people with disabilities, even when resources were scarce. And I don't think that it happened before. And these are on the books now. And this is something -- something changed this time. And it was more widely recognized

>> AMGED SOLIMAN: Indeed.

>> ANA TORRES-DAVIS: And I think that will carry into the future for any other public health emergency, because it set a standard now.

>> LEWIS KRAUS: Great. Thank you. Maybe one last question here. So for any of the healthcare providers in the audience -- and you focused a lot on my -- or not "my," but on policymakers and policy issues. How about for healthcare providers in the audience? Do you have any kind of rec me additions for them to take to deal with findings themselves, maybe not necessarily waiting for other policies and what not to happen?

>> ANA TORRES-DAVIS: I'm sure both Amged and I have some comments on that. So, am I understanding you right that you're asking Amged and I to opine on this or are you asking the healthcare providers in the audience to make a comment?

>> LEWIS KRAUS: I was wondering if anybody in the audience who is a healthcare provider, you know, are there recommendations from you to them about what they can do prior to even waiting for any policy guidance?

>> AMGED SOLIMAN: I would like to take a crack at that, if you don't mind.

>> ANA TORRES-DAVIS: Sure thing.

>> AMGED SOLIMAN: You know, right now it's largely not required -- well, I shouldn't say that. There's not as much of a requirement to learn and be trained and get continuing education, and the provision of healthcare to people with disabilities to actually learn clinical care and competency training for people with disabilities. That doesn't mean healthcare providers can't take it upon themselves to go out and learn that. It is advisable that they do so, because you have to take care of the patient. And there is over 61 million people in the United States that have some form of disability. And it would be pertinent for any healthcare provider that has never been trained in critical care, to obtain that training, I think it would go a long way in helping your patients. I would say a lot of people are on Medicaid, a lot of healthcare providers opt not to participate. It would go a long way in achieving health equity for people with disabilities if more providers chose to participate.

>> ANA TORRES-DAVIS: Absolutely. And I think another thing is from a patient-to-health provider relationship perspective, I think a lot has been said about inequities and barriers to healthcare, and it's hard to feel that you are included. It's hard to feel that you matter and you are important and that you are valued when you enter a building that doesn't have access for you or it's hard to communicate and you have to be very, very uncomfortable in asserting your rights and say, but I need this or I need that. Or I need someone to help me, you know, read this form or translate this for me. It puts a heavy burden on patients, and I think that understanding obligations under the ADA for accessibility, and just wanting to embrace all patients that come in the door you know, making an effort to get -- look at accessible medical equipment when you're replacing what you have right now, by something accessible. Try to have these

discussions about accessibility all around. Are your forms accessible? Are your online appointment making systems accessible? Are your telemedicine platforms accessible? Are you able to quickly have access to an American Sign Language interpreter? Do you have a way for someone to indicate when you're making an appointment that they need this? And can you arrange it in a time period that is reasonable? There are a lot of things that you can do to reduce barriers to care. And those are some of them.

>> LEWIS KRAUS: I'm going to add to that question that clearly working with people with disability in your community will help you if you are being proactive as a healthcare provider, you know, working with your communities will help, people in your communities will help, and if you are ready to be trained, if you're ready to find out more about the ADA requirements that you have, you can contact any of our regional ADA centers for that kind of training, and we are all equipped to be able to do that.

All right, with that we realize that many of you still may have questions for speakers, and I apologize if you didn't get a chance to ask your questions. We've got Amged's information right there on the screen, and maybe, Ana, you can put yours into the chat right now, and people can connect to you if they have more questions. If your question is about the ADA and how this relates to the ADA, you can contact your regional ADA Center at 1-800-949-4232. You will receive an email with a link to an online session evaluation for today's session. Please complete that evaluation for today's program. We really value your input and want to make sure that the funder knows the value of this as well. We want to thank our speakers today for sharing their time and knowledge with us. A reminder that today's session was recorded and it will be available for viewing next week at the ADApresentations.org in the archives section.

Our next healthcare webinar will be on April 28<sup>th</sup>, and we will have the Office of Civil Rights from the U.S. Department of Justice and the Department of Health and human services to discuss the latest issues that they are embarking on in healthcare and the ADA. We hope you can join us for that. Watch your email for the announcement of the opening of registration for that, which will happen two weeks prior to that webinar. All right, thank you again, Ana and Amged. Thank you all for attending today's session. And have a great rest of your day!

>> AMGED SOLIMAN: Thank you for having us.

>> AUTOMATED VOICE: Recording stopped.