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# *Committee Meeting*

of

## SENATE LEGISLATIVE OVERSIGHT COMMITTEE

*“The Committee will hear testimony from invited guests on the Department of Human Services’ Home and Community Based Statewide Services Transition Plan and the Division of Developmental Disabilities’ (DDD) shift to a fee-for-services provider-reimbursement system.*

*The Committee will reconvene at 1:00 PM to hear testimony from invited guests regarding DDD’s Return Home New Jersey policy”*

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**LOCATION:** Committee Room 4  
State House Annex  
Trenton, New Jersey

**DATE:** June 10, 2015  
10:00 a.m.

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

Senator Robert M. Gordon, Chair  
Senator Loretta Weinberg, Vice Chair  
Senator Paul A. Sarlo  
Senator Thomas H. Kean Jr.

Senator Stephen M. Sweeney  
*District 3*



### **ALSO PRESENT:**

Michael R. Molimock  
*Office of Legislative Services  
Committee Aide*

Eugene Lepore  
*Senate Majority  
Committee Aide*

John Gorman  
*Senate 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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**SENATOR ROBERT M. GORDON (Chair):** Good morning, everyone.

Would you please rise and join me in the pledge of allegiance? (all recite the pledge of the allegiance)

Can we have a roll call, please? I suspect it will be abbreviated.

MR. MOLIMOCK (Committee Aide): Senator Sweeney.

SENATE PRESIDENT SWEENEY: Here.

MR. MOLIMOCK: Senator Weinberg.

**SENATOR LORETTA WEINBERG (Vice Chair):** Here.

MR. MOLIMOCK: Senator Gordon.

SENATOR GORDON: Here.

Again, good morning, everyone.

I want to especially thank my colleagues, Senator Weinberg and others, who will appear later in the day for participating in this meeting, as it is scheduled on a non-legislative day.

And let me also extend a special welcome to the Senate President, Senator Sweeney, who will be participating throughout the hearing because of his great interest in the issues at hand.

Today, the Senate Legislative Oversight Committee is holding a two-part hearing focused on a number of important policies and programs administered by the Division of Developmental Disabilities of the Department of Human Services. This morning's session will specifically focus on two recent policy changes: the Department's Home and Community Based Statewide

Services Transition Plan, and the Division's shift to a fee-for-service provider reimbursement system.

The second part of the hearing, scheduled to begin at 1 p.m. in this room, will be devoted to the Division's Return Home New Jersey policy.

We have at least three goals for this hearing: first, we want to learn from the Administration why these changes were initiated and what the Department hopes to achieve; second, in keeping with the role of this Committee, we want to learn how these programs are affecting the clients; and finally, we want to identify any opportunities to improve the quality and efficiency of the services.

As many in this room are aware, earlier this year the Department released the new, so-called *Statewide Transition Plan*. It did so in order to comply with the requirements of a rule issued by the Federal Centers for Medicare and Medicaid Services -- or CMS -- issued in January, 2014.

The CMS rule required Medicaid-funded residential and day-supporter programs to become less institutional and more integrated within the community. However, the rule provided states with much flexibility to implement their own plan to best serve each state's particular needs.

The release of New Jersey's initial Transition Plan was met with sharp criticism by providers and clients. The critics alleged that the State chose to propose seemingly arbitrary requirements that eliminated opportunities for choice and self-

direction in residential and day settings. My office and those of other legislators were immediately contacted by parents and providers expressing very serious concerns regarding the negative impact of the proposed rule changes. Among a number of concerns, one of the most troubling was a severe limitation on housing choices for people with developmental disabilities. Under the initial plan, no more than 25 percent of apartment units in an integrated complex could be set aside for persons with disabilities; and no more than 4-6 individuals could live in a congregate setting.

Serious concerns were also expressed about a requirement that those participating in day programs spend 75 percent of their time in activities in the community as opposed to the day program site. According to the critics, no consideration was given to the medical or behavioral challenges of the individual clients. In addition, day program providers contended that the new rule would inhibit their ability to schedule group activities. They asserted that this provision would be nearly impossible to implement.

The overarching complaint was that the new rules appeared arbitrary and in conflict with CMS goals of, one, improving the quality of experiences of clients and promoting desired outcomes; two, responding to the highly varied nature of support needs; and three, accommodating the variable staffing and funding capabilities of the providers.

After a public comment period and significant protest by providers and families, the Department issued a revised Transition

Plan on April 17 of this year. The revised plan maintained benchmarks for residential settings, including those pertaining to group homes, but applied them only to new facilities. Existing housing was grandfathered. In addition, the 75 percent community activity requirement was loosened. Integrated activity time was reduced to 50 percent and could occur inside or outside day facilities.

We will also have the opportunity this morning to hear testimony on the Division's transition from funding services through the Community Care Waiver and the Family Support program, to an initiative now called the *Supports Program*. This transition will also include a change in provider payments from the current reimbursement-based system to a fee-for-service payment model. Critics contend this shift presents a number of challenges to already-burdened DDD community providers. For example: The conversion to fee-for-service may negatively affect provider cash flow, as payments will not be made until after services are provided. Because providers will no longer be paid for vacant slots, they may also find that their revenue stream is less predictable than under the current system.

The greatest impact, however, is expected to be the actual rates established by DDD. Based on the Division's draft rate schedule, many providers claim that the new rates are not sufficient to sustain programs and services.

We will have the opportunity today to hear from representatives of the Division of Developmental Disabilities, as

well as from a number of providers and families, concerning how these policies will affect the daily lives of clients.

We will begin with representatives of the Administration. I'd like to welcome Deputy Commissioner Dawn Apgar and Assistant Commissioner Elizabeth Shea; and I ask you to make your presentation. Thank you.

**D E P U T Y C O M M. D A W N A P G A R, P h . D .:** Good morning, Chairman Gordon, and thank you for the opportunity.

Good morning, members of the State Legislative Oversight Committee. My name is Dawn Apgar, and I'm a Deputy Commissioner with the New Jersey Department of Human Services, responsible for overseeing the Division of Developmental Disabilities -- of which, Liz Shea, to my right, is the Assistant Commissioner.

We're here today to share information about the Statewide Transition Plan; Return Home New Jersey; and the shift to fee-for-services, or provider payments.

I want to thank you for accommodating our schedules, and I'm hopeful that our attendance will bring a clearer understanding of these initiatives to members of the Committee.

As we have discussed previously -- and, most recently, at our Senate Budget hearing -- changes are happening nationally with regard to services for people with intellectual and developmental disabilities.

Before the late 1970s, developmental centers were the only option for people with developmental disabilities who could no

longer live with their family members. By 1977, more than 7,600 people lived in developmental centers in New Jersey. However, as community programs expanded, New Jersey saw a dramatic decline in census, and in the 1990s the State closed two developmental centers. Also, as you are aware, with the continued decline in census, the State closed two additional developmental centers this past fiscal year. The census, statewide, now is about 1,600 and declining.

As codified in the 1999 Supreme Court Olmstead decision, people with intellectual and developmental disabilities have the right to live in the community and to enjoy the experiences that enrich all of our lives. This decision was supported by the U.S. Department of Health and Human Services' Office of Civil Rights, as well as the Americans with Disabilities Act.

Based upon the Olmstead decision, many best practices have been identified and culminated in the U.S. Department of Health and Human Services Home and Community Based Services' final rule, which was issued in March of 2014. The rule requires all states to revise how they provide Medicaid home- and community-based services to seniors and people with disabilities. In order to comply, every state, including New Jersey, had to develop a proposed plan that it will follow in order to meet the Federal requirements by 2019.

The draft plan produced, as you stated, strong emotional and operations-based support for, and opposition to, various provisions. Over 1,000 comments were received in the form of

letters, phone calls, and testimony at the two public forums. The process successfully opened up an important dialogue that resulted in some very constructive and useful input, which was included in the revised plan.

I know that this Committee is also interested in Return Home New Jersey, which began in State Fiscal Year 2009 when nearly 700 adult New Jersey residents with developmental disabilities were receiving residential services in out-of-state, congregate care facilities. The State's inability to receive a Federal match on these services, in conjunction with significant uncertainties about our ability to adequately monitor the care and well being of individuals in out-of-state programs, has long been a concern. The ability to receive Federal funding allows the Division to serve more eligible individuals with developmental disabilities. And with regard to proper oversight, notably, New Jersey is not alone among states that have had issues related to out-of-state monitoring.

In fact, those issues were primary among the very concerns that led to the passage of Billy's Law in New Jersey in 2008. We are aware of circumstances in other states where the Federal Department of Justice and disability rights organizations have stepped in and questioned the care provided in some of the out-of-state facilities that were funded by New Jersey.

With this in mind, New Jersey has concentrated on returning out-of-state New Jersey residents to in-state placements in order to more closely monitor their care and safety, as well as to

bring them into a network of care that is often closer to their families.

Since 2009, the Division of Developmental Disabilities has carefully and successfully moved 170 people who were living in out-of-state placements to New Jersey, but there are still 371 individuals remaining out of state. Some of these relocations take quite a long time. We spend an extraordinary amount of time finding the right agency, the right location, and the right setting to ensure that the transition works for the consumer. It's worth mentioning that one of the challenges with this initiative is that some individuals have been out of state for many years, and families are understandably concerned about relocating their loved one.

The circumstances for each individual are different and are based upon each individual's support needs. These moves take time, with many relocations taking years to ensure appropriate transitions occur and services are in place.

The foundation of this effort is the many private community provider agencies in our state that meet the needs of individuals with significant intellectual and developmental disabilities each and every day. The Division works with more than 280 provider agencies that provide quality services and supports in community settings, which exist statewide. DDD supports nearly 30,000 individuals, including people with very complex needs, such as 24-hour nursing and behavioral supports. There are over 10,000

individuals being served in group homes and other comprehensive licensed settings across New Jersey.

Recent community expansion has resulted in many more resources and supports for individuals to live in New Jersey communities, and opportunities for those returning to New Jersey which did not exist previously. In fact, since Fiscal Year 2010, more than \$350 million in State and Federal funds have been invested in home- and community-based programs and services. All of that money, excluding that which is spent on out-of-state services, is matched with Federal funds.

Over the last two fiscal years, the Division of Developmental Disabilities opened about 1,200 new beds in community residences. Provider agencies have expanded their New Jersey service system to local communities throughout our state; and through their efforts, today people with developmental disabilities are no longer segregated from community life because of their disabilities and the care associated with them.

With regard to safety and appropriate oversight, New Jersey's residential programs are extensively monitored to ensure that the community homes are well run and well maintained, and provide residents with the services they need to live safely and successfully in the community. All must adhere to strict licensing requirements.

The Department's Office of Program Integrity and Accountability monitors agency-run community homes and performs annual inspections, unannounced visits, and follow-ups if

complaints or concerns are raised. Every incident that results in an injury, neglect, or exploitation is investigated by the provider agency, the Department's Office of Investigations, and local or State Police, as appropriate.

In addition, the New Jersey Central Registry of Offenders against People (*sic*) with Developmental Disabilities, which was passed by the Legislature and signed into law in 2010, prohibits the potential rehiring of an offender by another DDD service provider. This also prevents potential harm.

We're working with families every day to show them that the system of care has dramatically changed over the last several years. Many more residential and program options are available than there were when their child moved out of state. Many more rules and regulations regarding treatment and care have been implemented and enforced.

Lastly, I understand the Committee is interested in learning more about the Division of Developmental Disabilities' shift to the fee-for-service reimbursement. For decades the Division of Developmental Disabilities has been built on a cost-reimbursement contracting model. This model funds Division services through a network of third-party providers by contracting for capacity, and then applying a cost reconciliation process after the close of the contract. In the current model, the Division is the Medicaid provider of record and performs weekly claiming to the Federal government to access the available Federal match.

In accordance with the submission of the Comprehensive Medicaid Waiver to the Federal government in 2011, the Division began working to shift to a Medicaid-based fee-for-service model of payment. In early 2012, the Division began meeting regularly with providers and families to discuss this shift, solicit their input, and to plan for the change.

In March of 2013, the Division entered into a formal rate-setting process with a national rate-setting firm for the express purpose to develop standard rates for the 26 services that the Division will fund in this new model. The rate-setting process included advisory committees made up of providers, individuals with disabilities, and their families; and lasted approximately 18 months. The draft rate sheet was made publicly available in July of 2014, and since that time the Division has worked closely with the provider community to ensure an adequate network of service providers are available to operate in the new system.

This shift to a fee-for-service model will provide many benefits. First, the current model is less efficient, as services are paid for prior to service delivery and funding amounts vary depending on the initiative and the date of entrance into the system. The new system will allow us to pay for services after they are delivered, thus ensuring the State does not pay for unused capacity, and will provide standard rates across the entire service delivery system to provide for a more equitable model.

Second, each service provider will be a Medicaid provider who will directly bill under a prior authorization process.

But perhaps most importantly, this shift will allow new providers to enter the system, thereby creating a great deal more choice for individuals and families, and will also provide all consumers with individual budgets and an enhanced ability to self-direct their services.

The shift into this new fee-for-service model is expected to begin this July, and gradually over the course of the next 18 months. The Division is working with the provider community to finalize the details of our plan to provide bridge funding to assist current providers with cash flow needs during the transition, as we believe that will be critical to the success of the transition.

In terms of stakeholder involvement, the Division has recorded over a dozen webinars for stakeholders over the past year, and key members of the Division's management team have conducted over 175 presentations to providers, individuals with disabilities, and their families over the last three years in preparation for the shift. The Assistant Commissioner and her management team also have regular monthly meetings with providers and families to ensure appropriate input.

I hope you have found this overview helpful, we're happy to answer your questions.

SENATOR GORDON: Thank you, Deputy Commissioner.

Ms. Shea, do you have any comments to make?

**A S S T. C O M M I S S I O N E R. E L I Z A B E T H S H E A:**  
Not at this time.

SENATOR GORDON: Okay. I know that you two have to leave to satisfy other commitments in about an hour so, so I want to get a range of questions before you. And I thought I would start with Return Home -- which would be the subject of this afternoon's discussions.

Has the Department estimated what the budgetary impact would be of bringing those 370-some-odd individuals back to New Jersey?

DEPUTY COMMISSIONER APGAR: We testified before the Senate Budget Committee what the reinvestment has been in state services based upon the people who have already been brought back. In some cases, we haven't identified an appropriate in-state option yet, so we don't know what the costs would be. So estimating the complete savings would be difficult.

But based upon the individuals who have already returned to New Jersey -- and that's the 170 people who I spoke of -- the reinvestment, the money actually goes back into in-state for those who are at home with aging parents or are on our community waiting list. The reinvestment has been, to date, \$22.8 million.

SENATOR GORDON: So the \$22.8 million is the incremental Federal money that is coming in because of the opportunity to match -- \$22 million?

DEPUTY COMMISSIONER APGAR: Yes.

SENATOR GORDON: So if we're talking about 370, approximately, it's going to be in the \$40 millions, let's say? You know, just rough order of magnitude?

DEPUTY COMMISSIONER APGAR: Again, it would be difficult. I can only speak to what we have already reinvested based on the 170. But this -- as I said, it's \$22.8 million. In addition, I should just say-- I mean, there's the financial component, but really the foundation of this is the close monitoring and care. And so these individuals also get brought into our Medicaid system for acute health services. So we're also talking about doctors' visits and other visits where we don't have a network out of state. So in many cases we're paying for out-of-state medical care via voucher, with a 100 percent State money. When individuals come in, it doesn't only relate to savings that we can claim under our Community Care Waiver -- a Federal match; but it also means that some of their acute health and other benefits that we are paying for under State money can be covered by our in-state Medicaid program.

SENATOR GORDON: Okay.

Senator Sweeney, did you have a question?

SENATE PRESIDENT SWEENEY: Yes, thank you, Chairman.

I know you say it's difficult to estimate; but you have to have a number. You have to have a number that you're anticipating from everyone coming back. It's not possible to say you don't, because we know how much it costs. I mean, we've had so many come back--

Let me ask you a question differently than Senator Gordon. What would it cost just to let the people who are still there stay, and just put a moratorium on the situation?

DEPUTY COMMISSIONER APGAR: So Senator, one of the things that's most difficult -- and I actually brought a letter that I received this week from a Pennsylvania provider, where we had three individuals. As part of the Return Home process, we were actually able to work with this particular provider who is a provider in Pennsylvania. And so it was a lengthy process; it took us about a year to do so. But in this particular case, these three individuals are staying out of state and are being served under Pennsylvania's program. So again, it would be hard to estimate a cost related to them, and this provider was actually writing to thank us, with regards to the care in which we worked with both the provider, the families, and the state of Pennsylvania.

SENATE PRESIDENT SWEENEY: Could I just follow up?

SENATOR GORDON: Senator.

SENATE PRESIDENT SWEENEY: And I appreciate that negotiation, and I think that you would have the ability to do that with many people. And, again, understanding this in two ways -- as a legislator and as a parent -- wouldn't it be better to negotiate, to put a freeze, or make an option -- offer to families: bring them back who want to come back, but freeze the program where it is. Because I understand back then-- Because a lot of people have been gone for 30, 40 years. So I understand what it was then -- we didn't have the services here yet. And talking to many people who

are actually living this in a personal way, we still don't have all the services.

So that being said, wouldn't we be better off making this option for families -- to look at coming back, freeze the program for people going out of the state -- because we don't have to expand the program, but we don't have to pull people out of their placements -- and we negotiate. As you said -- and I congratulate you on renegotiating -- those three people, you got a better deal for them, and it made an enormous difference in people's lives.

You know, I asked Senator Gordon to do this hearing for a reason. This is extremely emotional, and I don't think anyone wants to hurt the disabled. But we can't look at this through a lens of a budgetary issue. These are families. So couldn't we do this a little bit differently, since we really don't know what we're going to save? Because we don't, right? I mean, there's no--

Well, let me ask you a question, maybe differently. And I apologize for this. But you had so many people out-of-state; you had to estimate a savings bringing them all back -- if you brought them all back tomorrow, right? There has to be a number; there has to be a number, there cannot *not* be a number.

SENATOR GORDON: Or at least, if there are comparable--  
- You're saying that there are comparable services in New Jersey now that some of these -- that there has been an expansion of community services. If you just make the assumption -- if they are going to be moving back to a comparable facility that presumably exists in New Jersey now, what would that number be? Given what

the number is in Pennsylvania, or New York or Delaware, or wherever.

DEPUTY COMMISSIONER APGAR: So I can certainly-- I mean, there's been an OLS report related to savings which we can provide you with the figures. I think-- I just want to stress that while we're talking on focusing a little bit on the money here, it's more than just the cost. And I know you, and I've met with virtually every family -- and I know you have as well. But there are situations -- and some of them I referenced in my opening testimony -- where not all facilities out of state meet the same standards that we have here in New Jersey. And besides paying for them, we have a responsibility to make sure that the care-- It's impossible for the State, with a person here, a person there -- some of these are not Medicaid providers in their own state; some of them are not licensed facilities. So it is a difficult situation and, in fact, we have brought some people back -- obviously they are not the people who you are hearing from -- but were, in fact, in need of additional supports and services that they weren't getting out of state, and health care that we would have never known about if they hadn't come back.

SENATE PRESIDENT SWEENEY: Well, right to the point where I wanted you to go.

As a parent, I think I know what's best for my child -- not a government. And this is not a political speech. Making families aware, educating families about programs that might have been created that might be better here now than they were -- it

really forced parents to go out of state because the care wasn't here.

You can't-- The issue (indiscernible) got from this-- Look, no one likes change, and we've closed developmental disabilities because it was the right thing to do -- to get people into placement. But no one can overrule a parent. And the government is actually overruling families right now. And that's why I think it gets so emotional -- that this should be provided as an option, and we should be able to sell this to families. If there are better services, we should meet with the families, we should say, "Look what we have." Because I'm a big believer in New Jersey -- making sure that New Jersey has all the services. They should; it's embarrassing that families had to leave. But we don't. So why would parents be so opposed? That's the question you have to ask. Why would families be so opposed, because their only concern is about their sibling, their child -- that's the only concern. And I think the Department's concern has to be more focused on family-based than program-based -- where we're just going to bring them all back; because that's what was going to happen, at first.

So I really think we're not looking at it through the right-- We're looking at it programmatically, rather than looking at it through a parent's eyes. As you said, you brought several -- over 160, 170 people back. And families are happy, correct? Well, give that same option to other families before making the decision to go over their objections, is my point.

You know, we don't have a budget number; we don't know what the savings are; we're in this situation where-- Look, it's a small number of people. The disability community, with governments, is always a problem. It's a big number to take care of people with disabilities. But it's a small population. But it just can't be, you just want to bring them back.

So again, we're looking at this governmentally, and why can't this be looked at where we can go sit with families -- as you have done -- before we bring more people back? Because the parents are right, the siblings are right; the government is not, on this one. That's my personal opinion. That's my editorial, and I apologize.

SENATOR GORDON: Well, in fact, I'd like to just follow up on that, and then I'll turn to the Majority Leader. (applause)

Please, (raps gavel) I didn't realize we had so many people from Teaneck here. (laughter)

And here's the problem for us, Ms. Apgar. We're hearing from these families, and they're telling us -- they're giving us different information. They're saying, as someone will -- I'm sure a number will, this afternoon -- that "I've been to 10 facilities and they're telling me, 'We can't take your child; we just can't handle this situation.'" And so what we see is a program in which we're really not sure what the savings are going to be. But let's just say they're \$20 million to \$50 million. And certainly every legislator is keenly sensitive to the need to stretch our budget as far as we can. But it seems as if we're not factoring in the heartache and the

anguish that is being inflicted on families that really feel that they finally have their loved one in the right place. And I agree with the Senate President; in fact, I sponsored legislative that would've called for a moratorium during which we could develop some criteria to identify that subset of people who really need to stay where they are. And I was very disappointed that the Administration would not agree to that.

Senator Weinberg-- Unless you wanted to respond to that?

SENATOR WEINBERG: Yes. Following up on this subject that's been raised by both my colleagues; and let me translate this into a real case -- an e-mail I got yesterday from somebody I know well. And he says his son will graduate from Woods in Langhorne on June 26. "They've offered us no choices of homes -- until last Friday. Why can't they just leave him at Woods until we find the right placement for him in New Jersey?" In other words, they want to put him in some temporary place until they can find the right placement. "He will regress terribly if he has to move repeatedly. But they won't even call us back," which sounds very different from the testimony you just gave -- about how you've met with each and every family.

I don't want to release names here, obviously, based on confidentiality. But when you've got somebody who is supposed to leave in a week or two, and that parent can't even get a call back, and there is no suggestion for a permanent facility to put this young man in-- And I happen to know the son also. So it would

seem to me there are a lot of gaps here. And the fact that this parent is claiming he can't even get a telephone call back about what's going to happen to his son--

So based upon the figures -- you know, those are numbers; this is a real case. And I hope you can address this.

DEPUTY COMMISSIONER APGAR: Thank you, Senator.

First, I just wanted to clarify something -- because I think this is very confusing to people when we talk about out-of-state placement.

So the individual -- and I can't speak to that particular case; and I'm happy to meet with you after this hearing and certainly contact that family directly. But that individual, based upon what you told me, was probably placed there by his educational entitlement.

So, in fact, there is no requirement that when a school district places someone out of state for educational reasons, because that particular district can't meet the educational requirements within that district to provide care -- there is no requirement that they even let us know. And so we find out that people are out of state, going to private school settings, and then, in fact, are going to -- once their educational entitlement ends at 21 -- are going to, in fact, need services from the Division of Developmental Disabilities. That person, while he is out of state, is really not that much different than many, many people. We have about 1,200 people every year who are out of their educational entitlement and living with their families, who also are going to

need to initiate services come June, July -- or whenever their school year ends.

So I can't speak to his case, but I just want to be clear that he's really entering in-- This isn't *return home* in the sense that the State never placed -- the State did not place him out of state.

As the Senate President said, we have not placed anyone out of state during the community expansion -- during this Administration. So that would be actually a good example of someone we would be bringing back into the state. Because as he presents for adult services for the first time, he will enter into an in-state network as an adult, and all the services and expansions that we have already had.

So I don't know what the gap is; sometimes it's notification -- and, again, I'm not speaking to him. Literally, sometimes we know a year in advance, sometimes we know two years in advance that someone is going to anticipate to have this need, either in the state or they're living outside the state. But literally sometimes we find out the week before -- that, come Monday, the school bus is not showing up and we need a day program or, in some cases, another option.

So while we're talking about it related to out of state, I just want to be clear that that's a little different than the families that I referenced where the State has, over the years, as the Senate President said, assumed financial responsibility for them in these out-of-state set ups.

SENATOR GORDON: However, there is a common denominator -- which is that these people who are aging out are being uprooted from familiar surroundings and need to be brought back to a place that can provide comparable care.

Now, this afternoon we're going to hear someone testify who has a child in this very situation -- who, at the end of the month, the school year ends and they're going to go into adult services. This person has visited-- This individual has a very special need. He becomes very anxious around electronics -- televisions, computers, any kind of stimulus like that -- and needs what his parents call an *electronic-free environment*.

And according to what we've been told, they've visited a half-dozen, 10 facilities in New Jersey and haven't been able to find this kind of environment for him -- other than one in which the person would be really in isolation. And, you know, that family is experiencing great anguish over that; and they're concerned that their son will act out and someone will get hurt -- either himself or someone else. And as the Senate President said, wouldn't it be a better idea to just -- let's put the brakes on for a minute, catch our breath, develop some criteria for those who can be brought back -- presumably a majority of those -- and those who, given their unique situation, cannot. And just refine the program so that we can carve out those vulnerable people and allow them to stay where they are -- particularly in light of the fact that we're really not sure how much money we're going to save by going forward.

DEPUTY COMMISSIONER APGAR: As you know, I think-- And this is a very difficult situation, and I know there's been many hearings and testimony given from individuals, and many attempts to be able to develop criteria, as you said, to compromise. And I think some families -- the two that you just mentioned that the State has not funded at all -- really are presenting not unlike someone who is in an in-state residential school, all right, and needs to-- A lot of people-- This is a stressful time -- the transition -- and so I think there's been legislative and other attempts at compromise. And the process, I think, is very stressful. I mean, your point of families having gone to 10 agencies and none have been appropriate, I really think speaks to the fact that-- I know, since I came to work for the State in 2010, that some of the families that are still out of state we started working with four years ago, five years ago. So we're not going to move them back until there is an appropriate service that a family feels comfortable with and that can meet their needs. And for some people, that's quite quick; and for others, it's a very long, stressful, difficult process. So it is difficult.

SENATOR GORDON: Senator Sweeney.

SENATE PRESIDENT SWEENEY: Thank you, Chairman.

Then we aren't pulling anyone back who doesn't want to come back then; that's what you're telling me. Because we are going to work-- What I'm asking you -- the process is, you identify an individual, you identify their needs; we pretty much know the needs of the community we're talking about. And you work with

that family until that family is comfortable that they are bringing their child back -- their adult child back into a setting that they are comfortable with. Is that what we're saying?

DEPUTY COMMISSIONER APGAR: I think, Senate President, that you would see that this is not unlike -- as you brought up -- the developmental centers closure issue. I think if you talked to any family whose son or daughter is out of state, they would say they want the person to stay there. So what I mean by that is people know what they know, and change is difficult -- which you said.

So what I do say is-- And even the 170; many of those people, who are very successful and-- And actually the families are very happy now. If you asked them before the person moved, "Do you want them to move?" they probably would have said, "no." And so our responsibility is to make sure that the services, the supports, the needs of the person, the right program, the right setting, etc., are met. And so we-- There's a very -- and I'm happy to provide it -- a pretty elaborate process which can take a very long time to make sure that happens, including a planning process.

So what I would say to you is families are fully engaged in that process, and ultimately have to be part of the Transition Plan, and sign off on the ELPs, and all of these steps in the process. So they are active participants and, ultimately, have to accept -- right? -- the-- But I think deep down, when you're talking about at an emotional level as far as-- You know, many of the families, I think, are moving and happy about that. But they're also quite

worried and, in fact, perhaps if given the option, would want to stay.

SENATE PRESIDENT SWEENEY: Can I follow-up, Chairman?

First, we're dealing with families that, for them, it's actually more of an inconvenience because they are out of state. I mean, you're travelling further to see your child. But back to where I'm coming from is, this is a very small population. How many thousands of disabled people are served in the State of New Jersey right now?

DEPUTY COMMISSIONER APGAR: We have-- As you know, the Division of Developmental Disabilities just serves those 21 years and above. And so it's about 28,000 people who are adults in our system.

SENATE PRESIDENT SWEENEY: So you have a population of 300 and whatever -- 70? We should work to try to bring them all back; we should work to develop programs in the State of New Jersey. But we shouldn't force anyone back, is my point. And why are we picking on a population-- It's actually -- I want to say it's a solution looking for a problem right now. And I'm looking at it differently. And I'm not thinking that anyone has any evil purpose here. But government is a safety net, so why can't the Administration let the Department work with the families? You've been successful in a 170 -- whatever the number is -- bringing people back where they're satisfied. And I take you at your word that they are all perfectly satisfied. But the other 300-- And this

isn't the developmental centers, so there's no question -- I remember the developmental centers. But families have to have a comfort level; they really do. There's a couple-prong approach here. And we're going to the finish line without running the race, I guess is my point. So why can't the Department put a-- Again, because basically you're telling me you're really not pulling anybody back unless they want to, correct? No one is being forced back. Everyone who is coming back is -- they are willing participants.

DEPUTY COMMISSIONER APGAR: So we're engaging everyone in the process of, as the Senator said, looking at providers, right; getting comfortable with what they like, what they don't like; what's appropriate; developing an appropriate plan; going out and visiting providers. So everyone is engaged in that process. That process, again, takes a very long time for some people. And through that process there are multiple opportunities for planning and for families to say that this is not acceptable, or they don't like this, or whatever.

Ultimately, we then, through that, develop something that meets the individual's needs. So ultimately, the family-- I mean, we can't go across state lines, pick someone up, and bring them back. I mean, ultimately the family has to take a look at that proposal and agree that it meets their needs.

SENATE PRESIDENT SWEENEY: But understanding that-- And again, Chairman, I said I wasn't going to ask any questions when I came here. Understanding that, what happens when the

family doesn't agree -- just like an IEP. Are they then forced to get an attorney, because we're going to pull these people back?

UNIDENTIFIED MEMBER OF AUDIENCE: (off mike) Yes.

SENATE PRESIDENT SWEENEY: Are they forced; do you know what I'm saying? What you're saying -- you're trying to find a solution, and I don't agree with your solution for my child -- for my adult, not my child. Do you just say, "Well, that's the best we can do and we think it's best," or do you allow that person to stay in a placement? Or does that person have to engage in litigation to try to keep the person there?

DEPUTY COMMISSIONER APGAR: So when we've people -- when you say *stay in the placement*, and people stay in the placement until an appropriate setting and an appropriate service is provided. And we've had that happen many a time -- where someone is moving and they decline in health before they move; their needs change. So we're not going to move someone until there's an appropriate setting.

As far as retaining, it is a process. So what happens is -- usually, I will just say -- is that the idea of, "Well, I just don't want to move," in general, is not-- We try to dialogue about what is it about this particular setting or placement. Is it the location, is it the day program, is it the roommate choice? So that usually when people can articulate what they don't like, or what they feel doesn't meet the needs, we're able to, given the robust service delivery system, find something else.

So it's really just like an IEP: coming to terms and negotiating between the individual -- who sometimes has his or own ideas -- the family, the out-of-state provider who is part of the process; as well as our own team and our in-state service providers, who are often creative because, if they are not providing the service currently or it's not the setting, they often will look across and develop something specifically just for that person.

SENATE PRESIDENT SWEENEY: But-- And I wish I could stop asking questions, but I can't, Chairman. (laughter)

SENATOR GORDON: What if I said no?

SENATE PRESIDENT SWEENEY: I would have to listen to you; you're the Chair.

But you didn't really answer my question. Number one, if there is no agreement, the Division determines that it's an appropriate setting, not the family. And I know you're not picking the people up out of state. So this is very important to a lot of people -- not just me. I know you're not driving out of state to pick someone up; you're just notifying them, "We're not paying for it anymore." And that is problematic. (applause)

Please, please no-- Listen, we're not trying to make points here. And I appreciate people being supportive. This is about, obviously--

So you're informing people, "We're not paying for that service anymore." So now you have a family that is really focused on-- Someone has no financial means -- what do they do? They are forced back. So it's not what you presented to me up to this point.

And that's what I've been trying to get to. This is what I've been trying to get to. If I, as a parent, do not agree, and I work through a process -- there should be a mediation process, there should be something. But for you to say, "This is" -- not you, but for the Department, to say, "This is the appropriate setting," against the family's wishes-- Listen, out of state -- it has to be a pain in the rear end to travel hours. We should have more services in New Jersey. New Jersey was late to the game providing services. But we need to build those services. So there really is no reason, except we're looking at dollars and cents; and that's what it comes down to. We are looking at dollars and cents.

And, I'm sorry -- government has a purpose. Government has a responsibility for seniors, and the disabled, and many others. And government services for the disabled are expensive. And we shouldn't be looking-- Just like they were going to shut down sheltered workshops, if you recall. We were going to eliminate sheltered workshops, and hundreds of people -- hundreds of people were going to be out of jobs, Senator. Do you know why? Because it was the Federal match with Medicaid -- with the Feds, the Federal match. So they were going to shut down a program that provided hundreds of jobs for people with disabilities who want to be ably employed but have no place to be employed, but want to have the respect and dignity of a job.

This is the same thing that this Department is doing, and I'm getting-- Look, it's a budget issue, and that's it. This is not about the client, and that's why this is wrong, Senator. (applause)

SENATOR GORDON: Senator Weinberg.

SENATOR WEINBERG: One more question -- from the plan, while you're here.

You said that in the revised plan -- in the April revised plan you've reduced the requirement for -- out of the day program - - from 75 percent to 50 percent, and are including within that some of the programs within the day program. Could you explain that a little further? What will those standards be? What must one be doing in the day program to qualify for that 50 percent?

DEPUTY COMMISSIONER APGAR: Sure, Senator.

So in the Statewide Transition Plan -- in the draft -- we had proposed that individuals be out in community-based settings with individuals who are not disabled 75 percent of the time.

I just want to give you a little context of that, because I know there was a lot of comments and opposition to that. But between the time that CMS came out with the final rule and states, in fact, had to submit their plans, there was a lot of dialogue with CMS. And, in fact, when the final rule came out and the determination that the final rule not only applied to residential settings but also applied to day -- which was a question right from the onset -- states were trying to really understand how they could look at their day and vocational service system and comport.

There were discussions -- national meetings where states, I guess, in the very strictest sense thought that the final rule meant that you couldn't have any congregate day at all; meaning that people with disabilities couldn't even come together under a

roof or a day program -- you mentioned sheltered workshops -- but whatever the setting. And so really that was sort of the initial reaction.

As a State, people have asked, "Well, why did you come up with the 75 percent? Like, how did that--" When we were thinking that that was the landscape -- that in fact perhaps CMS would interpret that to be no congregate day at all -- we thought that the 75 percent was an initial -- a draft proposal that perhaps CMS would be comfortable with; would meet their intent for community integration and still preserve, what we heard from many individuals, that they do need a hub. They do need a place where people can go and their services can be coordinated during the day.

So that I just want to be clear; and I don't know that we've publicly spoken about that with regard to the 75 percent.

As most of the comments that we got at the public hearings, the letters -- and you can actually see a summary of the draft comments. The summary of that is on our website; it's attached to our State plan -- most of them were about this day issue. So we heard from families, we heard from providers -- we pretty much, I think, heard from everybody -- that there was a lot of concern.

On the provider level, one of the major concerns was the operations -- like, how do you transport people, how do you get-- The transportation, I think, was probably one of the biggest issues. How do you get people out, and the staffing, and the rates? And so

how does this-- I think people embraced it, perhaps, as a philosophy -- not all, but some. But the logistics of sort of how to do that were problematic.

SENATOR WEINBERG: And if I may interrupt for a moment.

DEPUTY COMMISSIONER APGAR: Yes.

SENATOR WEINBERG: And added to the cost of how of you get them out -- get them out to *where*?

DEPUTY COMMISSIONER APGAR: So I'm glad you brought that up.

So some people-- I just-- When they testified, you know -- when they testified before us at our public hearings, and in their comments, there was -- people were saying, "Well, it doesn't make much sense, you know, getting in the van, or going to the mall and walking around as a group." I mean, that was never -- I just want to be clear -- that was not the intent; that people would get in a van and drive around for 75 percent of their day, or that they would go to a mall and not be integrated. Really, the intent was -- again, thinking about this backdrop of CMS perhaps saying a congregate day wasn't even allowed -- perhaps this was a way of fulfilling that requirement.

During the time-- Based upon the testimony, and between the 75 percent out of day and the time we had to submit our final plan, there were a lot of other discussions and a lot of other guidance with states and stakeholders; you know, dialogues. And so the final plan -- which, I believe, you'll hear from others and

they can talk about -- both families and providers -- about how they feel that we landed -- but we landed in a place that I hope CMS will accept, which is that the majority -- we say the majority, so more than 50 percent -- of people's time would be in meaningful -- not van rides and other kinds of things -- but meaningful community integration activities. And those community integration activities can be out of a center-base. And many people who testified said they were already at 20 percent, or 30 percent, or-- People are really out in the community a lot. They were just worried about that 75 percent standard.

And then, for those times where they're not out, a lot of the providers and families said, "We have people in and out of those vocations all the time. They are coming in to do yoga class; there's a school group doing this," and so the idea was that community integration cannot only take place outside these specific locations but, in fact, they can also take place inside.

So I think we've reached-- Again, I haven't heard anything where people are disgruntled by that -- where the majority standard is one that I think people embrace, because that's really the standard that they wanted -- that they do, and that they strive for anyway, and something that operationally is feasible.

SENATOR GORDON: I have a number of concerns on this whole area.

I had the opportunity to do a quick read of the January 2014 summary of the CMS final rule. There doesn't seem to be any of the benchmarking that we see in the New Jersey Plan. There's

no reference to 75 percent, 50 percent of time outside. I mean, how did you arrive at the concept of using these benchmarks, and is there any data to support whether 50 percent is the right number?

And let me just add one other thing. I also had the opportunity to get an evaluation of the plan from the perspective of a relatively small, 50-year-old facility in my District that is serving clients who are not able to perform the kinds of tasks and activities that I think are envisioned in this plan. These are people who have trouble using a seatbelt. And the Department seems to have developed this plan that might work for high-functioning individuals. There's a recommendation -- requirement, I believe -- that people go out and work at minimum wage jobs. And it just-- The requirements of this plan would undermine this institution. If I could just-- In fact, I highlighted a comment. "We feel the compelling reasons for change have not been balanced by the diverse needs and abilities of disabled individuals. We feel that the Division of Developmental Disabilities has ignored differences in disabled individuals, focusing on what may be reasonable goals for those disabled individuals who are relatively high-performing, while potentially undermining the well-being of those who are relatively less capable."

It just seems as if it's a one-size-fits-all, and it really doesn't address the diversity of needs. I mean, could you react to that?

DEPUTY COMMISSIONER APGAR: Sure, thank you, Chairman.

And again, I would be happy to talk to your specific program. I don't know what program you're referring to.

As far as minimum wage jobs and things like that, perhaps the comment that you were reading was related to our draft proposal. I haven't heard-- And I think we have addressed those concerns in the actual final plan. So we did receive, certainly, letters -- you know, the one-size-fits-all, and some of the things that you mentioned on the earlier-- But as far as the final plan, I have not gotten that kind of feedback. It sounded-- A minimum wage is not mentioned in the plan -- the earning of minimum wage, or going out to jobs. This day proposal would allow even those with the most intense needs. So we have-- Again, you'll hear from program providers, but we have people who basically need 24-hour nursing; and while going out, perhaps they go out of these center-based far less than the majority of their time by including the provision that it can be done in-house as well, and community integration can take place. Most of the providers and the families -- they testified at the hearings that groups are there, that they're coming in -- volunteer groups and others. So they can't be paid staff, but many of these day services are relying on community groups to come in and provide enrichment activities.

So I think it should be addressed, but I'm happy to follow up with that specific provider. Because we don't anticipate there being-- And we certainly wouldn't want a plan that doesn't encompass individuals who have very intense support needs.

SENATOR GORDON: In the case of this particular provider, which relies heavily on philanthropy -- I mean, it's a 50-year-old institution and beloved in the community, in fact, so they must be doing something right.

Their feedback -- their evaluation of the plan describes the very practical difficulties of being able to move people out; and how much time is it going to take to put someone on a van, and take them off; and that's going to-- How will we satisfy this requirement for outside people coming in? You really appreciate the implementation problems for a small facility like this -- one that has not been a Medicaid provider and now, suddenly, has to learn all about Medicaid procedures and how to provide the documentation that you're going to require before a check goes out. They're wondering: How much is this all going to cost us? We don't know because, at least as of May, they had not gotten any information on the rate. So they really have no idea, at this point, what exactly they have to do from an organizational standpoint, and how much are they going to get paid for it. It's kind of hard to run a business when you lack those facts.

Their final point was, "July 1? Are they serious?" It seems as if there are still some implementation problems that have to be addressed.

DEPUTY COMMISSIONER APGAR: Senator, could I speak to that?

SENATOR GORDON: Sure.

DEPUTY COMMISSIONER APGAR: So I think you really are referencing two issues, both of which are the subject of this particular hearing. One, with regard to the Statewide Transition Plan, I just want to close that, and then I will move into fee-for-service.

Really, I think what people need to understand is, this is a living, kind of, breathing document. And so that plan has been submitted to CMS; we've had some questions from them just related to sort of procedure things. Can a person who wants a non-electronic copy of the plan -- can they get it? So we've been communicating with them.

But the next step -- and I just met with a group yesterday and described this -- the next step is really to go out and to meet with all of the providers. And it sounds like, with the provider that you're talking about, perhaps they're struggling with just some ideas of how to implement it, or they may not have all the information. And so we are developing a draft assessment tool, which is required, as is every state. It will be out on our website, and it will be available for public comment -- which is required. We anticipate doing the specific site assessments -- and these include both day and residential -- in the fall. That is a process. So we've already actually started, even though we haven't started the formal process. In some cases, we've been meeting with providers for -- when the final rule came out, even before we submitted our plan -- about how are they going to comply, and ideas, and things. And so we will be going through that process with the -- that

assessment process -- and then based upon the process, even if-- And many of our sites -- I just want to be clear -- are not in compliance now. And what I mean by that is, the final rule requires lease-based housing. Most of our housing is not lease-based. And so we're aware that we need to implement lease-based housing, and the providers and individuals and families are aware of that. So we will be working -- we have until 2019 for these sorts of major initiatives which are system-wide: lease-based housing, choice of roommates. So you started talking about choice. This is really about, people have to have choice of roommates under the final rule; and in some cases people do, but it's not documented in a way-- So we're going to be working with agencies, between now and 2019, to make sure that some of these concerns, and remedies, and questions get answered.

With regard to the fee-for-service -- which I think also you shifted into -- as I spoke about, we have a pretty robust training, and webinar, and presentation schedule. We are providing technical assistance. I can't-- Again, I'm not sure if this specific provider-- Can I say, some of the smaller providers -- I don't know if they're small -- maybe are so busy sort of running their shop that it is hard to keep up. So we can certainly reach out to that particular provider to answer some of the concerns and questions that they might have as far as converting to fee-for-service. But there is literally a sort of handbook and presentation for every single step of the process.

Now, the anxiety that you discussed is one that I'm sure that you're going to hear about from some of the providers. And we are working through-- For example, the cash flow issue, which you opened with, is something that, based upon the feedback of the providers, they're worried, right? They are paid in advance now; they're going to be paid after-the-fact. We have, I think, come to an agreement where we will be able to make them whole, or we will have a glide path for them to move into complete fee-for-service over a period of time.

So this is also a process. July 1 -- we stopped using the word *first* because -- and Liz reminds me all the time -- because certainly we can't flip every person, every service; it's just not going to happen. But we-- One of the things that I think is really critical is that we can't launch the supports program, and we can't give individuals-- I met with a group of families yesterday, and many of those families were asking me, "When are the expanded services coming? When can I get the extra support services? When can I implement these more robust individualized budgets?" We can't do it until we move into fee-for-service. So while it's always a balance of-- And we've been working over years to implement this, and there's always a balance of making sure people have all the information and have all the help and hand-holding they need. We also have 30,000 families that are relying on us for expanded support and employment services, and other kinds of services. And until we get into fee-for-service, we can't implement the supports program. And we have amendments to our Community Peer Waiver

that also need to be stood up in fee-for-service. So there's a fair amount of pressure.

SENATOR GORDON: I am not insensitive to your need to get to your next appointment. But I'll close with one comment.

You know, it sounds as if you are trying to get some feedback from the community. But you might want to consider, if you haven't done it already, just actually putting together some kind of working group -- advisory group of providers and family members representing the gamut of the kind of service providers that are going to be participating in this program -- to learn about the practical issues of rolling this program out.

DEPUTY COMMISSIONER APGAR: So I want to actually allow Assistant Commissioner Shea to talk about that, because I know she and her executive staff are spending sort of 24/7 over the last few years doing just that.

So I want to give her the opportunity to talk a little bit about the advisory groups and our implementation.

ASSISTANT COMMISSIONER SHEA: Thanks.

Thank you so-- As Dawn said, and I think you referenced earlier, we've been shifting into fee-for-services -- it's been about a three-year process that we've been working with the provider community, individuals, and families.

I have a monthly, what's called *Provider Leadership Group* that I meet with -- the trade associations, as well as some key members of those -- on a monthly basis. It used to be bimonthly; years ago, I think it was a quarterly. It was bimonthly

for a long time and then last year or maybe the year before, as we knew we were ramping up a fee-for-service, we actually increased it to a monthly meeting to make sure that we were having at least monthly conversations.

I also dialogue with a family group monthly about this and everything else. And I would say that this -- the supports programs and fee-for-service in general really has been the primary agenda item for probably two years with that group.

As Dawn mentioned earlier in the testimony, we're out-- Members of my staff are probably out an average of three to four times a week presenting to family groups, as well as the provider community, about this shift.

I will say, though, I think the primary-- What you're hearing, I would really love to know -- either after this maybe you could just let me know who that provider is, or have them contact me directly so I can make sure I get them the appropriate information.

The rates have been out since last July. So if they don't have the rates, there's a communication disconnect. So I can make sure I get them the rates, without question.

The other thing about the timeline-- We are beginning the rollout in July, but understand that it really is a rollout. So it's probably going to take us about 18 months, and it will be very slow in the beginning because, sort of like anything else, this is a major shift. This is a shift for our staff; this is a shift for providers; it's a shift for families, for individuals with disabilities. There is a lot of

change happening. So we have to roll in slowly. And if barriers come up and things come up, and we only have four people in, then we hold it until we sort of -- we figure those out until (sic) we enroll additional people.

So it's really-- Whatever time it needs to take us, we'll sort of get there. We feel very confident, though, that the work that needs to be done with our provider community we've been doing. Are people nervous about that? Is there going to be change? Absolutely. But I think that the opportunity to communicate back and forth -- we have those advisory committees already.

Again, I would also-- If you know of anybody who's not participating in that, or it doesn't feel like they have an opportunity to provide that input, please send them my way and I'd be more than happy to make sure that they get involved in that.

SENATOR GORDON: Okay.

I think the Senate President wants to ask the last question.

SENATE PRESIDENT SWEENEY: Thank you.

Well, not a question -- a request, Chairman.

And thank you for holding this hearing; I think it's very important. There is a great deal of concern. And I know we haven't been easy, but these aren't easy jobs.

My request is that we-- I remember years ago-- How long is our housing waiting list -- 8,000-plus?

DEPUTY COMMISSIONER APGAR: Yes, we have actually --on the priority list, we have I think it's about 3,400 or so. But we

have quite a number of children on the list, too, because people use it--

SENATE PRESIDENT SWEENEY: Understood.

DEPUTY COMMISSIONER APGAR: Yes, so--

SENATE PRESIDENT SWEENEY: Well, I guess my request is: Can the Department break down by county, and start building the critical mass within the counties so that “if anything happened to me or my wife, my son wouldn’t have to go to Bergen County -- not that it’s not a lovely place, but it’s far away.” You know, this was talked about before, Mr. Chairman, and they looked at it. But to give families a little more confidence in the process and the system, we start developing the needs within the communities. Because obviously Bergen County’s needs are much larger than Gloucester County’s needs.

But the needs are the needs in all parts of the state. And we really need to start breaking this apart so that families have a little more confidence in this system. Because you wouldn’t have children on a waiting list if the families were confident. You know what-- And this is just something I would hope that they would-- I’ve been here; I’ve heard this 10 years ago; I’ve heard it 6 years ago. It would be nice, in my lifetime, if we would develop a better system so families wouldn’t--

As when my daughter was born, they told me, “Put your daughter on the waiting list.” I said, “I’m 33 years old.” He said, “It takes a long time.” That is scary.

So, again, thank you, and if you would look at that I would appreciate it.

And Chairman, I have to run to another meeting, but I can't thank you enough. This is an important issue for the people of this state.

Thank you

SENATOR GORDON: Thank you.

Ms. Apgar, Ms. Shea -- thank you very much for investing some time in this process and being here. I hope we'll be able to call on you again. I'm sure this is not the last discussion we're going to have on this. This is an involving policy. And I know we want to have -- we want to exercise our oversight and also make sure that those served by your organization have the input that they should.

Again, thank you very much for being here.

DEPUTY COMMISSIONER APGAR: Thank you for the opportunity.

SENATOR GORDON: Thank you.

We would like to hear, next, from two persons -- Tom Toronto, the Executive Director of Bergen County United Way; and also Lisa Parles, an attorney, parent, and advocate for individuals with developmental disabilities.

Mr. Toronto, Ms. Parles -- there you are. Welcome.

**THOMAS M. TORONTO:** (off mike) Thank you, Senator Gordon.

**L I S A M c C A U L E Y P A R L E S, Esq.:** Good morning, and thank you for inviting me to speak about this critical issue.

My name is Lisa Parles; I'm a partner in Parles Rekem law firm, representing individuals with disabilities and their families. I'm also the mother of a 24-year-old young man with autism, and have several concerns regarding the limited options for individuals with challenging behaviors offered under the new proposed plan.

The revised plan -- which is more restrictive than the Federal regs -- will limit options for the disabled, and in many circumstances could actually endanger the lives and health of our most vulnerable citizens.

There remains a great deal of confusion about what the plan does, what it does not do; what the Fed requires, what it doesn't. The plan continues to limit choices.

Under the plan, going forward, as the Committee has noted, DDD will only fund a 4 to 6 person group home, or set-aside units in a development where no more than 25 percent of the residents are disabled. But in addition, the plan prohibits settings where the participant's home and vocational programs are located on the same property. This is known as a *colocation ban*.

While only DDD can definitively answer the question of what they will require, going forward, it appears that there will not be funding available in New Jersey for farmsteads, intentional communities, or campus-based programs.

Now, why is there so much confusion over the mandates? Well, one of the reasons, I believe, is because rather than clearly stating the 4 to 6 bed limit, or the 25 density restriction, the revised plan pointed to two Federal programs: the Money Follows the Person and the HUD 811, neither of which dictates states' plans for adult services.

The initial plan was revised; and when it was, there was a great relief for many people that they were not going to have to move from their current residential settings. However, it's proven extremely difficult to get answers from DDD on whether colocated programs will be continued to be funded. It's important to note that there's a significant percentage of our population that needs its campus programs to be safe.

My son, Andrew, currently lives on Bancroft's Lakeside Campus in Gloucester County, and it provides him with appropriate support and supervision. The presence of onsite behaviorists is a key component, as is the ability to remain productive in the campus on days when his behaviors make it impossible to go into the community.

In addition, in a campus setting, if a crisis occurs the response time with additional staff is significantly shorter than in a community group home. His campus is not an institution, and his experience there on many days is much more inclusive than life in a group home. Under the proposed plan, it's still unclear and unsettled if this outstanding program for 48 individuals with the

most severe and challenging behaviors will be forced to change a successful clinical model.

On many days Andrew does participate in community projects, such as Meals on Wheels. However, in addition to working on these meaningful projects, Andrew has also tragically gone three days without sleeping, six days without eating, lost 100 pounds in three months, suffered a self-inflicted traumatic cataract, and, most recently, detached retinas to both his eyes which required surgery.

He was not successful in the community group home. It was also not an experience that led to more community integration. For all practical purposes, the only interaction that residents had with their neighbors was when the neighbors complained that the music therapist was too loud.

The notion that simply placing individuals in a group home leads to an inclusive experience is a fiction, and there are many, many Andrews out there whose needs cannot be met in apartment settings or community group homes. In order to keep them safe, colocated programs must be permitted. In fact, given the need, many more must be built.

The Federal rule allowing for campus settings, and settings for individuals to live and work in the same location allows for this. In the December 3, 2014 letter, CMS Director Barbara Colter Everett stated, "It's important to note that the regulation does not prohibit site-specific settings." The criteria is not based on physical characteristics or density. All regulations should be

based on the outcome-oriented criteria and the individual's experience and needs.

Given the continued confusion about what the Federal rule requires, I asked a national group, the Coalition for Community Choice, to review New Jersey's plan. Yesterday, I received a letter from the Coalition, and the National Coordinator states that New Jersey's plan "includes more stringent criteria than the Federal regs require, and are based on physical characteristics." They also pointed out that New Jersey has unnecessarily relied on two Federal programs in crafting this plan. Money Follows the Person - - which is a federally financed incentive designed to assist people at-risk of institutionalization -- does have a 4 to 6 bed limit. However, this Federal program in no way mandates statewide housing policy, and hasn't in most of the states.

Neither does the HUD Section 811, which is also in the plan. According to the National Coalition, the bed limitation is not mandated by the rules and may, in fact, be detrimental to New Jersey -- for states overly relying upon one type of setting may have run afoul of CMS rules.

Moreover, CCC explained that although HUD 811 contains a density limit of 25 percent, there are many funding sources for affordable housing that don't have this requirement. Why are we looking at this one? These restrictions have no place in the plan, they serve only to limit choice, and they're stunting future developments of the types of programs that are desperately needed in New Jersey.

DHS has ignored the revisions requested by stakeholders. Rather than clearly stating the bed limit or the density restriction, in a wily fashion they rewrote the plan in a way that kept these discriminatory restrictions. By citing other Federal programs they caused more confusion. So hopefully we can now move on from there.

A number of New Jersey residents have filed objections to the STP with CMS, based upon the State's failure to make changes that were requested by the majority of stakeholders. In addition, New Jersey citizens have objected to DDD's misleading reliance on Money Follows the Person and the HUD program.

They also based their objections on the lack of transparency in the process. The initial plan was released late in the day on January 26, 2015. There were only two public comment sessions, each of which was two hours long; and remarkably, the first one was scheduled for 10 a.m. the next day. Thankfully, there was snow and we had some time to read it.

At the second session, testimony was limited to 3 minutes per person and speakers were cut off even if they hadn't finished their statements. We have video of microphones literally being torn from people's hands -- including persons served. Approximately 80 people present wished to testify, but the session ended promptly after two hours, with only 36 having been given the opportunity to have their voices heard. At that point, despite pleas from the audience, DHS officials walked out of the hearing room to the dismay of stakeholders.

The unnecessary and untoward limitation of public comment was distasteful and it was disrespectful. Other states have provided far more opportunity for public comment and stakeholder input.

Throughout New Jersey's process there has been no transparency and very little cooperation. Unlike many other states, New Jersey released its plan at the 11th hour and left little time for constructive evaluation and revision. Many states began to plan early in 2014, issued multiple revisions allowing for review and discussion -- multiple revisions, multiple stakeholder feedback. They also provided more opportunity for public comment than did New Jersey. I have many examples, but one, Wyoming -- which is the least populated state in the U.S., and has a total population of 563,000 people, which is less than the population of Ocean County -- had 8 public input sessions.

In addition, New Jersey has failed to establish the type of cooperative process that exists where governments, families, and providers have collaborated with the goal of expanding housing options. For example, Florida -- they've awarded almost \$50 million in tax credits to invest in the development of accessible and affordable housing, mandating that 80 percent of the units be for individuals with developmental disabilities. In Ohio, 14 members of the state congressional delegation, including the Speaker of the House, recently sent a letter to the U.S. Secretary of Health and Human Services in support of farm communities, where residents live and work at the same location.

In addition to the right of integration, our disabled citizens also have the right to be adequately supported in programs that meet their actual needs, to be presented with options, and, most importantly, to be safe. To those who say that all campus programs should be barred, I ask the following: If other citizens may choose among options such as living in an over-55 community or on a college campus, why should the disabled not have that option of living within a campus community that keeps them safe and appropriately meets their needs?

New Jersey's plan must be rejected. Thank you.  
(applause)

SENATOR GORDON: Ladies and gentlemen, we have a long list of witnesses, and audience participation will only slow down the process.

Mr. Toronto.

MR. TORONTO: Good morning, Senator Gordon; good morning, Senator Weinberg.

Our organization develops affordable housing throughout the State of New Jersey, with a special emphasis on supportive housing for people with developmental disabilities. We build an extremely beautiful and innovative product; we've been welcomed into some of the towns with the most expensive real estate in New Jersey. For example, Senator Gordon, we're under contract for sites in Ridgewood and in Glen Rock; Senator Weinberg, we are under construction presently in Tenafly for supportive housing, and also in Fort Lee for supportive housing.

At the precise time, when municipalities are reaching out to us and others to help develop supportive housing specifically, the State has essentially cut us off at the knees with an arbitrary limit on the number of units that can be built, as specified in the imposed State Transition Plan. This is a State-imposed -- the State of New Jersey-imposed limit. The Center for Medicaid Management Services, as Lisa has pointed out, does not seek or impose numeric targets for unit counts in states' transitional plans. And, in fact, we are the only state transitional plan that sets these targets and these limitations, of about 20 or more that have so far been submitted.

Consider Airmount Woods. Purpose-built housing for people with autism in Ramsey, New Jersey; done with the full commitment and financial participation of both the Borough of Ramsey, the State's Housing Mortgage Finance Agency, the State's Department of Developmental Disabilities, and our own equity -- Bergen County United Way equity. This project was intended to be a template and a design -- it's for nine residents; it is the first publicly funded housing in the entire country specifically built for people with autism -- designed to be a template to be replicated with the full faith and credit of State government for that purpose.

It opened in June 2014; it is, today, obsolete due to the State Transition Plan.

Interestingly enough, though, the idea of replication still took hold, and we have sites in Lincoln Park, Wanaque, and Colts Neck, New Jersey, to replicate the Airmount Woods model. It is out

of bounds, interestingly enough, for two reasons: one is because it exceeds the so-called *rule of 4*; and secondly, it is considered an intentional community serving people with only one disability -- here in the State of New Jersey, which has regrettably the highest rate of autism of any state in the nation, and a burgeoning and extraordinary cohort of folks who are going to need residential services coming of age very soon. Our 12-acre site in Colts Neck -- where we have preliminary site plan approval, I might add -- was meant to be a place where we might also include a farming component.

Behind me is a beautiful mural of a pastoral farm setting here in New Jersey -- which is known as the Garden State -- and a farmstead ban exists, per the Site Transition Plan, which seems to me to be ironic.

I would add that, as a result of the recent Supreme Court ruling, we have municipalities continuing to reach out to us seeking to build supportive housing as a way of satisfying their affordable housing demand, avoiding builders' remedy lawsuits. We are also engaged with a number of market-rate developers, who have many multi-family projects that are moving towards site-plan approval -- where they would like us to partner with them and build supportive housing. One very acute case where we were about to go to site-plan approval is in Florham Park, where the Rockefeller group owns a significantly large site known as The Green. It is going to be developed with two hotels, three restaurants; Pulte Homes is going to build 400 residential units. And the Rockefeller Group is

conveying five acres of land, centrally located in the site across the street from Fairleigh Dickinson University, about a half a mile from the downtown of Madison -- a site that affords extraordinary amenities, the opportunity for vocational opportunities, and the hotels, the restaurants, the businesses that surround this particular site. They are converting five acres of land, with a value of about \$5 million and an expectation of us to build 40 units of supportive housing distributed in four different buildings. Per the State Transition Plan, we can only build, perhaps at best, one six-bedroom group home.

I would implore you to do all that you can to undo the State Transition Plan and modify it to eliminate these restrictions on housing. And I would suggest to you: What other group of people in our country are told in what number they can live, where they can live? If you were to suggest to senior citizens, as an example, that they could not live in groups of more than four, or the more than 25 percent of an overall market-rate development, I think that that would be an equal protection lawsuit. Yet, for some reason, people with developmental disabilities are being, by our own State -- have a restriction opposed upon them. It just seems -- as I stated to a committee hearing held by Assemblywoman Valerie Vainieri Huttle -- a misguided social experiment.

Thank you. (applause)

SENATOR GORDON: Thank you; thank you, Mr. Toronto.

I am baffled by the direction of these policies.

One thought that I had -- and I certainly would need to vet it with staff and our counsel -- is that the Legislature is afforded a mechanism -- I believe through the Constitution -- that allows us to reject regulations that are deemed inconsistent with legislative intent. It certainly is the policy of this State to provide housing opportunity for all, particularly the disabled community. And maybe that's something that the Legislature needs to consider.

I thank you both for your testimony.

Senator Weinberg, any questions?

SENATOR WEINBERG: No questions, but both of you made a comment that really made me even think further about this -- talking about senior citizens living together, whether in an assisted living or any other kind of congregate living.

It just seems so arbitrary and so impractical -- and Tom, as you know, I am well acquainted with the fine work you've done in Bergen County, and I have actually visited some of these places where people are living together happily, among themselves, with the just appropriate amount of supervision, close to their families, in great surroundings. And to think that the State would want to come in -- or even the Federal government; and it seems to be a large gap between what the Feds really said, according to your testimony, and what the State is implementing. And I think that's something that we need a much closer view of -- why would we want-- I mean, it's beyond me why we would not want to embrace and encourage this, rather than discouraging these developments or the ones that are already in existence.

So as far as I'm concerned, I think, Senator Gordon, you are right, I believe, about the constitutional ability of the Legislature to overrule some of these so-called regulations. But DDD is going to have to go a long way to convince me that what's in this plan is appropriate for the people who are going to be living there. (applause)

SENATOR GORDON: Thank you both -- thank you both very much.

Mr. TORONTO: Thank you.

MS. PARLES: Thank you.

SENATOR GORDON: We will next hear Suzanne Buchanan, Director of Autism, New Jersey; and Tom Baffuto -- and, if she's here, Kathy Walsh -- of New Jersey Arc and The Arc of Bergen and Passaic Counties.

Not surprisingly, we're getting a little behind schedule, so I would implore our witnesses to try to keep their statements brief.

**S U Z A N N E B U C H A N A N, Psy.D.:** Chairman Gordon, Vice Chair Weinberg -- thank you for the opportunity to appear before you this afternoon.

Autism New Jersey strongly commends the Department for their substantial efforts to bring New Jersey in compliance with the CMS final rule on Home and Community-Based Settings, as articulated in the Statewide Transition Plan. It's fundamentally a good plan that, as we all know, did raise some questions and concerns from the community.

Autism New Jersey is appreciative that the Department amended their draft plan based upon community input -- and I'll give some examples.

The Department clarified that it will continue to support the development of new group homes that comply with this HCBS final rule and Department policies. The Department also incorporated the community's feedback on the following concerns: more flexible requirements for community integration within day programs; site-specific remediation plans for existing residential settings to be determined compliant with the HCBS final rule and Department policies.

The Department also incorporated the community's feedback on the following concerns: more flexible requirements for community integration day programs; site-specific remediation plans for existing residential settings to be determined compliant with the HCBS final rule; and a waiver of policy prohibiting collocation of services when specific clinical reasons are provided and included in the person-centered plan.

In our view, there is only one remaining concern -- the size and density restrictions on new housing. The community's perspective is clear: provide us with a codified appeals process through which settings that exceed the quantitative limits can be evaluated. Because there are some settings that exemplify the fundamental principles of the HCBS final rule and its focus on choice, individuals' experiences, and outcome-oriented criteria.

The community needs as many options as possible, and numbers alone should not be an obstacle to finding someone a home they so desperately need.

Each of us here knows families who need or want something more or different than the settings allowed under the proposed rules. With more than 26,000 individuals with intellectual and developmental disabilities living with a caregiver over the age of 60 in New Jersey alone, now is the time to increase all housing options. It is our position that every plausible type of community-based housing options should be considered before it is excluded.

These policies should not limit housing choices; ideally, these policies would provide the processes by which a range of community-based choices can be made in the individual's best interest.

We look forward to continuing our dialogue with the Department to develop policies that do not unnecessarily restrict housing options.

Thank you for the opportunity to provide these comments. We look forward to the collective dialogue on behalf of individuals with autism.

SENATOR GORDON: Thank you, Ms. Buchanan.

Mr. Baffuto.

**T H O M A S B A F F U T O:** Thank you, Senator Gordon and members of the Committee. Today, I appreciate the opportunity to bring some thoughts to you on these subjects.

I presented some detailed testimony; and I know you have a long list, so I will be brief.

Basically, I would rather use my time to focus on the shift to fee-for-service. I think you've heard a lot about the Transition Plan.

One thing I do know is that from the Arc of New Jersey's perspective, we are fortunate to have you, Senator Gordon, Senator Weinberg, and certainly Senator Sweeney as advocates for us. And we appreciate you bringing these issues forward.

So I think one of the most important things to keep in context is that currently our system is going under dramatic changes. We've moved the kids with developmental disabilities to a new Department; we have Return Home New Jersey; we've closed two developmental centers; we're shifting the way funding is going to be going on; we've made a major change to eligibility regulations. All these changes have come at once. And for family members, individuals with intellectual and developmental disabilities, providers, advocates, to not only keep track of all these changes, but to react to all these changes, has been very, very difficult; and it has led to a great deal of anxiety on every single level. So it seems like every day there is a new change, and it's causing a great deal of concern.

And a lot of the initiatives that are going on we agree with, philosophically, and we think changes that are being proposed will ultimately lead to a better system. It's just -- all at once it's been very, very overwhelming for all of us.

And again, we hear there's been webinars, there's been information out there. But information is changing rapidly -- almost daily -- and it's just hard for everyone to keep up with everything.

So I could talk about a number of things that we-- The emphasis on employment in New Jersey -- we think that's a good thing; we think that New Jersey being an Employment First State -- that's a good thing. You know, all of these things-- We're moving in a positive direction; and even the new supports program that is being rolled out will give families and individuals more choices, more options, and, by the Department's own admission, there won't be a waiting list for that program once it's rolled out. Again, we see these things as advances in the system and that will help. But certainly there is a lot of trepidation as we move forward.

So I want to just talk a little bit about the fee-for-service system. You heard -- it's going to be a new way of funding these situations. So rate setting has taken place. The critical thing for us in this whole thing is: Are individuals going to have adequate budgets to get the supports and services they need, and are the rates sufficient so that there will be a healthy provider group out there for families to choose from?

At this particular point, it is difficult to make that assessment. I mean, we have the rates, but we don't necessarily have all the business rules surrounding those rates to know what the impact is going to be on the providers. For instance, let's talk about individuals. They're going to

be assessed using the New Jersey Comprehensive Assessment Tool. While we don't have a problem with that assessment tool, we don't think it goes far enough to capture all the information that we're going to need to make certain that the budgets are successful. It doesn't necessarily capture behavioral needs or medical needs. So an individual's budget could fall short under that situation. So it's important for us to know what that's going to be.

On top of that, everyone is going to get an assessment and a tiering -- what they're calling a *tiering* -- so that providers will know how many hours they're going to be able to have to support that individual.

So while we have the rates -- and we can take a peek at that -- providers, at this point, don't have the tiering information to know how many hours they're going to be able to provide for people. So it's very, very difficult for providers to make business decisions on how to move forward. And that information is absolutely critical; and as we're moving towards this new service delivery system, providers are really wanting for this information to make good business decisions.

So we really are struggling to get the information from the Department to really align business models; and certainly to assure families that their budgets are going to be adequate.

In addition to that, we're moving from a system -- right now we have case management -- into support coordination. This is a major change for families; and, again, while it may work out

that it's going to work out all right, right now it's just nerve-racking for families as we go through this.

And, you know, we're concerned that families are going to be able to get the supports and services they need. You know, everything is now going to be on a pre-authorized basis. So if a person has a budget, they're in a day program -- maybe they're getting a budget to pay for a person to be in a day program for three days. If the person gets sick, doesn't show up for the program, that pre-authorized money is removed from their budgets -- not paid to the provider -- and the person would lose that service. You can't carry that over to another month; that money is lost.

So there are all these nuances to the fee-for-service system that are causing a great deal of angst for everyone.

In addition to that, as the Department Commissioner testified, if a person doesn't receive the service, the providers are not going to get paid. So let's just look at residential services. There's about a 5 percent vacancy rate built into the rate. So if someone is living in a group home, that would translate to approximately 18 days they can be out of the program where the provider will get compensated in the rate. Well, if a person gets ill and is hospitalized, if a person has to go for rehabilitation -- well, we're saying these are people's homes. If they want to go visit their family or go on a vacation with their family, we are really going to be pressed up to limits on how long they can be out of that program.

And we certainly think the Department needs to dialogue with all of us on how these things are going to be implemented. It is really going to impact families. You know, housing-- We're hearing about a lot about the State Transition Plan, but I think families in New Jersey are struggling on how they are even going to receive housing into this new system, and what's that going to mean. And certainly providers are concerned; room and board is not a reimbursable service under Medicaid. How are providers going to get the money for that room and board, and how is the State going to address that? So we have a number -- a number of concerns that are out there.

And certainly we know SSI -- Supplemental Security Income is not going to be enough to cover all those costs.

They've also put some additional training requirements in -- you know, a number of administrative requirements that we're just struggling with how we're going to be able to implement under this new system.

So while we agree that standardized rates -- you know, moving to that is not a bad idea; as a matter of fact, it's long overdue in many instances. It's how we're going to implement these things, how quickly we're going to implement. Again, I was somewhat relieved a bit to hear the implementation might be longer than we originally thought. But starting out slow, working through a lot of these kinks, I think, will help on a number of levels. And certainly, the bridge funding that they're addressing will certainly help providers also.

I address a number of additional points in my testimony, but I do appreciate the opportunity to be up here to talk about these today.

SENATOR GORDON: Thank you very much.

Clearly you have a lot of experience implementing change in this field and appreciate the complexity of it. It does appear as if this Administration is trying to do an awful lot in a short period of time.

Senator Weinberg, do you have any comments?

SENATOR WEINBERG: Yes. And based upon the first four speakers we've heard from the community, it also seems that the Division has not done as great a communication job as they seem to think they have. So hopefully that gap can be filled.

Thank you.

SENATOR GORDON: Thank you.

Thank you both very much.

The next person we'll hear from is Robert Stack. Is he here?

Robert Stack is the CEO of an organization called Community Options.

Mr. Stack, welcome.

**R O B E R T   S T A C K:** (off mike) Thank you.

Mr. Chair, members of the Committee, again my name is Robert Stack.

HEARING REPORTER: Sir, I'm so sorry; I need you to come up here. Thank you.

MR. STACK: I'm sorry.

SENATOR GORDON: Now I can see you. (laughter)

MR. STACK: Thank you.

My name is Robert Stack, and my office is at 16 Farber Road in Princeton. I've been supporting people with disabilities for the last 47 years in different capacities.

I'm the President of Community Options. Our nonprofit was founded in my row home in Bordentown in 1989. Today, with almost 4,000 staff, we support thousands of people with disabilities. Our mission is still the same: to develop housing and employment for people with disabilities.

I'd like to thank you for inviting me to testify on the implications of New Jersey going to a fee-for-service model. Community Options operates within a fee-for-service model in all of the states we're in, with the exception of New Jersey. We know that there have been a lot of stops and starts with this program.

As lawmakers and advocates for your constituents, I want to commend you for how hard you worked and offer gratuity (*sic*) that you take this matter very seriously for these hearings.

I'd like to suggest a couple of ideas for the model -- a couple of questions. In this model, who is bearing the risk? Is it the State of New Jersey or is it the provider agencies? What impact will it have on families? What impact will it have on the people we support? Why are we going to this model? What are the goals of this change? Is it to serve more people? Is it to serve individuals

better? Is it to reduce the waiting list? Is it to increase the quality? If so, what is the research?

Individual lives are not as predictable as equations in a fee-for-service model. We need significant flexibility to accommodate the fact that some people with disabilities can and will, cycle into crisis. Payment systems cannot be narrowly defined because the community service system is highly evolved. Payment systems must accommodate a growing number of services and population characteristics. No one has a simple diagnosis. We all read about the higher instances of autism in New Jersey. We all know about our State placements. On a significant side note, today over a half a billion dollars is spent in this State for the 1,600 people who are residing in State-run institutions. If we got to a fee-for-service model, the question is what is it going to purchase? In the old days, it was straight-up answered; but now community integration is far more complex. In the late 1980s, when I was involved in the institutions, there was a bundle of 24- hour services equaling one per diem. Now the lives of people with disabilities are far different than the minimal constitutional standards of a bed and three meals. How did we get to this place right now?

I learned that New Jersey DDD started exploring the idea of moving from an expenditure-based contract to a fee-for-service arrangement several years ago. It started with a strong consultant group; the principal met with families, consumers, agencies to determine how the rate should be structured. He indicated he worked with several other states determining an effective rate

structure. It seems to be a very good evaluation, with interviews and collection of data. They published a final report in July 2014.

During this time, a series of meetings was held and we all walked through the process of data collection and determination of these definable rates. We understood the logic and felt comfortable with the outcome.

I'm not really sure what happened, but that report was dramatically changed. Now, we feel the program is not close to being defined.

In my opinion, transparency and consensus with all the stakeholders is needed to develop a model that will benefit those we support, together. If correct systems are in place, theoretically it should work without a problem. Maybe the Division of Developmental Disabilities should consider a better working group to look at what will be effective and what does not work. I know that my colleagues and I are not afraid to roll up our sleeves and work together in unison with DDD. I believe the divisional staff worked hard on this, but it needs more work. Our exposure so far has been meetings with limited representatives for questions and answers sessions. A great deal of time was spent discussing this process of tracking authorizations or consumer statistical analysis, Their sessions were very unclear, and many agencies asked important questions that are still left unanswered.

We can learn from other states. In Pennsylvania, the move to this model became so bumpy that a lawsuit between the Commonwealth and the providers ensued. Some smaller nonprofits

went out of business. All of us had significant cash flow issues until this was resolved.

There are collateral events that will impact the fee-for-service model. In Maryland, for example, laws were passed to reflect provider rate payments to compensate for their decision to increase the minimum wage. Has this been addressed in New Jersey?

I've seen what was effective and what was not effective throughout the country. As lawmakers, I know that you do not want to spend time on being told problems; I would, therefore, like to recommend a potential solution: Possibly the Division and their contracted providers act in tandem as partners. I suggest consideration be given for a one-year time-limited parallel pilot system -- a system in which this model is operated as a dry run with simulated billings, running payment numbers without actual payments. This will enable both the providers and the State to evaluate the efficacy of the program and adjust the system transparently, with the mutual stakeholders' concerns addressed.

We plan this journey together as equals now, with the welfare and safety of those who are most vulnerable to be given the highest consideration. We finish this journey after we all know that this process works and that most of the bugs have been worked out of the system. We work in concert to achieve a way that all stakeholders work to ensure that the integrity of New Jerseyans with disabilities are preserved and they live the best possible life that we can offer.

Thank you.

SENATOR GORDON: Thank you very much, Mr. Stack, for presenting this national perspective that you have. And also for recommending this, what I consider, intriguing idea of a *test run* of the new model.

Would your colleague like to make any comments?

**S V E T L A N A R E P I C - Q I R A:** Good afternoon.

Our concern--

SENATOR GORDON: Could you identify yourself for us?

MS. REPIC-QIRA: My name is Svetlana Repic-Qira; I am the Regional Vice President for Community Options. And I oversee our New Jersey operations.

Our concerns, as Robert had stated, is not having some answers when we're looking so soon to turnover to fee-for-service. One of the areas are the tiers that people are identified -- for the individuals we support. And we have no idea where people are falling into. And going into this blindly, and not knowing if we are going to be reimbursed in the same manner that we currently are, is concerning and causes anxiety.

SENATOR GORDON: Thank you very much.

As Senator Weinberg pointed out, it does seem that there is a disconnect between the perception that DDD has on how well it's communicating with the provider community and the perspective that you have.

Senator Weinberg, any questions?

SENATOR WEINBERG: No, thank you.

SENATOR GORDON: Thank you both very much.

MR. STACK: Thank you.

SENATOR GORDON: We will next hear from Gail Levinson, Executive Director of the New Jersey Supportive Housing Association; and Valerie Sellers, CEO and Board Member, New Jersey Association of Community Providers.

Welcome; thank you very much for being here.

**GAIL LEVINSON:** Thank you for inviting us. We appreciate it.

Senator Gordon, Senator Weinberg, members of the Legislative Oversight Committee, my name is Gail Levinson and I am the Director of the Supportive Housing Association here in New Jersey. We've been around for about 18 years. We have over 100 members; they're all over the State of New Jersey, mostly housing providers -- either developers of housing, construction or rehab, or providers of supportive services. It's all about people with disabilities living in communities of their choice with access to supportive services.

I have just some numbers that I wanted to share with you. I realize that this is about people with intellectual and developmental disabilities, but I know that you are concerned about the services for a wide variety of vulnerable populations, and (indiscernible) our constituents are those with serious mental illnesses, addictions, developmental disabilities, and many other special needs.

So we have an estimate of -- just sort of the numbers out there -- which I feel would be helpful for all of us. While I don't have numbers exclusively for the I/DD population, our estimates indicate that there are more than 41,000 people, adults or adult households -- very low income households and adults in New Jersey living with disabilities who receive Federal or State housing assistance in the form of either public housing units, public housing organizations, or rental vouchers.

And if you were to compare this with the approximately 120,000 adults with disabilities who are on the SSI rolls -- individuals receiving less than \$800 a month who live with disabilities -- we have a long way to go to provide housing assistance for people who are living on very, very low income.

So I'm sure some of those individuals -- there's a gap here of about 80,000 -- live in safe situations (*sic*). I would venture to guess that the majority of those people are living in substandard conditions, with aging parents, couch-surfing, using high-end cost centers such as emergency room shelters, prisons, and long-term care facilities because they have no other place to live. I know I'm not telling you anything that you don't hear from your constituents. But we have a long way to go. We have a lot of housing to create for people.

And so with regard to the Transition Plan -- my organization actually likes the Transition Plan, in terms of the way it outlines certain fundamental rights that people have to live in communities of their choice and to make selections about how they

want to live -- with issues of privacy, tenancy, and choice. But we think that the Transition Plan is too prescriptive, too rigid -- the 25 percent approval is something that did not have to be in there, and we have requested and will continue to request flexibilities. Because we just don't have enough choices in the State of New Jersey.

I would love the opportunity with my colleagues, in the future, to have another hearing where we can offer up some of these innovative, exciting choices that are out there that developers and service providers are beginning to create -- some of them very efficient, because we need to figure out less-expensive ways of housing people who have very, very little money.

So that's the--

SENATOR GORDON: I'd like to take you up on that offer.

MS. LEVINSON: Okay. (laughter) I would enjoy that. And I think that we can all pull together. There are a lot of people who are doing some very exciting things out there -- including shared housing, including nonprofit take-over of boarding homes that could be created into really lovely supportive housing environments. Some of them already exist in communities around the state, and we have to look at that, and we have to make some serious decisions about where we want to put our resources.

SENATOR WEINBERG: Yes, just let me interrupt.

I'd like to make a comment about that, because the boarding home issue is an important one that I know we're going to be discussing together in the not-too-distant future.

MS. LEVINSON: Yes.

SENATOR WEINBERG: But the boarding homes are regulated by the Department of Community Affairs. So they look at things very differently than the Department of Human Services or the Health and Senior Citizen Department would be looking at it. So I just want to point that out because it is a distinction that is causing problems today, in my opinion.

MS. LEVINSON: I understand. No, you're absolutely right. And I'm hoping, when we're going to have that discussion, that we can talk about ways that the Department of Community Affairs and the Department of Human Services can work together. And then to bring in, perhaps, some nonprofit organizations that can work to really take over some of these facilities. They're doing it in New York beautifully; and we really have to talk about it -- for efficiencies. But there's a lot there.

Just a future service issue -- just a couple of highlights, if I have the time.

As Tom Baffuto mentioned, there's a sea change going on here; it's so dramatic, that it's hard to sort of keep your head together on it. And every day there's something that you have to absorb.

But probably the most important thing is we have to capture the savings that this Medicaid system is affording us -- with the Medicaid match -- and keep it in the Human Services system to the best of our ability, because we have so many people to serve.

Secondly, as we move into fee-for-service -- I represent providers and they're scared because many of them that are nonprofits don't have deep reserves. And they are afraid that as they transition into the new system, quite honestly, they're afraid they're going to go out of business. So we need to keep -- we need to bolster them; and I think the Division is attempting to do that, but we have to watch very carefully to make sure that, as we move to Medicaid fee-for-service from contract-based, we don't lose our nonprofits because they're very dear, and they're doing great work.

There are some solutions to this, but we have to, sort of, hold the State's feet to the fire to make sure that they keep them moving forward with strength and opportunity.

The other piece of this is purchase of software -- electronic client health records and Medicaid billing. If we don't figure out a way to enable the nonprofits to afford these software systems, we're going to have Federal audits with tremendous penalties because we haven't figured out a way to properly bill and collect data. So I'm suggesting that we take a good, hard look at that and figure out a way to pay for it.

And then, finally, a majority of the housing and services being developed in New Jersey are for people at the highest end of the disability continuum -- I think with the Olmstead settlement, emergencies, Return Home New Jersey, etc. And that's important. And there's more who we need to serve.

But we also represent the needs of thousands of adult individuals with intellectual and developmental disabilities who are

living at home -- and have lived at home since birth -- with aging parents now. And we have to do something for them. And that's the Supports Program; it's rental vouchers. We have a rental voucher budget campaign that, I think, has been introduced as a budget resolution to get 1,000 new rental vouchers into the system. And we need the Supports Program so that people can plan forward and create some housing opportunities for themselves.

And finally, I just wanted to, again, thank you for the opportunity. I had mentioned it in the beginning, but there's a lot of good stuff going on out there, and I think that we have the opportunity to bring that to you. Some of it might even need legislation, and I think we can deploy resources in a manner that we've never done before. We're also interested in working with banks so we can get some private resources into the system, moving forward.

Thank you for your time.

SENATOR GORDON: Thank you. It sounds like there's opportunities for some exciting collaboration. And you certainly would have willing partners here.

Ms. Sellers.

**V A L E R I E S E L L E R S:** Thank you, Chairman Gordon, Senator Weinberg. Thank you for the opportunity to speak with you today.

I'm deviating from my testimony, which is always dangerous. But you've heard from so many others, and I don't want

to be duplicative. But I do want to point out some common themes that you're hearing.

One, I would start by saying that we have been at the table with DDD. And they have solicited our input, and we're appreciative of that. We have had an opportunity to make some significant changes in some of their early recommendations.

Having said that -- echoing what you heard from Tom Baffuto -- there are so many critical areas that absolutely have to be addressed before we transition into fee-for-service. I represent 62 agencies -- providers of services and supports to individuals with intellectual disabilities. The challenge that I face with my membership is that I have some who are very small, to those who are national organizations. It doesn't matter the size; this change can have a significant impact -- whether they're operating in five states, or you're just running two group homes. The concern, and the angst, and the anxiety that Tom Baffuto referenced is pervasive. It's not unique to any one type of organization. I think two or three people referenced the lack of information that's being given to providers -- the tiering that you're hearing. I was actually quite surprised when I came into this world two years ago that we weren't already in fee-for-service, because every other state is in this field right now, and many are moving into Medicaid managed care for long-term supports and services. Fortunately, we're not there yet.

But having said that, I thought, "Well, why would this be such a problem?" Well, two years later, I understand what the

concerns are. We don't have enough information. The infrastructure is not there yet. I do believe DDD is working to move toward that, but we are not there yet.

And let me just share some examples with you. You heard about the tiering. A year ago, when the rates were first released, providers were told, "Model the impact," so that you understand how you need to make programmatic or financial changes and be prepared for fee-for-service. Well, you cannot model the impact if you're not given the information to do so.

So we've been awaiting the tiering information and the acuity information for, probably, within the first two months of the rates being released. We've never seen that; and now, not only have we not seen that, more important -- we're being told that that information does not belong to the providers, it belongs to the individuals. And I respect that; but providers today cannot plan for tomorrow if they cannot model the financial impact.

With my smaller agencies, I've encouraged them to talk to other organizations and perhaps seek mergers or partnerships of some sort to remain financially viable or ensure the ongoing supports and services to those they currently service. They cannot do that because they don't know where they stand financially. And it is not just simply, "Well, look at the population you serve today, and try to estimate where you would be." That's overly simplistic, and that's not how good business practices are used. And that's what we need -- we need information to make good, sound business decisions, because as much as we are there to provide social

services, we're also here to be a business and remain intact and viable.

The other issue that we're facing is that -- and I think a pretty significant issue -- we don't have licensing regulations that are consistent with fee-for-service; and we can't move forward. I tell my providers that I'm very concerned; they are at risk. They are at risk of being noncompliant with State regulations and, more importantly, they're now having Federal oversight. So Medicaid comes in, and it's not a matter of just picking up the phone, or calling somebody from Medicaid and saying, "You know what? I didn't mean to bill this way," or, "I didn't mean to--" "We didn't have appropriate staff, but--" You don't do that with the Federal government. Medicaid -- you either get it right and you're compliant, or you're not.

So I've been around long enough to know that amending regulations takes a very long time. But we need to do that, and we need to do it now, and we shouldn't -- providers should not be held to existing regulations or policies. I've never been in a world where you use policies as standards; so I think that's something.

And I know DDD has welcomed that discussion, and they are moving forward. But we can't implement a system without making sure that the regulations are timely and appropriate to the world that we're living in.

I think the last that I would reference, in terms of fee-for-service, is that we now have hundreds of case managers. Their role is changing -- and we've been told it's to one of quality

oversight. They are auditors now. The concern that we have with that is that their actions are duplicative of those responsibilities that rest with licensing. So now we have individual case managers coming in and citing providers because they have a roll of paper towels that has not been replaced. This is not ensuring the safety and well-being of individuals. Rules have to be clarified, training needs to be provided, and perhaps most importantly, you have to have oversight so that those who have been charged with very specific responsibilities limit their actions to those responsibilities. This is a very big concern, because the providers are spending so much time on administrative tasks and responsibilities in response to directives from case management and licensing that they're not devoting the time that they need to, to the individuals who they're serving.

So all we are asking is not to move away from fee-for-service -- I think it's the appropriate transition -- but we have to give providers and, quite frankly, families and caregivers all the tools and information necessary to ensure that this transition is done right from the very beginning. We cannot keep backtracking and correcting things because we've been so quick to adhere to a timeline. The timeline should be-- The assurance that we get this right should drive the timeline -- not the timeline driving, as we roll out all these different facets associated with fee-for-service, with leases, and billing, and all the rest.

So I will leave it at that, and I've provided you with more extensive information in my written testimony.

SENATOR GORDON: Thank you very much. Thank you both for what I consider excellent testimony and real-world experience. I mean, it is clear to me that this Administration is not ready to pull the trigger and, perhaps is following the approach that might be described as *ready, fire, aim*. (laughter) Certainly, there's more work to be done.

Senator Weinberg, any comments?

Thank you.

SENATOR WEINBERG: Again, I think that, hopefully, there is a representative from the Department here to hear this testimony, firsthand, since the other two representatives had a very important engagement, I'm sure -- more important than what's going on here.

But, again, I think what's coming through very clearly is that the communication has not taken place -- whether we are talking about to families and individuals, to providers. I mean, just what you just pointed out about being asked to model the fee-for-service. Well, you can't do it if you don't have the information.

So I think that has to come from this Committee, back through the Legislature, and directly to the Department -- about what we perceive to be -- that their version of reality might not necessarily jive with reality.

SENATOR GORDON: And that's why we have an Oversight Committee.

Thank you both very much.

MS. SELLERS: Thank you.

SENATOR GORDON: We will next hear from -- we'll get a different perspective, I believe, from two parents, Nina White and Lisa Paterson. Are you here?

UNIDENTIFIED MEMBER OF COMMITTEE: (off mike)  
Lisa Paterson is not here.

SENATOR GORDON: I'm told Lisa is not here.

Is Nina White here?

Thank you very much, and welcome.

**NINA STEIN WHITE:** Thank you so much.

Forgive me if I'm a bit redundant on some of the issues we've already heard.

I am the mother -- with my husband, Jonathan White -- of three wonderful, adult autistic individuals. And I'm here to express concerns that are shared by the families and guardians of severely autistic individuals who exhibit extreme behaviors that require exceptional interventions and behavioral supports.

Our youngest son, Jacob, who is now 22, lives at Bancroft along with Lisa Parles' son, Andrew. And he is among the thousands of New Jersey citizens who are self-injurious, aggressive, and destructive. He needs and deserves the sanctuary of highly specialized and controlled settings.

Centralized campuses, intentional communities, and farmsteads have proven to be the safest and most economical models for supporting these individuals in creating a safe and productive life. New Jersey's revised Statewide Transition Plan continues to contain the ban on colocated settings, which are

programs where the residential and vocational programs are located on the same property.

Our son lives in such a setting. He, like so many others, requires this option in order to keep him safe.

My husband and I also have two adult children with Asperger's Syndrome; they are both highly intelligent and have completed college-level coursework. Our eldest drives, and will be performing in the New York Renaissance Festival this year. Our middle son continues to have struggles with depression and feelings of isolation -- despite his access to the community with no holds barred; but he still struggles. But he has chosen a career path and is working towards it.

Now, there are people who advocate for the universal inclusion of all people with disabilities; but I know firsthand -- with my wide spectrum of the autistic spectrum right within in my own home -- it's not always appropriate. And, in fact, when DDD placed our son Jacob in a group home, he was sent there with an old file; they were not equipped; he was self-injurious; they couldn't handle it. He was bleeding; they called the ambulance; the ambulance couldn't manage his behaviors; the ambulance called the police -- and the police pepper sprayed my son in the face and arrested him. He ended up with a series of hospitalizations; it was very ugly.

So this whole talk about planning and studying-- I'll say no more.

Our son Jacob has minimal speech capabilities. He does not say something “hurts,” or, “I’m frightened,” or “I’m nervous.” So on a regular basis, without expressive language, he just explodes, suddenly for no apparent reason -- we still can’t figure out why -- he explodes -- boom! -- into -- I mean, it’s horrific; it’s horrific.

He requires five trained staff to prevent him from striking his own head and biting his own hand. Even though he’s saying, “Calming down,” “stop biting,” it can take between 5 and 30 minutes for him to regain himself with the assistance of these five trained and supervisory individuals, who will hold him and talk to him until he can be released and stops hurting himself.

Recently during-- Jonathan and I, we go down weekly. We live in Hunterdon County; Jacob is at Bancroft at Mullica Hill. So our trip to see our son weekly is over two hours each way. During our regular weekly outing to a Chinese restaurant, Jacob went from happy to full-on tantrum without warning. We were not able to calm him, and he ended up running around the parking lot for 15 minutes, striking his head repeatedly: wham, wham, wham, wham, wham.

When we tried to intervene, he bit us. Caring individuals called the police for us -- one policeman came, not equipped to help us restrain him. Campus could not put a crew together to come out to help us to restrain our child, and we just had to let him ride out the storm.

In about 15 minutes, his neurological storm -- and, by the way, he's on a tremendous amount of medication; he's highly supervised by an on-site psychiatrist and nursing. But still he gets these storms. Once his storm hit climax, he was able to get into the car and we were able to bring him back to campus. And, fortunately, on that rant, he did not permanently injure himself or others -- whew.

So Bancroft Lakeside Campus keeps our son safe using a centralized campus model. They have behavioral and psychiatric interventions onsite. And he's in good control most of the time with the help of Bancroft's direct care staff and onsite supervisors, and there's a fluid interplay between his residential and vocational programs right there. He's as engaged as possible all day long, and that keeps him calm. Because his mind -- he does have some capabilities, but he needs to be constantly engaged by people who know what they're doing.

There is no way to create this intense behavioral support in a group home -- in a four-person group home or in an apartment, in an integrated setting. And what 75 percent of the population would want to be subjected to our son's frequent episodes? It's very distressing to see. I can't imagine people agreeing to live in an apartment next door to my son. I love him to the ends of the earth, and it's very difficult. We kept him home until he was 19, and we gave him up because we couldn't keep him from injuring his hand; he had cellulitis in his hand numerous times from repeated

biting. You know, we didn't call the glass guy until there were three broken windows at a time.

The need to transport Jacob to another location for intervention isn't feasible. If he is out of control, you can't bring him to a hospital or a clinic because he's not safe to transport. If Jacob were forced to go to a day program in a separate location from his residence, he would likely be more isolated. Because if he couldn't be transported, he might miss his whole day of programming; and if he isn't engaged by work or activities, he would be less controllable as he needs engagement to stay focused, and thus calm.

On many days, if forced to travel to another location for his vocational program, he, staff, and even members of the public who might be sharing the road would be recklessly placed in danger. And I've had to pull to the side of the highway with him in the car. And one of the other traits that made us know that we could no longer care for him ourselves, without this level of support, is he broke the rear window of our car with his head.

Sadly, low-functioning autistic individuals like our son haven't the awareness to wish to be part of the community at large. And in fact, the unpredictable nature of "the outside world" can be terrifying to those who have impaired processing and the need for sameness.

Getting Jacob into a more mainstream life could be part of a long-term goal. But ignoring his current needs to serve that end, and for the people who care for him and create his

programming -- to have that be the driving force of his programming is reckless and dangerous.

Campus programs, intentional communities, and farm communities can provide the consistent routine and anxiety reduction to give people with the autistic spectrum disorders, such as Jacob's, the most profitably productive life with the most efficient economic model. So our State really needs to keep its campus programs, and improve upon them, and increase them, and support wonderful programs like United Way. There shouldn't be these obstructions to what our vulnerable population needs. And he doesn't need housing provided by the State for financial reasons. He needs programs, and access to experts, and support.

With today's open door policies and excellent laws in place to protect the rights of these vulnerable individuals from abuse or neglect, colocated programs can provide excellent care and should be supported as a necessary option for families.

And I would like to add that we could do great things for all of our communities if we remove the outdated stigma of the word *asylum*. Asylum is a place where people can be protected from things that are not good for them. What is wrong with people living on a farm, and growing food, and inviting the public in to buy? I do it every day, and my life is exceedingly fulfilling. My farm is certainly not an institution and neither is Jacob's current program. So I hope that we can find some way to press DDD to look at this as a very important and necessary option in the spectrum of what our citizens can have access to.

Thank you very much. (applause)

SENATOR GORDON: Senator Weinberg, any questions?

SENATOR WEINBERG: No, just thank you for coming forth and giving a really vivid explanation of real life.

So thank you.

SENATOR GORDON: Thank you.

We will next hear from what will be our last panel for this section of our hearing. We will hear from Nadine Kaiser, the Executive Director of The Opportunity Center in Fairlawn; and from Bob Titus, Public Policy Coordinator of the New Jersey Council on Developmental Disabilities.

Welcome; thank you very much. Whoever would like to start.

**N A D I N E K A I S E R:** Yes. Thank you, Senator Gordon and Senator Weinberg, and Committee members, for your interest and this opportunity to speak with you about the State's Transition Plan developed by the Division of Developmental Disabilities, and its impact on programs like ours.

My name is Nadine Kaiser, and I'm the Executive Director of The Opportunity Center in Fairlawn, New Jersey. And I have with me Mr. Gary Leventhal, who is on our Board.

We know you want to focus on the State's Transition Plan, and will restrict our comments accordingly. However, we thought a more in-depth treatment of the issues, as well as some information about our program, might help give context and clarity to our comments.

Toward this goal, we have provided copies of our calendar that helps to illustrate the range of activities that we offer; as well as copies of a presentation, expanded to provide details that we have excluded from our oral presentation in the interest of staying within the allotted time.

The Opportunity Center has provided a day program for roughly 25 adults with intellectual and developmental disabilities -- primarily Down Syndrome and autism -- for 50 years. We are an independent, not-for-profit organization. We are, however, a part of an association of small day programs like ours. We are sure that other members of that association would also be happy to share their thoughts.

We are not a contracted agency, which simply means that we have never been subject to State oversight. That makes our challenges and culture shock a bit greater than some of the other programs that currently contracts with DDD.

Our greatest concerns: The following are some of our greatest concerns about the changes that are required by DDD and which are found in the Transition Plan, the policy manual, and the fee-for-service rate schedule, or which have been communicated through webinars.

Each of these concerns is greatly exacerbated by the speed DDD is moving and the timing of required changes. These primary concerns are: the new rates and what they mean to our ability to balance our budget; the requirement to provide transportation; complying with New Jersey's WorkFirst priorities;

the requirement that there not be a single facility schedule for all participants -- each individual should have a unique schedule that they choose, and which reflects their interests and goals; the community inclusion requirement; training requirements for staff.

We will address each of these concerns briefly.

New rates. The new and still-proposed billing rates are supposed to be effective July 1, 2015, for some individuals; and yet, the rates are not finalized. We are unable to determine what the new rates will provide in the way of income for our agency. The reimbursement rates are based on assigning our clients to tiers intended to reflect their needs, and this assignment has yet to take place for our clients. It's quite possible that the billing rates, together with other suggested changes, will mean that we are already out of business and we just haven't figured that out yet.

DDD has only recently scheduled some training on how we are supposed to bill for services through Medicaid. Some of us have never operated in the Medicaid environment and will need some assistance. This is particularly true for small programs like ours in which we don't have a full-time administrator, and we rely on program staff, volunteers, and board members to help us meet administrative requirements. It would be helpful if DDD extended the deadline and increased the communication and training before implementing the new rates.

Transportation. We, and most of the other day programs in our association, have never provided transportation to our program in the morning and home at night. There is a system that

works today for transporting individuals to and from day habilitation. Today clients are transported to the center by Access Link, county transportation, family members, or vans that are operated by the group homes. Why change? Why create the inefficiency that is guaranteed to occur if all the small day programs in the state have to learn how to do something new, and maintain the staffing and vehicles to provide transportation? This change, which was only introduced in the last couple of months, and was not part of the DDD original plan, could have the unintended consequence of diluting our focus on the individuals in our care.

In fairness, DDD has said that we can define the area that we will serve, but it has to be reasonable -- without providing any clear definition as to what is reasonable. DDD has said compensation for providing the service is included in the new rates, but we fear that the compensation will be totally inadequate. While DDD has not clarified when we will have to begin providing transportation, it could be as early as three weeks from now when the Supports Program is scheduled to begin. While we are hoping and urging that this transportation requirement will be withdrawn, at a minimum it should be delayed and clarified.

WorkFirst. New Jersey is a WorkFirst state, which means the first choice for post-school life is for individuals to work in or work towards employment and the competitive integrated setting. For disabled individuals who can do so now, or who can grow to do so in time with training and support, we applaud that

concept. However, we have a number of clients for whom work in a competitive integrated setting is not in the cards because their disabilities are too severe.

This would be obvious to anyone who saw their individual service plan, which might include such directions as “not to be left unattended,” “likely to wander off,” and “unable to assess danger.” Yet DDD has said they will no longer reimburse for time spent in noncompetitive, fully supervised employment. Some of our clients have participated in sheltered workshops for decades, and had the gratification that comes from doing a job, repackaging cones and other items. They work at their own pace and to their own ability in the supportive setting that our center provides. The amount of money involved is very modest, and is used to buy a catered, payday monthly luncheon. Why steal this gratifying experience from someone who has been doing it for many years, in favor of looking for competitive employment that they may never find?

No single schedule. As the calendar we have distributed shows, we do have an overall schedule for our program. It would be a major change to allow individuals to choose when and what activity to have at any time -- a change that we find difficult to see working for us and our clients. Whenever possible, we have given clients choices; and in deference to the State initiative, we have already expanded some of those choices. For example, if an individual does not want to participate in a scheduled activity, such as yoga or dance, they can grab a book, work in our computer room,

or do some drawing. The way we read the new rules, and the way DDD has explained them, the degree of choice we offer today -- with largely a single schedule applicable to all participants -- is prohibited in the future. Has DDD done any testing to see how this would work in practice, and what it might mean to staffing and finances? Right now, the degree of choice we are required to offer is undefined. Is it enough to offer the alternative of a book, a computer, or drawing as we do now? If an individual wants to attend a yoga class in the community at a certain time, do we have to honor that choice? It would be helpful to clarify the degree of choice we are required to offer.

We have also been told that we have to drive individuals to the class they elect. That is fine if we can control the options offered, but it would strain staffing and materially impact finances if we had to honor most requests. If any of our clients choose to participate in an outside program with the regular community, they might need to be accompanied by staff to make sure that they have a good and successful experience for all involved.

So the degree of choice that we are required to offer is crucial to maintaining a manageable staffing level and associated costs. We normally have a staffing ratio of no more than four or five clients per staff member. In order to illustrate the concern, let's assume, as is often the case, we have about 24 clients and 6 staff members at 1 p.m. Let's assume 22 individuals are happy to attend a class we offer in pottery; 1 individual elects to attend a class in yoga, and another elects a class in dance. Since we can't

send out our vans with just a driver, someone will need to stay in the van with one client, while the other client goes into the program. Our staffing will fall from 4 clients per staff, to 5.5 clients per staff member. Alternatively, we will have to employ more staff.

If we took the additional step of having staff accompany the individual to the community class, staffing would fall even more dramatically. It could be chaos.

We see this aspect of the DDD requirements as once again being more relevant to those individuals who are high-functioning and who may be able to travel from place to place with only a modest amount of support, and who can readily participate in a broad array of activities without supervision in a non-disabled population. That is not our clientele.

SENATOR GORDON: Ms. Kaiser, if you could try to summarize, given the hour. I can tell you that I, for one, have read your memorandum -- which I thought was excellent, and provided a high level of detail, and helped me understand just how unready we are for this program. So if you could summarize, because we'd like to complete this section.

MS. KAISER: Okay, I'll summarize.

SENATOR GORDON: And, of course, you and I are in close proximity, so we can talk.

MS. KAISER: Yes, we are; okay.

I guess, in summary, with all of this -- to me, as Mr. Caputo (*sic*) and so many others have said before me, the changes

are too quick for a place like ours that has never had this kind of monitoring. It's too much, it's too fast, and it's quite a bit overwhelming. And as others have said, we've tried to keep on top of everything, but every day there are more and more changes that they're putting through on the computer.

SENATOR GORDON: Thank you very much.

Mr. Leventhal, did you want to add anything?

**GARY LEVENTHAL:** No, in the interest of time, I'll reserve my comments.

SENATOR GORDON: Thank you.

Mr. Titus.

**KEVIN T. CASEY:** Actually, I'm Kevin Casey. I'm the Executive Director of the New Jersey Council on Developmental Disabilities. Mr. Titus is our Policy Director.

You've gotten some excellent testimony today, and I urge you to pay very close attention to it. In the interest of time, I'm going to emphasize a couple of things, and leave my written testimony with you and make a couple of quick suggestions.

One, you've heard again, and again, and again -- and you just heard that the amount of change that is occurring now is difficult to sustain and difficult for people to understand and react to. Many of the efforts that are being suggested by DDD are efforts that, by themselves alone, would take several years to implement. Trying to implement all of this at one time, in my view, threatens chaos in the system, frankly.

Two, I am a firm supporter of integration and inclusion. I believe that they are sound and solid policies and, in fact, ought to be the policy of the State of New Jersey. But you don't get families and self-advocates to accept new policy by attempting to force it on them. You get it by saying to them, "I think I have something better for your family member. Let me show it to you. Let me spend some time with you on it; let me talk to you about it."

The best way -- the absolute best way, in my experience, to get families to be resistant to any kind of change is to try and force that change on them. Do it slowly, do it carefully, and do it one person at a time. Instead of trying to-- Let me suggest to you that one of the things that hasn't been brought up in the conversation that is key to CMS's new standards is the concept of *person-centered planning*. The concept of person-centered planning is mentioned again, and again, and again through their document. So why not, instead of suggesting 75 percent, or 50 percent integrated time, why not have a requirement in each person's individual program plan that sets, for that person, based on that person's need, a certain amount of integrated time in the community? And certainly require providers to look at increasing that, over time, and that kind of thing -- but it should be based on the individual.

Let me suggest that the headaches we have seen in the process of developing all of the change that has been suggested -- if you have families, and self-advocates, and providers that felt that they had been heard, we might have a much smoother process. So

let me suggest to you that one of things that the Division ought to do is create a permanent advisory council or advisory committee, consisting of families, self-advocates, providers, and other advocacy organizations. That advisory committee ought to, at all times, have at least a majority of families and self-advocates; and every new effort of the Division ought to be run through that kind of process, and run through in a way that gives the entire DD community -- instead of one at a time -- the entire DD community a chance to sit down and discuss the new policies suggested.

And I would suggest to you, strongly, that if the Division is unwilling to create such a process by themselves, that it would be a very good thing if the Legislature would, frankly, require it.

Finally, I want to suggest that when you come to a point -- and Senator Gordon, you asked several questions on this -- when you come to a point where the family and the State disagree on what type of support, what type of service an individual needs and where that needs to take place, it might be a very good idea to set up a system where the family and the self-advocate has a right of appeal to an independent body. Not another part of State government, but an independent body of some type, with levels of expertise, that can both mediate between the family and the State and make a final decision, if that becomes necessary. But I think when you leave it in a situation where the State, in one way or another, can simply impose a new service system on a family or self-advocate without any real discussion, you leave a situation in which families are, by the nature of what they feel, going to be

upset and angry. I have, in my 45 years in this business -- and if you want to tell me I look way too young to have been at this for 45 years, I would be glad to hear that (laughter) -- I have never seen and never interacted with a family that said, when I said to them, "I've got something better for your family member," that said, "Go away." In fact, that is what most families are praying for, is something better for their family member, over time. And we ought to take advantage of the fact that that's what families want.

Thank you very much for your time, and thank you very much for the interest you've taken in this subject. (applause)

SENATOR GORDON: Well, I want to thank you for some excellent testimony and some definitive ideas that may well find their way into some legislation. We're certainly going to be reviewing the transcript of this meeting and try to cull out ideas, such as those that you've proposed, for some legislation that would improve the process.

I certainly have learned a great deal from the testimony that we've heard today. Certainly those of us in politics know that top-down usually doesn't work very well; but that seems to be the approach that's guiding the Department in developing and implementing these policies.

I think we need to put some brakes on the process and give this a little bit more thought. Certainly do -- interact more with the client community and hear from the families, and give the providers an opportunity to talk about what's going to work and

what's not going to work for them. And there may well be some legislation or legislative action that brings that about.

Senator Weinberg, any thoughts?

SENATOR WEINBERG: No, I agree with everything you just outlined, Senator Gordon.

I just want to add the particular case I brought up at the beginning of this hearing with the Assistant Commissioner, which she said sometimes they are just never notified in time -- these are the young people who are aging out of their educational institution.

I got an e-mail from the parent who said that they notified DDD a full year in advance, and are still waiting for a phone call back. I just want to keep the record straight. Because part of this is that people have to have faith in what they're being told -- in whether or not the Department is really dealing with families as individuals, with individual needs and goals. And whether or not the Department is really dealing with the providers and giving them the information that they need in order to be able to assimilate the role models -- whatever it is they're requiring.

But right now, it would seem to me that every provider we've heard from, as well as family members, seem to indicate -- as I said a little bit earlier -- the reality of what the Department has put forth and what the reality is for families and providers is not quite the same.

SENATOR GORDON: Thank you.

Let me thank you all.

Let me just recognize that the Minority Leader, Senator Kean, is here; he's joining us for the afternoon session. And speaking of the afternoon session, we are actually going to take a brief recess of about 30 minutes, and we're going to reconvene at 1:45 to focus on the Return Home New Jersey program.

For those of you who are suffering from pangs of hunger, we have something called *Café New Jersey* on the floor below, where you can get a quick bite. And I hope we'll see you all back here at 1:45 p.m.

Thank you very much.

**(MEETING RECESSES AT 1:15 P.M.)**

**(MEETING RECONVENES AT 1:45 P.M.)**

SENATOR GORDON: Good afternoon, everyone.

We're going to reconvene. For those of you who have just arrived, welcome to the Senate Legislative Oversight Committee.

We welcome Senator Kean, the Minority Leader; Senator Weinberg is here; I believe Senator Sarlo will be joining us a little later.

At this point in today's hearing we would like to shift our focus to the Division of Developmental Disabilities' Return Home New Jersey policy. As we touched on earlier this morning, due to New Jersey's inability to meet the needs of certain

individuals with developmental disabilities, several hundred New Jersey residents were placed in out-of-state facilities in order to receive the services they needed.

In 2009, DDD embarked on an initiative called *Return Home New Jersey*. The program was designed to transfer individuals receiving services at out-of-state residential facilities to community-based residential placements in New Jersey. The Division states that they are pursuing this initiative in order to obtain the Federal matching funds that are not available for out-of-state clients.

Based on financial criteria alone, the idea seems to make sense. We can maximize New Jersey's budgetary resources, while bringing New Jersey residents back to their home state.

For many individuals and their families however, this program represents nothing less than a complete upheaval of their lives -- and a frighteningly dangerous one at that. Many of the individuals affected have been living in their current residential facility for decades. The families would argue that these specialized, out-of-state placements are uniquely suited to meet the needs of their residents. Despite the well-established history of care provided at these facilities, the Return Home policy is forcing these individuals to accept placements in New Jersey facilities that are incapable of providing comparable services.

Even if we could set aside the potentially severe social, emotional, and psychological effects such a disruption would cause, we simply cannot ignore the very real health and safety issues that

may arise. Many of these individuals have severe behavioral and medical conditions that require constant supervision and care. The Division's attempt to move these individuals to facilities with caregivers lacking specialized training and unfamiliar with the unique needs of clients is a prescription for bad outcomes.

Maximizing Federal resources is generally a good idea. With respect to DDD's Return Home policy, however, we must ask whether these economies are truly worth the anguish and heartbreak this policy is inflicting on New Jersey families.

And with that brief statement, we will hear from a number of individuals who have experience with this program.

I would like to begin with Lisa Parles, who we heard from earlier today; and Carolyn Reichenbach.

UNIDENTIFIED MEMBER OF COMMITTEE: Lisa is not testifying, but she's here.

SENATOR GORDON: Okay. I understand that Lisa is not testifying.

Thank you very much, Ms. Reichenbach; proceed.

**C A R O L Y N P U R C E L L R E I C H E N B A C H, Esq.:** Good afternoon.

My name is Carolyn Reichenbach, as you said. And I would like to thank you very much for the opportunity to be here to speak today.

My 49-year-old brother, Richard, has been profoundly disabled since his birth. His more significant diagnoses include autism, epilepsy, severe intellectual impairment, and tuberous

sclerosis -- a rare condition in which benign but largely inoperable tumors develop on various organs, impeding their function. Nevertheless, Richard's friendly demeanor, his easygoing personality, and his big heart have endeared him to many people throughout his life.

For more than 30 years, he has happily resided at the Woods Services in Langhorne, Pennsylvania, where his progress has been both continuous and substantial. He works five days a week in the staff cafeteria on campus, gathers with friends in town for dinner on Fridays, attends services at the local Episcopal church on Sundays, and enjoys regular visits with members of his immediate family. Richard is happy, safe, and thriving at Woods.

Return Home New Jersey, specifically, threatens to change all this for Richard, and hundreds of others similarly situated to him, by compelling their relocation to unfamiliar group homes, in unfamiliar towns, with unfamiliar staff, and unfamiliar housemates -- often further away from their immediate families. I am compelled, as are many others in this room today, to ask why? Why are we doing this?

DDD claims to be pursuing these relocations under the guise of community integration, fiscal responsibility, and enhanced family nexus. In my opinion -- both as a lawyer and as Richard's guardian -- these reasons ring hollow. Richard, and other individuals at campus-based facilities like Woods, are already more integrated into the community in which they live than they could ever hope to be residing at 4-person group homes sprinkled across

New Jersey. Richard knows, personally, well over 500 people on campus, and over 150 off-campus. And virtually every time the two of us go into town for a visit it culminates in someone greeting Richard and immediately inquiring, with an eye towards me or towards Richard's security, as to who I am. They want to make sure that I'm okay to be with my brother. There is no greater comfort to me, I assure you, than to know that Richard has an army of people -- both on-campus and off-campus -- who are concerned about his well-being and watching out for his safety.

DDD's fiscal responsibility argument is just as illusory. Richard's placement costs out-of-state are significantly below the average out-of-state placement costs of \$155,000 a year, and the average in-state placement cost. Prior to today's session, I thought that was \$202,000, based on testimony that OLS received from DDD; but, after today's testimony, it looks like that range is up to \$285,000 to \$315,000.

Further, because Richard lives in a 4-person detached group home off-campus, his placement at Woods is already eligible for Medicaid reimbursement. It's already eligible, but DDD has chosen not to seek reimbursement for his placement there. I don't know why they've done that, but they've done it.

Lastly, DDD's family proximity argument is equally weak. My husband, my children, and I all live near Woods by design, and have done so for 20 years so that we can have regular contact with my brother. Any relocation of my brother at this point

would move him absolutely further away from his immediate family members who visit with him the most.

Even if there were a scintilla of truth to the reasons DDD cites, relocation remains inappropriate for Richard and many others similarly situated to him. DDD -- not my family -- but DDD placed Richard at Woods 30 years ago. They asked him to adjust, which he ultimately did, and they have agreed, for the past three decades -- three decades -- that his placement was appropriate. Therefore, DDD should be stopped from changing its plan this late in the game.

Notwithstanding the evident cracks in DDD's justification for Return Home New Jersey, the initiative itself is flawed. It imprudently implies a one-size-fits-all policy on New Jersey's disabled out-of-state residents, entirely ignoring the vast needs of this most vulnerable segment of New Jersey's population. In addition, Return Home New Jersey fails to take into account whether relocation is actually in a disabled person's best interest -- a shocking omission, given that that is what New Jersey law mandates -- a best interest standard.

Over the course of this past year, I have immersed myself in New Jersey's disability laws, I have educated myself about Medicaid reimbursement, I have spoken with dozens of families, and I have met with other legislators. As a result, I think I have a fairly sound grasp of what Return Home New Jersey is all about, and I also understand that there are statements being made

about Return Home New Jersey that are misleading and simply false.

So I would like to take a moment -- a brief moment to correct some of these more significant misstatements by giving you the facts.

The average in-state placement is considerably more expensive than the average out-of-state placement.

The higher costs of in-state placements often obliterate much, if not all, of the financial savings to be gained from any kind of Medicaid reimbursement that DDD would receive in-state.

Medicaid reimbursement extends only to the services, and not the room and board component, of the placement -- such that a percentage of each placement is not reimbursable.

Many of the restrictions encumbering DDD's ability to receive Medicaid reimbursement for current out-of-state placements are self-imposed and are not mandated by the Federal government. And I mentioned that earlier; as I said, DDD could qualify my brother's placement for reimbursement right now, and has chosen not to -- chosen not to.

DDD is compelling the relocation of out-of-state residents whose placements are already receiving Medicaid reimbursement. So people who are already getting reimbursement out-of-state are now being compelled to move back in-state.

DDD is intentionally marginalizing families during the Return Home New Jersey process, despite what Dawn Apgar said this morning. They are creating ELPs without family input, they

are scheduling meet and greets without notifying families, they are refusing to reschedule meet and greets when family emergencies -- such as deaths and hospitalizations -- arise.

A disabled resident's presence out of state does not affect his or her residency, as residency requires a legal state of mind that disabled individuals are incapable of forming. So these people who are out of state -- they remain New Jersey residents, despite what Commissioner Apgar will tell you.

Nelson Mandela once said that, "There can be no keener revelation of a society's soul than the way in which it treats its children." As the mother of four young children, but especially as the sister of a child trapped in an adult body, I couldn't agree more. And I can only hope that you are similarly inclined, and will do what you can to stop, once and for all, the inhumanity of Return Home New Jersey. New Jersey's disabled, out-of-state residents deserve so much better.

Thank you for your time and your interest today.  
(applause)

SENATOR GORDON: Thank you very much for your very compelling testimony.

Does anyone on the Committee have any questions? (no response)

Thank you very much.

MS. REICHENBACH: Thank you.

SENATOR GORDON: We will next hear from Dr. Ted Kastner, a mental health provider and primary care physician, I believe.

Dr. Kastner.

**T H E O D O R E K A S T N E R, M. D.:** Thank you, Senators Gordon, Weinberg, Kean, Kyrillos, Ruiz, and Sarlo, and invited guests. I am honored to have the opportunity--

SENATOR GORDON: Your microphone is not on. And, if I could just interject something. I forgot a minor housekeeping item.

The State Police has alerted us that Michelle Zeigler (phonetic spelling), who has parked in spot 3-423, a grey Acura, needs to move the car to parking level 1. So Michelle, if you're here, your car may become part of Return Home New Jersey if you're-- (laughter)

SENATOR KEAN: What kind of car was that, sir?

SENATOR GORDON: I'm sorry, Dr. Kastner; go right ahead.

DR. KASTNER: Thank you for the opportunity to testify today.

I've been a Medicaid provider serving people with intellectual and developmental disabilities for nearly 30 years. Over the past 18 years I've been Director and President of Developmental Disabilities Health Alliance. We are a healthcare organization specifically for persons with developmental and intellectual disabilities. Over that time, we've served nearly

10,000 clients of New Jersey DDD -- about 25 percent of all clients under service.

In 2010 alone we served more than 6,000 non-duplicated clients who live in the community. We currently operate five primary care locations, in Hackensack, Bloomfield, Toms River, North Brunswick, and Clementon in Camden County. We serve about 1,400 people currently, with about 900 who have mental health needs.

Given that we're one of the few practices that do accept Medicaid, we've been swamped with referrals for individuals who are in both the Return Home New Jersey and Olmstead programs. Over the last two years we have seen at least 74 individuals served in those programs, and I believe we're the largest provider of healthcare services to that group in the state.

As an aside, we receive no funding from Medicaid HMOs. We don't contract with Horizon, United, Amerigroup, or Aetna. Our funding is mainly from a cooperative agreement with CMS -- which will end in December. At this time, I couldn't tell you if we're going to be able to keep our office in Clementon. We're making plans to close our Hackensack office, and we're looking at the potential closure of two other locations.

I wanted to talk about Medicaid and the impact of the Medicaid program on people in the Return Home program. I'm sure you know that in an ICF/MR they use a bundled payment model, which includes all of the services that the individuals require; one payment covers physician services, primary care, neurology,

psychiatry, PT, OT, speech, nutrition, social work, psychology, educational services -- really everything. Because of the economies of scale, most institutions staff ICF/MRs with physician ratios of about 1 to 75 clients.

I'm sure you also know that every client of New Jersey DDD has to become Medicaid eligible, and that every person who receives Medicaid has to participate in a Medicaid HMO. So when individuals leave their current residence through the Return Home New Jersey program and come to New Jersey, they have to join an HMO and find a network that provides the same level of service that they received in a bundled model -- usually in an ICF/MR.

That HMO has to provide everything: primary care, mental health, dental; in addition to pharmaceuticals, durable medical equipment, diapers, homecare services, medical day -- everything that's covered by Medicaid's State plan.

If you look at the Medicaid HMO contract with the State of New Jersey, you'll see that Medicaid HMOs have to deliver at least four separate services. They're required to maintain a specialized network of providers who provide both physical and mental health services to people with developmental disabilities. They're responsible for providing a comprehensive care management program, which includes a needs assessment, development of care plans, referral coordination of care, continuity of care monitoring, and follow-up. Medicaid HMOs are responsible for implementing quality improvement programs and techniques to improve the quality of life of their members. And they're also

responsible for designing and implementing clinical pathways and practice guidelines.

In our experience, Medicaid HMOs in New Jersey do not meet any of those four criteria. And this has a significant impact on the success of people who are relocated to community settings.

We've looked at the 74 individuals who are currently served in the Return Home and Olmstead programs. Approximately 31 percent complained of lack of access to in-network providers, and 28 percent complained of the lack of care management services. Most of these complaints were directed to Horizon New Jersey Health because it is the largest Medicaid managed care provider in the state. And Horizon New Jersey Health, in particular, refuses to pay practices, like ourselves, for any out-of-network services whose members are unable to find the services that they need. They also do not provide any care management services at all, that we could learn of, to individuals with developmental disabilities. Both of those are clear violations of the State Medicaid HMO contract.

Of those individuals who complained to the New Jersey Department of Banking and Insurance, we found that there was no meaningful response to the complaints. DOBI sends the complaints to Medicaid, and I don't believe that Medicaid has reported to anyone that they received complaints from individuals in Return Home or in the Olmstead program. We have no idea what's happening to those individuals.

The primary measure of network adequacy in access to care is the quality of the provider networks. In a study published in 2013 in the journal called *Health Affairs*, an author named Decker examined the rate of physician participation in Medicaid managed care networks. They found that approximately one-third of physicians did not accept new Medicaid patients, and the range was 9 percent to a high of 54 percent in New Jersey. New Jersey was dead last by far among every state in terms of access to primary care services through the Medicaid program.

The same phenomenon was present in regard to specialty physician services. The range was 4 percent in Minnesota to 56 percent in New Jersey -- meaning that 56 percent of physicians in New Jersey would not see new Medicaid patients. California, which was second-worst, was better by 8 to 10 percent than New Jersey. We were so far out there, there was no other state that compared to our state in terms of those poor access rates to Medicaid physicians.

That information has been available for two years; everyone who I have spoken with has known about it. And there has been no response by HMOs or the Administration to address those network deficiencies. The Legislature needs to step up and develop specific criteria which can be used to measure network adequacy for persons with I/DD, and require that New Jersey Medicaid and its contracting plans meet those criteria. That would include making sure that there's adequate access to primary care,

mental health, dental providers, neurologists, and other specialty providers.

We spend approximately \$10 billion or more on our New Jersey Medicaid program. Only 80 percent of that is spent on healthcare services -- what's called the *health benefits ratio*. The Medicaid plans are permitted to keep 20 percent of that for the administration and profit of their plans. That's \$2 billion or more. It's a fantastic amount of money. But there's no accounting for how those funds are spent.

I strongly support the Out-of-Network Consumer Financial Protection, Accountability and Transparency Act (*sic*), because I believe that's one way that would provide access to expenditure data and would allow researchers, such as our organization, to understand how those dollars are spent. But I would have to tell you -- the language in that bill needs to be changed so that Medicaid HMOs can't claim that the use of public dollars is proprietary and protected by contracts between the plans and their providers. We're talking about \$10 billion or more in Medicaid funds which cannot be examined because Medicaid will not allow that claims data to be shared with anyone. We've tried through Open Public Records Act requests to examine that data, and have been told that we could not obtain it. We've worked with CMS to obtain it for the evaluation portion of our cooperative agreement, and have been told that the Federal government doesn't receive Medicaid claims data that sheds light onto how dollars are

spent. So I encourage you to incorporate that change in the pending legislation.

At this point, I know there are a lot of families who want to present, and I don't want to take more time. But thank you very much for the opportunity to present this to you, and I wish you very much luck in your work.

SENATOR GORDON: Thank you very much, Doctor.

It sounds as if we may have another topic that's worthy of a hearing in itself.

Certainly the issue of network adequacy has been something that we've looked at, and we had a hearing on that, actually, related to behavioral health; and the fact that there are only a few dozen -- maybe 30 psychiatrists in the state who are taking new patients around the whole state. And I'm sure that we're seeing similar patterns for these other specialized areas of care.

I think we-- I know I would like to have a further conversation with you about potential legislative remedies. And I could certainly discuss with the members of the Committee whether we should be looking at this in more detail. So I think we should.

Senator Kean, did you have a question or comment?

SENATOR KEAN: Thank you -- through the Chair.

Your last comment regarding the collection of the data -- you said the Federal government doesn't do it either. Is that a HIPAA problem?

DR. KASTNER: No, no.

SENATOR KEAN: What is the issue? Why is this data set incomplete?

DR. KASTNER: The Medicaid HMOs submit claims data to the New Jersey Medicaid. New Jersey Medicaid refuses to allow that claims data to be shared with anyone, because the Medicaid HMOs have convinced New Jersey Medicaid that it is proprietary information -- that within those cost claims are embedded information about the contracts and the rates that they pay providers. So New Jersey Medicaid will not share any of it with providers, with researchers, with payers, or with the Federal government. It's very easy to fix: You take out the name of the HMO; you take out the name of the provider; you strip the identifiers out the same way that you do for HIPAA, and then you can share that data. And you can see how New Jersey spends more than \$10 billion on healthcare services. But no one has seen it. I know that I've reduced ER and hospital use by 70 percent for my patients because I get the utilization data. But I can't tell you whether I've saved a penny, because I never get the cost portion of the claims.

SENATOR KEAN: Is there-- I apologize, for the record. My mike doesn't seem to be-- Maybe that's intentional. (laughter)

SENATOR GORDON: I had nothing to do with it. (laughter)

SENATOR KEAN: Nothing to do with it; (indiscernible), Mr. Chairman.

I guess the question is, are there other -- through the Chair -- are there other states that collect that data and distribute it?

DR. KASTNER: Yes. Every state collects the data, and most states share it. The Federal government shares all of its Medicare data with the public. You can go online and download whatever you want around costs, because they strip out the names of individual patients.

SENATOR KEAN: Right. But what states do it well, from an information distribution perspective -- from your perspective?

DR. KASTNER: Well, I think New York is a good example of that. I've been working in New York; we can look at their claims data and understand the patterns of care and the costs of care. I couldn't speak to many others states. It's not something in my area of expertise.

SENATOR KEAN: Okay, thank you.

SENATOR GORDON: Senator Weinberg, any--

SENATOR WEINBERG: No. I think it's obvious, based upon your -- Dr. Kastner's answer to Senator Kean's question, where we could go from here on that issue.

SENATOR GORDON: Thank you very much, Dr. Kastner.

DR. KASTNER: Thank you very much.

SENATOR GORDON: We will next hear from Marcia Adams.

Ms. Adams.

**M A R C I A A D A M S:** Thank you, Senator Gordon and the Committee, for this opportunity.

My name is Marcia Adams.

One of the basic flaws with the Return Home New Jersey, from its inception, is that it has entirely ignored the obvious: the negative and the disruptive effects of uprooting individuals with severe disabilities from their appropriate, long-term, out-of-state placements with familiar surroundings and highly qualified caregivers -- to what my son, and many others like him, is home.

These effects are, in fact, contrary to some of the stated goals of Return Home New Jersey, and it is vividly clear that the Division is disregarding its own mission -- which is to have the individual exercise their right to make choices.

A primary goal of Return Home New Jersey is to return individuals to a "comparable or better setting in New Jersey that meets their needs." However, due to many factors -- but especially budgetary constraints -- the community-based homes, known as *group homes*, are simply not equipped to offer the one-to-one staff support or on-site medical services that are required to properly address the needs of my son, as well as many of the individuals with severe and multiple disabilities, in order for them to enjoy security and to have any meaningful quality of life in a safe environment.

Another stated goal is to return individuals to New Jersey to be closer to family -- which completely ignores our state's

geography. Appropriate facilities in neighboring states, such as New York and Pennsylvania -- where my son lives, just 20 minutes from our front door -- are actually closer to some New Jersey families than an in-state placement.

As of this date, we have attended 15 meet and greets with DDD staff and provider agencies, with the intention of making proposals for New Jersey group homes for our 32-year-old son, Drew. Drew has successfully lived in a campus-style setting at Woods Services in Langhorne, Pennsylvania, for almost 14 years. Contrary to the Return Home New Jersey slogans, not one of these agencies offer comparable or better staffing and services than he already has in his current placement, nor have any been closer to our home. In fact, the offers for these proposed homes were two, three, and four times the distance from our home.

As a result of meningitis at the age of 3, Drew is blind, profoundly developmentally disabled, with right-side hemiplegia and an uncontrolled seizure disorder. At this very moment, our family is facing an offer of a group home which is 40 minutes from our home, where he will have a staff ratio of 1 to 4 -- rather than the 1 to 1 ratio he presently has at Woods, and he requires to have any quality of life. That is 1 staff to 4 individuals for a major part of his day. My son needs to be fed and clothed, have his diapers changed, and be guided by the arm or gait belt in order to safely navigate his environment. Yet, just one month ago, on May 5, 2015, when Senator Van Drew asked Acting Commissioner Connelly and Deputy Commissioner Apgar whether staff ratios in New Jersey

homes were equal to that of the out-of-state residences, they answered, "They are better." That is amazing. They are either misinformed or unaware.

It is no wonder families are terrified of relocation when DDD is reducing or eliminating services and staff. And it is no wonder that there are hundreds of cases of abuse and neglect reported each year because of it.

A few months ago Senate President Sweeney was quoted as saying, "Return Home New Jersey should be scrapped in order to protect the innocent, vulnerable people who are living a safe, happy life in their out-of-state placements." So the glaring question is, why are we -- who have worked hard through the years, and who have had to make the heart-wrenching decision for a residential placement for our beloved sons and daughters many years ago -- being pressured by DDD, who is blindly moving forward with this flawed and inhumane relocation called *Return Home New Jersey*.

In conclusion, I want to say the real question is, at what number of years is it okay to remove someone from their family and home, their housemates, friends, teachers, nurses, doctors, therapists, and relocate them to a new, untrained, understaffed family and home? Do you really think that the relationships built in 5, 10, or 15 years are any less valuable than those made in 25 years?

We are desperately reaching out to you, our legislators, to disregard the meager cost savings already admitted to by the

Division, and protect our family members from the inhumane consequences of Return Home New Jersey.

Thank you. (applause)

SENATOR GORDON: Thank you very much, Ms. Adams.

We'll hear next from-- I'm sorry, does anyone have any questions?

Senator Weinberg.

SENATOR WEINBERG: Yes, I do have a question, Ms. Adams.

We heard this morning from the Assistant Commissioners about this reach-out to families. Now, you said in your testimony you've attended 15 meet and greets with DDD staff and provider agencies. Was that just you and your family, or a larger group?

MS. ADAMS: No, that was my husband and I. They were meet and greets for our son.

SENATOR WEINBERG: And when you described the multiple disabilities that your son has, and the one-to-one staff ratio where he is right now, did any of these agencies say they could provide the same or better services?

MS. ADAMS: No, no. Typically, at those meet and greets, where-- With the budget that is following my son, because DDD works up a budget for each individual, these providers then say, "Well, we cannot provide the one-to-one," or "We cannot provide the medical," or whatever. Right now, we have an offer, as I said in my testimony, where one agency is saying they feel they

can provide the services. But the services are not the one-to-one staff ratio.

And we will go; it's tomorrow at 3:30. We will go and we will view the home, and we'll question them and ask them if they really think they can provide a safe environment for our son. They really don't know my son; all this is typically done on paper. And then they come in and they have the meet and greet where they meet him for five minutes.

They just can't do it.

SENATOR WEINBERG: Well, and also because of his sight problems, I would assume that his physical surroundings are extremely important--

MS. ADAMS: Absolutely.

SENATOR WEINBERG: --in terms of the way he feels comfortable or not comfortable.

MS. ADAMS: Absolutely. He can't watch TV or play a video game, but he loves to be outside and walk around. So he needs to have someone. And he has-- I didn't put it in there, but he has osteoporosis where he's getting infusions. And the endocrinologist said that the best thing for him is to be active, to be walking. So how can one staff walk four people?

SENATOR WEINBERG: So with all the meetings you've had, there is not one provider -- correct me if I'm wrong, if I misstate this -- who has said to you that they can provide the same services that your son is receiving now. Is that correct?

MS. ADAMS: Correct.

SENATOR WEINBERG: Okay. Well, after your visit tomorrow, if you can send us an e-mail -- I would appreciate hearing the outcome of tomorrow's visit.

MS. ADAMS: Yes. I think Senator Van Drew, as a follow-up that day, did say-- I think he was using our example; he said there was a family that have had a dozen-plus meet and greets and no one has been able to meet the needs of the individual. And Dr. Apgar said we will continue working with the family to find the appropriate placement -- that's been their song the entire time.

SENATOR WEINBERG: Okay. Well, again, another example of the actual reality not matching up to the earlier testimony.

Thank you, Ms. Adams.

MS. ADAMS: Thank you.

SENATOR GORDON: Thank you very much.

We will now hear from -- I'd like to call up two people -- Susan Henoeh and Robyn Levine (indicating pronunciation).

**ROBYN LEVINE:** Yes, Levine (indicating pronunciation).

Does it matter which order we speak?

SENATOR GORDON: No.

MS. LEVINE: Okay.

I am Robyn Levine from Mahwah, New Jersey. And first, I would like to take the opportunity to thank the Oversight Committee for taking the time to hear my testimony regarding Return Home New Jersey.

Please understand that my story is not meant to be an attack, but to share with you my experiences and my concerns.

Please understand that this policy impacts my daughter, who I have spent 30 years advocating for, as she cannot speak. Ashley was 14 months of age; came down, like Marcia's son, with bacterial meningitis. It left her with a stroke to the right side of her brain, and she has uncontrollable seizure disorder; she's very limited in her verbiage; she really can't speak too well. And DDD placed her, 13 years ago, up in New York because there was not an agency in the State of New Jersey that could accommodate Ashley.

As I sat here at the last Senate meeting, the State implied that the purpose of Return Home New Jersey is logical, and it has the best interest of our loved ones at heart. However, having a child who's already been placed in her home -- where she is living -- I now feel that this is has been an unorganized and horrifying process to go through.

I can firmly provide you with reasons why this policy is not financially, medically, or morally sound. If there was a ever time the legislative representatives should step in and protect its constituents, that time is now.

On June 12, 2014, DDD stated that one of the reasons Return Home New Jersey is so important is, and I quote, "significant uncertainties about our ability to adequately monitor the care and well bring of individuals in out-of-state programs." I sat here and heard them say that, the last time we were here.

I truly appreciate the care and concern that the State claims that they have for my child; however, 13 years ago, my daughter was placed by DDD into her current home. And there was not one facility, like I mentioned before, in New Jersey that could accommodate her. Never -- and I mean, never -- has any member from the State come to check in or monitor my daughter.

Up until this point, all communication has only ever been done on the phone. And I am sure if there was a line up of children, they would not be able to pick out my daughter. So the fact that they said it's about monitoring - I'm not quite sure about that.

Up until this point, I said, all communication was done on the phone. How can DDD claim that they know the best care for my child if they've never even met her?

The State also vocalized that, "New Jersey has concentrated on returning out-of-state New Jersey residents to in-state placements in order to more closely monitor their care and safety, as well as to bring them into a network of care that is closer." Unfortunately, my experience has been the complete opposite of their stance. Since 9 years of age, my daughter has required a one-on-one aide -- similar to Marcia -- because of her uncontrollable seizures. Whatever program she has participated in, in New Jersey, has asked for a one-on-one. Sometimes they say, "Oh, we can do this without--" and then it takes about a week later and they say, "Oh, my God. We need a one-on-one for Ashley; we cannot manage her without somebody with her."

We have a current letter from a neurologist stating that my daughter requires one-on-one assistance at all times. Yet, DDD informed me that they will not guarantee a one-on-one if she is brought home.

It was in her ELP -- which is an Essential Living Plan -- that Ashley must have a one-on-one; yet when I spoke to a member of DDD and I told them that, when they told me that Ashley would not have one coming back to New Jersey, do you know what the answer was? "Well, we will rip that out of her ELP so it's no longer in there." That's what was told to me.

My daughter currently resides in a home where there are 8 staff members for 7 children; yet every agency that DDD has suggested has had a lesser staff-to-child ratio, often with the nurse -- which is an LPN, not a registered nurse that she has currently out-of-state -- as being a *caretaker*. So now you have the nurse giving baths, feeding the children, and not being *the nurse* that she has now where she currently lives.

Locations for the suggested homes here in New Jersey have been in very unsafe towns, on busy streets, with much less monitoring than what my child is receiving now.

As for the comment regarding *closer to families*, unfortunately this is not true as well. DDD claims that they wanted parent input, so all of our families here, of Return Home victims, were asked to create ELPs to help the agency better understand the needs of our children and siblings. Yet there's a total disregard for this. We religiously -- my husband and I -- visit our daughter a

minimum of two times a week. So it is very important to me that she be no more than an hour away, like she currently is. We've already driven up in a blizzard when Ashley was hospitalized because of seizures. But it was an hour away. Yet, the suggested placements that Return Home New Jersey has given us have been three hours away, one way. So that's six hours (*sic*) of driving time before I even visit with my child.

How is this bringing my child closer to our family? I've been told -- and I know others as well -- that if we do not agree to these meet and greets-- And I hope that you understand what meet and greets are, because I'm not sure that you do. But we-- Once the child is out-of-state and they're trying to bring them back to New Jersey, you must go to a meet and greet and see the agencies that feel that they can provide for you. That is what a meet and greet is.

I've been told that if I do not agree to go to these meet and greets -- even though I know that the home is not a good match for my child -- I can be viewed as being non-compliant, and my daughter's funding for the place she's at now will be totally removed.

SENATOR WEINBERG: Let me interrupt you, if I may.

SENATOR GORDON: Sure.

SENATOR WEINBERG: So are you saying-- Well, repeat that; that if you don't agree--

MS. LEVINE: I am saying that if we do not go to these meet and greets, even though we know they're not in the best

interest of our child, funding can be taken away from where she presently is because we are being noncompliant.

SENATOR WEINBERG: And is that said to you by a staff member directly?

MS. LEVINE: It has been inferred to us -- okay? -- in telephone conversations. And that is why we had to get a lawyer -- because I needed to know what being *noncompliant* is. And it seems that noncompliant changes every day -- the definition of what noncompliant is for a person.

SENATOR WEINBERG: Okay.

SENATOR KEAN: Do you have examples -- do you know of examples where, through the Chair, where that's happened to other families, where they've received the same information?

MS. LEVINE: Yes.

SENATOR KEAN: (off mike) (indiscernible)

UNIDENTIFIED MEMBERS OF AUDIENCE: Yes.

SENATOR KEAN: Is there a format? I don't want to--

SENATOR GORDON: We would certainly like to learn about that.

SENATOR KEAN: Whether it's within the context of this open contact, or in a more private meeting--

SENATOR GORDON: Right.

SENATOR KEAN: --where we could figure out from what the tone and intonation, as well as the statements, are, without breaking all the various (indiscernible) between families and caregivers.

SENATOR GORDON: Right.

SENATOR SARLO: The *meet and greet* term comes from them, or is that something the advocates have come up with?

MS. LEVINE: The State comes up with the meet and greet. So for example--

SENATOR SARLO: Do they call it a meet and greet?

MS. LEVINE: They call it a meet and greet. So what happens is, you fill out-- The way the procedures work is--

SENATOR SARLO: They make it sound like you're going to go there and have wine, and cheese, and crackers with them. (laughter)

MS. LEVINE: Oh, I would love that.

SENATOR SARLO: That's what they make it sound like, right?

MS. LEVINE: That would be right up my alley.

SENATOR SARLO: It's anything but, it sounds like.

MS. LEVINE: Exactly. But what happens is, you get a call from the agency, called Caregivers of New Jersey. They tell you that an agency would like to see your child, okay? Sometimes it's done on the phone, but most of the time they come up to see your child, and then they decide whether they can take your child into their agencies. I've had four of these meet and greets; not one has said that they can handle my child and, as a matter of fact, two agencies that went up to see my daughter went crazy at her facility and said, "Oh, my God, we need to bring this back to New Jersey, because what they're doing here is amazing." So they want to bring

the things that my daughter has already back to New Jersey. How nice is that? So you're going to take this away from my child?

SENATOR GORDON: Senator Weinberg.

SENATOR WEINBERG: I just got a little more confused.

The agency does send somebody to actually see your child in person--

MS. LEVINE: Correct.

SENATOR WEINBERG: --in her current setting?

MS. LEVINE: Correct.

SENATOR WEINBERG: And you said you had four meet and greets?

MS. LEVINE: I've had two that have come up, one on the phone, and one that I am presently going to have.

SENATOR WEINBERG: Okay.

MS. LEVINE: So this will be my fourth.

SENATOR WEINBERG: Well, then of the three--

MS. LEVINE: Okay

SENATOR WEINBERG: --that you've actually had, has any of those agencies-- You know what my question is.

MS. LEVINE: Yes. Not one said they can handle her, especially with the amount of cost. Ashley would be-- She would be very expensive because she does need a one-on-one -- yet they're going to try to take that away from her.

SENATOR WEINBERG: So are you called noncompliant if you don't go to the meet and greet? Or are you called noncompliant if--

MS. LEVINE: You know, it's a fine line, I think we can all say.

SENATOR WEINBERG: Yes.

MS. LEVINE: You know, I don't know how many times you can say, "I won't go see this place," without being noncompliant. I did ask my lawyer -- because I felt like I needed to protect my daughter -- and when I spoke to her, she said, "We don't know any more what noncompliant is; it changes daily." But it is something that is being said. And you have to keep working along this process, otherwise the funding is taken away.

SENATOR WEINBERG: Okay.

MS. LEVINE: I lost my spot. (laughter)

SENATOR GORDON: Ms. Levine, if you could summarize, at this point.

MS. LEVINE: Yes, I will, real quickly. I'll start from here.

DDD was created to protect and serve as advocates for the disabled population. So I ask, why has DDD created a one-size-fits-all policy when they're supposed to be the experts and know that people with disabilities require individual modifications, accommodations, and needs?

The idea of returning home, for some, may be feasible; but for many, it is not. New Jersey should not be forcing families to take their severely disabled and place them in a home that may or may not work. And when posed the question, "What would happen

if our loved ones were brought home, and the home doesn't work?" The response is, "Well, we'll just have to look at it."

Please remember that the pawns in this match are people -- people who need the most support and help. For an agency that was created to advocate for people with disabilities, all they are doing is putting the lives of the disabled at risk.

I ask you, each and every one of you, if you had a medically fragile child who was thriving in their placement, in their home away from home, would you want them moved to a place where they won't receive the same supports? Think of that tonight when you go to sleep.

Thank you very much.

SENATOR GORDON: Thank you very much.

Ms. Henoach.

SENATOR SARLO: Actually, could I--

SENATOR GORDON: I'm sorry, Senator.

SENATOR SARLO: Robyn Levine, could you just come back one second?

SENATOR GORDON: Yes, I'm sorry.

MS. LEVINE: (off mike) Oh, I'm sorry.

SENATOR SARLO: I just, for the Committee's sake-- And Robyn, you know, we've spoken. And as the Budget Chairman, I was just actually being briefed by our staff. There is no savings in the proposed budget; the Administration has not shown us any savings. There is no line item for savings, as you know, for Return Home.

But I always say everybody who comes to the Legislature should serve on the Budget Committee one time, for one tour of duty, because you get a chance--

SENATOR WEINBERG: One tour of duty was enough, thank you. (laughter)

SENATOR SARLO: You get a chance to learn about every aspect of government. And sometimes things come to you during the Budget process; sometimes things come to you sooner.

I will say this to you: I, as a Legislator, first learned about this Return Home situation through you, and through your advocacy in the newspaper and throughout North Jersey. And all I can say is, I know you're frustrated, and all of you are frustrated, but it's not falling on deaf ears. Senator Gordon did a great job here today--

MS. LEVINE: I know.

SENATOR SARLO: --at this hearing, and I learned about this through you and your advocacy. And, you know, there's only so much we can do, but we're going to put language in the Budget again this year that will help put a moratorium on this. Whether the Governor takes it out or not, we're not sure. But there will be language in the Budget.

We'll do our best to continue to get to the bottom of this.

MS. LEVINE: We appreciate it.

SENATOR SARLO: We recognize, over time, no new clients may be going out and, over time, this process will end and everybody will stay here in New Jersey. But out of respect and

courtesy to those who are living out-of-state now, I think we have an obligation to continue to push on.

So thank you for educating me. (applause)

MS. LEVINE: Thank you. And we are all so appreciative; we really are. Thank you from the bottom of my heart.

SENATOR SARLO: But thank you for educating me on it.

SENATOR GORDON: Okay; Ms. Henoch.

**S U S A N H E N O C H, Esq.:** There are a few things-- I'm trying to decide whether to go backwards or forwards from my testimony because some of this I can answer from my experiences.

Well, first of all, I want to say thank you for the opportunity to speak with you frankly about our experience with DDD and Return Home New Jersey.

I'm here today because, though Dawn Apgar, for example, makes the process sound reasonable, that's not been our experience -- as I think every single person in this audience can speak to that. It has been an unreasonable nightmare, basically. And when Robyn talks about the situation, I can tell you we are very tired of the intimidation that we've experienced; the threats, constantly, of the cutting off of the funding; and the harassment. And I must say I've experienced a lot of that. I've had the ex-head of Return Home New Jersey literally yell at me on the phone multiple times -- that if I don't comply with this particular agency, there are no other choices and I'd better just shut up and take it. And that happened more than once. And I have to tell you, this is no way to run an agency, and no way to run a State.

And it's just pretty shocking to be caught up in something like this. I was raised in New Jersey; I'm a Rutgers Law School-Newark alumna; I returned to New Jersey in 2001. My daughter-- I will go backwards now, and explain a little more, then we'll get into some more of it, which I can explain to you.

But I am the parent and legal guardian of a 27-year-old daughter. This is my daughter, Sophie, who was born with Prader-Willi Syndrome -- a very rare and complex genetic disorder which occurs in 1 out of approximately 25,000 live births. She has no functioning hypothalamus; no functioning endocrine system; she has a long list of symptoms, including things like low muscle tone, cognitive disabilities; in her case, severe behavioral issues; and, most importantly, chronic feelings of insatiable hunger that can lead to excessive eating, morbid obesity, and death if not externally controlled.

She requires 24-hour care and one-to-one staffing at all times to monitor her behaviors, especially when she's out in the community. She also has multiple psychiatric diagnoses related to defiance and anxiety. She suffers frequent meltdowns -- what we call *meltdowns* -- more than 100 this past year alone, which required physical restraint. She becomes verbally abusive and physically aggressive towards staff and other residents -- punching, scratching, biting, whatever it takes -- with the intention to inflict injury; and she often does.

She poses a danger to herself and others, and requires three or four staff to one to ensure her own and others' safety during these episodes. She also often threatens suicide.

So you know what that means? It would trigger -- I'm going to go backwards again -- it triggers Danielle's Law in this State. And I don't know if you are aware of Danielle's Law, but it requires-- Actually, I had a conversation recently with Assistant (*sic*) Commissioner Apgar, and she agreed with me that Danielle's Law would pose a significant danger to my daughter's life here -- which is what I believed too -- because it requires staff in a group home to call 9-1-1 in any life-threatening emergency, which includes any escalated behavior where a person is a danger to him or herself or to others, or in cases of threats of suicide.

So that means, in the State of New Jersey they would have called 9-1-1 100 times this past year. She would have ended up like Tyler Loftus, without a doubt -- either in an emergency placement; dead because if the EMTs who come and hold her incorrectly -- because her musculature is not as strong, they can kill her; or she would end up in jail. And she would be kicked out of her placement to begin with. So that's another reason of great concern to even consider returning her to New Jersey.

Originally we kept her home; she's 27 now. We kept her home until the age of 17 because we have a very close, intimate family. And it broke our hearts to realize that we could no longer care for her and keep her safe. But her violent behavior and her

weight gain became so great that we had to consider an out-of-home placement.

DDD stepped in and realized that we were in crisis, and helped us move her to a nearby place. I don't know if I want to name names, but it was Woods Services. However, Woods had a mixed group of girls; they have a separate PWS boys facility, but not for girls. So she was in a mixed group; they had no idea how to care for her and, in fact, she gained even more weight.

Then she was abused and ran away across Route 1 in the middle of the night, barefoot. I mean, it was unbelievable. So we went and took her home. She had a psychotic breakdown at that point, at Woods. We took her home; she recovered after several months, and with the assistance of Prader-Willi Syndrome -- the United States organization -- we found the one place in this country where she belongs. It happens to be in [Oconomowoc](#), Wisconsin; it's called Prader-Willi Homes. They've been around 35 years. It's an intensive, therapeutic program, and it's working. She still has meltdowns, as I said; she's still full-blown Prader-Willi. But she is thriving there. She's extremely articulate, she's graduated high school. But she's also extremely manipulative. So whenever there's new staff which comes along, she just twists things and will have another meltdown.

But in any case, she works fulltime in a sheltered workshop and volunteers twice a week with a one-to-one job coach at a retirement home for farmers in Wisconsin. And she just loves doing that work.

She loves people; her hero is Martin Luther King. She loves animals. And she lives a full life, as best to her ability. She lives in a group home. This organization serves about 100 people from all over the country, because this is such a rare disorder and the people there have such intense behavioral needs that this is a subset of Prader-Willi. I'm sure there are some very low-key, nice Prader-Willi people, but none of them are at this place. So they know how to deal with difficult behaviors without having to call the police -- or, at least, in most cases.

She works fulltime, as I said; she has very close friends. She has wonderfully trained people who know how to deal with her at all times. She's learning a lot about life skills; how to work. She lives in a group home with 15 other men and women of all ages, ethnic backgrounds, from all over the country; fully staffed at all times. There's an in-house social worker, which is the only reason Sophie is able to function -- along with a lot of staff. She sees her twice, or three times, or four times a day.

And the joke is-- I mean, I don't even know what we're talking about, bringing her home here. To put a person like that with three other women, isolated, in a house without any services; and all of the things we've been hearing -- it isn't going to happen. I mean, I will do whatever it takes; I've advocated for this child since birth when she was misdiagnosed with spinal muscular atrophy. She didn't die; they were wrong. And I've had to advocate for her literally from the moment of her birth. And I will never stop advocating for her and fighting for her life.

She's home, she's safe in the one place in this country-- It costs a fraction of what any provider I've spoken to-- I've spoken to-- To get back to the provider issue, I've spoken to seven providers so far; most of them -- all except one -- had never even heard of Prader-Willi, even though both Apgar and Conger have now recommended -- "This is the one; all the others were ridiculous. This is the one." Then I speak to the one; I say, "What is your history and experience with Prader-Willi?" and they say, "We're looking it up on the Internet. I don't know."

To me, that's not sufficient versus what her needs are and what she's already getting for practically no money, compared to what these-- I mean, I'm just hearing from Carolyn what these prices are that they're willing to pay; \$315,000 -- are you kidding? And they still can't do it right, so we're wasting money.

I'm not saying the people coming up -- that New Jersey can't put something together for people coming up who have needs, people who are aging into the system. But we have some people with the highest needs, whether it's medical or behavioral, who are being taken care of properly, thanks to DDD, out-of-state in the correct placements. Leave them alone. What is-- I don't get it; I mean, I wish somebody could explain it to me. But I truly don't get it. We know that there is no cost-savings; we've known that for years. And now we-- The Commissioner acknowledged it in the last hearing. There are no cost-savings. What's the motivation? Dead silence. There is no motivation, so they came up with a

specious monitoring issue. There's no monitoring issue there; that's absurd.

So, I mean, I talk to my daughter every single day. I know what she eats, I know who's done what to whom; I know everything. If something were happening -- believe me, we'd know and we'd be the first ones to get on it.

So all I can tell you is that there's something really wrong happening with this at DDD. And we've got the STP problems, we've got other issues with the Medicaid -- what we just heard from the Doctor -- in addition. But this one is the most outrageous and the most egregious. And I know you've worked so hard, and we can't tell you how much we appreciate your efforts on trying to help us through this. And I just don't know what to say. I mean, we all have lawyers; we're all going to sue. And when the question comes up, "Well, how many lawsuits?" -- it's a joke. We're all going to sue, the bottom line, if worst comes to worst. And I don't care if I have to go on *Indiegogo*, or *Kickstarter*, or whatever -- bake cakes; my daughter is not coming home because she will die if she comes here.

The only responsible organization I spoke to was Arc of Warren County, that had any history working with Prader-Willi. They rejected her out of hand. They were the only ones who said immediately -- they said, "What's the situation?" They said, "Forget it. We do not have the resources to handle that behavior." They were the only responsible ones.

The last one I spoke to, by the way -- a group called I Have (phonetic spelling), or something -- again, I said, "What do you know?" She said, "Our nurse is looking it up as we speak." That's just not acceptable, I mean, for anybody, you know? It just makes no sense.

So I just want to end by saying thank you, again, and I hope that you can help us. And I hope that you can return some common sense to this situation because, clearly, DDD is out of control. And when she's talking about threats -- believe me, they keep escalating with my situation. For example, that time when Carrie Conger yelled at me. I rejected AdvoServ because they had no history, no program, no experience, no staffing, no nothing. And I said, "I don't think this is going to work," and she just went ballistic. It was at the end of a two-hour conversation which the Director of the program even acknowledged it wasn't going to work. And she just -- Carrie Conger just couldn't handle that.

So then the next few-- The latest one with I Have -- they wanted me to go visit the house. I had never seen any of these houses, because I don't want to waste anybody's time when I know that they don't know anything, because it's not going to happen. So I said I'm out of town working -- which was true -- and I could not make the appointment. So immediately Conger and everybody leaped to it and said, "Oh, well, let's just skip the prior conversation; we'll go right into a meet and greet and we'll send somebody out to see your daughter." Which is what's happening now with the next one -- which is Youth Consultation Services.

They're trying to skip over me; they didn't even inform me that they're trying to rush out to Wisconsin to go, literally, grab her.

I also got promised from Conger a long time ago that nobody would talk to my daughter, if they did go out there, because she will have another psychotic break because she can't handle anxiety of that level. She's not prepared to do that. So if she knew that there was even a possibility of her moving out of that place where she is so embedded and has a full life, she would just lose it. So I just turned that down, but we'll see what happens.

You see, they keep upping the ante here. And there are a lot veiled threats and not-so-veiled threats. And there is a lot of intimidation. And you talk to your social worker or your caseworker -- it's not above board, let me tell you.

So again, I just want to say thank you and, boy, do we need your help.

SENATOR GORDON: Ms. Henoch, thank you very much. Your testimony was both troubling and baffling with regard to the Developmental Disabilities.

MS. HENOCH: Yes, that's what I'm saying.

SENATOR GORDON: Any colleagues-- Senator Kean?

SENATOR KEAN: Thank you, Mr. Chair.

We have spoken by phone in the past.

MS. HENOCH: Yes.

SENATOR KEAN: Can you, from your perspective, can you lay out the -- how do you get to the stage of a meet and greet? I mean, from your perspective, as your talking, there's a phone-- I

mean, by regulations, how do they -- how is this process, from your perspective as a family, supposed to work in this case where it's a phone -- a family meeting, phone-- If you could just lay it out for us.

MS. HENOCH: There's nothing-- Part of the issue-- You know, it's great that you bring that up, because part of the issue, as far as we know -- the families -- there is no process, there is no protocol, and they change it on a whim. So when you say, "What are the regulations?" God only knows. From day-to-day, from moment-to-moment, literally, there's no-- I wish there was something written that we could follow, because I always end up calling Conger or Apgar.

I mean, I had another caseworker, for example; I picked up the phone one day and he was screaming into the phone. He said, "You'd better show up at the next meet and greet. And if you don't--" You know, it was insane stuff. I said, "Who are you? I don't even know who I'm talking to." And so I called Conger, and I said, "I don't know what's going on, but I wanted to find out." And she said, "Oh, well, we'll change your caseworker right now; and, by the way, here's how we're operating from now. It's a new -- I'm bringing a paradigm shift to the agency; we're having transparency, and we want to include parents 100 percent," all of that kind of stuff. And then it flips whenever she gets angry, or somebody else gets involved. You never know, moment-to-moment.

So how we get to a meet and greet -- they choose randomly, or they choose people who speak up, or they choose

somebody. They've got a few hundred people left to go. So we're all vulnerable, and they'll just -- they snatch you one by one, and say, "Okay, we're going to -- it's your turn. Go look at some cockamamie program." And if I'm working out of town -- which I often do, or whatever -- I'm allowed to do it by telephone. So then what happens is, what I first started to do was talk to these directors and programs by myself. Then they didn't like that idea. After four of them, Conger came on board and said, "Oh, no, no, no. From now on, I'm going to be in on all of your conversations." I said, "Why? It's fine. We're working it out." She said, "Because in case you have questions about DDD policy." I said, "I have no questions about DDD policy -- I'm finding out about the agency, not about you." She said, "Tough luck," you, know, basically. "You got it."

And then they changed -- shifted again. They just-- You never know what you're going to get. There's this veiled threat -- again, not-so-veiled -- that if you don't do this, they're going to cut your funding and all this other stuff.

Now, I don't think they've done that to anybody, although we'd have to ask. I don't know if they've actually cut -- but the threat is always out there. There's a tremendous power imbalance; that's the other thing we really have trouble with. I mean, we're terrified all the time. I mean, I feel like I have my daughter's life on my back during these conversations -- these meet and greets -- that every moment, if I say the wrong thing, it's like, "Yes, Massa." It's unbelievable. There is no equality here. There's

no respect, there's no understanding; it's out of control, I'm telling you.

And I don't care how reasonable they sound when they sit here -- it's not what we're experiencing. They've mischaracterized us -- I just wanted to make this statement -- as being afraid of the future, of being afraid of group homes, of living in the community. That's not what we're afraid of. We're afraid of the way they treat us now, and we know-- I'm supposed to say to an organization -- an agency that does not even spell my daughter's disability correctly -- I'm supposed to turn her over to them because they've looked up three websites? And they have a history of abuse and neglect? Not on your life.

I'm supposed to trust DDD? We don't respect them; they don't respect-- I mean, they've chosen an adversarial position from the start. The letter I received -- and we all received -- that announced Return Home New Jersey said, "We are cutting your daughter's funding in 6 months; we're relocating her to New Jersey. If you want her to stay in place, you have two choices: either you fund her yourself, or you make her a resident of the state of Wisconsin." I can't afford to pay for her, even though it's a fraction of that \$315,000, year in and year out, number one; number two, if she's made a resident of the state of New Jersey (*sic*), she goes to the end of their waiting list. She just doesn't walk -- waltz in, and they say, "Terrific; be here."

SENATOR KEAN: This is the 8,000?

MS. HENOCH: What?

SENATOR KEAN: This is the 8,000-person waiting list that you're talking about?

MS. HENOCH: The what?

SENATOR KEAN: The 8,000--

SENATOR GORDON: They said it was about 3,000.

SENATOR KEAN: The 3,000-person waiting list.

MS. HENOCH: Yes, yes. But I'm saying, in Wisconsin, we'd go to the end of Wisconsin's waiting list. Yes, that's-- I didn't understand--

SENATOR KEAN: I'm sorry; I didn't-- I'm sorry.

MS. HENOCH: Yes -- no, no, no.

So I mean, it's not as if the Federal system works that way. New Jersey's list--

So neither of those-- I mean, that was an extremely cynical position, I believe, for them to take initially. So already we were in an adversarial situation -- due to their choice, their way of dealing with us. The whole thing is just shocking to me.

SENATOR GORDON: Senator Weinberg.

SENATOR KEAN: I guess I'm done with my questions.

SENATOR WEINBERG: Oh, sorry.

SENATOR GORDON: All right, I'm sorry. Go ahead.

SENATOR KEAN: Go ahead.

SENATOR WEINBERG: I guess it's shocking to all of us, particularly based upon the opening testimony that we heard many hours ago.

You have a letter from them that says, in essence, either take one of these programs or get lost, correct?

MS. HENOCH: It basically said, "We're cutting your funding in 6 months." I mean, we keep getting 6-month extensions; this has gone on for a few years now. Then they decided-- Here's another version of the threat: They narrowed it down to 3-month extensions.

SENATOR WEINBERG: The family members who we're hearing about -- and I think we would agree to that -- are people who have multiple disabilities.

MS. HENOCH: Right.

SENATOR WEINBERG: They are unique, in terms of the combination of disabilities--

MS. HENOCH: Yes.

SENATOR WEINBERG: --that are unique to that individual.

I just heard from our Budget Chair that there's no savings put into the budget.

MS. HENOCH: Yes, exactly. That's what they all say. So I don't get it.

SENATOR WEINBERG: It can't be monetary.

MS. HENOCH: Right.

SENATOR WEINBERG: At least, I would assume it's not monetary if they haven't shown any savings. And they testified this morning they brought home about 160-some-odd people, and 370, I

think, are still in out-of-state placements. So we're not seeing savings -- or, at least not negligible in the budget.

Certainly what we've heard from providers is that they're not even ready to deal with this new -- all these new systems and methods of payment, and so on. And we're hearing from the families about, what I'll call, *unique* individuals -- those with really serious, multiple illnesses.

So maybe we could put to Dawn Apgar one question that says, "Why?"

MS. HENOCH: Yes.

SENATOR WEINBERG: "Could you give us a one-page answer?"

SENATOR GORDON: I'm not sure the answer is going to be very clear.

SENATOR WEINBERG: Well, certainly it's not, thus far.  
(laughter)

MS. HENOCH: She's going to-- She's not-- She'll also go into the whole monitoring issue; she's going to obfuscate it again, unfortunately. You know, you're not going to get-- She just -- she doesn't tell us the whole truth, and it's full of misinformation. You know, we're the ones who are at fault; we're just scared of the future. Are you kidding? No way. If you had something here--

I mean, my caseworker for Return Home New Jersey asked me -- in one word, she said, "What's your priority? What are you looking for if you could--" And I said, "Experience." So they

keep sending me to these-- Why are they wasting everybody's time? I don't get it. I mean, seriously, this is just mindboggling.

SENATOR GORDON: Senator Kean, I think--

SENATOR KEAN: No, I got it.

SENATOR GORDON: Thank you very much.

MS. HENOCH: Thank you. (applause)

SENATOR GORDON: We're going to hear next from Laura Kelly and Maureen Clark.

**MAUREEN CLARK:** I'd like to have Laura go first, if you don't mind.

SENATOR GORDON: Sure.

**LAURA KELLY:** Good afternoon.

My name is Laura Kelly; my awesome son, Zack, and my lovely daughter, Alexa. Alexa is 26 years old. Alexa has a triple diagnosis: Her primary diagnosis is autism; she has a secondary diagnosis of Lennox-Gastaut Syndrome -- it's an intractable seizure disorder; and Down Syndrome. Alexa is profoundly disabled; she functions between 4 and 18 months.

Last year, Alexa was removed from Woods Services and placed in a group home. It's been a really, really hard year; it has not gone well for her at all. She has been hospitalized twice with aspiration pneumonia due to choking events. There have been numerous medication errors, missing medication, and falsification of medication administration records to cover up the missing meds. Her one and only community outing she experienced with the group home this past year involved spending two-and-a-half hours in the

car while staff went shopping. In addition, her staff neglected to bring her emergency seizure medication with them.

In another incident, she was taken to the ER without family being promptly notified and with no medical records.

She is fed excessive amounts of junk food which caused her to gain 10 pounds within the first eight weeks of her arrival at the home. She is supposed to be on a restricted diet due to inflammatory bowel disease. I now provide the majority of her meals because following her diet has proven to be an impossible task for staff to handle.

There has been more than 40 different direct care staff she has had to cope with over the past year -- including four managers -- dressing, feeding, and bathing her. Talk about anxiety provoking. How would you like a total stranger in your bathroom each week assisting you? The agency is now looking for manager number five.

This is just a sample of the many problems she has encountered. This placement has left me unable to sleep. I feel anxiety-ridden all of the time. I have spent countless hours writing letters to DDD and DHS, and the agency that provides her care, Community Options. The majority of the time, I get no response from anyone.

I had a five-minute private conversation with Governor Christie in which he took my name and number on his business card and said he would have the DHS Commissioner contact me the next day. That didn't happen. Instead, I got to spend the next 10

days calling the Constituent's Office and bothering a lovely young woman, the liaison for DHS.

I finally got my conference call with Beth Connolly and Dawn Apgar -- only to be informed by Ms. Apgar that she has no control over the agency that provides my daughter's care, and she felt my daughter was not in a safe placement. Her recommendation was that Alexa move to another agency.

Ms. Apgar's statement left both me and my daughter's attorney dumbfounded. We retained an attorney for my daughter due to all the very serious, significant problems. So she, too, was on the call. She reminded Ms. Apgar that DHS supplies all the funding, licensing, and clients for agencies in order to do business, so they definitely have a say in how agencies conduct business. It's called regulations. But I guess Ms. Apgar is right; my daughter's group home has yet to pass an inspection in the two years it has been open. They even failed implementation of their plan of correction, yet were still able to maintain a full license status.

I inquired to the licensing and inspections agency how this can be, only to be informed by an agency employee that my daughter's group home was not that bad, and I should see some of the other inspection reports.

I am providing each of you your own set of inspection reports for my daughter's group home so you can see for yourself. I guess Governor Christie has no control in any of this, either.

So what happens when you can't take the stress of all this anymore and you get angry with the agency and DDD, and start

taking pictures of some problems -- like not having adequate food to follow a medical prescribed diet? You get kicked out. This is what happened to one of my daughter's housemate's family. They were not allowed into the group home for three months. It didn't matter that the agency was violating the client's right by not allowing her family to come visit her; and DDD was absolutely no help to the family in getting it resolved. They, too, had to hire an attorney.

I am *mad*. DDD removed my daughter from a very stable situation and put her life in peril. I have been begging the DHS and DDD Commissioners to have my daughter reassessed with the new New Jersey CAT, to no avail. I believe her budget would increase and this could help provide the support she needs to be in the community. If any of you could help me achieve this, I would be most grateful to you.

This is a very broken system. The direct care staff is not qualified to be doing this type of work. The majority of the time when they are caring for clients there is no oversight by management, especially on weekends. The only requirement for direct care staff positions -- including the house manager -- is a high school diploma or equivalency. I question if some staff even possess those credentials, as I find some are unable to read or write at the high school level -- including the managers.

I have great admiration, respect, and deep gratitude for the people who go into this field. The majority of them are caring women who have not had many opportunities in life. They are

willing to accept poverty wages for hard, challenging work. They are minimally trained and poorly educated. They have to deal with all sorts of challenges with clients. They contend with medical responsibilities, behavioral issues, as well as being accountable for all aspects of running a household, including meal planning and preparation.

Most direct care staff hold down two jobs, and some even three. They live on cheap fast food due to the time constraints of working two or three jobs, so they have no idea how to prepare menus or safely prepare and cook nutritious meals. If a client has a restricted diet -- like that of my daughter's -- it will not be maintained. The majority of time clients eat junk food such as frozen pizza, chicken nuggets, French fries, mac and cheese. Any wonder my daughter gained 10 pounds in eight weeks? That kind of rapid weight gain puts her on track for even more ailments, such as diabetes.

Do you realize that to cut hair for a living in New Jersey you have to receive 1,200 hours of training in a certified program in order to obtain your license? But to administer powerful drugs, provide nutritious meals, and maintain the hygiene, safety, and security of individuals with developmental disabilities, you just need to pass a criminal background check and not have a DUI in the past two years. This is a crime.

As for utilizing community resources, the community is not ready. The local ER is not prepared to be used as a clinic for this population. My daughter now has a protocol in place for every

time she vomits: 9-1-1 must be called due to her first hospitalization, because she was left unattended while vomiting in her bed. ER doctors do not know the right questions to ask of staff regarding medical consents and guardianships. I personally educated two community hospitals in our area so they know to call me if my daughter shows up there without me, and to inquire about guardianship and medical consent forms for the patients they are treating. The ER cannot rely on the direct care staff present because they may not have records with them; and if they do, they probably won't be correct.

I have provided an in-case-of-emergency information document about my daughter to the local EMS. This ensures that if a 9-1-1 call is made they have the correct medical and contact information. I cannot trust the agency to provide this information. Management has sent a client to the hospital from this group home without staff or records; and took my daughter to the ER without medical records, and was not even able to provide my daughter's correct weight to the nurse. Staff overestimated by 50 pounds.

The agency is supposed to be able to handle all her medical care and get her to all her medical appointments. This has been completely impossible for them to handle, due to total incompetency and the never-ending shortage of staff. They can't even provide familiar staff to care for her when she is unable to go to day programs due to seizures or illness -- so she gets sent anyhow.

There have been numerous incident reports in regard to my daughter. DDD is the decider if they need to be investigated by the Office of Investigations. Talk about the fox guarding the hen house. DDD and the community providers are too intertwined with each other for this policy. There is too much opportunity for corruption to occur since the providers need clients and DDD needs placements. Even when the Office of Investigations gets involved, they are supposed to wrap up an investigation within 60 days. My daughter's first hospitalization took 10 months, the second hospitalization took seven months for the investigations to be finalized: "unsubstantiated neglect" -- no surprise there.

Clearly there is a lot of money involved here. I find the agencies are in the driver's seat. I've overheard phone conversations between the agency and DDD asking for payment for services rendered, only to discover that New Jersey is one of the worst states for reimbursing their service providers. So what does that mean? It means that when a group home is poorly run -- like the one my daughter is in -- what does the State then do about it? Fine them? We don't pay them. Take away their license? You have no place to put clients. Nothing. The agency providing my daughter's care seems to be doing very well with this type of arrangement -- so much so that they may be the only nonprofit that can afford to lease office space in one of the most expensive locales in the country, midtown Manhattan on Fifth Avenue. But it took me 11 months of pleading to everyone -- the agency, DDD, the local

township -- to get three disabled woman an appropriate handrail installed so they could go in and out of their group home safely.

Do not put any more of our developmentally disabled citizens in jeopardy. They already have enough to deal with.  
(applause)

SENATOR GORDON: Thank you very much.

Go ahead. Do you have testimony to provide?

MS. KELLY: I'm sorry?

SENATOR GORDON: Are you finished with your statement?

MS. KELLY: Yes, I am.

SENATOR GORDON: Okay.

MS. CLARK: Do you want me to start?

SENATOR GORDON: Yes.

MS. CLARK: Oh, I'm sorry.

My name is Maureen Clark, and thank you for having me here today.

We are begging you to quickly pass a bill to stop the inhumane DDD Return Home New Jersey program. We need action now.

Our daughter has been at Woods in Langhorne, Pennsylvania, which is less than 10 miles from where we're sitting right now. She's been there for 36 years.

We are very frightened. For two-and-a-half years, we've been terrified because we don't see how anyone could take care of her in a group home; and none of the group homes wanted her.

And now it seems like they've decided to put her in an intermediate care facility, which is like a cross between a hospital and a nursing home. While she may get good care, she's going to be in a more restrictive environment than what she has been enjoying for 36 years. DDD keeps talking about community living, and now they want to put her in a hospital when she's been living in a beautiful ranch-style home for 36 years, on a scenic campus with day programs -- it's like living in a community. Now they want to take her out of it, to drag her back to New Jersey -- and she's been there for 36 years. She can't speak, she can't walk, she can't even feed herself. And she's so happy where she is; they know how to take care of her. She has everything she needs; she has medical experts there who know her needs, who can interpret what she needs. It's insane.

DDD could have been getting money from Federal Medicaid for placement in Woods -- as far as I can tell -- for all these years, and they just won't do it because it's in Pennsylvania. Yet, Federal Medicaid will pay in Pennsylvania. None of this makes any sense, and my daughter is going to be a victim of this. How do I talk to her and try to get her to understand why she's losing the same caregivers she's had for 15 and 20 years?

I'm sorry; I didn't-- (crying)

SENATOR GORDON: That's all right. Just take your time.

MS. CLARK: There's not going to be any cost-savings; it's probably going to cost the State more money than what they're

paying Woods for her care. The Acting Commissioner has said that OLS has said there's not going to be any cost-savings. And we just don't understand why they won't qualify a place like Woods.

I've lost all track of what I was saying -- except that she's happy at Woods. This is a picture of her; she has friends, she's in a house with women who are -- some of them can speak, some of them can walk. More can't, but they take care of her, they play with her. She's happy there, she knows everybody on the entire campus. And she's safe there. She does not trust strangers because she can't communicate with them.

I just-- Please get that bill passed. Don't make her leave after 36 years.

I'm sorry (crying); I lost track of everything I was going to say.

SENATOR GORDON: That's all right.

I think I speak for all of us here when I say that we're going to do something about this. (applause) I'm not quite sure what in the end it will be, whether it's legislation, or the budget, or some other way, or an audit of this program. We're going to try to protect your loved ones.

I want to thank you all for-- Unless you have additional comments you'd like to make?

Senator Kean, any questions? (no response)

We do have one additional person testifying -- Leslie Meril.

**LESLIE MERIL:** (off mike) If I can bring (indiscernible).

SENATOR GORDON: Ms. Meril, I think you're going to need to use a microphone.

MS. MERIL: (off mike) Just to let you know, before I get started, thank you very much to everyone--

UNIDENTIFIED MEMBERS OF COMMITTEE: We can't hear you.

MS. MERIL: This is Jesse's budget--

SENATOR GORDON: Maybe one of those microphones--

MS. MERIL: Hello. I am here representing my son, Jesse Meril, with regards to long-term support for a low-cost alternative.

My circumstances are somewhat different than many of the other adults in Return Home New Jersey -- whereas, my child is currently aging-out of his public school district after 10 years of a residential placement.

So good afternoon, and thank you for this opportunity to appear before your Committee today. This is the first time that I have ever done anything like this.

I am Leslie Meril; I am a single mother of a multiply disabled child. He is a young adult. I had to take the day off from work today to be here to share my story. I want you all to know how very -- extremely grateful I am to participate today. Thank you very much, Senator Gordon.

My purpose for being here today is to advocate on behalf of my son, Jesse. DDD has denied funding for his current placement for being out of state -- but not because it doesn't meet his needs, or that there is a comparable existing facility in New Jersey. Jesse

is 21 years old, a disabled young adult with the mental capacity of an 8-year-old. And he will age out of our local school district in Allendale, New Jersey, at the end of this month, June 30. And if anybody's counting, that's 20 days before I have no funding.

For 10 years, he has been in a safe, cost-effective, rural, residential program out of New Jersey -- part of Camphill North America. The budget for Jesse's placement, through DDD, is \$142,400. The very low annual cost associated with Jesse's current placement is \$60,765. This is so much less than Jesse's budget; in fact, his budget covers more than two years to maintain his current placement.

I am asking DDD to continue funding for Jesse's current program because it is the only placement that meets his special needs. He has very difficult-to-manage behaviors due to a traumatic brain injury at birth. No behavior modification methods worked for Jesse. Prior to Camphill, he attended multiple local New Jersey public and private schools, without success for him or his teachers. When behavior modification methods proved ineffective, Jesse was highly medicated. Medication also proved to be grossly ineffective.

The Triform Camphill -- in Hudson, New York -- model works for Jesse, because it is a campus built around a farming community where Jesse works and lives with the family and support staff in a house on a campus. It is electronic free: no TVs in the homes, no readily available computers, no electronic games. Weekdays, he goes to work every morning, and in the afternoons he

has classes. He has structured activities on weekends with opportunities to participate in culturally rich drama, music, art classes, and more. He has 24/7 support and supervision by a network of caring, trained staff who are like extended family. They live and work alongside the residents.

You might ask me, what has DDD New Jersey offered as an alternative? The answer: a much more expensive, one-size-fits-all that does not meet Jesse's needs. A group home in a mainstream neighborhood with three much-older residents and a stranger hired to watch them, with no plan for a structured work or study day program.

When I asked them about the day program, I was told, "After we meet him, we'll figure it out." They couldn't even provide me with an example.

Jesse cannot work at a grocery store or local business. Mainstreaming is overstimulating to him. He will act out, and he will be put in harm's way with DDD's more expensive, one-size-fits-all plan. My fear for Jesse is that he, too, will end up like Tyler Loftus.

I have received more than eight referrals from DDD. None of them could provide Jesse with the level of care he currently receives, or on a more cost-effective basis: safe farm campus, electronic-free environment, where he can walk to work and attend educational classes, learning life skills such as farming, gardening, bakery, home economics; the Weavery, the Pottery -- with a structured afternoon education program.

I ask you, who's benefiting from Return Home New Jersey?

I have found a cost-effective and safe home for Jesse 10 years ago, since he was 11 years old. Triform Camphill saves New Jersey -- and our Federal government -- tax money in comparison to the expensive DDD alternatives offered thus far.

On the New Jersey Department of Human Services' DDD website, it states that the goal of Return Home New Jersey is twofold, and I quote, "To ensure that individuals who have been placed out of state can return to a comparable or better setting in New Jersey that meets their needs, and to better manage the State's resources." With this in mind, how does Return Home New Jersey achieve this goal on behalf of Jesse?

I ask you again, who benefits from Return Home New Jersey? Certainly not Jesse, and not the taxpayers either. Please help me protect my son and save New Jersey money. I am asking for less money to continue in a safer, more supportive placement. Common sense needs to prevail.

Thank you very, very much for your time today. Thank you for allowing me to participate. (applause)

SENATOR GORDON: Thank you very much.

Senator Kean, a question?

SENATOR KEAN: No, thank you.

SENATOR GORDON: Okay.

Thank you very much, Ms. Meril. You are the last witness on our list.

I want to thank everyone for being here -- those who testified and those who, by your presence, delivered a very strong message.

You have informed us as no consultant's report or bureaucrats could, because you've put a face on this issue. You've told us about how disruptive this policy is to your lives, and really how heartless and nonsensical it is.

And we've also learned about some very troubling things: the intimidation -- the alleged intimidation, the poor communications with providers and families; just what I think is a wrong-headed approach here. It was mentioned by one of the witnesses that a more appropriate approach would be person-focused care, as opposed to this one-size-fits-all approach that may be somewhat easier to administer but does not make a lot of sense for the clients.

I am not quite sure what approach we're going to take, but we are going to act on this. I think it's important for us to review the material that was presented here. As I mentioned before, we may want to use the procedures available to us to turn back these regulations. I think the first approach we'll take is, as we have over many weeks now, trying to reason with the Administration; and just slowing down or establishing a moratorium until we really understand what is best for the clients.

There is a lot we need to focus on, and we really could not have begun these efforts without your help today and in the weeks we've been working with you. And I really can't -- words

can't express my thanks for what you have done for us. And I'm going to make a personal commitment to try to bring some order and common sense to this process.

Senator Kean, any comments?

SENATOR KEAN: Thank you, through you.

I want to echo the Chairman's thanks on this issue. And also, if I may, through the Chair, to the extent that there are follow-up questions that we have asked -- whether it be on the meet and greet processes, the regulations, those issues of intimidation -- if there are issues that are not appropriate to vet in a public testimony setting, please follow up with those issues -- through the Chairman, I would assume, and that office -- number one.

Secondly, to the extent that you do see other states that have a better process than this, please-- I understand it's all -- everything is individual in this issue, and in this instance, and this program. But to the extent that you see other states, as others have said in the past -- that New York has a better, more transparent process in some regards, to the extent --that I make, through the Chair, make that ask as well; it would be greatly appreciated.

Thank you.

SENATOR GORDON: Thank you very much.

At this point, I'm going to thank you again, and adjourn the hearing.

Thank you all very much. (applause)

**(MEETING CONCLUDED)**

