
Committee Meeting

of

ASSEMBLY HUMAN SERVICES COMMITTEE

*"Testimony from invited speakers who will discuss
the policies and practices of developmental centers"*

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

DATE: June 15, 2006
2:00 p.m.

MEMBERS OF COMMITTEE PRESENT:

Assemblyman Joseph Cryan, Chair
Assemblywoman Sheila Y. Oliver, Vice Chair
Assemblyman Peter J. Barnes Jr.
Assemblywoman Nilsa Cruz-Perez
Assemblyman William D. Payne
Assemblywoman Valerie Vainieri Huttle
Assemblyman Michael Patrick Carroll
Assemblyman Guy R. Gregg
Assemblyman Eric Munoz
Assemblyman David C. Russo



ALSO PRESENT:

Michele LeBlanc
Irene M. McCarthy
*Office of Legislative Services
Committee Aides*

Nicole Brown
*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 JOSEPH CRYAN (Chair): What I want to do is move on to the discussion portion of the meeting, which is going to go over the developmental centers in DDD.

I want to make a couple comments first, because the fact of the matter is, there's a lot of people here to talk. Time is time. And I just want to kind of go over how we're going to try and run this. And I want to thank the members of the Committee for your input, and see how we do.

What we're going to do is, we're going to bring up the folks from the developmental centers and the Department of Human Services first, ask if there are some brief comments if you have them, and then have the Committee give questions. In the same-- Then we'll ask for the associations and the provider agencies. We'll do the same. And then the families.

I've been trying to work as to how to do this best. And I really want to do this in an open dialogue. What I'd like to do is to take this Committee opportunity -- maybe through the prerogative of the Chair, but it's certainly up for discussion with members -- that we look for ways together that we can look for areas of improvement, whether it's legislatively or cooperatively.

Look, the reason we're here is -- let me be candid -- is because the advocates and the agencies have so many stories that, frankly, break people's hearts here. There is probably no other way to put it. What I want to try to do is, as best we can, to stay off individual stories, and work on policies, procedures, and issues together that we can highlight and look for ways to correct -- because that's what this is about, looking for areas of improvement. Because the consumers here-- You guys know it first hand.

You know it better than any member of this Committee. We want to work together to get a solution to issues.

So I don't want to be rude. I know we have individual stories that are going to be difficult. But there's a reason for that process, and I hope you respect it today.

I will tell you, as best we can, we want to have a dialogue.

So that's going to be our approach. I've spoken to a number of you about it, giving you time -- by the book, all right?

But we'll call up, first, Carol Grant, and the representatives from the developmental centers. And I believe the folks that are here are from Woodbridge, the North Jersey Developmental Center, Woodbine, and New Lisbon. And I want to take a little extra special note, and tell the folks here in this room that Bancroft was invited today, chose not to -- at the last minute -- attend. And I can assure you that those of us on the Budget Committee (*sic*) will not forget that.

Is that a fair way to put it, Bill?

I want to go over a couple of the ground rules here. This is on the mikes. And you can just correct me any time you want here.

Essentially, the middle mikes get you taped.

MS. LeBLANC: The middle four mikes get you taped.

ASSEMBLYMAN CRYAN: The middle four mikes get you taped, the outside mikes don't.

You're out of luck on the end, but we'll work on that as we get there.

Carol, why don't we lead with you?

I want to ask everybody to introduce themselves. If you have comments, make them. And then we're going to have the Committee open up in a dialogue-type format and see where we can go from here.

CAROL GRANT: Do you want the introductions first?

ASSEMBLYMAN CRYAN: Please.

MS. GRANT: I'm Carol Grant. I'm the Director of the Division of Developmental Disabilities.

ROGER PUENTE: I'm Roger Puente. I'm the Assistant Director for Quality Management.

GREGORY FENTON: Good afternoon. I'm Gregory Fenton. I'm the Deputy Director of the Division of Developmental Disabilities.

JEFFREY SCHROEDER: I'm Jeffrey Schroeder. I'm the Chief Executive Officer of New Lisbon Developmental Center.

JOHN DOUGHERTY: John Dougherty. I'm the Chief Executive Officer of Woodbridge Developmental Center.

ROBERT ARMSTRONG: I'm Bob Armstrong, CEO of Woodbine Developmental Center.

BRUCE WERKHEISER: Good afternoon. My name is Bruce Werkheiser, and I'm the Chief Executive Officer of North Jersey Developmental Center.

ASSEMBLYMAN CRYAN: Okay.

Carol, do you have opening comments?

MS. GRANT: I do. I will try to be as brief as I can.

On behalf of Commissioner Kevin Ryan, I really want to thank the Committee and you, Chairman Cryan, for providing the opportunity today to update the Committee on improvements made in our Division

over the last few years to ensure consumers in institutional community-based settings are protected and afforded opportunities to function with as much self-determination and self-direction as possible.

Over the last 20 years, DDD operations have focused on expanding the development of services in community settings, while reducing reliance on developmental centers. The challenge for the Division has been the increase in numbers of people receiving services. About 1,500 people enter the system nearly every year. And the breadth and diversity of their needs--

I want to emphasize that the health and safety of the people we serve, and the quality of the services we provide are our highest priorities. There are external and internal efforts made to ensure that we reach our goals in these areas. Considerable investments have been made between 2002 and 2006 to improve the quality of care in our institutions. Specifically, developmental center appropriations have been increased by \$95 million, which is about a 30 percent increase, over that period of time. Fifteen million dollars in physical plant and infrastructure upgrades have also been added. And we have, in fact, augmented our staffing complement in developmental centers by 1,000 new employees.

In developmental centers, quality is monitored internally and externally. The developmental centers are inspected by both the New Jersey Department of Health and Senior Services, and the Federal Centers for Medicare and Medicaid Services, CMS. These surveyors review client protection, active treatment, health-care services, as well as behavior management. When conditions are cited as needing improvement, these surveyors return to ensure improvements have been made. New Lisbon

Developmental Center was decertified by CMS in 2001 and recertified in 2002. I am happy to report that all seven centers are currently certified. Two facilities, New Lisbon and Woodbridge, are under U.S. Department of Justice consent agreements. Compliance with those agreements is monitored by an independent team at six month intervals.

But we're not satisfied with an exclusively external process, so we have placed heavy emphasis on developing a self-correcting system to manage risk and to minimize exposure of consumers to unsafe situations. We made this shift toward a risk management culture by doing some of the following:

We've created incident response units at all seven developmental centers to serve as an early alert mechanism for management. These are independent from the service delivery system and give a more objective review of serious incidents.

We've contracted with Labor Relations Alternatives, a leader in the field of incident management for the developmentally disabled, to provide state-of-the-art training to all staff on protecting people from harm, to train and certify investigators, and to build the State's capacity to continue this training.

We have upgraded the tools available to developmental centers to manage risk and improve the quality of services, using methodology such as revised manuals; standardized, computerized review tools; improved tracking and trending of incident data; ongoing technical assistance for issue resolution; and practice drills to evaluate medical emergency response.

We have increased the transparency through critical committee processes -- including incident management committees, human rights

committees, and behavioral support committees -- to ensure that restrictive measures are limited, and to recommend measures to resolve the issues these committees identify.

We also have had great success in significantly reducing the use of restraints. Using current bodies of research that point to new ways of addressing challenging behaviors, we have achieved the significant reduction in the use of restraints and restrictive procedures. Most noteworthy, since 2000, the use of highly restrictive mechanical restraints in developmental centers has had a significant decrease. There has been a 76 percent drop when used with an approved behavior plan, and a 46 percent drop when used in an emergency.

Highly restrictive mechanical restraints are used with a small percentage of people living in developmental centers. In 2005, they were used with 1.2 percent of the individuals as part of an approved behavior plan, with 36 total, and four of the individuals accounting for most of the use; and 3.5 percent, or 108 of people, in an emergency -- eight of these individuals accounted for most of the use.

Additionally, and I know it's probably of interest to the Committee, as a result of a recent serious vehicular accident involving residents of our North Jersey Developmental Center, the Division has reaffirmed, in writing, its strict guidelines regarding the transportation of individuals in State vehicles, and the requirement for seat belting and wheelchair tie downs, regardless of age or seating position. And this is pending the issuance of a Department-wide policy on this issue, which is expected to be -- to come forth shortly.

Managing risk is one-half of the equation in serving people with developmental disabilities wherever they live. The other is assuring quality of care and outcomes. Toward this end, we have done the following in our developmental centers:

As I've indicated, we've added 1,000 staff. We initiated person-centered planning. After a review of national best practices, we have created a new IHP process -- the individual habilitation plan -- that really begins to focus on individual's goals, desires, and interests, increasing opportunities to make personal choice and to become part of the community while still meeting Federal funding requirements. Person-centered IHP will be implemented at all developmental centers beginning September 2006.

We have improved psychology and behavior services to individuals with challenging behaviors. The Division has adopted the use of positive behavioral supports. We certainly have made a great effort to do this in our institutions. We are beginning that process in the community. In the institutions, the Institute for Applied Behavior Analysis, IABA, is an international leader in the field of positive behavioral supports. They have provided in-depth training on conducting functional behavior analysis, and providing positive behavioral supports. They have also trained Division staff to provide ongoing training, so that we're not constantly relying on the use of consultants to do that, and that it becomes part of the Division's normative process to do that.

We are, in fact, stepping up community placements. Over a period of five years, we've both had funded initiatives, and not had funded initiatives, to do that. And about 450 individuals have left. But there has

been a recommended -- in the Governor's '07 budget -- a significant investment of \$50 million to address this issue, which also addresses Olmstead mandates, to begin to reduce the number of people living in institutions from the current 3,053 to 1,500, over the next eight years.

Along with community capacity building, the first 180 people are expected to move to community settings over the next two years. DDD and its stakeholders recognize the time and planning such an important endeavor will take, and the importance of building appropriate community supports in order to move people out of developmental centers. It is equally important to support people who currently live in the community by enhancing and strengthening the current structure, and creating a framework for a continuum of community service designed to meet the diverse needs of people served, and reduce reliance on developmental centers. It is as important to divert people from the front door of institutions as it is to allow people to leave institutions to live in the community, and the kinds of continuum of services that needs to be built has to address those issues.

We are committed to providing full integration and assessing the infrastructure so that we understand -- from assessing individuals currently in institutions and looking at our community resource inventory -- what are the gaps that need to be filled in order for us to do this safely and responsibly.

We have put as much effort into bringing the kinds of health and safety, and management of risk, and quality outcomes to the community. We have spent the last three years implementing our five-year

plan to build a new platform that supports an expanded array of services that can address people's needs for a lifetime.

As a result of our -- of an external July--

ASSEMBLYMAN CRYAN: Carol.

MS. GRANT: Would you like me to move along?

ASSEMBLYMAN CRYAN: Yes, that's enough.

Just a quick follow-up before I ask someone else to speak.

Is there a seat belt policy currently -- just following up on that accident?

MS. GRANT: There are seat belt policies.

ASSEMBLYMAN CRYAN: Really?

MS. GRANT: The goal is to consolidate those and have one single, consistent, Department-wide policy affecting all Department programs. And that is under construction at this point. It should be issued shortly.

ASSEMBLYMAN CRYAN: I don't want to fall into a tome, but I have to believe that most of us up here are kind of amazed that we don't have something as basic for disabled folks as a seat belt policy, uniformly. Would that be a fair way to put it?

MS. GRANT: I appreciate the concern, and I agree.

ASSEMBLYMAN CRYAN: Okay.

MS. GRANT: I'm not going to disagree.

ASSEMBLYMAN CRYAN: Who's next?

Anybody else want to follow up with comments?

I don't need you to read the sheet of paper we have. Do you have comments, or areas that you want to talk about or highlight for your facility, or anything like that?

Anybody? No? Yes?

MR. SCHROEDER: I would just like to mention a few things that we've done at New Lisbon. We've been in the settlement agreement with the Department of Justice now for about two years. And in each of the four monitoring reports -- and this is a team of experts that comes in -- nationally recognized experts -- that comes in twice a year and really does a thorough review of the facility. And we have been making very good progress. In each of the four reports-- In fact, the monitor has acknowledged, and I quote, "the extraordinary steps that the Center has taken to meet the provisions of the settlement agreement."

Just a few things to highlight, and I will just give you a few statistics. I won't go into all the detail. Since 2001, we have decreased the population by 26 percent at the Center. This has created additional program space and living space for the people that they didn't have previously.

At the same time, the staffing at the Center has increased by 15 percent. So you can see, with the decrease in population and the increase in staffing, we have a much better staffing ratio than we've ever had.

We've increased -- decreased injuries by 66 percent, and decreased the use of mechanical restraints by 69 percent.

ASSEMBLYMAN CRYAN: When you say 69 percent -- from what to what, in terms of a number?

MR. SCHROEDER: I have that here. I can look it up for you.

ASSEMBLYMAN CRYAN: Roughly.

MR. SCHROEDER: In 2001, we had 4,138 restraints. Oh, I'm sorry, that's injuries.

You're looking for restraints, Chairman?

ASSEMBLYMAN CRYAN: You can give me both, the 66 percent in injuries, and the 69 in restraints.

MR. SCHROEDER: The injuries were, in 2001, 4,138. And these are even minor injuries -- even a scratch on your finger.

ASSEMBLYMAN CRYAN: Out of a population of how many?

MR. SCHROEDER: Five hundred and seven.

ASSEMBLYMAN CRYAN: Okay, 507.

MR. SCHROEDER: At that point, it was 690 people.

ASSEMBLYMAN CRYAN: Okay, so a 690 population in 2001 had -- of all types of injuries -- 4,169.

MR. SCHROEDER: Thirty-eight, 4,138.

ASSEMBLYMAN CRYAN: Oh, 4138. Okay.

MR. SCHROEDER: The most recent statistic is 1,391.

ASSEMBLYMAN CRYAN: And for that population which is now--

MR. SCHROEDER: For 507.

ASSEMBLYMAN CRYAN: What do you do differently?

MR. SCHROEDER: We've really concentrated on risk management systems. I think our biggest vulnerability with the department -- with the Center for Medicare and Medicaid Services -- was that we didn't have good risk management systems.

We hired, along with the Division, experts who helped us develop a system. We followed up. We train staff. We implement the system, Center-wide, and we take it very seriously. I sit in on a meeting every day to review all the incidents that occurred at the Center. And we're trying to take proactive actions to prevent these types of things from occurring. And, so far, it's been successful.

ASSEMBLYMAN CRYAN: Okay. I'm sorry. It gives us some idea.

Let me ask you one other thing. The injuries -- how many are major, and how many are minor?

MR. SCHROEDER: I don't have that breakdown, but I can get that for you.

ASSEMBLYMAN CRYAN: Could you?

MR. SCHROEDER: Sure.

ASSEMBLYMAN CRYAN: I think, through the Committee--

Is it fair to say the Committee would want to see that?

We'd ask all of you, if you don't mind.

Give us, in the same rationale, the 2001 numbers, population, injuries; and then what your current year numbers are.

MR. SCHROEDER: I can tell you the vast, vast majority are very minor injuries. But I'll get you that breakdown.

ASSEMBLYMAN CRYAN: And do you-- The other members--

This is an open dialogue. If you guys have questions, just kind of pump in.

Let me throw one out, and then just go.

For the rest of you, do you have the same sort of risk management type approach to where we are, and the numbers as well, in terms of injuries? Are they in the same type of declining area?

MR. DOUGHERTY: John Dougherty, from Woodbridge Developmental Center.

We also are involved in the DOJ process. We are in the earlier stages of it. We've only had one monitor visit, which was last January -- this past January. We've made remarkable improvement since the original Justice visit, which was back in 2003.

One of the things we've been focusing on is the risk management issues. And what we do there, basically, is review every single incident that ever occurs. We look for trends, we look for different types of analyses that occur, we look for potentially pocket problems. We look to see if there are system breakdowns, and we correct those problems so that we can ensure that there is no reoccurrence of certain things.

I also do not have specific numbers, but we've had a reduction in our serious incidents. We still have the nicks, and the bruises, and the scratches that happen in everyday life to any kind of an individual. But all of our serious incidents have gone remarkably well down. Things like fractures or lacerations that need sutures are very, very small in number.

ASSEMBLYMAN CRYAN: Okay.

ASSEMBLYMAN PAYNE: Mr. Chairman--

My mike is not working. (referring to PA microphone)

Are all those on? Are any of those lights down there on -- the red lights?

ASSEMBLYMAN BARNES: We can put a man on the moon, but we can't talk across a table. (laughter)

ASSEMBLYMAN PAYNE: Risk management-- The question was asked-- Did anyone here anticipate that the question might be asked about injuries, and about the degree of injuries, or anything like that? We don't have any answers now. We don't know how many people were injured. I think you mentioned it -- that you can get that back to us.

Do we have any-- Did anyone anticipate that, and does anyone have any figures that we can use to compare with -- the degree of injuries, the number of injuries? How does that break down. I'm sure that-- You said you could get it to us.

Does anybody presently have that kind of information with them today, that might have anticipated that we might have asked some questions along those lines?

MS. GRANT: No.

ASSEMBLYMAN CRYAN: You do. (laughter)

ASSEMBLYMAN BARNES: My mike is working, Mr. Chairman.

My question and my concern, in your experience -- maybe it would go for all of you -- but anyone who's had a major incident in your facility -- what kind of a program do you have? And is it written, and are there instructions for the employees, the attendants of what situation -- when a situation develops -- when they call for help outside the facility, which to me is very critical and has been a problem?

Do any of you want to comment on that?

Yes, sir. The man in the white.

MR. SCHROEDER: Last fall, with the passage of Danielle's Law--

ASSEMBLYMAN BARNES: Yes.

MR. SCHROEDER: We were required to train all of our staff in the implementation of that law.

ASSEMBLYMAN BARNES: That's what I'm saying. Do you all acknowledge having a program in place -- that they are trained, and they know when to call?

MR. SCHROEDER: Absolutely. And every staff member at New Lisbon, who has been hired -- all the existing employees, and everyone who has been hired since the implementation of that law has been trained.

ASSEMBLYMAN BARNES: And do you all believe that that is a very important piece of your training program?

MR. SCHROEDER: Yes. It's part of our orientation for new staff. Before they actually start working, they get trained in that law.

ASSEMBLYMAN BARNES: It's one thing handling the matter in-house. They have to be alert and trained when they call the outside assistance. That situation -- Danielle's Law -- was very critical.

MR. SCHROEDER: Absolutely.

ASSEMBLYMAN BARNES: Thank you.

MR. DOUGHERTY: I just wanted to point out that Woodbridge Developmental Center is a very unique organization, in the sense that most people think of developmental disabilities -- you're thinking of cognitive problems, retardation. Woodbridge-- The greater problem at Woodbridge is dealing with medical and physiological problems. Over 65 percent of those individuals that are there-- There is 470 individuals at

Woodbridge. And about 65 percent of them-- Their major issues are medical and physiological.

Well before Danielle's Law was ever in existence, we had that process in place. We called it Code Blue. And we were always using the 9-1-1 system, anytime somebody had seizures, or if they had lacerations that needed sutures. So we were well into that practice.

ASSEMBLYMAN PAYNE: You said that you were well into that practice before Danielle's Law came into being, right?

MR. SCHROEDER: Correct.

ASSEMBLYMAN PAYNE: I don't know whether any of the others were. And if not, is there any communication between-- Is there cross-training, or anything like that? Obviously, then, Danielle's Law might have been -- Danielle's tragedy might have been avoided. If, in your institution -- Woodbine.

MR. ARMSTRONG: Yes, sir. At Woodbine Developmental Center, in Cape May County-- We are a large part of the Cape May County community. We've been involved in the 9-1-1 system from the -- in the community for almost 15 years now. And we are an integral part of 9-1-1 response.

ASSEMBLYMAN PAYNE: Let me stop you right there then.

When we were discussing 9-1-1 calls -- using it -- there was a lot of opposition from some centers and some of the providers, saying, "This is unnecessary. It's something that we don't really need. We don't know how we're going to do it."

I attended some of the training. I think I saw you at one of the-- I attended some of the training that was going on down there. And it

was-- At that time, we needed to continue to make sure that this was going to be implemented. But we had so much hesitation -- so much resistance, rather, from so many areas. And I wondered whether or not we were living in the 18th century, or what have you. Because you're telling me now that this system has always been in place in your institution -- or your center. And the other ones did not have it, and really raised a big ruckus about having to go through this training. "How are we going to do it? Who is going to be responsible for it?" My God, I'm amazed of what I'm hearing here today.

Continue.

MS. GRANT: I just--

ASSEMBLYMAN PAYNE: Who was just going to respond?

MS. GRANT: Can I make a comment though, first?

ASSEMBLYMAN PAYNE: Excuse me.

Were you getting ready to add something?

MR. ARMSTRONG: Yes, but I'll defer to Carol.

ASSEMBLYMAN PAYNE: I'd like to hear what you have to say.

MS. GRANT: Go ahead, Bob.

MR. ARMSTRONG: Thank you.

The 9-1-1 system that I speak of is-- Because of the remote rural location that Woodbine is in, we are forced to use as much of the local resources and support as we could get, in order to get the amount of care that we need for the men. And in that process, I worked closely with the Cape May County Emergency Management director and the local services so that we could offer support to them, as well.

The issue of the 9-1-1, in regards to the facilities, wasn't as much the lack of use of 9-1-1, but the degree to which it's being required. We have, on staff, trained, licensed physicians and registered nurses around the clock, who afford elite medical care. We then use our on-staff licensed EMTs and ambulances to do that transport. I think the issues -- or the concerns that arose were that the facilities were not being recognized for the amount of resources currently -- already there and involved.

ASSEMBLYMAN PAYNE: Probably because there were unnecessary tragedies that were coming about. The facilities wanted to be recognized for what was going on. Unfortunately, however, we did have a situation -- situations, rather -- where, unnecessarily, someone died tragically. It was the -- facilities resist being mandated to do this? Is that what it is? We're mandating this so that we can save lives when it's necessary and err on the side of caution.

We've also been told that, "My God, the responders are going to get to the point where they're going to be very resentful of all of the calls that they're getting." I talked to the emergency people. None of them resented it. There was not a single bit of resentment or concern that they would be getting too many calls -- from none of the responders.

ASSEMBLYMAN CRYAN: Have any of you gotten complaints from the responders in your area that there are too many 9-1-1 calls?

MR. SCHROEDER: I haven't.

ASSEMBLYMAN CRYAN: Anybody? I'm sorry.

MR. DOUGHERTY: Not as yet.

ASSEMBLYMAN CRYAN: No? Okay.

MR. ARMSTRONG: Sir, during the seasonal rush in Cape May County, where the population -- tourist population grows immensely, there is a concern that rises, just during this time of year -- available vehicles -- *rigs* they call them -- to respond to emergencies. Again, I maintain--

ASSEMBLYMAN CRYAN: Well, let me ask you then, this way. In the other nine months of the year, have there been any complaints from the responders in your area that this law has created too much work?

MR. ARMSTRONG: I have not gotten any feedback from them regarding -- in that direction.

ASSEMBLYMAN CRYAN: All right. Thanks.
Assemblyman.

ASSEMBLYMAN MUNOZ: Thank you, Mr. Chairman.

I'm trying to get my light on. (referring to PA microphone)

You know, Dr. Grant, I think I'll take this opportunity to publicly scold you.

I was involved directly with the automobile accident -- the van accident -- that happened about a month-and-a-half ago. I was really shocked.

The Chairman asked about seat belt laws and policies, and this, that, and the other thing. If we take a trip with our family this weekend, we're not going to do what happened in that vehicle. And really, the people were hurt unnecessarily. We had some people at our hospital that were hurt unnecessarily. So I think I'm going to take this opportunity to personally scold you for that, because that shouldn't have happened.

I don't know what else to say. It affected people's lives.

ASSEMBLYMAN CRYAN: Does the law not apply to-- The Click It or Ticket It law -- does that not apply to people who have a disability?

MS. GRANT: I believe the law relates to the two front seats, for people 18 and older. I don't agree. I think everyone needs to be belted, regardless of position or age. And that's the instructions we've given.

ASSEMBLYMAN CRYAN: When will the policy-- Carol, when will it be in? And when will it be trained so that there is no-- When will that be done?

MS. GRANT: Well, the Division has already taken the prerogative of issuing an interim guidance to all of its operating entities -- that this is to happen. And the Department expects to issue its policy, which will be Department-wide, shortly. I don't know exactly when, but it's very imminent.

ASSEMBLYMAN CRYAN: Like in the next two weeks, can we expect--

MS. GRANT: I believe that it could be that imminent, yes.

ASSEMBLYMAN CRYAN: That would be-- This isn't really rocket science, right? Put the seat belt on.

MS. GRANT: Well, I think we're looking at what's national best practice in this area, how do we make sure of safety, what kinds of training do we need to do, those kinds of issues.

ASSEMBLYMAN CRYAN: I'll tell you what. I'm not an expert, but I bet that if you put in the policy, "click it," that would probably be--

MS. GRANT: We've already said that.

ASSEMBLYMAN CRYAN: I've got to tell you, those articles are just -- they're brutal. I mean, it's just such a disrespectful thing for--

MS. GRANT: I accept the comments.

ASSEMBLYMAN CRYAN: I'm sorry, Assemblywoman.

ASSEMBLYMAN PAYNE: We have a lot of policies. Just pick one of them. I heard that there were a lot of policies for seat belts. Maybe pick one of them, and maybe one might work.

ASSEMBLYMAN CRYAN: Assemblywoman, I'm sorry. Go ahead.

ASSEMBLYWOMAN VANIERI HUTTLE: I would just like to make a comment about the injuries. I, quite frankly, was astonished. I guess it was back in 2003, you quoted -- or you made a statement that there were 4,000 injuries to a population of 500 people.

It just seems to me that when you keep on saying that most of them were minor, obviously there were probably a few who had traumas, facial fractures, and lacerations that I've been reading about. And we didn't really address the neglect or the abuse of providers. And, obviously, there has to be some sort of improprieties, I would think, due to some of these injuries -- whether it's staff supervision. There's got to be oversight. Is there anything internally that you do? Do we get to see the internal employees -- if there is any neglect or abuse? Is there anything on record that has to be provided to the State?

MS. GRANT: We're talking about in the institutions?

ASSEMBLYWOMAN VANIERI HUTTLE: It seems to me there's just too many injuries happening. And there's got to be some of it due to some neglect and abuse of staff. And I don't know if you have an

internal policy that is made public, or what kind of oversight you do provide, as you have stepped up to have less injuries. To me, it's just alarming.

MR. SCHROEDER: We do have a policy that governs that. In fact, we have a very comprehensive, single policy on incident management, which I would also be happy to provide to the Committee.

MS. GRANT: I'd like to say, also, that we use the Department-wide system of unusual incident reporting, so that this does get filtered up to the highest levels, well beyond the institution and even the Division Director. It has been recognized as state-of-the-art. And it continuously identifies and addresses abuse, neglect, and exploitation. It's really the underpinning of our risk management system.

One of the things you should know is that, as we learn -- through our Department of Justice contact, or CMS certification around this area -- we share this information across all institutions so that we can encourage a culture of risk management that is continuous and has continuous quality improvement built in. We also have, obviously, the Administrative Order 408 that governs discipline of public employees in the event that there is abuse or neglect.

ASSEMBLYMAN CRYAN: I'll tell you what. Let me--

I just want to move on to one more topic. We've got other folks, as I mentioned. I haven't forgotten folks from the ARC, and Diane and Lowell, as well.

I just want to shift gears a minute.

And you can just follow up from there, Sheila, if that's all right.

Two areas: Communications-- The families all talk about the lack of the understanding when something happens. We talked about injuries earlier, incidents, and things like that. It's a consistent complaint. It's like pulling teeth, is what I hear all the time. And I have to be blunt here. Bancroft -- although they didn't, frankly, have the guts to show up today, or the decency -- is at the head of that list.

And I want you to talk for a moment about -- as a subject matter-- How do families get involved when there is an incident -- when there is a serious incident or, quite frankly, any incident that any family member, realistically, would want to know about? Let me follow it up, and then -- because I really want to stay out of Committee members' ways. I also want you each to at least touch upon your staff ratios, to how many -- to your population.

So those are two things I'd ask you to touch upon as we move on.

And, Assemblywoman, your question, whenever you're ready, after they go, if that's all right.

Anybody first? But, please, each one of you.

MR. DOUGHERTY: I guess I'll go first.

In regards to the communication of injuries: No matter what the injury is, whether it's a scratch or whether it is something major, the family is notified immediately. As soon as it is reported to our central office -- reported to the nurse's office -- the nurse-- After hours-- If it's anything after 4:00 at night, the supervisor of nurses will contact the family at home and say -- and describe the injury. If it happens during the day, Monday through Friday, it's the social worker's responsibility to contact the family.

Anything that is of any kind of a serious injury, it's thoroughly investigated. And the results of that investigation are then shared with the family, both verbally communicated by the social worker and in writing by our social work staff.

And just to answer the question on our staffing ratio: In direct care, we have one staff for every four client ratio. That's at Woodbridge Developmental Center.

ASSEMBLYMAN CRYAN: Why don't we just go left to right, if that's all right, from there?

MR. ARMSTRONG: Thank you, sir.

At Woodbine Developmental Center, we have a very similar approach. The level of injury that occurs-- Communication may be from the physician on hand, the RN who is assessing the situation, and then it's followed up by the unit management. And, at times, depending on the level, or the type of injury or issue, I get involved as well. A post-investigation estimation letter is sent to the family member or guardian, giving an indication of what went on and how we were going to -- what recommendations were made, and how we're going to prevent it from happening again.

And as far as our ratios are -- our staff ratios are concerned, I have 509 men who live at Woodbine Developmental Center, and 1,346 employees. I operate on about a one-to-six direct care staff to client ratio throughout the facility.

MR. SCHROEDER: At New Lisbon, again, it mirrors a lot of what John and Bob said happens at their facilities.

For the more serious incidents, typically -- or medical conditions -- typically, the physician will call the family and talk to the family. But in the vast majority of cases, it is done by a nurse. We use our discretion on when to call the family. It is always within the next working day. Some families would like to be notified at any time, and we duly note that and make sure that the families get called, even in the middle of the night, if that's their choice. Other families chose to be called at a more normal hour.

Our staffing ratios are similar to Woodbridge. It is one to four when residents are awake. When they are sleeping, it is one to eight.

MR. WERKHEISER: Mr. Chairman, we have very similar procedures for contacting families. Usually on day shift, we'll have a physician make that call directly to the family. If it's on off shift, it's going to be a registered nurse. And, again, we have similar procedures with -- which, if family members do not want to be called in the middle of the night if it's a minor injury-- If it's a significant injury or an illness, we will make that call in the middle of the night to let the family know that their son or daughter is being transported to a local hospital. The following day, a social worker will follow up with a contact to the family. And we encourage ongoing -- if it's a rehabilitative process, a broken limb or broken arm that needs follow up X-rays, we'll follow up with contacts to the families to keep them up-to-date on what the rehabilitative process is.

As far as our ratios go, we're currently at approximately a one to six ratio of clients to employees.

ASSEMBLYMAN CRYAN: Sheila, do you have--

ASSEMBLYWOMAN OLIVER: Thank you, Mr. Chairman.

I'd like to go back to the issue of transportation. And I guess I would direct my question to Dr. Grant, because my question refers to the entire population, not just those clients that are at developmental centers.

Is it required that everyone that transports our clients have a CDL? Is that a requirement?

MS. GRANT: Not at this time.

ASSEMBLYWOMAN OLIVER: And that probably is tied into the use of the type of vehicles that people are being transported in.

MS. GRANT: Correct.

ASSEMBLYWOMAN OLIVER: Because when I hear you say the two adults in the front have to be clicked in, and everyone else does not, that means that people with CDLs are not required to drive those vehicles.

MS. GRANT: Correct.

ASSEMBLYWOMAN OLIVER: That may be at the basis of the transportation problem. Because if I've got a driver's license, and I've been driving my four-door sedan most of my life, and then I come get a job working in the environment where I'm going to have that transportation responsibility, I really have not the requisite skills to drive eight people or nine people. So I think part of the policy has to be focused on the whole issue of CDLs. And I know that then speaks to cost of vehicles, and capital investment in the vehicles. So I think that's really what the basis is.

And anyone that drives in New Jersey -- we see people being transported, and we see, visually, the manner on the road in which those vehicles are driven. So I think that's part of the problem.

The other thing I'd like to know is, when you have community-based care, those organizations that you fund at the local level -- they are

then up to their own resources, in terms of who they can contract with for transportation? I see a lot of contracting going on in DDD.

MS. GRANT: Yes. Some agencies provide transportation directly, themselves, using their own employees. And other agencies do contract out. And they do have the ability, as 501C3s, or for-profit organizations, to do that.

ASSEMBLYWOMAN OLIVER: Have we provided any division or departmental standards to those subcontractor organizations? Because I think that's something else that has to be addressed.

MS. GRANT: I mean, the Division does certainly have a set of licensing standards that govern agency operations. In the last several years, the Division of Licensing has been centralized into the Department of Human Services. And I believe we have Jerry Schwazo (phonetic spelling), who might be able to help. He is the Director of the Office of Program Integrity and Accountability. But agencies are required to operate with our licensing standards, which we would be happy to share.

ASSEMBLYWOMAN OLIVER: I guess I'm just trying to focus--

MS. GRANT: On transportation.

ASSEMBLYWOMAN OLIVER: In the future, you need to take a look at these subcontractor transportation owner-operators. You need to focus some attention on that group there, because they're transporting a lot of your clients. And they're out there like Wild West City.

The other thing I'd like to know is, if we looked at these injuries, will we find repetition from center to center, in terms of -- is some

resident experiencing more incidents than others? Will we see that if we look at your data?

MS. GRANT: I might just add that this is one of the things that we look for. And that's why, when we talk about having a culture of risk management, that we are looking for patterns and trends, and we are looking for repetitive injury.

One of the reasons-- And our reporting requirements are very high, probably higher than other states. So we report, often, injuries that perhaps would not be required elsewhere. But, certainly, it was brought to our attention, by CMS and by the Department of Justice, that this was a critical issue. And every facility has addressed it. You might want to hear from the institutional CEOs.

ASSEMBLYWOMAN OLIVER: These are just things I'm trying to direct all of your collective attentions to, because I think it's at the basis of what some of the problems are.

MS. GRANT: We appreciate that. Thank you.

ASSEMBLYWOMAN OLIVER: And, lastly, I just want to ask about recruitment of staff. This is a tough job. And you've got to have a sense of a labor of love when you work in this environment. What experience are we having with the State-run facilities in maintaining, recruiting, and retaining people who really address these jobs as labors of love?

MR. SCHROEDER: I can tell you that one of the things that the Department has done, and the Division has done, is created part-time positions for us, which is something that we didn't have as many in the past. And now we have a great many part-time positions.

We find this to be an excellent way for us to see about new employees, so that we can kind of test them out. And, conversely, they can test us out a little bit to see if this is the type of career that they want to have. After six months, or four months, we can move them into a permanent position if they look like they're good employees, and this is a career that they want to move--

One of the things that we've also--

You spoke, Assemblywoman, of recruitment. We've started weekend recruitment, where our personnel people come in on a weekend to actually -- people who have full-time jobs can't get away from their full-time jobs -- actually can come to the center, be processed for hire. And that's been very successful for us.

ASSEMBLYWOMAN OLIVER: Thanks.

MR. ARMSTRONG: Assemblywoman, at Woodbine we have a multi-generation of folks that work there -- family members and extended family members. And the recruitment issue isn't as difficult as, say, up in North Jersey. They come based on some good recommendations from some outstanding employees that we already have. We have a low turnover. And it is a very difficult job. And you're absolutely right. It's a labor of love for most of them. And those folks do outstanding work for us.

ASSEMBLYMAN CRYAN: Let me-- I'm just going to move on, just in the interest of time.

One last comment, Carol: that is that the notification policy-- You just heard everybody speak -- a little bit of the same, but it's all a little bit different too. And how -- listening to it, sitting up here -- you could-- I can understand you sitting here, the frustration of people -- all well-

intentioned. This isn't shots. But everybody has a little bit different policy. One goes through the social worker, one is through the physician, one is day time, one is -- versus night time.

Just sitting here, you can clearly grasp why people would be so frustrated when it comes to something as basic as an injury to a loved one, which even -- I mean, three years ago, it was 4,138 -- right, four years ago -- and even now, at 1,391. Now I understand it.

What I'm telling you, Carol, bluntly, as the Chair of this Committee, and having looked around -- everybody on this Committee, as we were talking-- We need a uniform policy that recognizes that it should be family first. Okay? And if not, we'll legislate it. But we will look to you first.

With that--

ASSEMBLYMAN PAYNE: Who's accountable, Mr. Chairman? For the accident, for instance, who is accountable? Is anybody held accountable?

ASSEMBLYMAN CRYAN: Bill, I appreciate it. I've just got some time issues here that-- It's not meant to be rude.

ASSEMBLYMAN PAYNE: I understand.

ASSEMBLYMAN CRYAN: Here's what I want to ask you guys to do. Frankly, if I had enough seats, I'd actually ask you to come up here.

I want to ask, as we said, for the sake of time, for the ARC of New Jersey, and then for Diane and Lowell, to come up and give us -- I don't know, your thoughts on what we've had so far, ideas that explore.

And I want to kind of use this as a dialogue, even if some of you want to stay seated, if there's extra seats. But I'd like to ask--

I guess, Tom, are you speaking? (affirmative response)

Tom, come on up; Diane; Lowell.

Tom, why don't you go first? Just give us your thoughts. I guess I want to do this as a dialogue thing, more than anything else -- as opposed to speeches, as you can tell.

THOMAS BAFFUTO: Great.

First of all, Chairperson Cryan, I thank you for bringing the DD issues to the forefront. This is the second hearing that this Committee has held. And we appreciate that, because we want to look at the system. And we need a dialogue; and I think that's absolutely the way to go.

Certainly the ARC of New Jersey believes that all individuals with developmental disabilities have the right to live in an environment of their choosing, free of abuse and neglect, wherever they live, whether it be a developmental center, in the community.

And I guess we want to have a world that's safe for folks like that. Sadly, though, we do get calls, from time to time, from people living in their own homes with their families, people living in developmental centers, people living in community residences, where there is abuse and neglect.

And while we talk anecdotally-- I mean, we heard Gary Ruben (phonetic spelling), before this Committee, talk about how he desperately wanted to get out of a developmental center, and was successful. We also hear from other people who are very happy where they're living right now.

I think what it really comes down to is what we hear a lot about, which is the staffing, and really professionalizing that direct care staff. When we look at staff, it means training, making them feel important

about their jobs, really training in abuse and neglect, and all of those issues which we could spend time on, but I will go forward. It's also about infrastructure issues, and making sure that staff have the proper tools and things that they need to develop a safe and secure environment.

And, certainly, I think it's a culture of safety. We have the fortunate pleasure of having a safety guru on our board of directors, Fred Patterson, who is always talking to us about creating a culture of safety wherever people with developmental disabilities reside, whether it be in their own home with their folks or a development -- wherever it may be. And he is constantly pressing us to make sure staff have this vision of safety. We can do that. We can do a lot of training. But it really goes full circle back to the staff, and their attitudes towards people with developmental disabilities and how they feel about their jobs.

We could go into great detail. I know time is an issue. I'll pass it to my colleagues at this point.

ASSEMBLYMAN CRYAN: Either one next.

Go ahead, Diane.

DIANE CONWAY: Good afternoon.

Thanks again for having us, today. It is a pleasure to be here and speak about issues that are of importance to people with developmental disabilities.

I'm going to speak about the community, as I represent community providers. I really can't speak about developmental centers too well.

As Tom indicated, one of our biggest concerns and issues facing us is staffing. We are a human services industry. As such, the quality of

services for individuals with developmental disabilities is directly related to the quality of staff.

First and foremost is our ability to recruit and retain staff. The latest figures from our -- we do an annual salary survey at NJACP -- and the latest figures is that we pay direct support professionals -- which is what we're trying to call people who work directly with individuals with developmental disabilities -- we pay them \$10 an hour, on average, or \$20,800 annually. This, as a result, makes it very difficult for us to recruit and keep staff.

ASSEMBLYMAN CRYAN: Diane, can I interrupt you for a second? What's the average pay in an institution or center, roughly, if you were comparing?

MS. CONWAY: Well, I know that there's about a 40 percent disparity.

ASSEMBLYMAN CRYAN: Is that about right?

MS. GRANT: That's about right.

UNIDENTIFIED SPEAKER FROM AUDIENCE: About \$26,000 a year to start for direct care staff, around there.

ASSEMBLYMAN CRYAN: Around there.

MS. CONWAY: So it makes it very difficult.

Additionally, training is extremely important. And the training resources have not kept pace over the years with the needs. The training system was developed years ago for the community services, with a basic core of modules for direct support professionals. And this was delivered through lead agencies.

Well, since that has been developed, a couple things have happened. First of all, there are more programs, so there are more positions to train. There's a higher turnover rate now. So there are more times that a particular position has to be trained. And there has been a change -- a significant change -- in the skill level of direct support professionals, over the years, that we can hire.

Fifteen years ago, or 20 years ago, we were able to attract people who had a bachelor's level degree to work in group homes. Now we are hiring people who are -- have a high school level degree, who may have English as a second language. And the job has become more complex, and we demand more from our direct support professionals. So, clearly, there has been increased training needs. But the resources have not kept up with them. In addition, many agencies, in addition to this basic training, also do a lot of follow-up and in-home, ongoing agency-specific training throughout their tenure.

Many agencies have established various incentive programs to try to help with retention, which may-- These programs may get dissolved as resources diminish. Currently, there is a coalition that is looking at creating a statewide career ladder. Everyone agrees that this would be a great thing to do, but we need resources to implement it.

So NJACP really is recommending that a focus-committed plan to address direct support staff issues be created and implemented. There must be an investment in human resources in the community to improve our ability to recruit, retain, and train staff.

The second area that I want to quickly talk about is quality of care. We are all concerned about quality of care and offering not only safe

services, but services that will assist individuals with developmental disabilities to live the life they want to in the community. There are many factors that influence quality. I've already talked about a very huge one, staff recruitment, retention, and training. But there are others.

Flexibility of funding: There are many individuals who live in the community, right now, and who have lived in the community for a while, and who have aged or whose needs have changed. Yet, the resources to support them have not changed. So we need to address that, because this creates a gap between the individual needs and the funding support.

And then there's also increased accountability. The Federal government CMS, or Center for Medicaid and Medicare Services, has really increased over the past years. They are requirements of the State, and the State has passed those requirements for accountability onto us, the providers. So we need these systems to -- for staff to have this function -- to address this quality function in community services, and for increased technology.

So we have two recommendations. We recommend resources be dedicated to provide increased support needs for individuals with developmental disabilities as their needs change throughout their life. And we recommend resources be dedicated for quality management initiatives to establish internal systems of staff and technology, to comply with new Federal and State regulations.

And then we also have the other issues of the home repair, and renovation, and transportation needs that are also still there and that I've talked about before. Many of these recommendations have been included

in Governor Corzine's Human Services Transition Policy Group Report, so you can look at that.

Thank you.

LOWELL ARYE: Good afternoon.

I also want to commend the Committee for holding this hearing. I want to talk to you about ABCD and its member agencies.

ABCD's member agencies provide services to people with very significant, multiple and physical developmental disabilities, similar to many of the individuals who you just heard about earlier who live in Woodbridge. Unfortunately, the problem is that the resources available to ABCD members are not the same as those in the developmental centers. You heard that the developmental centers had over a thousand new staff. We don't have that ability. And the budgets over the last several years have not given us that ability. But my member agencies, who serve the same, identical population in the community, instead of in institutions, are trying to do what needs to be done with very little staffing ratios -- with as best staffing ratios as possible.

For this population, as you've heard already-- This population has significant medical frail issues, issues of transportation, staffing, and the like. We need more staff to do it. The bill that you heard earlier about fire safety-- The licensing regs in our -- the licensing regs say that someone has -- that the group homes have to leave -- have to be able to evacuate somebody within three minutes. My agencies -- who almost all of them are nonambulatory -- need additional staff to move those individuals out in three minutes. And they do it. But they don't really get the true staff, the

true dollars that they need for the actual costs to serve this population. And that's a real problem.

In addition, my agencies also -- because of the medical frailty of this population -- also have nurses, and they hire nurses and other significant medical staff to do that. But they do it by basically doing additional fundraising, and the like, because the actual costs are not provided by the Division.

So if we are going to move people out -- and your Committee just pushed forward a bill to actually do that, and to start to create a plan -- which I hope you all get posted before July 1 on the Assembly floor. That is a very important thing. But we need to ensure that there's funding available for that.

In addition, my member agencies have consumer and family advisory groups, which you were talking about. Many of these consumer and family advisory groups are linked to the board, not just to the executive directors, so that they know that -- what is going on with regards to the quality of services provided.

In addition, my agencies -- because of the medical frailty of the population -- have nutritionists, and all that, to do staff training on how to feed the individual and how to deal with some of those other issues.

I agree with Diane. The issues of staff training are important. Some agencies actually have their own career ladders in place and basically have done that. We have been pushing, for the last five, six, seven years, to move that forward within the Department. And we're hopeful, now, that there's some movement. But there has to be additional funds to deal with those issues.

In addition, the issue of staff -- of pay parity.

Mr. Chairman, you specifically asked the question about how much money does the average -- cost. It's not just salary. It's also benefits. The benefits, as you know very well, Mr. Chairman -- on the Budget Committee -- that the benefits the State employees get are phenomenal. The benefits that our member agencies have -- they try their best. They have some health benefits, but sometimes they're a little bit too costly for the individual's families. So they don't always do that. So, unfortunately, they have to go onto Family Care. So that also is an issue.

We really need to focus in on this, the aging of our population, which we have not focused in on. So many of these things that we're talking about are important things. We need to deal with those issues. We need to deal with issues of abuse and neglect. We have to deal with all those issues. But you also have to ensure that there is staffing available for the organizations.

I'm going to stop, now, and basically wait, if you have any questions.

Thank you.

ASSEMBLYMAN CRYAN: No.

In the interest of time, guys, I'm going to move on to the family members, because we did take some time. It's not disrespectful, it's just where I'm at.

Thank you.

The Family Care issue is really unbelievable. We really have members -- workers who are really on Family Care?

MR. ARYE: Unfortunately, yes, sir, they do. Because many of our agencies don't have the funds. They don't get it. And that's, unfortunately, the problem.

ASSEMBLYMAN CRYAN: It's tough. It is.

Thank you.

MS. CONWAY: They're the working poor.

ASSEMBLYMAN CRYAN: They're the working poor. They are.

Okay. The groups that are here for families: Peg, Kate, Marie, Frank, Helen -- who did I miss -- Kathy and Janette.

You guys know where we're going here, right? We just want to have a dialogue more than statements, as best we can.

How are you?

Why don't we do it this way? Why don't we go--

Why don't you lead. And then we'll ask everybody to introduce yourselves. And if you have comments, make them. We still want to know who you are.

Does that work for now?

KATHLEEN WIGFIELD: I think a few people have statements that they'd like to read, that are very, very good.

ASSEMBLYMAN CRYAN: I really-- We have them here. I think a lot of us have had the opportunity to read them.

MS. WIGFIELD: Okay. One of the big issues--

ASSEMBLYMAN CRYAN: By the way, everybody should know those statements will be in the record. That's very important they understand that.

MS WIGFIELD: I didn't write a statement. I didn't prepare anything.

I was listening to the directors of developmental centers here talking.

MS. LeBLANC: Excuse me, could you please introduce yourself for the record?

MS. WIGFIELD: Oh, I'm sorry. My name is Kathy Wigfield. And I want to thank you for having this hearing today.

One of the things that sticks out is the information-sharing with families. They're right, they do call you and tell you an incident occurred. They do tell you the injury. But if you ask specifics like, "What happened? Who was there--" "I'm not permitted to give you that information."

They also have-- The Division developed a circular. It's called "Circular 30," where parents and guardians are not permitted to have incident reports. A great deal of information is hidden from families when an incident occurs. And in terms of their investigations, investigations, investigations, it's all done for people, by people, who work for the facilities or for DDD.

I have had incident, after incident, after incident with my son. And there's no accountability. There's no answering to families, there's no answering for advocates. And the results of that was multiple deaths at New Lisbon Developmental Center. In the year 2001, I believe, CMS went in there and found gross neglect, gross abuses, which spurred the Department of Justice to go in there. And I can tell you story, after story, after story about the abuse and neglect.

ASSEMBLYMAN CRYAN: Kathy, do you mind if I ask you--

MS. WIGFIELD: Sure.

ASSEMBLYMAN CRYAN: Not that I don't -- I certainly care. You all know everybody on this Committee cares about this stuff.

Let's take New Lisbon for an example. And then I want to ask Carol about the incident reporting, and what Circular 30 means.

MS. WIGFIELD: Right.

ASSEMBLYMAN CRYAN: You heard us talk about some improved numbers here with New Lisbon.

It was New Lisbon numbers, right?

Give me your sense. Is the system -- just stay on New Lisbon for a second, without getting direct. Is it improving?

MS. WIGFIELD: Personally, no. They're getting better at paperwork, and they're getting better at their risk management issues, in terms of protecting the "facility and the agency." It's gotten better in the sense that they don't have the restraints -- the four-point restraints -- in the behavior support plans. But what I found, in the feedback that I get from other parents also, is that they call the police. They use Danielle's Law to call the police for behavioral incidences that occur, rather than really dealing with the issues and moving forward on incidences that occur.

I could give you examples if you want examples.

ASSEMBLYMAN CRYAN: No, I get the message.

Carol, can I--

I just want to shift over a little bit.

And then whoever is next-- And I apologize.

Carol, the incident stuff-- In particular--

MS. LeBLANC: Can Carol just come up here so we can hear her answer? Because she is not being recorded.

ASSEMBLYMAN CRYAN: Can you slide over one, Carol? I'm sorry.

MS. LeBLANC: Up here.

ASSEMBLYMAN CRYAN: You can join us up here. Why don't you take a seat?

I apologize.

MS. GRANT: I just want to bring my stuff.

ASSEMBLYMAN CRYAN: I'm sorry, Kathy.

MS. WIGFIELD: It's okay.

ASSEMBLYMAN CRYAN: Maybe this makes a little more sense.

Carol, are family members restricted from things like incident reports? Is there a reason?

MS. GRANT: Our records of confidentiality, and access to client and agency records, are, in fact, embodied in Division Circular 30, which actually are the regulations that implement New Jersey Statute 10:41.

Incident reports are discoverable -- I'm trying to make sure I have the right information here -- discoverable only under court order, in their full sense.

Jim, can you help me out on that. Is that about right?

Jim Evanochko is Regional Assistant Director -- had been our Director of Administrative Practice Office.

JAMES M. EVANOCHKO: Good afternoon.

I'll just take a minute.

My name is Jim Evanochko.

We do have regulations that were reviewed by the Attorney General's Office, in terms of confidentiality. We got advice from the Attorney General's Office as to what should be releasable to parents, and what shouldn't be.

The specific and usual incident report is an internal administrative document that's used in investigating and solving the problem, fixing the problem. So the regs do say that that is not a public document. We don't normally release it.

ASSEMBLYMAN CRYAN: How does-- If you don't mind me following up.

You guys just pipe in here.

How does a family member -- how does anybody -- get a sense of resolution that there's been a fix-it to a serious issue? How do we know that the corrective action has taken place? Let me put it to you that way.

MR. EVANOCHKO: I think you've heard each of the CEOs testify that what we do require, is that after the initial call to the family, we will give them a summary of what happened, what we found, and we will indicate whether or not there was something that required corrective action. We don't say what the corrective action necessarily is, whether it be discipline versus more training, or more staff, or reassignment of staff. But we do give them a summary, by policy, that we are taking actions to fix it, or that we didn't find that there was anything that was avoidable.

One of the things that's important to remember -- and I think I was sitting here listening to the reaction -- is that we heard that there were

4,000 injuries. And if you've got six or seven -- what was it, 500 or 600 people -- that's a lot of injuries. But I think the CEO from New Lisbon pointed out that this is all types of injuries.

Right now, I'll sit here and tell you I've got two types of injuries that would be reportable under our system. I got bit by my dog when I was playing with him the other night, and I stubbed my toe. Now, they're not anything that are life threatening, but these types of things are part of what goes into routine injury reports that we review in our developmental centers.

ASSEMBLYMAN CRYAN: One of the things we did here was ask for the breakdown.

MR. EVANOCHKO: Absolutely.

ASSEMBLYMAN CRYAN: And, again, in an effort to try and move forward--

It's pretty clear, though, that one's definition of *serious* sounds like it might be subjective. Is that a fair way to put it, because I see a couple heads nod?

And the thing is, if it's your loved one, you want to know what steps are taken so that they don't get hurt again. That's really what it comes down to. And we've got to work on a way to do that. You just can't have the type of reaction you just heard, and we've got to do something. And, obviously, I can tell you now, the Majority staff is going to give us Circular clarity on the statute. And what we can do, we'll do. There's got to be something. But you have to have a confidence level that your kid or your loved one is going to be safe, next shot out. And I think that's really what the problem is.

I'm sorry. Go ahead, Kathy.

MR. EVANOCHKO: I agree.

MS. WIGFIELD: Can I make a comment here?

ASSEMBLYMAN CRYAN: I'll tell you what we're going to do. And I'm sorry; I'm talking way too long. I've got to tell you, I'm up against a caucus here.

I'm going to go left -- folks to your -- to my -- your -- my left, and then to the right, and then we'll see where we go.

MS. WIGFIELD: I just want to ask one thing.

When they give you your reports about incidences that occur, could you also ask about how many sexual assaults occur in the facility?

ASSEMBLYMAN CRYAN: Yes, we can do that. Right?

Guys, any problem? (no response)

That's fine.

Thank you.

J A N E T T E V A N C E: Thank you, Chairman Cryan. Thanks for having us here today.

I gave you a statement.

I'm Janette Vance, from The Family Alliance. I have a written comment.

And I wanted to let you know that the answers to some of the questions that you posed to the developmental centers--

Is there a problem?

MS. LeBLANC: The Hearing Reporter is just asking that you speak into the mike so that you can be heard and recorded.

MS. VANCE: How is that.

MS. LeBLANC: That's better.

MS. VANCE: Thank you.

I wanted to let you know that some of the answers to your questions may already be in front of you. I brought you presents today. Each of the members got a CD from me.

And a lot of times-- I tune into your hearings all the time when I'm folding my laundry. And I notice that a lot of times commissioners will come before you, and they'll tell you what the report said, or what the Feds are saying. And so you're always getting it through someone else. So I thought maybe I would make you something that would bring you the actual information.

Some of the things you'll find on there are the actual monitoring reports on New Lisbon. That's what the Justice Department is saying. There is information in the most recent one regarding incidents, whether they were minor, moderate, or severe. There's also-- I believe she also gives some decent information on restraint use and a lot of things that you asked about.

Other times, I think you get half an answer when you ask a question, and you ask good questions. For instance, Ms. Grant pointed out that the restraint reduction -- and I think she was mentioning New Lisbon -- there was a 76 percent drop in planned restraints, and a 46 percent drop in emergency restraints. If you take a look at the most recent monitoring report, you'll find what Ms. Grant didn't tell you, which is that previously -- to this monitoring visit -- Ellinghaus (phonetic spelling) directed, or certainly strongly recommended, to New Lisbon that it eliminate its use of prone floor restraint. And she attached, I believe, to her report a copy of

the California Protection and Advocacy Report on the lethal hazards of prone restraints. That's on the CD, too. And that was some time ago.

In the most recent monitoring report -- and I've also come to find out by -- in my dealings with New Lisbon. I get along with them all very well. But these are the facts. They are still training their employees to use prone floor restraints. It's a program. I believe it's called "Handle with Care." I don't know if we purchase it. I don't know if it's a consultant. I know there's a Web site. But we are still using it, even after being directed not to. It's dangerous, and we really need to cut it out.

As far as the incident summaries after there is an incident-- The way it looks to us is that the wagons get circled, and then when we figure out what the story is, maybe we'll let you know. Ms. Wigfield has never received a written summary of an incident report. Never, I know. Risk management, yes -- but for whom?

The third kind of answers that I hear you Assembly people getting when you ask questions is that, "It's just so complicated. We couldn't possibly explain it all." It's almost like a filibuster, or something. And you brought up a perfect example. How do we get a seat belt policy? I've got a seat belt policy, too. It's like, "Put your seat belt on, or we're not leaving."

I don't know why everything just has to be so incredibly complicated. But I did try to bring you -- so you could look at it at your leisure -- the real information. The investigative findings into New Lisbon and Woodbridge are on that CD. The settlement agreements. The monitoring reports on New Lisbon are on there, as well. And a lot of other stuff, too. There's a contents page.

So I hope that helps, and--

ASSEMBLYMAN CRYAN: Oh, it will.

MS. VANCE: In the interest of time, I thought that was the best way to do it.

ASSEMBLYMAN CRYAN: You should be on the Committee.

MS. VANCE: Does it come with benefits? (laughter)

ASSEMBLYMAN CRYAN: Touchy issue these days around here. Watch out. (laughter)

M A R G A R E T K I N S E L L: Good afternoon, Chairman Cryan, members of the Committee.

My name is Peg Kinsell. I'm the Policy Director of the Statewide Parent Advocacy Network. But I'm also a mom of a young man with developmental disabilities.

The first thing I've got to say though is, if I got bit by a dog, it's one thing. If any single one of my kids gets bit by a dog, whether they're not the one with the developmental disability or not, I want to know about it.

Now, I was trying to put together a little bit of a wish list. So as we listened to the comments today, I just took a couple of notes, and I'm going to share them, and that's it.

My first wish is: I wish we didn't live in a state that segregated people with disabilities, from our babies on up. I did that to my son. I put him in a preschool handicapped -- it was called, then -- program. I put him in a special school. And that was 10 years ago. And when I saw -- my first foray into what was happening with adults with developmental disabilities in institutions, I snatched him out of a special services school. I put him

back into a regular school and said, "We're going to figure out a way to do this, because you're never going there."

Now, when we talk about money -- and money is on everybody's mind. And we all know that 65 percent of the people registered with disabilities -- with developmental disabilities -- are living at home with their families. The budget they get is 8.5 percent of that DD budget. Guess how much the people that are in institutions are taking up? Thirty-five percent of the DD budget.

And I will actually err a little bit on the side of the community providers. When we have community providers that are getting \$6 or \$7 less, sans benefits, than people at developmental centers, it makes it harder and harder for us to find good community providers for our families.

One hundred eighty people out of developmental centers, in the next three years, is embarrassing. But I want good places for them to go. I will tell you that if 180 people come out of developmental centers, I still have not gotten a commitment from anyone that those beds won't be refilled. So that's the first thing I would like you to ask. If we're really going to put those folks in the community, or are we just going to refill those beds off the waiting list? Because there are a lot of parents that aren't (*sic*) looking at institutions as their only choice, until they get there and find out.

Now, I wanted to say one other thing about oversight. We had a lot of issues with numbers. You heard a lot of gasps. A lot of percentages though-- I was glad Chairman Cryan said, "What does that mean? What are the numbers? What is 4,000 incidents? What is 1,000 incidents?"

I think that what we're missing here, though -- besides the reporting of incidents of restraints, seclusion, abuse, neglect, placement in the community, opportunities to be employed in the community; and now, my new segue, unusual incidents -- the number of unusual incidents -- and also the number of injuries that are the result of restraint practices. Those are all great numbers. But, you know what? We're talking about them here. Nobody else is talking about them. So I think one of the things you might want to think about doing is the public reporting of each one of those developmental centers, on all those numbers, so that we have an idea of what's happening. And maybe that will start to add a little competition to the puzzle and make things get better.

I don't want to take up too much time. I know that it's a busy time for everybody here. But I just can't tell you how much we appreciate the opportunity to start talking about some of these things with you guys.

Thank you.

ASSEMBLYMAN CRYAN: Thanks, Peg.

KATE BLISARD: Thank you for the opportunity to speak today.

My name is Kate Blisard.

I was invited by Family Alliance to speak as the Coordinator of New Jersey-ADAPT.

I have been a disability advocate for the past 25 years. And I've spent many of these years inside the developmental centers.

I'm going to cut down what I wanted to say. What I want to really say is that I've been working in developmental centers for 25 years. And when I started in 1985, and found children living in the first developmental center that I went into, I just couldn't believe it. I have a

sister who is a “client” of the service provider. And I thought, when I went there, “My God, my sister could end up in one of these places.” And they were nasty in 1985.

ASSEMBLYMAN CRYAN: Are they better now?

MS. BLISARD: I would say only because of the problems that have arisen, and the scrutiny from the Department of Justice in the past five years.

ASSEMBLYMAN CRYAN: Let me ask you this.

If you could tell this Committee to do one or two things to help make them even better, what would you tell us to do?

MS. BLISARD: I have some recommendations.

ASSEMBLYMAN CRYAN: Do you?

MS. BLISARD: Yes, I do.

ASSEMBLYMAN CRYAN: Are they in writing? Yes, they’re here.

Tell us what they are.

MS. BLISARD: I have my papers here. I’m sorry, they didn’t get distributed -- my little speech.

Let me say this, I’ve been-- The reason that I’m here, I think, is because I have become an advocate to get people out of the developmental centers. I’ve been doing it so long. I just stopped as of 2004.

My recommendation -- and I’ve said this before -- implement a closed door, zero rejection policy. That means, no matter what, no one goes into a developmental center, and no one goes back to a developmental center. Anything that that person needs can be done in the community.

I've been asking, on behalf of people living in the developmental centers for years -- especially during the closing of North Princeton Developmental Center -- to make a policy of -- a moratorium. It has not happened yet. And until New Jersey really decides that they want to have the people that are living in the developmental centers return to the community-- Until we do that, nothing will really change.

I have worked in seven of the nine centers. And I often say, since 1985, that they're all like my house: clean on the surface, and a lot of dirt underneath. One of the things--

The other suggestion that I make is that four of the centers -- now that we have seven that are operating -- four of the centers have been built around the turn of the 20th century. Maintaining the infrastructure is costly, impractical, and creates the illusion that all is well inside the gates.

Making those centers handicapped accessible over the years only came because of the Americans with Disabilities Act. And it's been done by piecemeal. I know, because I use crutches, and I use a scooter. And I have had to find ways to get to where I need to be in each center. If I experience that, so do the residents.

ASSEMBLYMAN CRYAN: You mean to tell me that four of the seven centers are not completely handicapped accessible?

MS. BLISARD: They're not. They're handicap accessible now. They weren't until they were forced to be.

ASSEMBLYMAN CRYAN: Oh, okay.

Kate, I hate to do this to you. But you kind of have to sum up a little bit. And I apologize for that, so much.

MS. BLISARD: Okay. That's okay. That's fine. I understand.

The other recommendation is to examine and reprioritize the operational moneys to maximize the welfare and safety of the residents. What are we spending on landscaping that we can't take and use for the people that live inside? Implement a strategy to downsize specific developmental center properties. And sell or lease such properties for revenues, for community living plans. Increase the wages. Direct care staff is so critical. I'm sorry, but community people that work in the community make \$9, maybe, an hour, with little or no benefits. Increase wages and benefits for community direct care workers to parity with those of developmental center employees. What they get in the center they should get outside. It can be done.

ASSEMBLYMAN CRYAN: Kate, I'm going to-- I'm sorry. We're up against a caucus that I didn't plan.

MS. BLISARD: I understand.

ASSEMBLYMAN CRYAN: And I've got to tell you something. We have this in writing. And I promise you something else. I promise you, as the Chair of this Committee, you and I, and some of the other members here, are going to have a sit-down to follow this up.

MS. BLISARD: Okay. Thank you.

ASSEMBLYMAN CRYAN: I really can't tell you how-- Really, I don't want to get into it.

Maria, sweetheart, how are you?

MARIA CARLINA CATHERINE TETTO: Fine.

ASSEMBLYMAN CRYAN: Do you have something to say today, Maria?

Frank, I've got to move along here, so--

F R A N K T E T T O: Maria, do your testimony.

MS. TETTO: My name is Maria Carlina Catherine Tetto.

I am speaking as an advocate and Board Member of the National Coalition on Self-Determination. The National Coalition on Self-Determination advocates for the right of all individuals to live at home and in the community of their choice, no matter how disabled they are.

Before March 2, 1998, I was a happy 12-year-old girl, living at home with my parents and my brothers. On March 2, 1998, I was hit by a pickup truck while crossing Route 46 on roller blades, and I almost died. I now have a brain injury.

I am a member of the most discriminated group of people. I am a person with a disability. I need help to live independently. I'm still happy, but that's because I'm living at home with my family. I don't remember being in rehab, in a hospital for nine months after my injury, but I do remember--

MR. TETTO: Do you want to stop?

MS. TETTO: Yes.

MR. TETTO: She'll submit her written testimony.

ASSEMBLYMAN CRYAN: I'll tell you what, Maria. You and I had the chance to meet. You came to my office one day, too, which was a very special day. And I need to do something here.

Frank, I'm going to cut you off. And I know how special you and Maria are.

But whether I like it or not, I have an issue that's come up for the rest of the members of this Committee, that we don't have a choice that we have to go to. I assure you this came up after we planned this today.

Actually, Maria, you're very special. And I think the way to close this hearing is by remembering what you just said to us. It gives us a sense of perspective as to what we're all in this for, and that's for very special people.

Folks and the family, I've got to tell you, what I'm going to do next time-- And to those of you who came from the centers, and everybody, I've got to figure out a way to structure this. Maybe we stay on just institutions -- I'm not sure -- for time-wise. We're going to have-- We're going to revisit this issue again. It's important. I know I saw heads bouncing here, in terms of ideas for ways -- in terms of how we can improve -- whispering, I can assure you, among our colleagues -- just from the ideas you gave us, in terms of reporting -- the one most recent, and some others.

We'll share some dialogue over the next couple of months. And I assure you we will have another hearing; that we'll structure and work in an effort, together, to improve the system for the Marias of the world, and for everybody else.

So, with that, I'd ask for a motion that we close the hearing.

Is there a motion?

ASSEMBLYMAN BARNES: Motion.

ASSEMBLYMAN CRYAN: Thank you.

(MEETING CONCLUDED)