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# **National Council on Disability**

# **Quarterly Board Meeting**

# **New York City**

## May 29, 2025

## 9:30 a.m. – 4:30 p.m. ET

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## **NCD Quarterly Meeting**

## **May 29, 2025**

## **9:30 a.m.**

ANA TORRES-DAVIS: Hi, everyone. Good morning.

I just want to make a couple of quick housekeeping notes for everybody. Today's meeting is being interpreted and transcribed for individuals who are Deaf and hard of hearing. Second, we have two phone lines open. One is for the public, and one is for NCD Council members and staff. The public phone lines will remain in listening mode only for the duration of the meeting.

And as a reminder, public comments are being accepted both in person this afternoon and via email.

With that, we are ready to begin the meeting.

SHAWN KENNEMER: I guess that would be me, right?

ANA TORRES-DAVIS: Yes.

SHAWN KENNEMER: Okay. Good morning, everyone. My name is Shawn Kennemer. I am the Acting Chair. I am the Vice Chair and currently the Acting Chair of the National Council on Disability.

I want to welcome everybody to New York. First I want to welcome the Council Members, staff, and the public who joined us today in person and by phone from around the country. It's great to be in New York. This is the home of our newest member, Kim Ridley, so thank you, Kim, for hosting us.

[Applause]

I also want to acknowledge one of the things that the Chair of the Council gets to do is appoint the Executive Director, and I am very pleased to announce the appointment of Ana Torres-Davis to the Executive Director position who is sitting up here on my right. She has been with NCD since 2015 as an attorney adviser, and I'm just really impressed that she's picked up the ball and ran with it. So if you get a chance, welcome her, and thank you for being a part of this.

So this morning we'll focus on public policy updates. We're going to be discussing policy proposals for the fiscal year '26, which include the work priorities, and voting to approve the release of our long awaited ground transportation report.

In the afternoon, we'll have two panels, one on the employment of people with disabilities and one on the youth and younger adults in nursing homes, and then a public comment period.

Tomorrow the Council Members will have their regular business meeting. Also a presentation on the Freedom of Information Act.

Ana, can you please start the meeting with a roll call?

ANA TORRES-DAVIS: Yes.

Shawn Kennemer?

SHAWN KENNEMER: Here.

ANA TORRES-DAVIS: Hoskie Benally.

HOSKIE BENALLY: Here.

ANA TORRES-DAVIS: Sascha Bittner.

SASCHA BITTNER: Here.

ANA TORRES-DAVIS: Theo Braddy.

Kim Ridley.

KIM RIDLEY: Here.

ANA TORRES-DAVIS: Risa Rifkind.

RISA RIFKIND: Here.

ANA TORRES-DAVIS: And Neil Romano is absent today.

Now for the staff.

Stacey Brown.

Joan Durocher.

JOAN DUROCHER: Present.

ANA TORRES-DAVIS: Kimie Eacobacci.

Anne Sommers McIntosh.

ANNE SOMMERS McINTOSH: Here.

ANA TORRES-DAVIS: Amy Nicholas.

AMY NICHOLAS: Here.

ANA TORRES-DAVIS: Nick Sabula.

NICK SABULA: Here.

ANA TORRES-DAVIS: Amged Soliman.

AMGED SOLIMAN: Here.

ANA TORRES-DAVIS: Keith Woods.

And Keith is here.

Netterie Lewis.

And we know that Netterie Lewis is here too.

And that concludes the roll call. I will yield the floor back to you.

SHAWN KENNEMER: Thank you.

So our first order of business today is the vote for the acceptance of the Council meeting agenda. I need a motion to approve the agenda.

SASCHA BITTNER: I'll move.

SHAWN KENNEMER: Sascha, thank you.

And a second?

KIM RIDLEY: I'll second.

SHAWN KENNEMER: Kim, second. Thank you.

Okay. Technology. Gotta love it.

With that, then, I need a roll call vote. Ana, will you please do a vote to approve the agenda?

ANA TORRES-DAVIS: Yes.

Shawn Kennemer.

SHAWN KENNEMER: Yes.

ANA TORRES-DAVIS: Hoskie Benally.

HOSKIE BENALLY: Yes.

ANA TORRES-DAVIS: Sascha Bittner.

SASCHA BITTNER: Yes.

ANA TORRES-DAVIS: Theo Braddy.

Kim Ridley.

KIM RIDLEY: Yes.

ANA TORRES-DAVIS: Risa Rifkind.

RISA RIFKIND: Yes.

ANA TORRES-DAVIS: All right.

SHAWN KENNEMER: Thank you. And then I do have Neil being out did give his proxy votes and he voted yes to approve the agenda.

Thank you.

At this time, I'm going to turn the floor over to Joan Durocher, who is NCD's general counsel and Director of policy for the policy update and to lead the discussion on the fiscal year '26 policy proposals. Thank you.

JOAN DUROCHER: Thank you, Mr. Chairman.

There are four things I will be covering during this report. First a brief update on our currently underway policy work, and recent executive actions. Second, voting on the changes to our extreme weather report. Third, voting on approval of our transportation report. And finally, fourth, I'd like to spend the bulk of the Council's time during this segment on discussing the FY26 policy proposals and then the Council can vote on those priorities.

First up, a couple items of note since the last council meeting.

NCD wrote to Secretary Kennedy last month regarding the MAHA commission, offering our assistance in developing its recommendations.

The commission just issued its initial report, primarily focused on childhood chronic issues. We're still reviewing it to see if there are any opportunities to provide any recommendations to the commission on disability policy.

We are still hopeful we might be able to provide some feedback.

Our 2025 progress report. Jed is drafting that and is getting close to a final draft, and that will be issued this October once it's complete.

Since the last council meeting, NCD issued a letter to the Illinois General Assembly reiterating our recommendations and findings in our assisted suicide report advising state lawmakers not to legalize assisted suicide because it has a disproportionate impact on people with disabilities in a variety of ways.

We have internally kicked off our work on the nursing home project. We have a panel at this meeting discussing the subject, facilitated by Council Member Ridley. We are also accepting public comment on that subject at this meeting.

As part of this project, NCD will be requesting the data necessary for the foreign analysis from CMS, and then developing an analysis of the data and a brief report.

Also since the last council meeting, Amy Nicholas and Chairman Kennemer held an emergency management meeting with several stakeholders to brainstorm on promising practices to minimize gaps in aid for people with disabilities in future disasters. On that front, I'm going to now turn to several Executive Orders or actions that have been guiding some of our work these last few months.

One of those EOs was regarding DEI, and we pulled down some reports or other public documents so we could review them and take out those references, per the order, if needed.

Most of those are relatively easy to correct without changing any recommendations substantively, though we are continuing to work on them as we find them, given the amount of recommendations we've issued over the years.

We pulled down our extreme weather report, and that one necessitated some changes that more substantively affected a few of the recommendations, so we included those in your preparatory materials.

We sent you the changes a couple weeks ago, and a big thanks to Amy Nicholas for going through the report.

I'm going to turn the mic back over to the Chairman for a moment to call for a vote on those particular changes, and then we can go back to my report. So Chairman Kennemer, if you could call for a vote on those changes.

SHAWN KENNEMER: Thank you.

Can I have a -- sorry. I'm on California time. It's still really early.

Could I have a motion to approve the changes to the report?

KIM RIDLEY: I'll move.

SHAWN KENNEMER: Kim. Do I have a second?

SASCHA BITTNER: I'll second.

SHAWN KENNEMER: Sascha, thank you.

And then can I have a roll call vote to approve the changes to the report?

ANA TORRES-DAVIS: You want me to do that.

SHAWN KENNEMER: Yes, please.

ANA TORRES-DAVIS: All right. Roll call vote on this. Shawn?

SHAWN KENNEMER: Yes.

ANA TORRES-DAVIS: Hoskie Benally.

HOSKIE BENALLY: Yes.

ANA TORRES-DAVIS: Sascha Bittner.

SASCHA BITTNER: Yes.

ANA TORRES-DAVIS: Kim Ridley.

KIM RIDLEY: Yes.

ANA TORRES-DAVIS: Risa Rifkind.

RISA RIFKIND: Yes, with reservations if I could ask a question.

ANA TORRES-DAVIS: Yes. I'll come back.

We have Neil Romano has also voted yes.

RISA RIFKIND: I just wanted clarification on one of the recommendations of a change on page 133. And maybe it's just not my full understanding of what is included. But I'm not -- I think I'm not seeing some of the same language on 133. There's reference to marginalized populations. Is that why that one's being taken out? Or...

And we can come back later. But I thought that didn't meet the requirement.

SHAWN KENNEMER: Can you email that and we'll have the staff respond?

RISA RIFKIND: Absolutely.

SHAWN KENNEMER: Thank you.

So the motion carries?

ANA TORRES-DAVIS: Yes.

SHAWN KENNEMER: Okay. Great. Back to you, Joan.

JOAN DUROCHER: Thank you. Back to my report.

Let's see here. The other EOs and/or executive actions that are in the mix were also included in your notebook materials. We would not normally include a list like this, but because addressing some of these EOs has taken a fair amount of staff time, Ana thought it was important to include them.

I'll briefly list them, and you can ask me any questions you may have at any time.

There is a hiring freeze at least through July 15th with an exemption for schedule A excepted service employees. We do not have any probationary employees at the current time, but if when the hiring freeze is lifted and we hire anyone, there have been some strengthening of the probationary periods for new employees so that if someone is not working out, there are some record keeping requirements and analysis needed and an expectation that they will be let go before the probationary period ends.

There are some significant changes to procurement policies that we're keeping an eye on, basically centralizing procurement in GSA while also lifting restrictions on buying in the commercial market if it's more cost effective.

There is a directive to repeal unlawful regulations. While NCD does not issue regulations, this one could potentially have an impact on NCD's work. This particular action requires that for everyone regulation issued, ten must be rescinded. This should be taken into consideration as we come up with new policy recommendations. So for example, if we recommend that some regulation be rescinded, we have to keep in mind that we should be thinking about the ten that might need to be pulled back if that's issued.

There are also several significant AI directives. While most of those have been directed at CFO Act agencies, which NCD is not, we are paying attention as it will eventually impact us more directly. To that end, I have included a policy project in our slate of projects for next year on AI and how it impacts, both good and bad, people with disabilities. I've also asked our current policy intern to review these latest EOs so we can get ahead of anything coming down the pike.

There are monthly reports due on the reorganization EOs which we are keeping up with. To that end, we have been in good contact with our own examiner and are checking in with him regularly regarding staffing changes at NCD's office.

That is the gist of the EOs that are applicable to NCD. There are a few others listed in the materials, but they are being handled as they come up and are pretty self explanatory.

Any questions on anything I've talked about yet?

SHAWN KENNEMER: Joan, can I pause you right there? We have a guest here that we would like to introduce and get in the record.

Kim, will you introduce our guest?

JOAN DUROCHER: Absolutely.

KIM RIDLEY: Can you all hear me?

It is my great pleasure to introduce both my colleague and friend, huge fan of ice fishing, by the way, Christina Curry, who is our Mayor's Office for People with Disabilities commissioner.

Christina, do you want to say a few words?

[Applause]

CHRISTINA CURRY: Should I come up there?

KIM RIDLEY: Sure.

CHRISTINA CURRY: I can go there too. Makes it even easier.

Thank you.

First I want to say good morning to everyone. My apologies. The traffic coming from the Bronx coming off the FDR, if you know, it was not fun at all.

The other thing I wanted to say is, yes, I do like ice fishing. Please feel free to invite me, because I love it.

So give me one moment, please.

Because I had it, and now I can't find the speech. Of course.

Breathe.

Okay. Here we go.

Thank you all. Good morning, everyone. On behalf of Mayor Eric Adams and the city of New York, I'm honored to welcome you to today's quarterly meeting of the National Council on Disability. While Mayor Adams regrets that he could not join you in person this morning, he extends his deepest appreciation for the Council's work and welcomes all of you, Council Members, panelists, and community participants, to New York City.

New York is proud to be a city where equity and accessibility are values where the lived experiences of people with disabilities shape our policies, programs, and priorities. As we continue building a city that works for everyone, your leadership and advocacy at the national level go hand in hand and inform the work that we do locally.

To the Council Members, thank you for your service and for bringing critical attention to issues that impact millions of Americans with disabilities. I am proud to call one of the Council Members, Kim -- good morning --

KIM RIDLEY: Good morning.

CHRISTINA CURRY: -- one of my very good friends.

I have to tell you that Kim is New York State's first ever Chief Disability Officer, and she was appointed by Governor Kathy Hochul.

[Applause]

I can't convince her to go ice fishing.

[Laughter]

We have to! I just want her to go out one time on the ice with me! It's going to be fun. It will be cold, but it will be fun.

Anyway, to our New York panelists and constituents that are here today, thank you for sharing your voices and your expertise. This meeting is a powerful reminder of what's possible when people with disabilities lead the conversation. We all know what I'm going to say after that if you know me: Nothing about us without us, ever.

We look forward to the ideas, insights, and actions that will come out of today's gathering.

Welcome to New York City!

Thank you.

[Applause]

SHAWN KENNEMER: Thank you so much. We really, really are pleased that you're here.

Joan, before I turn it back over to you, we're going to go back, make sure that we got clarification on our votes. We should have had two votes. Like I said, California time. I can use that, sure.

So let's go back. So I need a motion to approve the approval of the ground transportation report.

JOAN DUROCHER: I'm getting -- that's next.

SHAWN KENNEMER: Okay. So our first vote, then, was to approve the language in the disasters report. Correct?

ANA TORRES-DAVIS: Yes.

SHAWN KENNEMER: Okay.

JOAN DUROCHER: Yes.

SHAWN KENNEMER: That was our first vote. Okay.

JOAN DUROCHER: I'm going to transpose the two.

SHAWN KENNEMER: Then we're good. Then we're okay.

All right. Thank you, Joan. Back to you.

JOAN DUROCHER: Okay, good.

Okay. Thank you.

So now the Council will be voting on or transportation report titled Ground Transportation Update: Government and Private Industry Action is Needed to Improve Options for Wheelchair Users.

This transportation report was proposed by former Chairman Gallegos and covers several modes of ground transportation, examining the progress and lack of progress on accessibility for people with mobility disabilities and particularly accessibility for wheelchair users.

Last year after Council Member Braddy's proposal for an autonomous vehicle report was prioritized, we added that topic as well. The report is very detailed and contains information that would be hard to find elsewhere. It will be beneficial to people with disabilities, policymakers, Congress, transportation planners, and anyone that is interested in understanding the transportation barriers experienced by people with mobility disabilities every day, the impacts on individuals and society, and some proposed solutions to those barriers and promising trends.

Big kudos to our new Executive Director, Ana Torres-Davis, on researching and drafting this report.

I'll now turn the mic back over to Chairman Kennemer to call for a vote from the Council on this report, and then you can go back to me again.

SHAWN KENNEMER: Thank you.

Okay. So, to be clear, I need a motion to approve the draft of the transportation report.

RISA RIFKIND: I'll move. Risa.

SHAWN KENNEMER: Thank you. Do I have a second?

HOSKIE BENALLY: Second.

SHAWN KENNEMER: Hoskie, second. Thank you.

Let's do a roll call vote, please.

ANA TORRES-DAVIS: Okay. Shawn Kennemer.

SHAWN KENNEMER: Yes.

ANA TORRES-DAVIS: Hoskie Benally.

HOSKIE BENALLY: Yes.

ANA TORRES-DAVIS: Sascha Bittner.

SASCHA BITTNER: Yes.

ANA TORRES-DAVIS: Theo Braddy, are you on the line yet?

No. We will get your vote today, later today.

He's attempting.

Okay.

Kim Ridley?

KIM RIDLEY: Yes.

ANA TORRES-DAVIS: Risa?

RISA RIFKIND: Yes.

ANA TORRES-DAVIS: And Neil voted yes by proxy.

SHAWN KENNEMER: Great. The motion carries.

Okay, Joan, now we're back on track. Thank you. Back to you, Joan.

JOAN DUROCHER: Okay. So now the fun part. Several proposals were included in your prep materials for this meeting. We are going to walk through all of those proposals, and then the Council can debate and discuss the proposals, and then Chairman Kennemer will call again for a vote on your top three.

SASCHA BITTNER: [Off mic].

My mom is coming in a few minutes to do my proposal.

SHAWN KENNEMER: Absolutely. Yeah, we'll push it to when she's here.

JOAN DUROCHER: Okay. Great. Thank you, Sascha.

Okay. So let's see. The top two voted proposals will be addressed in FY26. Others will be addressed if possible, but this vote is designed to prioritize the work of the Council so staff has guidance on proceeding with our policy work.

Staff has worked with specified Council Members to develop each one of these. Either staff or a Council Member will describe each proposal in detail. I'm going to start with the housing tool kit, and Hoskie will be describing that one. So I'll turn if over to Hoskie.

RISA RIFKIND: Hoskie, if you want, you can use this one. I have one to the right if you want it. Yep.

HOSKIE BENALLY: Okay. Thank you.

ANA TORRES-DAVIS: I think that Sascha --

INTERPRETER: The interpreters were not able to hear that. Could you repeat that?

HOSKIE BENALLY: Thank you. Good morning Chairman Kennemer and Council Members. We're going to tag team on this policy proposal today. And it's entitled accessibility housing tool kit, an encyclopedia for housing developers.

There's a great need out there for affordable and accessible housing for people with disabilities clear across the United States. There's about estimated one out of four people with disabilities here in the United States and although there's that significant number of people, there's less than 6% of housings that are affordable and accessible. So we're bringing this policy proposal before the Council here today for consideration.

NCD consulting with advocates, they found out and identified that there are successful accessibility housing communities in the United States, one being in San Francisco, another one being in San Jose and Birmingham. And so this proves that it can be done. So we're proposing this, and I'll turn the time over to Council Member Bittner on the second part of this.

SASCHA BITTNER: [Off mic].

This project would create a tool kit for developers and will advocate on the barriers that developers regularly encounter in accessible, affordable housing.

This includes contracts, permitting processes, (inaudible), community (inaudible), and finding remedies in zoning restrictions, (inaudible), legal disputes, design complications, and most important, (inaudible).

At this time, there is no central registry for development for accessible, affordable housing.

I will turn it over to Council Member Hoskie Benally to do the rest of the report.

HOSKIE BENALLY: Okay. We feel that this tool kit, an encyclopedia, will stimulate interest and also having housing developers who specialize in creating accessible and affordable housing that's, again, very much needed clear across the country.

In 2022, the National Council on Disability put out a report called Strengthening HCBS Ecosystem, and in that report, they identified that accessible housing creates barriers for people with disabilities who transition back into their communities. Those that are still in institutions, residential programs, a lot of people with disabilities get caught up in that because they have no place else to go because there's a lack of housing resources. So they would like to be back in their communities and back with their families, and we feel that this tool kit would help provide accessibility to transition back into their communities.

The tool kit will also feel like, as it emerges, that housing developers will take interest in specializing in housing development in this area, and as well as time goes on to increase housing resources for those with disabilities.

I think one of the solutions that we feel that it will address is during disasters, that it will create accessible shelters, during disasters for people with disabilities, and it will also, as far as post disasters, have availability of housing for those that as a result of a disaster.

And then also that it will not create for people after a disaster, what happens is a lot of them are reinstitutionalized again because they've got no place to go, and again, they want to be with their community and their families.

So this is a proposal that we would like to provide to the Council here, and we feel that it is going to be of course a growing document as time passes. There will be other emerging needs and things that need to be addressed, but we feel that will stimulate even more interest and provide a resource for people with disabilities.

So thank you very much.

JOAN DUROCHER: Okay. All right. Thank you, Hoskie, Sascha. And I will add that NCD hasn't done a housing report in several years. I think we're kind of long overdue to take that up again.

Okay. So next I am going to turn to Sascha again to talk about the post-American recovery project or post-ARPA report.

SASCHA BITTNER: Yeah, give me one second.

Thank you, Chairman Kennemer and Council Members. My mom is going to read most of this.

Okay. Thank you, Chairman Kennemer and fellow NCD Council members. My mom is going to interpret for me.

I would like to do post-ARPA, what worked -- can you hear me?

INTERPRETER: Yes. Just read a little more slowly.

SASCHA BITTNER: What worked and did not work for people with disabilities under the American Rescue Plan of 2021. Congress enacted the American Rescue Plan Act, ARPA, $1.9 trillion COVID-19 relief package, which temporarily authorized several rare policy and program flexibilities to support people with disabilities.

For example, section 9817 of ARPA provided qualifying states with a temporary 10 percentage point increase to the federal medical assistance percentage Medicaid funding for HCBS from April 1st, 2021, to March 31st, 2022. This temporary increased funding allowed states to address HCBS workforce and structural issues, expand the capacity of critical services, move people off the HCBS wait list, and support caregivers.

This report would look at how successful these states were, including Medicaid waivers, HCBS waivers, as well as those under 1135 of the Social Security Act.

This policy project should also examine how many states used ARPA funding to place people with disabilities in intermediate care facilities and not in the community settings as Congress envisioned. This project should examine whether people with disabilities were able to participate in the $5 billion emergency vouchers intended to support people who are homeless or at risk of homelessness, recently homeless, or fleeing domestic violence, and examine barriers that they encountered. Finally, it should examine what happened to people with disabilities once these flexibilities ended.

And this report will be the first of its kind and came as a request of disability activists. It will be a follow up to NCD's 2021 report, the impact of COVID-19 on people with disabilities, which highlighted new funding flexibilities under ARPA.

Again, I thank my fellow Council Members for this opportunity to present this policy project. To my fellow Council Members today, thank you very much.

JOAN DUROCHER: Thank you, Sascha.

I am next going to turn to Amged Soliman on our staff, who is going to describe the disability curriculum project Neil is proposing.

AMGED SOLIMAN: Thank you, Joan.

Actually, Mr. Romano asked that I read a statement by him regarding this proposal.

Mr. Chairman and fellow members of NCD, I am sorry I cannot be with you today and I want to thank Mr. Soliman for reading my remarks.

I prepared my remarks because I am absolutely convinced that the healthcare of all people with disabilities rests upon having those within the medical community receive a proper clinical education in the care and treatment of people with disabilities. For generations advocates have fought for better healthcare for people with disabilities, and I believe that having a properly educated medical staff is of primary importance.

During my time as a member of NCD, spanning four administrations, we have tackled the issue of effective healthcare for people with disabilities many times. We fought for the simple recognition of our community within the dental community and had a degree of success after the yeoman efforts of this staff and many on the dedicated committee members.

But while recognition is a good start, it does not satisfy the basic need for better dentistry and dentists for those of us with disabilities. Prior to COVID, NCD issued a bioethics report that made the statement that people with disabilities needed to be respected and cared for based upon their inherent value of human beings and not based upon some algorithm or medical person's personal bias.

And again, while the report had impact on the recognition of people with disabilities, in the medical mess that was COVID, it did not cause the medical community to accept the responsibility to learn about the unique needs of those with disabilities under their care.

NCD undertook a massive medical initiative under the inspiring leadership of Chair Gordon and to what was needed from the federal government to help people with disabilities achieve their best medical outcomes and touched on the need for medical competency.

Now is the time for NCD to make this mandate for the next generation of medical professionals a must, and a primary focus of this council. The truth is, without a medical community trained to understand the issues of people with disabilities, they will continue to marginalize us and make faulty and biased medical decisions for Americans with disabilities, and that puts all of our lives in daily jeopardy.

The time for disability-educated medical community is now. In all my years of putting forth proposal to this body, I have never raised an issue that I felt is as important as this one. So I ask for each of my fellow members for your support of this proposal.

I would like to take a moment to thank one of our former colleagues, Dr. Rader, for his remarkable work in framing this proposal and his promise to support NCD's efforts to make this report a reality.

Thank you. God bless you all. Neil Romano.

JOAN DUROCHER: Thank you, Jed.

Next we will turn to Amy Nicholas on our staff or Chairman Kennemer to talk about the access to courts.

Hold on one minute. Here she is.

SHAWN KENNEMER: Amy, can you present this, please?

AMY NICHOLAS: Sure. What am I presenting on?

SHAWN KENNEMER: This is the advocacy in courts.

AMY NICHOLAS: Gotcha. Yes, I would be happy to. Can everyone hear me?

>> No.

AMY NICHOLAS: Thank you. Okay. Yes, welcome, everybody. The proposal that Shawn and I would like to move forward is the advocacy in the courts. It has come to our attention that during court proceedings, many people with disabilities do not have proper representation as to what their rights are in regards to reasonable accommodations during court proceedings.

There's also a divide between what is allowable, I should say, between state courts and federal courts. Federal courts are not required to follow the ADA. They have an administrative code, and the only thing in that code regarding reasonable accommodations for people with disabilities is prefaced for people who are Deaf and hard of hearing.

The recommendation that we put forth is to look into this issue. Every state and -- or every state court should have an accessibility coordinator, an ADA coordinator, to help field these requests for people with disabilities. Unfortunately, many people with disabilities are not aware that they are supposed to be provided an accommodation to receive equitable representation. And the lawyers who represent them also are not familiar with the needs or if it's an available requirement.

Another issue that was brought about is the way that the state courts actually address these recommendations or these requests. Many of these requests when they come in for reasonable accommodations are decided by the judge, or it's decided in court with both litigants being a part of the process, making it an adversarial issue.

Also, it was found in the research with this that a lot of these inequities and discrepancies happen in family courts. So the recommendation of the team, or of the Council, is to investigate why this exists. Ideally, look at all 50 states, find out where these ADA coordinators exist, if they exist, and if they exist, what is the process they use to determine whether an accommodation is required or accepted, and then provide as we normally do the findings and recommendations to help make it a more equitable process for all people, including people with disabilities, when going through the court system.

SHAWN KENNEMER: Yeah, and I'll just add to that. What seems to be an issue is, and I have dealt with it on a personal basis, for example, somebody who has autism is trying to navigate the court system, it's quickly get in, get out, somebody speaks to the prosecuting attorney, comes and says do you have an attorney, no, here is one appointed to you, the public defender comes in, and it could be a minor offense, speaks to somebody for 2 minutes and says, well, I'm going to get you 90 days suspended release and now you're a felon or now you've got something on your record, and the individual with autism is like, wait, what? You know.

And agrees to it because they don't know. And then when they're informed that this person has autism, they're like, no, I spoke to them. No, you spoke to somebody for 2 minutes, you don't know that person.

So the hope is that, you know, one of the fundamental aspects of living in the United States is the participation in the court system and to participate in your own defense, and if you're not provided the reasonable accommodation and you're not required, courts, judges are not required to follow anything. They are allowed to judges make the decision, and then as Amy said, it is the decision that is often made with the prosecutors or the second party in open court talking about somebody's disability in open court and what accommodations. And if they don't all agree that you should have that accommodation, you don't get it.

So I just think that this is a time that this really needs to be addressed. So, I thank you, Amy.

AMY NICHOLAS: You're welcome.

SHAWN KENNEMER: Anything else?

AMY NICHOLAS: It's an issue that NCD has not touched on before. It's a novel issue. So I think it's ripe.

SHAWN KENNEMER: And I will say, this was an idea I saw from watching a YouTube video, and I asked Amy, hey, what been this. So thank you for your work on this proposal.

AMY NICHOLAS: You're welcome. Thank you.

JOAN DUROCHER: All right. Thank you both.

Next I'm going to turn back to Jed again, and he's going to talk about the oral health project follow-up proposal.

AMGED SOLIMAN: Thank you, Joan.

So as Joan indicated, this would be a follow up to NCD's previous report, Medicaid Oral Coverage for People with Disabilities: A Fiscal Analysis.

So this I think is relevant to look back on again because it's no doubt that people with developmental disabilities in the United States suffer significant health disparities compared to their counterparts, including unmet dental needs.

Further, finding a cost means for people with disabilities is ideal. And certainly top of mind at present.

Accordingly, NCD published this report in 2022. The report was motivated by a central research question: Should states that do not already do so implement Medicaid policies that promote access to dental care for adults with I/DD and would doing so be cost effective over the long term?

The answer proved to be yes to both questions, because Medicaid adult dental benefits vary widely by state and because of the dearth of research on how Medicaid should best address oral health disparities for adults with I/DD, the report examined the relationship between state's Medicaid benefits and receipt of dental care among those with I/DD. The relationship between state waiver programs and receipt of dental care and the estimated cost and potential savings of implementing basic dental Medicaid benefits in states that do not currently offer it.

Additionally, the study examined the role of coordination between developmental disability agencies and Medicaid agencies for improving access to dental care.

Finally, the study identified promises Medicaid funded state and private strategies for expanding dental care for adults with I/DD.

Now, there's some interesting findings that came out in this report, including in the 12 states that did or do not provide dental benefits, the total estimated cost of providing extensive dental benefits to adults with I/DD would be approximately, based on the numbers at that time, 19.6 million annually. With those state government responsible for 7.3 million of that cost, again, at that time.

NCD estimated that these costs would be more than fully recovered through reductions in emergency department use and hospital admissions and reductions in the cost of treating several chronic diseases, the root cause of which are poor oral health. We estimated federal and state governments combined would realize a return on investment of approximately $7.7 million beyond recovering the initial cost annually. And the share of that return on investment for those 12 states would total close to $3 million annually, again, as of time of the publication of the report.

Interestingly, NCD found -- and this is probably most interestingly -- NCD found that of the 12 states that did not provide dental benefits, 11 of the 12 states would save more money than they spend by providing people with disabilities people with I/DD adult dental benefits, and the 12th state, Nevada, would spend $60,000 more than they save with such a program. Not a considerable portion of the state's budget and is virtually cost neutral.

Since NCD released its report, that state, Nevada, had indeed implemented such a dental benefits program for people with I/DD. The time is ripe for NCD to conduct a follow up to the report. Aside from exploring whether the remaining states in question have implemented similar programs, NCD should further explore how Nevada and potentially other states have fared since. For those states that have yet to follow NCD's recommendation, NCD should make a directed effort at presenting its recommendations and findings to states' respective policymakers.

Again, finding a cost neutral means of attaining policy objectives for people with disabilities is ideal.

Thank you.

JOAN DUROCHER: Thank you, Jed.

Finally, the proposed FEMA project. Kim will be discussing that one.

KIM RIDLEY: Go ahead.

JOAN DUROCHER: Or Amy, I guess.

AMY NICHOLAS: Good morning again.

At our March council meeting, we had an amazing panel with some survivors of disasters. Two of them made it through the L.A. wildfires and another one was from North Carolina, Asheville, North Carolina, with the flooding there.

From that panel, we realized that there's still a lot of work that needs to be done to ensure people with disabilities' safety before, during, and after disasters.

So we had a follow-up panel with Council -- with Chairman Kennemer as well as Kim and a couple other people about a month ago to troubleshoot and discuss ways to improve actions not only by FEMA but also by state and local entities, because FEMA and -- well, FEMA, as we know, is the federal entity and they streamline the information down to the state and local entities who in the end are the first responders to any disasters.

The proposal that we have sent forward is to provide a tool kit of sorts for state and local emergency management agencies. Each state, states that I have spoken to have access and functional need coordinators, to be able to respond more efficiently and effectively to emergencies in their counties. These state AFNs access functional need coordinators coordinate with every single county and city in their state. They foster relationships with their emergency management coordinators, and they promote coordination with the disability community and disability stakeholders.

This proposal suggests that we look at what states do have, these AFN coordinators, how they function, money they save, and then provide recommendations on how to -- or a checklist as to what these coordinators do in order to assist people with disabilities before, during, and after disasters.

This checklist, tool kit, whatever we wish to call it, is more important now than ever, especially with the proposed cuts to FEMA. The people that I've spoken with, my contacts within FEMA, have already had a reduction in force of people on the ground after disasters. It used to be that FEMA had a cadre of disability coordinators, subject matter experts, in what FEMA was able to provide for people with disabilities. That cadre no longer exists. When a disaster hits and FEMA hits the ground, there is no one on the ground that has that subject matter expertise.

So I think that as many reports have in the past is very timely. I believe this is extremely timely to have this report to support the states and the local entities to be able to effectively and efficiently provide the same services for people with disabilities during and after disasters.

Kim, if you have anything else you would like to add.

KIM RIDLEY: Not much, Amy, you covered most of it. But I do want to emphasize, well, first of all, reiterate everything that we heard in last quarter's meeting. The stories were so compelling. And the follow-up meeting that we had with all those participants just reemphasized everything that they said. It's something that we are looking at strongly in New York certainly, emergency preparedness.

And I do think that this warrants a deep dive look into.

JOAN DUROCHER: Okay. Thank you.

I also included the artificial intelligence project in the materials, but we have a new intern, Nathaniel Ross, who is working on that for us. He has a strong interest in this topic, and given the number of EOs and actions coming down the pike on AI, that seemed like a good idea. So do you not need to include that one in your vote, but I included it in the materials just so you would know what we would be having him work on.

I'm now going to turn it back to the Chairman, and you can discuss, debate, and then vote.

I think Ana, we had thought that each Council Member could vote on their top three, and then we'll prioritize them and select the top two. So I'll turn it back to you. Thank you.

SHAWN KENNEMER: Thank you, Joan.

Yeah. It's a lot of -- this is not our fun part as being Council Members. I just wanted to say to the Council members and the staff that worked on these proposals, excellent job. I think, you know, last council meeting that we had, we spent an hour or so just brainstorming in areas, and I think we got some really good proposals. And unfortunately we can't do everything.

I wish I could tell the staff to do it all, here you go.

So just know, any votes that we take up here doesn't mean we don't think every one of these proposals is important. It's what we think we should prioritize.

Yeah. So that, I think normally the way this works, we'll do a roll call and we'll have the Council Members vote and just say your top three that you would like.

I will say that if we can, and I know the staff, if there's opportunities and areas that we can do, we will be trying to work on portions of some of all of this, and then if we can't, then bringing it back up. As we say, resources are limited right now, and we're really trying to be fiscally responsible.

With that, I will -- let's see --

RISA RIFKIND: Is there opportunity for question?

SHAWN KENNEMER: Yeah, sure, let's take some opportunity for questions. Go for it.

RISA RIFKIND: Thank you.

This is Risa. Just echoing, I wish I could vote all of them for number one. Knowing that that's not an option, I'm wondering, you know, I love the thought to have some of these be suggested as a tool kit version, to take tangible action.

I'm wondering, though, are any of these proposals also with the tool kit having policy recommendation? Because I fear that something incredible will be created and how do we make it not just like a nice option but, you know, a strong recommendation to use, either a policy component, I think there were three tool kit options. So, any thoughts about that?

AMY NICHOLAS: I would be happy to address that.

RISA RIFKIND: Thank you, Amy. I asked it openly, looking at you.

[Laughter]

AMY NICHOLAS: I saw the glare.

RISA RIFKIND: Not glare.

AMY NICHOLAS: I'm sorry. Gaze. Wrong word choice.

Yes. There would be recommendations, there would be findings. I think with any of the tool kits, just like the American Indian tool kit, there were findings and recommendations in there that would be pointed.

I've also thought of dissemination, especially with the emergency management. In the past we have paired up with the National Governors Association, and I've made presentations to the NGA with all of the governors as to the tool kits and recommendations, in order to get it disseminated that way.

So yes.

RISA RIFKIND: Thank you. I appreciate that.

And then for the accessible housing tool kit, though, I feel like that one is slightly different because it requires nongovernmental partnership, with builders, developers. And I don't know if that's an Amy question. I don't think you were involved in that one. But I'm opening it up to any other colleagues about how to get developers to buy in. I just have concern that the will isn't really there even if delivering to them like a packaged easy way to do it.

AMY NICHOLAS: Just real quick, you're right, I was not involved in that, but just out of experience, I think with the developers is a matter of proving to them where it's going to save them money or where the profit is, right? It's a return on investment. So we find a findings and recommendations to lead them that way.

SASCHA BITTNER: Yeah, but I could share as someone who has been kind of involved with it that I don't really understand your question, and I have some of those same concerns as well.

SHAWN KENNEMER: So I would just say one of my concerns on that is if you're looking at getting others involved is that our role at NCD, you know, our mandate is to be the advisory for the White House and Congress. So I mean, it may be something that we can include in something, but is that really, if we're really looking to partner. Beyond popular belief, we're not an advocacy group. We are advisers.

Do you have a follow-up, Risa?

RISA RIFKIND: No, that makes sense and I do feel like that was a difference in that proposal is the audience for that one was developers. Unless I'm reading the proposal incorrectly. Please, colleagues, tell me.

KIMIE EACOBACCI: This is Kimie.

SHAWN KENNEMER: Kimie, go ahead.

KIMIE EACOBACCI: Yes, so this report actually would advise -- a lot of developers go off of federal policies, financial assistance, created by Congress, right, so we need to know from the developers how can we improve on those financial incentives, the barriers, so it's intended to inform federal policymakers, local policymakers who do the zoning issues, as well as the developers too, but we need the feedback from the developers, like what do you guys need to incentivize you to create more accessible housing, what are the barriers that you're encountering that we can address through policy.

SHAWN KENNEMER: Okay. Thank you, yeah, that makes sense. Okay. Perfect.

Any other questions?

On anything?

Any Council Members have questions on any other policies or other proposals?

Okay. Hearing none, then we'll start a roll of top -- we're doing top three? Is that what I, Joan?

JOAN DUROCHER: Yes, I would say do your top three, and then I can order those following the meeting and send is around to the Council. And I believe Neil submitted proxy votes as well.

SHAWN KENNEMER: Neil submitted top two proposals, but we can always get a third one from him as well.

Okay. All right. So --

>> Hello, can you hear me?

SHAWN KENNEMER: Yes. Hello?

>> Yes, this is Theo.

SHAWN KENNEMER: Thank you, Theo. Thank you for being present.

Great. Then let's start with -- yeah, I'll just -- I'll start.

Hold on. Give us just one second. We're trying to work out details how this is going to work.

The way we're going to do this vote is I will just call out names, and you tell us the three that you vote for, and then we'll go from there.

So Risa, would you like to start with us? Or you want me to start?

RISA RIFKIND: Can I pass it back to you, Acting Chair?

[Laughter]

I'm doing my tallies right now.

SHAWN KENNEMER: Voting right now, I would vote my number one would be the clinical competency. Two would be the advocacy in the courts. And three would be the FEMA project.

Hoskie, would you like to vote?

HOSKIE BENALLY: Okay. I'll go with accessible housing, transportation, and the clinical one.

SHAWN KENNEMER: I'm sorry, you said the housing --

HOSKIE BENALLY: Housing, transportation, and clinical one. Competency.

SHAWN KENNEMER: Clinical come system all right.

HOSKIE BENALLY: Yes.

SHAWN KENNEMER: Excellent.

Sascha?

SASCHA BITTNER: The clinical competency one, the FEMA emergency management, and then I/DD dental.

SHAWN KENNEMER: I'm sorry, can you repeat that?

SASCHA BITTNER: The developmental disabilities dental.

SHAWN KENNEMER: Dental. Oh, yes, yes, all right. Yep. Perfect.

Kim.

KIM RIDLEY: Oh, boy. So this is hard. I think I am going to -- I just want to preface my vote because with I probably would pick all of them as a number one if I could.

I'm trying to pick them based on covering the widest amount of people and targeting the federal government, because many of these things we're working on at the state level too.

I would, I think I would say courts, emergency preparedness, and the housing.

SHAWN KENNEMER: Risa.

RISA RIFKIND: I'm ready now. Thank you.

I'll take your lead, Kim, and do a little preface.

With my work with the health disparities committee, I see the need for the two healthcare ones, specifically, you know, around the dental, clinical, and then the emergency one. Just following the quarterly, last quarterly meeting, hearing those stories firsthand.

SHAWN KENNEMER: And Theo. Theo, can you hear us?

THEO BRADDY: Yes. Can you hear me?

SHAWN KENNEMER: We have you, yes. Your top three?

THEO BRADDY: Okay. Yeah, it would be clinical, FEMA, and the ADA coordinator. I might have the title wrong.

SHAWN KENNEMER: The courts. Yep.

Excellent. Thank you.

And then Neil Romano, he said his top two would be the clinical and then the oral health.

Are we missing anybody?

Okay. So that means, by my count, we have two for the housing, six for the clinical competency, three for the advocacy in the court, three for the oral health, and five for the FEMA project.

Correct? Is that what you guys had?

Okay. Great.

Then, Joan, you'll put that out?

JOAN DUROCHER: Yeah, I'll send that out to the full council following this meeting, and then the staff will put their plan together for how to deal with this in FY26.

Yes, so that concludes my report. Thank you very much.

SHAWN KENNEMER: Thank you, Joan.

Okay. So that puts us way early. This always happens. Which is good. I would rather be early than late.

At that, let's go ahead and take a -- says 15-minute break. Let's take a 20-minute break, and let's be back at, yeah, let's be back at 11:15. We'll take a 25-minute break.

All right. Excellent. Thank you.

[Break]

SHAWN KENNEMER: Okay. Thank you, everybody, for coming back. And we're back on the record.

All right. Great. We're back on the record now. Thank you, everybody, for coming back. We're going to continue, we do need to back up real quick. I was made aware, thank you, Risa, for pointing out, on the agenda, we did forget to, we passed over approval of the previous board meetings' minutes. So I'm going to ask if the Council Members all had a chance to read those. If so, if I can get a motion to approve, that would have been which minutes were those? March, right?

ANA TORRES-DAVIS: March 6-7.

SASCHA BITTNER: I move that we approve the meeting minutes.

SHAWN KENNEMER: Sascha moves. Is there a second?

RISA RIFKIND: I'll second.

SHAWN KENNEMER: Risa seconds.

And Ana, if you will read the roll.

ANA TORRES-DAVIS: Shawn Kennemer.

SHAWN KENNEMER: Yes.

ANA TORRES-DAVIS: Hoskie Benally.

HOSKIE BENALLY: Yes.

ANA TORRES-DAVIS: Sascha Bittner.

SASCHA BITTNER: Yes.

ANA TORRES-DAVIS: Theo Braddy.

THEO BRADDY: Yes.

ANA TORRES-DAVIS: Kim Ridley.

KIM RIDLEY: Yes.

ANA TORRES-DAVIS: Risa Rifkind.

RISA RIFKIND: Yes.

ANA TORRES-DAVIS: And Neil Romano voted yes.

SHAWN KENNEMER: Thank you.

Okay. Now that that housekeeping is done, now we're going to move on to our panel discussions, and I'm going to turn it over to Jed to introduce our panel.

AMGED SOLIMAN: Thank you. Good morning, everyone. Once again, my name is Amged Soliman and I serve as a senior attorney adviser at NCD, and today's moderator for this wonderful panel we have regarding employment.

The panel on employment initiatives and challenges for employment including employment of youth with disabilities is our focus today. Becoming employed and remaining employed has remained a challenge for people with disabilities. Even in the decades following the passage of the ADA, people with disabilities have been represented in the workforce at much smaller percentages than people without disabilities.

Most recent federal employment statistics again revealed that in 2024, 22.7% of people with disabilities were employed, in contrast to 65.5% of people without disabilities.

NCD is very happy to host this panel today to follow up on some of our previous employment reports and to learn about new initiatives and the challenges that remain for the employment of people with disabilities including youth with disabilities, including the transition from school to work. Really we're blessed to have so many amazing people to talk about this issue, and we thank each of you for coming.

And with that, I would like to introduce each and every single one of them.

Tonia Ferguson, esquire, is the Director of legislative affairs for the Council of State Administrators of Vocational Rehabilitation, comprised of the chief administrators of the public rehabilitation agencies serving individuals with disabilities in the states, District of Columbia, and territories.

Ms. Dana Barone, MA, is a VR specialist supervisor, and InVEST Project Director for Department of Labor and Industry office of vocational rehabilitation.

And we have Mr. Andy Sink with the Chief Disability Officer of New York State.

And we have with us Hannah Millson, Director for employment services at AHRC New York City, overseeing a number of programs supporting people with intellectual disabilities to prepare for, obtain, and maintain meaningful work.

MaryBeth Schneider serves on the NYS Chief Disability Officers team and on the career development and inclusion team at the NYS Department of Labor as the inclusive internship coordinator.

I would like to once again remind panelists, if you have a slide presentation, as a point of accessibility, to please describe any images that you might have in your presentation.

With that, I'd like to turn it over to Tonia to get us started, please.

TONIA FERGUSON: Good morning. Can you guys hear me okay?

Awesome.

So I am thrilled to be with you today. The Council of State Administrators of Vocational Rehabilitation highly values our relationship with the National Council on Disability in our enduring connection with empowering and maximizing employment outcomes for individuals with disabilities.

As mentioned, I'm Tonia Ferguson, an African-American woman with braids, with black pants, a black shirt, and a leopard print jacket.

So I will share, you know, my passion runs deep from having a son born with Down syndrome and autism, where from time to time, that really sent me into a place when he was born. Because of the "he won't..."

You know, he won't ever walk. He won't ever talk. He won't ever be employed.

Well, I will tell you the "won't evers" turned into, he simply did. He walks, he talks, and he is employed.

And I remember -- thank you.

And I remember going through Partners in Policy Making, which is an advocacy training in my state, when he was an infant, and at our graduation, the keynote speaker simply said: Presume competence. And to presume competence means to assume that someone is capable of learning, thinking, understanding. Even if they don't communicate in a way that is easily understood.

So, you know, I've taken that statement into my career as the Director of legislative affairs at CSAVR where I encourage our state VR agencies to actively engage our customers rapidly, to improve the results of high-quality, competitive, integrated employment.

So as mentioned, CSAVR, we tell the story of the vocational rehabilitation program. As mentioned, we have 78 VR agencies, including territories and blind agencies. So our top three principles are all around employment. Innovating solutions to achieve greater access to vocational rehabilitation services, building careers, and retaining talent in America's workforce, by investing resources to benefit our customers.

Customizing services and expertise that provide flexible supports and services to meet the workforce goals of our customers, while increasing the workforce participation rates of people with disabilities.

And so for some of you, that may be in the audience or on the phone that don't know about vocational rehabilitation, you know, the Rehabilitation Act amendment of 1998 was signed into law and reauthorized the Rehabilitation Act of 1973 and included significant changes to improved services for individuals with disabilities. You know, focusing on streamlining processes, expanding customer choice, and integrating vocational rehabilitation services with workforce development programs.

So VR is a federal and state program designed to assist individuals with disabilities to obtain, maintain, and advance employment.

You know, each state administers its VR program with federal oversight from the Rehabilitation Services Administration in the Department of Education. And a hallmark of the VR program is all about our specialize the customers train to work with individuals with significant disabilities, identify their unique needs, unique qualities, and develop a customized career plan.

And I will say, all of that, because many may hear that the national VR program is the best kept secret, but we're not. We have served over 1 million participants in the program in the year 2024. 52% of VR participants were employed.

So as mentioned, you know, the state of employment right now, I will share with you that back in 2021, you know, only 19.1% of persons with disabilities was employed. While 63.7% of individuals without disabilities was employed. And the rate of poverty of adults with disabilities is actually much higher than adults without disabilities. Adults with disabilities earn $8,185 on average than adults without disabilities. But I will say, we've got some wins. In 2023, we saw an all-time record in employment gains for people with disabilities. And the unemployment rate fell to its lowest level on record for those with disabilities.

But still, for youth with disabilities, the unemployment and underemployment of transition-aged youth still represents a huge barrier to full participation in adult activities. Many students with disabilities still face an employment narrative contrary to their peers without disabilities and obtain post-school employment and post-secondary education at significantly lower rates than their typical peers.

So in 2014, the Rehabilitation Act was reauthorized again in the Workforce Innovation and Opportunity Act, WIOA, Title IV, as we know, stated that it wanted to progress in engaging students and youth with disabilities through preemployment transition services. As we know, pre-ETS, which represents a unique, exciting opportunity for vocational rehabilitation agencies.

To flip that narrative, remove the stigma attached to students with disabilities, and assist the younger generation in achieving competitive, integrated employment.

Employment for people with disabilities should occur in fully integrated workforce. Individual jobs, right? Not groups of people with disabilities. Competitive wages and benefits as their other typical workers. Diversity of jobs where they've got mobility, not special jobs.

The top indicator of employment success for students with disabilities are paid employment prior to graduation and parental expectations. Because I can tell you, when my son was born, my expectation is that he would thrive side by side with his typical peers. Point blank, that's what I expected as a new mom, and I take that into my career every day.

So I'll shift a little bit just to share with you, you know, this panel is about the regional perspective. I'll share with you some state-specific projects and just share what they're doing with young folks and young individuals with disabilities.

So the New York State education department adult career continuing education services and vocational services is leveraging the power of peer facilitated model through independent living centers to deliver an array of supports leading to competitive, integrated employment, including preemployment services, independent living services, benefit planning as we know that's critical, self-advocacy, assistive technology, which all helps the competitive, integrated employment opportunities for people with disabilities either in or contemplating subminimum wage employment.

And then we have the Volunteers of America, Greater New York, in our New York VR agencies. They're thinking outside the box. They're focusing on homeless youth and adults with their career access program, looking at high rates of individuals with disabilities that have trauma and toxic stress, and posttraumatic stress disorder in this population. As we know, that's critical. May is mental health awareness month. And many individuals have adult diagnosis.

They're looking at comprehensive assessment of career exploration. You know, career planning, job skills training, and job readiness instruction, job placement, coaching, and retention, and case management.

And once again, that benefits assessment and assistance.

And then we have New Jersey State Department of Education and our VR program. They're working toward a pathways to postsecondary success, to increase achievement in competitive, integrated employment, by improving interagency collaboration of transition services and creating a statewide transition website that incorporates user friendly resources on transition services for children and youth with disabilities and their families.

So I will tell you, there is a return on investment for supporting youth in VR. You know, pre-ETS spending has increased, and students receiving services has gone up. We had in FY22 42 states increase pre-ETS funding. And in 2022, over 300,000 youth was served.

You know, CSAVR firmly believes that the insight and perspectives of NCD can help us in continuing to serve youth with disabilities, maximize the funding for transitioning youth.

So as I close, we know that working is fundamental to adulthood, and work is a route out of poverty.

A quote from Margaret Mead, a researcher and someone I've studied, focused on the cultural influences on human behavior, she said, "Never doubt that a small group of thoughtful, committed citizens can change the world. And indeed, that is the only thing that ever has."

So I appreciate the time to share with you, and look forward to if there are any questions.

AMGED SOLIMAN: Thank you, Tonia, we really appreciate that.

[Applause]

Next I would like to turn things over to Ms. Dana Barone, and if we could please load that first slide deck for this panel, please.

DANA BARONE: Good morning, everybody, and thank you for having me.

That helps, if you turn it on.

Good morning, everybody. My name is Dana Barone, and it's a real honor to be here today with you all. Hi, Theo, from Pennsylvania. It's good to hear your voice.

So I wanted to give you kind of, before I tell you what our challenges and our solutions are to the employment of youth with disabilities in Pennsylvania, I wanted to give you a little bit of a landscape of what is happening with OVR in Pennsylvania.

On the screen, how is OVR doing with our pre-ETS services? Well, we have attended 8,230 IEP meetings over the past calendar year, when I say 2024, program year.

We have attended 1,000 -- or I'm sorry, 1,214 youth had paid work experiences through OVR's "My Work" program at 297 sites across the commonwealth.

We also had 2,551 individuals receive counseling on postsecondary education opportunities. We had 6,178 students participate in instruction in self-advocacy. And then 6,394 individuals participate in job exploration counseling.

And finally, we had 11,000 students, 11,041 students participate in workplace readiness training, and 5,946 individuals participate in work-based learning services.

And I share all of that with you to, then, say our demographics are: 67 counties, 500 public schools, 170 public charter, cyber charter, and career and technology schools and intermediate units. As of 2024, there are 126,602 students with disabilities between the ages of 14 and 21 in Pennsylvania. And we have 15 OVR district offices, including 6 bureau of blindness and visual services district offices collocated within those district offices. And we have approximately 350 VR counselors statewide serving all Pennsylvanians with disabilities, not just youth.

And you add all of that, and we're also a commonwealth. So there's a lot of local control and autonomy given to local education agencies.

I share all of that to say that there's a big job for OVR to do in Pennsylvania in terms of delivering preemployment transition services to the number of youth with disabilities who need them. So I'm going to tell you a little bit about the challenges that we have in Pennsylvania right now.

So we have limited access to pre-ETS due to funding. Right? There's just not enough funding to deliver all of the services that are needed.

Transportation gaps. I am sure that Pennsylvania is not the only state that has issues with transportation. And this is something that Tonia alluded to, low expectations. And it's not just parents; it's teachers, it's providers, it's VR professionals, unfortunately.

We also have a lot of employer misconceptions about workers with disabilities in terms of safety, productivity, the cost of accommodations, and there's not enough opportunities for students to have work experiences and opportunities to develop work skills.

And then there's the ever present fear of loss of benefits and supports. If you gave me an hour, I could go on and on and on about social security and income limits.

And then you have, you know, intersectionality with other underrepresentive groups. Black, indigenous, people of color, LGBTQ+, English as a second language. So we have a large population of youth who are aging out of the foster care system, and a lot of youth with disabilities who are also involved with the juvenile justice system.

So those are some of the challenges that we're having.

So what's Pennsylvania doing about that? Well, we are very, very fortunate that our current Governor, Josh Shapiro, has been really supportive of VR. His wife, our First Lady, has really taken OVR under her wing as the special project. She promotes us whenever she has the opportunity to.

So Governor Shapiro has suggested an increase in our PA state match to draw down additional funding from RSA for our base formula budget, and additional match through bipartisan support when there are sweep up moneys, right, when other states don't spend their budget and funding is available for us to get with additional state match, we get it.

We also have two disability innovation fund model demonstration grants. So Tonia alluded to these. We were awarded the DIF-D subminimum wage to competitive integrated employment grant, the InVEST Project, $13.5 million for that grant.

And also the pathways to partnership grant which is really looking at partnerships to support youth who are transitioning from school to work.

So we are partnering with our Department of Education bureau of special education and our centers for independent living to promote person-centered planning. So we're doing a lot of training and technical assistance on charting the life course framework and tools out of the University of Missouri Kansas City, and we're also doing training on transition discoveries, which is a model that has been developed and promoted by Dr. Joan Kester out of the university.

We're also providing My Work experiences. This is a summer youth work experience. We're partnering primarily with municipalities throughout the commonwealth, but it's a group employment program. So you get a lot of bang for your buck, and students get an opportunity for a paid work experience during the summer.

Transportation. We are now for pre-ETS, for preemployment transition services, using zone transportation. So this is a flat rate payment for students' transportation to and from any portion of a pre-ETS activity. It's only paid when the student is in the car with the provider, and so we have a flat rate for 0-10 miles, 10-30 miles, and so forth.

We also have transportation provider agreement where we can provide reimbursement for individual fixed route transportation, and we can also do shared ride and individualized ridesharing supports through a regular fee schedule.

We can also pay our providers to coordinate those services on behalf of those individuals, and they get 10% reimbursement for coordinating that.

So that has been very helpful in addressing some of our transportation issues here in Pennsylvania.

Low expectations. Several years ago, we implemented what we call the early reach coordinator position. These are folks who have social work backgrounds who are going into the schools and talking to students as early as, you know, 14, sometimes earlier, depending upon what the school is asking us to do. And they do a lot of those job exploration activities, those career exploration, those self-advocacy trainings, in order to engage students and their families as early as possible in the school to work transition process.

We do as much as possible have our VR counselors attend IEP meetings, especially for those students who have more complex needs that are going to require more coordination of services in the transition process, to help establish some of those higher expectations for post school employment outcomes.

We do a lot of self-advocacy and self-determination training, as I mentioned, in order to help students find their voice.

We also, much like Tonia indicated, we did develop a presumed competence paper, position paper, and our use of our trial work experiences, and really we take the stance that individuals are no longer expected to prove that they can work through a trial work experience. Instead, we want our counselors to ask what does this person need to work, right? We're going to presume that they can work. What do they need to achieve that goal.

Our InVEST Project has three components to it. One of them is family engagement, because we know that individuals who are typically entering into sheltered employment are people with intellectual disabilities and autism to the greater extent, and that their family is very much involved in their day-to-day life. So we as an organization hadn't been doing such a great job of engaging family members because we want to recognize and respect the autonomy of the individual. But in those situations, we need to come alongside a family and help them get to the point where they know that their loved one can be safe and productive in the community.

So we're working with PA family network.

We're also focusing on person-centered planning, resource coordination, and wrap around supports.

And then again, the P2P project is collaborating with LEAs and looking at community-based instruction with our centers for independent living.

Employer misconceptions. We have a statewide business services team that provides disability awareness training, ADA consultation, tax incentives, referrals to the Job Accommodation Network, JAN, the VR NET through CSAVR. So we are really trying to arm employers with all of the resources that they need to hire and retain workers with disabilities.

We provide on-the-job training contracts. We have the MI Work program to expose employers to youth with disabilities in a short-term, safe kind of program, like there's no long-term commitment there, but it gives an employer exposure.

We have several Project SEARCH programs throughout Pennsylvania. When RSA, the Rehabilitation Services Administration issued the transition grants back in 2007, we received one of those to establish Project SEARCH throughout Pennsylvania. And we really have high statewide placement rates with Project SEARCH. 73.81%.

And then the InVEST Project. We are providing embedded positions within that grant project. One is an inclusion liaison, that is focused on helping the individual employer identify places where they can use universal design, where do they have unmet needs where we could possibly customize a position. And then we also have another position which is an employment support specialist who serves as a job coach for those individuals. So these are positions that are funded by the grant. They are employed by a community rehab provider, but their work is directed by the business.

Okay. Work experience and skill development. Preemployment transition services, I think we've covered that. But we're -- in Pennsylvania, we have a state -- we have the state minimum wage which is the federal minimum wage, but our Governor has established a minimum wage for any contractor or any employee or of the commonwealth which is $10.35 per hour. So any student who is participating in any of our paid work experiences is earning at least $10.35 per hour.

Doing mock interviews, job shadowing, informational interviews, and volunteer experiences. We're trying to use it all in order to get folks on the path to employment.

Loss of benefits. This is the bane of my existence as a VR professional.

[Laughter]

You know, our current social security regulations really relegate people to a life of poverty. People who are fully capable of earning good incomes to be more self supporting, we just need to let them have the services and supports that they need.

So we are introducing benefits planning services. We're encouraging people to use SSA work incentives, impairment-related work incentives, plans for achieving self support. We also have a PA ABLE account, medical assistance for workers with disabilities which is the Medicaid buy in program. We are collaborating with our partners at county I/DD programs to ensure that we are maximizing all of those things.

The InVEST Project, every individual receiving SSI and SSDI will receive benefits planning, and our family engagement provider, all of the InVEST family advisers went through the training through VCU so that they were more aware of those.

And then finally, we are asking our section 511 specialists who are those individuals that go into sheltered workshops to consider becoming certified work incentives counselors so that they can do on-site benefits analysis with those individuals.

And then finally, we have staff training for in terms of intersectionality, understanding, you know, underrepresented groups of people, training on cultural competence, the pathways to partnership grant is focused on underserved or underrepresented populations, and we have a memorandum of understanding with the Bureau of Juvenile Justice Services where they have provided us with some of their state budget to allow us to draw down more federal funding through the VR program.

We also have a similar type of MOU with the Pennsylvania office of developmental programs.

So those are things that allow us to maximize our federal funding and serve special populations of our customers.

So that is my presentation. Thank you so much. And I apologize if I went over.

[Applause]

AMGED SOLIMAN: Thank you so much, Dana. We really appreciate it.

Now I turn it over to Mr. Andy Sink. And if you could please pass that over to our friend.

Next slide deck, please.

ANDY SINK: Great. Thank you so much. Amged, about 10 minutes?

AMGED SOLIMAN: Maybe a minute or two more.

ANDY SINK: Okay. Great. Thank you so much.

Well, really excited to be here and honored to be here representing New York. My name is Andy Sink. I am the Employment First Director for New York State. I'm a man in -- white man in my late 40s wearing a blue suit, white shirt, yellow tie with little blue flowers.

And what I'm going to do today is do a walk through of our new Executive Order. It's so funny having people behind me. I keep wanting to turn and talk to the room.

I'm going to do a walk through of Executive Order 40 which establishes New York as an Employment First state. The slide deck itself, I could probably talk all day on each one of the slides, and so I'm going to do a relatively high-level overview of those things and of course we're available to talk about any of them.

I look forward, I was really excited to hear from Dana and Tonia about the exciting things in VR and in Pennsylvania. Look forward to talking more about those things.

So just a short run through of what I'm going to go -- all of my slides are text except for a couple that have graphs, and I will remember to describe them. And my colleagues will remind me if I don't.

So thank you for that.

So we're going to start with a little bit about why employment is such a big deal. We're going to go through the foundational principles of the Executive Order 40. Some of the things that we consider key components. A little bit of the time line in terms of what happens next, what's happening now actually. And then some key take aways and focus areas that will include a handful of things that are going on in New York.

Listening to my colleagues, it's tempting to talk about all of the exciting things going on in New York as well, so we'll just save that for another conversation in terms of what does employment look like in New York in terms of what is the playing field right now, the various grants initiatives going on.

At the risk of -- actually, first thing I want to talk about is, Kim Ridley, our Chief Disability Officer and my boss, was named Chief Disability Officer in New York in 2022 by Governor Kathy Hochul, which was an incredible statement for New York. Kim and the team and Governor Hochul have followed that up with a number of initiatives and charging us with improving quality outcomes for people with disabilities in New York.

When the office was established, one of the key things the Governor focused on was the dismal employment outcomes for people with disabilities and what that means. And so what's exciting about that is we have a Governor who not only believes in and is investing in employment and adjacent issues, but also knows how to talk about employment. She names specific evidence-based practices in several conversations, and so that gives -- it's a very exciting charge for us in New York, and I think it is the result of and resulting in incredible amount of momentum on this issue.

So why is employment such a big deal? I think most of the folks in the room know these things but I'll go through them quickly.

Lack of employment is a key social determinant of health, as is poverty. Both lead to poor health outcomes.

And low employment rates are pervasive for people with disabilities and the compounding effects are more significant than that of their nondisabled unemployed peers.

And so this slide is a little bit about the why, and there's also, the last bullet, it's like a how, what are we going to do. And we think what is going to improve those outcomes is the weaving of employment principles, like Employment First, into the day-to-day service delivery system in order to demystify and normalize the employment conversation.

So Employment First itself as a national movement and as a -- it is a civil right issue. It's a workforce issue. And it is most definitely a public health issue. Amongst others.

So one of the things that we're doing is really focusing on our large and very robust well-funded infrastructure, our public services and public health infrastructure, and trying to weave those employment principles into how we're supporting people with disabilities in New York.

I'm going to skip this one slide because we already talked about the dismal employment statistics. And I think one thing that, you know, depending on the statistics that I have up, and on the screen is a graph that has -- that talks about the poverty rate for people with disabilities and for people without disabilities. People with disabilities, it's a blue line going across between 2008 and 2021, goes between about 25-30%, it goes up and down. For people without disabilities, that number goes from about 12% up to about 15%. And what this is pointing out is simply the dyes parity between people with disabilities and people without disabilities in terms of poverty. As Dana said, a life on public benefits is very often a life of poverty. If we were to name, you know, the top three or maybe even the top one reasons why our employment outcomes aren't better, it has to do with earning and receiving public benefits, and not just those cash benefits, but Medicaid. And I'm going to talk a little bit about that before we get done.

The statistics that are cited here, both of these, if you're talking about employment and disability, you should be -- you know, you're going to hear about employment rates and poverty rates. And you may hear different numbers depending on where the data is pulled from, how it's analyzed, but the outcomes are bad, right? Like simply put, they are bad. These statistics are from the University of New Hampshire disability statistics compendium, which is one of our go-to sources as well as statistics from our Cornell University partners.

Okay. Just looking at time, so Employment First is a national systems change framework, centered on the premise that all individuals, including those with the most significant disabilities, which is incredibly important, are capable of full participation in competitive, integrated employment, which for the sake of time I will now refer to as CIE.

And in practice, this means that CIE is the first option and preferred outcome in the planning and delivery of services for those folks that we are supporting. And very importantly is an acknowledgment that we as a public health system and a services system don't do this very well. We have not done this very well. Statistics have remained poorer since they were started being measured. And in fact our services system is often a big part of the problem. And I think that's really important for us to continue repeating as we're having the conversation to really own that. That gives us a place to work from.

I'm going to skip that slide.

So I'm going to briefly go over the principles that are laid out in Executive Order 40, and these were worked on through an Office of Disability Employment Policy from the U.S. Department of Labor grant called the national expansion of opportunities network, NEON. Short version is we were building consensus among our stakeholders about what we wanted to have included in the Executive Order.

So I will just walk through these. Disability in no way diminishes the rights of people to live independently in their communities. Dignified workforce participation is a fundamental aspect of life for people with and without disabilities. People with disabilities including those with the most significant disabilities can obtain CIE within the general workforce. This one I think -- they're all really important, right, and I could talk too long, but competitive, integrated employment is the intended and expected outcome for all working age New Yorkers with disabilities. And I heard my colleagues use the term "expected." It's an expectation. And that needs to start very early. And that is for our families, for the folks supporting our families, and so that we're not, you know, for example, hitting that what we consider transition age and just starting the employment conversation. So that's a really important one.

And that is related to the next principle: All students with disabilities should receive the education, training, and services necessary to achieve CIE as adults, right?

Okay. So my next slide of principles: Person-centered planning and the valuing of individual voice are priorities and should be incorporated into policy, program design, implementation, and service delivery. This next one is one of my favorites. We refer to it as cultural model, and that is the principle that the workforce should reflect the diverse makeup of the community in which it resides. That is not limited to people with disabilities of course, but is inclusive thereof.

Public awareness of the value of employing people with disabilities should be increased, including engagement with the New York business community. I'm going to talk briefly about that in a minute.

And informed choice, respect for privacy and confidentiality, availability of assistive technology, and the inclusion of evidence-based practices in the pursuit of competitive, integrated employment, are essential. That's a very long sentence but what it's talking about is respecting privacy and confidentiality and really using what is available to us in terms of cutting-edge technologies to help us do this work.

People with disabilities receiving public benefits should be supported in efforts to work towards financial independence, as we already discussed. So at the risk of going on a rant about that, I will go to the next slide.

[Laughter]

So just a couple of key components. The Executive Order is overseen by Chief Disability Officer Kim Ridley, and there is an Employment First Director, that's me, and we are currently in the process of interviewing and hiring a data manager and a business liaison, who will work with the business community. And the short version there for -- and I'll go backwards, the business liaison, is really Employment First for the private sector. I'll talk a little bit about our state of a model employer executive as well, but this is learning from businesses who are doing this well, and we have to make sure that we're not just looking inwards to our public health and supported employment program, thinking that we are the subject matter experts in all things and making sure we're learning from large businesses who are doing this well.

And the data infrastructure is absolutely massive in this conversation in terms of, we talked about very often when we're doing the analysis on employment outcomes, we're using data that is not comprehensive. So whether we're measuring the public health system as a whole or we're doing a laser focus on specific program models, that data infrastructure needs to be improved.

So a primary part of this is our New York State primary agencies will adopt the E1st principles and plan to incorporate them. New York is relatively unique in that we have a very robust and well funded employment services infrastructure, and many of our major state agencies in addition to our partners that access VR have supported employment and rehabilitation and adjacent models, so our office for people with developmental disabilities, Department of Health, Commission for the Blind, office of addiction services and supports, all have an employment component. So that gives us a good starting place.

And my next bullet goes right to that: While those programs are a specific target for us to support and enhance, the Employment First Executive Order is not limited to our employment programs. It's targeted to our system as a whole. So if you look at a large public health system in New York, the office of mental health, one of the largest health systems in the country if not the world, we are serving thousands of people there but it's still a tiny percentage of the folks we are serving and supporting.

So the Employment First team and the chief disability office will be establishing an E1st steering and stakeholder committee, and New York, especially in the last 15 years or so, there's a lot of Employment First work going on. Whether it's called Employment First, whether there's an Executive Order or legislation attached to it, there's a lot of great work going on. So we want to make sure that those initiatives and activities are being leveraged, supported, and enhanced, and not duplicated.

Okay. So I'm getting a little close on time. I'm going to get to a couple of our key take aways and then a couple of related initiatives. Is that good, Amged?

AMGED SOLIMAN: Yep.

ANDY SINK: Cool.

EO40 is the result of the Governor's leadership and ongoing efforts. E1st has exist in New York for a long time. And I think we're at a really key turning point in terms of leveraging all of that momentum. Even in the face of what's going on at the federal level.

Employment First is not a new program or a project. It's how we do business. So I don't think that there's a specific model that's going to take us from poor employment outcomes to great employment outcomes. It's really about weaving these principles throughout the system.

We think that our Executive Order and the concrete parts of it, all available online of course if you wanted to look at the Executive Order and look at the various things that are required of our agencies and what we're looking to do. We think that that's unique. And there's a funded infrastructure for us to be able to do that work. But all of us in the room, I bet we have a job and then we have things that we do within our job or outside of our job to work on related initiatives, and that has been the way for Employment First for a long time. So having an actual staffing infrastructure to be able to do that work is very exciting.

Okay. So I'm going to jump to -- okay. So I'm going to shift to something a little bit different, but if folks have questions about Executive Order 40 or Employment First New York, please reach out. Be happy to discuss.

Another related Executive Order is Executive Order 31, New York State as a model employer. We often refer to that as the acronym SAME. The idea of government being a model employer as old as the idea of public policy administration, right? So New York has joined D.C. and some of our other partner states in becoming a model employer. And the goal is to improve the diversity of our workforce within the state system. New York, like many other states, the Civil Service system is tough. It's pretty rigid. So trying to figure out ways for us to be able to not only improve outcomes within our state employment system, but also to be able to measure those things. We don't, you know, there are a lot of gaps in that data, and there always will be because we're not going to mandate anybody to say that they have a disability. And so being able to improve outcomes, to improve, to achieve what we want under Executive Order 31 will be a mix of training, technical assistance, systems change, culture change, and of course data infrastructure to be able to allow us to measure that.

Okay. So I think the last thing I'm going to try to cover is, so I heard a couple of my colleagues mention the Medicaid buy in for working with people with disabilities. New York has long had a very strong Medicaid buy in for working with people with disabilities program. I'll refer to that as MBI. And there is no premium. So the buy in part is actually free. And currently, an individual can have a gross income of about $75,000 and have $30,000 in resources and retain free Medicaid.

It is massive. That is absolutely massive. It is underutilized. Our system in terms of how folks apply for it and get connected to it is not doing a good enough job, but the folks who know how to get to it and get through it, it is an absolute game changer.

And one of Chief Disability Officer Kim Ridley's earliest victories was getting New York State budget to approve an enhancement to the Medicaid buy in program. And stick with me, these numbers are incredibly significant. An individual, this stuff is pending right now, this is pending CMS approval, it's part of a waiver package, so this is not live, but this is what we hope to hear about very soon, maybe in the next couple of weeks. An individual can earn up to $600,000 and retain free Medicaid.

Now, that will include a sliding scale premium so it will no longer be free. Yeah, wow is absolutely right. Right?

[Laughter]

And an asset limit of around $300,000. Also -- wow, yes. Yes! Absolutely.

And it also eliminates the age 65 cap. And allows people to get married. Imagine that.

[Applause]

Yeah. Yes.

So I just want to reiterate that that is pending CMS approval. We are optimistic, but we're currently waiting.

So whether it's the original Medicaid buy in or the enhanced version, there is a way for folks to work towards their greatest level of financial independence and get over that poverty gap.

We're doing a lot of stuff pertaining to earning while receiving public benefits that I would love to talk about if anybody has questions.

And I think with that -- oh, our partners are going to talk about inclusive internships. And we were talking about Civil Service very briefly. The 55 B and C programs which allows folks who qualify to skip the test to be able to get into our state services system, went from 1200 to 1700 slots in 2025. So that number was stagnant at 1200 for a very long time and Civil Service added 500 as of this year.

Kim, is there anything else you want me to cover before I pass it on?

KIM RIDLEY: No. I think you got it.

ANDY SINK: Great. Thank you.

With that, I'll pass it over to my colleagues. Thank you so much.

[Applause]

AMGED SOLIMAN: Thank you, Andy. All of that was really fascinating. NCD has written about the marriage penalty and the benefits cliff, so it's really interesting to hear about what's going on in New York.

With that, I'll turn it over to Hannah and MaryBeth, who I believe is presenting the next slide deck together, so if we could please load that next slide deck, please, and I'm going to pass along the slide deck clicker that way. Thank you.

HANNAH MILLSON: Thank you, everyone. My name is Hannah Millson. I work for AHRC New York City, a large provider for people with I/DD. I'm a regional director for employment services.

MARYBETH SCHNEIDER: Hello. I'm MaryBeth Schneider. I work with the New York State chief disability office, and the Department of Labor. Hannah and I work, collaborate closely together on an initiative called partnerships for inclusive internships.

HANNAH MILLSON: Yeah, we're very excited to talk to you today about the partnership for inclusive internships, and it's wonderful to speak right after Andy because he sort of teed us up for something that our state is really invested in, in terms of being the state as a model employer. This is an inclusive internship program for internships in the public sector. The PII program began in New York City and has expanded to New York State. So we'll go over some of the highlights of this program, and then a few barriers that have come up along the way which will not be a surprise to you all today.

So here on the first slide we'll just talk a little bit about internships in the public sector. We have a photo of an intern who started with us named Hansel in 2022 sitting at his cubicle at his computer. He now works as a full-time employer for New York City as a benefits intake specialist, so kind of came full circle for him.

But again, the PII program connects qualified candidates, people with disabilities with internship opportunities in government agencies. When we began this program in 2019, it was clear that local government in New York City was one of the largest employers in the area. That's true for New York State as well, and it rings true that we want city and state government to reflect the population that it serves, so it's important to us that there are people within government at all levels of government who do have disabilities and making sure that our government is inclusive.

We know that people with disabilities are underemployed in the public sector. And that public sector jobs are considered, you know, the road to the middle class, they're excellent, well paying jobs, and they do offer a career pathway. So this particular industry is a great place to start in terms of connecting people with internships.

Yes, next slide. Thank you.

As I mentioned, the PII program began at AHRC New York City in 2019 within New York City. We partnered with the TAF foundation and social services to launch this program.

And I'll just mention briefly, AHRC New York City was founded in 1948, '49 by a parent who had a child with a disability, and since then have grown to be part of the Arc network. We're the largest Arc in the country and largest nonprofit supporting people with developmental disabilities in New York State.

Then in the '80s, AHRC developed the business sector and we were a pioneer in the field at that time, which sort of led itself to AHRC being a place that creates these new opportunities and creates these new projects, so we were thrilled to start the partnership for inclusive internships in 2019 and then watch it grow and expand across the state.

MARYBETH SCHNEIDER: Speaking of expanding across the state, I was brought on last April to take this PII model and to roll it out across state agencies where New York City is focused on city government. Some state agencies, I've been working specifically with New York State agencies to identify internship opportunities and create a pool of qualified candidates to fill those opportunities.

As Andy mentioned, EO31, state as a model employer, this is one of the strategies to get to this place of being a model employer, by having more pathways to include people with disabilities.

So as I mentioned, I work with not only interns in the traditional sense as in students, but really the interns that we work with through inclusive internships can be anybody who is at least 18 who is supported through access VR or Commission for the Blind.

Since we have a very diverse pool of candidates, diversely talented pool of candidates, we look for very creative opportunities for them in state government. And our goal, again, is to provide a valuable work experience. When I'm approaching our state agencies about hosting an intern, you know, one of the main things that I tell them is, just bottom line, it has to be meaningful work. People have to have skill building and walk away with, you know, something for their resume or some networking, or ultimately a job which would be awesome.

So that's our primary responsibility.

And also we're looking to create pathways. In addition to 55 B and some other opportunities for people with disabilities in state government, we look at inclusive internships as an opportunity to create that pathway. So I do a lot of structuring of internships around existing positions in organizations, so that a person can demonstrate their skills and abilities in different Civil Service positions. And again, as we mentioned before, we're looking to advance state as a model employer efforts.

HANNAH MILLSON: So I'll just tell you a little bit about the PII program model and how the internship program works. The PII program really connects the dots between service providers, VR services, supervisors from city and state agencies who are looking to host an intern, and the PII program acts as that sort of connector in the middle.

On the screen right now you'll see an image of five circles all sort of connected with the PII program in the middle that sort of outline the different elements. Like VR services, job seekers with disabilities, disability service providers, and employment opportunities in government. And we feel that this program is successful because it's a real win win. Well, win win win win for all of these different stakeholders because it really does move the needle and change a culture within government to allow people with disabilities to have a seat at the table and have those internships.

And then of course for our job seekers with disabilities, internships are very impactful. So the model itself works by the PII program being able to connect all those dots and we'll speak more about that and the impact that it can have.

The elements of the PII program that are sort of nonnegotiable that make our program successful, and MaryBeth mentioned that the internships are paid through VR services, either the New York State Commission for the Blind or Access VR, and/or OPWDD. So that's very important to us, that the internships are paid, and it makes a difference to the city and state agencies that it's at no cost to them, that VR services will pay for that.

The internships do have to have that real world work experience. One of the parts I think that's impactful about the program is that our interns are working across the board at city agencies. We have people at research and public policy, HR, architecture. MaryBeth just told me about an intern with an environmental agency doing bat analysis?

MARYBETH SCHNEIDER: Bat research.

HANNAH MILLSON: So we have interns across the board really sort of, you know, coming up against and facing those stereotypes of what can an intern with a disability do. We're not looking for specific internships and to pin, you know, pinpoint people into one thing. We're really trying to open doors across the board in city government and also help interns think more broadly about what does it mean to work in government. It doesn't mean that you're the Governor of New York State. There's like thousands of jobs that go into making our state run.

We also sort of offer concierge support for supervisors. That means overcommunicating with our supervisors, making sure they feel comfortable in hosting a person with a disability, bringing in extra support that might be needed, making sure that they can ask the questions that they may feel that they can't ask and really making sure that it's a good and solid working relationship to support our interns.

And then finally we offer very well rounded support for our interns, between social work support, executive functioning skill building, self-advocacy, resume building, getting your foot in the door, all of those things to make sure they have the best shot at a successful internship and then connecting to a job.

And then on the screen right now, there's an image of four PII program interns doing an onboarding session with an HR professional at Department of Social Services at 4 World Trade Center downtown in Manhattan with a beautiful view behind them of Jersey City.

[Laughter]

MARYBETH SCHNEIDER: Just to build on Hannah's discussion on concierge support for supervisors, this is a crucial part, to understand the work environment, understand who the supervisor of the intern is, and as everybody knows, the skill match is a little, you know, is something that we can work with but that personality match, the energy match is something that is very different. To be in those environments, I know that Hannah I'm sure as well as I go to each site, we want to be there, although I am not going to the bat research site, I just want to make that clear.

[Laughter]

I told them that. But it's such an important piece of this work, and I think it really helps to bridge that concern over welcoming a person with a disability into the environment. If we can identify what some of those worries are early, and it's most of the concerns are about wanting to make sure that person has a very successful experience, so that's a really important part of this model.

HANNAH MILLSON: We'll just go through three different barriers or lessons learned that we've seen. I think one of the great parts about the PII program and why we feel so lucky that Kim has invested in this program and understood it is because it really leads to tangible ways to think about, you know, issues with employment and disability.

So I'll let MaryBeth talk through the first lesson learned.

MARYBETH SCHNEIDER: So it's one thing to create opportunities for people, and then there's all these practical reasons and we've heard about some today. First of all, not all the interns are interested in working for a 40-hour position. In state government, I will tell you that we don't have a lot of part-time positions. So they're mostly 40-hour positions. So we have to help people work through that and get comfortable with some Medicaid buy in or some other resources that might assuage some of the concerns about working full time.

Benefits. I know we've had this conversation. I will not belabor it any longer. It's an issue. And it's largely because there's not good information out there for people. So we're fortunate in New York State to have a network of what we call disability resource coordinators in different regions in the state to help people kind of understand that, get a realistic picture of what they can earn before their benefits are impacted. And a lot of times it's, you know, their concerns about what the reality is can be addressed with some of these coachings.

And then, you know, there's some particularly I would say in Civil Service, you know, things are pretty prescriptive. I think Andy mentioned earlier the system is a little rigid. To talk about job carving or customization is a really new concept for a lot of state agencies, although I will tell you the first intern that I placed with Civil Service was kind of a job carving experience, and they actually hired him. They recognized having his skill set addressing one piece of the work really allowed some of the clinical staff to better address their parts of the work. So it was a real life example of how these things can be beneficial.

HANNAH MILLSON: Another sort of similar idea there is the barriers to entry that are present in Civil Service but also sort of in other sectors as well. As Andy mentioned, 55 B and C programs and also in New York City 55 A, many Civil Service positions do require an exam. So there are certainly -- there is some flexibility with those different programs but you do have to meet the requirements of the job. And sometimes those can be very challenging. Those many times require high school, associate's, college degrees, elements that we feel interns can successfully do the job and then it turns out, oh, you don't have the certification needed for that job and you've been successfully doing the job in an internship for 6 months. So there are certainly areas of advocacy that we're looking at in the city for trying to just talk about that and kind of lay it on the table, what kinds of requirements do we have for not only Civil Service jobs but in other sectors as well that maybe we're sort of overcertifying people for and what does that mean for not only our population but other job seekers as well.

MARYBETH SCHNEIDER: So we hope that, you know, that demonstrating this collaboration, between government and service providers and Access VR that we can address some of these barriers. It's really one of the main, I think, things that we've been able to demonstrate is that when there's, you know, the PII program is kind of in the middle as Hannah's graphic showed before, that we can address these barriers and create these opportunities, and we can problem solve together to address issues of benefits, of being able to customize jobs. And that's the benefit of the PII program overall. In addition to creating these opportunities, we can actually make them realistic.

HANNAH MILLSON: And just to wrap up, we'll talk about the value of internships. We know that internships are a very effective way to challenge stereotypes about what people with disabilities can do. And this program is creating a pipeline of talented candidates for opportunities within Civil Service. And 38% of the interns -- the PII program in New York City has been around a lot longer. So we have better data. 38% do go on to work for the organization that hosted them. And I will say a statistic I didn't put on here, 98% of supervisors say I want to hire my intern. But because of the red tape of, you know, government and bureaucracy, that can't happen all the time. There's not always an open line for them. But supervisors are typically very pleased with their intern. And then 57% of our interns go on to competitive employment shortly after an internship. Some folks go back to school, some go back to a service provider to continue to build skills, so not all of them are job seeking. As MaryBeth mentioned, not everyone wants to work in a full-time job. So that is something that we do see. But we know that internships really can change a culture and change minds about hiring people with disabilities.

Just some last statistics on the program. In New York City, to date we've had 251 interns placed across 17 different city agencies. I won't list them all, but those include places like the New York City Department of Social Services, MOPD with Christina Curry's unit, we've had folks at Department of Housing and Preservation, Department of Citywide Services, parks department. So again, across the board.

Right now we tend to do cohorts, so we have seven current internships available if you know people in New York City who want an internship.

99 of our interns have been hired by the city whether temp or full-time positions since we started the program.

And hot off the press, we will be -- Westchester, New York is interested in starting a PII program as well as Nassau County, so we're slowly infiltrating all the governments of New York.

I'll let MaryBeth speak to the state.

MARYBETH SCHNEIDER: So I just want to emphasize, I've only been doing this for a year. So my numbers do not look like Hannah's numbers. Next time I'm going first next time.

[Laughter]

So at this point, since April, we've had -- April 2024. Excuse me. We've had seven interns placed. And I am currently recruiting for five openings. We've had one intern hired and two others offered positions that had to decline for some of the reasons we've talked about already. Again, I'm pleased to say that the internship opportunities are very diverse, again, from studying bats to working in HR departments. I have a current intern working with Department of Homeland Security in one of their stockpile warehouses track inventory and sending inventory to places that is needed.

Currently we have positions developed or in conversations with about 14 state agencies from office of children and family services to Department of Homeland Security's dormitory authority, Office of General Services, etc. There's a lot of interest and excitement in the state agencies to be able to welcome an intern through this program.

And currently I'm working in two regions. I'm located in Albany, so kind of made sense to start there. Also just placed an intern in Syracuse, New York, and will be working to place another intern in Syracuse. So, you know, we kind of see this model developing by, as Hannah mentioned, bringing on more service providers in different regions of the state. I'll be continuing to make sure there's access to these internships across the state as well.

HANNAH MILLSON: And I'll just mention on the screen right now is a picture of another intern sitting at -- I guess you get a good sense of government jobs because she's sitting also at a cubicle typing on a computer. This is our first intern in 2019 prepandemic world which feels a long time ago, but she was hired, she works for New York City HRA, Human Resource Administration.

Thank you. Our contact information is here. MaryBeth again runs our state internships, and I'm more local here to New York City. But we welcome any questions.

KIM RIDLEY: Hannah, I just want to acknowledge that one slide that should have been in here is the recent award. Do you want to talk a second on that? Because that was a really big deal.

HANNAH MILLSON: Sure. The PII program recently won a Zero Project Award for innovations. And this year specifically was innovations in employment for people with disabilities. It's a global award issued by the Zero Project, based in Vienna. And they study different initiatives across the country within different types of -- like I said, this year's theme was employment. Some years it's technology. Some years it's emergency services. I think next year is.

So we were very proud to go over to Vienna, be a part of the conference, present on the PII program model. You know, we think it can be really scalable because it's an amazing, you know, every area has local government and every area has those jobs, and so we think it can be a scalable solution for fighting these employment numbers not only nationally but globally as well.

AMGED SOLIMAN: Thank you both, Hannah and MaryBeth, for that. We really appreciate it.

[Applause]

Mr. Chairman, I think we have a few minutes for questions and answers.

SHAWN KENNEMER: We do. I would like to start.

If you don't know, I operate an Arc in Bakersfield, California. We focus on employment as well.

One of the areas that I -- hold on. My screen just turned off -- that we're seeing in issues, and this could be voc rehab as well. When we partner with VR and do job coaching for individuals in the community, especially for people with intellectual developmental disabilities, what we see is they're very successful. We can have them very successful with a job coach.

Voc rehab says you have to start eliminating -- and our Department of Developmental Services says you have to start eliminating those job coaching services. So the individual ends up failing after those coaching hours.

Are you seeing that here as well? And how do we address that?

HANNAH MILLSON: Yes, that's a great question. I would say at AHRC and within our employment services more globally, we have the same issue, the fading of a job coach starts after 90 days and that can be a very challenging situation.

Within the internship program, we do, I would say one thing that we do up front is really that job matching and meeting with the supervisor and creating, you know, a sense of relationship with that team. For example, we recently placed someone -- well, I guess last year placed someone who is Deaf and does require ASL sign language within their unit, but the team said, well, we don't know, we don't understand this, we don't know, we don't even know, like kind of the basics.

So we brought in someone from VR services to speak to that individual really along with the individual who could speak for themselves about how they would like to communicate in order to make sure the work site could be as supportive as possible so that when the fading does happen, the team knows a little bit better, okay, how can we help to support, what kinds of things and strategies work best for this person, and then when the coach isn't there all the time, they know that they can still reach out to us, so that it doesn't go from everything is fine! And then oh, they're fired!

It's like, please feel free to reach out even as we're fading so after 90 days, 100 days, 120 days, you can still reach out to us. The service provider does have to then go in and help to navigate, but...

SHAWN KENNEMER: I often equate it to when I'm speaking to legislators on this issue is simple as somebody who asked to utilize a chair, after 90 days you should be able to walk if I teach you how to walk, right? So we have that issue.

DANA BARONE: Yeah, I agree, part of it is being really good at job development and job placement. That's key. And in really making sure that people have access to the accommodations and the technology they need to be able to be as independent as possible.

In Pennsylvania, we have a joint bulletin with the Office of Developmental Programs that kind of talks both of our organizations through the whole, okay, when is VR funding going to end and when is ID or MA waiver funding going to begin.

And we work together for a couple of things. Matching rates. We had a lot of providers who were playing us against one another because they didn't want to pay -- they didn't want to accept VR rates which were traditionally lower.

The other thing that we did was that Pennsylvania modified the VR program modified our job coaching policy to be more flexible for needs for people who had more complex disabilities for issues when people needed some supports for job retention, when people needed more supports for job advancement.

So we really tried to modify our policy to better meet the needs of our customers while also trying to deliver those services with a limited budget, right?

And you know this. The VR budget compared to the MA waiver budget is apples and oranges.

SHAWN KENNEMER: And I will say, I live in California, which has an amazing system for the intellectual developmental disabled populations. We're still facing these types of issues when it comes to this. Yeah, you're successful until we say that you should be successful without the supports needed. So trying to develop that. Just wondered if you had the same issues. Sounds like that's the case. Thank you.

Any other questions?

THEO BRADDY: Chairman, when you have a chance, could you announce me?

SHAWN KENNEMER: Yes, Theo, go.

THEO BRADDY: Just want to thank all the panelists, but I definitely wanted to acknowledge Dana for coming all the way to New York and being a part of the panel. I am a board member, so I know the great work of OVR. So I wanted to just acknowledge and appreciate the fact that she came and shared everything with NCD. So thank you.

DANA BARONE: Thank you, Theo.

SHAWN KENNEMER: Thank you.

Staff, does staff have questions? Ana?

ANA TORRES-DAVIS: I do have a question. Thank you so much for the great presentations today. We appreciate you coming.

In previous years, NCD has issued reports on employment. One, we did on pre-ETS in I think it was 2017 when it was just starting. And I can tell from your information today that it's grown quite a bit.

One of the things that I find curious, or I've always wondered about, is this challenge between you speak about the expectation of competitive, integrated employment and making that the expectation of parents and even the VR counselors and the professionals that work with students.

How is it -- how do you -- and this is for all of you, if you -- any information you can give on this.

How is it working with employers to help them understand that that's an expectation? That people with disabilities, you know, can come into that workforce and kind of make employers comfortable in this space, maybe employers who have never even contemplated hiring someone with a disability.

DANA BARONE: So in Pennsylvania, we've done a number of videos, success story videos of individuals who have come from sheltered employment and are now employed in competitive, integrated employment. So people with what a lot of people would consider complex disabilities that need a lot of support are working out in the community.

The other thing is, we really look to a peer to peer employers, like nobody can sell it to an employer like another employer. And so, in fact, you know, we have two -- well, three business partners with our InVEST Project. Sheetz, if you're familiar with Wawa, Sheetz is their competitor in the western part of Pennsylvania. They've been nominated or identified as one of the top 100 employers in the country for a variety of categories.

We're also working with Sintos and VF Corporation, which is a distributor for North Face and Vans clothing.

So we're working with big name employers that have a large national footprint who talk to other employers. We're presenting at, we just did a presentation at the Pennsylvania Food Merchants Association. So really getting out and talking to employers in their environment and asking champions within disability employment, the businesses, to talk to one another. That has been what we have found in Pennsylvania to be the most successful.

ANDY SINK: This is Andy from New York. Totally agree, Dana. So without repeating that, I'll just say yes.

And we -- it's one of the reasons why we have a business liaison on the Employment First Director -- or excuse me, on the Employment First team because we don't historically on the public health side or government side do it very well. And I think it's done really well in pockets, and it has to do with employer relationships and it has to do with developing the trust so that when an employer has a question and says, I don't really know how to do this, which is totally understandable, that there's somebody there that they trust and can talk through and can let them know that it's not going to immediately result in a lawsuit, but it might.

And totally agree, we have a couple of big employers that we've been talking to, including Wells Fargo and Microsoft, who both have incredibly successful programs within their businesses that don't rely on the state system to support them. Right? We very often, the things -- some of the things that we struggle with are the ongoing reliance on Medicaid, right, and what that means in terms of how you can support folks. So that's going to be a rant so I'm going to pause that right there.

But the -- and they don't necessarily have that challenge, so they're not trying, it's not the documentation and the golden thread that's going to allow them to not be hit by OMEG or hit by an audit. It's really how do we do this effectively. Because the heart of the conversation with business, which gets at the heart of the question, it's workforce. We're talking workforce purely, of which people with disabilities are a subset that are underutilized. It's a talent pool. And there's a lot of work there to be done in terms of making that case, but it's a workforce case. It's a business case. So yeah.

TONIA FERGUSON: And this is Tonia. I would just say at CSAVR, we always hear from businesses, I don't know what I don't know. And so CSAVR has a national employment team that just walks side by side with employers just to train them and share with them that you meet one person with a disability, you've met one person with a disability. You know, to deal with that stigma around what people in their minds think about a person with a disability. So it's all about that support. And we've noticed that, you know, once we give them the tools, that whole concept of presuming competence, they get it. It's like, oh, yeah. They can do this job. So it's really that training, that support, and letting them know that we're all kind of in this together.

SHAWN KENNEMER: Excellent.

We have some more time for questions. Anybody?

DANA BARONE: This is Dana Barone from Pennsylvania. I would just add to Tonia's, you know, part of the reason we are implementing charting the life course framework and tools within our two grant projects is that it really looks at the individual in a more holistic perspective in terms of what do they bring in terms of their strengths and assets, what do they have in terms of community resources, in terms of technology use, what do they have in terms of family supports.

And it takes just a little bit of the service supports, right, the eligibility types of supports, and they look at, instead of encapsulating the individual with the support, you know, by the supports around them, like how can we intersperse those supports where they're really, really needed. So that the person is living in a more natural way throughout every aspect of their life. And so we're really encouraging our staff to start using those tools to help the person develop their trajectory towards employment.

And so far so good.

SHAWN KENNEMER: Thank you.

I do have one other question, but I just want to -- so California years ago went to employment -- they tried to go to employment only services. That failed miserably.

Employment First is amazing. Employment only doesn't work. So just cautionary from my own personal experiences that we've had with that.

I know you briefly -- and I don't know who did -- briefly recognized and talked about families and how do you get families to recognize. And it's one of the issues that we face quite often as a barrier to employment. We can find jobs for people. Families are like, but they're going to cut my SSI and trying to communicate, they're not. You're going to be doing -- but how do you address that, and what can the fed, what can we do, I think, to bring attention to that, to get more training out there for people.

DANA BARONE: So we are doing family engagement as part of one of our grants. So we have seven family advisers across the commonwealth who are assigned to different 14(c) facilities, so sheltered workshops. They're assigned to different geographic regions. And they've presented to our VR counseling staff. We've encouraged our staff to reach out to them when they have young people who are transitioning from school to work. Or when you have an adult child who is still residing with their parent and there's some incongruence in what they want, we're bringing the family network in there to kind of help them as a family, as a whole unit, to figure out what that trajectory looks like for the individual within the construct of their family.

And so we're really encouraging our staff to look at families as the third customer that we serve, the first one being the individual with the disability, the second one being our business partners, and the third being the family member. Because it's a model demonstration grant, my hope is that we can demonstrate really effective outcomes as a result of implementing this intervention and propose to RSA that this be a service that we can fund moving forward.

ANDY SINK: Just to add a little bit to that, Dana, New York also has that grant, and I won't speak to that specifically, but I think one of the things that we're looking for, for future, is setting the expectation, so talking about when does transition start and transition starts from the jump, right, so not just within special education but within general education, and with the support system that's helping families and parents to navigate the various systems, that that becomes part of the habit from the beginning.

I will generalize and say that very often young people with disabilities are very early put on a different track or not put on a track, right? And so that conversation that may be happening -- and again, I'm generalizing -- for young people without disabilities where they're talking about work. What do you want to do, and setting the expectation that, everybody is going to work. That is the expectation. It's not just like it's a good idea. It is the expectation.

And so starting that very early and changing the habits for everybody around those parents and the caregivers who are taking the cues from the people who are supporting them. Well, I don't know how to do this, what do I expect from my child who has a disability, what does their future look like. And of course raising expectations for the education system that's supporting them and supporting the education system of course, not just raising those expectations but supporting them to be able to do that better and make sure that there is a seamless transition from the youth and young adult system to the adult system.

SHAWN KENNEMER: I think we have time for one last question.

Sascha.

SASCHA BITTNER: Yeah. So I know for me when I was growing up, what was really beneficial for my parents was them meeting other people with disabilities, especially with my type of disabilities.

Do you ever pair older people with disabilities with either parents or even the kids?

ANDY SINK: That is a fantastic question. And I would say that I don't think we do it very well. I don't think we're doing a lot, whether it be older people with disabilities or people with disabilities and I'll just use the term "peer" if that's okay to illustrate success and not just talk about it but show it. Like what does it actually look like.

I think in the mental health system in New York, which I spend a lot of time in, the peer support model is pretty significant. We need to do a better job, pay peers better and ensure they can build the services they're doing. So a lot of structural things need to change there.

But I love the idea of pairing older and maybe successful people with disabilities with parents and the support system to be able to illustrate. Because we can talk about it. We can talk about it all we want. But seeing that in action, and maybe how they figured out those things. Like there is a way to navigate public assistance and earning. It is complicated, but you need to be able to see it's a possibility to do that, and just be successful in the workplace.

SASCHA BITTNER: Yeah, I mean, not only parents, not only my perspective, but also my parents' perspective.

DANA BARONE: Yeah. We -- this is Dana Barone again. We just, we're working on another set of videos that are not specific to work but are about individuals within their families, how they navigated those efforts to become more independent. So we have a video that we just released of a young woman who has Down syndrome and her mother and they talk -- it's just a conversational video of how they navigated some things, how her being included in her regular classroom from the very beginning, all the way through high school, being included in high school sports and how they navigated the task of her learning to drive, right, and what that looks like for a young woman with Down syndrome.

You know, and so she does have her driver's license. And she's working in the community. And she lives by herself for 6 months out of the year in her family's home while her family is snowbirding. Her parents are snowbirding.

So showing, having that, and we're trying to come up with some more videos of people with more complex disabilities who are doing that as well.

SASCHA BITTNER: Thank you so much.

SHAWN KENNEMER: All right. Thank you.

I just want to thank Jed for his work on this, and for the panelists. Thank you for being here. Very informative. I really, I really enjoyed it.

At that, we are going to break for lunch now. We are going to resume back at 2:15.

[Applause]

[Lunch]

SHAWN KENNEMER: All right. We're going to start back up so we can get through our agenda.

Right now I want to thank everybody for coming back.

Right now I'm going to turn the floor over to our Council Member Kim Ridley.

KIM RIDLEY: Thank you, Shawn.

Can you guys hear me? Good?

Well, thank you. Just wanted to be on the other side of the panel for the first time here. Hope I do you all proud.

Good afternoon, everybody. Shawn, thank you again. It is my pleasure to moderate this panel on youth in nursing homes.

Prior NCD reports have highlighted the issue of youth in nursing homes. In our 2022 report HCBS Ecosystem, NCD found living in one's home with necessary services and support systems is safer than living in an institution, costs less, and is the desire of most individuals. As of 2022, there were 820,000 people with disabilities on wait lists. People with disabilities younger than 30 years old make up the fastest growing nursing home population. Waiting lists are numeric representations of the institutional bias because placement in a nursing home or institution is mandatory coverage by Medicaid but HCBS are not.

Our discussion today will help to inform an NCD report to further develop information from NCD's prior reports and hopefully fill the gap in the existing knowledge about younger people with disabilities in nursing homes. The report will address the most recent data and information available in the U.S. and existing policies, and trends that contribute to placement in facilities and those that keep them where they are not in need or no longer in need of skilled care. We look at the impact on their improved lives and opportunities. And as always, we will provide recommendations to improve existing policies that result in the institutionalization of younger people with disabilities.

I'm going to just quickly do some brief bios on our esteemed panelists. Our group here today, to my right, on our panel today is Suzanne de Beaumont, executive Assistant Director Open Doors money follows the person transition center. She is their Executive Director at the New York Association for Independent Living or NYAIL as we call it in New York State. Open Doors is a New York State Department of Health. Money follows the person funded program. Open Doors assists New York State residents living in institutional settings who wish to return in the community. To date Open Doors has transitioned over 8,000 people to a home of their choice.

Suzanne has worked for over 20 years in the field and believes passionately in the philosophy of independent living and the Olmstead decision.

And just a side note, I'm going to editorialize putting my chief disability office hat on. Both the New York Association on Independent Living and the projects that Suzanne oversees are instrumental in the work that we're doing in New York.

Cherice Redd, our next speaker after Suzanne, will be Cherice. Cherice is a proud alumni of strayer university, born and raised in Brooklyn, carrying with her resilience and transformation.

In 2018, her life took a turn after enduring a traumatic experience in a medical setting, she was placed in a nursing home and a variety of care facilities largely due to the lack of accessible affordable housing in New York City.

Currently she is completing her bachelor's in business administration with ambitions to bring her ideas to life, creating solutions to enhance the safety and quality of life for individuals with disabilities. Through every challenge, endurance remains her greatest strength, proving limitations do not define a person's potential.

Cherice, thank you for joining us today.

Nina Loewenstein. Nina Loewenstein worked nearly 20 years at Disability Rights New York and is now a supervising attorney at the Disability Law Center or DLC in Massachusetts. DRNY and DLC are both P&A systems.

>> If you could slow down just a little bit for the interpreters.

KIM RIDLEY: Nina conducted litigation and monitoring of class action settlements for individuals with psychiatric disabilities in adult homes and nursing homes. At DLC she conducts and supervises monitoring investigations and systemic advocacy and its range of PA programs. Nina has also served as a legal analyst for the long-term care coalition, a nonprofit organization dedicated to improving quality of care and quality of life for people in nursing homes and assisted living.

Nina graduated from Wesleyan University and New York University School of Law and holds a master's in public health from Boston University.

Nina, thank you for joining us.

And last but not least is Jeff Clausen. Attorney Jeff Clausen serves as senior deputy general counsel for the Commonwealth of Massachusetts, executive office of Health and Human Services. You have as long of a title as I do. Oh, my God. In this role, he provides legal counsel on Olmstead-related issues to various state agencies and programs, including MassHealth, the state's Medicaid program. The department of developmental services, the Department of Mental Health, MassAbility, and the Department of Aging. He has contributed to the commonwealth Olmstead plan and is currently involved in advancing the community living initiative, which seeks to further grow Massachusetts' ability to serve people with disabilities in the community and as an alternative to receiving services in nursing facility settings.

Jeff, thank you for joining us as well.

I'm going to first turn it over to Suzanne, but again, I'm taking the NCD hat off for a minute, putting CDO hat on. It will make far more sense for Suzanne to get into what she's going to get into with just a little bit of a higher level what New York State is doing on Olmstead.

New York has been working towards Olmstead since 2002, when the state legislature passed a law creating the most integrated setting coordinating council in New York. That council has been in existence and up and running since 2002. Its charge is to develop an Olmstead plan and then yearly update.

In its entirety of the 23 years, we issued one plan. And I say "we" because I've been sitting on this since 2002 in a different capacity than I'm in now. We have issued a report in 2013, not so much a plan. When Governor Hochul created the Office of the Chief Disability Officer in New York, she took the way that the MISC is run, it was supposed to rotate quarterly, and she put it under the charge of the office of the Chief Disability Officer, making the Chief Disability Officer the chairperson, which is me.

So in the 3 and a half years that I have been chairing our MISC, we have been working very closely with -- the MISC is made up of I want to say 12-13 agencies and 9 public stakeholders, 3 in the areas of expertise of disability, 3 in the area of expertise of seniors, and, oh, my God, the other 3. I am missing. This is terrible. There's 9 stakeholders. Public members. That we work very closely with.

And in that capacity, the stakeholders and the state agencies come together quarterly, but we also have established a bunch of committees, there are eight that have just gotten up and running, and New York has most recently hired an Olmstead Director and we are in the process of hiring an Olmstead Director. We have also hired an Olmstead strategic adviser.

So with all the work that this MISC council is doing with our stakeholders that sit on the MISC and some of the stakeholders and advocates across the state, it is our goal by the end of 2025 to have an effectively working Olmstead plan in New York State.

And much of what Suzanne is going to talk to you about, NYAIL, much of the work they do and in particular these programs are the tools that we are very much going to rely on heavily to at least in the areas of moving people out of nursing homes as part of our Olmstead plan. This is where we know our success lays. So with that, Suzanne, I turn it over to you.

SUZANNE DE BEAUMONT: Thank you, Kim, and thank you, Council Members for having me here today.

So as Kim said, I work for the New York Association on Independent Living, NYAIL, we're a membership association for all the independent living centers in New York State.

And we have been transitioning and diverting people from institutions really since the beginning of independent living. So this is natural work for us.

In 2014, we started the Open Doors Transition Center. It is funded through the Department of Health and is funded by the money follows the person demonstration grant at the federal level.

We serve both people in nursing homes and people in ICFs who want to return to the community and locally or in New York State, we work with the Department of Health as well as the Office for People with Developmental Disabilities, which is the I/DD state agency.

So Open Doors is designated as a local contact agency. So if you are in a nursing home, you get asked a question, something called section Q of the minimum data set, you get asked this question: Are you interested in getting information about returning to the community. If you answer yes to that question, that means that we, Open Doors, are supposed to get a referral from the nursing home.

So we accept referrals from the nursing homes. We will accept a referral from anyone. Whether it's the individual themselves, family member. You know, we've had church members call, you know, anyone who has a vested interest can make a referral to us.

We also get referrals directly from OPWDD, and one of the things that we have been doing since I think it was 2018 we started that was we have been educating the nursing homes on their section Q requirements. When we first started in 2015, they did not -- there was a lot of places, a lot of nursing homes that weren't referring to us, so we started educating them. And one of the things that we found once we started educating them about section Q and who they had to refer to was that they also were not as aware as they should be of basic home- and community-based services. So we started educating on that as well.

So, for example, OPWDD is the agency that we serve people with intellectual and developmental disabilities with, and probably 50% or more of the nursing home social workers didn't even know that acronym.

We're staffed by transition specialists. We have about 60 of them across the state. And the transition specialists meet with the individual as well as anyone and their family, anyone they want to have meet with us as well. The first thing that we do is we provide objective information about all the home- and community-based services that are available. Once we've provided that information, we ask them, are you interested in returning to the community. If they say yes, then that's when the hard work begins. Then it's really about what are the barriers, what's got you stuck here, we work very closely with the discharge planners in the nursing homes, we find barriers that, you know, really shouldn't be barriers. For example, coding. There's a number of codes within Medicaid that will get people stopped from enrolling in home- and community-based services, so we know how to resolve them.

And once we've been able to transition someone to the community, we will follow up with them for a full year after they've transitioned, just to make sure things are going as anticipated.

One of the biggest barriers that we found in transitioning is housing. That's not going to shock anybody. Section 8 wait lists can be 5-10 years long. The housing subsidies that are available through the waivers don't have somebody to kind of help you find housing.

We also have housing subsidies that are specifically for people with developmental disabilities. But they go through something called self directed services, which can be challenging. I've kind of listed a bunch of them here. We use something called empire state supported housing initiative, which is a program for people who are unstably housed. And we also have something called rapid transition housing program which is for high Medicaid users who are unstably housed.

But what I want to spend more time talking about is something called the Olmstead housing subsidy. I think this is unique to New York. The Medicaid redesign team understood that these long wait lists for Section 8 and for other subsidized housing were creating a situation where people were stuck in the nursing home but for housing. They could get the services they needed, they were ready to leave the nursing home, but they could not get housing.

So they created this Olmstead housing subsidy that functionally mirrors Section 8 where the individual is expected to pay 30% of their income, and they are limited to FMR, to fair market rent and what they're able to spend on rent. But what's really nice about the Olmstead housing subsidy is that it comes with a housing specialist. So it comes with somebody who their entire job is to find housing for you. They work with landlords. They work with developers. It's kind of their entire job to be looking for housing all the time. So we have found this to be much more successful.

They also have CTS dollars, community transition services dollars, attached to the Olmstead housing subsidy. So if you need help getting a security deposit, essential household furnishings, if you need grab bars or a ramp or something in order to make your housing accessible, they can do that. And at Open Doors we work very closely with the Olmstead housing subsidy because, again, it's specifically targeted to getting people out of nursing homes. So we work very well together.

They also have independent living specialists. So remember I said our transition specialists will work with someone for a year after they have left the nursing home. The ILS continues as long as the housing subsidy continues. So again, that's someone who is working with the person on an individualized service plan to help them continue to live independently in the community. And the Olmstead housing subsidy, because I probably should have said this already, it will continue as long as the person needs it. Once Section 8 or some other subsidy becomes available, then the person is requires to apply for it, but it will continue as long as the person needs it.

I kind of already said this, what CTS is. Oh, I will say this. Believe it or not, one of the things that we find is a big barrier to getting out of a nursing home is IDs. Who knew, right? But if you were somebody who had a car accident, had a stroke, had some catastrophic something happen and no one went to your apartment to get your birth certificate, guess what? It's really hard to get an ID. One of the things that CTS is able to pay for is the fees associated with reestablishing your ID. So, again, who knew that was such a big problem, but it is.

Now this panel is about youth, younger people transition. So I thought I would give you some numbers. So of the 5,080 people that we've transitioned through money follows the person and Open Doors, 588 of them were 40 or younger, so roughly 10%. Small number. 24 were under the age of 20 when we transitioned. We actually last year transitioned a couple of 18-year-olds. We have 120 people aged 21-25. 125 aged 26-20. 124, 31-25. And 195 people aged 36-40.

About 28%, 165 of them had intellectual and developmental disabilities. 40%, 237 people, had physical disabilities. And 32% had a traumatic brain injury.

So what are the things that are kind of specific to younger people getting out of nursing homes? First of all, New York is very -- I feel very fortunate to live in New York. There are a lot of services that are available.

That being said, the service system, how they interconnect is extremely complex. So if you took one person, let's say you had a younger person aged 20 who was in a car accident, right, they can be involved in SED, the state education department, right, because they could still be in school. They could be in the OPWDD system, which is the intellectual and developmental disability system. They could be in the traumatic brain injury waiver system. They could be in the NHTD, nursing home transition diversion waiver system. They could get something called managed long-term care, which is our Medicaid system for people who are duly eligible, Medicaid and Medicare. Or they could be in the regular Medicaid system, the MMC system. So one person, seven different systems. Seven different possibilities. And by the way, some of those, you can be in both, others you can't.

So for us, part of the issue with people, getting people out of nursing homes is understanding the systems. And I always think of, I try and put myself in the place of the individual. And I always wonder, well, how would they know this? How could somebody sitting in a nursing home, aged 20, how are you supposed to understand that?

Family involvement. So, you know, we have family peers, because sometimes we find that the families are concerned about the individual returning to the community. Oh, no, they should stay there because they're safe, right? That's the thing we hear over and over again. You know, and again, we're independent living so we believe everyone should be able to live in the community.

There tends to be a lot more family involvement when there's someone younger and they're in the rehab, but it's a little bit more challenging if the person has been in a nursing home for a long time. And we also find challenges when someone has a disability and they're trying to live on their own. So again, going back to the concept families might think, oh, but they're safe, they should live with us, but the individual, you know, wants their own place.

Housing. We already heard about housing. But the affordable accessible housing, a lot of that is for seniors. And we're not talking about seniors here. We're talking about younger people. And even if we can get them to make a reasonable accommodation and let someone live in one of the senior housing programs, because that's where the accessible housing is, then we get complaints. True story, we'll get complaints, oh, they're playing music at like 8:00 at night!

[Laughter]

And I believe this to be true. Every senior housing has the kind of community room right at the entrance, and there are people who sit in that community room and watch when you come and go. And they'll say, oh, well he went in and out three times yesterday and he had a girl with him!

So there's kind of challenges there as well.

Oh, and this is just an interesting thing to think about. There are also nursing homes for very young people, for children, and when you talk about the challenges with that, sometimes the challenge is the housing for the family, not necessarily, you know, we're supposed to use the saying, oh, well this individual needs housing, we have to find them an apartment. But we're working with a young person, a family right now where the young man is 3 years old and he is ready to leave the nursing home, he uses a vent, and the mom lives in a basement apartment and the nursing home staff have gone and said, he can't be in there, it's moldy, it's damp, and they're saying he cannot move back to that apartment. So we're working to find the family housing so this 3-year-old can go home.

And we're going to turn it over to Cherice, but I would like to say, Cherice, thank you very much for coming, but she used both the Open Doors program and currently uses the -- to leave the nursing home -- and is currently using the Olmstead housing subsidy to help her afford her housing. So thank you, Cherice, for coming.

CHERICE REDD: Hi, everyone. As she stated, I'm Cherice Redd. I'm 35 years old and I was in a nursing home for several years after I had gastric surgery and a medical error occurred it left me wheelchair bound and also affected my hearing and vision.

Being in a nursing home, it was very scary. It was hurtful to my pride. Because no one, I figured no one in their 30s should be in a nursing home.

On most days, I woke up crying. I did not want to be there. I wanted to go home. But unfortunately my home was not accessible to me because I lived on the second floor of a walk up.

I fought for a long time to try to get out of the nursing home, and my issue that I was hitting was everything was either not accessible or it was age restrictions that I had to be a senior citizen in order to get any type of assistance. And I felt like I was the only one in the world that had to be stuck in their 30s facing this obstacle because everywhere I turned, I was being told I was too young, I was too young.

And I said, okay, so how do we open up a nursing home or a facility for someone of my age group or younger. I said, isn't there children who might need, you know, 24 hour care or a little bit less but have to be in a facility? And I was told, they have family. Which also hurt because if you're in your 30s, yes, you want family, but not everyone else's home is accessible either.

So I was stuck with being in a nursing home without options. But then the nursing home, I kept -- I hate to say it -- annoying them. And I said, no, I'm not staying here, I cannot stay here, I would rather go live on the street at this point.

The social worker there said, okay, let me see what I can do. And she found out about the program and said maybe they'll be able to help you, and they did. They made it possible for me to regain life, to feel like a normal person, teen just enjoy my life.

And also I was that person that played music very loud in the nursing home, and I would get complaints from the administration all the time that we can't have the elderly listening to Tupac and Biggie Smalls, this is unacceptable.

[Laughter]

, you cannot do this. And at nighttime, the TV shows I watched, they're saying, we're not sure if it's a shootout outside or it's you. And I'm like, it's me. And they're like, no, no you cannot watch these things.

So now I'm trapped in a nursing home, I can't listen to the music I like, I can't watch the TV shows I like, I said, what am I supposed to do?

They said, we have to figure out how to get you out of here because you have the elderly walking around singing Tupac songs and they said, this is not okay.

I said, okay, so help me! I'm ready! I've been ready to go!

So I'm just truly grateful for the program because now I don't have to get permission to go outside, to go to the hair salon, to go to the nail salon, to go shopping, to do anything. It was very stressful. It makes you feel like, you lose your life the way that you're, you know, known to live because I wasn't born this way. So to me, I lost the way of living, and then to have a facility dictate how I have to live now, I felt like was probably a better option because this is not living. How can I live if I'm in my 30s and I have to be in a nursing home at a certain time, I can't spend the night out, I couldn't do anything. I literally felt like a prisoner to a facility and a prisoner to my body because I couldn't just get up and walk out.

I said, okay, this is not for you, Cherice, you need to figure this out, you need to learn how to maneuver the system, learn how to take care of yourself enough so that they can say, okay, maybe we can help her.

So I had to prove that to the nursing home, and once I did that, that's when they were willing to assist me a little bit better with the program, and the program was just amazing to me because I said, oh, you know, like Section 8 and things like that and all of these programs with the housing, I said, I'll be stuck here another 10 years! I said, I don't want to do that!

But it happened rather quickly and now I've been in the community a year and four months, and I eat what I want, I watch TV. And my neighbors are probably saying the same thing like oh, my God, but when I first moved in, I also alerted my neighbors that was probably in hearing distance that sometimes my TV may be a little loud because I have a hearing impairment, please bear with me. If it is too loud and it's disturbing you, please just ring my bell and say, hey, can you bring it down a little bit, I don't mind.

So now I kind of figured out how to do the large captions on my TV. So I don't have to disturb all of my neighbors. But on a Friday, Saturday, and Sunday, my neighbors blast music so I turn my TV up. I feel like, you know, we're all on the same page on the weekend.

And I've been finding more things, as you stated, I'm back in school. So I'm able to try and finish my education. Right now I'm also trying to see what else I can do, if I can open up a small business where I can work from home, so I'm looking into that because I like to bake. So I'm interested in creating my own spice line for sweet potato pies.

So I'm finding little things here and there to do, simple things like Friday -- was it Friday?

>> Yeah.

CHERICE REDD: Sorry.

Friday we went to the movies, and I went with little children. Her children. And we saw Lilo and Stitch. And it wasn't just about the movie. It was being able to say, I am going out when I want and I'm going to do something that I want to do. And I enjoyed myself, just getting out of the house, because in a nursing home, especially after COVID, you were like more of a prisoner because they -- I understood why, because they didn't want you to go out and be exposed and then come back and then expose your whole floor, which would be dangerous for others that have serious health conditions. So I understood that.

But what about me? What about my enjoyment of life? I don't want to stay in here 24/7. I said, it's horrible. But this is what we had to do.

But now? I get up whatever time I want, I don't have to worry about somebody coming in at 4:00 a.m. sitting on my bed because they're confused. I don't have to worry about the nurse round the clock, the staff around the clock. You know, so freedom is what I was granted. I was granted more than just a voucher and an apartment. I was granted my life back.

Thank you.

[Applause]

KIM RIDLEY: Cherice, thank you. I can't think of a more compelling story and argument for the work we are trying to do here with this panel, and you bringing that to all of us is invaluable. So thank you for being willing to share.

CHERICE REDD: Thank you. It's very important that you guys are doing this. Um, how do you say it. I'm trying not to cry. I'm so appreciative that there are people that are willing and fighting, because when you don't know who to fight to or how to fight, you do need the support to be able to fight, because as much as I wanted to fight and as much as I was voicing it, I didn't know who to go to and how to get the support, so I do appreciate everything.

KIM RIDLEY: Well, thank you.

Okay. With that, Nina, I'm going to turn it over to you.

NINA LOEWENSTEIN: Thank you so much. Cherice, you're a very hard act to follow. But it's really a wonderful kind of transition I think some remarks I'll make of really putting a face to the problem.

As you know, I have been working in protection and advocacy systems for many years, and the Council is probably quite familiar with the different functions of the protection and advocacy systems, the capacity to investigate facilities, to monitor facilities, to legally represent people in facilities in some cases to bring them out to the community, to do systemic cases over this litigation, and also to do systemic advocacy.

A bit of my background in the work relating to the nursing homes, in New York State, I had worked on the litigation called Joseph S versus Hogan, commission at the time, and that concerned moving people from nursing homes who had been discharged from psychiatric hospitals to nursing homes through really the large numbers of this was happening in the early 2000s, late '90s, and it was because of the Medicaid system to move people out of psychiatric hospitals into nursing homes, but there were many people who were moved out who didn't need to be in nursing homes.

And the largest problem was in the New York City area, and there were many discharges out of state as well to homes in New Jersey and Massachusetts that have either advertised neurobehavioral units or some other kind of behavioral unit. And people who are discharged tend to be younger. They often had other diagnoses of developmental disabilities or traumatic brain injury, but our work with them was when they were older usually and the settlement of moving them out.

But what I learned so much from particularly monitoring that litigation was that the difficulty with siloed systems that, you know, mental health housing system didn't necessarily have the capacity to have nursing support for someone who needed it, or if someone was having cognitive decline, how do you handle that. That is less of an issue for youth, and it's important to look at, you know, some of the characteristics which we will in a minute.

The other -- then as we shift to Massachusetts where I'm now working, we did a lot of monitoring during COVID and sort of remote monitoring, video calling and calls, but made getting a presence into a number of nursing homes. And sort of post COVID, at first we went back to a number of places and took on new ones, and we actually looked a lot at the transitions to the community.

So and now I'm supervising and continuing to back up other staff who are doing nursing homework, and I had also completed a report on a particular nursing home that had a neurobehavioral unit. So we'll get to that where we really did a dive into records reviews and had clinical experts.

So that's a bit of what I've done.

You know, I like to couch the work and the advocacy we're able to do, and, you know, which can involve periodic meetings with state agencies over these problems and the concerns we find in the research and studies, and I'm so glad you're going to be taking a look at this anew for your report. This is a good one, this health affairs, nursing home residents younger than age 65 are unique.

And keeping in mind, the work they had to do in this study, CMS doesn't break down these age groups, so it's like over 65 or under 65. So it's extra work to really look at this problem. And I would really encourage New York State, Massachusetts, Connecticut to be able to look at these demographics.

So but what we learned from the health affairs study was that this is a growing group. They're at risk of long stays. They tend to be people of color, Black or Hispanic. Homelessness can be a significant factor. They often have, the federal system, what's called serious mental illness, this is related to screening that goes into nursing homes for the prescribed antipsychotic medication, again, there's really these subgroups too. So TBI can be younger people. And TBI from a variety of reasons acquired, actually it's also acquired brain injury too. But the TBI is this traumatic. And that can be related to substance abuse. There can be hypoxia and so forth. There also can be physical disabilities, paralysis, cerebral palsy, multiple sclerosis. There tends to be a higher rate of use of ventilators.

On the good side, less likely to have dementia or terminal illness. But again, more likely to be in urban for profit facilities that are of lesser quality. And that gets at the investigation that we did that we'll talk about a bit more, but the quality of the care in the nursing home, if someone is stagnating and losing abilities and becoming more dependent, it gets harder to move out. So what's going on in the nursing home is important to the Olmstead goal, in addition to how vitally are the social workers working on this and how well do they know these systems. Inevitably you need an Open Doors coordinator like Suzanne and her staff to really be coordinating this.

So I have also added this resource because the waiver services are so important and the issues around inequities and access to housing without stable housing, you can't have those services and supports. So these are resources for making equity a focus in HCBS programs and implementing them for policymakers. So just wanted to add that resource for you.

One of the facilities we went into in New York after the Joseph S work where I noticed a large number of younger people with physical disabilities is the Coler-Goldwater nursing facility. This article from Center for Disability Rights precedes Open Doors but when we went in 2019 we still saw a large number and I'm sure the housing is an issue, is a huge factor. But so I thought, you know, the voices speaking in that article would be of interest to ya, so I just included that.

So before getting into the Massachusetts specific, just some remarks. Many -- the importance of the youth being a distinct group, and the many groups that they could fall in I think is important to keep in mind, but that they have, where they are in life, I think from what Cherice is saying, like what she likes to do, the company you keep, the goals you have for working, for -- that's going to be, you know, different from an older resident in a nursing home, generally speaking. Never say never. But those goals are part of what putting together a package of what are the connections in the community going to be.

At the same time, many of the Olmstead issues, facing all adults trying to leave nursing homes is important. So understanding these systems is important for all.

Housing that's accessible. Transportation. Bringing together if a person has multiple challenges, how to integrate from agencies, the importance that there can be of having like a backup government support that could be really important. We really saw that in moving people through, for example, the Joseph S work.

The workforce shortages that affect communities. The lack of personal care assistants. The challenges in New York, Massachusetts also. You know, nursing care in the community, the differences in rates that are paid to healthcare workers in the community versus facilities. These are all the challenges facing all ages.

So in Massachusetts, I think you would find fewer people with developmental disabilities in the nursing homes because there's quite a strict screening system, the patient admission resident review, preadmission screening. Thank you, Jeff. Is quite stringent for intellectual and developmental disabilities. And if someone is admitted, they're on 90-day reviews and I get into the background of it, but tends -- so probably those numbers were higher in New York than one might find in Massachusetts, but we don't have the numbers in Massachusetts.

But what we found through the monitoring we did, which isn't the whole system by any means, about you we got a lot of reports from administrators, social service Directors, when we did the remote monitoring, and again, we had observations when we were going into the nursing homes was that there was a growing number of younger residents who were homeless, who have substance abuse disorders, who have psychiatric conditions, and that it was slower to place them in the community. So there were some admitted from shelters with medical issues, and they didn't have anywhere to go when those issues resolved. So we heard this a number of times from different places.

And then kind of corroborating it, when I worked on the report later about a nursing home in Worcester and did some of the research, I found that there was -- it's mentioned on this slide and there's a link. There was an exploratory study in Massachusetts from 2023 where nursing home administrators were surveyed and said the same thing we were finding through our monitoring and that it was a struggle to serve the population, finding staff who were qualified. It's competent staff and I sent Amy that article because I found there was a pay wall.

And we monitored a Worcester nursing home that found over half of its residents had substance abuse disorders and were younger adults. And the Disability Law Center, much of its monitoring is complaint driven. We receive a complaint and think that's enough to take a look at a place, or multiple complaints and we might look at ratings of places and so forth. And the complaint spurring Worcester related to two residents in their 30s, one of whom complained to being left in bed without access to medication. Another was actually receiving an opioid treatment at the time and wasn't getting it consistently.

This was part of -- this nursing home was part of, it's like a one star and it continues to be, a part of the for profit Athena chain that was subject to the state, Massachusetts state Attorney General settlement concerning substance abuse treatment. Primarily for opioid use disorder but not completely confined to that.

Then they had found in a series of nursing homes operated, owned by Athena, violation of the federal regulation to provide necessary treatment to nursing home residents and a deceptive business practice under Massachusetts law.

During the year after we monitored, Massachusetts to its credit issued requirements for high SUD, service use disorder, nursing homes to receive add on rates for behavioral health and SUD, that they were required to coordinate services, have staff training, transport people to treatment.

You know, the one comment I would make on these add on rates which we observed more about when we got into an investigation later is that it tends to reward -- it tends to be based on acuity. So maintaining and preventing acuity isn't rewarded as much as sort of the staff time taken to manage so-called behaviors.

So we would love to see more of a rewarder keeping people stable.

And recovering. Recovery is a real word and it should be happening, even in nursing homes, if it can.

This is just a reference too that the phenomenon is quite widespread, CMS commented on the increase in the use of younger residents who have different needs from traditional nursing home populations. And CMS proposed and I don't know where this is going to go now but the minimum staffing standards were important for requiring, they're not in effect, but if it were to be changed, the nursing home is required -- they're already required to do an assessment of their own needs, but this kind of assessment is going to become more important as they determine their needs for staffing. And so the competency of the staff will depend on, relates to who is in that nursing home. So I just wanted to mention that.

And lastly, give plenty of time to Jeff, just wanted to address the investigation that we did do at Bear Mountain at Worcester. And there's a link to that investigation. The complaint given to getting into the nursing home, related to staffing and neglect. And we focused on the neurobehavioral unit because there was a high use of antipsychotic medication which has since lowered somewhat but there continues to be a high use of hypnotics/sedatives. And we noticed also that there was very little going on on those floors and they're supposed to have a program. Staff aren't engaging with the residents. And, instead, this high use of sedatives. So we had -- we reviewed records and we had a psychiatric nurse and also a neuropsychiatrist who commented on the need for interdisciplinary support, that the unit needs to be licensed for adequate oversight, specialized programs.

This nursing home isn't identified as high SUD, but there were a number of residents who did have that background, and so I had included as an example in that report which you can take a look at this young resident who would have been admitted about at age 40 in 2021 from Connecticut and a large number of people coming from other states to the Massachusetts homes. And she had gone into a cardiac arrest from an overdose and sustained a brain injury from oxygen loss and had a tracheotomy but remained there long after she was ready for discharge. It was difficult to discharge her back to a supervised setting in Connecticut with her medical needs, and it required, would have required a lot of advocacy. You know, the distancing from family that can happen is a real factor.

She is now in a different nursing facility in Massachusetts. Could go more into the needs she had that weren't met, but I think I want to really be able to turn the time over to Jeff and allow for questions, but those unmet needs, PTSD treatment, the lack of substance abuse treatment, the more unstable someone is and like this resident who then ended up going out on emergency hospital admissions, the harder it is, then, to move towards transition to the community.

So can leave it at that, that what goes on in the nursing home is important too, and where staff aren't engaged in residents, where the behavioral healthcare isn't coordinated with all the staff and the needs for rehabilitation for all the direct care staff to have the time and the patience working with residents so they can realize their maximum potential, which is a federal requirement, that that behooves, you know, the link towards leaving.

So thank you for your attention to this problem, and happy to answer questions later. Thanks.

JEFF CLAUSEN: All right. Perfect. Hi, everyone. My name is Jeff Clausen, and first of all, I want to just thank the Council for, you know, having this panel and inviting us here to speak and listening to the information that we want to share with you.

I also want to thank Nina and DLC. Their report was actually very valuable to state of Massachusetts, and we have incorporated a lot of changes as a result of the information that we receive from DLC. It's important for us all to, you know, share information and work together towards, you know, helping our society move forward.

So my discussion here is a little bit, I'm going to be talking more around the state's Olmstead plan. And I did put a report on everyone's chair, so everyone gets a little take away. They can take a look at that.

I will be going kind of at a high level because all the numbers and the facts are sort of in that report and you can take it and read it at your leisure.

But my slide deck here is really around framework for looking at this problem and how we move towards improved community integration for people with disabilities and move away from the institutional bias that exists in our country.

So Olmstead plans, on the first slide here, I'll use this clicker here. Does that work?

Yeah, the green button? All right. Little bit slow over here.

First slide here, Olmstead plans grew out of the Supreme Court's Olmstead decision in 1999, and sort of has like a legal background. What I think sometimes hangs people up is that they think an Olmstead plan is important to try to prevent legal exposure from an ADA claim against a state. But I think Olmstead, as Massachusetts has been viewing it, and thinking today about the prior panel discussions that we had today about employment and earlier on discussions around housing, Olmstead is so much larger than just as sort of a legal defense to a challenge. A state's Olmstead plan is a way for a state to communicate its desires to move forward and to create a more inclusive community as our societies continue to evolve.

I will say Kim mentioned earlier, you know, the institutional bias, and I think about the Medicaid program coming out in 1965 and making nursing facilities a mandatory service, and, you know, it's not 1965 anymore. It's 2025.

Okay. I'm going to get off my high horse for a second. But it bothers me that we have to use the words waivers as waivers being the exception to the rule and nursing facilities are the rule. It would be wonderful if we could move to a place where nursing facilities were not mandatory and waiver services were mandatory, and -- sorry.

[Laughter]

And that states had to show cost neutrality.

Wouldn't that be a different way of looking at things.

Okay. So Massachusetts Olmstead plan. Our first plan was in 2008. We're kind of on this 10-year cycle. So in 2018, we issued a new Olmstead plan. And at that point in time, we tried to open it up more and think about Olmstead more than just a plan that would come from our Health and Human Services secretariat, and we collaborated with our housing secretariat because housing, as many people have spoken today, is a big barrier to transition. It's not so much about health services; it's about what people need to be able to live in the community.

So our 2018 Olmstead plan, you know, starts with housing as being a primary issue of Olmstead.

I want to say we created the 2018 Olmstead plan to be a living document, and we created a commitment to revisit it every couple of years, but then around 2020 all of our focus got drawn into something else and we spent a number of years dealing with the pandemic and all hands on deck in the pandemic.

The pandemic as it has receded and we came back to the Olmstead report and we're still in a 10-year cycle and we envision doing a full on overview in 2028, but halfway through, we realized, it's the 25th anniversary of Olmstead and we used that as an opportunity to look at what the state had been doing and then try to assess how we are doing compared to other states, and then also chart a path forward.

We were also thinking a little bit strategically that a lot of stuff had happened from the -- people spoke earlier around the ARPA 9817, and there's a lot around those funds that we wanted to communicate out and we had a change in Administration so we went from the Baker to the Healy Administration, and we wanted to raise up the importance of all of this work for the Healy Administration. We have to keep on talking about this all the time so people don't forget about it so the Olmstead plan doesn't just sit on the shelf but is actually something people are aware of and value and that they sort of give preference to.

So the next slide. Nope. That's not the next slide. Yes, it is. Okay. I could use better glasses.

So the 2018 Olmstead plan, moving from a narrower view about moving individuals from facilities to the community and really what is it about the whole person, we came one these four pillars that are up on the screen there that I can't read from here. You know, expanding access to affordable accessible housing with supports. I'll just read this into the record because I can see it will go into the record. But Massachusetts recognizes that a robust system of affordable accessible housing is essential to helping individuals with disabilities transition to and remain in the community. Many people with disabilities need affordable housing that is accessible. They may also need services to help them find community based housing to move out of a facility like a shelter or nursing home or avoid having to move into one. We've heard some of these discussions earlier today. That is really an important pillar of Olmstead.

Secondly, you know, enhancing community-based long-term services and supports. Massachusetts recognizes that it is important for persons with disabilities to have access to a broad range of community-based services. Community-based services help people move into and stay in community-based settings. A person should be able to choose the services they need and have ready access to these services like mental health, personal care, substance use treatment, etc., to thrive in their home and communities.

And third pillar, which I think there was a panel earlier today on this, promoting competitive, integrated employment of people with disabilities. Massachusetts recognizes that to be fully integrated in community living, persons with disabilities have to have access to competitive job opportunities that are not segregated, meaning they should have the same opportunities and benefits in the same work setting as people with disabilities.

 without disabilities. Sorry.

And then the fourth pillar which is really important is transportation. Investing in accessible transportation for individuals with disabilities. Massachusetts recognizes that many people with disabilities rely on local and regional transportation systems and need access tie robust and accessible transportation system. Transportation allows individuals with disabilities to live independently within their communities and it connects individuals to employment, education, healthcare, and community life.

And I took the time to just read that just so you know, so we understand this is the framework that we're thinking about when we think about an Olmstead plan.

So in coming out with this report, we went and talked to a number of different agencies and gathered information. We did listening sessions in the community and tried to gather information. I think it's similar to this meeting today, it's really important to listen and understand what the situation is on the ground and not assume that you may have some ideas.

So there's a lot of detail in the report, but I also want to say that the Olmstead plan is not about looking backward. It's also about looking forward. And a key part of the Olmstead plan was setting some goals for ourself. And this is the community living initiative. So through the community living initiative, we've committed to transitioning 2,400 individuals in nursing facilities into the community over an 8-year period. And there's really three main prongs of this that we were thinking about. One is in-reach into nursing facilities to identify individuals who are interested in transitioning to the community and providing them with the supports necessary to facilitate that transition.

A recognition that individuals in nursing facilities -- in Massachusetts there is a robust Medicaid system around behavioral health services, but a recognition, well, a problem that we're trying to resolve is individuals in nursing facilities not having the same access to those services. So the second prong of the community living initiative is really focused on enhanced care coordination in nursing facilities to help connect individuals to the behavioral health supports they need, substance use disorder treatment, to enable them to be ready to move back into the community.

And then the third main prong of the community living initiative is really this acknowledgment that we need to expand residential services capacity, both group homes, 24/7 provider-operated setting for those who need that level of care, and then also housing supports through vouchers to enable people to get accessible housing, affordable housing in the community.

So these three things together are really what the community living initiative is focused on.

Next slide.

What did I do next?

Okay. So I'm just following along on my slide here.

Little deeper dive on in-reach and transition planning. One of the things that we set up was the community transition liaison program. And this is a new program built off of our aging service access points network. There's around 24 community-focused community agencies that are focused on promoting community-based options. And the CTLP program, we set up 45 teams. Each team is staffed with a transition liaison as well as a support person who can provide some clerical support. And they are tasked with going into, they have regional areas to go into and they are tasked with visiting each nursing facility in the region at least once a week and to build relationships with individuals in the nursing facility to talk to them about opportunities for moving into the community.

The idea is to sort of become familiar and known to individuals in the nursing facility. You know, every Wednesday there's a person there doing hair. People know every Thursday there's a CTLP person there who is willing to talk to you about whether you want to move into the community. The idea is to be physically present in the facilities.

And this is overlaid on the money follows the person demonstration that Massachusetts has. And I know New York has one as well. Our money follows the person demonstration includes state agency staff at our disability agency as well as our developmental services agency, who also go into nursing facilities and provide in-reach to talk about our 1915(c) waiver programs which are also another opportunity for transitioning to the community.

And then our third thing here on in-reach and transition planning is really this enhanced resident review process for individuals with behavioral health issues. There's been discussion here today around, you know, younger individuals in nursing facilities with substance use disorder or behavior health issues, and we have a number of enhancements to our PASRR process to identify these individuals and work with them and provide them the supports they need.

This includes, you know, we added a couple things that we did. We realized that while our DMH, our mental health agency, performs PASRR screening for persons with serious mental illness, that didn't mean individuals were eligible for community-based services. It was -- so we corrected that. We updated our regulations so if someone is determined to have a serious mental illness in a nursing facility, they are eligible for DMH services, including individuals who are in Massachusetts nursing facilities under a different state's Medicaid program and identified as having serious mental illness under Massachusetts process, they are eligible for Massachusetts DMH services which includes transition case management.

There's a lot of stuff in the report. I'm going to try to go a little bit quicker here.

>> No, not quicker.

JEFF CLAUSEN: I acknowledge I speak quickly. If you need me to slow down --

>> Yes, please.

JEFF CLAUSEN: You didn't need to wait this long to speak up.

One of the other things that we did, the federal screening and resident review requirements are that you are required to do an evaluation prior to someone entering a nursing facility, and once someone is in a nursing facility, the requirement is to do a PASRR screening if someone has a significant change. But we have been doing, going beyond that a little bit and doing annual reviews for everyone in a nursing facility who either is currently determined to have serious mental illness or who under the PASRR process in the past was determined to have serious mental illness but no longer meets the definition but they're still in the nursing facility, we still evaluate them as a way to ensure that they are being connected to the behavioral health services that they need.

Where am I on this deck.

Okay. Behavioral health community partners. Massachusetts a number of years ago we started a program for connecting MassHealth members, Massachusetts Medicaid, to behavioral health services in the community. There was sort of the acknowledgment that care coordination of behavioral health services requires a little bit more focus and support. But that -- and that program has been quite successful. But it didn't step into nursing facilities. So coming out of the report that DLC had done and others had raised up around behavioral health concerns for individuals in nursing facilities, and Massachusetts sort of seeing that we have broad coverage of behavioral health services just seems that nursing facilities, individuals in nursing facilities are not able to access them as well as individuals who are in the community.

So we leveraged this BH CP program and now we have this BH CP in nursing facilities program where individuals identified with serious mental illness are provided with a care coordinator that does a person-centered care plan for the individual to determine what their behavioral health needs are and help get them connected to the behavioral health services that they need. Or want.

And that also includes connection to DMH clubhouse services, which is -- clubhouse -- well, it's a community-based program where individuals with behavior health issues can go out in the community and learn about employment options and learn about reentering the community and it's a way to not be so isolated. So the benefit to individuals in the nursing facilities, they may be able to avail themselves of going to a DMH clubhouse during the day.

Now I'm moving on to the third prong here which is residential services and housing supports. And under the community living initiative, we, you know, continue growing our group homes and our money follows the person waivers by an addition of 400 slots over the next 8 years. And then we also committed to continuing to increase our DMH group living requirements over that same period of time. And then also to really focus on expanding our waiver capacity in our community living waiver which is the 1915(c) waiver for persons with disabilities but who don't require a group home environment but they can live in their own home with supports.

And then also, you know, working with our housing agency, a commitment to grow housing vouchers specifically targeted towards individuals with disabilities.

So that would be housing vouchers, not for individuals over 65, not for elders, but really for individuals with disabilities, and we also have a program targeting them to individuals seeking to transition from a nursing facility to the community.

And then finally, you know, housing, a lot of times, and Cherice kind of touched upon this earlier, is that someone may have a home to go to you about the home is not accessible. So under both our money follows the person demonstration and our money follows the person community living waiver, we provide home modifications up to $50,000 per modification when it's necessary to enable a person to transition from a facility to the community. And we are averaging around home modifications around 21 or $22,000 a job, so these are not insignificant home modifications that we are doing, these are not just grab bars, but actual structural changes, the widening of doors, the creation of accessible bathrooms, you know, things that are necessary to make someone's existing home in Massachusetts, being a state with lots of old housing, existing home available to individuals who could transition back to their own home if they just had the right accessible options in their home.

And so we -- there's numbers, by the way, in the report. That's a refrain, by the way. You can look at the report and you can see the numbers there that we've done I think around like 200 a year or some number.

All right. So I think my slide deck is going to exhaust people. I'll try to go quickly. I will say that you may see this graph on the screen here. It looks very familiar to one from an earlier panel. I liked that we all kind of work in silos sometimes but then we realize that we invent the same things working in the same spaces.

You can look at this slide later, but it kind of describes the role of the CTLP team as really kind of being the quarterback that worked between the nursing facilities, the families or the individual, the state agencies that may provide services, and really tries to be that center role.

And then the job descriptions of the two roles of the CTLP team, one of the things that we've discovered in listening sessions is some of the barriers to transition are really -- and someone mentioned this too -- it's paperwork, it's having IDs, it's really small stuff but it is super important. And we realize that one of the most important roles is the clerical role of the support person to the transition liaison person. It's just, we need someone who can go make photocopies, who can run and get the ID or work with a criminal offender record issue, if people have a criminal offender background that's making it difficult for them to get housing, they could work to clear that up to enable them to transition back to the community.

This is just a map here of statewide coverage. It's an important thing. So our 45 CTLP teams are based out of our 24 aging service access points so we have statewide coverage.

Moving on, another important aspect, thinking about the framework of how we try to make sure that this vision of changing the culture is able to happen, I just share this slide here, this slide actually is from planning stages so you guys are seeing the inside of state government here. But it was sort of a recognition, if the CTLP program is going to work, EHS, the secretariat, has to really stay committed to this and push it down to the EHS agencies which have to push it down to the astaps who push it down to the CTLPs. And we have to make sure from the bottom, top up, nursing facilities play along. So we issued bulletins, informing nursing facilities of potential sanctions for noncompliance with being open to helping CTLP teams do what they need to do in their buildings.

Deep dive. Here I am. So these are a number of PASRR enhancements, and this kind of provides a time line around the various areas where we're seeing some sticky widgets and what we could do to try to address the problem. So I touched upon a couple of these already around improved PASRR frequencies or the BH CP care coordination program, creating the clubhouse as a specialized service. And that is, you can take in your deck and look at a later time.

And also, here, going back to this idea of a framework. From the left diversion and on to the right discharge, what are the things that really states need to address in an Olmstead plan or as we look at this issue around individuals stuck in institutions. And from the left, consumer knowledge continues to be a problem. It's really complex. We have built a really complex system and it's really difficult for people to understand what their options are.

And then discharging providers, the second one here, hospitals are institutions and they kind of just go to what's easy for them. And how do you break this rote panel from hospital discharge to nursing facility. And we've been working in that space with some of our folks to try to break that pipeline.

And then the third one is, you know, transition support. People need assistance getting out, so what can we do to help individuals who are wanting to transition to the community, help them to transition.

Fourth one, residential capacity. You know, states need more 24/7 group home provider environments for those who need a 24/7 setting.

On top of that, individuals who need access to affordable housing.

And then underlying all of this, so that line there, is the HCBS workforce is, you know, struggling definitely coming out of COVID and continues to need support. A shortage of workforce really ends up making everything a lot more difficult. As well as, you know, just funding again.

So I have an example here, I won't go through this, but this --

AMY NICHOLAS: Jeff, I apologize. We're 10 minutes over.

JEFF CLAUSEN: I was realizing. I was going to say you can --

SHAWN KENNEMER: We're fine. We started 15 late.

AMY NICHOLAS: Oh. I apologize.

JEFF CLAUSEN: Watch out now.

Okay. This last thing here, going back to you guys can look at this on your own time. There's four videos here. These videos are of actual individuals in nursing facilities who have transitioned to the community, and we use these as educational tools for individuals or families who are concerned about transitioning to the community. So these are individuals who have transitioned in their own voice talking, similar to Cherice's story around how they ended up in a nursing facility, what they struggled with, and their fears of transitioning back to the community, and then really all of them are how now that they're back in the community, they have their lives back.

So those four stories are very powerful. And we download them on to devices and bring them into facilities so we can show people right away and they can see their fellow peers in the community.

So I'm going to stop there and I thank you for your time.

[Applause]

KIM RIDLEY: Thank you, Jeff.

SHAWN KENNEMER: Thank you. Is there questions, Council Members? Any questions with this panel?

RISA RIFKIND: This is Risa. I just have one. Thank you for all the information, all of you, and Cherice, thank you for being here.

You know, I listened to your story and comments and really appreciate you giving context to why all of the work that we do really matters.

But Cherice, you were saying how the social worker wasn't even aware of the services that are available. And so I don't know if it's a question or a comment, but I just wanted to emphasize that, you know, the connection to resources for those who need the knowledge to have the power. So I hope that continues to be a talking point. Because that seems like such a frustration but also a fixable thing. So thank you.

SHAWN KENNEMER: Thank you.

Any other questions?

I'll open it up to staff. Do you have any questions?

All right. So I want to thank Kim and the panel for your time. Thank you. It's very informative. And we're going to move over to now the public comment section. Risa.

I'm sorry. I got ahead of myself. No, we're going to do reports. Sorry. Council Member reportouts.

So this is, during this section is where Council Members provide a brief summary of the information they've received from the community and communications they've had with members of the disability community during the time between the current and last council meeting. Each Council Member will have approximately 3 minutes to share their updates.

Risa, do you want to start?

RISA RIFKIND: Only fair since I was caught off guard once when I shouldn't be.

No, thank you, Acting Chair.

So this is Risa. You know, I think this has been a time of continued concern for a lot of people with disabilities in our communities. And at my last update in March, I think I'm just going to repeat very similar theme of, you know, I've heard a lot of concern and panic from friends, from colleagues, from the community about what all these changes mean for them, for us in terms of employment opportunities, in terms of services and housing, and then very importantly in terms of Medicaid and Medicare. And that really seems to be a lot of the focus of a lot of the community work, so I just want to elevate that and also thank those who have been doing the work on our behalf in the community to ensure that we are continuing forward and not losing things that we have fought so hard to have.

I'll keep it short. Thank you.

SHAWN KENNEMER: Thank you.

Hoskie.

HOSKIE BENALLY: Thank you. I've had a couple of things going on as far as on tribal lands with American Indians disabilities, the Navajo Nation has now had provided 50 years of rehabilitation services that started back in 1975. So one of the things that we're planning right now, I'm on the Navajo Nation advisory council on disabilities. I'm their President. And we also working with the office of special ed rehabilitation services for the Navajo Nation, but we're in December we're planning a 50th year anniversary conference in regards to VR services and how far the Navajo Nation has come in providing VR services and some of the achievements that have been made.

The Navajo Nation had the first American Indian VR program, and was fortunate to be one of the original staff VR counselor at that time and then became Deputy Director.

So that's what we're planning right now. Looks like it might be down in Flagstaff. There's a casino there called Twin Arrows owned by Navajo Nation and we're hoping to get some national speakers there in regards to this celebration.

The other thing is we're planning a, meaning the Inter-Tribal Disability Advocacy Council, an American Indian symposium in November. And the idea here is to bring as many American Indian disability organizations together under, at one conference, because at this point we seem to be pretty fragmented. Sometimes we're in competition for the same funding. So there are reports that have been put out there from various organizations, and basically interviewing disability organizations, disability Navajo Nation government and others, and identifying what the issues are. But we do not have that opportunity until now to get everybody together and have one discussion about what the priorities should be for Native American disability issues and needs. The three pillars that looks like are going to be looked at are education, health, and welfare are the three things that we're looking at at this point in time. So that's going to be happening in November, and we're planning that for Albuquerque. And it's going to be virtual, because we're lacking the funding so we're hoping to do it in person but looks like it's not going to happen.

So those are the two things.

As far as VR, I just want to say that Indian tribes, we're in competition with each other every 5 years. We're not like state VR programs. Constantly, there's a year to year budget that's given by the government to the states, but in our case, we're always in competition, all the tribes are out there. So some might go 5 years and then lose their VR funding. As far as the Navajo Nation, we've been fortunate not to lose our funding.

So that's an issue out there that we constantly are talking about is why when we have a treaty with the federal government, that we're being treated differently. So that's my report. Thank you.

SHAWN KENNEMER: Thank you, Hoskie.

Sascha.

SASCHA BITTNER: I have spent a great deal of time the last few months advocating in defense of Medicaid. For example, on March 18th I participated in a press conference to save Medicaid funding at a hospital at the University of California San Francisco with Speaker Pelosi, Senator Shift, other Bay Area representatives, and very concerned medical providers.

Later that day I did a roundtable with Congressman Mark DeSaulnier. Because of the cuts to Medicaid, our Governor has proposed cuts to home support services, the most drastic involving overtime hours and less hours per caregiver. There's already a caregiver shortage, so this would further exacerbate the situation.

Also California had Medicaid for undocumented people and now Governor Newsom wants to eliminate that.

People with disabilities, like me, are very worried about our future and whether we will be able to live in the community with the supports we need. So advocate. Thank you.

SHAWN KENNEMER: Thank you, Sascha.

Kim.

KIM RIDLEY: Thank you. I think I might be a broken record. I do want to reiterate a bit of what you said about a lot of what we're hearing in New York is being very fearful of what's going to happen coming down from the feds and trying to have plans in place for whatever rumors do deem to be true.

So my office, again, putting CDO hat on and what I'm hearing from New York, I think that that's where our biggest fears lie.

Aside from that, much of the work that you heard about today that our office is involved in, both through the employment and wanting to make sure that barriers are knocked down wherever possible and that employment is always perceived to be the first option, that is something that we hear a lot about.

We are, as I mentioned a little while ago, full steam ahead to have an Olmstead plan, a real, effectively working Olmstead plan, not meant to sit on a shelf, similar to what Jeff said.

It will be something that will be updated annually, and all the things that are going into making that Olmstead plan are raised to my office on a regular basis.

If it's not home care or workforce, it's housing, it's transportation, it's employment, it's education. And even in New York we're lucky enough where we have agencies such as parks who are now wanting to be involved in the work that we're doing to make sure that the things that people do for fun are also inclusive to people with disabilities.

I also want to give a nod to ADA access, given that we're coming up upon the 35th anniversary. Something that our office also regularly hears about, but I just want to put forward that seeing as we are going to be celebrating the 35th anniversary in a few short weeks, hopefully the weather will cooperate with a July type of celebration. I do think it's important that we all take a moment to look at how far we've come and celebrate that, but also give a lot of credence to the work that we're doing here. And hopefully create a path forward so that 10 years from now we've accomplished a lot of the goals that we're talking about.

SHAWN KENNEMER: Thank you.

Theo, are you on the line?

THEO BRADDY: Yes, sir. Can you hear me?

SHAWN KENNEMER: Yes, we can hear you. Would you like to give your report?

THEO BRADDY: Yeah, yeah.

Definitely ditto to a bunch of what already has been said. But, you know, I wanted to acknowledge the fact that sometimes I feel this major contradiction among NCD representing the federal government to improve the lives of people with disabilities but at the same time the federal government is trying to dismantle and really oppress us in major ways. And like many people already stated, my constituents, you know, members, centers of independent living, state councils of individuals with disabilities from all backgrounds, they are feeling the sense of fear, a great sense of fear for the unknown based on what they are hearing that is coming down. The dismantling of ACL completely affecting people with disabilities and older adults. The Executive Order on DEAI affecting us in a major way. The 17 states that are attempting to cause Section 504 to be unconstitutional, they moved away from that and now they are trying to roll back the final rules that deals with, you know, medical equipment being accessible and ensuring bias is not used to deny healthcare. And also, just the fact that entities that in new construction that want to make buildings accessible, they're rolling all of that stuff back.

And there's a lot of fear. And I'm scared myself. I don't know what my future is going to look like and what the next generation future is going to look like. So I'm spooked about all of this. And hopefully I encourage everybody to continue to fight. Thank you.

SHAWN KENNEMER: Thank you, Theo.

For my report, I will say I've spent the last couple months dealing at the state level, if you're not aware, California is facing a state budget crisis, before the feds even came in. And dealing with and trying to advocate and speaking with legislators about the need for services in the I/DD community in California right now.

There seems to be an issue with educating of the education of legislators of what we need. So trying to educate them on, we don't need a high speed rail to nowhere. We don't need -- we keep getting push back with bucket concerns. Well, we only have so much money. Well, we can find billions of dollars in waste right now in California and nobody wants to listen.

I was raised with, you take care of the most vulnerable populations first. That's regardless of what's happening at the federal level. That's just in California what we're dealing with.

And so that, but we do have a strong community that has been pushing forward, so we continue to work on just the city and local, my city of Bakersfield, we have gotten massive buy ins, and now we're working on the county for accessibility at just our public transportation. So the city of Bakersfield, I am proud to say, out of 1,000 bus stops, they're down to 2 that are deemed not accessible.

So those are kind of the policy issues and the areas that I'm working, but on another note, I will talk briefly about my reportout what's been happening at NCD for a little bit.

Following Executive Orders, I believe the staff at NCD have done an amazing job, and I just want to thank them for all of their work and not flipping out, not deciding that there are going to be hills that we will die on together. Some of them aren't hills that we need to die on.

I will report that we have just recently been engaged with DOGE person that has reached out, and everything seemed actually very positive on that level for us. So as of right now. And, you know, we'll work where we can, and hopefully they'll have some ideas where we can make some improvements is what we're looking at. So look at it as a positive and then we'll fight when it's not.

But that being said, over the -- so I've been the Acting Chair since January? Yeah. Fun.

So kind of thrown in to being the Acting Chair. And then at the same time, our Executive Director at the time had some medical issues and needed to step down. But I am very pleased that Ana has accepted and become the Executive Director, and I just in talking with her and where we think the future can go with NCD, I think it's bright. And I think we are demonstrating our place, that we're needed here.

So once again, I just wanted to publicly thank Ana for stepping up and doing a great job.

And all the staff at NCD. You guys are doing an amazing job. Us as Council Members are up here. We get the spotlight. People don't call me Chairman, I'm Shawn. We don't do the day-to-day work. You guys do the day-to-day work. And I just wanted to thank the staff at NCD for all that they're doing, and that we're going to move forward and do great things.

So that will be my report.

With that, I will open it up to Risa for public comment section.

RISA RIFKIND: Thank you.

Today we are soliciting your comments on the topic of youth and younger adults in nursing homes, which will help provide information on an open project that has recently gotten underway. Your comments will be incredibly helpful as we shape this project.

We are also asking for comments to help develop our annual progress report. The progress report tracks significant events that have occurred during the year, including new policies, regulations, laws and other things that impact people with disabilities in a variety of areas. We have one preregistered. So if you were preregistered, you will be called on first. We will bump it from 3 minutes to 4 minutes, adhering to a strict 4-minute time limit for all comments. Once called on, please state your name, please also spell your name for the record, your organization affiliation if you are representing an organization, and proceed to provide your comment.

If we run out of time, we strongly encourage anyone who does not get a chance to give comment on either of these two topics today but wanted to, to please email your comment to NCD at the following email address: Publiccomment@NCD.gov. Again, that's publiccomment@NCD.gov.

With that, we will begin our public comment period. Once called on, we will find you in the room and provide a microphone. I just want to verify we have that microphone ready to go?

And we will call our one preregistered public comment, Rebecca Underwood. Rebecca, are you in the room?

No. Okay. Then we'll go on --

>> I'm on the phone.

RISA RIFKIND: Oh. Okay. This is Risa. We thought we were doing in-person only comment or email comment.

SHAWN KENNEMER: In-person only comment.

RISA RIFKIND: In-person only comment today. So I would encourage to you email that publiccomment@NCD.gov.

We have a number of people joining us in person, so we will be prioritizing the in-person comments.

Thank you, Rebecca, for joining.

We will move on to the other person who indicated on the sign in sheet, Dr. Nicholas Lawson, in the back, you will have 4 minutes.

>> Yeah, hi, I'm an MDJD person with a mental health disability former commissioner at the ABA Commission on Disability Rights. I have never been able to get a full-time job since I graduated from Georgetown law in 2021. Nothing compensated.

So I got to send a bunch of stuff through email. Born and raised in New York City.

So you know, mental health disabilities really aren't being included under the umbrella of disability rights. It's a problem. Now, you know, so it's only 12 or 13% right now nursing home residents are people with serious mental illness, but it's increasing. And it's a real problem. So, you know, other disabilities are included under the umbrella of ACL. SAMHSA is not doing it for people with mental health disabilities.

The office of mental health of New York State is really not doing it for people with mental health disabilities. I don't know who was there when commissioner Anne Sullivan talked about how involuntary commitment has been tremendously effective at decreasing, the basis for any of that.

So mental health rehabilitation service. We're not included in the Medicaid access rule. It's a real problem. So you have all this policy that is not applying to people with mental health disabilities, and it's going to get exploited.

So there's this CMS SAMHSA center for excellence behavioral health in nursing facilities. You can't find the word "Olmstead" on this website whatsoever. I think the quote is that it's to expand, you know, it's clearly to expand the use of nursing homes for people with mental health disabilities.

So I actually, I don't support SAMHSA as an independent entity or OMH as an independent entity. I would support it as a division of ACL.

Just a couple things, you know, I got to point out. So just other effects, the follow up from all of this is that a lot of the action takes place at the level of professional standards. The accreditation, licensing, norms, and none of that is being -- when you're not tackling that and you're not taking a muscular approach to dealing with that in the way that we have with, for example, HCBS quality measurements is great but does it include people with mental health disabilities.

It's a problem.

I want to just call your attention to this thing on, you know, on PASRR that Jennifer Mathis wrote to CMS, you can Google it, it has some great stuff that's going to be relevant for any of your future policy work in this area. So in terms of the protection and advocacy systems, you know, really super important. I'm glad I just found out that we have, that they have appropriations for 2025. So that's really good news.

There's criticism that they are reactive and are not taking, this is from people at the advisory committees that they're not taking a muscular approach. They've been criticized for engaging in lobbying activities.

RISA RIFKIND: 30 seconds.

>> But it still reflects a real need for the inclusion of people with mental health disabilities and those problems in these discussions.

So I'll do, I'll talk much more through email, but great job, and fingers crossed for appropriations.

RISA RIFKIND: Thank you, Dr. Lawson.

Is there anyone -- (alarm going off) that was the timer. We're good. Thank you, timer.

Is there anyone else in the room who would like to provide public comment today?

I see a couple of hands. Keith, would you be able to pick a person first?

Thank you.

And remember, state your name, spell your name, your organization affiliation, and proceed.

>> Yes, thank you. My name is Tyler Whitney. And I'm with an independent living center, southern Adirondack independent living.

I'm Tyler Whitney, proud to serve as the Executive Director of the southern Adirondack independent living in Queens New York, and a proud member of NYAIL and NCIL. We cover 17 counties, across all of our programs, including many communities inside the Adirondack park, a region known for its beauty but also marked by rural isolation and critical service shortages.

Thank you for the opportunity to speak today. And for focusing on an issue that demands urgent national attention. Youth with disabilities living in nursing homes. Let me be clear. As you know, a nursing home is not a home for a young person. It is not a place to grow. It is not a place to learn. And it is not a place to build a future.

And yet, in the absence of community-based options, far too many transition age youth, some only 18-19 years old, are being placed in institutions. Not because they need to be there, but because there's simply nowhere else for them to go.

This is especially true in rural, underserved areas like ours. In the Adirondacks and surrounding counties, we face severe shortages of direct care workers, accessible and affordable housing, Medicaid-funded supports that make community living possible. We don't even have enough beds for the older adults that nursing homes were designed for, and yet we're putting our young people there.

That's not just wrong; that is systemic failure.

And let's be honest, this disproportionally affects youth of color, rural youth, and those with complex disabilities who all too often fall between the cracks.

I would like to speak directly to the federal role and what it means even in a state like New York where HCBS programs already exist. Yes, New York does offer home- and community-based services through Medicaid waivers, but again, let me be clear, waivers are optional. HCBS is not guaranteed.

HCBS is the option. However, nursing homes are the mandate. Which speaks directly to the prevalent institutional bias that we continue to face.

In the north country, being eligible for services does not mean that you can actually access them. Not when there's no one to provide the services. There's no housing that's accessible. No workforce that's available. And no system in place that puts youth transitions' needs front and center aside from MFP program that you heard from earlier.

Right now you can qualify for HCBS in New York yet still end up in a nursing home. That is the cruel truth of an unequal system.

At SAIL, we work every day to support people with disabilities to live, work, and thrive in the community, but we cannot do it alone. We need continued access to and development of infrastructure for programs to avoid and/or transition from nursing homes just like the MFP program that you heard about earlier. We need more support for personal care attendants. We need more accessible housing. We need more youth-centered transition services. We need more flexibility in how Medicaid waivers are structured and delivered. Because every time a young person is placed --

RISA RIFKIND: 30 seconds.

>> -- it is not because they belong there. It's because the system has failed to build supports that people need.

This failure is fixable with the right leadership, with the right policies, and the right commitment. I would like to thank you for hearing me, and thank you for continuing to elevate the voices of people with disabilities across all generations. Thank you.

RISA RIFKIND: Thank you, Tyler.

I saw another hand in the front. Oh. There we go. Thank you. On your left, Keith. Thank you.

State your name and spell your name and any affiliation. Thank you.

>> My name is Sharon Shapiro, and I'm representing the Brooklyn Center for Independence and Disabled.

I want to begin with myself.

I have to be honest, as a person with a disability, the current climate is scaring me. Whenever people talk about an issue, whether it's from Congress or from the President's press secretary, they always mention the aging population. And that's important, but people with disabilities are rarely talked about on the public stage. And are rarely mentioned by politicians.

So I ask the NCD to please talk with representatives and the President's staff about this, because in order for any policy to be moved, we need to be acknowledged publicly and frequently.

I will submit more detailed comments, but long-term care and transportation are our biggest concerns, especially person-centered long-term care to hire our own PCAs.

And in New York State, the options are being limited, causing chaos throughout the state.

So I just want to raise that as the biggest issue, at least here.

I want to thank NCD for coming here and allowing us to hear these pretty good presentations. And if you can, when you go back, please tell our representatives to mention us a bit more often so we're on top of their consciousness.

Thank you.

RISA RIFKIND: Thank you, Sharon.

Is there anyone else in the room? State your name, spell your name, and state any affiliation, please.

>> Thank you. My name is Marc Safman -- Marc with a c -- Safman.

I'm a deafblind Black American, and I represent, well, I have a company Safman Consulting and lead advocacy for DeafBlind Leadership NOW, a group of deafblind Americans who are seeking leadership. We would like to take over have Helen Keller National Center be finally controlled by deafblind Americans.

But I just wanted to comment here on the number one issue facing all disabled communities is really website document accessibility by the private sector here in America. It's holding back innovation and business growth for everyone. It's suppressing economic opportunities and employment opportunities for communities, whoever they are. And it's time for leadership in America to embrace the DoJ's 2022 report and let us move forward. The rest of the world is moving forward. The European accessibility law, the Canadians have the Accessibility Discrimination Act, and it's time for America to join the 21st century on website accessibility. It's innovation. It's not inclusion. It's innovation.

Secondly, the thing with DOGE wanting to reinvent government. It's time that we look at embracing effective policies in employment.

And oh, I'm sorry. Oh, okay. I had to put down my CART.

With employment issues, a common sense approach is needed. The government, for example, the EEOC in 2023 issued a hearing and vision guidance. They did not issue deafblind guidance. But in the vision guidance, an example, they said that we expect the interactive process to begin within 24 hours. That's absolutely wonderful. However, what the ADA and EEOC have never done, the DoJ has never done, they've never outlined steps effectively explaining to businesses, entrepreneurs what an interactive process looks like, what you're dealing with when you have assistive technology, which is fantastic, it changes. You have people like myself, I had brain surgery in 1986 and began my career largely with pen and paper. As my hearing and vision changed, I had the internet. I lost so much because of my disabilities and I've experienced racism. What we need is to effectively explain to businesses how to do an interactive process when it involves assistive technology. I talk frequently with HR people who have no idea what I'm talking about. And then when I tell them what I need, they turn around and mangle it and talk to the tech team, and I as the individual can't make -- I can't say let me just talk to your tech team because the tech person will say, oh, you need a button. I'll be down in the morning to install what you need.

RISA RIFKIND: 30 seconds.

>> I think that the fact that the government has failed to explain to business these are the steps that we expect you to take, this is how you conduct interactive process, that is a very big barrier that can be removed very simply. And, you know, cheap to issue that type of guidance.

Secondly, you have things like instead of giving lawyers money, it's time to really do away with EEOC.

RISA RIFKIND: That's time.

>> And do away with New York State division on human rights.

Oh, okay.

RISA RIFKIND: Thank you. I'm sorry.

>> Move those things into the Department of Justice and the Attorney Generals because it's just duplicative and giving corporate attorneys money and it's not empowering individuals.

RISA RIFKIND: Thank you for your comment.

Is there anyone else who would like to share in the room?

I'm not seeing anyone else at this moment. So I will turn it back over to you, Acting Chair.

SHAWN KENNEMER: Thank you, Risa.

With that, that brings -- make sure I got this correctly...

Okay. That brings today's meeting to an end. I do need a motion to recess until Friday May 30th at 9:30 a.m.

SASCHA BITTNER: I move.

SHAWN KENNEMER: Sascha was quick before I could finish.

[Laughter]

Let's get out of here. Is there a second?

HOSKIE BENALLY: Second.

SHAWN KENNEMER: Hearing that, we are recessed until tomorrow morning at 9:30 a.m. Thank you all for attending.