
Committee Meeting

of
SENATE HEALTH HUMAN SERVICES
AND SENIOR CITIZENS COMMITTEE
ASSEMBLY HUMAN SERVICES COMMITTEE

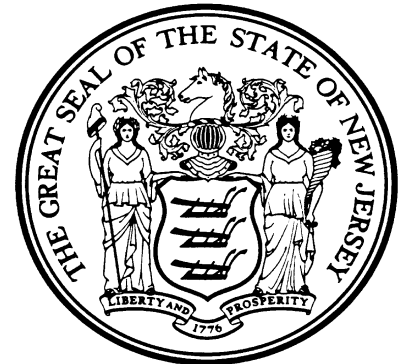
"The Committees will receive testimony from invited speakers regarding developmental centers and community-based services for persons with developmental disabilities"

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

DATE: May 7, 2010
1:00 p.m.

MEMBERS OF COMMITTEES PRESENT:

Senator Joseph F. Vitale, Vice Chair
Assemblywoman Valerie Vainieri Huttle, Chair
Senator Robert M. Gordon
Senator Fred H. Madden Jr.
Senator Diane B. Allen
Senator Thomas Goodwin
Senator Robert W. Singer
Assemblywoman Caridad "Cary" Rodriguez, Vice Chair
Assemblyman Albert Coutinho
Assemblyman Angel Fuentes
Assemblywoman Connie Wagner
Assemblywoman Mary Pat Angelini
Assemblyman Peter J. Biondi
Assemblyman Joseph R. Malone III
Assemblywoman Alison Littell McHose



ALSO PRESENT:

Eleanor H. Seel
Elizabeth J. Boyd
Michele LeBlanc
Irene M. McCarthy
Office of Legislative Services
Committee Aides

Jason Redd
Senate Majority
Kate McDonnell
Assembly Majority
Committee Aides

Victoria Brogan
Senate Republican
Matthew B. Malat
Assembly Republican
Committee Aides

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The Office of Legislative Services, Public Information Office,
Hearing Unit, State House Annex, PO 068, Trenton, New Jersey

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SENATOR JOSEPH F. VITALE (Vice Chair): Good afternoon. We're going to begin the hearing.

Thank you very much.

I first want to thank my colleagues in the Senate and the Assembly for coming this afternoon and joining us for this -- we hope to be the beginning of a dialogue.

We have a panel of experts who are here this afternoon to discuss-- Ken Ritchey is here from the Department -- from the Division -- to discuss these issues.

This hearing today is not--

UNIDENTIFIED SPEAKER FROM AUDIENCE: It's hard to hear you, Senator.

UNIDENTIFIED SPEAKER FROM AUDIENCE: We can't hear you.

SENATOR VITALE: The hearing today is not about any particular piece of legislation, it's not about a bill. It's about the issue, it's about how we provide services in the community and developmental centers. It's not about legislation. It's the beginning of a dialogue that this Legislature wants to have with the professionals, with our departments and divisions, with the provider community, and more specifically and more importantly with those who receive the care and their families as well.

We have that panel here today. We're going to limit the time for the discussion from our panels. We'll have opportunities for our legislators, my colleagues here, to ask questions during the course of the testimony. And we have others from the community, and from the unions,

and from other places who want to take the time to make presentations as well.

I would just ask us all to respect one another's opinions, and questions, and statements. In some ways, of course -- all of us here, of course, in the end, care about those who receive the care. It's sometimes a matter of how it is provided. And there are philosophical differences. But I think, in the end, we all want those who receive the care to get the very best care in the right place and at the right time.

I'd like to ask Chairwoman Huttle to make an opening comment as well -- to make a few comments.

Before I do that, I just wanted to let everyone here today know that Chairwoman Weinberg had a minor medical procedure this week, and she's still not up to coming down to Trenton, but she sends her regards and will be following this thing closely, of course.

Assemblywoman.

ASSEMBLYWOMAN VALERIE VAINIERI HUTTLE (Chair):

Thank you, Senator.

Good afternoon, everyone, and welcome. I thank all of you for coming here today, especially those of you who have difficulty in traveling.

Before we begin, I would like to acknowledge my Committee members and substituting -- Assemblyman Joe Malone today for Assemblyman Declan O'Scanlon. My Vice Chair, Caridad Rodriguez; Assemblywoman Wagner; Assemblyman Biondi; Assemblywoman McHose; and Assemblywoman Mary Paterson Angelini. And I also would like to acknowledge our staff for helping put this public hearing together -- our

OLS staff; along with our Majority staff, Kate; and my staff member, Andrea Katz.

Just a brief background: Before becoming -- or I should say the last couple of months as Chair, I've spent countless hours traveling around across this state to visit all seven of our State centers. I, quite frankly, found each to have its own personality, specialty, and population. And several of my colleagues on this Committee also joined me, including Assemblywoman Cleo Tucker, who could not be with us today. And I know that Assemblyman Malone has visited as well, along with all of my Committee members.

I think what I can say for all of us is that it was an eye-opener and a learning experience. And I found that these facilities certainly meet a vital need for our services among a particularly vulnerable population. I also visited group homes and I learned not only about the care options available to individuals with developmental disabilities in the state, but also about the need to expand those options to the many people who are still waiting to receive much-needed services and resources by the State.

I think we all know here today that we are grappling with an urgent waiting list of 8,000 people; not to be confused with the thousands more who are not in urgent need at this particular moment, but who will inevitably be joining the list as autism and other developmental disabilities continue to grow. So every one of these individuals, their parents, siblings, guardians are certainly terrified about the future of their loved ones when they are no longer able to care for them.

So I think and I know that our State has a moral obligation to provide the resources these most vulnerable individuals need and the peace of mind their caregivers deserve.

I have also met with families and advocates who are also fortunate enough to have that peace of mind. So regardless of how those family members felt about one option over the other, I think we can also agree on the need for choice. There is some division among the advocates testifying today. But from what I've heard, they all share a common goal, and that's ensuring that their loved ones have the very best care, resources, and services possible.

And I think, as you heard Senator Vitale -- the point of the hearing today is to start an important and necessary dialogue about all the stakeholders, the Legislature, the Department of Human Services, the advocates, the family members, the self-advocates, and all of you here today. We can work together to bring services and resources to the thousands who are without anything, and to expand the residential options available in the state.

So I believe that it is in the spirit of cooperation that we move forward today. And I, again, ask everyone testifying to be respectful of each other's thoughts and opinions.

And with that, I will turn it back to Chairman Vitale to call up the first witnesses.

Thank you.

SENATOR VITALE: Thank you, Assemblywoman.

Before I do that, I just wanted to recognize the members of the Senate Committee who came today: Senator Goodwin, Senator Singer, Senator Madden, Senator Gordon. Thank you for your attendance.

Our first panel is going to consist of Ken Ritchey, who is Assistant Commissioner of the Division of Developmental Disabilities at the Department of Human Services; and Eloise Hawkins, the CEO of the Vineland Developmental Center.

Ken, thank you for coming.

A S S T. C O M M. K E N N E T H W. R I T C H E Y: Thank you very much.

Good afternoon, Chairman Vitale, Chairwoman Huttle, and esteemed Senate and Assembly Committee members.

I am happy to be here today on behalf of our Human Services' Commissioner, Jennifer Velez, to talk with you about our vision for New Jersey's system of institutional care for individuals with developmental disabilities. We're delighted that there is a bipartisan legislative interest in this issue. And our hope is to begin an informed and constructive conversation that supports community placement efforts, respects the vulnerability of the people we serve, and values the fiscal resources provided by our State taxpayers.

To give you some context, let me begin by telling you that New Jersey has provided institutional care for individuals with developmental disabilities since 1888, when what is now known as the Vineland Developmental Center opened its doors. The institutional system was at its zenith in the 1960s, when New Jersey operated 11 developmental centers that were home to almost 6,000 individuals.

In 1981, the formerly favorable sentiment on institutional care was beginning to be reversed, and the Federal Medicaid program create the Home and Community Based Waivers as a funding mechanism to support states in their efforts to develop systems of community care. It was truly a revolutionary initiative. And New Jersey, I believe, was the second state in the country, in 1982, to have its waiver approved for community services. Between 1988 and 1998, as the community system began to take root, the Division closed four developmental centers.

When I came to DDD in 2007, the census in our seven remaining developmental centers was 3,100. To date, it's 2,722 and dropping. That same year, we issued our Path to Progress report, which provided a blueprint for expanding community living options in the community for people with developmental disabilities residing in our State institutions.

Nationally, we are among 40 states that still have publicly administered institutions. Eleven states and the District of Columbia have closed all their institutions, and 10 more states currently have plans underway to close one or more of their institutions.

As each of you already knows, or at least learned as you prepared for today's discussion, the institutionalization, the closure of facilities, and the movement of loved ones can be an extremely polarizing discussion.

Our continuing examination of the future of New Jersey's institutions has been in the context of the experience we gained when we most recently closed North Princeton Developmental Center in 1998. Our development centers are home to 2,722 fragile individuals with multiple

disabilities, many of whom have lived in those centers for decades. Moving them into the community is a complex undertaking that cannot be accomplished overnight or without careful consideration of each person's needs.

Furthermore, almost all of the residents have parents or siblings who have a lot of anxiety about the care their family member would receive in a community setting. Many families tell us they want their loved one to stay in the developmental center, including some who have tried a community placement. Our partner provider agencies do yeoman's work to help individuals and families acclimate to community living.

So we are not standing still. Since 2007, we have closed 10 cottages on four developmental center campuses. We are limiting admissions into our developmental centers to emergency placements, which is consistent with what is happening across the country. And, in compliance with the Supreme Court's 1999 Olmstead decision -- which declared that people with disabilities have the right to live in the least restrictive and integrated setting -- we continue to move individuals from developmental centers into the community.

In our Department's proposed budget for Fiscal Year 2011, we make the recommendation to consolidate the West Campus at Vineland Developmental Center. It is a women's-only campus and annex to the only developmental center that is actually split and has sites five miles apart. The census at the West Campus is 110. Approximately 30 of the 110 women who reside there would move to community placements, and the balance would be moving into other developmental centers, as appropriate.

Our work at the Department to deinstitutionalize is ongoing and thoughtful. We're confident that as we continue to apply the Olmstead principles to our operations, our developmental center census will continue to decrease and our ability to reconfigure the system with fewer institutions will evolve. Using our Path to Progress as a starting point, we've begun to revise and update that plan to address the issue of developmental center closings.

Commissioner Velez has discussed the need to close centers with Governor Christie, and he is anticipating a proposal from us. We look forward to working with the Legislature and the stakeholders during this process.

I would be happy now to answer any questions you might have.

SENATOR VITALE: Thank you, Ken.

Before we ask the members to ask questions, I'd like to ask our final panelist -- it is panel one -- Ms. Hawkins, the CEO of Vineland Developmental Center, to make her comments.

E L O I S E E. H A W K I N S: Good afternoon, and thank you for the opportunity to present comments on behalf of the developmental centers.

As Assistant Commissioner Ritchey has already stated, Vineland Developmental Center was the first facility to open, in 1888, so we have well over a hundred years of experience in providing services to people with disabilities. Our campus consists of two campuses, and also 20 group homes and supervised apartments housing about 140 women. We have been participating in the ICF/MR program for the last 30 years. At the time we began that participation, our census at the facility was upwards of 2,000 people. Since that time, our census has dropped by almost 1,600

people primarily going into community living arrangements. So we had much success in that process. Our census currently now is down to 421 people.

I'd like to talk a little bit about the people who live at Vineland Developmental Center. Although I will be speaking about their disabilities, I still want to be -- I want to caution you that I'd like you to understand them as people.

The overwhelming percentage of our ladies function at the profound level of disabilities -- 80 percent of our population. In addition to that, many of them have what we call *comorbidities* and other medical, behavioral diagnoses and disabilities on top of that level of functioning.

For example, about 142 people, 33 percent, have been diagnoses with cerebral palsy. Two hundred seventy-six of our ladies have also been diagnosed with uncontrolled or controlled seizures. Another 250, 65 percent, have been diagnosed with significant behavioral issues, including psychiatric diagnoses of bipolar disorder, borderline personality disorder; demonstrate behaviors of aggression, pica behaviors -- ingesting non-edible objects, self-injurious behaviors. In addition, a large number -- 95 percent -- of the people who live there have been diagnosed with significant speech impediments and primarily -- and a large extent are nonverbal.

For this reason, much of what we -- much of the services that we deliver are multisensory integration. Around the multisensory integration: repositioning, behavior modification, adaptive seating, and training in the use of adaptive equipment, prevocational skill training, and training in developing activities of daily living and self-care.

Even with the challenging behaviors and medical conditions that I just talked about, we still, at this point -- out of the 421 people we have live at the facility -- we have recommended 185, almost 50 percent of that population, for community placement. It is still our philosophy that people should be able to live in the most appropriate setting according to their needs and abilities.

There are a number of reasons why the entire population has not been recommended for community placement. The Assistant Commissioner just mentioned some of those reasons. I would like to just add that, at Vineland, we happen to have a large population of senior citizens with significant medical issues, including having to be fed through PEG tubes, having to breath through trachs and requiring oxygen support.

The staff at Vineland-- I want to just speak for a couple of seconds about the staff at Vineland Developmental Center. We have about 1,500 employees: 1,200 at the facility, 200 staffing the group homes that we jointly run with a community agency, PAFACOM. The staffing includes direct-care staff, human services assistants, cottage training assistants and their supervisors, head cottage training supervisors, and cottage training supervisors and management staff. As important, we have a full-time medical nursing staff. We employ specialists in the field of work activities, nutrition, occupational therapy, art therapy, music therapy, physical therapy, psychology, recreational services, and social services. We also have support services including housekeeping, laundry, maintenance -- everything we need to maintain the physical plant. This is representative of all the developmental centers, not just Vineland Developmental Center.

We are proud to provide services to the citizens of New Jersey who happen to live in developmental centers.

Thank you. (applause)

SENATOR VITALE: Before we take questions from the legislators, I want to just take an opportunity to welcome Senator Allen back to the State House. I can't tell you how wonderful it is to see you and have you back. You've been sorely missed, and we're glad you're here, so much.

SENATOR ALLEN: Thank you. (applause)

SENATOR VITALE: Members, would anyone like to ask a question or make a statement? (no response)

Really? That will move things along.

I'm going to ask, Assistant Commissioner, if you could stay at the table while we call up the next panel. And we'll do this throughout the afternoon. You can sit on that side. Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Panel 2: We have Lowell Arye, the Executive Director of the Alliance for the Betterment of Citizens with Disabilities; Liz Shea, Assistant Director for The Arc of New Jersey; and Executive Director Tom Baffuto.

Tom and Liz, are you both coming up?

Oh, just Tom.

Katie (*sic*) Walsh of The Arc; Stephanie Rosati-Pratico, self-advocate; Debbie Legutko -- I don't know if I pronounced that right, forgive me -- self-advocate; Adelaide Daskam, self-advocate; and Todd Emmons, a self-advocate.

And since we have such a large panel, we can give each one a couple of minutes each. If you need more-- But hopefully this way we have time for everybody to speak.

Lowell, I think if you'd like to start -- please, Mr. Arye.

KATHY WALSH: If it's all right with you, I think that we decided that I was going first. Is that okay?

ASSEMBLYWOMAN VAINIERI HUTTLE: That's fine, Katie.

MS. WALSH: Senator Vitale, Assemblywoman Huttle, members of the Joint Committee, thank you for this opportunity to participate in the conversation on this very, very important issue.

My name is Kathy Walsh, and I'm the CEO of The Arc of Bergen and Passaic Counties.

The Arc in New Jersey had its roots back in Bergen and Passaic in 1947. In the early days of The Arc, one of the top issues for parents was the developmental center beds -- getting more developmental center beds. At that time, there were no other services, and they needed a place where their sons and daughters could be well cared for. We fought very, very hard for those beds to be developed. And, in fact, on the weekends, The Arc even ran bus trips to go down to the centers that were far away -- Vineland, New Lisbon, Woodbine -- because that trip was so long for Bergen and Passaic that this was a way for parents and siblings to get down to see their loved ones.

By the early 1970s though, parents had started to think about other alternatives. They had some success in setting up schools, and work programs, and camps in the community. And they began to realize that

they could develop residential options, as well, that would be closer to home and in the neighborhoods where their sons and daughters had grown up.

From this idea, The Arc of Bergen and Passaic actually opened the first group home in 1970 in Paterson, and the first in Bergen County in 1980. And from that point on, through the '80s and '90s -- spurred on by these parents, The Arc and many providers developed many, many group homes throughout the state. And these group homes -- it was interesting because, at the time, the way a group home was developed was -- there were a number of people from the developmental center and a number of people from the community waiting list that would be -- that we would work together to develop a home for. So we were constantly pulling people from the developmental center and the waiting list to move the process forward of giving community opportunities.

Now initially, the folks who came out of the developmental centers were very, very independent. Some now are living on their own, living very independently in the community. But over time, the folks who the developmental center served -- and then, as a result, who the community served -- had greater and greater challenges. And as the centers learned how to best serve them, so did we in the community. We are both light years ahead of where we were back in the '70s and '80s.

So the question is: If the community has come so far, why do people still end up in developmental centers? And the answer is very simple: it's resources. New Jersey has not built a community infrastructure with adequate resources to meet all the needs. By this I don't mean that the community agencies are not willing and don't have the expertise. But what I do mean is that there aren't enough beds, enough staff, enough

professionals because those resources have not been put into the community over the years. And as a result, when a family goes into crisis and there isn't an appropriate bed available in the community, they do end up in the developmental center.

So what's the solution? New Jersey needs to invest in the community, and this can only be done, given the resources, by closing some of the developmental centers and ensuring that the funds that were tied to those centers are not diverted elsewhere. They must be used to develop the programs and resources, so that when families do go into crisis those resources are available in the community. And so for people who want to come out of the developmental centers, there is the appropriate resource to provide them with equal or better care in the community.

And I want to be really clear here, because I think that there's a lot of rhetoric that gets tossed back and forth when we discuss developmental center closure. And I'm not, for a minute, saying that individuals in developmental centers do not get good care. Developmental centers have kind, caring, and competent staff. And I know this for a fact, because many of them also work for us. For years we've shared staff back and forth with North Jersey Developmental Center. And those staff have shown that they can work in the institutions and in the community programs, and do a fine job in both.

Here is the bottom line: The Arc believes that individuals with disabilities have the right to have fully included lives in the communities of their choosing. But for this to happen, there must be an array of diverse, high-quality community resources that ensure this opportunity. And this array needs to not just be traditional group homes, it needs to provide the

whole spectrum of options, including specialized programs for people with medical and behavioral needs.

Any individual who is living in a developmental center and has expressed the desire and ability to move into the community needs to be given that opportunity. At the same time, it's understandable that parents with a loved one would be concerned. Their family member was probably placed in a developmental center because there was not an appropriate placement in the community. So why should they think that now, by magic, the community can serve their son or daughter? It defies logic.

But there is a way to do this that makes sense. The State needs to commit to a reasonable, planned process that ensures that resources -- which were not there when those families had to place their son or daughter in the developmental center -- are put into the community so that those needs can be met and that the transition plan for each individual takes all of his or her needs into consideration. Families must be an integral part of that conversation on the individual level for their loved one, but also on the macro level to ensure that the resources are in place for the system as a whole. We need to be honest, and we need to recognize that at this time there will be some individuals that the community does not yet have the resources to serve. That's not to say that it will never happen, but we need to be realistic with what can be done and when. Let's not scare families by putting the cart before the horse. There are individuals who are old, who are frail, who have lived there for all of their lives, and for whom a move to an unfamiliar environment may not be in their best interest. These concerns must be heard and honored, and planning must be individually focused.

As I said before, for many, the developmental center provides good care. Parents are rightly concerned that this continue. But we need to understand that good care is not exclusive to a developmental center and that life can be enhanced when good care is provided along with the opportunity for community life. In fact, studies have shown that community living with -- better quality of life comes from community living, and in a whole variety of areas which I won't go into. But one of those also includes safety.

We need to make a moderate and rational approach to community transition and the subsequent closure of a facility. We need to allocate the proper time and the funds to do it right, but we must do it. We must give the people the opportunity to live full lives.

Back in the '80s, one of my responsibilities was to visit developmental centers and meet individuals who were going to be coming out into our residential programs. Every year, around mid-February, I receive a call from the staff at my Teaneck group home, and they say simply, "Andrea wants to talk to you," at which point Andrea gets on the phone. Now, if you knew her, she's a woman of few words. So the conversation goes something like this: "Kathy?" "Yes, Andrea." "Me, you, dinner, no old school." And so we set up a dinner date for sometime around mid-March, which is Andrea's anniversary. It's the anniversary of when she moved from North Jersey Developmental Center to our Teaneck group home back in the '80s. Every year since that time, Andrea and I go to dinner to celebrate her anniversary. It's not something I initiated, it's something she initiated. And while we're at dinner -- usually after we order because that's priority, we have to order first -- she'll point to my cell

phone, and she'll say, "Call," which I know after all these years means I need to dial the number for Mary. Mary was the other staff who was there when she transitioned to the group home. Mary hasn't worked at our organization--

ASSEMBLYWOMAN VAINIERI HUTTLE: Kathy, excuse me. We have to just-- If you could, just wrap up, because we--

MS. WALSH: This is my end. Absolutely.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

MS. WALSH: Mary hasn't worked there since 1987, but she calls her every year to thank her for the group home. It's gone on for over 20 years. And that anniversary is important to her, because it's the date that changed her life. And it changed mine too because she reminds me that, every day, we all -- each of us can help someone change their life. It's well within our grasp, and we just need to collectively take that first step.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Just so we're conscious of time, if you could hold your applause we'd appreciate it so every speaker has their fair opportunity to speak within the time frame.

Thank you.

Lowell.

LOWELL ARYE: Yes.

My name is Lowell Arye. I'm the Executive Director of the Alliance for the Betterment of Citizens with Disabilities, better known as ABCD.

ABCD represents agencies throughout the state serving people with complex behavioral, as well as neurological and medical, physical,

developmental disabilities. More than 10,000 people are served by ABCD member agencies.

What I'm going to say to you straight out is that member agencies of ABCD serve people in the community who have similar or more complex needs than people who currently reside in the developmental centers. Specifically, most of the individuals who are served by ABCD are in wheelchairs, need assistance in bathing, feeding, many of them are unable to communicate verbally, and have behavioral and medical complex issues.

What I want to say to you is that for the last 30 years or more, Federal and State disability policy changes have been implemented to break down the barriers of exclusion, dependency, and segregation. Specifically, the Olmstead Supreme Court decision lays out that people have the right to live in the most integrated setting appropriate to their needs.

Many of you in this Legislature now worked with us and The Arc of New Jersey to move forward on a bill, that is P.L. 2006 Chapter 61, which mandated that the Division move forward on a plan to ensure that people could live in the most integrated settings appropriate to those needs.

Ken Ritchey talked about that. It's called the Path to Progress. The Path to Progress lays out that 250 people should be moved out every single year from the developmental centers over an eight-year period. Unfortunately, that plan has never been fully implemented.

Let me tell you one of the things that plan lays out. It includes how many -- who's in the developmental centers. On average, they're 50 years old, 57 percent have psychiatric diagnoses, 24 percent have cerebral palsy, 18 percent have autism, 39 percent have visual impairments. I'm not

going to go through the list, but what I'm telling you is that those are the same people who my member agencies serve with quality and safety in the community.

Unfortunately, as I said, this has not been fully funded. Kathy laid out that we need community infrastructure. This is something that clearly is the case. NJIT, New Jersey Institute of Technology, laid out, several years ago, a study that was asked for by DDD. What they found was that the reason that most people go into the DCs from the community for emergency reasons were three reasons: lack of barrier-free housing, significant behavioral and psychiatric problems, and medical needs that are not currently being met in the community. That means we need the community infrastructure in the community.

What I'm going to say to you is that if we fully funded the Path to Progress as it was supposed to be done -- not the 62 that are in the current budget, but the 250 -- that if we had funded it in 2009 and 2010, we would have moved more than 500 people out. Now, certainly, there are a number of people, and what happens is, a lot of people do move back into the developmental centers. However, when you figure out how many people move in and out, in effect we would have had a net reduction of 429 people coming out of the developmental centers. That is the size of one of the three developmental centers -- either Woodbridge, 410 residents; North Jersey, 400 residents; or New Lisbon, 440. This is something that we really need to make sure we continue to move forward on.

Where can we get some of the money? ABCD, for years -- literally over a decade you've heard me testify in front of this Committee.

We are not reinvesting our Federal funds into the community, and we must do that. It is imperative that we do this.

I will give you one example. In 2007, the State received \$194 million in retroactive community care waiver funds from the Federal government. Do you know how much the community got of that: \$50 million over three years. Think about that: \$50 million over three years. That means \$144 million of Federal retroactive money was used for other State purposes other than for our community services.

Budget language has been in place for the last five years, at least, which says that they limit and cap the amount of money that can be used for the community care waiver in the community. The rest of it goes away. That language must be eliminated, and we must be able to utilize those funds for that.

I will simply say, last, we call upon you and we call upon the Governor. Announce at least one closure. It's been more than a decade since we've close even one developmental center. Announce the closure of one developmental center over the next 18 to 24 months.

We've done it in-- Other states have done it. Maryland has closed one -- 153 people in 17 months. Other states have done it as well. Massachusetts is estimating it takes five years to close four institutions with 476 people. If you all funded the law that you all helped to write -- Senator Vitale -- for the Path to Progress, the 250 a year to move out -- we could have actually closed one already.

Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Lowell.

STEPHANIE ROSATI-PRATICO: My name is Stephanie Rosati-Pratico, and I want to start by thanking you all for giving me this opportunity to share my family's story and my experiences.

I also want to thank you for giving this issue the consideration and respect that it deserves. It's pretty obvious from the amount of people who are in this room today from various walks of life that this is a very emotionally charged issue, because it impacts many people for many different reasons in their life.

I can certainly appreciate the challenge that you have ahead of you on a very personal, emotional level. I am the mother of two children with Down syndrome. And although it felt like it was a lifetime away before I'd have to worry about where my children would live as adults, my son is soon to be 17, and so the reality of his adult life is approaching quickly.

If you ask my son John -- and actually, if it's okay, I'd just like to -- it kind of helps to put a face with the name. Thank you.

If you ask him where he will live when he's an adult, he will very confidently tell you that he will live in his own apartment. And if you ask him why he wants to live in his own apartment, he will very simply say it's so that he has the ability to walk around in his underwear. (laughter) It doesn't get any simpler than that.

In addition to my own children, and being a parent, and looking into the future, I am also the guardian of my 64-year-old aunt who lived in Vineland Developmental Center for 50 years. At the age of 12 years old, my grandfather had a massive heart attack and almost died. And at that point, he and my grandmother had to make the very difficult

decision to place her in a developmental center or, as we knew it, an *institution* -- which we later referred to as her *school* -- because he was a wonderful provider and caretaker, and he did not want to leave my grandmother, should he have another heart attack, to be the sole provider of three small children and then have to get a job. And, obviously, my aunt had extremely significant needs, because she is severely developmentally disabled.

I can remember as a child driving back and forth to Vineland with my grandfather to pick her up and take her back after her long weekend visits several times a year. And I would sit very quietly in the back seat crying and trying to hide that from him, because I didn't want to make his heartache any worse than it already did.

I think back to that now, and I remember -- or I know that that was probably my heart unsettled with the fact that we had to leave her there without any family. We live not far from here. We live in Hamilton. That had to leave a void for her. It was something that we accepted as normal for our family, and so we did what we had to do.

When I was given the opportunity in January of 2009 to move her out of the Vineland Developmental Center -- after 49 years of living there -- into a community placement, I was extremely nervous and excited. I can appreciate the families who sit in this room who have a loved one in a developmental center, and the fear and anxiety that goes through your body and your mind in making that decision. Was it right for us to make a decision to move her from the place that she had known all those years as her only home? I can tell you the thing that probably motivated me the most was, when we would bring her home -- probably over the last five years

-- I would notice that she would lay, often, curled up on the couch holding her ears in almost the fetal position. And in going down for my IHP visits and to visit her, I realized that the population of the developmental center had changed so much that here she was, a 62-year-old woman at the time, entering her golden years and probably wanting peace and tranquility in her life, just like the rest of us would at that stage, and not being able to have it. So she created that happy place for herself to be able to cope with every day.

I can tell you that moving her into the community has not been without challenge. There have been times where it's been difficult, but the overwhelming gains compared to those challenges are immeasurable.

And, again, I feel badly for the people who work there who may lose their jobs, or the other issues that surround this that make it so emotional, but the truth is, it's about her. And if I had to leave you with one thought, I can tell you that for her, as a person, being able to go into her apartment and seeing her -- it has to be 15 years ago, 20 years ago maybe -- the last time I saw her actually sit in a chair and peacefully watch television. She has been significantly delayed. She has very limited ability to communicate. But I can tell you from the smiles on her face and the laughter that I hear, that's infectious, that I have not heard since I was a little girl, it has had a positive impact on her life.

Does that change the fact that it is a very scary move? It is a very scary move. The fact that we don't have the best stability in our support systems is scary. I think we need to put more focus there to be able to support these individuals and give them the option of a choice in the community.

I mentioned that I have two children with Down syndrome. I'm sorry. I skipped right over John, because he's really the one who is talking about the apartment. I leave you with this thought. I hope that you will give this all the diligence it deserves. Because I also have an 11 year old who has Down syndrome. Her name is Sarah. She is as sweet as can be, but she has extremely significant medical issues. And I pray to God that it's not 50 years before she can safely and comfortably live in the community. Because chances are I'm not going to be here to see that. And I don't want her to have to experience that on her own.

So I think we have to band together and keep working at this to build a structure that can support what these individuals deserve.

Thank you for your time. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Stephanie, for sharing your stories. We truly appreciate it.

The next -- Tom -- I guess panel-- Do you have--

UNIDENTIFIED SPEAKER FROM AUDIENCE:
(indiscernible) (speaking from audience)

ASSEMBLYWOMAN VAINIERI HUTTLE: Are you coming up? (affirmative responses)

I guess before the three -- Lowell, Kathy, and Stephanie -- leave, if any of the Committee members have questions.

We do have one question.

Assemblyman Coutinho.

ASSEMBLYMAN COUTINHO: Thank you, Madam Chair.

It's for Lowell, just one question.

And before I do, I want to welcome everybody here and thank you for coming. It's obviously a very important issue for the State, and we look forward to hearing from all of you.

Lowell, you mentioned the issue of us not leveraging Federal dollars. I don't know if you may be able to -- even not today -- but to this Committee and also to the Budget Committees -- because on the Budget Committee, on which I sit, we're very much interested in the issue of trying to take advantage of any and all opportunities for Federal dollars. My friend Joe Malone is with us here today.

And if you can get us a list of either between-budget language or Federal dollars that the State of New Jersey is not going after, we will do what we can to try to incorporate that either into this year's budget or going forward.

MR. ARYE: I appreciate that very much. As Assemblyman Malone knows, this has been something that I say every year.

Right, Mr. Malone?

We have given this in the past. The problem is not-- There are two pieces to this. One is that for many years the State did not go after as much of its Federal funds for the home and community-based services waiver. And about four or five years ago, because of urgings from many of us in the advocacy world, they started to do it. They started to claim more Federal dollars. Unfortunately, they have then limited that amount of money and then saying only a certain amount of that money can go into the Federal -- can be used for community services. The rest of it goes back into the Treasury for other budgetary purposes.

I'd be happy to give you that list as well.

The second part of it is that, in the past, this Department has also not gone after other funds for it. We are one of about only 17 -- not even -- about a dozen states who receive no Federal funds from Family Support Services. This year the Division is actually talking about that and has actually convened a work group that -- the Assistant Commissioner has convened a work group to actually start talking about a family home support waiver so that we could actually get Federal funds. And we appreciate that, and we're very excited about that. There's currently over \$39 million in family support State-only money. And we could be maximizing our Federal money from that. Unfortunately, the concern we have in the community is that since they already take a lot of -- some of our money and don't use it for community services, we are concerned that unless they -- unless the Department -- and I'm talking about the Treasury now -- unless the Treasury allows the Department of Human Services to reinvest all of those Federal moneys back into community services, then we are not going to have the adequate resources to serve people on the waiting lists, people living at home. More people want to live at home and get in-home support than at any time. Over 80 percent of all people want to live in-home. In-support -- the family home support waiver is a great idea. We are very pleased and very excited that the Division is moving forward on it. But unless we get those funds and get it reinvested back into the DDD, we will not have the adequate supports necessary.

But I'd be happy to give you more information.

ASSEMBLYMAN COUTINHO: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Before I call the next panel, any other questions from the members?

I'm sorry, Assemblyman Malone.

ASSEMBLYMAN MALONE: Lowell, in your discussion, who has the ultimate decision-making authority in where an individual or loved one is placed? Who has that authority?

MR. ARYE: I think the person themselves first has the ultimate decision-making authority, and then at that point, if they are not able to make that decision and a court rules that, then it's the guardian.

ASSEMBLYMAN MALONE: Because I've had a hard time getting an answer to that question. And I think that really is the ultimate question: Who has that authority? I was told, "Oh, the State does, the court does." I think if we take it out of the hands of the individuals and/or their families, that's not a good situation. And I think we ought to be moving -- if we're not, we ought to be moving toward the individual or the families to make those decisions.

MR. ARYE: Assemblyman, I totally agree with you. (applause)

The U.S. Supreme Court ruled, in the Olmstead decision, that there are actually several things that have to occur. The first is that the individual themselves wants to move. That's the first thing. At that point then, the State has to make a decision -- an assessment -- whether or not the person -- through their professionals -- whether or not that person can live in the community. And then the third piece of it is whether or not there are funds available to do that. Those are basically-- There are several more. And I look to others who you will be hearing from shortly -- the

attorneys -- who can actually explain that more. But that's really -- that's pretty much what the Supreme Court said.

ASSEMBLYMAN MALONE: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman McHose.

We also have -- just an FYI for the members -- Assistant Commissioner Ken Ritchey is still with us. So if there are any questions that you may want addressed, he's still here for any comment.

Assemblywoman McHose.

ASSEMBLYWOMAN McHOSE: Thank you very much.

Stephanie, I have a question for you. When Lowell mentioned the fact that many individuals actually can be cared for in the community versus the developmental centers, you talked about the problems -- you had both problems and good things that you saw come from it. Is your aunt in a group home, is she supervised, is there someone living with her?

MS. ROSATI-PRATICO: Yes. She has almost 24-hour care. She goes to a day program from 9:00 to 2:00, and then she has a support person for the rest of the hours. And she's actually in a two-bedroom apartment.

ASSEMBLYWOMAN McHOSE: Okay. So there's a roommate and there are people around.

I guess -- because my experience touring the developmental facilities-- I was just curious to know whether the transition period from living in the developmental center to living alone -- if that was difficult, or how the staff-- I'm sure the staff are the ones who help transition the person. And everything is on an individual basis, I'm sure.

MS. ROSATI-PRATICO: I was just going to say that. I think community living looks different for every person because of who they are, what their personality is. I mean, it's no different than you and I. Some people like to live in a city setting, and some people like to live in the suburbs. That being said, I think the transition is no different than moving from one house to another house, or one community to another community, whether you have disabilities or not.

I think the important thing is that there are people around that person who can support them and who can identify their needs. She went through a transition. I was not disillusioned to think that she wouldn't. I can tell you that my mother and my other aunt, who are older, I think had this vision that everything was going to just-- Having had my own children and dealing with children with developmental disabilities on a 24-hour basis, I had a little better, clearer expectation, because I've been through different transitions in their lives. But I will tell you that each layer, as it resolved -- that spirit -- her spirit that I watched diminish had reappeared. I really do think it's about being supportive. She's very lucky, because she has a family that's close by. So we were able to be part of that support network. And I realize that not everybody has that, and so that has to be addressed. And I think that's where you said individuals and families -- it's going to be a very individualized plan.

ASSEMBLYWOMAN McHOSE: Thank you very much. I appreciate that.

That was my point -- that it's very difficult, in this situation, to have a sort of one-size-fits-all, because it's not the way it is.

MS. ROSATI-PRATICO: I agree.

ASSEMBLYWOMAN McHOSE: And I just want to applaud, publicly, the employees of the developmental centers that I visited. Because place after place -- when I asked these employees, "How many years have you worked here?" And the feeling and the sense that I got from the level of commitment that the people and the employees have-- And I just want to applaud any of you who are here today. I really think you do great work.

Thank you. (applause)

MS. ROSATI-PRATICO: Can I clarify one quick thought back to you? Because when you talk about that, it really-- Our desire to move her to the community-- She got good care. It had nothing to do with that. That's why I said that. It really-- The focus has to stay about the person. It was really about what was best for her. And it didn't have to do with her care, it had to do with her emotional and spiritual well-being, and her as a person.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman Wagner.

ASSEMBLYWOMAN WAGNER: Thank you, Madam Chair.

I just had one question in regard to the money that was returned to the Treasury -- and that large amount of money.

Could you explain to me, is that a problem with the process? What would you like to see happen?

MR. ARYE: Thank you for that question. (laughter)

ASSEMBLYWOMAN WAGNER: It really is a question that--

MR. ARYE: That's exactly it.

ASSEMBLYWOMAN WAGER: It's something I need to understand.

MR. ARYE: We believe that it's imperative that the money stays, that actually the language that is in the budget-- There is currently budget language that specifically limits how much money is used, through the community care waiver, that is put back into the Division. It actually says specifically -- that puts a dollar amount on and says that any money after that must be actually -- created a plan that the Director of the Budget and Accounting -- in effect, OMB -- must approve. That language, in my mind and many of our minds, must be eliminated. It should say straight out, "All funds from the community care waiver will be reinvested in the Division of Developmental Disabilities Community Services, and that any funds (applause) from consolidation or closure of a developmental center should also be reinvested in the community services." That's what it should say.

Right now, every year the dollar amount goes up a smidgen, but the assumption and the estimates are that they are going to net-- This year I believe there's been some differentials. OMB had some inaccuracies in their budgeting brief about how much money they're estimating this year. But I believe that in FY '10 they're estimating about \$20 million more than they're saying that they're going to -- that it says it limits. So that's \$20 million that we could use for community services and to help build our infrastructure.

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Before we call up the next panel, we have Committee Room 6 available. If any of you who are standing would like to be more comfortable, in Committee Room 6 we are streaming that as well. So if

anyone would-- If you're in the hallways, if you're standing, if you'd like to move into Committee Room 6, it is available.

And with that, I will call up the second panel.

Tom, maybe you can introduce the panel, and then we can move quickly through that.

T H O M A S B A F F U T O: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

MR. BAFFUTO: Thank you, Chairwoman Huttle, Chairman Vitale, for holding this much-needed hearing today.

I'm Tom Baffuto, the Executive Director of The Arc of New Jersey. I have some wonderful guests with me today. We have two self-advocates and a family member who I will introduce. But I just wanted to touch on a couple of very quick points. You've heard a lot already.

But The Arc of New Jersey believes strongly in supporting people in their communities wherever possible. We work to get people with intellectual and other developmental disabilities the support and services they need to maintain as independent a life as possible. We want people with developmental disabilities to have the same opportunities as everyone else: living, working, recreating in the community close to their families, friends, and neighbors.

One of our core driving principles at The Arc is to empower people with developmental disabilities with choice. We recognize that some people would prefer to remain at a developmental center rather than move into the community, especially those who have lived there most of their lives. We respect that choice. But at the end of the day, the reality is, we simply do not need seven large institutions anymore. The vast majority of

people in our service system (applause) are more appropriately served in the community. And every dollar we invest into developmental centers is one less dollar we spend building up our community infrastructure.

We need to make tough choices during these tough times. We need to balance the resources available for folks. And rather than continue to overinvest in State funding in institutions, we need to strengthen our investment in the infrastructure that is sorely needed to serve people, particularly people with complex medical and behavioral needs in community-based settings. If we're going to make sure that individuals and families really have a choice, we absolutely have to invest in the community too.

I think I'm better served now to let you hear from the folks who are with us. First, let me introduce a family member, Debbie Legutko.

Debbie.

DEBORAH LEGUTKO: Good afternoon.

Thanks for the opportunity to share my story with you today.

My name is Debbie Legutko, and I'm the mother of two young men, Frank and Derek -- and this is Frank's picture at his favorite spot, the firehouse -- both with developmental disabilities. My older son Derek, who has autism, is now 26. He works 20 hours a week at two different part-time jobs. He is very verbal and extremely knowledgeable about sports, music, and movies. Derek has been on DDD's priority waiting list for over nine years.

My younger son Frank turned 23 on April 9. He has been living at Hunterdon Developmental Center for almost 14 months. Prior to that he was living at home with 24-hour nursing care for 22 years. Frank is

autistic, on a ventilator and oxygen, and has had aggressive behaviors for many years. Early last year we became -- we were unable to manage his behaviors at home, and he became a constant danger to his caregivers and himself. Our only option was to find a nursing home or an emergency developmental center placement.

Before our situation became an emergency, he had been on the waiting list for residential services for over five years. In fact, you may remember me testifying before you in March of 2008 about the waiting list and how much we needed help. That help never came. And when our situation finally became an emergency, a developmental center or nursing home were the only options. After spending 21 years in the community, it was very upsetting for Frank and our family to see him admitted to the Hunterdon Developmental Center. I cannot even consider what would happen should our family face another emergency situation with Derek.

Frank now lives on a hospital ward with 14 other men; most are over the age of 50. There's no social interaction between the residents, and he considers the staff his friends. Since admission, his behavior has greatly improved, and his medical care is very good. His last trip into the community was in March, and trips are rare because of the staff he needs to accompany him. He cannot participate in Special Olympics for the same reason, something he really enjoyed in school.

For 21 years he was a part of the community. We gave him every opportunity to be out and about just like anyone else. He has traveled to Disney World, seen Broadway shows, and even tried his luck on the slot machines in Atlantic City. He loves amusement parks and the

excitement of the Jersey Shore boardwalks. He is always talking about Santa Claus and fire trucks.

His life now is not what I envisioned for him. But at the time, we really had no choice. I always hoped he could live in a community with other people needing the same level of care. People in our state are living longer with complex medical conditions, and it's time to be innovative. I really want to see him in a community placement.

So, for now, Frank and I do what we can to enjoy our twice-weekly outings. His favorite waitress at the Cracker Barrel calls him *my friend Frank*, and he likes to blow her kisses. They no longer ask for his ID at the Sands Casino. And the owner of the local Italian restaurant buys him lunch. He asks to ride past the firehouse. He is happiest when he is out and about. So as long as it's physically possible, I will continue our weekly routine and drive the 120 miles round trip. Hopefully it won't be for too long and he will have a home living with others as a member of a community.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Todd.

MR. BAFFUTO: Let me introduce-- You know, families are so important to what we do at The Arc of New Jersey. But equally as important are self-advocates who speak for themselves. We have two here with us today, Todd Emmons and Adelaide Daskam.

And we'll let ladies go first, Todd. Why don't we turn this to Adelaide?

ADELAIDE DASKAM: Hi.

My name is Adelaide Daskam. I'm from Community Access Unlimited, which is a good agency program for people with disabilities. And we do get our support and our needs 24 hours a day. A lot of us are in supervised apartments. A lot of us are on our own, where we have our own apartment, our rights, and everything else.

I have a brief story to tell you and everything.

Hi, my name is Adelaide Daskam. I was in North Jersey Training School for five years. I did not like the way I was being treated by staff. I was told when to eat and when bedtime was. I had to stand at the back of the line to go to the cafeteria. I did not like the way anybody in the institution was abused.

A lot of us people were taken either into the bathroom or into the office and be beaten by staff. If it wasn't the staff, it was the clients there. They would beat us up, like taking a ruler, or a shoe, or a chair and throw it at us. It was not right. I was one of them that was abused in North Jersey Training School, the State institution up in Totowa.

Now, since I've been out for 31 years, I have my freedom, have my own apartment, and I have my own cat and my own boyfriend. I am happy to be out in the community for 31 years, meeting new people, trying to get my brothers and sisters out of the institution where they could have their freedom, their life, where they can be happy and comfortable.

I am working with Community Access as a secretary, doing a wonderful job and everything, and I receive my paycheck every two weeks. Also, I help Community Access with people with disabilities when they come into our program -- how to understand the staff, how to understand the rules and the regulations of everything.

I have a friend who was from another agency program. They wanted to leave that agency program to come and be with me, to be with her sister -- but she's not my real sister. But inside she is a sister to me. And a lot of my brothers and sisters are here today who are glad that they all have their freedom and everything.

My friend Todd has been my best friend for many, many years. And we consider each other brother and sister. And I would like to see all of you please help my brothers and sisters out of the institutions.

And also, we have old buildings that are boarded up, old warehouses, and stuff like that -- old homes that are boarded up that could be fixed, rebuilt, made into a good place for people to live in. All these homes that are boarded up and other places can be built up for people with disabilities. Get them out into them. I mean, where is all this money going to? Nowhere. I mean, you keep these boarded homes, boarded buildings. Make them into new places for people with disabilities.

I mean, a lot of people with disabilities will feel 100 percent happy to be out of the institution. A lot of our brothers and sisters did not ask to be put into an institution. Back in a later age -- I mean time -- parents used to listen to the doctors. The doctors would say to the parents, "Put your son or daughter in an institution. They're not going to learn anything." But the doctors are wrong. If you let your son or daughter live with you or go to an agency program to live more independent -- like go food shopping, doing their own laundry, doing their banking, and stuff like that -- and get along with the people out in the community, everything would be 100 percent better.

But now since we have the institution still open, it's not good. A lot of our brothers and sisters are getting fed up living there. A lot of them want to be out in the community more.

Thank you very much. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Adelaide.

And please, folks, hold your applause.

But just a note on the abuse that you were speaking of, the Governor has signed a bill -- a piece of legislation just last week. My colleague, Assemblyman Fuentes, was one of the prime sponsors. And that is to create a registry of offenders, whether they are physically abusing the disabled population, sexually abusing, verbally abusing -- to put them in this registry to protect our most vulnerable population and have them never work in a facility, or a group home, or in a home, or anywhere to come in contact with anybody from the disabled population. (applause) So I do want to mention that. And I think it's certainly common sense that should have been legislated a long time ago.

But thank you for sharing your story, and we truly appreciate it.

Todd, she's a tough act to follow.

T O D D L e R O Y E M M O N S: Thank you very much, Assembly.

I want to say thank you for giving me this opportunity to talk to you today.

My name is Todd LeRoy Emmons. I am here to talk about my experiences living in the developmental center and living in the community.

Back in 1972 -- this is going back 38 years ago -- I was placed by my family into New Lisbon State School, which is now the New Lisbon Developmental Center, which everybody said would help me with my living skills.

My day at the developmental center was just exactly the same thing that Adelaide said. They decided what time I woke up, what time I went to bed, what time were my meals, what time I was going to eat. They decided everything for me on those days. I was never able to make friends in the developmental center or outside the developmental center -- I had friends inside the developmental center but not outside. I was treated unfair and unkind. The staff there was very, very abusive to me. They ridiculed me, they called me names over and over again. And I'm sorry I have to use this, but they called me *retarded boy*. How do you think I felt about that? I was hurt. I was hurt, I was angry, and I was very mad about it.

Back then I didn't know a lot about my choices, and I thought I was helpless and very alone. I did manage to leave the developmental center. I was actually placed in another group called Edward R. Johnstone back in 1974, and I was there until 1976.

My family and my case manager helped me get out of there. I am now living in a wonderful, supervised community (indiscernible) with the Bancroft group. I love living there. I've been living there for 28 years now, and I love them. They're my family. Now my day is-- I can go anywhere I want to go, I do everything I want to do. I used to-- I was employed for awhile, now I'm not. I am able to take the Transit buses. I have friends. I now even have a girlfriend that I love very much. And I'm

also, thanks to Governor Corzine, who was our former Governor, I am now the newest member of the New Jersey Council on Developmental Disabilities. I can't thank him enough for that.

I'm also the Chairperson for the Monday Morning Network. I'm also involved with our self-advocacy group, and I'm on so many other groups. I feel very happy and very valued -- contribute -- citizen. I vote in all elections. I have a wonderful townhouse where I live in Voorhees, New Jersey. I have a wonderful roommate. We get along very well. I have a lot-- My family and I are very proud of my accomplishments so far, and I'm looking forward to many achievements.

And everybody needs to live in the community, giving them a chance for happiness.

Thank you very much. (applause)

SENATOR BUONO: Thank you, Todd.

Any questions for our panel?

Senator Allen.

SENATOR ALLEN: Thank you.

First of all, thank you very much, both of you, for coming here today.

MR. EMMONS: Thank you.

MS. DASKAM: Thank you.

SENATOR ALLEN: You've been very helpful.

I would like to know-- Todd, you said that you left the center because your caseworker and your family helped you do that. Did you initiate that? Did you tell them, "I really want to get out of here?" How

does it work? And also, are there -- does everybody know how to make that work?

MR. EMMONS: For me, what was encouraging was that my family thought-- When they first put me in these two institutions, they thought it was going to help me with my living skills, but it was the reverse around. I mean, they tortured the heck out of me at the place.

With my case manager, who I had back then when I was living in Johnstone-- They said, "No, Todd doesn't need to be there in Johnstone anymore. He needs to be out in the community." And that's how it happened. And I got out of there on June 16, 1976. And that was actually my mom's birthday.

SENATOR ALLEN: Are there others who-- Well, it's been some time since you've been there, obviously. But at the time, were there others who also wished to be out but just didn't know how to go about it?

MR. EMMONS: Well, actually Johnstone is now closed, and I thank God for that. But I do have a lot of friends still in New Lisbon who are on the waiting list right now to be out of there. And I'm hoping and praying that this Assembly and Senate -- everybody can get them all out of there. Because I don't want to see anybody in there -- in those groups again.

SENATOR ALLEN: Again, I thank you both for being here.

MR. EMMONS: Thank you, Senator Allen.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman Wagner.

ASSEMBLYWOMAN WAGNER: Thank you, Madam Chair.

My question is very similar to Senator Allen's. I would like to know how much counseling takes place when you're making the choice. And if you go into the community, is counseling still available? And are you aware that it's still available, if it is?

MR. EMMONS: Either one of us? (affirmative response)

I really don't know if there is still a lot of counseling in there, because I haven't been in the State school in over 34 years. So I really don't know, Senator (*sic*).

ASSEMBLYWOMAN WAGNER: Is it available for you now if you need it in the community setting?

MR. EMMONS: I now go to a psychologist that I see, and I talk to him a lot about my own personal problems and stuff. And he's been helping me a lot with everything that I've been going through. So, yes, there is a lot of help with that.

ASSEMBLYWOMAN WAGNER: Thank you.

MR. EMMONS: You're welcome.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you very much.

SENATOR VITALE: Thank you. (applause)

Our next panel is this: Thomas York, Esquire, Sidley and Austin.

Mr. York.

THOMAS B. YORK, ESQ.: Yes.

SENATOR VITALE: You just flew in from Arkansas?

MR. YORK: No, no, I drove in from Harrisburg, Pennsylvania.

SENATOR VITALE: Oh, close enough.

MR. YORK: That's all right. I am handling a case currently in Arkansas. And I did fly in yesterday from Arkansas. So your information isn't entirely inaccurate.

SENATOR VITALE: If I can have you make a presentation if you'd like. And if we have questions afterwards, please stay.

MR. YORK: Sure.

SENATOR VITALE: Thank you.

State your name and, again, why you're here -- who you represent.

MR. YORK: I'm Thomas York. I don't know if I represent anybody in particular. I was asked to appear here, and I really welcome the opportunity to comment on these very important issues.

I am an attorney. I've been practicing for almost 30 years, and the last 20 years have been focused almost exclusively on systems for the developmentally disabled and people with mental health problems. And my background involves representation of a number of states, including Florida, Virginia, Pennsylvania, Connecticut, Massachusetts, Arkansas, Nebraska, California, and a few more that I can't think of off the top of my head.

My experience is not just in representing states in facilities, ICF/MRs, or large congregate institutional settings; it's also representing them and defending them sometimes in their community systems, and also in their waiver programs, and so on. And my experience and background perhaps is why I was asked to testify -- was because of my extensive amount of time that I've spent in ICF/MRs around the country in visiting different community programs.

For example, in the Arkansas case, I have spent four weeks at the facility, nonstop, visiting and touring the facility with experts from the U.S. Department of Justice, and then spent more days after that with our experts. And we also then toured the different community settings and so on. I've done that in a number of states and visited dozens of facilities across the country in many, many, many community settings.

And if you don't mind, I will try to shorten my presentation. I have submitted a written presentation. But I will try to shorten it, and just highlight that, and maybe deviate a little bit from it based on some of the comments I have heard here today.

I was formerly a deputy attorney general with the Office of the Attorney General in Pennsylvania. And I was subsequently chief of litigation for the Department of Public Welfare in Pennsylvania. And that is the state agency in Pennsylvania, as you probably all know, that covers facilities that deal with the developmentally disabled and people with mental health issues. And I've been in private practice now for a number of years.

For nearly 20 years I've been assisting states in designing and defending comprehensive systems of services and supports for persons with developmental disabilities, including preserving a choice-- (fire alarm sounds) (people exit room)

SENATOR VITALE: Thank you.

If you could all grab a seat or stand. Please stop talking now so we can resume the hearing.

Mr. York.

MR. YORK: Thank you, Senator.

I've had some strong reactions to some things I've said in the past, but I've never set off a fire alarm before. (laughter) It seems coincidental. It was right at the point where I was saying I was assisting states in designing and defending comprehensive systems of services and supports for persons with developmental disabilities. And right about then it rang. And the next point is probably the most important point in my whole speech: including preserving a choice for those who feel they are best served in a ICF/MR. And that's very important, the issue of choice.

I am a strong advocate for the right of individuals -- or in the case of many individuals, their families and/or guardians -- to choose the setting that is best for them, including ICF/MR settings and state-run developmental centers. I will outline a number of reasons that have led me to this position in a moment. However, I would like to note three important elements of my thinking at the outset here.

First, access to ICF/MR-level care is, in effect, an entitlement. Medicaid regulations are such that if a state offers ICF/MR services through its Medicaid state plan, then individuals who qualify for such services have an entitlement to them and, by Medicaid rules, are required to be given a choice of setting, including an ICF/MR setting.

Second, Olmstead preserves the right of individuals to continue to receive services in an ICF/MR if they choose to do so. It was not the intent ever of either the ADA or the Supreme Court's Olmstead decision to force individuals from institutional facilities if they did not want to leave, or to necessarily cause the closure of these institutions.

And third, many guardians of individuals who have lived in developmental centers, including a substantial number of individuals in

New Jersey, desire their loved ones to continue living in these facilities. Most of the individuals who are advocating for the closure of institutions are not the guardians, the parents, the family members, or even the individuals themselves. Rather, those individuals who are advocating for institutional closure have no stake in what happens to an individual who loses access to necessary services. It is important that we hear the voices of guardians, the parents, the family members in this discussion.

Problems arise when individuals from developmental centers are moved to the community without sufficient supports. You heard some great stories here today. And I think that was very nice that we heard some anecdotal stories. And it's wonderful that those people are doing well, and everyone should be proud of those individuals. But the reality is, I can give you many stories of people who have failed in the community and have had disastrous results too. And the other reality is, as proud as I am of those individuals who have succeeded, even though they're disabled -- the reality is that these people are not typical of probably the people who remain in your facilities right now. So if you're trying to decide whether or not you want to downsize your facilities, or maybe even close them, I think you have to understand that the two individuals who testified earlier are not, by any means, typical, I believe, of what's in your current developmental centers. (applause)

And another important point I feel compelled to make was that there were allegations of abuse that were, of course, very old allegations. Unfortunately, I cannot testify as to the individuals -- probably outstanding individuals who work at your developmental centers here in New Jersey, because I have not had the good opportunity to visit with them. But if they

are typical of the workers that I have found in most -- the vast majority of state facilities across the country, I would say that it is highly unlikely that these people are committing that kind of abuse here today. (applause) And I think it's a shame that these people-- If there was any implication that the current employees of your developmental centers are committing those kinds of abuses, I would say they are probably false. And I think-- I feel bad that these people have been tarnished in that way if that's what the implication was meant to be.

So problems arise when individuals do not have sufficient supports. For example, one state recently moved 47 individuals to the community with little planning, with the result that half had died within 15 months. Community services must be able to address the medical, psychiatric, and behavioral needs of the residents of ICF/MRs if these individuals are to be successfully relocated to the community.

There are several critical facts here. And the one other thing I wanted to note too: I have had great opportunity to work with many people from the State of New Jersey who are experts in my various cases. And you have some of the most outstanding experts. There's probably no state that I draw from more -- and I mean that very sincerely -- in just sheer numbers and in quality, than the experts you have in New Jersey. So I also learned a lot about your facilities from talking to those very experts.

I know New Jersey is fortunate and set apart from other states because it has access to provider organizations such as Developmental Disabilities Health Alliance, which specializes in meeting these needs. There is the type of organization that could serve as an example to provide services.

Some critical facts I think we should note: There are some very good reasons why we should be very cautious in calling for the closure of developmental centers. Here are some points I think your Committee should carefully consider. Again, I would ask you to look at the facts rather than on anecdotal stories or emotional appeal alone.

One is that individuals with intellectual and other developmental disabilities vary more than the general population, more than most people understand or realize, ranging from individuals a little different from the general population to individuals who need constant care. And I think you're talking about probably the people who are in your current State facilities -- need constant care.

People with severe and profound disabilities are far different in their needs. These people are quite different from the general population, often consisting of individuals who have no self-help or adaptive skills, who require personal assistance for all areas of their life, who have associated multiple disabling medical conditions, and who are often quite fragile. These are the individuals who, by far, make up the bulk of individuals in the remaining developmental centers in America, including the seven here in New Jersey.

Another point: Facility residents are a tiny percent of the IDD population; and I give you the calculation to show how small the actual number is in relation to the overall population of the disabled. It does not seem reasonable that such a small percentage of individuals results in such a contentious and continuing debate relative to their care. Thus, it is likely that the issue has been kept in the public eye more by the ideology of pro-

community advocacy groups than by professional decisions about service locations.

And remember, even under the Olmstead decision and other decisions like Youngberg, the key is professional judgement, where the professionals believe they need to be. And then, of course, overriding everything is the right of parents and guardians to make decisions as to where their loved ones should reside.

Number three -- this goes against some commonly believed but not verified opinions -- but cost savings are not assured in facility closures. A recent review of selected literature did not validate the firm conclusion that cost comparisons between institutions and group homes showed cost savings in community settings. And essentially what you're getting usually from these advocacy groups is a comparison of apples and oranges. So I think you need to take a close look at these comparisons and really determine whether or not your state would even save any money by closing facilities.

Number four: Pervasive supports are needed. Because of the small number of individuals and the lack of obvious cost efficiencies, it is likely that the current level of institutional use in New Jersey is reasonable.

Although many community advocates argue that the institutional model is an outdated and repressive system, and is better left as a relic of the past, they often reach such a position ideologically, based on outdated information rather than through a review of current empirical evidence from modern congregate ICF/MR settings. The remaining individuals in such settings are generally quite restricted in their functioning level, not at all independent, and require constant care and supervision.

I believe it is important that New Jersey explore what is the correct level of ICF/MR beds for your state. That is, I believe it would be grossly inappropriate to simply close all of your facilities based on the considerations that I am raising in this testimony. In fact, it is the fear on the part of parents, families, guardians, and others in New Jersey, as elsewhere in America, that this valuable resource will no longer be available and that their loved ones will receive inferior services in the community to their great detriment. The parents and family members of individuals in institutions are strongly advocating for the continuance of some of these facilities. I believe that you, the legislators here in New Jersey, need to seek and seriously consider the views of those who are closest to the individuals receiving services and who are typically their legal guardians.

And my number five point, which I've already touched on: Individuals and families have choices. And I've already pointed out that I think the Medicaid act, and the regulations, and the Olmstead decision supports that they be given that choice.

What I've already also touched on is number six: Positive outcomes are not always assured. When individuals with severe and profound disabilities are moved from ICF/MR facilities, the positive outcomes of increased integration, community involvement, and exercise of free choice are not always observed.

Outcomes for many mildly disabled individuals leaving institutions for community settings may be truly positive for them and result in an improved quality of life. However, that's not the population you're generally looking at here in the current developmental centers. However, severely and profoundly disabled individuals receiving highly

professional, complex ICF/MR-level professional services within institutions, who are then placed in HCBS Waiver settings, may have difficulty gaining access to these services, especially medical care, psychiatric care, and behavioral supports which are often difficult to access or sometimes simply unavailable.

When adequate health and other professional services are not as readily available as they are in ICF/MR settings, research and practice shows that individuals run increased risk of death, mental health crises, inappropriate placement in nursing homes, lack of access to needed services, and so forth. It would seem most appropriate at present to retain complex individuals in ICF/MR settings, if they choose them, in which these services are available and accessible until such time as some other service infrastructure for these individuals can be sufficiently developed in community settings.

So to conclude, in my opinion it would be rash to close IDD facilities in New Jersey that are certified to provide ICF/MR services, when substantial numbers of individuals with severe and profound disabilities are currently benefiting from such services and appear to require them. I do recognize that there may be some consideration of consolidation, and that may be possible. However, in my view, it would be wrong to begin on a program designed to close all developmental centers in favor of community-based services. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Please hold your applause.

Thank you, Mr. York.

Any members have questions for Mr. York?

Senator Allen.

SENATOR ALLEN: Your statistic of the number who dies is very frightening, and I'm wondering if any of that is based on New Jersey information.

MR. YORK: I think there are-- Senator, there are some studies that have done -- attempts have been made to do more nationwide. That particular one I gave you was from a particular state.

UNIDENTIFIED SPEAKER FROM AUDIENCE: What state?

MR. YORK: What state?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Yes.

MR. YORK: There have been efforts, though, to gather that kind of information nationwide. And those studies have generally shown -- and one of them I think was done by one of your doctors here in this state. Dr. Kastner has helped in one of those studies, and he worked with Dr. Strauss in California -- have generally shown that mortality rates are higher in the community, abuse rates are higher in the community, and other factors also. Turnover of staff is higher in the community. You don't have probably as good a staff outfitted in some of these community settings, staying as long and being committed there to a long-term job. And as you know, staff turnover usually results in poorer services when you have staff turnover. (applause)

SENATOR ALLEN: I asked about it being New Jersey-- As it happens, I served on the board of an organization that runs many group homes here in New Jersey and deals with many folks with developmental disabilities on many levels. And they do offer wonderful care and these sorts of things. I know many other groups that do. I honestly don't know

of any that don't. I'm not saying that they don't exist, I just don't know of them in New Jersey. And it just concerns me that we would be thinking that there were so many groups in New Jersey, if we can't point to them, that are doing such a poor job that they would have these problems occur.

I also must say, I do appreciate your pointing out that the folks who are working in the institutions are good, hard-working people who don't deserve to have that broad brush of abuse used.

I guess I would like to have further information from you, possibly written, on what you know about New Jersey in particular so that we can have a good sense of our state. I hear what you're saying about other states, but honestly that isn't what's important to me. It's what we're doing here. (applause)

MR. YORK: That's very fair.

SENATOR ALLEN: Thank you.

MR. YORK: I would be happy to try to provide some additional information for you, Senator.

SENATOR ALLEN: Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblyman Malone.

ASSEMBLYMAN MALONE: Thank you.

Mr. York, are you familiar-- In our hearings on the Budget Committee and in other situations, we've heard that Maryland is a model of success. Are you familiar with the Rosewood closing in Maryland?

MR. YORK: I have some familiarity with it, yes.

ASSEMBLYMAN MALONE: What were the results of that closure in Maryland?

MR. YORK: I can provide you with some additional data on that. I believe it has, again, mixed results, as with most closures. And, again, it's how you measure it. I mean, there are a lot of people out there who will give you data -- so-called -- I call it *pseudoscience* -- that will tell you how successful everybody is who has been moved out into the community, because they go in and gauge things like, "How happy did the person look when I went and visited them?" But I try to rely more on empirical, scientifically proven data which demonstrates the mortality rates, the abuse rates, and those kinds of things that are actually something that you can measure, that you can actually put your finger on. But I think I can supply you with some information from Maryland.

ASSEMBLYMAN MALONE: We had received a copy of a Justice report on the results of the Rosewood closing, and it's pretty horrifying. And anyone who would like a copy of that-- I just think that we need to look at other situations and how they were handled. And I would be very interested in getting, as the Senator was, some additional information from you from various aspects across the country.

MR. YORK: And another example -- and I don't think they'd mind me saying, because it was pressured on them by the U.S. Department of Justice, who is often my adversary in these types of cases. But Nebraska has had a bad experience recently too, where they were forced to move out a number of people rather abruptly. And the next thing you know, the parents and everybody are coming back in and saying, "My child is being harmed or has died now." And I think careful consideration has to be made before anybody is moved. So I would be happy to try to help you.

ASSEMBLYMAN MALONE: I'm assuming you have an extensive background in litigating against the Justice Department in closure issues.

MR. YORK: That's true.

ASSEMBLYMAN MALONE: How successful have you been in your litigations with the Justice Department?

MR. YORK: Well, many of the cases end up in settlement, so you would have to -- that would be somewhat subjective on how successful or unsuccessful. I think we've gotten the best settlements in the country. I'm sorry if I sound a little prideful there. But the only times we've taken cases to trial and finished the trial -- we've beaten them every time. They've never beaten us in the courtroom. So we've been very successful.

ASSEMBLYMAN MALONE: Categorized, at times, the Justice Department is being a little overzealous in their reach?

MR. YORK: Absolutely. I've been shocked. Being a former deputy attorney general from Pennsylvania, I thought they were cut from the same cloth as me, and that the truth would prevail, and the facts would prevail. And I find much of their advocacy is zealous -- they're zealously attacking things and coming from a political perspective rather than basing their cases on the facts.

ASSEMBLYMAN MALONE: Thank you very much.

MR. YORK: Thank you, Senator.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman McHose.

ASSEMBLYWOMAN McHOSE: Thank you, Madam Chairwoman.

Mr. York, I just want to thank you for bringing up the cost comparison, because that was one of the thoughts that I had as a layperson. I'm new to the Human Services Committee this year. And my concern was that although I know there are many, many good community-based service providers, I just couldn't understand and relate to the cost shift from the developmental centers to individual care. And I think that what you explained was helpful to me. So I appreciate that very much.

Thank you for being here today.

MR. YORK: Well, thank you very much. And I wish there were better studies on the cost comparison. Because there is a chance that you do save some money moving people to the community, although that, obviously, shouldn't be your only consideration. But what you're getting usually from the advocacy groups and other people who want to advocate their position is apples to oranges. They are not including everything into the cost analysis that they should. I would like to see a study that really breaks it down and includes all the same things in the same categories so that you can really say, "This is what the savings would be if you need to."

Again, I think parents' rights and choice might outweigh, sometimes, even if it is more expensive. You might still want to do what the parents want to do. But I'm just saying the cost analyses that I've seen, -- and we've litigated over in trials in courtrooms, have not stood up because they do not compare the same things.

ASSEMBLYWOMAN McHOSE: Thank you very much.

Assistant Commissioner Ritchey, do we have some of those numbers here in New Jersey?

ASSISTANT COMMISSIONER RITCHEY: Chairwoman (*sic*), Senator (*sic*), the issue is very, very complex because the funding formulas are totally different between the developmental center and the community waiver program. You have to factor in numerous discrepancies because when you're on the waiver, you build in a higher SSI payment, you have your Medicaid card. A lot of that is covered in the DC.

That being said, the other problem we run into is, when you move a person into the community today -- I can give you an exact budget pretty much down to the penny. It may not be there a year later. You have no comparison in the center, because all the costs reports are generated on averages for the center. So I can't start with John and say, "I spent exactly this dollar in the DC but now this dollar in the community."

So what I'm going to answer you-- I'm going to answer your question, but I want to put a lot of caveats here, because it is not simple analysis. In talking to various states, the range of cost difference -- not the reimbursement differences, because the waiver is reimbursed in a different way than, I say, from our funding -- is between 15 percent and 33 percent -- is what we best can see.

Looking at New Jersey, with the people we've moved in the last year, compared to average costs for that person in the center -- which is not their cost -- the differences of cost is about 26 percent. But that's not the reimbursement. So I want to be real clear. And I have seen no study that has really nailed uniqueness, because even the Federal government sees the institutional side differently than the waiver side.

ASSEMBLYWOMAN McHOSE: Thank you for that.

Thank you, Madam Chairwoman.

SENATOR VITALE: Thank you very much for coming. I appreciate you taking the time to be here and traveling so far.

MR. YORK: Thank you for the honor of letting me appear.

SENATOR VITALE: Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Next we have Dr. Conroy, the CEO of the Center for Outcome Analysis; and Dr. Spitalnik, the Executive Director of the Elizabeth Boggs Center on Developmental Disabilities.

Welcome to you both.

Is Dr. Conroy here with you as well?

D E B O R A H M. S P I T A L N I K, Ph.D.: I don't know. I haven't seen him, and he is about 6'2, so I assume--

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Well then it's all yours.

DR. SPITALNIK: Thank you.

Thank you so much, Senator Vitale, Assemblywoman Huttle, members, and guests. I'm pleased to have the opportunity to testify before you today.

My name is Deborah Spitalnik, and I'm Professor of Pediatrics at the University of Medicine and Dentistry, Robert Wood Johnson Medical School. I'm also the Executive Director of the Elizabeth Boggs Center on Developmental Disabilities, New Jersey's federally designated University Center for Excellence in Developmental Disabilities Education, Research, and Service. And one of our functions is to advise policymakers. And that's the context I appear before you today.

I'm also former chair of the President's Committee on Intellectual Disability, and also a former guardian of a man who lived at Hunterdon Developmental Center.

My goal today is to place our experience in New Jersey -- and it's very germane given Mr. York's testimony -- our concerns and opportunities for supporting people in a national context.

The information I'm sharing with you today comes from a national database, it's verified.

And I also have New Jersey-specific information, Senator Allen, which I'm delighted to share.

It's my goal today to contribute to a dialogue that affirms whatever position we're taking, we have the common commitment to the well-being of people with disabilities.

There has been, for the past 30 years, a clear direction in Federal and State policy toward community living for individuals with disabilities. This policy began under President Nixon, and it has always been a bipartisan commitment. This commitment is evident in the Developmental Disabilities Act, the thrust of Medicaid funding for long-term care services, the Olmstead Supreme Court decision, the Year of Community Living.

I also very optimistically share with you that in the New Patient Protection bill -- so-called *Federal Healthcare Reform* -- there are possibilities for increased revenue to the State, but only for community services.

Assistant Commissioner Ritchey talked about the individuals served by the Division of Developmental Disabilities. And I want to point

out that 70 percent of those on the Division's caseload live with their families, and that's in contrast to the national percentage of 57 percent. Additionally, we have a larger number of people living out-of-home in New Jersey, 22 percent.

For people in our state who utilize residential placements, we have a smaller percentage of people who live in small group homes, supervised apartments than the national average. We're about 20 percent lower. But we are two-and-a-half times higher in the degree to which we rely on large, state-run institutions. It also should be mentioned that New Jersey has the largest number of people placed in out-of-state placements, which is a great human cost in terms of separation from the family; and also very expensive. And, unfortunately, over the past 10 years we've seen a 500 person increase in the number of people living in nursing facilities, bringing our total to about 984.

The clear national policy trend, both from a legislative court, as well as financial perspective, is toward decreased reliance on state institutions and increased supports for families. Eleven states have only one institution. And as Assistant Commissioner Ritchey mentioned, 11 states have no institutions. Those states-- The individuals who live in those states are no less disabled than New Jersey citizens with developmental disabilities. New Jersey is one of only 10 states that has over 2,000 people in public institutions. Eight percent of the population in other states live in institutions, 25 percent in New Jersey. We have a large absolute number of people, we have a large percentage of people. And from a population perspective, we have institutionalized more people.

The level of intellectual disability -- and this speaks to one of the things Mr. York raised -- of individuals who reside in New Jersey's developmental centers is very comparable to the level of intellectual disability of institutions in other states. The one exception is that we have a larger number of individuals who are classified as having profound intellectual disability. However, I point out that our neighboring state of Pennsylvania has the same proportion of people who function in that range, and they have also, in contrast to our pace of developing community and reducing institutions, been much quicker.

The other point I think needs to be-- And let me tell you all some more. And we acknowledge that there are people in the developmental centers with very severe needs. But I assure you that for every person in a developmental center, there is a twin in the community who has as significant a disability. The difference may be that the population in the institution is slightly older. But for families who, through the day training program, through public education, through SSI, were able to keep their family members at home: There are families who have their family member on ventilators, who get up during the night and provide nourishment through feeding tubes, who deal with incontinence continually, and with medical challenges. So no one is disputing the needs of people in developmental centers. But let us be perfectly clear that we have the same needs among the 70 percent of families who have their family members at home.

As Commissioner Ritchey pointed out, in 1980 we had 7,262 people in New Jersey's developmental centers, which we then called *State schools* and *hospitals*. Between 1980 and 2008, we decreased the population

by 59 percent. At the same time, the rest of the country decreased its institutional population by 72 percent. Our neighboring state of Pennsylvania, who started out with the same level of population that Mr. York referenced, decreased its large congregate settings by 82 percent in contrast to our 59 percent. Our pace of reducing the size of institutions is slower than the national average.

But I do want to turn now -- and I had already prepared this, but I'm pleased to be able to respond to Senator Allen -- about our experience in New Jersey, our database experience in moving people from institutions to the community.

New Jersey has closed three institutions: Edison, which was a very temporary, small institution that was only open for three years; Johnstone Training Center, that Mr. Emmons mentioned where he had lived. Our major closing was at North Princeton Developmental Center. It was closed in 1998. When the closure process began, there were 512 individuals living there. Extensive documentation of the impact of this closing on our New Jersey citizens was developed by the New Jersey Institute of Technology, the Developmental Disabilities Planning Institute. Through measuring the status of these individuals prior to the closing and at regular intervals throughout, and comparing their experience and their well-being to other individuals who remained in New Jersey institutions, the Planning Institute demonstrated a couple of things that are very germane to this conversation, and I'm abbreviating.

One is positive outcomes. There was no evidence associated with increased mortality or other negative consequences -- New Jersey-specific data. And despite initial opposition, there was eventual support for

community living by a clear majority of North Princeton Developmental Center families.

We heard earlier about psychiatric and behavioral needs. These needs are often identified both as needs in the communities, deficiencies in the communities, and they are. And, unfortunately, they are a cause of -- an entirely preventable cause of institutionalization. For this North Princeton population that we measured, there were increased numbers of individuals receiving a psychiatric diagnosis, an increased use of antipsychotic medication, and a decreased use of behavior medication. What that means to me -- and there is, in this population, a higher incidence of psychiatric disorder and behavior problems -- and estimates range from 30 to 75 percent of the population. What this means to me is that when individuals move to the community, there was more address of their psychiatric need rather than just using chemical restraint in terms of behavior intervention. We don't have enough psychiatric care in the community, we don't have enough behavioral care, but we have the capacity to build that capacity. We do not have to put people in particular settings in order to address their needs.

As you know, Medicaid Title 19 is the underpinning for long-term care both in New Jersey and around the country. How we in New Jersey use Medicaid has a unique history, and it really reflects, I think, our pattern of service delivery. And I think we can do better with it.

The Intermediate Care Facility program that people mentioned -- Title 19, which both provided Federal funding, and standards, and improvements-- By 1977, 40 states had one ICF/MR. We did not, in New Jersey, enter this program until 1978. But when we did, it became the

impetus for reducing the institutional population by over 1,500 individuals, 21 percent of the population, in the five-year period between 1980 and '85. And Kathy Walsh, in her earlier testimony, talked about how The Arc of Bergen and Passaic, and many others, developed services for those individuals.

ASSEMBLYWOMAN VAINIERI HUTTLE: Doctor, I hate to interrupt, but we have quite a few speakers. I just wanted -- if you could wrap up.

DR. SPITALNIK: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

DR. SPITALNIK: I will be quick, but I hope to have as much time with the data as Mr. York was able to have. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Please, I think the applause is taking away your time as well. I would just like to have equal time so that we can have Q and A afterwards.

DR. SPITALNIK: Of course. And I can stop now. But I do-- There are two charts that I want to call your attention to.

And I meant no disrespect by that, but rather my eagerness to share New Jersey-specific data with all of you--

When we look -- and it's Table 4 in what I've provided you with -- that we have continued to lag behind. We are higher in institutional expenses than the nation, and we are lower in Medicaid community expenses. In New Jersey-- The other thing that I-- And so if you look at Table 4 -- and I won't commit the error of academics and belabor it -- but when you look at where we put our resources, they are more heavily in the institution.

We also know that institutional per diem costs have risen dramatically in New Jersey and that our per diem costs are higher than the national average. Our per diem costs are, on the average, \$219,987. In the U.S., they're \$128,000. The other I want to mention is that we have tremendous variation, within our developmental centers, of cost. And I think some of that may be accounted for by the fact that we are maintaining exceedingly outdated, ineffective, capital systems to which we continue to have to, of course, be responsive for their functioning. But those moneys do not go directly to the care of citizens with developmental disabilities.

I want to mention, in terms of the issue of choice, that choice is an issue not at which -- I affirm for all people with developmental disabilities and their families, but choice is an issue not only for individuals who seek an ICF/MR institutional-level of care, but also for individuals who seek a home- and community-based service level of care. This Legislature, under Public Law 1997, asked the Department of Human Services to develop a plan to end the waiting list in 10 years, by 2008. One of the elements of that plan and the recommendations -- which was a compromise brokered between the late, beloved Leila Gold, who was the head of the parents at Hunterdon, and community parents -- was to close three developmental centers in order to make those resources available to the community.

I want to close with a note of hope and revenue, which is that in the Patient Protection -- the Federal Patient Protection and Affordable Care Act there are three provisions that address long-term care, that hold the promise for New Jersey of increased Federal revenue. These are the new

State Balancing Initiatives Payment Program, which will be a four-year program that will provide a temporary increase in Federal matching rates for states that make structural reforms by decreasing the institutional population and increasing the community population; by the Community First Choice Option, which will enable assistance for people in the community, including people with profound disability, for personal care, for (indiscernible) and other kinds of supports -- such as people describe their family members need. This could provide an additional 6 percent Federal match for New Jersey Medicaid. And lastly, the extension of the Money Follows the Person Rebalancing Act, which has been extended through 2016. One of our challenges is that New Jersey follow these, that we position ourselves appropriately so that we can take advantage of these increased Federal resources and provide opportunities for all our citizens.

Thank you for your patience. And may I ask -- any questions.
(applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Any questions from the Committee?

SENATOR VITALE: I thank you Dr. Spitalnik. Thank you for being here and for your ongoing advocacy and hard work.

DR. SPITALNIK: Thank you.

SENATOR VITALE: There's been a lot of discussion today about choice, and that's appropriate. But respecting choice is certainly important. What kind of effect would-- If it is that the majority of individuals who currently reside in developmental centers -- their choice, the choice of the families -- for them is to remain there, how difficult would

it be to then close a developmental center or two in this state if the choice was to stay for most people?

DR. SPITALNIK: Thank you for that question. I think one of the issues that was pointed out earlier is that this Legislature asked the Department of Human Services to make a commitment to move individuals from the developmental center, under State law, and that the Division had developed a plan that involved 250 people moving a year. We have never had the available resources to move that number of people.

I would fight to the death for a family's right to make a choice. But I feel that the choice is for -- and it's under Medicaid law-- The choice is for an institutional level of care. It is not for-- There is nothing in Federal law that says you are entitled to a particular location. And I think the reality that we have is that we want to honor the choice of families and individuals who want an institutional level of care. But unless we consolidate, and rebalance the system, and take advantage of the home- and community-based services waivers, and these new Federal moneys, we are mitigating the choice of the 70 percent of families who are caring for their loved ones at home, some of whom have turned down placements offered because they are not the services they want for their family member.

Many of these families who are ill or aging are hanging on and continuing to provide care not only out of their love and devotion for their family member, but because the alternative to them of their family member going to a developmental center is the complete abrogation of their life-long choice. I mean, there is a range of abilities and needs, both in the centers and at home. But I have recently been reading -- and I think it will be available to you -- the list of things that families who have their family

member -- their daily to-do list of what families are doing at home. And there are families who are providing continence care, diapering, feeding, feeding tubes, cleaning ventilators -- whatever it is. And there are other families who can't leave their family member alone because of their need for supervision. We have to find a way to honor choice but to consolidate and/or close so that we can appropriately balance the resources in the community, and so that we can assure choice for all families. (applause)

SENATOR VITALE: Thank you very much. Thank you, doctor.

DR. SPITALNIK: Thank you very much.

ASSEMBLYMAN MALONE: I'm not sure you quite answered the Senator's question.

DR. SPITALNIK: I'm sorry.

ASSEMBLYMAN MALONE: If a family chooses, as their family choice, to stay within the developmental center, is it their right to make that decision?

DR. SPITALNIK: I think it is their right to make that decision on the advice of treatment, and also assuming that's what their family member wants.

ASSEMBLYMAN MALONE: Okay.

DR. SPITALNIK: But the question is--

ASSEMBLYMAN MALONE: No, I think the question that was asked is what the question is. The question is: If the family member chooses, along with the individual, to stay in the developmental center -- it is their right to do that?

DR. SPITALNIK: Yes, I believe that's what Olmstead says.

ASSEMBLYMAN MALONE: Okay. Thank you.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Excuse me. I'm a family member, and unfortunately we have to leave. The bus is leaving. Can I ask you one question, doctor.

SENATOR VITALE: I appreciate that. You can ask her privately if you'd like to after she's finished.

Thank you.

DR. SPITALNIK: Thank you for your time.

SENATOR VITALE: You can have a conversation on the side if you'd like.

Thank you.

Joe Young, Disability Rights New Jersey; and Sue Gottesman, New Jersey Council on Developmental Disabilities; and I think it's Elaine -- I can't read the writing.

Is Joe here? (affirmative response)

Joe, there you are.

Is Sue here? (no response)

Elaine Buchsbaum?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Alison Lozano.

SENATOR VITALE: Pardon me? Can you come up to the front table, please?

J O S E P H B. Y O U N G, E S Q.: Alison Lozano from the Council is speaking for Sue.

SENATOR VITALE: Okay. You can come to the front table please.

I just want to-- Those who are still scheduled to speak, I just want you to know that it is 3:45, almost 3:50. And we'd like to get through all of those who signed up to testify. I would rather have their -- reserve their time to testify. And if we could just keep our comments as brief as possible to summarize what it is that you've come to say. No more than five minutes each, please.

Thank you.

A L I S O N M. L O Z A N O, Ph.D.: I'm not Elaine Buchsbaum. Elaine had to leave to take care of a family matter.

I'm Alison Lozano, and I'm the Executive Director of the New Jersey Council on Developmental Disabilities.

I want to thank the Committee Chairs, Senator Vitale, Assemblywoman Huttler; and the members of the Committee for this opportunity to contribute to today's discussion about how to best design and deliver services to people with developmental disabilities in New Jersey and their families.

The Council appreciates the economic realities of the times and the budgetary challenges facing our State. These fiscal constraints make it particularly important to examine the consequences of maintaining a system in which nearly 35 percent of the Division of Developmental Disabilities' budget is used to maintain seven large institutions that serve only 7 percent of the state's more than 400,000 eligible people.

In addition, DDD maintains waiting lists of over 8,000 people who want community residential services or other supports that will enable them to live outside the developmental centers. Thousands of families who

care for a loved one at home do not get much in the way of family support dollars or self-directed service dollars to make their situations manageable.

By way of a personal introduction, I raised my niece who has a developmental disability. She currently lives in a supported living apartment five miles from our home in Mount Holly. She is part of her community and enjoys her life as fully as anybody else who lives in the community would do so. She, by the way, is supported in her community and her life supports run a par with the rest of us who live in the community, including social, medical, and psychiatric interventions.

The most important messages from families that they want you to hear today is that we live with the constant fear that our children will end up in an emergency developmental center placement, exactly where we have sworn they will never go. And speaking on behalf of Elaine, who is the parent of a 35-year-old man with autism, intellectual disabilities, and a seizure disorder, Matt lives with Elaine and her husband long past when she feels he should be doing so. He needs to have a place of his own separate from his parents and be ready for a day when they are no longer alive. And this is a great concern of Elaine's, if I may speak on her behalf.

Any State approach to services that fails to provide real community alternatives to institutional placement violates all that we families spend our lives working for to ensure that our loved ones continue to have a place to live and thrive in their community.

Attached to the written testimony that you have been given is the Council's response to information being circulated by an organization known as Advocates for New Jersey Developmental Center Residents. We believe that the group's claims that 96 percent of guardians and family

members prefer continued ICF/MR services over community services is inaccurate, and we demonstrate its inaccuracy in the attachment that you received.

In particular, based on information in the group's own publication, only roughly half of the total number of DC residents at the time the survey was completed had a family member or guardian respond to the survey at all. We have observed that the majority of New Jersey families prefer to have their sons and daughters with developmental centers (*sic*) live with them at home or near them in a community setting with appropriate supports, just as my child is supported in the community.

New Jersey, like most other states in the nation, has direct experience demonstrating the positive outcomes of closing large institutions. A study of the results of the 1998 closing of North Princeton Developmental Center, published by the American Association on Mental Retardation in 2005, found that individuals who transitioned out of the institutional settings have more friends, exhibited less challenging behaviors, perceived their lives to be better, and demonstrated significant increases in self-care skills over time. Significantly, the study also reported convincing evidence that the people who remained in institutional settings showed significantly decreased cognitive and social skills.

The United States Supreme Court, in the landmark Olmstead decision, concluded: Confinement in an institution severely diminishes the every day activities of individuals, including family relations.

Thank you very much for allowing me to make this presentation.

SENATOR VITALE: Joe.

MR. YOUNG: Good afternoon.

One of the advantages of being this far down in the order is that I get to throw out my first couple of pages again.

Let me try to add-- I'm an attorney for Disability Rights New Jersey. We actually have a suit at the moment going on against the Division of Developmental Disabilities over this issue.

But if my staff will turn off their computers and stop listening, let me indicate that we would-- The goal of the Olmstead is for the states to develop a plan. Mr. York was here indicating that he was defending states. We would be very happy-- We believe the floor below which the State cannot go is a plan. The State of New Jersey has published a plan; we would like to see the State of New Jersey fund the plan. If the State of New Jersey funded that plan over the next five years -- the plan calls for eight, but let's just deal with five for the moment -- over the next five years, not a single person in a developmental center now would -- who does not want to leave would be asked to leave. In all practicality, they will probably never be asked to leave. But there will still be hundreds of people living in developmental centers who want to leave, and thousands of people living with their families in need of community service.

So this hearing is not about forcing people out of developmental centers. It's unlikely that's ever going to happen in New Jersey. What do we need to do to get the people who are in there now, who have been waiting from months to decades, to leave? What do we need to do there now to help them get out?

And I will trust my written testimony for your summer reading at the beach this summer. (laughter)

SENATOR VITALE: Are there any questions from any members? (no response)

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

We have some family members from the centers. I believe they have either their sons, or daughters, or siblings. But I will call up Cindy Bartman, the State Coordinator, to come up with -- I don't know if they're all here, but I will call their names.

UNIDENTIFIED SPEAKER FROM AUDIENCE: They are.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Joanne St. Amand, Philip Metta, Sisto Caponera, Carol Mastropolo, Annie Esposito, Vito Colletti, Winnie Sekela.

Cindy, you'll orchestrate where they sit and where they come up, and if you want the second panel to come up after you. I think, Cindy, you're the spokesperson.

CINDY BARTMAN: Yes, I'll start, I'll kick us off.

ASSEMBLYWOMAN VAINIERI HUTTLE: Just have maybe a minute of--

Cindy, are you--

MS. BARTMAN: I can talk pretty loud.

SENATOR VITALE: Behind you there's a mike on, I think -- the table behind you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Cindy, if each member is going to speak -- if you could have maybe just your intro and then have each member maybe take a minute or so.

MS. BARTMAN: Okay. Thank you so much, Assemblywoman Huttle.

Good afternoon everybody.

My name is Cindy Bartman, and I'm the President of the Association for Hunterdon Developmental Center. Our panel consists of representatives from all seven of our New Jersey developmental centers. On behalf of myself and them, I would like to thank you for this opportunity today to speak with you and share with you the stories of our families, in their words.

We are the primary decision makers for our children the way that any parent or family member is, and we are the stakeholders in this matter of the future for our loved one's homes.

Here are a couple of facts that I hope you will find compelling: According to 2008 statistics, New Jersey is not number one, or two, or even 10th in the utilization of ICF/MR services as compared to each states' total population. New Jersey ranks 16th.

Secondly, you would think that with all this talk about the cost of developmental centers that our direct care workers would be paid the highest wages. Actually, in 2008, New Jersey came in as number 11 when ranked alongside the other states with large state facilities. And though our direct care staff are not the highest paid in the nation, New Jersey ranks among the lowest in staff turnover rate. The status of those who work in waiver homes is nowhere near as stable as this.

During Commissioner Velez's Senate Judiciary confirmation hearing this past March, she was asked to explain why providers of community group homes were not required to rebid their contracts on a

yearly basis. Ms. Velez replied, and I quote, “With respect to those served in the DD world, it is hugely disruptive for families to come to learn that the place where their son or daughter has been for a very long period of time, by a provider agency that is working well, may now lose a bid to the lowest bidder. That would be hugely disruptive to the system.” I actually took some pain in explaining this to the Comptroller’s office that, in this instance -- that if somebody is residing at a provider agency, and has done so for decades, to uproot that person because of a lower bid would be very disruptive for that family, for all families. And I still maintain that position. The disruption -- it’s very unlike almost any other system. The continuity for families really is paramount.

So I ask you, why would anyone think different for our family members and their homes at the developmental centers?

You’ve already been introduced to who will be speaking, so I’m going to give you an overview of Hunterdon Developmental Center and excerpts from letters sent in by families. And you have packets in testimonial form for both Senate and the--

SENATOR VITALE: We have all of that testimony.

MS. BARTMAN: You have all the testimony. You will have all the testimony.

SENATOR VITALE: So it’s not necessary to read all those letters, though.

MS. BARTMAN: We’re not reading all the letters. We’re giving you excerpts so everybody can understand what our families are going through. They’re short excerpts.

The census at Hunterdon Developmental Center is 561. Fifty-three residents have feeding tubes, seven have trachs, one is completely ventilator-dependent, three residents use nighttime ventilators, two residents have colostomy bags, nine have pacemakers, eight residents require daily catheter treatments, 86 receive respiratory therapy, 55 residents are severely retarded, and 461 residents are profoundly retarded. These represent 93 percent of Hunterdon's population.

For the survey of choice that was compiled by the Advocates for Developmental Centers residents, our return of responses to the survey was 516 from a census of 561. All but eight responses favored having their loved ones stay at Hunterdon. And these are all of the returns that I have. If anybody would like to see them, they're welcome to them.

So now I'm going to read you a few of the excerpts. Anne M.: "The developmental centers are needed and should not be closed."

Mary F.: "We would never want our daughter moved into a group home. This is our decision. We are her family, and we know what is best for her. We are upset every year with these notions that we would want community placement for our child. This attempt every year to abolish a system that works so well contradicts the fact that New Jersey cares for its most needy citizens."

Bill C.: "Eddie was one of the first clients of Hunterdon Developmental Center. The change in his life and our lives was miraculous. After 40 years, we are still impressed with the extraordinary amount of care that the clients of these centers receive. We know he has been happy, and that makes us grateful. The facilities are resources to be nurtured, not piggy banks to be cracked."

James H. says: “My son is at HDC, and the people working with him do an amazing job. They always include me in the decision making with everything he needs.”

Judith B. states: “I find it totally despicable that anyone could even dream of closing my brother’s home, never mind the audacity to try and close it. These special people do not adjust to change well. How cruel. It would be like punishing them. Do you really think it would be progress? No, they would regress. The ultimate decision maker should be the family.”

Emma P. states: “My son is 31 and has autism. He also has fatal food allergies as well as severe environmental allergies which can also be threatening to his health. My son’s doctors, his father, and I strongly feel that my son is safest in a developmental center where there is on-site medical attention.”

Tom B. states: “Most of the clients now in our developmental centers have the mental functioning of a 2-year-old or less. During the mass exodus from the centers in the ’90s, staff recommended those who could benefit from waiver services. The providers then came and cherry-picked the least difficult clients, leaving others behind. There are eyewitness accounts of residents leaving and then returning to the centers after failed experiences in the community. Of the past seven clients that staff were recently pressured into sending out into waiver services, five have returned to the Center in far worse medical shape than when they were initially discharged from HDC. One girl only lasted 12 days before coming back on a feeding tube because she did not eat anything for the entire 12 days that she lived in the group home. Another girl who was very active at HDC came back confined to a wheelchair. Another person came back with

multiple fractures. Two others came back with feeding tubes. We also know of a number of deaths.”

Jeff B. states: “I have been visiting HDC all my adult life and have spoken to staff and families, and I believe that it is a fallacy that a significant portion of the clients there wish to leave HDC or that their families would prefer community placement.”

Maria A.

ASSEMBLYWOMAN VAINIERI HUTTLE: Cindy, I hate to interrupt you again. The only reason I’m asking you to wrap it up is so that each one of the family members has an opportunity. You know what? We’re losing our Committee as well because of the hour.

MS. BARTMAN: Yes, I know. As a matter of fact, we’ve lost a lot of our parents.

ASSEMBLYWOMAN VAINIERI HUTTLE: So that’s why -- if we could wrap it up so that each one has an opportunity to say something.

Thank you.

MS. BARTMAN: Again, it’s excerpts of letters. You got the gist of what we’re all about. You understand that we did our own survey of families, guardians, parents, and siblings, and we have the cards here. And that was all published in our residential choice survey.

Carol Mastropolo, from New Lisbon, who is also not feeling too good.

SENATOR VITALE: Turn your mike off so she can turn her mike on. (referring to PA microphone)

Just use one-- There’s one right in front of you.

MS. BARTMAN: Give her a chance, she’s--

SENATOR VITALE: Take your time.

CAROL MASTROPOLO: It takes me a while.

SENATOR VITALE: For the record, just state your name and where you're from.

MS. MASTROPOLO: I'm sorry.

SENATOR VITALE: Just state your name and where you're from.

MS. MASTROPOLO: Yes, I'm Carol Mastropolo, President of New Lisbon Developmental Center (*sic*).

I'm not going to read all the excerpts either. You have it in the packet.

I would just like to tell you about my son. He's lived at New Lisbon for 29 years. He's happy there. He loves it. He's home quite a bit, but he never has a problem. We never have a problem with him going back.

Some people are under the impression that they languish -- the residents languish in the developmental centers. My son does not languish there. He is so busy. He goes to a workshop every day to make some money. He participates in Special Olympics. He goes to hockey games, and basketball games, and baseball games. And on the campus they always have, like, field days, weather permitting; diversity day. We have a huge family day picnic that everybody takes part in. He's happy there.

I would ask you to please consider not closing the developmental centers.

Thank you. (applause)

You don't know how hard that was.

SENATOR VITALE: Is there anyone else who wanted to--

MS. BARTMAN: Yes, we have--

J O A N N E R. St. A M A N D: Yes, my name is Joanne St. Amand.

I am the sister of Rosemary, a profoundly retarded woman who lives at Woodbridge Developmental Center for 35 years. She was not expected to live past puberty. Rosemary cannot walk or talk, she cannot feed herself nor take care of any of her most personal needs. Rosemary turned 55 last month, which is a direct reflection on the excellent care that she gets at Woodbridge Developmental Center.

I am also the President of the Woodbridge Developmental Center Parents Association. I am here today to represent all of the families at Woodbridge Developmental Center, and I am also going to read some excerpts to you from many of the letters that were sent out for this hearing. They are written from the hearts of these families. And I also thank you for your attention to allow us to express these feelings here.

First, the results of the survey of choice conducted by the advocates for the developmental center residents-- Our census was 404. We received 255 postcard returns. Of these, all but 15 are opposed -- all of them except for those 15 are in favor of the developmental centers. And I challenged my previous speaker to show me the data that says that our survey was not conducted properly. We did it from all but (*sic*) six of the centers, and we have the cards here to show you. Ninety-four from Woodbridge are in favor of staying at the developmental center. I want to make that perfectly clear -- 94 percent from me, yes.

The following are excerpts, and I won't read them all to spare you the time, but I will pick out a few.

Leonard L. writes: “Several years ago an attempt was made by Woodbridge Developmental Center to place Bobby in a family/community placement. Bobby resisted and was quickly moved back to Woodbridge Developmental Center. Residents of DCs are human beings with feelings and emotions. Please do not let them be caught up in a political number-crunching plan that may look good on paper but cannot truly reflect the impact that closing these developmental centers or reducing the staff and services at those centers will have on their lives.”

Juana M. writes: “I have always expressed my feelings about not wanting my son to be placed in a community group home. Do our choices carry any weight? Their homes are being threatened. Yes, community life does exist in these centers.”

Thomas, Kathleen, Brandon, Ian, and Chelsea write: “Most of the patients at the Developmental Center are not fortunate to still have family and relatives to advocate for them. As a result, they have no voice, no advocate, and no protector. There is an opportunity here for all involved to make clear that here, in New Jersey, we are our brother’s keeper.”

Gerry S., my mother, and 25 of my sister’s relatives write: “We, the undersigned, recognize that the waiting list crisis in New Jersey demands the expansion of community-based options. However, we are against any expansion at the expense of the ICF/MR residents. One size does not fit all.”

John P. writes: “If you read my brother’s Individual Habilitation Plan, you will see references that say that he would like to be put in a group home. There is a simple problem with that comment. My

brother has never spoken a word in his life, nor would he be able to understand group homes or communicate his desires in any other non-spoken way. I raise the point because it makes me wonder how many other residents' files contain similar statements that may cause decisions to be made that are not in the best interests of these individuals."

Anne D. writes: "We oppose the raising of the cost-of-care contributions. They do not receive enough money as it is, and they will live at the poverty level. Also, Maximus is a waste of State dollars, and the contract with New Jersey should be terminated."

Louis and Teresa write: "Our son has been in one-to-one care for years at Woodbridge due to his history of self-abuse. But we just heard that he is being taken off this one-to-one service due to the fine efforts of the staff at Woodbridge Developmental Center."

Please, I ask for all the residents and their families, keep all of our developmental centers open.

Thank you. (applause)

WINNIE SEKELA: Can you hear me?

SENATOR VITALE: Yes.

MS. SEKELA: I'm Winnie Sekela. I'm from Wayne. My son is Andrew Sekela. He's from North Jersey, and he lives there, and he loves it.

I have a long story which I will bring to--

These 8,000 people out there -- I was one of them. Maybe there were 5,000, but there were no facilities. So my life was hell. My son was always in danger. He lived in psychiatric units. He did not live at home. He would honeymoon and then have to go right back.

The neighbors: The neighbors the group homes have went to the police. They came to my house and said, “Why doesn’t this woman get rid of him?”

I kind of came into the system backward because Whitman was saying he is eligible but not entitled. And then she said, “You can’t say that to people anymore.” Nothing more was done. So he went into a group home -- which were absolutely smashingly, wonderful people. But my son was not group home material. They tried every way to get him-- He has a behavioral problem. But he’s neurologically impaired. Of course he’s retarded. At that point he was like 30 -- but he was about 5 years of age. He never improved.

Group homes look at them as what they think the person should do. This group home was very good. They tried everything. And toward the end they’d ask me to take him for the weekend because they were having a party or something.

It was then agreed-- He went to-- Again, Elizabeth psychiatric unit. They couldn’t contain him. Finally we agreed he’d go to North Jersey. And when he entered North Jersey, his priority on IHP was behavior. In three years they civilized him. His neurological condition -- any little thing that was wrong with him was taken care of immediately. He was absolutely ready for group home. I figured he was civilized now and it might work. He wanted to.

When he came out, the IHP and the proposal from the group home matched, which was great. But it didn’t when he moved in there. He was alone in there. He had his own room. That was wonderful. But there was no congenial mixture. The choices of friends just weren’t there for him.

He did things like -- he ran and jumped into the railroad tracks down in Wayne Mountainview. The train could have been coming. The staff couldn't get down to him. They called the police, who just about told them, "You better get him out of town." He took a bus. He was gone from 3:00 in the afternoon. At probably 5:00 or 6:00 the staff got a little worried and they started letting people know. At 10:00 I got a call saying, "We understand you took your son." I didn't. They were terribly annoyed. He finally told the bus driver. He rode New Jersey Transit. He has a great personality. And they dropped him off at Wayne General Emergency Room. And they were mad because he was eating ice cream. I mean, how close to 5 years old can you get?

There were so many incidents. One time the staff member -- duh -- put him on a bus in the middle of a blizzard because she had to go and do something. And it turns out the police were called. He was smart enough to go to people at the same railroad station he jumped in to tell -- he doesn't know what to do next. The police came. They reported it to the State, and this agency had to account for that.

But nobody was fired. I never saw anyone hanging their head. And it went on. But mostly my son was alone in this community placement -- alone. And they didn't offer him activities that were appropriate for him. And they centered him because he wouldn't go to things that he did not like -- like the Medieval thing, you eat this way? -- totally not him. He didn't have the choices. He did go back to North Jersey and, again, I can't tell you how amazing these people are. I have seen them work with someone who was very, very -- not alive -- just fighting out -- and turn him into an acceptable human being. Andy has-- He goes to work, he gets paid.

He doesn't think of it in cash, but he thinks of it as two cans of Pepsi and an apple. He gets it twice a week, and he enjoys it. He does the gardening, he does so many things.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Winnie. But I see that Phil came up as well, so I think he's patiently waiting. And we have a few more members. But I appreciate your stories. We all do appreciate your stories.

MS. SEKELA: Some of the things I heard today make me angry, because they're not true.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Thank you.

MS. SEKELA: And the fact that we're late.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Winnie. But we have some more family members. But we appreciate it. Thank you so much.

MS. SEKELA: By the way, thank you for having us.

PHILIP METTA: My bus is waiting for me. I was just told that, so I said, "Let me hurry up." That's why they moved me up here.

My name is Phil Metta. I'm the President of the Family Members and Friends of Green Brook.

Assemblywoman, before I present this, I have to say something. My daughter Phyllis went into the group home five years ago. She's retarded, has epilepsy, she's in a wheelchair, she's in diapers, and can't talk, etc. We had her home for 46-and-a-half years. Our doctor said she had to go. I was 79 years old. He said I had to go. Today I'm 84. But by God, I

said to myself, "This is amazing." So for five years she's there. So the first time-- We had her home for 46-and-a-half years.

So what I did was, when we brought her there, we went to visit her 30 days in a row. We drove 170 miles one way, stayed five hours, then drove back. We never left her before, and we had to find out what it was all about at this group home. I never heard of it. I knew of institutions, but never--

And then all of a sudden I started to feel good. I backed it off to four days a week, and now we're doing three days a week. But we're going to stay at three days a week. We travel 140 miles, we stay four hours up there, and then we come home. Why? Because I see what they do up there. Some of the stories you hear today -- not up there. By God, I'll tell you what.

My wife and I went away for the first time in 50 years. Our vacation, our first cruise, was just a couple of years ago. We went away for 10 days. Why? Because we were so comfortable knowing that my daughter was going to be well cared for at this group home. By God, I just praise these people and I thank these people. And that's why I became the President, so I can actually voice for these people and fight for them.

And now I'm going to get to what I came for. What I decided to do was, I decided to approach this a different way. Instead of talking about my daughter, I'm going to talk to you about--

ASSEMBLYWOMAN VAINIERI HUTTLE: Mr. Metta, may I just clarify? Where is your daughter. You're saying a group home. Where is she?

MR. METTA: I'm sorry, she's in Green Brook.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay, thank you.

UNIDENTIFIED SPEAKER FROM AUDIENCE: You meant Green Brook, not the group home.

MR. METTA: Oh, I'm sorry. Oh my God, pull that out of me. Oh God. I'm glad you pulled it out of me. (laughter) She's in a group home. I goofed big time. I mean, this is the first time she left us.

I approach this differently. Governor Corzine (*sic*) says everything is money, money, money. Okay, I want to talk about money. I found out there is an appropriation book. I went to the appropriation book and found out how much it costs for Green Brook. This is what it costs. Now, we have the smallest place. It's \$113.4 million for Green Brook. I said, "Wow, okay." There's only 84 people. We had 96. They died. I think two went to group homes, but the rest died because they're all old. Now, that's still a lot of money for 86 people.

But then I found out that our place is federally funded. Now, what does that mean? To me it means this: that if I write a check and give it to this worker with this hand, with this hand I say to the Governor -- I mean the Federal government -- "Give me the money to take care of that check." That's what federally funded means to me. So that means that the salaries, which are \$11.7 million up there, is paid by the Federal government. So now this is not such a big number anymore. It becomes \$1.6 million.

By the way, I recycle paper too. That's why I got it back--
(laughter)

Now, \$1.6 million is for building maintenance, food, and lodging.

So then I was told by the business administrator, “Mr. Metta”-- They all call me Mr. Metta there, by the way; they’re polite. They call me Mr. Metta and my wife Mrs. Metta for the five years we’ve been there, and nothing else. I appreciate that.

Anyhow, the Federal government says, “Let me pick up half of that.” “Wow,” I said to myself. Now the Federal government says, “I want to pick \$800,000 -- pick up half of that maintenance bill.” My God, they already said they’re going to pick up this much money, this much money, and this much money. Look what I did. I went out and bought a red pen so I can show you in red. The Federal government picks up \$12.5 million. That’s 94 percent of our tab up there, 94 percent. By God, I said to myself, “I’ve got a good cash cow here. He’s called the Federal government, and he’s taking care of it.”

So that means all the State pays is \$800,000, not the \$13.4 million -- \$800,000. Now, there are 84 people there, and I divided it here. And I got -- it costs \$9,500 a year to take care of my daughter and all the other residents in Green Brook -- \$9,500 a year.

As I presented this once, just recently, somebody said, “Yes, but Governor Christie said, ‘I need the money. Give me the \$800,000.’” I said, “Okay. Give him the \$800,000.” So let’s continue with the scenario. Everybody stops right here. Not me.

We have 246 workers up there. They’re going to demand unemployment compensation. Now, Governor Christie is very clear on that. “I’ve got no money left. We have so much unemployment, I have no more unemployment compensation.” So their answer to him is, “Do what Christie Whitman did, and Jon Corzine. Go borrow it and add it to the

deficit. We don't want to know that. We want to get paid." And look what they're going to get paid: \$7.9 million. He's pulling out \$800,000. He's going to save \$800,000, but this is what it's going to cost him when he closes us down. When he closes us down it's going to cost this much money. I'm a magician. Do you want to see this ugly thing go away? Put this back in there, open us up, by God, and this disappears. (applause)

And I'll tell you what, I did this for Woodbridge too -- the whole scenario. And the end thing with -- Woodbridge is going to be closed in January. Now, they pulled back \$8 million, and they're going to pay \$42 million in unemployment compensation. Now, that doesn't make sense.

ASSEMBLYWOMAN VAINIERI HUTTLE: Mr. Metta, you should give those numbers to Assemblyman Malone since he's on the Budget Committee. (laughter) And I think he might have some questions.

ASSEMBLYMAN MALONE: The question is--

ASSEMBLYWOMAN VAINIERI HUTTLE: And I apologize for calling you Phil, Mr. Metta. (laughter)

ASSEMBLYMAN MALONE: And I met Phil, and his wife, and his daughter, and his granddaughter last Sunday, and it was great.

MR. METTA: I'll tell you what. If you're my friend, you can call me Phil.

ASSEMBLYMAN MALONE: Let me say this to you: I didn't know that Green Brook -- other than some comments that had been made by Assemblyman Greenwald -- was being closed. It's not being closed. So the issue of whether Green Brook is closing or not-- Unless somebody knows something I don't know, Green Brook is not slated to be closed.

MR. METTA: No, no more.

ASSEMBLYMAN MALONE: Maybe Mr. Ritchey can confirm that.

MR. METTA: Okay, I have to run. The bus is waiting.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Mr. Metta. Thank you so much. (applause)

ASSISTANT COMMISSIONER RITCHEY: Senator and Chairwoman, there are no proposals in the Fiscal Year '11 budget to close Green Brook developmental center. There are no plans in the State Fiscal Year budget for '11 -- but it's under consideration to close Green Brook developmental center.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Second panel, if you want to introduce yourselves again.

Thank you.

And after this panel, we have three more panels.

Welcome.

V I T O C O L L E T T I: My name is Vito Colletti. I'm here as a representative of the Vineland Developmental Center. I'm going to read you excerpts from the letters that were sent to this group today. It is spoken from the hearts and minds.

For the survey of choice that was compiled by the Advocates for Developmental Center Residents, our return of response to the survey was 168 from a census of 441. All but 10 want the Developmental Center to stay open. I have all the letters here. If you want to look at them, you can get names.

Now, from the excerpts: Barbara A., "Our daughter has been in Vineland DC since January 22, 2010. She was having major behavior

problems with elopement, and hurting of staff in her day program with her efforts to get out of the door. At home she had been constantly running out of the door and down the street to the point where safety was a major concern. She went to Trinitas Hospital and then was admitted to Vineland. A group home had been identified to take her, but not for a month at least. At Vineland she has received excellent care. The staff is great. There are enough people available when she attempts to elope. She is a big girl, so it takes a couple of people to get her back into the building, sometimes with her fighting all the way. She has been attending a day program and is doing well enough. She had previously failed out of the four day programs in Ocean County due to her behavior. Thank God for the availability of Vineland. Where else are you going to go for a emergency placement of a developmental disabled person when it is needed fast? As a parent, I feel secure knowing that there are developmental centers available for my child and others when they are needed. I also know there are individuals who could not thrive in a community setting. The centers are there to serve them. What if my daughter fails in her group home? At least she has Vineland to fall back on. The mental staff is also great. They are able to get exams and lab work done on my daughter that, in the past, had to be done in an emergency room with her medicated and strapped down with six people to hold her. I guess you have to have the right people with the right training. Keep the DCs open and do not cut their budgets. They need every penny to continue caring for the developmentally handicapped in a respectful, careful manner, giving them the lives they deserve.”

Robert G.: “I feel that nonverbal people and those who present difficulties to the standard care would be placed at an increased risk of abuse and neglect.”

Vito and Mary C. -- this is my daughter: “As of now, my daughter resides in Jones Cottage on the West Campus. Unfortunately, rumor has it that Jones will be closing in the near future. This is going to present a major problem as my daughter is autistic and deathly afraid of moving to strange buildings. She’s also retarded in the effect that she doesn’t talk, doesn’t write, doesn’t read, cannot bathe herself, cannot feed herself -- with a little help, she does -- can’t brush her teeth, can’t take a shower. In fact, she’s retarded. She does not belong in an apartment building or a group home. And don’t even mention the word *nursing home*.”

Pat S.: “My daughter was put into a group home and then was moved to three homes before coming to Vineland. The first group home placement did not last due to my daughter’s screaming. The second group home was not a good place. And in the third group home, my daughter refused to do anything at all. She ended up in the hospital because the staff at the group home did not give her the medication she needed.”

Carol G.: “Our family has always been secure in the knowledge that our sister was safe at Vineland, well cared for and encouraged to live up to her potential. It is very disturbing to me that there is a possibility that she and so many like her could be deprived of the environment that has nurtured them for so many years. It may look good on paper, but I foresee utter chaos. As for group homes, I have often wondered about those who send questionnaires about group homes and if they are even remotely acquainted with the residents in question.”

Ruth B.: “I’m 82 years old, and I am a widow. To have this emotional situation confront our family at this time is extremely upsetting.”

Helen W.: “I am 85 years old. I do not want my daughter to move. She is happy.”

Linda C.: “My sister now lives at Vineland DC. She was forced out into the community during the Whitman administration and wound up in countless group homes. In the last placement, she was beaten and a lawsuit was filed. Fortunately, that agency no longer serves New Jersey. My sister has done well at Vineland, especially now as she needs the medical care as she battles a recurrence of breast cancer.”

France W.: “We have been repeatedly asked and given information concerning community placement, and we know that is not what is best for her. We hope that the Committees understand how important it is to keep the developmental centers open so the residents are not forced into a situation that their guardians are totally against for them.”

Heather J.: “My siblings and I have made it clear that our sister is not a candidate for community placement. It is in her best interest to remain at Vineland DC where she receives professional care from competent staff who know her extensive medical needs and daily routines.”

Karen G.: “I am my daughter’s legal guardian, and I know what is best for her. I know my daughter does not want to leave Vineland. And by forcing her to do so is in violation of her rights as a citizen.”

Thank you.

SENATOR VITALE: Okay. Who would like to speak next?

You can use that mike. (referring to PA microphone) That’s fine. Just turn that one off.

ANNIE ESPOSITO: You can hear me, right?

SENATOR VITALE: You have to turn that one off before you can turn that one on.

MS. ESPOSITO: How is that?

My name is Annie Esposito. I'm from Montville, New Jersey, and I am my brother Joseph Ciccolella's (phonetic spelling) guardian, along with my brother David. My mother is 75 years old and my father has passed away, so we are his legal guardians.

I, too, have all the letters. I'm sure you got that by now. So we have them from North Jersey, as well.

I am here as a representative of North Jersey Developmental Center families. I am going to read you excerpts from the letters, but they will be short, I promise -- to this group today. It is spoken from the hearts and minds of families. They include residents from Green Brook and those who did not identify themselves with a center in their letter. Thank you for allowing our voices to finally be heard.

Carol C.: "My son went into a group home at the age of 22. He had been in a residential school prior to that and developed a caffeine addiction due to the reward system that included coffee and soda. It was good to have him closer to home, but the staffing was less. And his addiction to coffee and biting was too much to contend with. My son was on the local town's police blotter for sneaking out of his group home and entering neighbors' homes looking for coffee. When they put an alarm on the door, he went out a window on the second floor and fractured his ankle. He still managed to get into the neighbor's house. He finally got to NJDC where he is safe. There are no neighbors to bother, and staff know how to

get him from place to place. An autistic man such as my son needs sanity and predictability, and a developmental center is where he is best served.”

Before I tell my personal story, I want to tell you that it does warm my heart to hear from those residents who are thriving in communities. However, my brother will never be able to live that reality. He has the mentality of a 7 year old. He is unable to get his point across. He speaks with a cleft palate, so you cannot understand him.

This is his story: My brother Joseph Ciccolella has been in developmental centers for the past 40 years. As difficult as it is not to have him home with us, we know that NJDC is his home. The care he receives is more than we can ask for. I come from a family of seven brothers and sisters. We grew up with Joey’s disability in our lives. And, yes, at times it was difficult. But it has made all of our lives richer, fuller, better knowing that we are Joseph’s voice and that we can be the voice of hundreds with no family to speak for them.

These developmental centers are not only necessary but the only existence these residents know. Think of taking anyone’s young children and ripping them from their home, and telling them that they can never go back home again. If we must fight for something in this world it should be the rights of the disabled.

I thank you for your time. Please consider keeping these developmental centers open.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

S I S T O C A P O N E R A: My name is Sisto Caponera. I’m representing Green Brook Regional Center.

First, I'd like to thank everyone who was involved in returning our clients back to that facility.

I will go on. I am here as a representative of Green Brook developmental center and their families. I am going to read you excerpts from the letters that were sent to this group. It is spoken from the hearts and minds of the families. They include residents from Green Brook and those who did not identify themselves with a center in their letter. Thank you for allowing our voices to finally be heard.

For the survey of choices that was compiled by the Advocates for Developmental Centers residents, our return of responses to the survey from Green Brook was 65 -- 65 votes -- that was 65 family members who wanted their clients to remain in the facility out of 91 returns. So that kind of explains the residents or the family members -- what they want.

I'm going to read five excerpts of the letters that I received.

This is Ms. Jessica H.: "By closing down the centers, they would be creating a lot of heartache and pain for the individuals in them, their families, as well as the thousands who have not been accepted into facilities. I think the State should leave them open and show more support to the cause, because as it is, there is not enough support for them and their families."

Mr. Joe H.: "My brother has been in both group homes and developmental centers. He currently resides in a developmental center, and I can tell you, unequivocally, that there is no substitute for the level of care and medical attention provided by developmental centers for an aging person with mental retardation. In each of the group homes he lived in, there were frequent staff turnovers. This precluded an in-depth familiarity

with the residents' physical and medical needs, and prevented the development of any emotional bond."

Mr. William S.: "My sister is currently a resident at Green Brook developmental center. There was a time when she lived in a sponsored home. The first one was very good, but the family moved away and my sister was transferred into a home under her care. This was the most miserable time in her life. The lady had to move and took residence in a second-floor, four-room apartment in western Newark. The crowded conditions aided-- My sister's walking difficulties led to many injuries including a broken hip. And finally, after a long hospitalization, my sister was sent to Green Brook. She is now comfortable in a clean, maintained room with another resident. She receives proper nutrition prepared and serviced to fit her health and abilities to digest. Medical services are available 24 hours a day, seven days a week. To remove her and other residents from this, their only recognizable home, would be tragic and unforgiving."

No. 4 letter, Ms. Mary M.: "My sister is now 80 years old and lives at Green Brook Regional Center. She has never spoken nor has she been able to function herself. She has lived in Green Brook for 20 years. I am familiar with the group home and know they are well-run. My sister's needs are a different kind of care. There are also many like her in the world who desperately need such centers."

And No. 6 (*sic*), Mr. Terry and Judy W.: They have asked us to speak about the contributions of care and the fact that raising the contributions to 100 percent -- which I think was originally 40 percent -- will cause great damage not only to their son and others who live in their

supervised apartments, but those in the group homes and developmental centers. And the letter is in your packet.

And my own personal story: My brother was a resident at Green Brook Regional Center, whom I visited every Sunday for 10 years. Since his passing, I have been obligated to the staff and to the clients at Green Brook to pursue the beneficial part of Green Brook. I've joined the Human Rights Committee. I've been a member of that for over two years since his passing. I also was instrumental in organizing the Families and Friends Association at Green Brook -- just before we had that tragic happening there, which most of you are well aware of.

Again, I thank you for helping bring them back to their home.

I'd like to thank, also, the staff members and also the doctors who take care of the patients -- I call them *residents* -- at Green Brook. Those of you who have visited Green Brook can attest to the well-being of all their clients.

And I thank you again for bringing them back to Green Brook. Please don't close all the facilities. We need them. And if there are 3,000 people waiting for placement in these residences, please let them in. Don't hold back and leave some beds open. We need them. And if we don't, we're going to be in trouble as a state. Don't follow the other states. We don't know the results of some of those -- what's happening in those states, as far as where these people have gone, their situations. We don't have any written statistics saying, "A certain so-in-so is living okay. This one disappeared, we don't know where he is at." We don't have those statistics. If we want to, we should, before we make any decisions as far as closing these facilities.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you very much, Sisto.

I just want to thank all the family members who came out today from all of the seven centers. I've been very impressed with your passion, your advocacy. And I thank you very much for sharing your personal stories. It's not easy, and we appreciate that.

Next panel: we have Kim Todd.

And, Kim, we also have-- I know you have two other people -- Ann Martinelli and Monique Wilson -- with you.

UNIDENTIFIED SPEAKER FROM AUDIENCE: No, I think they're--

ASSEMBLYWOMAN VAINIERI HUTTLE: We have Cindy Harris and John Vega. Would that be correct?

We have Cindy and John--

KIM TODD: We have more.

ASSEMBLYWOMAN VAINIERI HUTTLE: But if you want to speak on behalf of the community care providers, you can do that. And then we have a self-advocate, and we have a parent. I think that's sufficient.

MS. TODD: We've given you a packet of information that has a wealth of knowledge in it. We hope you take the time to review it.

I'm going to be very brief, because I would really like for you to hear from the people who have waited here all day. We have two family members who are from the community, we have several self-advocates, and also a best-practices expert who has been involved in many, many closures. I am going to yield my time.

But I would like to say to you that I think you face a Solomon's task. I think that there's an inordinate amount of information and wealth of knowledge that has preceded these discussions. I think the national agenda is set. I think Dr. Spitalnik laid that out very clearly. But I do believe that if New Jersey does not change its course of action, we do not have the fiscal resources to continue doing what we do. We have to embrace a new positive direction, and I respectfully ask that you consider the price that each person pays who is waiting for services in the community. We asked them to wait patiently while New Jersey continues to debate something that has already been decided nationally, while we maintain the status quo at 49th in the nation.

And with that, I'd like to yield my time to Judy Gran.
(applause)

SENATOR VITALE: Turn your mike off, Kim, please.

JUDITH A. GRAN, ESQ.: Thank you.

My name is Judith Gran. I'm a lawyer with Reisman, Carolla, Gran in Haddonfield.

I have represented institutional residents in 14 class action suits around the country in nine different states that have resulted in the closure of eight institutions, with two more scheduled to close this year. All of those cases also involved fix-up orders in which the institution had to improve services for people while they were there. And as a result, some of those states poured enormous, enormous resources into the institution with very little result.

An example is Arlington Developmental Center, near Memphis, in Tennessee, which is currently the most expensive institution in the

country, with a per diem of \$1,200 per person, per day. And there are 50 people left there. It's going to close. And the state's own compliance reports show that it is woefully out of compliance with the most basic components of the settlement agreement that the state signed in that case. So I think we've seen that it is very difficult to create a silk purse out of a sow's ear. The congregate environment is just not conducive to the individualized services and active treatment that people with significant disabilities need.

I want to make three points about the lessons of those cases that have resulted in institutional closure and, at the end, say a few words about what I see the State's responsibility here in New Jersey is.

The first lesson is that everyone can be served in the community. In most of my cases, every single person who left the institution went to a community living arrangement. And I'm not talking about group homes. I'm talking about highly individualized, personalized arrangements that might be called *supported living*, which is not a service only for people with mild disabilities. Everyone can be served in a supported living arrangement in which the team builds supports around the person to live where he chooses to live, with people whom he chooses to live with, and get all the support that that person needs to live his chosen and desired life.

Most of the people who moved to the community had severe and profound intellectual disabilities. Many of them had multiple physical disabilities, many of them had complex medical needs, all of the disabilities that people have talked about here -- tube feeding, tracheotomies, seizure disorders, brittle diabetes, cardiac conditions, cancer. Whatever it might be,

those people moved to the community and flourished there. People with extremely challenging behavior moved to the community and did better there because they were able to live a desired life, which reduced the challenging behavior. People with significant psychiatric needs moved and did well.

The second lesson is that people are significantly better off in the community. There is actually much more than anecdotal evidence of this. In the cases that resulted in court orders and consent decrees, court monitors followed every single person, every year, and looked at how well they were doing. In several of my cases, research studies were done on how people did when they moved from the institution to the community and found that they gained skills, that their challenging behavior lessened, that they were happier, that their families were happier and more satisfied. And I want to emphasize that: families liked the community. They found that people were safe, that people's healthcare needs were met.

SENATOR VITALE: Excuse me, did you-- Is this all in the documents that you provided to us -- the written testimony?

MS. GRAN: No, no, this is in addition. This is not in the document.

SENATOR VITALE: You don't have anything that you want to add?

ASSEMBLYWOMAN VAINIERI HUTTLE: Actually, may I just interrupt?

Kim, we have a list of speakers. I don't know if you are on the list. I want to give those who submitted their list. I don't have her on the

list. I apologize. So I just want to give time to those who have prepared their time for the list to come up.

MS. TODD: When I was asked to present on Wednesday afternoon, I was not aware -- I was never informed that I was able to have a panel. And what we had to do very quickly was choose some of the group. Our original group, of course, was Monique Dujue Wilson and Ann Martinelli.

ASSEMBLYWOMAN VAINIERI HUTTLE: That's fine. I don't want to take up time. If we can just move to the rest so this way all your speakers can have a minute or so.

Thank you.

MS. TODD: Perfect.

I'd like to introduce Mrs. Johnson, who is the parent of Reggie. And she is going to talk for probably 30 seconds. (laughter)

PATRICIA DAVIS JOHNSON: Good afternoon.

I am Patricia Davis Johnson, the mother of Reggie. I'm here today just to brag a little bit about my son.

First and foremost, Reggie was a resident at a DC for over 20 years. But today, since leaving New Lisbon, Reggie has made enormous strides. He is now the Chief Engineer of Environmental Services at his corporate office. Simply put, he's on the rise. Reggie is an active member of his community, and he loves exploring his neighborhood.

If Reggie continued to remain at New Lisbon, I fear he would not be the Reggie that we know today.

I love my son. And needless to say, I am very, very proud of him, and I am completely satisfied in his present support system.

Thank you. (applause)

SENATOR VITALE: Thank you very much. I'm sure that you're very proud of him and he has made great progress. Thank you for sharing that story.

Can you turn that one mike off so the other mikes can work?

Thank you.

Can you introduce yourself please.

C I N D Y H A Y E S (phonetic spelling): Yes, my name is Cindy Hayes. I'm a parent of a 19-year-old son with autism.

You have a lot of information there, but I will just really quickly kind of go through the highlights.

When my son was diagnosed at 2, which is pretty typical, I got very, very involved in advocacy and really looking at how I could create his future for him so that he could have every opportunity that my other two children had. So I started several nonprofits. I got very, very involved. I moved up here to New Jersey. I think he had outstanding support. I had been working on developing a program with -- actually it was at NPDC, on the property there, for a community-based program.

When he was about -- well, about a year-and-a-half ago, he started really showing a lot of very serious behaviors. Honestly, we were at St. Barnabas Hospital. They told me to take him to a developmental center. I said no. I then followed him to Baltimore and did everything I could do to keep him out of the center.

We finally ended up at Hunterdon Developmental Center. And I will tell you that I do appreciate everything they've done for him. They probably saved his life. But about two months into that visit we got

behavioral support. And I have been trying for over a year -- about a year and two months on Mother's Day -- to get him out of that Center, which is where we're spending over two times as much money on him for less appropriate services.

So I guess I'm here to say that if I felt this was the right placement for him, I would fight like crazy to keep him there, but it clearly isn't. So I know there are a lot of people like me trying to keep their kids at home with very little support. And only through an emergency and a crisis situation are they getting support. We need to think about, obviously, not just fixing the system, but putting together a community infrastructure that will allow us to address these needs long before they hit crisis as my son did. I think if I would have had different levels of support, he'd probably still be living with me now.

Thank you. (applause)

SENATOR VITALE: You have a microphone back there. You can certainly stay in your chair and speak from there.

Can you introduce yourself please, and where you're from?

HEARING REPORTER: Excuse me, sir.

You do have to come up here. I cannot record you there. I'm sorry.

ANN C. MARTINELLI: Good afternoon, everyone.

Thank you for this opportunity.

My name is Ann Martinelli. I am the parent of a young man, Joe, who is 25, with developmental disabilities. I'm also the President of Advocates for Alternatives, which is a grassroots education advocacy group, and we educate on self-direction.

For us, it's very simple. We are all the same. Everyone belongs. Everyone has the right to live in a community, we all do. Everyone in this room lives in a community. We do not segregate because someone has a developmental disability. We cannot segregate in the education, in our workplace, or anywhere else in our communities.

The people who live in New Jersey's seven developmental centers should have the right to remain there if they want to or if their family wants them to. However, for every person with significant needs living in a DC, there is someone living in the community with the same needs, with supports in their own home, a group home, or in their family home. The same services available in a DC -- medical, dental, mental health, assistive technology, durable medical equipment -- are available in our communities.

Our families are a new generation. Our children with significant needs attend local schools and participate in community activities. Our education system invests millions to fully include our children and empower them to become contributing citizens. When our children leave the education system as young adults, we expect them to continue to be part of the community. Yet many families place their loved one's name on a waiting list for community services and do just that: wait, sometimes for decades. They wait because they want their loved one to live in the community.

My family was one of the lucky ones. When my son Joe graduated from school in 2005, he was offered the opportunity by the Division to self-direct his supports and services. He has been doing that for almost five years now. He is fully included in the community.

My son's needs are significant. He needs help getting up in the morning, he needs help toileting, he needs help getting dressed. I feed him. My husband gets up in the middle of the night to turn him when he calls. His needs are great, but he is an active member of our community.

We believe our state can change. We must change. Public policy is not about making people happy, it's about serving citizens equitably. Right now, our public policy for people with developmental disabilities is not equitable. It must be changed. It's time we raised the bar and invest in the citizenship of all by developing a system that serves people when they need it and where they want it in the community of their choice.

Thank you. (applause)

MONIQUE DUJUE WILSON: Good afternoon.

My name is Monique Dujue Wilson, and I'm the parent of a 23-year-old man who is currently self-directing.

We are not affiliated with any provider agency. At this point in our life, we are doing it on our own.

I think it's really important that you know that a lot of the descriptions that were mentioned here about the people who reside in developmental centers absolutely fit the description of my son who, at 16 years old -- I was put in a position to put him in a developmental center or nothing else. I refused, and we piloted real-life choices or self-direction in New Jersey. He is now 23 years old, and he is living at home, and thriving, and becoming the young man that he was supposed to be.

I remember 15 hearings held throughout the state. Forty hours of transcribed, archived testimony from people with developmental disabilities and their families telling their stories to New Jersey legislators

and leaders in the disability community. The message: keep us together. We thought you understood. We thought you finally heard us after years of dwindling family supports, and the increase of more and more families choosing to support loved ones at home and wanting different choices in the community other than just centers and group homes.

In 2006, families and people with disabilities rallied, testified by the hundreds, wrote letters, sent pictures, thousands signed petitions to make it clear that people were thinking differently. Families wanted resources available to keep their families together rather than making a choice of group homes or institutional care. And I have an attachment to everything. Most of you will probably remember these hearings that were held in 2006. There are excerpts that you have copies of, of families who are not here to represent themselves, even family members that, today, probably six years later, have transitioned into adulthood. And most of us are still waiting.

These are actually the copies of the petitions.

MS. TODD: I'd like to clarify. These are the new petitions that have been collected to ask you to close the developmental centers.

MS. DUJUE WILSON: I'm talking about a set of petitions that came at this time. So this is not new information. Actually, I even included something that showed the disproportion of how funding -- and where people were living back in 2006.

Without needed supports, our family members-- The majority of funding was going to the residential and community placements, out of sync for families growing up in an educational system full of expectation and the promise of fulfilling adult lives for our family members, regardless

of their disability. Without needed supports, our family members were not living. And now, most families involved in that pivotal movement have joined the wait-listers, needing transition and adult services so that they can continue to go to school, to volunteer or work.

When waiting becomes impossible, unwanted placements out of the home become inevitable and common, not by choice. Crisis led to placements in developmental centers because there were no other choices given at that time. The overwhelming cry of information shared by families to the decision makers, to the DD system, and to the providers who support people within the system -- that people and families with developmental disabilities were moving in a different direction. Our thinking was heard loud and clear. In 2006, New Jersey moved toward self-directed services and began to recognize people wanted to be supported differently than in the past.

In 2010, the lists have grown. The misappropriation of where people live and where the money goes continues to be wickedly unbalanced. The climate within the disability community is tense and mistrusting. It is sad to see that the real issues of people and families -- have choice -- has been forgotten and lost in an ugly mesh of politics, selfishness, special interests, and egos that have nothing to do with the voice of the people.

I cannot understand how such a documented event in 2006, that created a historical shift in the thinking and the expectations of people with disabilities -- where they choose to live, go to school, and play -- can be ignored. The information is not new. Why do we continue to play the game of surprise while people wait and die to live?

ASSEMBLYWOMAN VAINIERI HUTTLE: Monique, do you have that in writing? Is that part of your testimony? Because we do have, as I say, two more panels.

MS. DUJUE WILSON: Yes, this is my testimony.

ASSEMBLYWOMAN VAINIERI HUTTLE: Are you wrapping up?

MS. DUJUE WILSON: I just have one more paragraph to go.

ASSEMBLYWOMAN VAINIERI HUTTLE: Are you wrapping up? Because we do have--

MS. DUJUE WILSON: Okay, great. What the majority--

ASSEMBLYWOMAN VAINIERI HUTTLE: Is John speaking, Kim? Is John Vega speaking?

MS. TODD: Okay.

ASSEMBLYWOMAN VAINIERI HUTTLE: We want to save some time for John.

MS. DUJUE WILSON: I have one paragraph.

SENATOR VITALE: Go right away.

MS. DUJUE WILSON: Can I continue?

SENATOR VITALE: Yes, you may.

MS. DUJUE WILSON: Thanks.

What the majority of people in the state want cannot be disputed. It is to live within a community with supports and services available to sustain a productive and happy life. There should not be an exclusion of choice to remain in a developmental center. But today, that option is not the majority, made clear for so many years.

People are being born with disabilities, surviving, growing up in families who challenge them to live life. The numbers grow, yet the support center resources cannot keep up. Why do we continue to support this archaic way of thinking? Who are we supporting?

Please rebalance this system so we can support a plan that allows opportunity for choice. I do not want to find myself here four years from now having the same stagnant conversation. We cannot continue to wait.

Again, my name is Monique Dujue Wilson. I am the parent of Khary Dominique Wilson. He is 23 years old, and he is striving to live.
(applause)

J O H N V E G A: My name is John Vega.

I live in Voorhees. I used to live at New Lisbon, but now I'm out of New Lisbon.

There was too much crime and trouble -- stealing and fights. But now I have my own room, my own privacy. I can do--

This is my friend Reggie Davis.

I can do what I want to do. I can go anywhere.

This is my staff. They help me out, treat me nice.

And whoever wants out from New Lisbon to the community -- if they want to.

MS. TODD: Thank you, John.

MR. VEGA: You're welcome. (applause)

SENATOR VITALE: Thank you, John.

MR. VEGA: You're welcome.

G A R Y R U B I N (phonetic spelling): Hello, my name is Gary Rubin.

I lived at Johnstone Training and Research Center for six-and-a-half years. I now live at Community Access Unlimited up in Plainfield. I have my own condo above Ms. Adelaide Daskam, who you heard from much earlier today. I have my own apartment. I live by myself. I'm in a relationship with a woman down this way. And, you know, life, to me, has been pretty good.

I also wear hats. I'm on a statewide network as far as our self-advocacy. I'm the Vice President of that in (indiscernible), up there near me. And I wear many hats, so to speak.

But hearing some of the things that I heard here today, like the word *retarded*-- Apparently people don't have enough respect for their own kind to be using that word everywhere. We just had a campaign, and believe me, we busted our tails trying to get pledges and everything else. So I can't believe some of the words I heard in here today.

Other than that, I'm free to do what I want, when I want. I live like everybody else -- like you guys -- when you leave home, go to bed at night, wake up the next day. It's wonderful. It's a wonderful feeling. People try to play God, like some of the DCs, and I don't buy that. This is the 21st century. It's time to wake up. Like my friend Monique said, it's time to change the state -- the course of everything -- and not have some of these people, against their will, living in these DCs locked up like they're at the Bronx Zoo, or the Turtle Back Zoo, or something.

That's that. I mean, I care about other folks, as well. And I am a true advocate. We need people like us out there so we can help the weaker ones, so to speak.

So I thank you for letting me speak today. Have a good night.
(applause)

MS. TODD: I would just like to close with something. As I said, you have a Solomon's task in front of you. I think that the wealth of research that precedes this, the innovative practices that have been tried and true, the missteps of the nation-- We have the opportunity -- at being just about dead last -- to not repeat it. And I ask us not to be afraid of change.

In New Jersey, we closed North Princeton. I have the unique, I guess, position of having worked at North Princeton. I joined the Department of Human Services as a guardianship worker. And the people I supported were at North Princeton and New Lisbon Developmental Center. I got to know them very, very well. And I have also kept in touch with them over the last -- all this time. They're doing well. I ask us not to be afraid.

I hold in my hand the key -- one of the last keys that closed North Princeton. I ask you to think about it as you sit in your chairs and make decisions about our future.

Thank you. (applause)

SENATOR VITALE: Jenelle Blackmon.

Is Jenelle here? (no response)

You're not Jenelle.

D O N A L D L. K L E I N: And I'm not Carolyn Wade either.

SENATOR VITALE: Well, we're thankful for some miracles.

MR. KLEIN: I'm Don Klein, Executive Vice President of CWA Local 1040.

Carolyn apologizes. She had a family emergency. You have her testimony.

Due to the lateness of the hour, I am going to be brief.

Local 1040 represents Human Services' institutions, Corrections, Veterans Affairs, Juvenile Justice. But we also represent residential care centers for the developmentally disabled in the community. And I know you've heard how polarized this issue is.

We've hired various experts over the years, both at Greystone and other facilities, who the Union has employed to consult with. And the overwhelming opinion of these experts is: You need a continuum of care. Yes, we need residential group homes, supervised apartments, and developmental centers. So we've seen both sides of the coin.

One of the big problems with the community now is that there are not services in place for them. As far as the developmental centers -- in the past 10, 12 years, they have not had capital improvements. So people can call them warehouses and say that they're dark places. But as you heard the parents say, this is their community.

But I just want to-- You have Carolyn's testimony. I just wanted to make some notes here to really make this Committee aware of some of the not-so-known intricacies of this fight between community and developmental centers. And it should not be a fight.

But several years ago, \$1 an hour was allocated by the Legislature and signed by the Governor for direct care salaries to be increased in the community. Well, as a Union, we had to fight for that dollar to go into the hourly rate of staff. They wanted management-- Management wanted that buck-an-hour. We have to fight for our people

who work in community care centers for \$10 an hour. We can't get a \$0.25 raise.

Unfortunately, a lot of folks really care for the developmentally disabled. However, there are a lot of unscrupulous providers out there. There are corporations who run group homes who, if they do not turn a profit, they leave and abandon clients.

SENATOR VITALE: Don, if you could, try to wrap up so we can finish up.

MR. KLEIN: Just some of my other points are--

Someone asked the question of who makes the decision. Well, it's different. I worked in a developmental center as a clinical psychologist. And the team made the decision. But now the teams are being dictated to by DDD. Everyone is community-ready. And it's wrong to take the care from the professionals to the bureaucrats who give these orders.

SENATOR VITALE: Thank you.

Jenelle.

J E N E L L E B L A C K M O N: Again, we want to thank you all for allowing us to speak before you today. I just want to reiterate Don's point that CWA's position is that we're not against community placement, we are for the care of these residents and choice. And this is a community that we need to address as that.

And I have, to my right, a social worker from Green Brook developmental center, and her name is Michelle Brito. I just want her to address the Committee for one second.

M I C H E L L E B R I T O: Thank you.

I will be quick.

I am a Social Worker at Green Brook Regional Center. Previous to my employment, I was -- I did work at an agency for group homes. And I do get involved with meetings in the facilities -- Olmstead's -- I'm out there (indiscernible). You name it, I see it. I'm on the front lines.

So I can tell you that, yes, I have seen placements that have been appropriate. Keep in mind that is with team interdisciplinary meetings. It's very involved. Those placements do fair well. We've also had some failures at our facilities, and pretty high-profile at that.

But my concern is, these clients don't have families to represent them. So when we speak for them, are we being heard? And I fear that there's a lot of neglect going on, and I see it.

Also being that we are-- We do care for our clients, and I do want to reiterate that. I'm not going to repeat myself, because there was a lot covered today. I don't want to repeat. Just to be heard, we do have very good, hard workers, as does the community. But we do need to make sure that it is per choice, and appropriate placements.

Thank you.

MS. BLACKMON: Thank you so much. We appreciate it.
(applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: I think we have one last panel, if the members would like to hold their questions. And then we can have some statements at the end.

The one last panel-- I'd like to call up Robin Sims and Rocco Mazza to close the hearing -- or close the panel, I should say.

Thank you.

Welcome, Robin.

R O C C A A. M A Z Z A: I believe my testimony was written and distributed to everyone on the panel, so I am not going to read my testimony.

SENATOR VITALE: That's when we clap.

MR. MAZZA: All I ask of you is-- I'll do you a favor and not read it, if you just do me a favor and read it. That would be great. Thank you.

And I've attached to that testimony some newspaper articles which underscore my points in the testimony, which is simply that privatization of the developmentally disabled is not a safe, and secure, and healthy idea. And these news articles prove that.

I will now defer to my partner here, Robin Sims.

R O B I N S I M S: Thank you.

Thank you, Senator Vitale; and thank you, Assemblywoman Huttle.

This is a wonderful opportunity. It's the first time that our voices in the developmental center community have been heard. So we applaud you for that.

For a very long time, families and those who are advocates for those who live in developmental centers have been trying to get someone to listen, someone to understand that the Olmstead plan for the State of New Jersey is based upon the lie or the myth that claims that thousands of residents of our centers wanted to leave. Nothing could be further from the truth. The Division of Developmental Disabilities knows it, those who are here to selfishly promote their own agencies know it, and now you all know it.

We have done the best we can through our various family, and friends, and associations of parents from our centers to ask the question of all primary decision makers regarding their choice: Where do they feel their loved one can get the best care according to their needs? They spoke, and they have said in overwhelming numbers that they wanted their loved one to remain in their current home in the developmental center.

Assemblyman Greenwald proposed a bill, but he never saw a developmental center prior to him making that proposal. He was persuaded, I think, by Kim Todd, who was here today, to put forth a bill that would close five of the seven developmental centers. But the big question is: Why? I mean, organizations like New Jersey Association of Community Providers and ABCD are actually lobbying organizations. Their dues are determined based on their DDD contracts, which basically means that you, the State holders of taxpayers' dollars, are paying for lobbying.

Well, I've had enough. The ICF/MR program started in the State of New Jersey in the late 1970s. And the Federal court created a standard of care and continues to monitor each center. Here is a study -- annual study of the ICF/MR surveys. They walk into our centers, they go through everything from top to bottom -- cabinets, how somebody is fed, how somebody is positioned -- and the standards are here.

According to the Federal funding source for ICF/MRs or developmental centers, a person must be in need of active treatment, which I think is something that Tom talked about. In order for a person to leave a center, they must no longer need this care. What we call *developmental centers* or *ICF/MRs* is our community. The community waiver is called

Home and Community Waiver, but nobody ever talks about the word *waiver*. What you are waiving is the ICF/MR standard of service. It means you don't need that level anymore. You are waiving it. Bye-bye service. And that's good for the people who can do that.

There is no way for a parent, at this moment in the State of New Jersey, to go and look at the option of developmental centers the way they go and look for schools for their children when they are school age. They are told from the Division things like -- and case managers -- "You don't want that choice. The centers are terrible." The environment of fear has kept people at home longer than families can bear. We need to allow those on the waiting lists to see the centers -- at least see them -- receive information about services and supports in the centers in an unbiased way, and let families think and decide for themselves.

I serve on the DD Council -- me, as the lone voice for those in developmental centers. But somehow they believe that their mission is to advocate for closure. But, again, nothing could be further from the truth. The DD Act is the Federal law that established and helps to fund the DD councils, the Boggs Center -- as Debbie said, the Center of Excellence -- and the New Jersey Protection and Advocacy, which is now called Disability Rights New Jersey.

How interesting is it that Elizabeth Boggs herself had a son at the Hunterdon Developmental Center, and now the center named for her wants to close them? What must she be thinking?

When the DD Act was drafted, Congress made sure -- and this is, again, a Federal Act that needs to be reauthorized. It hasn't been reauthorized in 10 years. But when the Act was drafted, Congress made

sure that it was clear that programs under the Act understood that individuals with developmental disabilities and their families are the primary decision makers regarding services and supports -- and such individuals and their families -- that they receive, including regarding choosing where the individuals live from available programs -- and play decisions -- which is what Tom talked about before -- in making roles (*sic*) in policies and programs that affect the individuals.

But they also went on and they said -- they made further language. This was, at the time, Henry Waxman, who was in charge of the Energy and Commerce Committee-- And it said the Committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to the Federal intent to use language or resources of this Act to support such actions, whether in the judicial or the legislative system.

So we now have -- the DD Council, in its policy statements -- which I'm including in the packet -- which basically are promoting closure. We have the New Jersey Protection and Advocacy suing the State. Here is a State entity suing the State and filing class action suits that the stakeholders never have the opportunity to opt out of. And it's really quite a concept. The Council that promotes policies that are not part of their mandate -- but they claim they are -- under the DD Act, the words "work to close developmental centers," does not appear. And yet it appears in the Council's various public policy statements.

Families and friends of those in developmental centers have fought this fight over and over again. This myth started -- and a lie, however -- in 2001. At that time, there was a memo stating that every one -- every single resident of an ICF/MR -- was eligible to live in the community unless they were either dangerous to others by having a criminal record; or two, they said in their own words that they wanted to stay. According to that memo -- which we love to call the *smoking gun memo* -- state that this was to be done no matter what the team or the family wanted. It didn't matter if the person could not talk when it came to moving out. But it sure did count when it came to staying. We would move a nonverbal person out. But unless you could actually talk and say you wanted to stay, you were determined eligible to live in the community.

When the DDD Planning Institute at NJIT went and interviewed people about this topic, they determined-- They went to people who said they wanted to leave the centers, they thought. But only a small number of those people who said they wanted to had the cognitive understanding of what community meant. Many stated they wanted to move but not to a group home. Some had been in group homes but did not want to return.

So what are we left with? An organization or two of lobbyists trying to get work for their members, parents not being given the opportunity to explore their choices of centers, parents and family members of DC residents who live in a state of anxiety and uncertainty. These folks whose children live in the developmental centers have our-- We have our phone calls monitored and counted, our visits counted, and the attendance at our annual planning meetings counted.

This is not what individuals in community group homes, or supervised apartments, or even at home have to do. They are considered smart enough to make those decisions for their loved ones. And yet we are sent letters that state if we are opposed to community placement, it must be due to the fact that we need some training. News flash: Our families are teachers, doctors, therapists, lawyers, etc. We have made our choice knowing full well what options are available and have chosen ICF/MR because it is the place our loved ones can and will live the most complete life.

The lobbyists and some community parents are trying to make our loved ones the scapegoats for their lack of movement from the waiting list. Our Federal reimbursement rate, as has been said here today, from the ICF/MRs is greater than those in the community care waiver. So our loved ones who move into the community will cost more in State dollars when moved into community settings when they get the same or better services. And the waiting lists will grow, and no emergency placements will then be available. People will die with inappropriate care, and this has been proven time and time again. It was mentioned, when Senator Allen was here -- was talking about the mortality study and asked about it -- if it had been done in New Jersey. The fact of the matter is, it has been done by the Developmental Disability Planning Institute at NJIT. They did this at the closing of North Princeton Developmental Center. But what did they say? They said, "If the time period was extended" -- and they only looked at this for 27 months -- "more persons would have died in the final model, and the final model might have been different." So we are now asking: Why are we not doing a 10-year look-back and see how many of the folks who left in the

same study are still alive? We had Dr. Katzman (phonetic spelling) here. I don't know if he's still here. But he volunteered to do this for the State at no charge. He would do the research, we would do a look-back, and we would know 10 years down the road where these people are. DDD refuses to do the follow-up study. What are they afraid of? Did they lose the former residents of North Princeton? Can this Joint Committee please compel them to do it? We need to know what happens to those who are leaving today. And it's important to track how many homes and other placements they go to once they leave the center. How many die? How many return to centers in damaged condition? And how many move to more than one home?

We must declare a moratorium on all movement until these questions are answered. This is particularly important for those living without family members. And the Bureau of Guardianship Services did not participate in our survey for choice. We wanted to know from them how many of the people they represented were they recommending to move or recommending to stay. It is our belief that the Bureau of Guardianship Services has tremendous caseloads and are unable to really effectively advocate when the system tells them one thing -- State employees being told by the Division -- sorry I keep pointing at you Ken -- to do something, and they are then in this position of: "What do I do? Do I keep my job, or do I advocate for the person I'm supposed to advocate for?"

SENATOR VITALE: Robin, thank you.

You're doing a terrific job. Do you have something that you can submit to us by way of--

MS. SIMS: I don't have it quite finished, but I do want to bring up just two more points.

SENATOR VITALE: Could you just kind of wrap it up then?

MS. SIMS: I will.

SENATOR VITALE: Thank you.

MS. SIMS: Speaking of spending, why can't anyone at DDD or the office of the Treasury tell us how much money is being spent on Maximus? Maximus is the contracted company that does the billing for the contribution of care for residents of developmental centers and group homes, among other things. We in the State of New Jersey hired Maximus at the same time that New York fired Maximus for -- citing them with fraud. And there are no other bidders now for this service. It just revolves every single year. We need to look into Maximus.

There's also one more survey. We brought you some questions here. Again, NJIT, DDD, Planning Institute sent out a survey that they're going to claim is for choice. The question of choice appears at Question 21 and 20, and it's buried down in here. The rest of this survey-- And we ask you, if you're presented with the survey itself -- we will present these questions to you to be shared with the Committee -- but it's about how many times we visit, what do we know about the community. We are harassed daily, monthly, weekly. Our individual plans for our children have been written in the first person. My daughter doesn't speak. My daughter cannot articulate. But it says, "My name is," "My mother said," "I like a puppy," "Blah, blah, blah." She didn't say a word of it. So these documents are fake. And now that we've finally begun to change it, the Division is not allowing parents to know that prior to meetings.

Lastly, I want to thank my son Benjamin, who has Fragile X syndrome, who came here today. He's 23 years old. He lives at home with his father and I. He came here because he loves his sister and because he wanted to tell you to leave his sister alone. And so he's been sitting here all day long.

I thank you, Benny. You're my best guy. (applause)

Thank you all very, very much.

SENATOR VITALE: Thank you, Robin.

MS. SIMS: Thank you.

SENATOR VITALE: Thank you.

Are there any closing comments from any of the members? (no response)

I want to thank you for your time and your patience.

Commissioner Ritchey, would you like to say a few words at the end? We also want to thank you for being here and spending the entire day with us.

ASSISTANT COMMISSIONER RITCHEY: At the risk of having everybody say, "Why is he saying anything," listening through everybody's comments, as all of you have done, it's clear-- And I'm pleased with the fact that our DCs are doing a good job for the people they serve. We would certainly be at a different place if we were also upset about their services. It is equally as clear that there has been -- well-documented by the families -- the good job our community providers are doing.

Clearly we will have, on occasion, problems in either setting. Neither should paint that setting with a bad brush. I think that the families that I've heard -- and I've spoken to many of these people since I've been

here over the last three-plus years -- believe strongly in where their son or daughter is, or where their son or daughter should be.

I can't say how appreciative I am that so many of you have sat here all day to listen to comments. In my public career, this is the first time I've ever had a legislator, such as Assemblywoman Huttle, ever visit every center in the state. (applause)

I commend you for that, Assemblywoman, and for the rest of you who have visited one or more. Because most of the time-- And I think if I could say for the Commissioner, who would have loved to have been here but could not, we care deeply about the folks, the families, the individuals we care for in every setting. We want people to be where it's appropriate, where they want to be while safe.

And I think, in summary, we are grateful to this bipartisan and joint Senate and Assembly review, because I think this is the first time I've ever been in a gathering where you got to hear everything. I don't think you got the answers today in every case. But at least we've given you an opportunity, and you've taken advantage of it to learn the issue from both sides.

And finally -- last comment -- Assemblywoman, thank you so much for mentioning the abuser registry.

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: If there are no concluding remarks--

I just truly want to thank my Committee on the Assembly side (laughter) -- not that we're showing off to the Senate side -- but my

Assembly members, I think you get an *A* in attendance. (applause) I had to get that--

SENATOR VITALE: The Senate is just older, and they're very sleepy when they get-- (laughter) They had to take their nap this afternoon.

ASSEMBLYWOMAN VAINIERI HUTTLE: And for staying the -- quite -- I didn't realize we'd be this long. But of course, even with the interruption of our fire drill -- I think we went out in a very orderly-- I mean, that was a first for me.

But thank you to the members who sat all the way through the hearing.

I just want to say that this is certainly not the end. It is a start for, I think, the State. And I want to repeat what I said -- that the State has a moral obligation to find the resources. And we should have a steady funding. I think if we had the funding, I don't think there would be any real battle here or debate, because we could have everything completely funded, and the resources in the community, and continue to keep the centers, where I saw -- which I don't think anyone brought up, but I was surprised -- one of the centers had a great medical facility where they had doctors trained at the center to treat this type of population in a very sensitive way. They had dental care, they had 24-hour care. And that's a model.

And I really want to commend Assistant Commissioner Ritchey, because you sat through all the testimony. And I know that together with Commissioner Velez and our Committees here, that we can really now address this within a timeframe. Because I think what I heard

today is the waiting list and the resources needed to reallocate into the community and to keep providing for our vulnerable population.

So with that, I think we're all a bit tired. But we have your testimony in writing. We will read it, go through it, and perform our due diligence as legislators.

And I really want to thank everyone for their passion. I truly appreciate you coming here and spending the day with us in Trenton.

Thank you so much. (applause)

(MEETING CONCLUDED)