CCD Hill Briefing
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Remote CART Captioning

>> Hello, everybody! Good afternoon. I'm hoping that the lunches will still be out there and you can grab what is left on your way out. Thank you for coming to today's briefing, an overview of the consortium for constituents with disabilities, existing disability rights laws, and some of the issues, the broad community of people with disabilities are facing today. I'm going to turn it over first --

>> AUTOMATED VOICE: Recording in progress.

>> ... Senator Duckworth's office is hosting today, and I want to give her a chance to say a few words and I'll pick it back up. Thank you, Stephanie, because I know you work so hard for the community every day. So thank you for everything you do.

>> Hi, everyone. I'm standing in for the boss, who said that she, unfortunately, couldn't make it today, but wanted to send her gratitude for everyone here.

Sorry, I should probably speak into the mic.

The Senator sends her gratitude for everyone here and everything that you do, and so happy to be a part of this wonderful briefing celebrating 50 years of CCD. And just want to say thank you, thank you all for everything that we do. We couldn't do our work without you. That's it. Thank you!

>> I'm told the sound isn't good, so please let me know if you can hear me. Is that better?

>> Yeah, a little bit.
>> Speak into it, okay.

Okay. For those who don't know, my name is Carol Tyson. I'm the government affairs liaison from the Disability Rights Education and Defense Fund and currently serving the chair of CCD. It is an honor to be with all of you. I'm going to start with acknowledgements and quick overview of CCD and pass it off to our wonderful panelists. We will hold questions until the end.

In mind of CCD's mission and values, I acknowledge that Washington, D.C. sits on the traditional and ancestral lands.

We acknowledge the Native peoples on the ancestral lands we gather as well as Native communities who make their home here today.

We thanked Senator Duckworth and Stephanie and I want to thank the staff of the Capitol Hill Visitors Center for hosting us for the wonderful lunch. Thank you for the sign language and CART interpreters and thank you to all of you, CCD members, congressional staff and friends for being here and all you do every day.

Formed in 1973, the consortium for constituents with disabilities is comprised of more than 100 organizations focusing on federal policy including disability-led advocacy and civil rights organizations, as well as service providers. Our broad membership leads to diverse and informed perspectives.

We advocate on behalf of people of all ages with physical, sensory, intellectual, developmental and mental disabilities and their families.

CCD seeks to ensure the self-determinations, empowerment, integration, and inclusion of people with disabilities in all aspects of society, free from racism, ableism, sexism and xenophobia as well as LGBTQ+ based discrimination and religious intolerance.

Our public policy work. For anybody who doesn't know already, it is carried out by 15 issue-based task forces, including the developmental disabilities, autism and family support task force, education, emergency management, and employment and training. Financial security and poverty. Fiscal policy, health, housing, international, long-term services and supports, rights, Social Security, technology and telecommunication, transportation, and veterans. Each task force is led by co-chairs and posts regulatory comments, letters, testimony, and other advocacy materials on our website.

For the current Congress and administration, they're also posted and available. We are available for consultation and work regularly with Hill and administration staff. I will now pass it off to our panelists, Carlean Ponder and Monica Porter Gilbert, who will talk about disability rights in the criminal legal system, Claire Stanley and Danica Gonzalves on an overview of fundamental disability rights and community barriers and Jennifer Lav in the community living and medical home and community-based services. Hopefully you found the fact sheets and the CCD overview and speaker biographies as you entered. We will share them via email and post them along with the CART transcript on our website. Thank you all for being here today and thank you to our panelists.

>> Hello, everybody! Now you can hear me. Hi, I'm Carlean Ponder. With the Autism Society of America. And I'll just tell you a little bit about my background before launching into the criminalization of people with mental health, disabilities and intellectual and developmental disabilities. I was an attorney with the Social Security Administration for 11 years, working on disability cases and doing some regulatory work and other work for the administration around disabilities. So a lot of the cases that I saw involved mental health, disabilities, and, as you can imagine, it's quite challenging working for a very large bureaucracy with lots and lots of rules around whose disability is eligible for benefits. That that person might need to sustain themselves.

So, at the same time, I started doing work in my local community around criminal justice issues, and that happened to intersect with mental health disability because a person in my local neighborhood was walking down the street a few years ago when they were stopped by a police officer, questioned, the person responded with behavior that was really a manifestation of their disability. The police officer indicated that he understood, he was dealing with somebody who was having a mental health episode, but nonetheless the police officer responded with violence and the person was shot and killed. And so that birthed my work in the community around the intersection of disability and criminal justice work. From there I went into the policy field with the Arc of the U.S., and my former colleague at the time, also on the panel too. And I got involved with the national work around 9-8-8, because it was an opportunity to elevate crisis response and to really focus on what was missing in our communities, which is an alternative to law enforcement for behavioral health issues. If you are having a heart attack, you don't call for a police officer, you call for an ambulance. So we really don't have an equivalent of that for people experiencing a mental health crisis or just a manifestation of their disability.

Now, with the Autism Society, I am working on building what we call a justice center. The official title is the Autism Center for Empowerment Education and Advocacy, and I might have gotten that wrong.

(chuckling)

It's a long title. But we call it the Justice Center for short, but it's the first of its kind in the nation because it is going to focus on autistic people. And you might be -- some of you might be wondering, why is there a need to build a justice center for autistic people? And we're beginning with criminal justice. I want to share a few statistics with you. There are approximately 5 million adults in the U.S. who are known to be autistic. And I say "known to be," because there was a lot of under-diagnosis, particularly in Black and brown communities.

Currently the CDC says 1 in 36 children are autistic. So, you know, there are still disparities in diagnoses that have long persisted in communities of color, but that may be changing. Autistic people tend to enter the criminal legal system in several ways. Autistic individuals experience mental health exacerbations at higher levels. Autistic people tend to report anxiety at higher levels than the general population. Autistic children tend to have at least one mental health condition, which also puts them disproportionally in contact with law enforcement, if you think about what happens in our schools. Sometimes with the use of police officers to deal with children as young as five years old. Autistic children do tend to experience disproportionate levels of discipline, as do all children with disabilities in schools, but particularly Black children with disabilities in school, discipline tends to be very harsh, and unfortunately discipline can also include the use of law enforcement.

A portion of people jailed. Three times -- people who have been jailed three times within a year have also reported having moderate or serious mental illness. So that's almost 27% of the people who are jailed within a year, they're there oftentimes because of behavior that related to a disability.

And I want to talk about race and disability too. So the interplay of disability with racial bias further complicates the link between disability and the criminal justice center. There is a disproportionate incidence of intellectual, developmental disabilities among low-income, racial and ethnic populations, which have higher rates of police involvement to begin with, because there's just higher rates of police involvement in the neighborhood. In 2015, for example, Black men between the ages of 15 and 34 were nine times more likely than Americans of other races to be killed by police officers. In 2014, a report found that 73% of people who identify as LGBTQ+ or people who are living with HIV had in-person contact with police in the past five years. Of those individuals, 40% reported verbal, physical or sexual assault or hostility during those encounters.

So, race, disability, and other intersectional identities definitely comes into play when talking about criminal justice and disability.

So the Autism Society is proud to be working with Neli Latson. I want to tell you a little about him. You can read more about him in our brief that is included in your packet, but Neli was -- he is a Black man with autism and intellectual disability, but he was 18 years old at the time when his life forever changed. He was outside of a library in Virginia, and police were called by somebody in the neighborhood who thought that Neli sitting outside of the library was suspicious behavior, and when police arrived, Neli reacted, you know, out of his disability, didn't like being touched, didn't like being spoken to, you know, aggressively, just the entire encounter was bad from the start. An altercation ensued, and Neli faced multiple charges as a result. I think he went to -- he did go to trial. The trial -- at the trial, the prosecutor actually weaponized Neli's identity as an autistic person and a person with IDD and sort of turned it into a reason as to why Neli would need to be locked up and kept away from society, because he was considered especially dangerous as a result of those identities. I think his original prison sentence was something like ten years. He did spend several years in prison. Part of that time he was placed in solitary confinement, and as a result of that he continued to have behavioral issues and, you know, decompensated mentally, and then that would just start another cycle of treating him with restraints and more seclusion and medication and just abuse, really.

So, for a person who is autistic, being in jail and prison is especially painful because there just aren't really accommodations for them. So it's good that we are talking about mental health accommodations when we're talking about law enforcement and policing, and even sometimes in our prison population. But autism and IDD can present a little bit differently. For example, a person who is autistic in a prison may have a behavioral outburst due to bright lights. And that is not typically an accommodation that is going to be made for them, or loud noise, for example. You know, think about a cafeteria setting and people slamming down their trays and plates and forks and knives. That's enough to -- could be enough to cause a sensory overload for somebody, and it could result in a behavioral outburst. That behavioral outburst then gets them in trouble. And for a lot of people, that trouble means solitary confinement. Which generally means you are going to further decompensate, as I said.

So one of the things that we are looking at at the Justice Center for the Autism Society is whether or not we can advocate for better accommodations or appropriate accommodations for autistic people and people with IDD who are currently residing in prisons and jails as of right now. Of course, we would like to do more and work on the prevention and stop people from going into the system, but, you know, we are constantly getting calls in, unfortunately, from families and autistic individuals who are facing significant legal issues, criminal/legal issues, generally as a result of their disability. I see things such as judges who refuse to allow people to present evidence that a person is autistic, that a person has a disability. It's kind of unbelievable that that is, you know, where we are at this point in time, but these are indeed the calls that we get in, the types of cases that we see coming in to the justice center, and so we really want to be in a position where we can tackle some of these issues from a national basis. So it's important for us to come and to speak here on Capitol Hill and to sort of set the framework for legislators to think about these issues not being one-offs, you know, not being something that may occur in one city or state versus another. These are really national issues that we see. There just aren't enough diversion programs, for example. That would be a much better option than sending people into prisons and jails that are designed to punish, not really to rehabilitate. And when you think about somebody who has -- who is autistic and perhaps has an intellectual or developmental disability, you can't really do that type of rehabilitation anyway. There was an article that somebody sent me yesterday in the state of Maryland where an autistic man did have a violent outburst in the group home that he was residing in and because it was a violent outburst, he was charged with a crime. But the question becomes what is appropriate. Is jail appropriate for this person who was presenting before the judge with, you know, the intellect of like a five-year-old? You know, what do we gain as a society by placing a person with those types of disabilities in a punitive situation for as long as 10, 15, 20 years? Because disability is there. The person does not, you know, come out with this new, you know, ability to comprehend or to understand, you know, how to not have a sensory overload in certain circumstances, because if the intellect is, you know, at five years of age, when the person goes in, and they're in for ten years, 10 or 15 years, that's still where they are when they come out, only you get a much more damaged person, if that person has been subjected to some of the things that we know that goes on, such as the solitary confinement. And, unfortunately, people with autism and IDD are more likely to be victim of this as well when in correction facilities, and people with mental health disabilities in general tend to be more victimized. So, you know, these are all issues that we need to consider at a national level when talking about jails and prisons and criminal justice. And I'm going to turn it over to my colleague, Monica, who is going to talk to you a little bit more about what we can do on the preventive end.

>> Thanks, Carlean. Hi, everyone. Good afternoon. I'll be brief and turn it over to my colleagues. My name is Monica Porter Gilbert. I use she/her pronouns and work at the Bazelon Center for mental health Law. Often when we talk about urgent need for non-police responses to mental health calls, the next question is: What should we do instead? And the Bazelon Center has conducted extensive research including interviewing community members and stakeholders across the country to answer this very question. Mental health crisis services must center peer supports, provided by people with lived experience of disability or receiving services. In the materials that we have provided today, we have listed numerous successful examples of peer-led hotlines and warm lines, peer-led mobile response services, as well as peer-led respite homes.

Just briefly, to highlight a couple, the Oregon Cahoots program, which as you may know is a two-person mobile team, a crisis worker and EMT. They carry police radios and may be dispatched by either the police or 9-1-1. But what you might not know -- and I didn't know this until my colleagues did this research -- is that most of Cahoots responders identify as a person with some sort of relevant lived experience, be that homelessness, disability or neurodivergence.

Cahoots teams may request police teams as backup but they rarely need to. In 2019 of the approximately 24,000 calls to which Cahoots responded, only 1.3% of those calls actually required backup.

Other mobile teams have successfully built on that model to explicitly incorporate peer services. And we know that when people with specialized training, including peers, serve on mobile response teams, upwards of 70% of responses can be resolved in the field. So only really in a relatively small number of calls should an individual actually need to be transported somewhere. In the instance they do, there are peer-led respite homes. Examples are listed in your materials. Just to briefly highlight one, in North Carolina, there is the Retreat at the Plaza, and this is a great example where not only do respite homes provide the most effective services, they also generate significant cost savings in the community. In 2021, a stay at North Carolina's Retreat at the Plaza cost $111 per person per day. As compared to in -- patient psychiatric treatment in North Carolina, which cost $2,573 per day. So we do appreciate many of our partners here in the room who are working with us on this, and we do encourage others to continue to prioritize peer-led and peer-involved alternative responses to mental health calls, so that people with disabilities can be served in their communities and communities can be safer for everyone. Thank you.

>> Hi, everybody, my name is Claire Stanley and I'm with the National Disability Rights Network and the vice chair of CCD. I'm so thankful that everybody is here and we have this opportunity to share. I'm also one of the co-chairs of the Transportation Task Force for CCD. Me and Danica are going to take a few moments to talk about the Americans with Disabilities Act and the Rehabilitation Act of 1973, two very important pieces of legislation that outline the rights of persons with disabilities.

So what is the Americans with Disabilities Act or ADA, as you will hear us call it. The ADA is a huge piece of civil rights law to protect the rights of people with disabilities against discrimination-based solely on their disability or sometimes their disability and other things. It's really important to talk about the passage of the ADA and not to take Danica's thunder, but also we'll talk about the Rehab Act, because in previous existing civil rights law, like the Civil Rights Act of 1964, disability was never incorporated into these laws. So it really took the passage of these laws to make sure that the rights of those of us with disabilities are protected.

So I'm going to talk briefly about the different components of the ADA and then I will talk briefly about who is covered by the law. There are several different what we call "titles" of the ADA, but the first three, Titles 1-3 are what we call a lot and have application that is really pertinent. Title 1 covers employment. A person with the disability has a right to work in a job as long as they can perform the essential functions of the job. They can never be denied a job because he or she has a disability. Title 2 applies to state and local governments. So whether it be a community center in your county, the state court system, whatever it is, persons with disabilities cannot be discriminated against for things like getting a copy of the court record in an accessible format, bringing their service dog into the court system, anything like that, they have equal access.

And Title 3 has to do with what we often call public accommodations. But in laymen's terms, that just has though do with going into a business. You know, I love my Starbucks, I have a service animal. And I have the right to go into that business with my service animal because of the Americans with Disabilities Act.

Again, not to talk over what Danica is going to cover, but it expanded with the Rehab Act of 1973 to private businesses and state and local governments.

The ADA applies to persons who have a disability, and a disability is anything that substantially limits one or more major life activity. And that was expanded in 2008 to also cover physical impairments that have to do with bodily functions. So it could be a diabetes or other medical conditions. And one thing that we really wanted to drive home is that a lot of times people think of the ADA as a law that you can use to go out and be extreme litigious and sue for momentary damages, but actually the way the Americans with Disabilities Act is written, you can only get what is called injunctive relief, meaning the entity has to fix the problem, but you are not going to bring in millions of dollars. And I think that's a misconception that people often have, because we see what people often describe as drive-by lawsuits. That's when people just bring lawsuits in order to gain money. There are state laws in states like California where that might be applicable and possible, but under the ADA itself, that is not possible. It's only injunctive relief. So people aren't out there just to gain money, but instead we want true access.

And with that in mind, I'm going to talk about a couple issues that we see before I pass it on to Danica, that are ongoing ADA violations and issues that people with disabilities face. I myself identify as a person with a disability. I am blind. The ADA was passed when I was two years old in 1990, but yet all of these years later, people are still facing many barriers and we want to highlight some of those barriers.

So keeping in time with the current era of 2023, website accessibility is an ongoing issue. Obviously websites weren't what they were back in 1990 when the ADA was passed, but the Department of Justice has said in very clear terms that websites and applications still fall under the ADA. They have said it multiple times, and just this past summer they began the process of a Notice of Proposed Rulemaking to promulgate regulations for Title 2 of the ADA for websites and applications, which we're extremely excited about. Website access is a huge thing. We saw during COVID and post-COVID that we do a lot of things online and we need to make sure those websites are accessible for all people with disabilities.

And then briefly another one I wanted to highlight is access for persons with service animals, especially in the transportation world. Many of us now in 2023 take rideshare services. Those are -- that is a blanket term for things like Uber and Lyft. I can't tell you how many times that as a service animal user I have been denied services by those kinds of companies because I have a service animal. But under the ADA, again, this important piece of legislation, they cannot deny me such services, but yet again the ADA is 33 years old and unfortunately we still see those kinds of issues. So Danica and I, who I will pass it off to in ten seconds, just wanted to illustrate that even though persons like myself who are often defined as the ADA generation because we have grown up with the ADA still experience many of these barriers. And I'm going to pass it to Danica.

>> My name is Danica Gonzalves, an advocacy attorney at Paralyzed Veterans of America. PVA is a membership organization of over 15,000 veterans that have a spinal cord injury or disorder, and our veterans with disabilities, also a co-chair of the CCD Transportation Task Force. Transportation is necessary for getting to a job, school, going to a doctor, grocery shopping, visiting friends or family. If you take Metro buses or rideshares, you likely understand the general exasperations of transportation. But people with disabilities, especially wheelchair and mobility device users, have significantly less options. Rideshare companies may have no wheelchair accessible vehicles, or they may even drive off when you -- when they see that the passenger has a disability. Public transit fails to meet accessibility standards. And wheelchair users may be secluded to a small one seat area on a lengthy train ride. People will fly for hours, get to their destination and then have to wait hours to get a wheelchair accessible transportation option to go the single mile to their hotel.

Accessible transportation needs to be a priority, especially with the new emerging modes of transportation like autonomous vehicles. In addition, across the United States, access to medical services is a general issue, and many feel that it is impossible. People with disabilities not only experience these issues, but also face additional barriers. Some providers outright flatly refuse to treat people with disabilities, or they may not have the accessible equipment to treat that patient.

Medical equipment like exam tables, exam chairs, and even important screening machines, like mammography machines are not accessible for people with disabilities. A disabled veteran who needed immediate dental treatment called every single dentist in his area looking for one dentist that had an exam chair that he could transfer on to, because he had been dropped by other dentists in the past. He didn't find a single dentist that had the exam and dental chair that he needed.

Without access to this basic care or life screening equipment, people with disabilities can develop fatal medical conditions. CCD continuously advocates for people with disabilities that are denied this regular medical care or vital screenings just because of their disabilities. Beyond equipment, medical equipment, some movable furniture and equipment also doesn't have the ADA scoping standards that are necessary. We hear stories from people with disabilities that are excited to visit their family and enjoy their vacation, or even renew their wedding vows, get to the hotel and the hotel bed is too high for them to transfer on to. This means they either have to sleep on the floor, sleep in their wheelchair, or get injured trying to get on to the bed or just have to completely cancel their plans.

These issues, these stories are things that we need to keep in mind when working on accessibility. The ADA does not apply to federal agencies. Federal agencies are covered under a different law that Claire has already mentioned, and that is the Rehabilitation Act. But like the ADA, the Rehab Act requires the federal buildings services and technology be accessible not only for people with disabilities but also federal employees with disabilities. This law was passed 50 years ago, 17 years before the ADA, and services, buildings, technology is still not accessible for people with disabilities and federal employees with disabilities.

Section 508 is the section that specifically talks about the accessibility of electronics and technology, and since COVID we have seen that reliance on employee tech system, websites, online portals and electronic devices, and the inaccessibility of these is even more apparent and highlighted.

Millions of Americans and veterans have disabilities. Federal laws prohibiting disability discrimination have been in place for decades but people with disabilities still continue to experience these barriers every day. Enforcement and oversight is necessary. Because of the lack of enforcement, people and employees with disabilities are rejected from accessing necessary services and opportunities.

Only with oversight and enforcement can the purpose of these laws be reached. When working on any accessibility laws, it's important to ask: What can I do and how can I understand the impact?

Without personal experience, it is difficult to answer these questions. People who know the most about accessibility barriers are the people with disabilities that experience them every single day. Their stories need to be involved in these discussions, because their experience will show how these will impact their everyday life. I'm now going to turn it over to Nicole.
>> Thank you so much. My name is Nicole Jorwic, the chief of advocacy and campaigns at Caring Across Generations, also co-chair of CCD LTSS lodge-term supports and services task force. I try not to do acronyms. I come to this work as an attorney but importantly as a sibling. I have a broth err that has autism and receives the services I'm going to talk about, Home and Community Based Services or HCBS. Home and Community Based Services are really important and also, unfortunately, scarce in a lot of places in this country. Chris -- I'm from -- we live in Illinois, so shout-out to Senator Duckworth and Stephanie. I actually live here, but my brother livers in Illinois, and Illinois is a state that has a 15,000-person waiting list for services and wages are particularly low. I've been a direct care worker providing services that are funded by the Medicaid Home and Community Based Services program, and ultimately now I have spent the almost last decade in D.C. advocating around these policies.

The policy that I think I probably talk about in my sleep is what I'm going to talk about today, which is Medicaid Home and Community Based Services. What are they? Home and Community Based Services ultimately are a source of dignity and independence and make it possible for disabled people like my brother and others, as well as older adults, to live in their homes and communities. Some examples of Home and Community Based Services are personal care attendant that helps somebody get out of bed in the morning and take care of their personal hygiene before they go to work. It can -- Medicaid Home and Community Based Services funds job coaches, so that people can work and have the support that they need on the job. A care worker assisting a disabled child with medication and therapies at home, those are Home and Community Based Services. Keeping them together with their family instead of separated into facilities and institutions. Community integration is really the thrust behind Home and Community Based Services, and for disabled people, these are the services and supports that let them live in their own homes with their families and in their communities.

The system relies entirely -- the provision of Home and Community Based Services on Medicaid. Medicaid is a very complicated system. Medicaid is not Medicare. This is something that a lot of people, including our elected officials, sometimes mix up. And it's incredibly important, because the complexity of Medicaid is part of why it's so often ignored, despite the extreme need for investment. Because there should not be anyone who is waiting for these life-giving services. Medicaid is a state and federal partnership that funds healthcare and these Home and Community Based Services for more than

90 million Americans, including 54 million older adults, children and disabled people.

Medicaid is the funder for healthcare and Home and Community Based Services also for the 574 tribal nations in this country. Throughout the country, Medicaid is a main funder for Home and Community Based Services for 7 million older adults an disabled people who rely on the services and support. But that doesn't account for the over 200 -- over 700,000 people currently on waiting lists, and that is only for people who know there is a waiting list to be on, and I know Jen is going to get into that more.

Many people don't know that Medicare's long-term care benefit isn't comprehensive. Unless you have saved hundreds of thousands of dollars to stay in your home, Medicaid is people's lifeline for Home and Community Based Services and all long-term care. Because of the inadequacies of Home and Community Based Services delivery system in this country, unpaid family caregivers are often the only option to fill in the gaps of care. That's actually where the majority of care is coming and that comes at a huge cost.

$600 billion of unpaid care was provided per AARP.

We have a fragmented system with uneven access and increasing costs. This is despite the fact that delivering HCBS is a win-when. People like and want these services. The outcomes are better. It's not a guess. We know this from data. The money follows the person program is a program that is almost 20 years old and first became law under President Bush in 2005 and it shows much better quality of life outcome measures force folks that move out of a facility into home and community-based care. HCBS is also a win-win because it saves money. From that same program, the Money Follows the Person Program, we have data that shows that per Medicaid beneficiary per month serving people in the community saves at least 20%.

Investment in Medicaid are also job creating dollars, doing everything from funding job coaching services for disabled people to be part of the workforce, also to the fact that Medicaid is the primary payer and employer for long-term care and paying the wages of the 47.7 million direct care workers in this country that we need a lot more of and will continue to need a lot more of. Medicaid is also popular. Polling that we have done at Caring Across Generations shows that 72% of Americans across the political spectrum view Medicaid and particularly Home and Community Based Services favorably and home and community-based care is desired by 87% of people who will need to receive care. We just had data that I just got this morning that 93% of people want to receive Home and Community Based Services, and the only way to do that is to make sure that we are doing much more, because the existing program needs a lot of work. But the good news is there is this interest and there is support. And I'm going to pass it over to Jen to talk about some of the complexities.

>> Thanks, Nicole. My name is Jennifer Lav. I'm a senior attorney at the National Health Law Program or NHELP and co-chair with Nicole of the long-term services and supports task force at CCD. And Nicole talked a lot about what some of the good news

is about how helpful HCBS is and how important it can be. I'm here with some of the bad news that Nicole started to discuss too, that people can't get these vital services, and to talk about why.

The first thing to know is that there are waiting lists to get these services. And that's something that is unique to Home and Community Based Services. Like, if you need to go to the doctor or you need though go to a physical therapist and your insurance covers the service if you need it, you can go as soon as an appointment is available, right? But for people who need Home and Community Based Services, it's different. A state can choose to say no matter how many people in the state need Home and Community Based Services, they only want 1,000 people to get it, or any other number that they choose. And everybody else has to wait for those critical services. As a result nationally, about 700,000 people who need Home and Community Based Services are out there sitting on waiting lists, and the average length of time is three years. But in some states it's as long as a decade. And then as Nicole mentioned, waiting lists don't even account for all the unmet need. Even in some states that don't have waiting lists, there are people who are incredibly underserved and not getting the help that they need.

And then all of this is compounded by racial disparities. Studies suggest that Black disabled people are less likely than white disabled people to get high quality HCBS. The people that provide these services, the aides that go into someone's home to help them, they're low wage workers, they're primarily women, and primarily BIPOC individuals. Due to chronic underinvestment in the system, there's simply not enough workers to meet the need out there. Providers are turning away new referrals or cutting back services, and that leads to major gaps. So it may be that you are entitled to a service on paper, but then there's no one available to fill the shifts. When people can't get these services, as Nicole mentioned, they might rely -- like they rely on unpaid care giving from family and friends. They might also just end up stuck inside their apartment, for example, you know, without a way to get in and out, and to access the community. Their health suffers. They might need to move to a more restrictive environment than they otherwise would need or want. So, you know, they might need to move to a nursing home, for example, when they could otherwise live in their apartment. This is not the picture of long-term care that we want to offer parents, family members, or we want for ourselves.

And the last point I want to make about home and community-based services, this is a disability rights issue. One of the reasons this is so central to CCD. There is a long history of people with disabilities being excluded from every part of society: School, work, home life. In 1999 the Supreme Court decided a seminal case you may have heard of called Olmstead versus LC. Which basically said unjustified segregation of people with disabilities is discrimination under the Americans with Disabilities Act. People have a right to live in the community. For the way you make that right a reality is getting rid of all the barriers we talked about that make it hard to access services and supports in the community. And that is why we are so passionate about HCBS, right? It's what people want. It's less expensive, it works better, and it's a key tool to achieving our civil rights.

And we would just ask, obviously, with Home and Community Based Services, with transportation with all of these issues, that you obviously see CCD as a resource when issues are coming up in your offices. Folks might need the care or support and might not know what they're called, but when you have disabled constituents, caregivers, care workers calling in, I guarantee what they're saying is they want more Home and Community Based Services and want more support and more money for direct care workers, but we're happy to translate and do briefings and share more of this data, but ultimately all of us in the 15 task forces of CCD are here as a resource so that we can provide the information that you need and would love to work on solving a lot of these issues.

And now I think we're open for questions.
>> Thank you. Thank you to each and every one of our panelists. We have time for one question from the audience, if there is one. If not, I have a question for the panelists. And we have a microphone. It can be brought. And I saw Liz's hand go up first. And I think Heather knows where you are and she's on her way.
>> Liz Weintraub with AUCD. I have a question about the criminal justice system. When you were saying that people are getting into the system because of behavior, did they think about talking to the person... maybe their behavior is coming out in a bad way, like hitting or whatever, and if people just take the time to talk to the person, maybe these issues won't happen again.
>> That's a great question, Liz. Thank you. The problem really is that the law and criminal justice law just don't factor in disability, and disability-related behaviors, because in the example that I mentioned with the autistic person with a severe intellectual disability, he did violently hit his -- one of his care takers, but he's going to be charged with assault, and he is charged with assault and a bunch of other things, because there is nothing -- you know, there's just nothing there that says that this person may have been reacting that way due to frustration, maybe his needs, for example, weren't being met. I know with autistic non-verbal people, especially kids you may see this type of behavior. You might see biting and kicking because, as a non-verbal person, they can't necessarily communicate directly with people about what their needs are, and so they express their frustrations physically, but, you know, the law sees it as an assault. So unless we have diversion programs that say this person has a right to have their disability considered as a mitigating factor in this case and in these charges, we're going to continue to see this pipeline. This is really a pipeline of disabled people coming into the criminal legal system, and it's sad. It's really sad. Thank you.

>> If I could just add briefly, because I appreciate the question about what if the first responder had just asked or engaged more with the person with the disability, and I want to chime in briefly, because often a question that we get is, well, can't we just train law enforcement to be better at these responses? And unfortunately the evidence indicates no, that this training does not work, and, unfortunately, in the area of Chicago, they found that after doing crisis intervention training, incidences of violence against

people with disabilities actually increased. And so all of the research that we have done indicates that the only way to ensure the safety of the person who is being responded to and the safety of the community at large is to be a mental health response to a mental health emergency, especially when it is peer-led.
>> We have -- CCD has a statement now several years old on policing and policing encounters and recommendations that is being updated right now. So we'll have the new version up. Thank you, Liz.

we have time I'm being told for one more. And I see a hand up. Heather, over to the... over to my right.

Thank you. And then after this we will close out. And thank you all for being here.

>> Hello, Lydia Brown from the National Disability Institute. This is a follow-up to what Liz was sharing. It's also about the comments made on the criminal legal system issues affecting people with disabilities. And I wanted to share for folks who are less familiar with this issue area and are newer to learning about issues facing people with IDD and the criminal legal system that speaking as someone who is an autistic self-advocate, would generally discourage using a framing of saying that a person has a mental age that is younger than a physical age, and that's rhetoric that I heard coming during our panel discussion, and when we're thinking about ways to better support people's access to communication and community-based services, that that discussion should be focused on promoting autonomy and presuming competence, rather than framing somebody as lacking capacity or framing somebody as having the intellect of a child. And that is especially so when we are speaking from an intersective perspective. Just an offering.
>> Thanks, Lydia.
>> Okay, I am -- we're going to wrap up. I want to ask the panelists if there is any last words, anything you want to share about your priorities going into next year. You don't have to. But just asking.
>> The CCD LTSS task priorities will remain among investments in Home and Community Based Services to do things like eliminate the waiting lists and also address the workforce crisis, because we can't hold folks off the waiting list when the current workforce is where it is and not being paid family sustaining wages, and so those will be in addition to insuring the protections of Olmstead and a lot of other work our main focus will be around home and community-based services.
>> Danica, PVA CCD Transportation Task Force co-chair. I just want to reiterate the importance of inclusion of people with disabilities and CCD in any type of decision making, rulemaking. We see a lot of things that have a great intention, but not necessarily understand how that is going to impact or better someone's life. So we are here as CCD to be a resource for that. And I'm going to pass it to Claire.
>> Thanks, Danica. Claire, with NDRN. To build off of that, one issue in the transportation space that we are seeing so much of is the development of autonomous vehicles, and just the growth of technology in general, and as decisions are made and advancements are made, we really want the voice of people with disabilities to be part

of that, because it's so exciting where technology and AVs are going, but if we're not part of the conversation now, we can easily be left behind and we always like to make the point in all forms of accommodations for people with disabilities that retroactively fixing a problem is infinitely more difficult, expensive, etc., than making something accessible from the get-go. Thank you.
>> As Nicole mentioned, CCD has a number of task forces that cover a variety of topics, including employment, education, and a number of important topics that we didn't get into in-depth today, but we really do appreciate everyone joining us today, and your mindfulness that every issue you work on is a disability rights issue. So please do come to us if you ever have any questions. We're very happy to be a resource.

>> Just to reiterate the need for diversion programs for people who have intellectual and developmental disabilities, autism or mental health disabilities away from jails and prisons, they're often just not the appropriate place to house people for types of instances that I mentioned earlier.

And then support for alternatives to law enforcement for a mental health crisis, just as Monica laid out in her comments.
>> Thank you to all our panelists. I want to thank -- this is Carol. I want to thank Charles at the back who has been helping with tech all year round. Thank you, Charles. And Heather who is next to him co-organized this event as a former chair. Thank you, Heather. Thank you, Stephanie, again. So grateful for you, and everything you do and for being here. And Senator Duckworth. And reminder that I'm told the lunches are still out there. So if you like them, please take more. Take the masks and take the little postcards with the QR code that will take you to the website, and you can grab a bunch. And I think that's it. We really -- the folks that we work with every day, thank you, and we look forward to working with you into the coming year. Thank you very much.