Committee Meeting of

LEGISLATIVE REVIEW PANEL ON STATE PSYCHIATRIC HOSPITALS AND DEVELOPMENT CENTERS

"The panel will receive testimony from invited speakers on issues related to the care and costs of providing services to persons with developmental disabilities residing in the State’s developmental centers”

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

DATE: October 17, 2011
10:00 a.m.

MEMBERS OF REVIEW PANEL PRESENT:

Senator Jeff Van Drew, Co-Chair
Assemblywoman Valerie Vainieri Huttle, Co-Chair
Senator Richard J. Codey
Assemblyman Louis D. Greenwald
Assemblyman Cleopatra G. Tucker
Assemblywoman Mary Pat Angelini
Assemblyman Erik Peterson

ALSO PRESENT:

Irene M. McCarthy  Jason Redd  Christina Velazquez
Michele Leblanc  Senate Majority  Senate Republican
Review Panel Aides  Kate McDonnell  Deborah DePiano
Office of Legislative Services  Assembly Majority  Assembly Republican
  Committee Aides  Committee Aides

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

*United States of America v. State of Arkansas*

submitted by

Thomas B. York, Esq. 1x

Testimony

submitted by

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Testimony

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Testimony, plus fact sheets
submitted by
Kevin K. Walsh, Ph.D.
Director of Quality Management and Research
Developmental Disabilities Health Alliance, Inc., and
Theodore A. Kastner, M.D.
President
Developmental Disabilities Health Alliance, Inc

pnf: 1-121
SENATOR JEFF VAN DREW (Co-Chair): I call this meeting of the Legislative Review Panel on State Psychiatric Hospitals and Developmental Centers to order.

Please rise for the flag salute. (all recite the pledge of allegiance).

May I have roll call, please?

MS. LEBLANC (Committee Aide): Senator Van Drew.

SENATOR VAN DREW: I’m here.

MS. LEBLANC: Assemblywoman Huttle.

ASSEMBLYWOMAN VALERIE VAINIERI HUTTLE (Co-Chair): Here.

MS. LEBLANC: Assemblyman Greenwald.

ASSEMBLYMAN GREENWALD: Here.

MS. LEBLANC: Assemblywoman Angelini.

ASSEMBLYWOMAN ANGELINI: Here.

MS. LEBLANC: Assemblyman Peterson.

ASSEMBLYMAN PETERSON: Here.

SENATOR VAN DREW: And I will start out by welcoming everyone and thank you for being here. And I think we all know why we are here. My Co-Chair, Valerie Vainieri Huttle, I don’t know if you wanted to have some comments to start us off?

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Just to welcome everyone as well; and I look forward to this meeting and hearing today. This is our second meeting, I think as we all know, dealing specifically on developmental centers. So I look forward to listening to the testimony and, at the end, making some determinations.
So thank you, Chair.

SENATOR VAN DREW: Thank you.

I know we’re going to start with Tom York, who is the founder of the York Legal Group; if he could come forward and present his testimony.

Welcome.

THOMAS B. YORK, ESQ.: Thank you.

Good morning, ladies and gentlemen. First of all, thank you very much for the invitation to speak here today.

SENATOR VAN DREW: Do you have your red button on? (referring to PA microphone) There you go.

MR. YORK: Is that better?

SENATOR VAN DREW: That’s much better; thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Great.

MR. YORK: Thank you very much for the invitation to speak today. It’s a privilege and an honor to be here and have a chance to talk to all of you.

I have a few points to make. First of all, I want to point out that I work both with developmental disabilities facilities -- or intellectual disability facilities, but also with those that deal with mental health issues. My focus today, though, is on the DD population, because I believe that is your focus here today, although I do have some insights, also, on the mental health side.

I want to point out that I have no bias; I’m kind of apolitical. This is not something that I’m biased against -- community settings. Community settings are, sometimes, a very good location for certain
individuals to be, but it has to based on the individual’s needs. And I also want to point out that I do not operate within the realm of political correctness; I mean, some people you’ll, I think, be hearing from will speak about what’s politically correct. Rather, my focus is on -- I think this comes from being a litigation attorney -- my focus is on the facts: what will hold up in court, what you can prove, and what you can’t prove in a court of law. Because, basically, I think that’s the best test, when somebody comes in and tells you something, or tries to represent something to you: If it won’t stand up in a court of law, it’s probably not the truth.

Now, going to those facts: I think one of the first and foremost facts is that the Olmstead decision does not require community placement. Many people mischaracterize the Olmstead decision and try to imply or even say that it requires that everybody be moved into the community -- and that is just completely false. I think, as you all are probably aware, the wishes of the guardian must be taken into consideration, and there are other factors including whether or not there’s a fundamental alteration to the state system, and certain funding issues that can be raised, too.

Along those lines, we recently won a case in Arkansas back in June of this year. It’s not officially reported yet in any of the official court reporters, so I brought 10 copies here. I thought that the board might want to look at that. One of the issues addressed in that case -- even though it’s a very long decision -- that also addressed the conditions at a facility -- it was Conway Human Development Center. One of the issues was Olmstead; and we won on the Olmstead decision. And the judge was very clear that Olmstead does not require that everybody be moved to the
community. And I think that’s one point that has to be made, right upfront.

A couple of things that I wanted to mention: One thing that I think states are making a mistake on is chasing statistics. If you follow the logical conclusion of chasing other states and trying to decide what to do, not only do you deny -- which is the most important thing -- deny the individual consideration that people need to have on where they should be placed, because you’re chasing some statistic to compare to some other state; but also those statistics do not, at all, accurately represent the quality of the services, in either an institutional setting -- which I don’t usually like to use that word, but since that’s the way they refer to it -- or in a community setting.

So there are a number of factors that have to be taken into consideration. And I know some arguments will be made to this panel that somehow or another New Jersey is lagging behind other states, and I think that is a false argument -- a pseudo-argument, really. You have to take into consideration many other factors, and I don’t think the members of this panel should be chasing the political correctness of what others states are doing; rather, you should be trying to decide what is the right thing to do for these people who need the services of an ICF/MR.

One of the other fallacies, or falsehoods, I believe that are promoted in order to get legislatures to close facilities is that it is cheaper to move people out to the community. I am telling you here and now that I’ve litigated this issue in a number of cases, and I have done extensive research, and that has never been proven in a court of law. In fact, I would argue that, from the statistics and the experts that I have worked with, the cost is
probably greater to serve the people in the community. And the problem is, is that you are being cited figures that are apples-to-oranges, essentially. That’s what they’ll give you: They’ll come up with some number and say, “It’s cheaper -- here’s what it will really cost.” The problem is, they will not include many costs that are covered at the institutional setting. Many of the services are already covered and included in those costs, but when you go out into the community, those costs are taken up by general Medicaid or other sources. And so there is no direct comparison.

Also the reality is, is over the years the lower-care individuals have all been, mostly, moved out of developmental centers, and the fact of the matter is, is that the people who remain are the highest care individuals. Those are the ones who require the most services and, therefore, there isn’t really a good comparison to the people who are already out in the community. You’re dealing with a population that has such high-care needs that when you go to the move them to the community, those people are going to cost you much more than what they would cost you in the institutional setting. And I think that’s the reality, and that’s what the proof is, and no one has proven ever in the court of law-- That the argument has come up, but no one has ever proven that, indeed, the costs go down when people are moved out. And the experience of states are contrary to that. In particular, if you look at some states that have now entered into settlement agreements with the U.S. Department of Justice to close some of their facilities and give up authority--

SENATOR VAN DREW: Your mike’s off.

MR. YORK: Sorry.
--to give control of their facilities to the U.S. Department of Justice in somewhat similar circumstances-- I mean, essentially, you -- if you decide to close all your State facilities, you’d be doing something similar to what’s happening in Texas or in Georgia, or other places like that. And what they have found is that the cost is prohibitively high. They couldn’t even project the costs. And many of them, for example -- like Texas now is saying that they’re not even sure they can honor their settlement agreement with the U.S. Department of Justice because the costs have escalated to so much more than what they ever anticipated when they negotiated a settlement, that now they’re talking many, many hundreds of millions of dollars to implement a settlement and actually close down all these state facilities.

And the other thing about being cheaper: You also have to look at the quality of services. I’m sure you, as legislators, you obviously have an obligation to protect the taxpayers of this great state. But at the same time, I’m sure you’re also very concerned about the quality of the services that are provided to the individuals who need these services. And the fact of the matter is, again, that probably the more secure the employees -- there is far less turnover -- are the ones who have worked in the State institutional settings. And they generally make more money than what is paid out in the private sector -- in the community settings. And this is a very, very important factor, because the quality of the services provided to individuals with DD is directly related to the consistency of the staff, and their devotion and their knowledge of the individuals who they serve. And you often lack that kind of quality of services in the community.
And I’ll give you an example which I know one of the individuals here, who is a friend of mine, who is going to be testifying later, Nancy Thaler-- We had litigated years ago the Evansburg Center case, and we were able to, effectively, defeat the U.S. Department of Justice in the state of Pennsylvania. And then I had to, after telling the governor’s budget director that we should defend that case because it made sense and that the facility was so good, within a matter of months they were also drawn into the Embreeville Center case. Embreeville Center was located outside of Philadelphia, and almost all the employees there felt that they were somewhat transitional, and they were there long enough to move to another job -- unlike Evansburg, where the employees had been there-- Everyone was there 15 years, 20 years, 25 years and was devoted. And I had to tell the same people who I was representing, and had won the Evansburg case on, that we needed to settle the Embreeville case because the quality of the individuals in that situation was not as good. And that’s a very important factor. And here in the State of New Jersey, my understanding is that the quality of your State employees is very good, and in all likelihood -- even though I haven’t done research on it -- in all likelihood, if it compares to other states, the quality of your employees -- State employees in your State’s developmental centers -- is probably higher than the quality of the individuals who are providing similar services in the community.

Now, along those lines that I just-- A couple of more comments, and then I’ll open it up for questions. I hope I haven’t gone too long. But the important thing, in my opinion, is to control your own destiny and do what’s right. And one of those things is to make sure you make wise decisions based upon the facts and what’s really good for the
residents of these facilities. And these facilities are getting -- as I understand, especially at places like Vineland -- are getting high-quality services. And I think you need to weigh that and decide how you’re going to develop a strategy to not only serve those people the best, but also, hopefully, economically benefit the State most. And I believe if you close places like Vineland you would actually end up spending more money; and also result in harm to these individuals, including-- Most of the studies that have been done. And unfortunately, there aren’t very many studies that have been done in this area on mortality -- and I think that’s, in part, because it’s politically unpopular to point out that people have higher mortality in the community -- but the studies that have been done point that there’s higher mortality in the community. There are even some studies that hint that there are higher abuse rates in the community. And when you factor those things in, I think after careful consideration that hopefully you’ll decide that, indeed, some of these developmental centers are a necessary resource and a good option for the people who would like to reside there.

Thank you very much.

SENATOR VAN DREW: Thank you, Mr. York. I know there will be some questions; I have a few myself.

Are there any states that you believe are role models -- good examples -- of a mix: of a community mix, as well as obviously working with and interrelating with the developmental centers themselves?

MR. YORK: That’s a good question. I serve some that I think have at least approached some good results: Virginia does a fairly good job; I’m trying to think who else seems to do a fairly good job. Pennsylvania did
a good job for a number of years, but I think in recent years they’ve shifted too far in the direction of single-mindedness -- of closing places down, or moving people out. I’m trying to think if there are others ones that have a good balance. Believe it or not, Arkansas is actually a good example, even though many people think Arkansas is a backwards state because it’s further in the south; that’s really not true. Arkansas has some real quality facilities and also has some good community setups -- situations.

But I could give that more thought, Mr. Chairman, and get back to you, and maybe give you a really good, more firm example by checking some of the statistics I have on various states that might give me some better representation of that.

SENATOR VAN DREW: That would be helpful, and we would appreciate that if you could.

Would you agree that a process -- and I think this is a leading question -- but a process is the best way to go about this to fulfill Olmstead; to look at the developmental centers as a whole throughout the particular state, determine statewide how all of them are functioning, where communities would be able to withstand more community placement, how much it would cost, how it would work, who would provide the services? I maintain we’ve had this discussion-- Let me just-- I’ll give my little statement here: My concern, as we go through this process -- not the process here, but the process of closing developmental centers -- is that, yes, it can sound politically correct, but at the end of the day, who’s going to supply the physical therapy, the dentistry, the other healthcare needs that are now provided in those communities through those community providers, very often in developmental centers? And, again, as we’ve all
heard, we have a backlog as it is now of people who are looking for community placement. We haven’t taken care of that issue, yet we’re now looking to put many more people into the community.

So I guess what I’m trying to say -- and I believe the Co-Chair would agree -- what our focus has been, it hasn’t been to say-- While I’m a great defender of Vineland, I do not believe it should be closed, it hasn’t just been, “Don’t close Vineland,” or “Don’t close any developmental center;” it’s been, “Let’s look at the global picture. Let’s understand how this system functions. Let’s understand what the repercussions are going to be.” And if we’re going to make that type of transition, let’s do it in a global way, statewide, so we have a complete and thorough understanding of the reaction that’s going to happen.

And that’s when I say, are there other states that have done that, and really done it well? Because I’ve heard some horror stories as well. I’ve heard some states that are okay, and I’ve heard some things that are really terrible; and my concern is we’re going to do this, it’s going to sound wonderful, and we’re going to have these individuals living in substandard conditions. The community providers are wonderful that are there now -- many of them -- however, if we push this too quick and we don’t think of what’s going to happen, we could be in trouble.

MR. YORK: No, I think you’re absolutely right, and I think you’re on the right track. Not that I’m recommending that any particular developmental center be closed. After an evaluation, maybe you would determine they all should stay open, or maybe you would determine -- or two might be closed, or something. But I definitely-- I would have to agree with you. I have some significant knowledge of Vineland -- not so much of
some of your other State facilities -- but from what I understand of your State system, I think closing Vineland first, if you were to close any of them -- which I don’t support closing any of them -- but if you were going to close Vineland, that would probably be a mistake for various reasons. Vineland is a large facility; it’s done very well in CMS reviews; and it’s not under attack by the U.S. Department of Justice at the moment. I understand it comes from a somewhat-- I think the unemployment rate is greater down in the southern part of the state.

SENATOR VAN DREW: It is.

MR. YORK: I think-- So you have to consider the economics of how you’re going to benefit the people, the citizens of your state. I think services are less available in the southern part of the state to support them than what might be in the northern part of the state.

SENATOR VAN DREW: Tom, just to interrupt: That’s one of the greatest fears. Services -- particularly in that part of southern New Jersey -- are minimal.

MR. YORK: So you’re right. If you’re going to think about moving these people, you have to consider their services. You don’t want to, as you said-- There are some disastrous situations -- like Beatrice, which I actually represented Nebraska in certain aspects of a related matter, but not in this matter where they had terrible losses. But they had-- Initially they agreed to close Beatrice, or downsize it, and they moved 40 people out and, I think, within six months, eight or nine of them had died already.

SENATOR VAN DREW: Mr. York, how do you get involved? Is it through the families -- when you’re involved in litigation -- through the unions? Just educate us.
MR. YORK: I do represent some families, but most of my involvement is because I was the Deputy Attorney General in Pennsylvania and started doing these cases, and then I was chief of litigation for the Department of Public Welfare, which is the agency in Pennsylvania. And I started representing states that would give me a call and inquire about representing them or asking questions about certain experts or strategy decisions.

SENATOR VAN DREW: So generally, the state itself--

MR. YORK: Yes, the state itself, generally-- Usually it’s the--

SENATOR VAN DREW: In other words, if you have a state government that doesn’t want to close -- let me make sure I understand this right -- isn’t so anxious to close--

MR. YORK: Either-- That is accurate in some cases -- they don’t want to close and they hire me to help to stop that. But also they hire me sometimes, too, to negotiate settlements. Sometimes I-- I follow what my clients ask me to do, even though I will tell them my opinion. But my clients have sometimes asked me, and they said, “We are going-- Our intent is to close this facility, and it’s already been made up politically, but we want you to work the best settlement possible with an advocacy group or with the U.S. Department of Justice to keep the costs down and keep it within the range of what’s reasonable.” Because otherwise you end up with, maybe, a settlement like you ended up with in Texas, where the costs are just ridiculous at this moment. I mean, the state does not even know how it’s going to meet its obligations that it signed off on, or if--

SENATOR VAN DREW: Do you ever represent the unions as well, or no?
MR. YORK: No, I don’t represent the unions, although I am usually on very good terms with the unions. I mean, usually they think I believe-- While my position is usually consistent with what they want -- because we’re often supporting or defending the services that are provided at a developmental center -- I don’t represent them directly.

SENATOR VAN DREW: Thank you.

Chairwoman.

ASSEMBLYWOMAN VAINIERI HUTTLE: First of all, Mr. York, thank you for your testimony. I appreciate that it’s based on fact, as opposed to some of the testimonies that we’ve had in the past based on emotion, whether it’s the families, or people -- stakeholders -- in the centers. But, I guess, back to the question that Jeff asked: The criteria for closing -- and I wish that our Commissioner was here today, because obviously she does lay out the criteria for closing Vineland. And whether that is because maybe it is the one that has the most capital improvements needed, or that is the one where there are 70 people -- or women -- already being moved. I’m still trying to get to, I guess, the actual goal of what is the criteria to close. If we have seven and you’re saying, “Well, maybe all seven can remain open, or maybe we shall close one,” what would your criteria be in closing which one. And when-- You know, Vineland is slotted to close in 2012 -- 2013. And Hagedorn, our psychiatric center -- which you’re not here to testify on, but obviously you have a lot of information on that -- is due to close in 2012. It seems they’ve already been slotted by this Administration and the Department, and they have their own facts to base their findings on. How would you counter that, or what would you say, or how do we determine which ones, if any, are going to be closed? And when
we do close, the other point that you brought up which, again, is what I’m not hearing, is you’re saying it’s not cheaper in a community. And I’m hearing that it is cheaper in a community -- to use the word cheaper. I think that’s what we have to balance here. We’re closing Vineland, and you’re moving 70 women; are they moving them into centers, are they moving them to the community? How do we balance the budget, the care for these individuals? And you also said these State employees are higher here in New Jersey than other states -- which is a great measure, I think, that we need to applaud at times; we don’t give enough credit to those caregivers in those centers. And I’ve said that as I visited those centers I’ve seen those caregivers first-hand really give the attention, the proper attention, I think the individuals in those centers need.

And the other point that I also want to bring up again is -- we don’t hear that often as well -- the Olmstead decision: It does not require community placement. So we’re basing a premise on a couple of things that run counter to what you’ve said today. We’re basing our decision that Olmstead does require placement in the community or a least-restrictive environment. It is cheaper in the community. And we are lagging behind -- you said New Jersey is not lagging behind. So the points that you said, quite frankly, run counter to what we’re hearing. I believe, from the Administration; and again our Commissioner is not here to testify. But if you can, maybe, be a little bit more specific on the points that you made.

MR. YORK: Sure, and I’ll try to cover all of them; and if I miss something that you wanted me to discuss, please bring me back to it.

First of all, on the cheaper issue: I am convinced, from my number of years of litigation now -- and I’ve been practicing law, now, for
almost 31 years, and over 20 of those years I’ve been pretty much specialized in the area of DD -- that if you bring somebody in here who supports a theory that it is cheaper for the present people, the present type of population living in DD centers around the country, to be served in the community, I will destroy them in a court of law. That will not stand up. Those numbers will not compare to what the numbers-- They will be comparing apples and oranges. They will be making a political argument to you instead of showing you the facts. So I encourage you to say to them, “Show me the proof. Show me the proof, demonstrate to me that you are considering all the same factors.”

Now, an aside from that, going on to beyond just the cost: First of all, I agree with you. My understanding is -- especially like I said, I have some knowledge of Vineland -- that the quality of the individuals working at your State developmental centers is very high, and I think that’s a real compliment. And that, somewhat, is represented, too, by the fact that when you look at the CMS reviews and other things that would cover those kinds of incidents, I think you compare very favorably to other states. So I think you should be very proud of the people who you have working in your developmental centers.

On the fact about the Olmstead decision: The Olmstead decision does support the language of the ADA that says you try to put people -- or should put people in the least-restrictive environment. The problem is the people who read that by itself and don’t read the rest of the decision, or the rest of the statute. The fact of the matter is you must also not have the parties who are going to be moved object; if they object to the move, they aren’t moved. And also you are allowed to take into
consideration certain financial considerations, including whether or not it would be a fundamental alteration of your State system. And one of those factors, for example -- there’s a number of things that are covered under that, so I won’t lecture you on fundamental alteration -- but one is, for example, if you can show by moving everybody out of Vineland and all your other developmental centers that you’re going to, essentially, limit the resources available to other people who need services -- the ones who are still in the community, or maybe in other settings or other types of individuals, and it’s going to be detrimental to them because everybody knows there is a limited State budget-- Every state I know right now is suffering some; I don’t know your exact financial situation, but every state that I work for has budgetary concerns right now. And if you can show that other people are going to be detrimentally impacted -- which is likely if you’re going to expend a ton of money to, probably, move all these people out -- you do not have to move them.

So when you factor these other things in, that’s what I mean by saying Olmstead does not require you to close State facilities -- it just doesn’t. It’s just false for people to tell you that.

Along the issue of criteria: I know that there are many factors, and often-- I settled a case in one state -- I won’t mention which one it is -- which the facility is still open, though, thank goodness. We didn’t have to give away the facility because the gubernatorial election was coming up and they said to me, “We need to settle this case.” So I always try to factor in what you think is important. But if you ask me what criteria-- And the reason why that gubernatorial election, it wasn’t because they felt -- this is one of the strongest facilities in the entire country -- it wasn’t because we
thought we would lose. But initially you take an onslaught of bad press when this case first hits, and the DOJ is putting on their case or the advocates are putting on their case at the start, a week or two before the election -- they haven’t even heard our side yet. And all the press headlines are going to be how terrible the facility is -- because it’s all exaggerated and these hired gun experts come in and say how terrible it is -- and we haven’t had a chance to debunk all that falsehood. And the person running for governor -- running for reelection -- didn’t want all that bad press at that time. So I had to factor that in and kind of compromise a little bit on what I would prefer.

Now, if you’re asking me in a perfect world -- and we’re giving up the concept of -- and there is a very strong likelihood that I might tell you I want you to keep all your State facilities open here if I reviewed them. But if you’re telling me I have no choice and we have to target one, and you’re asking me for criteria on one or more, the criteria I would use is defensibility in quality of services. Because I think that not only is that important to win the case if you’re later sued by the DOJ, or maybe you’re already under DOJ jurisdiction -- you’re being sued already, or if an advocate is going to sue you -- but it’s also the morally right thing to do, in my opinion. You want to keep the superior facilities because you want to have the best possible services for the individuals who are being served.

So my criteria would not be based on any type of politics or what is politically correct; or some places target just the largest facility because they think, “We’ll get rid of the largest facility; we can make the most impact,” or whatever. I don’t think that’s the best criteria, in my opinion. So if you’re asking, in a perfect world I would actually go in and
review each of the facilities -- if I was making the decision, which I know I haven’t been asked to do -- but I would go into each facility and do an analysis of the quality of services; not just look on the surface at CMS surveys, which give you some indication on how good the facility is doing and how well they’re performing, but do a more in-depth review of some of the records, and some of the decisions that are being made, and the Olmstead situation -- see what’s actually written into the transition plans: do they actually discuss the consideration of community placement? Have they made sure that the guardians are made aware of what’s out -- available out in the community, that kind of thing. And then try to weigh those in a way I think you could do very effectively -- that at least the ones, if you did have to close somewhere, the ones that remain would be very defensible and would be providing the highest quality services.

And that gets me -- I’m sorry to drift off here a little bit, but the issue of guardian consent is of the utmost importance. Not only is it recognized by the Olmstead decision, but I think it is a moral thing that we need to go to the people who have the most commitment to those loved ones and try to find out what their desires are. I’m a father of five children from 9 to 2, and I resent the fact that somebody comes in and tells me what I should do with my children, and thinks they know better than me. And I think that’s what we have happening here. And it is particularly outrageous when I hear, “Make them go to a community, and they’ll like it. We’ll, essentially, reeducate them. And once they’re forced to do it, they’ll love it; don’t worry about it. Just ignore what they’re feeling.” Well, I resent that, because I think those guardians not only are recognized under the law as having a right to have a say in this, but they also have a moral right, in my
opinion, to help judge for their loved ones what are the best services for their loved ones. Because it is not black and white as some of these advocates would tell you -- that the community’s wonderful and the institutional setting is terrible -- that's false. You should give them the options and let them help decide where their loved ones should be.

ASSEMBLYWOMAN VAINIERI HUTTLE: And just a quick follow-up--

MR. YORK: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: -- and maybe you can just say yes or no.

MR. YORK: Sure -- sorry.

ASSEMBLYWOMAN VAINIERI HUTTLE: No, no I appreciate the testimony, but I want to be, just, maybe more definitive, if you can.

MR. YORK: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: Because you gave a great criteria: defensibility in quality of services. Do you think, in your opinion, should Hagedorn be the first one on the chopping block -- out of the five psychiatric centers?

MR. YORK: I don’t know enough about your individual centers to know for sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: All right.

MR. YORK: So I would have to do a more in-depth review of those. So sorry--

ASSEMBLYWOMAN VAINIERI HUTTLE: How about, then, Vineland -- out of the seven?
MR. YORK: I would say Vineland -- definitely not from what I understand.

ASSEMBLYWOMAN VAINIERI HUTTLE: All right.

MR. YORK: And I have seen CMS reports from other facilities in addition to Vineland, and I do know some things about Vineland, and I have talked to some employees there, and I have talked to some residents, and so on. And Vineland, I think, compares very favorably, not just to other facilities in New Jersey, but I think Vineland compares very favorably to other facilities around the country.

ASSEMBLYWOMAN VAINIERI HUTTLE: Quite a testament.

SENATOR VAN DREW: Yes.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

SENATOR VAN DREW: Thank you, Chair.

And I just-- And then we’re going to ask for some other questions, because this has been very informative. And I believe you’re right about Vineland; of course, I’m somewhat parochial in the district that I represent. But while all of this is so informative, what we’re worked through with the Governor -- and you may have followed it in New Jersey -- is this task force is going to be a resource for information that we’re going to be using on another one -- in a bill that I sponsored, which is now going through a conditional veto, and has now gone through the Senate, and will be going through the Assembly -- which, in a sense, is like a BRAC commission. It is a task force -- it’s really more of a commission that is going to look and say, “Okay, which one should be closed if one should be closed,” and the results of that are going to be binding. That’s why this
testimony in this task force is so important, because it’s going to be used as part of the process. And probably you would be called there again for that one, and hopefully you could comply.

But the important point of Vineland, too, when folks say there are more individuals there who have indicated that they would like to move into the community, everyone should know in the real world that there have been folks from the State who were there-- Now, the process has stopped right now because we’re working on this other bill, but there were folks from the State who were there who were very aggressively working with those individuals -- the developmentally disabled -- who were there to push them into saying they wanted to go into the community. And that hasn’t happened at other ones.

And then I’ll leave it with this, and we’ll go around the table here and see what questions there are.

One of the worst parts of this process: We’re all in this boat together -- whether we’re serving in the community or whether we’re serving in the developmental center. And one of the most hurtful things-- I’ve been in this legislative house for 10 years now -- in the Assembly and the Senate -- was when I saw individuals from the other settings wearing T-shirts and with banners that said “Close Vineland.” “Provide more community service” -- yes, I’ll wear one of those T-shirts. But just to gain by hurting others I don’t think is a productive process. And that’s why this has been a really difficult process for all of us.

With that, I will obviously entertain questions from some other--

Governor -- Governor Codey.
SENATOR CODEY: Yes. I was just wondering: What knowledge do you have of Hagedorn, sir?

MR. YORK: Knowledge of what? I’m sorry.

SENATOR CODEY: Hagedorn -- thank you.

MR. YORK: Of where?

SENATOR CODEY: Hagedorn.

MR. YORK: I don’t have very much knowledge of that at all.

SENATOR CODEY: Okay. Well, they want to close it, as--

MR. YORK: Right.

SENATOR CODEY: --Ms. Huttle said, and transfer them, in large part, many of them to Trenton Psychiatric Hospital, which has convicted sex offenders, violent people, whatever. And to have them moved off a setting where no one has committed any crimes, and mix these people who have mental illness -- they’ve committed no crimes against society -- and have them walk amongst the others is, in my opinion, disgraceful.

MR. YORK: No, and I think it opens you up, not only to potential litigation as far as where they were moved, but also possible litigation-- We represent some individuals occasionally against private entities that serve the people with mental health issues or private entities that serve DD population, and these people are often abused and have some kind of bad result, and no one is there to protect their rights.

That gets to another point: You’re talking about, not only do you have at an ICF/MR a vast array of regulations that have to be applied -- I think it’s like 450 tags that have to be complied with -- which you don’t have in the community--

SENATOR CODEY: Okay, go back -- 450 what?
MR. YORK: Tags, they call them -- they’re requirements that are written into the regulation. They’re numbered.

So they have all these requirements. You don’t have the similar type of thing in a community setting. It’s a protection. And also you now have all these people in the community defending on the level that they’re not State actors, and people don’t get their normal civil rights either.

So when you move people out to the community sometimes, sometimes you’re stripping them of some of their civil rights that they would normally have.

SENATOR CODEY: Sir, in New Jersey they ship them, for the most part, to urban areas where every month when they get their small personal needs checks -- it’s robbed. They’re in rooming houses with, as Ms. Tucker knows, the worst sexual predators you could find; I mean, the lowest of the lowest. That’s what happens when you go in the “community” here in New Jersey.

MR. YORK: And you may well find even being the subject of a Department of Justice lawsuit then, down the road. We had a similar issue up in Connecticut -- Valley Hospital in Connecticut -- I defended, and they were upset by--

SENATOR CODEY: Well, maybe we could use you when you’re not breeding. (laughter)

MR. YORK: Up in Connecticut at Valley Hospital they were housing some people with forensic backgrounds; they were there for criminal reasons, in with the general population, and there were some severe concerns.

SENATOR CODEY: That’s my point.
MR. YORK: Exactly. And I think you’re taking some risks there. And I don’t believe that’s normally appropriate unless we’re talking about something, maybe, very minor of a criminal violation.

SENATOR VAN DREW: Thank you.

Assemblyman Greenwald.

ASSEMBLYMAN GREENWALD: Thank you.

Mr. York, I just want to-- Governor Codey is talking about the mental health institutions right now, and I want to veer back to the developmental centers--

MR. YORK: Okay, fine, yes.

ASSEMBLYMAN GREENWALD: --so it’s a separate issue. The Governor is very much on point accurate when it comes to the quality of care that is provided to the mentally ill. And I’ve seen in my travels around the state a somewhat different story when it comes to developmental centers. So I just want to make sure that for everyone who is listening -- there’s a distinction. Because I agree with Governor Codey and his concerns that he’s raised around Hagedorn and around the mentally ill.

But for the developmentally disabled my concern is that, you know -- a pound of prevention -- that old saying. And I’m very concerned that we are not able to meet those demands for very young families and young children who are developmentally disabled as they are aging through the system. So I was curious: Your position on, that you come from facts -- are you aware of how many people are currently in the developmental centers in New Jersey?
MR. YORK: I did at one time see a number, but it doesn’t come back to me. I know--

ASSEMBLYMAN GREENWALD: It’s roughly between 2,700 and 2,900.

MR. YORK: Right.

ASSEMBLYMAN GREENWALD: Are you aware of how many there are -- currently registered developmentally disabled in the State of New Jersey?

MR. YORK: I don’t know the exact number, no.

ASSEMBLYMAN GREENWALD: That factual number is somewhere around 48,000 and growing.

Are you aware of how many people are currently on the waiting list in New Jersey?

MR. YORK: I know it’s thousands, but I don’t know how many exactly.

ASSEMBLYMAN GREENWALD: It was 4,000 when Governor Whitman said that we would reduce that waiting list to zero. It more than doubled in a decade and it is now close to 10,000.

Are you--

MR. YORK: Which is not -- I don’t mean to interrupt you; I’m sorry -- but it’s not atypical of most states around the country.

ASSEMBLYMAN GREENWALD: No, no it’s not.

MR. YORK: There are several thousand--

ASSEMBLYMAN GREENWALD: Which is why this is such a crisis.
Are you aware of how much money we currently spend on the population that are the developmentally disabled in New Jersey?

MR. YORK: No, I don’t know the exact amount.

ASSEMBLYMAN GREENWALD: Okay. Let me share that with you, because these are the facts that are important.

MR. YORK: Right.

ASSEMBLYMAN GREENWALD: We currently spend about over $1 billion, and we spend approximately one-third of our budget on 8 percent of the developmentally disabled. Which means that we do not have enough money to deal with the other people on that waiting list, to provide the needs for them as families who -- I’m sure you’ve represented -- are trying and struggling to keep home.

You know, Tom, I appreciate -- and I’m a lawyer as well -- I get your position that you will tear anyone up in a court of law based on your facts. Based on a lot of court decisions that I have seen and cases that I have followed outside of your realm of experience, the facts in a court of law are not always the facts of reality and society and what we face. And the courtroom world is much different than the world of the people who are on that waiting list.

I’ll give you some other facts that are important here in New Jersey. We have 1 out of 98 kids that are born in this state who have autism -- varying degrees in the spectrum. We have what is going to be a burgeoning population of families that are going to need help for their children who are developmentally disabled. When you look at one-third of the budget being spent on 8 percent of the population; when you look at a waiting list that has now more than doubled; when you look at Olmstead
decision -- where I disagree with you slightly. I think it is a decision about putting people in the least-restrictive setting. But there’s a balance there -- that we cannot continue and we cannot afford to stay on the course that we’re on.

My concern as Chair of the Budget Committee, and what I’ve seen is an ever-decreasing amount of revenue going to this population of developmentally disabled -- that 48,000 number and growing-- The population that is in DCs has a fixed cost because of the capital costs and because of facilities that are antiquated. So that one-third is now higher than what it was, and it’s probably slightly more than one-third. And it is sucking resources and revenues from the loved ones of the families who have their children on the waiting list.

So as a lawyer-- I assume you’ve only represented families or states with kids in developmental centers.

MR. YORK: No, I’ve represented people in community settings.

ASSEMBLYMAN GREENWALD: Okay.

MR. YORK: And also I’ve represented states -- defended state systems of Medicaid reimbursement for people being placed in nursing homes and community settings.

ASSEMBLYMAN GREENWALD: Let me ask you this question then: If I came to you and asked you to represent my family who had a child on the waiting list and was being denied access to speech therapy, occupational therapy, and physical therapy because the State didn’t have enough money, and that money was going, primarily, to children of equal need and disability, how do you weigh the civil rights of
those two individual groups -- the families in the DC and the families that are equally in hardship with guardians and loved ones who are representing their interest?

MR. YORK: Well that--

ASSEMBLYMAN GREENWALD: Whose rights trump?

MR. YORK: That would be difficult to choose and say one person’s rights trump the other. But see, you and I, respectfully, disagree on the premise, I believe what you were saying. I do not believe you will recover or save any significant sums of money by closing these State facilities down. Now I could be wrong, but in my experience I believe you will find that that is not true.

ASSEMBLYMAN GREENWALD: So then the rights--

MR. YORK: So people-- So it is not a trade-off of one for the other, in my opinion.

ASSEMBLYMAN GREENWALD: But it is, in the real, factual world -- not the courtroom world. Those who are in the DC are then forced to -- because of the dollar amounts that we just agreed upon, and the capital costs, and the setting costs, and everything else -- they are the fortunate ones who then suck up the resources and the revenues so that the families on the waiting list -- that money is not available to them.

MR. YORK: Well again sir, I greatly respect your opinion--

ASSEMBLYMAN GREENWALD: Sure.

MR. YORK: --and certainly you know the budget here better than me.

ASSEMBLYMAN GREENWALD: Well--
MR. YORK: But my point is, is I do not agree that they would not still be sucking up that money and, in fact, maybe need even more money to place them in the community.

ASSEMBLYMAN GREENWALD: Okay.

MR. YORK: So--

ASSEMBLYMAN GREENWALD: But here-- So here’s my concern: As you said, your coming here with facts, yet you don’t know how many people are in our DCs, you don’t know how many DD are in the state, you don’t know how many are on the waiting list, and you don’t know how much of our budget goes to the developmental centers, and you’re not sure at the numbers of growing autism.

But here’s where we do agree: I have argued that we shouldn’t close all the DCs in the state. But there ought to be an educated platform as to which should close and how they should close. And I can’t believe -- and, you know, I would ask you this question again: Out of all the work you’ve done around the country -- and this is your area of expertise -- is there not a single state -- not one -- where we can look to a model of successful closures? Where we can marry a way to close a developmental center in a sound, economic fashion; marry that with the ability and the requirement to preserve what I have seen in these facilities around the developmentally disabled -- a remarkably skilled workforce that anybody would be honored to have as an employee? So any way to do this in a sound, economic fashion: preserve the workforce and protect the best quality of health care for these individuals -- whether they’re in a DC or in a residential housing. Is there not a single state out of 49 other states that has been able to mirror that? And, if not, with your learned experience and
expertise in this area, is there a way to mash up a number of states that have done some of them well and create a real center of excellence here in New Jersey?

MR. YORK: If you don’t mind, I’ll address the first part of your question, and then I’ll try and address your second part.

I thought I made it clear, and if I related otherwise to anybody I apologize. But I thought I made it clear that I was speaking from my experience; and in the states that I’ve seen, and all the studies I’ve seen, have never supported that it would save money to move people to the community. Now, you may be able to prove me wrong in New Jersey if you’re circumstances are drastically different than any other state I’ve seen, but I--

SENATOR VAN DREW: Could I just jump in here for one second, and I don’t mean to be rude, and excuse me. But I agree with you; and, in fact, when I spoke with Commissioner Velez they made it clear here that this is not a budgetary issue, in general. It is not a budgetary issue. In fact, as I’ve investigated this, at times it will absolutely cost more. Because when people-- When you have individual clients -- or consumers as they’re calling them -- and they’re on respirators, and need 24/7 care, and need a tremendous amount of medical attention which many of the ones who are left in developmental centers do-- Everyone should understand that the easy folks have been moved out; the folks who can go into the community easily have already been moved out of developmental centers. If you toured them -- I know my Co-Chair has seen them all; I’ve seen some of them. I’ve been in three of them -- and you see the individuals who are there, they’re pretty profoundly in need of a lot of care. And at times I have been told
that it will absolutely cost more because you’re going to duplicate the services that they need, which are quite intense, in small facility after small facility. And I’m not sure that’s always the best way to go budgetary or that it’s the best way to go even as far as care.

There’s just one other issue. Again, when we speak about moving them into the workforce-- And I know Assemblyman Greenwald -- Chairman Greenwald -- has had to wrestle with unbelievably horrific budgets, and I respect the work that he does tremendously, and I mean that -- but when we speak about these employees getting the same benefits: I’ve never seen it. Because I know the folks who are in a community -- many of them are wonderful people, they’re friends of mine, I’ve worked with them on a lot of issues -- but in general-- In fact, there’s even a facility that is close to Vineland that is private, and literally we’ve now had to make special arrangements to put those employees -- and you’re probably not aware of it, of what it is, but we all in New Jersey are -- on FamilyCare, because they can’t even provide them medical insurance anymore for their families and for them. So it is an issue with employees, and they’re not going to get the same level of benefits, and they’re not going to get the same salary. And that’s not the only reason we worry most about the consumers, but I know that in New Jersey there will still be budgetary issues, Louis. It’s expensive.

ASSEMBLYMAN GREENWALD: If I can.

Yes, I-- Just, if I can, because I want to frame the comments around that.

SENATOR VAN DREW: Sure.
ASSEMBLYMAN GREENWALD: I come back to my point, which has been, we should never close all these facilities in the state -- that’s why, because of the point that Jeff just made. There are some of the population, either through medical necessity or through, quite frankly, families who have lost confidence in our ability to do this. Until there is a consumer product that that family is positive enough in, confident enough in to move their loved one, that choice must remain open.

So I say that sincerely. But my concern is that-- I come back to how I started my comments. Our inability and our failure to address the needs of families with developmentally disabled early on is leading to patients who need greater medical care and, ultimately, some who end up in developmental centers -- because we do not have the resources to spend on a loved one early on.

So my position on this over the years, if you look at my comments in the newspapers, or legislation -- it has never been about saving money. But I do believe there is a way to transition, from a budget-neutral position, as the population ages out (indiscernible) and as we start to reinvest and move people in a more business-like fashion, designed around the best quality of health care for the residents at the best and most appropriate setting. Everything that we talk about in health care today -- that we’ve all supported in a bipartisan fashion, around accountable care organizations, around the pilot program with Dr. Jeff Brenner in Camden -- is about treating people in the most appropriate setting as early as possible. For part of the population of this, we have tragically missed that boat. But now going forward, my concern is if we don’t address this now, it will continue to cycle out of control, where we continue to spend more on less
of the population and more of the remaining population suffers and they get sicker.

Now, as I give you that backdrop to come back to, there must be a model somewhere in the country where there is a means -- and Jeff may be right, and you may be right, where we have never transitioned State employees with equal pay and equal benefits -- it doesn’t mean you can’t, okay? But I will also say these jobs were not created. We didn’t institutionalize people to create jobs, okay? We should never keep someone institutionalized to protect a job. That’s the wrong attitude. If they are compassionate and dedicated, those economics should be transitioned into the most appropriate setting. Because if that’s your loved one or, God forbid, that is you, you want to be in the setting that is most appropriate for you.

So I come to that and, again, I ask: Is there a way to marry that sound economic policy along with placing that skilled workforce -- which I respect and admire what they do. Much more so than what I saw at Ancora -- when I learned a lesson from Governor Codey and did a surprise visit there -- where I couldn’t tell the difference -- honestly could not tell the difference between a patient and a staff member, all right?

And then finally, in a way to do that to protect the quality of care? Is there any state where we’ve been able to achieve that, or is there a way that we could -- a mash-up of multiple states to achieve that goal and make New Jersey the center of excellence?

MR. YORK: A couple of comments, though.

First of all, again, I want to emphasize: I never said I was talking about the specifics in New Jersey.
ASSEMBLYMAN GREENWALD: Right.

MR. YORK: I wasn’t called here, I thought, for that purpose. I would be happy--

ASSEMBLYMAN GREENWALD: No but, Tom, I’m concerned--

MR. YORK: I would be happy to review the New Jersey system.

ASSEMBLYMAN GREENWALD: I’m concerned about your comment that nowhere that you’ve ever practiced or anything that you’ve ever read has it been achieved. And that’s an important fact. Because that is damning--

MR. YORK: Right, and you could prove me wrong here in New Jersey.

ASSEMBLYMAN GREENWALD: I don’t think--

MR. YORK: --but that would surprise me, because your system would have to be completely different than every other state I’m familiar with.

ASSEMBLYMAN GREENWALD: But Tom, that’s the point. That’s why you’re here. I don’t want to prove you wrong; I want to take your experience and expertise and learn from those mistakes and make it work in New Jersey

MR. YORK: Right. And the other--

ASSEMBLYMAN GREENWALD: So help me do that.

MR. YORK: I will -- I’ll try to.

ASSEMBLYMAN GREENWALD: Okay.

MR. YORK: I’ll give you my comments.
The other thing is, you seem to imply -- and, again, with all due respect, Mr. Assemblyman, because you’re more than entitled to your opinion and you may know better than me -- but you seem to imply that the institutional setting, as they’re referred to -- and, again, I don’t like using that term because it has bad connotations at times; so let’s say developmental center -- is never the most appropriate or least-restrictive environment. This decision will tell you otherwise. My experience will tell you otherwise.

ASSEMBLYMAN GREENWALD: Again, Tom, that’s why I said--

MR. YORK: Some of these facilities are the most appropriate--

ASSEMBLYMAN GREENWALD: Tom, that’s why I said--

MR. YORK: --and are the best facilities--

ASSEMBLYMAN GREENWALD: Let me just correct you. Maybe I’m not speaking it properly.

MR. YORK: All right.

ASSEMBLYMAN GREENWALD: That’s why I-- I’ll say it for the third time here: I’m not saying we should close all of them. There are some facilities where there will be, as I said just a moment ago, a medical necessity to keep some of the people there -- because I agree with what Jeff said. I also agree, though, that there are some families that would be better served in residential communities, but they have lost the confidence in the State; maybe because of some of the things that you’ve experienced in other states -- that we can do that.

So I’d even grant them -- I wouldn’t put my loved one in one if I didn’t see it work.
MR. YORK: Right.

ASSEMBLYMAN GREENWALD: But at some point, if we could make a system that fit those three criteria that I’ve laid out -- economic feasible so we can serve an entire population; protect the staffers that are remarkably skilled; and ultimately provide the best quality care in the least-restrictive setting, so that we know-- When we do that in every other form of medicine, it saves money in the long run -- a pound of prevention.

So there’s got-- I cannot believe that every other area of health care we can do that except around the developmentally disabled. There’s got to be a means.

So I’m asking you, in all of your experience -- and you may not have the answer today; but I’d love to meet with you and work on it--

MR. YORK: Yes, I would love to, too. And--

ASSEMBLYMAN GREENWALD: Can you imagine how much good you would do, as opposed to being in the courtroom, to create the model here that everyone else could follow? Because if it’s successful, they would follow it.

MR. YORK: And Mr. Assemblyman, that’s why I hesitate; because every state that I could think of that has effectively moved people to the community has some, maybe, flaw in what they did.

ASSEMBLYMAN GREENWALD: And you know why? I can tell you.

MR. YORK: Either the mortality rate is really high--

ASSEMBLYMAN GREENWALD: Right; and you know why?
MR. YORK: The expense was astronomical, beyond anybody’s expectations, or whatever. But I could say to you, in some ways they did a decent job because maybe the people were doing somewhat well in other ways; or they were effective in the sense of, within their five-year frame or whatever they said, closing them all down. But I really-- It's hard for me to recommend something that I really think had been mostly dealt with failure.

ASSEMBLYMAN GREENWALD: I understand. And Tom, you know why? Because I think in many of those states they were doing what I fear will happen here: They are chasing the money--

MR. YORK: Right.

ASSEMBLYMAN GREENWALD: --as opposed to creating a system. Now, I don’t have the background that you do in this and some of the providers do.

SENATOR VAN DREW: Assemblyman, respectfully, if we could just wrap it up, because I want to get to a couple other quick questions.

ASSEMBLYMAN GREENWALD: Okay, I just have a couple more, okay?

And you interrupted me for a second, too, and took some of my time.

SENATOR VAN DREW: I know, I know, so I’m giving you a lot of leniency here. (laughter)

ASSEMBLYMAN GREENWALD: That’s all right; I just want to remind you of that, in case you had conveniently forgotten.
ASSEMBLYWOMAN VAINIERI HUTTLE: We want to play fair here, now, all right? (laughter) Cool it, guys.

SENATOR VAN DREW: Here, here.

SENATOR CODEY: Who’s the coach from Detroit, and who’s the coach from San Francisco? (laughter)

ASSEMBLYMAN GREENWALD: That’s right.

But in Maryland, I think --- now you may correct if I’m wrong -- but in Maryland they were able to successfully do some closures of developmental centers because they worked with families to meet the concerns and expectations. Now, that’s only been two years, so I don’t know if enough has fettered out.

MR. YORK: And the cost has been higher than what they expected, too. And Maryland is a state I am familiar with because I’ve even been admitted to the bar in Maryland--

ASSEMBLYMAN GREENWALD: Right.

MR. YORK: --so I do some practice down there. But--

ASSEMBLYMAN GREENWALD: Tom, again, I’m not worried about saving money in this; I’m worried about trying to do it revenue neutral and spread those dollars around to serve more people.

MR. YORK: Well, and I think--

ASSEMBLYMAN GREENWALD: So if it costs me more--

MR. YORK: I think--

ASSEMBLYMAN GREENWALD: --than what--

MR. YORK: The people-- I’m sorry, I didn’t mean to interrupt.

ASSEMBLYMAN GREENWALD: No, no.
MR. YORK: If people like you and I got together, even though we may not agree exactly in principle, as our conversation’s revealing, I think maybe we could come up with a good system that would accomplish some of the goals that you’re trying to do.

ASSEMBLYMAN GREENWALD: Here’s my last question, then I’ll get off it.

ASSEMBLYWOMAN VAINIERI HUTTLE: That’s the plan.

ASSEMBLYMAN GREENWALD: Yes.

That’s why I’m asking you to step up and help, okay?

ASSEMBLYWOMAN VAINIERI HUTTLE: That’s the plan.

ASSEMBLYMAN GREENWALD: I’m asking you to take your experience with the failures you’ve seen to make a successful story here. Here’s my concern and, again, all I have is what I read in the paper. The Department of Justice comes into Georgia and they force the closures. You tell me as you sit here today, that that ended up being incredibly costly. That reminds me of a New Jersey experience that we had around the Division of Youth and Family Services where we did not fund the program properly; we allowed the most vulnerable in our society to slip through the cracks. We put people in the place who weren’t doing what they were supposed to be doing, and it ended up costing this State billions of dollars in damages and effects. Now, the fix has become a national model around the Division of Children and Families. But I will tell you: We could have done that system on our own, had we tackled it up front, and achieved the same outcomes for far less. But because it was dictated to us and we had to go beyond in order to protect the State from further liability, it ended up costing us more around the tragic population. I think that’s what’s
happened in Georgia, I think that’s what’s happened in Texas, and I guarantee you, as sure as we’re sitting here, if we don’t do this the right way, that’s what’s going to happen here.

MR. YORK: I agree with you entirely--

ASSEMBLYMAN GREENWALD: Okay?

MR. YORK: --in the sense that--

ASSEMBLYMAN GREENWALD: So doing nothing is not the answer.

MR. YORK: I agree with you entirely on that--

ASSEMBLYMAN GREENWALD: Okay.

MR. YORK: --in that you need to plan ahead and actually come up with some kind of plan. Because the difference is even in settlements-- I admit, I have a preference for litigation because I’m a litigator, and in states where we’ve beaten the DOJ, for example, they don’t come back, usually, at least for months, if not years. And so that’s sometimes cleaner and saves the most money. But I’ve also settled with them; and, for example, Northern Virginia Training Center -- I worked out a settlement with them. That settlement was complied with in a year-and-a-half and the facility stayed open -- which may or may not be your intention -- but the facility stayed open and there was a good settlement that was reached because it was carefully negotiated. Instead, you have settlements like in Connecticut -- The U.S. vs. Connecticut Southbury Training School -- that was implemented in 1988 and continued on until just two years ago, at the cost of millions and millions and millions of dollars to the state to try to litigate that. They had to hire me in, like, 2005 to take a
couple of years to get them out of a settlement that was almost 20 years old already.

You’re right -- you’ve got to plan ahead and come up with a strategy if you want to avoid those kind of bad settlements, or a bad plan that results in tremendous losses to the State, which is unfair to the State.

ASSEMBLYMAN GREENWALD: Tom, let me just-- And I’ll close with this. My plan is this: My plan is to figure out what is the right size for New Jersey; I don’t know if it’s two, five, or seven -- I don’t think it’s seven, okay? Mine is to make sure that with the limited resources we have we can serve as much of that population as possible, and do so in a way that provides the best quality of care, to treat people in the least restrictive setting, and to make sure that we do so in a way that is respectful to both the worker and the individual. And I think there’s a way to do that. I don’t know what it is -- that’s why we’re having these hearings.

MR. YORK: Well, and I--

ASSEMBLYMAN GREENWALD: But I can’t believe there’s not a way to get home on that issue.

SENATOR VAN DREW: Thank you, Assemblyman Greenwald, and thank you, Mr. York.

And let me end, and we’ll see if there’s any questions over there.

Very laudable goal; at the end of the day it would be very expensive. If you provide that level of community care, still keep some of the developmental centers, have the employees treated appropriately -- that would be very expensive. People have to understand: When you have profoundly developmentally disabled people and, rather than be in a
facility, if you have registered nurses and other healthcare providers who are only taking care of a few inside a home, it’s a wonderful process; it’s a very expensive process. Because you’re talking about people who are profoundly disabled, not people who are a little bit disabled. That is not cheap to do.

So at the end of the day, if we’re talking about the budgetary issue, that’s going to be very, very challenging. But that’s the purpose of this task force, and it’s going to be the purpose -- when we move into the other one, as well -- when we look at the possible closure of one, to do it in the most appropriate way. Louis, I agree with you, but I don’t think it’s going to be inexpensive.

And you folks may have questions over there, and we haven’t even asked.

Anybody on the other side?

ASSEMBLYWOMAN ANGELINI: I’m good right now, thanks.

SENATOR VAN DREW: Assemblyman Peterson.

ASSEMBLYMAN PETERSON: For the sake of time, I’ll-- Mr. Greenwald did a nice job asking those questions.

I will say this: I think part of the disconnect is that Lou’s talking about that we have a lot of people who are at home, and not in a community setting, whose parents are aging. And at some point they’re going to need to be in a community setting. And that is a budgetary fact -- I’ll defer to Lou’s number -- is that 8 percent of the population is consuming one-third of the budget. And how do we change some of that so that there’s enough money for those people who are currently being served at home -- can be served in the same community setting, which they are
currently being served in? He’s not-- I don’t believe that the intent is to take people who need to be in a developmental center and put them in a community setting; it’s how do we, budgetarily, provide those people who are already in a community setting with an assisted community setting that isn’t being performed by a family member? And the question being grappled with is: When you have a third of the budget being consumed by 8 percent of the population, how do you free up those dollars? And one of the ways to do that is to close a facility -- by doing that.

And I think that the questions posed about how do we do that, how do we make that determination so we make the right determination in the right way, is a valid one that we’re going to have struggle with here. Because it’s an important question on a more important issue, which is aging parents who are now doing the work that is going to have to be done within a community setting by the State.

MR. YORK: No -- and I think I understand now. I just meant -- and I’m talking more on the individual basis; that individuals do not get served in the community, usually, for cheaper. Now, do you have an unusual circumstance so I’ll qualify my answer a little bit? And if this is what Mr. Assemblyman Greenwald was referring to, this might be true of a situation. For example: There are situations where the DOJ has forced the downsizing of a facility to 50 people. At some point it does become -- because the overhead is so great, and now it becomes so heavy to carry those few people -- so few people at that facility that, maybe, in a sense of saving money by closing one facility, you could save some money.

SENATOR VAN DREW: Mr. York, that’s a good point. And I think that’s where we can possibly do some work as well, along those lines.
And real quickly, and then we’re done. You know, yes, they do use, percentage-wise, more resources in the developmental centers. If you were to look at a hospital, I’m sure that a cardiac intensive care unit, percentage-wise, uses more resources than, I don’t know, general admission or the pediatric unit or whatever. The people in there, again remember, some of them are pretty sick and need a lot of care.

I thank you so much. It was wonderful testimony. And thank you for being here.

MR. YORK: I really appreciate it; thank you. Thank you for the opportunity to speak to you all.

SENATOR VAN DREW: I’m sure we’re going to call you again.

MR. YORK: Thank you.

SENATOR VAN DREW: With that, from an entire other viewpoint, is Mr. Thomas Baffuto, the Executive Director of The Arc. And he doesn’t have his “Close Vineland” T-shirt on today. Good, Tom; I’m not going to get cranky. (laughter)

Thank you for being here.

THOMAS BAFFUTO: Good morning. Thank you, Senator Van Drew, Assemblywoman Huttle, for the opportunity to testify today.

Being from Bergen County, it’s always a good Monday after the Giants win, so it’s a good Monday today. (laughter) And I’m happy to be here to talk about this issue and chat a little bit about developmental centers. I appreciate the dialogue around this issue. It’s long overdue, and I think it’s been a very productive dialogue around it.
The Arc of New Jersey believes that all individuals with intellectual and other developmental disabilities have the right to live and be fully included in the communities of their choosing. For over 30 years there has been a clear direction in Federal and State policy towards community living for people with intellectual and other developmental disabilities.

While the majority of the states are actively discussing how and when to close developmental centers and promoting individuals’ rights to live in the least-restrictive environment, New Jersey continues to debate if developmental centers should close at all. In the meantime -- and I think this is significant -- we continue to institutionalize more people with intellectual and other developmental disabilities than every other state besides Texas. Eleven other states have eliminated their institutions altogether, while another 11 states have only one institution and 27 states plan to close or downsize their existing state institutions now.

Developmental centers were created in the 1800s to treat individuals with intellectual and other developmental disabilities at a time when no services were available and families didn’t have choices. At that time they were considered state-of-the-art. There were no other options for families.

But many things have changed over the course of 50 years, and we now have a wide range of supports and services available to people with intellectual and other developmental disabilities. And current best practice is community-based supports and services that allow individuals with intellectual and other developmental disabilities to be connected and
contributing members of their communities in the most integrated settings possible.

In this day and age it is widely accepted that institutions force an unnatural, isolated, and regimented lifestyle that is neither appropriate nor necessary. Studies have shown community living increases the quality of life for people with intellectual disabilities, and certainly having people with intellectual and other developmental disabilities in our community creates better societies as a whole.

The Americans with Disabilities Act of 1990 stated that, “historically, society has tended to isolate and segregate individuals with disabilities and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive problem.” Title II regulations under section 504 of the Rehabilitation Act require that public entities administer services, programs, and activities in the most integrated settings appropriate to the needs of the qualified individuals with disabilities, and define most integrated settings as one that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.

And in 1999 in the Olmstead case, the Supreme Court stated that “confinement to an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

We know that currently the U.S. Department of Justice is stepping up their enforcement of these efforts, and we believe that New Jersey must begin to take the civil rights of people with intellectual
disabilities seriously. Civil rights are a sacred benefit afforded all citizens of the United States, including people with disabilities.

While New Jersey has made some effort to change the way supports and services are provided to people with intellectual and other developmental disabilities, there has not yet been a true philosophical or fiscal commitment to eliminate State-operated institutions. Individuals on the State waiting list for services do not want or are not requesting institutions. Most people and their families are choosing community-based supports and services, leaving our State institutions well below their capacity. While the census of our seven institutions declines, per diem costs rise dramatically. As we continue to reduce our institutional census, we must consolidate our institutions. We simply do not need seven large institutions anymore.

The time for change is long overdue, and we need to move beyond the discussion of if and on to the discussion of how to close developmental centers. The issue isn’t can we do it -- we know we can, we’ve done it before and we’re doing it right now -- we’re moving folks out of the developmental centers very successfully. To that end, The Arc of New Jersey recommends that the State consider some of the following processes of institutional closure. And I lay a lot of this out in my regular testimony which I won’t go through, but we do agree with Senator Van Drew that we need a long-term plan and we need to look at how we’re going to address the closure of developmental centers.

The Arc of New Jersey believes we should close two over the next four years, followed by one center closure every three years until five
have been closed. Two centers will be remain open for folks who choose that or it is determined that they need that kind of a setting.

A planned order of developmental center closure based on, at least in part, of the age and the condition of the structure. At the very least, if we’re not discussing what costs more or what costs less, we know we can save money on facility costs and that money can be invested in supports and services in the community.

We need a bridge fund as we’re closing these -- that has been identified.

We certainly need individual plans for each developmental center, and a system -- a good system -- to evaluate each closure.

We need well-planned and targeted placements for individuals currently living in developmental centers. It should be noted that folks moving out of developmental centers are not moving into boarding houses. For the most part they’re moving into very highly regulated, licensed group homes or supported apartments in the community.

We agree there needs to be clear communication with and involvement of the families. Their concerns and their issues need to be addressed.

We need to assist developmental center staff in the transition as we’re looking at closure of developmental centers.

And I think it’s been said well: We need to examine and monitor the community infrastructure. Look where we need to improve some of infrastructure, and use some of the money -- as we save some money on just the physical plant, we can invest that in some of the infrastructure needs.
And certainly we need to reinvest any savings from the closure of developmental centers back into the community -- that is going to be absolutely important as we move forward.

We have a great opportunity to enhance our service system, making community-based supports and services better for everyone and preparing ourselves for future growth. This is our chance to take New Jersey from having one of the highest rates of institutionalization in the country to becoming leaders in the quality and cost-effectiveness of our services, while at the same time championing the human and civil rights of people with intellectual disabilities.

Thank you for the opportunity to speak to you today about this very important issue.

SENATOR VAN DREW: Thank you, Tom, and I appreciate you being here.

Governor Codey.

SENATOR CODEY: Yes, Tom, let me ask you this: What’s the waiting list now?

MR. BAFFUTO: You know, the waiting list is over 8,000 people.

SENATOR CODEY: Okay, so if I have a son or a daughter who is developmentally disabled, and I put them on the list today, what would you estimate the time before they got a placement?

MR. BAFFUTO: It would be a long time -- upwards of 10 years, maybe longer.

SENATOR CODEY: Okay, so we don’t have the beds right now -- the rooms -- whatever you want to call it.
MR. BAFFUTO: Right now we don’t.

SENATOR CODEY: Okay. The other thing you mentioned, which is very fitting, is how a developmentally disabled person is let out of the institution and into the community; and the setting is so different than the person -- if he or she were mentally ill. They go to a nice suburban setting, with a good staff, in a nice home. But the people who I’m talking about, the mentally ill -- because they’re mentally ill and there’s a stigma against mental illness -- they go to places that myself and Assemblywoman Tucker visit all the time, which are hell holes. So there’s a big and huge difference between the treatment and the placement of the developmentally disabled people and people who are mentally ill. And because of the stigma of mental illness, it’s almost like it’s all right to be developmentally disabled, but it’s not alright to be mentally ill -- because they’re two totally and distinct different groups of people who are treated so different. It’s pathetic -- pathetic.

I know you’re in the business of group homes, correct?

MR. BAFFUTO: Well, we’re in the advocacy business, but I don’t know--

SENATOR CODEY: I know, but you do do group homes though.

MR. BAFFUTO: Our chapters do, along with well over a hundred other service providers, yes. And those group homes, as I said, are highly regulated, licensed by the State.

SENATOR CODEY: You know the other thing, Tom, is-- And I don’t know about other legislators, but when we started group homes -- and I was involved in the first bond stuff and it was done bipartisan. But as
soon as the community would know that there was going to be group home, you would get all these calls, they’re all enraged, “You can’t allow it on our block.” I don’t remember when the last time I got a phone call complaining about the placement of a group home. Now all those fears seem to have evaporated -- which is good, because they learn not only are they not a detriment, they’re good neighbors.

MR. BAFFUTO: Absolutely.

SENATOR CODEY: Good people.

MR. BAFFUTO: I agree with that.

SENATOR VAN DREW: Thank you, Governor.

And I agree with both of you on that, and that’s why I’ve not -- as you know, until this latest issue -- have not been opposed to what they do. In fact, (indiscernible) he’s heard this story ad nauseum: halfway down the block from where I live; and my township, when I was Mayor, we welcomed you; you have other ones in our township. And it started out that way. When I was the Mayor, we had big town meetings, and people came and asked, “what’s going to happen,” and I-- “Everybody cool down; it’s going to be fine.” And you’re precisely right: We have zero complaints -- zero complaints about them. Quite frankly, I like some of them better than some of the other neighbors, you know? So I mean, they do a wonderful job and we’re glad to have them.

SENATOR CODEY: Which neighbors do you dislike?

(laughter)

SENATOR VAN DREW: Actually, you know what? I’m out in the middle of-- You’ve been to my house; there aren’t many neighbors around where I am. I’m in the middle of the woods.
MR. BAFFUTO: You know, I think that speaks volumes to the quality of services that our community providers are providing to folks with intellectual disabilities in the community. You know the services are good; the homes are well-maintained and kept up. So I think that speaks volumes of our service delivery system.

SENATOR VAN DREW: And it does, Tom. The issue here is not saying that we can’t do this at all; it’s to do it right, and it’s to do it at the right places, the right way. It can’t be done arbitrarily. And to do it right is not an easy task -- that’s the real issue at hand.

SENATOR CODEY: (Indiscernible)

SENATOR VAN DREW: Governor.

SENATOR CODEY: I do believe, however, that we’d still and always need State institutions for these people.

SENATOR VAN DREW: Absolutely.

SENATOR CODEY: I just want to make that clear.

SENATOR VAN DREW: There’s no question.

Yes.

ASSEMBLYWOMAN ANGELINI: Thank you.

SENATOR VAN DREW: Assemblywoman Angelini.

ASSEMBLYWOMAN ANGELINI: A comment to Governor Codey.

SENATOR CODEY: Yes.

ASSEMBLYWOMAN ANGELINI: I am very concerned, and I have a question for Tom. I’m speaking as someone who worked with the severely mentally ill for a number of years as we went through the deinstitutionalization of Marlboro -- as you’re very well aware of.
SENATOR CODEY: I’m a former employee. (laughter)

ASSEMBLYWOMAN ANGELINI: I know -- you put us on the map. Thank you for your advocacy on that.

But I feel like I have to wear my advocate hat for those people who are working with the mentally ill, and I’m very worried about the agencies that you keep referencing that are hell holes. We need to make sure that we’re on top of that.

SENATOR CODEY: You know, anytime you want, speak to the woman on your left and you can come and see them.

ASSEMBLYWOMAN ANGELINI: Well, and how they’re funded. And that’s not to get— But, seriously, that truly concerns me as someone who has worked with that population; it’s very dear to my heart.

SENATOR CODEY: You do have, down in Ocean County, one or two hell holes.

ASSEMBLYWOMAN ANGELINI: Well, we’ll talk offline. But thank you for your work in that area.

Tom, Senator Van Drew had mentioned that the issue, particularly around Vineland in that particular geographic part of the state, is that there are-- We’re very lacking in services -- community services -- in that part of the state. How would you remedy that in a particular area where there aren’t community services?

MR. BAFFUTO: Well, I think there are nonprofit agencies willing to provide services throughout the state. But I think to Senator Van Drew’s point: We need to get a clear picture of where people want to go, and I think they’re trying to do that with the residents of Vineland Developmental Center. So give geographic preferences, give preferences as
to their friends in the institution they want to live with -- so we know where we have look at the infrastructure, where we need to beef it up, where we need those supports and services. And then I think we could address it.

You know, I think there are needs around dental care and medical care that we can address once we know where the population is going to be moving to.

SENATOR VAN DREW: Thank you, Assemblywoman.

And again, that’s why I point out we need a system, we need to look at-- And you agree, actually; you said in your opening statement we need to look at the global picture, statewide, on what we’re doing as a system, statewide. Because, quite frankly, there are many folks in other parts of the state who say to me, “Gee, Vineland is not the place that should have been chosen.” Even people who are advocates for closing facilities did not think that that was a place that should be closed.

MR. BAFFUTO: Senator, just as a comment, though.

I think one of the traps we’re falling into is we’re spending a lot of time talking about it, planning about it and, I daresay, if it wasn’t for Assemblyman Greenwald we wouldn’t even be talking about closure at this particular point. We’ve moved 1,200 folks out of developmental centers and haven’t reduced the number of institutions. So if we keep talking and planning and not looking at closure, I think we’re going to be very shortsighted as we move forward.

SENATOR VAN DREW: Tom, Tom, I get your point, believe me, and I understand Assemblyman Greenwald’s work. There’s the big guy, too, in the Executive Branch; he’s pushing pretty hard. And if you’re familiar with the other legislation, it’s not just, “Well, we’re going to talk
about it,” it’s binding -- the results of that. Something is going to happen, whether we agree with it or not. We’re trying to make sure it’s done in the most fair, equitable, decent, humane way possible -- but it’s not just talk.

Yes, Co-Chair.

ASSEMBLYWOMAN VAINIERI HUTTLE: Tom, I apologize. I was outside -- I had an emergency, but I did-- I know what you’ve said; I’ve heard your testimony numerous times, so I do thank you for coming.

I do have a couple of questions. You plan to -- or you said you’ve moved how many people out of the centers?

MR. BAFFUTO: Well, since the last closure in 1998 we’ve moved over 1,200 folks into the community.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Here’s what I was going to ask Mr. York before, but I’ll ask you: Is it -- I don’t want to say cultural or generational -- but do the folks in the centers now-- They have, I guess, aging parents, correct?

MR. BAFFUTO: Yes.

ASSEMBLYWOMAN VAINIERI HUTTLE: And the culture of some of those parents -- they feel very secure that the State is providing that security for their loved ones. It may be a different generation coming up, with younger parents and they have a younger children that, right now, they’re able to have their families in their home or in a group home or a least-restrictive environment. My question is this: If we go full circle, and those younger members of the group homes or in-homes -- is now those parents start to age and they start to age out, would it be full circle in having that same -- I don’t want to say it’s a culture or a generational philosophy -- but do you think that philosophy will change again? If I’m a
parent and now I’m in my 80s, and I feel that, well you know what, the best security would be a center because I know the State will never go bankrupt -- well, I shouldn’t say that; but I know that the State will provide that care when I’m gone and my child is now aging out.

Do you think -- and I know this is totally off from what -- I don’t know if this has ever been even thought about -- but I know today the philosophy is least restrictive, and I’ve spoken with younger parents -- they want their child home with them; they want their child in a group home, or whatever. But as they get older, they age out and, again, one size does not fit all, as we know, and some people really need the skilled attention or feel more comfortable in a center. Again, it goes-- I say the word choice; you need the word choice -- when it goes to that word again, do you think it could go full circle as we age out, as parents, and the children start to age; do you think we’ll still, then, continue to have that need for a center?

MR. BAFFUTO: You know, at this point, The Arc believes in choice. And if families want to keep their son or daughter in developmental centers, we think they should. I don’t think it’s going to come full circle where people now living in the community are going to want a developmental centers. I mean, we’ve had 50 years that we’ve been looking at this, and I think 50 years gives us a good picture that people are not requesting those kinds of services. In addition to that, we recognize that people living in the community are getting older; we’re adapting the service delivery system in the community -- making homes accessible, finding ways to deal with our consumers who are getting older in the community.

I don’t think that’s going to happen; we have nothing to show us over the last 50 years that that will occur. And I think we can adapt the
community to accommodate folks. I mean, right now we have folks with very significant medical needs and supports living in the community; very significant behavioral needs living in the community. So I think we can deliver those services. And my personal opinion -- I don’t see us going full circle back to that again.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Assemblyman Greenwald.

ASSEMBLYMAN GREENWALD: Tom -- Valerie, I think, raised a very interesting argument on the generational, and I think it is generational because there has been generations of families who have seen State government fail at this mechanism. And I think it comes down to, as I said before, it’s a consumer choice issue. As a consumer, as a parent, when I see my children’s friends taking advantage of educational opportunities, whatever it may be -- you want to mirror and pattern those behaviors for your kids.

I don’t think this is any different as a parent of a child with disabilities. So if we can create a system in the community where the quality of care is top-notch, and there’s preventative medicine, and they are succeeding, then I think that next generation will be very comfortable with that setting.

It’s going to take a generation to get there, maybe to the point--And I don’t think you’ll ever close all the DCs. One of the things that I’ve argued is, if you could whittle them down from seven to two, you could create a state-of-the-art developmental center for the most high-risk healthcare conditions where they are really in need for a hospital-type
setting, but created in that type of setting for quality of life or late-stage quality of life.

But to the point-- I was interested as well in your comment that we’ve moved over 1,200 people into the community. How have you done that, and your cooperation with the State and the families to ensure -- and maybe we haven’t, but you’ll tell me if we have -- ensure equal or better quality of health care in those residences? In your mind, is it equal or better? And, if it is, how have we done that?

MR. BAFFUTO: Well, I think it is equal or better. Smaller homes in the community, having folks become part of their community -- The Arc thinks is better. No one leaves a developmental center without a very, very thought-out plan. Everyone has an individual service plan that clearly looks at a person’s needs, looks at the supports they’re going to need, and matches them up to a place in the community where those needs can be met and a person can live, you know, a quality of life, integrated into their community.

So I think the crux of it is the plan -- they have a case manager following them, making sure their plan is implemented. Typically they’re in group homes -- occasionally a supervised apartment. But again, those are monitored, those are licensed, and we’re-- You know, I’d be hard-pressed to say every single person was a success; the majority have been. It has been a smooth system. And in addition to that, we did some studies -- or the State did some studies -- looking at people when we closed North Princeton Developmental Center. And at the end of the day, the measurements they made, people agreed they had a better quality of life in the community.
Even those folks who didn’t want their sons or daughters to move out, once they were in the community they agree it was a better place for them.

So it’s well-planned and it’s well-monitored in the community.

ASSEMBLYMAN GREENWALD: And you know, Tom, I think we all have fear of the unknown, and I think that is a big part of-- I may not love what I have, but it seems safe, it’s okay, and where am I going to go and what’s it going to be? So I think the more examples that you have where there are those successful stories, the better it will be.

And there are going to be tragedies. There are going to be-- It’s not going to be perfect, because every healthcare-- I don’t care where you are, I don’t care what hospital you’re in, I don’t care what pediatrician you go to, every situation has a hiccup where it is not perfect. And so we have to be careful in the DCs and in the residential community not to point to the one and say, “Aha.” It really is about that choice and getting that comfort level for people.

And then my last question for you would be: There is a Federal program -- and I don’t know if my colleagues are aware of it; maybe you can explain it if you’re aware -- there is a budgetary issue here, and while this is not, to me, about saving money, it is preserving this revenue and serving as many as possible. But we have left money on the table at the Federal level where we could be enhancing this budget and serving more. And I think that program only has three years left. So Tom--

MR. BAFFUTO: Well, it’s called Money Follows the Person, which gives you additional Federal Medicaid dollars if you move folks out of the institutions into the community. They’ll give you more money to make that transition to help address some of those costs. And, in fact, we
have left money on the table. You know, we could have been drawing down more of that Federal revenue if we moved more folks out of developmental centers into the community.

ASSEMBLYMAN GREENWALD: And not spending any more of our State revenues -- spending the same amount and getting more.

MR. BAFFUTO: That’s correct.

ASSEMBLYMAN GREENWALD: Is that money sustainable?

MR. BAFFUTO: You know, I don’t know as much about that program. There may be another speaker coming up behind me who I think can address that in more detail.

ASSEMBLYMAN GREENWALD: Okay.

MR. BAFFUTO: So I think you’d get better--

The other thing I will say on your point, Assemblyman, we, along with many community providers -- The Arc is having an open house for families who have sons or daughters living in developmental centers. We’re opening our doors -- come on in, see; see what community living is all about. So whether it’s a chapter of The Arc or the many other good providers in the community, we’re opening our doors in November. We want people to come in and look so they can make informed choices.

You know, you’ve been out to group homes; many of the folks here have been. We want them to see, also, what options are available in the community.

ASSEMBLYWOMAN VAINIERI HUTTLE: Tom, just a quick follow-up. You said you’ve moved 1,200 out since when?

ASSEMBLYMAN GREENWALD: Nineteen ninety-eight.

MR. BAFFUTO: Nineteen ninety-eight.
ASSEMBLYWOMAN VAINIERI HUTTLE: And we have, I think, what -- out of Vineland right now -- maybe 70, a handful? I don’t know how many are moving out. If a center was to close, and let’s say you had 250, would you be able to move them out in an expeditious way into a community? Where are you going to find these-- Where are the homes? Are they being built at need? Are they being built pre-need?

MR. BAFFUTO: Well, that’s a great question. Right now we’re in the throes of great development for group homes. Many beds in group homes are being developed as we speak. Certainly there have been partnerships with the Department of Community Affairs; we have some vacancies in the system. So at this particular point -- yes, we are ready, we can move folks out to the community and, in fact, they’re putting homes online now in preparation for these.

I think as we move forward we really have to take a look at those resources; take a good, hard look at what our current capacity is and, again, through good planning, what are our future needs going to be? So now we’re ready; as we move forward, we need to plan.

SENIOR VAN DREW: And those folks being moved out would be given priority over those folks who are currently waiting?

MR. BAFFUTO: You know, I don’t know that it’s a priority. I think we are addressing both at the same time -- certainly the waiting list is at a very low level. But again, we have to say to ourselves--

SENIOR VAN DREW: So let me just go -- I want to be make that point.

MR. BAFFUTO: Yes.
SENATOR VAN DREW: The waiting list would be at a very low level because we have the folks who are in the developmental centers and they just can’t be moved into somebody’s house somewhere without—Because you know, Tom, you’ve been in those facilities. They need a lot of care.

MR. BAFFUTO: Absolutely.

SENATOR VAN DREW: Right, so they would get priority, obviously.

MR. BAFFUTO: You know, they—Again, it’s a planning process. We’re moving $X$ number of folks out of developmental centers, $X$ number of folks off of the waiting list.

SENATOR VAN DREW: So if we’re going to move that many people off the waiting list and out of developmental centers at once, we’ve got to have a whole lot of dough here. I mean, we’re going to be spending a lot of money and building a lot of facilities.

MR. BAFFUTO: Yes, but I think—

SENATOR VAN DREW: Okay, that’s good.

MR. BAFFUTO: --though, Senator, that there’s a lot of— You know, they estimate that they can save $30 million by the closure of Vineland Developmental Center. Now, even if it’s half that, that’s money we can invest, move folks off of the waiting list. We have resources out there, resources that we have to look at. I think we’d be short-sighted in not looking where we have some extra dollars to address the waiting list, to address community infrastructure needs.

SENATOR VAN DREW: Okay. One of the concerns of some folks is that we could move them out of developmental centers -- and again,
I'm not saying that process should not exist -- but move them out of the developmental centers, lose those jobs, put some of them in the community, build some of the housing they need, still have the problems with the waiting list, and still have the problems within the community with those folks who have actually lost employment. And I don’t want to have a debate about it, but I just want you to understand that concern.


ASSEMBLYWOMAN TUCKER: Yes, one of my concerns is the mixed population. When you move someone into a developmental center, do you segregate by age -- how they’re placed in the centers? Do you have special centers for senior citizens or the youth population? How do you address those needs?

MR. BAFFUTO: Well, moving folks from developmental centers into the community, all of those demographics are looked at. First of all, they’re asking folks where they want to live; presumably, we get folks as close to their families living in the community as possible. Then they’re looking at who do you want to live with? If you’ve lived in a developmental center for 10 years, 20 years, and you’ve developed friends, then we’re trying to put plans together to keep friends together. Then the next would be folks requesting to move into the community; providers would look at who wants to come out and where the best fit would be. So clearly if you have a group home with folks who are a little older, you’re not going to put someone very young into that group home. It’s very carefully planned on how folks are moving out and into what settings they’re moving into. If someone needs accessible housing, you know clearly those kinds of things have to be taken into consideration.
ASSEMBLYWOMAN TUCKER: Okay, the only other question I had was the wages. What are the wages a person who operates the group home pays their employees versus the people who work for the institution, and what benefits? Do you have the same type of benefits? Will they have medical benefits, and what kind of benefits would the workers have?

MR. BAFFUTO: You know, clearly the wages and benefits are not on the same level as the State; I think that’s been well-debated and that is true. So folks working in the community are going to get less hourly wage. While many, many of the providers offer health benefits, they’re not on the level of the State. And yet we’re able to attract and recruit a good workforce and provide quality services. We would love to see that gap closed, and I hope we would work with the folks around this table to close that gap, get wages increased, get benefits increased. I think that would be a great thing we could work on.

ASSEMBLYWOMAN TUCKER: Well, do you have any plans, if we close Vineland and other institutions, to take the employees that already have experience, that have been working, rather than recruit new employees?

MR. BAFFUTO: Oh, clearly that would be the preference. I mean, these are folks who have been providing good quality care, know the residents in the developmental centers. We would open our doors and hope they would come and work with the consumers. As a matter of fact, there are job fairs planned; there are ways we’re trying to connect folks who, potentially, could lose a job with available opportunities in the community.
ASSEMBLYWOMAN TUCKER: And with that, do you plan--
With the moving, your revenue would increase so, therefore, then the
salaries and the benefits should increase for the people who are working in a
group home, right?

MR. BAFFUTO: Well, I don’t know that. Unless we develop a
plan to work on that, it’s not going to be a natural that just because folks
are moving into the group home that wages are going to increase. You
know, those are basically cost (indiscernible) contracts.

ASSEMBLYWOMAN TUCKER: Well, I know you’re in the
business of making money, but in the meantime we still have to make sure
that the employees have proper wages and good benefits, right?

MR. BAFFUTO: I couldn’t agree with you more.

ASSEMBLYWOMAN TUCKER: Okay, thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: You know, that
leads to the-- I don’t know if it was asked before, but Mr. York said it’s not
cheaper in the community. I don’t know if anyone asked you if you could
counter that. Is it cheaper or is it not cheaper in the community?

MR. BAFFUTO: You know, I wouldn’t say the cost of care is
cheaper in the community. I think it’s close, maybe slightly cheaper, but
let’s just say for the example it probably is not. You have outliers in the
developmental centers costing more; outliers in the community. But I think
where we have the ability to save, and where we have the ability to grab
some dollars and reinvest in the community, is in the capital of these large,
aging developmental centers. So if we’re looking at just cost of care, I don’t
think we make the argument that it’s any cheaper. I just think it’s a better
quality of life for folks.
ASSEMBLYWOMAN VAINIERI HUTTLE: Back to the capital in the centers: I mean, I think -- is it North Princeton, right? It’s still there; I don’t know what the plan is, of course, when it’s going to be closed. These centers need-- There needs to be a plan for a center, whether it’s going to be -- for the State as well, because North Princeton is still sitting there. And I’ve travelled to these centers and they are wonderful campus-like facilities: a lot of acres, a lot of land, and a lot of potential. And I don’t know what else could be placed there at that point, but that’s part of the discussion as well.

MR. BAFFUTO: Yes.

ASSEMBLYWOMAN VAINIERI HUTTLE: Are there any other questions for Tom? (no response)

Thank you very much.

MR. BAFFUTO: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Next we have Nancy Thaler, Executive Director, National Association of State Directors of Developmental Disability Services.

Nancy, thank you for coming and welcome.

NANCY THALER: Thank you.

And to both Senator Van Drew and Assemblywoman Huttle, thank you for the opportunity to speak today.

I hope that you have in front of you written testimony; that we brought enough copies for everyone. And I’ll refer to some charts.

So just by way of introduction: I’m the Executive Director of the National Association -- of which the New Jersey DD agency is a member -- that 50 states’ and the District of Columbia’s directors of
developmental disabilities are members of the Association. And our mission is, as with all associations, to keep our members informed about what’s going on in the Federal government, and what to expect, and what opportunities there are; to disseminate information to them on state-of-the-art programs, to provide technical assistance, and we offer a forum for the state agencies to share information with each other about best- and promising practices.

Just a bit about myself: I’ve been in the field since 1971, and in my early years was what is now called a direct care worker. I worked as a house parent and I worked in institutions, and I spent another eight years in agency administration. For 10 years I was the Director of Developmental Disabilities in the state of Pennsylvania, appointed by, first, Governor Casey, and then Governor Tom Ridge. And prior to coming to the National Association here, I worked at the Center for Medicare and Medicaid Services for about three-and-a-half years.

So to talk about New Jersey and what is happening nationally, I think the reason I was asked to come was to talk about what’s going on across the country. So let me give you a summary.

States have been rebalancing their developmental disabilities systems for the last 40 years and have made a lot of progress. At the height of our census in institutions in this country -- in 1967 -- there were about a quarter of a million people; and today there are about 33,000. So that’s a significant drop -- 85 percent drop -- over those years.

Today we have 10 states and the District of Columbia with no institutions, and Alabama is about to join that list with the closure of
Partlow. And we have 16 states that have less than 250 people in their facilities.

Most of the people in institutions -- most of 33,000 people -- are in about 10 states. With over 2,700 residents in the New Jersey facilities, New Jersey ranks second just behind Texas in the total number of people in institutions. But another way to look at it is: How many people per 100,000 of population are in institutions? And, in that case, New Jersey ranks third, just behind Mississippi and Arkansas. So New Jersey has, in terms of the national picture, a fairly high rate of institutional services.

There is a another way to look at-- There are many, many ways to look at the data, and I should say to you that the data that I reference comes from two sources, both of them funded by the Federal government and both of them longitudinal 20-year projects. One is *The State of the States*; it’s done by the Coleman Institute of the University of Colorado. And the other is called *Residential Services for Persons with Developmental Disabilities: Trends and Patterns* (*sic*), and that’s a publication that comes out annually, also funded by the Federal Administration of Developmental Disabilities. And these two data sources have become the basis for how states compare what they do.

The imbalance-- A report was developed here for the DD Council using the same data set, and I’ve heard some comparisons about how much money is spent in institutions based on how many people. In their study they found that about 22 percent of the people getting services in New Jersey were allocated about 56 percent of the funding. So I think earlier people said about a third of the people were getting -- if I remember
-- 80 percent of the funding; I’m not sure what the quote was. But, nevertheless, obviously different pictures come up with the same story. And while not everyone costs the same, there is meaning to that disproportionate ratio. On a national basis, where there are institutions you generally find that about 15 percent of the individuals are using 35 percent of the resources. So wherever there are institutions in a state, you’re going to find this disproportionate balance.

But what’s been driving this incredible change in transformation across the country -- and there have been many, many factors over the last four or five decades. One is, early on, parents and advocates who were dissatisfied with the conditions in institutions and fought to close them -- reform them, and then close them. Willowbrook, Pennhurst, Partlow -- there has been a number of those.

I think the next big thing was the right to education, in 1975, because what the right to education did was make it possible for every single child to go to school. So parents who were looking at decades of taking care of a son or daughter at home now look forward to their son or daughter going to school like everybody else. And when they went to school, the expectation was they learned -- and they did; and pretty soon they’d come of age as adults, and why would you think about putting someone away who spent their entire life, up to that point, in the community going to school? So that fact, that children could go to school, I think changed parent expectations and experiences.

The rise of the nonprofit sector, like Tom’s association, has been robust and very progressive in the states. Most recently, the passage of the ADA; and then the Olmstead decision in 1999, which reinforced the
right to, not the least-restrictive setting but -- I think the words are -- the *most-integrated* setting. So anyone who wants the most integrated setting, the state was obliged to make those services available.

The other thing that's been driving this change over the years are lawsuits by the Department of Justice and protection advocacy that have made these facilities expensive as remedies were put into place. They got a lot of bad press, and states often both downsized and closed. Most recently, the state of Georgia has negotiated the settlement agreement with the Department of Justice to close all of its facilities, serving 700 people.

The other thing, and this is maybe the most powerful, is the money. In 1982, when Congress adopted the Medicaid Home and Community-Based waiver option in the Medicaid statute, it made, for the first time, money that used to fund institutions available in the community -- thus called the waiver. You waived institutional regulations so that you could use up some of the money in the community. And I would say there was an explosion of the use of the Medicaid waiver across the country in DD programs. We became the biggest users of Medicaid waiver money. But since then, many more things have been amended to the Medicaid statute. A state option called 1915(i), one called 1915(k), one called the Community First Choice -- these are all new state plans that incentivize states to develop home and community-based services.

You mentioned Money Follows the Person. New Jersey is a recipient of Money Follows the Person. This is money clearly to entice states to move people out of institutions. And what that money does is, basically, pay 100 percent of the cost in the first year of transition so that states don’t have the burden of the bridge money and developing services.
Most recently, just within the last two weeks, CMS announced the State Balancing Incentive Payment Program, which makes $3 billion available to states whose utilization of the community is less than 50 percent, and it allows them to earn an extra 2 percent on all their home- and community-based services if they agree to move in the direction of rebalancing their system beyond 50/50.

And lastly, the Federal Coordinated Healthcare Office has funded 15 states to develop and test programs to coordinate care. From the Federal government’s point of view, this is not about developmental disabilities, it’s about long-term care. And people are coming to realize that reliance on institutions -- whether they’re hospitals, nursing homes, or ICF/MRs -- which are what our institutions are -- regardless of what the model, they’re unsustainable as a primary mode of service. And so there have been, over the last 15 years, multiple Federal initiatives to get states to rebalance out of nursing homes and out of ICF/MR, and into home- and community-based services.

Lastly, people are -- not lastly, but next -- is the new generation of families, which people have spoken about.

But I also want to talk about the cost of institutional services and the concerns about system sustainability. The current economic crisis is forcing states to think about long-term sustainability; what do we build and how long is it going to be affordable in future generations? And so as they look at the average cost per person -- and if you have my testimony, on page 7 I have a couple of charts. The charts I have in the testimony are based on a study done by Dr. Lakin out of the University of Minnesota. And they show an average cost in a study he did in four states on
institution, group home, host family -- which is sort of like foster care -- and one’s own family. And in the four states using Medicaid data -- not just DD data -- so all the costs of general acute care, outpatient, all those things are all in there. There’s a pretty stark difference across these services. Though I would amend this chart. The per diems in the New Jersey facilities are, by the last publication -- the 2009 RISP Report -- the per diem is quoted, and it’s New Jersey’s data, is quoted at $265 (sic) a day, which is about $250,000 a year. That puts New Jersey at the very high end of cost of institutions. On the average, nationally, the per diem is $539 -- as compared to $685 -- under $200,000 a year. So if you were to replace New Jersey’s numbers in this chart, I would suggest the same thing will play out, probably with greater variance.

And so the question is, from a state budget point of view: Where do we get the most people served for the money? And this is, quite frankly, what people say is a no-brainer. But states are not looking at this kind of analysis to discuss whether or not institutions or community; they’re looking at it as an incentive to make robust services available to families, to enable them to serve their sons and daughters as long as possible and avoid the out-of-home service of any kind because it’s so expensive.

And this discussion and trend is even more true in aging services. Because we simply cannot afford $75,000 a bed in a nursing home, the incentives are being put in place to make it okay, possible, even joyful for family members to support their sons and daughters at home.

And I think that the ramifications in this population are more significant than the aging population. And the aging population, when it enters an institution, the length of stay is 18 to 24 months. When our
people enter any kind of service, it’s 50 years or 60 years. And so the decision we make early on has significant long-term ramifications. So if you make a decision you’re going to invest in families, your long-term care costs over 30 or 40 years are going to be significantly different than if you invite people to do out-of-home services.

So this concern about building systems that are sustainable over time is not only driving states to move out of institutions that they operate, but it’s driving them to expand significantly services to people in their own homes and to lessen the reliance on 24-hour services.

In terms of cost -- this is not in my testimony, but there were a lot of questions and comments before this -- person-to-person, it’s difficult to talk about, “is it more or less in the community?” And that’s actually not the way to think about it, because in the institutions, as Tom said, costs vary. There are people who live in an institution who can do a one-to-eight ratio -- that is one staff person to eight residents. But there are some people who are one-on-one. So even within the institution the costs vary. That’s true in the community, too. There are people who need little support; there are people who need a lot of support. And that’s transient over time -- it changes over time. But what is true is the aggregate. On the aggregate, if you have a thousand people in the institution, the overall average cost will be greater than the cost of that same group of people in the community. And I would suggest, while I haven’t done an in-depth study of the budget for your DD agency, at an average cost of $250,000 a person -- one of the highest in the country -- I would be surprised if it would cost that much to serve that exact same population in the community. Most likely not, but again you would have to look at the data to do that.
And so why move people out, other than we believe it’s good and better for them? Well, one of the other reasons is that in New Jersey you are losing population in your State institutions every year. Even though you admit that 60 or 70 people a year, more people are dying and getting discharged every year. So your census is going down even if you do nothing. And as the census goes down, the costs per person go up. And they go up because nobody wants to move into the beds. And so they will both get more expensive. But as you move people out -- and you have in the past -- you are building capacity in the community, not just for the people who are moving out, but now the people on the waiting list have an option. When those individuals die, hopefully of old age -- at a very old age -- you now have capacity for people on the waiting list, which is something that you don’t have in the State facilities. And, again, it’s -- having explained how many states are moving away from -- and have been for 40 years -- moving away from facilities, these are some of the drivers.

In regard to quality: I won’t bore you, but our National Association, in conjunction with the universities across this country -- university-affiliated facilities, of which you have one at Rutgers -- did a meta-study of all the studies, because this question comes up over and over and over again. So we published a meta-study built on 36 studies that are solid and evidence-based -- over 5,000 people -- and overwhelmingly, in every facet we look at, people do better in the community: skill development, language, communication, personal care skills, building relationships -- across the board, they simply do better. And for those who have spent their life helping people move, they know that from experience.
There are challenges that remain. The restricted availability of State funding, again hopefully compensated some with the new Federal initiatives and Money Follows the Person -- the balancing initiative. Probably the two biggest factors are opposition from employees and opposition from families -- both emotional, challenging, and difficult. In regard to employees, people who particularly have spent their lives caring for people, and who are really wonderful people and do a wonderful job. And I think Assemblyman Greenwald said this: We don’t create services so that people can have jobs. It’s a wonderful byproduct, because it creates employment -- good employment. But we first need to think about the interests of the people living in the institutions and what’s good for them, and also think about what’s good for their employees. And they need to be respected and accounted for. States have used a myriad of strategies -- usually multiple strategies. Things like guaranteeing employment in other State operations; if the facility closed over several years, retirements and sometimes increased retirement packages; retraining for new careers; assisting with the transition to private-sector employment; and, in my own personal experience in Pennsylvania, we had wonderful experience with staff in the facility actually becoming what are called shared-living or host family providers, where people who had no family and knew these staff for years and years and years and, frankly, were often going home with them on holidays -- they became providers.

It’s difficult; there’s not a slick and simple answer. I think, Assemblyman Greenwald, you asked the question about what have states created. There are a handful of states -- New York, Massachusetts, Connecticut come to mind -- and states who in their early years created
state-operated group homes and transferred state staff to them. I will tell you that they’re transitioning out of those in Connecticut right now; they are privatizing those facilities because as the state wants to transition out of large community homes, they have found it difficult to do that as a state government and have privatized those homes to do that.

Family opposition is the most complex challenge. What we know from 40 years’ experience is that people do better in the community, no matter what their age. And there was, in fact, interesting research that Temple University did -- the government funded -- around the Pennhurst closure, and found that the people who made the most gains were the people with the most significant disabilities.

We also know that once the person moves to the community, opposition virtually melts away. In Pennsylvania, having moved over 2,000 people out of institutions, I know of only one case where a sister wanted her sister back. Even the families who were the most strident, angry, demonstrating, just very, very, very difficult -- in the end, were very happy with the community agency and, when asked, wouldn’t go back.

So this is the pain of transition and opening up an old wound. When you talk to families, moms who institutionalized their children as children, they talk about it like it happened yesterday. They cry because it was such a painful decision. And once you talk about making the change again, it opens all of that emotional part of life up and it is very difficult. And so families need enormous respect and time. They have to be given as much control as possible, opportunities to choose the provider, even choose the home, even choose the staff. They need to have a relationship with the executive director of the agency they’re moving to, because they knew the
superintendent in the institution. And their confidence builds when they have a firsthand relationship with the people in power in the agency; helping them meet agencies, understand that some of these agencies are 50, 60, 70 years old. They’re as stable as the state agencies are. Their concerns and fears about abuse are right, but we need to be honest that those fears are the same no matter where their son or daughter lives. It happens in institutions, it can happen in the community. But what’s important is how vigilant we are and what systems we have in place to prevent it and address it when it happens.

And we have to make sure-- A big concern often is medical services, and I found from my experience in Pennsylvania that making sure that people have their primary care physician lined up before moving allays a lot of those fears. Because if you know who the doctors are, and you’ve had the first meeting before the move, it increases confidence in those.

And oversight: We under-describe the oversight system in the community. Federal agencies have ramped up their expectation significantly and states have put in place some really pretty robust systems.

And the bottom question always is: But don’t families have the authority, even if they’re guardians? Personally, I’d rather not go there. I think the discussion should be about what’s good for their son or daughter, brother or sister; and every effort made to ask them to be open, and to look at things, to plan together. And I have -- much to my surprise after years and years and years when I was in Pennsylvania -- ended up guaranteeing that their son or daughter could go back if it didn’t work. I’ve never met anybody who took us up on it.
I think there’s been a lot of talk about the waiting list, and I think I focused on that quite a bit. This is about building capacity, distributing resources equitably and fairly and evenly so we get the best service for the amount of money we spend. And as I said, and as we’ve said, the future is not there; I don’t think that families with sons and daughters, brothers and sisters who have lived their entire lives in the community are going to, because they’re 80, recommend that their son or daughter move somewhere where they don’t know anybody and where it’s far more difficult to see them.

Lastly, just as a mark of how significant a change has happened in the last 50 years, is there have been now six states -- and not states that have closed their institutions, necessarily -- who have issued public apologies to people with developmental disabilities for years of incarceration and years of sterilization. And I find that really moving, that a population who, in my lifetime, is discarded and disparaged and abandoned would now get public apologies from elected officials. I think that really speaks to the civility of our society and how much progress we’ve made.

Thank you.

SENATOR VAN DREW: And thank you for that very thorough testimony.

A few questions: I want to make sure I understood you right. So in your experience nationally, whenever this has happened, it’s all worked pretty much perfectly? There’s been no incidents, no concerns?

MS. THALER: Oh, I wouldn’t say that.

SENATOR VAN DREW: Okay.

MS. THALER: Nothing’s perfect.
SENATOR VAN DREW: What happened in New York state? I know I’ve read in the New York Times there were tremendous problems when it was done, and there were problems in the community providers -- more than we had even heard of in any institution. And that’s just one that comes to mind. I know there are numerous states.

I do appreciate your testimony, and I don’t want to be a contrarian, but it seems to me you’re presenting an extremely rosy picture. If everything was that easy and that beautiful and that perfect, I really don’t think there’d even be any discussion or debate about it. There has been considerable discussion in numerous states about very serious issues that have arisen, most especially when it’s not done correctly and there isn’t a thorough process that respects both -- and again, you’re right -- the consumers, those who live there, number one; but also the employees as well. There are different ways to do this, to try and transition there.

The first part of my question is that you didn’t discuss any of that at all; the second part of my question is: It was interesting, I think you said -- forgive me, I thought it was Pennsylvania where there were state institutions -- I mean, there were state community providers and now they’re privatizing them. And I would assume that is because of cost factors, because when we go back to this perfect world that we’re saying, “Gee, all the employees could just work in the community, and they would pretty much receive the same benefits and income and so forth,” I don’t know if that’s realistic; in fact, I don’t believe that it is if you look around the country and what happens.

So why did they privatize is the second question. The first question was some of the problems that have happened elsewhere. And
then thirdly I would say, in New Jersey, while there may have been some problems with some developmental centers, I can show you letters that I’ve received from actual consumers and people who work there, and they really do love and care for these people. There are some multigenerational people who work there. I don’t think anybody feels incarcerated or sterilized. They’re not concentration camps. I mean, these are very loving centers -- the ones I’m familiar with in particular. So I just wanted to clarify that.

So anyhow -- starting out with the privatization and what’s happened in some states where there have been problems.

MS. THALER: Sure. Just-- My reference to incarceration and sterilization is our history, and that is what happened in the early ’30s, ’40s, ’50s, and certainly we’re way past that now.

SENATOR VAN DREW: We certainly are. And in institutions, I wanted to clarify that for anybody who might hear this testimony, to even vaguely lead them to believe that we have people who are living in those horrific kinds of circumstances -- in general, the vast majority of times is not true. They are cared for and many of them are loved. Many of those providers who are there, you even pointed out yourself, take these folks home sometimes when they don’t have families.

MS. THALER: Many do; it’s how I got my son. My husband and I worked in an institution, and Eric came home with us on the weekends long enough until we became a family.

SENATOR VAN DREW: So they (indiscernible).

MS. THALER: Privatization: Connecticut, Massachusetts, and New York are the three states that created -- and a handful of other states, but they’re the three that come to mind, certainly, close to you -- that
created -- in the ’70s, maybe early ’80s -- state-operated ICF/MRs; generally 8 bed -- 8- to 15-bed. And so Connecticut is beginning to privatize them, and I think that one of the reasons is flexibility; that the rules around -- that come with the labor force and union rules related to work hours, etc., are less flexible than community agencies. And, quite frankly, sometimes states simply don’t want to be providing services directly because it’s a very small part of the state’s operation, and they find it difficult to supervise and manage it directly. In the case of Connecticut, it’s a very tiny part of the state system. And so for them it makes sense to just move those programs in with the large majority of their other programs in the private sector.

SENATOR VAN DREW: And speaking about that: For those groups that are in New Jersey now -- and I don’t want to name any individual -- but there are some community providers that are going through some fiscal distress and, again, haven’t even been able to provide health benefits for their employees anymore, which is pretty essential for an employee who is doing this kind of service. Why is that? If the money is following-- Educate me a little bit. What is the problem there? Why are they going under this kind of financial duress?

MS. THALER: In New Jersey or any state?

SENATOR VAN DREW: Well, in any state -- it’s a good question in any state; and even in New Jersey, in the community, it isn’t because of the developmental center. I mean, these are community providers -- and not The Arc, who I know is here -- but there are others who are going through some pretty severe distress and had to come back to the State and say, “You know what? We can’t give them health care anymore.
And in fact, if we have to give them health care, we’re going to close down or we’re going to send them back to the State.”

MS. THALER: Many reasons that evolve over time. I think the vast majority of community agencies do provide health benefits -- generally, not as robust as state-provided -- state government health benefits. Rates, probably, are the biggest driving factor in what kind of salary and benefits staff gets; the average community agency budget is at least 85 percent personnel -- that’s what the costs are. And if the rate--

The rate has to sustain a decent salary and a wage, and the agency’s administration of their rate needs to prioritize wages and salaries. So the rate set by the state has to be adequate and then the agency has to decide to use the rate that they get in a good way.

Now, what’s happened in some states -- I can’t speak to New Jersey, specifically -- but what’s happened over time is as budgets have gotten tighter, we see states cutting the rate of Medicaid services. So they’ll cut rates to doctors, dentists, providers -- all providers -- and when you do that, you cut into the capacity of these community agencies to pay wages and benefits. And when the government cuts rates in some Medicaid program, like hospitals or nursing homes, there’s a presumption that they can make up the difference through their private business, private insurance, other revenue sources. But in the developmental disabilities, there is no private insurance, there is no private pay. The only rate is the government rate because no family can afford this, and there is no insurance to cover it. So the providers in the DD systems are restricted even more than other Medicaid providers. And so while money is short, one would ask, “Why is it that those benefits get cut in the community and
not in the institutions?” Well, the benefits don’t get cut in the institutions; but having done this for 10 years in Pennsylvania, what you do is you reduce the number of staff you have in the institution to absorb the cost of the increased health insurance. So everybody is struggling with these increased costs differently.

And then in the community, or anywhere, if this happens too many years in a row and it’s compounded over time, it makes the problem even more difficult. So paying attention to what the rates are in all services is really important.

SENATOR VAN DREW: And just a last question: Experience in other states -- what do you think has gone wrong? Again, you told us all that can be done well -- and we appreciate that -- in some model states. There have been some states that have had some pretty serious issues, and we’ve all read about them. What goes-- Is it when you move too rapidly? When you don’t have, what I’m calling, a global plan? What are the safeguards to prevent some of these horror stories?

MS. THALER: It sounds like you’ve studied this pretty well and know the issues. I want to say, in New York state, the press that you’ve been reading -- that there are two issues in New York. Not to oversimplify here, but the mental health system over the years, their community services, there have been exposés about the quality. On the DD side, the exposés were about abuse in the state-operated facilities. There were three huge front page New York Times articles this past summer. The first was about quality of care in the state-operated programs -- homes -- I think they were community homes; then the subsequent articles were about expenditures or costs in the community system at-large.
But the essence to a successful transition for someone is knowing the person and planning for the person. And when that’s done well, and you take enough time to do it, the likelihood of success is fairly high. If there’s very little planning, or if-- I should say, in the earlier years of the deinstitutionalization, states tended to move people into homes -- that is, decide that these 50 people are going to go to these homes -- without planning for each person. As the years have progressed and we’ve gotten now to contemporary times, what you’ll hear states say is what you heard Tom say, that you use person-centered planning. People go-- Generally, you ask which community do they want to go to, you engage the families in choosing the provider, you get the medical services upfront. And as states have learned to do that better, the risks have diminished and the problems are much less. And even with all the best planning in the world, things can go wrong, but minimally as compared to when you don’t plan and you don’t take enough time.

One of the things that could be problematic is a drop-dead date for closure no matter what. The date for closure has to have some fudge room in it so that -- because as you move along you find out there are problems. Sometimes in the middle of transitioning, people have to go to the hospital because they have an illness; that will stop the process. So planning -- carefully planning is the key.

SENATOR VAN DREW: And that’s a little bit my concern.

I was just speaking with the Co-Chair; we virtually have given dates for closure with no -- two closures -- with no significant planning. I don’t see the entire planning process behind it: where the community providers are going to be, where the facilities are going to be built, how
we’re going to make up for the loss of providing certain services within these facilities. I mentioned it before, as far as, like, whether it’s rehab, or dental care, or physical therapy, etc. As you know, these facilities often provide that. So I’m not here to disagree with you, but what I’m here to say is it’s so important, as we move forward, that this isn’t just a quick, easy answer. This is a very complex process where we’re dealing with very vulnerable people who could easily be hurt, without question. And we have to make sure that if and when it happens, it happens appropriately, carefully, and not too quickly.

And I really agree with you about the date -- that’s what concerned me. We just-- In New Jersey, we just, sort of-- We set a date and we say, “We’re closing.” I don’t know how we can do that without all those other supports around it. And that’s not to put it off, or say we shouldn’t do it at all somewhere in the state, but it means that we have to have that, what I’m going to keep calling, global process to understand how all these community centers interact, where people would be moved. Some of them are going to go from one community center to another. Interestingly enough -- and I’ll leave folks with this; I know there are other folks who have questions -- some folks are saying, “Well the census is dropping in Vineland.” I’m going to use that as an example, because that’s the area that I’m most familiar with -- it is. But just so folks know why: It’s because they’re being moved into other developmental centers. They’re not being moved into the community right now. The census is dropping because they’re being moved into other developmental centers. So I think we have to look at the most appropriate way to go about this entire process.
With that, I know the Co-Chair is going to take over here; I think she talks a little less than I do, too. Lou smiled. (laughter)

ASSEMBLYWOMAN VAINIERI HUTTLE: I get to the point faster, Jeff.

SENATOR VAN DREW: I know.

ASSEMBLYWOMAN VAINIERI HUTTLE: Anyway-- I’m kidding.

Thank you, Jeff.

You certainly have a wealth of experience, and I appreciate your testimony. I wish that Mr. York was sitting here, really, side-by-side. I think, really, that’s what we need to do is to-- Because I can ask you the question, and then you can give me your opinion on-- Just for example: You say that New Jersey has lagged behind; and Mr. York says New Jersey is not lagging behind. And, again, those are the two positions that we are hearing -- and, I think, constantly -- and that is why this is such a debate that needs to really be debated together.

With that being said, your experience is in, primarily, Pennsylvania; and I guess you were also part of U.S. -- Federal -- area as well.

MS. THALER: Yes.

ASSEMBLYWOMAN VAINIERI HUTTLE: But do you know, firsthand, the seven centers? Have you visited the seven centers in New Jersey?

MS. THALER: Not in-- I have not visited your centers.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Because, again, Mr. York testified to the fact that we have seven great centers; we
have seven centers with highly skilled caregivers, and they are higher than other states. And it’s very difficult to say one-size-fits-all. And I know that Pennsylvania may have other areas of expertise; if they have maybe ICF/MRs -- where New Jersey really doesn’t have those type of skilled facilities -- where if you do move a patient or a member into a -- and I’m not going to say least-restrictive, because you said into a more integrated setting, and we’ll use that -- we may not have-- Again, as Tom said, from The Arc, we do have those facilities ready. But we may not have everything ready, in place, if there is a plan for closure in 2012, which is next year.

I do want to make, though, a couple of comments. In your testimony you say states may have institutional capacity to serve additional individuals. Families do not want institutional services, and they may make their preference clear in choosing to wait for years for community services, including New Jersey. The waiting list of our 10,000, let’s say, between 8,000 and 10,000 families, do you know if they are waiting for community services, here in New Jersey, or if some of them are waiting to be placed in centers?

And I ask that again because it goes back to what I think could be generational or cultural. Because, are they being counseled on what is best for them? Because you did mention -- which I don’t agree with, or you-- I guess, maybe you’re getting away from not addressing it -- the families’ choice. When you said if a family is ready to make that commitment, you don’t want to go there. You don’t want to really address their choices, and I really think it’s the families of the individuals that are being placed -- whether in a center or a community center -- I think it is up
to them. I’m digressing a little, because I’m trying to get all my comments out, and then I’ll go back to clarify what I’m actually asking you.

But I remember at one of the Human Services testimonies we heard from a family member. And she said not one of us up here could make any decisions, because we’re not sitting in her shoes, where she has to take care of her sister or her loved ones. And so I really think -- not that you dismissed it; you dismissed it in a very respectful way -- but I don’t think that we can dismiss the fact that families are the primary ones, are the primary decision makers to make those decisions. And the way you maybe turn it around, or counsel that, or dismiss it, I think that has to, really, be taken into account for the families that are making decisions for their loved ones to be placed.

So back to, now, my two questions: Those on the waiting list -- do you know how many of those on the waiting list are opting to go into centers in New Jersey?

MS. THALER: Two answers to your question: One is, if they’re waiting and they want to go in centers, then you’re violating the Medicaid statute, because they are entitled to a bed in an institution. Anybody who presents as wanting a bed in an ICF/MR is entitled to that, and I think the most recent court decision said within 90 days. So I don’t know if they’re asking for that, but if they are and they’re not getting it, that’s a problem.

Two: In talking with Dawn Apgar, your Director, in the last couple of weeks about her waiting list, and the waiting list initiatives, what was interesting to me is that half of the people who are coming off the waiting list are choosing services in their own home, not even in the group
home. So families are opting for continued support of their loved one with services in the home. And so to me, if half the people coming off the waiting list who could choose out-of-home are choosing in-home, that’s a pretty strong indicator of what families are wanting.

ASSEMBLYWOMAN VAINIERI HUTTLE: Which, then-- Is the culture changing then?

MS. THALER: Absolutely. I think the culture is changing for all of us; how many of us are looking forward to going to a nursing home? In the culture, generally, the assumption is, age in place. Stay as part of your family and your community as long as possible -- whether you have a physical disability or a mental disability, it’s just the culture is supporting people living with their family members in the community, because we know it’s healthier and people are happier being connected to the ones they love. So yes, I think the culture is maybe undoing something I think that-- In the early 1900s the culture wasn’t to put away; the culture was take care of your own. And we created these out-of-home placements and now I think we’re all rethinking it.

ASSEMBLYWOMAN VAINIERI HUTTLE: And the other point-- You know, because you were referring to the centers as institutions and other -- the 1900 perception. But haven’t you seen the centers -- well, I’m talking, primarily, in New Jersey -- primarily here in New Jersey -- aren’t they different than the perception that you were referring to back in the 1900? I would hope they are.

MS. THALER: Well, let me tell you. I know-- Tom York is a good friend of mine. Tom and I got to know each other because he represented me, litigating the DOJ not to close an institution in
Pennsylvania. We’d worked really hard to clean it up; at the time we happened to be closing two others and we didn’t want to do that. So I know that we can work really hard and make the facilities optimal, but it’s still group living; you still live with the— Your life is determined by the rhythms and routines of the facilities. You eat when people say to eat; you eat what people say to eat; you can’t go in the kitchen and get a glass of milk at night. There’s a— All I can say is, the same reason we try to avoid going to a nursing home when we’re older -- that is, you lose control of your immediate -- the things that matter to you -- is true in anything that’s large. And I would-- Although you’re not asking this, we have big discussions about, if it’s a 24-hour bed group home, how big -- eight? fifteen? four? And what we experience is that the smaller it is, the more intimate it is, the longer the relationships with staff, the lower the turnover. So size matters; it’s not the exclusive thing, but it’s a big determinate of the quality of our lives.

ASSEMBLYWOMAN VAINIERI HUTTLE: And one last question, and I know the members have questions as well. Would you recommend any of the centers remaining open in the State of New Jersey?

MS. THALER: There’s no role for me to recommend anything. I think my role is to say what’s going on across the country. We have 11 states now that concluded they don’t need public facilities, they don’t need big public facilities. We have a lot of others that are down to a very small number. Having worked in state government myself for 16 years -- 10 as the state director -- I never answered the question, “Should they all close?” because it wasn’t going to happen in my term anyway. In all these states that have no institutions -- never announced that they were going to close
them all. But when they got down to one, clearly they made some kind of
decision. And I don’t think there was any grand scheme to have two, or
none, or-- They just started the process until they got to a point where they
closed the last one. And we have 16, or however many Tom said, that have
one. Some of them are debating whether to close that last one; some of
them are not.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.
Did you--
Assemblywoman Angelini.
ASSEMBLYWOMAN ANGELINI: Thank you very much.
I have a question about the Money Follows the Person
program. It was stated earlier that New Jersey has left money on the table,
and I was wondering how New Jersey compares to other states. Do you see
that other states are leaving money on the table? And how do we fix that.

MS. THALER: All of this-- Many or most of the states with
the Money Follows the Person money have been lagging; and remember,
that MFP money is -- most of the states took it to get people into nursing
homes, and then some states took it to get people out of state institutions.
And that’s because the imbalance on the aging -- the physical disability side
-- is the opposite of DD; that is, in the DD world, 70 percent of the money
is in the community; 30 percent is in the institution. In the aging and
physical disability world, it’s the reverse -- 70 percent is in the institution.
So in a lot of states their initiatives have to do with aging and the physical
disabilities, and I think maybe 10 or 11 percent developmental disabilities.
So a lot of them are lagging on the nursing home side. The states that took
money to get people out of DD are generally keeping pace with whatever their plan was. I can’t speak to your state specifically.

ASSEMBLYWOMAN ANGELINI: Thank you.
ASSEMBLYWOMAN VAINIERI HUTTLE: Did you speak?
ASSEMBLYMAN GREENWALD: No, I haven’t.
Thank you, Chairwoman.
Is it Thaler (indicating pronunciation)? Ms. Thaler?
MS. THALER: Thaler.
ASSEMBLYMAN GREENWALD: Thaler. We’ve never met -- thank you.

MS. THALER: Thaler, if you’re German.
ASSEMBLYMAN GREENWALD: I think regardless of what-- People are trying to win arguments in this. There is no argument to be won here. You know, I come from a perspective of what is realistic and, as a parent, what would I want for my child? And I understand the history of what has happened here in New Jersey and, as a parent, I can see the frustration of people who have made the decision to put their loved one in a developmental center and finally have a sense that they’re safe. Those parents who I have talked to -- I appreciated your comment in response to Jeff Van Drew that it’s not perfect; you never said it was perfect. The DCs aren’t perfect, and the families that I’ve talked to have said that the DCs aren’t perfect.

We have got to figure out-- And, you know, the reason why I said this is an unwinnable situation -- and I have tremendous respect for what the Chairwoman is trying to do here. I think Mr. York is in a conflict; I think you have a conflict. And I think the best way to handle that, to be
honest with you because I think she’s right, is not to set -- to have a work
group with us, where we get you and Mr. York in a room. And there is no
direct answer to these questions, really.

But, I just-- I know-- And the point that you said that
resonated with me is -- you said it much more articulately than I did --
which was that these families on a waiting list -- and we’ve seen this --
they’re not putting-- No family in New Jersey -- I shouldn’t say no, we
shouldn’t be that absolute. People are not putting their families on the
waiting list because they want to put their family into residential housing or
a developmental center. They’re doing it because that waiting list has
become a purgatory. They are on that waiting list for 10 to 15 years. And
they’re just trying to hold a spot.

What they want is what you talked about -- which is what I
tried to articulate earlier -- which is if my child needs speech therapy -- if
they have a lisp, or they have a cleft palette, or they are suffering from a
significant disability -- I want them to get it as soon as possible. And the
revenues are short to allow us to get to that point, and we are spending
money in this one setting. And I think we are providing the best care for
this small population that we can, under the way our system is structured.
It doesn’t mean there isn’t another way.

And I guess I would ask you -- and I don’t say this to be
confrontational to Mr. York, I don’t say it to be confrontational to you, but
I believe you sit here with conflicts. But I ask you to set those conflicts
aside for a second, because we are searching for an answer. From your
experience around the country, what are the examples of developmental
center closures that have been mistakes that we should avoid, and what are
examples of successes that we could model after to do this in a humane manner, an economic fashion, and for the best quality healthcare outcomes?

MS. THALER: Could I get this question from the states that are in the midst of closure, and from the Department of Justice? And, in fact, my office has written guides and manuals for how to go about doing this, because it’s a complex and multi-faceted aspect.

You can look at your next-door state, Pennsylvania, which has done it both not very well in the past and learned from lessons and done it well -- and even learned as it was doing it with one facility. I think in the last five years most states that have done closures have used a personal planning approach and have been thoughtful about it; have not set drop-dead deadlines; have individualized services; have engaged families in a meaningful way to pick the provider, so--

ASSEMBLYMAN GREENWALD: I referenced Maryland earlier; I don’t know the outcome of that. Is that one that you would say, “It’s been a successful model,” or is it too early to tell? Because I know it’s only been about two years.

MS. THALER: Right, but nobody’s gone back. Nobody has asked for their family member to go back. Two years is a long time.

ASSEMBLYMAN GREENWALD: Right.

MS. THALER: I think that the closure of Rosewood was another model of doing it a person at a time, individualizing services, and doing it well. It will never be flawless; there will always be problems. The overall goal is to make somebody’s life better.

ASSEMBLYMAN GREENWALD: And I think, you know, I get tagged, I think, because I Chair the Budget Committee for this
institution -- that somehow I started talking about this as cost-savings. This, to me, is not-- I can’t say it enough: It’s not about cost-savings. We have a reality that we have limited resources, but I want to get the greatest bang for my buck.

Is there a way-- I thought what you said-- And I think too often we look at budget and budget needs in departments year to year, and I thought what I heard you say earlier is -- it was the point I was trying to make -- preventative care saves money in the long-term. So that there is a dollar amount that we might be able to associate with the families that are on the waiting list; getting them the care they need now and to what that is going to prevent down the line when we break this cultural trend that Valerie, I think, has appropriately said. Because, you know, it’s reduce care, reduce care. We’re fighting to get what we can. And then they get older and the parent is older, and they have no choice; and they don’t trust the home placement so they put them in a developmental center. That’s the trend, I think, you can break. If they can stay at home longer, get better quality care at home, have better healthcare outcomes, and then as they see a market of success and community placement, that changes the culture. I mean, is that like folly to say? Is that fantasy?

MS. THALER: No, and I think I understand now what you mean by preventative care.

In most of my time in states talking about -- not whether to close institutions or not, but how to build a sustainable system, long-term. And not to reduce it to an aphorism, but basically if we’re going to have sustainable systems, we have to learn how to support people -- support families and help people get a job. But the more people are active, working,
independent, and the more we buffer their families who can support them -- that is, replace 24-hour care -- the better. But the way to ensure that they can go on for a long time is to start early. If a family is desperate and exhausted, and they haven’t had any services for five years, it’s too late to talk about, “Well, let me give you a day program, and some respite care, and now life will go on.” But if people leave high school, and are greeted with a job, job training, some respite care, some in-home services, something that is a fairly -- well, a robust support package, which is going to be vastly less than $250,000 a year-- What we’re seeing -- no research yet; in fact, we’re looking for research, we’re looking to start some -- is that the arrangement in the family’s home will go on forever -- for a long, long, long time. And we’ve even seen instances where siblings, as the parents age, say, “You know what? If you can maintain the supports, I can do it.”

So we have to -- not only the developmentally disabled, but all disabled and elderly -- support families so they can support their family members at home. And if you mean by preventative, that absolutely.

ASSEMBLYMAN GREENWALD: Yes. And let me-- And I apologize, because you aren’t familiar with me and our background. I passed legislation here called the Accountable Care Organization with Dr. Brenner. One percent of the population -- it’s a pilot program -- 1 percent of the population in the City of Camden, which is one of the poorest cities in this country -- 1 percent of the population in that city was using 30 percent of the Medicaid costs. And they were using it in an emergency room setting because they didn’t have access to preventative care, primary care, physician care. In the first four months of this pilot, that medical cost that that 1 percent has used has been reduced by 40 percent, by working in
the community to get them into the least-restrictive setting that provides the best healthcare outcomes.

That population isn’t developmentally disabled; maybe some are. They’re poor, okay? This developmentally disabled community -- these families are suffering similar plights. And because they get sick, and because we don’t have the access to get the medical care into these families, that they are fighting for, for their children, we are seeing greater costs. You have children who have trouble with swallowing. Well, they aspirate. There are problems that they have and they end up in a much more costly setting, and it’s because we are struggling for the same dollars. That should not be a tug-of-war, as I tried to say with Mr. York, of the guardians of the people in the developmental center and the guardians of the people on the waiting list. It should be about what is the greatest bang for our buck to serve this community in the most humane way, to present all of them with the care that they need. I cannot accept, as some of my colleagues have suggested, that there is just no way to do that; that it’s going to cost more.

And there are comments-- You know, are people-- God I hope states aren’t building homes. You know, I keep hearing, “Well, you’re going to have to pay to build a home.” Why? (laughter) In this economy, with the foreclosure rate that it is, why would you build a home? Take a home on short sale, take a home in foreclosure, and renovate it. I mean, when I hear that there’s this cost associated, it just doesn’t make sense to me. It just doesn’t ring true.

So look, I come back to: Everybody’s heart at this debate is in the right place. But it is about finding how you serve this entire population with dignity and respect, and in the most cost-effective way for better
healthcare outcomes. And it should be cost-neutral now, with the idea of serving more than we currently do. And the saving is -- you know, this is the part that people have trouble with. We didn’t shrink government, so you didn’t save any money. No, I saved money because the cost-ratio growth rate would have been this, and you’ve brought it down to here and we get more healthy people. That’s how I see this playing out. Now, I’m only the Budget Chair, so I don’t know what I’m talking about, but other than that-- I mean, that, to me, is the outcome here.

MS. THALER: That’s the point of my charts on page 7, is that which model you pick determines cost. You could plug in New Jersey’s numbers in there and they’re probably going to be the same ratios, if not wider.

But the long-term costs of the first decision-- So if you look at supporting somebody with their family for the next 20 years versus in an out-of-home arrangement of some kind, the cost comparison is just really pretty dramatic. And so to me that chart incents us to beef up to support families -- family caregivers -- as much as we possibly can.

ASSEMBLYMAN GREENWALD: I would appreciate it -- because I don’t want to take up the time of everybody here today -- but if you could get back to the Chair, for the members of the Committee, examples of failures in other states that have gone about this process and either have not done the proper planning, and what was associated with the failure; and the successes. And if the successes-- I said early to Mr. York: If it’s a mash-up of multiple states, I would really like New Jersey to go from where I think we are -- which is at the bottom of the barrel -- to the top of the heap on finding what is the most creative way to deal with this and to
be a model of success. And for people who say, “Well, that’s just not possible,” I would point everybody to DYFS. New Jersey was an embarrassment. What was happening to children in this state was a travesty, and if you were in Pennsylvania I know you’re aware of it. And where we are today, we are a model of excellence for the rest of the country.

Now, how we got there -- to me, the means don’t justify the ends. We could have gotten there if we would have taken the lead. And before this is forced upon us, and it would be far more costly -- and before the closures take place, as I fear they are now with the drop-dead date as opposed to a planning process -- I would really like to get the input of people like you and Mr. York to figure out how we get there.

MS. THALER: When you ask for-- As an Association Director I’m not about to name failures, if you could respect that. In terms of states that have done it well over time, the little ones -- Vermont, New Hampshire; Oregon has done an amazing job; separate from closing institutions, Washington state is a dramatic success.

ASSEMBLYMAN GREENWALD: You know, I don’t mean to interrupt; I want to have a conversation. I apologize. You know, when you say that the smaller ones-- Well, the critics will come out and say, “Well, they were smaller, that’s why they were able to do it.” And I don’t mean to put you in-- And that’s why I said earlier: I think you’re both in a tough conflict, as you just said, because as the head I can understand why you don’t want to point to the failures. We’ve asked you here because we’re trying to find how to do this right. We don’t want to be one of the failures.

So my request of you would be, even if it is anonymous, if you can point us to the successes -- okay? -- publicly, and identify them, but
without naming the failures. If you could phrase it anonymously: State A, State B did this, and this is -- and it failed. And, quite frankly, the states that did this more recently learned from these mistakes. That would be helpful to us.

Otherwise -- and I don’t mean-- Listen, I would align myself with your testimony on the legislation that I introduced to your -- unbeknownst to you, we used your data. But -- and I say this with great respect -- if you don’t help us find the failures, this is a waste of all of our time, okay? We need your help, all right? So that’s why you’ve been asked to be here.

And with that, I thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Assemblyman.

And, quite frankly, we are going to reach out to you, and Mr. York, and others to really do, as I think Lou alluded to, sort of a working group so we don’t need to publicly continue to take-- And it’s really not about-- I know-- I really think this-- I’m trying to be as nonpartisan as possible because it’s-- You know, people in these centers and people in the homes, we don’t ask if they’re Ds or Rs; and I don’t think this is the goal at all. And that’s why this is a bipartisan working group to try to get a clear criteria on process. And I still have, though, my own-- I still struggle with the entire population, because the entire population includes high-care needs and lower-care needs, and those who can best integrate into a setting and those who -- and I hate to say cannot, because it’s proven that everyone can -- but those who choose, whether their families or their guardian choose, to stay in those settings. And I’m trying to see or find out, with the
help of professionals, is there still a continued need for some of the centers in the state? Because, again, Mr. York’s testimony and yours were completely opposite. And so I would like to continue to work together to get some of these answers to really come up with a blueprint for the State.

And so we appreciate, Ms. Thaler, all your testimony and your experience. And so I thank you; I don’t think there are any more--

Was-- Okay.

We have one last witness that I would like to call up. And thank you again.

Roger Monthie, President of the Age Plan, Inc.

Welcome, Mr. Monthie.

ROGER A. MONTIE: Thank you very much.

You guys want to stand up and stretch for a second? (laughter)

ASSEMBLYWOMAN VAINIERI HUTTLE: We’re almost there -- home stretch.

MR. MONTIE: Almost there, almost there.

Well, I probably am the person who is going to be slightly into the middle of everything. I’ll tell you a little bit about myself, and maybe that will give you an idea of where I’ve been and where I think we can go.

Good morning; thank you. My name is Roger Monthie; I am President of Age Plan, Inc. I was asked to speak to you today due, in part, to my 30-plus years as a state of New York employee, and my experience in overseeing the operation of New York state institutions.

During my career I provided administrative and clinical oversight to three different institutions: Broome Developmental Center, a 480-bed facility in Binghamton, New York; the Letchworth Village
Developmental Center, an 1,100-bed center in Haverstraw, New York, on your northern border; and the O.D. Heck Developmental Center, which is a 48-bed specialty unit for people with autism in Schenectady, New York.

For my career, I started first as a psychologist in a small little town in the middle of a very rural part of New York state providing support and services to people who were living in the community. I was part of a clinical team that not only provided supports and services to people with disabilities living in family homes, we also extended that service to individuals of any citizenship who had disabilities. So when one was talking about a model of support and services, in 1974 New York state had one. It developed regional centers that were state-operated that provided, at the cost of public dollars, support and services to people with disabilities of all ages.

Ironically, I started my career in 1974 in the community. The Broome Developmental Center actually was one of the brand-new centers built and opened in 1975. It was built and opened with the idea of relieving overcrowding in other major large institutions that, at the time, had anywhere from 4,000 to 6,000 people living in them.

I began to understand that the new wave of building an institution was, for all intents and purposes, the same as the old way. Because as it has been referenced before, institutional care is, for the most part, built on a model of management called *time and motion*. You have to provide a lot of meals to a lot of people and, therefore, you have to prepare them in the most effective way; and that tends to be what causes people to not like institutions.
My state career also involved overseeing the move of almost 2,000 individuals from institution to community support services that included the complete and total closure of the Letchworth Developmental Center in 1996. I wanted to share my experience with you so that it might aid in the development of successful institutional policies, practices, and decision making. I do not have an agenda of institutional care versus community care, although I think you will see the differences as I go through.

There are a number of important issues that should be considered on exploring the institutional care and its costs, as well as the transition of individuals from institutional to community support services. I also-- Let me digress for a second and apologize. I have a large written report which, unfortunately, I couldn’t find somebody -- any place in Albany, New York, at 4:30 in the morning to print it (laughter); so I will make that available to you electronically or by another means necessary right after my testimony.

During my career, New York state came to the conclusion that although quality services can -- let me stress can -- be delivered in large institutions, the cost of maintaining these institutions -- especially after taking into the account the changes in demographics, the actions of advocates, the interest on the part of individuals and their family, and the changing cultural revolution of the supports and services for people with developmental disabilities -- made creating services in the community a better option. New York state closed 13 developmental centers during my career; and significantly downsized the remaining six, in some cases changing the individuals who lived there to special populations.
I will take my limited time before you to draw your attention to five key facets that led and aided in the implementation of the decision and the process for closing those facilities.

First, let’s talk about fiscal. Fiscal realities significantly dominate the talking points when discussing the ongoing use, function, and need for institutions serving individuals with developmental disabilities. You can see that from your meeting today. This is not a new concern -- let me stress clearly, not a new concern -- and was a constant source of dynamic tension in our efforts to downsize institutions in the state of New York. However, in my tenure in New York state I came to realize -- whether on its own or under the strain of pending litigation -- that government had a responsibility to support each person in a manner that best allowed them to exercise their personal choice in a most integrated setting.

Although the fiscal impact of the care of a vulnerable population may seem like the most important factor to consider for deinstitutionalization, especially during difficult economic times, using only the physical (sic) lens to look at the issue of closure or not closure is a little bit like falling down the rabbit hole. You might have a nice experience, but when you wake up you realize that you’re not Alice anymore.

My experience is that the fiscal argument can be used both to support and oppose the deinstitutionalization of individuals with disabilities. This is because the physical (sic) argument depends largely on what factors one puts into the equation. Those supporting continuing institutionalization point to the issues of economy of scale for services, supports, the development of specialized expertise, and the positive
economic impact of the large developmental centers. Those who support deinstitutionalization emphasize the savings associated with no longer maintaining the infrastructure of a large, often old building or campus; duplicative costs at institutions for support services such as security, maintenance, food service, cleaning and laundry, as well as regulatory mandates in terms of clinical supports.

Relying on the magic bullet of fiscal advantageousness is foolhardy for two important reasons: one, the analysis of the system of care is too complex and is constantly changing because the people constantly change -- because life goes on. Peoples’ needs change as they age; peoples’ needs change as they grow.

And second, during the process of deinstitutionalization -- and this is very important to understand -- it is actually more costly to serve the individuals with disabilities because you have to fund the development of community systems and the closing of the institutional system at the same time, until the institution is closed. So to begin to think that you’re going to save money in the short-term is impractical and inappropriate because you have to maintain both: one that you’re now slowly -- or quickly, it doesn’t really matter -- supporting while you’re closing it, and the other one as you’re building it.

Second, we fail to understand the history of institutions, specifically in the area of human resources. There is little question that the clinical supports and services provided in institutions have and, in many cases, continue to be high quality. Historically, we have seen some of the largest breakthroughs in understanding how to support and serve people with a variety of different disabilities coming from institutions. Some of the
most advances in providing services to people with developmental disabilities came from centers across the United States, including right here in New Jersey -- at the Vineland Center, by the way.

However, equally, without question the lack of quality care has resulted in increased scrutiny of the institutional model. In 1992, I became the Associate Director of the Letchworth Development Center, a New York state institution opened in 1911 with a population that, at one point, reached over 5,000 individuals. When I began my tenure at the Center there were over 1,000 individuals supported by close to 1,500 employees. The Center was out of compliance on six of eight conditions of participation, and a total of 92 percent of the 390 standards for certification continuation and participation in the Medicaid program. It was also involved in a Federal class-action consent decree.

Even with all of that, there was quality staff and supports in services that were provided there. Since the staff at the Center was important -- and we truly believed that -- when we decided to look for closure based upon conditions, as well as based upon consent decrees, we found it important to maintain a relationship between the staff, the individuals, and the families. These relationships, many times, went beyond jobs. When we looked at the issue of services to individuals with developmental disabilities, we were very cognizant that the public service employee in the state system were dedicated, knowledgeable, valuable, and absolutely critical for the transition of individuals to a community-supported living system.

We came to realize that the safe, healthy, and successful placement of individuals from the institution to the community model
needed to include the transition of this valuable group of staff. That is not to say that one can or should attempt to accomplish a full-employment commitment; that is not possible. Instead, New York, during the closing of many of its institutions, included a limited number of state-operated community homes in the closure process. By no means was it a guarantee for every individual or employee, but it was critical to ensure the successful closure of the institution for two major reasons: first, the relationships that had been built over years between staff, family, and the individuals were able to be maintained in certain situations. We were able to, in fact, move people together that were friends at the institution into the community. This decision allowed us to successfully transition individuals with the most complex medical, physical, and behavioral issues, as well as complex histories, into the community.

The third way to look at this issue is one that you are immensely familiar with, and that’s the political lens. When we look through the political lens, New York’s successful transition from an institutional to a community-based support system depended upon a collective effort of all parties agreeing on the long-term benefit of integrating the individuals into the community of their choice, as well as understanding the changing political landscape. In New York, managing the many political agendas was significantly aided by several factors, including the support of the state legislature and executive branch, and the cooperation of and relationship with state workforce, families, and individuals themselves. Without that complete and unanimous improvement -- direction on care, attempting to close any system is looked upon as losing, not winning, even if you’re offering what you consider to be
the best. And I know in your terms, you’re struggling with the issue of whether that is even close to being the best option.

With respect to the state legislature and executive branch, it was critical that we had a closure plan that was updated annually and provided back to the state legislature; that was done by law. So as a director of a facility, I annually had to resubmit the plan, projecting what was expected to happen, how it was expected to happen, when it was expected to happen, and what was the impact going to be. I was also required to give them a report on people who had moved out: how were they doing, where were they, and what were they doing. That was critical, not only as an executive branch employee -- keep in mind, I served at the pleasure of the governor -- to not only maintain a sense of cooperation between the legislative and the executive branch, but also between both branches and the citizens at large. I cannot stress enough that it’s that part of open communication that makes any change in a system, as difficult as this one can be, successful.

Second, the state legislature in New York passed, in 1978, a law called the Padavan Law to ease the resistance of local municipalities. Fortunately, that’s not needed anymore. Local municipalities, local citizens, are really in tune with the idea of people with disabilities living with them as full partners.

And finally -- and this is even more critical -- by basis of law passed in New York state, the governor created a local and community group to discuss the use of the centers’ facilities and grounds after closure. It was critical to look at that facility that had been a member of that community, that had been an economic force in the community. What was
going to happen to it? How was it going to be used? And the use of local, driven groups made the successful transition of the Letchworth facility -- which at the time of closure was 600 acres, 150 buildings, 29 miles of roads, a water system that included three reservoirs, a full power plant -- a successful transition into public space, because that’s what the local people wanted. So the school took over a part of the campus and built a new high school. The town of Stony Point and the town of Haverstraw both got equal parts of the facilities, each one to use for different purposes. They maintained a connection to the public use policy, and successfully moved it into the private and public sector.

The second area to look at is the lens of clinical direct-support in administrative services and institutions. Although it is possible to deliver quality services in a relatively cost-effective manner in institutions, New York state had evidence -- and, quite frankly, I’m surprised that that’s not difficult to come onto -- that the same care could be provided in a cost-effective manner in the community. A limited exception -- and a very limited exception, and what tends to be an over-cost -- is the area of direct-care oversight; specifically, the night shift. You get the economy of scale in the night shift because you’re usually having units of 24, 48, 68 -- whatever the sizes you’re dealing with -- and therefore you can manage people sleeping with a lot fewer people than in homes of 10, 8, 6, 4, 3, etc.

But in so many other ways, there are economic benefits that are not realized until the facility is completely closed. And even in the area of direct-support services we found ways in which services were provided in a more economic way. What were some of those ways we discovered? First -- and these are personal experiences, I may add -- direct-care staff in small
community-based residential homes seem to be more willing to work together, versus large institutions where many times staff are moved from one area of support and services to another area of support and services, and very often don’t develop a lot of relationships while they’re being moved around. It’s called leveling; you do that in order to balance workloads, in order to take care of staff call-ins -- you move staff around.

What we found in the community is that staff tended to develop a family attitude. They tended to support each other slightly better. And that enhanced the quality of care and decreased the events of unknown origin and overtime.

We also minimized the negative event of moving very vulnerable people out of the institutions because we are able to keep people together who knew each other. And I can’t stress enough how critical it is with very vulnerable individuals.

A small utterance by an individual without verbal ability may be interpreted as pain, pleasure, hunger -- we don’t know. But the staff do -- who work with that person, day in and day out. And because they know it, they also know that something is wrong and we need to get the person some supports or services, especially in the area of medical care.

Because of that -- being able to move people with people who knew them, especially with people who were very vulnerable -- reduced the number of potential events, that I believe your first speaker was speaking to, when you move them completely into a situation in which people don’t -- they are unknown to those individuals. And no amount of transfer of knowledge can occur because so much of our knowledge is not transferable, it’s intuitive.
Smaller environments also lead to fewer behavioral crises, thus reducing the need for clinical intervention and one-to-one follow-up.

The shift to a community model has added benefit for reducing the need for large administrative and support staffs to provide security, maintenance of buildings and grounds, preparation of meals, cleaning and laundry.

Finally, the introduction of the Medicaid waiver system, as referenced previously, to the states allowed the unbundling of services from the ICF/MR to the individual designed community model. No longer did you have access provided based upon a model, but rather based upon the needs of the individual. This had the substantial added benefit of states not incurring a cost for service that the individual did not need.

Finally, and most importantly -- although most overlooked when closing or looking to close institutions -- is the symbolism that they represent in peoples’ emotions. Once the decision to close many of the institutions in New York, it was important to take into account the history and culture of years of institutional care that was provided in New York. It was not done under the guise of being inappropriate, poorly delivered, or in any way harmful. Yes, New York state was an epitome of the national disgrace provided to care of people in the Willowbrook state school. It was by no means -- from personal experience -- the provider of the worst care that I saw, either in New York or in other states, when I began in the field of developmental disabilities in the early 1970s.

Letchworth Village Developmental Center was more than a facility, though; and I had to recognize that as we were closing it. It was more than a facility for individuals with developmental disabilities. It had
started as village -- hence the concept of Letchworth Village. It had its own fire department, police department, hospital, school, clinic, and culture. Letchworth Village was a place where relatives, sons, and daughters lived and died. When looking at closure we knew we weren’t just closing a center, but were ending an era.

At the closing ceremony an elderly man came up to me and said he had travelled from California to see the place where he was born and lived until age 5. He told me he had fought in World War II, and settled and raised his family in California. And when he heard that Letchworth was closing he came to see his birthplace before it was closed. That struck me that we weren’t just closing a facility; we were changing a culture and we had to be sympathetic to that.

Looking through the lens of symbolism doesn’t tell you how or why to close a facility, but it will help you to provide a context for that decision, an appreciation of its history, and a lens to look at the future. A very good friend of mine once said, “One doesn’t need great leadership or new leadership; it needs excellent historians.”

I thank you again for the opportunity to provide you with this information. I also have provided greater detail in my written information, in terms of other things to consider when you’re looking at closure or changing any major system.

And I would be happy to answer any questions that you have.

ASSEMBLYWOMAN VAINIERI HUTTLE: I think that history was a very big help, I think, to the panel. Especially when you talk about the numbers in New York -- Letchworth -- a thousand individuals. I mean, I don’t think any of our centers have even close to that many.
How long did it take to close Letchworth?

MR. MONTHIE: Let me give you some frames. When I first came to the state of New York there were 32,000 individuals living in state institutions, and almost nobody had community placements. And that included 5,000 living in several different large centers. When I got there in 1992, with the complete authority to a) improve the quality of care; turn the center into being a center that did not have conditions of participation now; provide quality of care and to close the center, we were able to do that through the development of both state community homes, no larger than six people per home, as well as a healthy amount of development in the not-for-profit area. And we placed a thousand people and closed the center in 1996 -- four years.

ASSEMBLYWOMAN VAINIERI HUTTLE: And politically, because you did mention that -- and I think that’s important, although we’re trying to be nonpartisan -- but I think, politically, the two branches of government -- the legislative branch in New York and, of course, the executive branch -- and they did come up with a few, I guess, pieces of legislation that monitored it very well. How did you deal with the politics of it, as far as, I guess -- in the area where you were closing -- the political people there; and then, of course, the family politics of it as well. I mean, that’s what I think we are struggling with as well here.

MR. MONTHIE: I would define that as a big P and a little p.

ASSEMBLYWOMAN VAINIERI HUTTLE: Yes.

MR. MONTHIE: Neither is more important than the other. The big P is your P. It really was helpful to have consensus on the part of the elected officials that we were going to close. The reason why that was
important is because it allowed me and my team to approach everyone with the, “Let’s look at what we can develop,” rather than, “We’re going to figure out a way to stop it from happening.”

ASSEMBLYWOMAN VAINIERI HUTTLE: Good point, excellent point.

MR. MONTHIE: So that’s the big $P$. And I don’t think there’s any way to get around that. And there’s no easy direction; you know, great leadership is the ability to manage unforeseen negative outcomes of good decisions. There is going to be some negative outcomes. The issue is, do you have people in place who are able to manage those?

So what are the things that we had to do, soup to nuts? Let me give you some thoughts on it. I remember towards the end when it was clear that we were closing, we still had over a hundred family members who believed that it really wasn’t going to happen. Their resistance wasn’t just that they were happy with the care they were getting. I’d like to think that was the case, but it really wasn’t. Their worry was what every parent has: Who’s going to take care of my child when I’m not here? Who’s going to protect them? And the state of New York had proven that they were there to do it; and the State of New Jersey also has proven that you were there to do it. And to the benefit of my friends in the not-for-profit side who provide outstanding care, there is still a sense on some peoples’ part that, “How do I know that you’re going to be there? How do I know that you just don’t fold up your tent one day?” The State of New Jersey can’t go away. Public service doesn’t go away if we starve it of money, if we starve it of talent -- it just gets crummy, but it doesn’t go away.
And so, consequently, what we were able to say to them, “We’re not going away; we will make sure that even if your child goes to a not-for-profit, we have a regional center of staff. It’s still here. It has psychologists, and PTs, and OTs, and nutritionists. And we have them right here.” And we were there as a backbone to that.

We also didn’t give away our talent. Now, somebody said -- now, I retired five years ago and have since been running a private consulting business -- but there has been some discussions in New York state about doing away with (indiscernible). Terrible move; I would say it was a terrible move. There needs to be a public -- a robust public service system. It’s what gives us our freedom on a whole bunch of different levels. It is the nonpolitical side of public service. It’s got consistency. It’s got a place for new talent to come to.

So I would make the case that we were there for doing that. I remember talking to a little old lady who was 91 at the time. And she lived in the Bronx. And for 49 years -- she placed her child there when he was 5 -- she took a cab to the Port Authority, a bus from the Port Authority to downtown Haverstraw, and a cab from downtown Haverstraw to the campus with a box lunch on every Sunday. And she had done that for 45 years. And she came up to me in tears and said, “I don’t know how to go any other place.” And I said to her, “You’re not to worry. We will make sure that there is a person who will be there with you and your son and take him for your lunch.” And that was a guarantee we had to keep. And we kept it for another seven-and-a-half years. She still took the cab from the Bronx to the Port Authority. She took the bus to Haverstraw, and we met
her with her son. And then most of the time, ironically, still went up to the campus -- because she loved the grounds there -- and had lunch.

You can do those individual things unless you just eliminate it all; unless you say, “Well, we’re not going to get that because that connection isn’t there anymore,” and we can’t dictate that responsibility to anybody else but a public servant. So I don’t know how we would have been able to do it without it.

Now, again, it wasn’t one-to-one; but we were able to manage those situations well because we remained the provider of final and last resort.

So to answer your question: The small _p_ was managed a lot by the individual touches -- by understanding the culture, by understanding the staff, by assisting the staff as much as you could -- even the staff that we knew we had no place for in the community. Through the state level of resources -- civil service and other means -- we were able to offer opportunities in other state places. For example, I had three power plant individuals who went to work for one of the correctional facilities over in Westchester. They still operate the power plants. I had a number of individuals who we assisted with learning English as a second language so they could move from being a cleaner to being a direct caregiver. They’re wonderful caregivers. They were wonderful caregivers to their own family. We needed to get them so they could understand and speak English for the purpose of health care.

So there were a number of different steps we took. I outlined a number of them in my report, which you can look at. But there are ways to manage it. But ultimately, I think, in terms of some of the previous
questions I’ve heard, yes, you can do it. It’s not vogue anymore; vogue is, you know, minimize government, minimize public service, maximize the private. And I’m not opposed to that; I’m just saying that you may want to consider something that worked, and earlier on somebody was saying, “Has it worked?” It worked in 1974.

A quick sidebar: In 1974, I said to you, I was a psychologist in a clinical team that was put, by the state of New York, in that region to serve about 400 people living in family care -- which is a family relationship situation -- who had come out of institutions. People would be paid to -- like foster care; it was called family care. And we were there to provide clinical and oversight support to those individuals. At the same time, we all moved into that little town, ironically. We were coming from different parts: I was coming from Massachusetts with my family, and we, kind of, all got there. So we were part of that little village. One day I’m walking down the street and I bump into the lady who runs the local daycare center -- Head Start Program. And we were just talking, and she said, “Oh, I so wish I could have somebody come over and just look at one of my little kiddos.” I said, “Well, I’m a public servant; I’m paid on public dollars -- it’s your public dollars. I can’t give you full-time support and services, but there’s no reason why I can’t come over there and see you.” And we, in essence, helped people, little kids -- some of them who had early developmental disabilities -- not even get into the system because we gave them the supports, because we were there.

So government can work; government can make a difference. And you already have the expertise. If you saw my résumé you know that, for a short period of time, I was part of the monitoring team at New Lisbon
and at Woodbridge. You have good talent; I’m here to tell you that. The problem in institutions is not that they exist; it’s that that talent tends to be collectively held right there -- not just money, but talent.

So if you don’t lose all that talent, you could certainly transition that into the community.

ASSEMBLYWOMAN VAINIERI HUTTLE: Just one final question before I open it up. Out of the-- I guess, when the thousand left, did they all go into community settings? Did any of them-- So no one was moved into another center, so to speak?

MR. MONTHIE: No one was moved into another center; that’s correct.

ASSEMBLYWOMAN VAINIERI HUTTLE: And out of those thousand, any of them with really high needs of care?

MR. MONTHIE: There is no one you are currently serving in any institutions that we could not serve in the community, with one small exception: If you have individuals on ventilators -- I would be surprised if you do, in your institutions -- but if you do, that tends to be a healthcare level that really needs skilled nursing support and services.

ASSEMBLYWOMAN VAINIERI HUTTLE: What about the forensic side -- forensic units? Did you say you were affiliated with New Lisbon -- and which other one in New Jersey?

MR. MONTHIE: Woodbridge, yes.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. What would your plan be? Would you continue to, I guess, feel the need for forensic centers in the centers here in New Jersey?
MR. MONTIE: That’s a tough one to say. I’m not sure that you can get to the point in which you don’t need some form of support and service for people who are dangerous. Now, the problem I have is, is that I think we’ve opened that can, so to speak. We did it in New York, dramatically. And a lot of people get trapped into that system that aren’t as dangerous as we’d like to say, and then, unfortunately because we’re very good at creating histories and maintaining those histories, they sometime don’t ever get out.

So I would say that if you can make it short-term, intermediate, attentive to their specific clinical issue, ensure that their forensic side isn’t situational -- and what I mean by that is that a lot of the individuals that I served in forensics were the person left holding the television, because everybody else ran away; they were the last one there, so to speak. Or they were in a very abusive situation and they didn’t have the same resources that we may have to leave that abusive situation. I remember talking -- dealing with one individual who actually shot his father-in-law. Now, you can’t get much more forensic than that. But when you come right down to it, the father was beating the mother to death. He didn’t know any other options; he got the father-in-law’s gun and shot him.

He was of no harm to anybody else. His father-in-law wasn’t going to exist anymore, and so we placed him in the community. We placed him with, certainly, a lot of restrictions. We had individuals with monitoring anklets and a lot of different things. So we were cautious. So in the right setting, in the right state situation, you can look at even people with forensic histories. That being said, I really appreciate the fact that I had a center-based program for those individuals in order to ensure that
they were given the best care that they could be given while we were looking to see what kind of special supports they needed to live in the community.

ASSEMBLYWOMAN VAINIERI HUTTLE: And just-- That center-base, was that the regional center you were referring to in the area to give support?

MR. MONTHIE: Yes, there were actually two. A community-based regional center that, actually, I developed and operated in 1978. It was called the Homer Folks Transitional Center, which was there as an emergency, short-term crisis center for individuals who, not necessarily forensic in nature, but had any kind of disability. You know, had a bad weekend and they were threatening to hurt people, or run away, or something like that.

We did a similar model of that at Letchworth. We took one of our large ICFs that had been opened in the early ’80s or so and we converted that into a short-term transitional center for people with disabilities -- with behavioral disabilities. And then New York state actually created a number of large, free-standing forensic centers called Centers for Intensive Treatment -- one in Norwich, one in Sunmount -- and those were for individuals who were, for the most part, adjudicated or sent by courts for extended care beyond their legal internment.

ASSEMBLYWOMAN VAINIERI HUTTLE: If there are any other questions left on the panel? (no response)

You certainly provided, again, a lot of information for this panel. We apprecaite-- We look forward to your written testimony--

MR. MONTIE: Yes.
ASSEMBLYWOMAN VAINIERI HUTTLE: --so we can review it.

And we thank everyone, again, for coming to this hearing. And we will have our last hearing -- I believe we have a date. Kate, you have some time in November. We’re working on a date. We will inform the public.

Thank you very much. And with no further questions, this meeting is adjourned. Thank you.

(MEETING CONCLUDED)