BEFORE THE NEW YORK STATE
SENATE STANDING COMMITTEE ON DISABILITIES

NEW YORK STATE FORUM

A ROUNDTABLE DISCUSSION

TO EVALUATE THE STATE'S RESPONSE TO COVID-19
AT RESIDENTIAL FACILITIES FOR DEVELOPMENTALLY AND
INTELLECTUALLY DISABLED INDIVIDUALS

Virtual Roundtable via Zoom

June 3, 2021
Time: 1:00 p.m.

PRESIDING:

Senator John W. Mannion
Chairman
Senate Standing Committee on Disabilities

PRESENT:

Senator Michael Martucci (RM)

Senator Simcha Felder

Senator Roxanne J.Persaud

--oOo--

SENATOR MANNION: Good afternoon.

I'm John Mannion, Senator, and Chair of the Senate Standing Committee on Disabilities.

It is 1:00 p.m. on Thursday, June 3rd, and I'm convening the New York State Senate Roundtable to Evaluate the State's Response to COVID-19 at Residential Facilities for Developmentally and Intellectually Disabled Individuals.

I'm joined by my ranking member, Senator Michael Martucci.

And we also have been joined by representatives of Senate staff, including Senator Brooks, Senator Reichlin-Melnick, Senator Kaminsky, Senator Gallivan, Senator Mattera, and Senator Breslin.

I'd like to thank all my colleagues on the committee for moving so many important bills this legislative session.

We'll be speaking about some of those bills today because they relate directly to OPWDD's pandemic response.

When I was named Disabilities Committee Chair, I said I wanted to be a champion for this community.

This roundtable is the most significant

action the committee has taken in its short history, and it continues the Legislature's renewed focus and commitment to the IDD community, our -- and their families.

The committee takes its oversight responsibility extremely seriously.

I view our mandate today as getting answers for families and individuals.

Our support for IDD New Yorkers takes many forms.

I should include that we are joined by committee member Senator Simcha Felder.

During the budget negotiations, the Legislature completely rejected the Governor's cuts to OPWDD services.

We secured a cost-of-living adjustment for the IDD workforce, the first one in over 10 years. And I was proud to sponsor a vaccine clinic in Onondaga County where we administered single-dose Johnson & Johnson shots to over 200 IDD New Yorkers and their caregivers.

We also recently announced funding for Special Olympics unified sports programs, and were able to deliver good news to a north Syracuse family, that one of the members will be going to

Disney World for the 2022 Special Olympics U.S. games in Orlando, Florida.

The work that we do is real, and the results are real. Our commitment is unwavering.

Today we are joined by family advocates, self-advocates, providers, and other stakeholders, including DSP representatives. They come from every corner of New York, and I believe they have the greatest insight and perspective, including their personal experience with OPWDD's COVID-19 policies and actions.

Thank you to all of our panelists for your continued advocacy, and for taking time out of your day to explain your experiences to the Senate and to your fellow New Yorkers.

Every effort was made to ensure our panelists are representative of OPWDD's service community.

Due to the format and time considerations, we cannot accommodate all parties that wish to speak in person today.

We have received written statements from the Public Employees Federation, Michael Carey, Jim Moran, Nick Cappoletti, Russell Snaith, and Susan Hamovitch, that have disseminated to every member of the New York State Senate.

All materials related to this roundtable will be posted on the Senate website.

We are also grateful to OPWDD for agreeing on the importance of having this conversation. That agreement is evidenced by the participation of OPWDD Commissioner, Dr. Theodore Kastner.

Dr. Kastner is familiar to many of us.

His appearance before the committee today lends additional credibility to our work, and I look forward to hearing his insights in just a moment or two.

The Commissioner will be our first speaker, and will appear solo to allow for an extended conversation with senators.

The Commissioner will be leaving after our initial question-and-answer section, and then we will begin our panel portion of the program.

I will first say what I hope this exercise today is not; that it is not a forum to score political points, nor would it be a forum for unruly or disrespectful behavior, and it's not a forum to spread misinformation of any kind.

We are going to -- what we are going to do is begin to set the record straight, and make sure that the waters are clear.

As the moderator, I expect all participants to be professional, adhere to time limits, and help uphold the decorum of this proceeding.

I believe today is an important step towards a fully transparent and public accounting of OPWDD's COVID-19 response.

In addition to the facts that will be entered into the public record today, the Senate and Assembly have passed Senate Bill 6294, which is my legislation, mandating that OPWDD to produce a public report, evaluating its COVID response.

I want to memorialize the agency's challenges and its successes so that we have the information we need to strengthen its response to future public health emergencies.

I'd also like to mention Senate Bill 6295, that is my bill, mandating OPWDD purchase and provide PPE for all DSPs, residents, and other staff during declared health emergencies.

Make no mistake, the information ascertained today will be used to influence future public policy and future funding priorities.

Today's format will be an official New York State Senate roundtable. I believe strongly that this is the perfect format for this conversation.

All participants, from the Commissioner on down, are all here willingly and are eager to discuss today's topics.

Those topics will be almost entirely related to the pandemic response; however, we will take advantage of this opportunity to delve into some of the systemic issues that are plaguing the field.

Today we will be very thorough. I believe it will be extremely worthwhile. And I believe this is in the very best spirit of good government and legislative oversight.

However, I will also remind everyone that this body has additional investigatory tools and resources it can use to compel information and testimony.

Let's begin with an overview of our topics today, which are: Reporting and transparency. Program flexibility and new models of care. Personal protective equipment. Staffing (video and audio lost) and testing. Visitation. Vaccination. Fiscal impact and other challenges.

Each panelist will have two minutes to speak, followed by a question-and-answer portion.

I would like now to offer ranking member of the committee, Senator Martucci, up to five minutes

for his opening remarks.

Thank you.

Please go ahead, Senator Martucci.

SENATOR MARTUCCI: Thank you, Chairman.

I appreciate the opportunity to be here and express my views on these matters that, I think we're all in agreement, are so important to our state and to our IDD community.

I also appreciate your friendship and partnership on these important issues that impact our most vulnerable citizens.

Chairman, you have always been -- approached this the same way I have, which is in a bipartisan manner.

I certainly appreciate that, and I think we made a good team for that reason.

We're not here for politics, I agree with you, Mr. Chairman, but to get to the truth, and to be a voice for families who have lost loved ones due to the misguided policies of the administration.

I feel it's incumbent on us to get some answers and not be distracted.

Regardless what our governor says, all the lives lost in nursing homes in our OPWDD facilities matter.

And how and why they died is a legitimate issue for us as a Legislature to examine, but is the key issue that we need to be examining.

I am disappointed that we're here at roundtable today rather than a hearing, where we could have, if necessary, issued subpoenas to witnesses, and for documents.

I'm disappointed that it took us this long to have a public forum, but I'm certainly glad that we are finally here.

But I'm most disappointed and, frankly, pretty mad, that we're not focusing the efforts of this forum on only two things: The deadly OPWDD order of April 10, 2020, and the staffing crisis that's crippling our facilities and exhausting our hard-working providers.

The other issues in our discussion, and this list is surely important, and I'm concerned about them too, but what I see the widening list of topics to be is a way to water down the real discussion on what we should be having, and for that I'm very disappointed.

With regard to the April 10th order, here are the key questions that I have today, which should come as no surprise:

1. Why did Commissioner Kastner issue the April 10th order that required the readmission or admission of COVID-certified residents to these facilities?

2. Why has the department refused to even, up until today, which is June 3, 2021, when we know of the awful impact of this, orders of this nature, refused to rescind it, considering that there was a 459 percent increase in the deaths at group homes in April of 2020 compared to April of 2019.

Individuals in these homes were three times more likely to be infected and to die from COVID than in the general population.

And, 3. What communications did Commissioner Kastner and his department have with Governor Cuomo, the Governor's senior aides, Commissioner Zucker, or anyone else in the administration about this order in question?

Why has the Commissioner utterly refused to provide those communications to me or to this committee?

Basically, it comes down to the simple questions of:

What did the department know, and when did they know it?

And most importantly, what role did Governor Cuomo, who we now know covered up the deaths of nearly 15,000 elderly people in nursing homes, play in this decision-making?

I made attempts to collect this information. And after writing OPWDD and its commissioner directly months ago, requesting this information, I received only a partial response.

Conspicuously missing from this response were correspondence with the Governor's office that I requested with respect to this April 10, 2020, order.

When I publicly criticized OPWDD for failing to reply completely to my inquiry, the response was, quote: OPWDD is proud of the significant efforts New York has made to ensure the safety of people with developmental disabilities during the pandemic, and strongly disagrees with the misrepresentations and false narratives being perpetuated by certain politicians for apparent political purposes.

I know that this response was referring to me.

And what all New Yorkers now know is that the same narrative, which was sold to us for months about deaths in nursing homes, was a lie.

That's why we're desperately looking for answers today.

On the staffing crisis, the Chair and I both wrote Dr. Kastner in strong opposition to cuts to the voluntary residential program.

These have not been delayed or rescinded despite the massive infusion of cash in our budget. And not only should these cuts be rescinded, but I believe they imperil the ability of the department.

It's also important that we use these funds, the Home & Community-Based Services' federal medical assistance money that's been allocated in the recent COVID relief bill, to address just this.

Simply put, we don't need to make these cuts, and our overworked staff cannot handle any more reductions.

I thank the members for being here today, and all the organizations who will speak.

I deeply appreciate the work you do on behalf of the DDID community.

What I'm here to tell you is that you are the true heroes. And I'm proud to be an advocate for you, and most importantly for those that you care for.

Thank you, Mr. Chairman.

SENATOR MANNION: Thank you, Senator Martucci, and I understand your concerns.

I believe that today we are going to hit on the things that are truly the priorities here. And I don't believe that we're looking at anything related to a whitewash.

And with that, I will say that I'm looking forward to begin with our first panelist, which is Commissioner Kastner.

Thank you for being here, Commissioner.

DR. THEODORE KASTNER: Well, thank you.

Good afternoon, Senator/Chairman Mannion, Ranking Member Martucci, and other distinguished members of the Senate Committee on Disabilities.

I am Ted Kastner, Commissioner of the New York State Office for People with Developmental Disabilities.

Thank you for the opportunity to talk about OPWDD's response to the COVID-19 public health emergency.

From the beginning, OPWDD has been an integral part of the state's groundbreaking response to the COVID pandemic.

OPWDD's first positive case was reported on

March 11, and our second on March 13, 2020.

The scope of the challenges we would face hit home almost immediately, leaving no doubt that we were facing a widespread health crisis and needed to transition immediately from containment to mitigation strategies.

OPWDD and its providers, in response to COVID, demonstrated no limits in our commitment, ingenuity, and flexibility.

Our Office of Emergency Management was activated during the week of March 9th to coordinate our case finding, tracking, data analytics, PPE distribution, and other critical tasks on a 24/7 basis.

On March 13, OPWDD redeployed internal affairs investigators to New York City to launch a process that would be later recognized as contact tracing and identification. Nearly 100 of OPWDD's internal affairs personnel were in the field.

Simultaneously, we identified the need to understand the extent of the pandemic and guide our deployment of resources.

By March 16, OPWDD's incident management application was reprogrammed into an effective COVID-reporting system.

This was later expanded to include mandatory reporting of all infections and deaths of individuals through a 24-hour hotline, enabling real-time data to inform the immediate deployment of resources throughout the state.

As the pandemic progressed, we were simultaneously operating multiple initiatives.

We closely coordinated with the New York State Office of Emergency Management and their control centers.

In early March 2020, OPWDD created an internal process for tracking all of COVID-related tasks and assignments. The leadership met multiple times per day to implement hundreds of internal processes to improve our performance.

OPWDD's legal team promulgated guidance documents, under the authority of the Governor's executive orders, that mandated the reporting of COVID testing results, and created requirements for quarantine and isolation measures, and implemented immediate containment measures.

OPWDD has since developed over 100 guidance documents to assist providers in addressing the public health emergency, and temporarily eliminated or modified dozens of state and federal regulations

or rules, granting providers the greatest flexibility possible while maintaining the health and safety of staff and clients.

Since the very start, communication has been a primary goal.

OPWDD sought to keep stakeholders as informed as possible despite the rapidly changing landscape, by bringing them together to assess and coordinate our needs, plans, and activities.

By the end of the second week of March 2020, we were meeting with representatives of our provider, family, and self-advocacy communities, sometimes multiple times a day, in order to keep lines of communication as open as possible.

Those meetings continue to this day, now biweekly, so that we continue to gather feedback, disseminate information regarding data related to individual and staff infections and deaths, and to respond directly to questions.

We've responded to thousands of requests for information from people we support, their families, elected officials, and the media.

In addition, OPWDD launched a new website in April 2020 that is designed to be easier for individuals and families to navigate, and began

building an improved distribution list to help OPWDD better communicate with all stakeholders.

The new website now contains an extensive section with information and plain-language resources for families, as well as guidance for providers.

Finally, in April 2021, we began publishing COVID-19-related data on our website. The data is updated daily.

While Governor Cuomo was coordinating with other governors in our region, I was in contact with other state leaders in the field of intellectual and developmental disabilities, particularly in New Jersey and Connecticut.

We recognized the need to close day programs early on as they were a major source of the potential spread of the virus.

So on March 18, 2020, we took the unprecedented action of closing all certified day programs, sending 55,000 individuals back to their homes.

The following week, on March 24, 2020, we reluctantly imposed restrictions on community outings from and visitation to group homes in order to help ensure the safety of the approximately

35,000 vulnerable individuals living in certified group homes, as well as their families, and the tens of thousands of staff members working in those homes.

Every effort has been made to separate individuals who were either infected or presumed to be infected with COVID from those who were not infected.

When hospitalization is not medically necessary, care in the home is provided as safely as possible.

Residential providers must comply with comprehensive guidance about how to clean and disinfect, how to separate infected individuals from those who are not infected, and what other types of precautions are required by the CDC and the New York State Department of Health.

Individuals with known or suspected COVID-19 are placed in single-person rooms with a dedicated bathroom, or cohorted with others who are infected.

When necessary, an individual with COVID-19 can be moved to a separate cohorted setting, often in a different location or home.

Beginning the week of March 23, 2020, providers were authorized to establish temporary

residences to accommodate quarantine and isolation needs for individuals who could not be safely served in the residence or who lived at home with their families.

OPWDD coordinated with our residential providers, day-program providers, and families to allow as many as 100 vacant day-program sites to temporarily house individuals who may have presented a risk of infection.

In addition, we created an alternative housing resource through our crisis respite authority.

Providers were offered an opportunity to create a short-term COVID-specific residential capacity, using this flexibility, and we developed more than 100 opportunities across the state that could transition individuals if they were unable to be safely supported in the hospital, their group home, or their family home.

No individual who was symptomatic or infected with COVID, or who was discharged from a hospital, or voluntarily left their group home, was returned to their home if it was not safe to do so.

And I just want to repeat that.

No individual who was symptomatic or infected

with COVID, or who was discharged from a hospital, or voluntarily left their group home, was returned to their home if it was not safe to do so.

In late March 2020, OPWDD's clinical and state operations teams revised our training materials, and provided opportunities for remote training of all State-operated and voluntary-operated staff.

Based on the revised curriculum, we developed an assessment tool to verify that staff engaged in proper cleaning, hygiene, and infection-control measures.

The new tool was shared with every voluntary provider for their internal use.

OPWDD then used the tool to survey every one of its 1,025 State-operated group homes by early April 2020.

The tool was used by our field inspectors to survey more than 600 residential settings operated by nonprofit providers that we deemed to be high risk due to the presence of COVID.

New York State was one of the first states to apply for an Appendix K, the federal approval to allow flexibility in the use of waver funds in response to COVID.

New York was also one of the first states to use retainer funds to financially support providers during program closures.

Retainer funds were made available to day-program providers to retain personnel who would otherwise have been furloughed when day programs were closed.

Providers were able to secure up to 100 percent of the funding they had previously earned through the provision of services.

This staff resource was then able to be deployed by providers to address the needs within residential settings affected by COVID, or to create additional staffing capacity.

This was particularly important when agencies were forced to quarantine staff who were exposed to the virus and creating staff shortages.

The availability of retainer funds offered voluntary providers the support they needed to sustain revenue, and ensure that staffing levels were appropriate to maintain the health and safety of our individuals.

The federal government suspended retainer-fund payments to New York State in mid-July after 90 billing days.

In August of 2020, OPWDD offered day-program providers additional billing flexibility.

Day programs are now provided to bill for a full day of services, which previously lasted the minimum of 4.5 hours, after only 2 hours.

Day programs are also permitted to bill for half day of services, which had previously lasted two hours, after only one hour.

This flexibility will last until the end of the public health emergency.

New York's emergency waver was also modified to create alternatives to center-based day programming.

Up to 35,000 individuals were afforded the opportunity to receive habilitative services at their residence through Community Habilitation-R.

Individuals living with their families were also able to receive habilitative services and respite using remote technologies.

We encouraged providers to expand capacity to deliver day programs without walls.

We also temporarily suspended face-to-face visits with care managers, and allowed CCOs to remotely develop care plans.

OPWDD partnered with the New York State

Department of Health to ensure that individuals living in certified residential settings, and their staff, were prioritized for the COVID-19 vaccination.

As of May 14, 2021, nearly 85 percent of our individuals in certified residential settings are either partially or completely vaccinated.

In addition, 30.9 percent of staff working in certified settings have been partially or completely vaccinated.

Individuals with intellectual and developmental disabilities not residing in certified residential settings, and their staff, became eligible for vaccination in late February 2021.

At the present time, 35 percent of those individuals are either partially or completely vaccinated; in addition, 24.9 percent of staff working in community settings have been partially or completely vaccinated.

We are working with our stakeholders to improve vaccination rates.

Despite our best efforts, COVID took a toll on the individuals we serve, their families, and staff.

As of May 17, 2021, out of 128,000 people

supported by OPWDD, 10,633 people with developmental disabilities across the state have tested positive for COVID-19, including 7,127 individuals in certified residential settings.

In addition, of the more than 100,000 staff supporting these individuals, 15,078 staff across the state have tested positive for COVID-19, including 11,481 staff working in certified residential settings.

It is with great sadness that we report that 668 people with developmental disabilities, including 577 individuals residing in certified residential settings across the state, have passed away with a positive COVID-19 test.

However, as a result of high vaccination rates among our individuals, rates of infection have dramatically decreased across our entire system.

We are currently reporting only 10 to 20 individuals who are newly positive each week, and mortality has significantly dropped.

Now with significantly decreased rates of infection, we are using the opportunity to safely restore and redesign services.

Day programs have been allowed to reopen since July 2020, and are asked to submit a safety

plan to OPWDD, and to post that plan on their website, prior to reopening.

Visitation at group homes and community outings are now permitted for individuals in residential settings, but with certain restrictions and documentation in place.

We are screening all individuals, all staff, and all visitors in settings every day.

Last month we liberalized the use of quarantine in group home settings. Individuals who are vaccinated will no longer be required to be quarantined when they come in contact with staff or individuals who are potentially infected.

We are also undertaking outreach efforts to individuals, families, and providers through a series of focus groups, small forums, and discussions, to receive stakeholder input into what the "new normal" should be, and how we can meet service delivery needs in the future.

We also look forward to working with legislators to hear your ideas on how we can best meet our needs, going forward.

As we move forward, we remain diligent to prevent future outbreaks of COVID-19 among the people we support.

Since the onset of the pandemic, we have developed a surveillance capacity which allows OPWDD to respond within 24 hours to any known occurrence of COVID. We will build upon that resource as necessary.

Our internal affairs staff continue to track cases and make additional case identifications.

We deploy our licensing and certification staff to make unannounced visits to high-risk settings.

Anticipating the impact of influenza last year, we implemented a strategy to ensure immunization of those individuals and families who require flu shots.

In addition, this year we're prepared to renew our COVID-related responses, including proceed of a COVID-19 booster, if needed, as we move into a potential COVID-19 season in the fall of 2021.

Before closing, I want to personally recognize the heroic efforts taken by direct support professionals who continuously put the needs of the people they support above their own.

Working in a pandemic is frightening, wondering if you will be infected, infect the individuals you support, or bring the infection home

to your own family.

Direct support professionals and their supporting clinicians kept people alive and gave us hope during unprecedented times.

We are immeasurably grateful for their commitment and dedication.

I would also like to recognize the great work done by many of the leaders in our provider organizations who quickly devised creative solutions to unprecedented problems.

Thank you for your time, advocacy for our community, and the opportunity to submit testimony on the impact of the COVID-19 pandemic on the IDD community.

And I look forward to taking your questions.

SENATOR MANNION: Thank you, Commissioner, for that information, and for the outline of OPWDD's COVID-19 response.

I should mention that we have been joined by Senator Persaud.

The next phase of this will be that senators may ask questions of the Commissioner for -- if they are a member of the committee, for five minutes; that includes question and answer. And then three minutes if they are not a member of the

committee.

And at that point, the Commissioner will be excused, and then we will move on to the panelists.

So senators must raise their hands by using the "raise hand" feature on Zoom, and I'll call on you when it's your turn.

Again, members of the committee would have -- the Disabilities Committee would have five minutes, and any senators that are here that are not members of the committee would be three.

So I'll start with myself, and then we'll move on to Ranking Member Senator Martucci.

Commissioner, can you explain the differences between a nursing home and a certified OPWDD residence, and speak to the differences in the COVID response for these facilities as they may be unique from each other?

DR. THEODORE KASTNER: Well, Senator, I'm not responsible for the operation of nursing homes, and I have no particular expertise in the operation of nursing homes, their management.

I can generally say that nursing homes are much larger than our OPWDD certified facilities.

I can't speak to how nursing homes were engaged in the process of containment or mitigation

around the COVID infection.

I apologize, but that's really outside of the scope of both my professional experience and my role here at OPWDD.

SENATOR MANNION: And I think you may have alluded to, in some of your -- although not comparing them to the nursing homes, in your statement you had talked about the nature of these residences.

So along those lines, could you explain the role that the Department of Health and stakeholders, such as self-advocates or family advocates and providers, had in either helping to create the regulations and the guidance, or amending the guidance, as it relates to these residential facilities?

DR. THEODORE KASTNER: Certainly.

Just going back to review the timeline:

New York State received approval from the federal government to begin testing for COVID on February 29 of 2020.

On March 1st of 2020, New York identified its first positive case, and on March 2nd its second positive case.

At the time, New York City had very, very

limited testing capacity.

I believe it was on March 13 that New York State actually achieved 1,000 tests per day, which was an important milestone.

By January of 2021, the state was able to perform 325,000 tests per day.

But back in early March it was extremely difficult to get our hands around the extent of the infection.

You may recall that, on March 10, 2020, New York State implemented a containment zone, one of the first containment zones in the country, around the city of New Rochelle in an effort to contain what was then believed to be a localized infection.

Our first case occurred the next day, March 11, and the second case was March 13th.

March 13th was really a big day for us. We had a case that was confirmed in the morning, a case that was confirmed around noon, and by the afternoon a third case.

We were concerned at that point that individuals who were infected in group home settings were using transportation resources, whether they were public transportation or medical

transportation, to go to a day program where 200 individuals were working. And that after leaving those day programs, they went back to dozens of homes that were supported by up to 12 agencies across Brooklyn and Queens.

We met with our stakeholders daily, and through that weekend had numerous phone calls and meetings multiple times per day, to talk about moving quickly from containment to mitigation, and the need to close day programs because they appeared to be the primary vector for transmission.

We agreed with our providers that that was the prudent thing to do.

At the time, they asked us for a couple of days to alert their stakeholders that this would be coming.

We settled on Wednesday, March 18th, as the day we would close our day programs.

That was an extremely difficult and bold move on our part.

We severed the relationship between day programs and work for 55,000 individuals, but we felt that was the prudent thing to do.

A week later, on the 24th, as we continued to be engaged with our stakeholders, we limited

visitation to certified residential facilities, and we limited outings from those centers.

And it was simultaneous with those two steps that we began looking at creating alternative residential capacity, which I've described, and trying to stabilize not just our residential providers, but all of our families and individuals, to ensure that parents who had children living at home who were positive could get the support that they needed, particularly if they themselves were ill with COVID and couldn't care for their loved ones.

So we had a rapidly developing process, where we took what we believed to be prudent but rather extraordinary measures to protect our individuals. And by "protection" I mean to prevent transmission.

That was the key of all of our effort: If we could stop transmission, we could save lives and keep people healthy.

SENATOR MANNION: Thank you, Commissioner.

I may have a couple questions on the backside of this, but in -- I want to make sure that we move on to Senator Martucci for five minutes. And then if any other senators have questions, please use the "raise hand" feature.

Senator Martucci.

SENATOR MARTUCCI: Thank you, Chairman.

Hello, Dr. Kastner.

So maybe I'm -- I'm just starting maybe with my broadest question.

You know, from your perspective, why were infection rates and death rates in your facilities during the height of the pandemic so much higher than the wider population?

DR. THEODORE KASTNER: Well, I think, in general, there's two reasons that morbidity and mortality rates would be higher among people with intellectual and developmental disabilities.

The first is, our individuals have higher rates of comorbidities, medical conditions, that lead to higher rates of mortality.

And they're the same as every other group of individuals; heart disease, pulmonary disease, cancer, diabetes, hypertension.

All of those medical conditions increase the risk of having a poor outcome or dying after infection. And our individuals, particularly those in certified settings, have higher rates of those comorbidities.

The second is that congregate care setting,

by their very nature, have higher rates of transmission because there are more people moving through them.

In a family's home, the only people moving through are the family members; however, in a congregate setting like a group home, staff are moving through, and there are more staff than family members.

So everyone's acknowledged that congregate care settings have higher rates of mortality and morbidity.

We personally don't think that it's a reasonable comparison to look at the general population and our high-risk settings, our IRAs.

A more useful comparison would be the general population of the state of New York against the general population of people with IDD.

And we have been able to document that the rate of transmission to people in the IDD system is lower than the rate of transmission for the New York State general population.

We think that's a really, really important benchmark, because it validates all of the work that thousands and thousands of people did to prevent transmission.

The data shows that individuals with IDD served in our system were safer and had a lower risk than the general population of the state of New York.

And I'll walk you through the data if you would like.

SENATOR MARTUCCI: No. Thank you, Doctor.

I mean, look, unfortunately, almost half of my time is gone, so I'm going to kind of ask this next question as a combination so that you have the opportunity to answer.

So you know that I have been very critical of that April 10th order, an order that's still in place today.

The Chairman alluded before to the differences between a nursing home setting and the settings that we're discussing here.

So I guess my question is simple:

This order is eerily similar to the famous March 25th order for nursing homes. The language is almost identical.

Could you give us a little perspective in terms of, how this order came to pass, and, you know, who you received this guidance from to craft this order, and sort of, most importantly in my

mind, why this is still in place today, given all we know about how dangerous the nursing home order was?

DR. THEODORE KASTNER: So March 23, 2020, the CDC produced guidance that was disseminated to everyone, around the discharge criteria and the discharge process of individuals infected with COVID.

We used that as a starting point in developing the guidance that we then published on April 10th of 2020.

At the same time, we recognized that discharging people from the hospital, who had been hospitalized for COVID, would be a challenge.

We created an alternative residential capacity to support individuals who could not safely be returned to their group home.

So the guidance that we issued gave providers --

I'm looking at it right now. I think it's important to look at the document.

-- but gave providers the flexibility to determine whether or not they could safely return an individual to their homes.

There was no mandate, no requirement, that they be readmitted to a home.

The res -- I'm quoting: The residents who are symptomatic should only be discharged to a certified residence if there are clinical staff available who are capable of attending to the medical needs of symptomatic residents pursuant to the hospital discharge instruction.

There was an out for residential providers.

They were not forced to accept individuals back to their homes.

We created an alternative residential capacity to support those agencies and those individuals.

So I'm just reading from the document.

I think we created a flexible document that was able to address the needs of individuals and the provider agencies that supported them.

SENATOR MANNION: Thank you, Commissioner.

I am going to move on to Senator Persaud for five minutes.

But I would just like to mention I have some follow-up questions, and I think Senator Martucci may as well.

So we're going to have -- you know, if everybody's in agreement, and I think we would be, we'll go through, you know, another -- another

round.

Senator Persaud, you have five minutes.

Thank you.

SENATOR PERSAUD: Thank you, Chair.

Commissioner, it's great to see you. Thank you for everything that you're doing.

I just have a couple of questions that I'd like answered.

During the height of the pandemic, the DSPs at the residences were required to remain in place if there was someone there who contracted COVID.

Could you tell us how you handled that, because they were required to do so.

And in most cases -- in many cases -- I shouldn't say most -- in many cases, they were not compensated for the time, or given supplemental payments for the time, that they were required to stay there.

DR. THEODORE KASTNER: Senator, I have to apologize, but I am not aware that we published guidance requiring staff remain on duty if they were positive.

That may have been a determination made by individual provider agencies.

But I'm not aware-- and I appreciate being

corrected if I'm wrong -- but I'm not aware that that was a requirement that we imposed on provider agencies.

As far as compensation for staff, we have no role in directing the compensation to DSPs by the agencies that employ them. Those are individual conditions that are negotiated within each agency.

SENATOR PERSAUD: Okay, so I can be clear:

The individual contracted COVID and they were homebound. The staff was required to remain there.

So I had staff who were required to stay in place for two weeks at a time, because an individual in the residence had contracted COVID and was in the facility. And so they were required to remain there to take care of that resident, but they weren't compensated for (simultaneous talking; indiscernible) --

DR. THEODORE KASTNER: I don't disagree with your premise that staff were required to spend up to two weeks in a home if they were positive.

But I would say that that did not occur as a result of a directive or guidance or policy of OPWDD.

SENATOR PERSAUD: Okay.

DR. THEODORE KASTNER: The agencies created

their own policies around how they addressed their staffing needs.

And I'll take your word for it that this practice did occur, but it did not occur -- I don't believe as a result of policy or guidance or regulation promulgated by OPWDD.

SENATOR PERSAUD: Thank you.

And in the setting that you have, what -- are you offering any kinds of incentives to staff to become vaccinated?

We see the incentives are being offered all across the board.

And in this vulnerable population, we want as many staff as possible, as well as the residents, to be vaccinated.

Are you offering the staff any kinds of incentives?

DR. THEODORE KASTNER: We agree, Senator, that it is really important that as many staff as possible, and as many individuals as possible, be immunized against COVID.

We, as you've noted, and others have noted, have access to funding through the American Recovery Plan related to the enhanced federal matching of funds.

We are currently conducting public forums and -- you know, five public forums across the entire state, and another 35 or so meetings with various constituency groups, to solicit their thoughts about how we should use those enhanced federal funds to support our system.

I don't think it's a secret, we have heard recommendations similar to what you are recommending. And we will be looking at if it's possible for us to use enhanced FMAP funding to incentivize DSPs to become vaccinated, or to reward DSPs who have already been vaccinated.

So it's something we're looking at right now.

But I don't want to get ahead of ourselves because we haven't completed the process of soliciting public input.

SENATOR PERSAUD: Okay. Well, thank you for that.

My final question: Am I right when you said 10 to 20 positive cases per week you are still seeing?

DR. THEODORE KASTNER: Yes. Out of about 128,000 individuals, we are seeing positives.

SENATOR PERSAUD: Are your cases concentrated in one particular area of the state, or is it just

12 to 20 across the entire state?

DR. THEODORE KASTNER: It's across the entire state.

I will say that the focus has moved away from our residential programs and into the larger cohort of individuals who are living in the community.

This reflects more local conditions.

The high rate of vaccination in residential settings, about 85 percent as of two weeks ago, has probably granted immunity to the larger number of individuals living there.

So now it's not so much focused on residential; it's more community spread.

We're going back to, you know, where we started back in February and early March.

SENATOR PERSAUD: Thank you, Commissioner.

DR. THEODORE KASTNER: Thank you.

SENATOR MANNION: Thank you, Senator Persaud; and thank you, Commissioner, for those answers.

Quick questions here, for myself.

You did mention that the rate of transmission was lower than in the general population. And you had -- it seems like you have those numbers.

Can you please share the rate of transmission if you have them?

DR. THEODORE KASTNER: Oh, sure.

In the testimony I offered, I said that 10,633 of the 128,000 individuals we support have tested positive for COVID. That works out to about 8.31 percent of all the individuals with IDD that we support.

For the general population, data is widely available.

About 1.7 million New Yorkers out of 19.45 million New Yorkers have tested positive for COVID. That's about 8.74 percent.

In terms of a difference, our rate is about .4 percent lower, and that's about a 5 percent improvement in the rate of transmission for the general population.

And I think that's a really important metric because it validates the work and the commitment and the sacrifice made by thousands and thousands of people across the state.

Everyone who has worked to support individuals during the COVID pandemic need to know that it worked, it mattered, it was effective, and it saved lives.

That's really the takeaway for people.

Everyone should feel that they made a

difference in, collectively, the work that we produced.

SENATOR MANNION: Thank you.

From one of your statements, and then, also, your original statement, and then a response to a question, you used the phrasing that "no one was returned to a residential facility if it was not safe to do so."

By that do you mean that they were COVID-negative and/or asymptomatic?

Because I know you had used some of those terms.

DR. THEODORE KASTNER: No, by "safely return," what I mean is, what I refer to in the guidance document, that, basically, "discharged only to a certified residence if there are clinical staff available who are capable of attending to the medical needs of symptomatic residents pursuant to hospital discharge instructions."

No agency should have taken anyone back if they couldn't safely accommodate their needs in the home.

And if they couldn't accommodate their needs in the home, we had two alternative residential options to support them and those individuals.

That's the best we could do.

I think we were very forward-looking in building that capacity, having it in place and available, before we published the advisory on hospital discharges and admissions to certified residential facilities on April 10, 2020.

SENATOR MANNION: Okay. Thank you.

I will say, and I meant to mention this as my second round of time came, that, anecdotally, I do support exactly what Senator Persaud had said, which is I did hear of situations, as she listed, regarding COVID-positive workforce and having to remain.

You had mentioned, of course, tragically, that we lost people within the IDD community to this.

I don't know if I missed this, so I do apologize.

You had referenced the number of cases within the workforce.

Do we know of any deaths, or the number of deaths, of individuals who are a part of this workforce that died and were positive COVID-19 at the time?

DR. THEODORE KASTNER: Well, it's certain

that we've lost individuals from the workforce as a result of COVID infection.

I don't have that number specifically.

SENATOR MANNION: Thank you.

One last thing here.

So as far as transmission within the group homes, and it sounded like, from your answer, you know, we may not have rates of actual transmission that occurred with those homes, but do we believe that transmission was occurring in those homes?

DR. THEODORE KASTNER: It certainly was occurring, and we actually have data, and I presented that --

SENATOR MANNION: Okay.

DR. THEODORE KASTNER: -- the number of individuals who were living in homes. That's the numerator. And the denominator is about 35,000 individuals.

So we can calculate rates for that subgroup, but we also need to recognize that that's a particularly high-risk group in terms of transmission risk.

And it's really -- in terms of our evaluating our performance, it really isn't helpful to us look at transmission rates in group homes and compare it

to transmission rates for the general population.

We want to look for apples-to-apples comparisons, general population in New York State, general population IDD, or high-risk congregate care settings for OPWDD and other high-risk congregate care settings.

Those comparisons are more helpful to us in understanding the performance of our collective effort.

SENATOR MANNION: Okay. Thank you.

I appreciate it, Commissioner.

Five minutes for Senator Martucci.

SENATOR MARTUCCI: Thank you, Chairman.

So, Commissioner, I want to just circle back to the last thing that you and I were discussing in the first round of questions.

And I'm holding a copy of the order here. And I understand that you were explaining to us that the order has some flexibility.

And so I want to read just a paragraph from the first page of the order, where it says, quote:

No individual shall be denied readmission or admission to a certified residential facility based solely on a confirmed or suspected diagnosis of COVID-19. Additionally, providers of certified

residential facilities are prohibited from requiring a hospitalized individual who is determined medically stable to be tested for COVID-19 prior to admission or readmission.

So, look, I'm no attorney, but when we're talking about words like "shall" and "prohibited" in this order, how would a certified residential facility see any flexibility in an order that's worded in this manner?

DR. THEODORE KASTNER: So I'll [inaudible] the first sentence that you read is an antidiscrimination mandate.

We would not allow residential providers to discriminate against individuals based solely on the presence or suspected presence of COVID.

We use that phrase for every criteria against which we want to prohibit discrimination.

Whether it's the presence of HIV, race, ethnicity, culture, religion, sexual orientation, we do not tolerate discrimination. We don't want to tolerate discrimination against people who might be suspected of having COVID.

Now, you skipped a sentence.

The sentence you skipped says that "Any denial of admission or readmission must be based on

the residential provider's inability to provide the level of care required by the prospective individual pursuant to the hospital's discharge instructions, and based on the residential provider's current certification."

We gave residential providers an out.

They simply had to say "We can't do this. We don't have the staff. We don't have the capacity," and we would work with them to find an alternative residential setting.

Now, the sentence you did read following that, about certified residential providers being prohibited from requiring hospitals to test people for COVID is an issue around who's directing the care in the hospital.

Hospitals develop treatment plans. They manage appropriately.

When someone is ready to be discharged, they make that recommendation.

That does not prohibit a residential provider from obtaining a COVID test for an individual who is under their care.

But residential providers can't direct hospital care, and they can't use that as a reason not to accept someone back to the residence.

But they can come back and tell us, We can't support this individual because we don't have enough staff, we don't have the capacity.

And we worked with residential providers to create alternative capacity, and to have individuals be supported outside of the certified homes that didn't have the staff or the resources.

There is not a single provider who would say that we told them they had to take someone back, because we never told anyone they had to take someone back if they couldn't do it.

We told them, we're here to help you. Here are other resources you can rely upon.

SENATOR MARTUCCI: Okay. Thank you, Dr. Kastner.

I mean, look, here's what I would tell you:

You know, this certainly sounds like a requirement to me, and I think it sounds like a requirement to a lot of people, based on the way it was worded.

My last question is this, because I see I've got a little less than two minutes left, is with respect to the temporary residences that you were referring to that were set up, about 100 of them, or approximately 100 of them, around the state.

I guess my question is -- and I've heard from some providers who were part of setting up some of the residences -- in terms of who was sent to these residences, was that something that was directed by your department, or providers were setting up residences -- these temporary residences for their own folks who could not be cared for in those settings?

DR. THEODORE KASTNER: There were two separate residential opportunities that were created.

The first, we allowed providers who operated day programs to convert those vacant day program sites to create alternative housing.

And in many instances, residential providers were also operating day programs, and they could direct their individuals to those alternative residential settings.

We didn't have a lot of oversight in that. We wanted to give them flexibility and the ability to respond in a quick and nimble way.

The second option that we created was to support our residential providers, but also to support families who didn't have the capacity to care for either a loved one who was acutely ill, or

whose parents themselves were infected and couldn't manage the care of their loved ones.

So we created about 100 -- 120 beds, using the temporary emergency respite authority that we had, and those we directed people into.

But I'd have to say, neither one of those capacities was ever exceeded. Demand never exceeded our capacity.

We always had the ability to support people in either one of those residential alternatives throughout the entire pandemic.

We had capacity we built, and we didn't use it, and that's great; no problem with that.

We wanted to make sure that we could serve everyone that we needed.

And, Senator, just to -- I know we're going to run out of time -- I'm happy to meet with you and talk to you more about this. I'm really passionate about it.

I want all of our stakeholders to feel that they did what they could do, and it made a difference.

And I think I can convince you that we did the very best that we could.

So I'm happy to meet with you at some point

later and continue the discussion.

SENATOR MARTUCCI: Well, Dr. Kastner, I certainly thank you for your time today, and I thank you for your willingness to do that.

And I will certainly take you up on that offer.

Thank you, Chairman.

DR. THEODORE KASTNER: Thank you.

SENATOR MANNION: Thank you, Senator Martucci.

Thank you, Commissioner, for participating today. And we look forward, of course, to continuing these conversations to improve service delivery in the state of New York.

We have a long list of panelists, as we tried to be as inclusive as possible.

So thank you for joining us today, Commissioner. We appreciate that.

I would like to begin the panel-discussion portion of this roundtable.

Panelists will have two minutes each to deliver their remarks.

Senators will have the opportunity to ask panelists questions for two minutes per panel after all panelists have made their statements.

I'll call on members who have raised their hand using the "raise hand" function in Zoom.

Senators, please direct your questions directly to individual panel members if you can.

Our first panamel -- panel -- excuse me -- is reporting and transparency.

I'd like to introduce Marco Damiani from AHRC New York City.

MARCO DAMIANI: Thank you, Chairman Mannion and Ranking Member Martucci, for the opportunity to provide remarks today.

I'm Marco Damiani, CEO of AHRC New York City. We are the largest agency providing OPWDD-funded services in New York State.

In the early spring of 2020, a number of metro New York provider agencies formed a data collaborative to track the impact of the coronavirus.

At that time, the group served 3800 people with IDD in residential settings in New York City, which represents over 26 percent of all the certified beds in New York City.

Our data indicated that infection, hospitalization, and fatality rates for people with IDD greatly exceeded the rate of infection that was

being experienced by the general New York City population.

The rate of infection was about five times the general New York City rate, the rate of hospitalizations was almost three times that of New York City, and the fatality rate was two times the rate in New York City.

On April 20, 2020, a research brief by Dalton Stevens and Scott Landes from Syracuse University approximated those trends.

We were extremely alarmed by these rapidly emerging trends.

The data collaborative was quickly expanded upstate, and then statewide, folded into an unprecedented effort by the New York Disability Advocates.

These data provided essential and current information on COVID-19 within and across regions, as well as data that showed potential future trends in infections, hospitalizations, and deaths.

It enabled proactive provider response decisions for organizations who had access to the data.

These data proved invaluable and, no doubt, enabled people with IDD and staff to be designated

as Priority 1A for vaccinations.

Reports from others have mentioned a lack of transparency in the release of infection and hospitalization and fatality data.

OPWDD has given numerous verbal reports to provider associations, which has been very useful, but not as powerful as the public release of robust data.

This information would have been particularly helpful in seeing the need for PPE and educational response needs earlier on.

Going forward, a move toward more readily available key datasets during urgent or emergent conditions would be very useful for all stakeholders.

The upcoming 507 plan process should include key data-sharing commitments that can better inform system transformation characteristics and targeted resources to meet future needs and flexibility.

We need even stronger partnerships across providers, families, self-advocates, and government.

We want to learn from what we have collectively experienced.

Thank you very much for your time.

SENATOR MANNION: Thank you, Mr. Damiani.

We're moving on, next, I'd like to introduce Alyssa Galea from Disability Rights New York.

ALYSSA GALEA, ESQ.: Thank you, Chairman Mannion and Ranking Member Martucci, for the opportunity to speak today.

DRNY, along with the New York Civil Liberties Union and New York Lawyers for the Public Interest, conducted a seven-month-long investigation, examining the impact of COVID-19 on people with IDD living in group homes.

Many of the issues we identified are on the agenda today, so we're very encouraged that this conversation is being held.

But one of the biggest obstacles we encountered in conducting our investigation was a lack of transparency and difficulty obtaining data.

We know that OPWDD has collected data on infections and deaths amongst the staff and residents of group homes from the beginning, but did not share it publicly.

The requests made under the Freedom of Information Law in the year 2020 were subject to extensive delays.

OPWDD had telephone calls with certain stakeholders, but they were exclusive at invitation

only.

And as the protection and advocacy system at DRNY, we were able to get some raw data about resident fatalities from the Justice Center, but this was by no means an option available to the general public.

The lack of transparency shuts family as policymakers, provider agencies, and the scientific community out of critical conversations about reducing exposure and continuing outbreaks and preventing deaths.

OPWDD only started sharing the infection and fatality data publicly in late April of 2021.

And while this is a positive step, there's definitely a limitation on the accountability and ability to make timely changes to policies and practices when data is being shared so far after the fact.

What is being released now cannot change the impacts of the decisions that were made last year, but it can and should be used to shape future policies for future public health emergencies.

So we feel that it is critical, moving forward, that reporting requirements are put in place to ensure transparency and accountability

during public health emergencies, as well as that data reporting is timely, and includes comprehensive demographic information, to ensure that the practical and equitable impacts of emergency responses can be monitored as they occur and adjusted appropriately.

Thank you.

SENATOR MANNION: Thank you, Ms. Galea.

Next I'd like to introduce Erik Geyser from Arc of New York.

ERIK GEYSER: (Microphone is muted.)

SENATOR MANNION: Mr. Geyser -- yes.

ERIK GEYSER: Sorry.

Thank you, Chairman Mannion and Ranking Member Martucci, and all the other senators on the committee.

I'm Erik Geyser, CEO of the Arc New York, the largest voluntary provider of services for people with IDD in the state.

At the outset of the pandemic, our organization recognized the crucial need for real-time data to help us understand the impact of COVID-19 on individuals with IDD and inform our response.

We advocated with the State to address this

need.

While we did receive cooperation from OPWDD, the State did not initially have the capacity to collect the necessary data in their existing platform.

They had to identify and build a platform on to collect the data.

As such, voluntary providers took the initiative to meet the critical need independently.

The state of emergency was declared on March 7th, and within weeks the Arc New York was collecting weekly data to assess the impact of the pandemic on the people we support.

We quickly collaborated with NYDA to expand the reach of that data collection to hundreds of voluntary providers, including every chapter of the Arc New York.

We partnered with Syracuse University on a yearlong project, which included comprehensive data on infections, hospitalizations, deaths, recoveries, quarantines, and vaccinations.

Syracuse University published their first study in June, which found that individuals with IDD in residential programs were four times as likely to contract COVID-19, and two times likely to die of

infection.

The information shaped our pandemic response and supported our advocacy efforts.

The data collected by New York's voluntary providers helped secure vaccination priority for New Yorkers with IDD, and has been cited to drive policy change at the federal level.

We know data is vital in developing informed and effective public policy.

In the future, these efforts would be more streamlined, comprehensive, and impactful if they were conducted by the State and shared in real time with providers.

In the event of a future crisis, the State must have the resources and infrastructure to immediately undertake field-wide data collection and sharing.

Thank you for allowing me to share my comments today.

SENATOR MANNION: Thank you, Mr. Geyser.

I'm going to break my own rule here and just open up my questions to anyone here.

So I certainly hear loud and clear about the need for data in documents and it being a timely manner.

I'm going to go a little bit off of that and ask:

As different organizations were obtaining this data, were -- did anyone have the ability to engage in consultations on the guidelines developed by the Department of Health or procedures by OPWDD before the enactment of those guidelines, or after those guidelines were in place, to express that some improvements or enhancements might be made to those?

So I know it was a little long-winded, but what I will say basically is: Were there -- was there a consultation with either the Department of Health or OPWDD regarding guidelines as we got through this crisis?

Anyone can answer.

Thank you.

ERIK GEYSER: Mr. Chairman, maybe I'll take the question, and I believe you're referencing the discharge guidance, if I'm not mistaken.

Is that correct?

SENATOR MANNION: That could be.

You know, we're talking about a lot of things today, but it could have been in regard to that, or visitations, or whatever.

Any part of the guidelines that were in

place.

But, yes, thank you.

ERIK GEYSER: Yep.

My recollection is that we didn't consult with OPWDD prior to the release of that information.

But I should say that OPWDD regularly had stakeholder meetings and consultation, and received feedback from providers post the release of that guidance.

SENATOR MANNION: Thank you.

If any of the other panelists could provide context on that, that would be appreciated.

MARCO DAMIANI: I would agree with what Erik just said.

As we're a member of the Arc, and we were routinely given feedback and opportunity to give information to the Arc about what we were experiencing, and also receiving it.

We were not engaged prior to any guidance coming out, but had input when guidance did, in fact, come out.

ALYSSA GALEA, ESQ.: And I can say, on behalf of Disability Rights New York, we were not consulted before the issuance of any guidance or included in those stakeholder conversations.

SENATOR MANNION: Thank you. I appreciate that.

Senator Martucci.

SENATOR MARTUCCI: Thanks, Chairman.

So I think, really, mine is more -- less of a question and more of just a highlight.

You know, certainly what I want to say to all of you is I understand your frustration with respect to a lack of information.

Even as a legislator it was impossible for me to get information, you know, when I had reached out to the department.

I had sent the department a letter back in March, asking for some information, and only parts of that information came back.

So I certainly hear loud and clear your charge for us to work cooperatively as a legislature to figure out ways that we can help you get that data as we move forward, as it's certainly useful.

But I think, again, the lack of transparency is certainly worth highlighting.

And the other thing I would call out is, unfortunately, the department does have an abysmal history, as I've heard, about making information available via FOIL.

And things shouldn't be that way. It's not the way government should work, and particularly, when you're using this data to inform your decisions in terms of keeping people who you're entrusted with safe.

So I want you to know that your comments are certainly not lost on me.

And I look forward to working with the Chairman and others on ways that we can make this a whole lot easier for you, moving forward.

ERIK GEYSER: Thank you.

MARCO DAMIANI: Thank you.

SENATOR MANNION: Thank you, Senator.

One last comment, and I of course appreciate the panelists participating today.

That's one comment.

I appreciate your clear statement that the data needed to be provided in document form and needed to be timely.

The only thing I would add to that is that we have had a bill pass the Senate and the Assembly, it was my bill, that the OPWDD provide a detailed report, including that data.

Now that is as we, hopefully, are approaching the end here of what we're going through, and we

understand the importance of that timely information.

Let's hope we do not have another public health crisis, but we know that the data needs to be rapid. The State is probably best suited to provide that data, and should be provided to providers in writing and in a timely manner.

So I do appreciate everyone's participation today from the panelists.

We have, again, a long list of panelists participating.

I thank you all for what you have done, and for the research you have done, to make sure that families and individuals know that there are people out there that are fighting for them, that have their best interests at heart.

And I appreciate everything that all of you did throughout this very challenging time.

So thank you for joining today.

Next panel is -- will be program flexibility and new models of care.

Our first panelist is BJ Stasio from Self-Advocacy Association of New York State.

BJ STASIO: Hello, Senator, and thank you members of the committee, for having me today.

I'm honored to be here.

The comments from SAANY are as follows:

During COVID-19 it became necessary to offer alternative services, such as Com Hab remotely, and in people's homes, instead of day programs.

It is important to note that this flexibility expanded choice, which is positive, and people liked this option; however, it is also important to note that no service works for all, or will be chosen by everyone.

So while SAANY wants to see these flexible services continue, they must not be imposed on someone as an alternative to services they may have preferred prior to COVID-19.

People must be able to choose what services they would like, whether it is traditional services or the new options that become available during COVID-19.

One important consideration is that the remote services, particularly those offered online, can afford people new opportunities.

Not everyone has access to equipment and Internet.

Self-advocates within residential services should all have access to Internet services and

equipment, not simply to receive service options, but also to explore the world; make connections with their friends, family, and broader communities.

And I would like to take my last 20 seconds to say thank you to all the DSPs, and give them the wages they deserve for all they have done for all of us.

Thank you.

SENATOR MARTUCCI: 100 percent.

Thank you, Mr. Stasio.

Next, I'd like to introduce Yvette Watts from New York Association of Emerging & Multicultural Providers, Incorporated.

YVETTE WATTS: Thank you, Senator Manning, and other ranking senators, for this opportunity to speak.

As I said, I represent NYAEMP, which is the multicultural providers.

We serve -- our agencies serve many of the underserved and culturally diverse communities throughout New York and upstate.

And I just want to say that the flexibilities under the Appendix K, which enabled flexibility to the waiver, the Commissioner pointed out many of those flexibilities, which were critical to

agencies, especially mine, as a lot of these programs were shut down.

The Com Hab-R and certified residential settings was essential.

Telehealth provisions of servicing units, billing, and flexibilities, all this was essential for small to mid-sized agencies who don't necessarily have the resources or the funds like their larger colleagues.

And during the pandemic, it was extremely important because many of them don't have multiservices programs where they could depend on switching things around. Many of them only had day habs.

So these services were extremely important for them.

I ask, moving forward, that the resources and the data, as mentioned by one of my colleagues, be more ready available so that these kinds of things that occur, should the pandemic reoccur, my agencies can continue to serve the families and the individuals in these underserved communities.

It was extremely hard for them at the time, but OPWDD was there to support.

But I would say that if resources and data

were more readily available sooner, I think that would help things as we move forward.

Thank you.

SENATOR MANNION: Thank you, Ms. Watts.

Next, I would like to introduce Jim Moran from Care Design New York.

JIM MORAN: Thank you, Senator.

And really want to start by thanking you all for holding this roundtable today; a very important conversation.

I'm here to speak on behalf of the seven Care coordination organizations in New York, representing -- supporting approximately 110,000 people across the state.

Care Design New York specifically operates in 30 counties, including the, roughly, 10 counties that were hardest hit by the pandemic during the last spring.

And I want to focus my attention on some of that information.

While the CCOs predominately provide -- really are the backstop mainly for people who live in the general community, which is about 75,000 people, there are some 30 some-odd thousand folks that live in residential programs as well that

we also provide supports to.

So the CCOs were a critical part, not only in supporting the 70-some-thousand people living in the community, but also the backstop in helping the residential providers through the challenges, and our members and families, from a communication perspective. And we collected data.

And I did want to talk a little bit about the data as I get into what I would say is our recommendations towards -- in terms of innovation around a need for housing, for example.

So I'm attaching to my testimony, Senator, some data that we had collected across several CCOs, and particularly those who were hardest hit by the pandemic. That has been attached to the material that I sent you.

And I've given you specific data about Care Design New York, and the data that we collected throughout this.

So I just want to give you a brief summary of what we learned from the analysis about the infections.

Individuals with IDD, especially those in certified congregate settings, were significantly more likely to get infected by COVID-19 than the

general population.

That's kind of contrary to what the Commissioner had said.

For example, the statistic that the Commissioner provided shows that there were 10,000-some infections against a population of about 120 some-odd thousand.

But the reality of it was this:

Approximately 7200 of those 10,000 lived in group homes. And there are approximately 38,000 people living in group homes.

So you're talking about an infection rate within the group home community, which I included family care in those numbers, is about 18 1/2 percent.

So it's not less than 10 percent when you look at the hardest hit.

And the focus of this session is about residential programs, so I just want to clarify that.

Now, and I agree with the Commissioner on some of the reasons why this -- our population is vulnerable to the infection.

The age of the individuals, we have a high number of people who are over the age of 50.

The underlying health conditions.

And, quite honestly, the need for physical contact by staff because of the physical [inaudible] of our individuals.

And you had over 15,000 staff also get infected.

There were space limitations obviously in the programs. Many homes, individuals, are sharing bedrooms. There's one or two bathrooms, or three bathrooms, that have to be shared.

Very difficult to isolate individuals, in all honesty.

Despite what the Commissioner said about the availability of emergency capacity, it really did not exist. It took months to get that up and going. And it was through a bureaucratic process that was set up, that agencies had to get prior approval.

If agencies had waited to do that, more people would have been impacted by the virus.

Agencies were left to do this on their own, and figure out where to move people temporarily in order to isolate people appropriately.

So that leads me to the issue of needing to make sure that we have sufficient capacity in the community.

We had situations firsthand, every CCO has had this situation, where we had people whose family members were impacted by COVID. They were the primary caregiver and they had nowhere to go. We could not get them into one of those opportunities that the Commissioner referred to.

And so we were struggling to find locations of where people could go to be healthy and safe.

So I beg to differ with some of the statistics that were being mentioned by the Commissioner today.

We really need -- out of this, Senator, we really need a plan for developing capacity in the community for people who have nowhere else to go.

It's a problem not only from the pandemic perspective, but also on an ongoing basis. We struggle every day to find the appropriate housing for people that are about to become homeless.

That capacity is not readily available in the system today.

Thank you.

SENATOR MANNION: Thank you, Mr. Moran.

I think there's great consensus behind your thoughts regarding housing for sure.

And I appreciate you compiling that data, and

thank you for all the information that you provided.

Thank you.

Next, I would like to introduce Michael Seereiter from New York Alliance for Inclusion and Innovation.

MICHAEL SEEREITER: Thank you, Senator, and good afternoon.

Very interesting dialogue today.

I really appreciate it being the opportunity to participate.

On program flexibility, the residential -- alternative residential housing capacities that were discussed have been discussed several times now here, yeah, provided -- you know, COVID-positive individuals, a place to temporarily reside apart from individuals who were COVID-negative, or vice versa.

And this was, I think, a really important factor, because it allowed people to remain at or be discharged from the hospital to their -- to either their home or to the emergency respite housing location while they were COVID-positive.

It was a significant factor that did help offer alternatives here in this particular sector.

The community rehabilitation residential

program that BJ just mentioned, we're really happy to see that OPWDD is seeking to make this permanent, with some appropriate guardrails in their pending waiver amendment. We think that's appropriate.

Likewise, we have the telehealth flexibilities that were offered during the pandemic. It took forever to get them, but finally they were here.

We're really glad to see that OPWDD is doing the same with their upcoming waiver amendment as well.

And then the day hab retainer day payment program, the Commissioner talked about this, that lasted for 30 days -- excuse me -- 90 days, three consecutive 30-day periods.

The enhanced FMAP guidance that just came out from the Centers for Medicare and Medicaid Services authorizes states to seek and pursue another three consecutive 30-day periods in the year 2021.

So we would encourage thinking about that opportunity, given the fact that we're -- you know, that the latter half -- first half of the year was difficult.

Documentation. There was a temporary roll back on certain documentation requirements, allowing

staff to focus on the care and supports that they provide. And now OPWDD is looking to catch up, but we really need to revisit, and I think hold off on some of that, due to the staffing emergency.

As it was said yesterday, every minute spent on documentation is one that you take away from direct service.

And then I think, although the general piece of this, which is direct -- you know, we need a greater level of flexibility in this system, which is really only going to be achieved through a system overhaul of regulation and administrative memoranda, and really installing a different philosophy, you know, one that's strength-based, and supports people to make decisions about reasonable and appropriate risks that they can take, and encourages more -- we would encourage more conversation as part -- about this as part of the 507 process.

Lastly I would say, you know, new models of care, there are two things that stand out in my mind about what we've learned:

Access to and swift use of isolation and quarantine were absolutely key.

Individualized rooms and emergency respite capacity were directly responsible for far lower

rates of infection and death than in other settings where shared rooms were more common.

And smaller residences, smaller residence size, is key.

We really need to be moving our system -- our services system further along the continuum toward smaller resident sizes, and helping more people live more independently, including in things like noncertified options.

But, again, that comes back to a philosophical mind shift, and a philosophical shift of what our system is and how it operates, that we really hope we can be having more conversations about as part of the 507 process.

SENATOR MANNION: Thank you, Mr. Seereiter. I appreciate all that.

Next, I'd like to introduce Meri Krassner from NYC FAIR.

MERI KRASSNER: Thank you, Senator Mannion, and the members of the committee, for this opportunity to speak.

My name is Meri Krassner, and I'm a member of the NYC FAIR Executive Committee.

I'm going to say, reiterate, some of the things you've heard already. But I am a parent and

I speak from a slightly different point of view.

We're very appreciative of the flexibility offered by the Appendix K waiver for people in lockdown. Bringing day hab, telehealth, and other services into residences created a sense of normalcy.

We are grateful that if you chose to bring your family member home as a safety measure, and to lessen the burden on staff and residences, we are grateful it did not have negative financial consequences for our providers. We need them to survive.

Most people have found telehealth as a welcome substitute for many time-consuming and staff-intensive medical visits, but easy access, individual preference, and the ability to engage is critical.

We saw how the lack of flexibility left agencies struggling to figure out how to quarantine the sick; and to find staff for these alternative sites when they came online, how to staff residences; and the inability to get individuals exposed to the virus tested in order to isolate those positive as quickly as possible to protect others, and how help hospital personnel take care of

and serve people with IDD who were hospitalized with COVID.

As bad as it was for everyone, our family members with IDD were at greater peril without someone who understood them being there to communicate and advocate for them.

After a great deal of statewide advocacy, we did get the right for a staff or a parent to accompany them in the hospital, which was better for everyone, including the doctors and nurses.

Going forward from now we need to be cautious when reconsidering the use of virtual services. It's important to recognize that not all people in residences have the Wi-Fi access and the devices necessary to participate. Many people need support to use the technology. Staff may or may not have the ability to aid them effectively. And some people, like my son, do not relate to virtual services at all.

Com Hab-R has been extremely beneficial to many group home residences, ensuring some level of structured activities in their day; however, this should not be viewed as a long-range substitute for day hab services unless that is the expressed desire of the individual.

Providing all services on-site is in direct conflict with the mandate for community inclusion. Our family members want and need to get out into the world and to learn new skills.

For those older individuals ready to retire from their day programs, there should be flexibility to develop alternative social activities in the form of Com Hab-R or recreational senior programs.

Our greatest worry is that decisions about programming will be more cost-centered than person-centered.

During the pandemic we watched staff struggling to do their jobs while being at extreme risk of getting the virus and spreading it to their families and ours. We know how hard and complicated their jobs are because we as family members have done them, and do do them.

We know how undervalued DSPs are.

One thing we should do is look to them as a source of suggestions about how to deliver supports and services more effectively, as they do that every day.

Flexibility would be great for everyone.

Burdening DSPs and providers with excessive amounts of documentation does no one any good.

Agencies and DSPs themselves are a great resource in figuring out the difference between useful and counterproductive regulations.

This increases the ability to be innovative, and frees DSPs from excessive documentation so their time can be spent with those that they are tasked with caring for.

Thank you very much for listening.

SENATOR MANNION: Thank you, Ms. Krassner; I appreciate it.

And, next, I'd like to introduce Rhonda Frederick from People, Inc.

RHONDA FREDERICK: Hi. Thank you very much, Senator Mannion.

I really appreciate the ability to give this testimony, as well as thanking you as the Chair of the Standing Committee on Disabilities for calling this together.

I am from People, Inc., in Buffalo, New York, and I'm going to talk more specifically about the temporary-use respite.

My organization opened two such programs.

We had two respite homes that were able to be used for this. And we started to use them before OPWDD came in and said that it was something that we

could do.

It wasn't that difficult with OPWDD to set up, but they did not seem to be much of a realization of what it entailed.

Yes, we had two homes. Yes, we had bedrooms and bathrooms. We needed to get nurses, LPNs, and direct support professionals to staff 24/7. We had to find full PPE; masks, gloves, gowns -- everything.

We decided we needed to have a place outside for our staff to change their clothes; to put on scrubs, put on their PPE, and go out.

We had to have a place for them to take a break. It couldn't be within the house.

We ended up doing two homes because we did one home for people that we knew were positive, and one home for people that were under investigation.

We served over 100 people.

We opened it up to our own agency, to the community, and to other agencies, and we're really glad we were able to do it; and actually just closed on June 1st.

During the time, some of the things that became a little difficult:

The billing changed halfway through, how we

would be reimbursed.

There was onerous paperwork on who was there, who wasn't.

And the selection of people that were eligible to go there was not within our control, not within the control of the other agencies or the hospitals and families. It became very, very difficult.

We did -- we had to provide information on burn rate of our PPE.

Well, it didn't really matter what we told OPWDD because they could not help us in getting more PPE.

So we also gave our staff hazard pay. No idea how we were going to fund that.

So when -- in closing, I just want to say it was a wonderful idea.

It helped us keep our infection rates very low. We helped the community, but I think we did it mostly on our own.

Thank you.

SENATOR MANNION: Thank you for that insight, and thank you for the ability to be able to make those necessary changes for the people you serve.

Next -- thank you, Ms. Frederick.

Next, I would like to introduce Kathy Bunce, State-Wide Family Advocacy Network of New York.

KATHY BUNCE: I want to thank you, Senator Mannion, and members of the Senate Committee on Disabilities, for giving a voice to individuals, families, on this topic, and for your leadership and support for all people with IDD living in New York State.

You definitely are our champions.

My name is Kathy Bunce. I'm co-chair of the DDAWNY Family Committee. I live in Buffalo New York.

My daughter is 25 years old, and she has significant developmental delays and a seizure disorder. She lives at home with my husband and I as an exceptionally social young lady.

COVID was very difficult for everyone, especially for people like her who has high needs.

I'd like to start with recognition and thanks to all providers and DSPs who worked so hard to keep people safe during the pandemic, and continue to do so every day.

They were the definition of "essential," and continue to be.

And I want to credit OPWDD for their hard

work.

This was all new territory for everyone.

Fortunately, Western New York had two distinct advantages: The benefit of learning from other regions who were impacted early and hard, and the nonprofit agency leadership who communicated, collaborated, shared resources with each other and with stakeholders, to meet this challenge.

It was beneficial and lives were saved.

With the vaccine, we see business reopening, schools reopening, mask requirements removed nationally, yet we wait for guidance from Albany to catch up.

Changes were slow throughout, and we still wait for them to address the transportation issue.

We witnessed the success of an agile system in education with private schools who resumed last September in our communities. When positive cases emerged they closed for a period of time to keep people safe. They were agile and they were empowered to make those decisions.

Going forward, perhaps it's time to consider decentralization and a strengthened regional approach to supporting people with IDD.

OPWDD leadership in each region are

knowledgeable of the infrastructure available and the unique needs of the people served in their communities. They have strong partnership with the nonprofit agencies and, together, this team should be empowered to make decisions that are appropriate to ensure safety for the people they support.

We saw the benefits of communication, collaboration, and shared resources amongst our nonprofit providers in our region.

Decisions on care should not be one size fits all, and should not be managed centrally for the entire state. It doesn't work.

Thank you for the opportunity.

SENATOR MANNION: Thank you, Ms. Bunce.

Last panelist for this topic is Karen Nagy from Eastern New York Developmental Disabilities Advocates.

KAREN NAGY: Hi. Thank you, Senator, and thank you committee members.

We really appreciate your outstanding advocacy on behalf of families and people with IDD.

I represent families in the Capital Region, and speak for the steering committee at ENYDDA.

But I'm also a mom. We have a 31-year-old son who is profoundly disabled by autism, and he

receives residential services through a local nonprofit agency.

I'm going to adapt my testimony a little bit because I don't want to be redundant. A lot of the things that have been said don't need to be said again.

So I'm going to really focus on the staffing issue, because I think that some of the program flexibility really was dependent upon staffing that has been at critically low levels. And, really, the nonprofit industry has experienced staffing issues for the last five to six years since the onset of the minimum wage raise.

So, you know, in order to provide flexible programming, you have to have well-trained staff, you have to have -- be able to offer proactive interventions and reactive measures, to meet that individual need, and to respond to any of life's substantial challenges and changes.

We recognize that there's been a failure to thrive amongst a wide range of people across the state and country due to this virus, but preexisting direct-care staff shortages challenged that program flexibility during the pandemic. And the pandemic itself exacerbated an ongoing staffing crisis, and

it threatens the safety and stability of our loved ones.

So, you know, in closing, I would say we need to understand that the direct care of people with IDD has to be recognized as essential, and has to be socially valued and prioritized, and a worthy profession that supports a living wage in a diverse, primarily female and women of color who take care of our loved ones.

Thank you.

SENATOR MANNION: Thank you, Ms. Nagy.

And I think there was certainly a lot that all those panelists presented. And I think the acknowledging that part of our -- of one of the crises that this community faces is a good place to go.

Senator Martucci for two minutes of questions.

SENATOR MARTUCCI: Thank you, Chairman.

So first I see, unfortunately, I think Mr. Moran dropped off. But I'll just -- oh, there he is.

Perfect.

So, really, more of a highlight on your comment than a question -- I'll guess I'll make it

your question.

Could you tell me a little about the struggle you had with respect to the bureaucratic process of getting these respite sites set up.

And, I'm sorry, I don't have much time, because I also have a quick question, thanks to Ms. Frederick.

So if you could kind of fit that in in 30 seconds, or a minute, that would be great.

JIM MORAN: Yeah, I mean, we had worked with a number of the provider associations, some of whom are on this panel, and on the upcoming panels.

We have put together a proposal that kind of went nowhere in terms of to try to create a flexible model for the providers who were in the moment, trying to deal with this, as Rhonda just went through.

We were unable to get that. They had set up a more formalized process of approval.

And, quite honestly, it wasn't targeted to the areas where the largest pandemic was happening, which is in those 10 downstate counties at the time.

Too much time was passing on this. And by the time it got set up, quite honestly, things had already started to calm down.

So it just was -- it was a total bureaucratic process that was put in place in order to move forward with this.

SENATOR MARTUCCI: Thank you, Mr. Moran.

And then my next question is for Ms. Frederick.

First I'll say thank you to People, Inc., for stepping up and establishing those two respite homes.

Huge.

I've heard stories from providers in my area, the same that you told, about the fact that you were sort of on your own.

One of the questions I didn't get to with Commissioner Kastner was, can you just tell us, quickly, a little bit about how people were selected to be eligible to enter these homes.

I know you had some frustration around that.

RHONDA FREDERICK: It wasn't a real clear process.

They would -- their care coordinator, or their family, was to call the local DDRO.

The DDRO would -- there was a liaison. They would call our liaison, Can you handle this person? Then it would go back to the DDRO.

To be honest, in a couple of situations, we just had people calling us directly, and we tried to finesse it that way.

But it often took a couple of days, which it should have taken a couple of hours.

SENATOR MARTUCCI: Understood. Thank you so much.

And thank you all for your testimony. I appreciate it.

I'll echo the Chairman's comment and say, thank you for being here.

SENATOR MANNION: Thank you to all the panelists. I do really appreciate it.

And one thing that we hear loud and clear I think across the state, I'm sure Senator Martucci would agree, we hear it about Western New York and eastern New York, and I hear it and see it in Central New York, is that the providers, the advocates, work together to make things work.

And that's certainly shown through here with our panelists in this group.

So I really appreciate everyone participating today.

Our next panel is related to personal protective equipment, and our first panelist is

Randi DiAntonio from PEF (Public Employees Federation).

RANDI DiANTONIO: Good afternoon, Senator Mannion, and all the distinguished committee members.

First off, I'd like to thank you for holding this roundtable today.

I think it's incredibly important for us to review the things that have happened over the last 16 months, and what we can do, moving forward, to ensure that some of the mistakes and the issues that we saw are not repeated if we, God forbid, ever have a future public health emergency.

I want to say we appreciate, you know, that this was an overwhelming situation for everyone.

And like everyone on this call, we want to ensure that you're aware of all the things that went on.

So you do have our written testimony. There's a lot of information in there.

There's also several letters that I point your attention to, that went from PEF to the OPW Commissioner from the onset, up until early 2021.

I'll focus my comments on PPE.

So at the beginning, no surprise, there was

no real plan in place to deal with this. It was a scramble. Coordination was very disjointed between central office and the various DDSOs.

The comment by Ms. Bunce on the earlier panel about waiting for Albany is something I think all of us in the field experienced.

It has been disjointed for quite some time because of the centralization of how decisions are being made. And I do think that that is something we should certainly look at, moving forward.

Across the board there were insufficient and inadequate supplies of PPE. Many locations had no masks, no gowns, no eye or face protections.

Conservation of PPE lasted for several months.

At the very beginning, and up until maybe two or three months into it, people were being given one mask and told to use them for up to five days. They were being hung on bulletin boards to dry out.

This obviously undermines the quality of the PPE.

Gowns were reused. Several DDSOs were running out of gloves, cleaning supplies.

PEF represents the State side of the system, and, you know, we have also been dealing with crisis

staffing issues.

PEF ended up buying PPE and supplying PPE to many members and -- to help them stay protected.

Over time the agency did begin to provide more masks and other PPE; however, they still have not implemented any N-95 fit testing programs.

They are still opposed to our position that N-95 should be utilized, not just for aerosolized procedures, but also when providing up close and personal care.

We have had this conversation since the very beginning.

There is still no consistent testing process being done.

So it is very difficult to assess how accurate the numbers that were provided earlier are when you don't have a very formal testing process in place that is easily accessible to the staff.

Basically, at this point, you know, we know that, moving forward, we want to make sure we have all the supplies on hand.

The agency needs to be accountable, to have a sufficient PPE supply; to ensure staff are properly trained; fit tested, fit checked, for any interactions with COVID-positive or suspected

individuals.

There also needs to be clear procedures for procurement, which has fallen apart over the years because they centralized procurement through the business service center.

So I know I'm out of time, so I will limit my response, but thank you so much.

SENATOR MANNION: Thank you, Ms. DiAntonio.

Next panelist for this topic is Cyndi Borozny from the Arc of New York.

CYNDI BOROZNY: Thank you, Senator Manning [sic], and other committee members.

My name is Cynthia Borozny. I am the chief financial officer for the Arc of New York.

On the onset of the pandemic, the use of appropriate PPE was quickly identified as a critical factor in mitigating the transmission of COVID-19.

However, despite our vulnerable population, we were not granted priority access to PPE through state and local emergency agencies. We were offered no additional resources for procurement of PPE.

Our dedicated staff who provide 24-hour close-contact care were not identified as essential workers or provided the same protections other health-care providers were.

The Arc found itself scrambling to create contacts, and purchased PPE from vendors whose costs were rising with the demand. We were forced to develop an independent system for procurement and distribution of PPE, a system which required significant financial and operational resources to sustain.

Executive staff and chapter leadership took shifts unloading tractor-trailer trucks full of masks, gowns, gloves, thermometers, and other needed supplies. Our headquarters became an ad hoc PPE warehouse and distribution hub.

Our organization had strategic financial reserves which we used to purchase over $4 million in supplies. We were fortunate.

I have no idea what smaller providers did to ensure the safety of their staff and the people they support.

Thanks to recent policy changes, most of the PPE costs will be reimbursed by FEMA. But that was not a guarantee when we were draining our reserves, and the costs -- the other costs of the pandemic will have repercussions on our field for many years to come.

In the future, we need a streamlined system

for PPE procurement, distribution, and adequate funds to cover these costs.

We need staff to be recognized as vital frontline health-care workers, and we need to be better prepared and better supported to ensure that the safety of New Yorkers with IDD is required.

Thank you for the opportunity to share our experience with you today.

SENATOR MANNION: Thank you, Ms. Borozny.

Next, I'd like to introduce Margaret Raustiala -- Raustiala --

You can correct me, Margaret. I apologize.

-- from State-Wide Family Advocacy Network of New York.

MARGARET RAUSTIALA: And what -How do I get on here now?

Am I on?

SENATOR MANNION: You're on, Margaret.

MARGARET RAUSTIALA: Okay. Thank you.

Thank you for your leadership. You really hit the ground running; appreciate it. And we appreciate the great job you're doing.

Anyway, it was March of 2020, not March of 1820; yet with more than 37,000 community-based residential settings, apparently, New York State

neglected to plan for or distribute PPE to the residents and staff who lived and worked in these settings.

As a parent, I salute the providers and their associations who, in the face of zero assistance from government, were forced to swing into action and dive into a world where they had no contact or experience.

In those early days, when I learned of the dire need for PPE in my son Rico's [ph.] group home, I reached out to a longtime friend who I knew sewed.

Please, would she make masks for the residents of Rico's group home?

A former nurse, she knew what was required and came through with 30 masks.

If this sounds ridiculous, it's because it is ridiculous, and it should never ever happen again.

Much of the needed PPE was manufactured in China. The providers had to learn how to make foreign contacts, ensure that the vendors were properly vetted, pay for, and distribute PPE.

Of course vendors knew that they were desperate, so the cost of these -- this PPE was exorbitant.

My understanding is that the cost of PPE was

not reimbursed until recently for some, and still not for others.

It should be noted, as I think an earlier person mentioned, that under the American Rescue Act, at the increased -- FMAP would be used for -- you know, for reimbursing the providers for this PPE.

But this is spilt milk.

The important thing is it never happens again.

When New York State develops its plan for responding to future pandemics, and, unfortunately, the experts assure us that there will be future pandemics, the system of supports and services to individuals with developmental disabilities must be a priority in the same way that hospitals are priority.

Future plans must designate DSPs the backbone of our system, and other staff for OPWDD-funded services and programs, to plan accordingly for their need for PPE. And future plans must designate the service recipients of OPWDD-funded programs to be a priority, and plan for PPE.

People with developmental disabilities who live in congregate settings got sick with COVID

three times more often than the general public was from this disease, and three times more often they died.

Due to the lack of transparency regarding the number of residents in group homes that became sick with COVID, as well as the number that died from COVID, research to find out the percentage of the higher rate -- what percentage of the higher rate was due to the underlying comorbidities that Dr. Kastner mentioned, and what percentage was due to the lack of PPE early on, the State's slow response to providing guidance on quarantine, and the State's slow response to provide guidance on proper training.

New Yorkers with developmental disabilities, and those who care for them, will never again be forgotten and left to fend for themselves.

Thank you.

SENATOR MANNION: Thank you, Margaret.

I appreciate those strong words.

Next, I'd like to introduce Tom McAlvanah from New York Disability Advocates, and InterAgency Council of Developmental Disabilities.

TOM McALVANAH: That's great.

Thank you, Chair Mannion, and thanks,

Senator Martucci, and all the members of the committee, and thanks to our panelists, and thanks for having us here today.

When the pandemic hit, the IDD service system struggled to be recognized as a significant component of the public health system responsible for keeping our particularly vulnerable population safe and out of hospitals.

Our residential programs were left to finance the cost of the public health emergency on our own without any financial support from the State to meet the increased cost of PPEs, staff overtime, hazard time, sanitizing, and other equipment and supplies, and other COVID-related expenses.

NYDA did a survey that estimated that, between March and October of 2020, not 1820 as Margaret suggested -- we -- our providers spent out $34 million just to help get the supplies needed for their hero DSPs who were on the front lines every day.

It -- pretty much, and down in New York City, it took nearly six weeks to get any response. Certainly it took that long, if not longer, to get our DSPs recognized as essential workers. And you'll hear about that some more later.

But for us, we had to commandeer -- as Margaret mentioned, we commandeered orders from China. We worked with a local distributor.

IAC member agencies spent, initially, about three-quarters of a million dollars on it.

We worked with other NYDA partners later in the year, and we spent well -- millions of dollars to secure our own PPEs.

I'm just going to read to you, quickly, a couple of things.

One is, that the message from OPWDD, when we were trying to get PPEs, was first to source from a local supplier; which, of course, pay for it on your own.

Second was, to reach out to your local county's OEM.

And if did you not get a response from the OEM, then inform the incident management unit via an email, with a ticket number we received from OEM, your specific request, the number, and supplies, et cetera.

And on April 2nd we received an email from the OEM, that due to the national shortage of PPEs, collection swabs and other medical supplies, DOH and [indiscernible] cannot supply programs, like this

one particular provider, with these items.

It is critical that these supplies be prioritized for our health-care system, in particular for hospitalized patients.

I think what this really comes down to is, is that the entrenched bureaucratic processes, the compartmentalization of government, when a crisis hits does not work.

We have to, as New York State, remember that we provide 90 percent of the services, the not-for-profit community in this state, and 80 percent of the certified services.

And I know I'm out of time, I'm wrapping up.

What we need, is we need greater financial resources and supplies to help us manage the crisis.

When 9/11 happened, when hurricanes "Sandy," "Irene," and all those other related events, when blackouts happened, we didn't wait for OPWDD.

I was an executive director of a residence down in Lower Manhattan that got flooded out.

We immediately moved our people to a day program, set up bedrooms, had the staff who they knew there, and actually provided a safe and secure environment.

That's what this community does.

That's what our providers do every day; not waiting for a bureaucratic process to try and tell us how we should go about it.

We believe in our mission, we believe in the people and families we support, and we will always be there.

Thank you, Mr. McAlvanah.

Our last panelist for this group is Alyssa Galea from Disability Rights New York.

ALYSSA GALEA, ESQ.: Thank you again, Chairman Mannion, and the committee, for the opportunity to speak today.

It perhaps goes without saying that I don't think that we can overstate the importance of PPE to group homes. Their shared living spaces, the people who are there are at a greater risk of infection and complications from COVID-19. And the staff working there typically provide extensive hands-on care that makes social distancing physically impossible.

Since March of 2020, OPWDD and DOH's guidance has recognized the need for PPE to limit the spread of infection in group homes.

We all know that there's been a lot of trouble that group homes have had in getting PPE, and we know that there was a national shortage in

the early months of the pandemic.

But something told to us as a significant issue was the fact that group homes weren't considered a priority, so that [indiscernible] allocations PPE that was available.

We had providers reporting to us that they approached offices in their systems, and were told that they were not an essential health-care setting, or because they weren't a nursing home, that their requests were going to be denied or canceled by their local health departments and offices of emergency management, leading, as you've heard, to the providers having to compete in the private market, the higher price, and also sometimes poorer-quality PPE.

We really think that the people who live in group homes can't be an after-thought when it comes to policy, planning, and allocating resources.

We're talking about PPE here today, but we could really be talking about anything.

And people with IDD, and the staff who support them as well, need to be part of the conversation from the beginning at every level of the state and local governments to ensure that they're planned for and protected in future public

emergencies.

You had mentioned a bill to require OPWDD to provide PPE to their providers.

And we think, you know, DARNY, we definitely support that. But, you know, it's part of -- we really think it should be passed as part of a larger conversation for all resource allocations and planning.

We know this community needs to be at the table from the get-go.

Thank you.

SENATOR MANNION: Thank you very much.

And I agree, the conversation included items related to training and testing. And I don't even know if we're going to get there.

But back to Ms. Galea's comment, I will say, yes, there is a bill out there, but we want to do more good than harm.

So I'm interested to hear from anyone, as we have a bill, where OPWDD, in a public health crisis, would have to provide PPE for different providers.

Is that the right method?

I hear contradictory statements about the necessary -- the bureaucracy that we have to go through. And that maybe providers could obtain

these quicker.

Although, in a public health crisis, I know that was a tremendous challenge.

Would you be supportive of this bill, or, as it relates to PPE, would autonomy be better in trying to secure those?

I'm interested to hear from anyone.

TOM McALVANAH: I think, certainly, coordination is key.

And my apologies not knowing each piece of the bill that you have there.

But, clearly, it is a better response than -- than -- you know -- you know, we can't -- you'll have to source it somewhere else.

We actually need a better response from government when we have a crisis.

And I must say that eventually they came through.

I neglected my remarks, the Department of Health and Mental Hygiene in New York City eventually came through at the end of April to supply PPEs. But it was through them. It wasn't even through OPWDD.

Why DOH has to have the final say in terms of what happens to an OPWDD certified residence is a

little unclear to me.

SENATOR MANNION: And to Ms. Borozny, have you already been reimbursed by FEMA for the purchase of the PPE?

CYNDI BOROZNY: So we have received about half of our reimbursement, and we still have a few applications that are under review.

SENATOR MANNION: Thank you.

And, Ms. DiAntonio, you stated that your organization had provided PPE to your members.

Are you eligible to receive reimbursement dollars from FEMA as -- as a labor association?

RANDI DiANTONIO: I don't know, but it's certainly something our secretary-treasurer would be looking into and be very interested in.

I will say that, you know, some of the changes that happen on the procurement side many years ago, I think, influenced how this rolled out.

You know, when DDSOs had control over their local procurement, they knew what was needed, they could work with local agencies and within their own system.

And now everything goes through a centralized business service center. It takes much longer. They don't -- the types of things we need to order,

like gloves and medical supplies that we would have normally had on hand, we didn't, because it's been years of flat budgets.

And so there's definitely a lot of room for improvement in coordination, and shifting how local authorities are able to maneuver throughout purchasing.

SENATOR MANNION: Thank you.

Senator Martucci.

SENATOR MARTUCCI: Thanks, Chairman.

You know, you really covered, I think, all the questions.

And, certainly, all I just wanted to say to everyone was, thank you for all that you've done in terms of stepping up in the absence of the department providing leadership when it was needed the most.

So, you know, the story I heard from all of you is the story that I've heard from providers in my region, and providers that have reached out to me, which is that -- is what -- it's what Tom talked about, is that this is an industry of folks who don't wait; but, rather, act quickly.

And I think your quick actions undoubtedly saved lives.

So thank you for what you did.

And, certainly, I could not agree more with respect to the fact that it's so important that we prioritize DSPs as key -- as key, in terms of receiving PPE as we move forward, because you are as critical as it gets.

So, again, thank you all for all of your testimony today.

And thank you for, like I said, the -- lifesaving action that you took in the absence of leadership from the State.

SENATOR MANNION: Thank you, Senator Martucci.

Thank you to all of the panelists.

I think this is probably a good segue into staffing and testing, particularly, as I'm sure we will hear, about establishing DSPs as an occupational code with the Department of Labor, which is absolutely essential.

Being mindful of time, I'd just ask that all panelists and chairmen and others try to adhere to the two-minute rule, as we're up to two hours here.

I do think that this conversation is a very good one, necessary. And certainly, you know, there's being -- you know, I think we're only

validating what needs to be prioritized, and also seeing areas where we can improve.

So our next panel, as I said, is related to staffing and testing, and our first panelist is Joshua Terry from CSCA Local 1000.

JOSHUA TERRY: Thank you, Chairman; thank you, Senator Martucci.

I hope this is one of the final of these events that we do via Zoom, and not in person.

But thanks for having me.

I mean, CSCA represents 10,000 direct-support assistants within OPWDD.

They showed up every day of this pandemic; they kept coming to work in every part of the state, and they never stopped.

So I think we can praise them, and we call them "heroes," but I think our actions are going to speak louder than words in the next few years.

Senator Mannion, just to answer one of your questions earlier about deaths in the workforce, we've been able -- we found, sadly, 12 of our members in OPWDD who have passed away from COVID that they contracted on the job; and that's because they kept showing up, they kept taking mass transit to get to work.

And it's really sad.

But -- you know, and that may probably is an undercount, just because we don't always know. But that's our number.

What I want to talk about is the structural staffing deficit that we have inside of OPWDD.

COVID-19 did not cause this structural staffing deficit, but it definitely highlighted our needs.

Over the last decade we've had a decreased workforce in OPW of 15 percent.

This has caused massive increases in overtime. So just for example, since 2010, the average OPWDD employee works five additional workweeks of overtime every year.

I mean, so that's just how short-staffed we are.

Due to this staffing deficit and their status as essential workers, OP workers were required to go to work. Even if they had a positive COVID -- COVID-19 diagnosis, but were asymptomatic, they had to keep going in.

I mean, they -- we are so stretched, that even contracting this virus could not let them miss work if they were healthy in other ways.

We also had members that had to float from -- in clusters from home to home, which likely spread the disease into different homes among staff and residents.

One thing that I want to bring up, that we did found [sic], when the day habs closed, that freed up about 1,000 of our members to go back into group homes.

In those group homes, we have found that overtime was driven down so much because of the influx of staff.

So we know that staff -- more staff works, more staff will let us have our overtimes come down.

So what we need to work on is a statewide policy, between the State and the voluntary providers, to recruit, train, and retain these workers so that we don't end up in this situation again, because COVID's over, but we still have staffing needs.

And I know my time is up, but I'll be glad to talk about this further.

SENATOR MANNION: Yes, we agree, Josh, absolutely.

Next, returning is Marco Damiani from AHRC New York City.

MARCO DAMIANI: Thank you again, Senators Mannion and Martucci.

The IDD workforce is our most valuable asset. The work they did at the onset of the pandemic, and continued to do, is the definition of "essential."

Now, Josh just covered a number of staffing considerations, and don't need to repeat them.

However, I will add that we must continued to advocate for and achieve a living, not a minimum, wage, as well as a powerful career path, across New York State for the DSP workforce.

It's about equity, it's about stronger recruitment and retention, and it's about time. They have done more than enough to earn it.

One of the most challenging staffing issues early on was the availability of additional nurses.

We haven't heard a lot about this.

Group homes are just that: they're homes, not medical facilities.

So the immediate need to add nurses to group home staffing was extremely tough.

We were able to get some additional nurses through temp agencies at a very high cost, as, virtually, all available nurses were already deployed to hospitals and nursing homes.

More effective staffing models, with the assistance from government, to access these vital professional supports are needed going forward just in case.

Routine testing is one of the pillars of pandemic management.

When testing finally started to became available more broadly, we immediately applied for and received a limited-lab license just to get access to 2,000 rapid testing kits.

Most other organizations can't do this. We were lucky we could do it.

Many agencies are bearing very substantial testing costs. FEMA may or may not cover all of these expenses.

Rapid testing capacity is critical. We're talking a lot about vaccinations, and that's important. But rapid testing is critical. The technology is there, and readily available. Let's make immediate and full use of it, and be funded for it.

Thank you, again.

SENATOR MANNION: Thank you.

Next, I would like to introduce Rachelle Kivanoski from NYC FAIR.

My apologies, Rachelle, if I missed.

RACHELLE KIVANOSKI: No, you were perfect. Thank you.

And I want to thank Senator Mannion, Senator Martucci, and all the members of the Disabilities Committee for this opportunity.

My name is Rachelle Kivanoski, and I am a member of the executive committee of New York City FAIR, an organization of family advocates.

I'm also the mom of a young man who resides in a small certified IRA.

My son and I have both witnessed and endured this pandemic firsthand, including a two-week quarantine in his bedroom due to illness of one of his four roommates, and the prolonged lockdowns.

We so appreciate the dedicated lifesaving work of our DSPs.

We in New York City FAIR understand the challenge of developing nuance policies during the early chaotic days of the onset of the pandemic and lack of available testing.

What I would like to focus on today are the decisions made during the early fall that may well have contributed to potentially avoidable infections and deaths during the second wave of the pandemic,

and are still not adequately addressed in the newly revised OPWDD guidelines released on May 17th.

There were close to an additional 200 deaths, from December to mid-May, out of the total 669 deaths in group homes; once again, at a higher rate than the general population.

While the robust rate of vaccination has provided protection to the overwhelming majority of group home residents, significant risk remains as people start to return to other programs where the proportion of vaccinated individuals who reside in the community, and staff vaccination overall, remains below 35 percent.

Perhaps the most problematic existing guidance permits staff with known COVID exposure to continue working as long as they are asymptomatic, as Mr. Terry just said.

While OPWDD acknowledged the risk of asymptomatic transmission, the guidance clearly underplayed its importance, and relied only on masking, hand hygiene, and the almost impossible standard of social distancing within a residence.

The current COVID infection rate is very low, but it undoubtedly underestimates the level of asymptomatic infection in the community at large.

Since asymptomatic people generally are not tested, there is still no mandatory COVID testing for staff or residents even when there is a positive case in a residence or in a program.

The "see no evil" approach to infection control continues to put residents and staff at risk.

And I would like to echo Mr. Damiani in saying, in-home rapid testing kits are now readily available at a reasonable cost, especially if some of the enhanced FMAT funds are allocated for this purpose, and for providing incentives to staff to get vaccinated.

So we would like to recommend mandatory on-site pre-shift testing of all unvaccinated staff in all residential and day program sites.

Unvaccinated staff with known COVID exposure should not be permitted to work, and providers should strive to reduce assigning staff to multiple sites.

Thank you.

SENATOR MANNION: Thank you for your statement, and thank you for your recommendations.

Moving on, back to Michael Seereiter from New York Alliance for Inclusion and Innovation.

MICHAEL SEEREITER: Thank you again for the opportunity.

On staffing, direct support professionals, it's their dedication, their commitment, and their willingness to put themselves and their families in harm's way to support people with disabilities.

They were the most significant factor in why people with IDD were not more significantly impacted by COVID through this crisis.

As we heard earlier, DSPs literally moved in and slept on the floors and the couches of those with IDD that they support for weeks on end.

And we've hoisted DSPs up on our shoulders and lauded them as heroes; yet their pay is humiliating, and it speaks to a hypocrisy in our society's values and a correlated government prioritization for funding for this work.

During the early days of the pandemic, many DSPs said something like, if we aren't respected as a profession and compensated appropriately after this display of commitment, and risking our lives and our families' health and well-being during COVID, I'm done.

And now we're seeing that exactly come true with an unprecedented staffing emergency overtaking

us as we speak.

We must take immediate short-term and long-term steps to address this emergency now, and for the future.

We outlined many of those steps at yesterday's Emergency Workforce Summit, and we now need to take some action.

The other significant reason that people with IDD were not more impacted by COVID is the extraordinary measures that provider organizations went to to procure PPE and pay hazard and hero pay, largely without the reimbursement of revenue that we were just discussing.

Tom mentioned earlier about the cost the providers incurred for PPE.

Additionally, providers paid $130 million in hazard and hero pay from the period of time, from March to November; while at the same time, their revenue went down $327 million.

We need to use some of the enhanced FMAT resources to recognize and reimburse for these largely unreimbursed expenses, and to begin paving the way for bringing DSP wages back up.

Lastly, I think it's important that we recognize that DSPs are disproportionately Black and

Brown New Yorkers, not dissimilar to other caregiving and human-services sector professions.

As Jim Moran said previously, the nature of the work makes people susceptible to infection transmission with a virus like COVID. So it's not hard to surmise how COVID infection and death rates are higher in Black and Brown communities, in part, because -- in part, caused by the jobs that these people have, or had, as the case may be.

On testing, access to testing, it was a significant problem early on.

It is clearly linked to a significant lack of recognition by New York State; I would say Department of Health, the health system overall, about OPWDD, its system, and direct support professionals as essential workers, as others have noted before.

And it took exceptional levels of advocacy from all levels of stakeholders, and OPWDD included, to get IDD services, and others, like behavioral health, recognized as part of the public health system for the purposes of the pandemic management.

We can't let that happen ever again; we can never again be left as an after-thought.

Thank you.

SENATOR MANNION: Thank you, Mr. Seereiter.

Back to Jim Moran from Care Design New York.

JIM MORAN: Thank you, Senator.

I'm going to sort of shift away from my testimony, which is really focused on the vaccination and testing of employees. Clearly, it's a critical issue that has been talked about.

I wanted to shift to -- really, to a bill that you've now sponsored, Senator, and that is, at the height -- the ultimate slap in the face I see with all of this, during the height of the pandemic, that a budget proposal was put out to cut the rates of the service -- residential service providers; to eliminate hundreds of millions of dollars of funding to the residential providers during the height of a pandemic.

And the fact that, you know, well, that's because we've got to make the numbers work.

And, you know, as somebody -- as one of the parents said earlier, the State has been cost-centered as opposed to person-centered.

And at the height of a pandemic, to think that that -- that -- that really tells you what the feeling is of the value of not only the people that we're blessed to be able to support day in and day

out, but the people who work with those individuals to help them live the best lives possible.

I want to get behind your bill, Senator, and really applaud you for taking that on, because the last thing the providers -- service providers need right now is one more cut.

Enough is enough.

So, thank you.

SENATOR MANNION: Thank you, Mr. Moran.

I went out of order a little bit, so I apologize to folks.

I will make sure that I catch everybody.

But, next, is Julie Keegan from Disability Rights New York.

JULIE KEEGAN: Good morning -- or, good afternoon, Senator.

I really appreciate the opportunity to be here from Disability Rights New York, the protection and advocacy system for New York State.

Much of what I had planned to say is covered in a very comprehensive report that my colleague Alyssa Galea alluded to, which was based on a seven-month study, looking at the treatment of people in group homes in New York during the COVID pandemic, and the State's response.

And that is available on the Disability Rights New York website.

But I do want to highlight a few things that have been talked about here, to some extent, but the first is, with regard to staffing, is I want to emphasize also, that these are individuals, the direct support professionals, that are working in these very stressful times, not only getting paid less, but, also, because of the diminished workforce, having to cover extra shifts and working in a short-staffed situation.

These folks are disproportionately Black in New York. Only 17.6 percent of the general population is Black. But for direct support professionals, we're looking at 35 to 42 percent.

That's very significant.

Also, direct service professionals are disproportionately women, and they're people born in other countries.

So I think we need to be mindful of that when we're looking at pay equity.

And then, also, and I will say it also, there was heroic, absolute heroic, conduct by these individuals during this crisis.

And I totally agree with Michael, that more

people would have died had not these folks stepped up and stepped in and stayed for weeks on end to minimize exposure.

With regard to testing, what I wanted to say there, is that it's very shocking and disturbing that individuals in group homes are not given the same priority and the same protection as people in other congregate settings.

Although testing was not widely available at the outset of the pandemic, this has not been the case for many months.

And, indeed, over a year ago, New York State mandated staff testing in congregate settings other than group homes. Beginning on May 15, 2020, staff working in nursing facilities were mandated to be tested two times a week.

It's very troubling that people in group homes are not given the same protection as people in nursing homes and other congregate settings.

People in group homes require close physical contact with staff and confined spaces just as people with nursing homes do.

As Dr. Kastner mentioned today, people in group homes often have comorbid conditions that put them at higher risk of serious illness and death

just like nursing home residents.

There is no rational basis for this discriminatory practice.

For all of these reasons, the State must require and fund regular testing of staff who have not been vaccinated.

We recommend that both direct support professionals and provider agencies be required partners in creating the parameters of a testing mandate.

Thank you very much.

SENATOR MANNION: Thank you very much, Ms. Keegan.

Next is, we're back to Randy DiAntonio from Public Employees Federation.

RANDI DiANTONIO: Thank you, Senator Mannion.

So I am from the Public Employees Federation, but I've also worked for OPWDD for 23 years as a social worker.

And I agree with a lot of what my fellow panelists have said today about the staffing crisis, and that crisis clearly goes across all state agencies, but, in particular, OPWDD has been the hardest hit.

My colleague from CSEA mentioned about

15 percent of the workforce has been lost over the last decade.

That equates to over 4500 employees.

Let me say that again: Over 4,500 employees.

OPW had the most overtime of any -- 25 percent of the 19 million hours worked in overtime during COVID was OPWDD.

There's been a systemic effort to shrink the footprint of this agency and the critical levels of care. And we saw it magnified throughout this pandemic.

The shortages started to allow the agency to justify a trend of suspending services, closing group homes, because they couldn't staff those settings.

Many of our members who are not DSPs, but are habilitation specialists and nurses, were redeployed into the group homes, and were willing to do whatever they could to support their brothers and sisters, you know, doing the frontline work; however, a lot of this increased density in the homes, it increased transmission risks because people were being redeployed from one place to another.

We've seen over the last 10 years a loss of

3,000 beds. And that wait continues to increase because of staffing shortages as we speak.

Everybody has heard about the nursing shortages. And OPW is significantly impacted by their un -- inability to recruit and retain nurses.

We still have not seen hazard pay for our members who have been on the front lines.

There is a lot of things going on where short-staffing has increased the risks.

And I know I'm running out of time, but I want to address one issue related to the Department of Health guidelines that were issued.

These guidelines for returning to work after a positive case allowed agencies to bring people back after a much abbreviated quarantine period if they wore a mask.

But, basically, we were bringing back positive people into homes because we didn't have enough staff.

And I would just encourage, and I thank the Senate for passing Senate Bill 1765A this week, which would allow -- or, engage the agency in a reporting process on staffing and fills, but this has to be more transparent.

We need to know why vacancies aren't filled,

and why they're not recruiting and retaining staff.

And there are reasons for this, and we need to have these conversations.

So staffing is a critical need, and we look forward to partnering with all of you as we move forward.

SENATOR MANNION: Thank you, Ms. DiAntonio.

Our last panelist for the topic is Peter Zummo from the New York Alliance for the Developmentally Disabled.

PETER ZUMMO: Thank you, Senator, for your leadership in this area.

Being last means a lot of the good things have said, so I'm justed going to speak as a father and a family member.

I have a son, 23 years old, Andrew. He has autism. He's low-functioning and non-verbal. He lives in a certified IRA.

Andrew and his three housemates require 24-hour care. During COVID, the staffing of his house was reduced to a barebones level because there was no staffing available to fill all the positions.

Now that we're on the other side, staffing is still reduced. This has diminished my son's quality of life. For example, he rarely ever gets to leave

the house because there's never enough staff for him to do so. He only gets to go out when we, me or my wife, take him out.

DSPs are, ultimately, what make the house work. Without them there would be no residence for my son.

The DSPs that are now working with Andrew all stayed through their jobs through the pandemic.

They're dedicated, they care, but they also have to earn a living and pay their bills.

OPWDD must provide funding to the agencies that would allow them to pay the DSPs what they deserve for the work they do.

Lack of State funding has made a DSP's wage not a living wage.

That is no longer acceptable.

In addition, OPWDD has instituted cuts to residential rates that will take millions of dollars out of the system at the very time when millions of dollars need to go into the system to provide compensation for the DSPs.

It's actually surreal that, coming out of a pandemic, with an ocean of federal dollars coming into New York State, that OPWDD would cut residential rates at this time.

But it's not just residential. Many day habs are also closed, or have not reopened fully, due again to a lack of staff.

My son is lucky; he's in his day hab.

But I personally know of one person who lives in an IRA, who has not had day hab services since March of 2020 due to staffing problems. His IRA is provided by one agency. His day hab is another agency. He has received no services since March of 2020. He sits, watching TV, 15 hours a day -- I'm sorry -- for the last 15 months, he sits, watching TV.

It's unacceptable.

Proper staffing is essential to make this system work.

We cannot let our people down. Our population deserve to be treated with dignity and respect.

OPWDD needs to stay, stay the course, and provide the resources necessary to make this system what it should be.

Thank you.

SENATOR MANNION: Thank you, Mr. Zummo.

Senator Martucci.

SENATOR MARTUCCI: Thanks again, Chairman.

So I guess maybe the first thing I'll start off with is, the Chairman and I, I know wrote a letter together, opposing the cuts to the voluntary residential programs.

So I think we certainly share the sentiment that you all have raised with respect to that issue. Certainly, now is not the time to be making cuts to these programs.

So we couldn't agree more.

My thanks to Randy and Josh for being here.

And certainly, your membership, and, really, the DSPs, and other service providers around our state, who, again, [indiscernible] -- some of you have come back from different panels, so you've heard this before -- but have really filled a gap of leadership that this State left, and took absolutely life-saving action to make sure that things weren't even worse than they are now.

And, lastly, you know, I only had 10 minutes of questions with the Commissioner, but what was certainly positive that came out of my discussion with him was a willingness for he and I to sit afterward.

And I do have tremendous concerns with respect to the abbreviated quarantine period that

was brought up. I think that that certainly is a -- I have tremendous questions about, you know, how that not only affects the safety of our staff, but the folks that live in these facilities.

And then, lastly, I couldn't agree more with the importance of testing at this time.

I know, Ms. Keegan, you talked about it, and others, how critical that is that this State step up, not only mandate it, but financially support it.

So I look forward to continuing that conversation because I too am aware of that information that shows us that, from December to mid-May, our fatalities tipped up by 200.

And during that period I was making multiple requests to OPWDD about this data. And for a large portion of that time that data wasn't available.

So, unfortunately, it was a grim statistic that confirmed for us that the problem was far from behind us.

So you've certainly got my commitment that I'll be following up with the Commissioner on that, even though I did not have an opportunity to ask those questions today.

Thank you, Chairman.

SENATOR MANNION: Thank you.

Obviously, many concerning things that are coming up again, including, you know, the COVID-positive patients that were forced to return to work. That is the extreme nature of the workforce crisis I think that we're in.

And I can -- will just quickly say, to Randy and Josh also, thank you to your members for, literally, giving their lives to care for others. And my best to their family members as well.

For the family advocates that are on here, we can hear it, we can all hear it, you care about the people who care for your family members.

I had an aunt who lived in a residential facility.

We need to treat these people with dignity, respect, and equity.

And I think we're all on the same page there, and we're all going to make sure that we do whatever we can to make sure that they are properly respected, that they have that dignity.

And the only way to do that is to properly fund it, and we're all going to push together, as I know Senator Martucci agrees.

And the folks that I've had the pleasure of

meeting, that are across the screen, are going to push with me.

So thank you all for participating today.

Thank you for your advocacy for the people who do the work.

And thank you to the people who did the work, and who represent those.

So I appreciate it.

Our next panel will be on visitation.

Our first panelist will be BJ Stasio from Self-Advocacy Association of New York.

BJ STASIO: Thank you for having me back; I appreciate it.

And while we're talking about visitation, under certain circumstances during COVID-19, people in certified settings were restricted in terms of visitation to what they had believed as their home.

They were also restricted from participating in their community.

While the Self-Advocacy Association does not question the intent and importance of preserving health and well-being, even lives, their restrictions raised significant questions among self-advocates about rights.

It was very difficult for people to

understand why they could be told they could not have visitors or access to community when their neighbors, who did not receive services, could choose to do these things.

We asked OPWDD and New York State to explore these rights-related issues that have come up -- come to light in the future, to ensure the strategies to infection-control pandemic management are clearly based on a foundation of individual rights, and that that foundation of any necessary restrictions, should those exist, are communicated clearly in a manner that afford people receiving those services to understand their rights, and the recourse should they not agree with any restrictions, such as easy-read documents, for example, in plain language.

And I would like to say, from my previous panel, I support the point that Michael Seereiter made about smaller group homes. And if people wish to live in their own setting, I would like to -- for people to have the option to explore that.

Thank you.

SENATOR MANNION: Thank you very much, Mr. Stasio.

And next we are back to Peter Zummo from the New York Alliance for the Developmentally Disabled.

PETER ZUMMO: Thank you again, Senator.

Before I discuss the actual visitation issue, I would like to point out the effects of the long-term lockout that my son had to endure, and other residents of the system.

The lockdown caused physical, medical, and psychological harm.

He -- my son developed aggressive behaviors towards staff. We had to adjust his medication to address the issue. He developed alopecia from the stress he was under.

Other residents showed signs of severe regression and depression.

I know people that were forced to miss medical appointments because they were under lockdown, including one person whose glaucoma went untreated, and is now blind in one eye.

As for visitation, from March to July, my son was a virtual prisoner in his house. He was not permitted to have any visitors, he was not allowed to go anyplace or do anything.

His house is not medically fragile. None of the four residents have any comorbidities that would

increase the risk of a poor outcome should they have contacted COVID.

I was not allowed to see my son, even though I'm his guardian, and have the legal right and obligation to see him and check on his condition.

While such a draconian lockout may have made sense in March and April, to extend the total separation of residents from their families and guardians into July and beyond was excessive and unreasonable.

I would like to point out also that the effects of COVID were different from region to region in the state and in the OPWDD system. Treating all the regions alike is not the right way to do it.

I also think we need legislation passed that will establish an "essential family or guardian" designation, which I like to call "EFG."

The EFG would permit each resident, or her guardian, to designate one person who will be her EFG, and that EFG will be granted access to the house the same as if she was a staff member.

This way, if there are future lockdowns, one person from each family, either a guardian or a family member, is designated, and can go into the

house, check on their loved one's conditions, and see that they are okay or if they need anything.

I think if a lockdown is necessary in the future, it should be limited in time and scope only to what is medically necessary.

Locking out guardians and separating families for months at a time is not in the best interests of the residents.

Thank you, Senator.

SENATOR MANNION: Thank you, Mr. Zummo.

Next is, I would like to introduce Susan Constantino of CP Unlimited.

SUSAN CONSTANTINO: (No audio.)

SENATOR MANNION: Susan, you're muted.

SUSAN CONSTANTINO: After all this time, wouldn't you think we would know enough to not be muted?

Unbelievable.

I really started by saying, thank you, Senator Mannion, for everything you've been doing.

And for you, Senator Martucci, we -- I have affiliates who speak very highly of you and all of what you've been doing.

So thank you very, very much.

I come here in a little different fashion,

and so I'm not going to talk about what I had written to talk about.

But I would really like to talk to BJ and to Peter and to other parents, because this is a provider, and our providers across the state.

This was an extremely difficult time for us too.

It goes back to a lot of what's been said throughout all of this hearing.

The first part is, that there were no clear guidance that we received from OPWDD.

Guidance that's put in place and never taken out of place, guidance that was put in for actually, really, downstate, and went through the whole state, is not appropriate, and we know that.

But we also know that, as providers, the people we needed in our homes were our direct support staff. And we knew that we could not control where they were, except when they were with us.

We did not have enough PPEs in the beginning, but that changed, and we eventually had enough.

But we couldn't control who was really working with our folks.

And so the "lockdown," as you call it, and

for us it was, really, we didn't like to think about it that way, but it appeared necessary because our goal was to keep people safe, especially as we saw our individuals go into the hospital or our individuals pass away.

So that really was the reason why.

But I sat in meetings with OPWDD every week for months and months, and nothing changed. And that was wrong because we needed to have the guidance changed, it needed to be looked at differently.

But it goes back to exactly what was said on the last panel: If we would have had the availability or the access of testing, where we could have tested; where we could have tested our staff, where we could have tested, and asked our families to have these rapid tests, only those of us who were lucky enough to have some kind of a relationship with a PPS or with something else where we were able to get the testing, that could have helped.

So forgive us as providers that we locked you out. That was not what we really wanted to do, and we needed to really have a better way to do it.

But also forgive us for trying to keep people

safe, even though the repercussions, as you had talked about, Peter, were very great.

SENATOR MANNION: Thank you, Ms. Constantino.

Our last panelist for the topic is Margaret Raustiala.

MARGARET RAUSTIALA: Senator, I'm going to make your job a little difficult because I'm a parent. I represent Long Island Advocacy for the Developmentally Disabled, and I have a very different point of view from the other parent who spoke, and from the Self-Advocate.

March of 2020 OPWDD suspended all visitation in certified residences. It was the height of the pandemic, and little was known with certainty about how COVID spread, was transmitted, and how deadly was the disease.

Given the range of vulnerabilities of the people who live in certified residences, this seemingly draconian suspension of all visitation, in my humble opinion, was necessary.

Many families were understandably upset, but most, most, I believe, recognized the need for precautions.

Later, the memo suspending visitation was amended to permit, but not require, providers to

allow visitation outdoors with symptom checks, temperature taken, mask worn, and social distance when possible.

At the time of the pandemic, my son Rico was 49, and had never gone more than two weeks without visiting my husband and I in our home.

Rico would not talk on the phone or use FaceTime, and we were worried that if we went to visit him in the backyard, he would want to hop in the car and would wonder why he couldn't.

Consequently, after 49 years, we went 5 months, 5 months, before we saw him and could bring him to our home for a visit.

Staff took photos and short videos of Rico so that we could see how he was adjusting to his new life.

Words cannot express the gratification that I feel. This was a difficult time.

Some families were angered by the visitation policy. They believed that if the staff went out in and out of the group home, why not families?

At the time, at the beginning of the pandemic, Leanne took the position that, while separation of residence from their loved ones can cause significant stress and anxiety, as one of the

parents pointed out, it was necessary because the staff was needed. It required staff to go in and out. We don't require families to go in and out.

So as hard as it was, and as difficult as it was, it was the right thing to do.

As more was learned about the transmission of the virus, OPWDD recognized that new strategies were needed, going forward, and to extend the opportunity to visit residents in certified facilitates.

Eventually, protocols were in place to permit indoor visits by persons 18 years or older. These included, again, symptom, temperature checks, guidance, as to where in the home the visit could ideally take place, and requirements for mask-wearing, and as someone pointed out, social distancing, which is often very, very difficult, if not impossible, to achieve.

Since there was increasing evidence that the transmission of the virus outdoors was difficult, given its airborne nature, many agencies strongly encouraged people to come visit their child in the backyard, weather permitting.

The U.S. has now reached a new milestone, with the number of Americans who are fully vaccinated reaching 41.4 percent, as of the CDC

yesterday.

It was more -- the CDC has, like, come out with different guidance that's more stringent than the general public, but gives more flexibility.

Governor Cuomo recently announced that more than 60 percent of adult residents in New York State have had at least one dose of vaccine, and more than 50 percent of the adults are fully vaccinated.

In this case, we are pleased that visitation has become much more loosened up, and especially for those individuals where the resident and the person visiting them are both fully vaccinated, and the visitation takes places in the resident's bedroom or in a designated area away from other people.

We think that this is a very reasonable step.

And we hope that, as time goes on, and more is learned, and, eventually, more and more people are fully vaccinated, that the government will -- New York State government will continue to follow science, and make decisions based on the science that the CDC is coming forth with.

Thank you.

SENATOR MANNION: Thank you, Margaret.

All of that commentary was very powerful, and I can only imagine the range of emotions that your

family members and yourselves felt.

Well, just one quick comment, and then a quick question.

But, Peter, my comment is, that I think your idea is a fantastic one, and absolutely necessary.

And, hopefully, you know, we can -- our office can engage with you to talk a little bit more about that. But your EFG idea is a -- I'm a fan of, and it's absolutely necessary.

And, just, if there's any blessings that come out of this, I think that that, making that change, so that we can make sure that we have access to our family members, is important.

And I've heard this over the course of almost a year and a half how necessary that is.

Peter, you were going to say something, I think?

PETER ZUMMO: Yes. Thank you, Senator.

I appreciate your support in this. And, NYADD, we're 6,000 people strong throughout New York State. We're -- we'll be happy to work with you and your colleagues, and get this EFG legislation passed.

And I think it's a very good thing that is really needed in the system.

Thank you.

SENATOR MANNION: And then my last question, and I think some of the family members and advocates alluded to this, but, you know, were there any options --

I think, Margaret, you had mentioned this.

-- but any options that really were very good options, and, obviously, that was restricted at certain times --

You had talked about your -- the backyard visit.

-- but that were provided to residents to keep in touch that you found to be, you know, on par with, or close to, in-person interactions?

MARGARET RAUSTIALA: As I said, once again, the DSPs came through. They understood, and they would take photographs of Rico, or short videos, and send them to me, on their own. The DSPs really understood that we couldn't see him, and that this was the best thing in our family's case.

And to go back to the proposal that was made in terms of one person being permitted to visit, I still think that testing is going to be the key. I mean, we need -- we can't have -- I don't care who you are, we need now with testing, so that the

people we know who are getting together are free of COVID, or have been fully vaccinated and have that Excelsior pass.

SENATOR MANNION: I think we agree. Absolutely.

Thank you, Margaret.

Any other comments from anyone?

Thank you again, for the panelists, for sharing your story. And, again, I use the word "powerful," but it was powerful.

Thank you, again; I appreciate it.

Our next panel is on vaccination, and our first panelist is Susan Constantino from CP Unlimited.

SUSAN CONSTANTINO: I'm unmuted this time, I'm happy to say, having thought about it.

Well, I really want to thank the people who organized this because they gave me the happy thing to talk about, which is vaccinations.

And I would like to talk a little bit about, number one, thanking everyone, the Legislature, as well as, I believe, OPWDD, certainly NYDA, and all of us who advocated, that our individuals who live in certified residential programs were part of the 1A grouping, and that we were able to be in the

first group to get them vaccinated.

I think it was also important that our staff were in that group, and that made a big difference.

Even though we have not been very successful in getting our staff to accept being vaccinated, I do think that having them be in the first group, having it be easier for them to be able to do, and having them be able to observe our individuals receive the vaccine, was really important.

And we continue to try to keep encouraging that kind of behavior for them, that they would get vaccinated.

I do want to say that OPWDD required a very stringent data collection system on the vaccinations.

And in the very beginning, staff who really were -- who did not have the time and were unable to do this, we're really asked to report on vaccinations every single day. And we were -- it was overwhelming.

And so we worked with OPWDD, and we were able to -- or, a small group of us work with them in order to get that changed so it became at least weekly.

It's redundant. It doesn't really give us

what it needs because it's aggregate. It doesn't give us, like, in which areas are there particular issues about trying to get people vaccinated.

But at least it is data that we've got that we can look at.

But I think what was most important, and I think it's really important to give credit where it was due, the local health departments, once -- during the very beginning of COVID, when they didn't recognize us, they didn't know that the Office of Emergency Management didn't realize they were supposed to support us or help us, but once they learned that, and through the Governor's office, we actually got acquainted with many of them, particularly in New York City, they were magnificent in the vaccination part.

They really helped us to find the places where we would go.

They helped us to support smaller agencies so that everyone had a place to go.

They were -- we could call them and say, "This clinic needs 200 doses on this day," and it would be there.

So between the FQHCs and the long-term care pharmacies, and some other OPWDD providers that said

I'll have it in my own place, I think that there was a concerted effort, and it was an effort that succeeded, based on the fact that we have so many folks vaccinated.

My only comment -- last comment is just that, now we need to find ways to get our staff vaccinated.

We need support.

We don't have clear guidance on exactly what we can say or what we can't say, and that's not just OPWDD. I think it's everyone now looking at this.

But the day that we're able to say that it's required, and that we must -- that staff must be vaccinated will be the day we can all start to feel a little bit more comfortable.

Thank you.

SENATOR MANNION: Thank you, Susan.

The last panelist for this topic is Yvette Watts from New York Association of Emerging and Multicultural Providers, Incorporated.

YVETTE WATTS: Thank you, Senator Manning [sic] for this opportunity to speak again on this very sensitive topic.

First I want to thank my colleague Susan Constantino.

She, along with her large agency, demonstrated that networking and shared resources amongst providers is our greatest resource.

As she mentioned, in the beginning, there was a disconnect.

And we did get into the "A" category, but prior to that there was a lack of communication.

I know many of my small and midsize providers were at a loss. And families were contacting them, and they had nowhere -- where to go, what to do, were they even counted in this A1 category.

So once Susan connected us with the local DOH, we were able to work along with her to make a lot of those pop-up sites available, and to really find out what needs those agencies had.

Thank you so much, Susan. You know, I love following you on any kind of a forum.

I just want to say that, right now, the problem that we have, is the hesitancy rate is very high amongst the staff, and especially people of Black and Brown culture. And that has a lot to do with historic cultural concerns, but it also has to do, and I have to say this, I mentioned it yesterday, it's the lack of equity in compensation, the lack of trust.

These individuals do not -- I mean, now I'm talking as a mother of a 36-year-old female with autism.

And I hear them say, How can I trust someone that doesn't even care what I do, doesn't even care that can I pay my bills?

These individuals -- and then, you know, you talk about the day we will be able to do mandatory testing. Until we build that trust up, that's not going to work, because many of them feel, and they said it to me, that why should I trust someone to vaccinate me when they can't even compensate me or understand that what I do is important? I take care of individuals, but I want to be here. But that I can't -- that I don't feel like an essential worker. I feel like I am being abused.

And that's the way they feel.

I think that Michael Seereiter, another colleague, he was so eloquent in stating what he feels about the disparagy [ph.] and the lack of equity for our workers.

So as I said before, this is a circle of -- and once there's a piece that's not connected, if we don't -- we need those individuals, yes, to be vaccinated, but you cannot mandate individuals that

don't even want to work with you anymore.

It's very simple.

And I think that it's appropriate that we had the forum yesterday, and now we have this forum in which -- the platform in which to talk about what we need to do, moving forward.

So thank you, Senator, for this opportunity to speak.

SENATOR MANNION: Thank you.

Yes, and thank you for sharing.

And, you know, I'm almost embarrassed by the questions that I would have asked, because I know the -- you know, this is not about procedure, this is not about logistics. It's a much, much bigger, and more sensitive, picture than that.

And I appreciate both of you sharing that information.

I don't have any questions because I don't think we're going to have an answer.

So we do understand the importance of it, and I do hear resonating as it regards to testing, which has come up -- came up several times.

And, of course, we want people to be vaccinated, but we also want them healthy as they're working with others, and we want to help in building

a more trustworthy environment, yes.

YVETTE WATTS: Thank you.

SENATOR MANNION: Thank you.

Our next panel is fiscal impact and other challenges.

Our first panelist is Kathy Bunce from State-Wide Family Advocacy Network of New York.

KATHY BUNCE: (No audio.)

SENATOR MANNION: Kathy, you are muted.

KATHY BUNCE: I'm sorry. I should know by now.

The COVID shined a very bright light on a very fragile system.

For years family stakeholders have been sounding the alarm, and asking for investment in the workforce we desperately need. We have asked repeatedly, the services delivered through OPWDD is fully and fairly funded.

I know you've heard those words from us before.

The increased minimum wage, along with a decade of -- without a meaningful COLA -- there was a very, very small one, one year -- has nonprofit agencies at a huge disadvantage.

And as a parent I can tell you, I know,

shifts are long, pay is low, the work is hard, and overtime is frequent.

And then comes COVID, and it was the perfect storm; there were no services.

We were told by OPWDD that we may never get back to level of services, and families really were left to fend for themselves.

Now, our family, we were lucky. We were healthy. I have a husband who shared in the caregiver responsibilities.

And not everyone in the state has that option.

Without this workforce we have no future.

Without a capacity of caring DSPs, we will be returning to the days of institutionalization because families simply will not live forever.

My daughter attends a day program only three days a week because they don't have sufficient staff, but there is not one single staff member working there today that was there pre-COVID.

She was given priority because she's still living at home. So my husband will have -- when my husband has to return to work, we're really not sure what we're going to do.

Her certified group home is scheduled to open

at the end of the month. The opening date is contingent on finding staff.

Families are literally going door to door, handing out flyers, looking for people.

That should not be.

That should not be.

Other families are working shifts in the noncertified homes to cover the care and safety of their loved ones.

So in January there were 2300 open positions in our region. Now we have over 3300.

We need a sustainable system for our loved ones, going forward.

We need to stop these crazy 5-1 cuts.

We need to raise the wage because DSPs deserve to make a living wage. 10 years ago their starting pay was 35 percent above minimum wage.

There's been minimal investment in the most important workforce infrastructure to so many people; 130,000 people.

Now is the time.

They should be considered essential workers because they are essential workers. They're essential to my daughter, they're essential to my family, and to every other family member who has

ever had -- had to rely on services, at no fault of their own, by the way.

We need to fund the future.

We need to use those federal FMAP monies, and we need them to flow very quickly to the nonprofits to stop the bleeding.

These nonprofits are in a dangerous fiscal position. They serve 80 percent of the people and simply cannot fail. We simply cannot afford to lose one person from this system at any level.

We need immediate action to address the submarket wages, we need proactive planning and forecasting of future need, and we need to have a robust sustainable future for our children.

Thank you.

SENATOR MANNION: Thank you.

Next is Karen Nagy from Eastern New York Developmental Disabilities Advocates.

KAREN NAGY: Thank you, Senator, and committee members.

I'm following Kathy's lovely testimony, and it occurs to me, over all of these forums, that we keep hammering home the same points.

So I'm not going to -- I'm going to adjust again, and I'm not going to hammer home anything

that hasn't already been hammered home.

But I can say with unequivocal certainty that our provider, our nonprofit provider, kept our son and everyone else they served safe.

And we face an incredible staffing shortage at this moment due to burn-out, and the significant overtime pressures, that have occurred for our remaining staff.

So there's really a two-pronged problem here.

We have remaining staff that's burnt out, and just exhausted, from all of this care. And then we will have new staff coming in that we will need to train and spend money on.

So at a time when people with IDD, and especially like my son with profound autism, who doesn't do well with change, they have experienced significant regression, and they'll be adjusting to reopening full in-person services, environmental stressors.

I mean, many of us without disabilities are understanding the differences in our lives that have contributed to stressors that have driven to make different decisions after this pandemic.

So, you know, our staff is emotionally drained, burned out. We've lost many of them

already, and we're at risk of losing more.

So, essentially, our workforce is in crisis, and it has been in crisis.

And it's just -- you know, it's not acceptable that we don't acknowledge that, without it, the system, and all of the administrative costs that support it, are worthless.

So, you know, obviously, the additional FMAT dollars have to be -- that have been generated by the federal government are going to have to be used to stabilize the ongoing workforce crisis, or nothing else will matter.

We're going to spend a lot of money in training a large percentage of new staff.

We're going to spend a lot of money because, every time there's staff turnover, there are, essentially, additional behavioral incidents that have to be addressed, and incidents that have to be, you know, researched, and administrative procedures behind those incidents that have to occur.

And the recruitment and retention challenges are going to continue because of the low wages. They're not competitive in any way and they're not commensurate with the difficult work and responsibility that the job entails.

So I will close by saying, finally, you know, homes for individuals with IDD cannot be viewed as beds to fill.

They have to be viewed as holistic environments that subort [ph.] the adaptations and the necessary supports that ensure each individual's human right to quality of care.

And while we certainly appreciate the delay of the 5-1 cuts that you're hearing about through the pandemic, we strongly oppose them, and they're completely contrary to ensuring the human rights of individuals with IDD, and they're being proposed at a time when the system of care itself is at risk and incredibly vulnerable.

So, Senator Mannion, we thank you for sponsoring the legislation that will address this, and we thank you for everything that you have done, you know, on our behalf to date.

SENATOR MANNION: Thank you, Karen.

Competitive and commensurate, and I completely agree, and goes way beyond that.

Thank you for sharing.

Next, we are back to Tom McAlvanah from New York Disability Advocates, and Interagency Council of Developmental Disabilities.

TOM McALVANAH: Thanks again, Senators; appreciate it.

Critical services for people with intellectual and developmental disabilities are at risk.

While some of the planned cuts have been rolled back, and the first meaningful cost-of-living increase since 2009 was recently passed, people and families are still at risk of losing access to their current levels of services and supports.

Why?

Well, I think it was mentioned by Kathy that over the past decade, the not-for-profit agencies have been asked to do more with fewer resources.

The continued deferral of the statutory COLA for over a decade has significantly deprived providers of vital resources needed to maintain operations.

As a result, we don't have a staffing crisis; we have an impending staff disaster.

Right now executive directors are about to cover vacant shifts because they don't have enough staff in their residences.

One exec told me that he's going to provide direct care because he's got to get his staff on

vacations this summer.

Prior to the COVID pandemic, 37 percent of providers reported losing money on their OPWDD services.

Cash on hand has been a significant challenge for agencies, where 50 percent of providers had less than 40 days of cash on hand, and one-third had less than 30 days of cash on hand.

That's two payrolls.

And more than one in three already closed, reduced, or modified programs due to the financial hardship they were under, and that will grow.

Of course, folks mentioned the 5-1 cuts, and I won't go too much into it, but this action that will -- is taking place may [indiscernible], or have taken place, will now remove more than $230 million annually from providers already besieged with the losses and added expenses due to the pandemic.

Of course, OPWDD claims that residential providers' costs are reduced when their residents are temporarily away from home.

We know that not to be true. It doesn't change one bit our fixed costs, and paying the staff is still there.

So we know that these cuts come at a

difficult time, and also gives the impossible choice to families to say, take their children home for a visit and cost the residential provider half their daily rate.

Where was the 6.2 percent FMAT fund that all Medicaid services throughout this country, including New York State and OPWDD, that they earned, where was 6.2? Where did that money go?

The value of the increased income to New York State in the IDD sector, not-for-profit sector only, was over $50 million a quarter.

These dollars certainly could have addressed the shortfalls that OPWDD claims necessitated their actions.

So, finally, I just want to say that, you know, our not-for-profit provider community carries out the state's moral and legal obligation to provide services and supports to New York's most vulnerable citizens.

Why does New York State continue to look to the not-for-profit sector to fix their cash flow needs?

This pandemic should not be an opportunity to shrink the service system because there's little desire to put more resources into the sector.

If you look at OPWDD's website, there are 39,000 young people under the age of 20 that are provided services.

39,000 out of 128.

What's the future for them going to be if we're going to continue to shrink the footprint and financial resources that OPWDD is struggling to provide?

We need to start investing in this service sector now while we still have a viable one.

Thank you.

SENATOR MANNION: Thank you, Tom.

I appreciate the numbers, and I think there's certainly, again, consensus and agreement that we are at a breaking point, and we're holding on by a thread.

And I appreciate everything that the providers are doing to make sure that we continue to provide the services.

Next, I would like to introduce Gail Hamlin from New York Alliance for the Developmentally Disabled.

GAIL HAMLIN: Hi, good afternoon.

Thank you, Senator Mannion, and committee members, for the opportunity to speak at today's

roundtable.

And one of the disadvantages of speaking at the end is everybody has already said so many of the things that were so important, and things that I was going to touch upon. So forgive me if I repeat some of these things.

I am on the executive council for regional leads with NYADD.

I'm also the legal guardian for my older brother who lives in a group home residence on Long Island.

The past 15 months with COVID have certainly been an eye-opener, and it's also been a very big learning experience.

So the biggest issue that his agency, and I know others have right now, very much related to 5-1 cuts, their therapeutic leave, retainer day, and vacancy adjustment.

Obviously, I don't want to get too much into detail about it, but it's impossible to budget for these things because we never know when someone is going to need to go to the hospital. Right?

And families want to see their loved ones, they want to bring them home for weekends, these are things that are part of their therapeutic care.

The agency, again, can't budget for it, but they shouldn't be penalized for it as well. Right?

Time with family is part of their therapeutic care, and family is part of their essential network.

We cannot see more cuts. We need far better funding for this.

Another issue, again, everyone's been talking about it, and Karen and Kathy really touched the nail on the head and said it very eloquently, but wages are a huge issue, so I'm going to say it again.

But, Commissioner Kastner, his words, he said, quote, he was immeasurably grateful, unquote, for the DSPs, for their dedication to our people's health and well-being.

But how can we convert that sentiment into increased pay for the tireless work and efforts for all that the DSPs do?

They deserve better pay commensurate with their work.

So there can't be employer retention without the pay to go along with it.

And I see that my time is up, so I am going to say thank you for your time.

Thank you.

SENATOR MANNION: Thank you, Gail.

We are not going to have staff available if we don't properly compensate them. And we have to provide the providers with those dollars, and then they can provide people with a decent and living wage and -- for this delicate care that they provide.

So, thank you, Gail, for your words.

You are our last panelist.

Senator Martucci or Senator Persaud, if you have any final thoughts, I certainly would like to give you the opportunity before I have my final words.

It's been an important, and good three hours, a necessary three hours, maybe a long three hours.

But, regardless, I think important things came out as it related to the pandemic, and what we all also know, which are other crises, particularly one related to workforce that we have to address.

Senator Martucci?

SENATOR MARTUCCI: Thank you, Chairman.

So first I'll start by thanking you again for putting this together.

Certainly, you know, it's -- I'm glad that we had this opportunity, and certainly glad that

Dr. Kastner has availed himself in the future. I look forward to continuing conversations with him.

And I just want to take this moment for all of you who took the time -- part of the time out of your day to come here and give all of us some really important perspective on issues that certainly are very important to us.

You know, again, your perspective is invaluable in terms of shaping -- shaping, you know, our thoughts and our actions as we move forward.

So I will just end by saying thank you for your time today.

And I continue to look forward to working with Chairman Mannion and the other members of the committee to do all we can for the benefit of IDD New Yorkers.

Thanks so much.

SENATOR MANNION: Thank you, Senator Martucci.

And I thank Senator Felder for his attendance. He had to leave.

And, of course, thank you, Senator Persaud, as you were here throughout all of it, you heard all of it. I appreciate that.

And if you have any final thoughts, I would

like to make sure that you have that platform.

SENATOR PERSAUD: Well, thank you, Chairman.

I would just really like to thank you for putting this together.

I know we had a struggle last week. And, you know, this was worth it for everyone to reconvene and to hear everything everyone said.

You know, Senator Mannion and I had a conversation with the Commissioner about a week ago because of something I was not pleased with.

And, you know, we are dedicated to fighting for the IDD population.

I have my -- I tell the story all along:

I grew up with a friend of ours who was developmentally disabled. And -- but, let me tell you, he was the smartest person amongst all of us.

You know, he was a little older than us, but he was the smartest one amongst all of us. And we involved him in everything that we did. He was never excluded, on to today, he has never been excluded from anything.

And my mother worked in the industry for nearly 40 years.

And now my youngest brother has decided, you know, he left his job he was doing and he's decided

that this is his passion. And so he's currently working on a new home that was just opened on Long Island, and he just loves it.

So it's a field that I'm passionate about, and, you know, there's some legislation.

While we're on, someone saw it, and they called the office and said, Oh, make sure she signs on to one of Senator Mannion's pieces of legislation.

And I said, Don't worry. I will look at it, and then I'll make the decision.

So, again, thank you, Senator Mannion, for everything that you're doing.

And to all of you advocates, thank you for everything that you are doing.

And we're committed to working with you to ensure that the industry gets what they deserve.

That's what we're committed to doing.

So thank you again, everyone.

SENATOR MANNION: 100 percent.

You know, the pandemic clearly highlighted the need for the State to invest in the services.

Residents went without the services that they needed.

Providers across the state had to absorb the

costs.

DSPs had to work overtime, many times without hazard pay, without being tested, sometimes being COVID-positive, sometimes without proper protection.

And we all know that we can do better; we can do better for the people that provide the service, and we can do better for the people that need the service.

This past budget is, hopefully, the first of many steps to show that the IDD community is a priority just as the other senators and providers and advocates said as we met here today.

I look forward to continuing the work with stakeholders that were good enough to come today, and the many more advocates that were out there enjoyed us via live stream.

This is going to conclude our roundtable of evaluating OPWDD's response to COVID-19 at residential facilities, but we did much more, and we're going to continue to do more.

This is one step in the right direction.

Thank you to the panelists; the Commissioner; and, of course, my ranking member, Senator Martucci; Senator Persaud for joining me today; and Senator Felder who joined me earlier.

Thank you again, everyone, for taking the time.

We will all push together in our fight to make sure, and I'm stealing Senator Persaud's words, that everyone is included in every scenario, and that no one has to be forced to overcome barriers that we can't make sure that they can be overcome.

So thank you for joining, everyone, today.

(Whereupon, the roundtable held before the New York State Senate Standing Committee on Disabilities concluded, and adjourned.)

--oOo--