
Committee Meeting

of

ASSEMBLY HEALTH AND HUMAN SERVICES COMMITTEE

and

ASSEMBLY REGULATORY OVERSIGHT COMMITTEE

Assembly Bill No. 2849

(Limits use of restraints in individual habilitation plans for persons with developmental disabilities)

Assembly Bill No. 2850

(Requires training for staff working with persons with developmental disabilities; appropriates \$2,104,740)

Assembly Bill No. 2855

(Establishes "Matthew's Law Limiting the Use of Restraints")

Assembly Bill No. 3108

(Requires DHS to place persons as monitors in facilities for developmentally disabled under certain circumstances)

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

DATE: January 16, 2003
12:00 p.m.

MEMBERS OF COMMITTEES PRESENT:

Assemblywoman Loretta Weinberg, Chairwoman
Assemblyman Herb Conaway, Vice-Chairman
Assemblyman Jerry Green
Assemblyman Gordon M. Johnson
Assemblywoman Nellie Pou
Assemblywoman Joan M. Quigley
Assemblyman Samuel D. Thompson
Assemblywoman Charlotte Vandervalk

Assemblyman William D. Payne, Chairman
Assemblyman Joseph Cryan, Vice-Chairman
Assemblywoman Nilsa Cruz-Perez
Assemblywoman Connie Myers
Assemblyman John E. Rooney



ALSO PRESENT:

David Price
James F. Vari
Office of Legislative Services
Committee Aides

Wali Abdul-Salaam
Gabby Mosquera
Assembly Majority
Committee Aides

Tasha M. Kersey
Thea M. Sheridan
Assembly Republican
Committee Aides

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

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ASSEMBLYWOMAN LORETTA WEINBERG (Chairwoman):

Good afternoon, everyone.

As you know, this is a very crowded room with a lot of people who wish to testify, so I hope you will use as much decorum as possible. Please keep the noise level down back there. There are empty seats up here. I would suggest that people get out of the aisles and the doorways there in case we have to close the door, and please come and sit in some of the empty seats that are here.

This is a joint meeting of the Assembly Health and Human Services Committee and the Assembly Regulatory Oversight Committee. No wonder I can't remember it all.

Welcome.

Before I make any statements, I would ask, on behalf of the Assembly Health and Human Services Committee, David, would you please call the roll?

MR. PRICE (Committee Aide): Assemblywoman Vandervalk.

ASSEMBLYWOMAN VANDERVALK: Here.

MR. PRICE: Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: Here.

MR. PRICE: Assemblywoman Quigley.

ASSEMBLYWOMAN QUIGLEY: Here.

MR. PRICE: Assemblyman Johnson.

ASSEMBLYMAN JOHNSON: Here.

MR. PRICE: Assemblyman Conaway.

ASSEMBLYMAN CONAWAY: Here.

MR. PRICE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Here.

MR. PRICE: Quorum is present.

ASSEMBLYWOMAN WEINBERG: Thank you.

Assemblyman Johnson is a very able substitute today for Assemblyman Edwards, who is not able to be with us.

Would you like to call the roll, please?

ASSEMBLYMAN WILLIAM D. PAYNE (Chairman): We'd like to have the roll called for the Assembly Regulatory Oversight Committee.

MR. VARI (Committee Aide): Assemblyman Rooney.

ASSEMBLYMAN ROONEY: Here.

MR. VARI: Assemblywoman Myers.

ASSEMBLYWOMAN MYERS: Here.

MR. VARI: Vice-Chairman Cryan.

ASSEMBLYMAN CRYAN: Here.

MR. VARI: Chairman Payne.

ASSEMBLYMAN PAYNE: Here.

Before we go further, Madam Chairlady, I just need to make this announcement. We have been advised that the capacity of this room is 100, and that there's going to be a need for us, when we reach that capacity, to close the door and not allow anyone else in. And that is because of fire regulations, no other reasons, no legislative reasons at all. So we're going to ask you for your cooperation. We have a uniformed officer here, and others, that will help us to keep the room -- in that area. We may be able to have a little bit of a flexibility of, maybe, a few over that. But the room capacity is 100, and we need to have people cooperating so that we will not have any hazardous conditions. Many people here are in situations where they may need to have egress easily. So, if you will cooperate with us, we would deeply appreciate it.

ASSEMBLYWOMAN WEINBERG: Okay. I'm just going to lay a little groundwork, if I can, for some of this. Assemblyman Payne, on behalf of the Assembly Regulatory Oversight Committee; and the members of the Health and Human Services Committee; as well as Assemblywoman Previte and some members of the Family, Women and Children's Committee have been involved for quite some time with trying to improve treatment for the most vulnerable in our population, and that is treatment for developmentally disabled and brain injury. In the course of finding out about the issues surrounding that treatment, what became apparent to us is that some of these issues are around the use of restraints, how they are used, how they are applied, what type of emergency methods need to be used in order to protect the person being restrained, as well as any person around them that they might cause injury to.

For that reason, this hearing particularly concerns the use of restraints. We have two bills up that talk about the rules and regulations involved with how an institution or a group home can apply restraints to the vulnerable population that they care for.

One of the bills is A-2849, which is a Previte/Weinberg/Payne bill; a second is Assembly Bill No. 2855, which is a Munoz/Gregg bill, and then we have a Committee Substitute, in which, with the help of our staff -- and I'd particularly like to thank Meredith Schalick for the work that she has done in research on this issue. We have come up with a Committee Substitute, which I understand has been out there. It has been distributed, so there are many folks who can see it. We think it combines the best of both bills. Those are the first bills we're going to call for testimony.

Your comments -- because we have many people who wish to testify -- are limited to five minutes. Gabby, who is sitting in the front -- raise your hand so everybody knows who you are -- has a timer. You will be warned when you get to the two-minute and then the one-minute time limit. We are going to cut you off at five minutes. There's no 30 seconds beyond that. We have too many people from which to hear, and we would like to hear from as many of you as we possibly have time. So, please, limit it, and limit it to the bills that are on this agenda. That is, the restraint bills that I just outlined, the Committee Substitute, and then we will go into the two other bills -- Previte/Weinberg/Payne bill, which requires training for staff working with person with developmental disabilities in the use of restraints; and the last bill, which is a Weinberg/Johnson bill and requires the Department of Human Services to place persons as monitors in facilities for the developmentally disabled under certain circumstances.

Right now, we are going to just deal with the restraint bills. So, if that's what your comments are about, please keep you comments on that issue -- the two restraint bills, as well as the Committee Substitute.

So that's the framework and the ground rules.

Do you want to--

ASSEMBLYMAN PAYNE: Just as Chairwoman Weinberg has stated, we have spent a lot of time, a good deal of time, on trying to come up with that kind of legislation that will, in fact, be fair and be effective for all the clients. You can be sure that all the members of these Committees are concerned about providing the very best for the citizens of the State of New Jersey. There are differences of opinion. There are people on both sides of the issue. There are those who have various views. We want to ask that you

respect each other's opinions and respect the work that we've been trying to do. Keep in mind, always, that we have the interest of the citizens of the State of New Jersey at heart, as all of you do, too.

So your comments will be considered for after we have this hearing. Whatever comments you've made will certainly be seriously weighed when this hearing is over. I hope that we will be able to come up with the kinds of legislation and measures that will ensure that the relatives of ours and yours, who are clients or who may one day be clients in these facilities, will, in fact, be treated fairly, and that the treatment will be effective in helping to bring them along and improve the quality of life for all of them.

So we ask that you be considerate of each other, be considerate of the time, and that gives us an opportunity to hear everyone that has something to say.

Thank you very much.

ASSEMBLYWOMAN WEINBERG: Okay. The first--

Oh, another housekeeping issue. Please make sure that when you come to the microphone -- the red button means the microphone is on, which always interested me why we choose red to mean go here, but that's the State of New Jersey. And identify yourself, because this will be recorded -- so when the OLS staff needs this, so that when they do the printed testimony, we know who you are and who spoke. Please remember to do that. The microphones are in the front.

With that, the bills that we are considering at this moment are A-2849 and A-2855. I'm going to ask Assemblyman Munoz to come forward, if you are here.

ASSEMBLYMAN ERIC MUNOZ: I was hiding.

ASSEMBLYWOMAN WEINBERG: There you are. Thank you.

ASSEMBLYMAN GUY R. GREGG: I assume that means me, too?

ASSEMBLYWOMAN WEINBERG: Yes. I'm sorry.

Assemblyman Gregg, the co-prime sponsor.

ASSEMBLYMAN MUNOZ: I absolutely want to wish everyone good afternoon. I thank the Committee Chairs, Assemblyman Payne, Assemblywoman Weinberg, for allowing me to speak. Thank you, all the members of these joint Committees, all of which I know and respect very much.

I also want to thank Assemblyman Guy Gregg, who is co-prime sponsor of Assembly Bill No. 2855, and the other cosponsors of the bill that include people of both parties.

I guess I should identify myself. I apologize. My name is Dr. Eric Munoz. I'm an Assemblyman from the 21st district of the State, and also I am a Professor at the University of Medicine and Dentistry of New Jersey, at Newark University Hospital.

Over the last 25 years, I've done a lot in health delivery, from taking care of people, from being on all kinds of review bodies, State and Federal, local government. I live in Summit. I've been on their Board of Health. Last night I worked all night at University Hospital. As you well know, University Hospital has become a center of focus of a couple of kids up there, that I've seen, that we have to look -- and indicate how well we've been able to look after our citizens. Two kids that were locked in a basement are in our hospital and doing well. We have to say to ourselves, "Are we doing everything for our citizens, and can we do better?"

Now, relative to Matthew's Law and to restraints -- August 22, the Division of Developmental Disabilities made a number of findings relative to Matthew Goodman. And those findings were that Matthew Goodman died a preventable death. That means that because of the way he got treated, the way we as State officials, and we in charge of his treatment -- that Matthew Goodman died. They developed a number of findings, had various citations. But we have to look at that and say, can we do something better? And I would say, yes.

I've introduced the law, and the law deals with restraining individuals that are under care of the State. I would go back and say-- I work in an acute-care hospital. Twenty years ago, when I was a student, we could restrain people willy-nilly. There were very lax regulations. Those regulations have changed. Last night, for me to restrain someone required tremendous monitoring, a system that guarantees that we do it only as a last resort. We have to ask ourselves, in these homes, in these areas with kids and young adults that are troubled, are we sure that they're being only restrained as a last resort, number one; and if they are restrained, do we have a system in place that guarantees -- and I say guarantees -- that their care is proper, and they're not locked in a cellar, and they're not locked in some room, and they're not tied up with football helmets, and their head and their arms or their legs tied. When you look at the facts of these cases, I would say, whether you're a State Legislator or a citizen, you would be very troubled.

Just real quickly on what Matthew's Law does, it reduces -- doesn't eliminate -- but greatly reduces the use of restraints, and the mechanism that they're used. It increases the monitoring and accountability when restraints are used. It's modeled after other states that have recommended these changes.

There are components of staff training regarding the use of restraints, and there's also a Web site for public information relative to restraints.

I would close and say this. All of us -- and I agree with what Assemblyman Payne said, and Assemblywoman Weinberg -- want the best for our citizens of the State. I urge you, this is not about politics, this is about health. I got involved in this whole endeavor because I wanted and cared about people's health. I'm not a politician, and I would say this: I would say for all of you, make sure that we guarantee that our citizens are safe. I think there, right now, is a lot of public doubt, going back to the case in Newark: Are we doing the best for our citizens? I ask you to pass Matthew's Law.

Thank you.

I'm happy for any questions.

ASSEMBLYWOMAN WEINBERG: Assemblyman Gregg.

ASSEMBLYMAN GREGG: Thank you, Madam Chair.

Thank you, Chair.

I want to be very respectful for your time frame today. I can see you have a lot of folks to listen to, and quite frankly, I think that will be the best testimony that you will hear today.

Somebody would say, "Why is Assemblyman Gregg on this bill?" I started this road a long time ago, Assemblyman Payne, when I was the Chair of Regulatory Oversight. When I took over that Committee, or began that Committee, actually, I wasn't sure where that road would take us, and I had no idea that that road would take us into the health care of our citizens as dramatically as it did, and how that Committee dealt with those issues, which were not necessarily the issues I thought would be coming to my table first. The issues of the way we deal with our most vulnerable came about in that

Committee, and some of the, quite frankly, horrors that we do in some of our institutions came about.

I congratulate Assemblyman Munoz, and any of you, who have put your names on any of these bills. But I want to come as a parochial person today, thinking that our bill is best. It's not because our name is on it, it's because it's the toughest one. There's no question, when you talk about public health, it's not compromisable. We can compromise about 70 miles an hour or 65, we can compromise on many things, but I don't think at this time and place in our State is the time we should compromise on whether or not one bill is stronger or weaker than another. I don't think a brain-damaged individual, due to something that happened to them, like a drowning or something of that nature, should be considered differently than a autistic child. Because their behavioral situations may be the same, we shouldn't treat them any differently.

There may be testimony today to say we may be going too far with our bill. I say you cannot not go too far in this issue. You can't. We, as legislators, owe that to our citizens. We've let people die. That's serious stuff. So I don't think we should be debating about paragraphs and is's and of's, there should be more shall's today. And quite frankly, if anything in our bill is too stringent, I think we can deal with that six, nine, or 12 months later, talking about the stringency because we saved too many lives, as opposed to having one more child or citizen falling between the cracks.

So I come to you today -- listen to the testimony of these folks, look at the documents in front of you, and from my standpoint, take the toughest one.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you very much, Assemblymen.

Are there any questions for the prime sponsors of one of the three bills we're--

Don't take this personally, but we hope to keep the questions from us to as minimum amount of time as we can, so that we can hear from the audience. But -- sorry, Herb. (laughter)

Assemblyman Conaway first. (laughter)

ASSEMBLYMAN CONAWAY: Madam Chair, I think that was a personal comment. (laughter)

ASSEMBLYWOMAN WEINBERG: I was anticipating something.

ASSEMBLYMAN CONAWAY: Thank you, Assemblymen, for your presentation. I did have a question, in looking over some of the provisions of the bill. I wondered if you might not describe to me how the county-based human rights review board will work in the context of this legislation. I'll leave it at that.

ASSEMBLYMAN PAYNE: Speak into your mike, please.

ASSEMBLYWOMAN WEINBERG: Turn your mikes off. It can only be one--

ASSEMBLYMAN MUNOZ: They're off.

ASSEMBLYMAN GREGG: They're off.

ASSEMBLYMAN PAYNE: They're off.

ASSEMBLYMAN CONAWAY: I wondered how you envisioned the county-based human rights review board working in the context of this bill, and are there parallels to this? I'm thinking of the investigational review boards that hospitals sometimes use when you are dealing with experiments and things

like that. I see you have a position on who should serve on these boards. How do you envision that it will work? My concern, of course, will be, as I am a physician, and do believe in the -- I don't know, I don't know what the proper word is -- but I believe in professionalism as applies to health care, certainly. I'm wondering, do you think that this board will be in a position of second-guessing the decisions that health-care professionals make and as regards to treatment plans?

It's struck from the bill? Okay. So you guys don't know about-- That's not part of your, well--

ASSEMBLYMAN MUNOZ: Well, actually, I do, Dr. Conaway. It's an excellent question, and I'd be happy to answer, but a good question.

ASSEMBLYWOMAN WEINBERG: It is in the Committee Substitute.

ASSEMBLYMAN CONAWAY: Oh, okay. Sorry.

ASSEMBLYWOMAN WEINBERG: So, if you want to comment--

ASSEMBLYMAN MUNOZ: You know, would I just comment-- Dr. Conaway is talking about-- My concept of that is it would be an oversight group. There are other states that have it, Herb. I think that physicians and other health workers don't like to be oversaw. I'm a surgeon. We do. The reality of medical care in America in 2003, we have lots of checks and balances. So I see this -- when, I think that particular feature, which is not in Matthew's Law, is positive in the sense that it's an oversight, and there are other states that have implemented that. It's not a component of Matthew's Law, though.

ASSEMBLYMAN CONAWAY: You would agree, however, that the oversight is not, generally, by nonprofessionals, it's by your peers. And if there's an issue -- of course, things sometimes get into court, if somebody thinks

they've been injured. But generally, physicians are not in a position of being reviewed by nonphysicians as regards to their professional positions. Isn't that right?

ASSEMBLYMAN MUNOZ: The only way it's going to work is peer review. In any field, that's the way it's going to work.

ASSEMBLYMAN CONAWAY: And peer review.

ASSEMBLYMAN MUNOZ: Yes.

ASSEMBLYMAN CONAWAY: Emphasis on peer.

ASSEMBLYWOMAN WEINBERG: Assemblyman Rooney.

ASSEMBLYMAN ROONEY: Thank you, Madam Chairman.

I'm always interested in the geneses of bills, particularly on this one, because I know a little bit about the history. I know that Bancroft seems to be the target in question. I know that Matthew Goodman was, basically -- he was neglected, and as a result died. Actually, he was restrained and was-- It's a horror story. It's an absolute horror story from what I've been reading, and I'd like a little bit more about the genesis. And, also, the question I'd like to ask beyond that is -- has this happened in other facilities? Because we're looking at a whole group-- I belong, or actually I'm on the board, for three different organizations: New Concepts for Living, Spectrum for Living, and Life Opportunities. And right behind my house, I have another group. Bob VanQuinton (phonetic spelling) is here representing that group. And there's a group home, probably, within about three houses from my backyard. I was a little bit helpful as the mayor of the town to bring that facility there.

I'm concerned with the treatment in all the facilities. I'm concerned that one person would die as a result of being treated in one of these facilities. That bothers me. I'd like a little bit more about the genesis. I'd like to know

about Bancroft. I'd like to know if there's anything beyond Bancroft, because I don't want to throw out the baby with the bath water. And then I, also, see in some of our notes that Bancroft was issued an order to comply by January 2, 2003. It says here, "If Bancroft fails to come into compliance, DHSS will file an application for receivership." Has that happened? Do we know--

ASSEMBLYWOMAN WEINBERG: I'm going to interrupt you, Assemblyman Rooney, since I'm in charge of this portion of the questioning, and Assemblyman Payne will do the next. This is not a hearing on Bancroft. This is a hearing about the use of restraints, and that's why I spelled out the parameters at the very beginning. In our work, collectively, we found that many of the problems that are coming out of the treatment, particularly of developmentally disabled, revolve around the use of restraints. So we do not want to get into a hearing that we were not put into--

ASSEMBLYMAN ROONEY: Madam Chairman, there's one problem with that philosophy. And this is called by both versions of the bill, Matthew's Law. It's called Matthew's Law for a particular reason. It's Matthew Goodman and what happened to Matthew Goodman at a particular facility. I think it's very pertinent as to what happened, and I think that should be on the record because we have -- we're making a physical record. So I asked the question.

ASSEMBLYWOMAN WEINBERG: I know we will get testimony about what happened, but I just want to make very clear that what happened in this tragic case helped bring this discussion to the forefront. This is not a hearing on a particular institution.

ASSEMBLYMAN ROONEY: Okay. But again, I'd like to know if this is the exception or is it the rule? Is it happening in other facilities?

ASSEMBLYWOMAN WEINBERG: Well, I will tell you that I have heard talk and heard from parents that there is a disagreement with the way restraints are used, and that's what we want to talk about today.

ASSEMBLYMAN ROONEY: Okay. I have no problem with that. Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you.

Assemblyman Cryan.

ASSEMBLYMAN CRYAN: Good afternoon, and thank you both for being here.

I just have a couple questions. My questions are to the Committee Substitute, in particular, on Page 2, and they're also put on your original bill. Three-quarters of the way down the page, "the person is given the opportunity to move and exercise the parts of his body that are restrained at least 10 minutes for every 60 minutes of restraint." And then the follow-up to that is, "a member of the staff lessens or discontinues..." My concern here is -- and I don't have the knowledge that a lot of these folks -- and for better or for worse, I haven't toured one of these facilities. So, educationally, if you could help me. My concern is staff. I mean, clearly, one of the things that jumps out to me -- whether you referred it to Newark last week, or -- is that maybe staff issues aren't there. Yet we seem to increase the regulations here and the demand for the need, and, in particular, these two particular instances jump off the page at me.

Do we, in your opinion, have the staff necessary if we implement these changes, or is there a fiscal concern as well?

ASSEMBLYMAN MUNOZ: Through the Chairs, good question, Assemblyman. The bottom line is this. If you really look at the whole issue of

restraining, 20 years ago we used to be able to write willy-nilly. In hospitals, people got restrained. We've had to change. We had to train staff, and we've had to actually have additional staff. The bottom line is, I don't like people-- The reason I got approached, initially, about this -- I have to, periodically, tell people a loved one is gone or critically ill. I don't like that. And one person, if we could save one life or two lives or 10 lives, and it costs the State whatever it costs, I mean-- I was told years back in medical school, can we put a price on human life? The answer is no.

So I suspect there will be some associated changes needed. But if your son was in the facility, and I was the doctor, and I was to tell you that your son was gone because of this problem, that just doesn't cut it.

ASSEMBLYMAN CRYAN: With all due respect, it's not a question of whether it's my son or your son. It's a question, we have a bill in front of us, and I just want to understand without the emotionalism of it. Is there a cost impact, and do you have any idea as to what it may be?

ASSEMBLYMAN MUNOZ: I would say this. That over the years, there would be some cost associated with training, with doing things differently -- I mean, I'm an expert in medical financing -- I'd be ridiculous to say not. On the other hand, if we don't do it-- I mean, just read the front of the paper. I don't like doing that.

ASSEMBLYMAN CRYAN: I don't argue with you about the need. Again, to reiterate one last time about being argumentative, I just clearly want to understand, is it your envision that we would need additional staff as a result of the additional-- Clearly this bill, well-intentioned and clearly, I think, favorable, does anybody have any idea of what the fiscal impact is?

ASSEMBLYWOMAN WEINBERG: Assemblyman Cryan, the bill that talks to training, which will come up a little bit later in our agenda, has a very big cost attached to it and--

ASSEMBLYMAN CRYAN: That I understood, Madam Chair, and I know that that's not part of this bill. My concern was specific to those points of the bill, and do we have any -- do we or don't we? I don't think it's that unreasonable a question.

ASSEMBLYWOMAN WEINBERG: Whether you would need additional staff.

ASSEMBLYMAN CRYAN: That would be my--

ASSEMBLYWOMAN WEINBERG: Oh, I'm sorry.

Go ahead.

ASSEMBLYMAN CRYAN: And one last follow-up to the sponsors, and then I'll-- Are there any other conditions in this bill besides the two that I highlighted that you feel, or in areas -- because clearly you gentlemen have worked hard on this for years and years. Is there any other areas in this bill that we need to identify additional staffing levels for?

ASSEMBLYMAN MUNOZ: Assemblyman, I think that, as you pointed out, it's a good question. Really, it is. If we make this kind of a change, which is going to be a major change, you're going to hear people coming and say, "This is a major change." It's just like we did in hospitals over the last 20 years. It's going to be associated with changes in behavior and costs. There's no question about it, on the other side there's the human life side.

ASSEMBLYMAN CRYAN: I understand that.

Thank you.

ASSEMBLYWOMAN WEINBERG: Assemblywoman Quigley.

ASSEMBLYWOMAN QUIGLEY: Thank you, Madam Chair, and I will be brief. But there are other human lives involved, too, and I wondered if Dr. Munoz could speak to the question of staff safety. I had the unique and -- and I have to say, even in retrospect -- unpleasant experience of working three years in a mental institution. I know that there were times when the patients there acted out in such a manner that for the staff to unrestrain them for 10 minutes and let them exercise their limbs, they were in great danger. There had to be five or six staff persons present in a locked room when this happened.

So what is your impression of -- certainly we want to protect the safety of patients, but we can't ignore the safety of staff as well.

ASSEMBLYMAN MUNOZ: Assemblywoman, that's an excellent question. I started my medical career -- and to some of you, this dates me now -- at Marlboro State Hospital in the '60s. And if you ever saw the movie *One Flew Over the Cuckoo's Nest*, it was exactly like that. There's no question that sometimes patient and staff safety really is a factor, although medicine in the year 2002 has advanced so that there are ways that do take staff safety-- You don't want someone running berserk, through, and hurting people. But there are ways to deal with that. I'd say go back 40 years, to *One Flew Over the Cuckoo's Nest*, we don't want that in New Jersey anymore either.

ASSEMBLYWOMAN QUIGLEY: But medication -- I assume that's what you're referring to, has its drawbacks as well. We don't want patients who are continually overmedicated.

ASSEMBLYMAN MUNOZ: Absolutely. Correct.

ASSEMBLYWOMAN WEINBERG: Assemblyman Conaway.

ASSEMBLYMAN CONAWAY: I would just follow on what Joan said, Assemblywoman Quigley, that there are also questions of the safety of

other patients in the institution. Now, my background in this is that I serve on the Board of Family Service, and we deal with -- as a trustee -- a social service organization that deals with people who have mental health problems, developmental problems, and providing group homes and other services to them. And understand, in my dealings with the professionals there, that these are well-trained people, professionals, who have decided to dedicate their lives to people with very serious problems. They approach this as I hope all -- we in health care do, with always putting the patients' interests first and foremost.

One of the things that I wanted to ask you about is in your bill, the definition of aversive technique. I raise this now -- often we do this toward the end -- but while you're here and can think about it. I wondered whether or not you thought about -- and I'm going to suggest this to you, and I'm going to bring it up later as we get through the end of this bill and the definition of aversive technique -- that there should be some additional wording there that would outline or define the fact that the aversive technique should be used when the risk of not applying the aversive technique is greater. That is, the risk of physical or psychological injuries greater than not applying. And of course, you know in medicine, we always do risk benefit analysis for every modality and treatment that we apply. We have to always make a balance, always focusing on what's best for the patient.

So I was wondering whether or not, as we go through these deliberations and hear testimony, whether or not we might not tighten up this definition by adding in some wording that would suggest that we look at the consequences of not applying these aversive techniques, as they're described in the context of physical or psychological injury.

ASSEMBLYMAN MUNOZ: Dr. Conaway, can I respond to that question?

ASSEMBLYMAN CONAWAY: Please.

ASSEMBLYMAN MUNOZ: First of all, it gives me a great thrill to actually be asked the question by a fellow Assemblyman, who is also a physician. Congratulations, Dr. Conaway.

I want to just say, for the record, that I have the highest respect for people who work in these facilities. I mean, I've been to these facilities. It's a very challenging thing. A lot of the patients are difficult, and I have the highest respect for the doctors, for the allied staff, for the nurses. Relative to aversive technique, Herb, that really gets down to the medical decision-making. I was shocked. I'm a surgeon. I'm not a psychiatrist. I was shocked, and I think, probably, people in this room would be a little bit concerned about the whole idea of aversive technique. And basically, to educate you, that means you do things that try to present noxious stimuli to try to change behavior. Now that can be relatively mild, or it could be not so mild.

So I agree with you, that whatever we can do to tighten that part of the regulation or the law would be very important. And we want to try to keep these as tight as possible and make sure it's a medical decision, because those are the doctors that are caring for these people.

ASSEMBLYMAN CONAWAY: That raised -- just a follow-up. Because somewhere in the bill, they talked about the use of braces for bringing about alignment. And I'm thinking this is what a rehabilitation physician does as part of their training. To think that someone is going to review a brace -- a decision to apply a brace, a non-trained person, that struck me as odd. And so, I think these definitions, as they occur throughout the bill, need to be looked at

very precisely. I agree with you that the aversive-- I'm uncomfortable with the use of that word. I'm not sure that a cast -- you know, you cast someone's arm -- is that aversive? Well, that certainly treats the fractured arm or helps to align a joint that's out of place.

So I agree with you, there's a problem with that term. I wish we could come up with a restrictive, perhaps, or some other technique, recognizing, of course, that we are talking -- we should be talking globally and contextually. That is, a treatment plan includes something that is restrictive and something which is not so, which is perhaps a positive.

ASSEMBLYWOMAN WEINBERG: Okay.

Thank you very much.

ASSEMBLYMAN MUNOZ: Thank you.

ASSEMBLYWOMAN WEINBERG: And now I'm going to turn--
Oh, I'm sorry. I wasn't fast enough.

Assemblyman Thompson.

Remember what I said. We have a very large audience out there, so please, Committee members, hold your questions to simple questions where you really need information.

Thank you.

Sam.

ASSEMBLYMAN THOMPSON: Thank you, Madam Chair.

First, I have a comment in regards to one point raised by Assemblyman Gregg, and then a question for Assemblyman Munoz.

Assemblyman, you expressed your concern relative to who may or may not be included in the definition of traumatic brain injury patients, that -- in other words, the ones it may apply to.

Upon sitting down here, I received the comments from the Division of Developmental Disabilities, related to the legislation here. One of the recommendations that they make is a modification in the definition of traumatic brain injury. They recommend “means an acquired injury to the brain. Such term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to trauma.” So, if the sponsor should choose to make that modification, I think it would head in the direction that you’re speaking of there.

Assemblyman Munoz, one of the significant differences between your proposed bill and the Committee Substitute is that your bill would restrict the use of restraints only to emergency situations. Whereas, the Committee Substitute includes where it is included in the individual health plan.

ASSEMBLYMAN MUNOZ: Right.

ASSEMBLYMAN THOMPSON: One of my concerns here is, for example, what was referred to by Assemblyman Conaway, where an individual’s problems are not something that you’re going to rectify in minutes, hours, or even a day or so. But the individual represents a continuing threat to himself or to others. Under these circumstances, to me that would not constitute an emergency. I mean, if it is an on-going, continuous problem that is there, that’s not my definition of emergency. I would be concerned that if we were not permitted to include it in the individual health plans, then, okay, it’s not an emergency. It’s something that is there, every day, day in and day out. So I’m afraid that would be excluded under your bill -- utilization of restraints.

ASSEMBLYMAN MUNOZ: Through the Chair--

ASSEMBLYWOMAN WEINBERG: Yes.

ASSEMBLYMAN MUNOZ: Assemblyman Thompson, you're really bringing a key point, and let me explain this clearly for the Committee. If you go into a hospital, I, as a doctor, I have a health plan for you -- you have a heart attack, you're shot in the head, whatever it is. If I put in that health plan, just like these kids and these young adults that we could restrain as needed, that basically means that restraint is needed. What we're saying is that if, in fact, someone is going to be restrained, I don't, as a doctor, just write it willy-nilly in the health plan -- everyone that comes into a hospital, everyone that goes into a facility has a health plan. But if it's required that something different happens -- there's a different evaluation, a different monitoring, a different tracking -- that is what's happened in America's hospitals. That should happen in these facilities. If it doesn't happen, we're going to keep reading the same thing.

So it is an important part, Assemblyman, and it's an important part of the bill that you're looking at and we're talking about today, versus once you say, "Write it in the health plan." Every person who goes into a facility has a health plan. Basically, there won't be much change.

ASSEMBLYMAN THOMPSON: Madam Chair, I agree with one--

ASSEMBLYWOMAN WEINBERG: No. No. We really have to hear from the audience.

ASSEMBLYMAN PAYNE: Exactly.

ASSEMBLYWOMAN WEINBERG: Please. You'll have time to comment later.

ASSEMBLYMAN PAYNE: I was going to suggest that those of us -- we can question our colleagues at other days, other times. We hear their

testimony. But it's extremely important. We have countless people who want to testify.

ASSEMBLYMAN MUNOZ: Just get me off, Assemblyman.

ASSEMBLYMAN PAYNE: Right.

ASSEMBLYMAN MUNOZ: Do you want us to stay up here, or--

ASSEMBLYMAN PAYNE: So, if we can do that, if we can limit our, the Committee members, questions and then get some responses. But we can always be in touch with our colleagues if we have questions about their legislation later on. But I think we should try to give our audience an opportunity to speak.

ASSEMBLYWOMAN WEINBERG: You're on.

ASSEMBLYMAN PAYNE: Thank you very much.

I'm going to ask for Dr. Judith Favell to come to testify now, please.

UNIDENTIFIED SPEAKER FROM AUDIENCE: She stepped out to the ladies' room. (laughter)

ASSEMBLYMAN PAYNE: She did? Well, she missed her chance.

ASSEMBLYWOMAN WEINBERG: Doesn't that always happen at the Academy Awards? (laughter)

ASSEMBLYMAN PAYNE: We can move on.

Let's have Colleen Thoma, please.

Colleen. Is she here? Doctor? She can identify herself.

Make sure you keep in touch -- our timekeeper will keep in touch with you, and will let you know when you're--

Doctor, please identify yourself and your affiliation.

COLLEEN A. THOMA, Ph.D.: Yes. Hello. Thank you.

I am Dr. Colleen Thoma, and I work at Virginia Commonwealth University. I'm a professor there of Special Education. I've been there since September. Prior to that, I was a professor at the University of Nevada at Las Vegas, and while there, I worked with other members of the Nevada TASH group to pass Nevada Assembly Bill No. 280, which is very similar to Matthew's Law. It prohibits and/or restricts the use of aversive behavior techniques for all children and adults with disabilities. That bill was signed into law in the summer of 1999 and has been in effect in Nevada since then.

I'm here today on behalf of Assembly Bill No. 2855, known as Matthew's Law. I urge you to vote in favor of its passage. Like Nevada's law, Matthew's Law would have both in-place restrictions on the use of restraints, as well as training to staff that teaches them other techniques. What happens is, if restraints are used as part of an everyday plan as the habilitation plan, that is the first step that staff go to. There isn't the recognition that the behaviors are occurring for a purpose. That is often the only way children and adults with disabilities can communicate that something's wrong, that they don't like what's happening. And so the challenging behaviors occur. And if all we do is stop it, we don't teach them something else to do to communicate that to change the situation, and we don't have the long-term effects that are possible with positive behavior supports.

I know this works, not just from an ivory tower. I read it in a journal perspective. But I worked, prior to going for my doctorate, at an agency in Pittsburgh that worked with children who had failed everywhere else. This was kind of their last resort. They had failed because of the challenging behaviors, because they would hit people, because they would kick, because they would abuse themselves. They came into our program. We learned why

those behaviors occurred, and then we found ways to teach them other things to do. We were able to move them, then, from these group homes into living with families. They had friends in the communities. They went to regular schools. And those kind of long-term, really positive outcomes don't happen when you use just restraint and just stop the behavior.

The training was important in Nevada when the bill was passed. We didn't see an increase in kids being hurt. The emergency restraints were used until staff learned other approaches, until the children learned the other ways of communicating, and all of that did take a while. For the agencies that used really good positive approaches' trainings, we saw a decrease in the number of restraints. For those that used restraint training or crisis intervention training, it was just, really, another rubber stamp to have them use restraints again and again.

So today I urge you to be the voice of hope and to tell agencies in New Jersey that citizens with disabilities won't be hurt, humiliated, or worse -- killed -- in the name of treatment anymore. Vote instead for Matthew's Law, Assembly Bill No. 2855.

Thank you.

ASSEMBLYMAN PAYNE: Thank you.

Do we have any questions for Dr. Thoma?

ASSEMBLYMAN CRYAN: I have one.

ASSEMBLYMAN PAYNE: Assemblyman Cryan.

ASSEMBLYMAN CRYAN: Thanks, Doctor. Has it been your experience-- One of my concerns about this bill is that the result of putting more emphasis on restraints or putting more legislation on it will, in fact, keep the child institutionalized. I think the goal of everyone is to get children and adults

into group homes and out more in a society environment. Yet one of my concerns with this legislation is that if we vote for it, in fact, we restrict that option, because group homes wouldn't be able to handle the compliance in this the way an institution would. So, in fact, I'm kind of concerned that a reverse impact would happen -- we would keep more people institutionalized as a result. I don't know whether that's correct or not, but -- your experience here, and you touched upon it -- could you expand upon that concern and see if that makes sense?

DR. THOMA: Yes, thank you.

It was a concern. It was a concern for the other Assembly folks in Nevada as we worked for AB-280, but the opposite really was the case -- is that as we taught students more skills, as we really habilitated instead of just controlled what they did, they were more successful in the group homes. They were more able to move into even less restrictive environments. Maybe, again, a little bit in Nevada, because it's been a shorter period of time, but even more so with what we saw in Pennsylvania.

ASSEMBLYMAN CRYAN: So you're of the agreement that if we do more training and less restraints we can, in fact, create a more positive environment and maybe move towards more group home environments, as opposed to institutions.

DR. THOMA: Yes. And I think that, again, the type of training is really important, that we don't just use this crisis intervention training that teaches a little bit about de-escalating, but a whole lot about how to do restraints well. Again, it's another tool that people that feel more comfortable in using restraints -- and are more likely to use it.

The other point I wanted to make about the training is that in Nevada we didn't ask for or receive an extra dollar for training. We reallocated the money that was already there for group home staff and school district staff. For training, we just included more positive behavior support training, instead of the crisis interventions.

ASSEMBLYMAN CRYAN: Thank you.

ASSEMBLYMAN PAYNE: I'd just like to underscore that part. Was there additional moneys needed for training, or whatever? Just repeat what you just said about whether or not it cost more?

DR. THOMA: Yes. Again, we did not ask for or receive any additional money for training, as a result of the passage of 280. We just reallocated training dollars that were already there.

ASSEMBLYMAN PAYNE: Assemblyman Rooney.

ASSEMBLYMAN ROONEY: I was just thinking that, if she can't answer this question -- but somebody here should be able to answer it. We don't do any training dollars for any of these people in these group homes that we have, currently. So they're reallocating dollars. I'm concerned that there's no appropriation attached to this bill to deal with this. Each of these individuals and clients in these group homes, basically, have a contract with the State of New Jersey through the DDD. It runs, probably, about \$50,000 a year. I don't know the exact numbers at this point, but we're paying for that. I think there has to be an appropriation on this. They can reallocate. We can't reallocate anything because it's a matter of the services. There has to be a training component in here, and it has to be an appropriation.

ASSEMBLYMAN PAYNE: Reallocation, Doctor, from what -- another pool of money, correct? It wasn't additional moneys?

DR. THOMA: Right.

ASSEMBLYMAN ROONEY: It was training money for the staff.

DR. THOMA: Right. It was built into the state, but also, we found other grant opportunities, other people out there already doing training. There is a group in Oregon who, as part of their training, need to come to every state and--

ASSEMBLYMAN ROONEY: Well, you have to understand. There is no training, currently, for any of the staff, and there should be. There should be a totally separate bill dealing with training of people in these facilities. The problem is, too, we're talking about people who are making an average of \$7 an hour in New Jersey.

DR. THOMA: Right.

ASSEMBLYMAN ROONEY: So that this is another problem that we have. And we'll be hearing about that later, I'm sure.

ASSEMBLYMAN CONAWAY: After you.

ASSEMBLYMAN PAYNE: Thank you.

ASSEMBLYMAN CONAWAY: Just for the record. Having worked -- again, from my background working with a social service organization, working in the field of mental health, we, as part of our budget, have training that goes on all the time -- in-service training and other training.

Now someone may argue that it's inadequate. There's not enough of it. But to say that there's no training--

ASSEMBLYMAN ROONEY: There isn't.

ASSEMBLYMAN CONAWAY: --I think, is not accurate, respectfully.

ASSEMBLYMAN PAYNE: Thank you.

ASSEMBLYMAN ROONEY: May I just respond to that. I'm talking about the group homes that are operated by the people here. There is no training required for those people. Whatever the group home organizations do is not included by anything in State law or anything in our State budget. They're given a contract per person to basically house, feed, cloth -- the whole thing. So, in Health and Human Services, yes, there's plenty of training available. But in the independent groups that run these homes, they're not required by law, and they should be.

ASSEMBLYMAN CONAWAY: You said, "required by law," but we have a certification that we have to undergo, and our group homes are studied. There is an accreditation body and looks at aspects of training in our program, and it's part of our accreditation going forward. Not everything needs to be done by State law regulation, as I think you well know. But it's there as part of accreditation, and then, therefore, your ability to get access to State and Federal funding.

ASSEMBLYMAN PAYNE: Thank you.

Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: In answer to Assemblyman Rooney, A-2850, which is on our agenda today, is a separate bill requiring the training. It calls for the appropriation of \$2,104,740, and does state that it covers both private and public facilities.

ASSEMBLYMAN ROONEY: We're talking about current laws, Sam.

ASSEMBLYMAN THOMPSON: That is a separate bill.

ASSEMBLYMAN ROONEY: But I'm talking about a current law.

ASSEMBLYMAN PAYNE: Thank you.

Thank you, Doctor.

ASSEMBLYWOMAN WEINBERG: Is that Roy Carbone, from People Support Network. (no response)

S E L E N A A L L E N: Hello. I'm Roy's assistant, and I'll be saying his testimony for him.

ASSEMBLYWOMAN WEINBERG: Yes. Are there other people from your organization, here, that wish to testify? Well, why don't you come up at the same time if possible.

MS. ALLEN: Yes. My name is Selena Allen.

ASSEMBLYMAN PAYNE: And you'll identify whoever else is with you, please, Ms. Allen.

ASSEMBLYWOMAN WEINBERG: Ms. Allen, are you going to start on behalf of everyone?

I actually can't see who's speaking here.

ASSEMBLYMAN PAYNE: Just speak up, that's all.

All right. That's okay.

ASSEMBLYWOMAN WEINBERG: And let me reiterate, if you're not speaking into a microphone up at one of these tables, it will not come across for the transcript.

UNIDENTIFIED SPEAKER FROM AUDIENCE: (indiscernible)

ASSEMBLYWOMAN WEINBERG: You know, I'm really sorry. I don't want to put you to any more stress in terms of getting up here, but as I said, if your voice is not in the microphone, it won't come across in the transcript.

ASSEMBLYMAN PAYNE: Where's Mr. Carbone? Just raise your hand, or -- okay, if you're back there. If you'd like to come up, we can, also, arrange for you to get up here, too, if you would like to.

ASSEMBLYWOMAN WEINBERG: In fact, Assemblyman Conaway just pointed out, this is something for us to consider in the future in terms of having a portable microphone in here that could be hooked up.

So, thank you.

K A T E B L I S A R D: I'll start one more time.

Ms. Allen is staff person for Roy Carbone; and next to Ms. Allen is Mr. Ed Palermo; and next to Mr. Palermo is Robert Fesel -- all members of People Support Network. Mr. Fesel will use an electronic speaker, but we have done this before, and it will be picked up by the microphones. But it may take a moment to start the Liberator, if you could bear with us.

ASSEMBLYWOMAN WEINBERG: We will certainly bear with you.

Thank you, and welcome.

And Ms. Allen, do you want to start?

MS. ALLEN: Yes, I can start.

Good afternoon.

"My name is Roy Carbone. Thank you for the opportunity to speak today. I am a person with a significant disability. I am a disability advocate. I am here to say that no human being should be put in restraint because they have a disability. Restraints must not be the first or only way to help any person deal with any disability. There are other ways to help. There are people here today that can tell you about these humane ways.

I have served on the New Lisbon Developmental Center Human Rights Committee trying to solve the problems of abuse and neglect for people with disabilities who do not have a voice of their own. I have friends and colleagues who have suffered abuse, neglect, and isolation, and all in the name of treatment. People with disabilities have a right to receive services that do not cause violence, pain, or death.

How many people with disabilities have to be hurt or die before something is done? Your help is needed.

Thank you. Roy.”

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Your next person.

EDWIN PALERMO: My name is Ed Palermo. I’m here today to speak on Matthew’s Law. I, myself, was a resident in an institution and was threatened with restraints and handcuffs. I’ve watched most of my friends being put in handcuffs and locked away in isolation. Nobody deserves them. Nobody deserves to be in restraints. There are other ways.

I spent 19 years in an institution and watched half of my friends being put in handcuffs and restraints, and nobody deserves that.

I thank you.

ASSEMBLYWOMAN WEINBERG: Thank you. Thank you very much.

Next person there.

ASSEMBLYWOMAN VANDERVALK: Madam Chair?

ASSEMBLYWOMAN WEINBERG: Yes, Assemblywoman.

ASSEMBLYWOMAN VANDERVALK: May I just ask-- When you saw your friends being put in handcuffs and restraints, were they acting out somehow, or was this just normal procedure that they -- was on a regular basis?

MR. PALERMO: Well, they've had-- Some of my friends have gotten into fights where the campus police had to be called. They mainly just put the handcuffs on them just to put them on. Nobody deserves that.

ASSEMBLYWOMAN VANDERVALK: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Okay. The next gentleman.

R O B E R T F E S E L: (speaking on a Liberator) Good afternoon. My name is Robert Fesel. I live and work in Mercer County. I am here today because I am a man with cerebral palsy, and I can think for myself. I know the isolation of not having a voice to be heard. I know the terror of being restrained against my will and for no other reason than having a disability. I know because it has happened to me. It shouldn't happen to any person, especially a child.

Restraints are wrong because they put a person in danger, not safety. Restraints are wrong because they do not correct, they punish. Restraints are wrong because they rob the person and the caregiver of their dignity and humanity. Restraints are wrong because they stop us from striving for more humane ways of treating people with serious disabilities.

I come here today to raise my voice, to be heard, to say no more harm, no more hurt, no more inhumanity. No more restraints that kill. There is a better way.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Assemblyman Payne.

ASSEMBLYMAN PAYNE: Yes. Mr. Fesel, we have heard, a second time, that you were in restraints. I think the person that testified before you said, also, but that the people he saw in restraints was because they got in a fight with campus policemen, etc., etc., etc. You said you were placed in restraints. Under what conditions? Is it just used willy-nilly, or under what conditions have you been placed in restraints?

MS. BLISARD: That's going to take a minute for Robert to put it into the--

ASSEMBLYMAN PAYNE: Okay. We can move on to the next person and then get back to Robert, then, for an answer.

MS. BLISARD: Yes, if you want to do that.

ASSEMBLYWOMAN WEINBERG: Go ahead. Who is the next person?

MS. BLISARD: These are the three people that are testifying from our group.

ASSEMBLYMAN CRYAN: Did you say Robert works? Does Robert work?

MS. BLISARD: Yes, he does.

ASSEMBLYMAN CRYAN: What does he do?

MS. BLISARD: Do you mind if I speak for you, Robert?

MR. FESEL: (affirmative response)

MS. BLISARD: Okay.

Robert works with young children. He works with pre-school and kindergarten children. He tells them stories.

ASSEMBLYMAN CRYAN: Oh, yes.

MS. BLISARD: He works with them that way. He also has worked at the Daily Planet. No, you don't work there anymore.

Ed works at the Daily Planet. Okay.

ASSEMBLYMAN PAYNE: Ms. Allen, may I ask--
Is your red light on? (referring to PA microphone)

MS. ALLEN: No.

ASSEMBLYMAN PAYNE: It's not.

Can you turn yours off, please, Mr. Cryan.

MR. FESEL: Just I have cerebral palsy.

MS. BLISARD: "Just because he has cerebral palsy." Robert is a man of few words. (laughter)

ASSEMBLYWOMAN WEINBERG: Robert, your few words are doing a great deal of good up here. So, don't worry about that. I wish we had more people of few words. (laughter)

MR. PALERMO: As for me, I'm very boisterous.

MS. BLISARD: I think that's his answer.

ASSEMBLYWOMAN WEINBERG: Are there any other questions here? (no response) No, okay.

Thank you very much.

I know that this was probably not an easy trip for all of you to make or come into this crowded room, and we appreciate your being here and your input.

Thank you.

MS. ALLEN: Thank you.

MS. BLISARD: Thank you.

ASSEMBLYMAN PAYNE: Dr. Judy Favell. When we're able to clear the table, you'll be next. Identify yourself and your affiliation, please. Okay, why don't you go right ahead and identify yourself, please.

JUDITH E. FAVELL, Ph.D.: Yes. My name is -- oops.

ASSEMBLYMAN PAYNE: The red light on, please. (referring to PA microphone)

DR. FAVELL: Okay, good.

My name is Dr. Judy Favell, and I am a licensed behavioral psychologist and certified behavior analyst. For 30 years, I have devoted myself to the field of developmental disabilities. During my career, I have assumed a variety of roles, including President of the American Psychological Association's Division on Developmental Disabilities and President of the International Association of Behavior Analysis. And of these and other offices and roles that I have assumed across the years, the role I'm most proud of, though, the one that I most cherish, is that as a person and a professional who has assisted individuals with developmental disabilities to understand, and then to overcome, their very significant life-threatening, dangerous problem behaviors.

I'm proud, for example, for helping David conquer his problems with aggression. His aggression had injured countless individuals, including sending them to the hospital and putting them on permanent disability. And as a result of the danger he posed, he was kept in virtual isolation in his room for 18 years.

I'm proud of helping a young woman named Lisa overcome her self-injury. The paradox that Lisa presented was, here was this beautiful spirit and beautiful face contrasted with multiple scars across her arms and chest that she had inflicted upon herself by biting, sometimes baseball-sized, pieces from

her own flesh. And of course, in order to protect Lisa's life, and literally limb, she, too, was kept in restraint, not of the sort that we're speaking of today, but in chronic restraint 24 hours a day, seven days a week, missing all of life's experiences.

Now, David and Lisa, if you met them today, would bear no resemblance at all to the people I'm describing to you. They rarely, if ever, have episodes of these sorts of problems with aggression or self-injury. They lead full and good lives. They enjoy their jobs. They have friends. They participate fully in community activities. Lisa's favorite is strutting her stuff in shopping malls with her new, slender body, now that she's lost a full 100 pounds from the 340 pounds she weighed during the days when she was self-injurious. And David will participate in any community activity, so long as it's out in the sunshine and out of his room.

Now, the means and methods that helped David and Lisa succeed here are not mysterious. They achieved these successes through a process that anyone of us would want if we walked in their shoes. What would I want if I were Lisa? What would you want if you were David? First, I'd want to be free from my problems that had scarred me and left me self-conscious when in malls. I don't want my time wasted with hype and hopes about treatments that may not protect me and may not be effective. And what that means is, if we are to phase out restraint -- and we all desperately want to do that -- then we need to ensure that what is proposed as an alternative is equally effective in protection and in treating behavioral problems of this kind. Because the reality is that there are very few alternative treatments at this point in time.

So before we turn our backs on some of the strategies that may, indeed, employ restraint, if I were Lisa I'd want proof that there exists

alternatives that can achieve the same ends. Second, I'd want a full array of options to include in my comprehensive treatment plan. I would want lots of positive reinforcement to learn new skills. I'd want good, medical input to address my biological needs. And of course, I would want an enriched life. But if these and other elements of comprehensive treatment aren't enough to ensure safety and reduce my problems, I would want the option of adding restraint to my program. Just as in surgery and other invasive procedures, I want to have a chance to assess if the risks are worth the rewards. I don't want someone categorically removing options from my plan. And while there are some who claim restraint is not therapeutic, there are others that absolutely insist it is.

And who would I want to help me make these decisions about my treatment? I would want those closest to me, those who love me.

ASSEMBLYMAN PAYNE: Excuse me, Doctor. Please wind down. Your time has expired.

DR. FAVELL: Okay, sure. I would like my parents to be the ones who make these choices, not other professionals or advocates. And most of all, I would like to live in the community. I would not like the very interventions that are designed to be my treatment to, in fact, incarcerate me in hospital settings.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

Any questions for the doctor? (no response)

If not-- Oh, I'm sorry.

ASSEMBLYMAN CONAWAY: You raised some very interesting points. In medicine, we study and look for outcomes, and we decide based on a risk-benefit analysis whether or not we are going to proceed with a particular

treatment. We recommend to patients what we're going to do based on the evidence. That's what we do.

And you're right. That, perhaps, in a desperate situation, you might try something unstudied. But most of the time, most people, given the circumstances, will choose to employ things that are well-studied and supported by research and science. I'd like you to comment on -- let's see, it's in the bill under the definition of *mechanical restraint*. And in your experience, I noticed that, included in that definition, it says, "the use of a domed or enclosed crib shall be prohibited." I presume that means in all circumstances. I'd like you to comment on that and what you think the effect of that might be, as regards risk benefit and the safety of the person that might need that kind of closure.

And also, on the point I raised earlier with the sponsors, regarding the use of aversive techniques, whether or not there ought to be a consideration there that the nonapplication of the technique would, in fact, be worse for the patient. I think you suggested that in some of your comments. But if you could comment on those or that wording, I would appreciate it.

DR. FAVELL: Certainly. The use of cribs and domed cribs and so on, and enclosures, are first of all, I think, included in most definitions of mechanical restraint, because historically they were associated with misuse of restraint where children and adults were kept in enclosed cribs. They are, though, distinct from the methods and means of mechanical restraint that, I believe, we are trying to address here. And that is, the brief application of restraint used only until an individual is calm. That is the sort of restraint that I think we are speaking of, that I believe does have a role, possibly in emergencies, but best of all, in planned programs that carefully consider the alternatives and make arrangements properly before restraint is used.

So cribs and those sorts of restraints are often included, but they are not used in the sense that we are typically talking about using them, as part of a comprehensive treatment program.

ASSEMBLYMAN CONAWAY: But they're excluded here. They're excluded here under this bill, their use.

DR. FAVELL: Oh, I thought they were included. Oh.

ASSEMBLYMAN CONAWAY: It says, "the use of domed or enclosed cribs shall be prohibited." And what I'm asking you, based on your experience is, is that kind of a prohibition going to lead to a serious injury by some child when this can't be used? That's my question.

DR. FAVELL: Oh, I see. I'm sorry.

I think that, in fact, there are -- because of the history of misuse of that technique, they are widely prohibited. But there are, typically, mechanisms by which, certainly, arrangements can be made to make a crib for, say, an individual. I think that bears on the second part of your comment and question, and that is the definition of aversive and so on. I think it is our position that not only should decisions be made principally by parents, in consultation with appropriate professionals, but those decisions should stay as close as possible to individual cases. And so that what is appropriate for one is inappropriate for another. And that is part of the basis on which I'm concerned as a psychologist and a behavior analyst, also as a parent, that someone would remove, categorically, my right to choose among possible interventions for my child's behavioral issues.

ASSEMBLYMAN CONAWAY: Just one last question, if I may, Madam Chair.

There was testimony here that talked about the, I guess -- it was a blanket statement -- that some behaviors are misinterpreted or that professionals, I guess, either refuse or are not trained to look behind the meaning of these behaviors, which I, as a professional, find a little offensive. But can you speak to that issue, about how behaviors are used by those who have developmental disabilities, and your experience, as a professional, and how you deal with those kinds of things?

DR. FAVELL: Certainly. Part of any reasonable, well-conceived treatment plan is what we call a functional analysis, which deliberately and carefully asks what the meaning of these behaviors are and what are the conditions and the contingencies that precipitate them. And then in our treatment we try to teach alternatives.

For example, if by using aggression I'm trying to communicate my needs, then my treatment plan should absolutely include methods of teaching me alternative ways of communicating. That is just good, basic treatment. But I believe that the contrast between using restraint and understanding the meaning of behavior problems is no longer appropriate. In this day and age, both are attempted. We always attempt to understand the behavior, and we always attempt to, principally, emphasize positive procedures in its treatment. But that does not deny occasional need, in a few cases of very serious problems, for the use of brief and contingent restraint. It's no longer either/or.

ASSEMBLYMAN CONAWAY: Thank you.

ASSEMBLYMAN CRYAN: Thank you. Thank you, Doctor.

For Lisa and for David, if I can redirect, what types of restraints did you use?

DR. FAVELL: They were different. In David's case, there is a kind of wrapped arrangement where he assists himself to lie down and then he is wrapped in a cloth that enfolds him. And in Lisa's case, because of her self-injurious behavior, especially when she was in restraint, those restraints consisted of the Posey Company restraints on the wrists and the ankles.

ASSEMBLYMAN CONAWAY: You have to explain Posey.

ASSEMBLYMAN CRYAN: I guess I just--

DR. FAVELL: They're basically -- and they're not handcuffs. Those are reserved for a very different issue. They are soft, but leather, restraints that are applied to the wrists that would keep Lisa's hands away from her face and her arms, down by the side of her body.

ASSEMBLYMAN CRYAN: Doctor, in the bill we have a comment here that, "the period can't exceed one hour." You mentioned, in answering Dr. Conaway's questions about brief and repository -- I think it was the term you used -- is an hour adequate in terms of what--

DR. FAVELL: Typically, an hour is far longer than anyone needs. Once an individual learns how to calm, and the fact that he is, or she is, protected during this time, often restraints can consist of a minute or two.

ASSEMBLYMAN CRYAN: My last question is, if you could just elaborate -- what happened to David? What did you do? In a cloth? I just didn't understand it. David.

DR. FAVELL: It was a -- what's called a wrap mat, and it basically enfolds him. Essentially, his periods in restraint were no longer than 15 to 17 minutes, where upon he would calm and was very obviously calm, and then he would resume his activities.

ASSEMBLYMAN CRYAN: Do they still have restraints as part of their treatment today at all?

DR. FAVELL: Very occasional use, yes. And sometimes we can eliminate them altogether, which is what, of course, the point is. It's part of the reason why we are less supportive of emergency use of restraint, because we want it to be planful (*sic*) and carefully and deliberately designed. And if it is, over time restraint should be necessary less and less frequently and for shorter and shorter durations.

Now, in Lisa's case, I cannot remember the last time she attempted self-injury. So there's a case where, though restraints may still be in her formal written plan, it is rarely or never used.

ASSEMBLYMAN CRYAN: Thank you.

ASSEMBLYMAN PAYNE: Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: You just said that you opposed emergency-- I think maybe what you meant was you opposed restricting it to emergency use.

DR. FAVELL: I'm both opposed, restricting it to emergency use, but, also, if given my druthers, I would rather restraints be used in a planned way with a written program, but allows parents to consent.

ASSEMBLYMAN THOMPSON: You're not opposing emergency. You're saying you rather the plan was there.

DR. FAVELL: Exactly.

ASSEMBLYMAN THOMPSON: But if an emergency situation occurs, obviously you support it.

DR. FAVELL: Exactly. Exactly.

ASSEMBLYMAN PAYNE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Doctor, I have a question, and maybe gets to the root of some of this. I understand what you are saying about using restraints for a person who might cause himself injury, and part of his or her plan to teach them how to get over that is to restrain them during that time. Do you believe that restraints should ever be used as part of a punishment routine?

DR. FAVELL: Well, the word punishment is a difficult one, because its lay term is laden with such a volatile emotional meaning. I believe that restraints should be used to assist in decreasing a behavior problem. And technically, that could, in fact, be construed as punishment, because that's the technical term for punishment. But because of the emotional overlay, I prefer to talk about the use of restraint as a procedure called *time out from positive reinforcement*, and that's really what it is. It means that if I become self-injurious or aggressive, the intervention will protect me from myself or protect others, but during that period in which I am in restraints, I can also not get inadvertent and accidental reinforcement, for example, by intimidating others, or by actually being able to bite a piece of my own flesh. So, though I don't want to hedge on the term punishment -- and technically it could constitute punishment in that, when it is used, the behavior problem for which it's used may decrease -- the more technically appropriate, and I think a less emotional way to view it, is as time out from positive reinforcement. Does that make it worse?

ASSEMBLYMAN CONAWAY: That's great.

ASSEMBLYMAN PAYNE: Assemblywoman Pou.

ASSEMBLYWOMAN POU: I just have a real quick question.

Doctor, how often did you feel that you needed to restrain David?

DR. FAVELL: Originally -- and again, David, had literally, had his own wing of a developmental center, and originally David had aggressive episodes that were upward of 25 to 30 a day.

ASSEMBLYWOMAN POU: Okay.

DR. FAVELL: And now he goes months and months and months between episodes, and he is in full access to peers, staff, and the community.

ASSEMBLYWOMAN POU: Thank you.

ASSEMBLYMAN PAYNE: Let me -- I want to move on, but I do have-- I'm going to take the prerogative of the Chair and just ask a question.

Doctor, you said that David has now improved to the point that he is, now -- that he had restraints. You don't want to use the word punishment, so we call it something else maybe. I'm not sure.

DR. FAVELL: Well, time out, yes.

ASSEMBLYWOMAN WEINBERG: Time out from positive reinforcement.

ASSEMBLYMAN PAYNE: Time out from positive reinforcement.

We're at this point today because of the alleged abuses of many people who are clients in our institutions, etc. We're at this point because of that. We're not here because there are so few people who have been abused. We're here because, apparently, there are a lot of people who feel that their relatives, their children, etc., have been restrained, supposedly, as part of treatment, or what have you. That there seems to be, on the part of some, the proclivity to use restraints, rather than treatment, for instance. I wonder whether or not in your experience -- yours is very positive, obviously -- but in your experience, do you know of any of your colleagues or any of these other facilities where there have been abuses, where there has been punishment, where

there have been these kinds of restraints that are used as so-called treatment, etc., rather than positive behavioral support.

I mean, we're here today because of -- there's a bill that's called Matthew's Law, I believe. Because there's some who have said that he was restrained, etc., and there may be others. Let me ask you whether it is common practice for us to -- whether there's so few people, so few facilities that are abusing this restraint, or not, to justify this hearing today, for instance?

DR. FAVELL: In my professional experience, and I have been, again, not only a clinician and a researcher, but I've also done a great deal of work in national policy, and also consultation and work for the Justice Department-- In my experience, the abuses involved in restraint are, indeed, rare, and, in fact, can be held up against abuses in other kinds of practices that can range from surgery to the use of meals with individuals.

So I think the issue that was raised, and I was not responsive to, about holding the abuse associated with one intervention against abusive or improper practices in other domains, and against what happens if an individual's behavior problem goes unresolved -- I think that's the issue. No one made a decision to abuse David by isolating him for all of those years. They were afraid. People were in the hospital. They were out on disability because of his aggression. So there is a tacit and, I'm sure, quite gradual movement toward leaving David in his bedroom. I view that as an egregious a practice as restraining David, initially for 20 to 30 times a day, to help teach him that those behaviors were not acceptable and could not go on, while we rewarded him heavily for the alternatives.

So I think it's rare, and I think we have to hold the risk of abuse and misuse against the risks if we do nothing, or against the risks associated

with other sorts of interventions, including some of the most positive. Because I can mess with your mind by messing with your positive reinforcers, just as surely as I can by messing with threatening you with restraint.

ASSEMBLYMAN PAYNE: Thank you.

Just one last thing, and that is the behavior of David or others-- Do you think David definitely was an aberration of some of the reason why we're here today; or do you believe, as many people do, apparently, that there are abuses of the use of restraints that seem to be more than just at very rare occasions?

DR. FAVELL: I think that many of the measures -- in the joint bill are going to help strengthen mechanisms that should already be in place. But I have hope that parents are never forgotten in this process, because they are the best defense against abuse for their children. And then, equal to it are good oversight and monitoring. And equal to that are good reporting to the division and to the State about what the practices are. And then, I think, with those things, we will, indeed, not risk throwing out the baby with the bath water.

ASSEMBLYMAN PAYNE: Okay, thank you.

DR. FAVELL: Thank you.

ASSEMBLYMAN PAYNE: Dr. Conaway.

ASSEMBLYMAN CONAWAY: One other risk I'd like -- and I'm not sure I'm going to get to ask it of others who might come forward, and that is, you practice according to the catechism, if you will, of your profession. You're held to the standards of your profession, aren't you?

DR. FAVELL: Absolutely.

ASSEMBLYMAN CONAWAY: So one of the things that concerns me as -- in the face of interferences and your professional practices -- is what

risk that might put you, in terms of professional liability. That is, if you are prohibited from doing things which you know to be in the best interest of the patient and then the patient gets injured, are you then placed at some risk professionally, professional liability, etc.? So is there a danger in the things that you see in this bill that will put you at professional risk in terms of liability?

DR. FAVELL: Yes, indeed. And I think the one that is most concerning is the definition and the composition of the human rights committee, the county human rights review board. That, potentially, with individuals appointed to it who are not familiar with the clients involved, or who are not expert in what they are pronouncing, could effectively overturn decisions by families and by the interdisciplinary teams and by the providers who are expected and responsible for providing these services. If I come up with a plan with a family, and the provider feels that they can do it, and then a human rights review board overturns that, because of ideology or their own value systems or anything else, then, in fact, I think we are not only jeopardizing me as a professional -- and I won't participate under those conditions. Much more importantly, I think we are jeopardizing the well-being and the progress of the individual involved.

ASSEMBLYMAN PAYNE: We're not saying that the human rights committees can veto one person -- that cannot veto the entire plan. The people that are on this human rights committee, or whatever, are representative, aren't they? Do you believe that only people who are professionals should be on this committee?

DR. FAVELL: No, not at all. But New Jersey has had, and Developmental Disabilities has had, for many years, human rights committees that have functioned very, very well in a review and an advisory capacity. Most

of the facilities and agencies I know do have human rights reviews of their programs, and that is, in fact, regulated by the division circulars and rules. So human rights review is already required. It is this addition of insisting on it being a regional body, being appointed from afar, and, in fact, insisting on the role of an advocate from an organization that, I think -- and giving them approval capability that, I think, begins to add greater jeopardy to the process of getting decisions made. I'm all for human rights committees, and I believe they have served this State and the individuals within it very, very well.

ASSEMBLYMAN PAYNE: Yes.

DR. FAVELL: That's why I'm perplexed as to why it needs to be changed.

ASSEMBLYMAN PAYNE: Yes. I don't have the same fear about having the inclusion of others on this Committee. I don't think that this will have an inordinate amount of power to veto these things. I think that it's a matter of opinion here. The Commissioner is the one who appoints these, and they're not appointed before.

Thank you.

DR. FAVELL: Thank you.

ASSEMBLYWOMAN WEINBERG: Doctor, thank you very much. I think you've been very enlightening. You were when you visited my office, and were all the people who are dealing with professionals, we might have less problems. But I would like to say that it is really the lack of accountability that has created some of these problems throughout our bureaucracy, whether we're talking this particular population or the others that have, unfortunately, been in the news of late. So that's one of the things we're trying to correct in these bills.

DR. FAVELL: Oh, I understand.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

DR. FAVELL: Thank you.

ASSEMBLYWOMAN WEINBERG: The next person is Tom Bruno, who represents CWA Local 1040, and then we're going to call Janice Roach.

T O M B R U N O: Good afternoon, Madam and Mr. Chair. As you know, my name is Tom Bruno. I come to you today on behalf of CWA Local 1040's members, nearly 5,000 of which will be directly impacted by the proposed legislation you have before you today. I'm also a 24-year veteran of the Department of Human Services, having managed two aggressive units at Hunterdon Developmental Center.

The Bancroft events that surfaced several months ago and gave rise to this legislation served to wake up a department that had lulled itself into complacency. No one working in this industry was surprised by the unfortunate tragedy. It had always been a question of when, rather than if. I recall testifying before the Joint Senate and Assembly Budget Committees at the time when Governor Whitman announced a second round of drastic cuts in the Department's enforcement staff, which incidentally lends credence to Madam Chair's concern about the lack of accountability. And that, I believe, is where it really started.

I stated then that the cuts were a prescription for disaster, and I likened it to rollerblading toward sheer insanity without the benefit of protective gear. Regrettably, that statement was prophetic, and we find ourselves at this juncture today.

Local 1040 is pleased to see that attention is finally being given to the developmentally disabled. However, we have grave concerns about the main thrust of Bills A-2849 and A-2855. Everyone agrees that restraint use needs to be regulated and monitored. But to require the use of restraints for emergencies only places both the client and the staff at far greater risk of injury. For that reason, Local 1040 is opposed to the two bills as they are currently written, and would ask that serious consideration be given to amending them before presenting them to the General Assembly for a vote.

Webster defines an emergency as, “a sudden, generally unexpected occurrence or set of circumstances demanding immediate action.”

ASSEMBLYWOMAN WEINBERG: Mr. Bruno. I don't know if you've had the opportunity to look at the Committee Substitute.

MR. BRUNO: I was hearing about it earlier, but, no, we did not have a copy. It wasn't on my notice of the hearing today.

ASSEMBLYWOMAN WEINBERG: Okay, because that does enlarge the ability to use restraints under certain kinds of conditions.

MR. BRUNO: And actually, that would be helpful. From what I was hearing, I was anxious to get a copy, as a matter of fact. So I'll run down to the bill room after this.

But the definition of an emergency essentially means that an individual with a history of aggression cannot, truly, meet the definition of emergency, since their aggression is clearly predictable and not an unexpected occurrence. Staff in group homes are ill-equipped to deal with an ever-increasing population of dual-diagnosed individuals, which are being jettisoned from institutions under the Department's ideological approach -- which simply asserts that all institutionalized clients are viable options for community placement.

Often these workers are left alone with some or all of the group home residents, requiring these entry level workers to try to safeguard the other clients, while simultaneously trying to get authorization to restrain another one that is exhibiting violence -- simply will not work, nor will a one- or two-day in-service be the panacea to correct this.

I will say -- I'm going to, kind of, veer off my prepared statement and just say in answer-- I was listening to some of the questions, and Assemblyman Cryan had asked about, are there enough staff to implement this? And I would submit that the answer to that is no. If there's going to be-- In the institutions, they're already required to do all these things, pretty much. They're required, for example, to do 15-minute checks. They're required to release the limbs 10 minutes every 60 minutes. Those are already required by division circulars and departmental regulations. This codifies those division circulars, apparently, for the institutions, but it also then applies them to the private providers, which is a change.

That in itself, in answer to the question, is going to be a nightmare for the private providers, because, frankly, they have two staffs, usually, sometimes more, but ordinarily two staffs, except for on the midnight, which is down to one. And if something happens, and if somebody is supposed to go out shopping or whatever, they're not going to be able to leave the other group alone, because somebody has to do 15-minute checks. You're going to need an extra person there just for the opportunity to provide those 15-minute checks.

As far as the staff safety issue, we are concerned about that. And that, again -- and I was happy to hear that in the Committee's bill that there's, I guess, a provision to allow restraints to be used in, I guess, behavior modification programs of sorts, that would be beneficial.

ASSEMBLYWOMAN WEINBERG: It allows restraints to be used as part of the overall plan and with some very severe components attached to it, including input, and subjects those to review of the human rights board that we talked about earlier.

MR. BRUNO: Right. And I would see that as a step in the right direction, because waiting for an emergency to arise before you actually restrain somebody actually means you're allowing the situation to escalate to a dangerous level, and that does put both clients and staff at a safety risk.

None of these behavior mod programs, even as are currently written in the institutional settings, are permitted to have the restraints -- mechanical restraints of any sort -- without going through a whole review process. There's a restraint committee. There's a human rights committee. There's countless committees and signatures, including input from the parent, guardians, and that kind of thing.

So this, again, codifies something that's already being done in the institutions. It is going to be an additional burden for the private providers, I think, in some cases. And that is a concern.

ASSEMBLYWOMAN WEINBERG: Mr. Bruno, your time is up.
Thank you.

MR. BRUNO: Okay. Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Mr. Bruno.
May I have Janice--

ASSEMBLYMAN CONAWAY: I have a question.

ASSEMBLYWOMAN WEINBERG: Mr. Bruno?

ASSEMBLYMAN PAYNE: Mr. Bruno, there's a question from Assemblyman Conaway. (laughter) Unexpectedly, of course. Sorry.

ASSEMBLYMAN CONAWAY: Sorry.

You've already established, for the record, that you're understaffed in what you're currently required to do. Is that right?

MR. BRUNO: In the communities and the group homes, yes. I would say that we are.

ASSEMBLYWOMAN WEINBERG: But he's not speaking on behalf of the State institutions now.

MR. BRUNO: In some of the State institutions, we're understaffed, too. But in particular with this restraint legislation, this is going to impact, even more severely, the communities, I believe.

ASSEMBLYMAN CONAWAY: And could you comment just about, in terms of your daily -- having worked in the area. Because one of the things that concerns me as we legislate in this area and provide more regulation, are the paperwork burden that -- I see it in the hospital where I work, nurses. Can you talk about the paperwork burden that you currently have, and if you could, sort of, succinctly let us know what part of the paperwork burden is related to things that are associated with clinical care versus things that are not. Because I think as we move forward in this area, we need to think about that burden and the cost of that burden as we move forward.

ASSEMBLYWOMAN WEINBERG: That's not the subject of this bill.

ASSEMBLYMAN CONAWAY: It's not?

ASSEMBLYWOMAN WEINBERG: No.

ASSEMBLYMAN CONAWAY: All right. Never mind.

Sorry, I take that back. I'm off the topic, excuse me.

ASSEMBLYMAN PAYNE: Oh, that's so unusual for you, Doctor.

(laughter)

ASSEMBLYWOMAN WEINBERG: Oh, that was easier.

ASSEMBLYMAN CONAWAY: Oh, yes. I'm easy.

ASSEMBLYMAN PAYNE: May I ask Ms. Janice Roach, please. Identify yourself, if you will, please.

J A N I C E R O A C H: Hi. My name is Janice Roach. This is Carl Goodman. We're the parents of Matthew Goodman.

Matthew's Law is named after a real person, our son Matthew, who struggled to survive a system that completely failed him. In our opinion, he was robbed of human dignity and his civil rights were violated, with ever-increasing chemical and physical restraints. This must never happen again.

Matthew was diagnosed with pervasive developmental delay/autism. His educational and behavioral challenges were such that residential placement became vital to address this. He was eventually placed in an internationally renown facility located in New Jersey that was to provide him with educational and behavioral treatment that he needed to thrive. Despite being in new surroundings, his huge expressive smile and wonderful sense of humor touched so many lives. He was still a boy with feelings and emotions he tried to express. He loved to dance the hokey-pokey, draw with his Magni-Doodle, play with Play-Doh, go for walks in the woods, etc. He remembered the name of every person he ever met.

In general, Matthew had a love for people greater than anyone we've ever known, until his world changed at the age of 12. While living in an apartment and attending school on campus, Matthew contracted an unfortunate infection that progressed to a reactive arthritis. Swollen, painful joints and IV

antibiotics kept Matthew bedridden the summer of 2000 in Children's Hospital. A traumatic situation for any child, but for a child with autism, it was sheer torture. His greater comprehension level was contradicted by his limited ability to express it. This resulted in Matthew communicating his enormous anxiety and frustration by scratching and picking his ear, just as a caged bird pulls out his feathers.

Children's Hospital instituted the temporary use of restraint to further prevent self-injury. Upon discharge, the New Jersey facility's physician requested, and was granted, verbal approval to place Matthew in arm restraints for a few weeks, while he stayed at the medical facility to give him closer medical attention and for his ear to heal. He would then be released back to his apartment and back to school. Neither happened. Instead, in our opinion, Matthew was -- faced 16 months of torture through the continuing, increasing use of restraints.

We feel protocol designed to restore Matthew to his previous status was never implemented. Was he then penalized with restraint because of his unfortunate infection? Our son is not here to communicate to you the misery and indignities he suffered, but let us tell you some of the things he endured. We take simple things for granted. While in the restraints, he couldn't wipe his nose. He couldn't scratch an itch. He couldn't bend his arms. He could no longer hug or kiss myself or his father. He lived in an unfamiliar place. He couldn't see his roommates from the apartment, and he did not attend school as he did before. He no longer had control over anything in his life or his environment.

Matthew -- an important point -- would tell us weekly, "Take these things off." Matthew's sense of self-worth was gone. It became a world

Matthew did not understand. In the last four weeks of our son's life, he was engaged in a full-facial hockey helmet with black screening across his face, again, to prevent injury. In our opinion, all it did was teach him to become more anxious, more aggressive, and more self-injurious. He was cut off from the comfort of a human touch or from hearing or seeing clearly. No one would listen to our cries for help. Slowly, the will to live began to drain away, as he mostly laid on the floor.

The Division of Developmental Disabilities obtained videotape from the final six days of Matthew's life from the facility. They showed Matthew was forced to sleep with arm immobilizers on, socks covering his hands, staff dragging him.

In conclusion, the Division of Developmental Disabilities substantiated abuse and neglect of our son. Over this dreadful 16-month period, we feel our son experienced a terrible trial as he died piece by piece. Week by week, his personality withered away. I would become physically sick on the sidewalk after visiting my son at times. Please don't misunderstand me. I was not sitting idly by. I worked day and night to find another facility and contacted numerous agencies in two states. No matter how hard I worked, no matter how many agencies I contacted, I couldn't protect him from the abuse and eventual death.

Matthew's Law will help our institutionalized family members, and will hold those culpable who ignore this law. When we were asked to sign for the continued use of restraints, I was accompanied by my lawyer, signed against my will, as it was a condition of continued placement. It was sheer torture for me. If a parent is placed on a human rights committee, will the parent be willing to jeopardize their child's placement? Or, if the Division of

Developmental Disabilities appoints county-based human rights review boards, will they be able to adequately protect, monitor, or even enforce the basic care and safety requirements for the developmentally disabled?

I had reported my distress concerns on numerous times and received no assistance. On Tuesday morning, February 5, two days before Angel Flight would fly Matthew to a new facility I had found, I received news that no parent should ever hear. The nurse called from the medical facility to inform me that they could not detect Matthew's vital signs. Upon arrival at Children's Hospital, I found my son unconscious, but still encased in the arm immobilizers. His full facial helmet lay nearby. Thirty-two hours later, our 14-year-old son lay dead, never regaining consciousness. He died as a result of sepsis pneumonia and acute respiratory distress syndrome.

Shortly thereafter, we discovered that 911 was never called. He was not transported by ambulance to the nearest emergency room. I went to visit Matt, Sunday before he died, to tell him I finally found him a facility that offered to provide him with quality of life. We didn't make it.

Matthew's Law is a tribute to our son's life, just as Megan's Law and Amber Alert happened to their families. It is more than that. It can be a law that offers legal protection to individuals who have been classified as inferior, useless, a burden to society. Somehow society is under the illusion that the developmentally disabled do not love, do not feel pain, and do not have dreams and desires. In the end, it really doesn't matter if restraints are gloves on your hands, socks on your hands, arm immobilizers, full helmets, or ammonia squirts in a person's face. It's all abuse. It destroys the value of human life.

In closing, our son's headstone is engraved with "Wind Beneath My Wings," as Matthew, for what he endured, will always be our hero.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

Are there any questions?

Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: I have a question.

Janice, thank you for coming forth.

MS. ROACH: Thank you.

ASSEMBLYWOMAN WEINBERG: You know, we had many meetings over this issue. But we talk in terms of Committee Substitute, in any event, as well as one of the other bills about parent input into the plan. From what I'm hearing, you're saying that there really was no appropriate parent input, because you were told if you disagreed with this you would have to move your son from this facility.

MS. ROACH: Absolutely. I was given no choices. Absolutely not. I was given no choices. It was, "If you don't like it, he's out tomorrow."

ASSEMBLYWOMAN WEINBERG: And that's what was said to you.

MS. ROACH: Absolutely.

ASSEMBLYWOMAN WEINBERG: You would have had 24 hours to remove him.

MS. ROACH: Right.

ASSEMBLYWOMAN WEINBERG: Okay.

ASSEMBLYMAN PAYNE: Let me ask, do you know whether or not-- You're affiliated with other people who are advocates and interested in

this hearing. Are there others who have expressed the same thing, that the condition of continued placement is that they must be compliant? Is this something else that you've heard or was this just in your case?

MS. ROACH: Absolutely. That's one of the most serious issues -- is that it does not become a choice. A facility, if they're allowed to use the restraints and continues to believe in the restraints, as opposed to positive approaches, they are not going to just ask a parent to agree and then quickly be willing to do something different. In my opinion, restraints are the easy way out. But what does it teach? That's the most important point. What do they teach? They taught Matthew to become more aggressive, to have more anxiety, to pick more. So I think, even some of the parents that might look at a basket hold as an immediate cure for the problem are not looking at the long-term of increased anxiety, increased aggression.

Why shouldn't we expect more from staff that work with these people in concentrating on positive approaches?

ASSEMBLYMAN PAYNE: Did you say that you reported-- We mentioned a human rights commission, I think. That was in existence, is in existence, etc. Were you in contact with this commission?

MS. ROACH: I was completely out of the loop of any committee. I had asked numerous times to be a part of a human rights committee, to attend one behavior management committee, and I was told that they were not open to parents, period.

ASSEMBLYMAN PAYNE: Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: I see three things that you report here. We'll call it, sort of, generalized abuse, excessive use of restraints, and the lack of an ability to contest what they had for your child. I've asked the

sponsor here -- related to the same thing you're saying, Assemblyman Payne -- would you envision the review board as a place where parents could appeal what is being done to their child or the way it's being handled, as opposed to reviewing an initial IHP, for example?

ASSEMBLYMAN PAYNE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Yes. The Committee Substitute, first of all, limits the use of the restraint to one hour. We heard professional testimony, a little bit earlier from the prior doctor, that probably one hour is too long. It should, generally, be 10 or 15 minutes. In this particular case, this young man was kept in restraints many hours and many days.

ASSEMBLYMAN THOMPSON: I'm saying, if the parents disagreed with--

ASSEMBLYWOMAN WEINBERG: But I want to talk about all -- there's a whole variety of issues around it. And, yes, you could appeal. Now, the human rights -- these county advisory boards are appointed by the Commissioner of Human Services. They're not elected. It's an appointed board by the Commissioner of Human Services, and it, specifically, has, beside a parent and an advocate, it has professionals on it, as outlined in the bill. It also -- whoever reviews the case can't be associated with the institution involved.

ASSEMBLYMAN THOMPSON: But what I'm saying is that, while a plan may be submitted for review, if a parent has a disagreement with the plan or the treatment that's being given, can they go before this board and ask them to consider their complaints or comments? Would you like me to repeat the question?

ASSEMBLYWOMAN WEINBERG: No. I got the question. It was the answer I was having a problem with. (laughter)

ASSEMBLYMAN THOMPSON: In other words, can a parent request an appearance at that meeting?

ASSEMBLYWOMAN WEINBERG: Yes. The original plan that is worked out on behalf of the client, or the patient, as the case may be, would be reviewed by this board. This bill does not give -- specifically allow them to come before the board to ask for an overrule of this. It's something that we might consider, though.

ASSEMBLYMAN THOMPSON: That was what I was going to suggest.

ASSEMBLYWOMAN WEINBERG: Yes.

ASSEMBLYMAN THOMPSON: Thank you.

ASSEMBLYMAN PAYNE: Yes.

ASSEMBLYWOMAN VANDERVALK: Thank you.

I'm very sorry what you and Matthew had to go through. So where do we go from here? I think the previous question and answer should shed a lot of light to the future.

Are we going to hear testimony from the Department of Human Services? No?

ASSEMBLYWOMAN WEINBERG: I don't think so.

ASSEMBLYMAN PAYNE: I think there are representatives. Are there representatives from the department here? Yes, back there. They may be able to answer some of the questions.

ASSEMBLYWOMAN VANDERVALK: Yes. I know, from some previous work that I've done, that the department has an excellent way of

working with parents when they're trying to get them into group homes or into housing, in general -- out of institutions into housing. Because they work with the parents -- and it sometimes takes longer for permanent placement that way. But I was always impressed with the fact that they worked so carefully and closely with the parents. So to hear that there is no parent input or the parents are not being heard in an institution, I think that's a major, major gap in our system.

ASSEMBLYMAN PAYNE: Yes, I agree. One of the reasons for this hearing is to find out-- I was going to ask Ms. Roach-- One of the reasons for the hearing is to get suggestions, ideas, for us to consider, and before we bring these bills forward for amendments, etc. You're quite right. The fact that there is no place for a parent to have redress, to come before a body to express this, and your attempts over the period of time were rebuffed -- I think this is something that we need to consider in any kind of final passage of any legislation.

ASSEMBLYWOMAN VANDERVALK: Thank you.

ASSEMBLYMAN PAYNE: Assemblywoman Pou.

ASSEMBLYWOMAN POU: Thank you, Mr. Chairman.

I just wanted to follow up on some of the statements that have been said here today. I know that in your testimony you mentioned that -- the number of attempts that you've made to address your son's concerns, and your desire to serve on some of these boards or committees, were constantly overlooked or denied. Were you ever, during any time of your son's period there, ever brought in and discussed, or made a part of, his progress? Was there any report, or were you ever given any opportunity to have an input with regards to what -- the condition that your son was in during that time?

MS. ROACH: Okay. Let me just clarify that I hadn't asked to become a member of a committee. I had just asked to be able to attend a meeting where they were going to talk about my son's treatment plan so that I could-- Even if they wouldn't let me comment, I could, at least, hear what was being said and where the rationale was for the restraints. So they had indicated to me that I was not able to be a part of that, and that was period, end of story.

As far as being kept updated, I can't stress enough that-- As much as Matthew's rights were totally taken away, and he died piece by piece, every right that I ever had as a parent was completely taken away, completely. It's very difficult, because it certainly has made its mark on me also.

ASSEMBLYWOMAN POU: Mr. Chairman, I can't emphasize enough some of the comments that's been heard and stated here today. Clearly, when a parent is not even permitted to partake and even listen in to some of the conversations or some of the progress reports that are being given with regards to that child's development and that child's treatment, that's a real alarming concern to all of us. That's something that we certainly need to be extremely mindful of it, and do whatever we can to make this come to the surface and provide the most-- whatever it needs -- strengthening at the very, very highest level. We need to keep that in mind.

I just want to thank the parents. I think you're very courageous. It's been a very difficult time for you both, and I just wanted to express my sincere appreciation for you coming forward and providing us with your knowledge and insight on this.

Thank you.

ASSEMBLYWOMAN WEINBERG: Assemblyman Conaway.

ASSEMBLYMAN CONAWAY: Yes. I, in the first instance, want to express my sympathy and regret. I can't imagine how difficult this must be for you. And also, to associate myself with Assemblyman Pou's comments on your bravery in coming forward and letting us know about what has happened to your son and for being an advocate for change.

I just wanted to make a couple of comments on some of the things that you stated and strike me as just being, absolutely, wrong. As a clinician, in every instance, when I make a decision or work with a patient about a decision on treatment, that -- at least, in my own practice, and I think as part of good practice, and whether it's in physical medicine or in medicine as regards mental health -- that those treatment decisions and plans need to be made in consultation with the patient and the family, and the parents, when that parent is acting on behalf of the patient. When that doesn't happen, you get bad medicine. You get bad outcome. And, indeed, that is inconsistent, in my view, with good medical practice.

And so, in my view, you should have been involved at every step of the way, indeed, every day and every moment, as occurs in acute care hospitals when people are in the hospital for physical illness, and reviewing what was going on with your son. And to the extent that that was denied, that was wrong.

Let me also say that there are times -- and for the benefit of the Committee and for those in this room -- when there will be disagreements between clinicians and patients and family members as to the course of care. There are processes for the folks, the people involved in that situation, to withdraw from that situation in a way that meets with patient safety. So that

if there is a disagreement that can't be reconciled over care and treatment, people ought to be given an opportunity to find alternative sources of treatment.

Now, the problem here, of course, is that you were told, apparently, that you will need to find some alternative source the next day, and that strikes me as absolutely wrong. Certainly, from a medical/legal standpoint, from everything that I've heard, is a dangerous thing for a physician, a clinician to do or to be engaged in. This is further highlighted and compounded by the fact that the treatment options and alternatives are limited very often in these kinds of settings. So it makes that process more difficult when there is a disagreement over the course of treatment.

Lastly, let me also comment on this. I think it's going to be instructive for how this bill is crafted, as it makes its way to the floor, that there are differences in the use of restraint for behavioral change and the way restraints might be used when there's a medical condition involved. We may need to look at, in consultation with professionals, some way of making a differentiation there, when you have a medical illness, because of an infection or a broken bone or something that might require something that one will classify as a restraint, versus a restraint that might be involved in a behavioral program, just as a point of information.

But, again, I have been very moved by what you have presented here today. I think it's very valuable to us in what we need to do in bringing reform to this area. Again, and echoing what Assemblywoman Pou has said, thank you for your courage.

ASSEMBLYMAN PAYNE: Thank you, Assemblyman Conaway.
Assemblyman Rooney.

ASSEMBLYMAN ROONEY: Thank you very much.

I want to express my sympathy also. It's a very moving story. And when I first heard about it, I was extremely upset. I go back a long ways with DDD. In fact, I authored the original legislation that created the Division of Developmental Disabilities. Prior to that, it was the Division of Mental Retardation. And none of the services that go out today would have been possible without that. I feel very proud of that legislation. It really, really upsets me to hear something like this, that under contracts that we have with these agencies that something like this could happen to the most vulnerable of our citizens. So, again, I'm personally taken aback by that.

I also have a different perspective. One of the reasons that I did that legislation at that time was because I was involved with these three organizations -- well, actually, at the time, it was two. It was both New Concepts and Spectrum, and now Life Opportunities. All of these organizations -- I want to say this, because I don't want any broad-brush picture painted of other organizations because of what Bancroft has done -- these are organizations -- are formed-- They were absolutely created by the parents. They still have involvement and, basically, they're run by the parents of all the clients in these groups.

The parents have first and foremost and final say of what happens to their children. Unfortunately, you didn't have that opportunity. You had a for-profit organization. And for profit, they sacrificed, again, one of our most vulnerable. So I just want you to understand if this law is passed, Matthew will have his name on it, and it will be a tribute to him for bringing it to our attention. We need this kind of a situation. Unfortunately, legislators need this hit over the head, of someone being the sacrificial lamb, in this case. I just want to tell you, I agree with you.

Again, I have to also speak up for the other organizations that are totally innocent of what has happened to Matthew. I know that the department has found Bancroft liable in this case -- that is was abuse and negligence. That is your situation. It's not a hearing on Bancroft, but I just want the organizations to be recognized for the good that they do. This is not a condemnation of the entire DDD process and the developmental disabilities groups. I just want to say that from the bottom of my heart.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Assemblyman.
Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: I do note that in the Committee Substitute it calls for an interdisciplinary team to develop the integrated IHP. "The team shall consist of: the person receiving services; the legal guardian, the parents or family members, if the adult desires that a parent and family member be present; those persons that work most directly with the person served; and professionals and representatives of service areas who are relevant to the identification of the person's needs and the design of the program."

Of course, I gather this did not exist with your child?

MS. ROACH: Well, let me just be clear again -- that didn't mean that we were never at a meeting. We were not at human rights committee meetings. We were not at behavior management committee meetings. We had some smaller meetings, but there were no options to us. Our input was not there. It was, "This is how we're going to do it. This is how we're going to control his behavior," and that's it. "This is what we're going to do."

ASSEMBLYMAN THOMPSON: The second question is, of course, what we're having the hearing on today is the Committee Substitute.

Originally, the bill -- Matthew's Bill was A-2855, which has been modified here in the substitute. Do you have any problem with the substitute retaining the name Matthew's Law?

MS. ROACH: I don't know that I would choose to comment on that right now. I have full faith in Bill No. 2855. I don't know that I see a reason to compromise it, because I feel so strongly about restraints -- just not -- restraints not teaching anything positive whatsoever. So I would, maybe, refrain from giving you any kind of decisions on things like that at the moment.

ASSEMBLYMAN THOMPSON: Thank you.

MS. ROACH: I haven't had a chance to even look at it.

ASSEMBLYMAN PAYNE: Thank you.

Assemblyman Cryan.

ASSEMBLYMAN CRYAN: Thanks.

I think Assemblyman Thompson covered most of what I was interested in, which was, quite frankly, your comments on the substitute.

But just a couple quick questions for you, because the substitute still is Matthew's Law, limiting the use of restraints. So I wanted to ask, specifically, without asking Mr. Goodman to take them back out. The helmet -- as someone who is not familiar with this area, and I don't mean to be callous or insensitive in any way -- your son wore that how many hours a day?

MS. ROACH: Well, let's see. This was put on him the last month of his life to further prevent him from getting an injury on his nose. So he was in it, I would say, the majority of his day. It was taken off for sleeping, but it was-- Protocol was not followed. But if you wanted an accurate answer to that, you could go back to the Division of Developmental Disabilities, and they would certainly let you know that from the videotapes.

ASSEMBLYMAN CRYAN: To your knowledge, we heard testimony earlier from Mr. Bruno and some others, that what we're doing, in some cases, is codifying existing rules and regulations. Was that helmet and/or was the other restraint that you showed us with the arms and the legs, were they removed to your knowledge? Were they removed in accordance with the rules and regulations as you knew them?

MS. ROACH: Absolutely not.

ASSEMBLYMAN CRYAN: My other question--

MS. ROACH: That was well-documented. That's not my opinion. That's DDD's substantiation.

ASSEMBLYMAN CRYAN: Okay. And the restraint, not the helmet but the other, was designed to restrain Matthew's legs, arms?

MS. ROACH: Arms.

ASSEMBLYMAN CRYAN: Good God.

MS. ROACH: The other point -- I should bring it up while you're right on that -- is let us, please, also consider a suggestion. Is that, what's so important with any type of restraint is, especially -- the doctor would probably agree with me -- that you need to, most certainly, look at any medical conditions that might contraindicate the use of restraints. Matthew had documented circulation conditions, body temperature issues, and light-sensitivity issues. So those need to, certainly, be considered, especially with putting these things on, as to what risk it is causing in other areas.

ASSEMBLYMAN CRYAN: Your boy, you mentioned, lived in an apartment?

MS. ROACH: Yes, he did.

ASSEMBLYMAN CRYAN: For a second -- did he live with others?
Did others see him restrained?

MS. ROACH: Okay. No. He lived in an apartment prior to this. He lived in an apartment on campus and went to school, and then he developed a-- It was either strep or staff infection, that then lead to his hospitalization. When he went back, he went to a medical unit. And, yes, there were other people in there, sure.

ASSEMBLYMAN CRYAN: My last question is -- and, again, I was concerned about your comments on the substitute, but Assemblyman Thompson asked those -- were there any other restraints used on your boy, other than the mask?

MS. ROACH: Yes. It was these things (indicating restraints), and there were socks put on his hands, or gloves.

ASSEMBLYMAN CRYAN: Did anybody ever ask--

MS. ROACH: And chemical restraints.

ASSEMBLYMAN CRYAN: Chemical restraints?

MS. ROACH: Right. Medication to control his behavior.

ASSEMBLYMAN CRYAN: Did, in any point in the process -- and you've gone over this quite a bit, but just so that I clearly understand -- did anybody say to you, "We want to do these things. We think it's in Matthew's best interest. What do you think?"

MS. ROACH: Okay. They certainly, at times, would try to convey that they felt in was in Matthew's best interest, but the choice was absolutely never, ever given.

ASSEMBLYMAN CRYAN: Thank you.

ASSEMBLYMAN PAYNE: Assemblyman Rooney has indicated that we are not looking to make a blanket indictment against the entire industry, etc. However, I was going to ask, what facility was your son in during most of this time?

MS. ROACH: Bancroft NeuroHealth.

ASSEMBLYMAN PAYNE: Where is that located?

MS. ROACH: Haddonfield, New Jersey.

ASSEMBLYMAN PAYNE: Haddonfield, New Jersey.

The other thing is that we talk about restraints. I think I heard you mention something about ammonia squirts. What is that?

MS. ROACH: I was speaking very generally in my testimony--

ASSEMBLYMAN PAYNE: Sure.

MS. ROACH: --and although they were not used on Matthew, that is something that is used as a restraint. I would assume that it's done for the shock value of changing the current behavior.

C A R L G O O D M A N: Aversive behavior.

MS. ROACH: Aversive behavior, thank you.

ASSEMBLYMAN PAYNE: Aversive behavior.

Doctor, you're here. I was wondering what was the reason or whether that contributed to the improvement or teaching, whatever -- ammonia squirts? Doctor, do you know about such restraint?

ASSEMBLYMAN MUNOZ: Assemblyman, yes, it's what I said before. It's really like the 1920s. It's aversive therapy, squirting people in the face with noxious stimuli, as that's supposed to change their behavior. I mean, some of this stuff, if you really said it out loud in 2003, you'd think you were 100 years ago. So ammonia squirts are an aversive therapy. Try squirting

yourself with ammonia in the face, and that's what is done to some of these patients.

ASSEMBLYMAN PAYNE: I suppose that's why, as I said earlier, this is why we are here today. And as we said, it was not a blanket indictment, but as long as one or two-- As you said doctor, if we can save the lives of one child, one person, we should not put a price tag on this kind of thing. I think that our Committee, the Assembly Regulatory Oversight Committee, probably has a job ahead of us to, kind of, look into some of these conditions. We're talking about these pieces of legislation here today. But I think that we might consider, at some future date, looking into some of these techniques, etc., that are used, perhaps, at some of these institutions so that we can, in fact, see whether or not -- how widespread it is and whether or not there are other Matthew Goodmans out there waiting to happen.

So we just have to prevent that and avoid that, and we cannot allow any of these for-profit organizations to use intimidation, not only against the clients or their patients, but also cannot allow these for-profit organizations to try to utilize their so-called political clout to try to restrict members of the Legislature from looking into these things, you see. I think we should send a message loud and clear that we're not going to tolerate that kind of foolishness and that that's not going to happen.

So I want you to know, I want to thank you both for coming here today, and that we are certainly going to do whatever we can. We thank you for bringing this to our attention. Unfortunately, the circumstances that brought you here were extremely tragic, but we certainly hope that we'll be able to address a lot of these problems that have been brought up.

Assemblyman Green.

ASSEMBLYMAN GREEN: Thank you, Mr. Chairman.

As I listened to the testimony, I'm just concerned about who regulates, who controls, exactly, the functions of this facility? It's my understanding it's a profit, but at the end of the day someone should be able to talk about who gives them directions in terms of how they can deal with particular issues. I know today, if one of us had to go to a hospital, before the doctor looked at us they would call our insurance company, and our insurance company would tell them what they could do and what they can't do.

ASSEMBLYMAN PAYNE: Assemblyman, I think that might be appropriate for Assemblywoman Weinberg to answer it.

ASSEMBLYWOMAN WEINBERG: Yes. The Department of Human Services does the inspections and the licensing. And then this is another problem we have in the bureaucracy that we have to address at another time. Then it is the Department of Health that levies fines or deals with anything that they find that's wrong there. And then, when we talk about the licensing of the personnel, we have to go to the Department of Consumer Affairs and to the Attorney General's office, because they license the personnel. So even for us -- and I know Assemblywoman Previte, Assemblyman Payne, and I have been so involved in this issue -- had to deal with three major departments of the government. Three different major departments to actually get to the bottom of who is responsible for what's here. And that is another story which I'm hoping we're going to address.

ASSEMBLYMAN GREEN: Okay. My final question of the whole issue is that--

ASSEMBLYWOMAN WEINBERG: But it's the Department of Human Services that oversees the daily--

ASSEMBLYMAN GREEN: Like I said earlier, whether it's a hospital facility of this nature, the bottom line is that insurance companies don't allow you to do anything, especially when they're paying, unless they sign off on it. I'm just curious. Where did this fall through the cracks, where, listening to her testimony, she had no one to turn to? You're saying to me, you're paying for a service or an insurance company is paying for a service, yet, still, you don't have no input whatsoever. That's my question.

ASSEMBLYWOMAN WEINBERG: Well, the cracks developed however they developed, but I think that this case pointed up where some of those cracks are, and that is what this legislation is attempting to address.

ASSEMBLYMAN PAYNE: Thank you very much.

MS. ROACH: Let me just give a suggestion, that you might take Chris Clee's testimony that would follow mine, because she was Matthew's advocate from the Arc and can explain, maybe, some of the system failure that would address your questions.

And also, I just want to end. I'm going to just urge you to take a vote on Matthew's Law, Bill No. 2855, today, because, please, don't have any more tragedies happen -- and not just a death, but any abuses whatsoever. So I'm just going to urge you to do that.

ASSEMBLYMAN PAYNE: Thank you both very much, Ms. Roach and Mr. Goodman.

MS. ROACH: Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you.

Actually, the next person we would like to call on, because I can't find that other slip, the person you talked about -- but Dr. Cynthia Allen. Please come forward.

By the way, I owe a personal sense of gratitude, and I think we all do, to Dr. Allen. She happens to be the mother of a developmentally disabled young person herself. She also happens to be a neighbor of where my office is in Teaneck. But I will tell you that Dr. Allen did more research and turned up more inappropriate kinds of actions in certain places than the bureaucracy actually did, and she helped spear us onto a course that I think is helping to move along today. So I just want to personally thank you for the education you've provided.

CYNTHIA ALLEN, D.D.S.: Okay. I'm Cynthia Allen, and I'm speaking on behalf of Matthew's Law, Assembly Bill No. 2855. My son, Nick, and Matthew Goodman lived together in the same facility for six months from September 2000 to March 2001. My family and I can all testify that Matthew Goodman was on his back, on the floor of the unit, in both arm restraints and helmet, virtually all the time that we ever saw him. He was heavily sedated and asleep most of the time and seemed increasingly sedated during the six months we observed him. In fact, we did not think he was ambulatory, and were shocked one time when he got up and walked.

I can remember only one time when I saw him without the helmet, briefly. I almost didn't recognize him. When my parents -- my father is a retired pediatrician and my stepmother is a licensed clinical psychologist -- came to visit the unit, they were very taken aback and concerned about Matt's condition. My father asked me probing questions regarding his diagnosis and treatment, as it was hard for him and all of us to understand what was being done to Matt and why.

In addition to observing Matt in restraints all the time, I also saw him vomit several times on one occasion. As a health professional myself -- I'm

a retired periodontist -- I can testify that Matt was at very high risk of aspirating the vomit as he was lying flat on his back, in restraints, heavily sedated and asleep. Although I've not seen Matt's medical records, I understand he did, in fact, die of aspiration pneumonia, and I'm not surprised.

But that's not how I want to remember Matt. The image of him, which is seared forever in my mind, is that of the affectionate, outgoing boy he once must have been and whom I never met. On those rare occasions when Matt was awake, he would often reach his hand out and try to talk to me, as though pleading for help. I feel that all of us, both agencies and individuals alike, fell desperately short in helping Matt.

But there are many other Matts in New Jersey who still desperately need our help. My 13-year-old son, Nick, is one of them. Nick, who has severe autism and is completely non-verbal, was a resident of a group home at that same facility until this past June. At that time, I brought him home due to abuse and neglect issues that have been substantiated by the Special Response Unit of DDD. Since he returned home, he has exhibited many symptoms of post-traumatic stress disorder and has been so fearful he has been unable to leave the house or even the safety of his bedroom. His psychiatrist has given him a presumptive diagnosis of post-traumatic stress disorder and has stated that he is not to be forced from his room or the house to go to school. This statement precipitated much confusion among the various school personnel who were trying to work with Nick as to what force meant. But the American Heritage Dictionary defines force clearly as, "The use of physical power or violence to compel or restrain." Or is there, perhaps, a different definition of force for individuals with Nick's disability?

Nick has been subjected to restraints and aversive techniques since he was only 3. These techniques have never led to a long-term decrease in the challenging behaviors. If anything, they have escalated them. What starts out as a minor incident often explodes into a major one, as staff used reactive strategies and Nick panics and fights back, frequently requiring a four-person take-down. My son experienced six of these so-called emergency restraint procedures in one week last April, but no team meeting was held, no change was made in the treatment plan, no formal report was written, just more restraints.

So what do restraints teach? Restraints teach terror to already terrorized individuals. They teach helplessness, hopelessness, and powerlessness, intense frustration, and rage. I have seen all of these feelings in the eyes and the face of my own son while he is being restrained. The end result of aversive and restraint techniques in the short-term may be surface compliance, but, over time, all they beget is more violence. This results in more and more restraint procedures as a vicious cycle evolves, which can ultimately end in death.

I have valiantly attempted to stop this endless cycle for my son, Nick, but I can't do it without your help. This fall, when it became obvious that Nick would not willingly leave the home for any reason, a school program began coming to our home to try to lure Nick out and onto the school bus. This program said they would only use positive approaches. But when Nick did not respond quickly enough, the staff wanted to go to aversive techniques. The program suggested we remove everything that Nick enjoys from his bedroom and then compel him out of the house. But when Nick's psychiatrist said he should not be forced from the house, the school program canceled their contract.

The next group of school personnel who came into my home said they were using positive behavior approaches, as we had agreed, but then all they would talk about was getting my son out of the house in a week, which would require force. I had brought my son home from a residential facility to remove him from harm's way. I was shocked to find he was not safe at home from the ongoing threat of aversive and restraint techniques. Further, I felt that if anyone was successful in forcing Nick from my home and into another facility, he would fight for his life and end up in restraints just as Matt had.

My experiences clearly demonstrate that as long as aversives and restraints remain an option, agencies in New Jersey won't work long enough on positive approaches to allow them to be successful. They quickly fall back on what they know best -- aversives and restraints. Virtually every program in New Jersey resorts to these control techniques because there is no law to force them to use positive approaches. That is why there is almost no one in New Jersey who can work with my son using positive approaches.

Opponents of Matthew's Law say parents need options for their children's treatment. Parents desperately need options, but not from among the various aversive techniques. They need the true option, which is positive behavioral approaches. Parents only choose restraint, usually under coercion, because they have no real choices. If there is to be extra training for funding, please let it be for positive approaches. Believe me, staff and school personnel know only too well how to use restraints. Let's train people how not to use them.

I'd like to make a comment to the parents who are here today who believe their child needs restraints and aversives. Until very recently, I thought these were necessary for Nick, too, so I share your concerns. However, I

changed my mind after I found out about Matt's death. All I can ask is for you to consider whether you would still choose the restraints and aversives if you were presented with a truly positive approach that worked better.

The use of restraints and aversives is not simply a difference in treatment philosophy, as their proponents would have you believe. It is a human rights and civil rights issue. Techniques that are used on children, like Nick and Matt, are not permitted to be used in any other living population -- not political prisoners, not even animals. The Humane Society states that "all animal cruelty is a concern because it is wrong to inflict suffering on any living creature."

Sadly and tragically, it is too late to help Matt. But I beg you to pass Matthew's Law for Nick and for all the Matts and Nicks in the State of New Jersey. Their very lives depend on it.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you, Dr. Allen.

Are there any questions for Dr. Allen? (no response)

Cynthia, thank you again, and thank you for all your past input.

DR. ALLEN: Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

Mr. Vito Albanese, please, Senior, and Vito Jr.

V I T O A L B A N E S E S R.: Good afternoon.

ASSEMBLYMAN PAYNE: Mr. Albanese, is your red light on?
(referring to PA microphone)

MR. ALBANESE SR.: Yes, it is.

ASSEMBLYMAN PAYNE: Thank you.

MR. ALBANESE SR.: Can you hear me now?

ASSEMBLYMAN PAYNE: Yes. It sounds like a commercial to me. (laughter)

MR. ALBANESE SR.: Right. You're a funny guy, Mr. Payne. (laughter)

ASSEMBLYMAN PAYNE: You're okay, too, Vito.

MR. ALBANESE SR.: Good afternoon.

I wanted to thank Assemblywoman Loretta Weinberg and Assemblyman William Payne for the opportunity to testify at this Joint Committee hearing. I'd like to introduce myself. My name is Vito Albanese Sr., and sitting beside me is my son, Billy. We call him Billy as a nickname, he's Vito Jr.

VITO ALBANESE JR.: Hi.

ASSEMBLYMAN PAYNE: Hi. My name is Billy, too.

ASSEMBLYWOMAN WEINBERG: Hi.

MR. ALBANESE SR.: Today is an important and serious day in the lives of our disabled population. Today this legislative body can pass and must pass Matthew's Law, Assembly Bill No. 2855. Nothing -- anything less is a clear violation of our most vulnerable and voiceless citizens. The disabled population demands due process, equal protection under the law, civil rights, and human rights.

I want to take this opportunity to commend Assemblyman Eric Munoz, M.D., and his excellent staff for their leadership and courage in proposing and introducing Assembly Bill No. 2855; also, Assemblyman Guy Gregg and his excellent staff for coprime sponsorship of this historic and important piece of legislation; and all the cosponsors, as well, too numerous to mention by name. I believe 14 all total, and four Democrats to say the least.

Assembly Bill No. 2849 is a watered-down version of A-2855, Matthew's Law. A-2849 is not what the doctor ordered. It's generic and basic and takes away bits and pieces of DDD's policy and regulations already in place. We're here today to insist that DDD reinvent themselves and change the culture and climate in doing the people's business in New Jersey.

It is imperative on this legislative body to make strong recommendations to Governor McGreevey and the leadership of the New Jersey State Senate to make strong changes at the Department of Human Services, the Division of Developmental Disabilities, the Division of DYFS, and the Department of Health and Senior Services. We all have an obligation to protect the health and safety and welfare of our most voiceless and vulnerable disabled population.

My outrage sometimes is apparent, but today I'm calm because I know in my heart of hearts this body will do the right thing. I emphasize *right thing* in passing Matthew's Law, A-2855, as written, as is, not a generic form of this historic legislation. Matthew's Law is the only game in town. Anything less would be unacceptable to this outraged parent.

I'd like to touch on some bullet points in discussing some of my testimony. Division Circular 35, which the Division of Developmental Disabilities puts out as policy, is called Behavior Modification Plan. That must be abolished. Can't plan for the restraints. And if they use the restraint on a Behavior Modification Plan, it's never reported to any investigative body as abuse or neglect.

Division Circular 19, which was changed because of my son's case, because in that Division Circular, never called for a physician to order the use of the restraint. Division Circular 19, only the physician can authorize the use

of a restraint, not a direct care staff. If you're going to hire direct care staff at 7.50 an hour to give them the power to restrain, you're putting our children in a dangerous way. The training is not there. They're not trained properly. We were told they got the greatest training, but, yet, recently the Division of Developmental Disabilities filed a 50-page, serious deficiency report and showed no training.

Let's talk about the Vineland Training Manual, which I showed to some of the members of this Committee at a meeting recently. Those karate holds and police techniques -- and this is what's taught by DDD and to the facilities for the use of restraints. That Vineland Training Manual is an abomination and that should be abolished also. They're very dangerous, abusive, and deadly.

I'd like to bring to your attention one of the regulations in the Division of Developmental Disabilities. It's called 1044-B. And in 1044-B, restraints are prohibited in the use of community care residents. So how discriminatory is it that the Division of Developmental Disabilities use 1044-A for developmental disabilities -- to rescind it -- 1044-C for traumatic brain injury, but condone the use of restraints in those two regulations, but in 1044-B they are prohibited. Division Circular 14, in my opinion, is in conflict with any NJSA law.

Direct care staff: too much power to order the restraints -- not at McDonald's wages, no formal education. Direct care staff: no medical background in making an emergency judgment to use restraints. Positive approaches, not negativity. Talk, talk, talk -- diffuse the situation with cooler heads and use positive-talk approaches.

Everybody asks, what is an emergency? Well, I'm going to give you my definitive answer to emergency.

ASSEMBLYMAN PAYNE: Before you do that, Mr. Albanese, the emergency may be, is we go too much longer. If you could, kind of, take another couple of minutes or whatever to kind of wind up, because there may be some questions for you after this.

MR. ALBANESE SR.: I only have a couple of more minutes. Okay.

The definitive, in my opinion, is if we can use the picture in a hostage situation by police. The first thing they do, the police, is not going in there bullets shooting, billy clubs swinging, shackles, and handcuffs. They bring negotiators that are trained in psychology, and they talk down the situation. They're not using the restraint. That's my definitive answer to an emergency.

Look into what causes the emergency -- the environment, medical problems, mental health problems, lack of sleep, lack of food, just plain in a rotten mood. Us, as normal people, have bad days. Are there people out there to restrain us for a bad day? If we say, "No," to something or someone, it means no. If our disabled population says, "No," in a facility, their day consists of restraints, and I think that's outrageous. What part of no didn't this direct care staff understand? If I did to my disabled son what the facility did to him in the public, I'd be arrested for child abuse and endangering the welfare of an adult.

In concluding, let me just say this. Knowledge speaks, wisdom listens, so listen to the people of the State of New Jersey and do the people's business. Pass Matthew's Law, A-2855, as is.

ASSEMBLYMAN PAYNE: Thank you very much, Mr. Albanese.

Are there any questions for Mr. Albanese?

Loretta Weinberg.

ASSEMBLYWOMAN WEINBERG: Before anybody asks Mr. Albanese any questions, let me assure you that he knows every regulation by heart. (laughter) And again, he's usually right. So be careful if you wish to challenge him in any way, because I found that out through some bad experiences.

So, again, thank you for the education that you helped provide to us.

ASSEMBLYMAN PAYNE: Yes, Assemblywoman Cruz-Perez.

ASSEMBLYWOMAN CRUZ-PEREZ: I thought I was going to listen and not say anything, but I have to say something. Back in 1998, I introduced legislation that is doing the same thing you're asking to do for Matthew's Law. I swear, I wasn't going to get emotional. But I'm very upset, because Matthew, maybe, would be alive today if we passed this legislation back in 1998, and we didn't do it.

MR. ALBANESE SR.: That's Donald Latrenta's (phonetic spelling) bill.

ASSEMBLYWOMAN CRUZ-PEREZ: Yes.

MR. ALBANESE SR.: And it only goes so far, to school. It doesn't go into the residential portion.

ASSEMBLYWOMAN CRUZ-PEREZ: I know. It was going to be established all over, and I was willing-- I asked everybody to sit down with me and work on this legislation. It got released twice from committee.

MR. ALBANESE SR.: I called your office on numerous occasions, and I didn't get no response.

ASSEMBLYWOMAN CRUZ-PEREZ: It got released from committee, Mr. Albanese. My point is, that at that point we ignored what we're discussing today. We should not ignore this anymore. We're on the same page. I have a son in a special environment, and he was restrained about three months ago and got home with bruises everywhere. So, believe me, this issue is very sensitive to me. But I'm upset, because I proposed the legislation back in 1998 to eliminate restraint, unnecessary restraint, and it never happened. Now we have Matthew's death to really push this issue. Let's do it.

MR. ALBANESE SR.: Well, I'd like to get your commitment to come on as cosponsor to A-2855, if I can get your commitment to that?

ASSEMBLYMAN PAYNE: Thank you. Thank you.

Mr. Albanese, could you please restrain yourself? (laughter)

MR. ALBANESE SR.: Yes, sir.

ASSEMBLYMAN PAYNE: All right. Thank you very much.

Assemblyman Green.

MR. ALBANESE SR.: I want to thank Assemblywoman Vandervalk, that recently came on to Matthew's bill. I commend you.

ASSEMBLYMAN PAYNE: Mr. Albanese, if you would, we have a question for you, if you'll just wait a minute, please.

MR. ALBANESE SR.: Oh, all right. Okay. I thought you were almost done with me.

ASSEMBLYMAN PAYNE: Stop--

MR. ALBANESE SR.: Okay, stop-- You're a funny guy, Mr. Payne. (laughter)

ASSEMBLYMAN GREEN: I'm afraid to ask you a question.

MR. ALBANESE SR.: Don't be afraid.

ASSEMBLYMAN GREEN: But I'm going to ask anyway.

MR. ALBANESE SR.: Okay, sir.

ASSEMBLYMAN GREEN: I'm going to ask you very slowly, and I just want you to give me why you feel that the substitution is such a watered-down bill that it doesn't do anything. And like I was always taught, that you have to start some place. And listening, not all day long, to all the testimony, but I've listened to enough to know that all of us are concerned about the Matthews of the world and people like your son. I'd like to feel that this is the start, whether, if we'd had done this five years ago, maybe Matthew would be alive today. But I'm hoping that no matter what we come out of this Committee meeting with, that all of us can be on a positive note.

I know I'm going to be supporting whatever I can do, but if it takes this particular substitution in order to put us in the position where we can move ahead and some day we can, somewhat, bring a closure to anyone being abused, especially an individual who really needs medical help-- So I'd like to feel that -- hoping that you can look at it in a positive way, rather than just feeling, because you can't get the whole loaf, the part of the loaf that we're trying to move in that direction is not enough. Again, it's a question -- but by the same token, it's the way I feel personally, and I'm hoping that you can understand that without being negative, in terms of saying it's just watered down and it doesn't do enough.

MR. ALBANESE SR.: Well, can I respond to that, please?

ASSEMBLYMAN PAYNE: Sure. Please do.

MR. ALBANESE SR.: In the bill, it says that a physician would be called 24 hours -- to restrain. In any practice, right now, at DDD, in their Circular 19, it says, "A physician must be called immediately." You don't put

the cart before the horse. Once the restraint is there and there's an injury, then you call the doctor.

My son has serious orthopedic problems. He was put in basket holds. If a doctor came and examined him before they put him in these basket holds, your doctor would have said, "It's contraindicated, do not restrain this boy." Do you want to tell this boy that it was proper to put him in these holds? They don't even have policy and procedure if someone is sitting in a wheelchair at DDD, let alone the facilities. There's no policy and procedure, yet they had him on the floor in four-man takedown. He's no danger to himself or others.

There's a provider here in this room. I'm waiting for him to come and testify. I've got his book in my valise. You talked about ammonia sprays. Well, that gentleman uses that kind of stuff and is condoned by DDD. I got a book with 21 of his procedures, and I'm waiting for him to come and testify. (laughter) He knows who I am, and I know who he is.

ASSEMBLYMAN PAYNE: Thank you. Thank you.

Billy, at the last meeting we had, you asked me about your PT, I think. You said, "What about my PT?" Right?

MR. ALBANESE JR.: Yes, right.

ASSEMBLYMAN PAYNE: I haven't heard from you today. Your father is doing all the talking here. I mean, you have something to say once in a while, too. You asked me about that the last time.

Speak into the mike, Billy.

What were you looking for?

MR. ALBANESE SR.: Did you tell Mr. Payne you wanted your physical therapy?

MR. ALBANESE JR.: Yes, I did want PT. Yes.

ASSEMBLYMAN PAYNE: That's right. That's right.

Well, we'll see. I hope your father is following up on that to see to it that you get your PT.

Thank you. Thank you very much.

MR. ALBANESE JR.: Okay.

ASSEMBLYMAN PAYNE: Any other questions? (no response)

Thank you.

MR. ALBANESE JR.: All right.

MR. ALBANESE SR.: Thank you.

MR. ALBANESE JR.: Thank you.

ASSEMBLYMAN PAYNE: Thank you, Mr. Albanese.

I have to commend you, because you have been a very, very diligent advocate here. And as I said when I first met you a couple of years ago, just keep calling, keep calling, keep calling and don't give up, don't give up. You haven't, and I want you to continue doing that.

MR. ALBANESE SR.: Mr. Payne, we can't compromise another disabled kid's life. We can't compromise that.

ASSEMBLYMAN PAYNE: That's right.

Thank you very much.

Dr. Henning. Please identify yourself, Doctor, and your affiliation.

D A N A H E N N I N G, Ph.D.: My name is Dr. Dana Henning. I currently work as a private advocate and clinician with people who have developmental disabilities. I have for approximately the past 30 years. My master's degree is in special education with a behavioral emphasis from Temple University. My doctorate is also from Temple University, working with people

with severe disabilities. I had taught special education at Temple University. I had an appointment with Columbia University as Assistant Professor in the Department of Physicians and Surgeons.

I'm currently working with Nicholas Aquilino, which is Cynthia Allen's son. At an earlier time, I had spent a full day with Matthew Goodman, getting to know him and his needs when he was at Bancroft. I had been hired as a consultant, at one point in time, by DDD to work in one of their developmental centers in the Psychology Department to look at putting more positive approaches and decreasing the use of restraints in their facility. I also worked at Morristown Memorial Hospital at their Developmental Disability Center in New Jersey. I was charged with working with people who had medical needs, mental retardation, and behavioral needs. I was paired with a psychiatrist to deal with them.

I am based in Pennsylvania, although I work in the Netherlands and Germany, as well, on these types of issues. I was involved in the state of Pennsylvania when we started eliminating the use of restrictive procedures and restraints and had a statewide Positive Approaches Subcommittee.

One of the things that I would like to share with people is that there is not a need for these types of restraints in terms of restrictive procedures. There are alternatives available at this point in time. There needs to be training and education so that people are familiar with using them. Too often, there's a confusion, in that people talk about positive approaches, and they feel that it's the same techniques as others are using, but minus the restraints. That's inaccurate. A better term would be using the words *proactive approaches*, where there is a fuller spectrum of strategies that are used in terms of looking at sensory integration problems, where people with these types of developmental

disabilities are overreacting or underreacting to the environment, which can result in their behaviors.

There's a need for looking at communication in basic relationships so these people can reconnect with others, so that there's a value to being with others and less need for expressing their needs through behaviors. There are a slew of strategies, techniques, protocols that can be used with people who have these types of needs, without needing to resort to the aversive types of procedures.

People are telling war stories. I worked at Woodhaven Center, which at one point in time was considered one of the model programs in the United States. It was operated at the time by Temple University in conjunction with the state of Pennsylvania and served only those people who had the most severe behavior challenges, in addition to developmental disabilities. Those people received very restricted procedures when they were at the facility. Many of those people I now work with in the community. They continued to have their aggressive and self-injurious behavior when they were receiving restraints, when they had access to this full range of aversive treatments, and yet they were discharged into the community where we served them without those types of things.

We found that we could take people who had-- One woman, in particular, used to smash her fist through glass windows. We used hot whirlpools for her, to get sensory stimulation in other ways.

What I would like to suggest to people is that, if you're talking about using these restraints and assuming that you're giving people informed consent, informed consent requires that people have alternatives presented to them and that they're given some choices in saying, "This is a strategy that could

be used for your child, and this is the likely outcome,” as opposed to, “If you don’t use our strategy, you need to leave.”

I’d like to suggest that the absence of restraint is not the absence of treatment. I would like to suggest that teaching restraint or using restraint teaches people that being in control is what they should be striving for. And people with disabilities do not have that type of an opportunity. What I would, also, like to suggest is, we would not be using these types of procedures with people who don’t have these disabilities. These procedures are not limited to Bancroft. If you go into your developmental centers today on your way home, you will see these procedures being used.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Doctor.

Yes. Assemblyman Cryan.

ASSEMBLYMAN CRYAN: Thank you.

And thank you, Doctor.

Doctor, you testified that there’s not a need for restraints. Can you just reconcile that? Were you here earlier when we heard the story of Lisa and David -- how Lisa bit her flesh and David had aggression issues? And yet, through the use of restraints, as well as other positive reinforcement tools, they’re now productive and in society. In fact, restraint was a tool, as part of an overall program used and now is used minimal, if at all, in their cases. Can you help me with that, when you talked about a slew of strategies that don’t include that? Yet we’ve heard some positives. They seem to conflict.

DR. HENNING: When you’re talking about those two particular individuals, we don’t know, as we’re hearing these stories, whether or not they could have, also, gone without using restraints and restrictive procedures and,

also, ameliorated their behaviors and been without restraint at this point in time.

ASSEMBLYMAN CRYAN: But accepting things as they are, and a professional much like yourself, who spoke to us and clearly gave us what I think were a couple positive stories in that regards, would we-- One of the things I'm having trouble with here on this bill is saying, okay, restraints are bad. We've heard the stories and the emotional restraints that's with that, yet I'm also trying to reconcile that with the positive stories I've heard as well. Are you of the belief that there's no situation and no part of treatment that requires the use of restraint in any way, shape, or form?

DR. HENNING: I'll tell you, being from the Midwest, I guess I'm not as exuberant as some people -- as we always say, from out east, are. And so I always kept thinking, I have to be more respectful because there's going to be somebody who needs this. I can't say, "No, no one ever needs restraint," because I'm going to run into somebody. They must know something I don't know. But, in 30 years of working with these people, I haven't found that person yet.

ASSEMBLYMAN CRYAN: Okay. I appreciate that.

Thank you.

ASSEMBLYMAN PAYNE: Yes.

Assemblyman Green.

ASSEMBLYMAN GREEN: Yes. During the course of your testimony, you mentioned that you have worked with the two families -- Matthew's family and the other young man's family. When you said you worked with them, did you work with them on behalf of the facility or did you work on behalf of the parents?

DR. HENNING: When I was working with Matthew Goodman, I was actually hired by his school district--

ASSEMBLYMAN GREEN: Right.

DR. HENNING: --because there was going to be plans for creating a program for him, within the state of Pennsylvania, that did not use restrictive procedures. And I was identified as the person to go out to create exactly what that program would look like, and what procedures would be used for him in that type of facility, and what type of resources would be needed.

When it came to the case of Nicholas, who is Dr. Allen's son, I was asked by Dr. Allen, initially, to come out to do the preliminary evaluation for her son, which is how I met him. I was later contacted by her school district, who asked me to follow up and put together a program. At this point in time, I'm writing the initial report, which will set forth what types of supports he needs in order to be educated and supported in his home, with the idea of expanding his horizons so that he, again, wants to leave his room and wants to leave his house and return to society without force.

ASSEMBLYMAN GREEN: As a person, and I listened very carefully to your education, and I must say, it's great. For a person who has really been close to this particular situation, in general, what went wrong? When I say, from a medical point of view, you had the opportunity to deal with the family from a personal point of view. It's obvious there had to be someone that you reported back to say, "Hey, we're dealing with this the wrong way." It had to be someone who just, basically, had a deaf ear with your recommendations, because it's obvious, listening to your testimony, you had to see something was wrong there. What went wrong, if you don't mind, if you could just share that with me?

DR. HENNING: It's 3:15 already, and I imagine you want to leave by five-ish.

ASSEMBLYMAN GREEN: If you could do it-- Well, no, I'm not looking to stay here all day long, but I'd like to feel that you could sum it up, real quick, in terms of what would be your recommendation? I listened to Assemblyman Cryan in terms of, it might be a case out there where we might have to use some restraint. But the idea, listening to you, you feel like we don't really have to do that. Somewhere along the line, somebody didn't listen to someone, and I don't want to point fingers, but it's obvious. No one could have been closer to that issue than you, because of the fact that you dealt with them one-on-one at the same time you represented the district, and that was your job, I presume, to recommend what type of treatment and what was going on. I'm just curious, again, without getting into a lot of details, something had to go wrong.

DR. HENNING: I can give you the overview version.

ASSEMBLYMAN GREEN: Well, if you want to do that, I would appreciate that.

DR. HENNING: Okay. In the overview version, the first problem that went wrong was when we looked at the entirety of the program that was being offered to Matthew in the facility that he was in. After the point it was determined that he was injuring himself, because -- after his hospitalization. The program started to decrease all types of stimulation that a normal child of his age would need in terms of going outside, having friends, being able to do things, going to school. So there was a dearth of support for him. There was the lack of working on basic communication with this child who did have some speech. He was, even when I saw him, which was before he was so overly

medicated, he was a child who-- He reached his hand out to you. Even when his hand was in that restraint, he would try to get that arm up so that he could put his hand out so you would touch his hand. He was a child who really wanted people to him. And yet, by being in the-- He was in an earlier type of a helmet and these arm restraints, it kept people away from him, which really did eat at his soul.

He didn't have an opportunity for basic things. For example, the day I saw him, which was a full day, the group of people who lived in his unit were going out for fast food to get a Chicken-McNugget-type of thing, which was his all-time favorite food. At first he was told he was going to get Chicken McNuggets for lunch, and then there had been an error so that his order wasn't placed. So when the other children came back and they had their Chicken McNuggets, he got to watch these kids, but didn't have any. And yet, he expected -- this was the highlight of his day. He hadn't done anything all day. He was to watch that and not get upset.

Then he was told he'd get, like, a burrito or some type of a frozen food, and it went from this favorite food to that favorite food to that favorite food until it ended up with Spaghetti-O's, which was a very low thing on his list. And yet, we're looking for a child to not react to that. So just basic care-of-children things weren't there, of encouraging him to speak, encouraging him to communicate, wasn't there.

The day that I observed him, there was no semblance of what was offered in the written plan actually being implemented. There was no semblance of the releases that were to occur from those restraints being implemented. When we tried to create the actual program for him, to remove him, it was a nightmare of funding streams, of who's responsible for funding a program for

this child. My job was just to write out what the program would look like. And people would agree, "Boy, that looks just like it's going to serve all of the needs we have," but then they couldn't determine, well, what portion does the school pay for and what portion does mental health pay for, and so the arguments came between the systems.

Meantime, the recommendations that were going, for alternatives and suggestions, to the facility he was currently living in, none of the alternatives were being tried. The program just remained the same. When we look at Nicholas, we're looking at many of the same issues -- in that, in your state, there's very few people at this point in time who are trained, that we can go in there-- I can write a program that says this is the way it should look for Nicholas. But I live too far away to be the person who implements it on a daily basis.

We really need to get a core of people, here, trained -- not so much even the direct-care staff level. It's that mid-level person, so you can have people who can create these types of positive alternatives for people who know the proactive things -- who know how to use the technology, the communicators, such as some of the people who attended here know how to use in lieu of having speech -- to get staff so they can understand how to do the same functional analysis to what's behind the behavior. So there really needs to be a core of education in this state. There needs to be more alternatives to people, and there needs to be better safeguards to the systems that you currently do have in place.

ASSEMBLYMAN PAYNE: Thank you very much.

Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: Certainly, I think we'd all agree that these facilities have treatment programs that attempt to help the child get better, and so on, etc. Take the case of Lisa, for example, who was biting hunks of her flesh out. Now, unless you're going to have somebody sitting there 24 hours a day watching this individual and, if she reaches to bite, you're there -- you're restraining, i.e., you reach out to keep her from biting. We've heard much about utilizing alternative approaches, and I take that to be the treatment. How, without the use of restraint, would you prevent an individual like Lisa from, when she's left alone for two minutes, biting her hunks of flesh out or something?

DR. HENNING: Well, first up, most places that have regulations that allow the use of restraints require that when restraints are used staff remain in the immediate proximity. So, in even worse situations, which also exist, unfortunately, in this state -- and I've witnessed them -- where the people are in these restraints and then they're left alone, most of the time when they're in restraints there is somebody who is here.

ASSEMBLYMAN THOMPSON: But I get the impression that their restraint shouldn't be used, so, therefore, you wouldn't necessarily have that person there with them, since restraints aren't being used.

DR. HENNING: No. No. No. I would not say that you wouldn't--

ASSEMBLYMAN THOMPSON: So, I'm saying, how do you avoid the person injuring themselves or something else?

DR. HENNING: I would not say you don't need somebody to be with them. Initially, it's really a different deployment of manpower, in that you would, initially, get a really solid understanding of why the person is doing that

and work very intensely, perhaps two staff to that person, to figure out why they're doing it. Very often, it's for very silly reasons. We're looking at this as though it's always something so intense and complex and above what we understand. Sometimes people bite themselves because their skin itches, and they don't have the coordination to get their hand there and they can get their mouth there, and it relieves the itch. Some of the things are not as complex. So sometimes what we do for things like that is hand lotion. It's not a very high-tech thing.

You're looking at teaching her a way-- Perhaps, she's biting because she doesn't want to have to go into the workshop, and she knows that if she goes and starts to bite, they will restrain her and she doesn't have to work. Well, another alternative to that would be not making her go into the workshop. So what you're looking at are alternative strategies.

ASSEMBLYMAN PAYNE: Assemblyman Thompson, specifically, you asked how would you prevent a person from biting themselves, if they were doing that, without the use of restraints. I think you're talking about the long-term -- finding out the reasons why she does that and, therefore, reverse them.

ASSEMBLYMAN THOMPSON: That's what I'm saying. We all believe there's some treatment there--

ASSEMBLYMAN PAYNE: Sure. Sure.

ASSEMBLYMAN THOMPSON: --but until the treatment works--

ASSEMBLYMAN PAYNE: How do you prevent them?

ASSEMBLYMAN THOMPSON: --how do you prevent them from harming themselves or--

ASSEMBLYMAN PAYNE: Without restraint.

ASSEMBLYMAN THOMPSON: --harming someone else without ever utilizing restraints?

DR. HENNING: You may have, on a very rare occasion, a need of a use of a restraint in an emergency circumstance. Something that you're not predicting. I think other people have addressed it, as opposed to this young lady who sounds like we knew she was going to bite her hand. So we should have had an understanding -- or bite her shoulder, or whatever -- we should have had an understanding of why she was doing it.

ASSEMBLYMAN THOMPSON: So you're saying, so time can cure it?

DR. HENNING: But we're talking -- to find it might take a day or two. We're not talking it might take you six years or so.

ASSEMBLYMAN THOMPSON: Well, you mean these problems are that simple, that in a day or two you can analyze them and come up with a solution? I thought it was much more length to them than that.

DR. HENNING: Not for every one of them, but for a lot of them, yes. A lot of them are as basic as, "I don't want to go to that program, and then you're going to make me go to that program, and the whole time I'm in there I'm going to do X, Y, or Z to self-stimulate myself to get in restraints so I don't have to do the task that you're asking me." Are all of them that simple? No. But there are a lot of them that you can be eliminating just by listening. If the person doesn't want to go on the bus, there's a good reason why the person doesn't want to go on the bus, and we need to start respecting that.

It also can be things of sensory integration, where the person cannot understand the sensory input that's being given to them. And there's a slew of strategies to deal with that, that don't relate to restraint in any size, shape, or

form. Teaching a person to say, “No.” One of the first things that someone did with Nicholas, when he was attacking people when he was in his home, was to teach him to push his hand away to indicate go away. And that dramatically, within several days, suddenly dropped the incidence of his behavior. Because if you got too close to him, he could just let you know he wanted you to leave.

So where some of this is very intense and very clinical, the majority of it is not. Some of it is medical. Some of these self-injuries -- some people say as high as 80 percent of them are because the person has a medical condition that’s not been identified, and, very often, that’s not being explored. So there really are alternatives to it. It’s not something like, if you’re really working with difficult people, this is the only alternative you have. There are places, many places, that no longer use these things, even though they work with the same exact people who used to live and work in the facilities where these types of procedures that were used -- the same people.

ASSEMBLYWOMAN WEINBERG: Thank you.

Thank you, Doctor.

Let me just concentrate on something. Perhaps it will help clarify. Some members of the audience might not have closely examined the Committee Substitute. But the Committee Substitute, in most cases, incorporates a good portion of those things that we all agreed on, and then again, a good portion of the original A-2855, Matthew’s Law. The main difference between the Committee Substitute and A-2855, Assemblyman Munoz’s bill, is whether or not mechanical restraints can be used as part of the IHP. Under the original bill, under Dr. Munoz’s bill, mechanical restraints cannot be used in the IHP. They can only be used in the case of emergencies.

Anybody wants to correct me on the way I understand this, I'd be happy to hear it? (no response)

In the Committee Substitute, they can be part of the IHP, but there are a lot of safeguards -- my word -- built into it. They can only be used for the period necessary, so the person no longer poses a threat, those emergencies issues. They can't be used for longer than one hour, and attending or individual's treating physician must examine the individual no later than one working day. They can only be approved after there is an interdisciplinary team consisting of the parent/guardian, the county based human rights advisory board -- remember, whose members cannot be affiliated with the institution that's being reviewed. So that those things have to be carried out before those restraints can be used in the IHP.

One of the problems I'm having with all this, and maybe some of our future speakers will be able to address this, is, I've been visited by groups of parents who really believe that restraints, in very limited ways, should be part of their child or loved one's IHP. They do not believe they should be used -- and my word *punishment* -- I realize that we have many more technical terms for that, but not for punishment, or I forget how the doctor put it, "Time out from positive reinforcement," but that it is included in the IHP. Some groups of parents, who represent a large number of young people, honestly and passionately believe that that idea should be included in their child's IHP.

I would like any future speakers, because that's really the crux of the difference between the Committee Substitute and Dr. Munoz's bill-- Most of the other things we've incorporated, and I think have incorporated well. We also have some definition changes. Everybody received a very long letter from DDD, which mostly involves definitions and such. But I think that kind of

narrows it down to the differences between the Committee Substitute and the original Matthew's Law.

So, with that, the next speaker is Dr. Fredda Brown, Professor from Queens College, City University.

Dr. Brown.

FREDDA BROWN, Ph.D.: Hello. Thank you for the opportunity to speak before you and express support of Matthew's Law.

ASSEMBLYWOMAN WEINBERG: Would you identify yourself, first, for the record?

DR. BROWN: I am Dr. Fredda Brown, and I am a Professor of Special Education, specializing in individuals with severe disabilities. In more than 25 years in the field, in addition to my work as a professor, I've also been the Clinical Director of an agency that offered community-based residential programs for individuals with the most severe behavior problems, such as the level of those described by Dr. Favell.

I've also provided training and consultation across the country on the use of effective, positive strategies to support individuals who exhibit challenging behaviors. I have published numerous articles in refereed journals and have written many book chapters, as well as published three books in this area. Currently, I am the Editor-in-Chief of the refereed journal *Research and Practice for Persons with Severe Disabilities*, and I am also an associate editor for the refereed *Journal of Positive Behavior Supports*.

I would like to use my brief time here to clarify the issue of restraint, to describe the current state of behavioral technology, and point out some red flags to consider as you look at this bill.

We must distinguish between restraints used as an emergency -- which may be necessary, I feel, at some point in time, to prevent harm to the individual or to others -- versus restraint used as treatment or programmatic restraint. Emergency restraint is used for immediate protection for real emergencies. The goal is to protect the person or others, not to reduce problem behaviors. Programmatic restraint and aversives are implemented as punishment, that is, as a consequence for some targeted, inappropriate behavior, implemented with the goal of reducing that behavior.

I would like to clarify two important criteria for restraint that I think should be considered. Restraint is a staff action that should be used only in response to when an individual, or others in the immediate environment, is in immediate danger -- and not a predicted danger -- an immediate danger. I am familiar with cases where restraint is used for behavior that has, sometime in the past, been associated with or a predictor of more dangerous behaviors. As a behaviorist, I must inform you that if a behavior can be so easily predicted, then the behavior can be easily addressed using alternative strategies.

Restraint must also be used for the time that the person or others are in that danger. Restraint must be terminated as soon as possible, as soon as the danger is over. Most of us have seen what is called emergency restraint, except it's for hours, for days, and for months. This is no emergency, and there is no justification for this. This is an attempt to use restraint as a treatment, and the use of restraint as a treatment is simply a reflection of inadequate staff training.

My first experience with individuals who exhibited the types of behavior that results in restraints was in 1973. And I have to say, at that time, I personally used restraint, as well as a variety of other aversive strategies, and

we called it therapy. The difference, however, is that at that time we did not have the technology that offered us alternatives. Today we do have a technology. We have positive behavior supports, as has been described to you today. So today we have no excuse.

As a professional in the field, as an editor of a research journal, I can assure you of two things: We have the technology to effectively address problem behaviors without ever having to use restraint as a treatment, or other aversive strategies; and we also have the technology to reduce the need for emergency restraint. We can reduce that as well, even though I did say that I think that is sometimes necessary. Much of the need for emergency restraint is tied to incompetent environments -- that is, ineffective staffs, ineffective instructional strategies, and outdated behavioral strategies. The journal that I am the editor of has published research on effective and powerful technologies of supports since 1975. That's 28 years of research and practice in this area. *The Journal of Positive Behavior Interventions*, which is a newer journal, has been reporting this technology for the past four years.

There are hundreds of books, training materials, written about the use of this type of alternative strategies. We know how to do this, and we know how to do this without the use of coercive and punitive procedures.

There have been millions of dollars of Federal--

ASSEMBLYWOMAN WEINBERG: Doctor, excuse me, you have one minute left.

DR. BROWN: There are millions of dollars of Federal grants focused on the continued research and development in the area. This funding would not occur unless the funding agencies were certain of the strength and importance of the technology, unless we had a strong research to support this.

A couple of red flags: I'd like you to be cautious of recommendations that promote the use of programmatic restraint or other aversive strategies as a last resort, as was discussed here today. Including these strategies as an option along a continuum, ultimately, condones their use. Provision of such a continuum is an obstacle to systems change and the opportunity to truly embrace positive options. This continuum promotes the ineffective use of positive procedures. The positive procedures become procedural details that must be overcome to get to the end of the continuum.

ASSEMBLYWOMAN WEINBERG: Thank you very much, Doctor.

Are there any questions? (no response)

Thank you.

I'm going to call Sally Jankowsky from the Family Alliance to Stop Abuse and Neglect, I guess.

And then, Art Ball from COSAC.

Sally?

SALLY JANKOWSKY: Good afternoon.

Thank you for allowing me to speak. I am Sally Jankowsky, and I am the parent of a 38-year-old son who has a traumatic brain injury. I am his mother, his advocate, and his legal guardian. He was injured 19 years ago, and since then, I have been very active on committees and boards and, also, am a member of the Governor's Advisory Council for Traumatic Brain Injury. I am here to give testimony about Matthew's Law and the limited use of restraints.

I commend Dr. Munoz for his leadership, for introducing and proposing Matthew's Law, Assembly Bill No. 2855. This bill limits the use of restraints. Restraints, according to this bill, are to be used in emergency

situations with a medical order from the person's treating physician. Restraints are not treatment. They are a failure of treatment. Parents are told that, if they do not sign a paper for the use of restraints on their child, they must remove their child from the program. Parents are threatened. They truly have no say as to the treatment of their child. Their guardianship is useless. We are told -- and I have been told this, too -- "If you don't like it here, then leave."

If you could just think for a minute and put yourself -- imagine how these kids feel when someone comes at them with a restraint. They're frightened. Some of them can't speak for themselves. They can't speak at all, verbally, cognitively. Then somebody tries to restrain them, and, no matter what type of restraint, these children can't verbalize how they feel. They're kids. Some of them are adults, too, and they fear. They have fear. It just escalates that fear.

Why aren't they ever allowed to be people? They're people first. If they say, "No," to anything, then they're labeled *behavior*, but they're not allowed to be people. Everybody is allowed to say what they want to do, but because they're disabled, they're not allowed.

We need administrators that care, not just people with degrees and letters after their name. We need staff that is trained in positive approaches. We have staff doing these restraints. Why can't they be taught and trained to do positive things? We need accountability and responsibility from the facilitators, staff, and administrators. It's a must. They're not -- these points aren't considered.

I have been told several times that whenever there was an incident -- occurred with my son -- that it was his fault, when, in fact, after investigating the incident, it was the staff's fault. I had the similar incident in my son's --

when my son was in New Jersey. There was neglect on the staff's part. She didn't do what she was supposed to do. My son is in a wheelchair, and he requires a one-on-one.

The substitute bill enforces the standards that are in effect today. They're negatively effective. I'm sorry. The doctor has to be the one to implement any use of restraints, not the interdisciplinary team or the human rights people. That is what is being done now. We have that now. It doesn't work. The teams do not exist in accordance with DDD standards. It's not working. Who is going to get picked from the county? What are they going to know about a specific disability? The doctor needs to be the person. Get the doctor on staff. How many more deaths are needed so that rules are enforced correctly?

This is a bill, a substitute bill, that aids the providers. It helps the providers to do what they're doing now. We need Matthew's Law, authored by Assemblyman Eric Munoz.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you, Ms. Jankowsky.

Are there any questions? (no response)

Thank you very much.

Art Ball, from COSAC.

ART BALL: Good afternoon, Madam Chairwoman and members of the Committee. In the interest of time, I have written remarks, which I've handed in, but I simply would like to say that on behalf of the New Jersey Center for Outreach and Services for the Autism Community, we would like to offer our support for the Assembly Committee Substitute, which we have had a chance to look over. We believe that it allows for the restrictive use of restraints, but

we also feel that it increases the accountability and, hopefully, encourages their appropriate use.

So, again, if you would look over the testimony when you have the opportunity, but we would simply like to offer our support for the Committee Substitute.

ASSEMBLYWOMAN WEINBERG: Thank you for being brief, and we do have written testimony. Don't leave yet.

Does anybody have any questions?

Yes, Charlotte.

ASSEMBLYWOMAN VANDERVALK: I tried to think about this, and I couldn't come up with an answer. Why are we making a distinction between different types of injured individuals? I mean, whether you're brain injured or autistic or just a plain person who happens to have any type of injury or sickness or-- I mean, why are we making a distinction?

MR. BALL: Well, actually, I think some of the Ph.D.s or the medical doctors who are in the audience may be able to answer that better. From my understanding, depending on the type of disability that a person has, the type of treatment or the type of -- the treatment options that we would want to have available, they're going to be very different from person to person. Persons with a particular kind of disability may respond much better to one particular type of treatment more than one other. And I believe that that's the reason why they're in the bill that way.

ASSEMBLYWOMAN VANDERVALK: Well, I don't want to belabor the argument. It's just I am having a problem, internally, saying that-- I mean, if treatments are available or could be made available, it seems we have to go that route and not categorize by type of illness in the individual.

MR. BALL: It seems to me that the only distinction I see in the bill is, there's a distinction between those who have traumatic brain injury and other people with disabilities.

ASSEMBLYWOMAN VANDERVALK: Essentially, we're talking about -- aren't we talking about people that have neurological problems, some type of a brain problem?

MR. BALL: Yes.

ASSEMBLYWOMAN VANDERVALK: So what difference does it make if we're-- I mean, why are we trying to draw distinctions? Why don't we just treat them like people?

MR. BALL: Once again, all I can say is, because different types of treatment may be more appropriate for some particular person because of the type of disability.

ASSEMBLYWOMAN VANDERVALK: I don't mean to argue against you, personally. I'm just thinking out loud.

ASSEMBLYWOMAN WEINBERG: Yes. If I may--

ASSEMBLYWOMAN VANDERVALK: I'm sorry.

Okay. Go ahead.

ASSEMBLYWOMAN WEINBERG: Assemblywoman, I don't think this is the best witness to answer that--

ASSEMBLYWOMAN VANDERVALK: Right. I'm sorry.

ASSEMBLYWOMAN WEINBERG: --but we have some other professionals coming up, because he represents one aspect of the community.

But I would like to ask the question that I posed a little earlier, as to how we satisfy the differences in the parent community, and those parents that believe that this should be part of the IHP -- with those safeguards that we

thought we built into the Committee Substitute -- versus the original Matthew's Law that -- where there is no way to use restraints except under those emergency conditions. If you could speak to that a little bit, it might help clarify it for me and any other member of this Committee.

MR. BALL: My response to that is that I believe that the Committee Substitute bill does that. It sets some accountability, it sets some parameters, and it sets some safeguards, according to which restraints can be used. It talks about a county-based review board. It talks about human rights committees. It talks about things like that. It is my understanding, and my read of the bill is that, the parents of children upon whom these restraints or these treatments might be being used, that they are being included on those bodies. So they do have the opportunity to address that.

ASSEMBLYWOMAN WEINBERG: I know that you are a proponent, or at least that's what's been expressed to me, of being able to use restraints in the IHP. So if you could speak on behalf of the parents that you represent as to why you really feel it is important that it be in the IHP, as opposed to just being able to use it, and only being able to use it, in cases of emergency. What is the difference to the parents that you represent, if you can do that?

MR. BALL: When I hear the parents talking, they talk about-- And there's some of them who talk about the fact that the ability to make use of aversive procedures or to be able to use restraints in a planned way may have been the difference between whether their child is uncontrollable and needs to be institutionalized or, actually, is able to live at home.

What we've been hearing all afternoon is, and, especially, I think Dr. Favell had some interesting things to say-- It talked to using restraints when

necessary, but always lessening the use of restraints. There's a way to control the behavior.

I remember hearing the story of a young man, in speaking of aversive techniques. We can think of them as very noxious types of things, but there was a young man, and they put a rubber band on his wrist. When he was about to engage in a particular kind of behavior, or began that behavior, they would snap the rubber band. Now, quite honestly, I don't think that doesn't-- Is that something we'd like to have done? No. But it isn't something that's terribly, terribly onerous on that young man -- it doesn't seem to me. But that made a significant difference in his behavior. He said, "You mean when I do that, that's going to happen?" "Yes, it is." Almost immediately his behavior changed.

What we're talking about is parents who want -- who still would like the professionals with whom they work to be able to use those kinds of techniques.

ASSEMBLYWOMAN WEINBERG: Okay. Well, then, let me turn that around, based upon the testimony I'm hearing. Suppose they said that young man loved chicken nuggets, and they said to him, "We're going to give you chicken nuggets for lunch every day, but every time you do that behavior, you're going to lose part of those chicken nuggets." That's the other side of the coin. Do you have a reaction to that?

ASSEMBLYMAN CONAWAY: I have a reaction to that.

ASSEMBLYWOMAN WEINBERG: Well, don't tell me about cholesterol, because I could think of something else. (laughter)

MR. BALL: The chicken nugget is considered a positive reinforcement for picking the kind of behavior. Removing the chicken nugget

can be considered an aversive. But quite honestly, what is it? Is that really an aversive technique, or is it one part of something that's designed to make that young man or that person move in a positive direction? It would seem to me that withholding something that that person wants, such as a chicken nugget or an M&M or whatever that small reward might be, might be a very positive part of something that's designed to make a positive difference in that person's life.

ASSEMBLYWOMAN WEINBERG: I'm merely trying to illicit this, that everyone understands the actual issue that we are involved in. In spite of all the other papers in front of us, that is the crux of the difference between the Committee Substitute and Dr. Munoz's bill.

Thank you very much.

MR. BALL: That's exactly what it would seem to me, yes.

ASSEMBLYMAN CONAWAY: I was going to ask him a question.

ASSEMBLYWOMAN WEINBERG: I'm sorry. Go ahead.

ASSEMBLYMAN CONAWAY: I think the Chair's example highlights the care that one must take in the kinds of positive or negative reinforcements somebody uses. Because clearly, if you overuse the Chicken McNuggets, you'll end up, perhaps, with an overweight child.

ASSEMBLYWOMAN WEINBERG: I knew he was going to say that. (laughter)

ASSEMBLYMAN CONAWAY: So, the point being, of course, is that there are downsides and upsides, and you have to always balance risk and benefit as you go forward.

Now, I want to put this to you, and just let me know whether or not -- perhaps this is the wrong analogy to use -- for many people out there are parents. I'm a parent myself. My child -- we use time outs at home. We isolate

the child from the room. My daughter, if she jumps up on the couch, she has got to go in the next room. We talk to her, after it's done, why she has been in there, and she doesn't like it. My son, who is 2, we started on him about 2, 2-and-a-half. He gets to sit on the step. He doesn't like that. And if we say, "Are you going to have a time out?" he doesn't like this. And somebody will say, "Certainly, he doesn't like it," somebody certainly could characterize that as aversive. Do you think that that kind of -- and that's certainly a behavioral management that doesn't rely on corporal punishment, that uses, sort of, a negative kind of an action to control or shape a child's behavior. And of course, there are always consequences in life. Adults need to learn that. But is that an inappropriate analogy to use in this kind of therapeutic situation or not?

MR. BALL: I've heard that analogy used, and I think people have said, well, you can't take-- If you had a child and your child was about to run into the street, and you said very loudly, "No," there would be a real positive reason why you were doing that. Your 2-year-old would not understand, but they might understand the no. I've heard people say, "Well, you can't simply take that analogy and use it on people who have such challenging behaviors."

The thing that we need to recognize is, the aversive or the treatment that we use may need to be somewhat different for someone who has much more challenging behaviors, and someone for whom a very, very different method of treatment might be necessary.

I have two children. One has a disability, the other does not. She does not have autism. She has mild mental retardation, and there's some physical involvement. The way I discipline my girls is very different, because they both respond to very different things. I know that my 14-year-old, who has a disability, if we ask her, "You've just gotten to the point where you need to sit

in your room by yourself,” she hates that. My older daughter would go sit up there and read for a while. So what we do is, we do something that the person doesn’t like, and that’s a way to get a positive behavior.

But I think what we do is, we adjust it. We individualize it. Keep in mind, that when we talk about an individualized habilitation plan, the first word is individualized. Hopefully, what we’re doing in those plans is coming up with something that is very particular for that individual. We would also want to make sure that it doesn’t go overboard, the least amount that is necessary to enable that person to have a better quality of life.

ASSEMBLYMAN CONAWAY: I would call that training for adulthood, right? Because, of course, there are positive and negatives in what we do, in my view, right?

MR. BALL: Yes.

ASSEMBLYMAN CONAWAY: That’s life, really, isn’t it?

ASSEMBLYWOMAN WEINBERG: Thank you.

Thank you very much. Thanks, Mr. Ball.

ASSEMBLYMAN PAYNE: May we have Dr. Spitalnik, please.

UNIDENTIFIED SPEAKER FROM AUDIENCE: She stepped out.

ASSEMBLYMAN PAYNE: She stepped out. (laughter)

We’re getting ready to move on.

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

ASSEMBLYMAN PAYNE: Identify yourself and your affiliation, please?

DR. SPITALNIK: Yes. I’m Dr. Deborah Spitalnik. I’m a psychologist, Professor of Pediatrics and Chief of Developmental Disabilities,

and Director of the Boggs Center on Developmental Disabilities at UMDNJ-Robert Wood Johnson Medical School. I thank you for the opportunity to appear in front of you today. I also am the immediate past chair of the President's Committee on Mental Retardation. But I would address you in my role as--

ASSEMBLYWOMAN WEINBERG: Is that the President, as in the United States?

DR. SPITALNIK: As in U.S., yes. The President's Committee on Mental Retardation.

But I address you in my role as Executive Director of the Boggs Center, New Jersey's University Center for Excellence in Developmental Disabilities, and our responsibility to both improve services for people with developmental disabilities and advise policy makers. I provide these comments on the substitute legislation, and, also, with the intent of strengthening that legislation.

As sponsors of all of these bills, you are to be congratulated for promulgating these bills which begin to bring New Jersey into line with the growing national consensus on treatment and protection of individuals with developmental disabilities and those with traumatic brain injury. Your actions are courageous, but rest upon a firm foundation of research, clinical practice, and public policy that include the right for individuals to be free from harm and physical and chemical restraint, the right to be free from involuntary restraint, both things; and the view of not using restrictive treatments and relying on them for treatment.

The ARC of the United States promotes the use of positive behavior supports, as does the Association for the Severely Handicapped, the American

Association on Mental Retardation, and the Council for Exceptional Children.

As sponsors, you are to be commended for the intent of the bill and the specific description of the condition under which physical and mechanical restraints are allowed and not allowed. But the substitute bill needs to go further. In the case of the need for emergency restraint, the requirements go a long way to ensure the safety of individuals, both with traumatic brain injury and developmental disabilities, but there are still significant weaknesses in the bill. The difference that I pose to you is not the issue of whether we outlaw all restraints or allow them in some circumstances, but what do we do in addition to mandating or regulating the use of restraints?

The requirements that presently are enunciated in the bill do not sufficiently address the responsibilities of facility administration and professionals to address the behaviors at issue that have caused the need or the perceived need for restraints. The responsibility to conduct a functional behavior analysis, to understand the ecological conditions, as Dr. Henning spoke about -- the health, the environment, the individual's learning history and skills, the competency of staff -- that, those things that predict and maintain problem behavior such as aggression, self-injury, and property destruction.

This affirmative responsibility must be built into the bill and applies to both emergency situations and, also, any situations where one would consider planned intervention and the use of restraint. The requirement in the substitute bill, that the interdisciplinary team determines what less intrusive techniques have been successful in protecting the person or others, does not adequately protect the individuals and does not really permit the intention of the bill to flower and benefit these individuals. This law must be strengthened

by a requirement that a functional analysis of a person's behavior be conducted by an independent, qualified behavior analyst following any use of physical or mechanical restraints.

To restrain a person because the services and supports he or she is receiving are inadequate is too ineffective and to blame the victim. To train personnel to apply restraints safely does not ensure that they will be used appropriately, nor that they will reach the end point that we collectively desire of helping individuals live more independent, fulfilled life. Consultation with a review committee is not sufficient unless we mandate that that capacity is both within our institutions and our community programs.

I urge an additional caution with the language of the proposed bill and the monitoring of the implementation. This is something that Dr. Conaway mentioned. The notion of safeguarding equipment, while in some instances actually keeps people safe-- We cannot hide behind that rubric in terms of minimizing the need for active and appropriate positive environments and positive supports.

The Boggs Center at UMDNJ is interested in continuing to assist the Legislature and the Department of Human Services and the Division of Developmental Disabilities in developing this behavioral and programming capacity to make the issue of the use of restraints fade greatly, if not completely, into the background.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Doctor.

Yes, Doctor Conaway.

ASSEMBLYMAN CONAWAY: I wanted to look at the text of the substitution, and that would be on Page 4. I don't know if you have it in front of you or not.

DR. SPITALNIK: I don't, but I'm sure--

ASSEMBLYMAN CONAWAY: It's fairly straightforward, and I'll just pose it to you.

DR. SPITALNIK: Thank you.

ASSEMBLYMAN CONAWAY: In Section 3, subsection -- in Section 5, Subsection A-3 -- I think it was -- Page 4. It deals with the restriction or prohibition of "isolated in any manner." I'm curious as to how you would define isolated in any manner? I use the example of my children who I sent to the other room to change their behavior and to get them to listen.

DR. SPITALNIK: Right.

ASSEMBLYMAN CONAWAY: What do you think the effect of a prohibition-- How do you define that term? Is it separation from the group, which can be distressing? I mean, my children sometimes cry when I put them in time out.

DR. SPITALNIK: Right. Right.

ASSEMBLYMAN CONAWAY: Or are you talking about something that's much more prolonged or closed in, perhaps, or confining when you talk about isolation? It's not defined here. Do you have any concern about the use of that word and its prohibition in this bill?

DR. SPITALNIK: About permitting the use of isolation?

ASSEMBLYMAN CONAWAY: Yes.

DR. SPITALNIK: I think one of the shifts that other people have testified to, but I don't think have necessarily made as explicit, is that in the

technology of positive behavior supports there is-- Part of the theoretical underpinning is, that the reason for a lot of the kinds of behaviors that are often subject to restraints is an inability to communicate one's needs, and inability to form relationships in the traditional way that individuals without disabilities may, or to have enough stimulation in their environment.

The way that I think of positive behavior supports is, I come home and say to my husband, "I've had a horrible day. I need a hug." And my husband gives me a hug, and he's not reinforcing me for having a bad day. He's giving me a hug to provide me with supports.

Dr. Henning testified to Matthew reaching out for touch and for connection. A lot of the hierarchy of the traditional behavioral programming takes individuals who are living in the most deprived environments and deprives them even further, with the notion that until they learn to be good or compliant or fit the mold that our expectations of their behavior have, that we will not provide them with a rich, stimulating environment.

ASSEMBLYMAN CONAWAY: That's wrong. That's wrong.

DR. SPITALNIK: So I think the shift that I'm talking about, and the shift of why we can't just rely on the issue of the placement of restraints or when they're used, has to be towards enriching the nature of the environment that the person with the disability is in. It speaks to a lot of the concerns that Assemblyman Rooney was talking about in terms of staff and programming. So that's why I'm urging that you not just think of this as a bill regulating restraints, but a bill that deals with protections about restraints in the context of a rich environment that enables people to learn, to relate, and to develop.

ASSEMBLYMAN CONAWAY: I agree with that.

DR. SPITALNIK: Okay.

ASSEMBLYMAN CONAWAY: And I'm not a professional there -- but that sounds absolutely right to me, and from what I've been able to read, that we're talking about a wholistic view that involves this positive reinforcements that you're talking about -- and some of us believe -- in concert with some of the things that might be considered negative.

Would you talk about the routine intake and evaluation of a new patient in a facility dealing with those who have developmental disabilities? Now it sounded like, from your question, that a functional behavioral analysis is not done in every case?

DR. SPITALNIK: That's absolutely true--

ASSEMBLYMAN CONAWAY: That's true.

DR. SPITALNIK: --that it's not. A functional behavior analysis is not a one-time--

ASSEMBLYMAN CONAWAY: It should be an ongoing thing.

DR. SPITALNIK: A functional behavior is an ongoing response to an individual's behavior or the needs of the situation. To comment on your question about the intake, I think that would be highly variable depending on whether it was in a developmental center -- and I think there's variation across the seven State-operated centers -- a private facility such as Bancroft or Spectrum, or a group home or other community residential facility.

We do know that often individuals, when they come from institutions to the community, do not come with a complete package of information, so that we know that information about an individual gets lost. But the kind of analysis that I'm talking about should be done when an individual enters a situation, when they're both progressing and when new behaviors appear.

But my point to you, from a regulatory point of view, is that the use of restraints should trigger a professional and paraprofessional response that looks at the situation and tries to remediate the situation, and the relationship between the individual and the situation, that has caused the need for response. We can regulate response, but without enriching environments, without giving individuals communication skills, without giving individuals ways of negotiating that environment and relationships, we will not make the kind of progress that it is, clearly, your heartfelt intent to bring about.

ASSEMBLYMAN PAYNE: Assemblywoman Weinberg would like to ask a question.

ASSEMBLYWOMAN WEINBERG: Yes, I just have a quick question. Do you see cases where the use of restraints should be built into the IHP with these safeguards?

DR. SPITALNIK: Well, my colleagues in Pennsylvania utilize a system like that, but for a very small number of individuals -- there is the feeling there, and I think they have, as a state and as a system, paid a tremendous attention to both the issue of positive supports and behaviors -- situations where individuals who have had particularly intractable behaviors have needed to have the use of restraints applied. And so that I think, for such situations, building it into the IHP can make sense. However, my concern is that I think those situations are so far fewer than the degree to which we see that in place right now in our developmental centers, in New Jersey particularly, that I would want to assure a degree of rigor in making sure that other approaches were truly being put in place. Not until we got there, but also if we did get to the point of building this into the IHP, that we would continually and intensively be providing positive programming to diminish that use.

ASSEMBLYMAN PAYNE: Yes.

ASSEMBLYMAN ROONEY: I almost have my question answered, because Assemblywoman Weinberg said almost the exact thing that I was going to ask. Looking at this, with the IHP and everything, as far as the plan, what I'm hearing you saying in between the lines is, basically, it really is not-- I think there were two things that kind of struck me as -- was the safety of others where a restraint plan or restraint action by the provider occurred. If it was to prevent injury to another person, either with the staff or another client/resident, that might have been something that you would agree to. But I would like to get an idea of where you think restraint is absolutely -- should be applied in any situation? Can you give us any example other than where it's to prevent injury to another person? Can you think of any other reason why restraints should be applied to any of these clients?

DR. SPITALNIK: Well, I think the individual with a disability needs to be safe and staff need to be safe.

ASSEMBLYMAN ROONEY: We agree.

DR. SPITALNIK: I think that restraint is, as I see it, a last resort. And that, if one has applied restraint, that is saying to me that there are other things that, also, needed to have been in that environment, or need to be built into that environment, that would prevent that from occurring in the future. So I guess what I'm saying, directly, is that I'm not saying I would prohibit any use of restraint ever. I would certainly minimize it. I would tightly control it. But I would, also, use it as a constant trigger for renewing, reviewing, and enriching the environment and the programming that has come to bear. I think that the approach of only regulating restraint, without looking at the corresponding side of either the depriving or the potentially enriching nature of environments, will

not get us further along. I think the worst thing we could do is to drive this issue underground, because we would not have accountability for people's well-being and safety, and we, also, would not be fulfilling the responsibility for providing treatment for the people under the State's care.

ASSEMBLYMAN PAYNE: Thank you very much.

We'd like to move on. We have about another five or six hours of testimony here. (laughter)

ASSEMBLYMAN ROONEY: I have a 5:00 deadline, absolutely.

ASSEMBLYWOMAN WEINBERG: As a matter of fact, we're going to have to discuss how we're going to handle this, because, obviously, we're all going to be on sensory overload, and we will not be able to absorb this, and there are many, many people who have signed up to testify.

ASSEMBLYMAN ROONEY: Assemblywoman, if I might suggest we put a time limit. I have to leave at 5:00. I apologize, but that's my absolute deadline. It's been five hours of hearing. I think it should be continued to another time. Just explain to everybody either--

ASSEMBLYMAN PAYNE: Well, that would be very difficult to do. We have people here that came here to testify today, and if we say another time, I'm not sure how we would be able to handle that. Let's restrict our comments and questions to a -- very, very focused. Much of the discussion we're having now we can have subsequently, because I think there's going to have to be some further discussion on this.

Let me ask if Ms. Kathy Wigfield is here? Please, then.

KATHY WIGFIELD: Thank you for allowing me to be here today.

ASSEMBLYMAN PAYNE: Are you speaking into the mike? Is the red light on? (referring to PA microphone)

MS. WIGFIELD: Yes, the red light is on.

I want to thank you for allowing me to speak here today. I want to thank you for having these hearings.

I have a great deal to tell you, but it's not possible in five minutes.

ASSEMBLYWOMAN WEINBERG: Would you identify yourself first?

MS. WIGFIELD: Excuse me?

ASSEMBLYWOMAN WEINBERG: Identify yourself.

MS. WIGFIELD: I'm sorry. My name is Kathy Wigfield. I'm a parent of a developmentally disabled individual with behavior problems. He's currently in a moderate security unit in New Lisbon Developmental Center. Frankie was placed in New Lisbon Developmental Center in 1994. I cried when I brought Frankie down to New Lisbon, and I cry every time I leave there for the two-hour drive home, because of the treatment that he receives there. I am adamantly, adamantly, against restraints.

If any of you even have a doubt about restraints, I'd like to invite you to go down to New Lisbon Developmental Center with me and try on a four-point restraint, which they would very much like to put into my son's program -- in the IHP. I am continually being, to me, harassed. They even have down on his IHP forms that his proposed guardian adamantly or vehemently refuses four-point restraints. Since that was put on his IHP, they are saying that my son is competent and does not need a guardian.

I want to read what I had wrote here. My son is a Dallas Cowboy fan. He loves the Cowboys. One Sunday afternoon, he was watching a Cowboy game. They started losing--

ASSEMBLYMAN PAYNE: Excuse me. Can I just interrupt you for one second, please.

MS. WIGFIELD: Sure.

ASSEMBLYMAN PAYNE: You have it written, we have it here. Can you just go through and highlight -- and maybe just point out one or two highlights, because we do have it here, and it won't be necessary for you to read it. Just summarize it, if you will, please.

MS. WIGFIELD: I have also attached to that, if you could see, where he was charged with arson by the Human Services Police Department. There's also a letter in there from my son, in the attachments that I gave you. It's very hard to summarize these things, but my son was, basically, put in restraints because he got excited about a Dallas Cowboy game. This is how New Lisbon Developmental Center uses restraints. And I imagine DDD is very upset about Matthew's Law and would not want it passed, because it's, basically, how they deal with or develop behavior programs for people that do have behavior problems.

I have not yet seen a behavior program developed for my son that has been effective. Since he has been at New Lisbon Developmental Center, he has deteriorated a tremendous amount. It's very hard to sit here. I'm not a professional person. And with the restraints at this time, I guess, I'm not making much sense. But the restraints -- I absolutely support Matthew's Law. I could give you multiple, multiple incidences of abuse in terms of restraints. It's really a barbaric way to develop behavior programs, putting restraints in an IHP.

I hope all of you will review the information that I gave you. And I, also, gave you my name and phone number. Hopefully, somebody will call

me back after they've reviewed this information. It's much too much to go over here.

ASSEMBLYMAN PAYNE: Ms. Wigfield, thank you very much. Let me just say that you're not a professional, either am I, but you're a parent. I want to be clear. The reason why I did call you at this time is because we had a lot of professionals that have come before us. I want to make sure that we do have parents who, I think, are as -- the most significant part of this testimony. So I want to thank you very much.

I just had one question. You said that your son was arrested--

MS. WIGFIELD: For arson.

ASSEMBLYMAN PAYNE: A complaint was filed while he was a client or a patient or what?

MS. WIGFIELD: Yes. Frankie-- What had happened was he was neglected for the whole day by staff. He was supposed to be checked on, supervised, at least every 15 minutes. He had gotten up at 8:00 for meds, went to staff. Two staff people the night before said that he was upset. They made sure he had his medication in the morning. He went back to his room with no breakfast, no lunch. Nobody checked on him. Three o'clock in the afternoon he set a fire, and New Lisbon charged him with arson. I still feel New Lisbon should have been charged with a crime, not Frankie.

ASSEMBLYMAN PAYNE: I just wanted a clarification of that. This is a patient or a client in one of our institutions who sets a fire, and you're telling me that charges were brought against him for arson.

MS. WIGFIELD: Right. Because he has behavior disorders.

ASSEMBLYMAN PAYNE: Right.

MS. WIGFIELD: I was told by, off the record, a psychologist, New Lisbon is known for doing this.

ASSEMBLYMAN PAYNE: Okay.

MS. WIGFIELD: For charging a client that is both developmentally disabled with behavior problems. If he does not fit into their behavior program, they charge him with the crime.

ASSEMBLYMAN PAYNE: Thank you.

MS. WIGFIELD: Unfortunately, to them, the judge dismissed the case, based on the fact that Frankie's not competent to stand trial.

ASSEMBLYMAN PAYNE: Yes. I think it's kind of a paradox where we have people in an institution for treatment and care--

MS. WIGFIELD: Right.

ASSEMBLYMAN PAYNE: --and we have an incident. I just want to underscore that so I could understand.

Thank you.

MS. WIGFIELD: Right now, my son is a guest at a moderate security unit.

ASSEMBLYMAN PAYNE: Thank you very much.

ASSEMBLYWOMAN WEINBERG: We are going to have to limit the next speakers to no longer than two minutes. You're just going to have to highlight your testimony-- Well, it's going to be impossible for this Committee to absorb more information if you look at the amount of people who would like to speak to us. So I'm not being arbitrary. We are trying to get a cross section of professionals, providers, and parents, and consumers in this field. So you have to be patient. We're trying our best.

I'd like to call up Pat Amos, from the Family Alliance to Stop Abuse and Neglect.

And then, Diane Conway, from the New Jersey Association of Community Providers.

P A T A M O S: (speaking from audience) What I was looking to say was--

ASSEMBLYMAN PAYNE: Please.

MS. AMOS: This is off the record.

ASSEMBLYWOMAN WEINBERG: There can't be anything off the record. I'm sorry.

MS. AMOS: Okay. This is not about the testimony.

Thank you.

What I just wanted to say--

ASSEMBLYWOMAN WEINBERG: Please identify yourself first.

MS. AMOS: Oh, okay. I'm Pat Amos, and this is not about my testimony. I wanted to say that several groups of people have told me they had to leave and have left their testimony. So it may not be as bad as it seems in terms of who's left.

ASSEMBLYWOMAN WEINBERG: If we have written testimony, that's fine, and we've already received some of people who have to leave. But go ahead, I don't want to take from your time.

MS. AMOS: Sure. Sure.

I'm Pat Amos, and I have worked for nearly two decades as an advocate for families and people with disabilities. I have been on the Governor's Council for Developmental Disabilities, on their executive committee in Pennsylvania for years. I've helped and found and run and served as president of local and national organizations. I'm a parent of four children.

My first has autism. My second has Asperger's, a form of autism. My third has severe obsessive-compulsive disorder. My fourth is, perhaps, the most behaviorally disordered of all, because he just entered his teenage years. (laughter)

For at least the past dozen years, I've been receiving complaints from families residing in Pennsylvania and New Jersey concerning the inappropriate, frequent, and injurious use of restraints on children and adults in various facilities, not just any one. I'm here on behalf of those families, and I want to say to you that the restraint issue is occurring for one big central correctable reason, and then I want to segue into a quick critique of that substitute bill, which I've had a chance to look at.

ASSEMBLYWOMAN WEINBERG: Can you move directly to the critique of the substitute bill?

MS. WIGFIELD: Let me just read you my one paragraph, because that goes to the heart of the critique. New Jersey's current restraint regulations have created and perpetuated an unconscionable double standard in which a restraint classified as treatment is subject to far fewer safeguards, monitoring, and reporting requirements than the same restraint when it's classified as an emergency. The resulting bias in many facilities, toward classifying restraint as treatment, not only endangers people with disabilities, but inevitably results in the bullying of parents to get their consent, and the blaming of parents for giving their consent when the restraint leads to harm.

Now, that leads me right into -- and you're just going to have to forgive me for working off of notes. We've only had two days in which to look at this substitute. We really came prepared to talk about something else. I'll send you my comments in print later.

The key problems with the substitute bill are, about the only thing that remains in Matthew's Law is Matthew's name. The substitute bill condones physical and mechanical restraints as treatment components of the individualized habilitation plan, and when parents and the human rights committee give consent that would be the case. That's already the case in New Jersey. This is precisely the problem that Matthew's Law is intended to remedy. Restraint has no value as treatment. It represents the failure of treatment. It can only be reduced and subjected to proper safeguard when it is restricted to safety emergencies.

Two, when restraint is permitted as treatment, all the safeguards that Matthew's Law introduced -- medical oversight, parental notification, post-restraint meetings to adopt better approaches, retraining of staff in positive approaches, reporting to the State, and public documentation by facility -- are lost to that individual and that family. This is the current double standard of which I was speaking.

Three, the Division of Developmental Disabilities Circular 34 already provides for parental notification and approval by a human rights committee before restraints and other aversives can be used as treatment. It's in there. That has to happen already. Parents are coerced into signing permission under the threat that their child will otherwise be removed from the facility. And as we know all too well, the human rights committee has no particular incentive to refuse a request, and will act on the presumption that the facility staff and administrators are the experts who know best. And when an individual comes under State guardianship, their active protection in such a situation virtually disappears, along with their parents.

The very regulatory requirements that have lead to so many injuries and deaths would be cemented into legislation in this substitute, making it even more difficult to change them in the future.

Four, the substitute bill presumes to mitigate the problems of the human rights committees and their rubber-stamping of restraints and aversives and treatment plans, by mandating the county-based human rights review boards be appointed by the commissioner from individuals not affiliated with the facility or public or private agency. Appointment of new HRCs by the very State agency that has repeatedly failed to protect, adequately monitor, or even minimally enforce the basic requirements for care and safety of people's developmental disabilities, not to mention children in foster care, is not an encouraging prospect.

Fifth, aversives are not prohibited in this bill as they would be in Matthew's Law, except for persons with traumatic brain injury who are in a community residence. I want to go back to an earlier comment that was made here -- why can't we treat children as children? Why would we say that some people, because they have traumatic brain injury, will not be subjected to restraints and to aversives? That, I think, is one of the first glimmers of light that I've seen today. My mother always used to say, "Arguments give heat, not light." That glimmer of light, I think, can lead us out of this tunnel.

I just want to say that it also raises the question, which we see now in the Division of Developmental Disabilities's Circular 19, on restraint that says that some people, because restraints and aversives are medically contraindicated, will not have them used in their programs. It may not be part of their habilitation plan, because there's some physical reason why it could hurt them. That means that some people, by regulatory fiat and not by virtue of

their behavior, are already exempt. And the substitute bill would recognize yet another category to be exempt.

So again, we're saying, why not treat people as people? The problem with making this special category of people, who need to be restrained as treatment, and then putting that out there, was shown graphically a week and a half ago when the Camden County prosecutor came back in the case of Matthew Goodman and said, "We find no criminal behavior in what happened to Matthew. We find no criminal behavior because the intent" -- now intent is a very high standard, right? I could drive drunk and hit someone and say I had no intent to hit. I don't think the law will agree. But the intent at this point was not to hurt Matthew. It was to treat his behavior.

This leaves parents without even any legal footing to redress what happens to their children. This is why we're arguing so strongly for no restraints and aversives in the IHP, emergency use only.

That's as brief as I can be.

ASSEMBLYWOMAN WEINBERG: Ms. Amos, we allowed you to go well over the time.

MS. AMOS: I thank you, and I'm done.

ASSEMBLYWOMAN WEINBERG: I realize the pressure we are putting you all under. We do have your written testimony here.

MS. AMOS: You will have this, because I just had to craft this sitting there, right now.

ASSEMBLYWOMAN WEINBERG: Okay, thank you.

MS. AMOS: Thank you.

ASSEMBLYMAN ROONEY: Madam Chairman. I just want to get a-- You said something about Bancroft not being criminally responsible for this, according to the Attorney General's office? Is that correct?

MS. AMOS: Yes. The Camden County Prosecutor's Office, a week and a half ago, after a 10-month investigation, did return their decision that there would be no criminal prosecution, because there was no intent to harm. My argument is, that comes out of a climate that we have created in New Jersey that says these things are appropriate as treatment. Therefore, the staff only intended to stop his behavior. Over-enthusiastically, they stopped all behavior.

ASSEMBLYMAN ROONEY: I can't believe it. Because DDD has already said that they found them guilty of abuse and neglect.

ASSEMBLYWOMAN WEINBERG: We're not lawyers here, John, but I guess criminal intent is different from civil.

ASSEMBLYMAN ROONEY: But there's also criminal negligence, which is also--

ASSEMBLYWOMAN WEINBERG: Okay. Let's not argue the case.

ASSEMBLYMAN ROONEY: I know. I have a problem with the Camden County Prosecutor's Office, if that's the case.

ASSEMBLYWOMAN WEINBERG: Well, you can address that to the Senate Judiciary Committee.

ASSEMBLYMAN ROONEY: I think I will.

ASSEMBLYMAN PAYNE: Thank you very much.

May I call Diane Conway?

DIANE CONWAY, Ph.D.: Good afternoon, Madam Chairman and distinguished Committee members. My name is Dr. Diane Conway, and I'm the Executive Director of the New Jersey Association of Community Providers, representing over 100 private agencies in the State of New Jersey, serving over 35,000 individuals with developmental disabilities in the state.

The issue of restraint, as you can see today, is very emotional, and it's very highly charged and very divisive. You can see that I am going to be very brief, because you do have my written testimony. So, in the interest of brevity, I will just leave our thoughts in writing.

I support Assemblyman Rooney's comment that you cannot paint every provider with a broad brush. You have heard, in some instances, where the individual indicated that they--

ASSEMBLYWOMAN WEINBERG: I'm going to interrupt you. We're not going to talk-- Let's get back to the bill, specifically, and your feelings on the Committee Substitute.

DR. CONWAY: Yes. We do support, very highly, the Committee Substitute -- A-2849, A-2850, and the substitute. We do not support A-2855. Okay.

ASSEMBLYWOMAN WEINBERG: Now that I asked you to be brief, can I ask you to explain why? (laughter)

ASSEMBLYMAN PAYNE: You can't have it both ways, Assemblywoman. You can't have it both ways.

ASSEMBLYWOMAN WEINBERG: Oh, I've been trying to get through my life having it both ways. Why not try here? (laughter)

DR. CONWAY: Well, I think my written testimony goes into that. We do feel that there are individuals with significant behavioral challenges that

present a danger to themselves or others, and that they may need this as a treatment option. And if they don't get this, then they're going to be forced to be chemically restrained with some very significant medical, long-term, irreversible effects -- what are the options out there -- or they might be forced to go out of state to a program far away from their families and people who they love. And if they're out of state, New Jersey does not have the ability to monitor the service that they're getting, as well as they do if they're in state.

I also think that if you take this treatment option away, the few providers who are willing to serve these individuals with severe behaviors will be disinclined to do so. We do support all the safeguards that we've talked about today -- the functional analysis, the staff training that's indicated in A-2850. We are fully in support of that. You do have to have safeguards, and we're not advocating for haphazard use of restraints at all, but very focused, controlled use of restraints as a last resort.

And may I say that NJACP has asked DDD to establish a work group on restraints, and they have done this. That group is very active, right now, in reviewing literature, in reviewing Federal standards, in reviewing accreditation standards on a national level. So I would urge the Committee to use this as a resource in their deliberations.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you.

ASSEMBLYMAN PAYNE: Assemblywoman Pou.

ASSEMBLYWOMAN POU: Dr. Conway, I'm sorry.

Thank you so very much, Mr. Chairman.

Real quickly, I just read, quickly, one of your statements that talks about A-3108, and it talks about why you're not in support of this. It makes

reference to the fact that the bill does not include an appeal process prior to a monitor being assigned to an agency. I just want to relate that to the parent testimony that was given here before. What kind of an appeal process does an institution provide or allows a parent to have in the case of -- and let's use Matthew Goodman's situation. What appeal process did they have, if any? And I understood them to indicate that they didn't have any, yet one of your comments here, with regards to the bill, is that because this does not provide an agency that have an appeal process-- How do you make the distinction between the two?

DR. CONWAY: We're not advocating that the parent shouldn't have input into the treatment program. As it was related by Janice Roach, she should have had some input. We're not advocating that it happened that way. Parents are a very important part of the decision-making process for treatment.

ASSEMBLYWOMAN POU: Do you have an appeal process system, currently, for -- under your provider agencies? Is there, currently, a system?

DR. CONWAY: We wouldn't be the ones who would create that.

ASSEMBLYWOMAN POU: I thought I understood that you represented these provider agencies?

DR. CONWAY: The provider agencies, yes. But we wouldn't have an appeal process. Our association wouldn't do that.

ASSEMBLYWOMAN POU: No, no, no. I know that.

DR. CONWAY: It would follow the Division of Developmental Disabilities regulations.

ASSEMBLYWOMAN POU: Does an appeal process currently exist?

DR. CONWAY: I think it would be different for each agency.

ASSEMBLYWOMAN POU: So there's no standard appeal process for each provider, even though it may be the same level of service that that provider ought to be providing?

DR. CONWAY: If you're talking about the use of restraints--

ASSEMBLYWOMAN POU: I'm talking about any and all issues when dealing with a patient, the use of restraint or otherwise. Does the parent have an appeal procedure that they can go to when they're child is placed in that agency?

DR. CONWAY: No, I don't believe there is a standard.

ASSEMBLYWOMAN POU: I didn't think so.

Thank you very much.

ASSEMBLYMAN PAYNE: Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: You approached an issue that hadn't been mentioned previously here. We did hear Matthew's parents speak of how they were told that, "If you accept this -- or 24 hours, take you son out." But could an unintended consequence of not permitting restraints to be a part of the IHP be that the individuals with severe problems, they would refuse to accept these to provide them any kind of treatments?

DR. CONWAY: That probably would be the result -- that many agencies that have this option would not be able to serve those individuals.

ASSEMBLYMAN THOMPSON: They would be refused admission here in New Jersey. You said they'd end up having to go out of state or something.

DR. CONWAY: And then there wouldn't be very many options.

ASSEMBLYMAN PAYNE: Thank you.

Are there any questions? (no response)

Thank you very much.

ASSEMBLYWOMAN WEINBERG: Our next witness is Kevin Walsh of The Arc of New Jersey. And while Kevin Walsh comes forward, we were left a statement from Lowell Arye, executive director of Alliance for the Betterment of Citizens with Disabilities. And if you could work into whatever you're going to say, Mr. Walsh -- one sentence that strikes me on Lowell Arye's statement that he left is, "For some individuals, the use of restraints is requested by the individual to prevent them from their self-destructive behavior. Lesch-Nyhan disease is a rare genetic disorder," and he goes on to talk about self-mutilation. But whether or not we do not allow something in the IHP, whether such exceptions could be made--

KEVIN K. WALSH, Ph.D.: Thank you for the opportunity to speak today. In the interest of time, I would just like to address a few issues in the substitute bill that may not have been addressed before.

My name is Dr. Kevin Walsh. I am here today on behalf of The Arc of New Jersey. I am in my fifth term as the southern regional vice president of the Arc's Executive Committee, on their board. I'm also a professional, and I work in the field. Some of that information is on my written testimony, so I won't review that.

In general, the Arc is concerned that either bill, potentially, may have the unintended consequences of causing there to be fewer opportunities for people in community settings, because of the difficulty of managing people, either when they come in or whatnot. Our view is that we would like the Joint Committee to very carefully review some of the parameters in the bill relative to what it would take to actually implement that.

A lot of the testimony we've heard today has been, in my view -- I tend to go on data and large numbers -- is rather narrowly focused. But if you look at it, like, from an epidemiological standpoint, we've been hearing one very, very narrow viewpoint. The concern I have is that there are well over 150 providers out in the community who provide community services, who provide homes for folks. I think, when you look at the use, for example, of emergency restraints, that it may very well be that those are prohibited or so overly taxed, relative to the administrative accoutrements they have to wrap around them, that there may be a conservative movement of those folks to not provide opportunities for community living.

So I would like the Committee to take into account, for example, the physician review within one working day. In a group home, that is -- it seems to me almost impossible. The New Jersey Arc has convened -- oh, about a month ago -- five physicians, all of whom practice only in the field of developmental disabilities. And they said that it is nearly impossible to meet the review of approval for the contraindications of restraints. And I'm sure they would extend that to subsequent review. I don't even know how that would be paid for, how appointments would be made. It doesn't seem like that's realistic and may cause, then, agencies to say that they're not going to apply physical restraints.

I'm on the committee that reviews all of the programs with the State. I'm one of the two community representatives that reviews all the restraint programs that community providers submit their procedures and manuals for. I actually am the author of the Vineland Program that was mentioned before. It was written in the early 1980s. I'm a little bit afraid of walking back to my chair over there.

ASSEMBLYWOMAN WEINBERG: Dr. Walsh, as you said, we do have your testimony here. I'd like to ask a question.

DR. WALSH: Sure.

ASSEMBLYWOMAN WEINBERG: It said you're on the Restraint Work Group from DDD. When was that group formed?

DR. WALSH: It was formed, I think, three months ago, two months ago. It's had two meetings. It's been informing. What I think would be very good would be for them to come and address a lot of these issues. There is very many people who understand these issues who don't want to have the free use and unmonitored use of dangerous procedures with folks. There are very, very many people who understand these issues, who understand the protection of consumers, who understand the protection of valued lives, who understand the protection of community living as very important values.

We also understand how you might attempt to apply behavioral techniques for very challenging behaviors. My sense is, is that on balance, if you look at the State of New Jersey and what DDD has put into effect, on balance, meaning if you look at a representative sample, there are very, very many people who otherwise may not be able to be sustained in community settings because people can judiciously use emergency restraints and very judiciously use programmed restraints.

I think, sitting and listening to the testimony today, that feeling has not come through to me and, I think, to you, quite as strongly as it might otherwise have. I think that may be a good place where either -- I don't really understand the full stages of legislation -- but either at this point or later on that the New Jersey DDD Work Group on restraints, which is a very eclectic group and there's a diversity of opinion, might be helpful.

ASSEMBLYWOMAN WEINBERG: Yes.

Herb.

ASSEMBLYMAN CONAWAY: Well, I have heard what has gone on. Let me ask, and I'll try to be quick. Bringing back this Lesch-Nyhan Disease, here's a person who has "an abnormal compulsion toward self-mutilative behavior. The self-inflicted damage includes partial or complete amputation of fingers, nose, and tongue. According to research, these individuals are reported to be very aware of their disability and aggressive behavior toward themselves, and restraints are an important part of their treatment." Now, if we outlaw restraints, you would agree we, therefore, will be -- have a very difficult time treating people that have this particular disease.

DR. WALSH: Yes. Let me just clarify that. You may be reading off of Lowell Arye's document.

ASSEMBLYMAN CONAWAY: I am.

DR. WALSH: I know him, and I am familiar with the issue he was going to talk about. Lesch-Nyhan is a specific disorder within developmental disabilities. One of the characteristics -- I'm getting a little bit outside -- but one of the characteristics of that disorder is that there is frequent sustained self-injurious behavior. Part of the treatment packages in that situation, I think, typically use contingent restraint, and then teaching people to gain control over that behavior that is driven more or less by their syndrome. So there should be a period of time -- I would expect it would be the kind of sequence that--

ASSEMBLYMAN CONAWAY: We're running out of time. I wanted to be quick. Now the other question I had dealt with the issue of, sort of, treatment protocols. Because you raised an issue that, also, came to my mind when reading one of the sections here as, "shall be continued by written

order,” and, also, a section that I looked at before. One of the questions with these bills is what, practically, happens out in the field. Now, would you say that -- how do you see a protocol written, or as being used in this setting? For instance, now we use protocols in the hospital for post-cardiac surgery and treatment. Surgeons will use it very often in people coming out of vascular surgery. It’s used in pneumonia and everything else--

ASSEMBLYMAN PAYNE: What’s your point?

ASSEMBLYMAN CONAWAY: And these are things where people can make assessments that are not necessarily the doctor’s, so they can continue along in a timely way with a course of treatment. My concern here is, in a situation where you’re requiring the physician -- of course, the physician is there, at least, on a daily basis -- to be right on the spot when these things are -- when a restraint might be applied according to protocol. It might be impossible to be there. Do you think that we should, in this bill, allow some leeway for the use of written protocols when certain kinds of situations arise?

DR. WALSH: I think in the community it is different than the medical setting. I think we need to be very careful about having written protocols by physicians who are not present. In the community setting, where most people with developmental disabilities now live in New Jersey, they see providers of all different stripe. They see the kinds of doctors that you and I go to. They’re not going to be able to get a written protocol. They’re not going to be able to get a working-day review after that protocol. So my fear is, that if those provisions stay in the substitute bill, that what’s going to happen is that there will be many providers who cannot meet that, and then will, therefore, say, “We cannot do emergency restraints.” And what that will have the effect of doing will be to make certain opportunities for those folks not to be there in the

community, and they're going to stay in more restrictive settings.

ASSEMBLYMAN CONAWAY: I respect that you're right. Now, you guys are looking at this -- and the last question, Mr. Chair, Ms. Chair. The one suggestion that I have would, as regards the-- See, I believe in peer review. That if you're going to, sort of, look over and involve yourself in what a physician or a professional is doing, that the people who are doing that and reviewing those clinical decisions ought to be other people trained in the field. It doesn't mean that other people who are parties to the therapeutic program -- the patients, the parents, and others -- shouldn't be there in some sense. But in terms of reviewing actual decisions that are made, ordinarily that's done by people who are similarly trained and can review what you are doing.

Now, what happens if we were to require, when someone suggests, according to their evaluation, that an IHP include the use of restraints in particular circumstances, that's then kicked upstairs immediately to some kind of review panel to either assent or disagree with that decision made on the spot. Was that something that might be workable, and are you looking at that in your--

DR. WALSH: I believe that's already in place.

ASSEMBLYMAN CONAWAY: Okay. It happens automatically all the time. It's reviewed by some detached, non-involved member--

DR. WALSH: Right now, the policy in the division is that if you recommend, as part of an IHP, a behavior plan that requires that, that goes to a behavior management committee and it goes to a human rights committee review. Your human rights committee is somewhat different. It's county-based, which I think also poses some problems because providers cross counties.

People live in one county, go to a day program in another county. It may be reasonable to look at that provision, as well as being somewhat restrictive. A lot of providers are cross county, and so it would be hard to figure out how to work that.

But, right now, that does happen. Whether or not you believe those committees function well, whether or not there's enough oversight of those committees, may be different questions, but that's a question of oversight and not necessarily one that needs to be in the substitute bill.

ASSEMBLYMAN CONAWAY: And just for clarification, who sits on those review committees now?

DR. WALSH: Behavior management committees are populated by a group of professionals that would be the peer-review component. They look at the "quality," the potential outcomes of the behavior plan. The human rights committee, as per division circular, must be different in that it can only have three common members, I think, and must have people from the community, must have laypeople. The human rights committees take -- it's defined in the policy circular -- take a common-man approach to whether or not this seems to violate rights. That balance hasn't been described yet today, but I think that is there.

It might bear that the substitute bill, along the lines of what Dr. Spitalnik was saying, of beefing it up -- might be to have a look at that and to put in language that assures that that oversight process works well, so that there are outcomes on the oversight process, and that the division, perhaps, needs to look at that on a regular basis to assure that those committees, indeed, are doing what they're supposed to be doing.

ASSEMBLYMAN CONAWAY: Thank you for your answer.

DR. WALSH: Thank you. Thank you for the opportunity.

ASSEMBLYMAN PAYNE: Thank you very much.

We're going to do this in tandem now. This might be one way of saving some time. I'm going to call four people--

ASSEMBLYWOMAN VANDERVALK: Madam Chair and sir?

ASSEMBLYMAN PAYNE: Oh. Yes. Yes. I'm sorry.

ASSEMBLYWOMAN VANDERVALK: I note Assemblyman Rooney said he has to leave at 5:00. I really have to leave momentarily, and I really don't want to miss the vote. I don't know how much longer we have testimony.

ASSEMBLYMAN PAYNE: Well, we have about 50 people-- No. I think we have about 30 people more to testify. So, I guess, we'll just keep plodding along. This may have been, in hindsight, maybe a two-day hearing. I don't know. But the fact is that we have had people come here to testify, and maybe we can get a voluntary -- a show of hands of those who are willing to forego their testimony today. Can I see those who will not be interested in testifying? Let's see -- we have one, two--

ASSEMBLYMAN ROONEY: Why don't we ask for those who still want to testify? Some of them may have already left.

ASSEMBLYMAN PAYNE: All right, reverse. How many people here-- Let's hold them up so we can count the people and then we can, kind of, figure this out.

ASSEMBLYWOMAN WEINBERG: Well--

ASSEMBLYMAN PAYNE: We're going to be here all night. All right. About 20-some-odd people.

ASSEMBLYWOMAN WEINBERG: Assemblyman, we have a practical problem. If anybody wants to see a bill come out today, then there will be no bill released and there won't be a law about this, because the Committee members, certain Committee members, have to leave by 5:00. So there will be no bill, and we will sit here and hear the rest of the testimony. I cannot tell you, because this takes an act of the Speaker to get two committees together like this to again review those bills in front of us. So, it's okay with me. I will sit here and listen for as long as I possibly can.

I don't know, Chairman Payne, how you feel about that.

ASSEMBLYMAN PAYNE: Yes. Let me hear from--

ASSEMBLYMAN ROONEY: I apologize for having to leave, but tonight I think we have too many on.

I can't get my microphone on here. (referring to PA microphone)
Okay.

I apologize, but we have a reorganization meeting for a joint insurance fund tonight. But one of the things I see is that, maybe, neither one of these bills is the right bill. I'm seeing a situation where people are telling us that they don't believe the providers are qualified to--

(audience responds)

I'm sorry. I'm sorry. I'm sorry.

ASSEMBLYMAN PAYNE: Please, please.

ASSEMBLYWOMAN WEINBERG: Wait a minute. We're now going to be able to--

ASSEMBLYMAN ROONEY: Would you please let me finish what I had to say.

ASSEMBLYWOMAN WEINBERG: Excuse me, Assemblyman, we will not get anything--

ASSEMBLYMAN ROONEY: What I'm saying is that I--

ASSEMBLYWOMAN WEINBERG: We will not get anything done with people screaming from the audience.

ASSEMBLYMAN ROONEY: --don't think some of these providers are qualified to do restraints. That if there is a client that requires restraint, that perhaps this is-- The basic providers that we're looking at shouldn't be doing any restraints, in the aspect of Assemblyman Munoz's bill. That maybe what we should be saying is, prior to anybody doing any restraints, what we should be looking at is saying, "Look, this person needs special care that cannot be provided in a group home. That this person is a danger to other people."

ASSEMBLYMAN PAYNE: Right.

ASSEMBLYMAN ROONEY: And they should be, basically, placed. Then, the State of New Jersey has a responsibility, whether the Department of Human Services or DDD, to provide that care, the special care.

ASSEMBLYMAN PAYNE: That's the purpose of this hearing, to get these ideas.

I was going to ask for four people to testify in tandem today, which might give a different perspective on this whole thing. If I could have -- the screamers (laughter)-- If I could have the people that-- Let me read these names off. I think we have Mindy Maranon, Sandra Boyles, Judy Farrell, Melissa Gaunt. Are they here? Well, what about the rest? Can we have you up here, please, to testify? Okay.

We have the written testimony of the folks that I called, so I'm just going to ask you each to summarize what it is you're saying, okay? You can tell

time, and you can see the reality of the situation as it stands now. So, if we want to start out, I know you have a lot to say. We've heard it. But, come on, let's see-- Identify yourselves, and we can start out with the young lady on the right.

MINDY S. MARANON: Good afternoon. My name is Mindy Maranon. I can be brief, because I can talk very fast. I'll read my testimony. But, in fairness, I do need to say, and this is what I assumed from the testimony, there are 16 parents that I know of, personally, that were here that were not advocating A-2855. None of us have gotten to speak today. So I just needed to say that in fairness. Okay. I'm sorry, and I don't mean to be rude, and we're honored to be here.

My name is Mindy Maranon. I live in Monmouth County, and I am a wife and proud mother of 14-year-old twin boys with autism. If you understand that we know, firsthand, how bleak life can be for a person whose entire interaction with the world becomes a series of crisis interventions, i.e., emergency restraints or emergency aversives or worse, or worse, and this is worse. This is not-- You're worried about humanity and dignity? Imagine a world that shrinks to the inner confines of a closed setting or an overmedicated state. I don't know why someone thinks overmedicating a child is more humane, or overmedicating an adult, or the cessation of teaching -- we're all teaching staffs. Aren't we all entitled to improve and grow, be more involved in our community, not less, or being isolated from any normal community interaction because of episodes of aggression, impulsivity, and/or self-injurious behaviors?

My son's name is Matthew, also, and I have a son named Alan. I'm sorry I'm so upset. Use of protective blocking and positive supports are the

only available techniques for the treatments available for them at a public, specialized school. The result: Steady increase in both the intensity and variety of behaviors that cause my sons to be a danger to themselves and the community. If you want me to alliterate (*sic*), I will. Otherwise, we're talking about walks in our neighborhood were over; gone were extended family visits; outings became history; Challenger league baseball, soccer, and basketball -- a memory; swimming at our community pool went from daily to one time a summer with three adults in tow; parking lots became perilous hazards because they would throw themselves on the floor in front of moving cars, or-- We've been thrown out of some of the best places.

So we sought help and studied. I have studied applied behavior analysis. I've studied positive reinforcements. I sought positive reinforcements. I had natural setting therapeutic management, which is the graduate program at Rutgers, which is associated with UMDNJ, in my home teaching me. I went for crisis interventions. You name it, I did it. Anything to avoid using aversives and restraints. And nothing worked.

And finally -- I'm sorry -- we altered our home environment, utilized a plethora of plans, including medicating our sons. Loss of life quality brought us to Bancroft. Now, two years later, the 80 milligram Prozac level for my son Matthew is down to zero, and Alan is down to 20 milligrams. The boys have returned to horseback riding, weekly swims in community, invitations to relatives homes. My son's eyebrows grew back. My other son's face is no longer filled with oozing sores. They are now at the way it should be. They are now at arms-length treatment. In other words, they're no longer on any restraints. But that is the way it's supposed to be. There was never supposed

to be -- and I don't know what protocols people are talking about here. As a parent, you need to know that.

If Bancroft suggested something that I think is abusive to my children, you can bet I'm there. It's not happening. So are we always in agreement? No. But they have never been able to put into effect a plan where I felt would endanger my child. My children -- they never threatened me that I have to take my children out either. So I am confused. I need to show you the other side.

I'm sorry, again. Please excuse my ranting. And please know, as a parent, that if my repeated broken nose or torn rotator cuff, blasted shoulder capsule, ripped bicep tendons had been the price to pay to aid my children's advance, I, like every other parent in this room, would offer it up gladly. Do not mistake a rejection of A-2855 as misinformed or lazy, that would be a tragic error.

Next week, we are going to a Broadway show, *Beauty and the Beast*. Now that may not seem like a miracle in your eyes, but had you walked in our shoes during the bleak time, you'd surely shout, "Hallelujah," and count your blessings. Among these blessings is the fact that we live in the State of New Jersey, not Pennsylvania, not New York, and not Nevada.

With all my heart, I beseech you not to forsake our sons, and condemn New Jersey families to the desperate search for help outside their own state, which is what will happen. I'm asking for reason. I'm asking for a compromise bill. I'm sorry I've taken so much time.

And just to let you know, I did hand in letters from other parents who asked me to speak for them. Obviously, I won't take any more time.

I thank you. I understand what hard work you're doing here. But please hear our voices, too, and understand there are parents who are successful -- I'm just speaking for six parents who had to leave -- successful in maintaining their children in their home because of programs like this, who had to leave because they're still the primary caretakers of behaviorally challenged children.

I'm sorry.

ASSEMBLYMAN PAYNE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Assemblyman Payne, I just have to interrupt. I understand.

MS. MARANON: I'm sorry.

ASSEMBLYWOMAN WEINBERG: It's okay. But I need to know why you are supporting that--

MS. MARANON: I was advocating--

ASSEMBLYWOMAN WEINBERG: Are you supporting, when you said the modified bill, are you talking about the Committee Substitute?

MS. MARANON: I was advocating A-2849, because that's the only, really, other good option I know. I, specifically, do advocate uniform protocols around the state. I absolutely advocate a human rights committee, which is the way that programs that do it well do it -- with the human rights committee. And I absolutely agree with all of you -- parental input. Because you may have a child that's not disabled, but you know as a-- You're a doctor. What kind of foolish doctor thinks the doctor knows more about that child than the parent does?

ASSEMBLYMAN PAYNE: I don't understand. I don't understand which you're supporting.

MS. MARANON: I'm supporting what you're talking about now, which you haven't written.

ASSEMBLYMAN PAYNE: All right. Okay.

ASSEMBLYMAN CONAWAY: The substitute.

MS. MARANON: But the closest was A-2849, and the new compromise is a decent compromise, but you still have to get closer.

ASSEMBLYMAN PAYNE: Okay.

MS. MARANON: I am not supporting-- For people to mix up aversives with restraints and call them the same thing, means they're misinformed. And for people to say, "No aversives, positive supports," everything you were talking about, the way you discipline your children, that's an aversive. If you put your child in time out and he doesn't like it, that's aversive. That's an aversive. So people need to--

As emotional as I am being now, I'm asking you, as the legislators, people who are in this position, don't be as emotional as I am. Please make sure you get the informed information from people who do it and do it well. There are parents who would-- I would give my arm at one point to have my children at Eden Institute, where Dr. Holmes makes sure that parental input, human rights, and dignity are respected. And unfortunately, someone like that hasn't spoken, and I'm sorry if I'm being rude. I don't mean to.

ASSEMBLYMAN PAYNE: Thank you very much.

MS. MARANON: Thank you.

Does anyone want to see my beautiful children, you can keep the pictures. (laughter) Horseback riding, Great Adventure. I'm going to give them to an aide.

Thank you.

ASSEMBLYWOMAN WEINBERG: If I can show you pictures of my children. (laughter)

MS. MARANON: You may very well do that. I'm an advocate of all children.

ASSEMBLYMAN PAYNE: Do we agree that the speaker represents the sentiments of all of you here, in the interest of time? I mean, in one sentence each--

MELISSA A. GAUNT: I guess, I just wanted--

MS. MARANON: Can Missy please speak. She has children with hemophilia.

ASSEMBLYMAN PAYNE: Okay. Okay.

Your name please?

MS. MARANON: Missy, go ahead.

MS. GAUNT: My name is Melissa Gaunt, and I am here today on behalf of my children that not only suffer from psycho, social, emotional disabilities, but they also suffer from a medical fragile disability, as hemophilia.

ASSEMBLYWOMAN WEINBERG: Is your mike on? (referring to PA microphone)

MS. GAUNT: Sorry.

My children both are diagnosed with hemophilia, along with autism, bipolar disorder, attention deficit disorder and static encephalopathy.

My children have experienced many issues and grave issues at that. My child has been in a psychiatric institution for his bouts of climbing on the roof of our house, due to his inappropriate behavior. My child with autism has gone full-speed ahead at my house and had ended up in the hospital in critical

care for hitting his head and having a concussion, and whatever else. At the time, he had multiple bruises and contusions.

I'm begging you, that you consider this a serious offense. If you dare change this bill, you have no idea what this can do to society and to these people with disabilities. I am here, today, to advocate for the bill, A-2849 and A-2850, and I oppose A-2855. My husband and I work very hard to keep our children at home and to keep them safe and happy. These are our goals for our children. I'm an advocate for people with severe mental illness. I work volunteering at mental institutions. I know what aversive treatment is. All I can say is that we have tried everything possible.

Functional behavioral assessments are the first thing, first choice that we have made to find out what was going on with the child-- He was having-- They were both having these behaviors. When we figured out what the behavior was, we tried all sorts of treatments -- positive supports. When all else failed, and they were, like I said, on the roof of our house and self-injurious -- biting themselves -- we had to take other measures for their safety. This is what this is about -- safety. It's not about taking a piece of gum away and calling that an aversive treatment. This is about their safety, keeping them alive. And how my heart breaks for Matthew's parents.

But, please, have empathy for my family, too. Because it is the use of proper behavioral assessments and restraints that are keeping my children alive.

ASSEMBLYMAN PAYNE: Thank you very much.

Will the other ladies--

S A N D R A B O Y L E S: That was pretty emotional.

My name is Sandra Boyles. I have a 12-year-old son with autism and a 5-year-old daughter. I live in Cranbury, New Jersey.

I appreciate the efforts of this Committee to improve the lives of people like my son, but like, similarly, to these other two women, I am concerned about a bill such as A-2855 becoming law. My son is extremely aggressive and self-injurious. He can be extremely aggressive and self-injurious and has a long history of it. We, also, started him in a behavioral program that had all positive reinforcement, no restraint, no aversive, nothing negative. You couldn't even say no to him. He continued to get bigger and stronger and more aggressive, and hurting himself and hurting other people.

So we finally decided that what we needed to do was look for a different option. We went to Eden Institute, which is-- I invite everyone to come look, because they have miraculous results. They tried positive behavioral interventions on -- so they started with self-injury, very self-injurious behaviors. He would pound on his thumb until he would bleed and then smear blood all over my house. He would pound his head, that kind of thing. This is a day program. He would do it at school, and then he would do it at home. The positive behavioral approaches didn't work. It was endangering his health and his life. So we started with some very, not as positive, interventions until the least -- the level of lowest intrusiveness was used to stop these behaviors. Then, in addition, he was extremely aggressive, which-- I know that a lot of people -- that parents that have taught -- their children are living in a residential setting--

My child lives at home. He's in the community. He's in the grocery store. He's in the church. He's in the church nursery with babies. He could kill a baby. He could hurt another person. So we, also -- because we live

in the community, we want him to remain in the community, which is also cheaper to the taxpayers. We also addressed his aggression.

Now, all of this was done, initially, positively, and every single intervention that was tried, positive or negative, was okayed by the parents, by me and my husband. If either of us said, "No," that was it. Nothing happened, we didn't do it. And do you know what? If they tried it for five minutes and I said, "I changed my mind," they stopped. If they did it for five months and I changed my mind, they stopped. This is the kind of thing that needs to be done in order to keep these children in the community. Let the special-needs population be as much into the community as possible. Let's not force them into residential settings where they don't know their siblings, they don't know their families.

ASSEMBLYMAN PAYNE: Can I ask you a question, if I can interrupt you for a moment?

MS. BOYLES: Yes.

ASSEMBLYMAN PAYNE: You said, if you had some question about the treatment, and you said no, it was changed. They stopped. *They*, meaning?

MS. BOYLES: The school. All I would have to do is call the director of the school and say stop the treatment, and they did immediately.

ASSEMBLYMAN PAYNE: What school?

MS. BOYLES: Eden Institute, in Princeton, New Jersey.

ASSEMBLYMAN PAYNE: Okay. All right.

MS. BOYLES: And what I wanted to say was, he responded so beautifully to this treatment. And some of the stuff that people are talking about -- now I know there are-- His aversives and restraints that were used were

very, very mild. But it took an extremely self-injurious and aggressive child and turned him into a very manageable, nice cuddly child, and I was able to have another child. If you take this away, he will regress, because we have seen over periods when, for example, he's been on break and the behavior programs are not being used, and he will become dangerous.

And you talk about the rights of the handicapped. No one has talked about the rights of the siblings, and my daughter is 5. He lives at home. You're trying to take a child who is a wonderful child and a wonderful brother, and if you remove these kinds of interventions, he will, at best, hurt her, at worse, kill her.

MS. GAUNT: Excuse me, but this is the reality that people with disabilities, family members, caregivers deal with every day.

ASSEMBLYMAN PAYNE: Would you like to also--

MS. BOYLES: Excuse me?

ASSEMBLYMAN PAYNE: Would you like for your cohort--

MS. BOYLES: Go ahead. I'm done.

T I S H C A P A W A N A: My name is Tish Capawana, and my son, Joey, is 11 years old and autistic, and also goes to Eden Institute.

ASSEMBLYMAN PAYNE: Is your mike on, please? (referring to PA microphone) Is your red light on?

MS. CAPAWANA: Yes, it is.

ASSEMBLYMAN PAYNE: Go ahead.

MS. CAPAWANA: I'm sorry.

ASSEMBLYMAN PAYNE: All right.

ASSEMBLYMAN THOMPSON: Leave the button turned on.

MS. CAPAWANA: I just wanted to say, basically-- Well, Joey's been at Eden for eight-and-a-half years. My husband and I chose to send Joey there, because of the undeniable success of the comprehensive behaviorally-based services that they provide. I believe that passage of this bill, A-2855, would deny our family that choice. I can't stress enough how important it is for these families to have choices, especially families of children with autism.

I also want to point out that the State of New Jersey has always been known for the services available for the treatment of autism, and people move here from other states to get these services. So now our family, in particular, we've turned down a relocation opportunity in order to stay in this state, and now possibly that could be taken away from us.

The work Eden has done with Joey has helped immensely, not only with his behaviors but with all he has accomplished so far. And with their help and guidance together, we continue to help him make progress. Understand that this is a child who doesn't speak normally, learn normally, behave normally, interact normally, or respond normally. He tries to go outside without shoes or a coat in January. He helps himself to food off other people's plates. He has to have his bedroom door and the bathroom door closed at all times. He shuffles his hands on the ground until they callused and bleed. He presses on his chin until it bruises and bleeds. However, he would give anyone available a hug.

He has a good life in spite of his autism, but the reason that he has a good life is because we've been able to teach him appropriate behaviors, allowing him to be able to ski Special Olympics, run track and field. He's learned to swim. He's learned to roller skate and ice skate. I would not even

be able to take him on a walk without the services that I've gotten, and the help that I've gotten, from Eden.

I'm on a human rights committee at Eden Institute. That's just a part of the accountability process at Eden. It ensures the dignity and rights of Eden's participants. And some of the programs we review are for self-injurious or potentially life-threatening behaviors. Others are for less severe maladaptive behaviors, but all the programs teach appropriate alternatives -- always, always starting with the least intrusive method.

ASSEMBLYMAN PAYNE: Could I ask you to, kind of, conclude, here, because I think we've gotten a pretty good idea--

MS. CAPAWANA: Well, I just wanted to say, also, that--

ASSEMBLYMAN PAYNE: And just tell us which ones you support? You're opposed to A-2855?

MS. CAPAWANA: Right.

ASSEMBLYMAN PAYNE: And you're supporting?

MS. CAPAWANA: Well, A-2849 or the substitute bill that I haven't really read.

ASSEMBLYMAN PAYNE: Thank you very much. Thank you very, very much.

Now we're going to take a one-minute recess right now, and we will be back.

ASSEMBLYMAN THOMPSON: Mr. Chair?

ASSEMBLYMAN PAYNE: Yes, Assemblyman Thompson would like to--

ASSEMBLYMAN THOMPSON: So, in summary, in all four of your cases, your children were in treatment programs in which restraints were

used, and you feel that this was an integral and positive result, that it helped in the case of your children.

MS. BOYLES: It was absolutely necessary to the safety of other family members, especially other children.

MS. GAUNT: And their well-being, their safety. All other aspects are also being included, all other therapies.

MS. MARANON: I just wanted to say that restraints were used for a very short period for my children, but please understand the way A-2850 (*sic*) is worded--

MS. CAPAWANA: A-2855.

MS. MARANON: Thank you.

Aversives -- we're not talking about it, but that's a big part of what you're killing. Restraints aren't one piece. The aversives were a part of my children's program -- successfully were part of my children's program. They are no longer being used because they are no longer needed. When my children went to a program that barred the use of aversives or restraints and only allowed for restraining in emergency situations, the escalation of inappropriate behaviors and the decrease in any possible learning was a nightmare. I couldn't even take my children to a place where there was a parking lot. That's what I'm saying to you, from there to being able to take them to New York City -- two of them, 155-pounds-plus each -- to a Broadway show does not seem a lot to you. To me, it's amazing.

ASSEMBLYMAN PAYNE: Thank you.

MS. MARANON: Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

We'll take a recess.

(RECESS)

AFTER RECESS:

ASSEMBLYWOMAN WEINBERG: Okay. Could everybody take their seats again, please, because we will be hearing more testimony.

Okay. Lydia-- I apologize, but I can't read your last name. P-A-J-L-I-N-A-W-A-N. Is Lydia here? (no response) She did not indicate whether she was speaking in favor or not.

Angela Caristo from Cerebral Palsy, in favor of A-2855.

Angela.

ASSEMBLYMAN PAYNE: Just to remind you. We have two minutes of testimony now, because of the time constraints, please.

ANGELA CARISTO: Thank you. Good afternoon.

ASSEMBLYMAN PAYNE: Good afternoon.

MS. CARISTO: My name is Angela Caristo with Cerebral Palsy of New Jersey. Cerebral Palsy of New Jersey is in support of Assembly Bill No. 2855. We believe that restraints should be limited to only emergency situations to protect the physical safety of the person or of others. We strongly feel that restraints are ineffective and inhumane as treatment for people with developmental disabilities. Positive behavioral supports is a much more effective technique to treat persons with disabilities.

I just wanted to mention some other cases. *The Hartford Courant* found that across the country hundreds of patients have died after being restrained in psychiatric and mental retardation facilities. And even here in New Jersey, *The Star-Ledger* has found similar cases. They found at least 50 cases

alleging medication and treatment error at various developmental centers over the past seven years. Several centers violated a person's rights by repeatedly restraining them, tying them or holding them down without just cause.

In Pennsylvania, also, a similar initiative has been passed, which has been very successful. This initiative has led to a 74 percent reduction in the combined incidence of seclusion and restraint. Hours of restraints--

ASSEMBLYWOMAN WEINBERG: Excuse me, but there's one minute left, and we do have your written testimony. So go ahead.

MS. CARISTO: I just wanted to say that that was very successful and that they, also, found that it was effective both for people with disabilities and for staff that worked with people with disabilities. They found that staff injuries actually decreased because of -- there was no more need for physical confrontations.

So Cerebral Palsy of New Jersey urges you to support this important bill. It will limit the use of restraints and also require prompt reporting, which is very important to hold agencies accountable.

Thank you for your time.

ASSEMBLYMAN PAYNE: Thank you very much.

Paul Prior. (no response) He left.

Charles Richardson. (no response)

Diana Autin. (no response) Diana Autin.

Terri Howard.

T E R R I H O W A R D: Good evening.

My name is Terri Howard, and I serve as the Director of On-Site Training for the Crisis Prevention Institute of Brookfield, Wisconsin. It's actually colder here than it was in Milwaukee when I left.

CPI is an international training company committed to helping organizations create and maintain safe and respectful environments through quality, meaningful training, educational resources, and consulting services.

First, let me applaud the Committee's efforts for bringing the issue of safe management of challenging behavior to the table for discussion. We have worked with several states in developing legislation in this area. This is worthy of commending what you're doing, and to that end, we support the concept of limiting physical restraint and, also, mandatory training. And I guess that's where my comments focus on this evening.

I'd like you to take a look at incorporating the mandatory training pieces in whatever restraint legislation you eventually come up with. When training requirements are left vague and without direction, our experience is that extremes are often created. That is to say that without guidance, there will exist some facilities that will only train staff in physical restraints. This handicaps staff in providing preventive and proactive strategies, such as detection of early warning signs or antecedents that lead to aggressive behavior, and the need for physical management, verbal intervention skills, and personal detachment skills for staff. In addition, there will be those that boast a restraint-free environment, and therefore, limit training staff in safe, nonharmful ways of physical management.

While this seems to be a commendable goal, many times staff are ill-equipped, then, to deal with the realities of temporary, out-of-control behavior. This can result in staff relying on primal instinct -- in other words, fight or flight, or freezing up -- rather than safe ways of managing behavior.

It is our belief that mandated, physical restraint training should include elements such as verbal intervention strategies, staff debriefing skills,

and, also, understanding the risks of restraint. We also believe that training cannot be a one-time event. In everything that I've read in proposed legislation, there is information about mandatory training in six months or a one-time training. It has to be ongoing. So, in that, we would recommend ongoing training, refresher training, regularly scheduled refresher training sessions, and implementation improvements based on information learned from the debriefing process, which I also think is missing.

ASSEMBLYMAN PAYNE: Thank you very much.

MS. HOWARD: You're welcome.

I'd just like to ask Dr. Gina Del Gindice-- (no response) She left. All right. I would just tell you that the doctor was going to speak in favor of A-2849.

And, also, Charles Richardson was speaking in favor of A-2849 and A-2850.

Paul Prior, who left, was speaking in favor of A-2849 and A-2850.

Diana Autin was in favor of A-2855.

I'd like to call Carol Dougherty, who was opposed to A-3108. (no response)

Diane Gruskowski. Identify yourself, please.

ASSEMBLYWOMAN WEINBERG: Assemblyman Conaway just reminded me -- as you're getting ready -- we are going to hold the training bill. So if anybody wants to speak, specifically, on that, that bill is going to be held, and I'll explain it all later. But, go ahead.

DIANE GRUSKOWSKI: My name is Diane Gruskowski. First of all, I'm in favor of A-2855. I'd like to talk on neglect and abuse. My daughter, Danielle, was a beautiful 32-year-old young lady.

ASSEMBLYMAN PAYNE: Is your mike on? (referring to PA microphone)

MS. GRUSKOWSKI: Excuse me?

ASSEMBLYMAN PAYNE: Is your red light on?

MS. GRUSKOWSKI: Yes. Closer.

Danielle, who had Rett Syndrome, was developmentally disabled, non-verbal, non-ambulatory. Tragically, my daughter Danielle passed away November 5. The circumstances of Danielle's death is outrageous. Danielle had difficulty breathing during the night and a reported fever of 105 the morning of her death -- 911 was never called. Instead, Danielle was taken by the Edison Group Home van to the doctor's office in New Brunswick and -- where she arrived not breathing. CPR was administered in the doctor's office, but by that time, it was way too late for Danielle. Ironically, the hospital is directly across the street -- Robert Wood Johnson. When I asked the director what happened that day, he said to me, "I guess it was a bad judgment call." A life-threatening situation, and it's a bad judgment call.

Many changes have to be made in how the State allows provider agencies to operate. I've spent many sleepless and tearful nights since the death of my precious daughter, Danielle. I entrusted Danielle to a provider agency that assured me that all her needs would be met, and promised a good quality of life for my daughter. My daughter did not have a good quality of life at this facility.

New staff had to learn for themselves on Danielle, because there was no one to show them. I was there night after night so I could show staff what to do, otherwise Danielle may not have eaten supper that night or gotten a drink or repositioned. Danielle went from 105 pounds to a documented 78

pounds. It was up to me to let the facility know, because they hadn't noticed there was a weight problem. Danielle's prescription for a standing table was ignored for four years. This was a goal on her IHP. To this day, Danielle has never used a stander. The IHPs are not followed or taken seriously. Most of the staff isn't even aware of what an IHP is.

The facility and the caseworker, also, couldn't find a music therapist for another one of her goals. I had to find a music therapist.

ASSEMBLYMAN PAYNE: Ms. Gruskowski, your time it just about over, if you could just conclude it.

MS. GRUSKOWSKI: Well, can I read real fast? I just wanted to say that at this facility, she had cellulitis infection, she was covered with feces, impetigo, dehydration. She was impacted. She had her stomach pumped. Do you consider this good care? During her first 28 years, Danielle received excellent care at home. Emergency hospitalizations did not occur.

ASSEMBLYMAN PAYNE: The subject is the restraints. I mean, we're talking now. We would like to keep strictly to the legislation that we are -- rather than the general conditions.

MS. GRUSKOWSKI: The neglect and abuse?

ASSEMBLYMAN PAYNE: The restraints, please.

MS. GRUSKOWSKI: Yes. This is what it, specifically, deals with, neglect and abuse, is what I'm saying.

ASSEMBLYMAN PAYNE: Could you just please conclude it as much as possible. We'd appreciate it very much.

MS. GRUSKOWSKI: Okay. Well, Danielle was given a cold shower to try to wake her up. The agency director told me that it never happened when I questioned them. I insisted on an investigation and a report

from the Special Response Unit from DDD -- TREN-#1831. It started off, "Dear Mrs. Gruskowski, there is a preponderance of evidence to substantiate abuse, namely the caregiver administered a cold shower to awaken Danielle." There were three recommendations: One, the agency should cease this practice immediately. My question is, who is accountable? Where is the supervision, and where is the training?

Appropriate disciplinary action -- my question is, did staff received counseling? Did the victim receive counseling? No. Staff training on consumer rights -- the caregiver that worked with our low-functioning loved ones are not receiving the appropriate training.

ASSEMBLYMAN PAYNE: You don't believe me. We are all very, very impassioned about this entire area, but we're going to have to ask you to please conclude. You're talking about training and things like that. We're not going to deal with the training aspect of it today. So, if you can, just conclude. We'd appreciate it very much. There are other people that would like to testify as well.

MS. GRUSKOWSKI: Okay. Danielle is one of many victims of provider agencies. Even though I followed all the rules and the chain of command, I was let down. My daughter was let down. Shame on everybody. Everyone failed Danielle. I want you to feel my pain.

I'm here today, because I didn't know where else to go. There are many more Danielles out there with no one to speak for them. Please help us. Danielle will never be forgotten, and we will never go away. Therefore, I am against aversive treatment, especially for the developmentally disabled. Proper training and knowledge is essential. Certification is demanded. Monitoring should be done by an experienced, independent party only.

Thank you.

You have my written testimony. I have a lot more in there.

ASSEMBLYMAN PAYNE: Yes. Thank you very, very much. I appreciate it.

ASSEMBLYWOMAN WEINBERG: Margaret Griscti. I'm sorry. I'm sure I mispronounced that.

MARGARET GRISCTI: Yes. I'm Margaret Griscti. My son lives in the same group home that Danielle did. I'm going to summarize it, but my speech was only two minutes anyway.

New Jersey is going backwards instead of forwards, and the abuse, neglect, and deaths are escalating. Years ago, we had unannounced inspections, not any more. We had a public advocate, not any more. Other states are leaving aversive treatment behind, not New Jersey. So I support Matthew's Law.

As far as some of the bills containing training information, I agree with that young lady that was here from Wisconsin, was it? On-the-job training means no training. Training must be done before the job and be ongoing, as well as formal, not the haphazard way that it is done. Staff must be certified. My son, too, suffered abuses and neglects because of poor training -- cold showers, bruised feet, outdated food, fractured finger, improper doses of liquid meds, running out of food, poor dental hygiene, a broken femur, and never receives the proper training for the asthma apparatus that is needed for him.

As far as monitoring, A-3108 is the first step towards supervision and accountability. Supervision and accountability are nonexistent at every level. The State, the company, the group home managers, and the direct care

level -- everyone checks paperwork, not people. Bill No. 3108 is the first step, but we need many more steps. Independent monitoring is needed.

Thank you.

ASSEMBLYMAN PAYNE: Thank you.

What facility are you talking about?

MS. GRISCTI: Spectrum For Living.

ASSEMBLYMAN CRYAN: This is in Edison?

MS. GRISCTI: Yes.

ASSEMBLYMAN CRYAN: I have a question for you, in a follow-up. Did you have issues with the IHP? Because the bill we're considering is A-2855, and it deals with the IHP.

MS. GRISCTI: Again, as most people said, IHPs are not followed very well.

ASSEMBLYMAN CRYAN: I just want to be direct when I ask you, because-- Was your son and his IHP, was it part of his regular care and was it followed?

MS. GRISCTI: In my case, it was followed because I was up there, back every day. I visit every day.

ASSEMBLYMAN CRYAN: Okay. Because the IHP is a fundamental part of the bill that we're going to vote on. So, staying on the program here, did you feel as if the staff, in terms of the understanding of your son's IHP, was adequate and was followed?

MS. GRISCTI: The only reason it was followed is because I hung a sheet on his bedroom door with times and a routine for him. It wasn't because of the IHP.

ASSEMBLYMAN CRYAN: Because of your perseverance?

MS. GRISCTI: Because of my perseverance.

ASSEMBLYMAN CRYAN: Okay. Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

Nancy Weiss. (no response) Not here. Okay. Ms. Weiss was going to speak in favor of A-2855.

Dr. Christopher Oliva. Please identify yourself and your affiliation.

CHRISTOPHER M. OLIVA, Ph.D.: I'm Dr. Christopher Oliva, and I'm an Educational Behavioral Consultant working in New Jersey, Connecticut, New York, Pennsylvania, and Massachusetts. I've been in this field since 1973. I was trained as a behavior modifier when there wasn't anything else to do. There were not many strategies. It was very experimental. It was like what Skinner did to cats or dogs -- excuse me, mice and pigeons -- but applied to human beings.

In the 1980s, there was an advancement in behavioral science. It was called understanding the value -- the communication value of problem behavior. And since that time, we've developed positive behavior supports. It is a known technology, and proven. However, it seems that there are many professionals in this field that insist on using the '60s and '70s procedures. They have never really fully embraced positive behavior supports, even though they embrace the language.

When I work in New Jersey, at the request of a parent or a school district, and review a behavior plan of a child they're ready to send away to some residential school, I often find that there is a disconnect between the assessment, the functional behavior assessment, and the positive behavior plan, because they're really unrelated if the professional doesn't use the assessment to actually make the plan. And it happens frequently when that happens.

Parents, in my experience, that embrace the programmatic restraint and aversives are people that have not had -- their children have not had the benefit of real positive behavior supports. So there are people out there that have the words about positive behavior supports, but, in fact, they really don't do it. Blocking has substituted for restraint in many situations that I have been in. It has not been necessary to lay hands on people to keep them safe, whether it's head injury where people can block -- head injury with hands or against objects. It is a much less intrusive way to assist people to stop hurting themselves. Also, staff provoke people into those severe problem behaviors, behaviors that eventually require restraint. Positive behavior supports, when you truly do it, you do everything possible to avoid, on a meaningful level, to avoid a person from getting upset to the point where they hurt themselves or someone else. And when they hurt someone else, they usually hurt staff, because they're really angry at staff usually -- about the rules, the arbitrary rules, and the restrictive procedures that they've had, lack of choice in their lives.

ASSEMBLYMAN PAYNE: Thank you. Thank you very much.

ASSEMBLYWOMAN WEINBERG: Thank you.

ASSEMBLYMAN PAYNE: At one point, did you say that the assessment is not used, that they developed a plan in an institute.

DR. OLIVA: Many times, yes. This is in Federal law, in IDA.

ASSEMBLYMAN PAYNE: Okay.

DR. OLIVA: And they say, "Okay, Federal law. We've got to do this assessment." And then you look at the plan, and the plan bears no relationship to the assessment. Federal law says it's got to.

ASSEMBLYMAN PAYNE: Okay. All right. That's where monitoring comes in.

Thank you.

ASSEMBLYWOMAN WEINBERG: Richard Royse, from New Concepts. (no response) He was going to speak in favor of A-2849.

John Thvedt. (no response) Who was going to speak in favor of A-2855.

Andrew Howard, who asked, if possible, to testify early in the afternoon. (laughter) You are opposed to A-2855. I'm sorry. As you will see, this is the first time we noted that. My apologies. Had you asked to speak late, we would have called you early.

A N D R E W S. H O W A R D: I wasn't going to leave.

I'm here-- Again, my name is Andrew S. Howard. I'm the father and legal guardian of Elana D. Howard, a 24-year-old adult, living in a group home run by Bancroft NeuroHealth. Elana has been at Bancroft for over 10 years, previously in their children's residential program, living on, and then later off, campus, where she is now.

I thank you for the opportunity to address the limited people that are still here. I wish that the press was still here, but we'll take what we have. With respect to the pending legislation, I read on the Internet-- I was very disturbed by the definitions preceding the detailed bill, where they gave the example of aversive technique -- means the presentation of a stimuli or condition to decrease the frequency, intensity, or duration of maladaptive behavior by inducing distress, discomfort, or pain, which may place the individual at some degree of risk or physical or psychological injury. Who would be in favor of that as it's worded there? No one. I would be in favor of that, because I know my daughter, and I know it's worked. And so would any

concerned parent -- or if a child, like mine, who has behavioral problems that would otherwise severely limit their potential.

Are there other alternatives? Yes. There are various drugs which limit the frequency of outbursts, but would also further limit her ability to stay on task. More importantly, they would preclude the possibility of her ever flourishing or reaching her true potential. We've seen children that have been dealt with drug therapy. We've seen alternatives.

We would much prefer restraints on an as-needed basis. Elana alert and active than drugged into submission. Since Elana is on a regimen of anti-seizure medications, adding more chemicals to her system could only have some degree of risk of physical or psychological injury. Please try to understand that when you play doctor, there are consequences. Limit the tools that the professionals can use, and the next thing you know, the placement of behaviorally challenged people goes from difficult to impossible.

Alternatives for families would be between drug therapy and deceptive, and ultimately, more confined restraints than we are discussing here. Not being able to go to the restaurant, visit a mall, or go to a library are all forms of restraint. Instead of group homes in a community, there would be clusters of special homes sequestered to deal with their maladaptive behavior. I'm not ready to make that trade-off, and don't want anyone less aware of the specifics limiting my options.

If the State micromanages which tools can be utilized, you're not helping my daughter. In addition, you'll make the job of filling provider positions more difficult, increase turnover rates, and degrade the level of care that we're all here trying to improve.

ASSEMBLYMAN PAYNE: Mr. Howard, could you, kind of, conclude now, please.

MR. HOWARD: Excuse me.

ASSEMBLYMAN PAYNE: Your time is up. Just conclude your statement.

MR. HOWARD: Thank you.

ASSEMBLYMAN PAYNE: Thank you.

ASSEMBLYMAN THOMPSON: Your position is, you support the amendment, you oppose the amendment, or what?

MR. HOWARD: I'm against the amendment. I'm not in favor of amendment A-2855. I would prefer the State did nothing than move forward with a bill like this. I feel that this will set us back.

ASSEMBLYMAN THOMPSON: I'm referring to the Committee Substitute, as opposed to A-2855. What's your position on that?

MR. HOWARD: I have not seen that bill. From what I've heard here, in terms of the compromise bill, I would not be in favor of that. I believe that, again -- I know that Bancroft has been drug through the mud here. Nevertheless, we feel--

ASSEMBLYWOMAN WEINBERG: Excuse me, but that is not so. Bancroft has not been dragged through the mud here.

MR. HOWARD: Bancroft has been accused of--

ASSEMBLYWOMAN WEINBERG: Mr. Howard, I don't want to argue with you. We are--

MR. HOWARD: --for-profit agency, criminal.

ASSEMBLYWOMAN WEINBERG: Excuse me. We are dealing with bills that have to do with restraints. I said at the beginning of the meeting that this does not have anything--

MR. HOWARD: I heard you.

ASSEMBLYWOMAN WEINBERG: --to do with the hearing on Bancroft. We have reminded people who have veered off the subject, and you, too, are veering off the subject. So, please, stay on the subject of restraints.

ASSEMBLYMAN THOMPSON: The bill permits, with conditions, the use of restraints in the IHP.

MR. HOWARD: Yes.

ASSEMBLYMAN THOMPSON: The Committee Substitute.

MR. HOWARD: Again, having not been able to review that, I wouldn't want to state an opinion. I know that, right now, that the current laws in place seem to be very effective and have, in my case and cases that I'm aware, have been more than effective.

ASSEMBLYMAN PAYNE: Thank you.

MR. HOWARD: Thank you.

ASSEMBLYMAN PAYNE: May I have Diane and Jim Higgins here? Parent advocates, you'll identify yourself, please.

DIANE HIGGINS: Good evening.

ASSEMBLYMAN PAYNE: Good evening.

MS. HIGGINS: Our names are Jim and Diane Higgins, and we're the parents of Timmy Higgins, who is 11 years old, autistic, incredibly special, and a resident of the Bancroft Program in Haddonfield, New Jersey. Some background information might be beneficial both in terms of understanding how

Timmy came to reside at Bancroft, as well as our presence here today opposing this measure, A-2855, as it is currently proposed.

Three years ago at this time, our life was chaotic and extremely stressful. Timmy resided at home, and his autism manifested itself in many ways that are typically associated with autism. That is, lack of effective communication and socialization. Beyond these issues, Tim manifested other behaviors that were far more disturbing and dangerous. These activities included such things as breaking glass, attempting to eat glass -- because after all, it did look like ice cubes -- pouring liquids onto lightbulbs to see and hear the pop, removing oven racks, and climbing into the oven, walking across our fireplace mantel, just to name a few.

In addition, there was a constant threat of elopement, hitting, biting, pinching, and scratching himself and others. Coupled with all of this, Tim slept very little, averaging about four hours per night. Eventually, his behaviors grew to exceed over 1,000 per day, and Timmy required more intensive supervision around the clock. In fact, it was approximately at this point that the school that he then attended required two-to-one staffing for Timmy in the school setting in order to ensure Tim's safety and staff protection. Needless to say, life with Timmy at this time was difficult, exhausting, and unstable. We were frantic and continued our search for assistance to help with our son.

Timmy had already previously completed a five-week, in-patient stay at the Philadelphia Children's Seashore House, Biobehavioral Unit, in November of 1998, and was still a part of their outpatient program. However, this no longer seemed effective, and Timmy's behaviors escalated to the degree that another inpatient stay was warranted. This time, Tim resided for eight

months, from August of 2000 to March of 2001, at the Kennedy-Krieger Neurobehavioral Unit at Johns Hopkins in Baltimore.

As was stated previously, Timmy's maladaptive behaviors exceeded 1000 per day when he entered Kennedy-Krieger. Through a functional analysis of Timmy's problem behavior, it was determined that many of these behaviors were not maintained by environmental variables, such as to get attention or to gain access to preferred activities, but rather persisted independent of any social consequence provided and appeared to serve a self-stimulatory function. Based on these results, as well as other assessments, the treatment plan was developed and some of the components included: Three-step guided compliance, redirection, noncontingent reinforcement; high staff ratio; response reduction procedure, which was a 30-second basket hold for SIBs, aggressions, and disruptions; and other treatments. These recommendations did not evolve overnight but were part of an intensive and extensive effort.

Tim's behaviors, when he left Kennedy-Krieger, were reduced to a little bit over 50 per day. While the situation had improved, a residential placement was required for Timmy upon his discharge. His referral was sent to over 30 programs throughout the United States, and Bancroft was the only program that accepted the challenge of providing the measure of care and attention required by our son.

We provide this history as a context to our opposition to this measure. A small but essential portion of the protocols for Timmy requires the implementation of a 30-second basket hold for behavior, which we have outlined. It is not done solely for the purpose of physical restraint, but to provide instruction and understanding to a child who, very often, lacks these

means. It is not administered in a punitive manner but to explain to Timmy the type of act which is not acceptable.

ASSEMBLYMAN PAYNE: Ms. Higgins?

MS. HIGGINS: Yes.

ASSEMBLYMAN PAYNE: As you know, you've gone past your time. If you could just conclude it, and we appreciate it very much, in the interest of others.

MS. HIGGINS: Okay. What is explicit for us is the fact that this treatment does work. It's effectiveness is demonstrated both in the decline of these dangerous activities, as well as the fact that life with Timmy is now bearable. He comes home every weekend, and we can now envision a future with Timmy with a measure of promise, which we could not do previously.

ASSEMBLYMAN PAYNE: Thank you. Thank you very much.

Ms. Higgins, please, we have a question from Assemblyman Cryan.

ASSEMBLYMAN CRYAN: Ms. Higgins, what's a basket hold?

MS. HIGGINS: Pardon me?

ASSEMBLYMAN CRYAN: What's a basket hold?

JIM HIGGINS: A basket hold is essentially -- if you were to take your hands and, essentially, extend them behind. In this manner, either the staff-- I'll be the basket hold. (Couple demonstrate basket hold)

MS. HIGGINS: This is a basket hold.

ASSEMBLYMAN CRYAN: And in Timmy's case, a staffer does that for 30 seconds. Is that how it works?

MS. HIGGINS: Yes.

MR. HIGGINS: Yes. A staff trained in the techniques that were developed at Hopkins. Both my wife and I were required to be trained in these techniques before Timmy could be discharged.

ASSEMBLYMAN CRYAN: And were there any other types of restraints used for the success that you've seen with Timmy so far?

MS. HIGGINS: The only other type of-- That's the only restraint that Timmy receives. They had dropped -- and when he arrived at Bancroft, the restraint, for a time, was dropped out of his program because he had progressed, and he had reduced his behaviors to such that he was having very, very minimal ones. When they dropped the basket hold out of his program, his behaviors escalated through the roof again.

ASSEMBLYMAN CRYAN: My last question is -- and this goes to Assemblyman Thompson, I'm sure -- the Committee Substitute, are you opposed to that or are you opposed to -- because your original testimony, I'm sure, deals with the original A-2855?

MS. HIGGINS: Right. And we really have not had the opportunity to read the substitute bill yet. So we are unsure of our commitment towards that, or as to for or against.

ASSEMBLYMAN CRYAN: Thanks so much.

MS. HIGGINS: You're welcome.

ASSEMBLYMAN PAYNE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: I just wanted to point out what I pointed out through the course of the afternoon -- that the main difference in the Committee Substitute is that it allows the use of restraints as part of an IHP, along with the input that I enumerated earlier. So, under the

Committee Substitute, restraints are allowed in an IHP in consultation with a physician, parent, and the human rights advisory board.

MS. HIGGINS: Well, that's where we currently are now, I believe.

MR. HIGGINS: Thank you.

MS. HIGGINS: Thank you.

ASSEMBLYWOMAN WEINBERG: Dr. Jeffrey Chapnick.

J E F F R E Y C H A P N I C K, M.D.: Good evening. My name is Dr. Jeffrey Chapnick. I'm a parent of a student at Bancroft, and I'm also a physician, so I bring a dual perspective to this. Once again, this is a picture of my son, Billy, with his favorite pro-bowler, with whom he bowls in professional amateur tournaments. (indicating picture) A short time ago, my son was in a mental hospital for six months. So Bancroft has done wonders for him, using what I'd like to call the HEART tools -- Humane Effective Appropriate Restraint Technique. It would be a shame if these were to go by the wayside because of some -- it seems to be a wave of anti-restraint going on.

Bill A-2855 would be absolutely devastating to his quality of life. He has managed, despite his disability, to do many, many things. Passing this bill would hurt him terribly. It would effectively negate the efforts which have been made to integrate the developmentally disabled into the community and would take us back to the bad old days of Willowbrook, if everybody remembers those.

Bill A-2855 would effectively eliminate the ability of programs like Bancroft to provide their clients with anything remotely resembling a normal existence. Children like my son would not be able to safely go on outings to the community, to the supermarket. They would be reduced to an isolated, vegetative existence. The procedures in Bill A-2855 are unworkable and would

have the net effect of squeezing the dignity and humanity out of the lives of our children, forcing them again to be locked up behind closed doors out of sight and out of mind.

If we allow the bill, A-2855, to take away these tools, our children and those who care for them will be subjected to great danger. They will end up bruised, broken, and bloodied, filling the ERs of New Jersey. They will populate our trauma wards and ICUs. Without the ability or these tools, they will be reduced to a hermetically sealed existence -- no movies, no bowling, nothing.

We strongly support continued training and staff development programs for care providers, as it is quite vital that the State provide those who work with our children the resources and the compensation that they require and deserve. However, the draconian measures in A-2855 would be throwing out the baby with the bath water.

The final point -- taking away these valuable tools from our children's caregivers would be as foolish an act as prohibiting all surgeons in New Jersey from ever using scalpels again, simply because of one operation not having gone well. Overreaction is not the answer. Enlightenment, resources, training, and hope are the keys to our future and our children's future.

ASSEMBLYMAN PAYNE: Thank you very much, doctor. Thank you.

Lois Williams.

LOIS C. WILLIAMS, ESQ.: Good evening. I'm glad to see you stayed awake, and I have too.

ASSEMBLYMAN PAYNE: That's why we keep it cold in here.

MS. WILLIAMS: My name is Lois Williams. I am a retired schoolteacher, and I am an attorney. I'm not here in that capacity.

I'm here because I have an autistic son who is 43 years old. So I think I can top anybody for time living with a person who can hurt you really easily. I kept him at home until he was 35. My worst fears were that he would have to go to an institution. I did every possible thing to keep him calm. He went to day care, ARC. He would hurt the people at ARC. He would hurt the people on the school bus. It was pretty much of a catastrophe, but I wouldn't give in until one day I was sleeping and he came up and almost strangled me. My grandson was there, got him off me, and I realized that it was an impossible life.

When he went, first, to group home and he hurt someone very badly there, they didn't have restraints or anything like that. The next group home he went to -- they, also, didn't have restraints. It was a very nice home, and I kept hoping, "I hope he doesn't hurt anybody." Well, he didn't hurt anybody much at the home, but he hurt people at the day center. They were so afraid of him that they wouldn't keep him there. Now, I could have brought him today and illustrated that he's really tall and he weighs 200 pounds, and if he's angry, he's going to scratch you or strangle you, but I thought that that was kind of unnecessary. He finally had to go to Woodbine, where he had to stay for quite a while.

And then, by some miracle, a letter was received from a company named AdvoServ, and they said they would like to have him -- they thought, because he was autistic. They read his records, and they thought they could help him. He's been at AdvoServ, I think, about three years. He's not perfect and he's not cured and he's never going to be cured. This is why I am here to ask you to please keep the use of restraints in programs for the people that need them.

My son has always been a nightmare -- that someday he was going to kill somebody. And if you don't even think of the people that he's hurting, think of him. What will we do with him if he kills somebody? That was my nightmare. What will we do with him? Well, if AdvoServ can't use restraints, then what's going to happen to Timmy? Because he's going to hurt somebody.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

Kathy Mills.

KATHY MILLS: Good evening. My name is Kathy Mills, and I am here representing New Jersey TASH and the Building Futures Project, which is New Jersey's project on positive behavior support. This project provides training and technical assistance to families, schools, and agencies throughout the state.

I'm, also, a parent of a child with severe behavior challenges. My little boy is only 8, and he has displayed many of the behaviors that you've already heard about today. I won't go over them, because it will be repetitious. Beginning at age 5, my son's behavior became more and more challenging and out of control. After a couple of years of crisis, I connected with a behavior specialist from the State trained in positive behavior support. I attended parents' trainings and learned to apply support techniques and strategies over the next year. When I realized how it changed our lives in a positive way, I became involved in training other families.

Over the past two years, I, along with a parent/professional training team, have been involved in training over 30 families who have children with severe behavior challenges. We have worked with children with physical aggression and self-injury with positive results. We have not had to resort to any type of restraint or demeaning punitive techniques to achieve these results.

One question you may ask is: Why do we need to put these protections in place? They need to be in place because most of the children we are talking about cannot speak. They cannot go home or call mom and tell them that something is wrong. These children do not need to be managed and controlled. They need to be understood and supported. These are the most vulnerable people in our society.

There is an alternative. We have the expertise in New Jersey to begin to develop positive approaches for people with severe behavior challenges. There are several universities in New Jersey with nationally known experts in positive behavior support. We need to utilize these resources, now, and develop our capacity to support people in positive ways.

I've worked, also, in an institution in Pennsylvania, 20 years ago, and I restrained children in basket holds. And with what I know now, I could have prevented all of those behaviors with the knowledge about positive behavior support and what to look for -- behaviors that lead up to the outbursts.

Thank you.

ASSEMBLYMAN PAYNE: Yes. Can I ask you, you are in favor of this A-2855?

MS. MILLS: Correct

ASSEMBLYMAN PAYNE: That removes restraints. That removes the--

MS. MILLS: Excuse me? I'm in favor of Matthew's Law. Because of the positive behavior support that we're doing, a lot of people out there are doing positive behavior -- they're calling it positive behavior support, but it's not. It's behavior management. It has nothing to do with positive behavior support. We just want to see the work that we're doing grow. All the parents

that we work with, they're still having major problems with their children in schools, because nobody is trained. We're trying to get to people, but we do not have the resources to do that.

ASSEMBLYMAN PAYNE: Thank you very much.

MS. MILLS: You're welcome. Thank you.

ASSEMBLYWOMAN WEINBERG: Rita Hegmann, parent. Not here. She is here, I'm sorry.

RITA HEGMANN: My name is Rita Hegmann. I have a 23-year-old daughter with developmental disabilities. This is her picture. (indicating picture) I'm not in favor of A-2855, because my daughter has severe self-injurious behaviors. If you were to see her arms, she has scars on her arms that start here on her hand and go all the way up her arms, both on the outer and inner surfaces. She bangs her head. She pulls out her hair. I've been dealing with this for 23 years. I had her at home for 13 years, and then I had her in a facility in New York. I lived in New York originally.

She's now at Bancroft NeuroHealth. She is in their specialized unit there. I just don't feel-- They need these restraints, both to protect her-- I don't know what the alternative is when you have a child who's tearing out pieces of their flesh or banging their head on any surface that they can get to. She also functions at a very low level. I keep hearing about all of these positive approaches. And Bancroft -- it's not as though they don't use positive approaches, but restraints are used as the last measure for her.

Right now, she does have some coverings on her arms that we've been able to work with her to get her to protect herself. So she has some coverings that do protect her arms, so that if she does have behaviors, she will

not be able to get to her arms, and then they don't have to restrain her. Then they can just work with her the way it is.

So I'm not in favor of the law as it's written. I'd like to be able to read over the new amended law to see whether or not I would-- It seems like that's a compromise. I think it might need a little bit of work, but it certainly seems like it's a compromise. I'm just asking you not to get rid of something that's helping these children, to just really examine what's going on, to really look at it closely. I feel very badly for this mom. I don't know what I would feel like in her place. But I, also, know that I have to look after my daughter's well-being, and, right now, she needs those restraints to protect her from herself sometimes, unfortunately.

Thank you very much for allowing me to speak.

ASSEMBLYMAN PAYNE: Thank you very much.

Jane Gonzalez.

Good evening, Ms. Gonzalez.

JANE GONZALEZ: Good evening.

My name is Jane Gonzalez, and I'm coming at you from a little bit different perspective. A lot of parents and folks who spoke here today were from New Jersey. I am not. I'm from Pennsylvania.

My daughter, Rachel, is not autistic. She does not have PDD. She is microcephalic. She has a nonspecific diagnosis. My daughter suffers from a lack of myelin. Myelin is the white matter in the brain, which allows -- it's a conduit for messages to be sent through the brain to the appropriate areas and, effectively, helping her to function as a person. Because of the lack of this myelin, Rachel has neurological outbursts -- is what I call them. These

outbursts present themselves as behaviors, behaviors which are extremely self-aggressive, abusive, and destructive.

Rachel was maintained at home for five years of her life. And in those five years, we sought different programming for her. Her behaviors were very clear to us at a very early age, and we tried all treatments that were available to us in Pennsylvania. We tried redirection. We tried positive reinforcement. We had a sensory program for her. You may hear the term sensory integration, in which we utilized brushes and feathers and anything that we could get our hands on, to desensitize her nervous system so that it could handle the input that being alive asks it to do.

Rachel went through an early intervention program in Pennsylvania, and because of their inability, because of the laws there, to keep her safe and, effectively, by using a restraint when these outbursts occurred, I was frequently called and asked to come take Rachel home, come to pick her up from this program, because they could not keep her safe, nor the other staff persons or students, at this facility, safe from Rachel's behavioral outbursts.

Rachel, also, spent time in the Biobehavioral Unit at Children's Seashore House in Philadelphia. They, also, utilize redirection, and positive reinforcers. They also incorporate it--

ASSEMBLYWOMAN WEINBERG: Ms. Gonzalez, you're at the end of your two minutes, so could you please summarize?

MS. GONZALEZ: Absolutely.

My daughter came out of the Biobehavior Unit in Pennsylvania bald, and essentially was bald two other times at her own hands, because Pennsylvania does have a law like A-2855, and disallowed for the appropriate, effective humane treatment that she now receives. Rachel has gone into the

Linden's Program at Bancroft NeuroHealth with behaviors far exceeding 80 incidences per hour. Rachel came out of that program with a basket hold, visual screen. The visual screen has since been dropped. Rachel's behaviors continue, to this day, to decline. She does still receive a basket hold for self-injurious behaviors. And when this basket hold and this treatment is not utilized, her behaviors escalate quickly, in which she hurts herself severely. Without these options and treatment, Rachel's life would be one crisis after another.

Her body cannot handle the stimulation that is being asked her neurological system to handle. She needs this hug of life to maintain her ability to function in a community. And I ask you, and I do support your efforts today in the combined bill. I do support that, and I think it is a step in the right direction. And I thank you for all staying here and giving opportunity for me to speak to you this evening.

ASSEMBLYWOMAN WEINBERG: Thank you.

MS. GONZALEZ: Thank you.

ASSEMBLYWOMAN WEINBERG: Are there any questions? (no response)

Thank you very much, Ms. Gonzalez.

Joe and Laura Atkinson. Are they here? (no response)

Yes, we do have their written testimony. Joseph and Laura Atkinson did submit written testimony in opposition to A-2855.

Richard Tallman, who wants to speak in favor of A-2855.

R I C H A R D T A L L M A N: Good evening. My name is Richard Tallman.

ASSEMBLYWOMAN WEINBERG: Put your microphone on.
(referring to PA microphone)

MR. TALLMAN: Okay. Now it's on.

My name is Richard Tallman. I'm the father of an autistic 26-year-old young man, who happens to be sitting in the corner here. You haven't heard too much out of him this afternoon. Ten or 15 years ago, you would have. He displayed a lot of the behaviors that people have been describing. However, he attended a program that did not use restraints or aversive techniques, and he seems to have done pretty well by it.

In 1993, our youngest son, Jason, was placed in a residential treatment facility in Pennsylvania, on May 11. On May 12, we got a phone call that they had a problem with him, restrained him, and he had passed out. They took him to the hospital. When I called the hospital, they said, "He hadn't passed out. He stopped breathing." They had squeezed the life out of him, and he died the next day in Children's Hospital in Philadelphia. At the time, we thought it was an isolated situation, until I read the article in *The Hartford Courant* several years later.

Shortly after that came out, another child who lived about 20 miles from us died at the same place in Pennsylvania. So I moderate a list to everyone on the Internet dealing with restraint issues, and I've documented over 200 cases of this happening. There are programs out there that don't use restraints. There's one in Massachusetts that's semi-world famous, I would imagine -- don't use any restraints, but they have a great success rate. If you say use restraints -- if the only tool in your toolbox is a hammer, you're going to treat every situation like it's a nail.

In conclusion -- I'm going to make it short -- because I'm getting hungry, too. I see a lot of people have been showing pictures. I can't do that.

Janice can't do that. Because the last pictures of our kids were taken by medical examiners.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Any questions? (no response)

Okay.

ASSEMBLYMAN PAYNE: Peggy Kinsell, please. (no response)

Gone. She was going to speak in favor of A-2855.

Gerard Thiers. (no response) Gone. Was speaking in favor of A-2849 and A-2850.

Chris Martin Clee. (no response) She's gone. She was speaking in favor of Matthew's Law.

Lowell Arye. (no response) In favor of A-2849 and A-2850.

Dr. David Holmes. (applause)

ASSEMBLYWOMAN WEINBERG: You bring your own cheering section. (laughter)

DAVID L. HOLMES, Ed.D.: That's nice to hear.

Hi. It's nice to be here. It's late. I'm very pleased to be able to present my presentation to you. I'm not going to actually read it, because of the lateness of the evening. Let me tell you who I am. I'm the Panel of Professional Advisors' Chair for the Autism Society of America, which is the largest advocacy organization for parents and children with autism in the world. I've been the Chair of this Panel of Professional Advisors for six years, which is five years more than the average panel of the -- Chair of the Panel of Professional Advisors, because the Autism Society of America gives me the sense that I'm a

balanced professional in my views of what's appropriate and what's inappropriate for services.

I'm also a forensic psychologist, board certified, and I've been involved in many cases of child abuse, neglect, as well as wrongful death cases. I'm also an adjunct professor at Princeton, in the Psychology Department. But my day job is, I'm President and Executive Director of The Eden Institute in Princeton. This organization offers life-span services to those with autism. Not just anyone with autism, but those of more significant behavioral and cognitive challenges.

A recent position I had was on past -- and it's really nice to be past something -- chairman of the Chamber of Commerce of Princeton regional area. Now people would say, "Well, what's that all about?" I was actually sought out by the Chamber to be chair. Because I run a not-for-profit organization? No. Because they were so impressed with the quality of services that Eden offers some of New Jersey's most challenged human beings, and they see these folks with autism living and recreating throughout the community. And they know that, for example, this coming Sunday, we're taking over the Trenton Soup Kitchen -- people with autism -- serving those who are homeless and in need, because that's what Eden is all about.

It's interesting when I hear such passion from such opposite poles on an issue. When I hear such passion, I can see why we have individualized educational plans and individualized habilitation plans. Because when you have individualized plans, you have input from all stakeholders -- mommies, daddies, professionals that are serving these young people on a regular basis. Also, if family choice -- which I think is an issue in this matter as well -- in America was not an issue, I think we'd all be driving black Fords right now. So

you can see that Americans like to have options and they like to have choices when it comes to the services for their children.

Much of the testimony in favor of A-2855 this morning and afternoon sounds an awful lot to me, from my experience, as like abuse and neglect, not like effective treatment. I want us to keep that separate. I think the doctor was very clear. If we stopped all surgeries because somebody got stabbed in the stomach on Main Street, because a knife was used, that would be an abomination of what effective surgery is all about.

We all know the reasoning, faulty as it is, behind why a handful of professional advocates want to cease effective treatment of our most vulnerable of citizens. But until alternate procedures can be documented and proven beyond ideological belief systems, we must treat our children and adults with the dignity due them. That is, to give them the necessary treatment to live quality lives free of life-threatening behavior. For to do less would be the ultimate form of inhumanity, allowing people to live a life of despair and isolation.

I've been doing this, ladies and gentlemen, for all of my professional career, for 30 years. I'm only one of two service providers here this afternoon -- people who have dedicated our lives for 24 hours a day of services. Right now, I've got services happening, right now, for New Jersey's vulnerable citizens. And by the way, I am a citizen of New Jersey. I'm a taxpayer in New Jersey. I'm not from Wisconsin. I'm not from Nevada. I'm not from Pennsylvania. These are not bastions of appropriate services for people of autism.

New Jersey is known internationally for that. There is an article that just came out in *New Jersey Monthly*--

ASSEMBLYWOMAN WEINBERG: Doctor, you're getting to the end of your time.

DR. HOLMES: Right at the end.

--called "End of the Light." New Jersey's superior schools for the autistic have prompted a migration of families seeking a brighter future for their children. I didn't hear a lot of that today, and it's true. I'm very much opposed to A-2855. It will scuttle some of the very high quality service that we have in this state. I'm very much in support of A-2849 and its companion bill, A-2850. I have not read the recent one where you brought these two bills together -- supposedly A-2855 and A-2850 together. But if A-2850 included the same controls for aversives that you have included for restraints, I would be in support of that. I'd be in support of that.

You've heard from some of our families. We fully involve families in every treatment that we offer. Because if you don't have family support or support from the community at large, you can't be effective with these kinds of folks.

Thank you.

ASSEMBLYMAN CONAWAY: Thank you.

ASSEMBLYMAN PAYNE: Thank you, Doctor.

ASSEMBLYWOMAN WEINBERG: Any questions? (no response)

Thank you.

ASSEMBLYMAN CONAWAY: I've been to his place.

ASSEMBLYWOMAN WEINBERG: And just to correct the record, we did have several service providers here today.

DR. HOLMES: Okay. I only heard one other.

ASSEMBLYWOMAN WEINBERG: You might not recognize some from other parts of the state, but they were actually here.

Robin Turner.

ROBIN TURNER: Good evening. My name is Robin Turner. I'm Danielle Gruskowski's aunt and co-guardian with my sister, Diane Gruskowski.

Danielle was nonverbal. I wish Danielle could speak, and I wish she was alive, because I would have her here today talking to you and telling you about the abuse and neglect that she received at Spectrum For Living facility in Edison. I fully support Matthew's Law, due to the fact that it specifically states and it deals with aversive treatment, and it also is for abuse and neglect.

Actually, I'm sorry, I forgot to hand these out. I'm sorry. (referring to copies of testimony)

My first page is all the situations that happened to Danielle that are documented. They're actually documented. And facilities like this are able to get away with it.

I wanted to address Assemblyman Cryan regarding the IHP. The IHP was never followed, ever. It was only until we contacted the State and the State started contacting the provider agency, is when we were getting, maybe, them to even take it out of her file. It was never, never addressed.

From my point of view, and Danielle's point of view, she was not protected. When you are considering these bills, I would like you to really think about Danielle and all the things that she went through that you're going to read about. I also enclosed a picture in there of when she was impacted. It just goes on and on and on, and this is not a life for any child, your child, a normal child, or any kind of child.

I can only hope that you make all the right decisions for us. We need them fast, because there are many more Danielles out there, and I don't want to lose any more of them. They're too precious to me.

Thank you very much.

ASSEMBLYWOMAN CRUZ-PEREZ: I have a question.

ASSEMBLYWOMAN WEINBERG: Yes.

Nilsa.

ASSEMBLYWOMAN CRUZ-PEREZ: Robin, is that your name, Robin?

MS. TURNER: Yes.

ASSEMBLYWOMAN CRUZ-PEREZ: Okay. What happened to her in the picture?

MS. TURNER: That was our Christmas present -- December 24, Christmas Eve, 2000. That was the Christmas present that the facility gave to our family. She was -- a hot cup of tea was thrown in her face by the caregiver.

ASSEMBLYMAN PAYNE: What facility was this?

MS. TURNER: The Spectrum For Living in Edison, New Jersey.

ASSEMBLYMAN CRYAN: Anybody charged?

MS. TURNER: There is a lawsuit going on at the moment. We are also waiting for the autopsy from Danielle's death, because of the fact of the way it happened -- 911 was not called.

ASSEMBLYWOMAN CRUZ-PEREZ: I'm very sorry.

Thank you.

MS. TURNER: Thank you. Thank you very much.

ASSEMBLYMAN PAYNE: Robert Stack. (no response) Robert Stack was in favor of A-2849. That's the substitute.

Tish Capawana.

UNIDENTIFIED SPEAKER FROM AUDIENCE: She already testified.

ASSEMBLYMAN PAYNE: Oh, all right. She was in favor of A-2849.

Joe Young.

Identify yourself, please, Mr. Young.

JOSEPH YOUNG, ESQ.: Good evening. My name is Joe Young. I'm Deputy Director of New Jersey Protection and Advocacy. The New Jersey Protection and Advocacy is the State-designated protection and advocacy system for persons with disabilities. I've submitted written testimony prior to the hearing starting.

And just to respond to the Chairwoman's request, I won't read the testimony. At this point, as currently written, NJP&A supports the A-2855 over the Committee Substitute for the following reasons: The Committee Substitute, basically, only will legislate the current status quo. The things that are in the bill are actually what should be going on now, but are not going on. New Jersey Protection and Advocacy has responsibility for monitoring a great deal of what's going on in the developmental centers. When New Lisbon was under review, we were on the ground at New Lisbon every day for four months.

We read many, many IHPs at the developmental centers. The plans, the IHPs, are not individualized. Restraints are not provided for persons on exception basis. They are provided more on a routine basis. But even then, what's written in the plans are not followed. We read plan after plan after plan, which says: redirection, in order to try to get them to do something else; remove them from the stimulating environment; and then restraints. On plan after plan

after plan. There's no effort to do everything that we've heard here, before, about look what the causes are and things like that.

We're part of the Federal DD network, along with Dr. Spitalnik's UCE. We'd like to adopt a great deal of what she said. We're recommending, in fact, that the request that she had, that there be assessments prior to any kind of restraints being enforced, that there be stricter oversight. We don't think that the current human rights committees are empowered. We don't think that they're getting adequate training.

Currently, the IDT, again, rubber stamps. You also have to remember that a lot of people do not have parents, and the State is the guardian. For 4,000 people with developmental disabilities, the Division of Developmental Disabilities is also the guardian.

The other thing which hasn't been discussed today, which is one of the other bills that we encourage, is open reporting. The fact that restraints are being used should be open to the public of New Jersey so that everyone knows what is happening in these facilities. (applause)

ASSEMBLYWOMAN WEINBERG: That is in the Committee Substitute.

MR. YOUNG: Okay, thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Before you leave, can I just ask you a question.

MR. YOUNG: Certainly.

ASSEMBLYWOMAN WEINBERG: You are the State-designated Protection Advocacy Group?

MR. YOUNG: It's a Federal legislation that was passed as part of Willowbrook. And we were designated by-- Our agency is actually the privatized public advocate. As part of that, we were designated as the State Protection and Advocacy system, under Federal statute.

ASSEMBLYWOMAN WEINBERG: Without going into any specific cases, but the kinds of cases that we've heard about earlier, or during the course of this very long day, are those cases that were brought to your attention?

MR. YOUNG: We heard about most -- after the fact, after the injury had already occurred.

ASSEMBLYWOMAN WEINBERG: And then if you hear about them after the injury occurs, what do you do?

MR. YOUNG: We monitor the State's response to that. We make sure that the State conducts an investigation, that their investigation is thorough and that the agencies and the State respond to those concerns.

ASSEMBLYWOMAN WEINBERG: Well, I'm very happy to know about you, about the privatized advocacy group. Because having been through a situation that brought some of us here, I never heard you or saw you in that. So we'd be very happy-- We have the Chair of the Family, Women, and Children's Services Committee and the Chair of the Regulatory Oversight Board, and I, as the Chair of Health and Human Services, would be very happy to know what your work is about -- certainly not here, right now -- and exactly who and how you advocate.

Thank you.

MR. YOUNG: Certainly. We'll be in touch.

ASSEMBLYMAN PAYNE: And how you interact with the State agency. I mean, the State -- they're supposed to be regulating some of these

agencies, and we've had recent experiences where there's some 40, 50 violations, etc., etc., etc. I want to know what you people were involved in, at all, or if you had any oversight or any involvement. Very silent on it. We haven't heard any at all about that.

MR. YOUNG: We'll be in touch.

ASSEMBLYMAN PAYNE: Judith Farrell. (no response)

Sandra Boyles spoke already, right?

ASSEMBLYWOMAN WEINBERG: Yes.

And finally, Monica Brown, the last person who I have listed here. (no response) She's not here.

All right. Well, that concludes our testimony for those who have registered to testify.

Yes, Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: I just wanted to make a comment before we get to the vote.

Thus, certainly, what we know of what happened to Matthew was horrible, and it cries out for action. At the same time, we've also heard from many parents here who feel that having access to restraints is almost absolutely necessary in order to achieve what's necessary for their children.

I think that the Committee Substitute bill addresses this, plus it takes action to minimize chances that what happened to Matthew could happen to another child, and it has quite a few protections in there. And at the same time, it does permit, under controlled circumstances, the use of restraints. So I will be supporting the bill.

ASSEMBLYMAN PAYNE: Thank you, Assemblyman.

Anyone else? (no response)

ASSEMBLYMAN CONAWAY: Do you want a motion?

ASSEMBLYWOMAN WEINBERG: Before you do--

First of all, I would like to thank the real heros in our society. And it's not only those people who, on a daily basis, care for the kinds of folks that we've been talking about all day, but certainly the parents and guardians who love these people, who advocate for them, who give their hearts and souls to this. And you've done that to this endeavor.

Many of us, up here, have gotten the chance to know many of you over the last few months and have learned a great deal about this issue. You've been in our offices. We've been on the phone. We've been in e-mail contact. I will tell you that I have the utmost of admiration for the things that you all do in your daily lives, and for your ability to continue loving your relatives and doing the things that you know, because you're really in the best position most of the time.

I know my professional colleague here, to the right, will not always agree with me, but I believe the parent usually knows best, even without the degree.

ASSEMBLYMAN CONAWAY: I disagree with that. (laughter)

ASSEMBLYWOMAN WEINBERG: Having said that, I also believe that the Committee Substitute worked very hard at addressing all of the issues that were brought before us today and in the prior weeks and months that we've heard about this. And again, the Committee Substitute does permit use of restraints in an IHP, but only with these new county-based human rights committees, which cannot contain anybody who represents the facility that's being -- where the IHP is emanating from. It has to contain a mix of advocates, as well as professionals, and we believe that it goes a long way to answering

some of the problems that were brought up here today. Reporting requirements are involved in the Committee Substitute. We think that is very important. These will be published.

So just like -- I have a 97-year-old aunt in a nursing home. I can look on a Web page put out by the Federal government for Medicare and compare the problems in her nursing home, as opposed to any other nursing home in our vicinity. And that Web page is programmed into my computer. And as often as I visit, I also look at that, often. So that everybody who's involved in this issue will have a chance to look at the numbers, how restraints are being applied in the State of New Jersey.

I think we've done the best we possibly can. And if we release the Committee Substitute today -- tonight, I should say -- it will be done with an idea that we will, again, be taking a look at this before it comes up for a final vote. Certainly, on behalf of the two Committees involved, as well as Assemblywoman Previte and our Family, Women and Children's Services Committee, we will look at that bill, again, very carefully. We will take more input and speak to more of you, and we will have further time to amend this, if all of us agree it can be amended at the floor level before it goes before the entire Assembly.

I, for myself, I must say, I think we did the best work we can possibly do. I would hope that Janice Roach is going to agree that whatever the final version that comes out of this Committee and out of the full Legislature can be known as Matthew's Law, and that this, too, will be known as Matthew's Law. Because it is really the advocacy that you brought forth that started us on this road.

So that's all I have to say.

ASSEMBLYMAN PAYNE: I would, also, like to say that I have the greatest admiration for the advocates, for the parents, the relatives of people who are clients or who happen to be in this situation. I have to say that there's passion on both sides, and we saw that today. We saw people that were very passionate about the use of restraints and about the non-use of restraints. I think one of the things I have to give a great deal of credit to, for the parents and for the advocates, is that you are relentless, and you should be, and that you have, obviously-- Many times you're talking to the choir, because we are also deeply concerned about the conditions that exist here in our society and our community.

When we were elected, I certainly see my role as one whose responsibility is to try to improve the quality of life of people, to speak for those who have no voice. I feel that, obviously, it's a God-given opportunity to have that opportunity to be able to try to bring about some of the improvements in our society that's so sorely needed. Many of us have relatives who, also, are in the same situation or have been. So, therefore, we are able to be empathetic to what we're talking about. But it's obvious that there is passion on both sides.

But I have to say, I commend all of those who came today, because there was more light than heat. There could have been a great deal of heat and no light, but I think that we were able to get light from each person that testified. And as Chairwoman Weinberg says, that we will continue to look at this to try to see to it that we address those kinds of concerns that have been brought to us in the past, and I'm sure in the future.

Also, you can rest assure that we will see to it or try to monitor the implementation of these regulations, to see to it that not only are they written

in pen and ink, but, also, that they are implemented, to see to it that what we see is best for our citizens are implemented and carried out in the manner which they should be. So you can be sure that we are committed to doing the very best that we can. And hopefully, we will be able to have a piece of legislation that you will be honored to have called Matthew's Law.

Thank you very much.

Doctor-- Assemblyman, I'm going to refer to you again as Assemblyman Conaway. The hearing is over, Doctor.

ASSEMBLYMAN CONAWAY: Well, I just wanted to take a moment to thank all those who have come to testify. It's been a very long day, and your input has been invaluable.

I want to congratulate and thank my colleagues for responding when this issue was brought forward -- the Chairpersons, Assemblywoman Previte, Assemblyman Munoz -- for your advocacy on this issue. As we move forward, I hope that all will recognize that this is a work in progress; that we'll recognize that very often in life the truth of what needs to be done sometimes lies along a middle way and not on one end or another; that we recognize the difficulties that people who work in various institutions, the difficulties in which they find themselves, or, often, they don't have all the resources they need to do the job that they would like to do; that we recognize that the professionals -- who are involved with these children, dedicate their lives to their service and their betterment -- are doing the best that they can with their situation.

So, I'm hopeful that at the end of the day we will, and that when we get to this legislative process that we will bring forth the kind of reform that serves everyone's interests.

ASSEMBLYMAN PAYNE: Thank you, Assemblyman.

Assemblywoman Mary Previte.

ASSEMBLYWOMAN MARY T. PREVITE: My name is Assemblywoman Mary Previte. I chair the Family, Women and Children's Services. I am just beyond speech to express my thanks to Assemblyman Payne and Assemblywoman Weinberg and all the people -- Meredith Schalick, our staff person, who have really orchestrated this extraordinary view of democracy. I mean, look at what we have seen here. We've been going for seven hours with the tiniest little break, with Democrats and Republicans and parents and disabled people and educators and -- I can't even think of all the people -- to come to what is best for what we believe are the vulnerable children of New Jersey.

I would, personally, like to thank our two chair people that have directed this.

And, Meredith, thank you so much.

I will go home and think long about this amazing demonstration of democracy, of how we come to what we believe is the best for our people. I thank you most profoundly.

ASSEMBLYMAN PAYNE: Thank you.

ASSEMBLYWOMAN WEINBERG: On the Committee Substitute, we will vote separately as two separate Committees. So the Health Committee, can I have a motion on the Committee Substitute?

ASSEMBLYMAN CONAWAY: I move the Committee Substitute as amended. I move the Committee Substitute.

ASSEMBLYWOMAN WEINBERG: Second.

ASSEMBLYWOMAN POU: Second, yes.

ASSEMBLYWOMAN WEINBERG: Assemblyman Munoz's bill is joined in this, and he will be joined as a co-prime sponsor of this, also.

Can we have a roll call on the Committee Substitute?

MR. PRICE: On the Committee Substitute, for A-2849 and A-2855, Assemblywomen Vandervalk and Quigley are recorded as abstaining, and Assemblymen Green and Johnson are recorded in the affirmative.

Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: Yes.

MR. PRICE: Assemblywoman Pou.

ASSEMBLYWOMAN POU: Yes.

MR. PRICE: Assemblyman Conaway.

ASSEMBLYMAN CONAWAY: Yes.

MR. PRICE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Yes.

MR. PRICE: The substitute is reported.

ASSEMBLYMAN PAYNE: Now, I'd like to have a motion to move the substitute.

ASSEMBLYWOMAN CRUZ-PEREZ: I make the motion to move the substitution.

MR. VARI: Is there a second? (no response)

On Committee Substitute, Assembly A-2849 and A-2855, Assemblyman Rooney voted in the negative.

Assemblyman Cruz-Perez.

ASSEMBLYWOMAN CRUZ-PEREZ: Yes.

MR. VARI: Vice-Chairman Cryan.

ASSEMBLYMAN CRYAN: Yes.

MR. VARI: Chairman Payne.

ASSEMBLYMAN PAYNE: Yes.

MR. VARI: The substitute carries and is released.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

We have one more bill to consider today, or tonight again, is-- I explained earlier. We're going to be holding the training bill until we get all the funding mechanism worked out.

But the last bill that we have to consider is Assembly Bill No. 3108, which requires the Department of Human Services to place persons as monitors in facilities for developmentally disabled under certain circumstances. We do have amendments for that bill. I'm going to ask David Price from OLS to go over what those amendments are. But I will tell you that I think this is as important to address some of the other issues that were talked about earlier today. That because there are appeal processes, lawful appeal processes, that when the Commissioner of Human Services feels certain circumstances are warranted, she will be able to place a monitor in any facility, any time, up to whatever she deems appropriate, whether it's seven days a week, 24 hours a day, or less, depending upon the circumstances.

So, David, if you would go over the amendments on that.

MR. PRICE: The proposed Committee amendments to A-3108 are as follows: The amendments would stipulate that the Commissioner of Human Services may place monitors at a facility for persons with developmentally disabilities, if the Commissioner "reasonably believes," rather than has reason to believe, that the facility may be in violation of any Federal or State law regulation that impacts on the safety of a person receiving services from the Division of Developmental Disabilities. In addition, the amendments would

clarify that the Commissioner of Human Services may place monitors at a facility for persons with developmental disabilities up to 24 hours a day, seven days a week. The amendments would substitute the term “personal control” for physical restraint wherever it appears in the bill. And finally, the amendments revise the definition of mechanical restraint to exclude the use of a bedside rail and to clarify that the use of a domed or enclosed crib is prohibited.

ASSEMBLYMAN CONAWAY: I move the bill.

ASSEMBLYWOMAN POU: Second.

ASSEMBLYWOMAN WEINBERG: Roll call.

ASSEMBLYMAN CONAWAY: As amended, I should say.

ASSEMBLYWOMAN WEINBERG: Yes, move as amended.

MR. PRICE: On A-3108, as amended, Assemblywoman Vandervalk and Assemblymen Green and Johnson are recorded in the affirmative, and Assemblywoman Quigley is recorded in the negative.

Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: Yes.

MR. PRICE: Assemblywoman Pou.

ASSEMBLYWOMAN POU: Yes.

MR. PRICE: Assemblyman Conaway.

ASSEMBLYMAN CONAWAY: Yes.

MR. PRICE: Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Yes.

MR. PRICE: The bill is reported.

ASSEMBLYMAN PAYNE: I'll entertain a motion to adopt, as amended.

ASSEMBLYWOMAN CRUZ-PEREZ: As amended.

ASSEMBLYMAN CRYAN: Second.

MR. VARI: Roll call vote on Assembly Bill No. 3108, as amended.

Assemblyman Rooney was recorded in the negative.

Assemblywoman Cruz-Perez.

ASSEMBLYWOMAN CRUZ-PEREZ: Yes.

MR. VARI: Vice-Chairman Cryan.

ASSEMBLYMAN CRYAN: Yes.

MR. VARI: Chairman Payne.

ASSEMBLYMAN PAYNE: Yes.

MR. VARI: The motion carries. The bill is released.

ASSEMBLYWOMAN WEINBERG: That does conclude the business for today, but I'd like to take a moment to thank not only the Committee members for staying and listening and the joint effort that this resulted in, but to thank our staff members -- Wali, Meredith, the OLS staff, the partisan staff, and OLS who enables us to get a record of this today. So thank you one and all.

(MEETING CONCLUDED)