

Review Panel Meeting

of

LEGISLATIVE REVIEW PANEL ON STATE PSYCHIATRIC HOSPITALS AND DEVELOPMENTAL CENTERS

"Testimony from invited speakers on issues related to community placement opportunities for persons with developmental disabilities residing in the State's developmental centers"

LOCATION: Committee Room 16
State House Annex
Trenton, New Jersey

DATE: January 5, 2012
2:00 p.m.

MEMBERS OF REVIEW PANEL PRESENT:

Senator Jeff Van Drew, Co-Chair
Assemblywoman Valerie Vainieri Huttie, Co-Chair
Senator Joseph F. Vitale
Assemblywoman Cleopatra G. Tucker
Assemblywoman Mary Pat Angelini
Assemblyman Erik Peterson



ALSO PRESENT:

Irene M. McCarthy
Michele LeBlanc
Office of Legislative Services
Review Panel Aides

Jason Redd
Senate Majority
Kate McDonnell
Keith White
Assembly Majority
Review Panel Aides

Christine Velazquez
Senate Republican
Deborah DePiano
Assembly Republican
Review Panel Aides

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TABLE OF CONTENTS

| | <u>Page</u> |
|--|--------------------|
| Thomas Baffuto Executive Director The Arc of New Jersey | 2 |
| Kim Todd Chief Executive Officer New Jersey Association of Community Providers | 10 |
| Deborah M. Spitalnik, Ph.D. Professor of Pediatrics, and Executive Director The Elizabeth M. Boggs Center on Developmental Disabilities Robert Wood Johnson Medical School University of Medicine and Dentistry of New Jersey | 24 |
| APPENDIX: | |
| Testimony, plus attachments submitted by Thomas Baffuto | 1x |
| Testimony, plus attachments submitted by Kim Todd | 6x |
| Testimony submitted by Deborah M. Spitalnik, Ph.D. | 24x |
| rs:1-41 | |

ASSEMBLYWOMAN VALERIE VAINIERI HUTTLE (Co-Chair):

We do have some conflicts today with the Senators. There are committee meetings being held simultaneously, and we also have Budget that is still being held. And one of our members on the Assembly side is the Chair of Budget so, obviously, Mr. Greenwald is still in Budget. But we do have a full complement of the Assembly members here, and I thank everyone for being here.

I think in the interest of time, though, we can start. And if the Senators come in they will, obviously, be, you know, kept up to -- or given the opportunity to catch up to speed. But also everything is public, obviously. It's public testimony. There will be a written -- written comments that are provided, which is the committee meeting of the last session -- or the last Panel meeting. So we certainly have the information that will be disseminated to all of the members.

So with that, I want to welcome everyone to the third and final meeting of the Joint Legislative Review Panel on State Psychiatric Hospitals and Developmental Centers.

I think we can all agree that whether or not developmental centers and psychiatric hospitals remain open or some close, there is certainly a pressing need to create more capacity for community living. And therefore the topic of this final hearing is on the status of available housing in the community. And I expect that we will hear about current efforts to create more housing, as well as the road blocks in doing so.

So the goal of today's hearing is to come away with ways in which the State can help facilitate an increase in community placement so

those individuals who wish to live in group homes and other community settings have an opportunity to do so.

So with that being said, we do have, I believe-- Where are the members testifying? I think there were four somewhere. Regardless of the order, I do have a request from Tom Baffuto from the Arc. He does have a -- I guess a prior -- or a commitment right after this.

So, Tom, I'll call you up first. And if you would like to come up and state your name and affiliation, and give your testimony--

Thank you, we appreciate it; and welcome.

T H O M A S B A F F U T O: Thank you, Chairwoman Huttles and members here today. I appreciate you accommodating-- I have a board meeting tonight, so you never like those things to go on if you're not there.

ASSEMBLYWOMAN VAINIERI HUTTLE: Oh, it's tonight. I thought you said it was soon.

MR. BAFFUTO: Well, 5:00.

ASSEMBLYWOMAN VAINIERI HUTTLE: I have something tonight too.

MR. BAFFUTO: Well, 5:00 is soon. (laughter)

I appreciate the opportunity. This is actually my second time to come before this group, and I really appreciate the dialogue and being able to share with you.

I took a bit more of a broader approach to community supports, because I believe housing is just one small piece of the infrastructure needs that we have out there. And as we continue the dialogue, I think we really need to look at, really, the whole picture.

And regardless, as you said, Chairwoman Huttel-- Regardless if we're looking at developmental center depopulation and closing developmental centers, or just regular community living, I think we have to look at some of the infrastructure needs and support needs that we have out there.

Clearly, for 30 years people with intellectual and other developmental disabilities have been living in the community. And really back in the '80s, when we kind of shifted it up, we changed the Medicaid rules. The option of providing services in the community through our Home and Community Based waiver really opened up community living for our folks.

In my written testimony I've provided a great deal of information on the current capacity. I certainly won't go over that. I'll really just summarize what I've put in my written testimony.

But presently, as far as capacity living in the community, we only have about a 2 percent -- or a little less than a 2 percent vacancy rate in the system. So that means additional growth -- moving folks into (*sic*) the developmental center -- we're really going to have to look at developing new housing in the community.

We know that there is a current initiative between the Department of Community Affairs and the Department of Human Services to create 600 affordable units by 2013, and we think that's a good start. We think that's going to go a long way in helping meet the needs, as we move forward, of moving people out of developmental centers and getting them into the community. So that's a big component that we have coming on board.

But in order to know precisely where the development is needed, and to adequately monitor community capacity, we feel that the Division of Developmental Disabilities must do a better job in collecting, updating, and disseminating critically necessary data on the needs of individuals with intellectual and other developmental disabilities so that we're adequately planning, adequately identifying where, in fact, we need the housing.

Given what we do know about the needs of people living in our State developmental centers, additional professional infrastructure in the community must be developed to meet the medical needs, mental health, and behavioral support needs, and there must be substantial efforts to create more accessible housing options. As some of the data I share with you -- we know at least 47 percent of the folks living in developmental centers are using wheelchairs. So we need to develop accessible housing. We need to look at improving our case management system and, of course, addressing the direct support professional recruitment and retention issue.

So in no particular order-- Just in health care: Obtaining appropriate health care is a challenge for folks with intellectual and other developmental disabilities who often experience problems accessing primary health care, specialty care, and ancillary services. Barriers to this care include a lack of appropriately trained healthcare providers, inadequate Medicaid provider networks, healthcare provider misinformation, limited healthcare facility accessibility, and a variety of other things that I talked about in the community.

As individuals leave developmental centers where health care has been provided on site, they will face some challenges in finding

healthcare providers in the community. To that end, we feel we can make that easier as we make the transition. We need to ensure that people leaving an institution are accompanied by a complete medical record -- medical history. We need to include staff positions, including nurse practitioners and similarly credentialed providers, in residential provider settings so that they have access to this health care. We certainly need to promote primary health care delivery models. There is a great deal of talk about the new medical home pilot, which we think would work well for our folks living in the community. We need to provide market analysts -- analyze the market out there. We need to provide technical assistance, training assistance, business planning to access Medicaid expertise and programs. And now is as good a time as any to start piloting projects to support the capacity of the existing providers and engage new providers to provide medical care.

As far as mental health and behavioral services: In addition to the obstacles to obtaining appropriate medical care, access to mental health and behavioral services has been a long-standing problem for our community. Some of the provisions in the Department's comprehensive Medicaid waiver proposal -- that we hope will address the unmet needs of individuals with dual diagnoses of a developmental disability and mental illness -- include a dual diagnoses pilot program for children, amending the community care waiver to include behavioral supports; and the creation of specialized case management and care coordination protocols for managing dual diagnoses adults. We think this will go a long way toward significantly increasing community capacity for mental health services for people with intellectual and developmental disabilities.

However, we do not feel these proposals will fully address the lack of behavior services in the community, and we think there must be a substantial investment in creating additional behavioral services for adults and children with intellectual and developmental disabilities. In fact, we are proposing, and we would like to see in the Fiscal Year 2013 budget, an appropriation for \$7.5 million in new money specifically for behavioral supports, as this is a growing area of need that requires substantial development in order to adequately support individuals and their families in the community. And I hope you'll be hearing more about that as we move along in the budget season.

Certainly, as we talked about, accessible housing is going to be critical. So in addition to the medical and mental health needs of people with intellectual and developmental disabilities, the lack of accessible housing in the community is a substantial problem. In addition to the overall need for accessible housing, as individuals with intellectual and other developmental disabilities age we need more barrier-free community-based residential options for individuals with significant medical needs in order to avoid nursing home placements in the future. So we really have to assess where we're -- you know, what we have now and what our future needs are going to be as far as barrier-free living.

Certainly we agree that no individual should end up in an institution simply because there is no accessible housing available in the community. This is an area we certainly have to look at.

Case management: another area. As the State continues to move folks out of developmental centers, quality case management is vital to an individual's safety and success as they transition to the community. It

takes about 12 to 15 months to develop the necessary supports that will allow a single person to move into the community. And once the individual moves, the DDD case manager should continue to monitor his or her situation through personal visits out in the community. Not only is quality case management critical to the successful transition from institutional care to community living, but it can also prevent emergency admission to developmental centers by assisting individuals in obtaining the supports and services needed to avoid an emergency.

The Arc of New Jersey recommends, in this case, that DDD clearly define and communicate the role of case managers; utilize adequate, up-to-date information technology; put into place clear guidelines for case management; put in place mechanisms for evaluating the success of case management; and, when feasible, allow consumers the choice in determining their case management.

I imagine we can't talk about this issue without talking about staff salaries and COLAs for the community providers. As we look at how we can improve the capacity in the community to serve more people with intellectual and developmental disabilities, I can't stress enough the need for consistent cost-of-living increases in the provider contracts and rates to meet the skyrocketing cost to retain quality staff.

One of the biggest challenges the community faces in serving people with intellectual and other developmental disabilities is recruitment and retention of direct support professionals, and the demand for direct support professionals is only going to continue to grow. While the New Jersey Partnership for Direct Support Professionals workforce development has worked to create access to training and a career path for direct support

professionals, we really need to develop an aggressive plan to address this challenge.

Finally, safety regulation and oversight: Whether served in an institution or in the community, the safety of people with intellectual and developmental disabilities is paramount. Community placements offered through DDD are well-regulated, subject to appropriate oversight, and include investigatory and review mechanisms to protect the rights of people using these services. Additionally, we now have a Central Registry of Offenders against Individuals with Developmental Disabilities, which requires the Department to maintain a list of caregivers who have been determined to have abused, neglected, or exploited an individual with a developmental disability, and bars listed offenders from being reemployed or volunteering in Department-funded programs.

We believe we have a very strong and safe community support system out there, but we are constantly looking at ways to improve it; constantly looking at ways that we can make it stronger, safer, and better. Despite these challenges, we believe there is no reason that we can't continue to move folks from developmental centers and support them in the community of their choosing. We continue to serve people with intellectual and developmental disabilities with a wide array of quality services in the community. And I think it would be shortsighted to use these challenges as an excuse to halt the process. We see it as an opportunity to continue to make the services better.

So I am pleased to be here to have this conversation, because I think the opportunity is here to build up and improve on our community

service system, while making the entire system better for the 42,000 individuals registered with DDD, in preparing ourselves for future growth.

I have many more comments in my testimony, but I think because you have other people testifying I will leave it at that.

Thank you for the opportunity to provide this information today.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Tom.

I want to welcome Senator Vitale.

I don't know if you have any remarks or questions for Tom. But we're opening up with community housing and the needs for placement.

And I think the bottom line is the dollars, because before Senator Vitale remarks-- You talked about a whole host of other support services that are needed. And quality care and parity for the employees-- And I just want to mention that we, as a Panel, did have a conversation with OLS, and we asked them to compare, in accounting, the staff expenditures for community versus developmental centers. And there seems to be a feeling out there with a lot of the advocates that it would be less money in the community placement -- in the community than it is in the center. But we did not get that from OLS. It was sort of-- It sort of came out mutually exclusive. So I think the bottom line here is funding, and dollars, and how to achieve that.

I don't think you can answer that at this point, but it's a comment more than a question.

MR. BAFFUTO: I mean, at the very least, regardless of, you know-- I don't believe the Arc has ever been on record as saying it's less

expensive in the community, but I think at the very least we have facility costs -- large facility costs -- that when a center is closed, at the very least some of those funds can be used to build up our community infrastructure. At least it would be our hope that that's where the money would be used.

ASSEMBLYWOMAN VAINIERI HUTTLE: And a lot of those costs are covered, I think, under Medicaid and the community care waiver, correct? That was what--

MR. BAFFUTO: Well, for people living in the community, no.

ASSEMBLYWOMAN VAINIERI HUTTLE: Right.

Senator Vitale, I'm sorry.

SENATOR VITALE: I do not -- not at this time, thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay, thank you.

Any committee members for Tom Baffuto? (no response)

We've heard you so often, Tom, I think we've exhausted our questions.

MR. BAFFUTO: Well, thank you for the opportunity.

ASSEMBLYWOMAN VAINIERI HUTTLE: But we always appreciate your advocacy, and we thank you for coming.

Thank you.

Next we have-- Since I don't have my list I'll call up Kim Todd.

Thank you.

KIM TODD: Good afternoon.

On behalf of the New Jersey Association of Community Providers, our Board of Directors, and the thousands of people with intellectual and developmental disabilities our agencies support, we appreciate the opportunity to be here today.

ASSEMBLYWOMAN VAINIERI HUTTLE: Kim, just for the record, would you state your name and affiliation, please? I'm sorry.

MS. TODD: My name is Kim Todd, and I'm the CEO of the New Jersey Association of Community Providers.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

MS. TODD: We appreciate the opportunity to be a part of these proceedings today.

NJACP is a statewide Association committed to ensuring the continued progress toward greater quality of life for people with intellectual and developmental disabilities. Our organization is comprised of community-based organizations that provide the full spectrum of services for people who live in the community, from housing, education, respite services, and-- The list is here. I'm not going to belabor that.

But I wanted to talk a little bit about community development and what would happen if we were to close the institutions. And to look at that, I want to look at -- I want to take a couple of minutes to talk about the foundation of some of the endeavors that DHS has actually done before, that really mirror this community development, that would need to take place in order for us to close our institutions.

We have a rich history at DHS and in New Jersey of successful reforms in human services. This includes welfare reform, the creation of a children's mental health system from the ground up, mental health reform, and the reengineering of our child welfare system. These reforms retooled very long-standing policies and practices away from long-term residential care for the people that they supported and successfully transitioned people to be supported in the community.

These statewide systems introduced managed care principles, they retooled payment systems, and introduced data-based decision making which informed case management, treatment, and public policy around the needs of the people that are supported at DHS -- who are the most vulnerable population, which all of you know. They're no different than the DD population.

Having had a long career in State government at DHS, I had the fortunate opportunity to be involved directly in the planning, development, implementation, and roll-out of each one of these reforms. So with this lens I've talked to many of you and testified before. I come with the lens of being very confident that this system can be reformed and that we can build a community services system that meets the needs of people without institutions. And it's from that framework that I continually talk.

I have a whole lot here about national trends. I'm going to skip most of it, because you've heard most of it before. But I want to call to your attention that there are 12 states and the District of Columbia that operate systems with no institutions at all. They are New Hampshire, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, Maine, Indiana, and, most recently, Alabama. Alabama just closed its last institution actually last month, and they had, over the years, five institutions. They supported roughly 4,000 people, and they grew their human services system to support an additional 6,000 people, which took care of people in the community who would be averted from institutional placement. And it will be very interesting to watch how that happens, because actually it did just happen.

I also would like to call to your attention Maryland, which closed Rosewood. Rosewood was a DOJ-monitored institution that had many of the same problems as some of our institutions have, to be very frank. They closed that institution under the guise of Michael Chapman, who managed to take all of the resources of the institution, coupled that with the resources of the community, and in partnership with the people who lived at Rosewood and their families moved that institution to closure. And it was done in a very, very specific manner that had really good outcomes. They did satisfaction studies as they went along. And in the end, the consumers were well-placed, the families were all happy; and the staff were too, who used to work in the institution.

So there are different models to start to look at. There's across-- You know, after 30 years we took apart the different plans -- execution plans -- and there are a number of them to look at as models of how we can do this. Because it's not something that we really, in my opinion, have to invent. Because everybody has done it before us. That's the neat part of being at the end. You don't repeat anybody else's mistakes, and you can capitalize on their successes.

Hissom, in Oklahoma, has a fabulous person-centered approach -- that every person they put in the community -- they tailored the development in the community. California, which is another favorite of mine, is-- They took all-- They closed their institutions without displacing any state union staff. They were able to take all of those staff people and they created something -- I call it *staff without walls*. They became the mobile force to go out into the community. And they also looked at-- They had-- They closed it in the early '90s, so they had a lot of attrition and

early retirements. And they were able to backfill many of the state staff into other situations, into other work environments, very much like-- We have the same situation here with all of the retirements at DHS. Every day we hear someone is retiring. That is what we did with the staff when we closed Arthur Brisbane. And I was directly involved with that -- with each person at Arthur Brisbane. They were offered a choice of three positions, and we backfilled all of our positions with the staff and no one lost their job. Because, you know, when you're looking at this, you want to preserve those resources. And it is something to look at.

But you can look at the psychologists who work at our institutions, the social workers, the physical therapists. All of those are very much needed services in the community. They could be assigned to our regional offices and provide some of the services, and supports, and deficits that we think we have in the system -- that Tom was referencing. So I think that's a great model to start to look at.

Michigan has really looked at: What is a person-centered system? And they have closed their institutions using, again, that person-centered approach. But they've also introduced shared living, which is a housing approach that looks at and allows people to live in different living arrangements. And I've been working with the Division of Developmental Disabilities to put together a regulation that mirrors very much what has been going on across the country. And we looked at 26 models of shared living and have come up with a regulation that we think can work in New Jersey. So, again, that's another resource to look at -- our housing piece.

Alabama did their roll-out of housing. The last time I talked to you we were talking about developing housing and group homes. And I

think some of the discrepancy, in terms of my numbers as opposed to looking at OLS' numbers, is that we always talk about building a group home. And that's been the practice for many, many years in New Jersey. We build group homes. With the foreclosure market that we have today, I would say to you, "Why would you build anything, because you can turn around and get a house at a fraction of what you would have been able to have historically?" And with the accessible housing piece, that's what Money Follows the Person is for. In your packet I gave you two Federal funds that the Federal government has used as incentives to enhance match. And in the packet you can see what you can use it for. But those funds are for -- to provide people with assistive technology, accessibility, setting up the house. So it gives you very much needed Federal dollars. And New Jersey is eligible for up to \$30 million in Money Follows the Person. And the Community First Choice Act gives us another pot of dollars to actually build the community sector. And it's an additional 6 percent FMAP.

Now I've lost my place here.

So I think that we have the benefit of really looking at different approaches. But I also want to go back to New Jersey. We have a rich foundation in New Jersey of community. We have 300 providers specifically in the DD world, but we also have to look at the rest of the provider community. There are 1,100 providers. Debbie Wentz, who I think you talked to this morning, and Carolyn Beauchamp, who are the Mental Health Association execs-- We all work very closely together, and we are trying to accomplish cross-training so that we can address the behavioral health needs of our population. And frequently I will call

Debbie and say, "I have this provider who wants to provide services to this person, but they have this behavioral health piece. Will you help me?"

But I think one of the most incredible opportunities that has just come down the pike is the comprehensive waiver and the changes that are going to occur as we move toward the ASO model, where all of our behavioral health needs of the mental health population, the DD population, and the substance abuse population will be handled by that ASO. So you will have that provider network that is brought together under the guise of that entity to provide for the behavioral health needs in a very organized manner that triages case management and provides the services.

The second part, I think, when we talk about some of -- listening to some of the concerns, is the health piece of this. All of the DD population has been enrolled in managed care today. They provide-- It provides a medical home for them. And each of the four HMOs in New Jersey -- we've been working with the Division of Medicaid to -- and we've had a whole series of meetings of what this network should look like. And they are actively recruiting for new providers to ensure that they can provide the health services for the DD population. And it also-- They also are linking with-- I mean, we live in a medical hub. We live right in the middle of Philadelphia, New York. But also some of the best hospitals in the country are right here in New Jersey, and the networks are right here in New Jersey. So when we look at taking care of the medical needs of people in New Jersey, I think the Commissioner -- and rolling out that managed care thing -- it was a great opportunity to make sure that we do address the medical needs. Also, as the ASO comes online, there's a triage between the

behavioral health side of the ASO, as well as those HMOs. So then you have a coordinated set of care. So you truly do have that medical home then. And I think it's a great idea.

We have providers now-- I have providers in New York and Pennsylvania who have already done all of this, and we've had some really good conversations as associations. And we started to create medical specialty homes also that take advantage of the great assistive technology and technology fixes that we, as an industry, can take and apply to housing, to help people live more independently. My father-in-law is a quadriplegic, so I have very, very-- I'm very intricately involved in it. There are such things as *smart homes* that apply total technology to the entire house; wheelchairs that just -- you can program them to move. Today's world provides much, much different opportunities than we had when we closed North Princeton Developmental Center. I worked at North Princeton Developmental Center, New Lisbon, etc. So I'm very familiar with our institutions and those approaches. But when you go to-- If you were to go to-- I went to Minnesota two years ago to look at what they do. The opportunities that people have who have developmental disabilities are very different in other states. And that's always been my passion -- to try to drive that here.

So when we look at these things, and we look at the Federal dollars that we have that can help us with this very short timeframe-- If you note in the Money Follows the Person, it expires. We have a window, and it expires in 2015. The Community First Choice Act expires in 2016. So it's the opportune time to act to try to do this. Because after it expires, it will be our State dollars.

So I've given you a lot of other information in your packet. And if you have any questions, I will be happy to answer them.

ASSEMBLYWOMAN VAINIERI HUTTLE: And I see our Co-Chair, Senator Van Drew, coming in. But there are still those obstacles. Rosewood is in Maryland and -- different state. But the obstacle still is the family and individual concerns for those who already have their loved ones in the centers. And for them, this is their home. So that's one obstacle that I see when we're closing a facility. And it is mentioned in the Rosewood plan as well -- community provider capacity is what we've been talking about, because we don't have the homes readily available or the accessibility type of homes. We have no place for these people to be transferred to at this point. And, of course, the last is the court-committed individuals. So while you give great testimony with the greatest intent of placing these individuals in a place where they -- it is a home-like atmosphere where they are content to be -- there is still the other side of the choice -- and I don't want to say choice -- but the other side of some of the obstacles of families and their concerns. And those are some of the things that we're grappling with, as well as, of course, the funding.

And so those are the issues I think this Panel -- we have to consider. And I think that as we have your testimony, and listen to it, and we've listened to it before as well -- and we appreciate it -- and I think we have to go through this and see. Because I think Rosewood was about 18 months in closing.

MS. TODD: Seventeen.

ASSEMBLYWOMAN VAINIERI HUTTLE: And how long was North Princeton?

MS. TODD: North Princeton was two years.

ASSEMBLYWOMAN VAINIERI HUTTLE: Two years.

So there is a--

MS. TODD: So it is a phase. And I've never come to you saying we shouldn't have any institutions. And I respect families 100 percent -- that that's what they have chosen. And there are a number of initiatives that the Department of Human Services has put in place to try to talk to families. But in the end, it is the rule of three: that the team recommends the person, the person wants to go, and their family wants to go. So I've never come to you and said that I think we should close them all. It's really just right-sizing it so that it fits need and that people who want to leave can leave.

I'll leave you with one very short story.

ASSEMBLYWOMAN VAINIERI HUTTLE: I think the key is: who want to leave.

MS. TODD: Exactly. And we are on the same page there. It's not a debate for me at all. But I think it's also unfortunate for someone who wants to leave.

I had the opportunity to work with someone at New Lisbon many, many years ago. We won't talk about how many. But he's been in the community for eight years. I signed his IHP to leave a long time ago. He was able to leave eight years ago. Unfortunately, Gary died a couple months ago. He had eight really good years in the community, and he had all kinds of physical problems. But he had a great, great time while he was out in the community. If you asked Gary, he would tell you, "It was my preference to live in the community all of those years." And that's my

intent here; it is not to say that everybody who is in an institution has to go. And I do want to clarify that. I really do believe in choice. You've heard me talk about that; you've heard Assemblyman Greenwald talk about it. But for those who want to go, I hope that we will be able to figure out how to do it. Because if we don't, I think it diminishes New Jersey, and it devalues the lives of people with developmental disabilities and intellectual disabilities who do want to live in the community.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Welcome, my Co-Chair, Senator Van Drew.

SENATOR JEFF VAN DREW (Co-Chair): Thank you, Chairwoman.

First of all, let me apologize to everyone. I'm in the middle of a Budget hearing that is still going on. We just took a little bit of a recess, and I've got to run back there

Very briefly, the little bit I did hear of your testimony makes some sense. I think the words are important when we clarify that not every single individual who is in an institution should be in the community, but folks should have that opportunity -- that they should be able to move into the community if they wish to do so. That doesn't mean that we push them into the community or that we convince them to go into the community, but that they have that opportunity.

Secondly -- and I know I'm being repetitive, and you all heard testimony about this -- but it's done properly. The concern that many of us have is that we would do it too quickly or do it without the proper resources or dollars, at the end of the day, because we are so short on money in the State, as every state is, and that these individuals, at the end of the day, are

at risk. It's been done, in some places -- it's been done well. In other places it hasn't. And, again, forgive me because I wasn't here. But if we look at some of what has happened in New York state, and some of the other areas where I've read -- there have been some very -- difficult reading, actually, to go through it, because there have been some tragedies that have occurred. We want to make sure whatever we do in New Jersey we do it the right way.

These are -- I don't have to tell you, you know better than I do -- vulnerable human beings who deserve to have access to a good way of life and to be protected, because they also need that help. So as we go through this process, hopefully we strike that happy medium, and I believe that we will.

And, again, I apologize for not being here.

But the one thing that happened, Co-Chair, because I wasn't here-- Do you know what happened?

ASSEMBLYWOMAN VAINIERI HUTTLE: Are you getting us money? What?

SENATOR VAN DREW: No. I wish. I know, budget, right?

Your meeting is going to get done quicker.

ASSEMBLYWOMAN VAINIERI HUTTLE: You didn't get a joke out of that. No one laughed at that.

SENATOR VAN DREW: How come nobody laughed at that? Nobody knows me that well here? Come on. (laughter)

ASSEMBLYWOMAN VAINIERI HUTTLE: No, they know I'm still here. Mary Pat and I have been here since what time, 10:00?

SENATOR VAN DREW: With both here it's double--

ASSEMBLYWOMAN VAINIERI HUTTLE: And Cleo.

Well, thank you, Senator.

I really have to applaud the Senator for his commitment, especially in your area with the Vineland closure -- potential closure and with the continued Task Force that will continue to work on these issues. And hopefully we will come to some-- It's not even an agreement at this point, it's really a plan that's reasonable and practical. And I think in all practicality we're looking at the practical plan and the compassionate plan.

Any other questions for Ms. Todd?

Assemblywoman Angelini.

ASSEMBLYWOMAN ANGELINI: Question/comment. Can you hear me? (affirmative response)

You worked with DHS for a number of years. The closing of Marlboro -- I was involved with that at the county level. And to my recollection it seemed to go -- it took a long time. There was a lot of controversy. But once it actually happened, the plan seemed to work well.

That was when, the early '90s?

MS. TODD: Yes.

ASSEMBLYWOMAN ANGELINI: So now things have changed drastically. Do you see that we're in a better position? And if so, what is -- what makes the environment better now than in the early '90s?

MS. TODD: I think that when we closed the Arthur Brisbane Treatment Center -- was part of a child welfare plan. Sitting on the State side, we also-- I actually sat there and said, "How are we going to have a children's -- a mental health system with no psychiatric hospital?" It really-- I think it was a lot of the same things that you had.

Unfortunately, we had no choice. The State Monitor said, "You will close," so we did it. And we looked at how we closed things in the past. We, of course, went back and looked at Marlboro. But we also looked at how -- what other states did, etc., and borrowed from that.

And I am very, very proud to say that all of those kids were -- they had severe mental health challenges. And we, today, have a system that is able to have them in the community. And they have different types of programs. There are step up programs, there are step down programs as things start to be more complicated. The resources were put into it, a lot of it using the Federal dollar -- which I'm encouraging us to do also -- and it went. And the other positive side was that we were able to utilize very, very valuable, trained State staff in other places. So you had the added benefit of -- they stayed in the system, but you also had that cross-training. I sit here, and I've worked in substance abuse, mental health, DDD, child welfare, across. So you come with a different lens, and you approach your job with a different lens. And I think that's the benefit.

When we look at the DD side and the dually diagnosed, we have some providers that cross systems, so they have a contract with mental health, with DDD, and disability services. That organization has very different resources than someone who just does this. And I think that's how I would answer your question.

Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Next we have Dr. Deborah Spitalnik, from the Boggs Center on Developmental Disabilities, Executive Director.

As always, it's a pleasure to listen to your expertise. And we welcome you.

Thank you.

DEBORAH M. SPITALNIK, Ph.D.: Thank you so much.

You have my written testimony, and I won't go through all of it, even though I'm from the University and they sometimes require that.

For the record, Senator Van Drew, Assemblywoman Huttle, and distinguished members and guests, I'm very honored to have the opportunity to testify before you today.

My name is Deborah Spitalnik, and I'm a Professor of Pediatrics at UMDNJ, and also Director of the Boggs Center on Developmental Disabilities, New Jersey's University Center for Excellence in Developmental Disabilities. And one of our Federal mandates is to advise policy makers on issues of importance to people with developmental disabilities and their families.

And so my goal today is to place our conversation in the context of some larger national trends. And I'm going to approach community from a slightly different perspective. And you have very extensive testimony that's based on a variety of databases, including one that has not yet been released by the University of Minnesota. And I just want to highlight some of that and also make some recommendations for the kinds of things that we need to consider about community.

I think, as others have stated, as the Assemblywoman has reflected, the clear direction of Federal policy is toward community. That's a development that started with President Nixon, it's been true across Administrations. We see that both in the Olmstead decision, we see it in

the direction of Medicaid funding, and we see it at the State level in a variety of things that have already been discussed. And one of the most, I think, promising developments of that -- which I will talk a little bit more about later -- is New Jersey's application for a comprehensive Medicaid waiver and for rebalancing the delivery system. And really a theme of what I want to talk about is rebalancing our system.

The majority of the 43,136 people who are registered with the Division of Developmental Disabilities -- 70 percent of that caseload live at home with their families. And, in fact, 90 percent of the people served by the Division live in the community. In New Jersey, we have more people living with their families than in other states. And also I think that what we need to note is our waiting list of 8,177 people. And so as we talk about community, one of the things that we have to think about is: How do we create, how do we redesign, how do we reinforce, how do we support a system that really addresses, to the maximum extent feasible, the needs of all these vulnerable individuals and their families?

We know that New Jersey has a smaller percentage of people than other states who live in community residences, and we have 2,529 individuals residing in developmental centers. We have two times the national average of people living in developmental centers. As spoken about earlier, there are 10 states that no longer -- and the District of Columbia -- that no longer have large institutions. New Jersey is one of five states that still has over 2,000 people in these residences.

One of the things that I want to stress -- both with respect for the needs of people who live in developmental centers -- is that the needs of people in New Jersey are very comparable to the needs of people in other

states: the level of disability, the kinds of services that people need. And additionally what I want to stress is that given the number of people who have lived with their families, the needs of people in the community are as dramatic and as compelling; and that one of the traps that we dare not let ourselves fall into is to pit groups of vulnerable people against each other, and to try to find ways that we can serve people where they live -- where they choose to live -- and with the kinds of supports that they need.

I'd like to call your attention to one of the charts in my testimony on Page 11. It's labeled Table 3. And it is a reflection of the changes in expenditures for both -- for Medicaid money. As all of you know, Medicaid is really the driving force in financing in New Jersey's developmental disabilities services and services around the country.

And there are some things that I want to point out. In both New Jersey and the rest of the country, our expenditures for home- and community-based services -- what we call in New Jersey the *community care waiver* -- have doubled in -- from 1993 to 2009. What I think is noticeable is that we spend more in New Jersey in each category -- home- and community-based services, as well as ICFMRs, which is the Medicaid term for our developmental centers -- than in other parts of the country.

In most cases, our amounts of increase in each of our categories are larger than the rest of the country. And what I want to point out is that we have no diminution of the respect for the needs of people in developmental centers -- is that we spend, on the average, four times as much to address the needs of people in developmental centers as we do to address the needs of people in the community. We know that there are people in the community, we know that there are aging parents--

SENATOR VAN DREW: I'm sorry, I don't mean to interrupt you, but a quick question on that though.

DR. SPITALNIK: Yes.

SENATOR VAN DREW: On average -- I understand what you're saying. I've been in developmental centers and I've also been in community providers and people's homes as well. Many of the individuals who are now left in developmental centers, particularly in the most recent years, are very profoundly disabled as opposed to some of the folks in the community. Now, there are some folks in the community who are very profoundly disabled too. But what has happened is, as you know, there's been a process in New Jersey where the population of these centers has gone down, and they have shed the people who most want to go in the community or most easily can go in the community, which means the people who are left -- many of them, not all of them -- but many of them are the most profoundly disabled and require very, very serious attention. So I'd just like to point that out, as far as the cost factor.

DR. SPITALNIK: And, Senator, I certainly appreciate and respect that fact. I was the guardian of Elizabeth Boggs' son who lived at Hunterdon Developmental Center, who had profound disabilities, a seizure disorder, cerebral palsy. So I have a very personal appreciation for that.

And I think one of the challenges that we have, that is so difficult, is both to address the needs of the individuals who are in developmental centers, but also to address the needs of people who are living with their families -- not all of whom, but many of whom, have profound needs. We have families who, for the last 30 years, have been providing around-the-clock care. They have to suction their family member

during the night. They not only have to provide total physical care, they have to -- but there is behavioral supervision.

So I think part of our challenge is in no way an either/or, but how do we make the most efficacious use of resources so that families who have -- whose family member is living at home really feel that they can go to their grave in peace because they know that their family member will be taken care of. And it is a wretched situation that I think we're facing, both as a State, as a society, as a nation of: How do we find ways to expand the embrace of our empathy, to use our resources in a way that we get people -- as many people as possible -- what they need?

One of the things that I want to mention -- which is in no way disregarding your point, because I feel it very acutely, and I think the data would bear you out -- is that 90 percent of our population receives 66 percent of our resources. And we know that there is profound disability in the community also. We know the pressing needs of people with autism. And how do we find ways to address these needs? And I think that's one of the challenges we have.

One of the things that I want to point out is that the waiting list for the Division of Developmental Disabilities, about two years ago, became a waiting list for home- and community-based services. And there are many things -- and we could have long hearings on the whole issue of the waiting list. But one of the things we know from -- statistically is that the home- and community-based waiver grew at .3 percent in the last two fiscal years that we -- the last two fiscal years. Which means that if you are one of the people on this 8,000-person waiting list, you don't have many -- much hope that you're ever going to be in a position to receive waiver

services. And that 8,000 people who are on the waiting list are also a subset of the people who are living in the community.

SENATOR VAN DREW: If I may just interrupt you again.

DR. SPITALNIK: Please. You're not interrupting me. I appreciate the questions.

SENATOR VAN DREW: That is a good point. And I think for this committee to consider and everyone to ponder is the difficulty there, in that as you move people from the developmental centers into the community, they're going to need some significant resources as well, as well as the people you're already speaking of. So there's still going to be a real competition for resources, and there is still going to absolutely be some difficulty. Because, again, if we're moving people out of the developmental centers, some of them are going to need the type of care that you rendered when you worked within the doors of a developmental center.

There are those with whom I speak at times who believe that if we're to close the developmental centers, we'd all be so flush with money that everybody could be taken care of and everything would be fine. I think it's going to be a little bit more challenging than that because, again, you have two groups of people you need to take care of. Just because you close a developmental center, and X amount of dollars hypothetically are freed up, it doesn't mean it's all going to rush into the community to take care of the people who are on waiting lists. It has to take care of the people you're going to release and, perhaps, some of the people who are on the waiting list as well. So there is a competition for resources.

But one question I have to ask you -- it's just that I'm curious about your experience, which is a special kind of work and I applaud you

for -- and I really mean it -- for doing it; because I know people who do the kind of work you did. People who've done what you've done have such diverse opinions about moving people into the community. I meet people who are very talented and trained like you who are very passionate like you, and believe we're overdoing it and we're pushing too many people out the doors of the developmental centers; and then I meet other folks who are like you who are sort of advocates for it. Any thought on that -- why that is? Is it just purely opinion, or is it the experiences these individuals have had? And they're folks who are retired by the way. They're not, "Hey, I want to keep my job." They've been there, they're done.

DR. SPITALNIK: Right. Well, I think-- I have a couple of different responses to that, which is: I think, in many ways, the very difficult choices we face really epitomize a series of choices we have across human services, which is that we have limited resources and how do we use those resources in the most effective way possible. I think many of us -- and I have been involved in deinstitutionalization efforts, but I really come to you today to try to bring you the information within a variety of databases -- have seen remarkable growth in individuals and changes in their life with different kinds of opportunities.

I think one of the things that has been the experience in some states has been that the process of creating the infrastructure to support the needs of individuals who are choosing to leave developmental centers makes a positive difference in strengthening the entire system. So if we find ways -- if an individual, a family chooses to live in the community, and we find ways to support that individual who may have behavioral needs -- and the technology is certainly there -- then we have strengthened the entire

system; and that makes it more likely that the individuals who have never moved into an institution can continue to live with their family. And when they can no longer live with their family they can live within either a supervised, or semi-independent arrangement, or a group home.

And let me suggest some of the things, if I might, that I think could make a positive difference in what we need to do. I think you have shown extraordinary leadership in -- and the Assemblywoman -- in 2028, in terms of pushing New Jersey to develop a systematic plan for how we are going to use our resources and how we're going to address these very difficult decisions. Kim Todd spoke earlier about it. I won't belabor them, but there are opportunities for rebalancing our system in terms of drawing down increased Federal resources that, I think, can make a difference in the lives of people with developmental disabilities and their families.

I think that when we structure the community for people who choose to leave institutions, that that makes system improvements that make it possible for their twin, who lives in the community already, to function. I am not advocating closure. What I am really trying to heighten for our consideration is that the way that we use resources is leaving out a huge constituency of our fellow citizens. So I'm not pitting people against each other, and I know that it's very easy for this conversation to feel that it's institutions versus the community, people who are in developmental centers versus others. But moving forward, we need to find ways to utilize resources that strengthen the community system for people who live there now and for people who choose to move there.

I think a couple of things that are essential are that we do have -- that we do create a bridge fund, having planned systematically to utilize

in the community. I think your direction, in terms of really having an overall plan for the State, is essential. I think that we have to have information technology. One of the things that I know this committee, this Legislature, is so frustrated by is trying to get information about the individuals who are served through the Division of Developmental Disabilities. And I certainly share that frustration in trying to put together testimony. And it's also very difficult for providers to plan and for families to understand where they (indiscernible).

I think that there are things that we do need to put in place and strengthen. We do have some quality improvement and quality assurance across the system. It is required by -- through Medicaid funding. But I think we need more robust quality improvement and quality assurance. I think we need quality improvement that looks at individual and personal outcomes and well-being, as well as building on, for example, the national core indicators which New Jersey utilizes as part of the National Association of State DD Service Directors. But New Jersey has no mechanisms for taking what we learn from this national benchmarking and improving our system. So I think that's something that's very needed.

I think that we need to -- as Tom Baffuto alluded to earlier -- I think we need to strengthen case management and care coordination. I also think that we have to invest in families earlier. At this point, the only way that you can get services is really to have an emergency. And one of the things that we know is that when you provide people with in-home supports, when you provide people with autism and other behavioral disorders behavioral intervention earlier, your downstream expenses, as well as the intensity of the situations and crises, is better. New Jersey has been

planning a supports waiver for people who live in the community, which would be a meaningful amount of investment in supporting the family who cares for their loved one.

I think that one of the biggest challenges -- and I really look to the Legislature for supporting efforts that have begun -- is to really continue to develop the direct support professional workforce. I know one of the concerns that has been raised about the community in comparison to developmental centers is a higher rate of staff turnover. I am delighted to be able to report to you that through the New Jersey Direct Support Professional Career Path pilot, that was funded by the New Jersey Council on Developmental Disabilities, we were able to demonstrate demonstrable decreases in turnover for staff working in the community. This was such a success that the Department of Human Services adopted the College of Direct Support both for community providers, developmental center employees, as well as families and people who work for them directly in their home. One of the things that we advocated for that has come to pass is in making these courses available to staff, and looking to expand this to the developmental centers. We suggested that Vineland be the first place that the courses were offered for two reasons. One, to help staff understand that if individuals were moving to the community -- what the environment would be like that they were moving to; and also to give staff the tools if they were interested in working in the community. And we're delighted to report to you that over 100 staff at Vineland have signed up to take these online courses. And wherever they work -- whether it's in Vineland, another developmental center, or the community, or create a shared living

arrangement for someone they've been caring for for years -- I think this is an important development.

As you know, the community support for direct support workers in the community has been financially static for many, many years. And the whole issue of care giving is not only an issue for people with developmental disabilities, it's an issue for all of us in terms of what's going to be the competition with those of us in the baby boom generation who are aging, for people living longer with chronic diseases. And the Legislature can play a very important, impassioned, meaningful role by not only supporting financial increases for staff, but supporting career paths, supporting educational opportunities, working with the Department of Labor to have direct support recognized as a career, and also as a way of addressing some of the unemployment challenges we have in New Jersey.

The last thing I want to mention -- and, of course, I would welcome further questions -- is that the other thing we need to do is to encourage the development of employment opportunities for people with developmental disabilities, and also self-advocacy. We know that there are people in the developmental centers who go out to jobs. And the possibilities that jobs create -- not only for people in developmental centers, but for people in the community -- create both a counterbalance to a complete dependence on social services, but, more importantly, give people dignity and anchors in their life.

The Federal government, and we as a State, have invested a tremendous amount in the -- as is only right -- in the education of all children with disabilities. Part of that educational entitlement is an entitlement from transition from school to adult life, which includes

focusing on job sampling, community participation. When we move to the eligibility mechanism -- the way that we fund adult services -- we lose valuable ground in terms of our investment. So that the last thing, in closing, I would say is that we really need to refocus our efforts on employment of people with disabilities. And there is also -- and I will continue to wear my university hat -- there is wonderful data from around the country that even people with the most severe disabilities, with appropriate supports, can work and become -- have the dignity of contribution and, in many cases, become taxpayers rather than just utilizers of social services. And in New Jersey, we have a Medicaid buy-in where people can work as well as retain the benefits that they need to support their disabilities. So it is no longer an either/or choice.

I thank you so much for inviting me today, for listening, and I welcome your questions. I know that we have a shared commitment to the well-being of our vulnerable family members and our fellow citizens; and that it's only through dialogue like this that I think we can get to better solutions, within the economic and social context that we're in, that support the wishes, preferences, and rights of people with disabilities and their families.

Thank you so much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

SENATOR VAN DREW: Thank you.

Just one last question.

DR. SPITALNIK: Please.

SENATOR VAN DREW: Talking dollars and cents--

DR. SPITALNIK: Yes.

SENATOR VAN DREW: I think, if I hear you right, what you're saying is that we really need -- obviously we need more staff in the community, and we can train some staff that currently works; we need to pay the staff that's working in the community more. I think everybody would agree with that -- that they are underpaid and it's been very static for a long period of time. So that would be both for the folks who are in the community now, for the folks who would be released that are being deinstitutionalized, and for the folks who are on the waiting list. So there would be a good number more of individuals working in the community who all deserve a higher rate. I'm just thinking the dollars and cents of this too.

And capital-- I'm wondering if anybody has done these numbers.

DR. SPITALNIK: Can I comment on that, Senator?

SENATOR VAN DREW: Yes, I just want to finish this one part, and then--

DR. SPITALNIK: Oh, I'm sorry. I apologize.

SENATOR VAN DREW: There's also capital costs. Because as you know, in some cases -- and, for example, I have a community home right down the street from me. I always speak about it. I love it. They're great people. I have a barbecue every year and they all come over.

They built that facility especially for them, and it's a wonderful facility. It's a big ranch-style house, it has larger doors, a larger driveway, it's very accessible. It cost a good deal of money, but they were able to do that. So we would need money for rehab, and we'd need money for new construction, as well, as part of this process. And we would need, obviously,

money to help all those who were most recently deinstitutionalized and released -- some of them more profound.

Does anybody -- it's a real hard question, it literally is the million-dollar question -- have any sense of how that all adds up? In other words, if you got your wish list, which is what I articulated here, how short are we going to be financially? Because that's a lot of stuff. That's a lot of building. We know we went through a lot of dollars and didn't even get close in the past. It's a lot of building, a lot of structural work that needs to be done, a lot of staffing that would have to be done, and an increase in what we pay that staff if they're going to even be close to what they make inside the institution. And then what? There's a loss of some Federal funding but a gain of other Federal funding? How does that all add up? Where do we end up at the end of the day if we do all that? How short are we? Any idea?

DR. SPITALNIK: I don't, and I would feel irresponsible if I gave you--

SENATOR VAN DREW: Don't feel bad, nobody does, by the way, who I've spoken with.

DR. SPITALNIK: So maybe that's the (indiscernible) question. I think that there are a variety of considerations to put in place.

Part of the direct support issue is not only wages, but also making direct support a career. The path that people are on now, the way our systems are structured, is that if you are a good direct support worker you get promoted out of dealing directly with people, and that's the only way you can get a raise. And one of the things that the Boggs Center, The Arc, Community Providers, and ABCD have been trying to do is to

professionalize that role. So part of professionalizing that role is not just a dollar issue. I don't want to, in any way, dismiss the dollar issue, because it is essential and we know that many direct support workers wind up working two jobs, many of the direct support workers wind up using food stamps and other government benefits because they can't make ends meet for their families. But education and professionalizing this role -- and there are Department of Labor models in terms of healthcare workers -- would go a long way, and educational opportunities, to making that an important role.

I think part of the calculus in other states -- and I want to not overgeneralize. Part of the ways that people have utilized the ICFMR moneys, when they're using them in the community, is to -- and I think the term of art is *blending and braiding* sources of funding, of utilizing other kinds of moneys that are nondisability moneys -- but moneys that are related to low-income housing, moneys that are related to energy relief, food stamps, other things that can accrue to people. And, in part, some of the challenge that we have -- and this is really the work of the panel that will be established through 2928 -- is to deal with the issue of infrastructure and aging infrastructure that we have in many of the developmental centers. So some of the costs that we see in developmental centers are not only the care giving costs, the food, shelter, program, but they are the cost of dealing with some very challenging real estate. And so I -- that really is the province of that other thing. But I think we have to find ways that are not all or nothing, but find ways to as creatively as possible figure out how we use our resources to meet the extent of need.

For my professional work, we have seen such dramatic positive changes in terms of saving low birth weight and premature babies, of saving

children and adults with traumatic brain injuries. But the consequence of that is that the numbers of people with disabilities are not decreasing. The Individuals with Disabilities Education Act, Supplemental Security has made it possible for people to live at home, but those needs are bearing down on us, and the needs of aging caregivers are bearing down on us. And so I raise those for our shared consideration in how we try to use our resources in the most efficacious way that's respectful of individuals' right to choose, but also builds a sustainable community system.

I wish I had a clearer, more direct answer; but I think, Senator, you're asking the right questions. And I hope in dialogue that we can work out those issues person by person.

SENATOR VAN DREW: Thank you.

DR. SPITALNIK: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: And I think the question that the Senator has just asked is the question that this Panel is asking the Commissioner and the Treasurer -- quite simply the breakdown and the difference in costs between developmental centers and community housing, and the difference in the Medicaid reimbursement and the waiver. And we have letters that we've just distributed, and we will look for those answers and, hopefully, be able to have the testimony and everything together in a white paper, and we can move forward with that.

DR. SPITALNIK: That's great. Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: But, again, does anyone have any questions for Dr. Spitalnik? (no response)

Thank you very much.

DR. SPITALNIK: Thank you so much for this opportunity.

ASSEMBLYWOMAN VAINIERI HUTTLE: We appreciate your testimony.

And I think we did ask someone from DCA -- but I don't believe we have anyone here at this point -- because I think the plan for 2013 under DCA is to provide more housing in the community, and it's something that we need to also address.

If there aren't any more questions from this committee-- I believe this is our final hearing, and I want to thank the committee members. We will, again, as I said, get back together with a white paper in a timely fashion.

And with that, I will close my remarks.

Senator Van Drew, I think--

SENATOR VAN DREW: I'm with you. (laughter)

ASSEMBLYWOMAN VAINIERI HUTTLE: It's not that we're exhausted. But I think that listening to the testimony-- It is certainly repetitive of what we have dealt with in human services. And I believe that this was a very healthy Panel to begin to address the concerns directly and to come to some sort of conclusion.

And I'm happy to hear that most of the people today did mention that, yes, there is a need to provide that community placement, but there is also, respectfully, choice to be considered.

And so with that being said, we will have our papers written up with testimony and responses from the departments.

And with that I will ask for a motion to adjourn.

ASSEMBLYWOMAN ANGELINI: Move.

ASSEMBLYWOMAN VAINIERI HUTTLE: Moved by Assemblywoman Angelini and seconded by Assemblywoman Tucker.

Thank you very much for coming. We look forward to a productive continuation of this, or resolution.

Thank you.

(MEETING CONCLUDED)