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# ***Committee Meeting***

of

## **ASSEMBLY REGULATORY OVERSIGHT COMMITTEE**

*“Discussion on the Department of Human Services, Division of Developmental Disabilities Proposed New Rule, N.J.A.C. 10:42A ‘Life Threatening Emergencies.’  
The rules are proposed to implement the requirements of Danielle’s Law.”*

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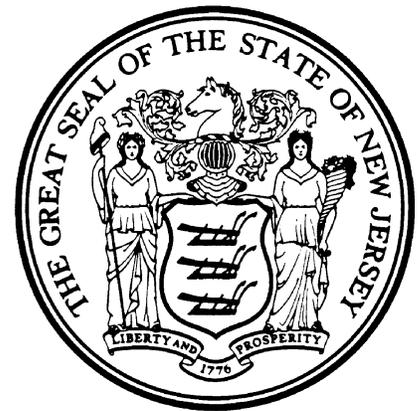
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**LOCATION:** Committee Room 8  
State House Annex  
Trenton, New Jersey

**DATE:** September 30, 2004  
10:00 a.m.

### **MEMBERS OF COMMITTEE PRESENT:**

Assemblyman William D. Payne, Chair  
Assemblyman Joseph Cryan, Vice Chair  
Assemblyman Douglas H. Fisher  
Assemblywoman Connie Myers



### **ALSO PRESENT:**

James F. Vari  
*Office of Legislative Services  
Committee Aide*

Wali Abdul-Salaam  
*Assembly Majority  
Committee Aide*

Nancy S. Fitterer  
*Assembly Republican  
Committee Aide*

***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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**ASSEMBLYMAN WILLIAM D. PAYNE (Chair):** Good morning to everyone.

I have a slight announcement to make, and we have to deviate just a little bit. And the announcement is that, at this incredible scheduling that we have here sometimes, I'm scheduled to testify before another committee at 10:00, which is, like, now. I have a major bill that's being considered that deals with the prosecutors in the State of New Jersey, and I'm the primary sponsor of it, and I have to testify for a few minutes. So, if you don't mind, since one or two of my Committee members are not here yet anyway -- if you don't mind, just talk among yourselves. Say hello to Billy over there and everybody else. (laughter) And I'll be back very, very shortly. I'm just going upstairs for a moment, okay? So I apologize for this.

**ASSEMBLYMAN CRYAN:** Hi everybody and good morning. We're going to start, and then we're going to do a roll in a second. But what I basically want to do is give you guys an idea of what we're going to do. The Chairman -- and I think he mentioned it a little while ago when he left -- he has a bill in another committee. And when he comes back, obviously, he'll take over the chair.

I want to get started. It's 10:30 or so. What we're going to do is, when we get started we're going to hear first from Terry Wilson, second from Senator Kean, so that you have an idea of how this will work from the beginning. And we'll go on from there. I know there's a number of folks that have signed up. If you haven't yet, please do so.

And with that, can I ask for a roll?

**MR. VARI (Committee Aide):** Sure,

Assemblyman Rooney is absent today.

Assemblywoman Myers.

ASSEMBLYWOMAN MYERS: Here.

MR. VARI: Assemblyman Fisher.

ASSEMBLYMAN FISHER: Here.

MR. VARI: Vice Chairman Cryan.

ASSEMBLYMAN CRYAN: Here.

MR. VARI: And Chairman Payne will be here momentarily.

ASSEMBLYMAN CRYAN: Is that it?

MR. VARI: That's it.

ASSEMBLYMAN CRYAN: Let's first hear-- Terry, why don't you come on up, okay? And Terry, just so that we're clear, you don't mind staying for the balance of the hearing, after you speak, right?

**DEPUTY COMMISSIONER THERESA C. WILSON:**

Not at all. It would be my pleasure. I'd like to stay.

ASSEMBLYMAN CRYAN: That's great. We appreciate that. So please, why don't you go ahead and give us your statement.

MS. WILSON: Good morning. May I begin by introducing myself and my colleague to the Committee. We are from the Department of Human Services. I am Terry Wilson, Deputy Commissioner for Services for People with Disabilities. My assistant -- and James Evanochko, Administrative Practice Officer, from our Division of Developmental Disabilities, is to my immediate right. I also want to say to the Committee, on behalf of Commissioner James Davy, he wants you to know that Danielle's Law remains one of his top priorities of implementation.

On behalf of the New Jersey Department of Human Services, I want to begin by thanking you -- certainly Chairman Payne, and Vice Chairman Cryan, and members of this Committee -- for giving us the opportunity to address some important concerns regarding the proposed rule that will guide the implementation of Danielle's Law. May I also thank the family members that are here today, whose work with the members of the New Jersey Legislature resulted in this important legislation and is most appropriately named in memory of Danielle.

We share a common goal -- to work towards improving the safety, health, and well-being of people with developmental disabilities or traumatic brain injuries. Every person deserves no less than our finest effort in this regard.

As the Department's Deputy Commissioner for Services for People with Disabilities, I chaired the work group responsible to draft the regulations N.J.A.C. 10:42A that appeared in the New Jersey *Register* on September 7, 2004. The proposed regulations represent the Department of Human Services' proposal to implement Danielle's Law throughout the more than 2,000 programs of the State and private agencies serving people with developmental disabilities and traumatic brain injuries.

This work group sought medical expertise and operational expertise from physicians, emergency medical technicians, as well as obtaining input from many subject matter experts: The New Jersey State Police, the American Red Cross, the American Heart Association, the Center for Disease Control, the New Jersey Department of Health, the Office of the Attorney General, and the

Governor's Counsel. It is our sincere intent to comply with both the letter and the spirit of Danielle's Law.

The goal in drafting this rule was to assure that 911 is called in life-threatening emergencies. It is critical that individuals receive timely and appropriate emergency medical services no matter where they live or where they attend programs, and no matter which agency provides their services.

In all cases, these regulations do require that 911 must be called in a life-threatening emergency, in accordance with Danielle's Law. It is equally important that there is accountability for that process, including training and policies that are clearly described in the rule. In drafting the rule, the work group focused on meeting these goals.

These regulations, however, are only proposed. Consequently, they are subject to an open comment period of 60 days which began September 7. During this open comment period, the Department welcomes input from all concerned parties. We respectfully remain open to changing the regulations based upon the comments received. Together we hope to assure that legislative intent in this matter is achieved. Safety is our primary concern.

It should be noted that we did not start with a blank slate. Emergency procedures are, and have always been, required by the Department throughout the many programs for people with developmental disabilities and traumatic brain injuries. Prior to Danielle's Law, service providers were required to have emergency procedures in place, including when it is necessary to obtain medical assistance. Each developmental center or provider agency is required to provide training for direct care staff members, and it is required that staff members are taught how to properly handle emergency situations. A staff

member trained in CPR and First Aid must be available on each shift in the community agency programs and in the developmental centers.

The staff training for employees of the agencies that operate programs in the community and the employees in the State-operated developmental centers requires that Red Cross training curricula for CPR and First Aid is utilized.

The curriculum regarding emergency medical situations include recognizing when it is critical to call 911. Since the need for Danielle's Law has become obvious to all of us, we know now that the training and emergency procedure protocol needs to raise the awareness and recognition of when to call 911. To continually assure the safety and well-being of those we serve, we believe Danielle's Law improves on these procedures and brings consistency, clear expectation, and accountability to the process of caring for vulnerable individuals.

The Department of Human Services has already taken steps to ensure compliance with the law. In November 2003, before Danielle's Law became effective in April 2004, the Department notified all of the service providers in New Jersey of the forthcoming law and advised their providers to become familiar with Danielle's Law requirements.

In April 2004, at the time Danielle's Law went into effect, the Department distributed to all provider agencies a detailed fact sheet with information and guidance to encourage calling 911 in emergency medical situations. The Department is monitoring compliance with Danielle's Law, and recently completed an analysis of the first three months that indicates Danielle's Law is being followed.

The Department serves thousands of persons with developmental disabilities and traumatic brain injury in a variety of different settings. It is critical to note that the State-operated developmental centers have, on staff, physicians and registered nurses 24 hours a day, seven days a week.

The rule provides that in developmental centers, the designated on-site supervisor, or medical professional, call 911 in life-threatening emergencies. These designated individuals respond to emergencies at the center, and since they are located on grounds, the emergency response time is expedited. The facility medical team can respond more quickly to life-threatening emergencies than a community-based emergency squad.

Community agencies do not generally have medical staff available on site. The rule allows the community agency to designate an on-site staff member to call 911 or to direct all staff members to call 911 directly. In either case, the agency is responsible to meet the requirements of Danielle's Law to call 911.

The Department has received a number of comments that the regulations allow for a designated staff person to make the call, rather than having the staff be responsible to make the call. This may be misinterpreted as if staff members are free to decide not to call 911 in a life-threatening emergency. This is not the case.

In the development centers and in the community agencies which designate a staff member to call 911, all staff members must alert the designated staff member to call 911. The designated staff member must make the call if there is a life-threatening emergency. The rule requires that a designated staff person is on site, on all shifts, available and accountable to call 911.

This is not a staff person located in a central office somewhere, or someone that staff would wait for the arrival of to the site to assess an emergency. This is included in the rule to reduce the risk of direct care workers not calling 911, because they believe someone else has already made the call.

The purpose of this public comment period is to obtain diverse reactions to the proposed rule and take all of these comments into consideration. The comment period and the subsequent review period allow for the necessary debate so that the regulations may ultimately be crafted in the best way possible.

The rule needs to ensure that 911 is called and emergency medical treatment is obtained. The Department remains open to revising this regulation once the public comment period has closed and all comments have the opportunity to be heard.

Every agency, every program, and every center serving people with developmental disabilities and traumatic brain injury is continually striving to meet the challenge of extremely complex and diverse medical needs. Every idea that improves the ability to do so is gratefully accepted.

I have distributed a chart that demonstrates the enhanced procedures that the proposed regulation will require as a result of Danielle's Law.

Again, I want to thank this Committee for the opportunity to testify today on the efforts of the New Jersey Department of Human Services to implement Danielle's Law, and reiterate that we are open to your direction. And we'd be pleased to respond to any questions that you may have.

Thank you.

And good morning, Assemblyman Payne.

ASSEMBLYMAN PAYNE: Good morning.

Thank you very much, Deputy Commissioner Wilson.

As I stated earlier, I apologize for having to testify at the Judiciary Committee hearing this morning. They were late starting, and I had to be there, and I appreciate that the hearing was started without me.

(phone rings) And we suggest that anyone who has a cell phone, please turn it off or put it on vibrate or something, or whatever.

As you are fully aware, we have known for several years now that the community is extremely concerned about those folks who are in our institutions, those folks who are most vulnerable in our society. And I'm sure that you and your Department is making every effort to see to it that our people in your charge are really cared for. We have learned of deficiencies in the past, which have caused great concern to many of us; deficiencies which caused, as we know in this case, Danielle's demise. We do know other cases where people, clients, or patients had not been cared for in the manner in which they should.

And I think we have continued to keep a spotlight on this Department and on the care that's being given to those, as I say, who are most vulnerable in our society, and under no circumstances will we relent. We have to make sure that we do not have a repeat of the kinds of things that we've had in the past. And from time to time, I, personally, have been accused of being too dogged about these things. But until we're able to correct all of the deficiencies that exist within our facilities, then I'm going to remain that way. Because as we say, we never know who might be in that situation -- you or I

might be in that situation ourselves at some point. And I want to make sure that we follow the regulation, follow the procedures. If, in fact, we have laws that are passed and regulations are being developed, that we follow that, that we do it in the open, and that we do, in fact -- not after the fact, but before -- take into consideration those kinds of thoughts or opinions or ideas that others may have. In other words, I know that you're going to see to it that we have an open-door policy in that area, because bottom line is that our children and our relatives and, even, ourselves need to be well-cared for.

My concern has been -- and just the other day I participated in a program in Essex County where MICA, where the state Mental Health Association has developed a program -- past 20 years as a matter of fact -- how to train workers who work for the county facilities and departments that are-- How to train them to recognize people who have some kinds of addictions or other problems, etc., and how to handle people like that, for instance. That the employees all -- all of them -- not just the social workers or anything, but all of the employees are being trained to recognize these signs. And it came to me. I said, well, this is rather propitious that I'm hearing that -- on that -- a couple of days ago. Because one of the things that seems to have been lacking in the past with many of our facilities, State- and private-run facilities, is that there has been a lack of training and really significant designation. I know that early on there was some discussion on the part of people who represent the employees that -- how are people going to recognize whether or not this is a true emergency, and what happens if they call in an emergency and it's not really one? What happens to them? I want to assure people that if, in fact -- to err on the side of caution. That no matter what, if, in fact, it appears that there is a situation that

needs immediate attention, that it has to be taken care of. But how does this happens?

It happens with in-depth training. It happens with people being exposed. What the Mental Health Association is doing is having role playing and things like this. So we have to make sure that we have the kind of training that enables a person, a layperson, or whomever, to make this call and be comfortable about making it, not being afraid that they may be reprimanded or they may have, say, some kind of problem later on. So I want to make sure that we do that. And also, very clear that we have a designated person, that makes sure that we identify clearly who that designated person is, so there's no question about it. The bottom line is that all of us are concerned about the care of the people that are in your care and our charges. And you can be sure that we are working to try to make sure that that happens -- that the people are cared for. And if necessary, we will continue to come down very hard on those areas that need to be improved.

With that, I have no more comments to make at this time. And I think that some other Commissioners may have a question or two to you, Commissioner.

MS. WILSON: Thank you.

ASSEMBLYMAN PAYNE: Mr. Cryan.

ASSEMBLYMAN CRYAN: Thanks. Thank you, Chairman.

It's important to recognize, and I want to emphasize, we're in the comment stage. So -- and you've made that clear. But I think everybody should realize that. So we're here to work together to get the best proposed

regulations. And in that vein, I do want to talk to you a little bit about some of the testimony that you gave and some other questions.

But the first thing that comes up, and the comments I've heard from the public and from others is, why not just make it so that people can get on the phone and dial 911? We're going to talk a little bit in a minute about State providers versus private providers, but what is the harm in having someone -- and I did hear your testimony, so I wasn't deaf -- but what is the real harm in having someone dial 911, since calls are routed in a particular area-- The idea of duplicative calls isn't really an issue, because once 911 has been dispatched, there's no -- they manage that themselves. They don't send four ambulances to one house. What is the real -- what is the problem with that, as opposed to trying to go through the staff member and EMT on site (indiscernible)?

MS. WILSON: Thank you, Assemblyman Cryan.

There are two situations in which individuals with developmental disabilities -- actually three -- or traumatic brain injuries live: In the developmental centers within our community provider agencies; and there are individuals that live in skilled family homes, where they are taken care of by a family member; or similar to a foster parent situation, in the communities. First of all, there's no problem in calling 911. We want to assure -- we developed these guidelines to make sure that people are able to know who called 911. If you work in a community setting in a group home, for example, there may be two people on site at the same time providing support and services. In that regard, you do want the person on site to make the call and someone to respond to the individual. So it's not a problem. It's a matter of knowing who made

that phone call. We did allow that guideline to happen for someone to do that.

In the developmental center, we have on-staff physicians, nurses, and other medically trained personnel. Staff do call. And most of the direct care staff are paraprofessional staffs, in most cases. They are the least trained medical staff, and they have available to them, right within that room often, maybe in the next unit, a physician or a nurse. And when they call for the help, that physician or nurse is able to respond and call 911. We are not telling staff not to.

ASSEMBLYMAN CRYAN: Okay. But in the State-run, or the other opportunity we talked about, they have to go through -- they have to notify the person in charge first. Did I misunderstand?

MS. WILSON: No.

ASSEMBLYMAN CRYAN: Okay.

MS. WILSON: In some group homes -- and you're talking community centers, community living arrangements -- there are sometimes one person on call, on site. That person has to call 911. If two of us are in a group home working together, one person calls 911.

ASSEMBLYMAN CRYAN: I got to tell you, I haven't looked at everybody else's testimony, but I'm sure it's going to come up -- the idea of just not having someone be able to dial 911 as opposed to a procedure, I think, is going to come up continually today. And I have to tell you, in all honesty, what's the harm? Pick up the phone if you think there's a problem, notify-- If you have staff on site -- a doctor, a professional, and you clearly laid out here -- still, what's the problem? Get on the phone, dial it, and what's the difference?

And if there's eight calls to 911, besides the fact that maybe it's people who could be doing something else for the brief moment or two, the reality is, if you call a 911 situation and they've already received the call on site, they tell you that and hang up. I mean, for every 911 call I've every made-- Maybe it's different in other parts of the state.

That's one area, I think, we're going to hear a little bit about today. And I have to tell you the truth: looking at the regs, somebody voted for this -- I think it was everybody's intention, in theory, that when we did that it would be a simple phone call and not, quite frankly, an administrative thing that -- I understand why you would come from that, and looking at it, and you talk about training.

I do want to mention a couple of others things and talk about it. One of the things that we have is -- and you were good enough to give us this chart--

MS. WILSON: Yes.

ASSEMBLYMAN CRYAN: --but it talks about the implementation of emergency procedures. And before Danielle's Law, it says, "All programs must have procedures." But then, under "implement emergency procedures," the fourth one down, it says, "When in doubt--"

MS. WILSON: Yes.

ASSEMBLYMAN CRYAN: I mean, why go with when in doubt? Why not just call? Why not just be proactive and call? What's the difference? Can you just expand on that?

MS. WILSON: Assemblyman Cryan, you're right. There's no harm in making a call to 911. A lot of our agencies in the community, in terms of

their settings, may have five, maybe six or seven staff members on site working with people. And at the same time, all five or seven people would dial 911, when, in fact, there is someone there to dial 911. And you do say, "Did you call 911?" and use that communication. So it's not harm. And I do believe, and as I said in my testimony, it's an issue of clarity, because we have allowed, in the rule, organizations to make sure it doesn't become complex.

ASSEMBLYMAN CRYAN: So we can work within the regs in this comment period to clarify?

MS. WILSON: Absolutely. That is our intent.

ASSEMBLYMAN CRYAN: And I think its the purpose of the hearing, as well, right?

MS. WILSON: Correct. We were not trying to make this difficult. We were allowing for organizations to have many different settings, in terms of day programs and group homes in the community, to be able to organize the approach and to ensure that we don't risk the safety of individuals.

ASSEMBLYMAN CRYAN: A couple of other things -- the Do Not Resuscitate. Can you expand on that a little bit, in terms of what you believe the law is and what the regs are and what the issue is? Can you or--

MS. WILSON: I was going to ask Jim Evanochko to do that thing.

ASSEMBLYMAN CRYAN: Hi, Jim.

**JAMES EVANOCHKO:** Good morning, Assemblyman.

The position with regard to the Do Not Resuscitate order, we sought guidance from the Office of the Attorney General. And what we were advised was that even though there is a Do Not Resuscitate order, it doesn't relieve us from making a 911 call. And what we should be doing, and we can

add this to the regulation, is that we can direct staff to provide a copy of that Do Not Resuscitate order to the emergency staff responding, and they can then decide how they will treat.

ASSEMBLYMAN CRYAN: So we've agreed here that what we're going to do, or we're going to make sure that the regulations are clear, is that the call is made, which is the intention of the bill. And then we'll let the EMTs or the folks that are there make that decision, and we'll provide them with that? Is that correct?

MR. EVANOCHKO: Precisely.

ASSEMBLYMAN CRYAN: Okay, makes sense.

The last thing I wanted to ask about was the -- on this training -- the fact sheet for Danielle's Law?

MS. WILSON: Yes.

ASSEMBLYMAN CRYAN: It just raises some questions with me. It's dated April 23, so it's a little-- But one of the things is, it lays out for those that may not have seen it, things like-- It tells providers when to call. And it says things like, "If the person is unresponsive to pain or stimuli, they should call." And it lays out some pretty -- "There's a weak pulse or no pulse." I am concerned a little bit that there's -- it sounds a little simplistic, but there's nothing here that says, "or in good common sense." Because it lays out very specific things, and I'd never want somebody to say, "Well, it wasn't on the list." I mean, that to me -- which leads me as well as to -- when I read that, Terry, I got to tell you -- what the reality is, what I say to myself is, do we really need training on this and are people trained well if we have to provide a fact

sheet? I mean, that's kind of the question that comes to me, and I was hoping you could comment on that.

MS. WILSON: Thank you. I would like to comment on that.

Actually, yes we do need to train people. As Assemblyman Payne said, there is an issue of training. We hire the best possible staff. But sometimes everyone's common sense is different, so we have to make sure that everyone knows what we expect in terms of emergency services, in terms of providing services to individuals with developmental disabilities. So we do have to go through what seems to be common sense. We have to train, and we have to make sure that agencies certify to our Department that everyone has been trained. It's important. We need to know, also, as well, when we look at individuals, what training gaps there are and make sure people understand the latest. And to call 911 is common sense, but everyone sometimes doesn't.

ASSEMBLYMAN CRYAN: Through the Chair, just to finish this last thing, and that's it for me. If you could add something here, I'd request if you would consider adding something where there's a more inclusive-- I'd hate to have somebody ever look and say, "It wasn't on the list." I mean, that to me just seems-- If you could prevent that, I would appreciate it, through the Chair.

MS. WILSON: Right. And I believe that list also says it's not limited to.

ASSEMBLYMAN CRYAN: It does.

MS. WILSON: Okay.

ASSEMBLYMAN PAYNE: Thank you, Mr. Cryan.

Mr. Fisher.

ASSEMBLYMAN FISHER: Thank you.

My question relates to when you say *staff members*. Are we talking about all staff? In other words, from the cleaning person who comes on site, or are we talking only about the registered caregivers?

MS. WILSON: My understanding when we look at the law, it does speak directly to direct care staff. So, in the case of your question, a housekeeper, maintenance, are not direct care staff. We're talking about those individuals that actually provide direct services to the developmental disabled population.

ASSEMBLYMAN FISHER: Thank you.

The reason I'm asking that question is, I'm a service worker. And I come into a room and I see someone who is obviously -- good common sense would tell that person that this person is struggling for their life -- are they empowered to be able to just call 911?

MS. WILSON: They're not empowered to call 911. But to comply with the law, it does speak to direct care staff. However, we all are accountable to call 911.

ASSEMBLYMAN FISHER: So is it permissible?

MS. WILSON: It is permissible. And I do want to also add that when you're in our developmental centers, all people that are served are served by direct care staff. A maintenance worker, for example, would not be alone in the facility with one of our consumers.

ASSEMBLYMAN FISHER: That -- you could positively say that?

MS. WILSON: It's required.

ASSEMBLYMAN FISHER: Why I'm asking you is -- I've been in institutions where there are service workers, and I know you're saying that

someone is supposed to be there from staff. But I also know that many times institutions and other care facilities, for whatever reason, even though statutorily they're supposed to have a certain complement of people and a certain number of people on duty -- but sometimes it just doesn't make it, even though -- and they're basically in violation.

So what I'm asking you is, just-- So I am -- and maybe I'm belaboring this, but I'm a service person. I come in there and someone is, as I said, obviously in deep trouble. That person on staff is told to call a registered person that is a caregiver to tell that person, who has to tell the emergency person on duty to make that call?

MS. WILSON: I understand the confusion there. All staff, when they begin in the developmental center, are trained in emergency procedures, including calling 911. My understanding in the law is that it applies to direct care staff, so we wrote our regs in compliance with direct care staff. However, we currently, and even prior to Danielle's Law, require all of our staff working in all of our facilities, whether it's a developmental center or community agency -- on emergency procedures.

ASSEMBLYMAN FISHER: So they're trained in emergency procedures, but not necessarily empowered to be able to make the call?

MS. WILSON: No. They will be empowered to make the call. If, in your example, I am a maintenance worker, and I am in the room with someone, and I'm the only one there, I'm going to call 911. They are trained to call. They always have been.

ASSEMBLYMAN FISHER: Okay.

MS. WILSON: We wrote the rules to comply with the law.

ASSEMBLYMAN FISHER: Okay, but that's all for now.

Thank you. Thank you.

ASSEMBLYMAN PAYNE: Mr. Fisher, you have additional--

ASSEMBLYMAN FISHER: Apparently not, not right now.

ASSEMBLYMAN PAYNE: Okay.

ASSEMBLYMAN FISHER: Thank you, Chairman.

ASSEMBLYMAN PAYNE: Thank you.

Assemblywoman Myers.

ASSEMBLYWOMAN MYERS: Thank you.

Good morning.

Let's go a little bit further to define this direct care staff. Can you give me an idea of how much money these people make?

MS. WILSON: Yes. Direct care staff are generally some of our lowest paid staff members. They're in the range of, say, \$23,000 and -- \$23,000 to \$27,000 a year.

ASSEMBLYWOMAN MYERS: Okay. And are there educational requirements for direct care staff?

MS. WILSON: Yes, there is educational requirements for direct care staff. It's currently a high school diploma or the equivalent, a GED, experience, and, perhaps, serving the developmentally disabled population.

ASSEMBLYWOMAN MYERS: They are required to have experience?

MS. WILSON: It can be substituted for some education.

ASSEMBLYWOMAN MYERS: Oh--

MS. WILSON: Yes.

ASSEMBLYWOMAN MYERS: --substituted for a high school diploma?

MS. WILSON: Yes. It has been considered.

ASSEMBLYWOMAN MYERS: And these people provide primarily custodial care -- bathing, turning, making beds -- that sort of thing?

MS. WILSON: They do provide custodial care, but we provide treatment and services within our developmental centers. And it's more than custodial care. But because of the nature of many individuals in a developmental center, some of their primary needs are the feeding, the bathing, and clothing of the individuals. But they also provide support in terms of recreation and social activities, and activities of daily living, skill learning.

ASSEMBLYWOMAN MYERS: Okay, but no medical treatment?

MS. WILSON: No medical treatment.

ASSEMBLYWOMAN MYERS: Okay. You stated in your written testimony that you had recently completed an analysis of the first three months of the law and had found that this analysis demonstrated that the law was being followed. Do you have any kind of report on this analysis for this Committee?

MS. WILSON: I wanted to bring that, actually, and I would be happy to provide that report, through the Chair, but I don't have it with me. They're still, kind of, going through it. But I did look at the preliminary information on the calls that come in that related to 911. We do, through the Department, have an incident review system. So we review each incident that's submitted to us and make sure that everyone was in compliance. It takes a lot of time to go through it, and we are in the first stages of reviewing that data. But if you'd like, I would be happy to present a report, through the Chair.

ASSEMBLYWOMAN MYERS: Through the Chair.

And from your review of this, have you seen a change in practice across the facilities? Are there more calls to 911, or are there more confusion about who should call? I mean, can you give us a general idea of what the analysis showed?

MS. WILSON: Yes. I can tell you there is more reporting to the Department of Human Services on calls to 911. And I do believe, when the law took effect, there certainly is a concern for many nonmedically trained professionals, that if they don't call 911, they will be penalized financially, significantly, for not calling 911. So they are calling 911 in fear more than anything else, and we do get those reports.

We also recognize that, at this moment, I don't see an increase in terms of people that have not called 911 in the past and should have. But people are making more -- they're afraid.

ASSEMBLYWOMAN MYERS: Thank you, Mr. Chairman. That's one of my concerns. Certainly we all want to be sure that people are properly taken care of, but it occurs to me that if someone calls 911, there's really no downside. And if someone doesn't, there could be a horrible downside. I mean, yes, indeed, someone could die, could suffer ill effects, or -- and get sued and get fired and on, and on, and on. And I know that there are problems in the health care field of recruiting people for these kinds of jobs, and I am concerned that we will create a climate, if we are not careful, where it will be even more difficult to get people to fill these jobs. And there are really caring people who want to do this work, who may out of fear not do the work. So I think we have to tread a very, very fine line here.

I know, just thinking back of myself and what I would do -- I raised three children. I worked in hospitals for about five years, so I have a little bit of background in nursing and medicine. And I can recall one time when my daughter, who couldn't have been 2 -- she was probably almost 2 -- was in her high chair screaming and not moving her whole right side. And I thought her arm must have gotten broken or something must have happened, because she was just screeching and not moving. So we got her to the emergency room, and she got in the middle of the examining table and the arm was moving, and she was just smiling and talking and carrying on. And there was nothing at all wrong with this child's arm. And there were other times when I agonized with a child with a croup in the middle of the night, thinking, "Oh, my God, do I rush this kid out or do I continue to hold them in the shower with the steam?"

We are talking about people who have a very low level of education and awareness, making decisions that doctors often have trouble making. I mean, certainly, we've all been in the situation where our doctor misdiagnosed something. It happens. And when we're talking about recognizing serious things, I think we have to be careful about where we're putting this burden. And if there can be procedures where there is a designated person right there that can be called in quickly, it seems to me that there is an argument to be made to allow that and not expect these low-level workers to make these judgments by themselves. And then also create a situation where you're calling in volunteer emergency squads.

I live in a rural area. We have volunteers for the most part, and you're talking about, "Oh, who cares if we call 911." Well, they're mostly people at night who are going to get out of the bed and spend the night

responding to this call and -- then Hunterdon County has a developmental center in our county. And we've already had some concerns with other State institutions, that I'm aware of, with the local volunteer squads. And certainly we want them to be called if there's any real doubt, but I am sympathetic to both sides of this. I'd appreciate any analysis that you have.

Thank you.

MS. WILSON: Certainly.

ASSEMBLYMAN PAYNE: Yes. I concur with the Assemblywoman. However, my thing is that, as we mentioned before, the training is extremely important. And even though these people, many of whom are -- have -- what -- limited education? What do you say, high school or equivalent thereof? They don't have to have high school diplomas or things like that?

MS. WILSON: They are paraprofessional staff members without college education.

ASSEMBLYMAN PAYNE: What do they have? High school education?

MS. WILSON: Mostly high school diplomas or the equivalent.

ASSEMBLYMAN PAYNE: And some, because they have, doesn't necessarily mean they don't have common sense, etc., or can be trained.

MS. WILSON: Yes.

ASSEMBLYMAN PAYNE: The point -- I think I would err on the side of caution. I would err on calling. I would want to make sure that these people are not fearful of reprimands, and that they will not be reluctant to make the call because they're afraid of something else. So the training is extremely

important. The training is very, very important, so they can recognize these things. But also, the training will tell them that you do not worry about making a mistake, if it's an honest mistake. Okay? Because people, first of all, as it's pointed out, they're averaging \$20,000 a year, \$9 an hour, whatever it is. It's too low, which is another issue that we need to deal with at some other time. We need to talk about people who provide this kind of service being paid so low, it doesn't make any sense.

But, again, must stress that if we make two bad calls and one good one, then it's worth it. All right? But the training -- I think part of the training has to be that if people have to be -- have to understand that they're not going to be reprimanded, fired, or penalized if, in fact, they make a mistake. I think if we dispel or get that out of their minds and then we train them how to recognize these things, I think that will go a long way in resolving this problem. But we don't need to have implanted in their minds, "If you make the call, you might get in trouble," or their unions say that we don't want them doing-- The training is key, and I suppose that has to be evaluated. Maybe the mental health players or whomever else is doing this stuff can help us in doing -- providing the adequate training that we need.

Let me just ask -- how many facilities do we-- We mentioned a private facility group. How many State-run facilities are there that are developmentally disabled centers?

MS. WILSON: We have seven developmental centers across the state.

ASSEMBLYMAN PAYNE: Seven State-run?

MS. WILSON: Yes.

ASSEMBLYMAN PAYNE: And what about the private ones or whatever?

MS. WILSON: About 2,000 programs.

ASSEMBLYMAN PAYNE: Two thousand programs. But I'm talking about the facilities, let's say, residential or what facilities? I mean, you say there's seven State-run-- Let me ask you, are State-run facilities a house with two people, three people -- or what are they?

MS. WILSON: No. The State-run developmental centers -- you may be familiar with. We have Hunterdon Developmental Center, North Jersey. We have anywhere from 600 people-plus at a developmental center, to the example of Greenbrook Developmental Center with about 200 people in it.

ASSEMBLYMAN PAYNE: Okay, all right.

I'm asking, now, for a comparable -- in the private sector-- I mean, I'm not talking about housing or whatnot--

MS. WILSON: Yes.

ASSEMBLYMAN PAYNE: Those that may have the 100, 250, or whatever. Fifty on up, I don't think there's thousands of those, are there?

MS. WILSON: No.

ASSEMBLYMAN PAYNE: Okay. Well, that's what I'm looking -- I'm looking--

MS. WILSON: There's nothing comparable to a developmental center in the community. These are-- Developmental centers, Assemblyman, as you know, are large facilities. In the community, we want individuals to look like they live like you and I do, so they're in group homes.

ASSEMBLYMAN PAYNE: Where's Bancroft? Is that a developmental center?

MS. WILSON: No, it is not.

ASSEMBLYMAN PAYNE: What is that?

MS. WILSON: That's a private, residential health-care facility.

ASSEMBLYMAN PAYNE: Which has X numbers of people?

MS. WILSON: Yes. The Department of Health and Senior Services actually licenses them, and we license, at the Department of Human Services, their community-based programs.

ASSEMBLYMAN PAYNE: All right. Then maybe I'm asking the wrong question. How many licensed facilities, similar to the one I just mentioned, are there in the state that we license? I'm sure there must be -- maybe there are some that are larger than--

MS. WILSON: I'm sorry, Assemblyman, do you mean that are equivalent to a Bancroft or--

ASSEMBLYMAN PAYNE: Similar to that. Yes, sure.

MS. WILSON: We have four private, residential health-care facilities.

ASSEMBLYMAN PAYNE: All right. Okay. Sure. That's what I'm trying to ask for. What are their names? What are their names? Do you know them offhand?

MS. WILSON: I think I do. Obviously, Bancroft, Keystone, St. Joe's School for the Blind, and Eastern Christian Residential Healthcare Facility.

ASSEMBLYMAN PAYNE: They would also be regulated by Danielle's Law and 911?

MS. WILSON: Everyone is.

ASSEMBLYMAN PAYNE: They would also be regulated by 911?

MS. WILSON: Yes.

ASSEMBLYMAN PAYNE: Okay. All Right. So there are seven State-run facilities with a population of up to 600?

MS. WILSON: Anywhere ranging from 200 individuals to over 600 individuals.

ASSEMBLYMAN PAYNE: And the four private facilities, what are their populations?

MS. WILSON: I would be able to provide you that information, Assemblyman. I don't have it off the top of my head, their numbers.

ASSEMBLYMAN PAYNE: Keystone, maybe 10 people or 100 people?

MS. WILSON: Oh, no. They have many programs. They probably have hundreds of people in there.

ASSEMBLYMAN PAYNE: And these are residential?

MS. WILSON: Yes. Somewhere in the neighborhood of 100.

ASSEMBLYMAN PAYNE: So combined -- of those four that you mentioned -- they are what? Can you give me a figure? In other words, the State contracted these people, I suppose. Do we have any idea of how many we were contracting for?

MS. WILSON: Well, yes. We have approximately 3,000 people in licensed facilities, from the Department of Human Services and/or licensed by the Department of Health and Senior Services.

ASSEMBLYMAN PAYNE: That's these four plus--

MS. WILSON: Plus community group homes, apartments.

ASSEMBLYMAN PAYNE: Community group homes may have three people, four people?

MS. WILSON: Right.

ASSEMBLYMAN PAYNE: Up to 10, maybe?

MS. WILSON: No. Group homes are less than five people.

ASSEMBLYMAN PAYNE: All right. Fine. I just want to get an idea of what we have, all right?

MS. WILSON: I understand.

ASSEMBLYMAN PAYNE: And with the seven State-run facilities, how many people, how many folks do we have there in those seven?

MS. WILSON: Somewhere in the neighborhood of--

MR. EVANOCHKO: About 3,000.

MS. WILSON: --about 3,000-plus.

ASSEMBLYMAN PAYNE: Okay. I just want to make sure that all these people are covered.

MS. WILSON: Everyone is covered.

ASSEMBLYMAN PAYNE: I just want to get an understanding, for instance, when we say, when I asked the question, do we say there's thousands of these places. That's not -- I guess I was asking the wrong question. So all of them will be trained?

MS. WILSON: All facilities, whether they're private, nonprofit, or public agencies and our State-operated facilities -- they all are required to be trained.

ASSEMBLYMAN PAYNE: We will do the training? Will the State do the training for these private facilities as well? Who will do the training to make sure that it's kind of uniform?

MS. WILSON: For the private facilities?

ASSEMBLYMAN PAYNE: Yes.

MS. WILSON: For the private facilities, we require the agencies to do the training to utilize CPR training, the American Red Cross training. But the State of New Jersey does not do it. We require the agencies to submit to us and certify to us that everyone has been trained in the proper procedures.

ASSEMBLYMAN PAYNE: And we monitor that very, very closely?

MS. WILSON: We monitor, and your license to operate depends on that.

ASSEMBLYMAN PAYNE: Thank you.

ASSEMBLYMAN CRYAN: Can I ask one more question?

ASSEMBLYMAN PAYNE: Sure.

Mr. Cryan.

ASSEMBLYMAN CRYAN: Terry, can you just, for a sense of context, the three months of the 911 that you looked at, how many calls are we talking about here? I recognize that there's a difference -- you may not agree -- but there's a difference between State and other, but how many calls did you -- are analyzed?

MS. WILSON: I'm being told 462.

ASSEMBLYMAN CRYAN: Good job, 462. You don't happen to know, which may be a little unfair, the difference between State, which has the screening, or the--

MS. WILSON: We can provide you that information. I can give you that breakdown, through the Chair.

ASSEMBLYMAN CRYAN: But you're comfortable that statewide we received four hundred sixty-two 911 calls. And if I understood you correctly, that's not really an increase from previous time periods, is that correct?

MS. WILSON: Those are some of the details that I'm actually drilling down to. Because, in fact, I believe that because of 911 law, people are reporting it more, that they're calling 911. So I need to be able to really drill down into what's going on and what the number of calls mean. So I'm not really comfortable, and kind of going out there.

ASSEMBLYMAN CRYAN: And I appreciate that. But I do have to tell you, I would much rather have an extra 911 call than-- If they're volunteers and they don't want to get up, that's their issue. But I'd just assume have people respond and be there on that issue, because I know people take their time to do that.

All right, thanks.

ASSEMBLYMAN PAYNE: Thank you, Mr. Cryan.

At some future time, could you give us the breakdown? For instance, 462 calls were made. What were the results? I'd like to know whether or not there were calls, useful calls, or -- were they, in fact, were emergency? I

would really like to have an analysis of those calls that were made, to find out just where we're going with that.

MS. WILSON: It would be my pleasure to provide that information.

ASSEMBLYMAN PAYNE: Thank you.

Thank you very much.

And there are no other questions for you, Commissioner. We appreciate your testimony this morning.

Thank you.

MS. WILSON: Thank you.

ASSEMBLYMAN PAYNE: We have a number of other folks who have signed up. However, if you don't mind, I would like to invite Senator Kean to please make his presentation now, if that's okay with everyone.

Senator.

**SENATOR THOMAS H. KEAN JR.:** Thank you.

ASSEMBLYMAN PAYNE: You could always say no. I'll let everybody else go first, because I don't know. That's up to you. (laughter)

SENATOR KEAN: I'm glad I'm facing this way, all right, and, therefore, I'll be brief.

Thank you, Mr. Chairman, Mr. Vice Chairman, members of the Committee. I think it's wonderful that we're having an Oversight hearing, and I think we need to continue to use this as a model to go forward and to ensure that any administration, Republican or Democrat, is fulfilling the will of the Legislature and of the Governor when that Governor signs the law.

I am here today, very briefly, because I was the original Senate prime sponsor of Danielle's Law. And I was pleased to be the prime sponsor, along with Eric Munoz and Guy Gregg, and Joe Vitale in the State Senate. The purpose of Danielle's Law was very simple. It was actually encouraged -- it actually would require 911 being activated for life-threatening emergencies, as it was not activated when Danielle was in trouble. And I think the issue we need to have is a very simple concept. People should activate 911 and be more biased toward activating 911 than not activating.

I serve as a member of the Westfield Rescue Squad, as a volunteer as well, and we prefer to be activated rather than not activated when there is even a potential of a life-threatening emergency. And I think that in my discussions in pushing this -- and this thing passed the Legislature unanimously. And in my conversations with former Commissioner Kroll, there's a very clear understanding that this was to ensure that the system would, indeed, be activated to ensure we would not have tragedies like we did before and going further.

As you noted, Mr. Chairman and Mr. Vice Chairman, the training is a very important aspect of this, to ensure that people -- that the best possible training is put forth. And now it's being served as a model for a national proposal on Danielle's Law. Congressman Rush Holt, who represents a big chunk of New Jersey as well, I think is going to be introducing this on a Federal level, using what the State has done.

So I want to applaud you, Mr. Chairman, Mr. Vice Chairman, and members of the Committee, for being passionate enough about this issue and ensuring that during the comment period that we have a possibility for the

Legislature to reexamine and reemphasize our intent, which I don't think -- in regards to the procedural aspects, nor the statement regarding the need not to contact 911 in certain circumstances, nor aspects of the applicability of the regulations -- meet the intent of the unanimous vote in the Legislature and the signing of it by the Governor to ensure that-- And in the end, we need to make sure that the most vulnerable citizens in our society are, indeed -- get and receive the protection that they deserve.

I want to thank you for going out of order, and I appreciate your time and your insights in this endeavor.

ASSEMBLYMAN PAYNE: Thank you, Senator Kean.

Is there anyone on the panel that has a question?

Assemblywoman Myers.

ASSEMBLYWOMAN MYERS: Yes.

You mentioned Commissioner Kroll, and I just didn't understand the reference to Commissioner Kroll.

SENATOR KEAN: Yes. Commissioner Kroll is the former Commissioner of Labor. There was an aspect of labor applicability in this regard, because there are various regulations going forward. And I just had a conversation with Commissioner Kroll, and former Commissioner of HHS, and a variety of the other commissioners. Commissioner Kroll was one of the people that had comments. I want to emphasize that this is an issue to which we had discussions across various departments, even though the final regulatory authority comes under now-Commissioner Davy's purview. This is an issue that had impact that a number of commissioners, in addition to members of the

Governor's Counsel office, the Attorney General, the Governor himself, as they were examining whether to support CB or veto it--

ASSEMBLYWOMAN MYERS: But my question is, do the employees who work in the group homes, where this problem with Danielle occurred, come under the Commissioner of Labor?

SENATOR KEAN: There are aspects where -- there are some regulatory aspects that do come under the Commissioner of Labor, is my understanding. And so that's why we had those discussions. And if you recall, the law passed -- or the bill passed both Houses of the Legislature and then took months before it was signed by the Governor. And during that period of time, there was a number of conversations to ensure that the intent of the Legislature was understood by this administration and we were going forward. And then the Governor had a bill-signing ceremony that was -- I think he was very clear on his statements at that juncture, which had a whole slew of the sponsors and everything else, that this was going to require 911, and also to encourage, if there's any question at all, that the 911 system is actually activated. And again, as a member of the Rescue Squad, but as well as, I think, a citizen, I think we'd rather have that system activated more than less in any personal circumstances at all.

ASSEMBLYMAN PAYNE: Thank you for clarifying that.

Assemblywoman Myers, any further questions? (no response)

Thank you, Senator.

SENATOR KEAN: Thank you, Mr. Chairman. And thank you to all of you.

ASSEMBLYMAN PAYNE: Our next person signed up to speak is Diane Gruskowski, Danielle's mother, with The Family Alliance to Stop Abuse. And they'll speak all together -- Douglas Gruskowski, brother; Robin Turner.

**DIANE GRUSKOWSKI:** Good morning, Honorable Assemblymen, Assemblywoman. My name is Diane Gruskowski. I'm honored to be Danielle's mom.

I want to express my gratitude to everyone that has gathered here today to discuss the proposed rules for Danielle's Law. My daughter, Danielle, was a beautiful 32-year-old young lady that brought joy and happiness into the hearts of many people. Danielle was loved very much. Danielle was my daughter, my pride and joy. God sent me one of his special angels to love and care for, and I welcomed her with open arms. Not many people can say that they were as blessed as I was.

My daughter Danielle was the inspiration for Danielle's Law. Danielle's Law requires that staff working directly with people with developmental disabilities or traumatic brain injury -- to call 911 telephone emergency services in life-threatening emergencies. With the wisdom of our legislators, June of 2003 the Senate and the Assembly unanimously passed Danielle's Law.

On October 26, 2003, Governor James McGreevey said, "Today, in memory of Danielle Gruskowski, we are establishing Danielle's Law, a law that will serve our most vulnerable -- speaking loudly for those who cannot always speak for themselves. Thirty-two-year-old Danielle died in the hands of caregivers who failed to get her proper medical treatment at a time when she

needed it most. No parent was there to save her. No law was there to protect her.” But now we have Danielle’s Law, a commonsense law.

On September 7, 2004, almost one year after the Governor signed Danielle’s Law, the proposed rules have come out. The rules proposed by the Department of Human Services have nothing in common with Danielle’s Law. The rules do not protect our most vulnerable children. What was the purpose of Danielle’s Law if nothing has changed? Under these rules, no one is accountable, lives will still be lost, and direct care staff still will not be required to call 911. This was not the intent of Danielle’s Law. We have an obligation to care for those who cannot care for themselves. We can take a tragedy and turn it into a safeguard and a protection. That is what Danielle’s Law was meant to do.

One of the major loopholes in the proposed rules state that if a staff member is unsure whether a medical condition, such as an elevated temperature, seizure, or other condition, has become a life-threatening emergency, a rebuttal presumption that the staff member has complied with Danielle’s Law -- they have also complied with the requirement to call 911 in a life-threatening emergency -- will be created if the staff member:

One, immediately contacted a medical professional. In Danielle’s case, the direct care staff contacted the facility’s designated person, who was off-site, who instructed her to call the facility’s medical professional, a registered nurse.

Two, conveyed to the medical professional the medical history and present symptoms. The direct care staff working with Danielle contacted the facility’s registered nurse at home. When the direct care staff working with

Danielle conveyed to the off-site medical professional, a registered nurse, that Danielle was having difficulty breathing, the registered nurse informed the direct care staff to give Danielle nose drops. The direct care staff immediately followed those directions. The registered nurse did not call 911 and did not instruct the direct care staff to call 911. By the time the Spectrum for Living registered nurse arrived at the facility the following morning, Danielle had been experiencing difficulty breathing for more than 14 hours. The registered nurse called Danielle's physician, another medical professional. She called the physician because she knew Danielle was having difficulty. Danielle was having difficulty breathing. When she called the physician, the nurse, told Danielle was having difficulty breathing -- the registered nurse, the medical professional -- said negative, that she was not having difficulty breathing. This was per documented evidence. Now, the registered nurse gave incorrect information that delayed urgent medical treatment that my daughter, Danielle, so desperately needed, and my daughter died. My daughter could not hold on any longer. Too much time elapsed to get her help. If the registered nurse had given the correct information, the physician would have instructed the registered nurse to call 911. Because the correct information was not given, Danielle's physician failed to recognize the seriousness of Danielle's condition, and still no 911 was called.

My daughter, Danielle, was a nonverbal, nonambulatory individual who needed 24-hour care. Documented evidence reports that Danielle had difficulty breathing for over 14 hours, difficulty swallowing her liquid medication, crying, a temperature of 105 degrees on the morning of her death. Her clothes were changed twice in the middle of the night due to sweating.

What other signs were they looking for? All documented reports state that Danielle had difficulty breathing.

Three, Obtain directions from the medical professional as to whether to call 911, and--

Four, Immediately followed the medical professional's direction.

The direct staff obtained direction from the registered nurse and followed the registered nurse's direction to give Danielle nose drops. Danielle's condition was much more serious than nose drops.

Fourteen hours later, the Spectrum registered nurse gave incorrect symptoms to Danielle's physician by informing the physician that Danielle did not have difficulty breathing, resulting in so much valuable time lost and resulting in Danielle's death. If the registered nurse had informed the physician correctly, based on the symptoms, the physician would have informed the registered nurse to call 911 immediately. I am pointing this out because two medical professionals were involved and still no 911 was ever called. This only goes to prove that this method does not work. It serves as a blueprint of how Danielle died; they took this incident and created the proposed rules.

The proposed rules are causing too much confusion and panic. You need a simple procedure. When in doubt, call 911. The first intuition about the situation is usually the correct one.

In Danielle's case, why did the overnight direct care staff, that was on duty, call the off-site supervisor? Because her intuition told her that there was a health problem. If there hadn't been an internal protocol, my belief is that Danielle would still be alive today.

Based on the proposed rules and regulations for Danielle's Law, how do you differentiate between medical professional, staff member who can provide immediate assistance, and designated staff? Three different terms used in this document.

The proposed rules and regulations for Danielle's Law appear to be written to protect the provider agencies and facilities from writing too many incident reports. And this violates the intent of Danielle's Law -- no one is held accountable. We need the Department of Human Services to take a stand and protect the clients they serve. The proposed rules and regulations for Danielle's Law indicate too many layers of things to do before direct care staff can satisfy the internal protocol requirement to make that 911 call in a life-threatening emergency. If we trust the staff working directly with our precious children, then why can't we trust them to use their judgment and make a call to 911 in a life-threatening emergency?

The part that is most painful for me and my family is that Danielle did not die from any of her disabilities. Danielle's life could have been saved if her direct caregiver was allowed to call 911, rather than call the facility's designated person, who was off-site, then directed to call the facility's medical professional, who was also off-site, when all along the caregiver knew how serious the situation was. But she had to follow the facility's protocol and a precious life was lost.

Let's keep it simple. When in doubt, call 911. Please continue to be a voice for our voiceless.

I would just like to take this opportunity to express a heartfelt thank you to The Family Alliance to Stop Abuse and Neglect for their tireless

efforts to keep our helpless and vulnerable children safe -- a group that has been very instrumental in the passage of Danielle's Law, which I am very proud to be a member.

I would like to thank you all very much and everyone here in the room. And God bless you all. Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Ms. Gruskowski.

Robin, do you have testimony? Fine. Robin Turner. Identify yourself for the record?

**ROBIN M. TURNER:** Robin Turner, and I would like to say good morning to the Honorable Assemblymen and Assemblywoman and everyone else here.

My name is Robin Turner. I am Danielle's aunt, guardian, and her advocate, as well as being a steering member of The Family Alliance to Stop Abuse and Neglect. Thank you very much for calling this important meeting to discuss the proposed rules for Danielle's Law.

Many New Jersey citizens all over the state have worked tirelessly to ensure that people with developmental disabilities and traumatic brain injury are protected and safeguarded in life-threatening emergencies, especially the helpless and the voiceless, like my niece Danielle.

On October 26, 2003, Governor James E. McGreevey signed Danielle's Law, which simply states, "A member of the staff at a public or private agency, who works directly with persons with developmental disabilities or traumatic brain injury, shall be required to call 911 in a life-threatening emergency." It sounds so simple.

Why is the Department of Human Services making a simple procedure, that any prudent person would do, so difficult by not allowing all direct care staff to make the call to 911 in a life-threatening emergency, which this law was intended and that Governor McGreevey signed? A person who is not prudent should not be working and caring for vulnerable, disabled people. Our children are human beings. Would a preschool, middle school, or high school hire a person who lacked prudence to work with their children? And by the way, the definition of prudent is practical, careful and sensible.

I would like to point out to you one of the many loopholes contained in the proposed rules for Danielle's Law. The proposed rules require facilities to adopt one of two procedures to require that a 911 call be made in the event of a life-threatening emergency. The choices that are given in the proposed rules for Danielle's Law are as follows:

Number one, require staff who work directly with people with developmental disabilities or traumatic brain injury to call 911 in the event of a life-threatening emergency. Or, number two, designate an on-site staff member to call 911 in the event of a life-threatening emergency. There should be no choice to make. Staff working directly with persons with developmental disabilities or traumatic brain injury must be required to call 911 in a life-threatening emergency. If staff working with Danielle had made the call, Danielle would be alive today.

In any life-threatening situation, people panic. Any emergency is scary, and often people cannot think straight. In certain types of emergencies, time is of the essence. A diagnosis must be made quickly by a qualified 911 dispatcher, otherwise someone may not live.

According to Capital Health Systems, an organization that teaches and trains 911 dispatchers, “breathing problems should always be considered a high-level emergency.” Danielle experienced difficulty breathing for over 14 hours, as per documented evidence, and no one at the facility called 911 to save her. There should be no question or confusion to call 911. Once the call is made, a dispatcher has a protocol to follow. It includes the dispatcher asking the caller, “Are you willing to provide care? I will walk you through it.” At that point, the direct care staff will answer, yes or no. This is called prearrival instructions. If anything, the call to 911 gives the direct care staff a sense of relief that help is on its way.

If the 911 call is a medical call, the 911 dispatcher will be able to give instructions on what to do to help the patient until EMS personnel get on the scene.

For example, if a client is bleeding, the dispatcher will instruct the direct care staff to take a clean cloth and place it over the wound, applying pressure. If the client is not breathing, the 911 dispatcher will give instructions on how to do rescue breathing. If the client is in cardiac arrest, they will give CPR instructions. Other instructions could be: get the medications ready that the client takes for EMS personnel to see, or to provide the DNR certificate.

Another major loophole in the proposed rules is, “Oh-I-thought-you-called -- no-I-thought-you-called syndrome.” The proposed rules state that a staff member need not call 911 if the staff member has a reasonable basis to believe that another staff member has already called 911 about the life-threatening emergency.

In other words, Assemblyman Cryan, if you and I were the caregivers and Assemblyman Cryan was in a life-threatening emergency, and I thought that you called 911 and you thought that I called 911 -- and then something happens to Assemblyman Cryan and he passes away, we've complied with Danielle's Law. We've actually complied with Danielle's Law, because we thought each other called. I mean, totally ridiculous. You can comply with Danielle's Law and never make the call to 911. This shameful loophole totally invalidates Danielle's Law and holds no one accountable. This proposed rule will only cause chaos and confusion. More than one person can call 911.

Nine-one-one has a computer-aided dispatch. If their center receives a duplicate 911 call for the same emergency, the computers get flagged, which alerts all the dispatchers that this call already came in. The second caller will be informed that 911 received the call and we are in route. 911 keeps track of calls and will tell the caller that this call has already been placed. This is done all the time. This is standard practice -- 911 have protocols in place to address issues such as these. This should not be an issue for the Department of Human Services. Perhaps the Department of Human Services did not do their homework.

An example of this would be if there was a major car accident on one of our highways. People who own cell phones feel it is their duty and responsibility to call 911. Fifty people call 911 for the same accident. Do you seriously think that the 911 dispatch will send 50 ambulances? Or if a house is on fire down the block, should I assume that my next door neighbor called so I don't have to call?

Why is there an excuse for direct care staff not to call anyway? It is quite obvious that these rules were heavily influenced by the provider agencies and unions. Even by their own admission at the budget hearing, the Department of Human Services said that the provider agencies and the unions were contacted. Excuse me for a moment. Thank you.

Why are internal protocols superseding the State laws? Internal protocols should be created and revised from the State laws. The Department of Human Services is undermining the unanimous decision that came from our Honorable New Jersey Assembly and Senators. It was unanimous because people like you saw the need for such a law, for direct care staff to dial 911 in a life-threatening emergency. When Danielle's facility where she lived followed their internal protocol, Danielle died. It didn't work. The proposed rules and regulations set forth here just perpetuate the same weak policies. The proposed rules are not protecting our weakest individuals. The abuse, neglect, and deaths will continue.

Senator Vitale, a prime sponsor of the bill, said on television, "The problem is that these facilities have an internal procedure that prevents direct care from calling 911." That is why Danielle's Law was written, to remedy this problem. Staff working directly must make the call to 911, and this must be uniform to prevent confusion.

Another catch word -- designated staff -- does nothing but confuse the issue. The staff person working directly with the ill consumer should follow a specific, clear-cut guideline as to when to call 911, issued by the Department of Human Services. It should not be left up to the discretion of the facility to interpret. The intent of Danielle's Law says persons working directly, not

designated staff. We demand that the Department of Human Services set one clear guideline and standard operating procedure that is sent to all facilities. There should be no distinction between private and public facilities. There should be no choices to make when we are talking about saving someone's life.

Internal protocols do not work. Designated staff members do not work. It is very simple, call 911 in a life-threatening emergency. The proposed rules and regulations for Danielle's Law are so confusing that after all is said and done, there is no one accountable. The proposed rules and regulations for Danielle's Law clearly violate the intent and the spirit of the law. And once again, the Department of Human Services are not protecting the clients that they are supposed to be serving.

In closing, it would be very outrageous and shameful if the Department of Human Services adopts these proposed rules and regulations for Danielle's Law as is. Be assured that my family will go back to our Honorable legislators and ask for Danielle's name to be removed off of these proposed rules if they do become the rule. We do not want Danielle's name associated with deaths that will continue, nor be a part of the shame that the Department of Human Services has created. Danielle's Law calls for an ambulance, not a hearse.

I thank you very much, from the bottom of my heart, for hearing my testimony today. Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Ms. Turner, for your very, very powerful testimony; and from your sister as well. I think that you are really on a noble crusade, and you can be sure that this legislation will

do what it is intended to do, and the regulations will see to it that that happens. I want to thank you for your testimony. And as I've said in the past -- the last several years, to all of you -- never relent. Always keep coming -- keep the pressure going to make sure that we get it right. And the squeaking wheel -- as I've so told to Vito back there, is that the squeaking wheel gets the oil. Just keep the pressure on, keep the pressure on until we get it right, because we are all on the same track with you. And I appreciate your bringing -- showing us what you could regard as some of the shortcomings here. I think that we all recognize that we have an obligation and responsibility to take care of those who cannot take care of themselves. I know this -- legislators in this Legislature to do exactly that; and I'm sure that my colleagues concur. We want to do the very best that we can to achieve this.

Are there any questions from any of our legislators, panel members?

MS. TURNER: I have one.

ASSEMBLYMAN PAYNE: Yes, go ahead.

MS. TURNER: I gave a copy of this. These are the petitions for the proposed rules for Danielle's Law. We've been going around the state and getting them. There's over 1,300, and that's only the beginning. These are -- I only gave you one copy there, because I didn't want to have to cut any more trees down. So this is the original copy here, and I'd like to present this, and I'd like to go on record that I have given this to Mr. James Evanochko, who is the Administrative Practice Officer -- that he has received these from me, in addition to the faxes that were sent over to him. So I'd like to be able to give this to him and go on record that I did that. Okay?

ASSEMBLYMAN PAYNE: Thank you very much.

MS. TURNER: Thank you very much for hearing us.

MS. GRUSKOWSKI: Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

Are there -- no questions? (no response)

Is Douglas going to testify?

MS. GRUSKOWSKI: No.

ASSEMBLYMAN PAYNE: Okay.

I see that we have -- come into the room -- Assemblyman Gregg, who is, I think, chairman of this Committee in an earlier time. But he's here, and I believe he would like to testify. Again, I apologize for those who have been waiting. I'm sure that Assemblyman Gregg will be direct and to the point.

**ASSEMBLYMAN GUY R. GREGG:** Thank you, Mr. Chairman, and thank you for noting my past chairmanship. I don't think anyone can follow the previous folks. I've worked with them for a number of years. As you know, I'm the prime sponsor on the Assembly side of this bill, with Assemblyman Munoz.

I want to thank you, the Committee. As a previous chairman, this is what the Committee is all about. It's about determining, when the Legislature speaks, that it's words are heard, and those words are implemented accurately. And in this case, it has not or does not appear to be going to happen that way if these regulations occur. There is no way that I can add to the testimony you've heard before. I feel strongly about it. Joe Vitale feels strongly. Senator Kean feels strongly. Assemblyman Munoz feels very strongly. We know what the words said in the bill. The members who voted for the bill know what the words said, and those are the words we want to be in the regulations.

The only thing I bring to the Committee, as the past chairman, is: you know the power this Committee has. It is a tremendous power -- that in the event that those regulations do not affect the will of the Legislature, we can put resolutions together that will change the regulations instantaneously, with simultaneous resolutions from the Senate and the Assembly. I come to you today saying those resolutions will occur if these regulations do not actually portray what was supposed to happen in that bill, which is to ensure that 911 is called -- very simple.

So I come today, thanking you for taking the time today on this important issue. And be assured, I will be working with you and your Committee in the event that our bill is not clearly stated in the regulations that are promulgated.

Thank you very much, Mr. Chairman.

ASSEMBLYMAN PAYNE: Thank you, Assemblyman Gregg.  
Janette Vance, from the Family Alliance.

**JANETTE R. VANCE:** Good morning. It is still morning, isn't it?

My name is Janette Vance, and I am the mother of an autistic child, and also a member of The Family Alliance to Stop Abuse and Neglect. I would like to thank the members of the Assembly Regulatory Oversight Committee for meeting to discuss the Department of Human Services proposed rules for Danielle's Law, and for allowing me to speak to you today.

By its own admission, the Department of Human Services wrote the proposed rules for Danielle's Law by working with providers and unions -- two extremely influential groups, neither of which, to put it mildly, were, on the whole, overly supportive of the bill. Even so, the language of Danielle's Law is

so clear and simple that I couldn't imagine any serious harm coming to it through the regulatory process.

I was mistaken. Eleven months after Governor McGreevey signed Danielle's Law, the Department appears to have succeeded in producing a document that virtually nullifies it. After translating all 19 pages of regulatory doublespeak into plain English -- that's a hobby of mine -- the Family Alliance feels that three very troubling messages emerge. I've explained them in detail in the written comments, and I've given you all copies; and those will go to Mr. Evanochko. So I'll only mention them briefly here.

The first is that the requirement that staff working directly with people with disabilities at private facilities call 911 isn't really a requirement any more. It's more of an option. We've, unfortunately, taken to calling it the "follow-Danielle's-Law-if-you-feel-like-it" option. At State facilities, the direct care staff member's first response to an emergency will never be to call 911. They will always attempt to contact somebody else first. Isn't that what they were doing before Danielle's Law?

The second message is, to put it rather bluntly, finger-pointing works. Staff members who do not call 911 are provided with a ready-made excuse to explain their failure: "I thought somebody else called."

The third, and perhaps the most damaging, message is: err on the side of danger. We can't think of any other way to describe it. A staff member who claims to be unsure whether a person's symptoms constitute an emergency are told that, rather than calling 911, they may contact a medical professional instead. The unsure staff member is considered to have met the requirements of Danielle's Law by describing the symptoms to a medical professional and

following the professional's advice. The requirement to call 911 can be met by not calling. It's that simple.

The enforcement section raises an interesting question, at least for us. What happens to the fines? The proposed rules only apply the fines to "staff members," and they define that term as employees present in the living or program area who work directly with the person served. At the same time, they create all sorts of new entities that appear nowhere in the law itself -- designated persons, supervisory staff members, medical professionals -- and transfer the responsibility of calling 911 to them. Medical professionals are defined separately from staff members in the proposed rules. Can they be fined? Designated persons and supervisory staff members aren't defined at all. It isn't clear whether they're subject to the fines or not. We do know, in order to be designated, they must be on-site; but that's not really the same as being present in the living or program area, is it? Is it possible to hold anyone accountable for violating Danielle's Law?

When I read the section in the proposed rules suggesting that unsure staff members need not call 911, I realized this is exactly what happened to Danielle Gruskowski, and we all know how her case turned out. Under the Department's proposed rules, it seemed likely that if Danielle were with us today, and her case played out exactly the way it did two years ago, then everyone involved would have met the requirements of Danielle's Law. This cannot be what the Legislature wanted when it passed Danielle's Law. Danielle's Law directs the Commissioner of Human Services to adopt rules and regulations necessary to effectuate its purposes.

I know that I am not alone in my belief that the regulations proposed on September 7 do nothing of the sort. The Family Alliance asks the members of this Committee to encourage the Department to issue rules that will implement Danielle's Law, not undermine it.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Ms. Vance.

Victoria Horrocks, Family Alliance.

**VICTORIA HORROCKS:** Mr. Chairman and members of the Committee, thank you for conducting this meeting and allowing me to present my views on this important matter -- the inconsistencies between the proposed rules for Danielle's Law and the law itself.

The question we are asking today is, why did the Department of Human Services create rules for Danielle's Law that have so little in common with the law itself? I have a few plausible suggestions about that. Let's ask ourselves, who actually wrote the rules? At the Assembly Budget hearings last April, when Assemblyman Cryan asked the Department of Human Services why the rules for Danielle's Law weren't done, the answer he received was, "We've been working with the providers and unions to formulate them, and they'll be done soon." We know that providers oppose Danielle's Law. One of them, David Holmes, of Eden Institute, told a reporter from the *Windsor Heights Herald* that "Danielle's Law would cripple an industry already at risk." He didn't stop there, but went on to insult Danielle's family and question the motives of our legislators. He said, "Politicians are listening to ideologues that come to them with a heart-breaking story. Then laws are written and they are

named after someone, and the politicians look good on TV.” The article itself is attached to my submitted statements.

Oh, by the way, I looked up idealogues. Does anybody know what idealogues means? I looked it up. It’s not in my Webster’s American College dictionary. But I went to the Internet, and your *dictionary.com* couldn’t find it, but the Merriam Webster online dictionary says it means, “an impractical idealist, theorist,” or number two, “an often blindly partisan advocate or adherent of a particular ideology.” Their thesaurus gives synonyms -- dreamer, castle builder, idealist, utopian, visionary. So idealogues would be people who strictly follow a certain ideology, like they might think that using painful, corporal punishment is the best and only proven way of training children to behave properly. And they follow that ideology in all their interaction with children. So I do a little education for myself.

It is also common knowledge that organized labor was vehemently opposed to Danielle’s Law. After it was passed by the Legislature, it sat on the Governor’s desk, unsigned for months. It isn’t too hard to believe that such a big payer could be responsible for the delay. Yet these were the people who worked with the DHS to write the rules that were supposed to effectuate the purposes of Danielle’s Law.

Why are providers and unions so opposed to allowing direct care workers to call 911 if they think a resident is experiencing a medical emergency? Danielle’s Law gives direct care staff the respect and responsibility they want and deserve. Danielle’s Law gives direct care staff a clear and uncomplicated procedure to follow. It treats staff like professionals, allowing them to take the best possible care of their clients without being second-guessed by others. It

gives providers a strong incentive to train their staff thoroughly, which is good for the clients and good for the staff -- clients receive better care, and staff receives skills and professional status. By the way, I believe providers need to share the wealth a bit with these direct care staff and pay them a lot better than they already are.

Danielle's Law allows direct care staff to go ahead and err on the side of safety without worrying that their employer will reprimand them, give them a bad performance review, or even fire them for calling 911.

Please, I ask this Committee, do whatever you can to have these rules amended to effectuate the purposes of Danielle's Law.

Thank you very much.

ASSEMBLYMAN PAYNE: Thank you very much for your testimony.

Any questions or comments? (no response)

If not, is Vito Albanese in the room?

Mr. Albanese.

Mr. Albanese, would you please identify yourself and your organization, for those who may not be familiar with you and for the record?

**V I T O A L B A N E S E SR.:** Mr. Payne, we're here again today, Mr. Payne. I'm becoming a fixture here from New York City. My name is Vito Albanese Sr. I'm a founding member of The Family Alliance to Stop Abuse and Neglect. And I'm here today to testify on Danielle's Law.

Good morning. Thank you, Assemblyman Payne, for inviting my comments before this distinguished body; and thank you to all of the Committee members for focusing today on the current State laws and rules and

regulations intended to protect children from abuse, neglect, and failures of not calling 911 in a life-to-death situation.

I come before you as the parent of son with a traumatic brain injury and as a founding member of The Family Alliance to Stop Abuse and Neglect, a grassroots organization dedicated to protecting the human rights and dignity of people with disabilities of all ages.

In the past two years, we have been active in New Jersey, New York, and Pennsylvania in identifying and eliminating specific, dangerous, and demeaning practices, and by fighting for legislation to protect the most vulnerable and voiceless population, the disabled.

My own son, Billy, was repeatedly victimized by abuse and neglect at out-of-state programs in which he was placed by the New York educational authorities. In Billy's case, New York proved to be totally unprepared to take a proactive stance in scrutinizing and approving the safety of potential placements for Billy, and also was unable to respond when indications of abuse and neglect came to light.

Now let's talk about Danielle's Law, and the proposed rules and regulations. Danielle's Law requires certain staff working with persons with developmental disabilities or traumatic brain injury to call 911 emergency telephone service in life-threatening emergencies. The proposed regulations say a designated staff person to make the 911 call. Who is this person -- the janitor, a volunteer, a vendor of medical supplies or food vendor service? Who is this designated person? This Committee has failed to ask Ms. Wilson to clearly define designated person. It could be anybody. I'm sure this Committee is getting my drift.

Designated staff person is a magic phrase and a magic bullet. Clearly, Danielle's Law calls for direct care staff to call 911 in an emergency, not some designated staff person. Should these words stand as proposed, it would clearly violate the intent and spirit of Danielle's Law.

I would like to read a letter written by Senator Joseph Vitale, a letter of support:

“Dear Ms. Grant:

“I am writing after careful review and consideration of the proposed new rule N.J.A.C. 10:42A, life-threatening emergencies, which was published in the *New Jersey Register* on September 7, 2004. I appreciate your effort to maintain a flexible system for requiring employees serving the developmentally disabled and traumatically brain injured to call 911 during a life-threatening emergency. However, as written, the proposed rule fails to capture the true legislative intent of Danielle's Law.

“Individuals with developmental disabilities often have very complex health conditions, including, but not limited to, seizure disorders and psychiatric problems. Every person with a developmental disability is a unique individual with different needs and varying levels of communication abilities.”

And let me give you a prime example. If someone is low functioning, nonverbal, how is that person going to say, ‘Please, call 911. I'm dying.’

“They often cannot express pain, distress, or any number of warning signs to alert someone of an impending emergency.”

It's simple, pick up the phone. In this day of technology, there's cell phones -- 911. That's simple, 911.

“This is why it is imperative for direct care staff to be trained to recognize an emergency within this special population and be responsible for calling 911 when they believe a life-threatening emergency is occurring.”

The letter speaks for itself.

I would respectfully ask, after today’s hearing, that this be referred to Senator Joseph Vitale’s Committee for further discussion on this issue, because that’s where it belongs also.

I would also like to read some quotes from Senator Tom Kean and Assemblyman Eric Munoz for the record, and I quote: “As prime sponsors of this legislation, we want to be assured that the regulations reflect the original intent of the bill: to protect the most vulnerable citizens of our society when faced with life-threatening emergencies. To do anything less is to dishonor the memory of the woman who inspired the legislation, the advocates who fought for its passage, and for the 120 legislators who supported its purpose,” and Governor James McGreevey who signed Danielle’s Law at a public meeting.

It is this parent’s opinion that DHS has done an end-run around the intent of Danielle’s Law by writing and proposing 19 pages of garbage, compared to a two-page bill. I read every page. It’s garbage in my opinion. And no disrespect to this Committee or the audience, it is a bunch of crap.

Clearly, Danielle’s Law was intended to save future deaths and serious injury. But DHS has caved in to the providers of facilities and the unions to water down Danielle’s Law as intended. This practice must cease immediately. We demand that Commissioner James Davy not amend, but rescind the proposed regulations forthwith.

This Assembly Oversight Committee is to be commended for its interest in the health and safety of New Jersey's children with disabilities, who are truly our most vulnerable citizens. Those who cannot speak or advocate for themselves require our highest standards of planning and oversight. It is time to be proactive rather than reactive in solving their needs for education and specialized care. You have begun that process today. And I feel certain that New Jersey will elect to take a leadership role enacting protective legislation that will make this state a national model and a leader in the disabilities field.

And I have a P.S.: Danielle's Law calls for an ambulance, not a hearse.

And I thank you very much for your time.

ASSEMBLYMAN PAYNE: Thank you, Mr. Albanese.

I say again that I also commend you and the others for your persistence, and for your clarity and indicating very clearly, and making sure that we remain focused on what the purpose of Danielle's Law was.

As a vice chairman of the Budget Committee, I remember the hearing at which time we were told that we were working on these regulations with the providers and with the unions, etc. And at that time, my ears shot up, wondering why it was that these interested groups were the ones that were working with the Department to come up with these regulations. These hearings are being held to make sure that folks who have a vested interest, or just citizens of New Jersey who want to see to it that our citizens are cared for fairly, are, in fact, included. And that's what I raised earlier.

MR. ALBANESE: We should have been brought to the table on these proposed regulations.

ASSEMBLYMAN PAYNE: When I raised the point earlier, that the process had not been followed the way it should have been, and that I -- we don't intend to sit on this Committee or any other committee where the people that are intended to be regulated or affected by this are excluded from the initial meetings. I mean, that's where it starts, initially. We have to have input from the very, very beginning, and we're going to correct that.

Thank you very, very much for your testimony.

MR. ALBANESE: Let me make one further comment. We have an infamous case of Matthew Goodman. There was another failure of 911. That's two years previous to Danielle. If Danielle's Law was in effect at that time, would we have saved another precious life also? That's another one -- no 911. That's two dead children that the State of New Jersey has to account for. There is no accountability, Mr. Payne. There has to be a time when there's got to be some accountability.

ASSEMBLYMAN PAYNE: Yes, and there has to be sanctions for those who are responsible for not carrying it out. I agree with you, and let the chips fall where they may.

MR. ALBANESE: All right. Thank you very much.

ASSEMBLYMAN PAYNE: Thank you.

Cynthia Haney? (no response) Oh, she's not here, okay. We have her testimony.

Jeannette Green? (no response) We have her testimony here, as well.

Kathy Wigfield. (no response) We have the testimony from Ms. Wigfield, who also has a very, very poignant story to tell, and her testimony will be included in our hearing record.

Margaret Griscti.

**MARGARET GRISCTI:** Good afternoon, Chairman Payne--

ASSEMBLYMAN PAYNE: Good afternoon.

MS. GRISCTI: --and Committee members.

My name is Margaret Griscti. My son lives in a group home where poor training has contributed to and caused abuse, neglect, and death. Provider agencies, as well as the State, have demonstrated they do not know what good training is. Their version of training is writing messages in a communication book, which is often illegible, or the staff has difficulty with reading and/or a language problem. Another favorite way of training is *A*, who was never trained properly, teaching *B*; *B* teaching *C*; *C* teaching *D*; and by the time it gets to *F*, everything is wrong.

How does this pertain to Danielle's Law proposed rules and regulations? The Department of Human Services says there will be "review of certification at inspection time." My questions are:

Number one, who will do the training? It is not specified. So will it be the *A-B-C* method or the communication book method? Neither of which is acceptable according to the definition of curriculum and training, which I have enclosed for you. And by the way, I'm a teacher by profession.

Number two, who will write the curriculum for Danielle's Law training?

Number three, what qualifications will the trainer have?

Number four, who will monitor the trainer, who will monitor the curriculums, and the actual training lessons?

It seems that no one monitors any other on-the-job training that takes place, so the training for Danielle's Law is just another thing written on paper without any supervision and accountability. For example, please look at the enclosure that I've given you with Dr. Dorsey's name at the top. Dr. Dorsey did a study of an agency. His study shows that out of 171 individual items that staff needed to be trained on, an average of 2.8 minutes was spent on each training lesson. So will Danielle's Law receive 2.8 minutes of training by the *A-B-C* method or the communication book method? Will the CEO give out certification for 2.8 minutes of training? Who will monitor?

I have a few suggestions:

Number one, all training needs to be done before employment. There should be a course for several weeks where appropriate training for Danielle's Law, as well as the other 171 items, is taught properly. Curriculums for these trainings need to be written by professionals -- EMTs, nurses, doctors, providers, of course -- and yes, even parents, who have 30 years of experience with their children, because they've kept them home for 30 years before placing them in facilities.

Second suggestion: Professional trainers need to be utilized to do the training, and not *A-B-C* or the communication book method.

Number three, each facility needs to name the specific trainer for Danielle's Law. Then, perhaps, maybe the inspection department can check to see if the training was done or not.

Number four, if the CEO or the executive director is certifying the training that his or her facility provides, they should be held accountable if the facility is held negligent because of poor to non-existent training on Danielle's Law. There is no mention of this accountability in the rules and regulations.

Presently, facilities have pages and pages of check marks for training that is never done. And the State of New Jersey, Department of Human Services, allows facilities to get away with it. There needs to be tighter controls on training, accountability, monitoring, and compliance. How well is the staff trained to take a client's pulse, blood pressure, or even their temperature? What about the overnight staff, that no one trains, in the middle of the night?

The additions I would like to make to the rules and regulations for Danielle's Law that would deal with 911 are:

Number one, a temperature that does not come down with aspirin, acetaminophen, especially for a nonverbal, noncommunicative resident, needs a call to 911. If the direct care staff has a concern over a medical condition, staff should err on the side of caution and call 911 first. That is why Danielle's Law was created. It was not created for facilities to be exonerated of all responsibility, as the present proposed rules and regulations provide. If in doubt, call 911. EMTs will advise you. I had that experience when my son was living at home. The first intuition is usually the correct one. Time is of the essence.

The second addition: A temperature of 104 and 105 should necessitate a call to 911.

Number three, any consumer who has a known medical condition as being highly allergic should have a standing, written doctor's order, written

every year or sooner if needed, for the administration of treatment, which is often Epi-pen, asthmatic nebulizer and inhaler treatments. This treatment should be given by staff. The only way this would be considered an emergency for a 911 call is if the treatments do not work after being administered. Treatment first. If treatment fails, call 911.

If it was a facility whose medical policies and procedures were at fault for causing the 911 emergency to be ignored, then not only does the facility need to be held accountable, but so does the Department of Human Services' Division of Developmental Disabilities, who allowed the facility a license to operate when a proper policy and procedure for medical emergencies was not in place. And again, if the CEO/executive director certifies this faulty training, he or she also must be held accountable. There's no mention of this in the rules and regulations.

I would like to thank all of the legislators present today for unanimously passing Danielle's Law, because it was intended to save a child's life in an emergency. However, the Department of Human Services has sabotaged the law. Please, I beg you all, to do something about it.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Ms. Griscti.

MS. GRISCTI: I also have a detailed fact sheet that was put out by the Department of Human Services, if you would like to look at that, for each of you. Thank you.

ASSEMBLYMAN PAYNE: Sure.

Ms. Griscti, Mr. Cryan would like to ask you a question.

MS. GRISCTI: Oh, I'm sorry.

ASSEMBLYMAN CRYAN: You talked a lot about training stuff, and I'll be clearer now. The thing I have a problem with is: How much training do you need to dial 911?

MS. GRISCTI: Well, I wasn't just talking about 911. I was bringing up a general thing where training needs to be in place before they -- to work in a facility like this, the training needs to be improved. It's very poor.

ASSEMBLYMAN CRYAN: Okay. So you're on the overall facility issues--

MS. GRISCTI: Right.

ASSEMBLYMAN CRYAN: --and I guess you're going a little bit to that April 23, of how to identify things and what's part of it?

MS. GRISCTI: Right. Right.

ASSEMBLYMAN CRYAN: Because I have to tell you, from my standpoint, sitting here, I mean the major problem I'm having -- and I've heard it enough here -- is that there's a different standard for State and private providers, as well as the fact that there's a layer of bureaucracy, or whatever you want to call it, instead of just picking up the phone, which to me just seems to be -- that seems fairly simplistic.

MS. GRISCTI: It is, but because of the internal protocols, the direct care people are afraid to call before they check with somebody. And the other problem is cultural. We often have people from other countries. In their country, a medical emergency is not the same as a medical emergency here. They're not sure when to call. They don't go to doctors as often as we go to doctors here. So their interpretation of a medical emergency may be different than ours. That's one of the big problems -- the language barriers and cultural

differences. And they do need training to recognize even their Centigrade and Fahrenheit temperature taking.

ASSEMBLYMAN CRYAN: A good point. I appreciate that.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Ms. Griscti.

Susan Bodnar. Let's see, if you'd identify yourself and who you're accompanied by, please.

**S U S A N B O D N A R:** Good afternoon, Honorable Assemblymen and Assemblywoman. My name is Susan Bodnar. I'm with the Carteret Fire Department. To my right is Chief Brian O'Connor, and next to him is Captain Paul Gadomski.

ASSEMBLYMAN PAYNE: Welcome.

MS. BODNAR: I'm here on behalf of Carteret Mayor Daniel Reiman. The Mayor has asked me to present this letter to the Committee:

"It has been made clear to myself and my administration that recently proposed revisions to New Jersey's Danielle's Law are in direct contradiction to the law's original purpose. Danielle's Law was signed into legitimacy by the Governor to establish definitive emergency procedures for developmentally disabled residents of our State's special care facilities. Benevolent or not, the Department of Human Services appears to be affixing the agenda of unionized health care workers to a statute that was meant to be a families' law. The pending amendments will obscure its intended beneficiaries or -- and at best render the law dysfunctional.

"At its inception, Danielle's Law established a series of standards and procedures by which our developmentally disabled receive emergency

treatment by special care staff. Workers are to receive appropriate training to handle life-threatening situations, in the event of an emergency are to contact 911 immediately, and so on. The revisions suggested by the Department of Human Services render the necessity of calling 911 ambiguous in the circumstance of an emergency, and to mitigate the level of accountability, if not professionalism, with which workers are to execute what should be a well-defined procedure.

“It can only appear that a law that was clearly created to benefit special care recipients has been hijacked in the interest of their providers. I would never undermine the importance of health care professionals, but amendments made to this legislation should be devised according to the concerns of our disabled, who as much as you and I should be regarded as respected residents of New Jersey and equally deserving of protective laws.

“I therefore encourage the Department of Human Services to leave the health care professionals’ concerns to an entirely different piece of legislation. Focus on the betterment of our disabled so we don’t have to displace Danielle’s Law with the name of another victim of poorly coordinated special care.”

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much, Ms. Bodnar. Is there additional testimony from either one of your gentlemen? (no response)

Yes, we have a question from--

ASSEMBLYMAN CRYAN: Can you take us through the-- If you get multiple calls -- you guys, you’re the front-line folks -- if you get multiple calls from the same facility reporting a threatening situation? If we called in

your area, how would the process work? Would you just be dispatched? Would you be told, if you're on the way, there's multiple calls, or would there just be one?

MS. BODNAR: Sometimes when the dispatcher calls us, they'll say there's multiple calls on this situation. But they primarily -- they'll just dispatch us right to the call.

**CHIEF BRIAN O'CONNOR:** But our standard response would stay the same. Like you mentioned, we wouldn't send five ambulances, we would send one. Just like a fire; we can get 10 calls, but we're still going to send our first response.

ASSEMBLYMAN CRYAN: Is there any concern about a burden on your system with multiple calls in any way?

MS. BODNAR: No.

CHIEF O'CONNOR: Not on multiple calls at all.

ASSEMBLYMAN CRYAN: Okay.

ASSEMBLYMAN FISHER: Mr. Chairman?

ASSEMBLYMAN PAYNE: Yes, Mr. Fisher.

ASSEMBLYMAN FISHER: Thank you.

I think I know the answer, but I just wanted to be sure. If a dispatch is made by -- for an emergency call, you can't -- if you were to get another call, you can't turn that call around, can you? In other words, I call 911 for an EMT, and it is determined by the institution, let's say, or wherever -- the staff members -- that they rushed to the scene and they realized that they have it under control. You can't then abort the call, can you?

CHIEF O'CONNOR: If we have a higher priority call, we can reroute the call if we're in route. Once we're on scene, we'll stay there. We won't leave unless we get an okay to leave.

MS. BODNAR: We have to go to the scene, though, and we have to obtain a refusal from the patient or the patient's guardian, or somebody on staff. I think that's what you're asking.

ASSEMBLYMAN FISHER: Right.

MS. BODNAR: If we have to go to the scene of the emergency and--

ASSEMBLYMAN FISHER: Once it's dispatched--

MS. BODNAR: Yes.

ASSEMBLYMAN FISHER: --you have to arrive at the scene.

MS. BODNAR: And we have to assure that there is no medical emergency. And there has to be someone, of a legal guardian or somebody, to sign off, to refuse medical care.

ASSEMBLYMAN FISHER: Okay. Thank you.

ASSEMBLYMAN PAYNE: Let me ask you a question that comes to mind. How many false calls do you get? What do you regard as false calls to 911? Are there a preponderance of those or what?

MS. BODNAR: There is no such thing as a false call. Because somebody's definition of emergency is something different. Somebody could be having a bad toothache, and to them, that's the end of the world, and that's an emergency. And we have to treat every emergency the same way. A CPR call and my-tooth-hurts call is going to be taken the same way. We have to provide

the same level of care to somebody who has a minor injury, as opposed to somebody who's in a serious injury.

ASSEMBLYMAN PAYNE: Recently in the headlines, there was a story about a so-called 4-year-old child that called 911 and said that her mother was not breathing, or something like that. And it turns out apparently that was a hoax. Do you experience that kind of call, or have we had those kinds of experiences where they're hoaxes, or whatever?

MS. BODNAR: We' experienced them. We go there. We assess what's going on, and we make the determination -- the family makes the determination of what's a hoax and what's not. So, for a child to call 911 and say, "My family member's sick," that's happened before. Somebody is sick, they just have a cold. To them, they pick up the phone and they say, "My mom is dying." To them, their mom's dying, they have a cold.

ASSEMBLYMAN PAYNE: Sure. But clearly, in this case, at least from what's been reported, apparently there was no emergency at all. They went out, I think the Police Department of Paterson, or somewhere, said that every call we follow up on. However, it seems as though this may have just been a hoax, a prank, or anything like that. I'm just trying to find out whether or not, not a child calling because he thinks that his--

MS. BODNAR: Yes.

ASSEMBLYMAN PAYNE: But I'm saying, somebody just calls 911 for no reason whatsoever, except to create a problem. Do you have any of those experiences or not?

CHIEF O'CONNOR: I would say they're very rare.

ASSEMBLYMAN PAYNE: All right. Which kind of underscores this whole business about people and these treatments centers, or places like that -- maybe unnecessary calls being made. The reason I asked that is because you're in the business, and your experience from the empirical data tells us that that is generally not the case. If you got to call, it usually is a justified call, and therefore should take the pinnings out of this business or this concern on the part of the Department, or whomever, that people may make calls unnecessarily.

I just thank you. Thank you.

MS. BODNAR: Well, when a call is made to 911, even if the agency calls back and says, "We don't want you coming," there is going to be a police officer that goes to the scene just to assure that everything there is okay.

ASSEMBLYMAN PAYNE: So there seem to be some built-in safeguards against people just frivolously making calls. And therefore, this concern or the over concern, on the part of the Department, that we have to safeguard against those kinds of things may be something like a pig in a poke or a red herring, it seems to me.

CHIEF O'CONNOR: Well, I think that's where you brought up about -- education is important. And what we're discussing, in Danielle's Law, is life threatening. So I think that's where you're not going to get that many false calls, as you referred to. Difficulty breathing for anybody is a life-threatening emergency.

ASSEMBLYMAN PAYNE: Thank you. And we just need to make sure that the caregivers, or whomever, or the janitor -- and we're talking about training -- everybody who walks in that facility. Just as we're talking about

training now for people who might have strokes, or defibrillators, etc. -- that everybody who comes into the facility must be familiar with this, even if it is, as we say, the cleaning people, etc., etc., etc. So I want to make sure that we do have the kind of training so that we remove the mindset of people saying, "I'm going to get in trouble if I make a call," and it turns out to be nothing. That's really part of their training. The training that we're talking about -- how do you recognize people who have life-threatening problems? Training also includes developing a mindset, on the part of people there, to dispel and to remove that big brother or somebody is going to penalize you if this turns out not to be the case. So that's one thing I think we want to make sure we stress, and get that across in this training. And we're going to get back to training later on about who does it, where it happens, etc., etc., etc., because it's still very vague in my mind.

Thank you very much.

MS. BODNAR: Thank you.

ASSEMBLYMAN PAYNE: Jena Feiner. (no response) She's not present, okay.

Is Deborah Keenan Lynch here? (no response)

We do have testimony from these folks, even though they're not here.

Derek Gruskowski. (no response)

Lowell Arye. Lowell, please identify yourself and your organization, etc.

**LOWELL ARYE:** Thank you, Mr. Chairman.

My name is Lowell Arye, and I'm the Executive Director of the Alliance for the Betterment of Citizens with Disabilities. I want to thank you, Mr. Chairman and the rest of the members, for allowing me to testify today on the proposed regs to implement Danielle's Law. I also want to specifically express my condolences to the Gruskowski family and friends on the loss of Danielle. Her death was a tragedy. And we all need to work together to ensure that quality services are provided to all people with developmental disabilities.

The Alliance for the Betterment of Citizens with Disabilities, ABCD, is a statewide organization representing member agencies that serve more than 8,000 people with developmental disabilities, specifically focusing on people with multiple physical developmental disabilities.

I'm going to divert briefly from my written testimony to say that I want to clarify something. There has been discussion with regard to provider agencies being included in the issues and review. Myself and several other provider trade associations were invited once to meet with the Department, two weeks before Danielle's Law implementation date. We were not given any paper. We were asked our opinions, and that was it. I have never seen any information about it, specifically, until I saw the regs on September 7. I was assuming that similar conversations were going on with others, as well. So I wanted to clarify that for you.

The proposed regulations -- we've only had 23 days, like everyone else, to take a look at them. So these are my initial comments based upon an initial review. We will be providing more specific comments later on to the Department, up to -- by November 7. We appreciate the difficult task that the Department has had in implementing the statute. There are places in the statute

that are unclear and open-ended, and we would and we do applaud the division and the Department's attempt to clarify these matters.

We believe that the proposed rules should be altered and simplified to ensure the safety of these individuals. We specifically think that there are certain parts of the rules that unnecessarily complicate emergency procedures and place an undue burden on staff. We believe that the aspects of these rules, if not addressed, will ultimately undermine the effectiveness of community care providers to respond to emergencies and ensure the health, safety, and well-being of individuals with developmental disabilities.

I'm going to go thorough some specific points, but won't go through my entire testimony. First of all, with regards to direct call policy: This Committee is specifically looking at the issues of legislative intent. Clearly, legislative intent and specificity in law says that there should not be two distinct call policies. The statute is extremely clear, and it has been written by you all and signed by the Governor. And it specifically says that a member of the staff who works directly with persons with development disabilities or brain injury shall be required to call 911. The law does not state that a public or private facility may designate a staff person. The proposed regs, as written -- and we will be commenting on this to the Department -- basically should not and cannot, according to a clear reading of the law, have two different standards for private facilities and the developmental centers.

In addition, you need to understand that if you have two different policies, the problem is, is that staff are basically migratory. They actually go from place to place. And if you have two different trainings and two different call policies, we will not be able to have -- and there will be confusion.

We do believe that staff needs to be protected and there needs to be a consistent policy with regards to some of these issues, specifically life-threatening emergency. There needs to be a better definition of an emergency. And specifically, what I'd like to say is that the statute is also very clear about that. It specifically uses the word, what a *prudent* person believes is an emergency. Now, at the meeting that we had with the Department, I laid out for them that they already had a definition for what a "prudent layperson" says is an emergency. That is actually in Medicaid Managed Care for the aged, blind and disabled. There is a contract with the HMOs -- meaning all the folks with -- on SSI, most of those living in our community with DD and other folks -- that the HMOs are required, and the Department, Division of Medical Assistance, actually has a prudent layperson's definition. I've listed it for you. We believe that that definition should be used. We also believe, and I know, that staff have been trained on that specific issue, because many of my member agencies have individuals who are in the Medicaid Managed Care Program.

With regards to training: specifically, some individuals, I understand, are concerned that the regs currently allow provider agencies to develop the training procedures. However, I'm going to go back to statutory intent and what the statute says. The statute says, "ensure that appropriate training is provided." That doesn't say the Department must do the training or whatever. It simply says that the Department ensures that the training occurs. We understand the concerns, but at the same time believe that we need to ensure that all consumer and staff safety training is incorporated, is continuously seamless. And we would like to ensure that. And so what we would like to do is, we agree that there needs to be better training of staff all

across the board. And we, as ABCD, have always said that there needs to be better career ladders, competency-based training for our staff. We concur with that, and we'd like to work with you all to do that.

We are concerned about the excessive fines. We know that the law is very clear about the excessive fines, but we are concerned that the economic impact statement written by the Department, unfortunately, does not talk about those -- that economic impact on the direct care staff. Direct care staff in the community only make \$18,900 on average. Now, compared to the developmental center direct care staff who make \$22,000 to \$27,000 a year, a \$5,000 fine is extremely difficult. We have an attrition rate in the community for direct care staff of 50 to 75 percent on an annual basis. This law, we believe, will clearly have a negative impact on an agency's ability to recruit and retain direct support professionals. And we are very concerned about that. We are going to ask the Department to include a payment structure that will -- if there is a violation of this law -- a payment structure which will allow the staff members to be fined in a more appropriate way. We are also going to be asking the Department and the division to provide assistance to those staff people if they need legal representation.

Specifically on the Do Not Resuscitate order and the issues of civil rights: We are specifically concerned that the provisions of the regulations that are being proposed requiring a staff member to call 911 even if the individual has a Do Not Resuscitate order is a violation of an individual's civil rights -- have looked at by the New Jersey Advanced Directive Act of 1991. I'm actually -- would love to hear a little bit more from the EMTs, some of their views. The Advanced Directive Act actually specifies, and we've cited the section of that

law that says, “emergency personnel are not required to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for them to carefully review and evaluate an advance directive without endangering the person’s life.” That means that if an individual -- if the EMT comes and they have to deal with the issues regarding that, the Do Not Resuscitate order, basically, is null and void. And we are concerned about that and would like to get more clarification from attorneys on that.

There are several other things. We do believe that the division should be notifying the executive of an agency when the director determines that a violation of Danielle’s Law does occur. Specifically, we are concerned because if an executive doesn’t understand that the division has made the determination of violation, then additional training for staff, disciplinary action when needed, would not be available.

I’m not going to go much further. I just wanted to say I really appreciate the opportunity to speak about this. This is an important issue. My member agencies who serve some of the most significantly vulnerable populations, people with multiple physical developmental disability, do want to provide the best care and services to people with developmental disabilities. They look forward to continuing to work with you and others in the Legislature, the executive branch, as well as the family member, to ensure that this is the case, and to actually implement Danielle’s Law as written and what the statute intended to say.

MR. ARYE: Thank you.

ASSEMBLYMAN PAYNE: Thank you very much.

In your initial statement, earlier in your statement you stated that you were trying to clarify the air, that you had not had any prior involvement or meetings with the Department while the regulations were being drafted. Is that what you were saying?

MR. ARYE: Yes, sir. What I said -- and I'll say it again for the record. We were invited -- myself and several other agencies who are basically, in effect, the trade associations for provider agencies -- were invited to a meeting two weeks prior to final implementation of the law, which was sometime in early April. And we spent about an hour and a half with the Department, with the representatives of the AG's office, as well as with the Governor's Counsel. They asked us our concerns. They asked us some issues, and that was basically -- We were not given any paper. We were not given any paper there or to be brought back. We never--

ASSEMBLYMAN PAYNE: And you assumed that that was happening with others as well.

MR. ARYE: Sir, of course.

ASSEMBLYMAN PAYNE: Not only care providers, but those persons who the--

MR. ARYE: Of course, sir.

ASSEMBLYMAN PAYNE: And what has been stated before is that that did not happen with the other folks, okay.

MR. ARYE: And I'm sorry that that did not happen, because that is what I was assuming.

ASSEMBLYMAN FISHER: Mr. Chairman?

ASSEMBLYMAN PAYNE: Yes, Mr. Fisher.

ASSEMBLYMAN FISHER: Thank you.

Then, as a representative of provider organizations, if the person, an employee, makes a 911 call, currently, because they're in doubt of a resident's status as to how badly they need care, immediate care-- You're talking about an entire group of institutions, correct?

MR. ARYE: Sir, what it actually-- Each of my member agencies-- One has their own policies and procedures and now have been directed already by the Department of Human Services, through their letters and things, to actually -- how to implement Danielle's Law. Each of my agencies have-- Some of my agencies -- and one of them is Bancroft Neurohealth, and another one is Spectrum for Living -- each have different group homes, skilled residences, etc, supervised apartments, etc. And it depends upon -- some have anywhere -- have only three individuals in the group home, others have six individuals in the group home. As you know, Bancroft Neurohealth, as a residential health care facility, is a little bit larger.

ASSEMBLYMAN PAYNE: Was that your question?

ASSEMBLYMAN FISHER: Not exactly. Every trade, every professional group has guidelines within its own industry. Are you suggesting that they would be handled differently if someone made that call?

MR. ARYE: No, sir. What I'm saying is that each of-- From what I understand is, that each of the agencies were given exact direction from the Department--

ASSEMBLYMAN FISHER: I'm talking about currently, first.

MR. ARYE: Currently, as of April 20-whatever--

ASSEMBLYMAN FISHER: Before this law was enacted. Let me try it that way.

MR. ARYE: Prior to the law enactment. Yes, sir. I understand that each of the agencies -- and I would have to go back to ask my agencies -- but they would have different policies and procedures that were actually approved by the Department and by the Division of Developmental Disabilities.

ASSEMBLYMAN FISHER: So it was mentioned earlier that there's great movement between homes and those settings. And so a person who provides that care might be totally confused between each institution, correct?

MR. ARYE: If they worked in the developmental centers and then later on in a group home -- or, actually, usually it's the other way around -- because their staff's salaries in the group homes are so much lower, that many people are actually going to direct care staff -- go to the development center to actually get additional funds, because they have much higher salaries. So there might be a difference. I know, from my agencies, they're immediately trained. Several of my agencies -- and this was actually asked, was stated -- several of my agencies do not allow a staff person to literally touch a client for the first several weeks, until they are trained and they're mentored and shadow other trained staff. Unfortunately, it does just depend upon the organization at this time.

ASSEMBLYMAN CRYAN: Do you mind if I ask him one?

ASSEMBLYMAN PAYNE: Yes, Mr. Cryan.

ASSEMBLYMAN CRYAN: Yes, you mentioned-- I'm going to get off that for a minute because I-- The law has been in place now for some time, a few months anyway. You spoke about the fact that the law has a negative

effect in terms of being able to-- Because of its fines and its intent, have you experienced where folks have turned down jobs because of this law?

MR. ARYE: We have not, specifically, on the law, because there have been, that I know of, no violations of Danielle's Law. It's just an added disincentive for it, when staff find out or perspective staff find out that it's possible that they could be in violation and have a personal \$5,000 fine against them, when they're only going to be making \$18,000 a year, maybe, many times without health benefits.

ASSEMBLYMAN CRYAN: Because you haven't seen that yet?

MR. ARYE: Not yet, sir.

ASSEMBLYMAN CRYAN: Okay. And I guess I want to go through, one more time, this input issue. An hour and a half meeting where you provided comments, right? That's what I'm hearing. Is that what you're telling me?

MR. ARYE: That was a-- I'm not going to say we provided comment. What I've said--

ASSEMBLYMAN CRYAN: Have you had an input into this, sir?

MR. ARYE: What's that?

ASSEMBLYMAN CRYAN: Have you been spoken to about this bill before that?

MR. ARYE: No-- Let's see-- Actually I spoke with Terry yesterday to let her know what I was going to be saying today.

ASSEMBLYMAN CRYAN: And how about the regulations before they were issued?

MR. ARYE: I had one conversation, one meeting, in April, where I was asked-- I was not told where they were going with it exactly. I told them exactly where some of our concerns and issues, as to what it should be--

ASSEMBLYMAN CRYAN: And isn't the comment portion, when it's posted, for that?

MR. ARYE: Yes, sir, it is.

ASSEMBLYMAN CRYAN: Okay.

MR. ARYE: As I said, and as you know, sir, there are many times when all departments, prior to writing regulations, do ask for comments from all the stakeholders. As I said, I assume they do that.

ASSEMBLYMAN CRYAN: They do do that. And you're okay with that? If you are-- I mean, I'm interested in that, because I've heard -- and I'm just not sure, this is new ground for me -- complaints that the unions have written rules, and I definitely picked up on that from some of the folks here earlier. But is it common practice for you that -- you've had input into, I assume, with the group homes, that it sounds like your opinion was actually solicited. Is that correct? And people that are affected and the workers, their opinions are solicited. Is that right?

MR. ARYE: My opinions were solicited once without any additional information provided to me by the Department on where they were going. I have not spoken to them since that day.

ASSEMBLYMAN CRYAN: So you didn't get any follow-up?

MR. ARYE: No, sir.

ASSEMBLYMAN CRYAN: I got that. I got that. But I guess I want to understand, because this law does affect workers that are organized

labor in the state, and I'm not taking a position one way or the other. It sounds like you've had, in your past practice, comments on bills or legislative, as far as interpreting its regulations. Is that right?

MR. ARYE: Yes, sir.

ASSEMBLYMAN CRYAN: Okay. So it's not uncommon for the Department to do that.

MR. ARYE: I have actually-- Well, the Department and the Division of Developmental Disabilities, on many of their regulations, have work groups that comprise the entire community. For example, when they did the--

ASSEMBLYMAN CRYAN: The workers, the providers, everybody-

MR. ARYE: The providers, workers, family members, advocates, a variety of folks. For example, on the waiting list regulations that were implemented about two years ago, there was a very large group of stakeholders that the Department brought together to ask for opinions and all of that, as well.

ASSEMBLYMAN CRYAN: Thanks. Thank you.

ASSEMBLYMAN PAYNE: Mr. Fisher has--

ASSEMBLYMAN FISHER: Just a follow-up on-- We now know that there are, as the way it is currently written, there are severe fines if you don't make the call. Institutionally, industry wide, what are the penalties in these contracts if you do make the call without going through proper protocol?

MR. ARYE: If they do make the call?

ASSEMBLYMAN FISHER: Yes.

MR. ARYE: My understanding -- and I would have to actually ask each of my member agencies if they have one -- but I highly doubt that any of my member agencies have anything that says, "Don't make the phone call." You need to-- I'm sure there are certain policies and look-see--

ASSEMBLYMAN FISHER: But I mean, through protocol, now. I understand you're not saying, "Don't make the call." We all understand that you would not say anything such as that. But it is said, and it now says, that the regs say that you have to go through a gatekeeper, to make sure that certain provisions are taken care of, before that call is made by that person.

Now, I'm asking you, I'm on the scene, and I am determined -- common sense, we talked about, and other words that sort of -- wiggle words -- that say, "I'm going to make that call." What's your response to that, if I do that?

MR. ARYE: I would have no problem, and I know that my member agencies would have no problem on it. I think that that's why I'm saying the *prudent* person, which is in the statute, that's what it is. I mean, I'm right now the caregiver for an individual, for four elderly individuals, and I'm dealing with this right now. So I know that that's the case, that there is the prudent person. And I know my member agencies, which say in their policies and procedures, and based upon what the Department has already told them back since the law was enacted, that that is the requirement to do. And that is what they have been training their staff to do.

ASSEMBLYMAN FISHER: Thank you, but there's still some disconnect here.

MR. ARYE: I understand.

ASSEMBLYMAN FISHER: There's some element that's missing. These two aspects don't connect.

MR. ARYE: I think-- Let me throw out to you that I think -- what I wanted to just clarify, and maybe I'm not catching what you're asking me. What I understand as the current, the proposed regulations -- there are going to be two ways of doing business in the developmental centers. One which is the staff person can call the other, which is that there is a designated staff person to call. It is my understanding that the proposed regs for private, community-based organizations, that they're not going to have a designated staff person. I would suggest that there be one call. The law is clear. My agencies now have it that 911-- If they, as a prudent layperson, believe that there is an emergency, based upon their own common sense, that they will call 911. That's, period, all that should be done. That's what the law says. That's what is, in my mind, common sense as well. That's what the policies and procedures that the Department sent out back in -- or the letters that they sent out, it wasn't policies and procedures, the letter that they sent out right before final implementation of Danielle's Law.

ASSEMBLYMAN PAYNE: What did the letters that were -- letters, policies said, whatever, sent out -- what did they say? We're developing the regulations now. What was sent to you all?

MR. ARYE: To be honest--

UNIDENTIFIED SPEAKER FROM AUDIENCE: It was just passed around to you. Just so that you know, it was just passed around.

ASSEMBLYMAN PAYNE: What was the procedure? What was included?

MR. ARYE: To be honest with you, I can't remember it, and I don't have it in front of me. I think you have it. I'm sure the Department can provide it to you. So I, unfortunately, I cannot say. And remember, I do not provide actual services. I am a person who works with both you all, as well as with the executive branch, with regards to a variety of issues.

ASSEMBLYMAN PAYNE: You represent the industry, right, for care providers?

MR. ARYE: I represent several -- 12 agencies who provide these services. I don't represent the entire industry, sir.

ASSEMBLYMAN PAYNE: All right. Okay. You represent -- you're an executive director of this organization, is that what you said earlier?

MR. ARYE: Yes, sir.

ASSEMBLYMAN PAYNE: And do these organizations have a uniform policy -- that the 12 that you represent -- in training or, I mean, are they doing all the same thing?

MR. ARYE: No, sir, they do not.

ASSEMBLYMAN PAYNE: They do not. They have-- It depends on whatever the agency is, right?

MR. ARYE: That's correct.

ASSEMBLYMAN PAYNE: They do their own thing.

MR. ARYE: However, they have asked me and they have directed me, and we have been trying to ensure that there be, actually, one certified competency-based training. Not just on Danielle's Law, but across the board on competency-based training to serve people with developmental disabilities on a variety of issues, as was discussed earlier.

ASSEMBLYMAN PAYNE: You're licensed by the State, correct?

MR. ARYE: Yes, sir, they are.

ASSEMBLYMAN PAYNE: You contract with the State?

MR. ARYE: That's correct.

ASSEMBLYMAN PAYNE: Yet the State does not provide you with the guidelines, curriculum -- that we talked about curriculum before -- for training, etc.? In other words--

MR. ARYE: There are certain required training-- I believe it's six hours or so of certain training for each of the staff.

ASSEMBLYMAN PAYNE: Who developed the training? Where does that come from?

MR. ARYE: I understand that it was developed originally by the Boggs Center on Developmental Disabilities.

ASSEMBLYMAN PAYNE: And that comes from the Department?

MR. ARYE: It's a federally based university center of excellence for developmental disabilities.

ASSEMBLYMAN PAYNE: That is provided to you through the Department of Human Services?

MR. ARYE: That is correct.

ASSEMBLYMAN PAYNE: And you're required to follow that protocol?

MR. ARYE: Yes, they are. And many of my agencies go above and beyond that, and have developed their own modules and trainings to go above and beyond that.

ASSEMBLYMAN PAYNE: Who monitors your agencies to make sure that they're following that? Who does?

MR. ARYE: The Department of Human Services and the division.

ASSEMBLYMAN PAYNE: How often?

MR. ARYE: Significantly. I mean, they license and review on an annual basis.

ASSEMBLYMAN PAYNE: You said on an annual basis. You said the stakeholders met with -- earlier, before the regulations were promulgated, correct?

MR. ARYE: Yes, sir.

ASSEMBLYMAN PAYNE: Do you not include the clients or patients as stakeholders?

MR. ARYE: I would, sir.

ASSEMBLYMAN PAYNE: But they were not included in these meetings?

MR. ARYE: As I said, I was invited to one meeting--

ASSEMBLYMAN PAYNE: Okay.

MR. ARYE: --to discuss. I don't know if the Department went to other -- asked clients, family members, anyone else to--

ASSEMBLYMAN PAYNE: Fine. Thank you. We're just trying to make -- clarify this, so that if, in fact, it was overlooked in the past, we expect that this same treatment would be provided for those of you with the unions and providers, so that the clients -- they're the ones, really, that are going to be the ones that are affected by what goes on here. And it seems to me that they

and their families are most important. You mentioned in the past and on a waiting list, for instance, that families were included. Okay.

But thank you very much for your--

MR. ARYE: And Mr. Chairman, I appreciate it. I agree that all stakeholders, and that's why I used that term, should be included in all conversations related to this.

ASSEMBLYMAN PAYNE: Thank you.

MR. ARYE: Thank you.

ASSEMBLYMAN PAYNE: Yes. This date that we have here, the April 30 correspondence from the -- signed by James Smith, regarding the law. And it has a fax sheet on Danielle's Law, which spells out things. And I hope there's something more than just this, but it spells out what is supposed to be done. If this is the criteria, if this is the instruction that's provided, then there's something that's lacking here. We need to have some answers. The fax sheet on Danielle's Law, have you seen it? It just points out what they're responsible for and to call 911 in the event of -- examples of life-threatening emergencies include, but not limited to, persons unresponsive, etc., etc., etc. I don't know what this is -- the training -- but there must be more. There has to be more than this.

Thank you.

Lynn Nowack, in favor of the proposed rules.

**L Y N N N O W A C K:** Thank you, Mr. Chairman, and members of the Committee.

I'm here today on behalf of the New Jersey Speech-Language-Hearing Association, which represents over 1,600 master's- and doctorate-level

professionals working in the fields of speech pathology and audiology, including over 230 professionals who work in the health care setting, many of whom in developmental centers.

We've interpreted this law that it would apply to speech pathologists working in these settings. What I want to point out is a few of what we believe are some positive pieces that are in this proposed ruling from the Department. NJSHA believes that the rules clarify and specify the procedures that health care professionals must follow in the event of life-threatening emergencies, so that they know the appropriate route to take to comply with the law and to ensure the health of the consumer. I believe it's important that the rules clarify what constitutes a life-threatening emergency.

And as the Deputy Commissioner pointed out, it is not an all-inclusive list, but certainly says that -- not just specifically these things, but does give some clarification as to what are life-threatening emergencies. And for example, a seizure that lasts five minutes or more.

Another critical clarification in the regulations addresses the situation where only one staff member who is trained to provide immediate assistance is present, and a life-threatening emergency occurs. That staff person shall provide the immediate assistance and then call 911. We point out the instance of somebody who is choking, and that qualified person is there to apply the Heimlich maneuver, and then call 911, and believe that's an important clarification.

As a professional organization, we also appreciate that the rules clarify that -- provide for department review of all reports of instances where 911 calls are not made, given, from the perspective of the seriousness of the penalty,

for a violation of \$5,000. So we just wanted to raise some of those points before the Committee, and really appreciate your taking our testimony today, of a little more detailed testimony before you.

Hilda Pressman, who is the Chair of New Jersey Speech-Language-Hearing Association's Health Committee wanted to be here today, but she is out of state on professional business.

Thank you very much.

ASSEMBLYMAN PAYNE: Thank you very much.

Any questions?

Mr. Cryan.

ASSEMBLYMAN CRYAN: Thanks. A quick one. I have two of them. The Heimlich example that you used. The way the bill reads, the way the regulations read, I guess what bothers me is even if the staff member was administering the Heimlich maneuver, the other person couldn't dial 911 while they were watching. Do I have that wrong? If I do, just tell me. I'm not bashful.

MS. NOWACK: I don't know. I would have to ask the Deputy Commissioner.

ASSEMBLYMAN CRYAN: But the way I interpreted it is, you can report and then -- the designated person has to call.

MS. NOWACK: I think if only one person is present--

MS. WILSON: If one person is present, we have to call 911.

And your question, Assemblyman Cryan, about what's the harm. That's an example. You're giving a Heimlich maneuver and someone else is making a phone call. You don't want everybody walking away from individuals

in need of care and assistance. And that may not be one person. It could be another kind of emergency going on. These are very vulnerable citizens. And if everybody leaves and goes to call 911, who is taking care of the individual? So you end up with organized chaos, because everyone is saying, "I got to call 911." Who's taking care of the person in crisis?

ASSEMBLYMAN CRYAN: Point made.

And the other thing is -- one of the other things I had a problem with is that the Department reviews all the calls, and the non-calls were-- Could you just reiterate for me, you're in favor of the Department reviewing non-911 calls. Is that right?

MS. NOWACK: No. No, no. What I'm saying is that the bill -- and I left it back in the office -- specifically lays out these penalties for a violation. And what the rules clarify is that there's a procedure for the Department to review where there was a violation or alleged violation, so that it sets up some review before the person potentially loses his or her license and is fined \$5,000.

ASSEMBLYMAN CRYAN: It said it here. I just didn't make it there. Thanks.

MS. NOWACK: Sorry.

ASSEMBLYMAN PAYNE: Thank you very much.

MS. NOWACK: Thank you.

ASSEMBLYMAN PAYNE: We have Bonnie Baker. (no response)  
Okay, Bonnie's testimony is here. She's not here.

Mary Rindosh.

**M A R Y R I N D O S H:** (speaking from audience) I'm Danielle's grandmother. I hope you'll read my testimony.

Thank you very much.

ASSEMBLYMAN PAYNE: Thank you, Ms. Rindosh.

Thomas Baffuto, The Arc of New Jersey.

**T H O M A S B A F F U T O:** Good afternoon, Mr. Chairperson, members of the Committee. I'm Tom Baffuto. I'm the Executive Director of the Arc of New Jersey. And thank you for holding this hearing this morning.

At this particular point in the hearing, I don't know that I have too much new to add. I think you've heard a lot of the concerns. From the Arc's perspective, we understood there was 60 days to review the regulations. We have a rather large board of directors. We take the time to talk to families, talk to our board, talk to agencies, health care professionals. We're in the process of doing that right now, and we fully expect to submit comments regarding the regulations once we've gathered all that information. It has been our experience, though, that Commissioner Davy and his staff are very responsive when we submit comments. And when they put regulations out, we've had a good track record of having them. So we are confident that some of our concerns regarding Danielle's Law will be heard.

One of the things, and this is not part of the testimony-- And as a matter of fact, what's in the testimony you've heard already. So I'm not even going to go through a lot of that. But some of the things that do concern me is -- as the Executive Director of the Arc of New Jersey, I've had a lot of opportunity to go out and visit providers and see things going on. And I know in the State of New Jersey there are a lot of good providers. And there are a lot

of good staff members making very low salaries, working hard, exercising good common sense, doing the right thing. But I also know it is not a perfect system. There's a human element in it, and that's causing us problems. I hate to paint everyone with a broad brush, but I think what we're all committed to here, today, is to get to the perfect system. And I daresay we all want that, and we must continue to work towards that.

And Danielle's Law is one more step in this process of continually trying to get to that perfect system. And clearly, one death is far too many, and that's what we're working towards here. In regards to Danielle's Law, similar comments we have. It's a critical issue. The regulations need to be clearer. And I guess sometimes when you're going from law to regulations, it's not always easy to make them clear. But the Arc would submit that the designated staff call policy may create confusion, waste time in the event of an emergency. We suggest an only direct call policy, as you've heard already. We also object to the wording that allows a staff person who has reasonable basis to believe that another staff person called 911, they would not call. We don't think that's a good idea either. When in doubt, call. And as we've heard, even if it's multiple calls, there's no harm, no foul. Let's exercise on the side of caution. Make sure those calls have been made.

We'd also like to see wording addressing individuals or in hospice situations. The last thing we want to do is not respect the dignity of folks in those situations. I think maybe the regulations could be a little clearer around some of those things. And I think clarity -- again, in life-threatening emergencies -- we feel some items just need to be clarified, as bleeding and burns. If we're expecting direct care staff to make some value judgments on some of those

things, we have to be very, very clear about some of those terms. And I think that we can address some of those things in the regulation.

The Arc of New Jersey has other concerns, but in the sake of time here, we'll submit those regulations. We appreciate your holding those hearings, and we look forward to submitting our comments and having the Department consider them.

Thank you.

ASSEMBLYMAN PAYNE: Thank you, Mr. Baffuto.

Diane Conway. Ms. Conway, identify yourself for the record please.

**DIANE CONWAY:** Yes. Good afternoon.

I'm Diane Conway. I'm the Executive Director of the New Jersey Association of Community Providers. We're a trade association that represents over 100 agencies throughout New Jersey to serve people with develop--

Sorry. Should I start over?

ASSEMBLYMAN PAYNE: Yes, please.

MS. CONWAY: Okay.

Good afternoon.

I'm Diane Conway. I'm the Executive Director of the New Jersey Association of Community Providers, NJACP. We are one of the trade associations that represents over 100 agencies that serve people with developmental disabilities in the State of New Jersey. We appreciate the opportunity to come today. I've submitted a written testimony, and I'm not really going to read that to you.

We don't have a problem with calling 911. Providers strive to work and provide a positive and safe and healthy environment for people that we serve. Many have the policy of calling 911. I don't know that there's a standard policy, whether there's a designee or not. I think that could create some confusion. And we don't have a problem with what we've heard today in terms of people calling, directly, 911.

We are in favor of the standards and the regulations that were put out. We do have some concerns. It is in the beginning of the comment period, and we would like to take until November 6, when the comment period closes, to officially respond to them. I think you've heard most of our concerns, though, already today -- the Do Not Resuscitate and the hospice situation is our major concern with the regs, the proposed regulations right now. We do feel that people have the right to dignity and respect in that kind of situation.

And that's really our major comment today. I'm sure that we can provide further, before November 6.

ASSEMBLYMAN PAYNE: Thank you very, very much. We appreciate your coming today to testify.

Any questions? (no response)

Thank you.

Peg Kinsell.

**P E G K I N S E L L:** My written testimony will be e-mailed to the Committee. I also don't want to take a lot of your time, but I want to add a few comments on behalf of the Statewide Parent Advocacy Network. We appreciate the opportunity to present testimony, and especially also want to

offer our thanks to the Assembly Oversight Committee for holding these hearings about Danielle's regulations.

As you know, as everybody said, Danielle's Law was signed by the Governor in October 26, 2004, after such a wonderful bipartisan effort, and to be a part of that and to advocate and work with the Legislature and the Family Alliance has been an honor for us and a learning experience all along.

I also come to you as a parent. I have three children, and one of my sons is a son with developmental disabilities. So I have my heart in this issue as well. It's never any parent's wish to have legislation designated with your child's name, because typically that means some kind of hurtful circumstance, up to and including the death of a child, is what the mitigating factor is behind that. When that is the circumstance, and then the regulations that are proposed actually define the protocol that caused the death, I think it's even crueler yet. Sorry, there's still an emotionality piece to this whole thing for me, and I apologize for that.

We have a couple of issues at SPAN. One is that we were impressed with Ms. Wilson's list of all the people and agencies that they sought input from when crafting the regulations. We found a glaring omission, though, in that consumers and advocates and family members weren't part of that group. I think that's been a mistake. We know how hard everybody's worked on that. And I think we might as well have these conversations now and try to get these things sorted out so this works for everyone.

A couple of other things that I just want to say -- I had some comments that the Executive Director of ABCD made, as far as the migratory faction that the staff has, and why it's so important for this policy to go across

the board -- whether it's private, whether it's developmental centers, no matter what the caregiver is -- that there is one single policy and everybody knows what it is and there's no question. We think that's imperative.

We also know, because chiefly we advocate, with children, better in educational settings also. And because, as Assemblyman Payne had brought up earlier, the death of Matthew, also at Bancroft, was another situation where there was a designated professional and medical professional, and that child still was loaded into a van with no vital signs and carted around for an hour instead of having 911 and an ambulance called. Part of the problem that we feel -- and there's going to have to be other conversations and more testimony about this issue -- is that-- In a situation like Bancroft -- where you can have a child or an adult in a residential placement -- under Department of Education regulations, under Department of Human Services regulations, under Department of Health and Senior Services regulations; and not knowing or not having real clarity on who the primary caretaker is, where the primary responsibilities are -- are how these kids fall through the cracks all the time. And it's time that we start to look at this and start to have some definitive accountability about our kids and our adults, because they're members of our family. And you know what? They deserve to live just like everybody else does.

I appreciate again -- I apologize for the emotionality, but I appreciate your time. And anything that SPAN can do to help in the process, we'd be happy to.

Thank you.

ASSEMBLYMAN PAYNE: Thank you very much. You needn't apologize for the emotionality at all.

Any questions here? (no response)

Thank you very much.

Ms. Janie Hostetler. (no response) We have copies of it. Very good. Thank you very much.

I believe that's the extent of our testimony, people that are here. We do have a letter from Congressman Rush Holt, who says that he "believes that the regulations for Danielle's Law should reflect the spirit and original intention of the law. The law, which was conceived to prevent any future tragedies like that of Danielle, focuses on specific emergency procedures to be taken by care facilities in our state. As you may know, I plan to introduce a bill to bring Danielle's Law to a national level. I am doing so to assure that families all over the country can feel confident about the care of their loved ones. Thank you for your invitation and I wish you success."

The letter was -- pointed out that he had been invited to speak at the Family Alliance rally, and he was sorry that prior commitments did not permit him to be there. However, I might add that Congressman Donald Payne is also joining with Congressman Rush Holt to support that legislation.

We have a letter from Senator Joseph Vitale. I think it was mentioned earlier that an Assembly hearing should be held by the Senator. I'm sure if he feels that it's necessary, he can certainly take the initiative to do exactly that. But I'm sure that the testimony that we have heard today will be shared with and will be available to Senator Vitale and his staff, as well.

We have a letter from Tom Kean and Eric Munoz, both of whom have expressed their concerns.

Guy Gregg appeared with us.

And also Michael Panter and Robert Morgan, Assembly people from the 12th District.

I think that concludes this hearing, but let me just say that, obviously, the comments that we have heard today, the testimony that we have heard today should certainly clarify, should certainly highlight the very extreme concern that many of us have with the manner in which the regulations so far have developed. We do know that this is a procedure, the process by which -- and this is appearing in the public commentary. But there were some concerns that there were other people who were privy to discussions prior to this period. And I -- one of the things we want to underscore is that those of us who may be stakeholders -- who are not the providers, not the unions, etc. -- should also be given as much consideration, at the same time, as those who helped to mold what we've come up with.

What we've talked about today is that we have a set of regulations, draft regulations, that we have discussed; and we are recommending a number of changes, so that they, in fact, do carry out the law as it was intended. But these draft regulations came about as a result of meetings that were held already with certainly some groups and not with the clients. And I think that that's what we are somewhat concerned about. That what was presented to us was as a result of input from care providers and other people of interest, and not by the stakeholders. And I think that's one thing that we want to make sure that we do correct. And I am certain that my concern, at least, is that training -- and I was going to say I'm certain that this fact list is not really what we're talking about, as far as being a curriculum or training, etc. I'm certainly going to recommend that there be uniform training. That there not be -- the organization

-- the young man, representing that organization, states that he's not sure whether each of his -- the 12 institutions that he represents will follow the same protocol.

I think that it's extremely important that we have credible curriculum and training for people, so that regardless of whether they're working in the State facilities or private facilities, that when there's an emergency and 911 applies there, the need for it, that, in fact, everyone is able to be trained to do that.

And the last thing I'd like to say is very, very key -- very, very key. That people who are, as we've stated over and over again, people who are not being paid very, very much for the work they do -- yet we know that these people are dedicated to the clients they work with; we know that -- that they do have judgment. And I think what we need to do is look at the possibility of somewhere -- we've talked about this time and again -- about making sure that the kind of remuneration that these people receive is sufficient so that they themselves will be able to not only provide care for others, but they themselves will be able to provide health care and whatnot for their own families. We know the situation, when so many of them cannot even afford to have insurance for themselves. So that seems to be a dichotomy that needs to be taken care of.

But we thank you very, very much for your being here, for the testimony -- will be extremely helpful, and I'm sure that the Department has listened very, very carefully at everything that we've talked about today. And I think that it will be reflected in the regulations that will finally be promulgated.

Thank you very much.

And Mr. Cryan would like to--

ASSEMBLYMAN CRYAN: That's my question, Terry. Without going through everything line by line. First off, are the minutes of this hearing considered public input for you, for these regulations? Are they good enough.

MS. WILSON: Yes.

ASSEMBLYMAN CRYAN: Okay. So what happens from here?

MS. WILSON: Well, if I may add additional clarity to the issue of input from major stakeholders, so I can talk about the input process. Our Department of Human Services' integrity, and quite frankly mine, as far as I'm concerned, is important. And we did ask for conversation, not specific input to any proposed regulations, but to listen to people. And I have to apologize to the families if they do not believe they had an opportunity for input. There was the same. I have held, and I still continue to hold, a parent advisory committee, in which some of the families that are here today are represented. So we have discussions. I'm cautious. The Department is cautious about how we seek provider input from major stakeholders. We don't give out papers. We have a discussion and dialogue, so that information can be included in some -- anything that we do, and in this case, in Danielle's Law.

So from our Department's perspective, and really more from my perspective, through the parent advisory group which I hold with these families that are represented here, we had conversations. And I listen to them regularly on the telephone. I think they would share that with you. So I think it's important to hear that there was opportunity for dialogue. And that dialogue's with families, with providers, with staff, etc.

So I appreciate the opportunity. So the next step is, after the closing of comment period, we will take each comment -- some of them may be the same, like we heard today -- but they get combined and we put that comment in the *Register* with an answer. Some will cause us, certainly, as I mentioned in my testimony, to make a change. And that's what the comment period is for. It's an opportunity for change. And for everybody that's going to be impacted by Danielle's Law, they have a chance to make a comment on our proposed rules.

ASSEMBLYMAN CRYAN: So, through the Chair, can I request that when the comment period finishes, that when you go -- your next step is to do the *Register* and then put that out. Would you forward, through the Chair, a copy for each member of this Committee--

MS. WILSON: Yes.

ASSEMBLYMAN CRYAN: --so that we can have it without having to search through the *Register*, to be candid?

MS. WILSON: It would be my pleasure.

ASSEMBLYMAN CRYAN: I appreciate that. And also, is it-- And I admit, I just haven't read the *Register* lately -- I'll 'fess up to that. Do you highlight -- this is what was our original regulation and this is what we're doing now? Is that how it's done?

MS. WILSON: Yes.

ASSEMBLYMAN CRYAN: Okay. All right.

Thank you.

Oh, by the way, how long after the closing period, after November 6, does that happen? And are these rules the binding rules?

MS. WILSON: Where's John?

ASSEMBLYMAN CRYAN: Are these the regulations until the *Register* is done, and how long does it take -- how long is that period, November 6 to when?

MR. EVANOCHKO: Okay. Normally what will happen is when we prepare the adoption of the regulation, we will have that reviewed internally and by the Governor's Office. So normally we have to give for an adoption approximately 60 days. So as soon as we have had a chance to go through all of the comments, prepare a response, and put in the amended wording, which would indicate what was there in the proposal and what we were proposing to adopt in the adoption, then we would be able to get that out. Generally speaking, it would be about three months at best, from the time the comment period closes.

ASSEMBLYMAN CRYAN: And until that period, are these the regulations that-- The ones that are proposed, are they in effect?

MS. WILSON: No.

MR. EVANOCHKO: No, they are not.

ASSEMBLYMAN PAYNE: What's in effect?

MS. WILSON: I'm sorry.

ASSEMBLYMAN CRYAN: What's in effect?

MS. WILSON: The law. And the law, as everyone knows, clearly says call 911. The regulations operationalize the law. And therein is a lot of today's comments, concerns, and confusion. And also, my comment to you: my concern's, quite frankly, in a developmental center, of an organized chaos, because everyone will call 911. It is important. We're not asking to give anyone

any exemption. I want to make sure everybody is taken care of. That's what our Department wants. I don't want everyone to walk away to call 911 and leave vulnerable people.

ASSEMBLYMAN CRYAN: Okay. And I know you caught my flavor here, and I'm sure the others as well, so I think I would also be remiss if I didn't say, also, thank you. You sat here for three hours, and let's face it, you don't have a-- This isn't always a mutual friendship room. So I appreciate the fact that you stayed here and you take it to the end. That's reasonable.

MS. WILSON: It's very important to our Department.

ASSEMBLYMAN PAYNE: Thank you.

I guess my understanding is that until the regulations are in place, Commissioner, this fact sheet is what people are supposed to follow? I mean, they should follow, or what?

MS. WILSON: That was used by the Division Director, Jim Smith, to just provide some additional information. It wasn't for training. It was a fact sheet, a ready reference sheet. The training that agencies already have in place, they're expected to follow. They were told to follow the law, call 911, and to incorporate that in as part of their training.

ASSEMBLYMAN PAYNE: Thank you.

Just in conclusion, let's always keep in mind that the 911 call should be for an ambulance and not a hearse. I think that's something that really underscores this entire thing.

Thank you very much.

MS. WILSON: Yes.

ASSEMBLYMAN PAYNE: This meeting is concluded.

**(MEETING CONCLUDED)**