Committee Meeting

of

ASSEMBLY HUMAN SERVICES COMMITTEE

"The Committee will receive testimony from invited guests concerning the impact of COVID-19 on group homes, developmental centers, and community-based residential programs. The Committee will discuss the challenges that the residents and staff of these facilities have encountered as a result of COVID-19, such as PPE supply, availability of testing, mental health services, and support for Direct Support Professionals"

The following bill(s) will be considered:

Assembly Bill 4138, Assembly Bill 4239

LOCATION: Committee Room 11
State House Annex
Trenton, New Jersey

DATE: June 25, 2020
1:00 p.m.

MEMBERS OF COMMITTEE PRESENT:

Assemblywoman Joann Downey, Chair
Assemblyman Nicholas A. Chiaravalloti, Vice Chair
Assemblywoman Shanique Speight
Assemblywoman Cleopatra G. Tucker
Assemblywoman Valerie Vainieri Huttle
Assemblywoman Aura K. Dunn
Assemblywoman Jean Stanfield

ALSO PRESENT:

Adaline B. Kaser
Office of Legislative Services
Committee Aide

Nebnoma Anita Ouedraogo
Assembly Majority
Committee Aide

Robert Geist, Jr.
Assembly Republican
Committee Aide

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Meeting Transcribed by
The Office of Legislative Services, Public Information Office,
Hearing Unit, State House Annex, PO 068, Trenton, New Jersey

ASSEMBLY, No. 4138

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED MAY 11, 2020

Sponsored by:
Assemblywoman VALERIE VAINIERI HUTTLE
District 37 (Bergen)
Assemblyman DANIEL R. BENSON
District 14 (Mercer and Middlesex)
Assemblyman THOMAS P. GIBLIN
District 34 (Essex and Passaic)

SYNOPSIS

Requires Division of Developmental Disabilities to develop public emergency response plan for service providers and facilities serving individuals with developmental disabilities.

CURRENT VERSION OF TEXT

As introduced.

(Sponsorship Updated As Of: 5/28/2020)

AN ACT concerning the development of a public emergency response plan for providers of services to individuals with developmental disabilities and supplementing Title 30 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. a. As used in this section:

"Commissioner" means the Commissioner of Human Services.

"Assistant commissioner" means the Assistant Commissioner of the Division of Developmental Disabilities in the Department of Human Services.

"Department" means the Department of Human Services.

"Division" means the Division of Developmental Disabilities in the Department of Human Services.

"Patient" means a person with developmental disabilities who receives services from the division or any relevant service provider or facility.

"Public emergency" means an environmental, public health, or public safety emergency that is occurring in New Jersey or in one or more counties, regions, or other parts of the State, and which is officially recognized and declared as an emergency by the Governor of New Jersey or by the President of the United States.

"Relevant service provider or facility" means any person or entity that is licensed, certified, or otherwise authorized by the division to provide services to individuals with developmental disabilities or their families in the State.

"Relevant services" or "services" means services that are provided to individuals with developmental disabilities or their families.

b. The assistant commissioner of the division, in consultation with the commissioner, the Commissioner of Health, and the Director of the State Office of Emergency Management in the Department of Law and Public Safety, shall develop and oversee the implementation of a public emergency response plan for relevant service providers and facilities in the State. At a minimum, the public emergency response plan shall:

(1) establish guidelines and best practices for operations, activities, and procedures that are to be undertaken or implemented by relevant service providers and facilities during a time of public emergency, including, but not limited to, guidelines and best practices governing the general operation of relevant facilities and the actions that are to be undertaken by staff, visitors, and patients in association with the provision or receipt of services during a time of public emergency;

(2) identify the means, methods, and channels through which relevant service providers and facilities will be able to obtain

personal protective equipment (PPE), electronic communications equipment, and other resources deemed by the division to be necessary for those providers and facilities to continue to operate and provide services in a safe manner that is conducive to the health, security, and well-being of patients, staff, and visitors during the course of a public emergency; and

(3) address various possible public emergency scenarios and provide for the application of differing standards and best practices under paragraph (1) of this subsection and the use of differing sourcing methods pursuant to paragraph (2) of this subsection for different types of public emergency, as appropriate, while highlighting the standards, best practices, and resource sourcing methods that are applicable for the purposes of any currently declared public emergency.

c. The division shall:

(1) prepare a public emergency response plan, as required by this section, within 30 days after the enactment of this act;

(2) review and revise the plan: (a) on at least a biennial basis after the plan's initial preparation under paragraph (1) of this subsection; and (b) immediately upon the declaration of any new public emergency in the State; and

(3) provide a copy of the initial response plan developed under paragraph (1) of this subsection and a copy of any revised response plan developed under paragraph (2) of this subsection to the Commissioner of Health, the Commissioner of Human Services, the chairs of the Assembly Human Services Committee and the Senate Health, Human Services and Senior Citizens Committee, or their successor committees, and all relevant service providers and facilities, within 10 days after completion thereof.

d. An updated copy of the response plan prepared pursuant to subsection c. of this section shall be posted on the Internet websites of the department, the division, and the Department of Health.

2. This act shall take effect immediately.

STATEMENT

This bill would require the Assistant Commissioner of the Division of Developmental Disabilities (DDD) in the Department of Human Services (DHS), in consultation with the Commissioners of Human Services and Health and the Director of the State Office of Emergency Management in the Department of Law and Public Safety, to develop and oversee the implementation of a public emergency response plan for service providers and facilities in the State that provide services to individuals with developmental disabilities and their families. At a minimum, the public emergency response plan is to:

1) establish guidelines and best practices for operations, activities, and procedures that are to be undertaken or implemented by relevant service providers and facilities during a time of public emergency, including, but not limited to, guidelines and best practices governing the general operation of relevant facilities and the actions that are to be undertaken by staff, visitors, and patients in association with the provision or receipt of services during a time of public emergency;

2) identify the means, methods, and channels through which relevant service providers and facilities will be able to obtain personal protective equipment (PPE), electronic communications equipment, and other resources deemed by the division to be necessary for those providers and facilities to continue to operate and provide services in a safe manner that is conducive to the health, security, and well-being of patients, staff, and visitors during the course of a public emergency; and

3) address various possible public emergency scenarios and provide for the application of differing standards and best practices and the use of differing resource sourcing methods, as appropriate, for different types of public emergency, while highlighting the standards, best practices, and sourcing methods that are applicable for the purposes of any currently declared public emergency.

The division will be required to: 1) prepare a public emergency response plan, as required by the bill, within 30 days after the date of the bill's enactment; 2) review and revise the plan on at least a biennial basis after the plan's initial preparation and immediately upon the declaration of any new public emergency in the State; and 3) provide a copy of the initial response plan and any revised response plan to the Commissioners of Human Services and Health, the chairs of the Assembly Human Services Committee and the Senate Health, Human Services and Senior Citizens Committee, or their successor committees, and all relevant service providers and facilities, within 10 days after completion thereof.

An updated copy of the response plan is to be posted on the Internet websites of the DDD, DHS, and the Department of Health.

ASSEMBLY HUMAN SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4138

with committee amendments

STATE OF NEW JERSEY

DATED: JUNE 25, 2020

The Assembly Human Services Committee favorably reports, with committee amendments, Assembly Bill No. 4138.

As amended by the committee, this bill would require the Department of Human Services (DHS) to develop and oversee the implementation of a public emergency response plan for persons and entities that are licensed to provide services to individuals with developmental disabilities ("licensed service providers"). The department will be required to develop the plan in consultation with the Department of Health (DOH), the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, licensed service providers, and the State Office of Emergency Management in the Department of Law and Public Safety.

At a minimum, the public emergency response plan is to:

1) establish guidelines and best practices for the general and specific operations, activities, and procedures that are to be undertaken or implemented by licensed service providers during a public emergency;

2) to the extent feasible, identify the means, methods, and channels through which relevant service providers and facilities will be able to obtain personal protective equipment (PPE) and other equipment or services that are critical to the maintenance of ongoing operations during the course of a public emergency;

3) address various possible public emergency scenarios and provide for the application of differing standards and best practices and the use of differing resource sourcing methods, as appropriate, for different types of public emergency, while highlighting the standards, best practices, and sourcing methods that are applicable for the purposes of any currently declared public emergency; and

4) be consistent with, and incorporate, any guidance published by the U.S. Department of Health and Human Services, the federal Centers for Disease Control and Prevention, and any other federal agencies that are involved in the remediation of public emergencies.

The department will be required to: 1) prepare a public emergency response plan, as required by the bill, within 60 days after the date of the bill's enactment; 2) review and revise the plan on at least a biennial basis after the plan's initial preparation and as soon as is possible following the declaration of any new public emergency in the State; and 3) post the initial response plan and any revised response plan on the DHS Internet website.

COMMITTEE AMENDMENTS:

The committee amended the bill to require the DHS to develop and oversee the implementation of the public emergency response plan, instead of requiring the Assistant Commissioner of the Division of Developmental Disabilities in the DHS to develop and oversee the plan in consultation with the DHS Commissioner and the Director of the State Office of Emergency Management.

The committee amendments require the DHS to develop and implement the public emergency response plan in consultation with the DOH, the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, licensed service providers, and the State Office of Emergency Management.

The committee amendments require the public emergency response plan to be consistent with, and to incorporate, any relevant guidance published by federal agencies that are involved in the remediation of public emergencies.

The committee amendments remove a provision that would have required the response plan to be submitted directly to the DHS and DOH commissioners, as well as to licensed service providers and to various legislative committees, within 10 days after completion thereof. Instead, the amendments require the initial response plan and any revised response plan to be posted at a publicly accessible location on the DHS Internet website.

The committee amendments make technical changes to the definitions section to remove references to terms that are no longer used in the bill and to replace the stigmatizing term "patient" with the term "client." The amendments also make minor wording changes throughout the bill to refer to "licensed service providers," to remove redundancies, and to clarify the bill's purpose, and they additionally alter the bill's synopsis to reflect the revised purpose of the amended bill.

ASSEMBLY, No. 4239

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED JUNE 8, 2020

Sponsored by:
Assemblywoman VALERIE VAINIERI HUTTLE
District 37 (Bergen)
Assemblywoman AURA K. DUNN
District 25 (Morris and Somerset)

SYNOPSIS

Allows in-person visitation for immediate family members and legal guardians of residents of community-based residential programs and group homes during COVID-19 pandemic.

CURRENT VERSION OF TEXT

As introduced.

(Sponsorship Updated As Of: 6/22/2020)

AN ACT concerning certain community-based residential programs and group homes and supplementing Title 30 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. As used in this act:

"Community-based residential program" means a developmental center, supervised apartment, community care residence, nursing home or any other residential setting, which is licensed and regulated by the Department of Human Services.

"Group home" means a living arrangement that is operated in a residence or residences leased or owned by an individual licensed by the Department of Human Services; which provides the opportunity for individuals with developmental disabilities to live together in a home, sharing in chores and the overall management of the residence; and in which staff provides supervision, training, or assistance in a variety of forms and intensity as required to assist the individuals as they move toward independence.

"Resident" means any child or adult whose primary residence is a community-based residential program or group home that is operated by, or under contract with, the Department of Human Services.

2. a. During the public health emergency declared pursuant to P.L.2005, c.222 (C.26:13-1 et seq.) in response to the coronavirus disease 2019 (COVID-19), the Department of Human Services shall require the operator of a community-based residential program or group home to allow in-person visitation between a resident of the community-based residential program or group home and the resident's immediate family members and legal guardian.

b. Each visitor of a resident of a community-based residential program or group home pursuant to subsection a. of this section shall be subject to all restrictions and limitations imposed by the department in response to the coronavirus disease 2019 (COVID-19), which may , but not limited to requiring each visitor to:

(1) undergo a complete screening for exposure to, or symptoms of the coronavirus disease 2019 (COVID-19);

(2) practice social distancing, including maintaining a six foot distance between the visitor and all residents and staff while in, or on the premises of, the community-based residential program or group home; and

(3) wear a non-medical facial covering while in, or on the premises of, the community-based residential program or group home.

3. The Department of Human Services, pursuant to the "Administrative Procedures Act," P.L.1968, c.410 (C.52:14B-1 et seq.) shall adopt rules and regulations necessary to effectuate the purposes of this act.

4. This act shall take effect immediately.

STATEMENT

This bill requires that during the public health emergency declared pursuant to P.L.2005, c.222 (C.26:13-1 et seq.) in response to the coronavirus disease 2019 (COVID-19), the Department of Human Services (DHS) would require the operator of a community-based residential program or group home to allow in-person visitation between a resident of the community-based residential program or group home and the resident's immediate family members and legal guardian.

As used in the bill: "community-based residential program means a developmental center, supervised apartment, community care residence, nursing home or any other residential setting, which is licensed and regulated by the DHS; "group home" means a living arrangement that is operated in a residence or residences leased or owned by an individual licensed by the DHS; which provides the opportunity for individuals with developmental disabilities to live together in a home, sharing in chores and the overall management of the residence; and in which staff provides supervision, training, or assistance in a variety of forms and intensity as required to assist the individuals as they move toward independence; and "resident" means any child or adult whose primary residence is a community-based residential program or group home that is operated by, or under contract with, the DHS.

Specifically, the bill stipulates that each visitor of a resident of a community-based residential program or group home would be subject to all restrictions and limitations imposed by the DHS in response to the public health emergency, which may include, but not limited to, requiring each visitor to: undergo a complete screening for exposure to, or symptoms of COVID-19; practice social distancing, including maintaining a six foot distance between the visitor and all residents and staff while in, or on the premises of, the community-based residential program or group home; and wear a non-medical facial covering while in, or on the premises of, the program or home.

ASSEMBLY HUMAN SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4239

with committee amendments

STATE OF NEW JERSEY

DATED: JUNE 25, 2020

The Assembly Human Services Committee favorably reports, with committee amendments, Assembly Bill No. 4239.

As amended by the committee, this bill would provide for the Division of Developmental Disabilities (DDD) in the Department of Human Services (DHS), acting in consultation with the Department of Health during a declared public health emergency, to develop guidance for, and to require the operator of a DHS-licensed community-based residential program or group home to allow, in-person visitation between a resident of the community-based residential program or group home and the resident's immediate family members and legal guardian.

A "community-based residential program" includes a developmental center, supervised apartment, community care residence, nursing home, or other residential setting for individuals with developmental disabilities, which is licensed and regulated by the DHS.

A "group home" is a living arrangement that is operated in a residence or residences leased or owned by an individual licensed by the DHS; which provides the opportunity for individuals with developmental disabilities to live together in a home, sharing in chores and the overall management of the residence; and in which staff provides supervision, training, or assistance in a variety of forms and intensity as required to assist the individuals as they move toward independence.

COMMITTEE AMENDMENTS:

The committee amended the bill to make it applicable to all public emergencies, not just the COVID-19 public health emergency. The amendments remove the provision that would have provided for the formal adoption of rules and regulations on this issue and instead require the DDD to develop guidance on in-person visitation. The committee amendments also alter the bill to remove specific requirements pertaining to in-person visitation in order to give the DDD flexibility and discretion with respect the development of policies and guidance on this issue. Finally, the amendments update the bill's synopsis to reflect the revised purpose of the bill.

Joann Downey
Chair

Nicholas A. Chiaravalloti
Vice Chair

Shanique Speight
Cleopatra G. Tucker
Valerie Vainieri Huttle
Aura Dunn
Jean Stanfield

Adaline B. Kaser
Office of Legislative Services
Committee Aide
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NEW JERSEY STATE LEGISLATURE

ASSEMBLY HUMAN SERVICES COMMITTEE

STATE HOUSE ANNEX • P.O. BOX 068 • TRENTON, NJ 08625-0068
www.njleg.state.nj.us

COMMITTEE NOTICE

TO: MEMBERS OF THE ASSEMBLY HUMAN SERVICES COMMITTEE

FROM: ASSEMBLYWOMAN JOANN DOWNEY, CHAIRWOMAN

SUBJECT: **COMMITTEE MEETING - JUNE 25, 2020**

The public may address comments and questions to Adaline B. Kaser, Committee Aide, or make bill status and scheduling inquiries to Lisa DeRosa, Secretary, at (609)847-3860 or e-mail: OLSAideAHU@njleg.org. Written and electronic comments, questions and testimony submitted to the committee by the public, as well as recordings and transcripts, if any, of oral testimony, are government records and will be available to the public upon request.

The Assembly Human Services Committee will meet on Thursday, June 25, 2020 at 1:00 PM in Committee Room 11, 4th Floor, State House Annex, Trenton, New Jersey.

The committee will receive testimony from invited guests concerning the impact of COVID-19 on group homes, developmental centers, and community-based residential programs. The committee will discuss the challenges that the residents and staff of these facilities have encountered as a result of COVID-19, such as personal protective equipment supply, availability of testing, mental health services, and support for Direct Support Professionals.

Due to the public health emergency, the State House Annex remains closed to visitors and the public will not be allowed to attend the meeting in person. The public may view the meeting on the New Jersey Legislature home page, at https://www.njleg.state.nj.us/. The Committee will take oral testimony on bills, by telephone and/or video, limited to three minutes.

If you are interested in registering your position with the committee, you should fill out the registration form for the committee on the website. If you wish to testify, check the box on the form "Do you wish to testify." The form must be submitted by 3pm on June 24, 2020.

Committee contact information will be forwarded to you. The public is encouraged to submit testimony electronically in lieu of oral testimony.

Written testimony will be included in the committee record and distributed to the committee members. Written testimony should be submitted to OLSAideAHU@njleg.org.

(OVER)

The following bill(s) will be considered:

<u>Released/Aca</u> A-4138 Vainieri Huttle/ Benson/Giblin	Requires Division of Developmental Disabilities to develop public emergency response plan for service providers and facilities serving individuals with developmental disabilities.
<u>Released/Aca</u> A-4239 Vainieri Huttle	Allows in-person visitation for immediate family members and legal guardians of residents of certain community-based residential programs and group homes during COVID-19 pandemic.

Issued 6/18/20

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ASSEMBLYWOMAN JOANN DOWNEY (Chair): I will call to session our Human Services Committee for today.

And I'm very happy to see everyone. Thank you so much for all my members, and Vice Chair, and for all of the speakers who are here to attend. And for everyone from OLS -- thank you all for helping to do this.

This is our first remote hearing, so if we have a few glitches I hope everyone understands. But we're going to do our best to make it as seamless as possible.

To begin with, I want to just -- please, all of us, say the Pledge of Allegiance. I do have a flag here (indicates), so I'll hold it up. And if we could say the Pledge. I can't stand, though, because otherwise you won't see the flag. (laughter)

(all recite the Pledge of Allegiance)

Thank you, everyone.

And then I was going to ask if we can all just take a moment of silence for all of the people who have passed as a result of COVID-19. It's been such a horrible time for everyone throughout the nation and in New Jersey. Obviously, we've suffered a lot here.

So if we could just take a moment of silence. (moment of silence)

All right; thank you, everybody.

And could we do a roll call, please, Addie, first?

MS. KASER (Committee Aide): Yes.

Assemblywoman Stanfield.

ASSEMBLYWOMAN STANFIELD: Present.

MS. KASER: Assemblywoman Dunn.

ASSEMBLYWOMAN DUNN: Present.

MS. KASER: Assemblywoman Vainieri Huttle.

ASSEMBLYWOMAN VAINIERI HUTTLE: Here.

MS. KASER: Assemblywoman Tucker is not in the room yet. Assemblywoman Speight.

ASSEMBLYWOMAN SPEIGHT: Here.

MS. KASER: Vice Chairman Chiaravalloti is not in the room yet.

ASSEMBLYMAN NICHOLAS A. CHIARAVALLOTI (Vice Chair): I'm here.

MS. KASER: And Chairwoman Downey.

ASSEMBLYWOMAN DOWNEY: Present.

MS. KASER: You have a quorum.

ASSEMBLYWOMAN DOWNEY: Thank you.

First, I'm also going to -- before we get to the Bills and to the hearing, I want to just say a couple of things.

First, good afternoon and thank you to the members, again, of the Assembly Human Services Committee for attending this important meeting. Today we will hear testimony from invited guests concerning the impact of COVID-19 on group homes, developmental centers, and community-based residential programs.

The Committee will discuss the challenges that the residents and staff of these facilities have encountered as a result of COVID-19, such as personal protective equipment supply, availability of testing, mental health services, and support for Direct Support Professionals.

The COVID-19 pandemic has disrupted so many aspects of our daily lives, but its impacts are especially acute for those people who are living with disabilities. While most individuals with disabilities are not inherently at a greater risk for contracting COVID-19, they may face additional challenges and barriers that come with this pandemic. These barriers may include communication and the practice of certain recommended public health strategies, such as social distancing and frequent hand-washing. This also includes existing barriers in health care settings, such as issues with the use of personal protective equipment, or PPE, which can complicate communication for patients with hearing loss and trigger anxiety attacks for some people who are not used to seeing their caregivers wear PPE

While nursing homes have come under the spotlight, little attention has gone toward congregate living facilities that house residents with intellectual, developmental, cognitive, and other disabilities. According to the Associated Press, at least 5,800 residents in such facilities nationwide have already contracted COVID-19, and more than 680 have died.

In the State of New Jersey, of the 1,238 people living in the five developmental centers run by the State, 414 residents have tested positive, including 389 who have recovered, with 32 deaths. There have been 453 employees who have tested positive, including 313 recovered and one death. According to data supplied to the State Department of Human Services by group home operators, 133 residents have died from the virus, and 842 have tested positive out of a population of about 24,000 in community housing.

We mourn for every precious life that has been lost, as well as for the pain and stress that these individuals and their families have endured. Our state can and must do better by this vulnerable population, and that’s what we’re going to be looking at here.

Thank you to all of those who have submitted testimony. And to those who will be testifying today remotely via telephone or video, I understand that the COVID-19 pandemic has greatly complicated the workings of our normal legislative process. But it is working, and I'm thankful to all those who continue to support our Committee's efforts to improve and protect the lives of our disability community. We look forward to receiving all of your testimony.

So we're going to-- I want to thank everyone again, and just remind everybody that the meeting is being recorded. So it will be available for future viewing on the website archives. So remember that, in case you need to go back; or just so you know as we're speaking, and in case you have to mute yourself for any reasons.

We're going to first go to the two bills that we have today, and I'm going to ask-- Addie, can you do me a favor and start by reading Bill A-4138?

MS. KASER: I certainly can.

ASSEMBLYWOMAN DOWNEY: And I know it has amendments, too.

MS. KASER: Yes, it does have amendments.

Assembly Bill 4138 requires the Division of Developmental Disabilities to develop a public emergency response plan for service providers and facilities serving individuals with developmental disabilities.

The Committee did amend the Bill to require the DHS to develop and oversee the implementation of the public emergency response plan, instead of requiring the Assistant Commissioner of the Division

Developmental Disabilities to develop and oversee the planning and consultation with the DHS Commissioner.

The Committee amendments further require that DHS develop and implement the public emergency response plan in consultation with the DOH, the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, licensed service providers, and the State Office of Emergency Management.

The Committee amendments require the public emergency response plan to be consistent with and to incorporate any guidance published by relevant Federal agencies that are involved in the remediation of public emergency.

The Committee amendments remove a provision that would have required the response plan to be submitted directly to the DHS and DOH Commissioners, as well as to licensed service providers and to various legislative committees within 10 days after completion thereof. Instead the amendments require the initial response plan and any revised response plan to be posted at a publicly accessible location on the DHS internet website.

The Committee amendments further make technical changes to the definition section to remove references to terms that are no longer used in the Bill, and to replace the stigmatizing term *patient* with the term *client*.

The Amendments also make minor wording changes throughout the Bill to refer to "licensed service providers" to remove redundancies and to clarify the Bills' purpose; and they additionally alter the Bill synopsis to reflect the revised purpose.

ASSEMBLYWOMAN DOWNEY: Okay, thank you.

And I notice that Assemblywoman Cleopatra Tucker is also on by phone right now. So I just want to acknowledge her, okay?

So at this point, I just want to ask, first, if-- Assemblywoman Vainieri Huttle, would you like to speak on your Bill?

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Chairwoman. Thank you very much for posting this Bill today.

We've all seen how the outbreak of COVID-19 has caused an unprecedented emergency; but it's also taught us valuable lessons on preparedness. This Bill would require, as you heard, the Division of Developmental Disabilities to develop a public emergency response plan for service providers and facilities serving individuals with disabilities.

You know, at the onset of COVID-19, many providers were unable -- just like everyone else -- to obtain PPE to protect themselves and the individuals they serve. However, the dedicated staff who serve these vulnerable communities definitely deserved the access and the same protection as those working in our healthcare settings, especially when so many individuals with developmental disabilities have underlying medical conditions that can place them, obviously, at a higher risk.

So this legislation not only provides for the current outbreak of COVID-19, but I think it's important that other future public health emergencies are also included.

So with that, I thank you for posting this Bill, and I'm hoping that we can get this out of Committee and, hopefully, to the Governor's desk in time, God forbid, for another outbreak or any other public emergency.

Thank you, Joann.

ASSEMBLYWOMAN DOWNEY: Thank you very much, Assemblywoman.

And it's very appropriate, so I was very happy to be able to put this on for today.

I wanted to also look around just to make sure-- Okay; I know we have-- Is Tom Baffuto on? (no response) Okay, let's see. Anyway, I see that he doesn't need to testify; he's in favor, from The Arc of New Jersey, and no need to testify.

Does anyone else need to speak on the Bill? If you want to speak on the Bill, please just-- I'm going to look at participants; raise your hand if you need to.

Does the Assemblywoman need to -- does she want to speak on this? Assemblywoman Tucker?

ASSEMBLYWOMAN TUCKER: Oh, no.

ASSEMBLYWOMAN DOWNEY: Okay; just double-checking.

All right.

JAVIER ROBLES, J.D.: I'm sorry; could I ask a question?

ASSEMBLYWOMAN DOWNEY: Sure.

MR. ROBLES: With the Bill, why -- especially the Department of Human Services -- why doesn't the Bill cover every division, including the Division of Disability Services? That has various programs geared towards people with disabilities and personal care settings, as well as the nursing agencies within the Department of Human Services. Why isn't it broader? And it seems more specific to just DDD.

ASSEMBLYWOMAN DOWNEY: Now, you know, the Assemblywoman addressed that.

But I just wanted to say, for everyone who doesn't know, Javier Robles is the Chair of the COVID-19 Disability Action Committee, and Director of the Center for Disability, Sports, Health and Wellness at Rutgers University.

And I have to tell you, Javier, for two seconds, you did confuse me between you and Nicholas Chiaravalloti, you have a very similar look, especially on Zoom. (laughter).

MR. ROBLES: Yes, well, he looks a lot better than I do. (laughter)

ASSEMBLYWOMAN DOWNEY: All right; so do you want to address this, Assemblywoman?

ASSEMBLYWOMAN VAINIERI HUTTLE: Sure. I actually did think that was Nick. (laughter)

Javier, I wasn't quite clear on your question. Why does it not cover *what*?

MR. ROBLES: Well, from your reading it seems that the Bill is more DD-specific, as opposed to a general bill, which I believe should cover all of DHS. And all of DHS, all departments within DHS that serve people with disabilities across the board, regardless of what that disability is, should have a plan in place and should provide you all with what those plans are, so for the next pandemic we have a better outlook on what we actually need to do.

ASSEMBLYWOMAN VAINIERI HUTTLE: Yes, I think that the Bill broadly covers DHS in consultation with the Department of Health, the IDD Ombudsman, OEM, DDD providers. And I think together, developing a public emergency response for DHS-licensed service providers, is something that I think we can mandate. I don't know if we are excluding anybody else; I'm hopeful that this includes everyone within the State, and in those departments, and those providers. So if not, maybe you can send something to me. But I believe it does.

MR. ROBLES: All right; thank you.

ASSEMBLYWOMAN DOWNEY: Okay.

So with that, I think we're going to go right to-- At this point, I need a motion to amend and release the Bill.

UNIDENTIFIED MEMBER OF COMMITTEE: So moved.

ASSEMBLYMAN CHIARAVALLOTI: Second.

ASSEMBLYWOMAN DOWNEY: Okay, thank you.

May I have a roll call, please?

MS. KASER: on the motion to amend and release Assembly Bill 4138, as amended, Assemblywoman Stanfield.

ASSEMBLYWOMAN STANFIELD: Yes.

MS. KASER: Assemblywoman Dunn.

ASSEMBLYWOMAN DUNN: Yes.

MS. KASER: Assemblywoman Vainieri Huttle.

ASSEMBLYWOMAN VAINIERI HUTTLE: Yes.

MS. KASER: Assemblywoman Tucker.

ASSEMBLYWOMAN TUCKER: Yes.

MS. KASER: Assemblywoman Speight.

ASSEMBLYWOMAN SPEIGHT: Yes.

MS. KASER: Assemblyman Chiaravalloti.

ASSEMBLYMAN CHIARAVALLOTI: Yes.

MS. KASER: And Chairwoman Downey.

ASSEMBLYWOMAN DOWNEY: Yes.

MS. KASER: With the unanimous "yes" vote, the Bill is released, as amended.

ASSEMBLYWOMAN DOWNEY: Okay, thank you.

So the next Bill that we have is A-4239.

Addie, would you please read that Bill, with the amendments as well?

MS. KASER: Certainly.

Assembly Bill 4239 allows in-person visitation for immediate family members and legal guardians of residents of community-based residential programs and group homes during the COVID-19 pandemic.

The Committee did amend the Bill. The Committee amended the Bill to make it applicable to all public emergencies, not just the COVID-19 public health emergency. The amendments removed the provision that would have provided for the formal adoption of rules and regulations on this issue, and instead require the DDD develop guidance on in-person visitation.

The Committee amendments also alter the Bill to remove specific requirements pertaining to in-person visitation in order to give the DDD flexibility and discretion with respect to the development of policies and guidance on this issue.

Finally, the amendments update the Bill's synopsis to reflect the revised purpose.

ASSEMBLYWOMAN DOWNEY: Okay.

Now again, I was going to ask -- Assemblywoman Huttle, would you like to speak on your Bill?

ASSEMBLYWOMAN VAINIERI HUTTLE: Thanks, Chairwoman, again, for posting this.

As we all know, at the onset of COVID-19 DHS suspended family visits, day programs, and group activities for individuals with developmental disabilities. While this obviously was necessary to control the spread of COVID, there is certainly no question that individuals with developmental disabilities may have experienced adverse effects from this separation.

These changes have also been a difficult transition for families, that I believe contacted many of us. So often families act as both advocate and assistant caretakers and caregivers to their loved ones who reside in group homes across the state. And last week, thankfully, DDD issued visitation and screening guidance for provider-managed residential settings, which is certainly an important announcement in ensuring that DD residents have the opportunity to visit with their loved ones, who are their strongest advocate.

But while COVID-19-related restrictions ease around the state, there's no telling what decisions will be made next. So this Bill would allow in-person visitation for the immediate family members and legal guardians of residents residing in community-based residential programs and group homes during the COVID-19 pandemic, and also public health emergencies.

It's important, as we know as lawmakers, to codify measures to ensure that these vulnerable populations have access to see their loved ones with the proper restrictions and public health protocols in place. And I'm hoping that this Bill will provide that opportunity.

So thank you, again, Chairwoman; and to my colleagues.

ASSEMBLYWOMAN DOWNEY: Thank you again, Assemblywoman Vainieri Huttle. Thanks for bringing the Bill forward, and for your testimony.

And I want to first note in here that we have Mary Abrams--

ASSEMBLYWOMAN VAINIERI HUTTLE: Chairwoman, may I interrupt for one second?

ASSEMBLYWOMAN DOWNEY: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: I would be remiss if I didn't include my colleague Aura Dunn as a Co-Prime, and it shows a bipartisan effort when it comes to our vulnerable population.

Aura, I didn't see you there.

ASSEMBLYWOMAN DUNN: Thank you very much.

I was hoping to make some remarks.

ASSEMBLYWOMAN DOWNEY: Oh, absolutely.

ASSEMBLYWOMAN DUNN: What I'd like to reflect on is how we're all equal players here. There's no different levels of a dais or down on the floor. So I really enjoy that -- that we're all here, as fellow stakeholders, speaking with one another.

So I just-- Chairwoman Downey, I wanted to thank you and the rest of the Committee for this revised amendment language, which will help safeguard the rights of the families of the developmental disabled. As Assemblywoman Huttle noted, we've been hearing from several family members throughout this crisis, from both group homes and developmental centers. And it's critically important for these patients and their families to have the assurances of regular visitation, which we know is just as critical to health and well-being.

I know this is also the beginning; I know we'll be examining what took place during this crisis and if there was an increase in other adverse effects that required medical attention during this lockdown circumstance.

So again, I'm very pleased to have been working with Assemblywoman Huttle on this. I thank you for your strong work on this important issue, and showing the importance of a bipartisan approach to addressing problems and finding reasonable commonsense solutions, one of the main things that drove me to serve in public service.

So I look forward to much more fruitful work together with you out of this Committee, and I will be voting "yes" on this Bill.

ASSEMBLYWOMAN DOWNEY: All right; thank you very much, Assemblywoman.

MS. KASER: I apologize; I see that Sam Friedman has his hand raised.

SAM FRIEDMAN: I apologize; I only raised my hand because I didn't know the order of events, and I knew that my comments were more broad than just the two bills, and I wanted to make sure.

I can wait; no problem.

ASSEMBLYWOMAN DOWNEY: You can speak now. I mean, this is not perfect right now; we're just kind of going with it. And at least I know who else I have to make sure I call on.

So why don't you go ahead and speak, Sam, anyway.

MR. FRIEDMAN: Thanks very much; I appreciate it.

I'm Sam Friedman. I'm President of VOR, the preeminent national organization advocating for human rights and real residential choice for individuals with intellectual disabilities.

I'm also Chair of the New Jersey Developmental Centers Families COVID-19 Alliance; and co-guardian of my sister Jackie, whose home is Green Brook Regional Center. And I wear those two hats today.

Thank you, Chairwoman Downey, for this opportunity. Thanks to you and Assemblywoman Vainieri Huttle for your long-time support of the 1,200-plus souls who reside at the five State-run developmental centers.

And thank you, Ombudsman Aronsohn, for helping us and them be heard. We families and guardians, who speak for them and speak out for them, are grateful to you.

Ironically, it's thanks to this virus that our marginalized constituency is finally here at the table -- finally invited to its first hearing, other than those about facility closures and our loved ones' eviction as a *fait accompli*; finally communicating directly with the State; and finally on the same COVID-19 panel, or task force, with advocates representing other components of the disability community, where they are learning our needs as we learn theirs.

Here's what it took to get here, which is the self same as why we belong here as much as anyone. When SARS-CoV-2 was, for most, an abstraction, we saw it--

ASSEMBLYWOMAN DOWNEY: Sam, I'm sorry to interrupt you. I think I might have made a mistake in terms of what you were testifying to.

Are you testifying just about this Bill, or is this your testimony to be able to speak generally on COVID-19?

MR. FRIEDMAN: I'm speaking on COVID-19 and its relation to the intellectually disabled folks at the centers.

ASSEMBLYWOMAN DOWNEY: Okay. I'm sorry; can I ask you to hold off, though, then?

MR. FRIEDMAN: Certainly.

ASSEMBLYWOMAN DOWNEY: Because I thought you wanted to speak on the Bill.

MR. FRIEDMAN: No problem.

ASSEMBLYWOMAN DOWNEY: Okay.

MR. FRIEDMAN: No, I just wanted to make that--

ASSEMBLYWOMAN DOWNEY: Okay; but we're looking forward to the rest of your testimony. Let me just put on here -- I know that Mary Abrams from New Jersey Association of Mental Health and Addiction Agencies is in opposition, but no need to testify. She has written testimony that's been submitted and that should be available to everybody.

Then we have Jacob Caplan from Easterseals, in opposition, and you are testifying.

So Jacob Caplan, you're on.

JACOB CAPLAN: Hi; thank you, Chairwoman.

ASSEMBLYWOMAN DOWNEY: Welcome.

MR. CAPLAN: I appreciate the opportunity to share our perspective on this, and to also share my personal perspective on this.

As a brother of someone with an intellectual disability, I just got to see him, for the first time since this crisis began, over the last weekend. So I could personally sympathize with what the families are going through, because I'm going through it as well.

That being said, while we understand the intent of this Bill, and we have worked very hard to make visitation safe and accessible for our families and guardians during the pandemic, the safety has to come first.

As previously written, the Bill didn't offer the flexibility needed to the service agencies. We've recently received the amendments to it, and we would like a little bit of time to review them. But we still have some hesitation. And as mentioned previously by the sponsor of the Bill, the Department of Human Services has released comprehensive rules for safe visitation and for screening procedures. At this time we believe that this existing framework is sufficient to achieve the goals that are set forth in the legislation.

We are, however, very heartened to see this issue being taken seriously by the Committee and by the sponsors of the legislation. Families and guardians, as we all know, play an essential role in the care of those in our group homes, and the intent is always to include them when safely feasible to do so.

The COVID-19 pandemic has created challenges for visitation that we have never had to deal with in the past. And we believe the State correctly suspended all visitation in an effort to minimize exposure to this virus for an already-vulnerable population. However, now that New Jersey is slowly reopening we want to ensure that our community is included in that process, too.

Easterseals New Jersey commends the hard work of the Legislature and of this Committee for keeping health, safety, and inclusion at the forefront of the conversation. We look forward to working with the Chairwoman and members of the Committee to continue the important discussions about how we can ensure the well-being of those in our care. While we cannot definitively support A-4239 today, we believe that there is an opportunity for service agencies, sponsors of the Bill, the Committee, and relevant State agencies to work collaboratively to craft a thorough and flexible solution that ensures access to visitation while protecting the safety of our program participants and the staff members who provide their care.

Thank you.

ASSEMBLYWOMAN DOWNEY: Great; thank you very much.

We also have Valerie Sellers from New Jersey Association of Community Providers, in opposition, testifying.

VALERIE SELLERS: Chairwoman, we received the amendments last night; and I think it addressed the concerns that we have with the Bill.

I think that the primary concern is that -- if we're in a public health emergency it really should be at the discretion of the Commissioner of Health, in collaboration with the Department of Human Services and any other relevant Department in the State. And that, really, if it's a public health emergency, then he or she is charged with making that determination of what's in the best interest.

ASSEMBLYWOMAN DOWNEY: So thank you; thank you very much, Valerie.

And we have also Tom Baffuto from The Arc of New Jersey, in favor, testifying.

THOMAS BAFFUTO: Yes, thank you, Chairwoman Downey.

I'd like to thank Assemblywoman Huttle for her sponsorship, and for the amendments.

You know, I think it's fair to say that COVID-19 has put a tremendous strain on all of us, and social distancing has been very difficult for all of us who enjoy spending time with our family and friends. But while it was a necessary step, social distancing has even been harder for the families that have loved ones living in group homes and for many who fully don't understand why they haven't seen their families for weeks and, now, even months.

Limited in-person visits, though, have been necessary -- not to keep residents away from their loved one, but to keep people healthy and safe. And that has to be the primary purpose of everything we do. And while I understand it's been a long three months, and we agree families that have been kept apart from their loved ones should be allowed a visit, so long as the requirements set forth in this legislation, and the amendments, are maintained. We, too, think that the guidance for residential providers on visits with families and friends was a good set of guidance, which we support. And in my written testimony I ask that the sponsor amend the language to match the guidance. We're particularly concerned about in-the-home visits; the visits have to be outside at this point.

So we fully support the guidance, and we support this Bill with the amendments.

Thank you, Chairwoman Downey, for an opportunity to testify.

ASSEMBLYWOMAN DOWNEY: Thank you very much, Tom.

And we also have Toby Davidow, who is a private citizen in favor, who wants to testify.

TOBY DAVIDOW, Ed.D.: Thank you, Chairwoman Downey; and you got my name perfect. Not many people do that on their first try. (laughter)

Thank you very much.

ASSEMBLYWOMAN DOWNEY: Thank you.

DR. DAVIDOW: Good afternoon. My name is Dr. Toby Davidow; I am an advocate for elder abuse awareness, as I partner with other advocacy organizations for national and State reform on guardianship and visitation rights.

And I am in support of A-4239; and I appreciate the Committee, especially Assemblywoman Vainieri Huttle, bringing this forward and for the Committee considering this.

I would like to highlight three key points from my written testimony, as well as briefly share my story.

While justified during the first wave of COVID-19, completely banning visitation to vulnerable adults has been an infringement on their human rights.

Second, several studies have shown that living in group homes and nursing homes leads to extreme loneliness and premature death. It can be compounded by a resident's diminished capacity for understanding why their loved ones stopped visiting.

And three, a nationwide trend has been occurring among the vulnerable population, long before the pandemic flared, where abusers isolate their wards for control and money. This current isolated environment is ripe to allow more fraudulent activity to take place.

My childhood Cherry Hill, New Jersey, home essentially became a group home when my mom's caregiver Ann and Ann's husband, Gary, moved in, in 2014, a mere four years after my dad and Ann had met. Four people were living under this one roof with three tenants having significant ailments. Mom had multiple sclerosis and dementia, Gary purported to suffer aphasia and other cognitive difficulties after suffering from a major stroke, and my dad was mentally frail as a result of being my mother's caregiver for over 20 years.

Within two months of moving in, surreal events unfolded. My parents' personalities shifted, as my mild-mannered dad became more combative and elusive; while my sweet mom became passive and aggressive toward me and her sister. Locks changed, doorbells stopped working; my pictures in the home disappeared. My mom's closet contents were thinning, while my mom's beloved care team were barred from the home.

Meanwhile, Ann's name -- not her husband's -- began appearing on all my parents' estate documents, including deeds, trusts, healthcare initiatives, and financial accounts. All the while my family's and my name were removed.

By December 2017, just three years later, the household was swiftly reduced by 50 percent after my mom and Gary passed away within two months of each other. No notification was made to either family that either were ailing, or that they had even died. My mom was cremated against her original burial wishes.

My dad and Ann married in secret a mere month after Gary had passed. Although my family and friends still try to reach out to my dad, our phone numbers, e-mails, and social media accounts are blocked.

We remain gravely concerned about his welfare. Had there been a law in place protecting my mom and dad's visitation rights, I may have had a fighting chance to save them both.

So in conclusion, New Jersey just needs to do a much better job of ensuring that the vulnerable stay connected to their loved ones. It can start by passing 4239 for group home visitation rights to be restored, as isolation and group housing do not always mix well.

But the conversation should not stop there. I hope you'll reconsider two bills that were referred to this Committee earlier this year: A-3648, the New Jersey Predatory Alienation Prevention and Consensual Response Act; and A-794, which reinforces visitation rights of incapacitated persons.

I truly thank you, the entire Committee, for the support and care of our most vulnerable populations.

ASSEMBLYWOMAN DOWNEY: Thank you so much.

It's truly appreciated to hear your testimony. Thanks for sharing your very personal story to try to help and really explain why it's so important.

And we'll take a look at those Bills as well.

DR. DAVIDOW: Thanks very much.

ASSEMBLYWOMAN DOWNEY: So thank you; and I want to just say now, at this point, unless I see that any-- Do any of our members need to speak on the Bills? (no response)

If not -- it doesn't look like it -- I'm going to, at this point, ask for a motion -- I'll entertain a motion to amend and release the Bill.

ASSEMBLYMAN CHIARAVALLOTI: So moved.

ASSEMBLYWOMAN DOWNEY: And a second?

ASSEMBLYWOMAN STANFIELD: Second.

ASSEMBLYWOMAN DOWNEY: Okay, thank you.

And can we then have a roll call?

MS. KASER: Yes.

On the motion to amend and release Assembly Bill 4239, as amended by the Committee, Assemblywoman Stanfield.

ASSEMBLYWOMAN STANFIELD: Yes.

MS. KASER: Assemblywoman Dunn.

ASSEMBLYWOMAN DUNN: Yes.

MS. KASER: Assemblywoman Vainieri Huttle.

ASSEMBLYWOMAN VAINIERI HUTTLE: Yes.

MS. KASER: Assemblywoman Tucker.

ASSEMBLYWOMAN TUCKER: Yes.

MS. KASER: Assemblywoman Speight.

ASSEMBLYWOMAN SPEIGHT: Yes.

MS. KASER: Assemblyman Chiaravalloti.

ASSEMBLYMAN CHIARAVALLOTI: Yes.

MS. KASER: And Chairwoman Downey.

ASSEMBLYWOMAN DOWNEY: Yes.

MS. KASER: With the unanimous "yes" vote, A-4239 is released, as amended.

ASSEMBLYWOMAN DOWNEY: Okay; and I want to thank everyone.

Now we're going to move on to the hearing portion.

And what I wanted, first, to put on the record is that we did receive written testimony -- I believe it's six or seven pages-- from the Commissioner of Human Services, Carole Johnson. And the Commissioner-- I'd like to read all of it, but it's too much, at this point. So what I did was basically just summarized some of the things that were in it to put on the record. And then anybody-- I believe all the members should have copies, and if they don't, just please request it. And the same for anybody else who would like a copy, they can request it from OLS -- from the Office of Legislative Services.

But basically DHS recognizes those in our community who have demonstrated their caring, dedication, and resilience throughout the pandemic, including the IDD community and their families. The frontline staff at the developmental centers, as well as the teams of professionals at group homes and provider agencies, have shown their indefatigable support for those we serve. This includes our DSPs, self-directed employees, support coordinators, individuals receiving services, their family members, guardians, and providers. We acknowledge the tireless work and sacrifices they have all made during this unprecedented time.

Since the start of the pandemic, New Jersey Human Services has worked to provide extensive assistance and support to our network of community-based providers so that they are able to continue operating and serving clients. Specifically, New Jersey Human Services has provided a temporary wage increase for DSPs; provided $60 million in enhanced payments to residential providers recognizing the added costs in staffing, food, and other essentials; helped to sustain day programs through bridge payments to providers following the necessary closure of congregate day programs; modified rules to quickly allow families and providers to hire direct staff to support their loved ones; implemented Medicaid policy to ensure no one loses Medicaid eligibility during the pandemic; and provided more than 22,595 respirators, 367,000 surgical masks and 472,000 gloves to our community partners and agencies.

And I know, personally, that they were delivering it themselves -- like, actual staff members from DHS -- the Department of Human Services. And I do thank them for all that they have done with that.

And thank you, Commissioner Johnson, for your support.

So I'm going to go now to our next person. I'm hoping that we can have, first, Paul Aronsohn speak, who is the IDD Ombudsman.

I want to thank you, Paul, for being here. Thank you so much for all your hard work always. I know we had a number of conversations during this time, and I look forward to hearing more of your testimony, as does everyone else.

PAUL S. ARONSOHN: Great; thank you.

Good afternoon, Chairwoman Downey and members of the Committee. Thank you for holding today's hearing and for including all of us in this important discussion.

Without question, we are living through an extraordinary moment in human history -- one that has challenged all of us, individually and collectively, in ways never before imagined: our physical health, our mental health, our emotional health, our economic health. In unprecedented fashion, all aspects of our lives have been under siege.

That's true across the country and our world, and that's certainly true across New Jersey.

Indeed, there are really no words that can adequately describe this moment -- from the loss of family and friends, to the loss of jobs and businesses, and to the loss of so many other important things in our lives, including our overall peace of mind. The pandemic has and continues to take a damaging toll on each and every one of us in ways we don't even fully understand yet.

And for many individuals with intellectual and developmental disabilities, the impact has been especially difficult, especially challenging. That's because many of these individuals are particularly vulnerable due to underlying health conditions and medical complexities. Many have severe challenging behaviors, which can be triggered by changes in routines. Many aren't able to practice social distancing because they depend on the physical assistance of others in group homes, in intermediate care facilities, as well as in their own homes.

Many are unable to wear personal protective equipment, namely face masks, due to respiratory conditions or sensitivity to touch or texture; or physical limitations which prevents them from using a mask always.

Many have communication disabilities, which pose a whole range of additional challenges. From those who need to lip-read who are prevented from doing so because others are using standard face masks, to those who need someone to accompany them and speak for them during hospital stays.

And many are students for whom remote learning just doesn't work, and for whom the absence of in-person teaching and in-person therapy can be particularly damaging.

In the Ombudsman Office, we know of these challenges through our direct and personal connection to many of these folks. Through daily phone calls and e-mails, we have been in regular contact with individuals and families, responding to questions, listening to concerns, and learning firsthand about their often very difficult experiences.

And we've been sharing those insights with our colleagues throughout the Murphy Administration in an effort to inform their thinking and to shape their decision-making, doing our best to make sure that the voices of these individuals and their families are heard in a meaningful way. And we've had the opportunity to work closely with legislators, advocates, and providers from all over the state, including many of you participating in today's hearing.

Going forward, I hope and expect that we will all benefit from lessons learned over the past few months -- good, bad, and otherwise. I hope and expect that we will engage in honest, thoughtful, and open conversations about what worked and what didn't; acknowledging the unprecedented nature of this experience, while fully recognizing and fully owning our responsibility to get it right.

And going forward, we will do everything possible to make sure that individuals with intellectual developmental disabilities and their families play a central role in these conversations. Because to get it right we need to make sure that they have a seat at the table and that their insights and experiences inform our State's emergency management planning, preparedness, and response. Now, more than ever, their voices must be heard.

Thank you very much, Joann.

ASSEMBLYWOMAN DOWNEY: Thank you so much.

Paul, as Ombudsman, you have been an extreme, not only advocate for the community, but-- I mean, I cannot believe, seriously, how much you've done with very little help. And it's greatly appreciated by all; it's definitely greatly appreciated by me. And you were definitely a wonderful appointment, that's for sure, because we look forward to spending much more time with you in developing all of these additional future protections and help in response.

So thank you, Paul. You're always at the table, and we really appreciate it.

MR. ARONSOHN: Thank you very much; I appreciate that. I appreciate the partnership.

ASSEMBLYWOMAN DOWNEY: Thank you.

Next, we're going to have Gwen Orlowski, another wonderful advocate, and Executive Director of Disability Rights New Jersey.

Please, Gwen; thank you so much for being here.

GWEN ORLOWSKI: Thank you.

Thank you so much, Chairwoman Downey and the members of the Committee, for inviting me to speak here today on how the COVID-19 public health emergency affected individuals with disabilities.

And in the interest of time, I will keep my remarks brief, knowing that the Committee has our written testimony.

I would add, at the outset, that Disability Rights New Jersey supports the testimony of our DD sister agency, the Council on Developmental Disabilities, as well as the DD Ombudsman. And I've kept my remarks here now to issues more specifically within our legal expertise.

As the Committee may be aware, Disability Rights New Jersey is the federally funded designated protection and advocacy system for people with disabilities in the State of New Jersey. And I'd like to highlight four areas of our recent work that I think may be helpful to the Committee.

The first is that Disability Rights New Jersey believes that it's essential during a health emergency that we have meaningful access to residents of developmental centers, group homes, and any setting where an individual with an intellectual or developmental disability is receiving services. An essential function of Disability Rights New Jersey is to be present in any setting where an individual with a disability may receive services. We are ears and eyes collecting, verifying, and analyzing information to ensure that human, civil, and legal rights are upheld.

Throughout the COVID emergency, Disability Rights New Jersey has been in regular, weekly conversations with the Department of Human Services Division of Developmental Disabilities regarding developmental centers, group homes, and individuals receiving services in their own homes. Those conversations are more fully set forth in our written testimony, and I really hope that you can see that our testimony is a huge shout-out to DDD in their willingness to be engaged with us throughout this. Those conversations have allowed us to fulfill our essential role to monitor, investigate abuse and neglect, and to provide direct representation during this pandemic. And this was all because DDD was transparent, forthright, and always available to us. And I would add that that is similarly true for the State Medicaid agency.

And most significantly, we've been able to resume monitoring, through virtual monitoring, in the developmental centers since late May; and we hope to begin in-person monitoring safely in the near future.

During a healthcare crisis, the essential role that Disability Rights New Jersey plays in assuring accountability, freedom from abuse and neglect, and a focus on the rights of individuals is an invaluable piece of emergency planning.

And I would just quickly note -- I don't know if the Committee has seen the frequently asked questions that CMS released yesterday about nursing home visitations. But they talk about the role of the long-term care Ombudsman in that FAQs; and I would say that our role is similarly important across the spectrum of settings where individuals with disabilities are receiving services.

Our second point is that it is essential during a healthcare emergency that the State have healthcare facility visitation policies that protect the civil rights of individuals with disabilities, and allow for compassionate care situations. And I know that this has already been discussed a little bit, with respect to the Bill that was passed out of Committee, so I'll just note a couple of things.

The first is that Disability Rights New Jersey was really engaged in the beginning to advocate for exceptions to the hospital visitation limitations for individuals with disabilities. And we appreciate the May 12 guidance policy from the Commissioner of Health. And we've asked, in a letter yesterday, that she also extend that to nursing homes. That's a little bit different than the current outside visitation policies, because it does allow for indoor visitation in appropriate circumstances. And similarly, I would point the Committee to yesterday's CMS guidance, which also gives a broader interpretation to compassionate care situations; and that the State look at expanding those visits consistent with the Federal guidance that came out yesterday.

My third point is that it's essential, during a health emergency, that the State's allocation of critical care resources policy does not discriminate, on its face or in its application, against individuals with disabilities. And I recognize this is the Human Services Committee, but this is an issue that was really critical and important early in the pandemic -- the risk that there would be a shortage of critical care resources, especially ventilators. And while we appreciate that the State developed a plan, and that they didn't intend discriminatory impact, we do believe that the policy, as written, has an unintended disparate impact. We've outlined those reasons in letters to the Department of Health and in our testimony, and we ask that the State re-look at that policy to ensure that, should it be needed in the future -- and we really hope that it never needs to be invoked -- but that should it be, that it protects individuals with disabilities and does not have a disparate impact with respect to the allocation of critical care resources.

And I have one final point -- and I appreciate your patience -- and this is consistent with recommendations in the Manatt Report, related to nursing homes.

Prior to the onset of this COVID emergency, we began a project to identify individuals with documented serious mental illness, as well as intellectual and developmental disabilities, who were living in nursing homes. Those efforts were interrupted by COVID, but we have reason to believe that there are individuals who may be inappropriately placed in nursing homes contrary to the Federal PASRR law. And what we did learn, in April, is that this is not a hypothetical problem. We did begin an investigation into the Andover nursing homes; I'm sure the Committee is familiar -- they were the subject of significant reporting by the *New York Times* -- and that investigation is ongoing. But we have received information that over 300 individuals at Andover 1 and 2 were individuals with documented disabilities. And of the individuals who died of COVID-related reasons, 50 of them were individuals with disabilities.

So we support the Manatt recommendation to have a task force that focuses in part on assuring quality affordable home and community-based settings. And if nothing else, this emergency showed us that individuals with disabilities in institutions, including developmental centers and nursing homes, were at much higher risk of infection and, tragically, death.

So thank you again for allowing me to testify, and I would be happy to answer any questions you might have.

ASSEMBLYWOMAN DOWNEY: Okay, thank you so much. That was extremely well said, in terms of bringing into perspective a lot of the terrible things that can happen when people aren't able to go in and see what's going on with individuals in those communities.

So thank you very much for advocating, again, on behalf of all of our residents who need you.

Do I have anybody-- I want to make sure nobody's raising their hand yet, because I'm going to go on, then, to the next speaker just to make sure everyone can speak.

I think, first, I have Carole Tonks here, who is the Executive Director for the Alliance Center for Independence.

CAROLE TONKS: Good afternoon, everybody.

Thank you, Assemblywoman Downey and the Committee, for the opportunity for me to speak today.

ASSEMBLYWOMAN DOWNEY: Thank you, Carole.

MS. TONKS: Thank You.

As Assemblywoman Downey said, I'm the Executive Director for the Alliance Center for Independence. We are one of 11 centers throughout the state, and one of 400 centers throughout the country. We serve people with all disabilities and all ages in assisting them in learning the skills to live independently.

Historically, people with disabilities have been left out of emergency planning and left behind during disasters. Because of this, our office has been involved in disaster planning since Hurricane Irene.

I'm also the parent of a 36-year-old autistic son. My son Jason attends a day program; he lives at home with my husband and me. Jason requires full care in dressing, toileting, eating, and all of his daily needs. He does not have verbal speech; he has social anxiety, as well as behavioral and sensory issues.

And as not to paint a bleak picture of him, he's loving, he's funny, he's compassionate; so I don't want that all to be so bleak.

But my son has been home since the end of February. He had health issues when he was younger, making him immune-compromised. And life has been really challenging. His behaviors have increased, he demands constant attention. He sat next to me last night at 1 o'clock in the morning while I was typing this, because he does not sleep at night anymore. And he has regressed. Due to my son's behavior and sensory issues, he will not wear a face covering. I do not know when his day program will reopen; I'm not sure I would even feel comfortable sending him back. But as a parent, I worry about losing his spot.

My story is no different than many other families struggling to work and care for their disabled child or adult. We have many questions and not a lot of answers, especially those who have children with severe disabilities. What happens to my son if he cannot wear a face covering? Is he going to be left behind and have no program available to him? These are questions I can't answer.

Over the past several months our office has made wellness checks to 3,500 of our consumers, as well as calls to those on the Middlesex County Register Ready list. We heard a lot of stories during those calls, and a lot of tears. We kept a running list of concerns that we kept filtering to Paul Aronsohn -- thank you, Paul, for all of your help -- and I'd like to share some of them with you today.

I would also like to point out that while this session is focusing on people with ID and developmental disabilities, people with all disabilities are affected by COVID, and I ask that the Committee does not lose sight of that.

So I, kind of, bulleted these out to talk about, and these were stories that we got specifically from families and people with disabilities during our calls.

So I'm going to start, first, quickly with congregate care. It is obviously a large issue affecting individuals not only in nursing homes, but group homes, developmental centers, and long-term facilities. We are all aware of the lack of PPE and the shortage of staff. A shortage of home health aids, etc., puts people with disabilities at risk of being placed in nursing homes if they do not have the adequate supports at home. And I know of people with disabilities who will not go into the hospital even when they're sick, because they are afraid that they're going to be released to a nursing home.

Testing: Residents and workers in the developmental centers have been tested for the virus; group homes still have not been tested. We have been unable to receive an answer as to when this will happen, and we do not want to see group homes turn into the next nursing homes, so we feel it's imperative that the testing begin.

We heard from a family that told us of their adult child who lived in a group home and tested positive for COVID. She was taken to the hospital, and the hospital wanted to release her to a nursing home -- where there have been staggering death tolls. So again, people are hesitant to even go in there; we have to find better placements than trying to release people into nursing homes.

Group home staffing: Our agency was made aware of other agencies that are running group homes and not assigning their DSPs to specific homes. DSPs are not equipped with PPE -- or were not, at the time -- and some were told not to wear them in the home. The only protection is that their temperature is taken upon entering. DSPs should be assigned to specific homes to help contain the spread of the virus. They should be provided with the proper protection for their safety, and the safety of those residents living in the home. This issue really needs to be addressed prior to a possible resurgence in the fall.

We received a call from an elderly grandmother caring for four children with disabilities; three with autism. She would not allow her home health aide into their home because they did not have face coverings. Currently staff who fulfill caregiving roles across a variety of settings -- from nursing homes and long-term care facilities, to home and community-based settings -- perform many of the same or similar services as frontline hospital staff, but without the same protections. This means that many of these workers, and those who they care for, are not given the same level of access to necessary PPE as hospital personnel, leaving those they care for vulnerable to infection and cross-contamination.

Long-term care facilities: Families and guardians that have a loved one in a long-term care facility were not getting updates on how their loved ones were doing. We heard of several situations where residents in the facility were testing positive and family members were not even informed.

It was also brought to our attention that families in at least one developmental center had no contact or information on their loved ones for over a week.

Long-term care facilities must do a better job in contacting families and guardian, as well as having technology to allow residents to keep in touch with loved ones.

Resources for families: The people working the resource hotlines are very nice and very compassionate. However, there is a need for additional training on providing accurate and complete information that addresses the needs and situations for disabled individuals and their families. Many families calling -- well, I won't say the *hotline* -- calling one of the hotlines for assistance were given wrong information and given resources that were from other states, making families extremely frustrated.

Support coordinators also need to be given the resources to help families during these times. We have had numerous calls from families asking questions or unable to get in touch with their support coordinators; and also calls from support coordinators, asking if we knew anything about *parental hire,* which is a program which pays families to act as DSPs for their children.

Technology: Many people with disabilities and their families do not have access to tablets, laptops, smartphones, etc. Many do not have Internet service, and are unable to access important information. For those without technology, to keep them connected to their peers and online events, we are seeing a great increase in social isolation for family members and people with disabilities. This is especially true among elderly families. Online support groups can be a helpful solution to keep people connected; however, there are limited groups for families who have older children. And also, if you don't have the technology, you cannot take advantage of this.

These are just a few examples of the challenges facing people with disabilities and their families. I will e-mail my list and testimony; I didn't get a chance to do that today.

But we need to commit to expanding home- and community-based services, and reduce the number of residents in congregate settings for services within the community. The disabled community has been saying it for years: Nothing about us without us. People with disabilities and family members need to be part of the decision-making process, and be a part of emergency response planning and preparedness. These policies that are being implemented are not coming because of preparation; but instead, they're coming out of reaction.

This July marks 30 years of the Americans with Disabilities Act. We're tired of fighting for civil rights. New Jersey can do better; we can do better for the welfare and the lives of our most vulnerable citizens. They are at stake.

I thank you for your time, and I'm happy to answer any questions.

Thank you.

ASSEMBLYWOMAN DOWNEY: Thank you, Carole. We greatly appreciate it. You're always very insightful and, again, another great advocate.

Thank you.

MS. TONKS: Thank you.

ASSEMBLYWOMAN DOWNEY: I just want to go to-- I'm sorry that I'm moving, because I want to make sure everyone gets a chance to speak. And hopefully, if anyone has additional questions, we can get those at the end; because again, I want to make sure everyone gets a chance to speak.

Next, Tom Baffuto, the Executive Director of the Arc of New Jersey.

MR. BAFFUTO: Thank you for convening today's hearing, and for focusing on the needs of people with intellectual and developmental disabilities and their families.

I'm proud of the 20 local county chapters of The Arc; and hopeful that, in partnership with State leaders, the system can continue to provide the services for people with intellectual and developmental disabilitie, and their families the programs they depend on.

I want to start by acknowledging the Department of Human Services Commissioner Carole Johnson; the Deputy Commissioner Sarah Adelman; and especially Assistant Commissioner Jonathan Seifried, who oversees the Division of Developmental Disabilities. The Department has exhibited excellent leadership in the time of crisis, and they are dedicated to the well-being of those we serve. And this has included open lines of communication, including weekly webinars with providers and families; a 20 percent enhancement rate for residential providers who have been caring for individuals at group homes 24 hours a day, 7 days a week; retainer payments for day programs, which is to help providers maintain staff; and a temporary $3-an-hour wage increase for our DSPs working in group homes. The funding for these items has helped providers retain staff and facilities so they can focus on the health and safety of those they serve. Direct Support Professionals who care for individuals with intellectual and development disabilities are often responsible for assisting with passive daily living that cannot be accomplished while practicing social distancing.

Already you've heard a lot about PPE. When the pandemic first hit, available PPE was distributed to hospitals and nursing homes, but not to our group homes, even though the population we serve can be both medically fragile and more vulnerable to the COVID-19. While DHS did distribute two small shipments of PPE, it was much later into the crisis, and community provider agencies were mostly left to fend for themselves in securing these supplies.

During these past three months, providers have spent thousands of dollars, without any reimbursement from the State, on PPE, medical supplies, and cleaning supplies to keep those they serve and their staff protected. And while the State makes moves to reopen programs for individuals with intellectual and developmental disabilities, their staff will continue to need PPE in months ahead when they start receiving services outside the home.

In the past three months, the Direct Support Professional workforce has proven to the State what The Arc of New Jersey already knew: That these staffers are more than just employees; they're essential to our community, and their work should be both elevated and admired. These staffers have put their own health on the line to continue caring for those they serve. They kept spirits up during the stay-at-home order, reassuring individuals who were scared about contracting the virus. They found ways to keep people engaged, to practice abilitative skills they were no longer receiving at day programs or at employment sites; and they kept people in touch with their families through virtual means and phone calls so that the social distancing didn't have to mean isolation.

Unlike those who could work remotely and safely from home, DSPs continued to venture out every day so that those who needed them wouldn't be left alone. We cannot thank our incredible DSPs enough.

So as we look back over three months -- and we still have a long way to go in this unprecedented time -- we do have some recommendations. While the past three months have presented obstacles we have never seen before, the road ahead is clearly paved with unique challenges that will require both creativity and additional funding in order to be successful.

Social distancing requirements and face coverings present distinct challenges for people with intellectual and developmental disabilities. They may not understand why they're being asked to stay six feet apart, while for others a full day of wearing a face covering will likely prove untenable.

Providers are looking at all new mechanisms for serving people with disabilities. Facility and vehicle modifications, schedule modifications, transportation reconfigurations -- these are all going to be very challenging issues to face.

We are pleased to be included in the current DDD reopening committee, and we hope to continue this needed dialogue so that all perspectives are taken into consideration before plans are implemented.

As we move towards reopening, the State must continue the day program retainer payments and the enhanced residential rate until providers are fully operational again. This is going to be absolutely critically important.

When day programs do open, it will be a slow process. Providers will need to limit the capacity to these programs; and until providers can safely serve a full roster of individuals, the enhanced residential and day program retainer payments are absolutely critical.

Additionally, we urge the State to continue the $3-an-hour increase for DSP wages. COVID is still here, and the DSPs are putting their health on the line every day just by showing up to work. We must continue this increased wage to maintain staff during the weeks and months ahead.

The State must also create a system that allows for quick and easy access to the PPE. When the pandemic first hit, available PPE was distributed to hospitals and nursing homes, but not to our group homes. We need to make sure that that is available as we move forward. And should the

State face another pandemic in the future, or a second wave of COVID, there must be a mechanism for quick and early access to PPE. A stockpile must be created so providers can receive the supplies they need to ensure everyone's safety.

In addition, providers must be reimbursed for the thousands of dollars they spent so far on this protective equipment.

Also, as the State prepares for a potential second wave of COVID, people with intellectual and developmental disabilities and DSPs must be prioritized when it comes to testing. While testing is now more readily available, our system struggled at the start of the crisis to get needed testing to prevent further spread of the virus. Our system is equally important to nursing home staff and first responders; and should we face another health crisis in the future, this population must be given quick and easy access to testing.

In addition, in-home testing must be made available to individuals with intellectual and development disabilities who cannot go to a testing center. During the height of the crisis, providers had great difficulty waiting in long lines at testing centers with their clients who were ill and experiencing positive COVID symptoms.

Finally, we recommend that DSPs be deemed *essential workforce* for any future emergencies. Not having this designation added to the difficulties providers faced when trying to staff group homes in the midst of a health crisis. While nursing home workers were deemed *essential*, our staff was not given the same level. And it was very confusing during that time, and that's made it more challenging to support people with intellectual developmental disabilities. This needs to be changed, going forward.

In conclusion, we want our population and their staff to be given the same prioritization and considerations as other vulnerable populations in any future crisis.

Thank you, Chairwoman Downey and members of the Committee, for prioritizing these issues and convening today's hearing.

Thank you.

ASSEMBLYWOMAN DOWNEY: Thank you, Tom. Very enlightening; thank you for all your recommendations as well. We will look into all of those. And we'll keep up the conversation, obviously.

The next person is Cathy Chin, Executive Director of the Alliance for the Betterment of Citizens with Disabilities, ABCD.

CATHY CHIN: Hello; good day, Chairperson Downey--

ASSEMBLYWOMAN DOWNEY: Hello.

MS. CHIN: --and members of the Committee.

ASSEMBLYWOMAN DOWNEY: Nice to see you.

MS. CHIN: Nice to see you; thank you so much. And I hope you and your family are well.

Thank you, Chairperson Downey and members of the Assembly Human Services Committee. My name is Cathy Chin, and I'm here on behalf of the Alliance for the Betterment of Citizens with Disabilities.

Thank you for the opportunity to allow me to apprise you of the impact COVID-19 has had on individuals with developmental disabilities and providers in the community.

Trauma: Individuals with developmental disabilities experience exposure to trauma at a higher rate than non-disabled people. Their mental health needs go unrecognized, mainly because the disability overshadows the mental health issues, which often lead to misdiagnosis and incorrect treatment. We should anticipate that the mass trauma that is COVID-19 may lead to increased mental health problems for individuals with developmental disabilities -- whether or not they had PTSD prior to the pandemic -- and for the staff who work with them every day. A good place to start, for both recognition and treatment, is to increase the practice and access to trauma-informed care, otherwise known as *TIC*.

Family visitation became a very serious issue over the last number of months. We are grateful for the efforts of the Commissioners of Human Services and Health, advocates, and legislators who worked to remove this painful barrier to people who love and care about each other. While we must remain ever vigilant regarding the health and safety of those living in group homes, we must also consider their well-being.

Frontline staff: Agencies paid essential workers bonuses, boosted overtime, and enhanced payments and provided daily meals. The Governor and the Commissioner of the Department of Human Services recognized their value and the needs they faced and provided a temporary wage increase, extension of emergency child care access, provision of short-term supports for renters, and additional food stamp assistance.

We learned some -- or I learned some additional factors because of this pandemic.

One: Frontline staff and managers from residential and day programs worked long hours, sometimes without protective gear, taking an enormous risks so that others could stay home.

Two: According to the Department of Human Services, reported incidences of abuse and neglect have decreased by 60 percent during the pandemic. Many believe the reason is because residences were fully staffed with people working with higher wages and benefits.

Three: Essential workers current wage is so low that they cannot save for emergencies through which they will be asked to sustain the rest of the community. And four: They and we will benefit from providing them a living wage. We ask that the enhanced employee payment provided by the State remain for the duration of the pandemic.

And finally, provider additional expenses due to the pandemic. DD providers have worked round the clock to prevent and treat COVID-19 in their licensed residential settings, spending more on labor, supplies, and technology, in addition to loss of revenue from decreased occupancy due to residents' hospitalization, death, and return to family homes.

In preparation for this hearing, in a survey conducted by ABCD for the period March through May 2020, nine of my agencies -- representative agencies of residential providers were able to turn around the information pretty quickly and reported a total cost of COVID-19-related expenses -- this for just nine providers, residential providers -- to be $7.75 million in a three-month period. Sixty-four percent of which went for workforce-related costs, 16 percent for cleaning and PPE, and 19 percent for residential vacancies. Many of these providers are applying for Federal grants, so we anticipate that some of these costs will be reimbursed. Obviously, these expenditures will increase over the duration of the pandemic.

In addition, retainer payments made to day program providers have been instrumental in sustaining them throughout this crisis and in their ability to reopen when permitted. We ask that the enhanced residential payment and the day program retainer payment provided by the State remain for the duration of the pandemic.

And finally, throughout the crisis the Division of Developmental Disabilities worked with and for us. We cannot thank them enough.

Thank you.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Cathy.

The next person we have is Valerie Sellers, CEO of New Jersey Association of Community Providers.

Thanks, Valerie.

MS. SELLERS: Thank you, Chairwoman Downey and members of the Committee. I appreciate the opportunity to talk to you today.

And I'm going to try not to be redundant with my two colleagues who have testified before me.

So I was asked my perspective on how our members fared during these past three months. And I, too, want to say that we applaud the efforts of DHS and DDD. They have been remarkable over this period of time. They have listened to us, they have solicited our feedback, and they had a really good understanding of the challenges that were being faced by the providers. And I think that's in large part because of the ongoing communication. Cathy referenced weekly calls, webinars; we had our own special call with DDD once a week. So they really deserve to be applauded for the efforts that they put in, both the Commissioner, the Deputy Commissioner, and the Assistant Commissioner, Jonathan Seifried. No easy task that he had over these last few months.

But you also asked, what were some of the challenges that we faced? So I'm going to share just three of those.

I think first and foremost is that every department in this State needs to have an understanding of this community. It became very apparent to us, as policies were being formed and procedures were put in place -- they didn't understand the IDD community at all. And so what happens is, it just continued to delay the issuance of policies and procedures, because we had to keep going back and saying, "You can't put someone with IDD alone in an emergency room, in the hospital, without a support system." And eventually, with gratitude to the Commissioner of Health, that was changed. But we should not have gone as long as we did without understanding the needs of this population, especially in a public health crisis. It's critical that they understand the particular needs.

I think what you also heard from both Cathy and Tom has to do with PPE. No surprise; we know that's a huge issue. And I, too, have to applaud our members because they did a remarkable job. The fact that they showed up, and many of them moved into the group home so as not to put their families at risk or the individuals they were serving at risk. I mean, they really went above and beyond all of our expectations. And without them and the work that they did, I don't know that we would have been as successful in keeping the deaths as low a number as it is, and the incidents of COVID. They really went-- And without PPE; so let me speak to the PPE.

As you heard, we were on our own; we were literally left on our own to acquire PPE. And we were deemed *essential employees,* so that was even more shocking. We're essential employees; you expect them to go to work, and we're not going to afford them any protections.

The agencies were placed in a position of competing against every other entity seeking to purchase PPE. And they found that they either couldn't access it, or had access at exorbitant costs. They were placed in a position of competing against each other; and in many cases, they had to be creative; and I think you'll hear about that later. One agency reported they bought disposable raincoats to use as gowns. Another had their staff washing their gloves at the end of each shift so they could wear them again the next day.

We cannot be placing people at risk, whether it's the staff or the individuals being served. To me, it's unconscionable that we didn't afford this extremely vulnerable population with the protection that they need and that they deserve.

The other issue relates to funding; and you too heard from Cathy and Tom about that. And I have to applaud DDD on this issue as well. They really recognized the financial impact that the pandemic was having on the provider community, with the closure of day programs, with many leaving the group homes to go and be with their families. So DDD provided retainer and enhanced rates. And it was because of that, that I think the agencies are now able to move forward with the reopening of their programs. Had there not been this funding, it really begs the question of what programs would have been able to sustain operations and be ready to reopen, albeit slowly, but reopen nonetheless.

And the $3 wage increase -- that's critical. But as Cathy pointed out, most agencies were paying enhanced rates just to keep staff, because they were so fearful, many of them. And they were taking risks, and they needed to be compensated for those risks. So oftentimes agencies increase the hourly rates, and they well deserved those rates. And we hope that that will continue on an ongoing basis until, or if, COVID subsides, or the risks are not as great.

We, too, surveyed our members, and we found that over a three-month period they spent $25,000 to $1.5 million on retrofitting facilities for quarantine. So many of them took their day programs or other sites and literally retrofitted those sites so in the event somebody had to be quarantined they had a space to go to. Because there was no one there telling us where someone should go in the event they tested positive.

So I don't want to repeat everything that Tom and Cathy said, but if these retainer payments and the enhanced rates aren't continued, the reality is the families are not going to come back wholesale; they're not. It's going to be a slow return to day programs and, potentially, people coming back to the group homes. And that's understandable, with the fear factor and people wanting to keep their loved one close to home -- which places those providers in an even more precarious position in their ability to sustain the programs. So in a program that might have had 85 people, and they only have 20 people returning -- absent that additional funding, that day program cannot continue to operate.

So I guess my three points, in summary, are we have to protect the workforce and the people who they are serving; and be a priority in the State of New Jersey, which we were not. Two, any entity that is going to develop policies and procedures that impact this community must have a thorough understanding of this community. And three, we need to sustain this community of providers, so that it is there as the safety net for when people want to return to the programs, and they can do so and feel safe and resume their lives as they knew it before the pandemic.

So I thank you for the opportunity to comment today; I appreciate it.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Valerie.

And I know that you have-- Carolyn, you're here also; Carolyn Suero, the VP for Admissions and Development at Alternatives.

CAROLYN SUERO: Yes.

ASSEMBLYWOMAN DOWNEY: You also wanted to testify, right?

MS. SUERO: Yes, please.

ASSEMBLYWOMAN DOWNEY: Thank you.

MS. SUERO: Thank you.

Good afternoon, Chairwoman Downey and members of the Assembly Human Services Committee.

I am Carolyn Suero, VP of Admissions and Development with Alternatives, Inc., and Board Member for the New Jersey Association of Community Providers.

Alternatives provides a wide array of services for people with intellectual and developmental disabilities throughout Central Jersey.

I would like to thank you for the opportunity to submit testimony regarding the impact of the COVID-19 pandemic on some of New Jersey's most vulnerable citizens.

When New Jersey's stay-at-home order was initiated, provider agencies needed to act swiftly to establish procedures with the safety of individuals with IDD and the Direct Support Professionals who serve them at the forefront. DSPs -- who are, indeed, essential workers -- are responsible for the care of the individuals they serve, often 24 hours a day, 7 days a week. While many of the state's residents were quarantining in their homes, our frontline workers -- not unlike those employed in hospitals and skilled nursing facilities -- returned home and into their communities when their shifts were complete, and a new rotation of staff arrived, increasing the exposure to all involved.

Many DSPs hold multiple jobs due to the low wages afforded them, further increasing potential exposures. Pre-pandemic staff turnover rates were exacerbated by the added challenge of retaining staff during a public health crisis.

DSPs who play a critical role in ensuring that people with IDD live rich, meaningful, and healthy lives deserve a living wage -- not just during this crisis, but into the future as well.

As positive cases increased in New Jersey, providers determined that they would need to secure their own PPE for their frontline staff. This was accomplished through many efforts. Provider agencies became creative by making protective gowns from oversized t-shirts, using coffee filters to enhance the effectiveness of homemade masks, and more, all while upholding their commitment to providing the highest quality of services possible and incurring significant unexpected costs.

In addition to the costs related to PPE, the pandemic has resulted in other financial implications for providers related to the closure of day programs and some families choosing to care for their loved ones at home. Providers were issued retainer payments to offset some of the financial loss, and a temporary $3-per-hour increase was issued for DSPs. Going forward, providers cannot absorb reductions in funding. In fact, they need increased funding to sustain services.

Thank you for your time, and I'd be happy to answer any questions.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Carolyn. We truly appreciate it.

We're going to go on, next, to Darren Blough, Senior VP at Bancroft, please.

Hey, Darren.

DARREN BLOUGH: How are you?

ASSEMBLYWOMAN DOWNEY: Good, thank you for being here.

MR. BLOUGH: Thanks for having me.

Good afternoon, Chairwoman Downey and members of the Committee.

Thank you for allowing me to testify today. I'm Darren Blough, Senior Vice President at Bancroft, one of the state's largest nonprofit service providers supporting individuals with autism, intellectual and developmental disabilities, and brain injuries.

I'm also immediate Past President for the New Jersey Association of Community Providers, or NJACP.

Like all of New Jersey, Bancroft has faced challenges presented by COVID-19. But today we count ourselves among New Jersey's success stories, and I'd like to share why we believe that is, and what worked for us, and where there's room for improvement.

First and foremost, thank you to our partners at the State, from the Governor's Office, to the Legislature, DHS, DDD, and DCF. We are grateful for the swift, yet thoughtful, guidance and responsiveness to the issues service providers faced from day one.

We also appreciate your commitment to ensuring agencies, like Bancroft, remain financially secure through the crisis; ensuring that payment for services continued without interruption, and providing additional funds to compensate the staff who provide our essential services.

Bancroft took the COVID threat seriously weeks ahead of the State shut down. The steps we took to prevent spread of the coronavirus in the earliest days of the pandemic we believe are directly responsible for a low infection rate among both staff and those we serve.

We suspended community outings early on, implementing our own stay-at-home order. We closed State programs with support and guidance of DDD, shifting resources to providing in-home support for our residential clients during the day. We mandated staff wellness checks, and limited the number of programs where staff could work to make contact tracing easier; and we suspended visitation. This was not easy; it was very difficult, but a critical decision to protect both our staff and those we serve.

Throughout the process, having the autonomy to make the right decisions for those we serve has been essential. Like everyone else, we struggled in the early days with the price in the crisis to secure PPE and to get testing for COVID. But it was the breakdowns in communication, as well as a lack of understanding from local, county, and State agencies about the work we do and how we operate that proved to be the unnecessary stumbling blocks along the way. Perhaps our greatest challenge has been navigating local, county, and State departments of health, and navigating conflicting guidance, which often resulted from a lack of education about what human service providers, like Bancroft, do and who we serve.

Similarly, that lack of understanding affected our ability to seek help from local hospitals. A case in point: We had an emergency room doctor who threatened to have one COVID-positive individual dropped off on our doorstep rather than keeping him in the hospital where he could be isolated. While we did have isolation plans in place for our general population, this particular person had a behavioral and medical acuity that meant he simply could not be isolated and kept safe in our facility. The hospital did not understand the reality of our situation, because they didn't understand the population in question.

We do deeply appreciate the State's recognition of our Direct Support Professionals and the essential role they play in caring for the individuals we serve. The temporary wage increase was meaningful to them, and to us, as a provider who values their contributions to care and support every day, but especially through this pandemic.

In all, we commend the State for its response to this unprecedented situation. And while we expect the coming fiscal year to be a tough one, we are grateful for the support we have received, which has enabled us to weather the storm without diminishing our services.

What is clear is that as we move forward toward this new abnormal, we will need to do so together. We know that some things will never go back to the way they were. And while it may sound daunting, I believe it also presents an unprecedented opportunity to assess the way we do things, and re-evaluate the relationship between service providers and our partners at the State.

So I thank you for your time, and I'm happy to address any questions you might have.

ASSEMBLYWOMAN DOWNEY: Great; thank you so much, thank you so much.

MR. BLOUGH: Thank you.

ASSEMBLYWOMAN DOWNEY: We're going to go next to Jacob Caplan, please, from Easterseals.

MR. CAPLAN: Hello.

Chairwoman Downey, I'm Jacob Caplan, Advocacy Manager with Easterseals New Jersey.

Easterseals New Jersey is grateful for the opportunity to share our perspective on the impacts of COVID-19 and what it has had on our agency, our staff, and those we serve.

Thank you to Chairwoman Downey and the members of the Human Services Committee for scheduling this hearing in order to receive our feedback and listen to our concerns.

COVID-19 has had a severe impact on the disability services offered in New Jersey. The past several months have been an incredibly challenging time for Easterseals New Jersey, and the human services industry as a whole.

There have been sector-wide furloughs and layoffs, a massive reduction in revenue, and cutbacks to available services. Our agency has been working through these monumental challenges while also dealing with the medical impact COVID-19 has had on our tight-knit community. These obstacles have, unfortunately, been foisted upon nonprofit service agencies at a time when the need for our services has never been higher.

When a crisis occurs, caregivers and Direct Support Professionals are among those hardest hit. As a critical part of the healthcare infrastructure, particularly at the community and individual levels, their unique potential for contribution to pandemic preparedness cannot be overstated.

One in four Americans lives with a disability, and many people with disabilities face heightened risk if their DSPs are unable to perform their critically needed services. It is our responsibility to give DSPs and caregivers the necessary counsel and resources in order to protect themselves and those in their care. According to the New Jersey Division of Developmental Disabilities, more than 30,000 people across New Jersey are employed as DSPs. This group of passionate caregivers has proven to be an essential part of our collective response to the pandemic. We could not be more proud of the amazing work that they continue to do.

Easterseals New Jersey provides services to nearly 5,000 New Jerseyans living with intellectual disabilities and mental health challenges. Some of these services are indoor activities that have had to close during the pandemic. These include day habilitation, employment services, and individual counseling and case management. These Services have been curtailed in order to ensure the safety and health of our program participants and staff. Unfortunately, however, this is a sword that cuts both ways. By reducing service, our program participants have lost access to the care they need, and our staff has lost access to the employment that sustains their livelihoods.

The long-term damage done to some agencies may be irreparable. And for those agencies that can recover from the shutdown, the services we offer may not look the same for some time. Day habilitation, as an example, has been particularly hard hit. This service was already in need of additional support before the COVID-19 pandemic struck, and that is even more so the case now.

Additionally, we have had to restructure our day habilitation-related transportation programs to be compliant with social distancing and other important COVID-19-related health guidelines. We are making difficult choices about who will have access to services in the coming new human services reality.

Our residential services and supportive housing staff have been working throughout the pandemic though. Their efforts have been truly inspiring, but it does take a toll on them. We need to ensure that our essential workers are paid a fair wage and acknowledged for their tremendous efforts during this challenging time. Easterseals staff, from our employment services and day habilitation programs, have been working hard to maintain contact with their program participants through virtual means. While this cannot replace the interactions that the program participants are used to, our staff's ability to think outside the box has been inspiring to see.

As New Jersey begins to reopen, it is important that those living with disabilities and mental health challenges are included. We must work together to ensure that the State and service agencies work collaboratively to ensure that those we serve have access to care and are also protected from undue exposure to COVID-19. Steps such as ensuring access to PPE, setting clear guidelines, guaranteeing a living wage for DSPs, reimbursement for remote services such as Telehealth, and maintaining regular communication between agencies and State regulators will enable a successful reopening of the human service industry in our state.

Easterseals New Jersey stands ready to assist in the reopening in any way we can. We look forward to working with the Legislature, this Committee, the Department of Human Services, the Department of Labor, and the Governor's Office in partnering on a safe and sustainable reopening for services in New Jersey for people living with disabilities.

ASSEMBLYWOMAN DOWNEY: Thank you so much.

And now, next, we're going to have Jeff Feldman, Director of Advocacy and Communications at NASW, one of my favorite groups, of course. I know how hard they work too, so can we have you speak also, Jeff?

JEFF FELDMAN: Yes, thank you so much, Assemblywoman.

Good afternoon, Assemblywoman and distinguished Committee members. Thank you for the opportunity to testify today.

My name is Jeff Feldman, and I'm with the New Jersey Chapter of the National Association of Social Workers. We represent the interests of the more than 20,000 licensed social workers in New Jersey and the clients that they dedicatedly serve.

With regard to the developmental disabilities community, social workers are most often found in the ranks of senior and executive management at agencies and facilities that serve the DD community, including in the day programs, residential facilities, and social service agencies. And in these roles we're well situated to see the needs of organizations, the direct service workers they employ, and the clients who they serve.

I do want to, first, commend the Department and the Division on the work that they've done. Because in the face of trying and unprecedented circumstances, I think that the response was as good as it could be. And so that is commendable.

And I'd also like to thank all the speakers who have come before me who have spoken so eloquently on this issue.

In the interest of time, I'm going to skip most of my introductory remarks and focus mostly on the observations that we've had based on our conversations with provider agencies. And I just want to reiterate also, before I forget -- as Mr. Aronsohn said at the very outset -- we talk about the developmental disabilities community a lot. And I think it's just extremely important to repeat that we're not dealing with a monolithic population. It's not just developmental disabilities, period. We're dealing with a range of syndromes and spectrums that include everything from vision and hearing loss to autistic spectrum disorder, cerebral palsy, Down syndrome, and more. So we really do need to make sure that, as we're considering policy and actions that are going to be taken during the time of COVID, we remember that these are individuals. And while there are some similarities, everybody has unique circumstances as well.

Based on the lessons that we've learned and opportunities where we can improve situations moving forward during the time of COVID, one of the areas that we absolutely need to highlight, and has been highlighted before, is the need for adequate PPE among provider agencies and staff to ensure the health and safety of all individuals served. And I think that as was said previously, the State needs to absolutely begin stockpiling supplies of PPE for providers in the DD community. Obviously, many many providers are going to need PPE at this time, but we need to actually make sure that we are amassing a supply, and that we have some of that supply specifically set aside for the providers in our DD community.

Another area that we need to address is what will happen if there is another COVID-19 outbreak. The abrupt stoppage of the day habilitation programs in mid-March -- which occurred over a weekend, and left maybe 72 to 96 hours to prepare -- the abrupt stoppage left providers with little time to create new or temporary enrichment or habilitation programming for the individuals who would be remaining in their homes, whether that be family homes or residential and group homes. And so we really need to ensure, prior to the onset of the fall when risks of exposure to COVID-19 will likely increase again, that the Department, and the Division, and all the agencies and providers that are involved have contingency plans in place for how we will continue to provide services to individuals in the event of another lockdown. And probably contingency plans would need to be reviewed quarterly, so we can reflect the most current learning and forecasting about COVID-19 and the steps that must be taken to safely provide services in the midst of an outbreak.

Third, and lastly, with the medical system essentially shut down, I believe we've heard testimony before that many individuals who were in need of medical care had to be taken to hospitals for non-emergency, but urgent, medical issues. And this lasted for the first six or seven weeks of the pandemic, resulting in individuals not being able to get the services they needed in the emergency room because their Direct Service Providers were not able to be with them; and also extreme lengths of time of just waiting in the emergency rooms for treatment and being exposed to COVID-19 while they were there waiting to be seen by a medical professional.

So going forward, we need to ensure that individuals with developmental disabilities, as well as other medically fragile individuals, are able to seek and receive treatment in more tightly controlled and less populated environments during COVID-19. Whether that be in small group or private practice settings, or in their home via mobile services, rather than having to resort to treatment in hospital emergency rooms.

It's also important to remember -- and I think this was pointed out earlier -- that Telehealth, while it may be a feasible option for certain persons with developmental disabilities, we cannot assume that Telehealth is going to be a practical treatment modality for the entire IDD community when in-person treatment is limited. So again, trying to identify locations where people can be treated in a less populated environment with limited exposure will go a long way towards ensuring the safety of the community.

I want to thank you for your time and consideration on this issue, and again, commend all the work that you've done. Our team is available to you for further consultation as you require.

Thank you so much.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Jeff; we truly appreciate it. Just like with everyone else, thank you for all your efforts and your help. We'll keep in touch, obviously.

Also, next, Carrie Conger, the Assistant Executive Director for Premier Supports New Jersey.

CARRIE MOORE CONGER: Thank you so much.

I'm going to be really brief, because I pretty much have the same lessons learned as many of my colleagues and professionals who've already spoken ahead of me.

You know, I am the Assistant Executive at Premier Supports, and we are a community service provider. We provide services to adults with intellectual and developmental disabilities, both in residential settings and in day habilitation programs.

I just want to start with saying that, again, like everyone else, the State's quick response to the coronavirus pandemic through the Division of Developmental Disabilities of the Department of Human Services was not only appropriate, but I think many of us would agree probably saved many more lives and kept many people healthy. As a service provider, we felt that not only did we receive timely and frequent communication from the Division, through weekly webinars and their constant communication with the provider community, but ongoing support from the dedicated State staff who are working with other service providers, who had very similar challenges and concerns.

I think that there were a few areas in the response to this pandemic that created some challenges, but also great opportunities for us in the event of any other sort of health emergency or health crisis. Like everyone has said, PPE is probably one of the biggest concerns. We asked staff to go in there and put their lives and their families' health on the line to protect and to care for individuals with intellectual and developmental disabilities. And for a period of time we were all vying for and scrambling for the same PPE that everyone else was getting. So we really hope that-- Going forward, it would be critical to have an infrastructure set up, in the event of another wave or another health crisis, for agencies, Direct Care Professionals, and even families that have individuals living in their homes to have access.

Additionally, we've seen that there's now mandatory testing for the individuals who are living within the five developmental centers. It would be really ideal to have that same requirement for the individuals who are living in residential settings as well. Again, we've talked about their congregate settings; they're around each other. And in some cases, we do have asymptomatic individuals who are coming in contact with other individuals.

So hopefully, as we continue to move forward, we'll be able to do testing for all individuals in residential settings as well. And hopefully, we can be flexible and perhaps have mobile testing. We've tried, as others have said, sitting in vehicles, waiting in line for testing. It's not ideal. Taking them to the hospital, being exposed to other individuals who may already be sick -- not ideal. So if we could come up with a way to support those individuals and keep them at minimal risk to any kind of other individuals who may be carrying the virus, that would be ideal.

And finally, to Jeff's point as well, the medical community that serves individuals with disabilities really needs to become better educated on the unique needs for individuals with intellectual developmental disabilities, and to try to be more accommodating. Again, as Valerie had brought up, not allowing the caregivers or the Direct Care Professionals to come to the hospital was a huge barrier for many of our individuals who either had limited or no verbal communication skills. And it did, as Jeff pointed out, result in them sitting in emergency rooms for far longer; while our staff was calling the hospitals consistently, and then taking nurses and doctors away from what they should be doing, which is taking care of the individuals in the emergency rooms.

We need to find ways to treat medical and mental health issues, that are not necessarily emergency, in a way that is, again, responsible and dignified for individuals with disabilities. Telehealth has been great for some of our individuals; some of our individuals, that's still not an option for them. So perhaps working with some medical providers to have isolated offices open, or have minimal individual interactions so that they can still get the health care that they need without being exposed to an emergency room.

I just want to thank you all for your time. Again, I am available to answer any additional questions.

And again, I just want to take a moment to thank Jonathan Seifried, the Assistant Commissioner of the Division of Developmental Disabilities, and his dedicated staff for continuing to ensure that individuals with intellectual and developmental disabilities in New Jersey are being kept safe and cared for in the midst of what has been just a completely different time than I think any of us could have imagined.

ASSEMBLYWOMAN DOWNEY: Thank you so much.

Next, we're going to have Javier Robles, the Chair of the COVID-19 Disability Action Committee, and Director for the Center for Disability Sports, Health and Wellness at Rutgers.

MR. ROBLES: Great; thank you.

ASSEMBLYWOMAN DOWNEY: Thanks, Javier.

MR. ROBLES: Thank you so much for allowing me to testify today.

And I would note that at least four of the members of that group are sitting here today with us; so hi, all.

I also wanted to let you all know I started a Facebook group called *People with Disabilities Helping Each Other Survive the Coronavirus* around the same time we were having a lot of these issues. So we're up to about 700 members, and we've had a lot of feedback from them, as well as a lot of feedback from the group that we're working with. Our ultimate plan in this group is to come up with a recommendation or a set of recommendations for the Governor, the Legislature, and others who would want to read it.

So I will just read this, to make sure I don't miss anything.

Today we stand at the crossroads of what has been and what could be. The systemic failures with which people with disabilities and people of color have been confronted are unprecedented and overwhelming.

By the State's own estimates, about half the people who died in the State of New Jersey died in nursing homes, and many of those were people with disabilities -- psychiatric disabilities, or developmental disabilities, as well as physical. These facilities, as well as our own facilities, are woefully unprepared for what many knew was coming. As the CDC and the World Health Organization has stated, it was not a matter of *if* it would happen; it was only a matter of *when* it would happen.

The State of New Jersey, its departments, and those that I had contact with were unprepared, plain and simple. The COVID-19 Disability Action Committee is in the process of preparing our own report by people with disabilities, their family members, and advocates. We have been meeting for almost two months to identify what went wrong, who was affected, and what we can do to fix the problems in the future. We anticipate a final report by this fall.

During the height of the pandemic, people with disabilities, their caretakers, and family members were unable to secure PPE, which we've all said. When some of these individuals reached out to government agencies, including some in Human Services, they were told that they would have to purchase their own PPE, although they were members of existing programs in those departments.

Testing was also an issue; I won't go too much into that. But it's obvious that we need to do a better job at testing and making sure people have tests at home, and that those tests are available not just to individuals with disabilities, but the people who work with them and their family members.

People with disabilities lost Direct Support Professionals and have no option to replace them. Many family members and their friends were forced to step in to ensure the survival of people with disabilities in their own homes.

There was no plan beforehand as to what visiting homemakers, personal care assistants, direct support professionals, or other programs at Human Services, Department of Health, or other departments would do. That is unacceptable. Thousands of people depend on professionals in these departments to ensure their safety and well-being.

Food security was also an issue which many of us, including myself, had to deal with. We need existing programs, including supermarkets, etc., to be able to provide food that is both healthy and reasonable for a lot of people with disabilities at DHS, a lot through Medicaid, a lot who receive personal care services. These were, as far as I knew, not existent at all. Many of the members who we talked to or we've worked with said that they actually ran out of groceries, and the only way that they could get groceries was to ask a friend or a family member to go to the grocery store for them, putting themselves and the person who would bring their food at risk.

Individuals with disabilities and their families across all departments should be able to make health decisions which affect themselves and loved ones, as well. The fact that many state citizens died unable to see or talk to their family members is unacceptable. Moreover, the fact that without input from people with disabilities, their family members and/or advocates, our State adopted the Pittsburgh test, which is a scale to evaluate who receives life-saving equipment and who does not, is a slap in the face to our democratic values. It is illegal under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the laws of discrimination against New Jersey. It is not easy to trust a system which does not incorporate the views and values of people with disabilities as well on committees and lawmaking bodies. No adult with a disability -- whether it is intellectual, developmental, physical, or sensory -- should have their rights taken away. Many did without family members present. This is especially troubling as it relates to individuals with developmental and intellectual disabilities. It shows that the fight for equality in this country is far from over. This is something we also saw in nursing homes -- family members unable to speak with or to see their loved ones before they passed away. No hospital member or committee should force a DNR on a person who is disabled or elderly without a trial or fair hearing. All hospitals should, instead, offer to perform CPR or other life-saving measures, unless the individual or the family have expressly stated that they do not want that.

The lives of individuals with disabilities matter to someone. They should matter to this body, and they should matter to our State government. We must come up with policies that take into account the worth of individuals with disabilities and the elderly. This cannot be done without the input of people with disabilities, their family members, the elderly, and the other advocates.

This pandemic affected many people with disabilities, but it was especially troublesome for those who have to see doctors, dentists, and other mental health professionals.

Many people with disabilities who receive dialysis or other life-sustaining treatments were highly vulnerable, with no alternatives in place. Many had to either forego treatment or risk getting infected with coronavirus to receive that treatment. Many people, including myself, waited for doctors who were unable to see me, as well as other people. Providing Telehealth, although it's not a perfect alternative, would probably be a great option for many people. The State of New Jersey was not set up, nor does it appear that they were in contract with many health providers for Telehealth services. I think that this is an important thing that should really be fixed, in the short term as opposed to the late term. The inability to leave your home during the pandemic was destabilizing and stressing for individuals with mental health conditions who see therapists on a regular basis. The fact that many could not reach their therapists or doctors and had no Telehealth services available to them exacerbated a problem that need not have happened. The State of New Jersey must do a better job in ensuring that Telehealth is an option for all.

People with disabilities of color were overwhelmingly affected during this crisis. Many, especially those who have language barriers or live in poor communities, were not only unable to get PPE, but were unable to communicate with any health professionals, and had people who would not show up to their house for fear of contracting coronavirus.

I think this Department also should do a better job at outreaching in different languages to people, especially those who are Latino or people of color.

During the pandemic so many people on the front lines died in order to take care of others. We should honor their memory by ensuring that people on the frontline -- doctors, nurses, visiting homemakers, personal care assistants, Direct Support Professionals, and parents who take care of their children -- receive fair and honest wages. Not just temporary wages -- which is great -- but constant wages. New Jersey is one of the most expensive states to live in, in this country. And the people who support people -- like myself, parents, and other individuals -- with disabilities in New Jersey barely make a living wage in this state, and that is unacceptable.

The fact that many individuals could make a lot more money working for FedEx or Amazon and not risk their life going into multiple homes-- They have to make enough to feed their family. It's totally unacceptable. Moreover, doctors, and nurses, PCAs who assisted those should receive some type of hazard pay on top of what they receive.

Another issue which our members have noted is communication access, especially in the Department of Human Services, which houses the Commission for the Blind, and it also houses the Division for the Deaf. This is extremely important. Many people who have either visual or hearing disabilities were unable to communicate with people for a long time because Telehealth and other systems weren't set up for them. This is especially true -- and I know Carole knows this -- for people who read lips, and our elderly and hard of hearing. When we started wearing masks, no one could read lips. So for these people, it was extremely difficult, especially if they have to access a doctor or healthcare professional.

So I'm going to stop there; I'll submit the rest of my testimony.

And thank you.

ASSEMBLYWOMAN DOWNEY: Great; thank you so much, Javier. That was extremely helpful. Thank you so much. I know you'll keep working on all these things too with us, so thank you.

And next we have Sam Friedman.

MR. FRIEDMAN: Thanks very much.

In the interest of time, I'll pick up pretty much where I left off a little while ago.

Thanks again, Chairwoman Downey and the Committee.

Ironically, it's the virus that got us to this point where we -- the families and guardians of the 1,200-plus souls in the developmental centers -- are finally at the table.

Here's what it took to get here, which is the self same as why we belong here as much as anyone. When SARS-CoV-2 was, for most, an abstraction, we saw it coming for our loved ones. My quarter-century's public health experience -- including work with the former CDC Director and the FDA Commissioner -- didn't hurt. We researched the CDC, CMS, and outside experts' findings and recommendations concerning how this virus intersects long-term care facilities; figured out what to do to save lives;

formulated a no-frills blitz of a citizen lobby campaign; non-stop wrote, called, pleaded, and begged any and everyone who might help us; and cried in between. Our efforts were salutary in getting DHS -- which, in fairness, was up to its eyeballs in the hell of this pandemic at that point -- to stop waiting for fevers and coughs and to, instead, test all residents and all staff in our State-run ICFs for COVID-19. In some, DHS needed us to help it save lives. We did this. Not outside, or self-proclaimed, or government paid and appointed advocates. We did this.

Just as we knew what's what then, we will be crucial to our loved one's well-being going forward. But only if there is two-way communication, something that's been denied us until now.

DHS, and not only DHS, must renounce the history and culture of marginalization that was the State's relationship to us. If we are kept and removed as adversaries, and not brought in as families and guardians -- except after the fact -- the State is wronging our loved ones.

DHS has opened the door a crack. We are heartened and grateful, particularly to Assistant Commissioner Seifried, who several weeks ago generously gave of his time to us. But there has to be more; we won't go away, we can't. Let us in.

As I speak, cynical voices are using the pandemic to try to close more centers. You've heard such talk today, in code. One way they go about this is to intrude on guardians' rights and rightful roles. But when one of my colleagues gratefully tells me, "I learned last Friday that my brother at" -- name your developmental center, because it's all of them -- "my brother tested negative a second time," those same voices rush in to condemn us over their newfound knowledge of this supposed inequity.

It's the same with PPE. We weren't alone on getting PPE. DDD had it ready, and the centers had it ready. DDD and the centers do many, many, many good things, and the centers are good places overall. However, we hear these folks try to have it both ways, and they can't anymore; we won't allow it.

The straight answer to the question, "Why did we have the testing? Why did we have the PPEs?" is this. The developmental centers offer the immediate care facility an array of program and service supports. This is the most stringent and comprehensive service category there is under Medicaid. This level of care is sometimes a better choice than home- and community-based services. It depends upon who you are and what you need. One size does not fit all; it's about choice. I don't know yet how to help you get the COVID-19 testing you need, but I'm trying to learn how and will do everything I can to help you, per your wishes, providing you will do the same for my sister, per my direction, and don't presume to speak for her. That's my job, not yours.

Yes, as Ms. Tonks said, *nothing about us without us.*

We appreciate the intent of both A-4138 and A-4239. Time won't let me say more here. We think we can help you improve the Bills, if there is time, and if you can use our input.

Our written testimony will expand on our thoughts.

Thank you again for the opportunity. I'd be happy to answer any questions that I can.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Sam; we truly appreciate it. And we'll definitely speak again.

MR. FRIEDMAN: Yes.

ASSEMBLYWOMAN DOWNEY: Next, the last person we have right now is Mercedes Witowsky, the Executive Director of New Jersey Council on Developmental Disabilities.

Sorry you had to wait so long; thanks, Mercedes.

MERCEDES WITOWSKY: No, thank you.

And I'm sorry; I actually missed the first part of the hearing. I am on the DDD Reopen work group. So I got on about halfway through the hearing, so thank you for this opportunity.

As Executive Director of the New Jersey Council on Developmental Disabilities, I'm very pleased to be before this Committee today. But some of you who know me also know that I am the parent of a young woman with disabilities. My daughter Tina is now 30; she became disabled as a result of a stroke at the age of 16. So much of my work at the Council is really guided by what I like to refer to as *walking the walk.*

I have provided, earlier today, written testimony that outlines 20 discrete issues and challenges, and a number of recommendations that have been informed by individuals and families of individuals with disabilities. But I will just briefly, in the spirit of time here, highlight four areas, and they include inclusion, service and system flexibility, the technology divide, and communication.

For the brief time that I've been able to join, I have heard about the inclusion. And I speak generally about this, and it is really a theme throughout my written remarks.

Unfortunately, our State systems do not globally recognize and consider people with disabilities as decisions are made; and this really, really needs to change. That clear example of hospital visitation caused so much anxiety, fear, and concern that -- our lives are complicated enough -- to have to address that in an advocacy way, to get that guidance correct, should have been the first time out the door, not after weeks and weeks of more pain and suffering amongst this already horrible situation.

The next issue is on service and system flexibility. So we are really pleased that DDD, early on in its work, allowed for electronic signatures on service planning documents. They allowed for remote services, and also allowed families -- including parents, spouse, and guardians -- to become self-directed employees for their loved ones. This was in preparation for what was to come.

These practices make sense; they offer flexibility. And we advocate here today that the State permanently continue these practices. Because while it makes sense, it also doesn't add any cost, and it immediately improves people's lives.

The next area I'll focus on is technology and Internet. So like all of you, we immediately turned to technology and Internet to remain engaged, to do our jobs, and to access critical information. At the Council, we immediately learned that this was not the case for many individuals and many families of individuals with disabilities. I believe that as we face COVID, we've also reached a point with an even greater technology divide. There are far too many people who came right to the Council and told us that they couldn't continue schooling, they couldn't be engaged with family or friends, and have access to all the critical information that we all see in the media and through other sources.

So we know that we wouldn't be here today on this Zoom platform without technology. The time has really come for us to recognize this, and solve this challenge.

The last item I'll focus on is communication. There are approximately 24,000 people with IDD in our service system under DDD. The New Jersey Council, on average, reaches about 2,000 people each year who we track. And DDD has done an incredible job in offering these information sessions on a regular basis; there was one earlier today. But we know there are also 24,000 people in this system, and we know that 24,000 people do not participate in these sessions.

So we ask that the State send old-fashioned letters, real mailed letters, so that Division participants -- on a periodic basis, but especially now -- are able to access information on an equal playing field and have information that they need to inform them and to move forward.

So again, thank you for scheduling this hearing. The 20 items that I've included in the written testimony are full of other recommendations. I hope there's an opportunity for someone to have that -- to take some time to review that.

NJCDD is here to take the next steps with you and the State in doing what we can during these times.

Thank you, Assemblywoman.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Mercedes; that's wonderful.

Thank you.

You know, just to-- Because I know we've been here for a long time -- I know it's tough just sitting here on Zoom for all this time, and I want to thank everybody for their patience and their ability to sit, and listen, and take all this in. It's really -- it's wonderful to be able to have all of you involved.

I just wanted to, really, just summarize, really quickly, some of the things that we picked up from here that we'll continue to look at, and we'll continue with more of everything once we see all the written testimony. And we'll keep up the conversations, of course.

But I wanted to just say, first, it was amazingly acknowledged, by pretty much everyone, what a great job DHS has done; how Commissioner Johnson, Carole Johnson and her team -- including Sarah Adelman, and Jonathan Seifried, and all of them -- have done such a wonderful job trying to help and keep you informed as best they can, and working with all of you. So I just want to, again, acknowledge that.

The other things that we've talked about -- procurement and access to PPE for the communities. Testing -- better testing availability early on. Being able to visit people who are their family members in these different communities, in these different settings. Being able to make sure our DSPs continue to earn that increased amount of money of the $3 per hour. Because, obviously, it's helped a great deal, and they are right on the frontline helping, as well as everybody else in hospitals.

Then, also, remembering that a lot of people will be helped with Telehealth. But, in general, we have to look at not everyone will be helped with Telehealth and try to find other smaller, more private settings where you have a low risk of being able to contract the virus -- need to be looked into for those in your communities.

Being able to get access to -- just generally to the system being more inclusive; being involved in making the decisions, being able to work on that technology divide, being able to work on-- The issue with food insecurity was a big one; Javier had mentioned that was important.

The whole thing about who makes those decisions about who gets life-saving medicine and equipment, who -- generally, what family can be present during certain things, especially for this community that needs much more assistance.

We're still not-- Obviously we made a lot of decisions based on things that were happening pretty quickly here in the state. Overall, I think that what they've done was really good; but of course, there are things that needed to be done much better, and especially in this community -- in our communities of disability.

So we are going to continue to take this forward and try to do more to help so that we can continue, during this current pandemic, because we're not-- You know, COVID-19 might seem over to a lot of people, but it's not done with us; it's still here. We need to continue to work within the realms of that, so we need to continue making these plans now, and then for the future as well.

So again, I want to thank you all, because there's a lot of work that goes into this, but we can't do it without all of you. We're all partners in this together, and it's truly appreciated.

So thank you again to all of you.

I know that OLS has to make a closing statement too before we all leave, right Addie?

ASSEMBLYWOMAN VAINIERI HUTTLE: Chairwoman, I'd like to make some remarks, please.

ASSEMBLYWOMAN DOWNEY: Sure; and I'm sorry.

I normally would, like, let everyone speak more. I was just trying to look at the time.

But yes, of course, Assemblywoman, any other Assembly members -- if you want to say something, you can do that.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

I will defer to my senior members, if they'd rather -- if they'd like to go. Otherwise I'll--

And thank you, Chairwoman, for that long list, and quite comprehensive, which we all benefited from -- this comprehensive panel.

I am disappointed that we did not have representation from DHS or DDD, because that would have really completed this discussion and enabled us, as legislators, to conduct our oversight role. You know, what stuck with me throughout this hearing was a comment from Ms. Sellers. You noted, "We should not have gone on this long without understanding the needs of this population." And I would say beyond that, beyond understanding the needs, we need to see the needs. And unfortunately, this pandemic, to me, showed that this vulnerable population remained invisible. So while there's progress made today, there's much more to be done.

And with the absence of DDD or DHS representation, I am going to defer to Mr. Aronsohn; so lucky you.

I understand that you have an annual report that you submit to the Legislature. So I would ask that we do examine the number of nursing home admissions and psychiatric -- intensive psychiatric care admissions, and

9-1-1 calls that went on during this time of the pandemic in centers and group homes.

And finally, I submit to those who are on the Council that our day program providers are treated as the small business owners that they are. And if they cannot reopen in enough time, those programs will not be available for the returning clients.

So thank you again.

ASSEMBLYWOMAN DOWNEY: Thank you, Assemblywoman.

Did any other members want to say a few words before we close out? (no response)

Okay, I just wanted to make sure.

And I know that Assemblywoman Tucker was on the phone, so I don't know whether she still wanted to say anything as well. So I'm going to, again--

ASSEMBLYMAN CHIARAVALLOTI: Chairwoman, I just want to thank you for hosting this hearing. It was very informative.

I want to thank everyone who presented testimony. And I think -- I just want to associate myself with the comments of Assemblywoman Dunn and Assemblywoman Huttle. I think the members on this panel have provided true leadership; and quite frankly, I continue to learn from them, and from those who give testimony each and every hearing. So I do appreciate everyone taking the time to present.

But thank you.

ASSEMBLYWOMAN DOWNEY: Thank you very much, Assemblyman.

And anybody else?

ASSEMBLYWOMAN TUCKER: Yes.

ASSEMBLYWOMAN DOWNEY: Hello, Assemblywoman.

ASSEMBLYWOMAN TUCKER: Hi.

I just want to thank you for convening this hearing. I think it was very important that we had a chance and an opportunity to hear what we can do better in our facilities. And I thank all the people who participated today to bring us up-to-date, to where we need to do more. And I just thank everybody for all the information they shared with us; and we make sure that we're going to take it in and consider everything that was said today, and try to make the situation better.

And thank you.

ASSEMBLYWOMAN DOWNEY: Very good; thank you.

Anyone else? (no response)

All right; I just want to make sure.

So now, Addie, your turn.

MS. KASER: All righty, then.

ASSEMBLYWOMAN DOWNEY: First of all, thank you, by the way.

MS. KASER: Well, you're quite welcome.

Concerning the post-meeting reporting process for today's meeting, Assembly Rule 10:16 requires members to confirm their votes by signing the vote record for the bills and resolutions being reported by the Committee. However, because current circumstances do not allow members to be physically present and to sign these vote records, an authorized waiver of the rule has been obtained and a new procedure is being used.

The Office of Legislative Service Committee staff will transmit the vote records to each member, and the Majority and Minority Committee Aides. OLS asks that the members review the vote records within 24 hours and notify the OLS Committee staff regarding any corrections that may need to be made to those records. If the OLS staff does not receive a notification that there is an error, OLS will conclude that there is no correction needed, and the original recorded vote will remain in place.

So please let me know, when you receive the vote tallies, if anything looks abnormal; and otherwise we'll proceed with your votes as recorded.

ASSEMBLYWOMAN DOWNEY: Great; thank you, Addie.

And I think that's it.

Again, I want to thank all of you; and I'm going to adjourn this meeting.

Be safe, be well.

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(MEETING CONCLUDED)