

1 BEFORE THE NEW YORK STATE  
2 SENATE STANDING COMMITTEE ON DISABILITIES  
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3 NEW YORK STATE FORUM

4 A ROUNDTABLE DISCUSSION

5 TO EVALUATE THE STATE'S RESPONSE TO COVID-19  
6 AT RESIDENTIAL FACILITIES FOR DEVELOPMENTALLY AND  
7 INTELLECTUALLY DISABLED INDIVIDUALS  
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8  
9 Virtual Roundtable via Zoom

10 June 3, 2021

11 Time: 1:00 p.m.

12 PRESIDING:

13 Senator John W. Mannion  
14 Chairman  
15 Senate Standing Committee on Disabilities

16 PRESENT:

17 Senator Michael Martucci (RM)

18 Senator Simcha Felder

19 Senator Roxanne J. Persaud  
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21  
22  
23  
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1           SENATOR MANNION: Good afternoon.

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

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

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

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

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

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

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

25          This roundtable is the most significant

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

5 The committee takes its oversight  
6 responsibility extremely seriously.

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

9 Our support for IDD New Yorkers takes many  
10 forms.

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

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

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

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

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

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

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

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

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

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

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



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

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

7 Dr. Kastner is familiar to many of us.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1       for his opening remarks.

2               Thank you.

3               Please go ahead, Senator Martucci.

4               SENATOR MARTUCCI: Thank you, Chairman.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

5           2. Why has the department refused to even,  
6       up until today, which is June 3, 2021, when we know  
7       of the awful impact of this, orders of this nature,  
8       refused to rescind it, considering that there was a  
9       459 percent increase in the deaths at group homes in  
10      April of 2020 compared to April of 2019.

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

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

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

22           Basically, it comes down to the simple  
23      questions of:

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

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

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

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

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

21          I know that this response was referring to  
22    me.

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

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

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

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

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

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

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

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

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



1           Thank you, Mr. Chairman.

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

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

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

11          Thank you for being here, Commissioner.

12          DR. THEODORE KASTNER: Well, thank you.

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

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

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

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

25          OPWDD's first positive case was reported on

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

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

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

10 Our Office of Emergency Management was  
11 activated during the week of March 9th to coordinate  
12 our case finding, tracking, data analytics,  
13 PPE distribution, and other critical tasks on a  
14 24/7 basis.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 35,000 vulnerable individuals living in certified  
2 group homes, as well as their families, and the tens  
3 of thousands of staff members working in those  
4 homes.

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

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

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

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

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

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

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

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

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

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

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

24 And I just want to repeat that.

25 No individual who was symptomatic or infected

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

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

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

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

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

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

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



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

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

8           Providers were able to secure up to  
9           100 percent of the funding they had previously  
10          earned through the provision of services.

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

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

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

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

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

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

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

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

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

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

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

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

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

25           OPWDD partnered with the New York State

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

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

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

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

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

20 We are working with our stakeholders to  
21 improve vaccination rates.

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

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

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

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

10 It is with great sadness that we report that  
11 668 people with developmental disabilities,  
12 including 577 individuals residing in certified  
13 residential settings across the state, have passed  
14 away with a positive COVID-19 test.

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

18 We are currently reporting only 10 to  
19 20 individuals who are newly positive each week, and  
20 mortality has significantly dropped.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 to your own family.

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

5 We are immeasurably grateful for their  
6 commitment and dedication.

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

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

15 And I look forward to taking your questions.

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

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

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

1 committee.

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

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

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

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

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

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

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

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



1 around the COVID infection.

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

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

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

17 DR. THEODORE KASTNER: Certainly.

18 Just going back to review the timeline:

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

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

25 At the time, New York City had very, very

1       limited testing capacity.

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

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

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

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

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

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

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

1 transportation, to go to a day program where  
2 200 individuals were working. And that after  
3 leaving those day programs, they went back to dozens  
4 of homes that were supported by up to 12 agencies  
5 across Brooklyn and Queens.

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

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

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

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

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

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

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

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

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

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

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

20              SENATOR MANNION: Thank you, Commissioner.

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

1 Senator Martucci.

2 SENATOR MARTUCCI: Thank you, Chairman.

3 Hello, Dr. Kastner.

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

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

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

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

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

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

25 The second is that congregate care setting,

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

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

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

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

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

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

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

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

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

7           SENATOR MARTUCCI: No. Thank you, Doctor.

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

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

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

18          So I guess my question is simple:

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

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

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

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

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

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

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

17 So the guidance that we issued gave  
18 providers --

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

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

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



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

7           There was an out for residential providers.  
8           They were not forced to accept individuals  
9           back to their homes.

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

13          So I'm just reading from the document.

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

17          SENATOR MANNION: Thank you, Commissioner.

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

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

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

1 round.

2 Senator Persaud, you have five minutes.

3 Thank you.

4 SENATOR PERSAUD: Thank you, Chair.

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

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

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

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

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

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

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

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

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

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

8 SENATOR PERSAUD: Okay, so I can be clear:

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

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

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

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

24 SENATOR PERSAUD: Okay.

25 DR. THEODORE KASTNER: The agencies created

1       their own policies around how they addressed their  
2       staffing needs.

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

7               SENATOR PERSAUD: Thank you.

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

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

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

16              Are you offering the staff any kinds of  
17      incentives?

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

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

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

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

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

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

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

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

22           DR. THEODORE KASTNER: Yes. Out of about  
23    128,000 individuals, we are seeing positives.

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

1 12 to 20 across the entire state?

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

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

7 This reflects more local conditions.

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

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

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

16 SENATOR PERSAUD: Thank you, Commissioner.

17 DR. THEODORE KASTNER: Thank you.

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

20 Quick questions here, for myself.

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

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

1 DR. THEODORE KASTNER: Oh, sure.

2 In the testimony I offered, I said that  
3 10,633 of the 128,000 individuals we support have  
4 tested positive for COVID. That works out to about  
5 8.31 percent of all the individuals with IDD that we  
6 support.

7 For the general population, data is widely  
8 available.

9 About 1.7 million New Yorkers out of  
10 19.45 million New Yorkers have tested positive for  
11 COVID. That's about 8.74 percent.

12 In terms of a difference, our rate is about  
13 .4 percent lower, and that's about a 5 percent  
14 improvement in the rate of transmission for the  
15 general population.

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

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

24 That's really the takeaway for people.

25 Everyone should feel that they made a

1 difference in, collectively, the work that we  
2 produced.

3 SENATOR MANNION: Thank you.

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

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

11 Because I know you had used some of those  
12 terms.

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

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

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



1           That's the best we could do.

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

7           SENATOR MANNION:   Okay.   Thank you.

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

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

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

19          You had referenced the number of cases within  
20      the workforce.

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

25          DR. THEODORE KASTNER:   Well, it's certain

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

3               I don't have that number specifically.

4       SENATOR MANNION: Thank you.

5               One last thing here.

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

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

14              SENATOR MANNION: Okay.

15              DR. THEODORE KASTNER: -- the number of  
16      individuals who were living in homes. That's the  
17      numerator. And the denominator is about  
18      35,000 individuals.

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

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

1 to transmission rates for the general population.

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

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

10 SENATOR MANNION: Okay. Thank you.

11 I appreciate it, Commissioner.

12 Five minutes for Senator Martucci.

13 SENATOR MARTUCCI: Thank you, Chairman.

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

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

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

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

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

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

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

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

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

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

23 Now, you skipped a sentence.

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

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

6 We gave residential providers an out.

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

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

16 Hospitals develop treatment plans. They  
17 manage appropriately.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



1 later and continue the discussion.

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

5 And I will certainly take you up on that  
6 offer.

7 Thank you, Chairman.

8 DR. THEODORE KASTNER: Thank you.

9 SENATOR MANNION: Thank you,  
10 Senator Martucci.

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

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

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

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

21 Panelists will have two minutes each to  
22 deliver their remarks.

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

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

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

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

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

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

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

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

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

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

1       being experienced by the general New York City  
2       population.

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

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

11              We were extremely alarmed by these rapidly  
12      emerging trends.

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

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

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

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

1 as Priority 1A for vaccinations.

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

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

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

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

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

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

22 We want to learn from what we have  
23 collectively experienced.

24 Thank you very much for your time.

25 SENATOR MANNION: Thank you, Mr. Damiani.

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

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

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

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

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

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

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

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

1       only.

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

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

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

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

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

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

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

7 Thank you.

8 SENATOR MANNION: Thank you, Ms. Galea.

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

11 ERIK GEYSER: (Microphone is muted.)

12 SENATOR MANNION: Mr. Geyser -- yes.

13 ERIK GEYSER: Sorry.

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

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

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

25 We advocated with the State to address this

1       need.

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

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

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

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

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

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

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



1 infection.

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

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

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

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

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

18 Thank you for allowing me to share my  
19 comments today.

20 SENATOR MANNION: Thank you, Mr. Geyser.

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

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

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

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

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

15 Anyone can answer.

16 Thank you.

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

20 Is that correct?

21 SENATOR MANNION: That could be.

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

25 Any part of the guidelines that were in

1 place.

2 But, yes, thank you.

3 ERIK GEYSER: Yep.

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

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

10 SENATOR MANNION: Thank you.

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

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

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

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

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

1           SENATOR MANNION: Thank you. I appreciate  
2           that.

3           Senator Martucci.

4           SENATOR MARTUCCI: Thanks, Chairman.

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

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

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

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

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

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

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

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

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

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

11          ERIK GEYSER: Thank you.

12          MARCO DAMIANI: Thank you.

13          SENATOR MANNION: Thank you, Senator.

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

16          That's one comment.

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

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

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

1 understand the importance of that timely  
2 information.

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

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

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

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

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

19 So thank you for joining today.

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

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

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

1 I'm honored to be here.

2 The comments from SAANY are as follows:

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

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

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

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

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

22 Not everyone has access to equipment and  
23 Internet.

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

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

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

8 Thank you.

9 SENATOR MARTUCCI: 100 percent.

10 Thank you, Mr. Stasio.

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

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

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

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

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



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

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

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

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

15 So these services were extremely important  
16 for them.

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

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

25 But I would say that if resources and data

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

3               Thank you.

4               SENATOR MANNION: Thank you, Ms. Watts.

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

7               JIM MORAN: Thank you, Senator.

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

11              I'm here to speak on behalf of the seven Care  
12      coordination organizations in New York,  
13      representing -- supporting approximately  
14      110,000 people across the state.

15              Care Design New York specifically operates in  
16      30 counties, including the, roughly, 10 counties  
17      that were hardest hit by the pandemic during the  
18      last spring.

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

21              While the CCOs predominately provide --  
22      really are the backstop mainly for people who live  
23      in the general community, which is about  
24      75,000 people, there are some 30 some-odd thousand  
25      folks that live in residential programs as well that

1 we also provide supports to.

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

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

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

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

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

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

1       general population.

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

4               For example, the statistic that the  
5       Commissioner provided shows that there were  
6       10,000-some infections against a population of about  
7       120 some-odd thousand.

8               But the reality of it was this:

9               Approximately 7200 of those 10,000 lived in  
10       group homes. And there are approximately  
11       38,000 people living in group homes.

12               So you're talking about an infection rate  
13       within the group home community, which I included  
14       family care in those numbers, is about  
15       18 1/2 percent.

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

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

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

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

1           The underlying health conditions.

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

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

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

11          Very difficult to isolate individuals, in all  
12          honesty.

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

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

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

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

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

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

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

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

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

19          That capacity is not readily available in the  
20          system today.

21          Thank you.

22          SENATOR MANNION: Thank you, Mr. Moran.

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

25          And I appreciate you compiling that data, and

1       thank you for all the information that you provided.

2               Thank you.

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

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

8               Very interesting dialogue today.

9               I really appreciate it being the opportunity  
10       to participate.

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

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

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

25              The community rehabilitation residential

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

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

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

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

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

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

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



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

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

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

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

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

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

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

3 And smaller residences, smaller residence  
4 size, is key.

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

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

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

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

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

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

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

1 I speak from a slightly different point of view.

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

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

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

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

1 and serve people with IDD who were hospitalized with  
2 COVID.

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

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

11 Going forward from now we need to be cautious  
12 when reconsidering the use of virtual services.

13 It's important to recognize that not all people in  
14 residences have the Wi-Fi access and the devices  
15 necessary to participate. Many people need support  
16 to use the technology. Staff may or may not have  
17 the ability to aid them effectively. And some  
18 people, like my son, do not relate to virtual  
19 services at all.

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

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

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

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

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

18          We know how undervalued DSPs are.

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

23          Flexibility would be great for everyone.

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

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

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

8           Thank you very much for listening.

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

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

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

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

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

22          My organization opened two such programs.

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

1       could do.

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

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

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

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

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

18              We served over 100 people.

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

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

25              The billing changed halfway through, how we

1 would be reimbursed.

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

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

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

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

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

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

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

21 Thank you.

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

25 Next -- thank you, Ms. Frederick.



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

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

9           You definitely are our champions.

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

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

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

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

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

25          And I want to credit OPWDD for their hard

1 work.

2 This was all new territory for everyone.

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

9 It was beneficial and lives were saved.

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

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

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

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

25 OPWDD leadership in each region are

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

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

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

13 Thank you for the opportunity.

14 SENATOR MANNION: Thank you, Ms. Bunce.

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

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

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

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

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

1 receives residential services through a local  
2 nonprofit agency.

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

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

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

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

1       it threatens the safety and stability of our loved  
2       ones.

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

10              Thank you.

11              SENATOR MANNION: Thank you, Ms. Nagy.

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

17              Senator Martucci for two minutes of  
18       questions.

19              SENATOR MARTUCCI: Thank you, Chairman.

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

23              Perfect.

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

1       your question.

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

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

8                So if you could kind of fit that in in  
9       30 seconds, or a minute, that would be great.

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

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

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

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

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

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

4           SENATOR MARTUCCI: Thank you, Mr. Moran.

5           And then my next question is for  
6       Ms. Frederick.

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

10          Huge.

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

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

18          I know you had some frustration around that.

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

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

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

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

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

6           SENATOR MARTUCCI: Understood. Thank you so  
7           much.

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

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

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

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

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

22          So I really appreciate everyone participating  
23          today.

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



1       Randi DiAntonio from PEF (Public Employees  
2       Federation).

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

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

8               I think it's incredibly important for us to  
9       review the things that have happened over the last  
10      16 months, and what we can do, moving forward, to  
11      ensure that some of the mistakes and the issues that  
12      we saw are not repeated if we, God forbid, ever have  
13      a future public health emergency.

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

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

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

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

24              I'll focus my comments on PPE.

25              So at the beginning, no surprise, there was

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

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

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

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

14 Conservation of PPE lasted for several  
15 months.

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

20 This obviously undermines the quality of the  
21 PPE.

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

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

1 staffing issues.

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

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

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

11 We have had this conversation since the very  
12 beginning.

13 There is still no consistent testing process  
14 being done.

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

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

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

1 individuals.

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

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

8           SENATOR MANNION: Thank you, Ms. DiAntonio.

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

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

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

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

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

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

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

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

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

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

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

25          In the future, we need a streamlined system

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

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

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

9 SENATOR MANNION: Thank you, Ms. Borozny.

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

12 You can correct me, Margaret. I apologize.  
13 -- from State-Wide Family Advocacy Network of  
14 New York.

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

17 Am I on?

18 SENATOR MANNION: You're on, Margaret.

19 MARGARET RAUSTIALA: Okay. Thank you.

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

23 Anyway, it was March of 2020, not March of  
24 1820; yet with more than 37,000 community-based  
25 residential settings, apparently, New York State

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

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

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

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

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

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

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

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

25 My understanding is that the cost of PPE was

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

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

8 But this is spilt milk.

9 The important thing is it never happens  
10 again.

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

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

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



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

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

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

18 Thank you.

19 SENATOR MANNION: Thank you, Margaret.

20 I appreciate those strong words.

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

24 TOM McALVANAHA: That's great.

25 Thank you, Chair Mannion, and thanks,

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

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

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

15 NYDA did a survey that estimated that,  
16 between March and October of 2020, not 1820 as  
17 Margaret suggested -- we -- our providers spent out  
18 \$34 million just to help get the supplies needed for  
19 their hero DSPs who were on the front lines every  
20 day.

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

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

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

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

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

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

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

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

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

1       one particular provider, with these items.

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

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

9               We have to, as New York State, remember that  
10 we provide 90 percent of the services, the  
11 not-for-profit community in this state, and  
12 80 percent of the certified services.

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

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

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

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

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

25              That's what this community does.

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

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

7           Thank you, Mr. McAlvanah.

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

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

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

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

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

1 the early months of the pandemic.

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

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

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

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

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

1 emergencies.

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

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

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

11 Thank you.

12 SENATOR MANNION: Thank you very much.

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

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

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

22 Is that the right method?

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

1       these quicker.

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

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

7               I'm interested to hear from anyone.

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

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

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

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

17              And I must say that eventually they came  
18       through.

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

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



1       little unclear to me.

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

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

8               SENATOR MANNION:   Thank you.

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

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

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

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

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

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

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

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

8               SENATOR MANNION: Thank you.

9               Senator Martucci.

10              SENATOR MARTUCCI: Thanks, Chairman.

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

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

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

24              And I think your quick actions undoubtedly  
25       saved lives.

1           So thank you for what you did.

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

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

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

12           SENATOR MANNION: Thank you,  
13      Senator Martucci.

14           Thank you to all of the panelists.

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

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

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

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

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

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

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

10 But thanks for having me.

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

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

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

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

1           And it's really sad.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

17 We haven't heard a lot about this.

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

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

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

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

5           Routine testing is one of the pillars of  
6           pandemic management.

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

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

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

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

22                 Thank you, again.

23                 SENATOR MANNION: Thank you.

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



1           My apologies, Rachelle, if I missed.

2           RACHELLE KIVANOSKI: No, you were perfect.

3           Thank you.

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

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

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

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

16          We so appreciate the dedicated lifesaving  
17          work of our DSPs.

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

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

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

3 There were close to an additional 200 deaths,  
4 from December to mid-May, out of the total  
5 669 deaths in group homes; once again, at a higher  
6 rate than the general population.

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

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

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

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

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

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

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

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

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

21          Thank you.

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

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

1           MICHAEL SEEREITER: Thank you again for the  
2 opportunity.

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

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

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

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

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

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

1 us as we speak.

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

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

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

14 Tom mentioned earlier about the cost the  
15 providers incurred for PPE.

16 Additionally, providers paid \$130 million in  
17 hazard and hero pay from the period of time, from  
18 March to November; while at the same time, their  
19 revenue went down \$327 million.

20 We need to use some of the enhanced FMAT  
21 resources to recognize and reimburse for these  
22 largely unreimbursed expenses, and to begin paving  
23 the way for bringing DSP wages back up.

24 Lastly, I think it's important that we  
25 recognize that DSPs are disproportionately Black and

1 Brown New Yorkers, not dissimilar to other  
2 caregiving and human-services sector professions.

3 As Jim Moran said previously, the nature of  
4 the work makes people susceptible to infection  
5 transmission with a virus like COVID. So it's not  
6 hard to surmise how COVID infection and death rates  
7 are higher in Black and Brown communities, in part,  
8 because -- in part, caused by the jobs that these  
9 people have, or had, as the case may be.

10 On testing, access to testing, it was a  
11 significant problem early on.

12 It is clearly linked to a significant lack of  
13 recognition by New York State; I would say  
14 Department of Health, the health system overall,  
15 about OPWDD, its system, and direct support  
16 professionals as essential workers, as others have  
17 noted before.

18 And it took exceptional levels of advocacy  
19 from all levels of stakeholders, and OPWDD included,  
20 to get IDD services, and others, like behavioral  
21 health, recognized as part of the public health  
22 system for the purposes of the pandemic management.

23 We can't let that happen ever again; we can  
24 never again be left as an after-thought.

25 Thank you.

1           SENATOR MANNION: Thank you, Mr. Seereiter.

2           Back to Jim Moran from Care Design New York.

3           JIM MORAN: Thank you, Senator.

4           I'm going to sort of shift away from my  
5 testimony, which is really focused on the  
6 vaccination and testing of employees. Clearly, it's  
7 a critical issue that has been talked about.

8           I wanted to shift to -- really, to a bill  
9 that you've now sponsored, Senator, and that is, at  
10 the height -- the ultimate slap in the face I see  
11 with all of this, during the height of the pandemic,  
12 that a budget proposal was put out to cut the rates  
13 of the service -- residential service providers; to  
14 eliminate hundreds of millions of dollars of funding  
15 to the residential providers during the height of a  
16 pandemic.

17           And the fact that, you know, well, that's  
18 because we've got to make the numbers work.

19           And, you know, as somebody -- as one of the  
20 parents said earlier, the State has been  
21 cost-centered as opposed to person-centered.

22           And at the height of a pandemic, to think  
23 that that -- that -- that really tells you what the  
24 feeling is of the value of not only the people that  
25 we're blessed to be able to support day in and day

1 out, but the people who work with those individuals  
2 to help them live the best lives possible.

3 I want to get behind your bill, Senator, and  
4 really applaud you for taking that on, because the  
5 last thing the providers -- service providers need  
6 right now is one more cut.

7 Enough is enough.

8 So, thank you.

9 SENATOR MANNION: Thank you, Mr. Moran.

10 I went out of order a little bit, so  
11 I apologize to folks.

12 I will make sure that I catch everybody.

13 But, next, is Julie Keegan from  
14 Disability Rights New York.

15 JULIE KEEGAN: Good morning -- or, good  
16 afternoon, Senator.

17 I really appreciate the opportunity to be  
18 here from Disability Rights New York, the protection  
19 and advocacy system for New York State.

20 Much of what I had planned to say is covered  
21 in a very comprehensive report that my colleague  
22 Alyssa Galea alluded to, which was based on a  
23 seven-month study, looking at the treatment of  
24 people in group homes in New York during the COVID  
25 pandemic, and the State's response.



1           And that is available on the Disability  
2           Rights New York website.

3           But I do want to highlight a few things that  
4           have been talked about here, to some extent, but the  
5           first is, with regard to staffing, is I want to  
6           emphasize also, that these are individuals, the  
7           direct support professionals, that are working in  
8           these very stressful times, not only getting paid  
9           less, but, also, because of the diminished  
10          workforce, having to cover extra shifts and working  
11          in a short-staffed situation.

12          These folks are disproportionately Black in  
13          New York. Only 17.6 percent of the general  
14          population is Black. But for direct support  
15          professionals, we're looking at 35 to 42 percent.

16          That's very significant.

17          Also, direct service professionals are  
18          disproportionately women, and they're people born in  
19          other countries.

20          So I think we need to be mindful of that when  
21          we're looking at pay equity.

22          And then, also, and I will say it also, there  
23          was heroic, absolute heroic, conduct by these  
24          individuals during this crisis.

25          And I totally agree with Michael, that more

1 people would have died had not these folks stepped  
2 up and stepped in and stayed for weeks on end to  
3 minimize exposure.

4 With regard to testing, what I wanted to say  
5 there, is that it's very shocking and disturbing  
6 that individuals in group homes are not given the  
7 same priority and the same protection as people in  
8 other congregate settings.

9 Although testing was not widely available at  
10 the outset of the pandemic, this has not been the  
11 case for many months.

12 And, indeed, over a year ago, New York State  
13 mandated staff testing in congregate settings other  
14 than group homes. Beginning on May 15, 2020, staff  
15 working in nursing facilities were mandated to be  
16 tested two times a week.

17 It's very troubling that people in group  
18 homes are not given the same protection as people in  
19 nursing homes and other congregate settings.

20 People in group homes require close physical  
21 contact with staff and confined spaces just as  
22 people with nursing homes do.

23 As Dr. Kastner mentioned today, people in  
24 group homes often have comorbid conditions that put  
25 them at higher risk of serious illness and death

1 just like nursing home residents.

2 There is no rational basis for this  
3 discriminatory practice.

4 For all of these reasons, the State must  
5 require and fund regular testing of staff who have  
6 not been vaccinated.

7 We recommend that both direct support  
8 professionals and provider agencies be required  
9 partners in creating the parameters of a testing  
10 mandate.

11 Thank you very much.

12 SENATOR MANNION: Thank you very much,  
13 Ms. Keegan.

14 Next is, we're back to Randy DiAntonio from  
15 Public Employees Federation.

16 RANDI DiANTONIO: Thank you, Senator Mannion.

17 So I am from the Public Employees Federation,  
18 but I've also worked for OPWDD for 23 years as a  
19 social worker.

20 And I agree with a lot of what my fellow  
21 panelists have said today about the staffing crisis,  
22 and that crisis clearly goes across all state  
23 agencies, but, in particular, OPWDD has been the  
24 hardest hit.

25 My colleague from CSEA mentioned about

1 15 percent of the workforce has been lost over the  
2 last decade.

3 That equates to over 4500 employees.

4 Let me say that again: Over 4,500 employees.

5 OPW had the most overtime of any --

6 25 percent of the 19 million hours worked in  
7 overtime during COVID was OPWDD.

8 There's been a systemic effort to shrink the  
9 footprint of this agency and the critical levels of  
10 care. And we saw it magnified throughout this  
11 pandemic.

12 The shortages started to allow the agency to  
13 justify a trend of suspending services, closing  
14 group homes, because they couldn't staff those  
15 settings.

16 Many of our members who are not DSPs, but are  
17 habilitation specialists and nurses, were redeployed  
18 into the group homes, and were willing to do  
19 whatever they could to support their brothers and  
20 sisters, you know, doing the frontline work;  
21 however, a lot of this increased density in the  
22 homes, it increased transmission risks because  
23 people were being redeployed from one place to  
24 another.

25 We've seen over the last 10 years a loss of

1       3,000 beds. And that wait continues to increase  
2       because of staffing shortages as we speak.

3               Everybody has heard about the nursing  
4       shortages. And OPW is significantly impacted by  
5       their un -- inability to recruit and retain nurses.

6               We still have not seen hazard pay for our  
7       members who have been on the front lines.

8               There is a lot of things going on where  
9       short-staffing has increased the risks.

10              And I know I'm running out of time, but  
11       I want to address one issue related to the  
12       Department of Health guidelines that were issued.

13              These guidelines for returning to work after  
14       a positive case allowed agencies to bring people  
15       back after a much abbreviated quarantine period if  
16       they wore a mask.

17              But, basically, we were bringing back  
18       positive people into homes because we didn't have  
19       enough staff.

20              And I would just encourage, and I thank the  
21       Senate for passing Senate Bill 1765A this week,  
22       which would allow -- or, engage the agency in a  
23       reporting process on staffing and fills, but this  
24       has to be more transparent.

25              We need to know why vacancies aren't filled,

1 and why they're not recruiting and retaining staff.

2 And there are reasons for this, and we need  
3 to have these conversations.

4 So staffing is a critical need, and we look  
5 forward to partnering with all of you as we move  
6 forward.

7 SENATOR MANNION: Thank you, Ms. DiAntonio.

8 Our last panelist for the topic is  
9 Peter Zummo from the New York Alliance for the  
10 Developmentally Disabled.

11 PETER ZUMMO: Thank you, Senator, for your  
12 leadership in this area.

13 Being last means a lot of the good things  
14 have said, so I'm justed going to speak as a father  
15 and a family member.

16 I have a son, 23 years old, Andrew. He has  
17 autism. He's low-functioning and non-verbal. He  
18 lives in a certified IRA.

19 Andrew and his three housemates require  
20 24-hour care. During COVID, the staffing of his  
21 house was reduced to a barebones level because there  
22 was no staffing available to fill all the positions.

23 Now that we're on the other side, staffing is  
24 still reduced. This has diminished my son's quality  
25 of life. For example, he rarely ever gets to leave

1 the house because there's never enough staff for him  
2 to do so. He only gets to go out when we, me or my  
3 wife, take him out.

4 DSPs are, ultimately, what make the house  
5 work. Without them there would be no residence for  
6 my son.

7 The DSPs that are now working with Andrew all  
8 stayed through their jobs through the pandemic.

9 They're dedicated, they care, but they also  
10 have to earn a living and pay their bills.

11 OPWDD must provide funding to the agencies  
12 that would allow them to pay the DSPs what they  
13 deserve for the work they do.

14 Lack of State funding has made a DSP's wage  
15 not a living wage.

16 That is no longer acceptable.

17 In addition, OPWDD has instituted cuts to  
18 residential rates that will take millions of dollars  
19 out of the system at the very time when millions of  
20 dollars need to go into the system to provide  
21 compensation for the DSPs.

22 It's actually surreal that, coming out of a  
23 pandemic, with an ocean of federal dollars coming  
24 into New York State, that OPWDD would cut  
25 residential rates at this time.

1 But it's not just residential. Many day hab  
2 are also closed, or have not reopened fully, due  
3 again to a lack of staff.

4 My son is lucky; he's in his day hab.

5 But I personally know of one person who lives  
6 in an IRA, who has not had day hab services since  
7 March of 2020 due to staffing problems. His IRA is  
8 provided by one agency. His day hab is another  
9 agency. He has received no services since March of  
10 2020. He sits, watching TV, 15 hours a day -- I'm  
11 sorry -- for the last 15 months, he sits, watching  
12 TV.

13 It's unacceptable.

14 Proper staffing is essential to make this  
15 system work.

16 We cannot let our people down. Our  
17 population deserve to be treated with dignity and  
18 respect.

19 OPWDD needs to stay, stay the course, and  
20 provide the resources necessary to make this system  
21 what it should be.

22 Thank you.

23 SENATOR MANNION: Thank you, Mr. Zummo.

24 Senator Martucci.

25 SENATOR MARTUCCI: Thanks again, Chairman.



1           So I guess maybe the first thing I'll start  
2 off with is, the Chairman and I, I know wrote a  
3 letter together, opposing the cuts to the voluntary  
4 residential programs.

5           So I think we certainly share the sentiment  
6 that you all have raised with respect to that issue.  
7 Certainly, now is not the time to be making cuts to  
8 these programs.

9           So we couldn't agree more.

10          My thanks to Randy and Josh for being here.

11          And certainly, your membership, and, really,  
12 the DSPs, and other service providers around our  
13 state, who, again, [indiscernible] -- some of you  
14 have come back from different panels, so you've  
15 heard this before -- but have really filled a gap of  
16 leadership that this State left, and took absolutely  
17 life-saving action to make sure that things weren't  
18 even worse than they are now.

19          And, lastly, you know, I only had 10 minutes  
20 of questions with the Commissioner, but what was  
21 certainly positive that came out of my discussion  
22 with him was a willingness for he and I to sit  
23 afterward.

24          And I do have tremendous concerns with  
25 respect to the abbreviated quarantine period that

1 was brought up. I think that that certainly is a --  
2 I have tremendous questions about, you know, how  
3 that not only affects the safety of our staff, but  
4 the folks that live in these facilities.

5 And then, lastly, I couldn't agree more with  
6 the importance of testing at this time.

7 I know, Ms. Keegan, you talked about it,  
8 and others, how critical that is that this State  
9 step up, not only mandate it, but financially  
10 support it.

11 So I look forward to continuing that  
12 conversation because I too am aware of that  
13 information that shows us that, from December to  
14 mid-May, our fatalities tipped up by 200.

15 And during that period I was making multiple  
16 requests to OPWDD about this data. And for a large  
17 portion of that time that data wasn't available.

18 So, unfortunately, it was a grim statistic  
19 that confirmed for us that the problem was far from  
20 behind us.

21 So you've certainly got my commitment that  
22 I'll be following up with the Commissioner on that,  
23 even though I did not have an opportunity to ask  
24 those questions today.

25 Thank you, Chairman.

1           SENATOR MANNION: Thank you.

2           Obviously, many concerning things that are  
3           coming up again, including, you know, the  
4           COVID-positive patients that were forced to return  
5           to work. That is the extreme nature of the  
6           workforce crisis I think that we're in.

7           And I can -- will just quickly say, to Randy  
8           and Josh also, thank you to your members for,  
9           literally, giving their lives to care for others.  
10          And my best to their family members as well.

11          For the family advocates that are on here, we  
12          can hear it, we can all hear it, you care about the  
13          people who care for your family members.

14          I had an aunt who lived in a residential  
15          facility.

16          We need to treat these people with dignity,  
17          respect, and equity.

18          And I think we're all on the same page there,  
19          and we're all going to make sure that we do whatever  
20          we can to make sure that they are properly  
21          respected, that they have that dignity.

22          And the only way to do that is to properly  
23          fund it, and we're all going to push together, as  
24          I know Senator Martucci agrees.

25          And the folks that I've had the pleasure of

1 meeting, that are across the screen, are going to  
2 push with me.

3 So thank you all for participating today.

4 Thank you for your advocacy for the people  
5 who do the work.

6 And thank you to the people who did the work,  
7 and who represent those.

8 So I appreciate it.

9 Our next panel will be on visitation.

10 Our first panelist will be BJ Stasio from  
11 Self-Advocacy Association of New York.

12 BJ STASIO: Thank you for having me back;  
13 I appreciate it.

14 And while we're talking about visitation,  
15 under certain circumstances during COVID-19, people  
16 in certified settings were restricted in terms of  
17 visitation to what they had believed as their home.

18 They were also restricted from participating  
19 in their community.

20 While the Self-Advocacy Association does not  
21 question the intent and importance of preserving  
22 health and well-being, even lives, their  
23 restrictions raised significant questions among  
24 self-advocates about rights.

25 It was very difficult for people to

1 understand why they could be told they could not  
2 have visitors or access to community when their  
3 neighbors, who did not receive services, could  
4 choose to do these things.

5 We asked OPWDD and New York State to explore  
6 these rights-related issues that have come up --  
7 come to light in the future, to ensure the  
8 strategies to infection-control pandemic management  
9 are clearly based on a foundation of individual  
10 rights, and that that foundation of any necessary  
11 restrictions, should those exist, are communicated  
12 clearly in a manner that afford people receiving  
13 those services to understand their rights, and the  
14 recourse should they not agree with any  
15 restrictions, such as easy-read documents, for  
16 example, in plain language.

17 And I would like to say, from my previous  
18 panel, I support the point that Michael Seereiter  
19 made about smaller group homes. And if people wish  
20 to live in their own setting, I would like to -- for  
21 people to have the option to explore that.

22 Thank you.

23 SENATOR MANNION: Thank you very much,  
24 Mr. Stasio.

25

1           And next we are back to Peter Zummo from the  
2           New York Alliance for the Developmentally Disabled.

3           PETER ZUMMO: Thank you again, Senator.

4           Before I discuss the actual visitation issue,  
5           I would like to point out the effects of the  
6           long-term lockout that my son had to endure, and  
7           other residents of the system.

8           The lockdown caused physical, medical, and  
9           psychological harm.

10          He -- my son developed aggressive behaviors  
11          towards staff. We had to adjust his medication to  
12          address the issue. He developed alopecia from the  
13          stress he was under.

14          Other residents showed signs of severe  
15          regression and depression.

16          I know people that were forced to miss  
17          medical appointments because they were under  
18          lockdown, including one person whose glaucoma went  
19          untreated, and is now blind in one eye.

20          As for visitation, from March to July, my son  
21          was a virtual prisoner in his house. He was not  
22          permitted to have any visitors, he was not allowed  
23          to go anyplace or do anything.

24          His house is not medically fragile. None of  
25          the four residents have any comorbidities that would

1       increase the risk of a poor outcome should they have  
2       contacted COVID.

3               I was not allowed to see my son, even though  
4       I'm his guardian, and have the legal right and  
5       obligation to see him and check on his condition.

6               While such a draconian lockdown may have made  
7       sense in March and April, to extend the total  
8       separation of residents from their families and  
9       guardians into July and beyond was excessive and  
10      unreasonable.

11              I would like to point out also that the  
12      effects of COVID were different from region to  
13      region in the state and in the OPWDD system.  
14      Treating all the regions alike is not the right way  
15      to do it.

16              I also think we need legislation passed that  
17      will establish an "essential family or guardian"  
18      designation, which I like to call "EFG."

19              The EFG would permit each resident, or her  
20      guardian, to designate one person who will be her  
21      EFG, and that EFG will be granted access to the  
22      house the same as if she was a staff member.

23              This way, if there are future lockdowns, one  
24      person from each family, either a guardian or a  
25      family member, is designated, and can go into the

1 house, check on their loved one's conditions, and  
2 see that they are okay or if they need anything.

3 I think if a lockdown is necessary in the  
4 future, it should be limited in time and scope only  
5 to what is medically necessary.

6 Locking out guardians and separating families  
7 for months at a time is not in the best interests of  
8 the residents.

9 Thank you, Senator.

10 SENATOR MANNION: Thank you, Mr. Zummo.

11 Next is, I would like to introduce  
12 Susan Constantino of CP Unlimited.

13 SUSAN CONSTANTINO: (No audio.)

14 SENATOR MANNION: Susan, you're muted.

15 SUSAN CONSTANTINO: After all this time,  
16 wouldn't you think we would know enough to not be  
17 muted?

18 Unbelievable.

19 I really started by saying, thank you,  
20 Senator Mannion, for everything you've been doing.

21 And for you, Senator Martucci, we -- I have  
22 affiliates who speak very highly of you and all of  
23 what you've been doing.

24 So thank you very, very much.

25 I come here in a little different fashion,



1 and so I'm not going to talk about what I had  
2 written to talk about.

3 But I would really like to talk to BJ and to  
4 Peter and to other parents, because this is a  
5 provider, and our providers across the state.

6 This was an extremely difficult time for us  
7 too.

8 It goes back to a lot of what's been said  
9 throughout all of this hearing.

10 The first part is, that there were no clear  
11 guidance that we received from OPWDD.

12 Guidance that's put in place and never taken  
13 out of place, guidance that was put in for actually,  
14 really, downstate, and went through the whole state,  
15 is not appropriate, and we know that.

16 But we also know that, as providers, the  
17 people we needed in our homes were our direct  
18 support staff. And we knew that we could not  
19 control where they were, except when they were with  
20 us.

21 We did not have enough PPEs in the beginning,  
22 but that changed, and we eventually had enough.

23 But we couldn't control who was really  
24 working with our folks.

25 And so the "lockdown," as you call it, and

1       for us it was, really, we didn't like to think about  
2       it that way, but it appeared necessary because our  
3       goal was to keep people safe, especially as we saw  
4       our individuals go into the hospital or our  
5       individuals pass away.

6               So that really was the reason why.

7               But I sat in meetings with OPWDD every week  
8       for months and months, and nothing changed. And  
9       that was wrong because we needed to have the  
10      guidance changed, it needed to be looked at  
11      differently.

12              But it goes back to exactly what was said on  
13      the last panel: If we would have had the  
14      availability or the access of testing, where we  
15      could have tested; where we could have tested our  
16      staff, where we could have tested, and asked our  
17      families to have these rapid tests, only those of us  
18      who were lucky enough to have some kind of a  
19      relationship with a PPS or with something else where  
20      we were able to get the testing, that could have  
21      helped.

22              So forgive us as providers that we locked you  
23      out. That was not what we really wanted to do, and  
24      we needed to really have a better way to do it.

25              But also forgive us for trying to keep people

1 safe, even though the repercussions, as you had  
2 talked about, Peter, were very great.

3 SENATOR MANNION: Thank you, Ms. Constantino.  
4 Our last panelist for the topic is  
5 Margaret Raustiala.

6 MARGARET RAUSTIALA: Senator, I'm going to  
7 make your job a little difficult because I'm a  
8 parent. I represent Long Island Advocacy for the  
9 Developmentally Disabled, and I have a very  
10 different point of view from the other parent who  
11 spoke, and from the Self-Advocate.

12 March of 2020 OPWDD suspended all visitation  
13 in certified residences. It was the height of the  
14 pandemic, and little was known with certainty about  
15 how COVID spread, was transmitted, and how deadly  
16 was the disease.

17 Given the range of vulnerabilities of the  
18 people who live in certified residences, this  
19 seemingly draconian suspension of all visitation, in  
20 my humble opinion, was necessary.

21 Many families were understandably upset, but  
22 most, most, I believe, recognized the need for  
23 precautions.

24 Later, the memo suspending visitation was  
25 amended to permit, but not require, providers to

1 allow visitation outdoors with symptom checks,  
2 temperature taken, mask worn, and social distance  
3 when possible.

4 At the time of the pandemic, my son Rico was  
5 49, and had never gone more than two weeks without  
6 visiting my husband and I in our home.

7 Rico would not talk on the phone or use  
8 FaceTime, and we were worried that if we went to  
9 visit him in the backyard, he would want to hop in  
10 the car and would wonder why he couldn't.

11 Consequently, after 49 years, we went  
12 5 months, 5 months, before we saw him and could  
13 bring him to our home for a visit.

14 Staff took photos and short videos of Rico so  
15 that we could see how he was adjusting to his new  
16 life.

17 Words cannot express the gratification that  
18 I feel. This was a difficult time.

19 Some families were angered by the visitation  
20 policy. They believed that if the staff went out in  
21 and out of the group home, why not families?

22 At the time, at the beginning of the  
23 pandemic, Leanne took the position that, while  
24 separation of residence from their loved ones can  
25 cause significant stress and anxiety, as one of the

1 parents pointed out, it was necessary because the  
2 staff was needed. It required staff to go in and  
3 out. We don't require families to go in and out.

4 So as hard as it was, and as difficult as it  
5 was, it was the right thing to do.

6 As more was learned about the transmission of  
7 the virus, OPWDD recognized that new strategies were  
8 needed, going forward, and to extend the opportunity  
9 to visit residents in certified facilities.

10 Eventually, protocols were in place to permit  
11 indoor visits by persons 18 years or older. These  
12 included, again, symptom, temperature checks,  
13 guidance, as to where in the home the visit could  
14 ideally take place, and requirements for  
15 mask-wearing, and as someone pointed out, social  
16 distancing, which is often very, very difficult, if  
17 not impossible, to achieve.

18 Since there was increasing evidence that the  
19 transmission of the virus outdoors was difficult,  
20 given its airborne nature, many agencies strongly  
21 encouraged people to come visit their child in the  
22 backyard, weather permitting.

23 The U.S. has now reached a new milestone,  
24 with the number of Americans who are fully  
25 vaccinated reaching 41.4 percent, as of the CDC

1 yesterday.

2 It was more -- the CDC has, like, come out  
3 with different guidance that's more stringent than  
4 the general public, but gives more flexibility.

5 Governor Cuomo recently announced that more  
6 than 60 percent of adult residents in New York State  
7 have had at least one dose of vaccine, and more than  
8 50 percent of the adults are fully vaccinated.

9 In this case, we are pleased that visitation  
10 has become much more loosened up, and especially for  
11 those individuals where the resident and the person  
12 visiting them are both fully vaccinated, and the  
13 visitation takes places in the resident's bedroom or  
14 in a designated area away from other people.

15 We think that this is a very reasonable step.

16 And we hope that, as time goes on, and more  
17 is learned, and, eventually, more and more people  
18 are fully vaccinated, that the government will --  
19 New York State government will continue to follow  
20 science, and make decisions based on the science  
21 that the CDC is coming forth with.

22 Thank you.

23 SENATOR MANNION: Thank you, Margaret.

24 All of that commentary was very powerful, and  
25 I can only imagine the range of emotions that your

1 family members and yourselves felt.

2 Well, just one quick comment, and then a  
3 quick question.

4 But, Peter, my comment is, that I think your  
5 idea is a fantastic one, and absolutely necessary.

6 And, hopefully, you know, we can -- our  
7 office can engage with you to talk a little bit more  
8 about that. But your EFG idea is a -- I'm a fan of,  
9 and it's absolutely necessary.

10 And, just, if there's any blessings that come  
11 out of this, I think that that, making that change,  
12 so that we can make sure that we have access to our  
13 family members, is important.

14 And I've heard this over the course of almost  
15 a year and a half how necessary that is.

16 Peter, you were going to say something,  
17 I think?

18 PETER ZUMMO: Yes. Thank you, Senator.

19 I appreciate your support in this. And,  
20 NYADD, we're 6,000 people strong throughout  
21 New York State. We're -- we'll be happy to work  
22 with you and your colleagues, and get this EFG  
23 legislation passed.

24 And I think it's a very good thing that is  
25 really needed in the system.

1           Thank you.

2           SENATOR MANNION: And then my last question,  
3 and I think some of the family members and advocates  
4 alluded to this, but, you know, were there any  
5 options --

6           I think, Margaret, you had mentioned this.

7           -- but any options that really were very good  
8 options, and, obviously, that was restricted at  
9 certain times --

10          You had talked about your -- the backyard  
11 visit.

12          -- but that were provided to residents to  
13 keep in touch that you found to be, you know, on par  
14 with, or close to, in-person interactions?

15          MARGARET RAUSTIALA: As I said, once again,  
16 the DSPs came through. They understood, and they  
17 would take photographs of Rico, or short videos, and  
18 send them to me, on their own. The DSPs really  
19 understood that we couldn't see him, and that this  
20 was the best thing in our family's case.

21          And to go back to the proposal that was made  
22 in terms of one person being permitted to visit,  
23 I still think that testing is going to be the key.  
24 I mean, we need -- we can't have -- I don't care who  
25 you are, we need now with testing, so that the



1 people we know who are getting together are free of  
2 COVID, or have been fully vaccinated and have that  
3 Excelsior pass.

4 SENATOR MANNION: I think we agree.  
5 Absolutely.

6 Thank you, Margaret.

7 Any other comments from anyone?

8 Thank you again, for the panelists, for  
9 sharing your story. And, again, I use the word  
10 "powerful," but it was powerful.

11 Thank you, again; I appreciate it.

12 Our next panel is on vaccination, and our  
13 first panelist is Susan Constantino from  
14 CP Unlimited.

15 SUSAN CONSTANTINO: I'm unmuted this time,  
16 I'm happy to say, having thought about it.

17 Well, I really want to thank the people who  
18 organized this because they gave me the happy thing  
19 to talk about, which is vaccinations.

20 And I would like to talk a little bit about,  
21 number one, thanking everyone, the Legislature, as  
22 well as, I believe, OPWDD, certainly NYDA, and all  
23 of us who advocated, that our individuals who live  
24 in certified residential programs were part of the  
25 1A grouping, and that we were able to be in the

1 first group to get them vaccinated.

2 I think it was also important that our staff  
3 were in that group, and that made a big difference.

4 Even though we have not been very successful  
5 in getting our staff to accept being vaccinated, I  
6 do think that having them be in the first group,  
7 having it be easier for them to be able to do, and  
8 having them be able to observe our individuals  
9 receive the vaccine, was really important.

10 And we continue to try to keep encouraging  
11 that kind of behavior for them, that they would get  
12 vaccinated.

13 I do want to say that OPWDD required a very  
14 stringent data collection system on the  
15 vaccinations.

16 And in the very beginning, staff who really  
17 were -- who did not have the time and were unable to  
18 do this, we're really asked to report on  
19 vaccinations every single day. And we were -- it  
20 was overwhelming.

21 And so we worked with OPWDD, and we were able  
22 to -- or, a small group of us work with them in  
23 order to get that changed so it became at least  
24 weekly.

25 It's redundant. It doesn't really give us

1       what it needs because it's aggregate. It doesn't  
2       give us, like, in which areas are there particular  
3       issues about trying to get people vaccinated.

4               But at least it is data that we've got that  
5       we can look at.

6               But I think what was most important, and  
7       I think it's really important to give credit where  
8       it was due, the local health departments, once --  
9       during the very beginning of COVID, when they didn't  
10      recognize us, they didn't know that the Office of  
11      Emergency Management didn't realize they were  
12      supposed to support us or help us, but once they  
13      learned that, and through the Governor's office, we  
14      actually got acquainted with many of them,  
15      particularly in New York City, they were magnificent  
16      in the vaccination part.

17              They really helped us to find the places  
18      where we would go.

19              They helped us to support smaller agencies so  
20      that everyone had a place to go.

21              They were -- we could call them and say,  
22      "This clinic needs 200 doses on this day," and it  
23      would be there.

24              So between the FQHCs and the long-term care  
25      pharmacies, and some other OPWDD providers that said

1 I'll have it in my own place, I think that there was  
2 a concerted effort, and it was an effort that  
3 succeeded, based on the fact that we have so many  
4 folks vaccinated.

5 My only comment -- last comment is just that,  
6 now we need to find ways to get our staff  
7 vaccinated.

8 We need support.

9 We don't have clear guidance on exactly what  
10 we can say or what we can't say, and that's not just  
11 OPWDD. I think it's everyone now looking at this.

12 But the day that we're able to say that it's  
13 required, and that we must -- that staff must be  
14 vaccinated will be the day we can all start to feel  
15 a little bit more comfortable.

16 Thank you.

17 SENATOR MANNION: Thank you, Susan.

18 The last panelist for this topic is  
19 Yvette Watts from New York Association of Emerging  
20 and Multicultural Providers, Incorporated.

21 YVETTE WATTS: Thank you,  
22 Senator Manning [sic] for this opportunity to speak  
23 again on this very sensitive topic.

24 First I want to thank my colleague  
25 Susan Constantino.

1           She, along with her large agency,  
2       demonstrated that networking and shared resources  
3       amongst providers is our greatest resource.

4           As she mentioned, in the beginning, there was  
5       a disconnect.

6           And we did get into the "A" category, but  
7       prior to that there was a lack of communication.

8           I know many of my small and midsize providers  
9       were at a loss. And families were contacting them,  
10      and they had nowhere -- where to go, what to do,  
11      were they even counted in this A1 category.

12          So once Susan connected us with the local  
13      DOH, we were able to work along with her to make a  
14      lot of those pop-up sites available, and to really  
15      find out what needs those agencies had.

16          Thank you so much, Susan. You know, I love  
17      following you on any kind of a forum.

18          I just want to say that, right now, the  
19      problem that we have, is the hesitancy rate is very  
20      high amongst the staff, and especially people of  
21      Black and Brown culture. And that has a lot to do  
22      with historic cultural concerns, but it also has to  
23      do, and I have to say this, I mentioned it  
24      yesterday, it's the lack of equity in compensation,  
25      the lack of trust.

1           These individuals do not -- I mean, now I'm  
2       talking as a mother of a 36-year-old female with  
3       autism.

4           And I hear them say, How can I trust someone  
5       that doesn't even care what I do, doesn't even care  
6       that can I pay my bills?

7           These individuals -- and then, you know, you  
8       talk about the day we will be able to do mandatory  
9       testing. Until we build that trust up, that's not  
10      going to work, because many of them feel, and they  
11      said it to me, that why should I trust someone to  
12      vaccinate me when they can't even compensate me or  
13      understand that what I do is important? I take care  
14      of individuals, but I want to be here. But that  
15      I can't -- that I don't feel like an essential  
16      worker. I feel like I am being abused.

17           And that's the way they feel.

18           I think that Michael Seereiter, another  
19      colleague, he was so eloquent in stating what he  
20      feels about the disparagy [ph.] and the lack of  
21      equity for our workers.

22           So as I said before, this is a circle of --  
23      and once there's a piece that's not connected, if we  
24      don't -- we need those individuals, yes, to be  
25      vaccinated, but you cannot mandate individuals that

1 don't even want to work with you anymore.

2 It's very simple.

3 And I think that it's appropriate that we had  
4 the forum yesterday, and now we have this forum in  
5 which -- the platform in which to talk about what we  
6 need to do, moving forward.

7 So thank you, Senator, for this opportunity  
8 to speak.

9 SENATOR MANNION: Thank you.

10 Yes, and thank you for sharing.

11 And, you know, I'm almost embarrassed by the  
12 questions that I would have asked, because I know  
13 the -- you know, this is not about procedure, this  
14 is not about logistics. It's a much, much bigger,  
15 and more sensitive, picture than that.

16 And I appreciate both of you sharing that  
17 information.

18 I don't have any questions because I don't  
19 think we're going to have an answer.

20 So we do understand the importance of it, and  
21 I do hear resonating as it regards to testing, which  
22 has come up -- came up several times.

23 And, of course, we want people to be  
24 vaccinated, but we also want them healthy as they're  
25 working with others, and we want to help in building

1 a more trustworthy environment, yes.

2 YVETTE WATTS: Thank you.

3 SENATOR MANNION: Thank you.

4 Our next panel is fiscal impact and other  
5 challenges.

6 Our first panelist is Kathy Bunce from  
7 State-Wide Family Advocacy Network of New York.

8 KATHY BUNCE: (No audio.)

9 SENATOR MANNION: Kathy, you are muted.

10 KATHY BUNCE: I'm sorry. I should know by  
11 now.

12 The COVID shined a very bright light on a  
13 very fragile system.

14 For years family stakeholders have been  
15 sounding the alarm, and asking for investment in the  
16 workforce we desperately need. We have asked  
17 repeatedly, the services delivered through OPWDD is  
18 fully and fairly funded.

19 I know you've heard those words from us  
20 before.

21 The increased minimum wage, along with a  
22 decade of -- without a meaningful COLA -- there was  
23 a very, very small one, one year -- has nonprofit  
24 agencies at a huge disadvantage.

25 And as a parent I can tell you, I know,



1 shifts are long, pay is low, the work is hard, and  
2 overtime is frequent.

3 And then comes COVID, and it was the perfect  
4 storm; there were no services.

5 We were told by OPWDD that we may never get  
6 back to level of services, and families really were  
7 left to fend for themselves.

8 Now, our family, we were lucky. We were  
9 healthy. I have a husband who shared in the  
10 caregiver responsibilities.

11 And not everyone in the state has that  
12 option.

13 Without this workforce we have no future.

14 Without a capacity of caring DSPs, we will be  
15 returning to the days of institutionalization  
16 because families simply will not live forever.

17 My daughter attends a day program only  
18 three days a week because they don't have sufficient  
19 staff, but there is not one single staff member  
20 working there today that was there pre-COVID.

21 She was given priority because she's still  
22 living at home. So my husband will have -- when my  
23 husband has to return to work, we're really not sure  
24 what we're going to do.

25 Her certified group home is scheduled to open

1 at the end of the month. The opening date is  
2 contingent on finding staff.

3 Families are literally going door to door,  
4 handing out flyers, looking for people.

5 That should not be.

6 That should not be.

7 Other families are working shifts in the  
8 noncertified homes to cover the care and safety of  
9 their loved ones.

10 So in January there were 2300 open positions  
11 in our region. Now we have over 3300.

12 We need a sustainable system for our loved  
13 ones, going forward.

14 We need to stop these crazy 5-1 cuts.

15 We need to raise the wage because DSPs  
16 deserve to make a living wage. 10 years ago their  
17 starting pay was 35 percent above minimum wage.

18 There's been minimal investment in the most  
19 important workforce infrastructure to so many  
20 people; 130,000 people.

21 Now is the time.

22 They should be considered essential workers  
23 because they are essential workers. They're  
24 essential to my daughter, they're essential to my  
25 family, and to every other family member who has

1       ever had -- had to rely on services, at no fault of  
2       their own, by the way.

3               We need to fund the future.

4               We need to use those federal FMAP monies, and  
5       we need them to flow very quickly to the nonprofits  
6       to stop the bleeding.

7               These nonprofits are in a dangerous fiscal  
8       position. They serve 80 percent of the people and  
9       simply cannot fail. We simply cannot afford to lose  
10      one person from this system at any level.

11              We need immediate action to address the  
12      submarket wages, we need proactive planning and  
13      forecasting of future need, and we need to have a  
14      robust sustainable future for our children.

15              Thank you.

16              SENATOR MANNION: Thank you.

17              Next is Karen Nagy from Eastern New York  
18      Developmental Disabilities Advocates.

19              KAREN NAGY: Thank you, Senator, and  
20      committee members.

21              I'm following Kathy's lovely testimony, and  
22      it occurs to me, over all of these forums, that we  
23      keep hammering home the same points.

24              So I'm not going to -- I'm going to adjust  
25      again, and I'm not going to hammer home anything

1       that hasn't already been hammered home.

2               But I can say with unequivocal certainty that  
3       our provider, our nonprofit provider, kept our son  
4       and everyone else they served safe.

5               And we face an incredible staffing shortage  
6       at this moment due to burn-out, and the significant  
7       overtime pressures, that have occurred for our  
8       remaining staff.

9               So there's really a two-pronged problem here.

10              We have remaining staff that's burnt out, and  
11       just exhausted, from all of this care. And then we  
12       will have new staff coming in that we will need to  
13       train and spend money on.

14              So at a time when people with IDD, and  
15       especially like my son with profound autism, who  
16       doesn't do well with change, they have experienced  
17       significant regression, and they'll be adjusting to  
18       reopening full in-person services, environmental  
19       stressors.

20              I mean, many of us without disabilities are  
21       understanding the differences in our lives that have  
22       contributed to stressors that have driven to make  
23       different decisions after this pandemic.

24              So, you know, our staff is emotionally  
25       drained, burned out. We've lost many of them

1 already, and we're at risk of losing more.

2 So, essentially, our workforce is in crisis,  
3 and it has been in crisis.

4 And it's just -- you know, it's not  
5 acceptable that we don't acknowledge that, without  
6 it, the system, and all of the administrative costs  
7 that support it, are worthless.

8 So, you know, obviously, the additional  
9 FMAT dollars have to be -- that have been generated  
10 by the federal government are going to have to be  
11 used to stabilize the ongoing workforce crisis, or  
12 nothing else will matter.

13 We're going to spend a lot of money in  
14 training a large percentage of new staff.

15 We're going to spend a lot of money because,  
16 every time there's staff turnover, there are,  
17 essentially, additional behavioral incidents that  
18 have to be addressed, and incidents that have to be,  
19 you know, researched, and administrative procedures  
20 behind those incidents that have to occur.

21 And the recruitment and retention challenges  
22 are going to continue because of the low wages.  
23 They're not competitive in any way and they're not  
24 commensurate with the difficult work and  
25 responsibility that the job entails.

1           So I will close by saying, finally, you know,  
2 homes for individuals with IDD cannot be viewed as  
3 beds to fill.

4           They have to be viewed as holistic  
5 environments that subort [ph.] the adaptations and  
6 the necessary supports that ensure each individual's  
7 human right to quality of care.

8           And while we certainly appreciate the delay  
9 of the 5-1 cuts that you're hearing about through  
10 the pandemic, we strongly oppose them, and they're  
11 completely contrary to ensuring the human rights of  
12 individuals with IDD, and they're being proposed at  
13 a time when the system of care itself is at risk and  
14 incredibly vulnerable.

15           So, Senator Mannion, we thank you for  
16 sponsoring the legislation that will address this,  
17 and we thank you for everything that you have done,  
18 you know, on our behalf to date.

19           SENATOR MANNION: Thank you, Karen.

20           Competitive and commensurate, and  
21 I completely agree, and goes way beyond that.

22           Thank you for sharing.

23           Next, we are back to Tom McAlvanah from  
24 New York Disability Advocates, and Interagency  
25 Council of Developmental Disabilities.

1           TOM McALVANA: Thanks again, Senators;  
2       appreciate it.

3           Critical services for people with  
4       intellectual and developmental disabilities are at  
5       risk.

6           While some of the planned cuts have been  
7       rolled back, and the first meaningful cost-of-living  
8       increase since 2009 was recently passed, people and  
9       families are still at risk of losing access to their  
10      current levels of services and supports.

11          Why?

12          Well, I think it was mentioned by Kathy that  
13      over the past decade, the not-for-profit agencies  
14      have been asked to do more with fewer resources.

15          The continued deferral of the statutory COLA  
16      for over a decade has significantly deprived  
17      providers of vital resources needed to maintain  
18      operations.

19          As a result, we don't have a staffing crisis;  
20      we have an impending staff disaster.

21          Right now executive directors are about to  
22      cover vacant shifts because they don't have enough  
23      staff in their residences.

24          One exec told me that he's going to provide  
25      direct care because he's got to get his staff on

1 vacations this summer.

2 Prior to the COVID pandemic, 37 percent of  
3 providers reported losing money on their OPWDD  
4 services.

5 Cash on hand has been a significant challenge  
6 for agencies, where 50 percent of providers had less  
7 than 40 days of cash on hand, and one-third had less  
8 than 30 days of cash on hand.

9 That's two payrolls.

10 And more than one in three already closed,  
11 reduced, or modified programs due to the financial  
12 hardship they were under, and that will grow.

13 Of course, folks mentioned the 5-1 cuts, and  
14 I won't go too much into it, but this action that  
15 will -- is taking place may [indiscernible], or have  
16 taken place, will now remove more than \$230 million  
17 annually from providers already besieged with the  
18 losses and added expenses due to the pandemic.

19 Of course, OPWDD claims that residential  
20 providers' costs are reduced when their residents  
21 are temporarily away from home.

22 We know that not to be true. It doesn't  
23 change one bit our fixed costs, and paying the staff  
24 is still there.

25 So we know that these cuts come at a



1       difficult time, and also gives the impossible choice  
2       to families to say, take their children home for a  
3       visit and cost the residential provider half their  
4       daily rate.

5               Where was the 6.2 percent FMAT fund that all  
6       Medicaid services throughout this country, including  
7       New York State and OPWDD, that they earned, where  
8       was 6.2? Where did that money go?

9               The value of the increased income to  
10      New York State in the IDD sector, not-for-profit  
11      sector only, was over \$50 million a quarter.

12              These dollars certainly could have addressed  
13      the shortfalls that OPWDD claims necessitated their  
14      actions.

15              So, finally, I just want to say that, you  
16      know, our not-for-profit provider community carries  
17      out the state's moral and legal obligation to  
18      provide services and supports to New York's most  
19      vulnerable citizens.

20              Why does New York State continue to look to  
21      the not-for-profit sector to fix their cash flow  
22      needs?

23              This pandemic should not be an opportunity to  
24      shrink the service system because there's little  
25      desire to put more resources into the sector.

1           If you look at OPWDD's website, there are  
2       39,000 young people under the age of 20 that are  
3       provided services.

4           39,000 out of 128.

5           What's the future for them going to be if  
6       we're going to continue to shrink the footprint and  
7       financial resources that OPWDD is struggling to  
8       provide?

9           We need to start investing in this service  
10      sector now while we still have a viable one.

11      Thank you.

12      SENATOR MANNION: Thank you, Tom.

13           I appreciate the numbers, and I think there's  
14      certainly, again, consensus and agreement that we  
15      are at a breaking point, and we're holding on by a  
16      thread.

17           And I appreciate everything that the  
18      providers are doing to make sure that we continue to  
19      provide the services.

20           Next, I would like to introduce Gail Hamlin  
21      from New York Alliance for the Developmentally  
22      Disabled.

23      GAIL HAMLIN: Hi, good afternoon.

24           Thank you, Senator Mannion, and committee  
25      members, for the opportunity to speak at today's

1 roundtable.

2           And one of the disadvantages of speaking at  
3 the end is everybody has already said so many of the  
4 things that were so important, and things that I was  
5 going to touch upon. So forgive me if I repeat some  
6 of these things.

7           I am on the executive council for regional  
8 leads with NYADD.

9           I'm also the legal guardian for my older  
10 brother who lives in a group home residence on  
11 Long Island.

12           The past 15 months with COVID have certainly  
13 been an eye-opener, and it's also been a very big  
14 learning experience.

15           So the biggest issue that his agency, and  
16 I know others have right now, very much related to  
17 5-1 cuts, their therapeutic leave, retainer day, and  
18 vacancy adjustment.

19           Obviously, I don't want to get too much into  
20 detail about it, but it's impossible to budget for  
21 these things because we never know when someone is  
22 going to need to go to the hospital. Right?

23           And families want to see their loved ones,  
24 they want to bring them home for weekends, these are  
25 things that are part of their therapeutic care.

1           The agency, again, can't budget for it, but  
2           they shouldn't be penalized for it as well. Right?

3           Time with family is part of their therapeutic  
4           care, and family is part of their essential network.

5           We cannot see more cuts. We need far better  
6           funding for this.

7           Another issue, again, everyone's been talking  
8           about it, and Karen and Kathy really touched the  
9           nail on the head and said it very eloquently, but  
10          wages are a huge issue, so I'm going to say it  
11          again.

12          But, Commissioner Kastner, his words, he  
13          said, quote, he was immeasurably grateful, unquote,  
14          for the DSPs, for their dedication to our people's  
15          health and well-being.

16          But how can we convert that sentiment into  
17          increased pay for the tireless work and efforts for  
18          all that the DSPs do?

19          They deserve better pay commensurate with  
20          their work.

21          So there can't be employer retention without  
22          the pay to go along with it.

23          And I see that my time is up, so I am going  
24          to say thank you for your time.

25          Thank you.

1           SENATOR MANNION: Thank you, Gail.

2           We are not going to have staff available if  
3 we don't properly compensate them. And we have to  
4 provide the providers with those dollars, and then  
5 they can provide people with a decent and living  
6 wage and -- for this delicate care that they  
7 provide.

8           So, thank you, Gail, for your words.

9           You are our last panelist.

10          Senator Martucci or Senator Persaud, if you  
11 have any final thoughts, I certainly would like to  
12 give you the opportunity before I have my final  
13 words.

14          It's been an important, and good three hours,  
15 a necessary three hours, maybe a long three hours.

16          But, regardless, I think important things  
17 came out as it related to the pandemic, and what we  
18 all also know, which are other crises, particularly  
19 one related to workforce that we have to address.

20          Senator Martucci?

21          SENATOR MARTUCCI: Thank you, Chairman.

22          So first I'll start by thanking you again for  
23 putting this together.

24          Certainly, you know, it's -- I'm glad that we  
25 had this opportunity, and certainly glad that

1 Dr. Kastner has availed himself in the future.

2 I look forward to continuing conversations with him.

3 And I just want to take this moment for all  
4 of you who took the time -- part of the time out of  
5 your day to come here and give all of us some really  
6 important perspective on issues that certainly are  
7 very important to us.

8 You know, again, your perspective is  
9 invaluable in terms of shaping -- shaping, you know,  
10 our thoughts and our actions as we move forward.

11 So I will just end by saying thank you for  
12 your time today.

13 And I continue to look forward to working  
14 with Chairman Mannion and the other members of  
15 the committee to do all we can for the benefit of  
16 IDD New Yorkers.

17 Thanks so much.

18 SENATOR MANNION: Thank you,  
19 Senator Martucci.

20 And I thank Senator Felder for his  
21 attendance. He had to leave.

22 And, of course, thank you, Senator Persaud,  
23 as you were here throughout all of it, you heard all  
24 of it. I appreciate that.

25 And if you have any final thoughts, I would

1       like to make sure that you have that platform.

2               SENATOR PERSAUD: Well, thank you, Chairman.

3               I would just really like to thank you for  
4       putting this together.

5               I know we had a struggle last week. And, you  
6       know, this was worth it for everyone to reconvene  
7       and to hear everything everyone said.

8               You know, Senator Mannion and I had a  
9       conversation with the Commissioner about a week ago  
10      because of something I was not pleased with.

11              And, you know, we are dedicated to fighting  
12      for the IDD population.

13              I have my -- I tell the story all along:

14              I grew up with a friend of ours who was  
15      developmentally disabled. And -- but, let me tell  
16      you, he was the smartest person amongst all of us.

17              You know, he was a little older than us, but  
18      he was the smartest one amongst all of us. And we  
19      involved him in everything that we did. He was  
20      never excluded, on to today, he has never been  
21      excluded from anything.

22              And my mother worked in the industry for  
23      nearly 40 years.

24              And now my youngest brother has decided, you  
25      know, he left his job he was doing and he's decided

1       that this is his passion. And so he's currently  
2       working on a new home that was just opened on  
3       Long Island, and he just loves it.

4               So it's a field that I'm passionate about,  
5       and, you know, there's some legislation.

6               While we're on, someone saw it, and they  
7       called the office and said, Oh, make sure she signs  
8       on to one of Senator Mannion's pieces of  
9       legislation.

10              And I said, Don't worry. I will look at it,  
11       and then I'll make the decision.

12              So, again, thank you, Senator Mannion, for  
13       everything that you're doing.

14              And to all of you advocates, thank you for  
15       everything that you are doing.

16              And we're committed to working with you to  
17       ensure that the industry gets what they deserve.

18              That's what we're committed to doing.

19              So thank you again, everyone.

20              SENATOR MANNION: 100 percent.

21              You know, the pandemic clearly highlighted  
22       the need for the State to invest in the services.

23              Residents went without the services that they  
24       needed.

25              Providers across the state had to absorb the



1 costs.

2 DSPs had to work overtime, many times without  
3 hazard pay, without being tested, sometimes being  
4 COVID-positive, sometimes without proper protection.

5 And we all know that we can do better; we can  
6 do better for the people that provide the service,  
7 and we can do better for the people that need the  
8 service.

9 This past budget is, hopefully, the first of  
10 many steps to show that the IDD community is a  
11 priority just as the other senators and providers  
12 and advocates said as we met here today.

13 I look forward to continuing the work with  
14 stakeholders that were good enough to come today,  
15 and the many more advocates that were out there  
16 enjoyed us via live stream.

17 This is going to conclude our roundtable of  
18 evaluating OPWDD's response to COVID-19 at  
19 residential facilities, but we did much more, and  
20 we're going to continue to do more.

21 This is one step in the right direction.

22 Thank you to the panelists; the Commissioner;  
23 and, of course, my ranking member, Senator Martucci;  
24 Senator Persaud for joining me today; and  
25 Senator Felder who joined me earlier.

1           Thank you again, everyone, for taking the  
2           time.

3           We will all push together in our fight to  
4           make sure, and I'm stealing Senator Persaud's words,  
5           that everyone is included in every scenario, and  
6           that no one has to be forced to overcome barriers  
7           that we can't make sure that they can be overcome.

8           So thank you for joining, everyone, today.

9  
10           (Whereupon, the roundtable held before the  
11           New York State Senate Standing Committee on  
12           Disabilities concluded, and adjourned.)

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