Committee Meeting

of

ASSEMBLY HUMAN SERVICES COMMITTEE

"The Committee will hear testimony from invited guests on the issue of abuse and neglect of individuals with disabilities in group homes and other congregate care facilities. To understand the magnitude of this problem and the barriers to safety and healing survivors with disabilities face, the Committee will invite survivors or their family members to share their experiences.

The Committee will also hear from the Department of Children and Families (DCF) and the Division of Developmental Disabilities (DDD), as well as from operators of congregate care settings, on what is currently being done to provide adequate protection for all individuals. National experts and advocates will provide testimony on prevention strategies recommendations and steps to improve the effectiveness of response to the abuse and neglect of individuals with disabilities"

LOCATION: Remote Meeting Via Zoom

DATE: October 22, 2020
12:30 p.m.

MEMBERS OF COMMITTEE PRESENT:

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

ALSO PRESENT:

Adaline B. Kaser	Nebnoma Anita Ouedraogo	Natalie Ghaul
Office of Legislative Services	*Assembly Majority Office*	*Assembly Republican Office*
Committee Aide	*Committee Aide*	*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

Joann Downey
Chair

Nicholas A. Chiaravalloti
Vice Chair

Shanique Speight
Cleopatra G. Tucker
Valerie Vainieri Huttle
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Jean Stanfield

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NEW JERSEY STATE LEGISLATURE

ASSEMBLY HUMAN SERVICES COMMITTEE

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COMMITTEE NOTICE

TO: MEMBERS OF THE ASSEMBLY HUMAN SERVICES COMMITTEE

FROM: ASSEMBLYWOMAN JOANN DOWNEY, CHAIRWOMAN

SUBJECT: **COMMITTEE MEETING - OCTOBER 22, 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 remotely on Thursday, October 22, 2020 at 12:30 PM.

The committee will hear testimony from invited guests on the issue of abuse and neglect of individuals with disabilities in group homes and other congregate care facilities. To understand the magnitude of this problem and the barriers to safety and healing survivors with disabilities face, the committee will invite survivors or their family members to share their experiences. The committee will also hear from the Department of Children and Families (DCF) and the Division of Developmental Disabilities (DDD), as well as from operators of congregate care settings, on what is currently being done to provide adequate protection for all individuals. National experts and advocates will provide testimony on prevention strategies recommendations and steps to improve the effectiveness of response to the abuse and neglect of individuals with disabilities.

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 committee will receive oral testimony from invited guests during the hearing by telephone or video. Invited guests will be sent instructions, in advance of the hearing, on registering to testify and submitting written testimony for inclusion in the committee record and for distribution to the committee members.

(OVER)

The public may view the meeting via the New Jersey Home Page at https://www.njleg.state.nj.us/.

Issued 10/15/20

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ASSEMBLYWOMAN JOANN DOWNEY (Chair): I just want to say hello to everyone, and I'll make an opening statement.

But I first would like to be able to, again, welcome you to the Assembly Human Services Committee, where we're having an important hearing on abuse and neglect of individuals with disabilities in different homes and congregate settings.

So what I'd like to do first is be able to do the Pledge of Allegiance. And I have a small flag here; so if everyone can stand, I'll do the pledge. (all recite the Pledge of Allegiance)

Thank you, everyone.

Okay, so now we need a roll call. So we have to make sure whoever is supposed to be here on my Committee is here.

So can we have a roll call, please?

MS. KASER (Committee Aide): Assemblywoman Jean Stanfield.

ASSEMBLYWOMAN STANFIELD: Present.

MS. KASER: Assemblywoman Dunn.

ASSEMBLYWOMAN DUNN: Here.

MS. KASER: Assemblywoman Vainieri Huttle.

ASSEMBLYWOMAN VAINIERI HUTTLE: I'm here; present.

MS. KASER: Assemblywoman Tucker.

I didn't see her come into the room, but I may have missed her.

ASSEMBLYWOMAN DOWNEY: No.

MS. KASER: No? Okay.

Assemblywoman Speight.

ASSEMBLYWOMAN SPEIGHT: Here.

MS. KASER: Vice Chairman Chiaravalloti.

ASSEMBLYMAN NICHOLAS A. CHIARAVALLOTI (Vice Chair): Here.

MS. KASER: And Chairwoman Downey.

ASSEMBLYWOMAN DOWNEY: Here.

MS. KASER: You have a quorum.

ASSEMBLYWOMAN DOWNEY: Great; thank you.

And I want to first acknowledge all of the Committee members on this Committee who are here and present to listen to this important testimony. Thank you for being here.

And I thank all of you out there for coming to this important hearing.

And first I want to mention, it's also, in terms of the importance of the month, we have-- October is Disability Employment Awareness Month and Breast Cancer Awareness Month. So this is something obviously-- We like to make sure that we mention to people and remind people, and make sure that we are doing more to raise awareness for all our causes. So for this month, we have those couple. And now I'm going to give you a background of the hearing. So again, good afternoon to everyone, and thank you so much for being here.

Today's hearing is going to discuss, during this hearing, abuse and neglect of individuals with disabilities.

Now, according to the U.S. Census Bureau's 2000 census, approximately 1 in 5 Americans have a disability of some sort. Unfortunately, a large number of this population will become crime victims at some point or another in their life. Individuals with disabilities are 4 to 10 times more likely to become victims of abuse and neglect, and it is our duty to give them safety and security. This is especially true for the places where they live; their own places where they're supposed to be safe.

According to a 2018 Office of Inspector General joint report, 49 states had media reports of health and safety problems in group homes and other congregate care facilities. We need to really look at these numbers and stats, and realize that this is the time to re-evaluate again the systemic abuse. It's a systemic issue, and it's bringing more attention -- we have to be able to bring more attention, basically, to this matter because we need to make sure that everyone has the ability to live safe from harm in their own communities. It has to be everyone.

After learning more about these issues-- By the way, I want to just mention, too, that we had a serious issue that came up last year with Bellwether. And for any of you not familiar, I just want to remind people about how, in May of last year, Bellwether, which is-- It was a hedge fund-owned company that grew to become one of the state's largest group home providers, with 62 homes caring for about 460 people. And they had repeated cases of abuse and neglect, which included all kinds of things between, by the way, from deaths to people just being literally not cared for at all. People who needed to just have special diets who weren't provided those special diets; people who had to live in homes where there were sticky floors, and it was disgusting because nobody cleaned it up. So it's those issues, to the really great, grave issues of, like I said, death.

It's just a reminder to us-- And I want to remind everyone, I even made a statement. And I looked back at this statement, because this is why I wanted to do this hearing. I mean, it became really clear that Bellwether was nothing where we needed to be in terms of helping our members in this community, in terms of compassionate care and being able to make them feel safe and comfortable. And it was inhumane; basically, we saw inhumane treatment and allowed people to be abused and neglected. Not that we knew it; but once-- When these things are known, right away we need to take care of it, and we have to try to prevent it from ever happening. That's the major goal -- to try to see what we can do to help prevent these kinds of things.

It's very hard, but I know we can do this, and we need to work together. And again, the importance of this hearing is to be able to bring some of these cases and circumstances to light so people learn, and we can help, as the legislature, to be able to bring -- whether it be more laws, try to put forth more regulations -- just more awareness. All of these things are important.

Back then I said, "I strongly support the Department of Human Services' choice to shutter Bellwether's operations for good." And as Chair of the Human Services Committee in the Assembly, I will continue to fight to ensure people with disabilities receive the respect they deserve, and that this never happens again. That's why I need to continue this, and work with all of you.

And after learning more about these issues, I sponsored a Bill, A-4013, Billy Cray's Law; and what that Bill would do is establish requirements for installation of cameras in the common areas for group homes, and basically allow for those who can't speak for themselves to be able to be protected. Because if their guardians or they are able to consent to having those cameras in the homes, that there is some ability to look back. And IF there's bound to be or believed to be, abuse there's some way to check it. It helps both the people -- the residents who live there, as well as the people who work there in case there are allegations that are not true.

So I'm looking forward to, again, hearing more here to see how people feel and whether this is going in the right direction, which I believe it is.

And just to let you know why I support this Bill is because the Bill is named in honor of Billy Cray, an individual with developmental disabilities who, at 33 years of age, was found dead in a group home where he resided. And his amazing mother, Martha Cray, has advocated very strongly, together with others, to be able to have this law pushed forward -- this Bill, I should say -- pushed into law. And we're going to continue to work on that.

It's imperative to enhance the quality of life of people with disabilities; and through this, we're hoping that making this technology more available in group home settings will be able to strike an important balance between protecting both privacy for those who don't want it, but also, at the same time, protecting the people who need it the most and protect them from becoming victims. It will hopefully help parents and guardians rest better at night, too.

The Bill respects the rights of individuals with intellectual or developmental disabilities, making sure that we're placing a premium on their individuality and recognizing that different people have different needs and different preferences. And many vulnerable New Jerseyans struggle to feel safe, again, in their own home. By passing that Bill -- which I hope will come soon -- we will be able to expand the safety net for this community, and respect their privacy and protect their overall well-being.

Again, I'm looking forward to hearing, now, from all of you. And we have panels of people actually here. It's amazing, all of you, who have agreed to come and testify. So thank you, again, in advance.

The first panel that we have is an advocate and family panel.

And first I'd like to call on someone who I admire and respect very much; who is our ID, or Intellectual Disabilities, and DD, developmental disabilities, Ombudsman, Paul Aronsohn.

Hi, Paul; it's good to see you.

PAUL S. ARONSOHN: Hi, there; good morning.

ASSEMBLYWOMAN DOWNEY: We'd love to have you testify when you're ready.

MR. ARONSOHN: Great, I'm all set.

Thank you; and good afternoon, everybody -- Chairwoman Downey, and members of the Committee, invited guests.

Thank you for holding this very important hearing, and for inviting so many individuals and families to be a part of this difficult, yet necessary, conversation.

I know that there is a very limited time today to provide in-person testimony; but it was good of you to encourage as much written testimony as possible.

Clearly, this is an issue/area that our State government takes very seriously. And over the years, steps have been taken to minimize, if not outright eliminate, abuse and neglect of individuals with disabilities in group homes and other congregate care facilities. The implementation of the Stephen Komninos Law, beginning in 2018, is just one of the most recent, most sweeping examples of the efforts that have been made in this regard.

Yet we know that abuse and neglect still exist, and the testimonies presented today will speak to that ugly truth. We also know that there may be a very fine line between abuse and neglect. For some, neglect is arguably its own form of abuse.

My hope, therefore, is that today's hearing will be an important milestone in our collective efforts across our two branches of government to fix that which is broken, and to make safer our system of care for people with disabilities. That might mean more than oversight. That might mean more training; that might mean more use of monitoring technology; or that might mean some combination of all of the above.

Regardless, at a minimum, it should mean more transparency with respect to investigations into abuse and neglect. Present practice is for allegations to be investigated, but not fully shared with the public or even the individuals or families involved. More transparency would be the right thing to do, as well as the smart thing to do. The right thing because individuals and families deserve to know the details of any investigation involving them or their loved one. The smart thing, because such investigative reports provide us all with opportunities to learn, to improve, and to make necessary changes.

So again, today's hearing is providing a platform to jumpstart difficult, yet necessary, conversation -- one that is long overdue, one that will hopefully move us closer to ending abuse and neglect of individuals with disabilities. Suffice it to say, we can't get there soon enough.

ASSEMBLYWOMAN DOWNEY: Thank you very much, Paul. I'm glad that you're here.

MR. ARONSOHN: Sure, absolutely. I appreciate it.

ASSEMBLYWOMAN DOWNEY: And part of the process always.

MR. ARONSOHN: Yes, absolutely. Thank you.

ASSEMBLYWOMAN DOWNEY: I also just want to let people know that-- Oh, wait; actually, the next person I'm going to call is Bonnie Brien.

Is Bonnie here?

BONNIE BRIEN: Thank you very much for holding this hearing.

I'm just going to read what I wrote, because I get nervous when I look at everybody.

So one year ago today, October 22, 2019, my daughter Rachel was admitted to the hospital the day after her 34th birthday. She never left. She passed away on November 15 from common medical issues that went unreported and unaddressed, in a timely manner, to us as well as her primary care physician. As a result, serious complications developed from which she suffered terribly over three weeks that ultimately led to her passing.

By all indications, Rachel's illness and untimely death were preventable. In fact, if her medical issues had been addressed appropriately, it is highly likely that she would have celebrated her 35th birthday with her twin sister yesterday.

Rachel became seriously ill while living in a supervised apartment under the care of a State licensed residential provider. While some might have referred to Rachel as a *complex nonverbal individual* as a result of her cerebral palsy, seizures, and chronic episodes of constipation and dehydration, her general care was no more complicated than caring for a young child. Indeed, daily monitoring of her health concerns -- when conducted in a proper and timely manner-- allowed her to live a full life in the community. She lived with us until she was 31, during which she never experienced the serious medical conditions that led to her passing.

Unfortunately, her general physical care became unsafe for us to care for her as we approached our mid-60s, forcing us to seek residential care with a community provider.

That said, it is clear to us that some of the provider's staff lacked basic oversight training, specifically the so-called *fatal five* -- the five most commonly identified causes of preventable death in persons with I/DD: aspiration, bowel obstruction, seizures, dehydration, and sepsis. And not only did staff lack this basic training, they had totally disregarded our numerous attempts as her family and those who knew her best -- the experts -- to provide ongoing education with respect to her daily care. Consequently, she experienced a serious series of health concerns that went unreported to us and unaddressed for weeks prior to her hospitalization.

As a result, the lack of training and oversight led to a rapid deterioration of her health.

At our request, the DHS investigated this situation, but has denied our family a copy of the investigative report, leaving us to wonder what they investigated and how they came to their conclusion.

At a minimum, we deserve a copy of the report and other relevant documents. Rachel deserves this, and we desperately need to understand how the licensed provider failed to conduct simple oversight of her daily care in order to prevent her death.

Needless to say, the loss of our daughter has been and continues to be unbearable on a personal level. But it also highlights concerns that demand attention.

Significant gaps in the statewide system, at both the State and provider level, have resulted in unknown countless preventable illnesses, accidents, and even death. We need to protect these vulnerable individuals who require constant and consistent health oversight in a manner that alerts paid caregivers when medical attention, outside of an obvious physical injury, is required. There's no accounting for subtle changes in behavior that may indicate a medical condition is developing or has worsened, and the need to notify a parent/guardian, as well as advice from a medical professional, is warranted.

A number of initiatives are currently under consideration with the Legislature that have the potential to greatly improve current health and safety practices, including video monitoring. But fixing the entire system must be a priority.

As an advocate for this population for more than 30 years, I continue to work with the current Health and Safety Subcommittee of the Family Advisory Council, which consists of family members and the leadership of the State's Division of Developmental Disabilities. Going forward, I would also welcome the opportunity to work with this Committee because what happened to our family shouldn't happen to another family. And what happened to Rachel shouldn't happen to anyone's child.

Thank you.

ASSEMBLYWOMAN DOWNEY: Bonnie, thank you so much for sharing your personal story.

You know, it's important to hear about Rachel and about what happened, because these are the kinds of things that people need to be more aware of, so we generally go in the right direction and do the right thing so, like you said, this doesn't happen to anyone else.

What happened to Rachel is unacceptable on all sorts of levels, and it's so tragic. And again, I'm so sorry.

We're going to go -- we're going to hear a number of stories. And we have a few more people left to testify regarding their own personal stories.

The next person is Connie Shazar.

CONNIE MANCUSO SHAZAR: How are you?

Thank you for inviting me.

ASSEMBLYWOMAN DOWNEY: Thank you so much for being here, Connie.

MS. SHAZAR: Thank you for having me.

ASSEMBLYWOMAN DOWNEY: Go ahead.

MS. SHAZAR: I have a 22-year old son now, and he has been in group homes since the age of 13 to 18; five of them. Some of them have been shut down since; one of them, at 18, was run by a drug dealer who actually sold drugs on school playgrounds. And I'd let the CMO workers know, and they said, "What do you want us to do with this information?" I said, "I don't know. Gee, I would be a little leery; I guess the guy paid his dues in jail," and I left it at that. If you'd like to know the details, I'd be glad to privately share that with you.

My son has been bullied. I've gotten e-mails saying he was jumped by three guys -- there are bruises all over him -- and that all I should do is press charges. Nothing changed; it didn't matter, because the kids were still there and the staff was still there.

My son had broken a tooth, and all I got was a $50 gift card and an "I'm sorry."

My son-- Everything gets stolen from these kids, by the way. So I tried to get him DVRs to occupy him, and good sneakers and clothes. Always stolen; always, always. And he'd look like rags when I'd see him.

He had lost tremendous amounts of weight, and came home full of bedbugs. And when I questioned it, they said, "They're not bedbugs." I had submitted pictures of what he looked like before going into a group home, and what he looked like after. And I hope you've had a chance to view them, because it's horrific -- it's beyond horrific.

I saw my son with half his face drooped once, like Bell's palsy. I had questioned that, and I was told, "No, no, he looks the same." I took pictures, and you can obviously see a difference.

I also wanted to go through the food issues. I would question what they're eating, because my son would tell me, "Mom, they put steaks in their cars and tell us we're not going to get our snacks tonight if we tell on them. We eat chicken and rice every day, or beans and hotdogs."

.And my son -- he's high functioning, so he's no fool. And a couple of times I have driven in the back unexpected and have seen some of the staff actually smoking cigarettes with these kids. And I was told, "They have written permission; they're over 18." I doubt it.

Anyway, I got a phone call from Trinitas Hospital; they wanted me to come right over. When I got there, the doctor took me in a room and said, "How did PCP get into your son?" And I said, "What?" And my son said, “Mom, there’s *PSP* in me.” He was naming the game system, *PSP.* He was only 15; he was drunk, and he’s been getting drunk since, by the way. Even -- he’s part of sex trafficking now; he’s been drugged. I’ve been trying to get guardianship, and that’s another issue which I’ll talk about privately what happens.

And now he has records. I had five kids staying at my house last summer who have fallen through the cracks. I was providing for five children, who fell through the system of care, in my home. I took these kids out of the woods. They were foster care kids; there was no transition after 21 -- 18 to 21. There is nothing; there is no plan of action. And they’re not intelligent enough to look up 2-1-1, and what to do, and find the shelters; or they’re full.

So I took these kids in and found them-- One by one, I got them places. I don’t know what happened to them since.

I was on the board of the FSO for over 10 years volunteering my life to help these kids and hoping to change the system. I was just, also, invited back as a nominee, because they want me back.

I got an e-mail that my son had bruises all over him several times, and that he has been jumped many times.

I know they need some-- They absolutely have to have cameras in all the common areas. That’s like -- that’s not even a question at this point. That’s not even a question. Around the house, in the halls, in the common areas. The staff has-- They do become very complacent. They just joke with these kids. They’re not educated enough. They need to have ongoing training properly. And then if there are cameras on them as well, maybe they’ll do their jobs better; because they become very complacent and, you know, they just sit back and-- I've seen it over, and over, and over

So I'm in a position where I am willing to do whatever it takes to save my son. He has autism, he has learning disabilities, he has Oppositional Defiant Disorder, he has Mood Disorder, and now he has Schizophrenia Affective Disorder. And I'm hearing label after label through the years: intermittent explosive disorder; he kicked my car this week. He has assault charges, and I am trying to save him from going to Ancora where, a son like mine was killed there last year by another patient -- in Ancora.

That's when I took him to the hospital -- the local crisis. They sent CARES from Trinitas over, and the Trinitas woman evaluated him. She told the doctors, "He absolutely needs to be in-patient. He's a threat to himself and others." Well, they let him go; they could not find a bed. And all they had to say was, "I'm sorry. In that moment, he wasn't presenting. There aren't enough beds." And what they are doing, they get away with it.

These kids, at 14, can sign whether they want services or not. That is ridiculous. They do not have the insight to know. And some of these staff members cannot be pushing their own agenda on our children, whether it be religious, whether it be political. Because my son came home believing in Satan, and he told me a staff member is a Satanist and I almost had a heart attack. I insisted he go to a Christian church; that's my belief. And they kept telling me there's no staff available. If my son is living somewhere, he'd better get to church every week, because that's how I raised him. Another staff told him he's 18, he could do what he wants now.

So my son's life has been destroyed by this system; he fell through the cracks. My son was so difficult -- it has been an uphill battle.

My husband committed suicide. This year will be the third year that I have to live without my husband; I don't plan on losing my son.

And my son also has things too people put in his head. "Oh, does your mother blame you for your father's death?" No, I have never done that, and it's sick that someone -- a professional person would put that in my son's mind and confuse him more than he's already confused.

He has completely deteriorated beyond belief. And I need help, because I haven't been able to get guardianship -- which is another story I'd be glad to privately discuss.

No family should suffer a loss of a husband or a wife because the State is not doing their job. And my husband felt like a failed father.

Thank you.

ASSEMBLYWOMAN DOWNEY: Connie, I'm so sorry. It's heartbreaking listening to everything that you were just telling us.

You know, we are going to have a conversation. Can you please do me a favor and reach out to my office, okay? I'm going to make sure that you get the information, okay? I'm going to ask Anita or Tom, who's here from my staff; from either the Majority Office, Anita, or from my staff to make sure they e-mail you, and we'll make sure that we talk. We'll really get into all the details and see what we can do, okay?

MS. SHAZAR: And you will be so shocked at the things I have, and pictures. And I've kept every note, I've kept every e-mail. It's horrific.

Thank you.

ASSEMBLYWOMAN DOWNEY: I really appreciate, and I'm sure everyone does appreciate that you're here. And thank you for sharing all of that.

MS. SHAZAR: Thank you for having me.

And I'm going to mute you now, but I look forward to receiving your e-mail.

ASSEMBLYWOMAN DOWNEY: Okay; thank you.

MS. SHAZAR: Thank you.

ASSEMBLYWOMAN DOWNEY: The next person we have to speak, also as an advocate or family member, is Lou Berman.

LOU BERMAN: Hi, good morning -- or good afternoon, rather.

ASSEMBLYWOMAN DOWNEY: Thank you for coming.

MR. BERMAN: I'm just -- I'm a little bit overwhelmed from what I've just heard. So I'm going to try to muscle through this.

My testimony is going to be a bit charged, but it will be professional, of course.

And I wanted to just start off quickly by sharing some reviews on a simple website, *indeed.com,* about certain organizations and companies. And I'm not going to name the names, but I think there are some in this group who know me, and know my son's story, and my story, and know where these events had occurred.

I'm going to read some things that just show up on *indeed.com.* It took me about five minutes to do this.

"I have experience working at a campus in Mount Laurel with the children. When persons served are having behaviors, the managers just watch from the camera in the hub." This is a place that has cameras, by the way. "You have no knowledge of any communicable diseases you could be exposed to." These are employee statements. "They do not prepare you for what you're getting into. Honestly, the kids should be staffed with trained professionals, not entry-level young adults with no experience. They'll try to force you and staff into units that you're not trained in and comfortable." "Poor management." "We feel as if employees are temporary and interchangeable." Again, "Poor management."

So then they go and ask a question. They say, "What would you do to make this place a better working environment?" The answer was, "Shut down the program," which my son was in. "Shut that program down."

So my son attended this place for about eight years. Easily hundreds of injuries over the course of this time. Not one time did I get notified that they, or an employee, or anyone was responsible for any kind of neglect, injury, or abuse. Nothing. Black eyes; broken teeth; head lacerations; severe anal rashes from no wiping assistance; chemical burns, because they left dandruff shampoo in his hair for days; twisted and swollen knees; busted teeth; missing teeth, after I paid to fix them. Not to mention the absolute insanity of no parental visitation for four months with this COVID? I can't even look at this kid behind the glass? You're going to just rip us away? And I'm going to touch on why that's so important -- as to how this system took away our oversight.

Apparently there's a strain of COVID that must be unique to Mount Laurel, New Jersey, because I can't even look at this kid behind a glass? The coronavirus in Mount Laurel must be able to transmit through glass, apparently. That's cruel, it's inhumane. You won't even allow us to lay eyes on our own kids. So you want to talk about abuse -- that could be maybe worse than a bruise on his body, feeling that his own father-- I'm all that he has; I'm the only one. His mother is gone, his mother's family is not involved. I'm the only one. I am his only blood relative, the only person who loves him. And I'm ripped like that -- like I'm some kind of exponentially higher risk. Meanwhile, 1,200 employees can go on that campus -- before and after work they can go get medical care, they can go and do whatever they want to do. The delivery man can go there, the FedEx guy can go there, the people who drop off the food can go there, the employees can come and go whenever they want, but I can't see my son, okay?

I want to share a little stat with you, because I don't want you to think this is just so emotionally charged without some facts.

So in the *New York Times* they wrote an article -- it was Nikita Stewart on June 9 -- describing that 50 percent of the abuse reports dropped during COVID. So whatever the normal amount of abuse claims that were submitted by parents, teachers, people who see these kids -- 50 percent are gone. It said the steep decline could be a sign that an unseen epidemic of abuse is spreading behind locked doors, according to the police prosecutors and Child Protection officials. These are folks who are involved; that's what they just said, as this virus has shuttered the city and the fragile system of safeguards designed to protect children has fallen apart.

But that's insanity; that's insanity. We took away the main -- the balance of us as parents to go and protect these children. Because I can tell you, these facilities aren't calling up and they're not snitching on themselves. They're not ratting themselves out; they're not going off and saying, "Hey, I just -- Little Johnnie was in the corner here, and I just punched him in the head." They're not going to do that; nobody's going to do that. The only balances are us, the teachers, or the small percentage of those in those facilities who do care.

I'm just going to kind of close and say that I reported, just recently, seven instances of abuse and neglect supported by photographs, by video, by documentation. And the official letter I got back from the facility had the audacity to tell me that they could not determine any kind of abuse or neglect based on all the injuries I just shared with you. And that's all the injuries in one year.

So let's talk about cameras for one second. We want to develop cameras? If we're going to do cameras, we need to insist that parents and guardians have a right to view them. Because when my son's teeth got knocked out, "Oh, we can't show the video." I had to go file a police report, okay? And thank God that detective showed me -- had the decency to show me what happened. They threw my boy around like a rag doll, like a rag doll. They knocked his teeth out. But the reply that you get from these facilities, even if they have cameras is, they say, "Well, there's nothing -- we didn't see any instances of abuse or neglect." Really?

So I'm going to be following back up again, because apparently DCF and DDD have dropped this. They have no intent, as far as I'm aware, to continue to pursue and find out exactly what happened and how this facility could have just said, "There are no instances of abuse or neglect."

But we have a 50 percent drop in abuse claims. And if that's not enough for us-- You know, how many kids have to die? How many kids have to be abused? How many kids have to be hurt? We have red light cameras at intersections, but we don't protect the most vulnerable of our population. They shouldn't -- this is a no-brainer, a no-brainer. And parents need to have the access, because we're the only oversight -- all of it.

And I thank you for having me. I'm so sorry I got upset, but it's so-- I thought I was in pain before. When I heard what these women said, I can't even-- I'm just-- I'm very sorry, and I thank you for having me.

ASSEMBLYWOMAN DOWNEY: Lou, it's so important that you're here, and that you're sharing, and that you're also helping to support the other people here who've gone through these things with their children.

But Lou, I wanted to say-- You know what? With the Bill -- I'm going to look at my Bill again. I've looked at it, I can't tell you how many times, but I'm going to review it again just to make sure it's pretty clear that you're going to -- the one that I have about these failings to make sure that there's no issue about parents having the ability to go and look at the actual video.

So that really -- you brought to light something that we weren't even thinking about as we were going through all this. So I'm going to make sure that the language is pretty clear that the places -- the common areas -- you'd have the ability to be able to see that. I think it's clear, but I'm going to go back and check.

So thank you for bringing that to our attention.

The other thing is, there is a Bill-- Our wonderful Assemblywoman here, Valerie Huttle, had a Bill to make sure that people could go visit. And I'm trying to figure out where it is. I thought we-- Maybe Assemblywoman, do you have any more information on that right now?

ASSEMBLYWOMAN VAINIERI HUTTLE: Thanks, Chairwoman.

First of all, listening to these horrific stories -- and many of them are even exacerbated during this pandemic -- pre-COVID we've had similar tragedies and similar abuse and neglect. During COVID, obviously we don't have the family members who really are holding their loved -- or the facilities or group homes or staff accountable. And that's an issue.

Yes, the Bill -- that I believe went through Committee -- would allow family members, during a public health emergency, to be able to communicate with their loved ones. We had the same type of concerns in our long-term care facilities -- the Social Isolation Bill -- that was signed into law. So we are pushing this one; hopefully we get this done quickly. Because, quite frankly, not only are we, probably, experiencing a second wave, but with or without COVID we need to have protections and oversight in place.

And listening to these stories -- I don't want to take up time, I want to listen to the rest of the testimony -- but I'm happy to be part of the camera bill, chairwoman. But apparently even with these hammers, there still seems to be issues. And I want to get to the bottom of that. Because as we heard from Connie, her son had cameras; and as we listened to Mr. Berman's story, it doesn't seem to be as helpful. And I think we need to continue to have oversight on the staff and the facilities though.

I just want to continue to hear the testimony, and hopefully, Joann, together with our colleagues, in a bipartisan way, we can stop these horrific stories and try to resolve some of these issues together.

ASSEMBLYWOMAN DOWNEY: Yes, thank you so much, Valerie. I appreciate your-- You know, I know all your great advocacy in this area, too. And I really appreciate the fact that we'll be able to do more. And hearing all these stories -- this helps us. So thank you, to all of you.

And Valerie, is your Bill A-4239? Is that correct? I just want to make sure people can track that too, if they wanted to. But I think that's the Bill number.

ASSEMBLYWOMAN VAINIERI HUTTLE: Yes, that's it.

ASSEMBLYWOMAN DOWNEY: And I think it's stuck in the Senate. I know DHS had issued guidance to allow in-person visitation, but obviously there must be an issue. And so, Lou, we're going to have to-- Can you do me a favor, Lou? I'm going to have -- we're going to reach out to you, too, to find out what the issues are.

MR. BERMAN: I can tell you, quickly.

So DCF came out with an order on page 3, subsection *c* -- I have it memorized -- in which, unfortunately, going all the way up to the head of DCF, when I had appealed to them, that Governor Murphy was very clear that physical visitation would be permitted in an outdoor environment with appropriate PPE and social distancing. And then DCF, unfortunately, deferred to every facility and said, "You folks do what you want to do."

So in my case, you know, they would-- Even though the order was there, they still refused to enforce that order.

ASSEMBLYWOMAN DOWNEY: And how old is your child?

MR. BERMAN: Well, Louie is now 21.

ASSEMBLYWOMAN DOWNEY: Okay.

MR. BERMAN: But he's no longer at the facility. He was; now he's in a D.C.

ASSEMBLYWOMAN DOWNEY: Okay.

MR. BERMAN: So soon he'll be coming home with self-direct care; which I'd love to have a sidebar with you with that because--

ASSEMBLYWOMAN DOWNEY: Yes, yes we'll definitely speak about all those things too, so--

ASSEMBLYWOMAN VAINIERI HUTTLE: And I want to jump in.

That's why we need to codify these orders into law. Again, not only during this pandemic; but as we continue to move forward, if we ever have another public health emergency we need to definitely codify these orders, and we need to do this quickly.

ASSEMBLYWOMAN DOWNEY: Yes, absolutely, Valerie.

All right; I totally agree.

We're taking all these notes, too. I don't know if you notice -- I keep looking down at my pen; we're writing notes. And also our staff is paying attention -- okay? -- to everyone who is speaking.

ASSEMBLYWOMAN DUNN: Assemblywoman -- Chairwoman Downey?

ASSEMBLYWOMAN DOWNEY: Yes; how are you, Assemblywoman?

ASSEMBLYWOMAN DUNN: I just wanted to just kind of, piggyback on-- I had a quick question of both Mr. Berman and Ms. Shazar. And I know this is very painful, and I just was hoping that you could share just some more insight. Just -- if you could describe the home; just how many residents are in the home with your son? I know there's a variety of settings. But that might also help give us some insight as we look into this issue of strengthening the visitation rights and things like that.

If you wanted to go first, Ms. Shazar.

MS. SHAZAR: My son is not in a group home right now. He's been in hotels, placed by DDD. (Indiscernible), re-placed.

When he's in these places, he's been so traumatized. He is fighting me, then he spites himself because the system that I'm begging him to trust is the one that hurt him. And when he was in these programs, I would beg and advocate. I was told, "If you don't like it, then take your kid out." Then when I did take my kid out, they would say, "Well, why'd you take him out early?"

So a lot of parents get that. I mean, I've seen -- he's been in group homes where there are 7 to 10 kids. He's been in Willowglen Academy, where it was institutionalized lockdown. And my son eloped (*sic*) there gazillions of times; so lockdown or not, he got out. There was no oversight other than, "Your kid's missing." We live in, like, the wooded area, and there are black bears here. "Oh, that's great; he's going to get eaten up," I'm thinking.

I can't tell you how many times I've had to run to these places. It's just horrendous. My son, one time, called me and he said he got punched in the chest by staff. And he said, "Mom," he was crying on the phone to me, "they're not letting me call." I said, "What?" I couldn't even believe he could say it. He literally walked to the police station and tried to report it. And they didn't see him as serious, and they just took him back.

ASSEMBLYWOMAN DOWNEY: So these were different settings, right, Connie? You were like-- So he was in different settings even -- whether it be a small group home, 7 to 10, or--

MS. SHAZAR: Yes. Five to seven I think works better.

But there needs to be accountability, because when these kids leave that home, they're vulnerable. There needs to be complete insight (*sic*). This woman literally drove my kid here without a phone call. I go to look outside, and she says, "I am done with your kid," and she just dropped him off and drove away. There was no accountability from the Mentor home; there was no accountability to nothing. I mean, she literally just dropped him off at my door. She said, "He's a nightmare." I was sending her money -- which I didn't know I wasn't supposed to do -- because I wanted to make sure that she was taking good care of my kid. I was practically bribing her, I guess, yes -- because I was so fearful that he wasn't being cared for properly, you know? And it led to -- when he came back home--

And then the sex trafficking. The policeman said, "Your son has been sex trafficked," and his arms were all scarred up. He was drugged. I mean, it just got so crazy, and it's still not rectified because he fell through the cracks. Just like with the school system -- they were so tired of him, they literally pushed him through. Three days-- I get, "Your son's not graduating." Three days later, he comes home in a cap and gown, screaming his head off at me. "Where were you at my graduation?" I almost had a heart attack. I said, "Are you kidding me? Are you kidding me?"

ASSEMBLYWOMAN DOWNEY: There are so many-- I can tell, we could talk a lot about all these other issues, too. And I know there's a lot, and I want you to be able to share all of that.

And I'm sorry, Assemblywoman. I know you wanted to like-- You know what we're going to do? I want to hold off on all the questions, though, until the end of the panel. Like, let's get through all of the advocates and the family panel first; and then anybody who has questions, in terms of my Committee members -- anyone can ask their questions at that point, okay?

And I'm sorry; I should have mentioned that -- I should have said that earlier, all right?

And Connie, thank you, again.

Next, we're going to have Jen Bubb Brown who's going to testify.

Jen, are you there?

JENNIFER BUBB BROWN: I am here, yes.

ASSEMBLYWOMAN DOWNEY: Okay; thanks, Jen.

MS. BROWN: Hi; how are you doing?

ASSEMBLYWOMAN DOWNEY: Great; the floor is yours.

MS. BROWN: Okay. Great; thank you very much.

Let me just get my notes here.

Good afternoon, Chairman Downey and members of the Committee.

Thank you for holding this hearing today.

My name is Jennifer Brown; I'm a parent and professional with 20 years of experience in the field of developmental disabilities. I'm the mother of three adults.

My oldest son Kyle is 23, and currently lives at Hunterdon Developmental Center in Union Township. His primary diagnosis is Phelan-McDermid Syndrome, a de novo genetic syndrome that is considered rare. Not much is known about the syndrome. He's also been diagnosed with autism, bipolar anxiety, intellectual disability, mitochondrial metabolic disorders, catatonia, OCD, ODD, intermittent explosive disorder, and has a behavioral disorder that does not respond to treatment.

He's a really complicated young man to support. He's also the bravest, kindest, and sweetest young man you'll ever meet.

Kyle has been in many different settings. He has been in the local school district, out-of-district placement, in-patient psychiatric hospitals, medical hospitals, emergency room settings, respite, group homes, out-of-state campus settings, his own apartment, and now the Developmental Center. He often requires two to three people to be with him to keep him and others safe.

We've seen the best and the worst of what the service system has to offer. I can tell you that at every setting he has experienced, at some point, abuse, neglect, or exploitation, or all three at the setting. I've yet to see any of the official incident reports for any of the events. The lack of transparency and accountability is unacceptable.

The staff at Hunterdon reported to me that Kyle is the first admission in six years. There was staff on his admission team that had never done an admission. It's 20 minutes from our home, and it's the first time in a very long time that our son is close to home, to the home he grew up in.

It's been a huge relief to our family, as we were able to see him on a regular basis prior to COVID. It's also, oddly enough, the setting where we don't worry about abuse and neglect as much as the other settings.

Why does my son receive better care at this 50-year old institution than he did all the other places and providers we have tried?

I have three minutes to tell you about the abuse and neglect that my son has sustained throughout his life. My son is not able to report to me when he has been abused, or who has abused him. He doesn't have the ability to express when he has been neglected. It is often through his behavior that we piece together what has happened.

I'm not sure which instance to tell you about. His abuses started in preschool, when a speech therapist was observed yelling at him while he was strapped into a Rifton chair. A sweet, 3-year-old child being subjected to the very worst behavior from an adult.

When he would come home from school, he would have me hold and rock him for hours; and this is how we figured out something was wrong.

At his out-of-district placement, restraints, seclusion, and behavioral adverses were written into his plan as part of his education plan. These tactics were not used as a last resort, as is best practice. These were used as part of his plan.

There was a respite provider who lost him for 24 hours when he was 11. I was in the hospital and unable to care for him. I had no idea where he was, and the agency stopped returning phone calls.

He has been abandoned twice at hospital ERs by providers. The one time the staff told the hospital that we lost our parental rights to him, and we were not able or should not see him -- which was not true.

He was tied to a bed, even though he was calm and hadn't presented with behaviors. We later found out that the agency had a staffing emergency and they didn't have enough staff for the evening shift, so he had to go.

Then there was the provider that so traumatized my son that he refused to take showers for six months; we still don't know why.

I'm not suggesting that having Kyle at Hunterdon Developmental Center has been without its own trials. It is an institution, and it is not person-centered. Kyle is one of 450, and is treated as such. His staff, day-to-day, do their best to meet has unique needs; but as a rule, they are not set up to provide care in this way.

In this setting, he is overmedicated. There's only one psychiatrist on staff at Hunterdon, and he is refusing to lower the dose. We don't have access to outside providers, and so he remains overmedicated. The staff that treat him on a daily basis have been consistent, and have worked to establish a relationship with Kyle. They are not scared of him, and they have the support they need in order to care for him. It is working right now, but it is not the long-term solution.

I want you to know how difficult it is for me to tell you that I feel Kyle is best served in an institution. I have spent the last 20 years as a professional, promoting person-centered community-based settings -- the kind of place where the person rents her own place using a supported housing connection voucher, and staffs it with people who they want supporting them.

There is something deeply wrong with our service system. This system has become difficult to use, and we as parents and allies don't have access to parts of the system that we need. We need to be able to access the system and provide self-directed employees with training.

Kyle was in his own home; and on March 17, 2018, he was purposely given too much of his medicine. The result was a painful side effect called *dystonia;* it's where his entire body contorts into a muscle spasm. He wasn't able to eat, or walk, or stand. His staff denied any knowledge of the overdose.

On March 31, 2018, a staff member reported that he was instructed by the lead support person to give Kyle extra medicine in the bathroom, as it would not show up on their cameras. Instead, the staff alerted the BCBA we had on staff, and he called the police. The lead staff was terminated; and on her way out the door she emptied out his bank account and his food stamp card. The issue was investigated by the Department of Human Services OPIA. Because of the Komninos Law, my husband and I, as his guardians, were able to be a part of this process. The caregiver was put on the central registry and will not be allowed to work in the field. The Hunterdon County Prosecutor's Office was notified; and after a short investigation, they decided it didn't rise to the level of charges.

After this incident, he was moved into an emergency placement. In this placement, he had a behavior after being ignored by staff at the home; 9-1-1 was called. Staff reported to the dispatcher that she was being assaulted. I was on my way, and when I arrived there were over eight police cars and two ambulances at the home. I explained to the police that he has a profound intellectual disability, and that while I was sorry that the staff was hurt, he was not at fault. They refused to listen to me, and instead the police restrained him in a prone position, handcuffed him, and removed him from the home.

During the interaction, they disparaged me as a mom, suggesting if I was a good mom he would be home with me.

Cameras are important, yes; we had cameras in my son's home. He was still abused and exploited. We need more training, transparency, and we need to make the service system in New Jersey easier to use for people who are self-directing, so that my son can leave the institution one day and go back into his community where he will be able to share his gifts--

I'm sorry.

ASSEMBLYWOMAN DOWNEY: No, you're good.

MS. BROWN: You know what? I didn't raise this child -- we didn't go through all that we went through for this to be *it* for him. We have to do better. I feel so disingenuous because I'm a professional out there, all over the state, helping people figure this stuff out. And I can't figure it out for my son.

Thank you.

And I'm sorry; I didn't mean to cry through the whole thing.

ASSEMBLYWOMAN DOWNEY: No; you know, you're a mom. We want to cry -- the rest of us. I mean, you're amazing. And you have to remember how amazing you are because you're fighting always for your child.

You know, it doesn't-- You know, it's the system that's not where it needs to be. But you're always fighting; you're doing everything you can to help your child. And we're going to continue to work with you to try to make it better.

MS. BROWN: I spend most of my day fighting, not only for my son, but for other people's sons and daughters as well. And the service system-- You know, cameras are a good thing, but there's so much more that needs to be done. And, you know, I think the only thing I can think is to go back and read Paul Aronsohn's report again, all 7,200 pages of it. And every single word that he puts in that report is it. We need to focus on that and make it better, so that we can get Kyle out of the institution. Because that's not-- My husband and I have gone almost kind of bankrupt three times caring for him, doing everything that we possibly can for him: lawyers, doctors -- you name it. This can't be the end; we have to do better.

And I really appreciate you taking the time to listen to all our stories, and to actually, maybe, do something about this.

Thank you very much.

ASSEMBLYWOMAN DOWNEY: Thank you, Jennifer; thank you.

All right; we're going to go on to the next person who's here, who is Lisa Gutowski.

Lisa, are you here?

LISA GUTOWSKI: Yes; hi, I'm here.

Thank you.

ASSEMBLYWOMAN DOWNEY: Hi, Lisa; thank you.

MS. GUTOWSKI: Hi.

My story is my son; he just turned 21. He has been in the system. Basically he's nonverbal, and he-- I'm sorry; all these stories have just really-- I've been crying, like, non-stop. It's terrible, but I understand because I'm going through this; I've been going through this for 21 years.

So finally, I got him into-- He's very -- he has a lot of behavioral problems and he has a lot of medical problems. And honestly, we were not able to care for him. He needs, like, an army to care for him. And we finally got him into a group home; we got him into Legacy. And after-- Their policy was, we weren't allowed to see him for two weeks so they could get him used to the system; but we could call. And every day, "He was doing great, he's getting it, blah-blah-blah." And he was still going to school; the school called me and said, "We are calling institutional DYFS because all the parts of his body that were not covered by clothes have cuts, bruises, and welts all over them. We know it wasn't you or anything, of course, because he was there. But we're letting you know, so when you call, just act like you don't know anything is terrible."

So then they came, they looked at him, they took him away. They took him to Jersey Shore Medical Center. The doctor looked at him and said this was a terrible case of child abuse. And then we ended up having to take him home, and the State did charge the place with child abuse.

So a year later I get a letter in the mail that there was a court hearing that I was never notified about, I was never invited to, and they lessen the charge of child abuse to just a misdemeanor. Because these places -- there are not enough places for people like my son. My son is nonverbal; he has a lot of behavioral, he has a lot of medical. There are not enough places for them, so they're letting these places stay open because, what are they supposed to do with them, you know?

So then my son got necrotizing pancreatitis; my son was home with me for about two years. I really couldn't care for him, but I had no other options. It was really -- he's running outside naked; everybody knew. But the police would just keep bringing him back and say-- Like, we would go and run after him. And it was just -- there was nothing we could do.

So he got necrotizing pancreatitis a year-and-a-half ago; he was in a coma for three months. He came out of a coma; his medical needs were now a whole new level than they were before. So now I really couldn't take care of him. I had to give him-- He also became a diabetic; I had to give him shots. I couldn't do this. My son is, like, 6'2"; you know, he's a big guy.

And so we finally-- I had to get a lawyer. We finally got him-- No place in New Jersey would touch him. They said, "No, the behavioral is too bad, the medical is too bad; we're not touching him." So they wanted to keep him, still, just in Jersey Shore Hospital, just sitting there. We finally got a lawyer; the lawyer -- we got him into the Woods in Pennsylvania. So my son is in the Woods in Pennsylvania right now.

So we thought everything was going well. You know, the pandemic hit; we couldn't see him anymore. I was going every two weeks to see him, because it takes me about two hours to get there. And so the pandemic hit; we weren't allowed to see him. I get a call in July that-- "Did you get a call about your son?" "What happened to my son?" "Well, your son -- we saw a staff member walking by--" No, "A nurse was walking by while a staff member was hitting your son in the leg with a brush and screaming f-words at him, basically."

Now before that-- I'm sorry; let me just say before that -- before that I was getting calls constantly that my son was -- they said that he was self-injuring himself. He had a huge knot on his shin, the size of like a football on his shin. He had a black eye. He got a cut above his eye that needed stitches. There were constant things, and they were saying that my son was self-injuring himself. And my son never was a self-injurious person. He would attack *you*, but he wouldn't attack himself. He was smart enough not to do that.

So then, all of a sudden, now we know that this staff member is abusing my son, okay? So I, like, throw a fit; I'm like, "I want this person out, blah, blah, blah. I want to press charges, I want to do this, I want to do that." So basically what happened is, the staff member did not get fired; he just got moved to a different place. But he still has his job. The nurse that made the testimony -- basically, it means nothing. We did do an abuse case; it went nowhere. My son is still there. My son just turned 21, so they're trying to get him back into New Jersey. But there's no place that even wants to touch him, because his medical and his behavioral are so big. So I don't even know what I'm going to do.

But the point was that I asked if I could get cameras in there. I said, "Can I please just put cameras in his room? I'll pay for them, I'll get them installed, everything." "No, no, no." You know why? Because people don't want to be caught, and that's it. And that's what's going on in the world right now. We've got all these terrible things that are happening in society that now people are using their phones and videoing and people are being accountable for. Well, you know what? They don't want to be accountable in those places, because there are not enough places open. And they're saying, "Look, we don't know what to do with your kids." And that's another problem.

But, you know, the fact is that our kids can't be abused. My son is going to be moved. You know what? My son has gone to two group homes that both abused him. He's going to be moved, probably, because New Jersey is going to want to have him back here. He's going to get abused again; I know it. Like, I know it. Like, how sad is that, that I know that my son has no chance of not getting abused? Because it just happens, because he's nonverbal, nobody's going to tell. And you know that-- I don't know; it's just -- it's so heartbreaking, and it's just-- It's like, I just feel hopeless, honestly.

I mean, I really appreciate all of you, and what you're trying to pass. And I just hope that-- People have to be more accountable for what they do to people like this, you know? Like, to our children. Our children are like babies, you know? They don't know; it's just terrible.

So I appreciate you; thank you so much.

And that's, really, all I have to say.

ASSEMBLYWOMAN DOWNEY: No, thank you, Lisa. Thank you so much. Thanks for being here and, again, sharing some really tough information about your own life that really-- It's hard for all of us to hear, but you have to live it; you have to live -- you've lived it and have to continue to go through it, just like all these other wonderful parents.

We have a couple more -- I have one more parent, I think, advocate, who I want to call -- Marie Ruth Wargnye.

CYNTHIA ROWBERG: Hi; can I just interrupt for one moment?

ASSEMBLYWOMAN DOWNEY: Yes.

MS. ROWBERG: I'm also a parent waiting to talk. So I hope you--

ASSEMBLYWOMAN DOWNEY: I don't have, like, all of your names on here. But what we'll do is, when we're done with these few people -- I have to have one expert, who has to leave by 2:30 -- so I need to have Lisa Parles speak right after Marie Ruth. And then we'll get -- we'll take down-- I'll look at who else -- I'll ask who else is a parent to raise your hand. So I'll just put down your names on here, okay?

MS. ROWBERG: Yes. I did everything in a timely matter, as did my daughter.

ASSEMBLYWOMAN DOWNEY: Okay.

MS. ROWBERG: And it is very important as well.

ASSEMBLYWOMAN DOWNEY: We'll make sure that you speak, okay?

All right; so let's get to Marie Ruth first.

BARBARA WICHOT: Excuse me. I'm a parent and legal guardian, and also--

ASSEMBLYWOMAN DOWNEY: Yes; I think we have your names on the other side. I think I have a -- because you're part of the family panel -- additional family panel that I have. So you're here; I see your name on here, Barbara.

MS. WICHOT: Okay.

ASSEMBLYWOMAN DOWNEY: I have a bunch of you on the second page here. So I think you're all on here; I just didn't see that you're all on the family panel on the second page, okay?

So right now let's go on to-- Marie, we're going to come back to you -- okay? -- once you figure out-- Figure how to get yourself unmuted; and in the meantime, we're going to go to Lisa Parles, because I know you have to leave early.

LISA McCAULEY PARLES, Esq.: Right; thank you.

ASSEMBLYWOMAN DOWNEY: Thanks, Lisa; thanks for being here.

MS. PARLES: Oh, my pleasure.

Thanks for giving me the opportunity to speak about this critical issue, which we know from all the speakers so far, and also from Paul Aronsohn's report, it is not a 2-alarm fire, a 10-alarm fire, it's a million-alarm fire. And it's only become more exacerbated through COVID because of the isolation, and parents not really being able to see their children or interact with staff in the same manner. So I really appreciate that you're addressing this topic.

I'm a partner in Parles Rekem, which is a New Jersey law firm that represents individuals with disabilities and their families. We also represent some not-for-profits as well.

I'm a founding Board Member of the National Council on Severe Autism. I've spoken a number of places on the topic, particularly for the population of individuals with severe and challenging behaviors. I've spoken at the United Nations, the U.S. General Accountability Office, and various legislative committees. And, most importantly, I have met and spoken with a number of parent groups looking at this issue of how we can make this better.

Most importantly, though, my most important description, credential, defining characteristic is that I'm a mother of a 30-year-old non-verbal man with severe autism, bipolar disorder, complex medical and complex behavioral needs.

Without question, this Committee could fill not only days, but months; and you're going to hear from numerous families who are going to present more harrowing facts than we've even heard so far, with instances of abuse and neglect.

I started my career as a sex crimes prosecutor in the Brooklyn DA's office, and I never imagined that private practice would bring to me so many situations involving broken bones, bruising, sexual assault, medication errors, and just other horrifying scenarios.

In the 27 years since my son's diagnosis, I have visited programs throughout the country -- both on my own, and also with a number of national groups -- where we're particularly seeking information about program elements that lead to safe environments, engaged satisfied families, supported well-trained staff; and probably most importantly, healthy and safe persons served. I particularly focused on the needs of individuals with little or no language, challenging behaviors, and complex needs -- a population that the only way they thrive is that if we've got well-designed and frequently reviewed data.

I've actually given a lecture in a couple of different presentations with some other professionals on what are the key elements. And it's an hour-and-a-half to two hours, so three minutes is going to be a little bit of a challenge. So I've just pulled some of the key pieces, but I would love to stay continually engaged with the Committee and its work.

So I think one of the key components of these prevention strategies is definitely camera and surveillance systems. But they can't be intended to only catch wrongdoing. Now, catching wrongdoing is important, because no matter what system we have in place, in every field there's going to be bad, evil people who are going to hurt the vulnerable population. So it is an important part that we are there so we are able to, essentially, catch this wrongdoing and act appropriately and swiftly.

But in programs that I have visited that have success from an individual's perspective and the families', they use the cameras not just for that, but most importantly they use them as training tools. They use them to support staff. They use them as mechanisms for instructive feedback.

One program I visited in Kansas -- which had one of the most elaborate systems; it was a private provider in connection with the university -- they had systems where the clinician literally sat at a screen -- always manned by clinicians -- where if there was movement, it would come to the center of the screen and the clinician could talk in real-time to the staff. The staff could reach out in real-time. If the instructions didn't help, then they actually had response teams that they could call. Now, this particular program tended to (indiscernible). Plus their programs -- they had a campus program and ones in the community, where they were always very close to each other so these response teams could get there quickly. But it was a very, very elaborate system. And as I always do, I spoke to staff when I visited this program, and I asked, "How did you feel about this?" And they uniformly said, "We were terrified. We thought it is just going to be punitive; it's going to be like having Big Brother, you know? We didn't like the idea."

But once the program proved that it was about providing support and feedback -- and they said it was really going to be used to support them and help them better serve the residents -- they really welcomed it, because it was used as support and input.

So we can't just put those cameras out there and just wait to roll them when someone gets hurt. It has to be an interactive process with a fully staffed clinical team. And we are not -- except for a handful of places -- not doing it in New Jersey, and particularly in our under-21 system.

A second key element is that you have to have engaged, experienced clinicians who actually spend time with the residents. Don't sit at the desk, don't fill out forms, don't produce graphs, and certainly don't sign off on plans. They have to observe them; they have to work directly with them. But they also have to model effective interventions and interactions with staff. We expect so much for these staff members to have instincts that sometimes we, even as parents, don't have. And it is a really terrifying situation, often, for them. I'm actually working with a university now where we're doing focus groups with staff to find out how best to support them. And so many of them love the field, but leave because they don't feel supported.

Now, a barrier to effective clinic services is that caseloads are much, much too large; and they don't adjust the number based on the severity and the complexity of the person served, which puts a lot of the clinicians in terrible situations.

A third critical element is communicating and connecting with families; but in a meaningful way, okay? And communications can't start when there's an incident. It has to start at admission with a commitment to viewing families as partners. I have seen programs where parents are treated as part of the treatment team. They have useful information, they have helpful histories, but most importantly they -- other than COVID times -- see and interact with their loved ones. So they need to be part of that team so they can not only know what the intervention is, but also be part of developing the intervention.

The other thing is that programs that are successful that I have seen across the country -- that, again, there just seems to be not just happier families, but have less injuries, less hospitalizations, families that are out talking about how proud they are of the program. Because the agencies are engaging the families in important ways, like program development and design; not just fundraising. And fundraising is important, and if we're going to do it well we need philanthropic support all around. And I support that agencies ask for that help, but that can't be it. They've got to be on the substantive committees, like the Human Rights committees -- (indiscernible) parents on human rights. What about strategic planning? The partnerships that lead to a sense of a joint mission that are committed to quality -- that's the key component to creating these safe, successful programs.

Now, I would be remiss if I didn't address what I consider to be among the worst situations -- although it's hard to rank these tragedies -- and that's cases involving peer aggression; and where individuals are often frightened themselves, and harmed, providers are under attack, families are worried and heartbroken. And among the most troubling were situations where programs failed to act quickly in communicating, and failed to increase necessary staffing and support immediately. It just goes on for too long.

In these situations, though, we are failing not only the target of the aggression -- and my son has been a victim of peer aggression, and also was in a placement where also a housemate was the target of peer aggression -- but we are also failing that individual who is engaging in the aggression. They are, all too frequently -- they're not getting the benefit of the analysis of the function of the behavior; they're not getting an effective intervention plan. Often when families also raised an issue about peer aggression they're told what I consider the most despicable response, which is, "Well, your kid has problems, too. And if we take this person out of here, God only knows what we're going to put in next."

My heart broke for not just my son, but broke for that individual who just did not have the help and support that was not only going to make him successful, but make other people want to be with him. So it's just a failing all around.

Now, one strategy that programs in other states have employed, that I think leads to success, is where they actually do projects with smaller individual units available, including one-bedrooms often in clusters. So the cluster is important because it allows for a quick team response, intensive supervision, protection of victims. But probably most importantly, the ability to remove, assist, treat, and support the individual who is exhibiting aggression.

Now, I'm not going to say -- and those of you who know me, know that I am just a strong advocate, and some may even call me a zealot -- is that we need, in New Jersey, these campus-based cluster programs. But big is not always bad, but big is not always good; in the same way small is not always good, or stand-alone group homes can be good and bad. The model itself, the structure, is not going to do it alone. It does help, though, when you have these other pieces where you have engaged clinicians and parents on the team, and cameras used for the right purposes. It sure does help when you've got lots of these small units that are together that can keep people healthy and safe.

I think I've gone well over, so I'm just going to end. I have about nine other things that I think we've seen as the characteristics. But I do just want to say that throughout these situations we can all commit to families being kept informed, that effective treatment is put in place, and that all persons are treated with dignity and respect.

So I'd like to end by thanking the Committee for investigating situations that cause what I would describe only as unimaginable suffering for all involved.

Thank you. Sorry I went on.

ASSEMBLYWOMAN DOWNEY: Thank you.

We definitely will look at some of these other things that you spoke about; and I'll definitely reach out to you, and I'm sure some other people who are on the Committee will want to do so as well. So we'll reach out.

Thank you, Lisa, for your help always, and your advocacy. And thanks for your testimony.

MS. PARLES: Thank you. And I know how heartbreaking this is, because I've lived it myself, too.

ASSEMBLYWOMAN DOWNEY: That's what makes it more powerful coming from you.

So thank you.

MS. PARLES: Thank you.

ASSEMBLYWOMAN DOWNEY: I see that Marie Ruth -- you look like you finally figured out how to unmute yourself.

Hello and welcome.

MARIE RUTH WARGNYE: Thank you so much for having me.

I want to thank you, all of you, for giving me an opportunity that I didn't have for 20 years -- to at least speak. And I just heard all the people who came before me, and I am all broken again.

I thought I was alone; now I see that-- My blood pressure is very high, and I know I'm going to go through everything I've prepared to tell you.

I want to thank Paul Aronsohn, my Ombudsman, who, a few days ago, he made a miracle. It's because of him that I'm here today to talk about my child.

I was born in Cameroon, in Africa. After my parents passed away, I went into -- they sent me to France because my elder brother was a priest; and he passed away five years ago.

And I grew up in France, and I had my children. I have five children; and I lost my daughter in 2016, and it left me broken. My blood pressure, the stress-- And taking care of Christopher -- I went in 1999 -- I was married here -- to pick up my son to come here, because I thought that education and law -- that I would be protected here. Everything that I've been through -- my mother died in my arms; all my siblings passed away; and they sent me to France. And my children are my family.

So Christopher was born premature after 6 months pregnant because I have sickle-cell anemia. And they gave me transfusions that were no good because I have jaundice and gout. That's what I'm going through now.

And Christopher was choking in the womb after I was six months pregnant. That's why he was born early.

So I've been taking care of this child who was born at six months. I took him back to my home after two months, three months after incubating.

So I've been taking care of my child. Until I had to move to America -- with the problem with the family. And I thought that here I will be protected and my child will be protected. And today, after I heard all of you, I'm in despair. I knew that Paul did a miracle; he put me among you today. And I think that is the very (indiscernible) for all of us who have to hope that people -- I forgot her name; the lady who just spoke -- they're going to help us to put an end to the super sufferings, so much pain, so much heartbreak.

So Christopher is 34 years old; this is my baby (shows picture). This is my baby when he was born. And I, when I go to see him, he just likes to kiss me and jump on me. He plays Beethoven on his keyboard; he was taught. I just come here because I want him to be in a music therapy class. And when I went through everything I went through, then I went to see a doctor. A doctor told me that my blood pressure is very high and I'm going blind. So I had my son with me in the doctor's office, and they called DYFS. I didn't know what *DYFS* meant. They said they are an association that can help me while I'm going to hospital, because I'm alone, to take care of him. And after six months they're going to give me back my child.

He's 34 years old now. I can't even help him. They abused him. I don't want to go through it because of everything people were saying. I even heard somebody saying that he's from Willowglen Academy. This place -- I have people calling me to take my information; to take his disability, you know?

And they are abusing me and abusing my child. There were three times that I saved my child. I'm glad that he is still alive. One time I called my son and he told me, in French-- He speaks only French; and they speak to him in English -- when I called him, he said, "Mommy, my tooth is killing me." I took a (indiscernible); they put my son in Lafayette. I went there; I found, myself, my son on the floor burning with fever and I called them and said, “I’m taking my son to the hospital.” They said that DYFS said that if we go there, I’m not supposed to get close to my child. And she called the police on me. What did I do? The (indiscernible) -- they said they were going to help me. After six months, I ended up going through psychiatric evaluation. What was normally a psychiatrist was a social worker; a social worker said I was a narcissist. I am a narcissistic and I am crazy. And I have to go through another psychiatric evaluation to compare the social worker and the real psychiatrist.

I came here to you -- I’m a mother. I’m just a mother. I just lost my daughter and I lost my son. And I just want my baby. Please, anything to have my son back. His (indiscernible) made him -- they sent you a message that we call him Tiki; our Tiki. We want him back even in this condition that he is in now.

The day I went there, also, when a staff pushed him on the floor and broke his teeth -- I went there because (indiscernible) went to the room and took a belt. I never said that my son could be restrained. He’s not violent; he’s a pianist. He plays piano all the time.

And now we are here today, I’m going to tell you I wrote my story. Please, I have a 200 blood pressure; I cannot talk anymore.

ASSEMBLYWOMAN DOWNEY: No, no, I don’t want you to push too much.

I want to find out a little bit more about your story, though, because there are many little pieces here.

But you did speak to Paul? So Paul, maybe we can have another conversation too with you, okay? We’ll set something up, okay?

MS. WARGNYE: I appreciate that, because what I heard before reflected exactly what I've been going through -- but alone. I'm from Africa, my son is a French citizen. They took him away, and the judge mocked me. DYFS went to the judge; the first judge said that he doesn't see why he has to take my guardianship. DYFS took my file and went to another judge behind my back. They took my guardianship.

And when I reported abuse, I went -- I saw people with Christopher eating feces. And I cook; I'm a performer. I went there when I was alone; I went inside. I went there and I cooked for everybody.

One day they had a celebration for families. I performed for them. Christopher is a good pianist; they don't put him in school. Every time that I talked to the guardian he would tell me that they're going to take him to a music therapy class. Everything that they promised -- that he can come to visit me twice a month -- they don't even care. They mock me.

ASSEMBLYWOMAN DOWNEY: In the United States?

MS. WARGNYE: In New Jersey.

ASSEMBLYWOMAN DOWNEY: I just wanted to double check, because I lost that and I just wanted to make sure.

And I'm going to speak to Paul; we're going to get something set up -- okay? -- to talk more.

MS. WARGNYE: Because now I'm very troubled by the whole story, and I'm afraid for my child--

ASSEMBLYWOMAN DOWNEY: Yes.

MS. WARGNYE: --and I'm afraid because he's in a good (indiscernible) now.

I wrote to Paul and-- Excuse me; I am very traumatized by the story. And my blood pressure is 200.

ASSEMBLYWOMAN DOWNEY: No, that's why I want you to rest. Turn yourself on mute again. If you want to stay and just listen. Or if it's too much, don't feel like you have to stay on, okay?

MS. WARGNYE: Yes, because my friend, my neighbor, who is helping me, just discovered the situation. He didn't know that it exists -- that something like that exists in the United States of America,

I became a citizen. I did everything. I pay taxes, I do everything. I don't understand why they refuse to give me my child back. I want just to be able to go back to France with my child -- to his family. The day that I came and I saw my son had been abused -- the finger, the teeth; he lost so much weight. The people in the house eating the feces and eating in the garbage. And when they see me coming, they jumped on me. That's why now, since -- two weeks ago I went and they received me in the backyard. And it was the COVID virus gave them the opportunity to hide their vile action-- because they locked them in the house, they gave them medicine, and they didn't give them food. And when there was a storm, they locked them in the darkness with no electricity. There was water everywhere. And those people were locked in there without food.

So if they don't do anything in Willowglen Academy, in that group home, my son -- I don't want to lose my child. I don't want to lose my child. The people over there I saw, I don't want to give them-- I don't know if they have parents. My son is with four people; I never saw their parents.

I go there, I called the police, and when I called the police, they took the police aside and they told them that I'm not allowed to see my child. What did I do?

ASSEMBLYWOMAN DOWNEY: Yes, that's more about what I want to talk to you about too. So let's talk some more about this. We're going to get into all of the information. Like I said, we'll reach out to you. I will definitely set something up with Paul; okay, Paul? And so we'll reach out to you.

I'm going to go on to the next person, only because I want to hear everyone speak. But I really appreciate it, Marie. Please rest, okay?

MS. WARGNYE: I pray for you for what you did. You are helping families, you help us. God bless you; God will pay you. Everything goes around, comes around.

I want to thank Paul; Paul is a good person.

ASSEMBLYWOMAN DOWNEY: He is.

MS. WARGNYE: I've been here 20 years. This is the first time that somebody has even heard me.

So thank you.

I have a confession for all of you. I share your sorrow; we are all the same.

ASSEMBLYWOMAN DOWNEY: Yes.

MS. WARGNYE: Thank you for saving our children. I just want them to return my baby.

ASSEMBLYWOMAN DOWNEY: Thank you, Marie.

MS. WARGNYE: Thank you so much.

ASSEMBLYWOMAN DOWNEY: Thank you so much.

MS. WARGNYE: This is Christopher Amie Manga. And I never did anything wrong. I want him back, to go back home to France.

Thank you so much.

ASSEMBLYWOMAN DOWNEY: Thank you, Marie Ruth.

Okay; we have a lot of other people, and I'm sorry. So if you've not been called yet, it's not because-- There are a lot of people here.

So I'm going to call next Gwen Orlowski, Executive Director of Disability Rights New Jersey.

Hi, Gwen; thank you.

You're up. We're happy to have you here.

GWEN ORLOWSKI: Thank you so much.

I have some prepared written statements, which I'm going to read in a second, as written.

But I would be remiss not beginning by saying that as the Executive Director of Disability Rights New Jersey -- I've been in for just shy of two years now -- I would be inhuman not to be moved by the stories that we've heard here. They're incredibly compelling and heart-wrenching, and know that we -- our focus is solely on creating a system that creates an environment for individuals with disabilities that is safe; but also fully integrated into our society.

So with that, I'll begin my prepared remarks.

So thank you, Chairwoman Downey and members of the Committee, for inviting me to speak here today about the subject of abuse and neglect of individuals with disabilities.

Disability Rights New Jersey is the federally funded, designated protection and advocacy system for people with disabilities in the State of

New Jersey. A core function of a protection and advocacy agency, including Disability Rights New Jersey, is to have a regular, ongoing presence in settings for individuals to receive services, and to investigate instances of abuse and neglect wherever individuals may reside.

Our mission also includes advocating for the fullest measure of civil rights for individuals with disabilities.

Disability Rights New Jersey recognizes the prevalence of abuse and neglect among individuals with intellectual and developmental disabilities, and the vulnerability of individuals who are reliant on caregivers to attend to their most personal needs.

The Centers for Medicare and Medicaid Services intent in establishing the Home and Community-Based Services Settings final rule, is a bare minimum to ensure individual rights to privacy, dignity, and respect in all settings providing home and community-based services. And this poses a particular challenge to us, and to you, the Legislature, to find that balance between ensuring safety and preserving individual rights. But there are possibilities.

I want to digress from my written comments for one moment, because I can hear it running through a lot of what has been said today. Some of the focus of my comments are on using Medicaid as a funding source, and the Home and Community-Based Services Settings -- how critical that rule is. So that's in the context of when we fund services through Medicaid. I just want to be clear on that -- that when we're using Medicaid as the funding source, we are required to follow the rules that have been set up by the Federal government in a particular HCBS rule.

In order to prevent abuse, a comprehensive approach is needed. First, it is important that all individuals with disabilities are empowered to protect their rights and autonomy. Second, families and other support persons should be engaged in the care and treatment of individuals with disabilities. They need to be taught how to identify possible abuse, including physical markings such as bruises and changes in behaviors.

Investments are needed to build the confidence of direct support professionals in order for them to have the skills they need to provide high-quality supports that people with disabilities deserve. Investments also need to be put into effective supervision and coaching of direct support professionals.

Finally, service providers and families should develop collaborative relationships so that all involved in the care of individuals understand the needs of the individual, and work to develop and promote appropriate care plans using person-centered methods.

In 2018, the Office of the Inspector General, Office of Civil Rights, and the Administration on Community Living published a joint report and looked specifically at ensuring beneficiaries' health and safety in group homes through State implementation of comprehensive compliance oversight. These recommendations best reflect practices the State can take to address the abuse and neglect of individuals in group homes without sacrificing the privacy and dignity of individuals who require a higher level of support to live as independently as possible. And there's a citation to that report in my written testimony.

New Jersey is only a few years into the implementation of Stephen Komninos Law, which was established to reduce abuse and neglect, and address compliance, accountability, and cooperation with families. It is clear that protective measures have been more successful in reducing abuse and neglect, and we fully support the kinds of actions that explore quality home and community services that respect the individual rights of all.

Although there's been some discussion about using electronic monitoring devices in congregate living settings in an effort to prevent abuse and neglect, the use of EMVs in community settings does raise serious concerns related to potential civil rights violations, as well as other issues, that could lead to unintended consequences.

And here, Assemblywoman Downey, I would really love it if perhaps staff from our office could have an opportunity to talk with you more about that.

The CMS' HCBS final rule requires that providers receiving Medicaid HCBS funding support individuals with disabilities, then provide the opportunities and access to the community, and "ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint." Video cameras that monitor individuals' movements and activities in living quarters does have the potential to violate privacy of individuals. This is a real concern -- that the camera will impinge on privacy without preventing abuse or neglect. And it could also have implications under the Federal rules that need to be taken into consideration.

Disability Rights New Jersey understands and shares the desire to protect our most vulnerable citizens. Collaboration among State agencies, individuals with disabilities who would be most affected, families, and federally mandated DDF entities would be a good place to start exploring real and lasting prevention measures without sacrificing the privacy and dignity of those we're trying to protect.

Thank you again for allowing me to testify today, and I'd be happy to answer any questions that you have.

ASSEMBLYWOMAN DOWNEY: Thank you; thank you so much, Gwen. It is greatly appreciated.

And yes, we'll have more conversation.

MS. ORLOWSKI: Wonderful.

ASSEMBLYWOMAN DOWNEY: I have, next, Sharon Levine, Director of Governmental Affairs and Communications at the Arc of New Jersey.

Hi, Sharon.

SHARON LEVINE: Good afternoon, Chairwoman.

Thank you for allowing me the opportunity to speak, and for holding today's hearing. I greatly appreciate it.

So it's critical that, as we talk about abuse and neglect, a lot of the conversation focuses around our direct support professional workforce.

And I just want to take one moment to sort of recognize the exemplary efforts of this workforce during the COVID-19 pandemic.

Although we've always known it to be true, DSPs really shined during the COVID-19 shutdown. They cared for individuals with disabilities who had COVID, they acted as substitute family members when families couldn't come at the height of the crisis, and they put their own health and safety on the line -- and the health of their families -- by coming to work every day. And you'll have to remember that the work that DSPs do can't be done from six feet apart. It can't be done remotely. They perform critical tasks that are intimate in nature. And so I really just want to take one moment to commend them for the amazing work that they did.

I also want to just point out that during this terrible COVID crisis, while the long-term care facilities were really hit incredibly hard, both with cases and unfortunately deaths, our system -- you can look at the data -- although there were infections and, unfortunately, some deaths, the statistics show that our group home operators, our community providers, were really able to keep the numbers much lower than our long-term care facilities. And I believe that the credit to that goes to our DSPs and our community providers who worked so hard to protect people during this very difficult time.

In regards to potential abuse and neglect, we always want to ensure that the staff who are caring for some of our most vulnerable citizens are of the highest caliber, and that the services that these individuals receive is of the highest quality. As a society, as a system, and as a State, we should never, ever accept any acts of abuse or neglect. There must be a zero tolerance of any incident that falls into any one of those categories.

One act of abuse and neglect is one too many. But as the State and lawmakers, as you look to improve the system, you must do so in a way that roots out bad apples while also recognizing that bad apples do not represent the majority of the DSP workforce. Certainly, the system needs regulatory protections, and we do have a number of protections already in place. As the service model for people with I/DD shifted away from institutional settings with more of a focus on community living, the protocols for keeping people safe have increased and improved to reflect that need. Already in place in New Jersey is the Central Registry of Offenders against

Individuals with I/DD, which was spoken about, and which the Arc of New Jersey helped to spearhead and we support fully -- that anyone who commits an act of abuse and neglect is barred from any further employment in this field: Danielle's Law, Tara's Law, and, most recently, the Stephen Komninos Law.

However, one of the things I want to point out is none of those laws include appropriations for community provider organizations that employ DSPs. The best way to prevent abuse and neglect of people with I/DD is to appropriately fund the system and raise wages for our DSPs. DSPs handle everything from tasks of daily living, toileting, feeding, bathing, medication management, community integration. Their wages don't reflect the importance of their work.

We're grateful to the Governor, to this Legislature, for your support; the Department of Human Services for the recent budget that Governor Murphy signed, that included $40 million in State and Federal dollars, to raise DSP wages starting in January. That's a significant recognition of this workforce. And so was the temporary wage increase that began October 1, 2020, to reflect the extra danger that DSPs are facing in light of COVID.

But I would be remiss not to point out that DSP wages have been in need of an increase for many years, or that community providers are competing for the same pool of workers as the hiring manager at your local Target. And most importantly, that minimum wage is scheduled to increase every year on January 1 through 2024, but that law did not include a simultaneous wage increase for our DSPs.

So we've struggled to hire and retain staff because of low wages; and now entry level workers -- who are not responsible for things like pureeing meals for individuals who have oral motor problems, or administering medication, or helping someone in the shower -- are now guaranteed a wage bump, a minimum wage bump every January, and our DSPs are not. If the State values the lives of people with I/DD, we need to also value the staff and pay the staff who care for them. This will eliminate DSPs from needing to work multiple jobs, this will attract workers with a higher level of education, and this will keep employees from looking for something that pays better at the first chance they get.

Additionally, we must create a plan to put the DSP profession on a career path. This will help reduce the system's high turnover rates. And the State must also increase funding for additional training so that DSPs can continue to increase and grow their skills.

We must also take whatever steps are necessary to prevent abuse, certainly; but we cannot design a service delivery system that believes all DSPs are on a mission to do harm to people with I/DD.

Not included in my written testimony, but clearly from the stories we've heard today from the families, a lot of the stories shared with us today came from families who wanted to care for their children at home. And they did their very, very best, but they needed more help. And it's clear from the stories that we must increase community-based support for individuals who have the most significant behavioral challenges and dual diagnosis, which is an intellectual developmental disability and a mental health challenge. At the Arc of New Jersey we've long advocated for community-based mental health services for this population. And as you heard today, we need additional funding to increase the group homes or residential settings that are designed specifically to meet the needs of this sector of our population: the individuals with significant challenges, with extreme behavior challenges, with co-existing mental health challenges. And we need to have these unique group homes and residential settings staffed by DSPs who are uniquely trained to support individuals with these challenges. Funding for that will keep individuals and their families out of emergency rooms, and they will have fewer interactions and engagements with law enforcement. These families need more support, and that funding would help support them.

Unfortunately, mental health services for this population is not always readily available. There are long wait times; geography in the state plays a part of it. Sometimes you live in one area of the state and you have to travel two hours to see a provider with mental health services who is willing to help a person with intellectual and developmental disabilities. And so I would urge this Committee to look into ways to increase the number of mental health providers who can better support individuals with significant challenges, both behaviors and mental health challenges.

I just want to urge you to keep in mind that the majority of the workforce is dedicated and committed to those they serve. Not even a pandemic could keep DSPs from nursing sick individuals who were confirmed COVID back to health, or offering comfort when families could not be by their bedside.

As you move forward with next steps after today's hearing, please remember that DSPs risk their own lives, risk getting COVID. At the beginning of the crisis, they didn't necessarily have PPE, but they still showed up to work, and they supported people through a pretty horrid ordeal; and they genuinely do care.

So I just want to provide that perspective to this Committee, and I thank you for taking a look at this very important issue.

Thank you, Chairwoman.

ASSEMBLYWOMAN DOWNEY: Thank you, Sharon.

You know what? Some of these issues we were looking at before COVID, which we will get back to -- which is the career path to try to help to increase -- for DSPs' higher wages; more incentive for people who are better qualified and keep that consistency and constant workforce. That's so important for this community. So we'll still be looking at all that, and all the other things that you talked about -- like I said, I wrote down. And I know everybody else is doing the same here.

And I like how you talked about the mental health providers for the DD community. We also had been looking at and trying to develop -- find a better place here in New Jersey to be able to help with that. That got stalled, but we will definitely go back to that as well.

So we'll include you in on the conversation, and I'd really appreciate your support.

MS. LEVINE: Thank you, Chairwoman. I appreciate being included in the dialogue.

ASSEMBLYWOMAN DOWNEY: Thank you.

Next we have-- We're going to go to our provider panel. We only have, actually, one person. And then we're going to the experts' panel, because I know I see Dr. Spitalnik, who I love -- I know she's been hanging in there a long time -- sorry; and then more family members.

I just wanted to give you that, so you know you're not being forgotten.

Next we have Kathie Joyce-Medvitz from the New Jersey Institute for Disabilities.

Is she here?

KATHIE JOYCE-MEDVITZ: Hello, how are you?

ASSEMBLYWOMAN DOWNEY: Thank you for being here.

MS. JOYCE-MEDVITZ: Thank you for having me.

Yes; I'm Kathie Joyce-Medvitz from New Jersey Institute for Disabilities.

Good afternoon.

Thank you for giving us the opportunity to present some insights related to the care.

For more than 70 years, our Institute -- New Jersey Institute for Disabilities -- formerly known as the Cerebral Palsy Association of Middlesex County, which is headquartered in Edison -- has served people with disabilities throughout the state.

From humble beginnings in an abandoned garage, NJID has evolved and transformed to meet the needs of more than 1,500 infants, children, and adults with intellectual, developmental, and related disabilities.

The choices for adults with disabilities mirror choices available to all individuals. We at NJID use person-centered models to afford everyone the dignity and respect which they so rightfully deserve. We offer comprehensive programs to help adults with disabilities achieve fulfillment and individual success.

We recognize the uniqueness of every person and, therefore, we tailor our programs to those expectations of individuals and families. We design group homes and day programs with choices to help those individuals succeed and expand -- exceed their expectations.

At NJID a team of compassionate professionals with years of experience offers understanding, information, and guidance on the most appropriate and available options. NJID has helped hundreds of individuals and families make wise decisions about community living and participation through the successful transition of persons from developmental centers, family homes, residential schools, and other settings.

In our group homes, the person-centered design of each service extends beyond medical supervision and accommodations. Each person is encouraged to participate in home life, from meal planning and preparation to leisure activities and entertainment, in and outside of the home. In our services we develop a family-like environment in our group homes, with usually just four individuals sharing the home, sharing meals together, discovering ways for independence with the support of dedicated, skilled, and compassionate staff. We welcome family involvement, and we encourage it.

NJID day programs also provide small group instruction and activities. Individuals are encouraged to participate in advocacy activities and have unlimited opportunities to share opinions, discuss and learn about their individual rights, and question operations in order to improve services.

The heart of every program is the person-centered programs we have developed; and NJID invests a great deal of time and resources to assure that employees are educated, skilled, and supported as they assume their responsibilities.

Potential employees -- as mentioned by both Gwen and Sharon -- go through a lot of clearances through the State. We have our Department of Human Service clearance, a fingerprint check; potential employees go through the Medicaid Exclusion list; we go through CARI checks; Central Offenders Registry, which is vital; and of course drug screening. These are mandated throughout the State, and they are part of the pre-employment process.

Once hired, employees go through training -- comprehensive training, both on-site and through the College of Direct Support. These classes include the recognition and prevention of abuse, neglect, and exploitation; life-threatening emergencies, known as Danielle's Law; the Stephen Komninos Law. These courses include knowledge tests with a minimum base 80 percent competency to continue on with the training. These mandated courses are regularly reviewed at NJID through staff meetings, and annually through formal curriculum.

To further enhance employee knowledge and skill we provide trainings in communication styles and the importance of communication; understanding personal care, individualized personal care, positive behavior supports, disability etiquette, crisis management techniques, medication and healthcare administration training. We provide individual and program adaptive equipment training. We provide training on individual rights to all employees, and we also provide, among other things, dietary guidelines and mealtime strategies to individuals who will be working with our individuals in all settings.

Foundations of positive behavior supports is designed to provide tools for employees to work proactively with the individuals we serve. These strategies enable staff to teach functional skills to enhance the quality of life for the individuals whom we serve.

The education and strategies discussed in these courses are designed to prevent abuse and neglec, as they help the employees reduce resentment, and build skill, and teach proactive strategies and approaches.

In crisis training, a framework is provided for employees to recognize and give skills to intervene, when to step away, how to assist individuals to help them with their normal routines -- and sometimes return them to their normal routines.

Training emphasizes that the Direct Service Professional -- known as the *DSPs* -- know the individuals with whom they are working; recognize signs when help is needed, and remain calm and composed, which is fundamental to preventing abuse and neglect. These trainings, as I mentioned earlier, are provided annually. NJID provides employees all the tools necessary to be successful in their responsibilities as they become accustomed to their work and as they continue to work.

We advocate for and ensure that the rights of our individuals served are always protected. We have procedures and practices regarding human rights and dignity of all the individuals served. They've been written, adopted, and communicated to all of our employees through our organization's code of ethics and training.

Our policies ensure that individuals are protected from abuse and neglect. We recognize the need for incident management and review, as well as have established policies and procedures to provide consistent, prompt, and accurate reporting. This includes investigative processes.

The use of electronic health and incident reports expedites the processes and allows for a multi-level review process within hours of a reported event, which creates opportunity for immediate feedback and correction. There are clear expectations for staff to be involved and cooperate in all unusual incidents.

Here at NJID we refer to General Event Reports, and they are completed for all individuals who are involved in an accident, those who may have an injury and/or exposure to a blood-borne pathogen, which is required. Also, unusual incident reports are completed in compliance with the DDD New Jersey regulations, which many of you are familiar with.

All GERs are reviewed by our supervisory staff, the Quality Assurance staff; and upon entry of the event, the Incident Review Committee will review it on a monthly basis. The Committee will react to incidents with specific protocols and identify areas of additional training, if needed.

At NJID we have our Incident Review Committee. It's an established Committee of internal professionals, which includes our Executive Director, department directors, as well as RN supervisors and the compliance supervisor.

The purpose of the Committee is to proactively identify quality issues affecting individual rights, care, and satisfaction. We address any policy and procedural changes as needed, and we assess trends. We identify information and track that information for departmental use and improvement.

Behavioral events are also documented.

ASSEMBLYWOMAN DOWNEY: Kathie?

MS. JOYCE-MEDVITZ: Yes.

ASSEMBLYWOMAN DOWNEY: I appreciate that you're going into such great detail about all the things that they're doing, which is wonderful. Can you-- I mean, it sounds like you're doing a really amazing job over there, but I need, unfortunately, to make sure everyone gets to be able to talk today.

MS. JOYCE-MEDVITZ: Okay.

ASSEMBLYWOMAN DOWNEY: Can you-- I don't know if you have something you want to wrap up with, but we can always-- Did you have this in writing; like, did you submit testimony?

MS. JOYCE-MEDVITZ: Yes. When Anita contacted me, she sent me four questions, which is what we had answered. So yes, I have it in writing -- a prepared statement, yes.

ASSEMBLYWOMAN DOWNEY: Good. Can you send that to all of us on the Committee? Can you send it to me, and then we'll get it to everyone on the Committee? And then they can read the whole thing.

MS. JOYCE-MEDVITZ: Okay, sure.

ASSEMBLYWOMAN DOWNEY: That would be wonderful; I'd really appreciate that.

By the way, do they have cameras over there? I was just curious.

MS. JOYCE-MEDVITZ: We do not have cameras in our residential facilities; no. We have cameras on the outside of the premises; yes--

ASSEMBLYWOMAN DOWNEY: Okay.

MS. JOYCE-MEDVITZ: --but not on the interior.

ASSEMBLYWOMAN DOWNEY: All right; thanks Kathie; I really appreciate it.

MS. JOYCE-MEDVITZ: Okay.

ASSEMBLYWOMAN DOWNEY: Thanks.

And we have -- next I'm going to go--

All right; I'm going to go with you, Dr. Deborah Spitalnik.

Thanks for waiting so long. It's good to see you.

DEBORAH M. SPITALNIK, Ph.D.: Thank you.

And I don't consider it a *wait*. I feel that we're together here in bearing witness to the pain and the experiences of the families and individuals for whom we work.

So my thanks to you and the Committee for this invitation.

On a personal note, Chairwoman, as a breast cancer survivor, as the mother of a young breast cancer patient, I thank you for extending the auspice of the Committee to all our human concerns.

I'm here today in my role as Director of the Boggs Center on Developmental Disabilities, New Jersey's federally designated University Center for Excellence under the Developmental Disabilities Act, the same Act that authorizes Disability Rights New Jersey and the Council. And we are grounded in the Federal legislation -- and I hope all move forward by it -- which does, unfortunately, as circumstances today have been spoken about, recognize that individuals with developmental disabilities are at greater risk than the general population in terms of abuse, neglect, and the violation of their legal and human rights.

It also recognizes the importance of individuals and their families being involved in the design of services, and in the determination of the course of their lives; and the recognition that people do not have access to adequate supports.

As you move forward in thinking about remedies to ensure the safety, well-being, and full participation of people, I would urge the Committee to be thinking -- even though the vulnerabilities may be transcendent by age, by specific diagnosis -- there are differences between systems: those systems that serve children, and how they're organized; and those that serve young adults and adults in their maturity.

In addressing the issue of prevention, I'd like to offer three interconnected strategies for our consideration.

One, developing a culture of empowerment, respect, and dignity for the lives of people with disabilities as active members of their community; two, addressing the crisis in the direct support workforce that our colleagues from the Arc have spoken to so forcefully; and the role of the Federal Home and Community Based Services Settings Rule.

As we realize our commitment to preventing abuse, all of these strategies rest upon having a competent direct support workforce.

So first, speaking about creating a culture of empowerment and dignity. These are not just words; they have a base -- this has a basis, both in our commitment to people with disabilities; and in, really, an evidence base of experience, of research about the effects of isolation, and, in effect, disempowerment. And I'll refer locally to the experience of Dr. Nancy Razza, former adjunct faculty member at the Boggs Center, Director of Clinical Services at the Arc of Monmouth -- an expert in people with intellectual disabilities and co-occurring mental health disorders. And I quote Dr. Razza's words that capture our experience.

"Settings don't create safety. People create safety, and people create the lack of it." And that, "Each and every interaction teaches empowerment or disempowerment; that we are valued or devalued."

And this applies, of course, to people with disabilities, but it also applies to staff and the importance of assuring a qualified, competent workforce. Not only one that is recognized financially so people can live their lives -- to have health care for themselves and their families, where abuse is rooted out through the Registry that Sharon Levine spoke about -- but the importance of having a trained work staff. A competent, qualified workforce is essential in preventing abuse and neglect, and assuring that people have the high quality, stable supports that they need. The President's Committee on People with Intellectual Disabilities -- which I had the honor of chairing at some point, and serving on -- has recognized many of the things that have been enumerated before: the growing demand for services, the competition for direct workforce, fewer people on the staff, lack of access to salary, the stress of providing care to people who have needs, insufficient preparation of people.

And Chairwoman Downey, I know that you have been focusing your attentions, also broadly, on the issue of workforce. The importance of this is embedded in Medicaid policy; and Gwen Orlowski reported, in her testimony, that we are funding services through Medicaid. And there's a toolkit for State Medicaid agencies. We need to have a set of core competencies. We need to support providers in having the resources and the time to help people do that -- not the least of which is the understanding and the ability of providers to work with families. And as Lisa Parles spoke about, recognizing family members as part of the team. The need for transparency.

We also need to -- and this is the third element I want to mention -- we need to implement the Home and Community Based Services Settings Rule. We need to assure that people have a presence in their community; that they have connection to other people.

Some of this has been discussed -- in terms of having cameras, I know that comes from a place of deep caring and wanting to assure safety. Having moved into this field more than 40 years ago at the height of deinstitutionalization litigation, one of the things that we know is that abuse can be invisible. If we have cameras in public spaces, that doesn't prevent abuse in private spaces -- unless we support the workforce, and treat the workforce with the dignity that we need to demand from the workforce, that they make available to the people who we support.

I say to all of the families, as a family member with a serious mental illness myself, I know the fears of needing to rely on others for care. But the only way that we can keep people safe and thriving is to ensure that we have a competent workforce.

(addresses Ms. Wargnye in French)

I welcome this opportunity.

I thank you for even reflecting that you were keeping me waiting. It is a privilege to walk alongside families; it is our sacred responsibility. But we must meet that responsibility with the adequate resources to provide the kinds of services that keep people safe.

You, as the Human Services Committee, understand it as deeply as any of our elected representatives -- that this is a human enterprise, and we need to strengthen the ability of all of us to support people who have disabilities of any sort, particularly those who have the behavioral challenges that challenge us in terms of our ability to be patient, supportive, and assist individuals in learning and accessing their community, and exercising their gifts and capabilities.

Thank you for the privilege of being with all of you today. The Boggs Center stands ready to continue our role in building capacity for the full participation of all people with disabilities, from all backgrounds, with all languages, and in all parts of our state.

Thank you so much for the opportunity to be here, and for the work that we're collectively embarked on.

ASSEMBLYWOMAN DOWNEY: Thank you, Dr. Spitalnik; it's always a pleasure.

Thank you so much for everything you do.

MS. WARGNYE: *Merci beaucoup.* I am touched deeply.

Thank you so much.

ASSEMBLYWOMAN DOWNEY: Next, we have Bob Titus from the New Jersey Council on Developmental Disabilities.

And then we're going to go to the rest of our family members, okay?

ROBERT TITUS: Hi, everyone.

I'm Bob Titus. I work for the New Jersey Council on Developmental Disabilities, but I'm also a parent. My son, who is 37, is a group home resident.

I have some prepared remarks, and also just a few reflections.

I would be remiss, I think, to not mention and to thank again Assemblywoman Huttle for the Bill that established the Office of the Ombudsman, by which we have come to have the services of Paul Aronsohn.

New Jersey has had a long and checkered experience with congregate care for individuals with intellectual and developmental disabilities. The seriousness of this problem, and the barriers to safety and community that people with disabilities face, is also well documented. It deserves decisive and immediate action, and the Council thanks this Committee -- and you, Joann -- for convening this session.

Government must continue to recognize and guarantee the civil and human rights of individuals with intellectual and developmental disabilities. This includes advancing laws and regulations that provide individuals with the information, skills, opportunities, and supports to maintain meaningful, fulfilling, and productive lives, and to live free of abuse, neglect, financial, and sexual exploitation.

NJCDD believes that laws and regulations are the proper foundation for protecting these rights; but that State policy -- including enforcement and accountability, as well as staff supervision and training -- are equally essential. Individual and family concerns and needs must be heard and respected by legislative and administrative leaders, and given the highest degree of urgency.

Providers of congregate living must embrace the voices of individuals and their loved ones. Supports and services must be driven by individual needs with goal-oriented outcomes. There are many layers of complexity in ensuring the health, safety, and positive outcomes of individuals with I/DD. We support the provision of credentialing opportunities, career pathways, and ongoing competency-based training and mentoring, embedded in system policies and sufficiently funded for staff responsible for the well-being of those in congregate living.

And in this you're hearing the same -- we're part of the same course and the same urgency that has been expressed by Deb Spitalnik and others; by Gwen.

I did want to mention something else that really hit home to me that was said by Lisa Parles -- and that's the participation of family in parts of governance for places that do provide resident service, such as a Human Rights and Strategic Planning Committee. I've done it myself, and I do think it makes a huge difference in how the -- as it was put by Deb -- the culture of indignity and empowerment takes place in our community.

I do want to say, also, that the Council on Developmental Disabilities sponsors the Regional Family Support Planning Councils, of which there are many in New Jersey, to cover the entire state. And over the years and months, we've had a lot of reports of incidents reported in those Councils. These range from sexual assault and victimization of individuals, to the improper and unhealthy imposition of dietary neglect -- which I think we've heard in the testimony today -- as well as reports of loved ones suffering as a result of improper staff support, supervision, and oversight. Guardians have been subjected to threats and hostility to the point of being highly restricted from seeing their loved ones after complaining about poor living conditions. And this is pre-COVID I'm speaking of, not COVID. And we would hope that the government would not tolerate this activity, especially as it is a violation of State regulations and Federal law. It's been a topic of numerous visits with legislators; again, a reason why I'm very glad -- we're all very glad to take part in this discussion.

I have a number of points concerning prevention. I know a number of speakers today have spoken about prevention; the Council agrees with them wholeheartedly that this is the root of getting to solving many of the issues involved with abuse and neglect.

I'll just mention a number of them without getting into any detail.

Individualized services/planning/staff training. This, again, has been mentioned by the experts in the field who have been here; and has been also testified to in the negative, by the lack of that experience, from those who have had very negative experiences in the system.

Promote equality with a culture of respect and dignity. Again, Deb said it perfectly.

The need for transparency -- as many of us have said and believe.

Generic training considerations. And Bonnie Brien, earlier, mentioned the *five fatal training areas,* which are aspiration, bowel obstruction, dehydration, seizures, and infection/sepsis. These need to be mentioned, and really go into the same context as DSP compensation. Because our DSPs are not doing babysitting. And I know I'm speaking to the choir here. But as Sharon has said so eloquently, it needs to be said again, and again, and again, as we go forward in funding these DSPs.

Planning for action together, which we're doing here.

And then the values, which are values that were taught to us from our youth, and have to do with respect, and dignity, and the Golden Rule.

And then, one more time, I'll mention the Direct Support Professionals, who are so vital to this system.

That's what I have to say.

Thank you very much; again, I appreciate the invitation.

ASSEMBLYWOMAN DOWNEY: Thank you so much, Bob.

Always insightful, too; thank you so much. Thank you for being here and helping, as always.

MR. TITUS: Thank you; thanks all of you.

ASSEMBLYWOMAN DOWNEY: We have-- Next, I'm going to call on Brittany Bur and Cynthia Rowberg.

Now this is the rest of our family members.

BRITTANY BUR: Hi.

ASSEMBLYWOMAN DOWNEY: Hi; sorry for your wait, and thank you for staying and being here.

MS. BUR: Yes, of course.

So I'm here to speak about the abuse and neglect that my sister Ashley has experienced in multiple settings.

Ashley is total care; she's non-ambulatory. At this stage -- she went into a facility being able to eat and, like, totally enjoying her food, to now she's fed completely by tube. She's nonverbal, but she's very aware of what's going on around her and interacting through eye contact, the laughter, and smiles, and a few words here and there. Just this super bubbly, beautiful, loving person who has sustained at least 10 injuries -- physical injuries: multiple broken bones; a double fracture of her forearm; a black eye; missing tooth -- because, you know, a tooth just falls out of your mouth; a broken foot, broken finger, a broken hand. The list goes on and on, for which we have received zero explanation for any of these injuries. I mean, the going to the police -- I have a list here -- we've gone to the Division of Developmental Disabilities, the Department of Human Services, New Jersey Department of Health, Department of Consumer Affairs, a complaint to the Joint

Commission; a complaint to CMS, multiple police stations, multiple lawyers. Nobody wanted to help. If I hear one more time, "Oh, well, you know, these things just happen." No, these things do not just happen, and they should not just happen.

And it took us two-and-a-half years to finally get in touch with Paul Aronsohn, who was the first person to actually help and step up. And we finally moved her to a medical group home in February, like, two weeks before the coronavirus outbreak. And there she did not sustain any physical injuries, but-- Oh, she did get a burn on her arm; that's not true. But no broken bones.

But she was put into a coma because of medical malpractice, and we couldn't see her. It was torturous, to the point where my mother was beside herself saying, "At least a broken bone can heal. But I don't know that she'll come out of a coma." And that's just a position that no family member or human being should ever be in -- where your two options are broken bones or comas.

So finally Paul helped us move Ashley yet again. She just got in; that process took several months.

And, you know, this whole COVID-19 pandemic situation is like the perfect setup for abuse and neglect because families cannot be involved. We're not allowed in. And, you know, these cameras-- The fact that it's 2020; in a daycare -- my friend had a baby in 2011, and they had nanny cams in the daycare where she could just check on her baby. That's a vulnerable population; this is an even more vulnerable population. So this is just insanity. And if I hear one more time with the HIPAA, HIPAA -- like, no; things need to change.

So I'm also a licensed therapist, and so is my mother. We have a private practice. And I know I would like to connect with all of these family members, and really support each other, and try to be the change for our loved ones.

Thank you.

MS. ROWBERG: And I'm Ashley's mother; my name is Cynthia. I was a teacher for 32 years; I'm now in practice as a psychotherapist with my daughter Brittany.

And the overwhelming reason that I went into becoming a psychotherapist was because there was nobody who was helping the DD population, which we both have a lot of experience with. And Brittany was a special ed teacher prior to that. And nobody was working with the families. Nobody was helping navigate. And I hear the stories and I just want to say, you parents are just such warriors, and my heart goes out to each one of you. And I understand, and I can honestly say I understand the struggle.

Ashley actually is -- as Britney kind of gave you a little background -- she's very small. She's only 5 feet tall and 88 pounds. So she's not hard to move around. She really has sustained so much abuse on her body. We tried to work-- She was at Matheny School and Hospital for-- She was home for 17 years, and then her medical needs were overwhelming. And it was the safest thing to put her into -- what we thought -- Matheny.

It went well for a number of years. They had a changing of the guard at the top, and they changed the way everything was run and organized. And it was injury, after injury, after injury, after injury. And nobody-- What I have come to is that nobody truly cares about this population. I'm tired of words. Words are wonderful, but it's the actions that speak and really provide a change.

All of our lives are changed, but mostly Ashley's because of what she's endured.

Being put in a coma because a nurse from the medical group home forgot to call the doctor and tell them that her blood work was normal, and they continued to give her saline -- normal saline through her feeding tube for six days, even though we went and peeked through the window and said, "Something's wrong; call the Director of the place."

We tried to get nurses in there -- really, that I would pay for, to get her proper medical attention because her endocrinologist said, "We cannot send her to a hospital. We are at the height of COVID."

We ended up transporting her three hours away where there wasn't any COVID at that time. And the hospital said, "We are so outraged by the neglect. Look at your daughter's teeth." Her teeth hadn't been brushed; she had-- I don't know; this was early May, and she'd been there since February 19. Her teeth hadn't been brushed.

And we couldn't see her. What could we see peering through a window?

When they finally did go to draw her blood at the place -- she has gone from Matheny to Universal Institute Group Home, Medical Group Home -- they wanted to put a heat pack on her arm to draw up her veins. They put it in the microwave, didn't test it, and put it on her arm and had a second degree burn.

MS. BUR: This is not a practice that nurses use; and no one who we've spoken to, no medical professional, has ever heard of this.

MS. ROWBERG: Her toenail came off because they hadn't taken care of her personal hygiene. She did not have her diaper changed for 14 hours; sat in her excrement overnight and got a Stage 2 bed sore. This happened both at Matheny and at Universal.

Ashley cannot speak for herself. We are the only voices she has. I have written e-mails out the yayhoo to everyone. Brittany told you who we contacted. Paul Aronsohn didn't just listen; he heard us -- he heard us, and he helped. And he became -- he wasn't fearful of becoming involved.

I have lawyers who said, "Oh, no, we can't take the case because Matheny has deep pockets." Where is integrity? It took four months to get Ashley -- more than four months to get Ashley moved from Universal to now she's at Spectrum For Living in Closter. It took four months.

Do you want to know-- On a daily basis, "Oh, we're trying to change her Medicaid. We're trying to change this." It was not until I said, "I'm going to contact the media if this is not done at the end of the day," and I'm convinced that that's the only way to go.

Parents, please, I want you to contact me right now. I can help in some measure, even if it's just you being able to unload more of your story. But I feel that we will be empowered together; together is how we're going to make this change. United -- get this out there; get this into the mainstream media. What will it take, how many more deaths; how many more? We must work together.

This meeting is so important, and I thank Paul a thousand times over for involving us.

It's true. But my daughter -- 14 injuries, 10 at Matheny and 4 at the group home; 4. She's 88 pounds.

ASSEMBLYWOMAN DOWNEY: It's just -- it's incredible to hear these things, honestly.

Cynthia, thank you; and Brittany. And thanks for all that you do as well. And I think it's wonderful that you work now in the area, trying to help, so that families can get the kind of therapy and feel heard, like you were actually talking about. I think it's really important, so thank you.

I have to go on to some more family members, but we'll reach out to you as well, okay?

MS. ROWBERG: Thank you.

ASSEMBLYWOMAN DOWNEY: The next person we have is Denise Buzz.

Denise, are you here?

DENISE BUZZ: Thank you very much. So I can begin?

ASSEMBLYWOMAN DOWNEY: Yes. Thanks, Denise.

MS. BUZZ: First of all, I would like to thank you very much, Assemblywoman Downey, and Assemblywoman Huttle, who I have testified to before several years in the past.

And most specifically, as many of us have said, Ombudsman Paul Aronsohn for his tireless efforts; and again, Assemblywoman Huttle, for passing legislation that brought him on. He has been a godsend to our community.

I also want to applaud Sharon Levine for her invaluable testimony. I staunchly support every word that she said.

My parents were exemplars for the perfect way to love a child who was not their own. In September 1962, my parents took in a 5-

day-old infant who had been born in a charity clinic and abandoned by her birth mother. She wasn't even given a name until almost a year later.

Because she was so tiny, we named her Penny. A year later, she was legally named Angelique Colt. At 2 months old, my parents noticed that she was not responding to light and she was not reaching the activity level that a two-month-old should be doing. She was sweet and lovable, but silent. They took her to a New Jersey State neurologist whose examination concluded that she was neurologically half brain-dead. She was birthed with forceps in the charity clinic.

And he told my parents, and I quote: "She is blind, half brain-dead, and a vegetable. She'll probably not live very long; put her in an institution and forget about her." End quote.

My father was so enraged, my mother said that she had to hold him back. He came home and he sat us all down and he said there was no way that they were possibly going to abandon this sweet baby girl to such a horrible fate.

My parents decided to make her family. She developed sight at 3 years old, she spoke her first word at 6 years old, and the rest is history. Today, at 58, she is not only not a vegetable, she has developed a limitless vocabulary; she has activities that she loves to do.

For 14 years, she attended a private shelter workshop where she completed assembly work. She helped with roll call because she knew every single person's name in that program whether they had been there for a year or 14 years. She would proudly bring home her bi-weekly paycheck at $2.50 -- yes, $2.50 -- but to her it was riches. She called it *sa-cents*, so she could buy ice cream that she loved so much when we would go out.

For 45 years, Penny lived a wonderful and happy life; even after my father passed away, my mother continued to care for her in spite of tremendous odds and challenges presented to her through DDD.

I am sure that the stress that was caused to my mother resulted in the first of her series of strokes. She had her first stroke in 2000. We thought we were doing something good for both of them, and after investigating five group homes, we decided on the Roselle House in Millville, which would be ideal because it was only fifteen minutes from where my mother lived in Williamstown. It would give my mother the necessary respite to recuperate, and it was also close enough that she could bring Penny home on weekends, which was good for both of them.

It was a year of hell. My mother was hounded by the house staff to keep sending Penny back to them -- not for any other reason than they were worried about losing her SSI checks. The year of hell resulted in Penny being hospitalized not once, but twice, with critical urinary tract infections; countless calls from the house in the daycare program, Parents and Friends Association in Vineland, that they were basically trying to cover up their neglect. We had to provide new wheelchair seating because it reeked of urine. She would come home weekend after weekend reeking of urine. We had to replace her chair pad several times throughout that year.

They complained about everything, and yet when we showed up unannounced at both the house and the daycare program, twice we found her being isolated, put away, and the staff said that she was quote-unquote, “acting up.” In the 14 years she attended the shelter workshop she never once was punished for acting up. She never acted up.

The year of 2000 ended in her leg being broken, which began a series of lies and denials on the part of the Roselle House staff, and DDD approving a completely erroneous incident report. They refused to provide quality rehabilitation therapy. They lied about the circumstances of her so-called accident, which the hospital emergency room and an independent orthopedic specialist's examination testimony refuted.

After a five-year legal battle -- a torturous five-year legal battle -- it resulted in an unsatisfactory out-of-court settlement. That was in 2005.

Over the 17 years of fighting for every cent that DDD had to relent to provide, I believe that we had turned a corner when she was assessed with an NJ CAT Survey and allotted an annual sum that could truly help her. And since 2017, DDD has denied her full access to her complete budget.

Even though Penny survived the physical abuse, she continues to be a victim of a system that relies on underqualified and unqualified administrators and providers -- who are often there for their own personal economy, and not the person-centered services that they are supposed to provide to guarantee the health and safety of these special souls to whose care is entrusted to them.

Regional and State level bureaucrats have never met her, never seen her, can't be bothered to meet her, don't know her story, don't know me, can't be bothered to consider the lifetime of care and love and devotion my parents and myself have shown this amazing young woman. Because of certain bureaucracies, deliberate denials, and delay, her leg is permanently damaged, and their attitude is, *what difference does it make, she's in a wheelchair.*

The difference is that she can no longer comfortably sit in her wheelchair for more than four hours. We cannot find a daycare program that will take her because they cannot take her to relieve herself; she would come home in wet diapers. We cannot take her to many of the places she loved to go on daily outings because we have a time limit that we have to get back so that she can use the bedpan.

She has never, before or since she was in the Roselle House, wet herself, because she knows how to ask to use the pot. She has been reduced to being a semi-invalid, which she is not. Her quality of life has been permanently and irrevocably ruined. Every effort I make to ensure her safety and wellbeing, DDD denies and keeps changing the reasons and rules for the denial. They continue to punish her because they don't like my outspokenness and my fierce advocacy.

My sister, as a survivor-- She survived because we brought her home, and kept her home, and loved and protected her. My mother has since passed away. It is my sincere hope that she will live out her days in her home with her DSPs -- who are absolutely fantastic. Again, Sharon Levine is right on the money.

However, she continues to be a victim of bureaucracy that seems to want to deny responsibility for the quality of her care and the quality of her life. And I've heard far too many horror stories -- the stories that we've heard today -- of disabled individuals who live wonderful lives with their parents and their family, and if they outlive their family they were consigned to facilities whose philosophy is that staff are not supposed to get emotionally involved. And they hide behind this wall of indifference and deliberately dismiss the humanity of these beautiful souls.

Many of these souls too soon die of neglect, physical abuse, or simply a broken heart. It's a nightmare that each family member who cherishes their special loved one lives with. I know it's a nightmare I live with every day. And nothing is going to change unless, first and foremost, our elected representatives -- who we rely on to shepherd our tax money to care for those less fortunate -- change the perception and attitude, and see these beautiful souls as having the very same rights as everyone else.

I echo other family members: Actions speak louder than words. While I am grateful -- I can't tell you how grateful I am for this opportunity to speak -- we need this to translate into significant action. Nothing will change until all humans' hearts change; their attitude and perception of these beautiful souls change.

I just want to close with-- President Barack Obama was speaking in Philadelphia a couple days ago, and he said that, "Hope is not simply a matter of blind optimism and then blithely ignoring what the problems are." We cannot ignore the problems of this institutional and systematic abuse and neglect of our loved ones. He went on to say that, "Hope is believing that in the face of difficulty that we can make things better." We can take the long hard look, we can admit the problems that we have, and we can take specific steps to change them.

I will continue to devote my life, my effort, and my fierce advocacy for guaranteeing my sister's rights, and I look forward to more significant action in that direction.

Thank you for your time.

ASSEMBLYWOMAN DOWNEY: Absolutely.

I want to say, Penny is extremely lucky to have you, that's for sure. And to have had her mom and dad. Your parents were amazing people.

MS. BUZZ: Well, thank you Assemblywoman Downey. And I hear that a lot, but it sometimes doesn't help when I'm asking for things that she is eligible for, that she's denied. It makes it really tough sometimes.

ASSEMBLYWOMAN DOWNEY: And I don't understand that, so I want to look into that. And I'm going to speak to Paul, I'm going to speak to a couple other people about the things you were talking about, okay?

MS. BUZZ: I appreciate it, thank you.

ASSEMBLYWOMAN DOWNEY: Thanks, Denise. And we'll reach out to you as well, okay?

MS. BUZZ: Thank you.

ASSEMBLYWOMAN DOWNEY: Next I have Gerard Redmond.

GERARD REDMOND: How are you doing?

I originally came on here just to speak about one brother, but being two heads of two major organizations came out to speak about their organizations, I feel like I should speak about my other one.

I am the sibling of two disabled adults. One who I wasn't going to speak about, who is in an NJID group home in north Jersey -- I won't say what group home. And she brought up the fact that they don't have cameras in their common areas yet. I'm sure by now she knows who I am. I find that-- for some reason, I find that very hard to believe, considering what happened to my brother and other people in that group home. And it had nothing to do with the staff.

A couple years back, my sister received a call from a parent about her daughter in this group home who was very upset, very afraid because they had put a new resident in there who had a tendency to have mood swings. It was caused by his disability, not, you know-- He didn't do it on purpose. And that they put fences up all the way around it. They asked me if I'd go over and look because they didn't feel it was safe. I went over and looked just to make sure that if there was a fire they could get out, and in the back they had the proper hardware on the doors and everything. As I had in the past, I had gone in there unannounced; the group home was always clean, staff was always wonderful.

Fast forward now a couple weeks-- I'm going to do (indiscernible) because I want to hit on both brothers. A staff member called -- I believe it was a staff member, I don't want to say it was a staff member -- my sister and said that our brother had been physically assaulted a few times by this resident, and that's when we reported it. I believe I myself -- she could correct me if I'm wrong -- I went before this review committee and we brought it up, and their story and what we were being told happened to my brother -- our brother -- were basically two entirely different things.

And when I left that meeting I said it would never happen again. Well, it did. After going through this, we had to have another meeting, and back and forth, and-- They were sort of hard-nosed about this one resident in there. Then finally the State came to somewhat of an agreement -- I don't know what it is because of different rules and regulations I'm not allowed to know -- everything was worked out.

But to me, if they had cameras in that common area, there would never have been a question of what was happening to my brother. My brother was non-verbal; he can't get out of the way when someone is going to be physically violent to him, and when I asked if they were taking him to the hospital, they said no, he had no bruises on him. But how do you know it's not affecting him mentally?

But anyway, he's still in the group home, and everything is going fine, and the staff is excellent. And because of COVID-- Which gets me to the next part. The reason I haven't seen my brother all summer, until Sunday -- the reason I saw him Sunday, was at my other brother's wake.

Which brings me to this part-- I'm sorry. It would have been easier if I didn't have to bring Joseph up. He was in another group home which is run by Sharon Levine, who paints an extremely rosy picture about things. He's been in an Arc group home -- I'm just using their names because they were both on here -- for over 20 years.

And in that 20 years, they've called him the mayor of The Arc, they gave him an award one time where the family and friends he grew up with packed the room to help raise money for him at $100 and some-odd dollars a plate. Everything was fine. They always promised that he would be there forever. And I believed them. And my parents believed them.

Then, on June 22, he came down with pneumonia and he had to go to the hospital. I went over to the hospital and obviously they wouldn't let me in because of COVID, and we couldn't get anybody in there. So we couldn't see him.

So here he was, he's 60 years old, down syndrome, he's going through dementia, and he's locked away from everybody he knows -- including the staff of the group home. Which is also very good, by the way. Never had a problem with staff.

He was in there for about a week -- six days -- but because nobody in there knew how he was and everything -- he was having a hard time getting up to walk, so they decided to send him to rehab. So they sent him over to a rehab-slash-nursing home over in Manchester.

Well, for the first 14 days, the only time I could see him was by banging on a window. And then we couldn't see him at all, because they moved him to-- After 14 days they moved him to another floor -- which I couldn't see him, and you had to wait until they would bring him outside.

But even after he was moved to that floor it was another 14 days I couldn't see him, because he was still in isolation from everybody because he came from the COVID floor, even though he had (*sic*) COVID. We were all able to see him for 15 minutes at a time outside. He was just going down further and further. It got time for us-- We were trying to get him back into his group home, and all of a sudden they informed us he can't go back there because he's not walking.

Now, in the nursing home, we were trying to get him physical therapy, but the Federal Government -- after so many weeks -- turned us down twice. We even offered to pay for it and send a physical therapist in there; we were not allowed.

We were going back and forth thinking that The Arc was going to help us because they always promised us he'd have a home. Then -- I forget the date here -- in a meeting, it was on a Friday, they informed us he's not coming back because the group home is only for ambulatory and he is not ambulatory. Which, alright, we can understand that. But they always promised and they always said they had other things. But then they said there was no place in any Arc for him to go -- which turns out, in the end, not true -- and that we wouldn't be able to place him anywhere in the state because of COVID.

That's when I reached out to Paul.

Going back and forth -- I don't know how it all happened -- finally, between The Arc in Ocean and The Arc in Monmouth, The Arc in Monmouth found a placement for him. In that time, he came down with pneumonia again and was placed back in the hospital.

Now, here we are. We're trying to get him out, and we knew we couldn't send him back to where he was, because we knew he wouldn't be able to get physical therapy; so we were able to get him moved over to a rehab center in Eatontown and we knew we could get physical therapists in there -- either through them or through private physical therapists.

But by the time he got there, he had deteriorated, his lungs filled up so much that the last time I saw him, October 13, the doctors and my sisters and all just decided it was time to let him go.

ASSEMBLYWOMAN DOWNEY: I'm so sorry.

MR. REDMOND: That's basically it. I said I didn't want to talk about Joe, but Matt was something-- He was always outgoing. At his wake, even during COVID, we had people coming that grew up with him; and even people from the Ocean Arc and the Monmouth Arc. I couldn't even tell you, the room was packed. He was the life of the party wherever he was. And he died homeless.

And it was because of bureaucracy, it wasn't because of anything else. But, to be told-- And I'm not picking on either one of the organizations. Both organizations were great, and both their homes were clean, and every place he's ever been with The Arc was fine.

That's why I decided to go on this. It's a little early for me to go on it because we just buried him Monday.

But not to take up everybody's time-- I don't know.

ASSEMBLYWOMAN DOWNEY: No, it's truly--

MR. REDMOND: They should put cameras in the common areas, not so much-- Because what happened to my brother Joe, it would never have been a question of what happened if there was a camera in that common area.

And I agree with the one woman who said the cameras should be monitored. Yes, they have to be monitored. The families-- I personally believe the family shouldn't have 24/7 access to the cameras, but if something happens they should be allowed to see the footage of what happened. The common areas are very important -- not just outside the buildings, the common areas inside. Like kitchens, hallways, living rooms. This way if anything happens, it protects both the staff and the resident.

ASSEMBLYWOMAN DOWNEY: Gerard, I appreciate that.

That's actually what the Bill provides, so I appreciate that.

Thank you so much.

MR. REDMOND: I don't want to take up too much of your time, but that's--

ASSEMBLYWOMAN DOWNEY: I wish-- I mean, we have a little more time and we're trying to give everybody time to speak; and we could speak on and on, I'm sure, with everybody, because the circumstances are just so important. But you know, I want to make sure everybody gets a chance.

But I really do appreciate you being on here and sharing.

Thank you for understanding more, too, about-- Like you said, the problems within the system. We need to know that so we can fix--

MR. REDMOND: Yes, it's not the staff. The staffs are excellent in both places.

ASSEMBLYWOMAN DOWNEY: That's great, that's good to know though.

Thank you.

MR. REDMOND: Thank you.

ASSEMBLYWOMAN DOWNEY: And then we have, next, Jennifer Sue Worley.

JENNIFER SUE WORLEY: Yes, I'm here.

ASSEMBLYWOMAN DOWNEY: Hi, Jennifer.

MS. WORLEY: Hi.

I sort of have a different situation to bring up. I now have my daughter home in an apartment setup with staff that I hire. But her history is very troubling.

She's suffered abuse at New Jersey State licensed group homes. My daughter has 84 Unusual Incident Reports. And we, as legal guardians, have been refused access to them by DDD and the State of New Jersey.

I have called the Governor, I have called DDD; no one will let me see those reports unless I get a court order. And they said if I do get a court order, they will appoint a deputy to represent the State against me. So that, to me, is a threat.

One of those UIR dates corresponds with a CT scan of her head that I found this week. We do not know what happened. Why did she have a CT scan of her head? These UIR reports also include non-consensual sexual contact. None of these incidents were reported to the police or to us as guardians -- we sought out to see those reports.

In all the group homes she's been in -- and there were seven -- she did not receive treatment for medical conditions or psychiatric conditions. She was declared incompetent and incapacitated, but we were not given any rights as to how she was treated.

DDD represented us. Our case manager and her supervisor told us that as medical guardians, we could not protect Elizabeth or have any input into her behavior. We even refused to sign an IHP in protest. This group home called in New Jersey Disability Rights to attempt to remove us as guardians. They actively built a case against us, and yet we are still her guardians.

There was a clinical specialist in the day program who did not report Elizabeth telling her about multiple rapes by members; or the man that was in that meeting -- contrary to HIPAA -- that said he was glad she was being raped because if the other guys weren't doing it, he would. And then he went into great detail about how he would rape my daughter. And this was never reported to the police. Paul Aronsohn has seen this document.

Over 60 times, Elizabeth was either transported to a male group home or men were brought into her group home for sexual activity in company vans. Elizabeth suffered-- This group home allowed her to lose weight, down to 103 pounds, without ever notifying the guardians. They kept us away.

They lied to us that she had been seeing doctors. But now we have letters from the doctors that they had never seen Elizabeth. She now has half of her teeth. Her arm was broken in Bellwether by a staff member, and it was never reported to police. Her arm is now weak for the rest of her life.

She was beaten by another staff member in 2016, but it was never reported to the police, and we now have hospital records. Elizabeth has been repeatedly raped. Two doctors recorded her statements in writing -- a day program doctor and a psychiatrist that comes to the day program. It was never reported to the police.

She has had many pregnancy tests. I don't know what happened. She has had tests for HIV, gonorrhea, and syphilis.

DDD lied to us about other housing options. They never disclosed to us the self-direct program. DDD then put her into Bellwether, after investigations were already underway regarding abuse, neglect, and death.

She ended up in the hospital for three months. Then DDD, instead of allowing us to take her and put her in a hotel -- which I heard some other parents say they were allowed -- convinced CAU to take Elizabeth, after they had originally refused her. But DDD convinced them.

They were not a proper placement for Elizabeth, and Elizabeth was further traumatized. CAU gave her the wrong medicine and argued with me on the phone about giving her the right medicine. (indiscernible) belonging to another client when we removed Elizabeth.

Elizabeth was beaten in Conant Park on July 14th by a staff member on her first day on the job. She was not qualified to deal with my daughter. CAU staff lied to the responding police officers, saying that the guardian wanted her taken to Trinitas Psychiatric. I had not even been notified.

Elizabeth was treated at Overlook Hospital the next day for a sprained shoulder, sprained wrist, cuts, and bruises. But the pain medication given to her was never filled until four days later. They returned Elizabeth's personal belongings; not all of them.

CAU allowed her access to scissors and glass. This was directly against her NJISP. Elizabeth locked herself in a bathroom and cut off all of her hair. She was not allowed to be near scissors or sharp objects.

CAU took her to Overlook Hospital for treatment, without advising me. I found out -- this was another instance -- by email from the hospital. I called them and said, "what are you talking about, I don't know that my daughter was in your hospital." I've gotten a letter of apology from Overlook.

Incidents that I reported to DDD have been marked *unsubstantiated*, when I personally heard the incident on the phone or was involved. CAU gave me the medicine belonging to another client when we went to remove Elizabeth.

Very important: The rights and responsibility are not totally applicable to individuals who have been declared incompetent by the court. DDD uses it against the safety of the clients and against parents.

I now add an addendum to the form stating what rights Elizabeth cannot exercise since she has guardians. Elizabeth now suffers from PTSD and serious psychiatric issues, and she refuses to eat. Her body is weak, and she has trouble functioning daily. Elizabeth is now in crisis.

She was in group homes. She has not had one incident since we brought her home 14 months ago into her own apartment. We have cameras. We have cameras, and we have video, we have audio, and I can talk to Elizabeth through the cameras. If she's upset, I can calm her down. It is just such a good option for parents, and DDD is keeping it under the wraps; that they will not tell parents that this is an option.

I just think that cameras are so important, but DDD cannot have control of those tapes. The Bill says DDD can access the tapes, it does not say guardians can. So we have to do more -- for Elizabeth and for all these other kids.

And that's about what I have to say. But there's a lack of training, and my girls who I hire are not the quality of what they had in the group homes. The group home staff, all they had was a driver's license and *maybe* a high school diploma. They were untrained.

But that's it.

ASSEMBLYWOMAN DOWNEY: I'm sorry. I am reeling with all of this, just listening to your testimony regarding your poor daughter.

Honestly, I don't even know-- I can't even say anything, this is just unbelievable.

MS. WORLEY: I had begged DDD for help, and DDD does not do anything. And she can hardly walk. She can't eat because she doesn't have teeth -- they allowed her to refuse to brush her teeth, refuse to shower.

These group homes are out of control.

ASSEMBLYWOMAN DOWNEY: Well, we're definitely going to talk to DDD about it. They were supposed to be here, but they submitted testimony that I think is available. I'll just double check, but I'm pretty positive that-- I know that DCF submitted testimony.

Anita, if you can just let me know for sure whether DDD submitted testimony too. But any testimony that was submitted -- written testimony -- can be available to the public. Just request it from people here, from OLS.

MS. WORLEY: This is group homes-- And now I want to show you, this is how she walks now. She can't even straighten up. Her arm is in a claw.

ASSEMBLYWOMAN DOWNEY: I can see it, now, yes.

MS. WORLEY: She can't even straighten up to walk. What happened to her? 84 incident reports. I need to know what happened.

ASSEMBLYWOMAN DOWNEY: We're going to look into it. Again, I'm going to speak to a few people, too. We're going to get ahold of you, too, Jennifer, okay?

ASSEMBLYWOMAN HUTTLE: Chairwoman, can I interject for one second? I know we're going to take questions later, but on the record, you said DCF and DHS has provided testimony. I would, for the record, ask you to submit each and every one of the testimonies we heard today to go back to DHS and DDD.

They have to hear this, whether they are listening online or not. I want this transcribed and I want them to hear it, and I want answers.

ASSEMBLYWOMAN DOWNEY: Absolutely. Absolutely.

Because they should be here to be able to talk about it, and they're not here to talk about it, so they need to provide answers.

Thank you Assemblywoman.

I know other people need to share their stories, but I want to thank you, Jennifer. You're amazing. Hang in there.

MS. WORLEY: We will.

ASSEMBLYWOMAN DOWNEY: You're incredible. We're going to get to the bottom of all of this, okay?

MS. WORLEY: Yes.

ASSEMBLYWOMAN DOWNEY: All right. The next person we have is Alexandra Lusardi.

ALEXANDRA LUSARDI: Yes, I submitted a written testimony. And I-- To tell you the truth, I mean, after listening to all these stories, I feel that I'm not alone. But it's very hard, because I'm still going through it.

My daughter has been in and out of the hospital for the past three years. I just want to thank Paul for inviting me to this, because it has opened my eyes to the widespread neglect -- that I was thinking that I was going through such difficult times and that there was nobody else going through this.

And I'm too emotional right now, and I told this to the person who invited me -- right now I can't remember her name -- that I get too emotional because I'm going through it right now.

But I really thank you for everything you're doing. And I really cannot go on because I'm too emotional. Thank you.

ASSEMBLYWOMAN DOWNEY: I'm glad you submitted some written testimony. I'll make sure everyone gets it on the Committee.

MS. LUSARDI: Thank you.

And I'm really sorry, and after all this, I didn't even think you were going to call on me.

ASSEMBLYWOMAN DOWNEY: No, we want to hear from everybody. I'm going until they cut me off, because I want to hear from everybody. I think it's important.

MS. LUSARDI: But thank you for everything you're doing. I pray for all of us, all of you. Thank you.

I mean, right now, one of the things that is going on-- My daughter is in Long Branch, and they want to send her to a group home, but due to COVID there's no visiting in this group home. And I cannot agree to that.

ASSEMBLYWOMAN DOWNEY: Where is she right now?

MS. LUSARDI: She's in Long Branch Hospital -- Monmouth Medical Center. And I was hoping-- They had told me there was a group home in Mercer County, where I live, by the Arc of New Jersey. But apparently that group home is not ready, and they are suggesting a group home in Piscataway; but you know, we cannot visit because of COVID.

I don't understand, I don't understand what's going on. I mean, this opened my eyes that I really want to ask. Tomorrow we have a Zoom meeting with the hospital, and I really want to ask that. I want to be able to visit, like somebody said, at least outside, and to be able to accompany my daughter to medical visits, etcetera.

Thank you for doing this and thank you for inviting me.

Thank you.

ASSEMBLYWOMAN DOWNEY: I'm sorry. I know we don't know the details, but I really am sorry for what you're going through.

I'm going to read what you've submitted.

MS. LUSARDI: Please.

ASSEMBLYWOMAN DOWNEY: I'm sure the rest of the members will do the same.

And just so everyone else knows, I just did confirm that DDD did submit written testimony, so anyone who wants a copy of that can get a copy of that.

We're still going to have to listen to everything here today, and get all the testimony submitted as well.

MS. LUSARDI: Is it possible to also access what happened today?

ASSEMBLYWOMAN DOWNEY: Yes, it's recorded.

MS. LUSARDI: Oh, it will be recorded, okay. But not written?

ASSEMBLYWOMAN DOWNEY: It can be-- Well, we're asking for it to be transcribed.

I'm not sure if it's available for everyone transcribed, so I can find out for you. We'll get that information to you, okay?

MS. LUSARDI: That would be helpful. Thank you.

ASSEMBLYWOMAN DOWNEY: Absolutely.

So I'm going to call-- If you want to speak at some point, just let us know, Alexandra, just somehow let me know, okay?

MS. LUSARDI: Thank you, thank you.

ASSEMBLYWOMAN DOWNEY: I have next, also, Iris Rivera.

Hi, Iris.

IRIS RIVERA: Hello, how are you?

I'm an advocate from Passaic County, and I have a community group, The Passiac County Parents of Adults with Disabilities.

I came here today just to support the families, and I know it's a need in our community -- especially developmental disabilities -- and it's an issue.

I know one Spanish family -- and I thought she was going to be here participating, but I don't see her -- but what I can see and hear from the families-- I'm with you, families. Our voice, we're going to make sure our Governor hears our voice, and we have to be together in power.

And I see the system is broken, and we need to fix the system. And I just wanted-- Cameras are good; I know they can have some independency (*sic*) in the cameras, but also the administrators. We have different administrators -- we've got individual group homes, and we have facilitators that work in different associated group homes.

My suggestions to the Bill is to start beginning when an incident happens; the same way incidents in your house, in the store, and in the bakery-- They file a police report and they follow up. They need to be following an incident in any group home. They have to be (indiscernible) with an attorney because this isn't going with urgency, they've been doing this for years and nobody is investigating.

And we need to fix this. The same way you have major crime with a doctor, we're doing crime with Medicaid. The same way you do domestic violence, you have a unit. I would like to create a unit that (indiscernible) for developmental disability to follow up when an incident happens at a group home or other institution, because this has to be fixed.

This is the only thing that I can say today: Just support the family and advocate. And I don't see a lot of Spanish community here in the group either. Maybe something happened, and I need to raise that voice for the Spanish community, too. They need to find out we are here, and we are going to support them.

Thank you very much for your time. Have a good day.

ASSEMBLYWOMAN DOWNEY: Thank you very much, Iris.

We have, next, Nancy Page. I know you've been there for so long.

NANCY PAGE: That's okay, I appreciate the opportunity, I really do.

I agree also that it is not acceptable that DDD is not present, and I would love to hear how I can get a copy of their testimony. I'd love to hear that.

Again, my name is Nancy Page; I'm a mom, I'm a legal guardian to our daughter, Lauren Page. I am also a registered critical care nurse and I have a lot of experience being head of a nursing quality control program at a very large medical center in New Jersey, so I know good care when I see it; and it's very frustrating when I see there are problems identified and nothing -- very little -- is being done about it.

Lauren, just briefly, was born back in 1980. She turned 40 this year. Her developmental delays became pretty evident by the time she was 2, and pretty much spent all her education in special ed programs. By the time she was a teenager, there were signs of some impulse control and she was diagnosed as bi-polar, followed by many other mental illness diagnoses. There's quite a list, and actually none of them really seem to be correct. She does have neurological impairments from frontal lobe damage from birth, from forceps delivery, and she has developed seizures.

So she ended up spending high school in a neuro-rehab facility in New Hampshire, because New Jersey admitted they could not meet her needs at that time. She got a high school diploma, came back to New Jersey, and was moved directly to Advoserv group home. And she did pretty well there, I have to say. In the beginning they had consistent staff, they were very well-trained. Lauren's a very friendly, chatty girl, and was actually pretty happy there and had made a home there -- we did have her home every other weekend, and we kept seeing the same happy Lauren until about 2017; by then, Advoserv was then Bellwether.

At that point, we started seeing changes in Lauren; very anxious, very angry. We were having a lot of problems. Lauren has food allergies and those dietary needs were disregarded very frequently. And then also, too, her seizures -- she was not being treated by her doctor regularly for seizures, she wasn't taken to the doctor regularly, and they would treat her seizures with an EpiPen. And I happened to find that out because an EMS guy called me; he saw I was a guardian and wanted to say he had been at Lauren's home three times that week where staff had given her an EpiPen when clearly she was having a seizure.

Also, too, her dental care-- I was told she was going to the dentist. I could see her teeth were deteriorating, and although they claimed she went to the dentist every six months, it turns out, under investigation, she hadn't been in two years. So subsequently, she had about $17,000 worth of dental work after having some teeth pulled.

So what happened was, in March in 2017, Lauren had been moved to a home of all males, which could not have been-- It was probably one of the worst things -- not the worst -- but one of the worst things Bellwether did to her. She continued to deteriorate. Lauren would tell us things that we just couldn't believe were true. We would ask for explanations and of course they said Lauren was making it up.

In March of 2017 I got a phone call from the nurse at Bellwether that she was calling the police because Lauren would not sit and no one could understand why, and when the nurse investigated, her whole back and lower body was bruised. The nurse actually called the police herself and there was an investigation. Due to legal issues, I can't really get too far into that.

But in May, Lauren called us and said the night before a staff member had punched her in the eye and that she had gone to the hospital, has to have surgery. No one from Bellwether called me -- or her father, who is guardian -- and I drove to there. It's a two hour drive -- I was there in about an hour -- and I packed Lauren up and moved her out of Bellwether. And within a week or two, Lauren had surgery on that eye. They had a total blowout of an orbital bone and she required surgery, so now she has an implant supporting her eyeball.

Then Lauren was home. I had nowhere to put her. I actually, foolishly, thought DDD would step in and try to help us, knowing Lauren is not someone who would fare well at home with very little structure, no behavior program, no social outlet. We realized Lauren wasn't just angry anymore, so we took her to the doctor and she was quickly diagnosed with PTSD, and she had to undergo weeks of specialized therapy. During that therapy, apparently, it came out that Lauren had been sexually abused many times at Bellwether, and the therapist came out and told me that if I didn't take her to the police that she would. Again, that's another investigation.

Unfortunately, no one came to my rescue and it was very hard to take care of Lauren all day by myself, but I fought through the system and found that I could get something called a Support Coordinator. Well, my daughter hadn't lived at home for many years and this was all new to me, and it was obviously all new to the State of New Jersey. So by the time we got that set up, I quickly realized I was not offered any type of behavioral support in the home. My husband, who was starting to retire, had to stop working to help me take care of Lauren, because she's a big girl and when she gets upset she can be strong.

So with the dual-diagnosis, I tried to find a group home for Lauren to move into -- well, that was pretty much impossible. Thanks to Paul Aronsohn, he helped us get Lauren's NJ CAT appropriately re-evaluated, and so we did hear from another group home who did try very hard, but were not themselves able to meet Lauren's needs either.

The dual-diagnosis population in New Jersey is, as I'm sure you probably already know-- These clients need more opportunities for placement with staff that receive extensive, ongoing trainings with competencies, and certainly a mentorship. As far as I could see at Bellwether, people were hired-- If they could walk in and talk, they were hired and put into a home with very little mentorship. It seemed to me the only thing most of them were learning were some bad habits from staff that had already been there.

But I have to say, too: Video surveillance is a must. I mean, it's obviously not the sole answer, but it definitely -- I don't think it would hurt. They're our most vulnerable population, they deserve a safe place to live that can meet their needs; and not forgoing Lauren's siblings-- It just changes the whole dynamic of the family.

I thank you for the opportunity. I know my story is pretty similar to a lot of other peoples', some certainly much worse, but we're still kind of at a loss as far as where Lauren goes. So I'm not going to hold my breath for DDD to help me.

ASSEMBLYWOMAN DOWNEY: Well, we're going to look into all of that.

MS. PAGE: Yes. Unfortunately, too, there's still a diagnosis--

ASSEMBLYWOMAN DOWNEY: This should not be how the families feel. This should not be how you feel, and so many others have talked about -- there's been a lot of you speaking about this.

MS. PAGE: It's so hard. She's like a completely different person, you know? People say, "she used to be so fun, and funny, and happy." And now she is such an angry, angry person and doesn't trust anyone -- I mean, which I can see.

ASSEMBLYWOMAN DOWNEY: Of course.

MS. PAGE: All the therapy in the world isn't-- Yes.

But thank you for the opportunity. I appreciate it, and we'll all keep on trucking, right?

ASSEMBLYWOMAN DOWNEY: Well, and for you as a parent, it's just horrible that you have to all go through this as people who love their children, their family members. It's just, like I said, heartbreaking.

But I really appreciate you sharing and telling us, so that we know, so we can try to see what we can do to help. Paul is here-- People are listening.

MS. PAGE: I know you guys are the good guys. (laughter)

I hate to put it that way, but after a while you kind of wonder, like--

ASSEMBLYWOMAN DOWNEY: We're listening, that's for sure. So we really appreciate it. Thank you.

It's hard for us to even really say anything, because nothing makes that better right now, except to try and fix the system, right?

MS. PAGE: Yes. I just hope someone else down the road doesn't have to go through what we're all going through.

ASSEMBLYWOMAN DOWNEY: That's right. And Nancy, that you don't have to continue to.

Alright, so Nancy, after you we have Kathi Logan.

KATHI LOGAN: It's nice to meet you all, thank you so much. I have so much to say so I'm just going to get it out as fast as I can.

It started probably four years in my daughter's group home. I feel sorry for the one woman who brought up the Woods group home. I don't like to say the name, but my daughter is in an Allies group home -- she has Prader-Willi syndrome -- Allies is affiliated with Woods.

Almost four years ago I had to get her a restraining order against -- for my daughter. It's my daughter Tammy -- Tamaryn -- and she had two roommates, Denise and Jackie. Jackie we had to get a restraining order against, temporarily -- still, it's still going on -- to get her out of the house, because not only her Prader-Willi syndrome, her behavior problems -- beating them, everything.

Allies told their staff to stop calling the cops, so I had to start calling the cops. State Police told me I can call for a well check anytime, so she was moved out of the house and another roommate moved in, who, turned out, she didn't have Prader-Willi syndrome. Once again, it's a Prader-Willi syndrome group home. Her behaviors were worse than Jackie's. She beat my daughter on numerous occasions, worse than Jackie did.

She was new in the house -- She was locked in her room her whole life, this girl. She did not know how to be around people, so the staff at the time -- who aren't there anymore because I had an investigation, and they were all drug tested -- they took them to a Philly mall. This one attacked my daughter in the mall. Unbelievable. They told security they would call, they would handle it, when they got home they would call the police -- not true. They never called the police. I have no proof.

My husband is a police officer who just retired July 1 after 30-something years. He called and spoke to Philly police, which he's had dealings with before, and there's no record of it whatsoever, so there's no proof other than my pictures of her bald spots, scratches, bite marks -- everything, because the staff that was there with her and Tammy -- one staff, two girls -- stood by and didn't even try to break it up.

Her room has-- All the rooms are locked, because Prader-Willi syndrome, they steal from each other. My daughter has an alarm on her door. Her room is constantly being robbed. It's locked. Her mail gets robbed. I have police reports up the gazoo. She has been physically and mentally abused by the staff.

She worked at TJ Maxx in Clinton, New Jersey, for 10 years -- was just awarded. Had one late left -- they need a 24 hours, one-to-one. They knew she had one late left, and this staff decided to take the long route to work. TJ Maxx let her work for two hours and then fired her -- after she was just awarded for 10 years.

And we were at the house for a meeting that day, so I told her, "Tammy, just don't wait. We hit traffic." -- because we were an hour and a half away, with no traffic. I said, "Just go to work and I will see you afterwards. If you're not here, we will stop by TJ Maxx." So she left 45 minutes before she was due to be in work, and since the staff took not the 25 to 30 minute route, she took the long route, so Tammy got fired.

There's just so much to tell. Her birthday present -- September 26 -- all her brand new presents were robbed out of her room --

locked room, mind you. It's not the other two girls in the house doing it because they can't get the keys, they're in a locked office. Staff falls asleep while they're working, the girls steal the keys and rob -- because everything has to be locked up, they need 24 one-to-one at all times, other than when they're in their rooms.

I have pictures of the staff sleeping, because one of the higher-ups told Tammy, "When a staff is sleeping, take pictures." And he went back on his word and said he never said it; but he told me, I have the proof. I've been keeping-- Once I started realizing what was going on, I started keeping my own proof, I started keeping a diary.

She's had staff -- her one-to-one -- fall asleep at her job with her, where she stole nine bags of candy. And instead of the staff knowing you don't go to management, you make her put it back, she went to management. Tried to get her fired that day.

Then she had another staff, who I do have a police report against, saying to Tammy-- Tammy worked four hours Monday, Wednesday, and Friday for all these years. Hunterdon is the one who got her this job. On Wednesday she was telling Tammy it's her fault. She just bothered Tammy the whole time she was there, Tammy was hysterical. Her manager was asking her, "what is wrong?" She can't talk -- her staff is with her -- because she's afraid to talk.

She got home from work and one of the higher-ups was there, so she asked if she could speak to her in her room, privately, and she told her what happened at her job. And they sent the same staff to her job with her on Friday. The only place cameras aren't allowed are outside the bathrooms, and when she opened up the main door to walk into the hallway to go to the bathroom, she slammed the door closed on my daughter's arm and bruised her whole entire arm. My daughter got in a stall and started sending me pictures, and she was so afraid to say anything to her manager because the staff has to be with her all the time.

She's been punished-- Last winter, she was made to walk up and down-- I mean she's in Stockton, there's bears there, there's fox, there's everything there. In 23-degree weather, that was her punishment. They made her walk up and down the road just to get even with her.

I've had so many investigations done. So many people are not in the house anymore because, obviously, they came up positive for drug use; whose boyfriends belong in gangs -- I started getting threatening text messages on my phone, "you're going to die b-word." I had to go file a police report for that. It was a landline. I told the police here, in Hazlet, it's a landline, my middle daughter looked it up. They wanted to call it from the police department phone; I said you can't do that because they're going to know it's me. They know where I live. My information is in that house.

So the police report had to be done over again, because when I told them that, they told me they put in the police report that I didn't want to go further with the investigation -- which was not true. We got that taken care of; in the meantime, by the time they finally got around -- it's a small town here, it's a dead town -- they got the landline disconnected.

Her room-- When she was working at TJ Maxx, she got fired after 10 years and being awarded on March 25 of '19. I know because it's the day of my mother's death. Before, they were robbing her money out of a locked safe in a locked office; her work money. Years ago, they stole money out of her bank account.

I didn't even know she was getting food stamps until a food stamp lady called me -- an investigator -- telling me that somebody has the food stamp card and on their way home at 3, 3:15 in the afternoon they're stopping and buying candy and soda. And I said, "Well, what do you mean Tammy gets food stamps? I don't know anything about this." She said, "Unfortunately, you're her legal guardian and her mother, so therefore you will have to pay it back."

ASSEMBLYWOMAN DOWNEY: Wow.

MS. LOGAN: The upper management doesn't care about anything. Nothing, nothing, nothing at all. The UIR investigators don't care about anything. I've listened to all these stories; I've sat here crying, story after story after story, because it's all the same thing. Some are worse than others -- thank god my daughter can speak, what happens to the ones who can't?

Now, this one who slammed the door closed -- and that's a big metal door, I've been there many times -- she was not fired. They found it to be an accident, they put her in a different house. But, in the meantime, she was in anger management classes.

I just-- We're trying everything. We have been fighting for over a year to get her New Jersey CAT changed because of her Prader-Willi syndrome and the behaviors that come with it. She's tier C, level C, she should have the dash-A after it for the behaviors.

She has tried to run away from that house, but because they have the alarm, she got caught. The staff who pulled up and saw her climbing out her window to get into a car with a man, didn't know if it was a cab, an Uber, a Lyft -- never thought to get a license plate number, nothing. It was reported over six months after, so nothing could be done about it, it couldn't be put down.

I could just go on, and on, and on.

ASSEMBLYWOMAN DOWNEY: I'm going to have to reach out to you as well.

Where is she right now? She's still--

MS. LOGAN: She is-- Yes, she is. We are trying desperately. There are agencies interested in her, but because of her CAT form, she doesn't get enough-- I don't know what term you would call it. I have everything written down.

ASSEMBLYWOMAN DOWNEY: Does it have to do with reimbursement?

MS. LOGAN: Acuity.

ASSEMBLYWOMAN DOWNEY: The acuity level. Okay.

MS. LOGAN: When her first New Jersey CAT form was done, Allies did it wrong. They didn't have Prader-Willi syndrome down. It specified a mild retardation or something-- I mean, anyone who knows anything about Prader-Willi syndrome, they eat themselves to death. They have to have a one-to-one, 24/7. They eat frozen meat, cat food, their own vomit.

There's just so many things, and I know I don't have enough time, and I know there's other people--

ASSEMBLYWOMAN DOWNEY: But we can follow up and try to find out more.

By the way, have you spoken to Paul? I'm just curious.

MS. LOGAN: I have not. And I have the article when he was first appointed, but my bag is this big (*indicates*) of all my daughter's-- I have police reports and everything separated in files, and every time I see these articles in the Asbury Park Press--

ASSEMBLYWOMAN DOWNEY: Because he might be able to help you with what you're trying to do in terms of changing the status, and that will help. And then we can work on the other stuff.

But I think you should reach out to Paul and see what can be done quickly regarding that, okay?

MS. LOGAN: Yes. She-- And the sad thing is, the newest roommate doesn't have Prader-Willi syndrome. The other one, Denise, has been there -- with Tammy -- from the beginning. They were both in the children's center in Pittsburgh together, at the Prader-Willi Institute there. But they're going to move the girl back in if Tammy leaves, and I worry about Denise because they are so small, and Denise is -- she looks like she's eight years old. And she's functioning because of Tammy, and I worry about her so much because her sister is in Tennessee trying to get her into a group home there, and they're so behind; and I'm just so worried about her if Tammy leaves.

But I want her out of there, because between my health problems, my anxiety-- But imagine Tammy -- she leaves her room and goes in the yard, and her room is a locked room with an alarm on her door and it's being robbed.

ASSEMBLYWOMAN DOWNEY: That's something we're going to have to look into, because I don't understand how this continuously is allowed to go on. So we're going to have to look into all this with you.

But definitely reach out to Paul, okay, about the (indiscernible).

And thank you, Kathi. Thank you for being on here and telling us about what's going on over there, okay?

MS. LOGAN: Yes.

ASSEMBLYWOMAN DOWNEY: Thank you for sharing about your daughter.

MS. LOGAN: Just the meeting alone-- And I have been dying to meet and talk with him. Just to talk to him.

I was at the gay pride festival a year ago -- March -- in Asbury, and Governor Murphy walked up to me and my two daughters and there was so much secret service there, and all I wanted to do was ask him for a card just so I could talk to him and explain to him what's going on. My daughter can talk, how about the ones who can't?

ASSEMBLYWOMAN DOWNEY: Well, that's why, again, I think-- First of all, we're listening. And then the other thing is, like I said, Paul is incredible and he cares a lot. So he will help do what he can, and he works directly with the Governor.

MS. LOGAN: I absolutely love the Governor. I love him, and I am just so excited. This has just made my-- Everything.

ASSEMBLYWOMAN DOWNEY: Well, reach out to him and we'll look forward to hearing and talking to you soon again, okay?

MS. LOGAN: Please. If you need me, please contact me.

ASSEMBLYWOMAN DOWNEY: Yes, we have your e-mail addresses. Thank you.

MS. LOGAN: Thank you so much.

ASSEMBLYWOMAN DOWNEY: And then we're going to call up next, Rocio Uribe. (no response)

Rocio Uribe, if you can unmute yourself at some point let us know and you can speak, okay? Just let us know.

I'm going to go to the next person, who is Margaret Valenta.

Are you still here Margaret? No?

MS. KASER: I think she may have left, Assemblywoman.

ASSEMBLYWOMAN DOWNEY: Yes, I don't see her on the list. Okay.

The next person is Barbara Wichot.

MS. WICHOT: Hi, good afternoon.

ASSEMBLYWOMAN DOWNEY: Thank you for hanging in.

MS. WICHOT: My name is Barbara Wichot; I have an MBA, I used to work for the American Broadcasting Company as a research analyst. I am a mother and legal guardian of our son.

I want to thank Paul for inviting me today.

I'm 64 years old, and I can't leave this earth without testifying. I want to speak to you about the abuse our son has had to endure for the past 18 years.

In 2002, he was hit by a van as an 11-year-old boy, right in front of my husband. He sustained a severe, traumatic brain injury and was placed in a coma. He was not supposed to live through the night. Our son had to relearn everything, starting with a swallowing test. He learned to hold his head up, sit, stand, walk, talk.

The real challenges began immediately. PIP insurance: $8,500 dollars a day for his bed. No negotiated rate in the State of New Jersey. Children's Specialized was paid over $2,000 a day, crossed off therapies, took away physical therapists, placed him in a room with three other patients, including a toddler jumping on the bed, and four parents staying in the same room. A monopoly.

Out of school for a year, having every imaginable therapy. The new challenge: To be allowed back in school. IEP resource room, signs on the door, small group instruction, signs out in the hallway -- instead of room 102. Needs to be changed.

Bullied. Made fun of by students, and the teacher's remarks, because they totally-- They said they never had a student return to school after such a severe accident.

Our lives were changed in an instant. I have two other children. We were a successful family. They were successful in everything: school, sports, leadership, volunteering in their community. Completely gone.

The school disobeyed the doctor's orders. The prescriptions. We had to go through the court of administrative law. We went through New Jersey Disability Rights for compensatory education.

We needed help. We went to all levels of DDD, up to the Commissioner. No, they wouldn't pay for out-of-state services -- but they had nothing in New Jersey. The brain injury? I feel all it is, is a shell. We get nothing.

We were sent by the Philadelphia Children's Hospital -- an expert there, an expert doctor -- to go to Illinois, the Center of Comprehensive Services. It took a lot to go there. We had to use our private insurance. It took forever. I flew there every other weekend, rented a car, and drove the whole state of Illinois to get to southern Illinois -- by myself. My husband had to stay home and take care of our other children.

They told us to give our son 30 days to get acclimated to the program. I called every single day, speaking to everyone -- his case manager, everything. When we went there to be reunited with our son, he was in the same clothing as when he was entered there -- not bathed, not changed -- for 30 days.

We called all authorities. They had millions of dollars in violations. And you know what? My daughter even wrote to President Obama, as it was his hometown state. The Walter Cronkite School of Journalism wrote about group homes in Illinois. They had to be taken down.

I saw for myself the homes. They were actually just fire traps with narrow hallways, narrow stairways. But where else was I going to go? My state provided nothing -- nothing. Zero understanding of our son's needs.

Instead, he was made to be a problem. A problem at school, a problem with everything. This went on. When he was 17 years old, we filed for legal guardianship through the court. No guidelines, no manuals. You're on your own. Guardianship certificate documents are not recognized by doctors, hospitals, police, sheriff, the courts.

Constantly blocked with certificate in hand -- no training, they don't know what it means. Procedures are not followed. Medically, clarity is needed. We are in charge of his medical needs and everything else. We don't need a judge to rule for involuntary placement.

New Jersey Cares is a stumbling block to medical care. A weight of taxpayers' funds. No hotline to call and get help immediately at 4:31 p.m. in the afternoon, or on a Saturday night, a long weekend, or in a blizzard during a state of emergency.

Twice I took my son to Saint Joseph's ER. His meds had been changed. Every package says if you see a change in them, you need to seek immediate medical care -- and that's what I did. But his care was blocked by the New Jersey Cares person that came after 24 hours. The next time, I took my son to Chilton ER for evaluation. He was kept in the ER for four days. New Jersey Cares -- two more times -- cares not needed.

In the a.m., my son was transferred to Carrier. Completely changed his meds to a diagnosis he never had. Injured at Carrier. Despite six medical personnel behind the counter, no one called a medical doctor. I went for a meeting and they said he was ready to be discharged. Our son's arm was swollen and dark pink like a baseball bat. We need a medical doctor.

He was sent to Robert Wood Johnson ER for an MRI of his arm. Seven hours later, he became impatient. They administered one double dose of vancomycin. "Doctor will be in the first thing in the a.m." Somehow we were going to have to try to get through this night.

No doctor till 5 p.m. the next day, and didn't order the MRI stat. The head nurse states patients in the ER have first priority now.

No MRI until third day, but gave the wrong meds to our son and he couldn't complete the MRI. A CT scan was done after my request.

On Sunday, a call from Carrier discharging our son. We were notified to come and get his belongings. My son was medically cleared at the Robert Wood Johnson. We had been put in a holding pattern for four days. I signed documents and I was taking our son out AMA: against medical advice; being the fact he was already there for four days; he was already at Carrier prior to that; he was already at Chilton Hospital for four days before that.

I was taking him to our son's primary care doctor, who was an infectious disease doctor. They sent police to remove our son, to take him to St. Joseph's Hospital in Paterson, again barring me. At 12:01 midnight, our son was put in an ambulance and told he had to sign documents to be in-patient at Carrier. Son said, "I can't. My parents are my legal guardians." He was forced to sign. He was locked up there. I called 9-1-1, the Somerset Police were called. "Mr. Sweeney said the doctor committed him." But he had no legal documents. He had to apply to the court. The only person that had a legal document was us.

It's an abuse of power. And the police were going along with what Mr. Sweeney told them. Our son was not fed and was ignored. For the fact that our son had been moved around from hospital to hospital, transported in an ambulance, now locked in another area of the hospital where he had not previously been, and not fed, I reported it.

I called everyone in the resource book manual. It was a blizzard, and there was no help. And no returned calls. When he was released three days later, his arm was huge and deep pink.

His primary infectious disease doctor sent him to Morristown Hospital. Surgery that night. A nuclear scan was done and he had an infection in his bone -- osteomyelitis. Six weeks of IV; our son could have lost his arm. And it was reported to DDD in Trenton.

I received a call as a follow-up-- I have the woman's name, I'm not going to say it. "Oh, well, I'm on my way to another meeting. I'll be driving for the next hour and you could call me so I can get the information." She's attending to another meeting, she's driving her car, and this is the best we can do after we have been in and out of hospitals and my son just had surgery.

In 2018, the same arm became infected. We went to Morristown, where he had previously gone. They gave the wrong meds, the hospital security guard put him in a headlock, snapped and broke his finger, put his thumb in his eye and fingernails in his face, kneeled on his infected arm -- in front of me. All emergency personnel stood there and said nothing. Unresponsive.

My husband and I spoke calmly to the hospital director, and the hospital called three police officers and a Sheriff to walk us off the hospital property. I called DDD from a nearby parking lot. The woman said, "Call tomorrow after 10 a.m." I called 9-1-1. The same police officer was sent that had just escorted us off the property.

I said my son needs a well check, and then the officer reported he was fine. The next morning, the hospital inserted a PICC line into our son with no call to us. And then we were told we need a surgeon. His finger was broken into a point. Now what am I supposed to do?

This has happened repeatedly, because there is a lack of knowledge. I also want to tell you how everyone makes them problematic because they are undereducated. In the court setting, a judge said, “Is he capacitated or is he incapacitated?” This brings to mind a young woman in a vegetative state in an Arizona facility the same age as my son, who was impregnated by her male nurse. She gave birth. Did she have to decide if she’s capacitated or incapacitated? Should her parents have turned their cheek?

We need to listen to victims. Our children are being victimized in every arena, and it is the government’s job to protect their most vulnerable citizens, including our son and everyone else who has spoken today.

For two years, there is a commercial-grade camera in the public right-of-way on our street, right now, watching our son as soon as he goes out of our home. Our town official issued a permit to our neighbors to allow this. It is against the 4th Amendment of the United States Constitution, and it is harming our son.

Because of false charges, our son’s face has been beaten into the sidewalk after he was put on the national news for something he never did -- and the case had already been dismissed the week before. This isolated our son further from his community. Accusers need to be held accountable, and if false claims are found, the punishment needs to be doubled.

I want protection for our son from being beaten and mistreated the rest of his life. I want these false claims removed. Hospital security read these false records, and take it out on the patient. We need to pass the Convention on the Rights of Persons with Disabilities, and immediately make an emergency number to call, and training and changes need to be made.

I welcome a call from this committee, Governor Murphy, and President Trump. Thank you.

ASSEMBLYWOMAN DOWNEY: Thank you.

Barbara, again, I just-- I've been sitting here for a long time listening to all of these horrendous stories, recounts of what's been going on in peoples' lives, and it's killing me, seriously. It's just unbelievable to listen to all this.

So I can only imagine what you must feel like if it's bothering me so much just sitting here listening to it for these number of hours.

But I'm just so sorry that you've had to go through all this and, again, this is something we need to look into. It's not acceptable -- none of this is acceptable.

MS. WICHOT: It's not acceptable. And not only that -- he has two sisters whose lives have been completely ripped apart, because we have had to devote ourselves to our son because he doesn't have the correct services.

And my daughter said to me, it's already been half her lifetime ago that she lost her parents. It's not fair.

ASSEMBLYWOMAN DOWNEY: It's not.

And your poor child, it had nothing to do with him either. That's sad.

MS. WICHOT: I want my son under State care. I want to tell you: It took 10 years for our son's accident case to come up in the Superior Court and the defendant, he said, "If you make a case against me, I'll claim bankruptcy." Well, he did. And it has been in bankruptcy court in Reno, Nevada, for eight years, and it is going to be dismissed next week.

I have reached out to the Department of Justice. They have perpetrated fraud. I have flown to Nevada. I have spoken to the U.S. Trustees in person. I wrote to the Region 17 Trustee-- U.S. Trustee. I called the Executive Director of the U.S. Trustees, Mr. Clifford White, in Washington, D.C.

I have written my Congressman, Congresswoman, Senator Corrado. I have reported things to New Jersey Disability Rights -- they said they can't help me. I called The Arc and spoke to the head of that -- they said they can't help me. I called National Disability Rights, I received a phone call back. *Oh, we can't help you, contact your local disability rights.* You know what? Where is the protection? I want an answer.

ASSEMBLYWOMAN DOWNEY: This is all terrible.

I'm going to reach out to you again and we're going to try to figure some of these things out, too. This is just incredibly horrible.

I'm so sorry.

MS. WICHOT: It is just further heartbreak. Further abuse. We should never -- never -- have to live through this. Our son-- God allowed him to live. I prayed out loud in the trauma room to save my son, asking Him also for all the people in the trauma room to use their skills in the utmost. God allowed my son to live, and you know what? This system is broken, and you're killing him. You're killing us.

Please help us. Please.

ASSEMBLYWOMAN DOWNEY: I'm sorry Barbara, thank you.

We're listening, and we're going to do whatever we can, I promise you that.

MS. WICHOT: I will help. I will help. I have-- I am a research person. I have lots of suggestions. I know a lot of the points that are weak within this state. I know where there are problem areas. I can offer suggestions. That, I can hope to do.

ASSEMBLYWOMAN DOWNEY: I'll appreciate that, okay? Thank you.

There's only a few more people, I just want to thank you all for being here for so long. It's so important, I really appreciate it.

I know they all do, too.

ROCIO URIBE: Can you guys hear me?

ASSEMBLYWOMAN DOWNEY: Who is speaking?

Oh, is this Rocio Uribe?

MS. URIBE: Yes, I'm the one that-- I was having technical difficulties.

ASSEMBLYWOMAN DOWNEY: I'm sorry. Go ahead.

MS. URIBE: My story is-- I'm just at the beginning stages of entering into the adult world of disabilities. I hung onto my son as long as I could, because I knew that things were going to be extremely difficult dealing with the system -- dealing with the people that would be surrounding my son.

But I had no choice in December, and I had to go through the motions and let him go through where he had been at. And he ended up in an emergency bed for about six months, and that was my beginning of learning residential settings. And the experiences that I had there -- I did a lot of e-mailing and so on and so forth -- was the unprofessionalism of the staff that I came across that was in this place where my son was at.

There was the serious issues of the food -- the type of food that these individuals are being fed. My son requires some sort of special diet, and eats certain things and cannot eat other things, and that was an enormous problem. It was very difficult dealing with the professionals, because you really don't know who is who or what's what in this environment.

I wrote a letter complaining about the staff being unprofessional, the rotating of staff -- I got used to somebody and there was somebody turned over.

My son has a lot of behaviors, and that's why I had to figure out a way to let go in order to save him. My story -- right now I am jumping through hoops. You have no idea what I'm doing, so that I don't end up dealing with some of the things that I hear everyone here say. I am doing everything I can to not let that happen.

Having said that, I think the system is bad. My son transitioned in August to a permanent placement. It was horrifying for me trying to figure out what to do, and I was told that I couldn't see my son for 30 days. I could try to see him, but then my son had what I call a flare-up, and the individual that runs the homes basically told me that I could not see my son for the rest of the time.

Then things just got bad from one thing to another, so I have been a thorn in their side because I am concerned about what they are doing with my son, I am concerned about the diet aspect of it that they are really having a hard time following. Even though I give them prescriptions, he's got letters from the doctors-- And really, what happens is that his reactions to food is not that you require an EpiPen; it's that he ends up in a behavior. And so the whole thing is to just try to keep him from getting the way he does, and so it gets pretty scary.

My story is not -- at this point -- like the stories I'm hearing, because I'm working very hard to make sure that doesn't happen. I talk to a lot of people, I ask a lot of questions, but someday I'm not going to be around for my child; and I'm wondering what that means given what I'm seeing, given the amount of difficulty from the professionals that run these homes. And how they're running is a feeble profit (*sic*) -- that's basically what it is.

This is not like you're going to visit your child at his or her apartment, so you're subject to whatever. It's very political and it's very difficult.

So my situation right now that I'm dealing with is the diet, and the lack of support and supervision in the home to address some of the issues that are going on. And like I said, I'm jumping through hoops to make sure that I'm not going to have this horrific situation to deal with somewhere along the line.

And I want to tell everyone here that as I'm listening to the stories, I'm sorry that you are all going through all that. Something needs to be done, even for the voices that are not heard -- like one of the parents said.

Thank you for your time.

ASSEMBLYWOMAN DOWNEY: Thank you very, very much.

Are you-- Is he at the same place right now?

MS. URIBE: Which one?

ASSEMBLYWOMAN DOWNEY: Is he at the same place that he started out with, or is he at another placement now?

MS. URIBE: He just transitioned into an apartment at residential in August.

ASSEMBLYWOMAN DOWNEY: Right. He's over there?

MS. URIBE: He's over there right now.

A lot of what's happening right now-- Because I've been on top of things trying to make sure, because my fear is what they're going to do with my child, like everyone that I'm hearing the stories here, that they've been on this journey.

I'm just at the beginning of the adult world of residential and group homes, and my experiences have been extremely difficult. I have tried to reach out to parents-- I did reach out to Paul, because I was beside myself, because I was told that I could not see my child for 30 days, and I found that unacceptable. It happened anyway, I just didn't fight it. But they got their way.

I did make a statement that there's got to be a law that you cannot do that to a family member or parent, to keep you away from your child for 30 days while they're transitioning into whatever it is.

So, yes, he's in a new setting right now. And, like I said, my heart goes out to everyone here, okay?

ASSEMBLYWOMAN DOWNEY: Well, thank you, and keep us advised, okay?

Thank you. I wish you a lot of good luck with that new placement.

MS. URIBE: Thank you very much.

ASSEMBLYWOMAN DOWNEY: Next person: Maria Varghese.

It's your turn, finally; I'm sorry.

MARIA VARGHESE: I want to thank you for the opportunity to speak today.

One of my biggest concerns that I have, as a parent who has had a child in some different facilities, is safety. And I think that we've all been discussing the same thing -- we've been discussing the safety of our children.

And I think one of the things that has to happen is to have accountability. When my son-- In April of 2014, I was forced to put my son in a facility which was two hours away from my home. And I never wanted my son to go there because I had visited that facility on three different occasions, and I didn't think it was a safe facility -- just from what I would gather by my visit.

But when my son was sent there, I would go visit him and it would be the same thing that some of these other parents have voiced. Of course, you know, some of the things that these other parents have gone through are even worse, and my heart goes out to them.

But I just wanted to let you know that I would go visit my son, and he would have bruises on him. One day I went to visit my son, and he ran into his room and he lifted up his shirt and he had all these scratches on his back -- all these scratches. I was so ignorant, because I thought my son probably did something to himself. I could not conceive that he had been abused, you know?

So we need to have accountability. Because when I would go into this particular facility, the staff were not being supervised. And sometimes there were two staff on a Sunday -- I would always visit him on a Sunday -- and sometimes on a Sunday you would have two staff, and there would be about four or five people, and then another staff that would be looking at the cameras.

On this particular facility, my son was never taken out. It was like he was placed in a jail. He was always kept in his room, kept in his room. And of course, then they're going to say that they get violent, that they become aggressive -- but how can you not become aggressive or violent if you're never taken out? You're never taken anywhere? You're just kept in that room and medicated.

Also, in this facility that my son was in, in the middle of the night my son had problems with his teeth. He wasn't taken to the dentist, and they took so long to take him that he ended up having four wisdom teeth that all had to be removed at the same time. There was one particular night that he woke up in pain -- this is what I heard from the staff -- and he was upset and he went to the bathroom. There was another boy down the hall, and that boy bit my son. There was no staff to prevent this from happening. He took a chunk out of my son's arm -- he bit him.

I didn't get a call until a day later to let me know. And my son was also taken out that night by police without shoes and taken to a hospital. Then they called me from the hospital, and when I got to the hospital, my son was restrained. Why did my son have to go through all that suffering? They should have been taking him for his medical checkups so that he wouldn't have all those problems. I don't know how many weeks I had to advocate to get him a doctor to get his teeth fixed so that he wouldn't keep having that pain.

He was also found with the worse ear infection that an ER doctor had ever seen. He had such a bad ear infection that his ear was protruding out of his head, it was humongously swollen, and the doctor -- when I spoke to the doctor from the ER -- told me that was the worst ear infection he had ever seen on a person.

Not only that, but there were other times-- There was a Sunday that I was there. I was going to go visit my son. I looked through the window as I was going into the home where he lived, and there was a staff watching two boys. It was my son to the staff's right, and to the left was this other young man who had already bitten my son. He had already bitten my son. So my son, when he saw me, he got excited, he started jumping because he saw me. And the staff blew a whistle, another staff came from another house, they restrained my son right there in front of me. Three men. And I yelled at them not to hurt him. And then they said to me, "we're not going to hurt him, we're not going to hurt him."

Finally, they let him up and I was in the kitchen hiding. I looked to what they were doing, and one of the staff -- and this was at Bancroft, at the Linden -- one of the staff took a table and shoved it at my son's chest right in front of me. Right in front of me, he shoved that table at my son's chest.

Another time when I went to visit my son-- This was during the week. Another time when I went to visit my son, this other staff gave him a bear hug -- they call it a bear hug. The guy that gave him a bear hug looked like a football player, and he hurt my son, because the next day my son couldn't get out of bed. I called and they said that he wasn't feeling well, he couldn't get out of bed.

I have been there so many times at that facility, and I would see that they would not bathe him, his room was filthy, he was filthy, he smelled -- it was just terrible. And that was only one of the facilities that he had been in.

Then he had been in another facility, the one that he was in most recently, and the same thing would happen. I would go there, there would be dirty clothes on the floor, wet clothes with clean clothes. He would be filthy -- they wouldn't give him a bath. If I were to give him a bath, they would complain that they didn't want me to give him a bath, because they didn't want any parents in the home giving their children a bath -- because if I heard them treating or mistreating another child in a way that was not appropriate, I would let the person, that I have to, know what I had heard.

But the people from this facility, Legacy Treatment Services, do not want anybody to say anything if they see anything in that facility. It's like what all the other parents were saying: You can never say anything. Even at the hospitals, when I'd been to the hospitals, the people from Legacy Treatment Services were telling the people from the hospital that I should not be there -- even though I'm his legal guardian that I should not be there, that I'm interfering -- the staff that was at the hospital.

So I just want to be able to also say that there was a particular night while he was at Legacy. Sometimes in Legacy, they would only have two staff in the middle of the night and there would be more -- there would be four or five different persons being served there. There was one particular night my son woke up -- the two women that were there could not handle his behavior, so what did they do? They called the police and my son was taken to a hospital, Willingboro Hospital in New Jersey, and he was so tortured at that hospital.

They put him on four-point restraints. They were restraining him with his hands pulled behind his back, and they would restrain his legs and they would keep him like that for hours. I would hear him screaming. I would hear my son screaming while I was waiting. They wouldn't even let me go in to see him, they would tell me to get out, and I had to stay in this little room. It was like a jail. I couldn't even see my son while he was screaming.

I also spoke to the director, and I let her know--

ASSEMBLYWOMAN DOWNEY: Why was this happening?

MS. VARGHESE: Because he was taken out of the facility, because the facility didn't have enough people there to handle emergencies. So what they would do is they would call the police, and he would be handcuffed and he would be taken to whatever -- to the hospital.

ASSEMBLYWOMAN DOWNEY: And then once he gets to the hospital, though, then they restrained him like that because they don't know what's going on? Is that what they're saying?

MS. VARGHESE: He was kept in that hospital in Willingboro, New Jersey, from October 24, 2018 to November 8, 2018. He started developing problems with his muscles. It was a CPK level that was very, very high because they were restraining him and it was affecting his muscles.

When I would go visit him, there was nobody there to brush his teeth; there was nobody there to give him a bath. I kept speaking to the advocate at the hospital, and finally the advocate at the hospital was able to go upstairs, and I think they gave him a bath maybe one time. I don't even know-- Maybe they washed him up a little bit.

What I'm trying to advocate for today is that I think there's a lack of supervision in these facilities; that the staff sometimes are not being held accountable, and it's just been my experience when I go to some of these facilities, it just seems like there's a very small ratio of staff.

And I think that, as one of the other mothers has said before, these kids are so vulnerable, and we need to step up our game and really make an effort. Why can't the staff have some kind of training before they come into these positions?

A lot of the staff that I would get to meet there, sometimes they would be angry. You couldn't really say anything to them, because they would get upset or we would have to face retaliations. The mothers that would go there would have to face retaliation if we said anything. I don't think that this should be happening.

ASSEMBLYWOMAN DOWNEY: And the crazy thing is that they have training programs, so I don't really understand any of that, which is what we're going to have to look into. I don't really get this. That particular place, too.

This is mindboggling to hear some of these things, that all of these staff members-- There's some really great staff members, and then there's these other people who are just not. Obviously, they're not doing a good enough job being able to, like you said, either train them or make sure they vet them properly to make sure good enough people are there. We need to pay them more-- It's all these things that we were all talking about.

Marie, I really appreciate you telling us about some circumstances--

MS. WARGNYE: Can I have one minute?

ASSEMBLYWOMAN DOWNEY: Yes, Marie Ruth?

MS. WARGNYE: I want to show you my son that I showed you in the picture. How he became.

I think that he was abused, because I spoke and reported them-- Any time I reported them, they took off my guardianship, they took everything.

Well, I didn't want my son in a group home. I didn't want to give my son away while I was sick and I'm alone. I am from France, I have nobody here. My family is not here.

And with a problem with that, I don't know nothing in the court. I have never been in justice-- I'm just a mother.

ASSEMBLYWOMAN DOWNEY: And like I said, I'm going to still talk-- I'm going to go back to Paul, too, and talk about your case again with him, what's going on with you.

So thank you, Marie Ruth.

And I know we have Kumar Smith left, right, Mr. Smith?

MS. KASER: I don't see Kumar Smith anymore, Assemblywoman.

ASSEMBLYWOMAN DOWNEY: No? He was on for a while. Okay. Poor person, he probably had to wait so long. But this was important to hear everybody, I think we got everyone.

I had originally wanted -- I mean, it's so late -- I had originally wanted us to be able to ask some more questions, but I know it's very late, and I think there's a lot to digest.

Before we want to close, I want to see-- Do any of my committee members have a question or two that they really feel like they need to ask right now, before we close up?

KUMAR SMITH: I'm Kumar Smith -- I'm here.

ASSEMBLYWOMAN DOWNEY: Hello, Mr. Smith.

MR. SMITH: I'm a Support Coordinator, but there was -- I want to say, Cynthia and some other people, there are people that love and care about our individuals, so don't get that wrong.

Please understand that that's first and foremost. There are people who really love what they do. I was a DSP and I've been in Social Service -- in all aspects of Social Service. Also in different states too; the state of Georgia and the state of Nevada.

So coming to New Jersey -- coming back to New Jersey, I should say, it's my home -- I was kind of disappointed with New Jersey.

ASSEMBLYWOMAN DOWNEY: Yes.

MR. SMITH: I'm not so excited about New Jersey.

ASSEMBLYWOMAN DOWNEY: Tell me why?

MR. SMITH: Jersey let me down. New Jersey is very-- They have a lot of, I want to say, structure and State laws that (indiscernible) dedicated to our people. We're not dedicated to those who really need us and we work for.

First of all, for me-- I'm a sage. I'm a sage, that's the first and foremost. So to me, I'm here to serve, and I've been brought here to serve.

And some people-- I know everyone comes from a different aspect of life, but I know what I was here to do. When it comes to DDD and providing services for individuals who are juvenile delinquents, that's what I've been employed here to do, and DDD was something interesting I got in. Because I've been at an agency and I was trained, and I thought at first-- It seems as though these agencies have things together, but sometimes there are cracks in certain things, there's cracks in -- what do I want to say -- their procedures and their policies and all these things, because they're man-made, everything is man-made, they're cracking.

So at the end of the day, my individual really and truly was Glory Holly Thomas. And I don't know if Delores was able to speak -- because I've been busy, I've been trying to do work at the same time -- but Delores had my individual, who was Glory Holly Thomas, who I got within this year, I may say. Maybe last year.

But when she came to me, Delores presented me with cases of abuse, neglect, from the previous agency. And as a DDD Support Coordinator, where do we take that? DDD may not do as much as they need to do, you know. She fell-- I mean I have pictures, Delores has pictures, I'm not sure if Delores was able to speak.

ASSEMBLYWOMAN DOWNEY: No, I don't think so.

MR. SMITH: But at the same time, I just want to at least communicate for Glory Holly Thomas that the way she was treated was totally unfair. I am disgusted with how these other individuals were treated. I cry in my soul, because it's so unfair.

If you look all across the board, on a universal scale, the injustice that's going all around the world-- It's not only in DDD, but it's all over the place. But if we don't start learning how to love each other, and be more serious about our individuals -- yes, be more serious about our individuals no matter what they are, what color of their skin, whatever-- No matter what (indiscernible) dedicate ourselves to that. Then I think-- Sorry to (indiscernible) as a Support Coordinator, I would love to see my individuals now, and I miss my individuals.

ASSEMBLYWOMAN DOWNEY: I appreciate you speaking up and talking about your-- Because I think that we also heard from a lot of the families that some of the places and some of the people who were at some of the group homes were wonderful. Their DSPs -- they spoke highly of a lot of the DSPs, and I think a lot of people recognize that the Direct Support Professionals -- there are many wonderful people out there who care about this community and want to do the right thing and help them.

So I don't doubt that, I don't think any of us doubt that, but we just think that-- What you said, there's a lot of cracks, there's a lot of issues that we need to really take care of. So that's what we need, that's what we're doing here, is trying to learn about them so we can do better. Because we are in a bad place--

MR. SMITH: That's the problem; because a lot of times we talk, and there's nothing being done.

ASSEMBLYWOMAN DOWNEY: Right.

MR. SMITH: Come on. You guys all have so much power, it's unfair to these people. When you see the pictures of their faces and people losing teeth-- It's unjust. As a Support Coordinator, I would drive and go every day to just visit my person just to make sure they're safe. And that's what my purpose is.

The thing about it is: I know my purpose, but does everyone else know their purpose? Does everyone have love in them? That's the question -- do people have that love in them to really take care of these people?

UNIDENTIFIED MEMBER OF AUDIENCE: Because you love your job. Not everybody does.

ASSEMBLYWOMAN DOWNEY: That's right.

MR. SMITH: Right, I love my job.

You know what? I've been brought here my second or third time -- who cares -- to do that, specifically, because I know there's people out there who don't want me to do my job.

I've tried to get to DCF and have them-- I tried to apply for DCF so I could work with children, because I know there's children out there being abused. So much in social work from state to state, you have these cases that are despicable to my soul. When you hear and listen to these cases of children being abused, people who have disabilities being abused-- You don't want to get into these homes.

Yes, the cameras are okay, and that's all good. Keep checking up on these people, don't stop. Don't stop, people. These are peoples' lives. If you (indiscernible) you can sit there and (indiscernible)-- Wake up. Come on, let's wake up, people. Where are we? People are dying over what? People are getting hurt over what? Some of these people are going to the hospital over what?

ASSEMBLYWOMAN DOWNEY: Well, Mr. Smith, we're going to be working on that. I appreciate you, and if--

MR. SMITH: Work hard, please. I love my people, I don't want to see them hurt or-- It's hurtful, because I have another case that I just recently got and the individual is not being treated right in his home.

It's a waste of time to go to DDD because they aren't going to do anything.

ASSEMBLYWOMAN DOWNEY: We're going to be looking into what's going on at DDD too; we've heard enough of that too, in terms of that we need to look into that. So we appreciate that you're bringing that up again.

But right now, it's been a long, over-- I don't even know how many hours it's been. So we need to, at this point, try to make sure none of my committee members have any questions of any of the people who are here.

If not, I'm just going to say I want to be able to thank everybody. Because this has been a long period. Four-and-a-half, almost five hours?

So, I want to say I appreciate everyone staying, too, for the most part. Most people stayed, except for people who had to pop in and out because they had other meetings.

These are complex issues -- extremely important and complex issues that we need to address. It's unbelievable some of the things that we've all heard here today -- and not that it's unbelievable to the people who have experienced them, but for the rest of us to hear.

And it's really important that you lend your voice to this, this way we can have that information and try to do what we can to help more. And I appreciate, Paul, you being here this whole time listening to everyone as well, as I know you'll help and meet with us, and talk to us and help us get some stuff together and figure out how we can do more.

We're definitely going to call to task DDD and find out what's going on at DDD, and have them answer a lot of questions, as the Assemblywoman Valerie Vainieri Huttle had stated. We are going to make sure that this testimony here today is transcribed, and make sure they read it and they watch it; and we want some answers.

And all of the testimony that has been submitted, you can get a copy of. So any of you, where you e-mailed to be able to get onto the

Zoom hearing, e-mail Anita the same way, just telling her -- remind her who you are, what you're looking for, remind her it's from this meeting, and ask for those things and she will get that to you.

And in the meantime, we have your e-mail addresses, and for anything that I need to follow up on and all of us need to follow up on, we will reach out. And you can also reach out to me basically through Anita as well, and my office.

Honestly, I just don't know-- There's not a lot to say right now, because there's a lot of work to get done. And I wanted to thank you also for reminding us how much work we have to do, because since Bellwether and the atrocities, the terrible things, and hearing more about Bellwether here today-- There's so many other places and so many other things we have to fix.

But also remembering there's a lot of good DSPs, a lot of people who are out there working hard. So we have to make sure that we're protecting our most vulnerable, but also propping up and helping to train the people who are working with our most vulnerable, making sure that we include our families, as was stated by a lot of our experts.

Making sure that we take care to show people that we do care -- by not just speaking, but we need some action, I totally agree. It's not good enough that we just listen; we have to actually follow through, and we intend to. We have a lot to deal with, I know, and we will continue to try to fight to make sure that this system works better.

There's a lot, though, there really is; because we need a better system for the DD community, so those with dual-diagnosis -- that's a whole other thing. We need a facility here in New Jersey that works for the people, so they don't have to send their children, their sibling, somewhere outside of the State.

We have all kinds of issues for those with complex medical needs; that we need to be able to have even the understanding in a community. I was upset to hear about the police, and what was going on with Morristown Memorial Hospital and the security guards there. We're talking about a lot of different systems, not just one area.

And we will try to go into all of those areas-- We're not going to try, we're going to work on all those areas. I just know this isn't going to happen overnight. You're going to have to hang in there with us, and help us to advocate continuously, because we'll reach out.

But this is important. Because we need your names, we need to know who you are so that we can actually have examples and be able to explain why the system is not working. And you helped us to be able to see how the system is not working.

MS. SHAZAR: Can I just say one thing?

There's one common thread throughout this whole thing; behavior issues. And if there's a behavior issue with every comorbid population -- that we had a phenomenal suggestion that there be a behaviorist or behavior specialist viewing so that they can communicate and share with them, and maybe they can all have Nurtured Heart Approach -- I've taken it twice, it's wonderful -- because we need good role models for our kids.

ASSEMBLYWOMAN DOWNEY: I think--

MS. SHAZAR: So I think the behavior assistant at every group home is essential -- especially ones with behavioral issues.

ASSEMBLYWOMAN DOWNEY: Yes.

MS. SHAZAR: And also, the people that are dictating who gets guardianship and who doesn't-- Prosecutors and lawyers need to be trained on this population, because they usually deal with dementia and Alzheimer's.

That's all I wanted to say.

ASSEMBLYWOMAN DOWNEY: You are totally right, and we have all kinds of bills regarding these things, too, about all kinds of training; and we are going to look into what we have out there, too, that we're lacking -- that we're missing here and that's not getting done.

So we will definitely follow up on all those issues.

I think that honestly, Lisa Parles had a lot of great suggestions, you're right. So we will include her in on this as well.

But--

MS. BUZZ: Assemblywoman Downey, if I could just take a second? I figured out my video issues, and I just wanted you to see my sister, Penny. I don't know if you can see her, this is Penny. Eating dinner.

MS. WICHOT: Hi, Penny.

ASSEMBLYWOMAN DOWNEY: Thank you, it's very nice of you to introduce us to Penny.

MS. BUZZ: Say hi, Penny. (laughter)

ASSEMBLYWOMAN DOWNEY: Thank you very much, Denise. That's very nice. Thank you.

MS. BUZZ: Thank you.

MS. URIBE: I'm just asking a question: What's the possibility of fixing the situation with the food in these places?

ASSEMBLYWOMAN DOWNEY: With the food -- you mean the nutrition?

MS. URIBE: Yes. And I'm not talking about a nutritionist. I'm talking about the reality that people-- How do I say this, I don't want to insult anyone.

It's about cooking. It's about cooking real food. It's about reading the ingredients in the supermarket. So many things that are purchased in these homes is a lot of stuff that you stick in the microwave, and hot pockets and corndogs, and I'm just speaking--

ASSEMBLYWOMAN DOWNEY: The problem is that we need to change the culture. The culture has to be changed of how these group homes view their role, and they're going to say also it's a matter of money, as well.

So we're going to have to look into both sides of this and figure out how we can--

MS. URIBE: It really doesn't cost a lot of money to buy potatoes, and season up a chicken, and make some rice.

ASSEMBLYWOMAN DOWNEY: It's not about that, it's about-- They're going to say it's about, if they had to make sure everybody was doing that, they wouldn't be able to do that. I'm sure they would come up with some excuse regarding that.

MS. URIBE: The bottom line--

ASSEMBLYWOMAN DOWNEY: You can say it keeps them healthier; the problem is that they really do want to look at the nutritional needs of their residents. They have to. So that's their job. We have to make sure they're following through. Like you said, accountability--

MS. URIBE: They're not. They're not, because I have prescriptions for my child, and letters, and in both places that he's been at, even like yesterday, I went into the pantry -- there was stuff in there that had soy in it, my son can't have soy -- you know, soy lecithin is used in everything -- so it's a big problem.

And it's a problem, because it's not an EpiPen situation for my child. It is a behavior issue.

ASSEMBLYWOMAN DOWNEY: You're absolutely right.

And I think that's the thing: That they are not, like you said, trained well enough to know these things, so that needs to be addressed as well.

And then they need-- On top of that, if we want them to be trained and to learn how to take care of their residents, the people they are caring for better, again we have to look into the whole thing about making it a better profession so that there are more involved, more invested people in the profession who want to look at it as a long-term career, and to really, you know, again, do all these things.

To invest in their knowledge regarding how they are treating all of their clients, their patients, however you want to see it -- their residents.

MS. SHAZAR: It is also the same thing -- it's never in the budget, of course -- but we can all start grant writing. I'd be glad to help. (laughter)

I mean, I'd be glad to cook; I'm Italian, I'm great, I'll be good to make lasagna, whatever I have to do.

But the cleaning-- There is no professional cleaners there. They let the kids do it, and I have seen-- I don't even want to tell you how disgusting some of these places are, but that's another issue.

That's all I wanted to say. Thank you.

ASSEMBLYWOMAN DOWNEY: I know Dr. Spitalnik is just champing at the bit to try to figure out how to work on some of these things. (laughter)

MS. WARGNYE: How about me, I bought my own food and go there and cook for everybody, the staff-- I just want to know, Assemblywoman, how can they take somebody's child in this country?

They took my child. His family needs to see my child, and they block him, and they punish him not to come to visit me.

ASSEMBLYWOMAN DOWNEY: I don't understand. We have to look into. I promise you I am going to speak to Paul.

And Paul has been, I noticed, very intense on all of this, taking all these mental notes here--

MS. WARGNYE: Please thank Paul. Please thank Paul for the miracle that he just did for me.

I think that I'm going to survive. I've just come back from the coma in hospice. I think that God let me live to talk about this issue and to serve not only my child but the four people who are in that house who don't have parents. I consider them my children.

And when I called the police, they called the police and they told the police that, "she's not allowed to get close to the children."

ASSEMBLYWOMAN DOWNEY: There are other things that I want to look into, I don't really understand some of these-- How this is allowed.

Those are all the things we--

DR. SPITALNIK: Chairwoman, I think it's also very clear that there are multiple layers of issues.

There is certainly clear agreement, as you just captured, about training of direct support professionals. There are issues of how people are assessed for their individual budgets, in terms of acuity. There are issues for, no matter how much monitoring, that there isn't transparency and including families in the information. By bringing us together you have raised-- But there are no single solutions. But it's really looking systematically.

And I think it's, again, very important that everyone has protection and safety. The issues with the children's system and the adult system are different -- different providers, different departments -- and they're going to require a different set of strategies.

So I am so grateful that you have engaged with all of us, and to the families for sharing their heartbreak we just really shared.

So thank you for your leadership.

MS. RIVERA: I just want to say thank you.

What is it going to be after you do your investigation? What is the next level? This is a hearing, now you're going to investigate. What is the next procedure, that way I can have an idea what's going to happen here. ASSEMBLYWOMAN DOWNEY: Well, I definitely am going to have a hearing on the one Bill I told you about in terms of the surveillance cameras, the Billy Cray's Law.

MS. RIVERA: Oh, another one? There's another one?

ASSEMBLYWOMAN DOWNEY: I don't know when it will be, but that's for A-4013.

MS. RIVERA: Okay.

ASSEMBLYWOMAN DOWNEY: But that's only one step. There's all these other layers as Dr. Spitalnik, and others -- what we were talking about. There's all these different things that we have to look at, and I'm sure between Assemblywoman Huttle, between the rest of my Committee members, Assemblywoman Speight, between also Assemblywoman Tucker -- who is not here, but I'm sure she will be interested in helping in all of this. We have Assemblywoman Stanfield, Assemblywoman Dunn.

We are going to all be looking into this and trying to figure out different ways that we can be able to help on all of these issues. And I'm hoping we'll all come together and talk about it, because it is so multi-layered and complex, and we're probably going to have to reach out -- not probably, we will be reaching out, I'm sure -- to a lot of you to be able to make sure we have all of the information that we need. Because you gave us enough of what we need to know there's an issue, but we will definitely need to get more details, and we'll do that, okay?

MS. RIVERA: Thank you for speaking to us, because I was not really sure. It's going to be-- This is a hearing, but it's going to be another hearing with a bill?

Okay, thank you.

ASSEMBLYWOMAN DOWNEY: Probably a few bills, probably not just one.

Assemblywoman Huttle, did you want to say something?

ASSEMBLYWOMAN HUTTLE: I just want to close, because I have, actually, another Zoom at 6:00.

And I want to thank everyone for their commitment, for hanging in there. Obviously it's the most important thing in their lives to stay with this particular Committee Hearing for four or five hours. But what I would like to say is just one thing: Thank you, Chairwoman, for making sure that everyone was heard, and that you allowed everyone to speak.

One bill will not solve this issue. I don't think one size fits all. Unfortunately, when I heard about Hunterdon, I heard about Woods -- I've also heard great stories. So, again, it depends on the situation, and we have to come up with the solutions.

We as a legislative body cannot do that without the oversight of DHS and DDD. So I just want to make that clear, and I know that you agree with me, that we will make sure they hear this testimony, and we will get answers from them after-the-fact of this hearing. Because I don't know what their testimony could have provided without hearing the families first.

And I want to thank Paul Aronsohn for being really a great liaison and ombudsman, and a caring person. I think that's what we need -- is care. And we need empathy, and to just continue to advocate. Because as everyone said, this is the moral test of government. We're helping those people that are most vulnerable.

And so I stand committed, and I want to thank you; but I want to go get ready for my 6 p.m. Zoom. And we will continue to follow this.

Thank you to everyone who stayed on the call.

MR. ARONSOHN: Thank you, everyone.

ASSEMBLYWOMAN DOWNEY: Thank you, Valerie. And DSF as well.

MS. WICHOT: Appreciate it.

ASSEMBLYWOMAN DOWNEY: Thank you, Addie.

I want to thank the people from the Assembly Majority office, so Jim and Lisa, thank you so much -- or James, I'm sorry if it's James -- but thank you so much for -- and Anita -- thank you so much for everything you did to stay on and help everybody, and hang in there this whole time.

I really appreciate it. I'm sure everyone here appreciates it.

MS. PAGE: Thank you, everyone; thank you, Anita.

ASSEMBLYWOMAN DOWNEY: Take care everyone.

Please be well, be safe.

(MEETING CONCLUDED)