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# *Committee Meeting*

of

SENATE HEALTH, HUMAN SERVICES AND SENIOR CITIZENS  
COMMITTEE

ASSEMBLY HUMAN SERVICES COMMITTEE

*"Testimony from invited speakers and the public concerning the pending closures of the  
North Jersey and Woodbridge Developmental Centers"*

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**LOCATION:** Montclair State University  
Montclair, New Jersey

**DATE:** February 13, 2013  
11:00 a.m.

**MEMBERS OF COMMITTEE PRESENT:**

Senator Joseph F. Vitale, Chair  
Senator Barbara Buono  
Senator Nellie Pou  
Senator Samuel D. Thompson

Assemblywoman Valerie Vainieri Huttle, Chair  
Assemblywoman Cleopatra G. Tucker, Vice Chair  
Assemblywoman Shavonda E. Sumter  
Assemblywoman Connie Wagner  
Assemblywoman Mary Pat Angelini



**ALSO PRESENT:**

Elizabeth Boyd  
Irene M. McCarthy  
*Office of Legislative Services  
Committee Aides*

Eugene Lepore  
*Senate Majority*  
Keith White  
*Assembly Majority  
Committee Aides*

Christine Shipley  
*Senate Republican*  
Kevin Nedza  
*Assembly Republican  
Committee Aides*

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

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## TABLE OF CONTENTS

	<u>Page</u>
Susan A. Cole, Ph.D. President Montclair State University	1
Assemblyman Patrick J. Diegnan Jr. District 18	7
Pat Lepore Freeholder Passaic County	8
Thomas Vahalla Mayor Borough of Metuchen	11
Andre Sayegh Councilman City of Paterson	12
Edward O'Malley Deputy Mayor Township of Cranford	14
Lou D'Angelo Councilman Borough of Totowa	14
Carolyn Fontanella Councilwoman Borough of Totowa	15
Anthony Picarelli Councilman Borough of Totowa	17
Linda Zani Thomas Founding Member The Parents Group	18

## TABLE OF CONTENTS (continued)

	<u>Page</u>
Joanne R. St. Amand President Woodbridge Developmental Center Parents Association	23
Kevin Tremble Private Citizen	23
Thomas York, Esq. Private Citizen	26
Cindy Bartman President Association for Hunterdon Developmental Center	29
Sam Friedman Private Citizen	39
Assemblyman Craig J. Coughlin District 19	46
Jeffery Jones Mayor City of Paterson	47
Virginia O'Brien Private Citizen	53
Salvatore Pizzuro, Ed.D. Private Citizen	55
Harriet Fass Private Citizen	58
Denise Sussina Private Citizen	60
Thomas Baffuto Executive Director The Arc of New Jersey	63

## **TABLE OF CONTENTS (continued)**

	<b><u>Page</u></b>
Daniel J. Keating, Ph.D. Executive Director Alliance for the Betterment of Citizens with Disabilities	72
Deborah Good Member Board of Directors New Jersey Association of Community Providers	76
Carolyn C. Wade President Local 1040 Communications Workers of America	83
Gerald Newsome Vice President Local 195 International Federation of Professional and Technical Engineers	87
Rex Reid Political and Legislative Representative New Jersey Council 1 American Federation of State, County, and Municipal Employees	90
Martha Cray Advocate Family Alliance to Stop Abuse and Neglect	93
Karen Cameron Advocate Family Alliance to Stop Abuse and Neglect	95
Aileen Rivera Advocate Family Alliance to Stop Abuse and Neglect	96
David Dayya, D.O. Private Citizen	97

## TABLE OF CONTENTS (continued)

	<u>Page</u>
Eric Richard Legislative Affairs Coordinator New Jersey State AFL-CIO	101
Robert Rutland Private Citizen	102
Michael Chomicki Private Citizen	104
Juana Mitchell Private Citizen	105
Marie White Private Citizen	106
Deborah Traylor-Smith Private Citizen	108
Marylyn Carr Private Citizen	110
Sheri Joyner Private Citizen	110
Brent T. Sjaardema Private Citizen	115
Thomas R. Hines Jr. Private Citizen	117
Susan Mason Private Citizen	118
Khalilah Shabaz Private Citizen	121
Terry Campagna Private Citizen	122

## TABLE OF CONTENTS (continued)

	<u>Page</u>
Judy Natoli Private Citizen	123
Gary Yacono Private Citizen	123
Cheryl Yacono Private Citizen	127
Steve Hazen Private Citizen	129
Carl V. Hazen Private Citizen	129
Kathryn H. Bergin Private Citizen	130
Barbara Cockefair Private Citizen	132
Marie Reid Private Citizen	133
Gaylord Reid Private Citizen	134
Edith Servino Private Citizen	135
Alan Ferrer Private Citizen	136
Frances Finkelstein Private Citizen	137
Carrie Miller Private Citizen	139

## TABLE OF CONTENTS (continued)

	<b><u>Page</u></b>
Essie Feldman Private Citizen	140
Donna Vacca Private Citizen	143
Debra Trepkau Private Citizen	144
Gary Mortoro Private Citizen	146
William G. Holy Private Citizen	154
Nancy Maza Private Citizen	158
John J. Pydyszewski Private Citizen	161
Kirsten Schenk Private Citizen	162
Gillian Speiser Private Citizen	163
William Urion Private Citizen	164
Jacqueline C. Guillot Private Citizen	164
<b>APPENDIX:</b>	
Testimony submitted by Carolyn Fontanella	1x

## **TABLE OF CONTENTS (continued)**

### **APPENDIX (continued):**

	<b><u>Page</u></b>
Testimony, plus attachments submitted by Joanne R. St. Amand	9x
Testimony submitted by Cindy Bartman	16x
Testimony submitted by Sam Friedman	20x
Testimony, plus attachments submitted by Virginia O'Brien	25x
Testimony submitted by Salvatore Pizzuro, Ed.D.	30x
Testimony submitted by Harriet Fass	32x
Testimony submitted by Denise Sussina	33x
Testimony submitted by Thomas Baffuto	35x
Testimony submitted by Daniel J. Keating, Ph.D.	38x
Testimony submitted by Deborah Good	42x

## **TABLE OF CONTENTS (continued)**

### **APPENDIX (continued):**

	<b><u>Page</u></b>
Testimony, plus attachments submitted by Carolyn C. Wade	44x
Testimony submitted by Gerald Newsome	145x
Testimony, plus attachments submitted by Rex Reid	147x
Testimony submitted by Martha Cray	152x
Testimony submitted by Aileen Rivera	154x
Testimony submitted by Eric Richard	156x
Testimony submitted by Robert Rutland	157x
Letter addressed to Senator Joseph F. Vitale and Assemblywoman Valerie Vainieri Huttle from Michael Chomicki	158x
Testimony submitted by Deborah Traylor-Smith	159x

## **TABLE OF CONTENTS (continued)**

### **APPENDIX (continued):**

	<b><u>Page</u></b>
Testimony submitted by Marylyn Carr	160x
Letter addressed to New Jersey State Legislature from Brent T. Sjaardema	162x
Testimony submitted by Thomas R. Hines Jr.	164x
Testimony submitted by Susan Mason	165x
Letters submitted by Terry Campagna and Judy Natoli	168x
Testimony submitted by Gary Yacono	192x
Testimony submitted by Carl V. Hazen	195x
Testimony submitted by Kathryn H. Bergin	196x
Letters submitted by Marie Reid and Gaylord Reid	198x
Letter submitted by Alan Ferrer	200x

## **TABLE OF CONTENTS (continued)**

### **APPENDIX (continued):**

	<b><u>Page</u></b>
Testimony, plus attachments submitted by Frances Finkelstein	202x
Testimony, plus picture submitted by William G. Holy	204x
Letter submitted by John J. Pydyszewski	209x
Letter submitted by William Urion	210x
Letter submitted by Frederick Maier Private Citizen	211x
Testimony submitted by Michael Hazen Private Citizen	213x
Testimony submitted by Mary Hazen Johnston Private Citizen	214x
Testimony submitted by David Schlett Private Citizen	216x

## TABLE OF CONTENTS (continued)

### APPENDIX (continued):

	<b><u>Page</u></b>
Testimony submitted by Eileen Oujo Private Citizen	217x
Letter submitted by Joseph R. Milbrook Private Citizen	218x
Letter addressed to Senator Joseph F. Vitale and Assemblywoman Valerie Vainieri Huttle from Theresa Maresca Private Citizen	219x
Testimony submitted by Dante Chrystal Sidney Katz Private Citizens	221x
Letter submitted by Isabel Sly Private Citizen	223x
Letter submitted by Margo Post Marshak Private Citizen	224x
Testimony submitted by Christa Sinagria Private Citizen	225x

## TABLE OF CONTENTS (continued)

### APPENDIX (continued):

	<b><u>Page</u></b>
Letter submitted by Ruth V. Mason Private Citizen	226x
Letter submitted by Donald N. Vacca Theresa Vacca Private Citizens	227x
Testimony, plus attachments submitted by Georgia Vann Private Citizen	228x
Testimony submitted by Kathy Toth Private Citizen	230x
Letter addressed to Senate Health, Human Services, and Senior Citizens Committee, and Assembly Human Services Committee from Linda Tucker President Elect New Jersey Speech-Language Hearing Association	232x
Letter addressed to Senator Joseph F. Vitale from Charles Kenny Council President, and Michele R. Charmello 3rd Ward Councilwoman Township of Woodbridge	245x

**TABLE OF CONTENTS (continued)**

**APPENDIX (continued):**

	<b><u>Page</u></b>
Testimony submitted by Eileen Fralinger Private Citizen	247x
Testimony submitted by Walter Shenk Janice Shenk	249x
rs: 1-176	

**ASSEMBLYWOMAN VALERIE VAINIERI HUTTLE (Co-Chair):** Good morning, everyone.

Before we start our public hearing, I would like to introduce Dr. Susan Cole, of Montclair University.

Dr. Cole, thank you. (applause)

**S U S A N A. C O L E, Ph.D.:** Thank you very much.

I am delighted to welcome you all -- Chair Vitale, Chair Vainieri Huttle, and the Committees -- the Senate Health, Human Services, and Citizen (*sic*) Services Committee; and the Assembly Human Services Committee. We are delighted to be able to offer the campus for this very important hearing today. And I extend a very warm welcome to the members of the community who are unfortunately behind me at this point in time.

For those of you who have not been to Montclair State University recently or, in some cases, at all, this is New Jersey's second largest university, with 18,500 students. It has experienced an enormous amount of growth over the last several years. We have grown 36 percent in our enrollment over the last decade. And we now graduate 4,242 people a year. That is significantly -- 2,000 more degrees a year than were granted just a decade ago. So it gives you a sense of some of the growth.

Some other signs of growth -- you can see actually from the windows of this wonderful facility, if you look north -- not from this window -- but if you wander out into the lobby and look north, you will see the new, 2,000 beds that have been built -- the first project under the New Jersey Economic Stimulus Act -- and the largest student housing project ever built in the State of New Jersey. If you look out of these windows you

will see lots of construction all over the campus. And if you try and walk from north to south or east to west on the campus you will work your way around trenches and all kinds of construction machinery. And that is because we are in the midst of the second project undertaken under the New Jersey Economic Stimulus Act, and that is a rebuilding, construction of an entirely new energy infrastructure for the campus. It's a massive project, and we are getting it done in 18 months while the campus is running full force. So it's pretty exciting, logistically. But it is also a massive project that was undertaken, like the first, without State funding, without University funding, through public-private partnership.

The other big news on the campus is the opening this year of our new School of Communication and Media Studies. And that, of course, has been an enormous change in development for the institution. And you see the consequences of a lot of that work in the many media partnerships that we now have on campus, from NJTV, to WNYC, to a whole range of local media who are now using our multiplatform news facilities in order to reach people throughout the State of New Jersey.

You have before you on your table our most recent economic impact report. It will give you some idea -- there it is, thank you -- of the consequences -- the positive consequences of Montclair State economically to the State of New Jersey.

There is one other thing you have before you, and that is this little document. What I tried to do for the very important work of this Committee is to give you, in one page, some idea of the enormous investment that Montclair State has made in programs, institutes, centers, clinics all focused on the subject of human services. So if you glance at this

you will begin to see just a little bit of how much a university community contributes to the State in these very, very important areas.

And finally, in closing, I want to thank all of you for the support that you have given to the Building Our Future Bond Act and to the reauthorization of the other bond legislation. There is nothing that is more important to higher education in the state than the work that you have done to support those programs. And you can see, if you look around Montclair State, that when we get -- occasionally -- support from the State (laughter) for the work that we do-- When we get it, we put it to good use for the people of New Jersey. We are here to serve; it is what we do.

So, finally, I welcome all of you to Montclair State University. And I'm very happy to have you here today.

Thank you. (applause)

**SENATOR JOSEPH F. VITALE (Co-Chair):** Thank you, Dr. Cole. Thank you for hosting this for us today and for that really great commercial for Montclair State University. It is a fine institution. Thank you so much for your hospitality.

I wanted to introduce the members of the Senate who are here today: Senator Pou, Senator Buono, and Senator Thompson.

Thank you for coming up.

We are going to, today, listen to and hear from a variety of elected officials, family members who have relatives and loved ones who currently reside in developmental centers, community providers, members of our labor unions, and also from the members of the people -- to hear your concerns as well.

Of course, we're here today not only to do that, but also to discuss what are the planned closings of North Jersey Developmental Center and the Woodbridge Developmental Center -- Woodbridge in my hometown -- and to hear from those experts, but also from the members of this panel, to understand the consequences of the closing and what that means. But, moreover, what we can do as a Legislature, and advocates, and individuals to serve our committees that have influence over policy -- how it is that we can provide for the best care for those who are currently residing in those two centers, and also even talk a little about: Does any of that make sense at all? If so, what can we do to make it a better transition. There are challenges in terms of capacity in the community; there are challenges for those who reside in these developmental centers who really cannot thrive, survive -- not even survive, but certainly not thrive in a community setting. And we all have experience as members, but you certainly have more experience than we do, having lived this issue and these experiences every day.

So with that, I will ask Assemblywoman Chairwoman Huttler to make some comments also.

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Good morning.

Along with Senator Vitale, I also welcome you to today's joint hearing.

I also want to thank Dr. Susan Cole for hosting us here today. It's a beautiful room and, of course, a beautiful campus.

Thank you very much, Dr. Cole.

I also want to introduce and thank my colleagues who are here this morning. Starting from the end, Assemblywoman Mary Pat Angelini, Assemblywoman Shavonda Sumter, and Assemblywoman Connie Wagner.

It's very ironic that today is February 13, and the first meeting of the Task Force was convened on February 13, 2012. I found that to be a little tid bit and very interesting. Over the summer, the New Jersey Task Force on the Closure of State Developmental Centers issued a binding recommendation to close two centers within five years, taking into account the needs of the residents of the developmental centers to be closed, and the operational concerns of the developmental centers and the community services system.

Now, as you heard from Senator Vitale -- and most of you know, I see a lot of friends and family members in the audience today -- these two developmental centers provide residential care for some of our most profoundly developmentally disabled residents in the North Jersey region of the state. And since the closures were announced, I have received many calls, e-mails, and visits from my constituents in Bergen County and residents of the neighboring areas expressing concern about where their loved ones would be placed.

Now, I understand a great worry is how far away the residents of North Jersey and Woodbridge will be from their families and support systems living in the northern region of the state. So whether or not the Legislature takes action to keep one of these centers open, I think the goal here today is to make sure that all residents of North Jersey and Woodbridge Developmental Centers are in the most appropriate residential

setting, and that they retain and maintain access to their families who provide critical support.

Senator Vitale and I invited Commissioner Velez today to provide an update. I understand she has a prior engagement. However, I am certainly disappointed that no one from the Department of Human Services is able to join us today, considering the significant impact these closures will have on the entire developmental disability system.

So with that, we will hear testimony.

I will turn it over to Senator Vitale to call the first panel of speakers.

Thank you.

SENATOR VITALE: Thank you, Chairwoman.

We also want to just do a little bit of housekeeping. In order to be able to get through everyone here today who would like to make a comment-- We certainly have a list of those who signed up prior to the hearing -- elected officials, family members, community providers, union members, and members of the public; provide an opportunity for everyone to have a say and to speak. We just ask that you try to really summarize and maintain your comments and make them as -- I wouldn't say as brief as possible, but as concise and to the point. I know there is going to be some redundancy because I think a lot of us here -- certainly a lot of the families that are here today -- share a common opinion in many ways, and have a common goal and common concern. So if it is that we can do that and get through it, we're going to try to adjourn by 2:30 because some of our members and members of the public have other engagements this afternoon. So if we could move it along as quickly as possibly -- but

respectfully to get through all the testimony -- that will be helpful for all the members as well.

ASSEMBLYWOMAN VAINIERI HUTTLE: And I just want to take a moment to introduce Vice Chair Cleo Tucker, who has arrived as well.

Thank you.

SENATOR VITALE: Thank you.

Welcome, Vice Chair.

Our first panel will be Assemblyman Pat Diegnan, from South Plainfield; Freeholder Lepore; Freeholder Duffy; and also, if I could, Mayor Tom Vahalla, from Metuchen.

**A S S E M B L Y M A N P A T R I C K J. D I E G N A N J R.:**  
With your permission, Chair people, I've asked the O'Brien family to join me.

SENATOR VITALE: So we'll do that first, and then the others will follow.

ASSEMBLYMAN DIEGNAN: Thank you for holding this hearing. It's difficult for me to put into words the sorrow--

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

ASSEMBLYMAN DIEGNAN: Thank you.

It's difficult for me to put into words the sorrow -- and I've been trying to come up with the correct term -- the sorrow that I feel that we have to have a hearing like this today. I've asked the O'Brien family to join me. Their daughter has been at the Woodbridge Developmental Center for 28 years -- 48 years, I'm sorry.

The Chair just mentioned the most appropriate setting or residence for these particular residents of the facility-- The most appropriate location is where they are at today. (applause) A society is gauged by how it treats its most vulnerable citizens.

I'm proud of what Dr. Cole talked about recently -- or just a few minutes ago about the support that the State has given for higher education. And that is appropriate and proper. But these residents don't have a voice. They don't have the ability to sit before you today and explain their circumstances. (applause) And I know that you all feel the same. And I, again, share the same frustration that Chairperson Huttles shares -- that nobody from the Administration is here today. That says legions, and it's really disappointing.

With that, Mr. Chair, I won't take your time. I know you have a lot of family members who want to testify.

She's going to wait for the testimony, subsequently.

Thank you, again, for giving me the opportunity.

ASSEMBLYWOMAN VAINIERI HUTTLES: Thank you.

SENATOR VITALE: Thank you, Assemblyman.

We have Freeholder Lepore and Freeholder Duffy; and Mayor Vahalla, from Metuchen.

**FREEHOLDER PAT LEPORE:** Thank you, Chairman.

Good morning, everyone.

I want to thank Dr. Cole for hosting this event.

First off, Freeholder Duffy and I want to thank Chairman Vitale and Chairwoman Huttles for holding this meeting in North Jersey and hearing testimony on this important matter. We are honored that this joint

Committee allowed us to come and give testimony on this issue affecting so many of our constituents and our residents.

This issue is so important not only to our constituents in Passaic County, but to all of the residents of North Jersey. The North Jersey Developmental Center, in Totowa, is home to 347 residents with a variety of developmental disabilities. Now these patients will most likely be shifted to a center in Vineland, creating a major inconvenience for family and friends who want to visit their loved ones.

Additionally, the NJDC employs many residents of Passaic County who will become unemployed if this facility is closed. Passaic County is already plagued by an unemployment rate above the State and national average. We cannot afford to lose these jobs as well. Right now we are looking at 2,000 individuals losing their jobs if these two facilities are closed in Totowa and Woodbridge. Five hundred people in the Passaic County facility are being laid off. This is unacceptable. With New Jersey still lagging behind in terms of job creation, this should not be the approach our State government should be taking.

After this reorganization is complete, heavily populated North Jersey will be without an institutional care center. With a facility serving fewer residents in a lesser populated part of the state, many people have questioned if politics, not sound policy, played a role in which facilities close and which stay open. (applause)

Moreover, we should not be balancing our State budget on the backs of the developmentally disabled. (applause) I understand as well as anyone the burdens of balancing a budget. I've done it as mayor and as a freeholder. But there has to be a better way to plug this budget than

displacing the developmentally disabled and shedding 2,000 jobs. As representatives of the Passaic County Board of Chosen Freeholders, Terry Duffy and I are urging you to do whatever you can in your power to keep these vital facilities open in Woodbridge and in Totowa.

In closing, we would just like to reiterate one important message. Do not balance our budget on the backs of the developmentally disabled. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Let me interrupt, Freeholder.

I understand the applause is -- we understand where it's coming from, but it's interrupting the sound. So if you could just hold the applause and be more respectful of the speaker.

Thank you.

FREEHOLDER LEPORE: In closing, it is not responsible to use the most vulnerable among us as pawns in a political chess match.

We thank you again for hearing our testimony and coming to North Jersey to continue the dialogue on this important issue to Passaic County.

Thank you very much. (applause)

SENATOR VITALE: If I could just reiterate what the Chairwoman said. The folks who are doing the sound today are recording this hearing. It's affecting that when you all applaud. I certainly recognize the need to, and I appreciate that as well. But if you could hold your applause, it does interfere with the recording system.

Thank you.

Mayor.

**MAYOR THOMAS VAHALLA:** Thank you, Senator.

Good morning, Senators, Assembly people. Thank you for allowing me to address you this morning on this very, very important issue.

My name is Tom Vahalla. I'm the Mayor of the Borough of Metuchen.

Recently, at our January 18 meeting, the Borough Council passed a resolution, unanimously asking that the developmental centers in North Jersey and in Woodbridge not be closed. The closing of these centers, which are the homes for the most severely developmentally disabled citizens, is unconscionable. These centers service and meet the needs and care for some of our most vulnerable citizens. In fact, closing these two centers will be to the detriment of these citizens that they are supposed to support.

I have spoken to psychologist Robert Capra, the Director of Special Services at Metuchen School District, regarding these closings and the change that it will create. He stated that this type of change could be detrimental to the patients that you're trying to serve. Many patients being served do not adjust well to change. In fact, added stress of a significant change like this may illicit extreme reactions in ways that they may harm themselves or others around them.

I know Metuchen residents have relatives who are being cared for at these centers. The added stress on moving them to different facilities will also place a greater burden on their families. Metuchen also has a number of residents who work at the Woodbridge Center. The loss of their jobs will have a negative affect on them, and our Borough and its economy.

As a young boy growing up, I had an uncle who was serviced at a center like this in Pennsylvania. I remember traveling the distance to visit him on weekends. I fully understand the stress and strains on the family members, and I understand the issues with which they are coping.

Please find a way to keep these centers open. It is the morally right thing to do. If we in government cannot take care of the most vulnerable of our citizens, then who do we care for? My religion teaches: Whatsoever you do to the least of our brothers and sisters, that you do unto me. Please find a way to prevent these closings and provide the proper service to the citizens with the greatest needs.

Thank you very much. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: I'd like to call up Deputy Mayor Ed O'Malley, from Cranford; Councilman Andre Sayegh, from Paterson; Councilman Lou D'Angelo, from Totowa; Councilwoman Carolyn Fontanella, Totowa; Councilman Anthony Picarelli; and Councilwoman Michele Charmello.

SENATOR VITALE: If you would just introduce yourself.

You have to use one of those two mikes. (referring to PA microphone)

Thank you.

COUNCILMAN ANDRE SAYEGH: Good afternoon.

Andre Sayegh, Councilman from the City of Paterson.

SENATOR VITALE: You can speak, and then we'll do the rest.

COUNCILMAN SAYEGH: Mr. Chairman, Madam Chairwoman, I want to thank you for this opportunity.

I am here today to stand in support of keeping our developmental centers open.

Quite some time ago, a number of our residents who will be adversely impacted came to a City Council meeting in Paterson and told us about the hardship this would cause and how they would be adversely affected. Our unemployment numbers in New Jersey are high; our unemployment numbers in Paterson are high. If these developmental centers are closed, our unemployment numbers in the state will be higher and the unemployment numbers in the city would be even higher. And this is something we can least afford. Not to mention you can't displace the disabled as well, because it would adversely impact families throughout North Jersey and the entire state.

So the Paterson Municipal Council took action. We unanimously adopted a resolution calling for our North Jersey Developmental Center to stay open. At that time we also went to the Totowa Borough Council and asked if they could do the same. And as you can see, I have two of my counterparts here, and obviously they followed suit. They said, "We stand in support as far as the solidarity is concerned" -- it does exist -- and we want to keep our developmental centers open. So I'm not only speaking on behalf of myself, but I'm speaking on behalf of the entire Paterson Municipal Council.

A number of our residents, a number of our neighbors will experience hardship if these developmental centers were to close. And so we're calling on you as our champions to stand up for us and make sure that what is done is the right thing in this matter, and that individuals are not displaced -- either those who are employed or those who happen to reside at

these developmental centers. And it's especially encouraging to see-- We have our Senator, Senator Pou and our Assemblywoman Sumter from Paterson-- And we know that you are true to the test and you will fight to ensure that individuals are not displaced and others are not unemployed.

Thank you very much. (applause)

**DEPUTY MAYOR EDWARD O'MALLEY:** Thank you.

As a matter of note, I hadn't intended to testify. I'm here more because I'm concerned about effective, and efficient, and compassionate care for the most vulnerable among us. And I have looked into the Task Force that was set up to consider closing centers, and I cannot find any component of providing for appropriate medical and developmental care for these people. So I'm hoping to hear more -- that, in fact, people are concerned about care and that's the driving factor in whether or not centers close.

Thank you.

**SENATOR VITALE:** Could you please state your name for the record?

**DEPUTY MAYOR O'MALLEY:** Ed O'Malley, Deputy Mayor of Cranford.

**SENATOR VITALE:** Would anyone else like to testify on the panel?

**COUNCILMAN LOU D'ANGELO:** I'll defer to the Councilwoman.

Everything our colleague said is very on. And, obviously, we all support -- it's our backyard. So we will definitely miss these folks and,

obviously, the economy, etc. So for the sake of time I'm not going to-- I'm going to go on. I'm going to let the Councilwoman take over.

**COUNCILWOMAN CAROLYN FONTANELLA:**  
Councilwoman Carolyn Fontanella, Totowa Borough.

While some people refer to the individuals who live at NJDC as *clients*, I prefer to refer to them *residents*. Some other people may even refer to the residents of NJDC as *special needs individuals*. I, on the other hand, simply say they are very special. These men and women reside at the North Jersey Developmental Center, 169 Minnisink Road, Totowa, NJ. Not only is this their address, but more importantly, this is their home. This is the only dwelling many of these residents have ever known. These individuals have faced challenges throughout their entire lives unlike any challenge that you or I have ever experienced.

I find it disturbing that their lives can just be uprooted at any time, leaving them with no option but to face yet another challenge, a challenge that is totally preventable. These residents need stability in their lives and it is up to everyone here to be their voice, to speak on their behalf and ask that their lives not be interrupted and their home not be disturbed.

The families of these residents have also faced a lifetime of challenges regarding their loved ones. Looking beyond these challenges, family members have been able to find a sense of comfort in their own hearts and minds knowing that the developmental center has provided a safe and caring environment for their relatives who reside there. Family members, both immediate and extended, live nearby this facility, making it easier for them to visit their loved ones on a regular basis. Many of these family members are beginning to age, and would find it nearly, if not

totally, impossible to maintain regular contact with their relatives if they are transferred. Please keep in mind that spending this valuable time with their relatives who are diagnosed with developmental disabilities is not a luxury, it's a necessity. These frequent visits are an important element in adding to the stability of the lives of their family members. Moving their relatives out of this facility -- or *home* as I would prefer to call it -- would create an undue burden for so many people.

Should this residential facility close, a severe hardship would also be created for the staff members at the North Jersey Developmental Center. It will certainly, without a doubt, cause financial difficulties for the proud individuals who work so hard every day to make NJDC the best possible residential facility in northern New Jersey. This amazing staff provide so much more than a service to the residents at NJDC. While it is true they assist the residents in all of their activities of daily living, please let it be known that they provide something much more important and valuable. They have created a home for the residents; a home that is filled with love and care.

It is the responsibility of the elected officials of our state to act responsibly when developing a fiscal plan. However, when developing this plan, we must keep in mind that no dollar amount is too excessive when considering the value of the loving care and attention that these residents receive and truly deserve. These residents, as well as the employees, are priceless. The staff members at NJDC truly enjoy what they do and they do it everyday with love in their hearts. I applaud them for transforming what might be described as an ordinary, everyday job into an extraordinary lifetime filled with joy -- for it is these individuals who have created an

atmosphere filled care and compassion. I have personally witnessed the joy that these residents experience, and I commend each and every one of these employees. I would like to publicly take this time to thank them for their personal dedication to the residents of NJDC.

You truly make a positive difference in the lives of these very special people.

The Borough of Totowa is so very blessed that North Jersey Developmental Center considers our borough their home. Please know that we consider you our friends and, most importantly, our neighbors, and we would like for it to stay that way.

I strongly encourage our local and State officials to recognize the importance of our responsibility to these residents and reconsider keeping the North Jersey Developmental Center -- the home to some of the most incredible people I have ever met -- open.

I thank you for your time and attention. (applause)

**COUNCILMAN ANTHONY PICARELLI:** I actually didn't plan to testify either. We were going to both defer to our Councilwoman for the sake of time.

But I do just want to reiterate that we don't consider them only residents of North Jersey Developmental Center, we consider them residents of Totowa. And we're here because we support them, and we're here to protect them.

Thank you. (applause)

**SENATOR VITALE:** Do we have any questions from the members or any comments you'd like to make? (no response)

Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Next on the agenda for those wanting to testify are family members. And I would like to call up Linda Thomas first, from the Parents Group; Joanne St. Amand.

LINDA ZANI THOMAS: Hi.

Where should I sit?

SENATOR VITALE: In front of the microphone, center.

MS. ZANI THOMAS: This one?

SENATOR VITALE: Yes.

MS. ZANI THOMAS: Hi, everyone.

ASSEMBLYWOMAN VAINIERI HUTTLE: Cindy Bartman, Kevin Tremble.

Thank you. Go ahead.

MS. ZANI THOMAS: Hello, everyone. And thank you for having us all here today.

SENATOR VITALE: Could you speak into that microphone.

MS. ZANI THOMAS: First, I was just going to say hello. It's nice to see everybody. And thank you for having everybody here today.

I am here-- My name is Linda Zani Thomas. I am one of the founding members of The Parents Group. We are a group of five special-needs moms. No one is at a developmental center, no one is residing there. We have all the kids at home. They're young adults now.

We are community organizers and creative problem-solvers. And we are dedicated to the creation of safe, high-quality day programs, recreation activities, and community residences for a very special group of adults. And this group, in the parlance of the State, is called *Level 4* adults. Is everyone on the panel aware of this designation?

ASSEMBLYWOMAN VAINIERI HUTTLE: Why don't you clarify?

MS. ZANI THOMAS: This designation, Level 4, is given by the State to distinguish adults who have very severe developmental delays and they are medically fragile. So there is a medical component. So these are the ones who need the most intense help. And many of them reside in developmental centers and many of them reside at home. In fact, more of them reside at home and are on the waiting list for community placement. So, first of all, my remarks are going to be based solely on Level 4 adults. And I know many people in the audience who I've had the chance to meet today fit into that criteria.

It is very interesting to see how this largely nonverbal group of adults has dominated the media. I live up here in North Jersey, and there is an article almost every day, every week by Harvy Lipman -- I hope -- if he's here, I'm waiving to him -- about this group of adults. And it's really encouraging to see how much attention is being paid to their lifestyle and their living arrangements. So we have a big opportunity now where this largely nonverbal group of very, very needy adults is actually captivating the State's attention. So we need to do a lot of work to create things in the community that match or exceed the level of service and support that this group of adults are getting at the developmental centers.

In an article in *New Jersey Spotlight* yesterday, it was said that 307 of the 339 residents at Woodbridge -- that is 90 percent -- are classified as Level 4 clients. There are at least 40 more at North Jersey Developmental Center living in the Meese Building -- I'm sending a shout-out to everybody there and everybody at Woodbridge -- and perhaps

thousands on the community placement waiting list. These people are all in play, whether voluntarily or involuntarily, for movement into group homes and other housing in the community. I don't need to tell anyone in this room right now that there is a tremendous amount of work that needs to be done in the community regardless of whether you're coming from a developmental center or you're coming off the waiting list. And The Parents Group is up to this challenge.

I want to say something about New Jersey. New Jersey has been derided for being number one in the sheer amount of developmentally disabled adults residing in developmental centers when, actually, those centers may be the current gold standard for community living for Level 4 clients. So maybe we should be proud of how well we are taking care of Level 4 clients at the developmental centers. And The Parents Group point of view is: We need to take what is happening at the developmental centers and match or exceed it in the community.

It sounds easy, right? Well, we have already begun this, and we are working on a concept that we are calling *the total package for optimal community living for Level 4 adults*. And we've identified five components of high-quality community living for this group. Number one: safe, comfortable, attractive housing in friendly neighborhood settings. Number two: stimulating, safe, and loving day programs, because now the services would be unbundled and they still need to have safe, quality, stimulating activities -- therapies and the like -- and now they would move into a day program setting. At those programs and at the residences: high-quality staff who are paid respectfully for the importance of their work. Four: rigorous oversight regulations, equal or greater to those provided by Medicaid in the

State at developmental centers. I never thought I would fall in love with a Medicaid regulation document. But the conditions of participation in that document are really stellar, and that is why the care -- is one of the reasons why the care at the developmental centers is so great for this population. Number five -- and the most difficult of all -- is a comprehensive constellation of medical and therapy services equal or greater to those provided in the developmental centers. That is going to prove to be very eye-opening when we quantify that, and we are going to do that. Because that piece of the puzzle is the difference -- could be the difference between life and death of some of the adults who come out into the community. That is something that's kind of been overlooked -- or thought that once they come out they get everything covered by their insurance companies. I am telling you right now that the Level 4 group of clients -- young adults who are relying on private insurance and policies that are given, like the managed care, like the (indiscernible) policies -- we are not getting good coverage for equipment, therapy, medical services, dental services. The actual medical care that Level 4 clients are getting at the developmental centers is far greater than families are able to give them and are able to afford to give them at home. Right now they are being serviced much better, and they are living probably, in aggregate, healthier lives in the developmental centers.

Now, the State has done a lot of work on the family support program, which is going to subsidize us who have this group living at home. I think we're supposed to be receiving about \$15,000 that we could use toward equipment and things that are not covered. This is a great help. Is it enough? I don't know. I'm going to get back to you.

Who are The Parents Group, and what are we doing? I'm almost done. But I wanted to tell you that The Parents Group, which is five moms -- myself; Dr. Marsha Wilks, from Paterson, Vicki Allen, from Wyckoff; Linda Salerno, from Ramsay; and Lisa Crilly, from Wanaque. We banded together about two-and-a-half years ago. We created the concept for an innovative, high-quality, stimulating, and safe medical day program called the Red Ribbon Academy. We created that in collaboration with a great provider called Community Options. And we worked directly with Dawn Apgar and her staff at DDD. We worked with them for years, and I'm proud to say that this innovative program is opening March 15 in Wayne. And I hope that everyone will follow along with us.

If you need to get in touch with me, we're at [parentsgroup365@gmail.com](mailto:parentsgroup365@gmail.com).

What else did we do to get ready for the community residences, whether or not you're coming off the waiting list or you're coming out of a developmental center? Dr. Marsha Wilkes and I personally contacted every single mayor in Passaic County who still had COAH funds, and we personally urged them to set these funds aside for special needs housing by one of the best providers of housing anywhere, and that is Tom Toronto of Bergen United Way. We also wrote to Governor Christie when those funds were in jeopardy and urged him to continue to make those funds available for special needs housing. We also met with two families from North Jersey Developmental Center to get their input on what optimal community living is like for this population. And we plan to meet with representatives from Woodbridge as well.

In conclusion, I would like to say that everyone has a friend in us. I want everyone to know that The Parents Group and many others are working to create programs, housing, and services that we can all be proud of, that are not just passable, but truly innovative and reflective of best practices; that New Jersey is going to be number one in how we treat Level 4 adults. I can see it. It's definitely going to happen.

We are looking forward to sharing our concept with you in the near future, and we need your help to make it a reality.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Joanne, you had something short -- as far as a film -- that you wanted to show.

J O A N N E R. S T. A M A N D: Yes, I have a short video of my sister.

ASSEMBLYWOMAN VAINIERI HUTTLE: I think Linda spoke so well on behalf of the families, maybe you would like to show a piece of that film with some remarks.

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Would you like to show a portion of that film?

MS. ST. AMAND: Yes. Is there some place to plug that in?

ASSEMBLYWOMAN VAINIERI HUTTLE: While they're doing that, Kevin, would you like to--

K E V I N T R E M B L E: Sure.

Good afternoon.

My name is Kevin Tremble. I reside in Tenafly, New Jersey. My brother Richard Tremble is at Woodbridge Developmental Center and has been there for over 45 years.

I wrote a note back to the social worker at Woodbridge -- I finished it actually this morning -- because we had Richard's annual evaluation assessment last week. So I'd just like to take a moment to share those thoughts with you that I expressed to Ms. Toni Williams at Woodbridge.

"Dear Ms. Williams, please convey our appreciation to the Cottage 4 team who cares for Richard. My daughter Elizabeth and I found the assessment meeting with the team on February 7 to be comprehensive and professional.

"Richard seemed in good spirits and appeared well cared for. Thank you.

"On behalf of Richard's family, we feel his quality of life is quite stable, and we wish his long-time residence in his community at Woodbridge Developmental Center to be continued.

"We are concerned that the disruption of his continuity of care at Woodbridge Developmental Center may threaten his emotional security, his stability, and ultimately his physical well being. The threat of removing him from his present community into a facility far from our ability to visit and to address his circumstances of care is disturbing to us. We have to question the level of care he would receive at some other care facility. He is extremely vulnerable to mistreatment because he's nonverbal, immobile, and unable to feed himself. And I'm learning some of the--" As an aside, "I'm learning some of the language" -- as we just heard from the previous

presenter -- “of his level of disability. And I guess we desire that he remain as close as possible to the family so we may continue to monitor and assure ourselves that he has the same state of care that he has been receiving in his community at Woodbridge Developmental Center.

“Thank you.”

As I composed this letter this morning, I had mixed emotions. It’s hard to sit here and listen to people talk about the most vulnerable in our society. Over the years that I have visited my brother, I have been impressed, with my other family members, about how well he is treated and cared for. And to the credit of the State -- as the previous presenter said -- I believe his current community and his current condition is a credit to those who care for him. And I urge you to find a better solution. This one is, quite frankly, outrageous in my mind, egregious, and I think abusive to most people.

So I thank you for the opportunity to present to you.

(applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Joanne, while we’re waiting to try to get that set up, I’m also going to call up Tom York and Sam Friedman.

SENATOR VITALE: We’re trying to-- We want to move along all of those who would testify today, and give everyone an opportunity. So if it is at all possible to keep your remarks within a two or three minute time frame--

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Tom.

Thank you.

**THOMAS YORK, ESQ.:** Good afternoon, ladies and gentlemen.

My name is Tom York, and I'm an attorney. But I'm not here really in a capacity as an attorney. I'm here because of my experience representing various developmental centers all around the country, and also being exposed and visiting many community placements, and dealing with all the professionals who deal with this population. And I have some insights I hope to offer to this panel. And I will try to keep it short.

The key is to focus on the facts, not on the political ideology that's being imposed by people that all facilities, all developmental centers are bad. That's just false. What you want to do is you want to review the facts. There are a number of falsehoods that are circulating around the states that have led them to seek the closure of facilities. And I'm going to address a few of these falsehoods right up front.

One is that equivalent care can be provided in the community. That is absolutely false for this population. (applause) I've seen this throughout many states around the country. The level of ICF/MR -- or now ICF/ID is the latest terminology in care -- at a larger congregate facility is far superior, especially for this type of population. We're talking about a population that now has been narrowed down to the most dependent, most disabled, the ones needing the most care. And it does not easily translate over into the community. Not to mention there are not many service providers -- adequate service providers in the community to provide services to these people. You will find that many states that have closed their facilities or moved people out-- For example, there aren't enough dentists who want to take this type of population. They don't want to care for these

types of individuals. They don't have the expertise to do it, if they do choose to take on these tasks.

The other facts are too-- Even though, unfortunately, there aren't enough studies because of this political ideology that scares many professionals into doing these -- stops professionals from doing these types of studies-- But the ones that have been done -- is that mortality rates are higher in the community, abuse rates are higher in the community. So you're essentially telling people that they need to move their loved ones out into the community where they're at greater risk. And I guarantee you people will die as a result of that decision. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Tom, thank you.

We would like to give everyone the time to speak.

Tom, if you could just have your remarks more concise, because we have many speakers after you.

MR. YORK: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you. We appreciate it.

MR. YORK: And I would be happy to give more details, but the other falsehoods are that it is more integrated out in the community. That is a falsehood. Many of these people go out into the community and they are actually more isolated than they ever were in the developmental center.

Another one -- a big fallacy that you should all be aware of -- and I understand the arguments here that these -- that the cost should not be the only consideration. But it's a falsehood that you're going to save a lot of money by moving these people out into the community. That's

absolutely false. The studies do not support that. It has never been established in a court where it's actually been challenged. What they do is, they do false comparisons to come up with those numbers. You have comparisons by these advocacy groups that are trying to promote people being moved to the community that essentially compare apples to oranges. They will give you statistics out in the community that don't even include medical care, or don't even include sometimes housing, and most certainly doesn't include the quality of care that they receive at these facilities -- a comparison of the quality at these facilities. For example, you do not get the high level quality of individuals serving the people in general out in the community that you do at the State developmental centers. If the New Jersey developmental centers are like the many developmental centers I've toured over the country and spent weeks in at times, they're probably the best of the best. They're the best employees, they're committed to these people, and you just don't -- you're not able to duplicate that out in the community.

And the final matter is: It's a fallacy also that it doesn't matter how far away the facility is from their loved ones. If you make people drive hundreds of miles -- often the parents are the most crucial part of the care and well being of these individuals. And it does greatly matter. And it's very disappointing that the Task Force didn't take that into consideration as they should have. I think they assumed everybody would be moved to the community. So that's the assumption they started with.

I could elaborate more on all of these, but because of the shortness of time, I thank you for the opportunity to speak to all of you.  
(applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Tom.

Joanne, if you want to hold your remarks until we try to get that film-- If not, I will ask Cindy, and then of course Sam. And then after the family members I have a couple of elected officials who would like to speak in between the family members as well.

Cindy.

**C I N D Y B A R T M A N:** Is it on? (referring to PA microphone)  
(affirmative responses)

Chairwoman Huttle, Chairman Vitale, and distinguished members of the Joint Legislative hearing of the Human Services Committees, my name is Cindy Bartman. I live in Waldwick, and I'm a life-long resident of New Jersey. My legislative representatives are Senator O'Toole and Assemblymen Russo and Rumana.

I am the President of the Association for Hunterdon Developmental Center and the New Jersey State Coordinator for VOR. And I have been involved with the serious and life-dependent issues we are here for today for many years, and have been working with families in my current positions for about 5 years.

Thank you again for holding this hearing today and taking the time to listen to us. I'm going to emphasize some of the points that you have not heard but you will be hearing from families today.

I also want to let you know that we have close to 4,000 signatures on these petitions that will be going to the Governor regarding keeping both Woodbridge Developmental Center North Jersey Developmental Center open.

You'll be hearing from a family member about the difference between the Federal standard of care ICF/MR -- that is the developmental center vs. the Home and Community-Based Services Waiver -- and how the Community Care Waiver is not equal to or better than the Federal ICF/MR level of care. You will be hearing from a family member that home- and community-based services do not work for everyone. You will also hear from a mother and a brother who clearly need to be near their fragile and vulnerable loved ones who require the federal ICF/MR level of care.

What this will mean -- when you hear from these family members -- is that developmental center facilities need to be available in their current locations. The residents require the level of care provided in developmental centers and the families need to be able to visit. The geographic locations of the Woodbridge and Hunterdon Developmental Centers, built in 1965 and 1969 respectively, were carefully planned to provide better access to families of their loved ones -- a critical component to their well being.

In preparation for today's proceedings, I revisited the October 17, 2011, testimony for the Joint Legislative Panel on State Psychiatric Hospitals and Developmental Centers, where Nancy Thaler talked about capacity in the community and explained that when the residents of our developmental centers move to the community and die in the community, then the people on the waiting list will have a place.

Yet the waiting list has grown by leaps and bounds since New Jersey closed North Princeton Developmental Center, and it will continue to grow regardless of more closures because there is no law that provides for a timely receipt of waiver services for anyone on the waiting list. In fact,

according to the August 30, 2012, report on the audit of the Division of Developmental Disabilities Administrative Support Services, as of March 2012 there were approximately 8,100 individuals on the Division's waiting list, of which 4,900 were considered a priority. The average waiting time is about 12 years. I guess the game plan here is to speed that up via the quick demise of our loved ones in the community once they are yanked from their developmental center homes that they have known and thrived in for decades.

Indeed, according to Bernie White, who served as the Deputy Director of the New Jersey Division of Developmental Disabilities for 32 years, a high rate of mortality arose nationally when residents were transferred from the large developmental centers to the community. In California, death rates were 47 percent higher for residents transferred into the community than if they had remained in the larger centers. Ohio experienced similar results.

The Federal standard of care inherent in the developmental center, labeled ICF/MR, is critical to the survival of our family members. For this level of care, staff must meet certain training criteria, and the care process has to meet certain Federal standards. The standard of care is not required through the Community Care Waiver. As a matter of fact, when a resident leaves a developmental center, they waive their rights to this level of care. But again, this level of care is critical to the day-to-day survival of our family members.

You'll be hearing today from a family member who will tell you that family guardians and developmental center interdisciplinary team members are being strong-armed by the State to acquiesce to the

predetermined plans for closure and transfer of residents. These plans include moving residents of other developmental centers without family guardians to “create a slot” for residents of Woodbridge or North Jersey who have a family guardian. I have been informed that this scenario is being played out in the Woodbine Developmental Center. So as you can see by this example, the displacement effects of closure will affect all developmental center residents.

It has been pointed out by many independent observers that the Task Force process was a political process meant to arrive at a foregone conclusion. The Task Force report did not mention our need to care for our family members who cannot care for themselves. It did not take into account the needs of the residents.

But that is in keeping with the way in which DDD doles out placements. “She was transferred to three different agencies within a year because of behavior problems. The staff couldn’t handle her,” commented Mrs. Smith about her experience with community providers in a recent interview with the *Record*. In the same article, Carol Conkling explained how her son jumped out of a window in a group home and broke his ankle. And then there was Mrs. Adams, who explained that her daughter is severely intellectually disabled and physically limited and needs help to go up and down stairs, yet State officials showed Mrs. Adams a group home with three flights of stairs and no emergency exit upstairs.

What struck me even more deeply than these personal examples of blatant disregard and negligence by both the Department of Human Service, Division of Developmental Disabilities, and the Community Providers, is a story that I heard told by a representative of the

Arc during part of his testimony in Trenton before the Task Force last year. It was about a resident of an Arc group home who, upon developing Alzheimer's disease, was relocated to a nursing home where she soon died thereafter. Apparently this is a common-place occurrence, and there are many developmentally disabled persons dying in nursing homes.

As I said in the beginning of my testimony, I've been involved in advocating for developmental center residents for many, many years. That's because my brother Clifford has been a resident of the Hunterdon Developmental Center since the facility opened in 1969. Cliff was 6 years old then. Our mother, Edith Bartman, at 89, is still Clifford's guardian and she sees her son often and regularly. We as a family are afraid for Clifford's future. Now 50, Cliff runs a very high risk of developing Alzheimer's because persons with Down syndrome are predisposed to the disease. The team at the developmental center assess and monitor his condition, looking for any change in his status going forward. If Cliff should develop Alzheimer's at this time, the professional staff would not have to throw him out of his lifetime home to die in a strange and uncaring place.

I am representing the families of the residents in developmental centers across New Jersey. We have provided handouts which tell some of our families' stories. But these are just a few. There are many more family members throughout the state, and many here today, who all have similar stories.

Can all of the family members present in the room say "here," please? (audience responds)

Chairwoman Huttel, Chairman Vitale, we are all here to ask you to look for a solution within your powers to keep available all the

centers in the state and to take action against this decision to close Woodbridge and North Jersey Developmental Centers. Allow residents to continue to receive the care they need in their center, and keep these centers in their geographical locations so the family members can continue to visit and preserve their family life.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Cindy.

I understand the passion and the length of your testimony. And I think as we sit here and listen, none of us will disagree that we cannot limit you in time. But if you could try to be cognizant of the time, because we have many more members -- many more family members and officials who would like to speak. So if you could not duplicate-- Again, I say that with all my heart because I hate to just say you have two minutes or three minutes. So try to be within a couple of minutes. And if you could just highlight the main points. Because there certainly would be an opportunity for our members to ask questions as well. So we have a lot of testimony. It is 12:45. So I'm going to have Sam--

Do you want to wait to see if we have--

MS. ST. AMAND: No, I'll go ahead next.

ASSEMBLYWOMAN VAINIERI HUTTLE: And then I'm going to ask the elected officials, and then continue with the rest of the family members.

Joanne, thank you.

MS. ST. AMAND: Distinguished members of the Joint Committees, I thank you for the opportunity to speak here today on such an important, critical subject.

My name is Joanne St. Amand. I am a resident of Cranford and a proud graduate of Montclair State University. I am the sister of Rosemary Sciarrillo, a 57-year-old profoundly intellectually disabled resident of Woodbridge Developmental Center. I am also the President of Woodbridge Developmental Center Parents Association. I am here today not only on behalf of my sister, but all of the residents of Woodbridge Developmental Center.

I want to focus today on the standard of care provided at the developmental centers compared to those in the community group homes. I agree with Drs. Walsh and Kastner, two prominent experts in the field, that we must continue to provide Federal standards of care known as Intermediate Care Facilities for people with Mental Retardation -- which we are replacing with Intellectual Disabilities. And it's referred to as the ICF/MR level of services that exist in developmental centers. It's a Federal standard of care.

Let me tell you about my sister Rosemary. I did have a little video, but it looks like we're not going to be able to show that. Ro's disabilities are typical of the other women in her cottage. She is profoundly intellectually disabled. She is a 57-year-old but she looks about 20 years younger. She is physically smaller in stature, and her back is twisted from severe scoliosis. She cannot sit in a regular chair; she needs a specialized wheelchair. Her arms are short and her hands are half the size of mine. She has a cognitive age of a 3-month-old. She can't walk, she can't talk, she

cannot roll over by herself. She rarely makes eye contact for more than a couple of seconds. Rosemary has to be lifted and carried from her bed, to her wheelchair, to the bathing area. Wherever you place her she will stay until you move her again. Rosemary needs help with everything. She has to be bathed and dressed. She is incontinent. Rosemary cannot feed herself. She cannot chew and her food must be pureed. She suffers from dysphasia and all of her liquids need to be thickened so she doesn't choke, aspirate, or develop pneumonia. She dehydrates quickly and so her liquids also need to be monitored. She suffers from severe constipation. She has epilepsy, which is well controlled now at Woodbridge Developmental Center. Ro cannot tell you when she is not feeling well. She depends on the experienced staff to figure it out. Her trips to the ER are always traumatic for her, and I generally arrive when she does to be at her side and answer questions. Even simple blood work and urinalysis is an ordeal. Her veins are small, and to get her urine you need to use a catheter. Rosemary made two trips to the ER last month. I made sure I was there and I arrived when she did. I stayed at her side until she returned back to the center. There are 330 residents at Woodbridge, and Rosemary's condition is typical of those.

Why is it important to keep the developmental centers open? Let's go back to the care provided at the developmental centers compared to those provided in the community. All developmental centers follow the Federal standard of care, that's the ICF/MR Medicaid program. It's fundamentally different to the Home and Community-Based Services, also referred to as the Community Care Waiver.

The Federal ICF/MR model requires comprehensive interdisciplinary planning and treatment services according to Federal guidelines. The Federal law requires ICF/MR facilities to provide individualized active treatment plans, programs administered on site by licensed professionals. Clinical professionals and active treatment services are bundled. They must be available to all individuals in the developmental centers. The professionals are either on staff or hired as consultants. Comprehensive services provided at the developmental centers include medical, dental, psychological, neurology, dermatology. The list goes on, and I've provided you with a table.

Developmental centers residents have to waive their right to this Federal standard of care -- this ICF/MR program -- when they transition into the Community Care Waiver. The community placements do not provide anywhere near this level of programming. You just heard from a woman who has -- who is in the community who has witnessed that. The services are unbundled. Individuals funded by the Community Care Waiver must locate services in the community setting and access them through the Medicaid programs. Individuals can have appointments with doctors who rarely see them or anyone with their disabilities on any regular rate compared to what we have at the centers. Just last week we had an individual who went into respiratory distress and was easily recognized by the respiratory therapist on grounds. The doctor arrived immediately, inserted a breathing tube, stabilized him before the ambulance even arrived. We all have a good idea of what would have happened to him in the community.

In order to maintain receipt of Federal payments, facilities providing the ICF/MR standards of care are held to 378 specific standards reviewed annually. Home and community care based services has no body of Federal guidelines and is not required to follow them.

It is well documented that moving into the community can be a life-ending environment for our developmental citizens at the centers. In a very large study of over 22,000 individuals, co-authored by Dr. Kastner, it was found that a risk-adjusted mortality rate was 72 percent higher in the community than in the institution. As is well-documented in the field, we will be putting these lives in danger in moving residents out of Woodbridge Developmental Center. The Federal standard of care, the ICF/MR model, assures that the residents have immediate access to a wide range of desperately needed professional services and supports, and therefore developmental centers need to remain open. We need to maintain these locations at our current centers so residents remain geographically close to their families and so family members like me can be at my sister's side when any situation arises. We need to maintain the experienced staff and professional services which already exist at these sites.

It's time to be morally responsible to our intellectually disabled residents in the centers. It's time to stand up to the bullying by government employees, by misguided ideologists, by organizations who continually favor their clients who are much less impaired. We need to work together for what is right for everyone. We need to look at other models like the Community Resource Center, which already exists in several states. We have components of this model already at our centers. The lives

of our family members are in your hands. Please find a way to keep these centers open.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Sam Friedman.

**SAM FRIEDMAN:** Chairman Vitale, my name is Sam Friedman. I grew up in Westfield and graduated when you did.

Chairwoman Huttle, I now live in Englewood, and you're my representative.

Thank you, members of the Legislature, for hearing us out.

I first want to thank Linda Thomas, whom I've never met, for her work and for making our case to keep the developmental centers open.

I'm co-guardian of my younger sister Jackie. She had two strikes against her before she was born -- Down syndrome, and severe brain damage when her umbilical cord broke and cut off her oxygen. Her heart stopped, she was virtually stillborn. She survived only due to medical heroics. And her fate was essentially sealed. She will never utter a word or comprehensible sound, or play with a toy, or look anyone in the eye, or show facial recognition of anyone or thing, or train her eyes for more than a moment. Of course she can't care for herself or control her bodily functions. Taught to walk, and stiff of posture due to Harrington rods spinal fusion that arrested her scoliosis, she is only led like a docile pony, never setting out on her own. Taught to feed herself by rote, she doesn't see the pureed food she spoons out and jams in. Imagine a 2-month-old, but one with half a century's experience who pokes herself and pinches you real hard. That's Jackie.

But Jackie most certainly has a life at North Jersey Developmental Center, where she has lived for 47 of her 48 years. That life depends upon very good 24/7 custodial care, which she needs; nursing care, which she needs; structured recreation, which she needs; occasional therapeutic intervention, which she needs and will need more of as she ages; and, just as importantly, human love, which she needs. This Jackie gets from staff who have known her for decades; from a rookie who's fallen for her and visits with her own time; from her foster-grandmother Eleanor, who now finds it hard to make the trip from nearby Paterson; and from me, her brother. Once or twice a month I help feed her. Since she has the family sweet tooth, I try to get her some soft chocolate, or take her out to keep her walking, or put her on her beloved gondola swing from her childhood, knowing I will have to pry her off of it. When in the mood, she will draw my arms around her to hug her and sink into me to have me cuddle her.

But I commute to Queens, I work long hours, have a family, and can't burn the candle like I used to, so I see Jackie when I can. When she is in the hospital, I stretch myself so as to get there to be her advocate, just as you do or would do for yours. Only Jackie needs this more so. She can't say, "It hurts." And it's sad to say some clinicians can't read the signs.

I'm here now to beg you to use whatever clout you have to stop the State from delivering strike three to Jackie and many hundreds like her. Eviction from North Jersey will tear her from all that sustains her. All the inputs and oversight that, together, comprise the Federally-prescribed level of care given at developmental centers, the surrogate family who loves and cares for her, and my loving presence in her life. Together, these elements

have kept her alive and relatively well long beyond what otherwise could reasonably be expected.

For Jackie, transfer to New Lisbon Developmental Center -- the nearest center with room at the inn -- located in the Pine Barrens, on a line between Camden and Toms River, is the gulag. I simply won't be able to get there, even in a crisis, and I'm younger and fitter than most of our distraught family members.

Geography, Chairwoman Huttle and Chairman Vitale, is determinative, and the State knows it. Jackie -- more cognitively limited than some, not yet as medically complex as others -- is typical of North Jersey and Woodbridge residents, severely impaired in body and brain, constitutionally frail, vulnerable in the extreme, and helpless beyond imagining in the face of bureaucratic forces.

When the State Division of Developmental Disabilities Assistant Director -- as recently quoted in the *Bergen Record* -- says that Jackie and her fellow developmental center residents do not have unique needs, that "Thousands just like her are being well cared for in the community," and that it is really just a matter of educating us families so that we see things right -- I promise you, Senator and Assemblywoman, that she is ignorant, perhaps willfully so.

In the past few months, as a representative of the Coalition fighting this -- this, the mother of all eviction notices -- I have indeed been educated. I've learned this: First, those who reside at the centers comprise the most severely impaired iceberg-tip of New Jersey's disabled population. Their conditions are, on average, more complex and extreme and,

consequently, their needs are more wide-ranging and intensive than other disabled persons.

Second: The closures are intended to shift funding away from the most severely disabled, and instead toward the needs of other disabled folks whom the State has thus far failed. Other gubernatorial priorities may also stand to gain funding. How else do you explain that only two centers in the northern third of the state have been ordered closed, while those in the central third of the State are, for all intents and purposes, full, other than by a political deal among the Governor and South Jersey legislators? (applause)

Third: This pushing of our loved ones en masse into yet-to-be-created group homes owes to a political wind that is undeniable. But it has nothing to do with the needs. And the Olmstead Decision explicitly sides against forcing out those who don't want out. Moving out offers less than nothing to Jackie and her peers. The Center's literal silent majority cannot benefit in the slightest from any advantages that community placement might afford others. But Jackie, and those like her, do stand to lose much, namely the Federally mandated level of care and resources that applies to developmental center residents. That standard is much more robust than the so-called Community Care Waiver level of care and resources that applies to group home residents. Indeed, what they waive are further needed services. That's why an overwhelming majority of North Jersey family member guardians -- 184 out of 195, or 94 percent -- chose continued developmental center placement over community placement. (applause) That was in a survey conducted less than four years ago when they weren't coerced. Here is the proof. (applause)

Lesson number four: There is no nice way to say this: The fix is on. Pressure on guardians to choose group homes has been pervasive. From the get-go we were called to meetings where high-level State reps we normally can't talk to made personal appearances. Their mission: getting it through our heads that choosing group homes brings with it the perquisite of geographic choice, and lots of it. But should we opt for developmental center placement, well, then, first, there would be no room at the inn anywhere mid-state for any but a lucky few. Second, it wouldn't matter much anyway, because no matter that we are the guardians, we'd have zero choice with respect to where our loved ones would go. Only frequent visitors, they told us -- those few who because of a combination of geography, private wealth, and non-working status could afford to visit their loved ones constantly -- only they would get a shot at placement in Central Jersey centers. As for working people like me? Forget about it. Your loved one will be bussed south. And did you want to maybe reconsider whether group homes might be a good-enough fit? So-called *survey forms* -- which we were directed to fill out pronto -- incorporated this Hobson's choice into their wording and graphics. A kindly group-home pitchman, courtesy of a State contract, closed the show. He brought with him his wares -- Exhibits A and B, if you will -- slick publications depicting 13 South Jersey community placements and another 9 outside of Baltimore, each and every one of them a rousing success and zero failures. Absent was any substantive information or discussion on the relative value of the Federal level of care versus the lesser Community Care Waiver level.

Lesson five was the most bitter. The State is overtly pressuring the treating professionals to enforce the fix. Higher-ups are directing the

social workers, therapists, and other caregivers -- who assess fitness for community placement and write that into our loved ones' annual Individual Habilitation Plans -- to push community placement over developmental placement. How? In the very wording of their assessments. "It's almost like we're being bullied," reported one assessor; "Blankety-blank did call me about those kinds of wordings," another staffer told me, referring to phrases in the plans that tend to favor developmental center placement that were ordered to be stricken or rewritten. This State pressure on the staff who treat, who are State employees, is not just ill-advised or a lousy business, it is unarguably immoral. It is, on its face, the suborning of unprofessional conduct, and it is perhaps even illegal. It serves to obstruct appropriate assessment of disabled people's needs. It's not enough that State higher-ups have stacked the deck; they're hell-bent on removing from it the few trump cards -- no matter how honestly come by -- that might contribute to a winning hand for some disabled residents. The State can't even abide truth telling by its own as to which residents need the Federal level of care and resources. It's almost Soviet.

Senator and Assemblywoman, because care and treatment of the disabled is not my strong suit outside of what I know about Jackie, I've fallen back on my health and journalism background and borrowed from the reporter's rulebook. I've sought input from top developmental disability professionals elsewhere who don't have a dog in this fight, so to speak. Their frank opinions haunt me. One program director who has overseen both residential facilities and group homes, and even presided over a residential facility closure in another state, said this to me-- She said, "I would be very concerned for the low-functioning residents who have been

cared for in the centers for many decades, who will be losing the people and the world they know. Even were their physical well-being to be well attended to in their new settings, I expect that a good number will die soon.”

Chairman Vitale and Chairwoman Huttle, I implore you. We are the 94 percent. Commit to undoing this palpable wrong and inveigh upon your colleagues to join you. If you do not, the State will variously disperse and ship south our loved ones. If you do not, any follow-up study linking these forced evictions to fatal outcomes will come too late for our loved ones. If you do not, the label *anecdotal* will attach to the calls that I or others make to you to report the declines and demises of our loved ones; but we will know; and, hence, you will know.

Spare us and yourselves from the fate of knowing that we did not stop New Jersey’s most vulnerable citizens from being done in by cynical political expedience. In return, we can promise to give you only, for the rest of our lives, our votes and our inscribing your good deeds in the hearts and minds of our families, friends, and communities, including the next generation. A further promise we can give is not ours to give: You will sleep better at night. (applause)

One more sentence, I promise. Jackie’s life, and her fellow residents’ lives, are literally in your hands. Their desperate times call to you, through us, for your desperate measures. Thank you for hearing us out today. (applause)

SENATOR VITALE: Our next panel will be--

I welcome Assemblyman Craig Coughlin, from Woodbridge. Assemblyman, thank you for coming. Come on up.

Mayor Jeffery Jones, from Paterson; and Ginny O'Brien and family.

Ginny, do you want to bring your husband with you?  
(affirmative response)

**A S S E M B L Y M A N C R A I G J. C O U G H L I N:** Good afternoon, everyone.

Senator Vitale, Assemblywoman Vainieri Huttle, I'd like to thank you and the members of the Committee for giving the families of those who are most affected by this report the opportunity to express their concerns, and their thoughts -- and their outrage, frankly -- about this decision. Clearly they can, in a way more personal and more meaningfully, express the reasons for -- the reason this ought to be reconsidered, and can express their heartfelt thoughts about their loved ones better than I ever could.

Suffice it to say, I was present at the Woodbridge Council meeting when many members of the -- the family members of the patients at the Woodbridge Developmental Center appeared. And I was touched by their commitment to their loved ones, to their regard for the facility, and for the people who serve as the employees there but who have really taken on the role of a family members and dedicated to the folks. And I think we can't forget that what we're really talking about is people's homes. These are not just facilities; these are places where, as we have heard, people have lived for decades. This is where they live.

But what I would really like to touch on is what the report is itself. And I've had the chance to review it. Candidly, it is, at best, incomplete. The report cites many of the meetings that they had. I've

reviewed the minutes. They asked for documents. But with regard to the final decision making, it's wholly devoid of specific findings and facts. It ignores regional considerations. The most populous part of the state is now left without any developmental facilities. It completely ignores Factor E, which is the repair and maintenance cost of the project. There is absolutely no documentation with regard to that -- whether the committee ever considered it or not. And it's hard to believe in some instances, based on what we've heard today, that there wasn't overwhelming opposition to community placements in many issues.

If my sons had given this to me as a homework assignment to take a look at before they submitted it, I would have told them, "Get back to work," because they didn't do their job. And if I was their teacher, I would have given them an *F*.

I would urge the Committee to send this back with a report that says, "You have to do a better job." We may have voted for it, but we didn't vote for them to get it wrong, and we didn't vote for them to ignore 20 percent of what we asked them to look at.

Thank you very much. (applause)

SENATOR VITALE: Thank you, Assemblyman Coughlin.

Mayor.

**MAYOR JEFFERY JONES:** Thank you for giving me the opportunity to say a few words from the City of Paterson. And I say the City of Paterson specifically, because we have the responsibility to deal with less. And when you deal with less, you find it very complicated to provide even the basic degree of support and services.

So as a City wrestling with our challenges every day, I can only imagine what is going to happen from the standpoint of families who've gotten accustomed to having support, and dedicated services, and knowing that their loved ones will be taken care of. I can only imagine what their frustration level is going to be. It must be equal to mine, or will be greater.

Greater how? Well, we're 150,000 folks. We speak 52 different languages or more, so we don't have a good way of communicating. So if in the facility you've had, through history and record, the opportunity to talk with a caregiver, and you've established some degree of relationship, that may be severed.

We're also the county seat. We expect to get a lot and get nothing. So that expectation or that fear, that challenge of driving miles and miles away only to find that maybe your loved one is not well-supported can be rather daunting. That could be to the point where you go home and you bring more chaos to your home.

We are one of the poorest cities in the state. We're not quite sure why. Everyone keeps telling us that we have the best and the brightest, but we still can't figure out why we're the poorest. Yet we host the lion's share of nonprofit, faith-based, and other community- and health-based agencies, none of which are the folks who are residents of the city.

So my concerns are -- and I understand that time is of the essence. My concerns are an ill-conceived plan delivers an ill-prepared outcome. Whether or not those who sat and discussed it -- whatever information and research was used, it was used. But when we start talking about the end gain, whose lives are lost, what families go into complete

disarray because the critical factors were not considered, it would be too late to undo the damage.

I'll say to you that we, the City, have experience -- and you may be familiar with it as legislators -- RCA Mount Laurel. I use those headings because at one point in time it was a boundary. This boundary allowed certain communities not to develop low-income housing in their neighborhoods. They were able to say, without question, "We don't want them." I can tell you that at some point in time, when communities and individuals start to take a look at what they perceive to be the challenge they're going to face, those boundaries are going to find themselves growing and building. It's the nature of what things are.

So our unstable Paterson will probably be one of the places by which conversations will be had. It's inevitable. I can tell you I get calls all the time about drug treatment centers and things like that -- things I can't even fight back. I can't fight them back because they have friends in high places. So my parallels to a City struggle, as simple as I've tried to make it, are no different to what the families are going to face or are facing as they look down this road. There are very high walls. They seem to be designed, obviously -- at least in the discussion -- to make things better. But, in fact, I think we're going to be contributing to making them worse.

I heard the gentleman who sat here a few moments ago talk about his particular circumstance. And I can tell you, not long ago I attended a few funerals of residents in the city. And I will close on this. They were healthy, well. They lived pretty decent lives, I would say -- 80s and 90s, whatever the case may be. They went into the hospitals which were designed to provide them with the best of care and make them well.

Within days or weeks, each one was transferred to a hospice center and families were told to come.

We are, in fact-- If we don't think about this and make sure this is a well-conceived plan, make sure that, if it's not too late, say, "Let's take a good assessment of this," we will be committing the same sort of challenges that many of the hospitals face. And I'm not knocking hospitals. Life is life. But everyone who sent their loved one had a different expectation. The expectation was they would see them one more time the last time they saw them in the best of health. And instead, what they got was pain and suffering.

I ask you, if it's not too late, reconsider it or give some more time. There's nothing like making sure you made the best decision with all the credible facts.

I thank you for giving me a moment to speak. And I hope that you will be guided by the best of options.

Thank you. (applause)

SENATOR VITALE: Mayor, thank you for your comments.

Are there any comments from the members at all? (no response)

The decision to close the developmental centers in North Jersey and Woodbridge is not the decision of this Committee or its members.

MAYOR JONES: Understood.

SENATOR VITALE: I know you know that.

And the Administration has made this decision based on a number of factors; factors that we don't, in most cases, support. And in the end -- and I think you, and the Assemblyman, and others have made this

point in a very smart manner -- is that we don't have the confidence that what the State is proposing to do can be accomplished at a level that supports the equity and the needs of the patients who are the residents of these facilities. Community placement is incomplete and insufficient for those who are the highest functioning. And I use *highest functioning* as a relative term, because those who live in a developmental center -- *high functioning* is a relative term. But for those who have profound disabilities, living in the community is not an option, and moving them somewhere else down south, away from their families or support groups, is going to have a detrimental affect on their emotional state, their psychological state, and their physical well-being, I believe. And it would take an act of the entire Legislature, both sides of the aisle, to make the case to the Governor and to the Commissioner, that this has to be rethought.

The Department of Justice, in the Olmstead Decision, found that Americans with disabilities -- require states to integrate individuals with mental disabilities into the community and out of residential centers whenever: one, state treatment professionals have determined that community placement is appropriate; two, the transfer from an institutional setting, to be less restrictive, is not opposed by the individual; and three, community placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. I think at this point we fail all three criteria.

MAYOR JONES: I would concur.

SENATOR VITALE: And so it is that we have to-- And so I think that in terms of the rush to judgement, the rush to move this forward is wrong. I don't believe for a moment that the Commissioner and the folks

who work there don't care for a moment about these individuals. They certainly do, and they're all good people. But they take their orders from above. But they're also very professional and they do care.

That being said, it's the responsibility of every member of both Committees -- the Senate side, Health and Human Services; and the Assembly Human Services Committee -- both Democrats and Republicans -- to take a look at this through a lens that is not political, that contemplates the well-being of all these residents.

I visited Woodbridge; it's in my hometown. I grew up there just a couple of miles from that facility. And as the Assemblyman said and others have said, this is their home. They're residents of Woodbridge. They're my friends; they're my neighbors. They're not just sort of these individuals locked away in an institution that we drive by every day. I view that differently than East Jersey State Prison, which is considered to be (laughter) my neighbors and my friends. But it is that they are residents of Woodbridge; they have been for decades. And I believe they should remain there. And if there is going to be community placement it should be in this area, for some of them who can make it in the community and make it in a manner that they can thrive, not just exist.

So that's the challenge at the very core of this, I believe. At this point it may not be a completely ill-conceived plan, but the resources and the planning to get this done is far from complete and far from the right thing to do.

MAYOR JONES: Senator, if I may just say this -- and I apologize -- my words were not to say that this Committee has that authority. I do recognize the process.

But as you've said, for far too long we've been divided by aisles, we've been divided by philosophies, we've been divided by ideologies, and now we've been divided by geography. The vast truth -- the majority of my concerns is this: Communities are not ready. We don't know what this now looks like. This is a new version of life for us. But we failed miserably before this new juncture in terms of doing the basics by which communities and neighborhoods needed to be sound and straight. So that's really my position.

Before we add another straw to the proverbial camel's back, let's be clear. And I understand. So my words to you are to encourage, to support, to bring on those who can -- and make this a public conversation. Social services, health-related based services is something we need to, as a community, as a nation, be much more mindful of and cognitive of, and take a look at a matrix. But the matrix can't just be about the individual, about the institution. It has to also include the footprint of the community that will also have to bear some of that responsibility. That was my--

SENATOR VITALE: Well put. Thank you.

MAYOR JONES: Thank you.

SENATOR VITALE: Thank you.

Ginny -- Mr. And Mrs. O'Brien, thank you.

**VIRGINIA O'BRIEN:** My name is Virginia O'Brien, and I'm here to speak for my daughter Catherine.

I want to thank everybody for giving me this chance.

My daughter Catherine will be 52 years old in March, and she is classified as profoundly retarded at a 7-month age level. She is not one of the higher functioning individuals you see in the Special Olympics or in the

community home promotional literature they keep sending us. She must have all her needs taken care of 24/7 by the caring professional staff at Woodbridge. She has been at Woodbridge for over 47 years. She was just an infant when we put her there. And that is her home, and I hope it remains the same. She must have all her needs taken care of by the caring professional staff at Woodbridge. She gets bathed; diapers changed; dressed; hand fed a special pureed diet developed by the nutritionist; carefully moved in and out of her wheelchair; and monitored by the nurses, physicians, therapists, and personal care attendants constantly -- a level of service and oversight only available at an ICF/MR facility.

The Olmstead Decision clearly states that it does not mandate the closing of developmental centers and is only intended to allow those higher-functioning individuals who wish to move into the community to do so. The results of a written survey taken by the parents associations show that 96 percent of the parents and guardians responding do not want their loved ones moved out of the developmental centers. Why is the State forcing these closings on the most vulnerable citizens of the state who cannot speak for themselves? They are not just numbers and dollar signs on paper, but they are human beings who will suffer and perhaps die because of the State's political agenda. The State is affecting not only those individuals, but also the parents, guardians, and relatives who may never be able to visit their loved ones again because of their inability to travel two or three more hours each way if they are moved to South Jersey. Decisions should be made on the basis of what is best for the health and quality of life for those individuals and not on what seems to be cheaper.

And what about the thousands of people on the waiting list for placement? What will happen to them if all the developmental centers are eventually closed and their caretakers can no longer care for them, and the community homes are either not available or not capable of providing the necessary quality of care?

I know I am not able to sleep at night because of my concern for my daughter's future. But I do not know how the politicians who are perpetrating this travesty can sleep at night because of their lack of compassion for their fellow human beings, no matter how physically or intellectually disabled they are.

If the Governor could push this law through to close these centers, then he can also have the power to reverse this decision and keep these centers open if he has the compassion and the will to do so, especially if he has your urging and support.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Mr. and Mrs. O'Brien, Assemblyman Coughlin.

Three more family members-- I'd like to call up Dr. Sal Pizzuro, Dee Sussina, and Harriet Fass.

Dr. Pizzuro, since you're here, do you want to start with--

**SALVATORE PIZZURO, Ed.D.:** I'm sorry?

ASSEMBLYWOMAN VAINIERI HUTTLE: You can start.

DR. PIZZURO: Thank you.

SENATOR VITALE: If I could just reiterate that we are trying to move this along. There are nearly 80 individuals who have signed up to

testify today, and so we have to get through everyone's testimony in a manner that is brief and summarized.

Doctor, if you could not just, plainly, read your testimony we would appreciate it.

DR. PIZZURO: I'll briefly paraphrase my remarks.

I know most of you.

I'm Sal Pizzuro.

Chairman Vitale and Chairwoman Huttie, thank you for giving me the opportunity to speak.

I come to you with some interesting remarks regarding someone who contacted me last spring. That individual served as the Deputy Director of the Department of Human Services for 30 years. His name is Bernie White. And he first called me last spring when we were discussing the issue of closing the Vineland Developmental Center. And he contacted me-- He's now 86 years old, and he's residing in Florida in retirement. And he came to-- He called me to talk about the mortality rates that occur when people are deinstitutionalized. And he mentioned to me that he looked at this issue 30 years ago when he was a State official. And he found that the mortality rates of individuals who exit the developmental centers start to rise based on certain criteria.

One is, if they are relocated to either another developmental center, or a group home, or a community setting that is further away from where their families reside. They said it's a marked increase. And he said at the time he investigated -- and he looked at the mortality rates in California and Ohio at the time -- California was experiencing the same phenomenon.

Now, Bernie happened to call me again Monday night. He keeps in touch with what's going on in New Jersey. And he wanted to talk to me about this very same issue. He said that when he mentioned and documented the mortality rates 30 years ago, it was kind of similar to what I think the way our Administration would respond today. They probably wouldn't react to it other than the fact that there is a real move to close at least one or more centers in New Jersey -- right now, Woodbridge and Totowa.

He also mentioned something else. He mentioned mortality rates rise markedly if there are nonambulatory individuals who are deinstitutionalized, either to another setting with other clients of the same functioning level or to a setting in the community that's less restrictive. And he pointed out to me that Woodbridge has an inordinately high number of nonambulatory cases compared to the other developmental centers.

Bernie was really concerned about this. I discussed it with some of my colleagues who already spoke this morning. I can't help but react to it as well. I think there is a phenomenon here that's being overlooked. My experience-- And with all due respect to the members of this panel, my experience with the current Administration is that if I mention -- and I have already mentioned -- the mortality rate issue, it's going to fall on deaf ears. But we're talking about life and death issues. And I think this is something we cannot take lightly. And to me, if I have to compare the importance of dollars and cents, and life and death, I'm going to support someone's life every time.

So very quickly -- very quick paraphrasing -- please consider these issues when you discuss this.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Sal.

**HARRIET FASS:** My name is Harriet Fass. I live in Bridgewater, and my legislators in the 23rd district are Assemblymen John DiMaio and Erik Peterson, and Senator Michael Doherty.

Thank you for holding this hearing today.

My sister, Arleen Brause, is 61 years of age and has been a resident of Woodbridge Developmental Center since 1965. Woodbridge is her home. She is very comfortable there and gets excellent care from the competent staff. She is happy and feels secure and comfortable at Woodbridge. She enjoys interacting with her fellow cottage mates and the dedicated staff. They are her extended family. She also enjoys participating in the on-site and off-site recreational activities.

She was placed in a community group home in 1982, which proved to be a very bad experience. Because she was so routine-oriented -- she was uprooted from her routine and the comfort of her home at Woodbridge -- her behavior deteriorated; she regressed and became depressed. She suffered a severe set back and mental breakdown at the group home.

The living conditions were horrendous. The only activity was watching TV with the cigarette-smoking, unsupervised staff. We don't want her to experience that ever again. She returned to Woodbridge thanks to the help of Senator Donald DiFrancesco, New Jersey Senate District 22,

from 1979 through 2001, and his commitment to the civil rights and well-being of the developmentally disabled.

Because of the keen observation of the developmental center staff, Arleen was diagnosed with a swallowing disorder and she needs close supervision while eating her mechanical soft diet. When Hurricane Sandy hit, the clients were always a priority. The facilities were powered by generators. Direct care and medical staff were on-site and remained for a double shift when the next shift was unable to travel to Woodbridge. Some of the many advantages of a developmental center is there is ample staff to fill in the gaps and medical assistance is always available. There were no interruptions to upset the clients' routine. This would not be the case in an individual group home. As a matter of fact, this Committee has heard testimony in December that many people who ended up in shelters near the shore after Sandy were from group homes and few trained staff were available to help them.

My sister does not adapt well to change. Routine and regimentation are very important to her. She is emotionally unstable; has fears and phobias; and is easily agitated, frequently screaming and crying. When her routine is altered she can be extremely disruptive. Any change in her living conditions would be detrimental to her well-being and we believe that her civil rights would be violated. Closing developmental centers should not be the decision of those who have no personal interest. We, the family members, are the ones who know what is best for our loved ones. (applause)

We feel that Woodbridge Developmental Center is the best place for my sister. Community living is not the answer for most clients

currently living in developmental centers. Their mental and physical well-being should always come before saving dollars. The clients of Woodbridge Developmental Center cannot lose their home. The developmental centers must stay opened. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

D E N I S E S U S S I N A: Hi, my name is Denise Sussina. I live in Clifton, in the 34th Legislative District, home to Assembly Speaker Oliver, Assemblyman Giblin, and Senator Nia Gill.

Thank you for the opportunity to speak to all of you today.

I am the mother of two wonderful daughters. My oldest daughter, Kristy, is a 34-year-old successful licensed clinical social worker. A social worker who, for the past 10 years, has worked with emotionally disturbed children and adults in a variety of settings. With all her clinical expertise, she is keenly aware of the dangers her younger sister is about to face. That is my younger daughter, Lori Ann, who, for the past 15 years, has been a successful paper shredder, envelope stuffer, and gardener. I am equally proud of both of them.

Lori cannot speak for herself. She cannot lobby for the health care she desperately needs and deserves. She would never be able to attend a forum such as this. But while we are here telling her story, she is in the safe care of her other family, the healthcare providers at NJDC, where she has resided for the past 15 years.

Lori just celebrated her 30th birthday with her friends at NJDC. For me that is 30 birthdays trying to understand and come to terms with the diagnosis of pervasive developmental disorder, an atypical form of autism which has robbed Lori of the life a mother dreams for her daughter.

Thirty birthdays with multiple psychiatric diagnosis including intermittent explosive disorder, mood and bipolar disorders, ADHD. Birthdays celebrated on multiple psychotropic medications such as Zonogran, Haldol. The doctors say they're to decrease aggression, decrease overall agitation which has many-times lead Lori to hurt herself and others, including property destruction.

Before being placed in NJDC, Lori's first 15 years were spent home going to a variety of special ed schools, multiple doctors and psychiatric programs. I became a single parent trying to cope with the needs of both my daughters, knowing that Lori's disorder was worsening, requiring all my attention.

After multiple ER visits and commitments to children's psychiatric facilities, Lori lost her battle with independence and became a permanent resident of the State and placed at NJDC. Our lives were a series of explosive and violent episodes often brought about by a change in routine and environment for Lori. Watching her pain and remorse after each crisis is what finally lead me to realize that no single person -- not even me, her mother, who loves her unconditionally and with every fiber of my being -- could singly care for Lori. Lori requires a much higher level of care, a structure which can only be achieved in a setting where there is constant care from multiple disciplined caregivers. She is not a candidate for a group home with limited staff, and should not have to move 100 miles away from the only life she knows. If there was any way for Lori to reside anywhere other than the utmost closely supervised psychiatric setting she would live home with me. For many years Lori has required an aide just for her needs, and they have been unbelievable at NJDC. With the State no longer

wanting to provide that additional care even -- though her moods and affects are liable -- it seems the State is still preparing to move her and others like her to a lower level of care.

I am very thankful for the many devoted staff at NJDC. I too have been devoted to NJDC and to my daughter. I am a registered nurse who works full-time in an intensive care unit for 32 years and part-time as a dialysis nurse. I work alternating 12-hour shifts, yet I always find time to visit with Lori every day for the past 15 years. NJDC is close enough for me, where I can bring her dinner and help her with her p.m. care -- tub time -- before going to a long night of work taking care of people -- other people's daughters and families.

When I was told the only recourse -- the best for everyone -- was for Lori to live in a State institution -- a developmental center -- it was the hardest thing I had to do -- to let her go. But hindsight is 20/20, and after 15 years with care at NJDC, I know in my heart I made the right decision. Lori is happy in her home with her friends, and I have peace of mind knowing she is safe and only a phone call away from where I live and work. What will I do -- what will happen to her if we are so far apart? The plan to move the residents could only further compromise their mental health. The chatter about the closing has already started anxiety and aggression among the residents, all associated with the fear of abandonment for the other residents too.

I feel this decision is brutally unfair. You are asking me to choose between the care of my daughter's needs, and being able to see her regularly and to be a stable part of her life. Please keep NJDC open and

don't allow it to close. Help Lori and I to live the rest of our lives safely, in close proximity of each other.

Thank you for holding this meeting today. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Dee, Harriet, and Sal. We appreciate your comments.

We'll be able to-- If any of our colleagues would like to speak-- We still have a number of testimonies to listen to.

Thank you.

We'll be calling up community providers at this point, then union speakers, and then we will hear from members of the public.

Tom Baffuto and Sharon Levine, from Arc; Daniel Keating, Alliance for the Betterment of Citizens with Disabilities, Executive Director; and Donna Bouclier, Senior Policy Analyst; and Debbie Good, past president of the NJACP.

**T H O M A S B A F F U T O:** Thank you, Chairman Vitale, Chairwoman Huttle.

I appreciate the opportunity to testify today. I think I've testified at every hearing you've had on this issue. You certainly know where The Arc of New Jersey stands.

I'm Tom Baffuto, the Executive Director of The Arc of New Jersey.

We do support the results from the Task Force. We simply feel we just don't need seven developmental centers anymore in New Jersey. It is our understanding of the regulations that the Task Force's recommendations are binding, so the testimony I put together today is

really addressing some of the capacity issues in the community as we move forward.

It should be noted-- And one of the core principles of The Arc of New Jersey is empowering people with developmental disabilities and their families to make choice. To that end, we understand many people will choose to keep their son or daughter in a developmental center, and we certainly support that choices. We also recognize those selecting that option will really be faced with a great burden and increased distance to visit their loved one. Ultimately, it is our hope that suitable community homes can be found and identified for these folks to ease that burden.

But as we look at the residents in North Jersey Developmental Center and Woodbridge Developmental Center, we want to start out by saying it's critical that each and every one of those folks, regardless of where they're moving to, has an individualized and in-depth plan to make that move as successful as possible.

When we were looking at the housing needs in the community, we sort of looked at what other states did. Eleven states now have no developmental centers, another 11 states have one developmental center. And they pretty much all use the same types of options: very small, four-person or less, community homes -- homes that are really involved in the community. And right now, over the last few years, we've been using those options. We've been successfully moving people from the developmental centers into the community.

As a matter of fact, in this fiscal year alone, we have 200 beds that have been developed for folks moving out of developmental centers off the waiting list, and we have another 100 -- at least 100 additional homes

(*sic*) that will be coming online. So it's clear we have the ability to develop the homes, develop the beds, and meet the needs as we're looking to close our developmental centers.

So we really applaud this rapid development, this ability for the community to mobilize and deliver on those beds. And it should be noted that our present system is working very efficiently, and we have less than a 2 percent vacancy rate. So the homes and the beds that are being developed that are out there are being used efficiently.

In addition to that-- You know, you have my testimony. I don't really want to--

UNIDENTIFIED SPEAKER FROM AUDIENCE:  
(indiscernible) (speaking away from microphone)

SENATOR VITALE: I'm sorry, you'll have an opportunity to speak later. We're not going to interact with those who are going to testify.

Thank you.

You can hold your question until later.

UNIDENTIFIED SPEAKER FROM AUDIENCE: But I might not remember it 20 minutes from now. (laughter)

SENATOR VITALE: Well, you can write it down. Someone will give you a pen.

Thank you, Tom.

UNIDENTIFIED SPEAKER FROM AUDIENCE: It's a medical question for him.

SENATOR VITALE: Go right ahead.

MR. BAFFUTO: I don't want to take too much time. You have our testimony here. So what we're really concerned about is the-- We

know that a lot of the folks in the North Jersey Developmental Center, Woodbridge Developmental Center are going to have behavioral support needs, medical needs. And we really have to take a good, strong look at what's available in the community. We're very, very excited. And as we thought, a number of very creative and exciting programs are being developed now to work with folks with very, very significant support needs.

That being said, the Legislature, the Department of Human Services-- We have to take a good assessment of what we're going to need and use the next five years to build that infrastructure in the community as we meet the needs of the folks moving forward.

In addition to that, everybody moving out of a developmental center should be followed with a very comprehensive and very complete medical history that includes a variety of documents so that we can make the smooth transition. Nothing can be left out of that. It has to be a complete package.

So we really don't know what the final date is going to be of when the developmental centers will be closing. But we need to use this time efficiently. We are successfully supporting people in the community from developmental centers -- have been doing it the last couple of years. So we know we have the ability to do it. We just have to use this time properly as we're planning and moving forward.

You have the rest of my testimony. Thank you very much for being able to join you here today. (audience reacts)

SENATOR VITALE: Please, everyone, it's a very emotional issue. I understand that; we all understand that. Please be respectful of one another and let everyone have their say and testimony.

Is there any member who would like to make a comment or ask a question? (no response)

I would, though, if you don't mind, Tom.

You mentioned-- So in your estimation, how many, over time -- you mentioned -- you said five years.

MR. BAFFUTO: I don't think I said that. I thought that was the recommendation of the Task Force.

SENATOR VITALE: But you testified that it was a five-year recommendation by the Task Force.

MR. BAFFUTO: Yes.

SENATOR VITALE: So tell me, in terms of raw numbers, how many residents are we talking about?

MR. BAFFUTO: Well, it's my understanding that, right now, we have 340 residents at North Jersey Developmental Center and 321 at Woodbridge Developmental Center.

SENATOR VITALE: And the recommendation is, over five years, those two institutions close, right?

MR. BAFFUTO: Yes.

SENATOR VITALE: And transition those 661 residents to some form of care somewhere.

MR. BAFFUTO: Right.

SENATOR VITALE: So tell me, out of the 661, how many are really nonambulatory, who need to be relocated to a developmental center. Do you know?

MR. BAFFUTO: Unfortunately, I don't have that data with me, but I know it's available. (audience reacts)

SENATOR VITALE: Everybody, look, really. I have questions to ask, and I need answers to those questions. You have a right to your opinion and to be heard, but not in that manner. I would just appreciate you not speaking up like that.

Thank you.

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

SENATOR VITALE: Sir, you will have an opportunity to testify later.

Tom, continue please.

MR. BAFFUTO: That information is available; I just don't have it with me today. The Department of Human Services clearly has that information. They did a thorough review of everybody in the developmental centers, so we should clearly be able to get those needs.

SENATOR VITALE: So just in terms of those who will be -- who, if it at all happens, are then relocated to another developmental center-- In your experience -- and, Tom, you've been doing this a long time -- these are people who are very delicate in 100 different ways. And if the State is expecting these individuals to now relocate and to restart their lives as they are with new caregivers, in a new environment, in a new place miles and miles away from their homes and their families, that just doesn't make sense. It doesn't make sense from a medical perspective, it doesn't make sense from a moral perspective. I mean, how is it that-- And I'm sure we'll hear from experts who say it can be done and whatever. But to me, in my experience, how can that happen where it is that the patient isn't disrupted? These are vulnerable individuals who can't be disrupted. Every minute of

every day is a challenge. And we're going to uproot them and move them 120 miles away to new caregivers, a new environment, a new dynamic, a new everything for them. How does that not affect them in a manner that is not helpful?

MR. BAFFUTO: Well, I think it is. Anyone moving, at any time -- for any of us it's very, very traumatic, which is why it needs to be done in a very, very planned way with very comprehensive plans looking at all their needs. I mean, I'm not certain how the decisions were made to close what developmental centers. Certainly no one asked my opinion. But those were the two that were recommended by the Task Force. Clearly it's going to be a problem with the distance there.

ASSEMBLYWOMAN VAINIERI HUTTLE: If I may, I think the problem lies-- I have the 70-page report, and I've read it several times. Unfortunately it really contains very few statistics. And no records, really, that the members requested were ever really in this report. And, of course, we have a binding recommendation; we also have nonbinding recommendations. And the last nonbinding recommendation says -- the ninth one says, "Honor the rights of residents to continue to live in a developmental center if they so choose."

Now we're asking, in all fairness, questions we don't have the answers to. Families that we just heard from -- they don't have any answers. And I think that's what we're trying to do today. And, unfortunately, the Department of Human Services is not here to give us any answers, to give us any plan. And I think before any closure there needs to be a plan in place. And, quite frankly, in the 70-page report of the Task Force, I don't see the plan. And so we're trying to get answers. And,

unfortunately, again, we don't have them directly coming today. But you can rest assured that we will get answers for a plan before these closures take place. (applause)

SENATOR VITALE: Senator Thompson.

SENATOR THOMPSON: Mr. Chairman, maybe I misunderstood Mr. Baffuto's testimony. But I didn't understand--

SENATOR VITALE: Sam, can you speak into the microphone?

SENATOR THOMPSON: I didn't understand Mr. Baffuto's--

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

SENATOR VITALE: You just have to get into the mike closer.

SENATOR THOMPSON: I'll try to get it straight here.

Maybe I misunderstood Mr. Baffuto's testimony. But I didn't understand Mr. Baffuto necessarily advocating do or don't (indiscernible) or so on. I thought he was simply saying for those people who are going to be moved into the community by choice or so on, etc. -- who choose to go -- that's a proper thing to be done out there -- to see the facilities they move into are adequate, and so on, and so forth.

Am I correct, Mr. Baffuto?

MR. BAFFUTO: Absolutely correct.

SENATOR THOMPSON: He was not necessarily saying, "If you don't want your people moved to the community -- they should be." He was just saying for those who want to move, and it's appropriate, that they have the right facilities out there for them. And I can't see why anybody would object to that.

SENATOR VITALE: Let me just follow up with that.

If one of the elements of moving out of a developmental center is with the permission of the individual--

How is that worded, Chairwoman?

ASSEMBLYWOMAN VAINIERI HUTTLE: "To honor the rights of residents to continue to live in developmental centers." So if they choose not to--

UNIDENTIFIED SPEAKER FROM AUDIENCE: Not an option.

SENATOR VITALE: So, Tom, in your understanding of the document, are they saying that if -- there is no option? They're saying that if you don't want to leave, you still have to leave. I mean, it's not, "If you don't want to leave, you don't have to."

UNIDENTIFIED SPEAKER FROM AUDIENCE: I was told that, "The Division would make the decision for you."

SENATOR VITALE: Sir, did you sign up to testify?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Yes, I did. I'm so sorry, sir.

SENATOR VITALE: You can wait. Thank you.

MR. BAFFUTO: I'm sorry. What was that question, Senator?

SENATOR VITALE: The question was: In the nonbinding recommendation -- one of the recommendations -- it states, not verbatim though, that the individual may or may not be moved based upon their rights. And so if they determine that their right is that they want to stay or they need to stay, what happens?

MR. BAFFUTO: It is my understanding -- and I'm only as good as the document that you're reading -- is that they will have the right to live in *a* developmental center. Perhaps they can't choose which one.

It should be noted that that's the document from the Task Force, right?

ASSEMBLYWOMAN VAINIERI HUTTLE: Right.

SENATOR VITALE: Right.

MR. BAFFUTO: All right. That's not a document that I produced; it was the Task Force that produced the document.

SENATOR VITALE: No, no, I'm not suggesting you did. I'm just asking for your opinion on documents that were prepared by someone else.

MR. BAFFUTO: Clearly, the Task Force has determined that two developmental centers should close. They identified the developmental centers, and they've also said in their recommendations that if a person or a family member chooses to keep their son or daughter in a developmental center, they can. They just may not be able to stay in the two that they've chosen to close.

SENATOR VITALE: Thank you, Tom.

**DANIEL J. KEATING, Ph.D.:** Thank you for the opportunity, Chairman Vitale and Chairwoman Vainieri Huttle. We appreciate the Committees being here also. We know how dedicated and responsible you are for the lives of people with developmental disabilities in the state, and we appreciate your concern.

You have my testimony. I'm not going to read the whole testimony. I'm just going to reiterate something that my colleague Tom

Baffuto said. We do support the closing of two institutions -- two developmental centers. We did not choose the developmental centers that are in the report, and I think that's the point that was being made. We are simply stating that we do believe that we can, in the community, provide for more people the option of living in the community if they so choose. But we did not choose which two centers. That is not our -- somebody said earlier, the dog in the fight. Well, that's not our fight.

But we are here in the community to support people living in the community. We believe that we can provide quality supports and meet the challenges of people. And in my testimony -- and, again, I'm not going to read it -- but at the closure Task Force hearings, Patricia Carlesimo, from LADICIN, reported on a case who had moved from the developmental center in Vineland into the community, who has a very significant situation. She has quadriplegia; dependent upon others for assistance with all activities of daily living including toileting, bathing, positioning, transfers, feeding, etc. She has thrived in the community. She went from 50 pounds at the developmental center to 110. She is not without medical issues; has been hospitalized eight times. But each time she went back home to her community. I'm not going to say all (indiscernible), but that's the case.

We do understand and appreciate the concerns of those who are skeptical about the approach and do not see the individuals who reside in the developmental centers as being able to live in the community. Yet we do serve people with identical needs in the community. So I wanted to make that point.

The other thing I wanted to state is that at ABCD -- while we support the closure as recommended by the Task Force, we do encourage that the money that may be saved from those would be reinvested into the community, because we can then provide better services. I've heard a lot about jobs. We would love to have people come and work in the community. We need more community people. We also believe that the developmental centers that exist -- should they be moved out -- could still serve as medical hubs or centers where the increased needs of people from a medical and dental perspective-- We do have those needs in the community, and this might be a way to use more money to serve more people.

I'll conclude with that point.

But we do look forward to working with the Legislature and with the Department to continue to see how we can help support more people, and in the community, as possible.

SENATOR VITALE: Thank you.

Any comments from the members, any questions? (no response)

I just have one question, Dan.

Have you been to one of the developmental centers?

DR. KEATING: Pardon me?

SENATOR VITALE: Have you visited one of the developmental centers?

DR. KEATING: Yes, I have. In my career I've been to developmental centers.

SENATOR VITALE: In your experience-- And if you're looking at one of the centers -- take Woodbridge and North Jersey -- 300-some-odd residents. In your opinion, how many of them are -- would be able to live safely, appropriately, and maybe sometimes in a better environment if they didn't live in the center? Not all, but how many-- Because there are some who are, of course, profoundly disabled and need to have the kind of care that can't be provided in community settings.

DR. KEATING: Senator, I guess, ideally -- and I know this is going to be a very popular opinion this morning -- but I believe that ultimately with the right supports and the right resources, everyone could live in the community. And I believe that, not today -- I am not saying today -- but I think ultimately, as a society, if we provided the same level of supports to people in the community, that ultimately they can.

Thirty years ago, as a young psychologist starting out, I was fortunate to be involved with the closing -- the court-ordered closing of an institution in Pennsylvania called Pennhurst. I did the family study. I listened to the families because they felt no one was going to listen to them. I asked the families -- I did a survey, and we understood their concerns. But the court ordered the institution closed. It closed, and the success of those people-- We still talk to people today who came out of Pennhurst.

Now, I'm not saying today-- Obviously, we can't just close those centers today. But over the course of 5, 10 years, I believe that we can serve those people safely and adequately with the right supports.

SENATOR VITALE: Thank you.

**D E B O R A H G O O D:** I'm Deborah Good, and I represent the New Jersey Association of Community Providers. I'm on the Board of Directors, and I've been the Association's past president.

Like Dan, I'm going to deviate from my script. I will give you a copy of that.

I think the most important thing is, I have been working in community services for over 40 years with this population, as well as Pennhurst, in Pennsylvania. And I've been working with placement in the State of New Jersey for the last 30 years.

There are organizations -- over 300 organizations in New Jersey that are currently providing support to people just as severely involved as the people living in the institutions. And I think it's kind of unfortunate that all of these hearings I've been to wind up becoming a tug-of-war between jobs and the communities.

The people who work in the institutions are incredibly qualified people. Between the direct support staff, the doctors, the nurses, the therapists-- These are people with tremendous expertise.

What we, as a provider organization, oppose is the large congregate grouping of individuals in large institutions. And I think as partners with the State of New Jersey, with developmental disabilities, and with local communities, we need to develop supports in the community and redeploy some of the same staff that are working currently in the institutions. And I think if the salaries were the same, we would have a smooth transition of moving people who not only live in the institutions, but work in the institutions. And there is no reason why we couldn't develop the types of programs that are needed right in the communities of

Woodbridge and Totowa. I mean, there really is no reason to talk about people going to Vineland away from their families. I mean, there are community programs in the communities that you are representing now. And we are currently supporting people with severe needs, just as severe as the ones in the institutions.

So I really think it's unfortunate to get into these tug-of-wars, and we should all be working toward the same goal of providing quality programs for people with developmental disabilities, regardless of what their functioning level is. And there are a lot of people who, for whatever reason, many, many years ago did not place their son or daughter in an institution and have them living at home. And they're successfully living at home. They're not dying. So I think the concerns about mortality and everything else-- I mean, we really need to work together, not at opposite ends of the pole.

I know, right now, the agency I work for -- we're responding to a proposal from the State that has to be in this Friday. And we plan to develop four homes in the next year for 16 individuals -- 4 each -- coming out of developmental centers. So this is happening every day. People are being placed out of developmental centers successfully. And they do have severe medical and behavioral needs.

Thank you very much for listening.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

I think we have questions from the Committee.

Assemblywoman Wagner.

ASSEMBLYWOMAN WAGNER: Thank you.

I just have a question. From the previous testimony, my understanding that there are thousands of people on the waiting list, and the waiting list is anywhere from 8 to 10 years. So why would I not go to the waiting list? And if I want to put people in the community, why wouldn't I provide community homes for those people who want it? And I don't understand why we would be closing institutions and still have thousands of people on the waiting list. Why can't I handle the thousands of people on the waiting list? (applause)

MS. GOOD: We're doing both.

DR. KEATING: I think the waiting list -- all the people on the waiting list are not waiting for residential placements; some are. Some people get on the waiting list very early in life with the hope or expectation that when their turn comes up, they will have residential placement.

The concept of the waiting list is being addressed. We need to get rid of the waiting list, and we need to start serving and supporting people on that list. So I don't know that it's as easy as just going to that list and doing that. But we have seven developmental centers. We don't think we need seven. And we believe that we can support people in the community and take the resources that are being dedicated there and devote them to serving more people on the waiting list.

ASSEMBLYWOMAN WAGNER: While I understand what you're saying, to me it doesn't make sense, logically. In my mind, I need to take care of the people who need the help now and who are asking for the help now before I go to people who aren't asking for the help right now. (applause)

SENATOR VITALE: Any other questions?

Senator Pou.

SENATOR POU: Thank you, Mr. Chairman.

I was listening to -- I think it was one of the parents who spoke before. And I'd just like to ask the members of this panel who are in front of us right now--

There were some questions or comments with respect to what occurred with Hurricane Sandy. Could you please address what was your assessment of some of those particular centers or facilities that were caring for these very critically disabled residents? What actions did you see? And I particularly want to know, in the case of an emergency-- I believe one of the statements was that there was no back-up generation. There may not be back-up generators in any one of these facilities that is indeed available in many of the developmental centers. So that's just one example. There are many others.

But if you could, please assess that. Because that's only a very small fraction of what the actual concerns are that maybe you will be hearing from many of the parents who are here today -- concerns about their siblings, their children; as well as making sure that those families that have the need-- As well as the information that is really going to give them the kind of relief that their children will, indeed, be taken care of.

MS. GOOD: I can say that we -- the agency I work for -- we successfully relocated over 100 individuals to various hotels throughout the state with their staff, two individuals to a room, with no incident.

SENATOR POU: What were the conditions of -- the needs of these particular residents?

MS. GOOD: Very, very wide variety. There were some nonverbal, some incontinent, some needing to be diapered and changed, pureed food. We relocated to hotels that had kitchenettes so if somebody was on a pureed diet, we were able to accommodate that. So we did not have one incident, I'm proud to say.

SENATOR POU: And was that available to them, through the Chair, 24 hours -- the service?

MS. GOOD: Yes. Well, their staff went with them.

SENATOR POU: Their staff was there for 24 hours a day.

MS. GOOD: And we had staff come in and relieve people.

SENATOR POU: Right. No, I understand. But throughout the entire time?

MS. GOOD: The whole time their residence that they normally live in was without -- if it was without power. It wasn't always without power issues. Sometimes it was issues of roads being closed or whatever. So we were proactive, and we moved people before the total crisis occurred.

SENATOR POU: Through the Chair, how long were they displaced for?

MS. GOOD: It depends on the section.

SENATOR POU: Give me an example.

MS. GOOD: Some of them were, maybe, three days; some were four and five days.

SENATOR POU: In the event that any one of those centers had been lost entirely, as some of the homes as we know -- to have happen -- what would have been -- what would be the backup program that you

would -- or system that you would have to making more permanent or longer-term residency requirements for them? What would you have done in that case?

MS. GOOD: We would do what the normal population would do: either stay in a hotel, rent a house, or purchase a house. I mean, we pretty much treat our individuals like they were with families. So we do pretty much everything that a family would do who was caring for a family member at home who had a severe disability.

SENATOR POU: Again, through the Chair, I recognize that the hotel availability is probably the fastest; perhaps the rental, not impossible. The purchase of a home would take some time, I'm sure. So the only two options it sounds to me that you would be able to do are the two that I've just indicated, creating, clearly, some obstacles in terms of what kind of care that resident would have that would be so very different from what their normal, regular medical needs -- whether or not you would be able to provide them with the medical needs--

MS. GOOD: Like I said, we did not have incident. Anybody who needed medical care got the medical care they needed. Any special diets were accommodated.

SENATOR POU: Any other member of the panel have any comments?

DR. KEATING: Yes, I would like to address that.

ABCD members serve about 10,000 people. All of our providers -- much as what was said previously by the previous folks -- worked extra shifts, stayed. People were not left alone, despite anything--

The people who showed up at shelters, from my understanding, were not people who were living in group homes. They may have been people with disabilities living in the community by themselves or with family, but not necessarily providers.

The options that you spoke about-- There are a wide range of options. Some of my programs have day programs that they were able to convert for a short period of time into residential settings -- where they could put beds, and bring food, and have medical services brought to where they needed or get them to the community. I mean, Sandy was a disruption to everyone. But I think that the community providers did a wonderful, fantastic job in maintaining the health and safety. We had no incidents whatsoever either. And I think that it's unfair to say that because people are living in the community that they would not have the -- be as safe. Because the people who provide those services are very dedicated, and very professional, and very concerned about the people they support. So there is a wide range.

SENATOR POU: I don't doubt that, sir. I really don't. I'm sure that's all true.

I'll tell you what I think though, however. What I do think is unfair, is that in the entire State of New Jersey -- if you're talking about all seven different developmental centers -- that none will be available in the North Jersey part of the state -- in the region. And I think that is unfair. (applause)

DR. KEATING: Senator, I appreciate that. That's not our decision. I want you to understand that it is not our decision to close those two developmental centers. That is not our decision. We are just saying

that we believe that we have too much capacity. And if somehow you were able to persuade the Division to move those, that would be fine. We're not arguing that point.

Thank you.

SENATOR POU: Thank you.

SENATOR VITALE: Any other member? (no response)

Thank you very much, panel. Thank you for your time.

Next, I'm going to ask Gerald Newsome, from IFPTE Local 195; Rex Reid, AFSCME Council 1; and Carolyn Wade, CWA Local 1040.

You're not going to all read your testimony, right? (laughter) I know you're good at this without having to read testimony.

**C A R O L Y N C. W A D E:** We're going to give summary, because you've heard a lot of what we would say. But we're trying to give summary.

Let me just say good afternoon, and let me thank you for the opportunity to speak before you today.

My name is Carolyn Wade, and I'm President of CWA Local 1040. We represent about 9,000 members; about 800 of those are in Woodbridge and North Jersey Developmental Center.

Let me just go off my script and just say that I am -- I laud you for taking the time to hear what you've heard today, and to sit there and not be broken up as we were, because it's very, very sad about what is happening. We represent the workers at the developmental centers. And we are extremely concerned about the closure of these two facilities. We're even more concerned about the devastation of services that will be caused by the closure of these facilities.

We have lived through the closure of several facilities from Johnstone Training Facility all the way back, to last year when they closed Hagedorn. We have seen what closures do; we have seen what deinstitutionalization does for people. We've seen them living under bridges. We've seen the Department of Human Services not knowing where their clients were years later. We've seen the clients abused because their behavior was far too aggressive for the community. And we've seen constant recidivism of these clients back into the developmental centers. That's why they want to close them -- because they have no place to put them-- Where do they go then?

We also represent workers who are not -- who are in the community. So we see both sides of the spectrum. We see what we have in the institution, and we also see what we have in the community. We represent such agencies like Mercer Arc, the community care respite providers. And these are people who take care of the developmentally disabled in their home. We represent hundreds of them. So we know what's going on out there as far as care is concerned.

In the developmental centers you have well-trained staff with full-time doctors, nurses, and dentists, and a whole complement of people to support the needs of this very fragile group of people. The developmental centers have licensed professionals, where as in the group homes that we represent in the community -- the community providers -- they're not licensed. Our people receive constant training. In the community, if you get two weeks of training and then you go to work, that's a lot. And we're speaking from experience.

I don't want to be critical of the speakers who preceded us, but I sat and listened to them. I said, "Do they really know what's going on where the rubber hits the road?" We know what's going on because we represent those people. We negotiate contracts with them. And all we hear is, "We don't have money." But yet they're saying what they can do. We know what our workers have to do. In the Woodbine Developmental Center -- where we represent the workers during Sandy -- they served as a shelter with a full complement of people there to work. And that was a shelter for the community. But yet you want to close all of them.

I've heard many people talk about Bernie White, who was the former Deputy Commissioner for the New Jersey Division of Developmental Disabilities. Bernie has said things that trouble all of us, things that we know but, because we're not -- we don't have the statistics-- Bernie knows that once you go into the community -- and he's said it to us -- 47 percent of the people usually end up dying. But you don't hear that from the Department because they choose not to keep these kinds of records or to do anything about it. A good example is at North Princeton Developmental Center. When it closed, there was a study that was done by the New Jersey Institute of Technology. And that study showed -- and this was about the North Princeton people. They stopped the study. But they said if we had gone just one month further into our study, the mortality rate would have been astonishing. But these kinds of things you don't hear from the Department because there is just no follow-up.

We're not the only ones who are saying that the services are not available in the community. You've got the American Academy of Developmental -- I'll use the acronym AAMD. They're saying that their

nurses, and doctors, and their dentists are not trained to handle this population. The AAMD stated in their health disparities consensus statement that was released in 2011-- They said that this population is medically underserved in the community. Many physicians just do not know how to treat this population. They do not feel that they are competent to even deal with this population. We're saying that before you move into the community, training and education is an absolutely necessary component that goes along with just a roof over their heads.

Additionally, more than half of the residents we care for in the developmental centers -- if you have heard -- have so many medically complicated disabilities that it's even difficult-- There is no way they can meet those needs in the community. However, in the institution, we are trained to do this. This is all our doctors do, this is all our nurses do, this is all our dentists do, this is all our direct care people do. So we are good at what we do for these residents.

Again, as I said before, we work in the community. You do not find this type of comprehensive care that you have in the developmental centers in the community. At best the care is fragmented. We are there, we know what happens, we see what happens.

I almost take umbrage with the statement that was raised by the previous speaker when they said that our people should follow the clients in the community. The turnover is so large in the community because the pay is so poor and they're so undertrained. Our people would not-- We certainly wouldn't recommend that they work in that setting.

The State is recommending closure without even taking a look at the bigger picture -- that means putting our vulnerable citizens at stake. I

speak for those individuals without a voice so that maybe they can be heard. Because we are not just workers, we are their families too. We are there. (applause) You can't work with this kind of population without loving what you do and loving the population. We see them as families because when the families are not around, we are there. When they need a hug we are there to give that. So there is a connection. Jobs are our concern, but we are even more concerned about what is going to happen to these people.

So I ask you as a Committee, whatever you can do to help us to stop the closure of these facilities and probably save many lives, that you would please do this. And I say this from the perspective that I, too-- It has a personal thing with me. I have a grandson who has special needs. And as I was sitting, listening to these families, I say, "My God, is that going to be my daughter years from now when he will need these services?" And that's why I say I have mixed feelings. And I laud you for sitting, hearing this. But I have a personal something in this because I certainly would like, if my grandson needed these services -- that they would be there and not go into a community place where money becomes the driving factor of whether they care.

I thank you for listening. (applause)

**GERALD NEWSOME:** Are you ready for one of us?

**SENATOR VITALE:** Sure.

**MR. NEWSOME:** Good afternoon. When I started writing this statement it was good morning (laughter), so it's been a long, long day. But it's a very important day. We have a lot of things that have been

addressed; there are a lot of things that have been repetitive. So I'm going to try to not be repetitive.

SENATOR VITALE: Sir, just for the record, state your name and organization.

MR. NEWSOME: I'm Gerald Newsome. I'm Vice President of Local 195, IFPTE.

We're a little different flavor in this because we represent the members who actually make sure everybody's in a safe environment -- lights on, heat on, and stuff like that. But we have a vested interest. We also represent the members who clean the places. So it is that family-type of element that goes on.

The part that I'm going to talk about is what is happening in other states with this thing. We did a little research in centers in California, Illinois, Kansas, and Virginia. And the common thing for closing was they always cited budget savings. California also cited activism by Arc and United Cerebral Palsy. Illinois was budgetary reason; Kansas, to balance the state budget, cost savings, and better -- less restrictive care; Virginia cited cost savings, and better and less restricted care. We don't buy any of this.

There has been complete opposition in most of these states in reference to what was going on. Illinois was really right. Just like you guys -- this panel -- they had bipartisan support to overturn closing of institutions, but they also had a governor who had enough oomph to get it done. And we didn't have enough votes to veto oversight. So this is similar to what we're going through.

We know this Task Force was put together. You know the Task Force came out talking about Vineland. We're really not in favor of closing any centers. And it is not our opposition to group homes. There is a place. But this population that we're talking about -- the place is developmental centers. And when you talk about the care, you talk about the services-- If you go into looking at why we need to keep these places open, you look at what's immediately available to the residents who are in developmental centers. You have access to immediate medical attention, you have continuity in care, you have all these things going for you that you don't have -- as Carolyn just spoke on -- in the group homes.

We're just looking at -- and to make things short -- there are reports that have been done. There is a 1999 -- this is a long time ago -- report from Robert Shavelle, David Status, and Steven Day. They did a report called "Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities After Transfer Into the Community." We look at this, and we look at this; we keep talking about mortality rates. And anyone who could stand up here and say that's not the most important reason -- that if you're going to make a decision that is going to put somebody in harm's way -- that you already did studies in other states and saw what is actually going to happen, and yet we're going to follow behind that decision-- And we know the study says there's a 40 -- the death rate being 40 percent higher -- 47 percent higher than expected for a comparable person living in an institution -- that reports the reasons that the mortality rates in institutions, compared to other residence types, are the continuity of care, centralized record keeping, and immediate access to medical care.

We can't afford to do this. We have to take and look at what is in the best interest of those who can't help themselves. That's what each one of you guys probably go into office for -- to do something, to serve the people. These are the people who can't help themselves. So we're looking at you guys. We heard about this done deal. There isn't any done deal until it's really done. So we're saying, "Let's look at what is happening. Let's take a step back and do the right thing." That's all we're asking. (applause)

**R E X R E I D:** My name is Rex Reid. I'm the Political and Legislative Representative for AFSCME Council 1 in the State of New Jersey. I represent the workers at Woodbridge and North Jersey Developmental Center.

I'm not going to read my testimony, but I am going to highlight some important facts.

The developmental centers generate, by employees, about \$91 million. And it's distributed in your districts throughout the year. Some 166 of them are in the 28th Legislative District, and they generate \$8,460,356; 356 of them are in the 35th Legislative District -- that's \$18,143,896; in the 20th District, 193 of them feed \$9,836,438 into the community. And that's from an average median income of \$50,966. I won't read the other 33 districts that the workers of North Jersey Developmental Center and Woodbridge Developmental Center come from, but the statistics are there. And I'm pointing out to you that this comes from across the state. It's not just Totowa and Woodbridge. They represent 35 of the 40 legislative districts across the state. So this is money that would be lost across the state.

I say that to you because the Task Force -- the Governor's Task Force on Closing determined that finances lost -- the cities wouldn't be hurt. But I ask you: Can your district stand to lose any part of \$91 million in these hard economic times?

The Task Force looked at the unemployment rates of Middlesex County, at 8.2 percent, and Passaic County, at 10.8 percent, and compared it to Cumberland County's rate of 12.9 percent and came to the conclusion that these two counties -- with a combine unemployment rate of 19 percent -- would fair better if their centers would close because of the density of the population. I would say to you that is part of the flaw with the Task Force's report.

First, the workers at the Woodbridge Developmental Center and North Jersey Developmental Center come from 35 of the 40 districts of the state, and their loss would be felt across the state. Second, because of the population density of Middlesex County versus the population density of Cumberland County -- we're looking at a 3 to 1 difference in the number of unemployed and a 2.5 to 1 difference between Passaic County and Cumberland County. I say this not to say that keeping Vineland Developmental Center open was wrong, but to say that closing any of the centers is wrong. The conclusions of the Task Force were wrong.

The Task Force also said that the centers should be closed due to decline in census. The census could only decline because admissions to all developmental centers is closed. The Task Force ignored the families' input and denied them the choice Olmstead gives them.

If you choose to close developmental centers, then there is no choice. The residents who live in developmental centers need to be where

they are because of the care and attention they receive. We're asking you to find a way to save developmental centers -- the homes of the residents.

Thank you. (applause)

And I do have in my testimony the statistics for the other 33 centers and what it means in terms of loss of revenues to those municipalities that are in those districts.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Rex.

SENATOR VITALE: Any comments from the members? (no response)

Thank you for your testimony. (applause)

Thank you.

We're going to now move on to the public portion of the hearing. There are many people who would like to testify. We want to have an opportunity to hear everyone, but that can only happen if it is that each one who testifies -- if you come up as a group, you have one person testify for your group. And each person who testifies should be limited to one minute to get through all of the people who are here. There are nearly 90 folks who have signed up to testify.

Camille Egan, from Woodbridge Developmental Center, submitted written testimony, but she declined to testify. Thank you. And there are others mixed in. I will announce them later.

The first -- let's have a group come up: Aileen Rivera, Martha Cray, and Karen Cameron.

Again, we need you to have one person speak for the group, and one minute for you. And I know that our friends on the side are going to have a loud cow bell.

Thank you.

**M A R T H A C R A Y:** Good afternoon, Senator Vitale, Assemblywoman Huttle, Committee members, and viewing audience.

I am sitting here in disbelief and with much sorrow with what is transpiring with the closure of Woodbridge Developmental Center and North Jersey Child Developmental Center. I know that both are valued centers. Both centers, for years, were home for so many and acted as a safety net to those who cannot thrive out in the community. My heart goes out to all the families that now have to relocate their loved ones. And I know that that could be devastating.

Thank you for inviting me today to testify, and also share my thoughts and recommendations on changes that need to be made to make the quality of life for the developmentally disabled better in New Jersey. By that I mean developmental centers and group homes.

With that being said, I am talking about better oversight, transparency, and accountability. And by that I mean too -- regarding developmental centers and group homes. It is time that abuse, and neglect, and death among the developmentally disabled must stop being front pages of newspapers, and the top stories on the 6:00 news. The time to change is now.

I am not only fighting for the rights of my son to be safe from abuse and neglect, but for all the developmentally disabled in New Jersey. My son, Billy Cray, 28 years old, lived residential care since he was 10 years old due to his challenging behaviors. He has autism, PDD, impulsivity control; he's a runner, he does property damage, and he aggresses on people

when he is either provoked or, for some other reason, having anxiety. My son endured three sexual--

ASSEMBLYWOMAN VAINIERI HUTTLE: Martha, I hate to be the one because -- Senator Vitale just left for a break. But your minute is way overdue. Could you just wrap it up? I apologize. In your own words.

MS. CRAY: My son has endured three sexual assaults, knocked out teeth, black eyes, and bruised body -- both at the developmental centers and group homes.

So what I'm saying here-- And I also want to emphasize that this is not all direct care staff. There are many, many good direct care staff with heart felt--

But I wanted to bring up the recommendations -- as we spoke with Senator Vitale -- surveillance cameras: safeguarding those with developmental disabilities from abuse and neglect is more important than the right to confidentiality. There are cameras in so many places -- in businesses. And every time you drive through an intersection there is a red-light camera there. So I think that outweighs -- it's more important to give transparency.

Also, somebody who was up here prior mentioned training and staff. My son has been in both, and in the developmental center he was in, the staff said -- and the CEO did say, "We're not equipped to deal with the behaviors your son has. We're getting mostly autistic coming in, and we're just not equipped to deal with his challenging behavior." So he moved back out into the community.

The point I'm trying to make is -- with the certification -- home health workers cannot walk into someone's home without being certified. And I really think this is a very vulnerable population we're talking about, many with multiple disabilities who are very fragile -- medically fragile, rather. And it just-- We are trying to work together as families, with the Family Alliance to Stop Abuse and Neglect, to fix the infrastructure. The oversight that is supposed to be overseeing these facilities -- developmental centers and group homes.

So I am here today to offer our recommendations. I hope I've covered everything.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Martha.

Now, you're speaking on behalf of Aileen. I think we were calling you up as a group.

MS. CRAY: This is Karen Cameron.

**KAREN CAMERON:** Karen Cameron.

I'll make a short statement.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

MS. CAMERON: Martha did a good job covering everything.

My son is autistic, bipolar. He has many diagnoses.

One thing I wanted to tweak my testimony about is-- The gentleman who came up -- I think it was Mr. Baffuto -- I don't know if I'm pronouncing his name properly -- from Arc -- or someone. And with all due respect, when I heard the sentence that we're looking to make a smooth transition-- To me that told the whole story. There is no such thing as a smooth transition for the developmentally disabled. The diagnosis in itself

-- being autistic or developmentally disabled -- means you are extremely rigid, prone to outbursts, property destruction, hurting others, aggression with any change, not just major change like moving from one setting to another.

So basically I'm closed to the closing of developmental centers. I'm sure some people could relocate, but not all. A large majority--

And I'm with Martha and Aileen. We need cameras, we need better staff -- not better staff, we need better-trained staff.

ASSEMBLYWOMAN VAINIERI HUTTLE: Martha did say that.

MS. CAMERON: Okay.

ASSEMBLYWOMAN VAINIERI HUTTLE: Can we give Aileen just a few months -- a few seconds, rather. And then we can call up the other members.

Thank you, Aileen.

AILEEN RIVERA: Can you hear me?

ASSEMBLYWOMAN VAINIERI HUTTLE: Yes.

MS. RIVERA: My name is Aileen Rivera.

I'm very saddened by what is going on with the developmental centers.

The community is not for everybody. I'm not saying it in a bad way, but people have different needs. My whole mindset on this is: If something is not broke, why fix it? This has been their home for many years. They've had the shelter, and they're fine. Leave it alone. Let them be.

The community -- it offers-- My son is in the community. I don't have complaints. But even in the community the whole system has to be revamped. I feel that our children who have developmental disabilities -- society is still in the stone age days when it comes to our community, because they're not up to speed with giving them what they need. They're helping them, but not to the extent that they need the help. Abuse goes on.

And I'm with them with the cameras. When you go to the ATM machine, there are cameras there. The lives of our children are more valuable than an ATM. So why can't our children have cameras also for them if there are cameras for ATMs?

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Aileen.

Thank you very much.

Any questions from the Committee? (no response)

If not, I'd like to call up Dr. David Dayya, if he's still here.

I know you need to leave early.

Is Beth Marmolejos still here? (no response)

**D A V I D D A Y Y A, D.O.:** I'm Dr. David Dayya. I'm a physician and also a public health professional.

I'm kind of wearing a couple of hats here. I'm here because--

ASSEMBLYWOMAN VAINIERI HUTTLE: Could you speak into the mike?

DR. DAYYA: I'm here both as an expert -- medical expert, and I'm also here to represent my sister Mary who is a resident at Woodbridge.

I had a question. I know the gentleman left earlier who represents the community placement. I was hoping to hear it from -- some of you hinted at it. You asked them specifically for statistics.

I would just say, "Is there any scientific--" given that I'm a researcher as well -- "Is there any scientific evidence that placement -- community placement is as good or better than the institutions that they're in, the facilities they're in?" I've already done it. It's kind of a rhetorical question. But I'm just going to tell you they don't have any evidence. There is a-- They can't give you what you're asking regarding the statistics. That's just a fact. I've already looked, and that's just the truth. So they believe they could provide better care. You have to decide if you're comfortable allowing them to do it -- who have a vested interest in placement, whether or not their belief is good enough for you. I don't think it is, and I think a lot of these families don't either.

I want to thank you for giving us the opportunity to address you. I want to send greetings to the Governor, the State Legislature. We've gathered here because this is an important hearing and it's a crucial one. It's a make or break hearing for a lot of us. This is probably one of the most, if not the most, important appeal I've ever had to write or present before a body like yourselves. This is on behalf of my sister Mary, the residents at Woodbridge. The Center serves the needs of those who suffer from profound mental retardation. They're very low-functioning, and they're in need of constant, ongoing care and attention. As with other families, it's struck us deeply with sadness and outrage that these centers were going to be closed. Our sister had been placed there years ago by our

parents. It was a difficult decision for them, as I'm sure it is for many of those who are here.

We've done this. We've considered even placing our sister-- We've looked at some of these facilities. It's interesting to know -- they didn't tell you this -- but the minimum ratio that you require them to provide staff to their residents -- a lot of them, that's all they'll do. They won't provide more staff than is required by law. They'll just meet the minimum standards to satisfy you and argue that that's good enough. I don't think it is, and I think a lot of you don't either.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

DR. DAYYA: I'm going to wrap it up.

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Because we have all of these people to testify as well.

DR. DAYYA: It's difficult to be both a medical expert and to speak on behalf of someone in a minute. There was an attorney up here who had five minutes.

These are the weakest and most vulnerable members of our society. They're politically disenfranchised, powerless, have no vote or voice in our political affairs or policies. Instead, it rests on us to speak for them, defend them, to vote and legislate on their behalf, and to act in their best interests.

We considered taking Mary out. We looked around at some private facilities. In all honesty, that was her home. She was comfortable there. And we knew that-- They want to get you to believe that you can fit everybody into a box. I could have marched in heads of psychiatry here who would tell you that you can't do that. There are some low-functioning

people who are better served by packaging the resources in one place for them. Community placement is not good for everyone. It's not a one-size-fits-all. (applause)

I don't want to sermonize here, but this is a very heavy decision before you. Scripture teaches us that you will be judged not by how you treat the King, but by how you treat the least among you. (applause) For us, we ask that-- There is no greater calling than the cause of defending those who are historically ignored, misunderstood, feared, persecuted. No other group in history has been pained or has had to suffer to the degree because of their unfortunate illness as this group has. Let us not fail them now when they need us most. Let us not fail those who society has failed from the beginning of existence. They're not our children alone; they're society's children. Newtown's tragedy reminded us that on that horrible day -- a parent losing a child -- when one parent loses a child, all of us lose a child. In many respects we are both bound by the -- we are all bound by the same basic truths.

We request that you, the Legislature and the great State of New Jersey, join us in the good fight in our effort to immediately and unequivocally rescind all efforts to close the Woodbridge Developmental Center and the other center in North Jersey. (applause) These centers serve the needs of the profoundly mentally retarded. If we lose this fight, what is next? Services for the elderly and the demented elderly, children with special needs? It has to end here, and you have the power to stop it here. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

DR. DAYYA: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Eric Richard, New Jersey AFL-CIO. No need to testify or are you testifying? I didn't realize. I thought it said no need to testify.

**ERIC RICHARD:** I'll be very brief.

Chairwoman Huttle, members of the Committee, good afternoon.

My name is Eric Richard, representing the New Jersey State AFL-CIO, the largest labor organization in the state.

First and foremost, I'm really here to just say thank you to you for holding this hearing. I recognize that this is going to be a very long process. And the AFL-CIO really is here to serve as an advocate for the residents of the developmental centers, to serve as an advocate for the families of the residents of those developmental centers, and to serve as an advocate for the caregivers who are employed by those developmental centers.

There has been some very emotional and sometimes heartbreaking testimony that has come from some of the panelists prior to me, and I really can't match some of the emotion from those panelists. But what I can do is bring to you a passion that our organization represents as we move forward through this policy debate. We've had a lot of policy issues our organization has been involved in over the years, but this is truly one of the most emotional issues that our organization and our affiliate organization has been confronted with. And we recognize that it's a very difficult position for you to be in as policy makers as well.

So I understand time is short. We've distributed written testimony. But if the AFL-CIO could have one ask -- and, again, that would

be for you to be -- to act not just as representatives of your districts, but as representatives of all residents of these developmental centers. These folks really depend on you today moving forward to act on their behalf.

So as the AFL-CIO, we ask for you to join us as a passionate advocate for these residents, join us as a passionate advocate to defend the jobs that would be lost in these developmental centers. And we look forward to working with you as we move forward.

Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Eric.

Eileen Lampkin, Jane Johnston, Randy Broderick, Kathy Chang, Waheedah Muhammad, Jean Davison, Dante Crystal, Deborah Hambrick, Robert Rutland, Marie White, Michael Chomicki, Carol Barrett, Deborah Traylor-Smith, Susan Froietti, Juana Mitchell, Marylyn Carr, Sheri Joyner.

State your name, please.

**R O B E R T   R U T L A N D:** My name is Robert Rutland. My twin brother is Doyle Rutland, a resident at the Woodbridge facility.

My brother is profoundly disabled. He cannot walk, talk, or even feed himself. My twin brother is both mentally and physically retarded from birth. What this means is, his mind never developed. For the last 47 years, he's been at a mental stage of a 4-month-old, and as such he needs care 24/7, around the clock care. Imagine, if you will, having a 47-year-old infant. He needs more care than can be provided by one of these residential homes that they're providing. He needs help with feeding, exercising, lifting him from his bed to his wheelchair and back again, dressing him, giving him baths, giving him his medications, as well as

changing his diapers. Again, he is, for all intents and purposes, a 4-month-old.

My brother is totally defenseless and helpless. He can't sit here and tell you fine people that this is wrong. He can't sit here and tell you that you're taking away -- or this group is taking away his home and everything he's known for the last 40 years. That's how long he's been in this institution.

He is oblivious to most of the world; and the fact that his life and the lives of these defenseless, handicapped people depend on the intermediate care facility for the mentally retarded. I implore you, do not close Woodbridge Developmental Center. By allowing it to close, you and everyone else who is involved will have blood on their hands, because there will be a few people here who die as a result. Do not take from those who have so little and can't help or defend themselves. Please think of their family members such as myself. I am physically handicapped and don't get to see my brother as often as I'd like to. If you close the Center and move my brother to Hunterdon or the next nearest facility, which is two to three hours away, I fear I won't be physically able to visit my brother again.

Please understand, Woodbridge is not just a facility, it's his home. And the aides and people who have been there for him are extended members of our family. To close this facility is to do irreparable damage not only to the residents, but the workers and the families of all involved. By closing these facilities and taking this home away from my brother and others like them, it would be paramount to stealing candy from a baby. Just as a baby cannot defend himself or speak up for himself, neither can many of these residents.

With all due respect, I beg you, don't allow this closing.

Thank you for your time and consideration.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

State your name.

**MICHAEL CHOMICKI:** My name is Michael Chomicki. I live in Stewartsville, New Jersey.

My brother Henry Chomicki is 50 years old and a resident of Woodbridge Developmental Center for 35 years. He doesn't speak. He has a seizure disorder. And as a result of many medications over the years he has lost his teeth, which now presents a severe risk of choking. He's self-abusive, bangs his head and frequently punches his face. He easily gets frustrated and has no means of communicating any pain or any other issues afflicting him. He cannot make choices or decisions for himself.

He has a very safe, structured home at Woodbridge Developmental Center. All of his medical, dental, orthopedic, dietary, and behavioral issues are dealt with on a 24/7 basis by trained professionals. He has a consistent routine to his life and seems very happy and content. Because of my brother's lack of safety awareness and self-injurious behavior, he needs the Woodbridge Developmental Center, with all its safety nets in place, to protect him and allow him to enjoy a safe life.

As a family we were very surprised, saddened, and very afraid for my brother Henry when we heard of the decision of the Task Force to close Woodbridge Developmental Center. We're a very close family and visit him twice a week. It's very important to see him in person as Henry can't communicate with us via any other means due to his condition that I mentioned previously.

We understand that other developmental center placement options would be in the far south section of the state, a two- or three-hour commute from Woodbridge, which presents a hardship on our family regarding visitation options. We really request that you really think this decision through and overturn the decision of the Task Force and keep the developmental centers open. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

J U A N A M I T C H E L L: Hi, my name is Juana Mitchell. My son Kerr currently resides at the Woodbridge Developmental Center. He's been there for around 25 years.

I'm not going to go into all the details regarding his condition or what he can and can't do, because it would take up too much time. But I do want to address the fact of the developmental centers closing.

I have always thought that Woodbridge would be there for us. It is a part of Kerr's life and my life. It is his home and family. He has family there. I'm there constantly. I'm very much involved in his life regarding all issues. When I'm not there, I'm constantly on the phone so I know what is going on. And I need to be able to get there whenever. I do not drive. I live in Bloomfield, and it does take me a couple of hours each way. He needs to be somewhere I can get to. It would be very devastating for not only him, but myself, if we were not to be able to see each other on a regular basis.

I'm asking, please, keep both developmental centers, Woodbridge and North Jersey Developmental Center, because there is no other real option. Actually, we're at a dilemma. You say we have choices, but we don't. I just wish that you would take regard -- more regard in our

choice and our rights, which seem to be being overlooked during this whole issue.

There are a lot of things that haven't been addressed. Again, it would take up too much time. But to try to see the overall picture, which I don't think has been really looked at from *A* to *Z* -- maybe *A* to *M*, but that's as far as you got. So I implore you also, please keep the developmental centers open.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

MS. MITCHELL: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: The next speaker, please state your name.

**M A R I E W H I T E:** Marie White, and I'm here to talk for my brother Doyle Rutland. This is also my brother. They are twins. They are my younger brothers. I am my brother Doyle's legal guardian. I am the oldest in my family.

When they put my brother in Woodbridge, it was a very, very hard decision. They kept him at home as long as they could. My brother cannot do anything. He is, like he said, three or four months old. He is a baby trapped in an adult man's body. He can't feed himself, he can't go to the bathroom himself, he can't clothe himself, he can't do anything for himself.

I was literally scared when they put him in this institution that he would not get the care that he could get at home. I've come to find out that he's getting better care than we ever could have imagined giving him. When you see him -- if you could have seen him at home and if you could see him now, he is different. He is happy. He is with a true family. They

understand him, they know him. When something is wrong, they know because there is not one person or just somebody coming in and clocking in to take care or do their job. These are people who take this job as part -- they're going home to their family -- their second family. They come in and know these kids. Again, they're kids trapped in adult bodies. They can't do for themselves. These people -- the staff -- they know when something is wrong -- "This child," Doyle or whomever, "is not acting right. We have to find out what is wrong with him." I would not know that because I don't take care of him on a daily basis.

Every time I go I am so happy that he is doing better. He can't talk; he can't do anything. All he can do is make noises and pound his hand on the table. He sits in the chair. He does have restraints on his legs because if he doesn't, he kicks walls and stuff like that. It's involuntary. He has broken his foot before. But they do everything that they need to do to make sure that he's safe and healthy. He's always clean, his nails are always trimmed, his hair is always cut, he is constantly going to the dentist to have his teeth done and be taken care of.

I am asking you for nothing more than to support us in keeping this hospital open. He needs it. It is not their responsibility to balance our budgets in the State. There are other places to cut money. Please don't cut it here. He needs to be there. They've told us year in and year out that my brother would not make it past 18. I swear it's because he is in the hospital that he has made it as long as he has. I am asking you--

I thank you for giving me this time. I know I'm not doing a very good job. But I'm begging you, please take these people into consideration.

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Where is your brother again?

MS. WHITE: Woodbridge Developmental Center. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

**DEBORAH TRAYLOR - SMITH:** Good afternoon.

My name is Deborah Traylor-Smith. I'm not going to read the entire statement. You've been provided with a copy. I'm going to just jump around a little bit just to highlight some of the things I'd like you to know.

I'd first like you to know about my daughter Kesha. She's been a resident of North Jersey Developmental Center for 27 years. Kesha is 42 years old. She's profoundly intellectually disabled. She has limited functional speech, she has aggressive behavior issues, she suffers from epilepsy, petit mal seizures. She has experienced 50 to 100 petit mal seizures a day. But thanks to the care and medical treatment she has received at North Jersey Developmental Center, her seizures are under control. In fact, I have not seen her have a seizure in at least 10 years. There are not enough services in the community for -- that would be equal to or better than what she's already getting at North Jersey Developmental Center.

I agree and respect the basis behind the Olmstead decision relative to intellectually or mentally disabled individuals having the desire, the functional ability, and the right to live in the community, an environment they believe best supports their wants and needs. However, not everyone living in a developmental center has the desire or the

functional ability to live in the community. My daughter would not survive in the community. She started in community. It did not work. She's been at North Jersey Developmental Center for 27 years, and she's received excellent care.

I just want to say that this concept of community placement-- I believe, and I submit to you all, that North Jersey Developmental Center is my daughter's community placement. She lives in an environment that her family believes best meets her unique needs. She lives with a group of people who are much like her. They fellowship with each other and have a common interest to live in a safe, secured, loving, caring environment. Her community at NJDC has street names like Maple and Willow Avenue, Sycamore and Hemlock Street, Linden and Walnut Lane, just to name a few. Her neighborhood has a healthcare center, a school, a vocational center, a hair salon, swimming pool, picnic area, basketball and bocce courts, all of the things you would find in the community so-called outside of North Jersey Developmental Center.

I would like to say to you on behalf of my daughter and all of the developmentally disabled living in developmental centers-- I ask that you take the necessary steps to stop the closures of these centers. I also express my sincere thanks and appreciation to you for allowing us to come before you and share our story. We need your help to save our loved ones' homes. Please do not let us and them down.

Thank you so much. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

SENATOR VITALE: Is there a Brent Sjaardema, Sheri Joyner, Louis Scesa?

What's your name, please?

**MARYLYN CARR:** Marylyn Carr.

**ASSEMBLYWOMAN VAINIERI HUTTLE:** I called you earlier. Is that it?

**MS. CARR:** You called me before, yes.

**SENATOR VITALE:** Sir, your name?

**ASSEMBLYWOMAN VAINIERI HUTTLE:** That's Brent.

**SENATOR VITALE:** And Joyner. (affirmative response)

Thomas Hines Jr., Louis Scesa, Steve Canale, Eugene Raisley, Kathleen Spinella, Susan Mason.

We have a chunk here, so we're just trying to get through the testimony. If you could summarize your comments, thank you.

First, we'll just start at this end of the table and work our way over. Use the long mike. Thank you.

**SHERI JOYNER:** Good afternoon.

My name is Sheri Joyner, and I thank you for the opportunity to voice my opinions about the decision that is being placed before us today.

**UNIDENTIFIED SPEAKERS FROM AUDIENCE:** Can't hear you.

**MS. JOYNER:** I'm sorry, Sheri Joyner. I wanted to thank everyone for the opportunity to speak today and voice my opinions on the decision that we're faced with today.

I'll be brief as I didn't really have the intention to testify. But I felt it was my duty to voice my opinion and speak on behalf of our most

vulnerable and voiceless citizens of the United States of America and residents of New Jersey.

My brother Kent Joyner has been a resident of Hunterdon Developmental Center for close to 40 years now. He is profoundly intellectually disabled, with many physical and mental disorders -- limited speech, partially blind, with little to no cognitive ability.

For most of his life he has only -- he has thrived and received the very best of overall care at Hunterdon Developmental Center. He considers it a lifelong home where he has developed lifelong relationships, not only with other residents but with staff who care for him deeply as if they were his family and he were theirs.

The high level of care that he receives allows him to thrive there and live a happy life given the hand that he was dealt at birth. An integral part of his overall well-being and happiness is knowing that his family is nearby and a short drive away. And he looks forward to those visits like clockwork, knowing that he will see his family and be able to interact with them on a weekly basis or however often we can get there.

I implore those who are working tirelessly to strip him of that happiness and well-being, as well as other -- those at other DCs -- to reconsider this decision. I'm not feeling any emotional tie from those who are making this decision. I challenge you to, when you lay down at night and close your eyes, think about if this was your life being stripped away without choice -- if it was your loved one, if it was your 5-year-old child being shifted somewhere, and not having a real option to live nearby and you would not be able to see him. Can you live with that? I'm not sure any of you have any personal connection to this decision. It sounds very

political to me and that's so disturbing. I implore you to think about that when you sleep at night.

We want to look beyond the politics and into your hearts, and think of this on a human level and imagine if this was your life or your loved one. Please stop, pause, and rethink the human destruction that we are embarking on.

Thank you. (applause)

SENATOR VITALE: Thank you.

MS. CARR: Hi, my name is Marylyn Carr.

My son Eugene Carr is at Woodbridge Developmental Center. He has been there for 37 years. That is his home, they are his family. You are destroying people's lives. Not only the people there, the people who work there, but their mothers, their sisters, their brothers. We're hurting. There is no emotion in any one of your faces -- not at all.

I want to ask you: Do you believe in God and God's words? Do you? Do I get an answer?

SENATOR VITALE: Ma'am.

MS. CARR: I want to ask a question.

SENATOR VITALE: I'm trying to answer your question. That was a question for us?

MS. CARR: Yes.

SENATOR VITALE: I can speak for myself. Yes, I believe in God, and yes I care.

MS. CARR: Fine.

SENATOR VITALE: But let me just make one correction -- and I said this up front -- unfortunately the decision to close the

developmental centers was made by the Governor. The Legislature can only do so much. We don't have the authority to overrule the Governor's decision. What we can do -- and I'm limited to this -- is to advocate for all the things that everyone has said here today -- to care for those who have been living in these institutions for all these years and contemplate what it really means to them and their families. And we take that very seriously. I'm from Woodbridge and I've been to the Center many times. I know-- I don't have a relative there, and I can't speak from personal perspective, but I can see what it means to everyone. We all do. And so as a Committee and as individual legislators, we're going to do what we can and hope to convince the Administration to make policy changes in that respect. We don't know if we can be successful. Again, the decision ultimately lies with him and the people who work for him. We are a separate branch of government. We make the laws, and the Governor either signs them, rejects them, or enforces them. And in this matter it was an administrative decision only legally allowed for him to make. And so it is that we will try to do what we can to right whatever wrongs we see fit and to support the families here today.

ASSEMBLYWOMAN VAINIERI HUTTLE: And I just want to add that the members on this Committee have opted to come here today. Connie Wagner is not on the Committee; she opted to come in and sub in for someone; as well as Shavonda Sumter has opted to come in and sub for someone. The Vice Chair and myself are sitting here trying to listen and absorb everything without interrupting the speakers, without giving our commentaries. We are listening intently.

If anyone else would like to share their sentiments, maybe now is the time.

ASSEMBLYWOMAN SUMTER: The only thing I would like to share is, yes, I am a believer. I believe in the Lord.

ASSEMBLYWOMAN VAINIERI HUTTLE: I only said the Assembly side. (laughter)

MS. CARR: Can I finish what I was going to say?

ASSEMBLYWOMAN SUMTER: And the other thing is, we have family, friends, and loved ones who work at North Jersey Developmental Center. By trade I'm in behavioral health, so I have a special interest in making sure that we are not doing harm to a vulnerable population. So I'm gaining a lot of information by the testimony that's shared today.

MS. CARR: My point in asking that question is that these are God's children. These are his innocents; the least among us. And he did say-- They are the innocent, they are the helpless, no voice, without sin, without an evil and selfish thought. God said, "What you do unto the least of mine you do unto me." I hope everybody can--

I don't know. All I can say to you, if you do this to these innocent children -- and they are children -- you may not pay for it in this lifetime, but you will pay for it in the next. This is how God judges us -- how we treat each other. And these are his innocent children.

SENATOR VITALE: Thank you.

MS. CARR: I don't think I can say anything else. Everything else has been said to you. We are brokenhearted mothers, fathers, sisters,

brothers. We wouldn't be here before you if we didn't need your help in keeping this place open.

I will never see my son again. I hope nobody ever has to go to bed at night and pray to God, "Take my son before you take me so I know he's taken care of." Please, I'm sorry.

SENATOR VITALE: It's okay. Don't apologize.

MS. CARR: I have paper's here. I have gotten the *Star-Ledger* and the *Home News Tribune* to write stories. They can tell you more that I have to say and what all of these people have to say. There are many people out there who know what's going on.

SENATOR VITALE: Thank you.

MS. CARR: I'm sorry.

SENATOR VITALE: It's okay.

Sir.

**B R E N T T. S J A A R D E M A:** I'm Brent Sjaardema. I live in Hawthorne, New Jersey.

I thank you, Assemblywoman Connie Wagner, for being in our midst today. And congratulations on your addition of Hawthorne to your legislative district. You were the Assemblywoman of the 35th District before we were redistricted.

And congratulations to you, Senator Pou, for your Senate victory.

My brother, John Sjaardema, lives at Woodbridge Developmental Center. It's been his home since the Center opened in 1965. I can relate to the respondent next to me when she talked about parents saying perhaps it would be a comfort to know that the child was

called home to be with the Lord before the parents passed on. But my parents didn't have that to comfort them. They let me know, as the only sibling, that they wanted me to become the legal guardian of John to look out for his interests. And I expect that my parents are looking down from above on me now, and they're with me here as I testify before this Committee.

I can remember as a little boy going down to Woodbine Developmental Center, in South Jersey, before Woodbridge opened. North Jersey had just women at that point in time. It was a blessing to be within an hour. We used to have to spend family time -- a whole weekend out of a busy schedule to go down to Woodbine. Woodbridge was a blessing.

Closing the only two developmental centers in the metropolitan northern New Jersey area would be contrary to Olmstead because it would take away the contact of the family, which is a huge, important part of the community. It's really important that the developmental centers remain open. These are vulnerable people. They're voiceless, but they're people who need your help, need your care.

So I come before you imploring you to do your best. I realize that it was not this Committee that made the decision. It was the Task Force formed by the Governor. I don't believe the Task Force was representative of the constituents who were involved. And I believe that this Committee, in all that it can do, is the best last hope to be able to retain these developmental centers for the blessing and benefit of the people who are cared for in them.

My brother has never spoken a word. He has a six-month developmental evaluation from a psychiatrist. This I know because this was

a necessary part of my becoming legal guardian. And he would be vulnerable in the community. He would not understand the risk of traffic. New Jersey traffic is pretty busy. And the risk in the community would be tough.

The last thing I'd like to say is, Assembly Speaker (*sic*) Loretta Weinberg has formed a committee to look at the risks associated with community living for the developmentally disabled. It is certainly premature to move forward in the closure of developmental centers before that report is in. I think her report needs to be looked at. And I think it's *prima facie* evidence that she has this kind of concern of the risk of community living, particularly for those who have profound developmental disabilities.

Thank you.

SENATOR VITALE: Thank you.

Mr. Hines.

**T H O M A S R. H I N E S JR.:** My name is Tom Hines. I'm from Woodbridge. My nephew is Henry Chomicki.

Senator Vitale, Assemblywoman Huttle, and Committee, I appreciate this chance to speak to you.

My nephew, Henry's brother, already addressed his health problems, which are severe, so I won't go into that part of that. Just to say that it is going to present a real difficult hardship for us to go to South Jersey to make a visit. We visit weekly, and this is going to put a real hardship on us.

Another thing I would like to say about the Woodbridge Developmental Center is that it was built years ago by a generation that

especially recognized the problems of the disabled. The buildings there are friendly to the people who need them. They're wheelchair accessible, special showers, bedrooms that can be watched from a certain area. You're not going to have this in a group home. There is specially trained staff -- doctors on call, everybody who is there.

This was done right. Let's not break with the good things that were done by the generation before us. Let's not let this commission tear down what's been done. This isn't broken; it shouldn't be fixed. It may need a little tweaking here and there. I hope you all will do everything you can to save the developmental centers.

Thank you. (applause)

SENATOR VITALE: Thank you.

**S U S A N M A S O N:** Thank you, Senator Vitale, Madame Vainieri-Huttle, and other representatives -- Senators, State Assembly Representatives of New Jersey, and Committee members of the State Health and Human Services and Senior Citizens Committee,

My name is Susan Mason. I'm an RN. I am licensed in New Jersey, but I live and reside in Florida. I'm a guardian of Katherine O'Brien, who resides at Woodbridge Developmental Center.

Thank you, all, for taking your precious time out of your busy schedules to hear the pleas of the families of those affected by the decision to close Totowa and Woodbridge Developmental Centers.

I currently reside in Florida, where a Federal investigational report was just published in September, 2012, regarding the Florida state system. As a result of that report, I cannot bring my sister to Florida for care. If New Jersey is moving to the future care of the mentally retarded

model from other states, then I encourage you to read that investigative report of the U.S. Federal government on Florida.

New Jersey remains a leader in the care of those medically fragile clients diagnosed with profound mental retardation and microcephaly. My sister has the mental capacity of a 7-month-old baby, and has survived to 52 years in Woodbridge Developmental Center. Never before, in the newest standards of care, have I seen her so well taken care of in the Center, with caring workers who are stable and knowledgeable in their positions. These are employees who care as their vocation, not for a paycheck. My sister requires total care and cannot speak for herself. Therefore, she depends on her family, her medical professionals, and caretakers to speak on her behalf.

We are all against this decision to close Woodbridge. No one surrounding my sister was consulted because my sister's care was not considered. Her rights to receive progressive, total holistic care are now compromised. Chances are high that she will be transferred out of my parents' reach, therefore separating her from her family, who are currently very active in her care, and isolating her from those who love and care most for her.

Community care is inadequate to meet her needs. While the law looks great on paper, the law only accommodates physicians, dentists, specialists, etc. to grant her one visit, then abandon or refuse her care thereafter, thereby dumping patients. That burden will then fall to the family to continually pursue medical care on her behalf instead of on-campus holistic care which is present in the Woodbridge setting.

The difference in the quality of care is stark and significant in positive outcomes. The parents of these clients in the developmental centers are aging and would not be able to navigate the system, thereby increasing their healthcare risks. She is 52 today for a reason. The institutional care is the right way to care for her. Her life expectancy before institutional care was significantly lower, and will decrease again if forced out of my parents' reach or into community care. This is inhumane and an atrocity to put the most vulnerable at such risk due to a decision made through a political agreement, not by those surrounding my sister who are intimately involved in her care.

Florida's state of health care is a warning for you on the path you pursue. Please change this and consider each clients' care on an individual basis, not by corralling them to their deaths.

On behalf of my sister, I thank you again for listening and hope your response will change this decision made by Governor Christie, as I am sure if this were his mother in the care of the developmental centers, he would not have signed such an agreement to close. He would have found another way, as I am sure you can. Take this moment to change a bad decision and bring peace and hope to my family and other families who await this decision's reversal. There are other ways to balance this budget without compromising the health care of the most vulnerable of New Jersey.

The link for the Federal investigative report dated September 2012 on Florida's service system for children with disabilities with medically complex conditions is [www.adag.ov/olmstead/documents/florida\\_findings\\_letter.pdf](http://www.adag.ov/olmstead/documents/florida_findings_letter.pdf)

Thank you very much for your time. (applause)

SENATOR VITALE: Thank you very much for your testimony.

I want to read some names of those who have attended this afternoon in support of this issue: Eileen Oujo, sister at Woodbridge Developmental Center; Mark Russilb, Hunterdon Developmental Center; David Schlett, from Edison, submitted written testimony; Sonia Watt, North Jersey Developmental Center; and Joe Caserta, from Morristown, New Jersey.

The next panel to come up, please, would be Khalilah Shabaz, Joan Butman, Dorothy Bakman (phonetic spelling), Helena Douglas, Terry Campagna, Cheryl Yacono, Gary Yacono, Cecilia Feeley.

Again, we still have a ton of folks here. I know you'd like to say a whole heck of a lot, and I don't blame you, but if you could, keep it kind of brief. Thanks. But get to the point; get to the meat of it.

Go ahead, whoever wants to go first.

**KHALILAH SHABAZ:** Good afternoon.

My name is Khalilah Shabaz, and I work at North Jersey Developmental Center. I'm going to make it very short.

Yesterday, one of my family members went to a group home. We were very sad. If you could have seen my baby look in my eyes and grab my hands, it was so sad. Everybody was crying.

Someone said that they have a choice. She doesn't speak, so she didn't have a choice. We are her advocates. Regardless of what we say, we know she's not going to make it in the community. And for someone to come into our home and take away our children -- it's sad. It's like the

government just has the right to do whatever they want to do to our children.

It's not so much a job. We are attached to these children, young people. We're attached to them. They're like our family. I take them home with me on the weekends and the holidays sometimes when it's allowed. They are my family.

This lady next to me -- she's there every day to see her son -- every day. And we're family.

I'm finished.

**TERRY CAMPAGNA:** And the love -- oh my God.

I get to sleep at night because of people like her who are there to take care of my baby.

There was a woman here who said that she prays, "Take my baby before I go." But since this has happened -- my son is going to be 30 next month -- I'm praying, "God, take him so I know he's safe." Because when you close these places, you destroy all of us.

And remind Governor Christie, that for each one of these babies he's ripping their homes away from, there are tons of voters behind them. Remember that these children are loved. They may not be perfect but they are our babies.

And this is the aunt right here. I have extended family who go and see my baby. On the holidays he gets to come home because it's local, it's geographically good. And he gets to be with the people who love him.

Let God guide you in this decision, because you don't want the blood of these children on your hands. Because there will be a day of judgement. God is real, and he is returning. Know that. (applause)

**JUDY NATOLI:** I will be brief.

My name is Judy Natoli. I live in Cedar Grove, New Jersey. I would love for Governor Christie to come and visit us, being that he was unable to come here today.

From what I understand-- I guess he doesn't care much about his voters, since I heard he's in California trying to collect money from the GOP. And I feel shame on him. He should have been here today to hear everyone -- their hearts aching.

I'm almost done.

**MS. CAMPAGNA:** You tell them, Judy.

That's my sister. (laughter)

**MS. NATOLI:** And it's true. It's all about family.

It is so disheartening to even have to have this conversation with each and every one of you.

I will make it brief. But I can't believe of all the places to try and save money, they take it from the disabled. Shame on him.

And I want to say to all of you up here-- One of you -- all of you should have said-- When this came to the table you guys should have said, "This is a nonissue. This is to be taken off the table. Get the money from somewhere else."

**GARY YACONO:** I want to thank you. I know it's been a long day.

My name is Gary Yacono. I live in Rochelle Park with my wife Cheri. I grew up in North Bergen -- little connection there.

This is going to be as brief as I can make it. I cut most of it out but I will leave it behind with you.

I found out from a Kathy, a state representative of New Jersey, that they were closing Woodbridge. I asked her if I could see a copy of the Task Force report. She said, "The report is not done yet, but we know what two centers are being closed." So that was a little of a shock. How do you know what two centers are being closed and your report isn't even done yet?

We represent -- the guardian of my step-nephew, legally, Billy Blank, who is a resident of Woodbridge. He was there for 44 of his 50 years of life. I remember him visiting when I was 11 years old -- only a few years ago.

The employees there are his extended family and loved ones. His daily routines in the place he has lived his entire life is all he knows. Please tell the Governor, "Don't foreclose on his home," or we'll have to foreclose on his home next election. (applause)

Imagine if you will, yourself, with health problems such as Billy, in a wheelchair, unable to communicate by speech but only by gestures and noises he can make; knowing the same surroundings your entire life; the mental capacity of a child, at 50 years old, yet very aware of other people. They know who they are. He knows his surroundings. He throws kisses to workers, the employees, his family at Woodbridge. They love him there. They told me at his last meeting, which I go to every year, that he helps them when another patient there is in trouble. He actually makes noises and let's them know. So he actually helps them.

All during these meetings we said, "We don't want him leaving Woodbridge." I just got a letter in January telling me, "Come to a meeting in February and tell us what community placement do you want to put him

in.” It’s been in his records for years -- every year, including last year -- that we don’t want him in a community setting. He has medical problems. At Woodbridge, he gets immediate medical help. He throws kisses to all those employees who are there who he loves. And they love him. The hugs all go around, as somebody said.

I will hold the Governor and this State responsible for any health problems or negative issues that may affect Billy from any move if he loses the only home he has ever known.

The *Record* newspaper reports -- let’s get back to that Task Force report -- how inadequate it is, and how terrible it is -- the Task Force that the Governor put together. The *Record* newspaper reports that there are almost no available beds at the Hunterdon and Greenbrook facilities. They are the only other two centers slated to remain open in the northern part of the state -- if you want to call them north of -- northern New Jersey.

Don’t force older relatives and others to visit these people in developmental centers. The centers that are staying open are 91 miles, 131 miles, and 145 miles from Totowa, and even further from their homes if you live in Bergen County, like some of us do. This is a hardship on them, makes them spend more money for tolls and gas. You heard today that many of them will not be able to do it. And do you know what? It’s not environmentally sound to be burning all the fuel, is it? Let’s get green in New Jersey here.

Vineland was to close, and this decision was reversed -- which was reported to be a deal between Governor Christie and State Senator Jeff Van Drew from Cape May County, which includes Vineland. Let’s keep

politics out of this decision. We know you're all on our side. We're speaking about people's lives.

I'm going to ask the Legislature -- all of you fine people here who represent us so well -- to tell the Governor, who also was elected by the same people who are sitting here today-- And they're sitting here on Ash Wednesday. They've taken time off from work. And I applaud all of them who arrived here today for doing that.

Serve all the people of this state -- that includes these people in these centers -- do the right thing. Tell them, "Stop this and reverse this decision." He wants to be President? Well, reverse this decision. Do the right thing. Stand up, open your heart. If he has a heart, tell him to open his heart and keep these developmental centers open for all those who need them.

Little Billy-- He has been there his entire life since he's 6 years old. I've been going to Woodbridge since I'm 11 years old. And I'm here now; with his mother, his grandmother, his step-grandfather in heaven. And I'm legal guardian to protect him. Please help me protect him. Tell us what we need to do to keep these centers open.

The gentlemen who talked about community placement -- the numbers don't add up. We have people on waiting lists. We don't have enough community centers. And they want to close two developmental centers. The numbers don't add up. The dollars might be in Mr. Christie's budget, but the numbers don't add up. We have more people who need these centers. And we are all here today standing up and speaking up to them. Do you know why? Because they can't; and we need to protect the people who can't protect themselves.

Thank you so much for being on our side. (applause)

**C H E R Y L Y A C O N O:** Hi. I'm Cheri Yacono. This is my husband Gary. And I am co-guardian to Billy, should, God forbid, anything happen to my husband.

Billy's mom, unfortunately, died from cancer in 2000. She visited him two or sometimes more times a week despite being a single parent -- divorced parent -- with a lot of other medical issues of her own.

He is unlike many of the people who were mentioned today in the same developmental center and others. He is not thinking or behaving a child, but *childlike*. He is considered an age of about 7 years old. Because of this, we have been told -- and Gary just mentioned -- my husband just mentioned another letter we received -- not that we're surprised -- again, that we're supposed to be talking about placing him in a group home.

Just because you are able to make gestures, recognize and understand what people say, and you have some abilities beyond some of the more developmentally challenged people in the same setting, does not mean that you will be happy in a group home. This would be a punishment to him. He would only understand this as taking him away from the only love and home he's ever known in his entire life.

The people who are there are, indeed, his family. If there are any of you here today, please stand up and acknowledge yourselves. I would love that. Unfortunately, so much time has gone by, I'm sure anyone who was here earlier has probably left, because everyone has other things they need to do today. But these people are his family. They love him as one of their own. They have taken him on trips to the stadium. His great love is baseball and sports. They make sure that he has a working television

and that he has DVDs and things that he needs, from the small fund he gets from the State to make his life a loving one. He would not receive this at an outside facility we know would be manned by people at minimum wage who would be transient, looking for another job, who would not be properly looked at in terms of their background. I don't know if the Arc people are still here. Please, try to tell me that all of these people -- you look at every single one of them -- at their backgrounds, and you'll do a background check with every one if they're only going to be there a few months. And then you're going to have someone else there. Please try and tell me how they're going to have the comprehensive background, as the entire team Billy now has at his disposal, at these group homes. Because I don't buy that. I don't see how that's possible. And many of the people who have been discussed here today have far worse situations than my nephew has.

Our fear -- all of our fears, and the reasons we can't sleep at night, and the reasons we watch the newspapers, and the reasons we plead with you here today and our Governor to do something about this -- is that these people dear to us will no longer have quality of life. It will be taken away from them without their having the ability to say anything about it at all.

And I dread the day when I may be responsible, or my husband, for telling him, "I'm sorry Billy. We have to take you away from your home." I don't even know how to go about doing that. It was difficult enough to tell him about the death of his mother.

If any of you have people in your lives similar to this, please try to understand from where we come. If you do not, try to put yourselves in

our position. It is not an easy one. We do not ask this because we don't have anywhere else to be or because we're being selfish. On the contrary. We're trying to look out for people we love and do what's best for them.

I thank you for listening to us. I hope you will do your best to change the Governor's mind. And I agree with my husband. If he really feels this is the best course of action, my course of action will be other than voting for him. And I will encourage everyone I know to do the same.

Thank you very much. (applause)

SENATOR VITALE: Thank you.

Cecilia Feeley, Jacqueline Guillot, Steve Hazen.

**S T E V E H A Z E N:** There are four of us, but we'll have one speaker.

SENATOR VITALE: Okay.

MR. S. HAZEN: You can call others. I was just going to stand behind my brother.

SENATOR VITALE: Your brother will speak?

MR. S HAZEN: Yes, he will.

**C A R L V. H A Z E N:** I have a written statement here.

SENATOR VITALE: In the interest of time, we're just trying to--

MR. C. HAZEN: Let me make this very, very brief.

SENATOR VITALE: Thank you.

MR. C. HAZEN: I passed in the written statement. I timed it yesterday. It was 2 minutes, 36 seconds. I was really trying to be good, because I heard 3 minutes was the limit.

Our story is -- Michael John Hazen -- very similar to everyone else's story. He can't live in community placement. He lives in Woodbridge. That's his home; that's been his home for 40 years.

I am a school teacher. Every once in a while some kid comes up to me and needs something. And I'm lucky because sometimes I can actually do something for them. Sometimes I get to be Superman. That happens once in a while, and it's really cool.

This is your day to be Superman or Wonder Woman. So good luck. I hope you guys can do something for us and for this huge crowd that has spent the day here with you.

Thank you very much. (applause)

SENATOR VITALE: Thank you for your time. Thank you for waiting.

Kathryn Bergin, Barbara Cockefair, Gaylord and Marie Reid, Carol Conkling, Edith Servino.

ASSEMBLYWOMAN VAINIERI HUTTLE: Did you want to start with the mike? (affirmative response) State your name again, please, since the Senator -- I probably did not pronounce it correctly.

**KATHRYN H. BERGIN:** Kathryn Bergin.

ASSEMBLYWOMAN VAINIERI HUTTLE: Oh, that was an easy one.

Welcome.

MS. BERGIN: I'm a retired special ed teacher. My daughter is 58 years old. She has lived at North Jersey for 48 years. She's physically strong because her past medical problems were cared for promptly and correctly. She is quite independent in the cottage. She can use the elevator

alone. It's just two stories. She has her own room, furniture, and TV. There is an RN dispensing medications. And the clients eat at the cottage, which is attractively decorated and changes with the seasons. She needs specially prepared food because she has no teeth.

Her daily activities-- She can walk too. She attends church, goes on trips, enjoys cottage parties, and attends camp at (indiscernible), Pennsylvania in June. I take her to lunch every Sunday because I live only 25 minutes away. Sounds good, right? However, she can dress herself but cannot tie her shoes or shower independently. Her eyesight is very poor. She is afraid of stairs and having an open railing. Most importantly, she has no speech. She has a rare syndrome called Rubinstein-Taybi. It's caused by a gene alteration in the first trimester. No speech was one of its symptoms. She communicates quite well, with those who know her well, by gesturing, a few sounds, body language; but will be totally lost with strangers at a new facility.

As an example, one day there was a substitute nurse in the cottage on duty. When my daughter went in for her meds, she kept striking her hand on the counter. The nurse asked the staff, "Why did she do that?" The answer: "She wants you to crush her pills before she takes them." She cannot swallow lumps. She would be lost if they did not know that.

Closing North Jersey and Woodbridge is wrong and poor planning. North Jersey (indiscernible) for clients who are too physically handicapped to live in one of the cottages. They will need a nursing home. There are, as we know, around 9,000 or 10,000 people in New Jersey at home waiting on the list for years for community placement. Suddenly,

700 clients are ahead of them for all those mythical group homes. Those at home and their parents are all getting older. Keeping North Jersey and Woodbridge open, and developing Vineland into a geriatrics facility, would be wise. This will be needed soon.

Thank you. (applause)

**B A R B A R A C O C K E F A I R:** I'm Bobbie Cockefair, from Pompton Lakes, New Jersey. Kay and I have been friends, and bonded since the early '70s. I've raised our special child at home where I sympathized with Kay's problems -- or joys -- down at the Center.

I hope you keep the Center open. I know how important it is. So often I'll say to Kay, "Let's do something after church," and she'll say, "Oh, you know I go down and have lunch with Jenny." I go, "Oh, I forgot." But I know she's devotedly done this for years and years.

Now, because I've had a son at home, I became a leader many, many years ago -- I think it's 31 years we've had an Explorer Post that has provided recreation, dances, Bingo parties. The Pompton Lakes Elks sponsor us. I know the effort that it takes to do this, because guess where the buck stops? I'm the one who starts the dances, I'm the one who does-- It's too much. I'm the one doing it.

In the community, you ask DDD, any of the case workers-- "Oh, well, they don't have that service, they don't have the other service." We have to go miles for dental care. Now, parents cope with this because they're younger. Now you can see I'm getting a little snow on top. This is getting harder and harder to do. But I do know we have many who come out of North Jersey -- come into the community and don't successfully

succeed. It is not the easiest thing to do -- to come into the community when they've been in an environment.

Also, I'm a Special Olympics coach. We will lose our bocce courts because North Jersey has the only bocce courts anywhere around. So this means my bocce team will not be training. Also, we go there for the basketball skills. So there are things like that I'm going to have to chase up some school that will host the basketball skills for the Olympics. So closing North Jersey needs to be-- It needs to be open. (applause)

SENATOR VITALE: Thank you.

**M A R I E R E I D:** Hi, my name is Marie Reid.

My daughter is at North Jersey Developmental Center. When she was 10 months old she had measles encephalitis and it left her with brain damage. She was in a special ed class. By the time she reached 18, her behavior -- we just could not handle her at home anymore because we had to go to work. So on an emergency she did go into North Jersey. She's been up there now 28 years, and she's doing wonderful now. The staff there is great with her, and she gets great medical care. She did have a lot of seizures, but they have those under control now. She made a lot of friends there, and I would just hate for the centers to close. The State really needs them. And I always say that our Governor -- he should be proud that he has places like this to put our special clients in where they need to be. I'm not against group homes. A lot of clients can function in a group home. But I know my daughter cannot. So I hope you can help us change that decision.

Thank you. (applause)

**GAYLORD REID:** My daughter Stephanie has been at North Jersey Developmental Center for the past 28 years, and this move is very upsetting to her as well as to our family.

We do not understand the logic behind this decision by Governor Christie and his Task Force to close the Developmental Center, which provides the necessary level of care and supervision for each individual client.

Moreover, this Governor has no idea what is best for our daughter, but we do. We feel that our daughter is being pushed out in a community that will not understand her and her special needs, and people like her. I know she will not get the same care and level of supervision she receives at NJDC. The caring staff at NJDC oftentimes take the place of the family for the many clients who do not have families or no one to speak for them.

When my daughter first went to North Jersey Developmental Center in 1984, she had very, very bad behavior problems that my wife spoke about. We could not keep her home anymore. We had to go to work, which was very difficult, but we made that decision. The Center has done such great things for her. We are happy with the way she has come out and the friends that she's made there, the staff.

I'm the President of the Parents' Council at North Jersey Developmental Center for Cottage 1 that houses 30 to 34 girls. These are unbelievable -- the young ladies we take care of there. And every second or first Sunday in December, I have the privilege of being Santa Claus. And when those girls come out and see me in my red uniform, they treat me like I'm six feet tall. I'm only 5'7." (laughter) But they give me such a hug,

such love, such compassion that you would not believe. And to this day when I visit there they call me Santa. That's my name. That's one of the big privileges I've been blessed with in my life. And I would not like to see that changed.

I appreciate you guys being here. I know it's been a long day. But we do say thank you very much -- from the bottom of my heart.

In closing, I want to say something I heard a long time ago when I was young, and I always kept it in my head. "There will be people who will, at some point, not know what happened. There will be people who will watch things happen. And then there will be people who will make things happen." We ask you to please make this happen for us. We really need your help.

Thank you very much. (applause)

**EDITH SERVINO:** My name is Edith Servino. I'm here with my sister Amelia Keyes.

We are here to give voice to our brother Joseph Servino, affectionately known as Joey. He currently lives at the Woodbridge Center. Joey cannot speak with words, so I'm going to briefly tell you what he would say right now.

"Please, at my age of 63, and after 47 years being in my home at Woodbridge, do not take this away from me and take me away from my friends and neighbors whom I love and love me deeply. My disabilities are many, and I have many medical problems. I need the quality of care that has been given to me -- testimony to the love I have.

“Like you, I want to be happy. I need the Woodbridge Center to safeguard my protection since I cannot talk, walk, or defend myself. Please help me and my friends.

“Thank you.

“Joey Servino.”

And from my heart, I thank you for your care and compassion, and ask you to further advocate for all of the people we speak about today.

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Next, we have Amelia Keyes, Dee Galluccio, Alan Ferrer, Daniel Kardash, Essie Feldman, Winnie Sekela, Marvin Schwartzman, Rona Waltzer, Carrie Miller, John Cilia, Barbara Duda, Donna Vacca, Frances Finkelstein.

Welcome.

If you would like to start, state your name again, please.

**A L A N F E R R E R:** My name is Alan Ferrer, and I’m here for my brother Chucky Ferrer, who cannot speak for himself.

I’m going to read a letter. Actually, it’s a postcard right now, it’s been here so long.

Our State government has decided to close the Woodbridge Developmental Center within the next five years. I’m appalled by this decision. All of a sudden Woodbridge was chosen. Why? My brother has been a resident since he was 11. He is now 58. He needs 24/7 care. The community cannot take care of him. Woodbridge Developmental Center has an excellent staff of doctors, psychologists, nutritionists, social workers, and all kinds of therapy. They even have a hospital on the premises.

The place is clean. The staff always meets with me every year to acquaint me with everything they are doing for my brother. The goals are always set for his well-being. And once he meets those goals, they set new goals. They've never stopped trying.

Our State says that the Woodbridge Developmental Center meets certain criteria in order to close. What is that criteria? What is really behind this closure? Is there a land developer who is interested in the properties of Woodbridge Developmental Center? What will happen to the residents? Can they take their place in the community? Is the community equipped to handle them? Could there be another Newton, Connecticut, coming from that?

And the only thing I can say in conclusion is that we have to have these questions answered or we'll end up regretting this closure for the rest of our lives. That's all I have to say.

Thank you for listening. (applause)

SENATOR VITALE: Thank you.

**F R A N C E S F I N K E L S T E I N:** Distinguished panel, my name is Frances Finkelstein.

My son is at North Jersey Developmental Center.

You all have a copy of my statement, so I'm going to make it brief.

Our son has multiple and profoundly complex psychiatric and developmental diagnoses. We have grave reservations about this change based on our son's previous disastrous past experience living in a group home, despite the fact that my husband and I were both serving on the sponsoring agency's board of directors. And, in fact, my husband wrote the

grant for the home, which was not the agency's first. However, he does have very challenging behaviors as well as being mentally retarded. He has a mental age of about 6 or 7. He has 12 sets of pills when he comes home for a visit -- 12 individual, different types. So you can appreciate what they were probably up against, as well as we were. He's been at North Jersey Developmental Center for five years now. He lived home until he was 26; he's 54 now.

If the Division of Developmental Disabilities is unable to show us group homes in this area that they consider suitable, how can they possibly replicate the highly professional medical and direct care services that he currently receives to maintain his mental, psychological, and physical equilibrium? It's as if the State is trying to sell us parents and guardians an automobile that has yet to be designed. It's a "trust us" moment.

North Jersey Developmental Center needs to remain open for those individuals for whom living in this safe village offers more intensive services, skilled staffing, and personal freedoms, as intended by Olmstead, than would be accomplished by massive dislocations for fragile individuals and dubious promises of trust.

My real question is: What's the fallback plan? Given that my son was in a group home and failed disastrously to the extent that his case manager -- his State case manager said he's not fit to live in the community, and he went into Ancora Psychiatric Hospital for two years, and then went into New Lisbon-- If this happens again, what's the fallback? I really need that kind of information before we can make an informed decision.

Thank you for your consideration. (applause)

**CARRIE MILLER:** Carrie Miller.

My brother John Miller -- we refer to him as John-John; the school refers to him as Johnny -- has been at Woodbridge Developmental Center 34 years. He has an equivalent of about a 6-month-old. He needs total care for eating, drinking, being washed, dressed -- all his needs. He has a seizure disorder that they have brought under control over the years. And I feel it's because of the staff -- all the staff who are there.

When my mom put him on the list, we were told it would be a 10-year waiting list for him to get in. So in rare form it happened in less than a year -- that there was an opening. So the family made the decision to put him there.

We feel if there was a group home that was suitable for him -- we would have him at home if that was how it could be. We feel the school meets all his needs. He's happy, he's content. When he did change cottages quite a few years ago, it took time for him to adjust to it. He will bite into his wrists, he will punch his face when he's not happy. So he will self harm himself. And the concern for our family is that he will not adjust well to being moved from the only place he's known as home his whole adult life. He's 41 now.

And the only other group homes that are going to remain open are more than an hour to a couple hours away, which would be a burden. I'm primarily the one who visits, although he has nieces and nephews, and great nieces and nephews who come once in a while with me. I'm the primary one. It used to be me and my mom, but she passed away in October, otherwise she'd be sitting here arguing.

The staff there loves him, takes care of him. And I think for all us families, that's what gives us peace of mind every day to go on with our lives and be able to do what we do. I was a single mom, brought up my daughter -- and knowing that he's cared for.

So I just hope and pray that my brother and the other residents will all be allowed to remain in what's considered their homes. And my questions are the same as this lady and this gentleman, so I won't reiterate them.

**ESSIE FELDMAN:** I'll be brief for you.

My name is Essie Feldman, and I thank you for letting me speak here. Maybe it will give you some cause to reconsider closing Woodbridge.

My brother Howard Warringer (phonetic spelling) has been there since he was 14 years old; he is now 58. My parents, when they passed away, left him to me. So now, as the older sister-- Actually, he now thinks I'm his mother, I think, because he doesn't leave me alone.

He's been there for so long, and he needs the care that he gets. I think in speaking with all the people you've heard, you don't hear any complaints. We don't have a complaint. We have nothing. The people there have been so kind -- the people who work with him. And it takes an army to take care of my brother. If he could be at home, he would be with me.

This is my brother. Tomorrow -- it's funny -- it's Valentine's Day. He was born on Valentine's Day. He will be 58 tomorrow. He's been there for so long. And if you think a group home would be suitable for him, I would be thrilled to put him in a group home. Do you know why? I

would think he was near normal. He isn't. He is not near normal. He runs out into the street. He doesn't know about-- The refrigerator -- he would have that refrigerator door right -- it would be off. He is so strong; he's powerful. You just can't-- I mean, when I come to visit him he takes my wrist so lightly -- and I'm across the room. And they have to say, "Howard, she's not a ragdoll. Slow down." So we can't put him in a group home. It wouldn't be suitable. He can't do stairs even though he does walk.

Woodbridge -- I don't know if any of you have been to Woodbridge. Have you? Woodbridge has the ability to be a model institution. It has everything. It has grounds, it has the facilities for the residents there, it has a hospital, it has everything. When I go there, I can actually walk down to the canteen and take him to the canteen and sit there for hours with him. And when I walk on the grounds of Woodbridge, it is so quiet and peaceful. I'm happy that he's there.

I don't know what everybody is actually thinking. I have some questions. We're shooting things at you, but I'm not getting any answers. My questions are: Have you actually ever seen Woodbridge? Have you actually ever gone there to see the residents who are there? I just saw something that Harriett showed me. It said 76 percent of the residents there are nonambulatory. What does that tell you? And the wheelchairs that they have -- I've never seen wheelchairs like this in my life. They are contraptions because a normal wheelchair -- they can't -- these people can't sit in a normal wheelchair. And I know for a fact -- for the group homes that they did open -- the neighbors are very, very irate. They don't want these people in their home. They don't. They disturb the block. It's not funny. It's a serious, serious problem.

SENATOR VITALE: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: I just want to answer you quickly. We had the Assembly Committee take a tour of all seven centers, so most of us have seen Woodbridge. I don't think the issue here -- with us anyway -- is that there are any inadequacies with any of the centers. That's not the issue. The issue is the potential closure of two in North Jersey -- geographically -- which would affect most of the families here. And secondly: Are those resources being placed into the community? We don't have the answers as well. So we're trying.

We're trying to have you vet and make your comments. And we are going to take this testimony and probably produce a white paper. I think the Senator and I are speaking about producing this as an executive summary that we can present not only to the Legislature, but to the Governor. And we would continue to ask for your advocacy and your comments to implore the Governor and the Administration. Because this -- especially this Committee anyway -- with Senator Pou and the Assembly members here -- we hear you. And we are trying to be the voices for the voiceless. But it is just this Committee. And so we're trying to get the answers, and we're trying to forward these testimonies and remarks that all of you have given so passionately today.

MS. FELDMAN: The bottom line is: Do you really think it's going to help? I mean, we're sitting here tearing our hearts out over this.

ASSEMBLYWOMAN VAINIERI HUTTLE: We're being streamlined. Hopefully this will be presented so people can hear this, the Administration can hear this. This is why we were asking before for no

applause so we could get the comments and testimony down without any interruptions.

I can speak for this Committee. We are going to take your voices to the rest of the Legislature, the rest of our colleagues, and the Governor.

Thank you.

MS. FELDMAN: The other thing is that many of the residents there today have no parents left. It's up to the siblings now. You can see all these residents are in my brother's age bracket. And I'm much older. I could be my brother's mother, I'm that much older than he is. And what is going to happen in a few years if I'm not around and something happens? Are they going to be shifting -- changing gears again?

These things, for these individuals -- it's not like you and I. We can adjust to the changes; they can't. They can't speak, they can't do anything. My brother speaks repetitively. "It's cloudy, it's raining, be a good boy," over, and over, and over again. That's all he can say.

SENATOR VITALE: Thank you.

MS. FELDMAN: It's very hard.

Thank you.

**D O N N A V A C C A:** Hi, my name is Donna Vacca. I'm the sister of Paul Vacca.

He's been at North Jersey Developmental Center for the past 21 years. He is now 51 years old. He was home at the time. My parents, of course, got older and couldn't handle him.

To move him out of North Jersey would be a real heartbreak to my parents. They're up in age; they can't drive as well. It's going to tear them apart.

He is profoundly retarded and has cerebral palsy. He does not walk steady. He needs 24-hour care. He cannot take care of himself at all. If he is moved out of his home where he is now, he will regress. He has regressed in the past. That, we know, for sure. I got married, I moved out of the house, Paul regressed. Paul would not-- My father was up 24/7 with him every night. Of course my father was working at the time, and it was very hard on him.

I just ask if everyone would please consider not closing the developmental centers where Paul and all the other clients feel safe and know their surrounds. That's all.

Thank you. (applause)

SENATOR VITALE: Thank you.

John Pydyszewski, Nancy Maza, Diane Ferrara, Lori Centrella, Marygrace Zetkolic, Mr. and Mrs. Fred Maier, Tom Damiano, Gary Mortoro, William Holy, Debra Trepkau, Patricia McMillan, and last name is Urion.

**D E B R A T R E P K A U:** My name is Debra Trepkau. My sister is Jane Dundaro. (phonetic spelling) She is at Cottage 18 at Woodbridge State School. She's like everybody else they described. Her birth certificate says she is 53 years old, but physically and mentally, she's about six months old -- between three and six months old.

When she first got to Woodbridge, she was about 12 years old. She wasn't there very long and ended up in the hospital. After a lot of

tests, and back and forth between the regular hospital and the Woodbridge hospital, they found she had major kidney problems. They told our family that her lifespan would be short, and now she is 53 years old. And that is due to the staff and doctors at Woodbridge State School. They have taken excellent care of her. She is blind, she has seizures -- the whole realm like everybody else.

When I went through my bout of cancer, I did not have to worry about Janie because the staff took care of her. All I had to do was make phone calls to check up on her, and I knew she was fine.

I read the article in the *Star-Ledger* about Vineland, and I was very disturbed. I don't understand why they have to close both schools up in the northern area. I live in Parsippany. So for me to go down to any of the southern area facilities -- that is a long hike for me. Unfortunately, due to the cancer, I cannot drive that far down. You're talking four hours for me. And I'm the only one. I have an uncle who is elderly who goes to see my sister, and he can't make that drive. I don't think that's fair to any of the families to do that. And I'm sure a lot of the families now are getting up in age.

My sister would not do very well in a community setting. She just could not handle it. Some of her caretakers have been taking care of her for 30 years. They know her inside and out.

I would ask you all to think how you would feel if they came up to you and said, "We're taking your home away from you, and we're putting you in another house that you have no say about." And that's what you're doing to them.

I got a letter from the DDD saying I have to pick a place. And if I don't pick a place, they're going to pick it for her. It doesn't matter what I pick. They're just going to pick it for me anyway, and I don't think it's fair. She needs to stay at Woodbridge. That's been her home for over 40 years. I still think they cannot take both schools out of the northern area, because it's not fair to all of us. (applause)

SENATOR VITALE: Thank you.

**GARY MORTORO:** Hello. My name is Gary Mortoro. I grew up in Brooklyn, then Bergen County. And, unfortunately, now I live in Florida.

Before I was talking about transferring -- and that's the case down there for 30 years.

I hate Florida. It's a backwards state -- politically backwards. And the kind of corruption we see there, we see here. But here's the difference -- basically what I'm trying to get at. The Northeast has always been one of the most progressive areas educationally. We see collapse in everything in our society. This is just one tiny aspect of it.

I am 63 years old, my sister is 61. I had three older brothers, two were stillborn, the third one lived and then died. And my parents were Italian American -- very much for kids. I came along, Prince Charming. Then they tried for a second one, and my sister was born two years later.

Because of the miscarriages and the fact that my mother used to pass out often because of low blood pressure, she was to have no medication. As a result of a medical error, she was out for 15-and-a-half to 16 hours, never felt the birth-- That was the cause of her retardation. I'm

just stating that because of the different types, etc., so that you have an idea.

From the time she was born it was close to a year before the doctors said they really knew. She didn't meet certain criteria of development. And they said, "You have to think of the normal one." So they placed her at a very young age of 5 -- and I will go back to that in a second -- because I have experience -- it seems like with everything I've heard here today. But it's a lot of frustration. Somebody mentioned apples and oranges -- this is incredible.

My love is marine biology, fish, and music. So I was pre-med. I did oceanographic research and come from a science background. They say, "Think outside the box." We all use the saying; we all hear about it. Everybody says it; very few apply it to the reality -- the box being whatever it is you're involved with in life.

This whole concept of closing down these facilities -- which has occurred before -- the disgrace under Whitman. Thirty years ago, in the early '70s, my mother protested in Trenton. I said, "Mom, you might get arrested." She said, "Good." Right now I feel the same darn way.

This is the most unconscionable -- unquestionably the most inhumane consideration or action that is about to occur -- or has occurred with states that already have gone on--

My sister is completely, profoundly retarded. She's ambulatory, never spoke a word in her life, measurable IQ -- as most are at Woodbridge. She doesn't know me intellectually as a brother. I come from Florida in a heartbeat. If she's sick, I'm up. I come periodically to visit. As soon as I can, I'm moving back up to this area.

But the point is, years ago I was told -- in comparison of states -- and I just want to confirm that -- don't even think of Florida. That's how superior we were. And I was talking with representatives from Indiana several years ago before the incidents they had there with the governor and closing the DCs.

Anyway, to me, it's a completely unconscionable act. Studies have been done. People are mentioning mortality rates. I'm sorry. I wrote a speech out, and then I said -- I just got in from Florida -- and I said, "The heck with it. I'm running late. I'm just going to go by the gut, and I hope I don't cut off or -- I probably will miss things."

When my sister was first placed in the Jersey system, it was in the early '70s -- my father died in the '60s -- approximately '71 to Vineland. She stayed there a short while and then was transferred to Woodbridge where she still resides. We lived in Bergen County. On summer days, that drive on the Parkway was a six- to eight-hour drive. So I completely sympathize with what people are saying here.

I completely feel terrible. I think Governor Christie is a sharp guy, sharp individual. He knows how to dance. He knows how to dance politically. We've seen the 13 and the 16 shoes come on already, and we've seen reaction here. But I thought with the sympathy that he had for his mother's breast cancer there might be more of an understanding for this type of situation. I've written Governor Christie letters since October. Somebody requested a meeting -- hey, at this point I'm ready to forget it -- I just finally got a 51-word answer telling me that.

These are people who don't understand. You can't tell them, "Go brush your teeth, go through that door to the restroom." You're there

with them every minute -- not all -- we're talking about the most profound. And listen, as an underlying principle-- I'm sorry. I apologize for not -- if going over time. Just give me a heads-up or something.

But these are the most profound. That's all I can say. I mean, you can be completely profound by being nonambulatory. But these are mentally as well.

We are well aware of abuse nationwide. We are well aware of the snake pit reference that was made before to the institutions of the old time. Robert Kennedy -- 1967 -- said, "Let's close this snake pit down." Does anybody remember that one? I'll get back to that in a second.

ASSEMBLYWOMAN VAINIERI HUTTLE: Gary, I'm sorry to interrupt. Could we get back on point, because we have--

MR. MORTORO: Yes, I am. I'm sorry.

ASSEMBLYWOMAN VAINIERI HUTTLE: You can fast forward to 2013. (laughter)

MR. MORTORO: Okay, anyway--

ASSEMBLYWOMAN VAINIERI HUTTLE: I'm sorry. It's just that we have a few more speakers.

MR. MORTORO: No, no, I'm sorry too. I'm overstressed, overtraveled.

ASSEMBLYWOMAN VAINIERI HUTTLE: No, we understand. We're listening, but--

MR. MORTORO: I know, I have to hurry it up.

ASSEMBLYWOMAN VAINIERI HUTTLE: I was afraid we were going to go from '63 and go back--

MR. MORTORO: Oh, no, no, I just wanted to--

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

MR. MORTORO: We heard in the presentation with Vineland -- was subject as the target -- the closing. Remember the abuse with the amputation of the arm? Why? Why did we do this? Sensationalism. We'd show the bad stuff happening in the institutions. That will happen in any institution. That will happen in any hospital, any group home, any personal family home.

Now, why I mentioned that -- in '63-- In '63, this government, as you know, experiments -- and still does -- funded by the CA and the military-- My sister went to Willowbrook by the advice of all the doctors. Think of your normal son, 5 years old-- She wasn't-- Anyway, it was an experimental nightmare. And if any of you are interested -- Carol Rutz -- R-U-T-Z -- 2001 Indiana lecture. She goes into what was happening in these institutions. And that's why they got such a bad name. And Nick Trent (phonetic spelling) was one -- "Get rid of these people. We don't want to see them. Put them in the communities" -- I mean "put them in homes." And then you see a change in opinion because people are looking for answers. We don't have the answers, unlike breast cancer, unlike many others. This is completely 100 percent hopeless.

SENATOR VITALE: Sir, could you--

MR. MORTORO: My sister--

SENATOR VITALE: We need to move it along. If you could send us all of your research and your documents in writing to my office and to the Assemblywoman's office--

MR. MORTORO: I had sent you a letter, Senator Vitale. And I appreciate--

SENATOR VITALE: If you have some of the documents and research, that would be great.

MR. MORTORO: Yes, I just--

SENATOR VITALE: I know you brought up a whole stack up there with you.

MR. MORTORO: Oh, no, no, that was for myself.

SENATOR VITALE: For your notes.

MR. MORTORO: I just got off the plane yesterday. My suitcase -- and everything was (indiscernible)--

SENATOR VITALE: No problem. We gave everybody a minute to make their presentation, and we're well past that.

ASSEMBLYWOMAN VAINIERI HUTTLE: We really didn't follow, but that's okay.

MR. MORTORO: Can I have two minutes?

SENATOR VITALE: Could you just wrap it up?

MR. MORTORO: Olmstead Act -- Bader -- she echoed what Kennedy wanted in '63. Olmstead does not demand community placement. It says it should not be denied -- community access.

We do not have the group facilities. We need to work on this entire thing. The Olmstead Act is intentionally being distorted. It is being distorted for political and expedient reasons.

The studies on mortality-- There were many comments on mortality. That one -- somebody, I can't recall the name, I'm sorry -- mentioned the study by Shavelle -- 41 percent. However, that study, when continued, found an excess mortality rate of 88 percent. This is the California study by Shavelle. In New Jersey we cut the study off. Governor

Christie, Dawn Apgar aren't too happy with these results. What's the best thing? Cut them off.

It's been quoted, "We have enough research." We have enough research? You turn that stone 1,000 times and 10,000 times more. We don't have enough research. These kids will be abused. The flat out bottom line is, their lives, upon transferring -- I'm talking overall -- to a -- to group homes -- and there are great group homes -- are going to be shortened. They are not going to have the care that they do now. They have one-to-one care of everything -- doctors, psychologists, etc.

One last story.

SENATOR VITALE: Sir, we really have to move on.

MR. MORTORO: And this is it. I apologize.

SENATOR VITALE: It's okay. Don't apologize. Your testimony was great.

MR. MORTORO: One last, quick thing please.

SENATOR VITALE: Go ahead.

MR. MORTORO: You see, this is what I really can't understand -- especially as an educator--

SENATOR VITALE: Just do it. (laughter)

MR. MORTORO: Yes, I'll do it then.

My sister never really had seizures, thank God -- fortunate. She's two years younger than me, she's 61 now. September 4 she fell to the ground at Woodbridge where she's been living. And it's an excellent place. I consider the workers there like family. Over the years there I've had some problems. But like I said, I've had those problems with my own doctors, etc.

They rushed her to Rahway Hospital. She was having seizures. She went into a coma. She was stabilized at Rahway. They kept her there. Because I would not allow for a surgical feeding tube they said she must go to a nursing home. Went through a selection -- chose one of the two best nursing homes in that surrounding area. She was there.

Long story short--

ASSEMBLYWOMAN VAINIERI HUTTLE: Short story long.  
(laughter)

I'm sorry. It's the time. A lot of us didn't eat or have anything to drink yet.

MR. MORTORO: What I was going to say -- this was one of the better nursing homes -- and I've checked on it. And my mother, unfortunately was in one. So I knew what I was checking for. It's a good nursing home. They don't-- The workers probably do not have all the training that those in a group home may have -- but excellent with respect to their care.

My sister came out of her coma -- Tuesday morning -- an aide noticed at 8:30 in the morning. Now, that Sunday -- I was up here for the whole month.

SENATOR VITALE: Sir, we're done.

MR. MORTORO: Okay, we're done.

SENATOR VITALE: Thank you.

MR. MORTORO: Wait, wait--

SENATOR VITALE: Don't. You're wrapped up, you're done.

MR. MORTORO: You got it.

SENATOR VITALE: Thank you.

MR. MORTORO: Fifty-two hours -- the nursing home never gave her any water, any food. (applause)

SENATOR VITALE: Sir, they love you.

MR. MORTORO: Dr. Krishna Patel, from Woodbridge -- I begged and pleaded. I had heart pains. I went home Sunday, came back Thursday. She came out of the coma Tuesday at 8:30. At 2:45 I called the nurse because I was in Florida with chest pains.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Next.

MR. MORTORO: The doctor never knew. And in the remaining 52 hours before she left the nursing home -- no water, no food. Fourteen days. It's amazing that she's alive. This is an anomalous situation. What's happening here is an atrocity of inhumane proportions.

SENATOR VITALE: We're with you. Thank you, sir.

Mr. Holy.

MR. MORTORO: I'm sorry. I really apologize.

SENATOR VITALE: It's all right.

**W I L L I A M G. H O L Y:** You folks really have some endurance. (laughter)

My name is William Holy. I thank you for your time and attention today.

I'm the brother and legal guardian of my sister Patricia Ellen Holy, who is an adult resident at Woodbridge Developmental Center.

And what this presentation that I've handed out to you doesn't say is that I've been a real estate professional for 30 years and was also a Councilman in the Borough of Mount Arlington, New Jersey. So I'm keenly aware of the financial pressures that the State is under and that the

Governor is under, and the continuous demand of more services with diminishing resources to accomplish what he has to accomplish.

Having said all that, I would like you-- My sister's photograph is the last page of the statement that I've handed to you. And I respectfully request that you take a look at it for a few seconds. Patricia is now 63 years old. She was brain damaged at birth. And as you can see, she is profoundly mentally incapacitated. She's lived in the State institution since she was 3 years old and has been a resident of the WDC for more than 50 years.

As with the rest of the residents of Cottage 1, my sister is totally nonambulatory and has no capacity for cognitive thought nor any of the normal physical capabilities that you and I take for granted. She can't speak, walk, hold anything in her hands, nor focus her eyes. She sits belted into a wheelchair or lies curled up in her crib in a semi-fetal position, and has done so for her entire life. She requires a special hoisting apparatus to be moved from her wheelchair to her bed and vice versa. Her cottage mates are all in similar states of severe mental retardation. My sister responds only to soft music, bright sunlight, and to the familiar voices she hears daily by reaching toward the stimulus with her right hand, with her arthritic fingers clenched, and with what appears to be the semblance of a smile on her face and a soft giggle. When she is in distress, she moans and she has a pained look on her face. She can no longer eat because her digestive system, at her advanced age, is shutting down and so she is fed through a GI tube. Someone else has had to feed, bathe, change her diapers, and clothe her for her entire life. Her original prognosis was for a life span of less than eight years, yet she still lives on at Woodbridge, which is attributed to modern medical science and the loving and expert care she

receives there. She is basically an angel waiting to happen, with no ability to care for herself at all. Every other resident of her cottage is in an analogous situation of profound mental incapacitation with no options except to live their lives in the care of others, like the wonderful people who have cared for my sister all her life. They have nowhere else to go for the living assistance they need.

Group homes are not the option for people like my sister. Such facilities lack the medical and logistical capabilities to care for severely mentally challenged people. Yet, for the last few years, I have been frequently receiving notices that ask me if I would consent to her transfer to such facilities in the face of budget cuts that are proposed to alleviate the strain on the State's resources allocated for the care of such people as my sister and the other residents of WDC, and those of the other institutions scheduled for closure. So, something is radically wrong with this proposed approach to resolving the financial problems that plague the State in that regard. The proposed cure doesn't alleviate the financial problem. It simply transfers them to another venue and exacerbates them because of the associated overcrowding it will cause in other institutions, and the diminution of the quality of care that my sister and her fellow residents of Woodbridge will experience. They now are cared for with extreme -- I don't want to divert, but the people there are wonderful.

In addition, the effects on the working population of the surrounding communities will be equally devastating. Many of the people who care for the residents of WDC are long-term employees of this institution, nearby residents, and many minimally compensated individuals who will lose their jobs. Because of the level of their compensation, those

individuals may not be able to find equivalent employment elsewhere, causing, in the near term, an increase in the disbursement of unemployment benefits; and potentially, in the long term, an increase in living assistance benefits such as food stamps and even possibly welfare. So the potential cost savings of closing the WDC will be reduced by the increased costs of other social programs.

Finally, the architectural and structural condition of the WDC campus of buildings is sound, but the support infrastructure -- that is, the electrical, heating, ventilation, and plumbing infrastructure -- is obsolete, making the facility expensive to operate. There are extremely cost-effective approaches to resolving these problems, however, without throwing the baby out with the bath water. The central plant of the WDC supports the electrical requirements of the entire WDC campus of buildings. But the central HVAC plant, I am told, also supports the Rahway Prison, which is miles away. Because of the increased cost of utilities, central HVAC plants like this one give way to installation of local modular HVAC systems, incorporating unitary modular chillers and modular hot water condensing boilers, which are incredibly efficient to operate and will reduce the operating expenses of the facility. The lighting systems there incorporate obsolete high-energy light fixtures that could be replaced with LED fixtures that operate at a fraction of the cost, which would also further reduce the operating costs of air conditioning to the facility.

If such a solution were proposed for the WDC, the front end cost of retrofitting the buildings and the installation of a local HVAC plant for the prison would be recovered in a few years because of the resulting millions of dollars a year in annual utility cost savings.

Finally, in addition, State and Federal grant money might be available to further reduce the capital costs of such a retrofit.

In conclusion, an ancient Chinese proverb -- to paraphrase -- the mark of a truly great society is how that society treats its young, its elderly, its poor and its infirm. We are a great state. The Governor and the State Legislature are working tirelessly to balance the State budget and bring fiscal responsibility to New Jersey. The overview of their work, however, must necessarily take into consideration the plight of those, like the residents of the Woodbridge Developmental Center, who cannot care for themselves. If we are to remain a great society, as the proverb says, the approach to resolving the issues we are dealing with here today must consider the long-term effects on the residents themselves, the local community, and the overall State budget. Innovative, out-of-the-box thinking must be brought to bear to resolve all the issues confronting us without taking away the lifeline of those who have no other way to survive, which is what the closure of the WDC would precipitate.

Thanks very much for your time and consideration. (applause)

SENATOR VITALE: Thank you, sir.

**NANCY MAZA:** It's real short. (laughter)

My name is Nancy Maza. I represent my brother Gary. He's in Woodbridge Developmental Center. He's been there since it opened in '65. Before Woodbridge Developmental Center was even built, the only thing available was Marlboro Psychiatric Center. He was a 10-year-old kid who was put into a men's facility. He has never spoken a word since that day.

Now he is 61 years old. And they say that on a good day he has the IQ of a 2-year-old. Yes, he can dress himself. He doesn't know left from right, so it doesn't make any sense to him which foot the shoe goes on. He doesn't talk. His communication skills are tantrums and abusive behavior more for himself. But if you are at arm's length or foot's length, you will get kicked or hit. By age 10 his strength was already that of three men. So at 61, it's going to hurt.

He's gone out on a lot of trips with the school -- probably more than I have in my lifetime. And he loves that. But he has no boundaries. And they were on a group trip. I think they went to the movies and, they said, walking out in the parking lot he nailed somebody who was going in. And the guy was going to turn around and punch him. Staff was able to step in and stop it. He said, "But then he shouldn't be in the community if he can't be controlled." Well, he's 61. And if you couldn't control him 40 years ago, he's not going to get any better now.

I don't understand disrupting his life. We build community 55 centers for us and for my peers to move into. He has all that at Woodbridge. He has the swimming pool. I don't know if he uses it, but there are other clients there who can use it. They've got the canteen where they can go and have their ice cream and have their good times. The picture I gave you-- I said I would never put my brother's picture out; that it was personal. But you need a face. You need to know that he's a 61-year-old man. He's not a kid. He's stuck. He's a little boy stuck in a man's body. He can't be in the community because he doesn't understand.

Woodbridge does a wonderful job. But the forms that they even have to fill out for the State-- His IHP paperwork, that I just got, said

he's a fabulous guy and he does great work in skills. He's never worked a day in his life. He doesn't do arts and crafts, he doesn't look at a magazine, he doesn't like animals, he doesn't like a horn blowing. How is he going to deal with that in the community?

They said that there is so much medical care he can get anywhere in the state. When he has to go for special testing, he has to go to Newark University Hospital. Why not Kennedy? It's a community hospital. They say that's where the contract is. But that's an ambulance ride. That's expensive. There are a lot of different ways that the government can look into for cutting funding.

If he's at home -- I used to bring him home. I can't do it anymore. I can't handle him. He's not toilet trained. You can put a diaper on him. I'm telling you right now, as God is my witness, it doesn't work. I didn't have a job, and I sat on lawn furniture until I got a job and could afford new furniture because he destroyed everything in the house.

I love him, but I'm afraid of him. When he goes into his tantrums, he's going to knock over lamps. He's put his foot through the wall, he's broken windows. How can you put somebody like that into the community? How high are you going to dose him and make him mummified? He's not on anything now except a vitamin. But he's in a safe environment where he doesn't get hurt and they know how to handle him and take care of him so he doesn't hurt them.

Thank you. (applause)

SENATOR VITALE: Thank you.

**JOHN J. PYDYSZEWSKI:** I just say thank you to all of you for hanging in there today and giving me an opportunity to speak. I appreciate it.

My name is John Pydyszewski. My brother Keith is 55 years old. He has been in the Woodbridge Developmental Center for over 40 years.

His story has been told over and over again today. I'm not going to retell it.

I would like to, if I may, Senator Vitale, follow up on something that you said hours ago. You said at one point -- and correct me if I'm wrong. I thought you said at one point that it would take an act of the Legislature to undo the closure of the developmental centers.

**SENATOR VITALE:** What I think I said was I think it could. The Legislature could act and pass legislation -- a law -- make a law.

**MR. PYDYSZEWSKI:** My question--

**SENATOR VITALE:** But for it to become a law, the Governor would have to sign it.

**MR. PYDYSZEWSKI:** I understand that. I fully understand that.

**SENATOR VITALE:** So the concern is that we don't want to offer anyone false hope, and pass a piece of legislation through both Houses of the Legislature -- provide false hope, and at the end of the day what we propose is never enacted or taken seriously by the Administration. So we have to work in other ways in which to find solutions to the issues that you face.

MR. PYDYSZEWSKI: To my mind, if we don't try -- if we don't try to do that? At least doing that we're doing something, we're taking an active role.

And, sir, my question to you was going to be: How do I get started on something like that. I mean, we have a lot of powerful legislators who have been here today. I think it would be a great start. And at least if nothing else, it would send a message to the Administration on how serious everybody is. And I would be willing to put in as much time as it takes, talk to as many legislators as it takes to do that. I'm offering that to you.

SENATOR VITALE: Leave your information with one of the staff folks and we'll get to you.

Thank you.

Thank you, all. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Gillian Speiser and Kirsten Schenk.

**K I R S T E N S C H E N K:** My name is Kirsten, and this is my co-worker Gillian. We work with people with disabilities actually in the community.

SENATOR VITALE: A little closer to the mike. Bring the mike to you.

MS. SCHENK: My name is Kirsten, and this is my co-worker Gillian. We work with people with disabilities in the community -- people with disabilities who live in the community, and we're here to deliver testimony on behalf of two of the individuals we work with who happen to have disabilities.

**GILLIAN SPEISER:** So, essentially, we heard all the arguments today. But working with people with disabilities, we've seen firsthand what people with disabilities can enjoy in the community. And we feel that living in the community--

**ASSEMBLYWOMAN VAINIERI HUTTLE:** Could you speak more into the mike so they can hear in the back? Thank you.

**MS. SPEISER:** We believe that people with disabilities living in the community have the ability to recognize their rights and have the opportunity to give back to their communities. Again, we work firsthand with people with disabilities, so we see that through our jobs.

And today, as you've heard, more and more people are living -- people with disabilities are living in the community because there are more options available. And there is research out there to back up the point that people with disabilities can achieve more fulfilled lives in the community. And the organization we work for basically believes that people with disabilities can live like everyone else with the proper supports. And our members have successfully been able to do things that everyone else can do, like go out in the community, go out with friends, get married, live with one another, and make choices about their daily lives. Our organization actually encourages that.

So we just wanted to kind of put it out there that there really is no shame in having a disability. And we ultimately believe that the current funds the State has for serving people in the institutions should be following the people into the community, and then also serving those on the waiting list as well.

SENATOR VITALE: Thank you very much. Thanks for your work.

Sir.

**WILLIAM URION:** Hi, I'm Bill Urion.

I won't go into my daughter's story. She's at Totowa. Her story is the same as everybody else's.

But I issue a challenge to you. Check in and find out. The Governor wants to put them out in the community. Find out if the communities want them. I'm from Hunterdon County. And we've had a few areas in Hunterdon County where they have resisted group homes -- not for the fact of the clients; it's for the fact of the people who are working in the group homes. There are no background checks on them. There have been criminals, there have been problems. The communities don't want the group homes because of the employees.

It's not easy for Arc just to go out and buy a house -- a four-bedroom house and move clients into it. It doesn't work that way. Building codes require changes to that house to make it safe. It's not an easy transition to take people and put them out into the communities. It's not easy for the communities to accept them. So these are things that have to be looked into and have to be changed -- particularly the people working in the group homes. Their backgrounds are not, lots of time, favorable.

Thank you. I appreciate it. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

SENATOR VITALE: Thank you, sir.

**JACQUELINE C. GUILLOT:** Hi there.

I was so anxious to do it, and now I feel like I'm almost begging to come up.

SENATOR VITALE: No, no, we had your slip. You're the last speaker.

MS. GUILLOT: I want to thank you very much for holding this meeting -- this hearing. And I want to thank the representatives at Woodbridge Developmental Center who take such good care of my brother for over 30 years.

I believe the drive for this community placement is for the State to save money. I believe it's false economy. I believe it's all about the dirty word *privatization*, analogous to the charter school versus public school situation.

I know a lot of people have spoken about their own family members, but I would like to speak on behalf of the workers, especially the direct care worker who isn't making a large amount of money, and the one who has the most direct contact with our relatives.

I believe in the community setting the direct care worker will not have the same pension benefits and health benefits as those similar workers doing the direct care in developmental centers. And I believe this is what is happening all over our society -- charter school versus public schools, the public soldier versus the mercenary soldier who makes \$100,000 as compared to the public soldier who makes maybe \$18,000 a year. Also, the government does not have to pay veterans' hospitals later on. Such is the same with the direct care worker at the developmental center. In the community they will not be making -- getting those healthcare benefits and they will not be getting pensions.

The direct care workers at Woodbridge and Totowa -- they have the incentive to stay 20 years to get those -- that pension. This is an incentive to stay and not have a great turnover of workers in the community. In other words, those workers can stay and get to know our relatives -- who best care for them.

So far as-- Also, in terms of thinking of the low-level direct care worker-- They're going to have this situation as a co-employment situation. I myself have worked as a contract -- in a co-employment situation. I don't know about any of you, but it's bad enough to have one employee rather than two. I can imagine that the direct care employee in a community setting is going to essentially have a co-employment situation where they're working not just for the agency, but for the State government as well. If the State government finds that a particular community home is not doing well, it can close it on a dime. And what is going to happen to the direct care worker who might be a good worker? Does she go and work for the next agency? Do you know what happens when she does that? She loses, maybe, her vacation pay. I've been in a co-employment situation. I worked at Merrill Lynch as a contractor for 20 years under three different vendors, three different employers doing the same job. Each time a new vendor came in I lost my vacation pay because I became a new employee, all of a sudden, to the new vendor. So I lost my vacation over three times. So I can imagine the direct care employee in the community setting, number one, is not going to have the incentive of the pension to (indiscernible), is not going to have good health benefits, and also can work under the threat of being -- her agency being closed on a dime. And maybe she wants to continue -- is a good worker and wants to continue in that work but will

repeatedly lose other such benefits as vacation when she goes on to the next agency. Also you have to think in terms of, if a group home is closed for not doing well-- It can be closed on a dime. Look at Mayor Bloomberg. He closes charter schools on a dime.

I read of a similar situation. As I said, privatization is all over our society. And I think it's a bane to our society. It will drag our society down. I was reading about a similar situation with foster homes in New York also being privatized. It was being run by a church. This church was-- They were giving this church group that was running this foster home more, and more, and more money. And finally this church group that was running this foster home-- They took on more than they could manage and one of their foster homes was shut down. What happened with those foster children? They're vulnerable just like the profoundly retarded. They were shuffled around from district to district to whatever district needed a political football or whatever district needed the jobs.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Jackie. Jackie, could we have your last name?

MS. GUILLOT: Guillot.

ASSEMBLYWOMAN VAINIERI HUTTLE: I think we called you before, but we just wanted to make sure.

We're just going to wrap up and give the members of the Committee an opportunity to speak. I don't know if you're concluded with your remarks.

MS. GUILLOT: I've also been told that transfer-- If I find that my brother is situated in the community home and it doesn't work, there's such a thing as transfer. I know from personal experience -- in 1972, my

mother wanted to transfer my brother from Woodbine to Woodbridge. My mother was very ill. We were traveling three hours to visit my brother, and we wanted to transfer him to Woodbridge one hour away. Also, my brother was doing very poorly at Woodbine. My mother, for two years, pressured the State, "Please, please, please," relocate my brother -- transfer him. Finally my mother spoke to a social worker who leveled with her. She said, "Ms. Guillot" -- to my mother -- "The only way you're going to have George placed at a new placement is to bring George home." I don't have this luxury. At the time my mother was sick, but she had my father to help out, she had me to help out. I am single. I have my own problems. I can't bring my brother home in an interim between a transfer.

Also, who are running these group homes? I just gave you the example of the foster home in New York being run by a church. I don't exactly see on college syllabuses how to run group homes. How are these people trained?

I mentioned the distance. It's difficult for the families.

SENATOR VITALE: Thanks, Jackie. We appreciate your testimony.

We're going to conclude now with some remarks.

MS. GUILLOT: May I say one more thing?

SENATOR VITALE: Sure.

MS. GUILLOT: This may sound cynical, but I like the idea of centralized care for the retarded. I know it's like a one-minute of history. Probably many of you remember when Geraldo Rivera went to Willowbrook and he showed the atrocities of Willowbrook. Woodbridge Developmental Center is wonderful, but I want -- I prefer the centralization.

Because if there is another-- If there are these group homes and one is doing atrociously, the society might think it's an isolated situation, a unique situation. And when I hear it's just four people -- they said the average would be four people per group home -- the society might think, "Oh, it's just that one group home," and that it's unique -- that's a bad situation. If you have a centralized situation-- And Geraldo Rivera was looking out for the most vulnerable. And if they go in and see that a thousand in a developmental center might be not receiving adequate care, I think society would react more to seeing a thousand are under poor care than letting them kid themselves that maybe it's only the isolated, unique community home that's doing poorly.

And the last thing I want to say-- The architecture -- the previous man who was just up here said he was a real estate agent. The architecture of the campus at Woodbridge Developmental Center is catered to the handicapped. There are circular hallways for people in wheelchairs. My brother wanted to get some exercise by propelling himself in his wheelchair. What is he going to do? Go up and down a very short hallway in a community house rather than having the open spaces of the architecture at Woodbridge Developmental Center, which was built specifically for the handicapped?

I thought it was a great idea to look into renovating the HVAC, electrical, and the plumbing -- to save money that way, rather than to save money and not offer the direct care workers the pensions and the benefits they deserve to care for our handicapped family members.

I thank you very much for holding this meeting. I am my brother's only family. I am the younger sister. This has been like a cloud

over my head all my life. I am not in good health myself. I have lupus. It means I have an autoimmune disease. My immune system is attacking my own DNA. So many of us are aging and having our own health problems. To think in terms of travelling two hours instead of the 45 minutes it takes me now to visit my brother is extremely upsetting. And I'm going to speak in colloquial terms: If it ain't broke, don't fix it -- try to fix it. Woodbridge is wonderful. I go to bed at night, even with my own problems, and feel that my brother is taken care of. And I don't feel I would be able to feel that way if my brother were in the community.

Thank you. (applause)

SENATOR VITALE: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

I would just like to ask the members if they have any closing comments, starting with Assemblywoman Shavonda Sumter.

ASSEMBLYWOMAN SUMTER: Thank you.

I would just like to thank Senator Vitale and Assemblywoman Huttle for hosting the hearing today. I gained insight into the trials and tribulations of the families of our most vulnerable citizens. So I'm looking forward to working diligently to come up with solutions that are genuine, real, and realistic.

From my background, a patient showing up in an emergency department who was just placed in a community -- which is a foreign neighborhood to them -- being treated by providers who don't know what is best for them--

MS. GUILLOT: May I say something? At one point my brother had a broken hip. He was sent to Orange Orthopedic Hospital. Do

you think the community can take care of the profoundly mentally retarded? They put him in a room way at the end of a hallway. They brought him his dinner. The dinner was covered by a dome. Nobody even showed him that under that -- the dome was to keep the food warm. Nobody even picked the dome up to show him there was food underneath that dome. Besides that, he had a broken hip and was trying to crawl out of the bed.

ASSEMBLYWOMAN SUMTER: Ma'am, I say all that to say that we understand your plight, and we understand what you are living with. And to the best of my abilities, my capabilities, I will make sure that the voice is heard and the testimony is heard that was shared with us today.

I'm from northern New Jersey -- Paterson. North Jersey Developmental Center is in our region. As well as supporting Woodbridge Developmental Center and all the other providers in the state, we want to make sure that the best care that is necessary for our most vulnerable citizens is provided.

Thank you. (applause)

MS. GUILLOT: Thank you.

Please keep Woodbridge and North Jersey open. Please, please, please.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman Connie Wagner.

ASSEMBLYWOMAN WAGNER: I want to thank each and every one of you for coming here today. And for those of you who have stayed until the end, you're real troopers.

But what I did sense from each one of you is your unconditional love for your family members, and the pain that you're going through, and the security that you need for the best possible care for your loved ones. And whether that be in Totowa or whether that be in Woodbridge, you're here saying you want your loved one to remain there because he or she is getting the best possible care.

I can promise you that I will work with my colleagues. I will work with Senator Vitale, I will work with Assemblywoman Valerie Vainieri Huttle to come up with a solution. I am one of those who truly believe that you have the power. We are your vehicle. And I understand that maybe we can't do this, but I'm having a hard time accepting that, because I do believe people have the power if you don't give up. You haven't given up yet. You're here today. But in my mind I'm sitting here saying, "What else can we do?" Because it's your message. I know I react at my office when I see -- "Oh, my God, where are all these e-mails coming from? What do they want me to do?" And I react, and I read that. And now you have to go back -- whether it be your Rotary Clubs, whether it be your churches, whether it be your senior centers, wherever-- You have to go out and spread the word why it's important. Because you know what? It's your family today; it's somebody else's family tomorrow. So you have to continue the work and get the word out there. You know about this problem.

And it's so unfortunate to me because-- Sometimes in this business I think about, "If it's your problem, it's your problem. It's not my problem." Well, we have to make it everyone's problem. We have to care about each other. You need to carry the message. We will be with you, and we will work on a solution. But you can't give up. Because if you give up

now and think it's just us, we might not be able to do it. But if there's a ground swelling, you can.

I had four students here before -- interns. I said, "I want you to see what democracy is like." They left. But one of their words were -- they could not understand how heartless people could be. They got that message. They were very, very upset. So you know what? We can do this with your help. I have to believe that. Otherwise I wouldn't be doing this line of work.

Thank you very much. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Vice Chair Cleo Tucker.

ASSEMBLYWOMAN TUCKER: I want to thank everybody for coming out and telling us your story, and how you believe and you hope for the best; and how you want your loved ones to stay where they are.

We know how hard it is on you to have to come here and tell us your personal stories, but it's something that we need to hear. And this story needs to continue to be heard throughout the whole State of New Jersey. We in the North Jersey area shouldn't have to be penalized for somebody else's comfort. We have to make sure that we continue to fight for the North Jersey -- both of our developmental centers here in North Jersey, so our families can be secure and know that they have a safe home, a safe haven they can go to.

For those who choose the group homes, that's all well and good. Because everything doesn't work for everybody. We know that some people would like the choices. But we heard from you today saying that you want your loved ones to stay where they are, and you want to not have

these developmental centers closed because you can be there with your loved ones and not have to travel out of your way.

So we're saying that we hear you. We want to continue to have hearings and continue to do things so you can express yourselves to us and we can express your thoughts to others.

Thank you so much for coming out today. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

We sat here for probably over five hours -- and most of you were here early. And I know many of you, because it didn't just start today with me. When I became Chair of Human Services -- I guess it was several years ago -- a couple of pieces of legislation came before my desk about closing developmental centers. And before I could entertain any piece of legislation, I had to see firsthand the centers myself. When I thought of institutions, I wanted to see really what they were all about. And so my Assembly Committee -- at the time we visited all seven. And I have come to say that they are not institutions, but centers -- centers for people who are provided the best opportunity that can be provided. We met with the care workers. They are family.

On the other side of the coin, I went and visited group homes. I went and visited those homes in the community. For every person who is either in a center or in a home, we can't make those decisions as legislators. And when we hear from the family members, only the family members know what is best for their loved ones.

With that being said, I have always been an advocate for choice. For those of you who want to remain in a center, you should remain in that center, especially if you are pleased with them. There are

many also in the centers who want to go out into the community, and that is all well and good, as well, if they're able to do that.

My concern is: If you close two institutions, not only in northern New Jersey-- But where are the resources after closing those institutions going? Are they going to close or plug the budget? We can't have that. They need to go and make those resources in the community even better for those people who choose or opt to go into the community.

We heard about the waiting list. And I think Assemblywoman Wagner said it very well. For those on the waiting list who want to go into community, place them in the community. For those who want to remain in the centers, let them be in the centers. We are going to try, through legislative process, through maybe other types of legislation -- but we're trying to get to the Governor and this Administration. And that is why I think this hearing was so important that Senator Vitale and I decided to do it. Actually, we decided to do this before Superstorm Sandy. And so two months fast forward-- Again, on the day the Task Force convened -- February 13 a year ago -- the answers-- What I'm frustrated about is that you have letters and you have no answers to your questions.

And hopefully the testimony today has been live streamed. The Department will hear the testimony. We have written testimony. It is recorded, and we will take your testimony to the Administration.

And with that, we hope that we can make some change, or we can make a difference, or we can at least assist those of you-- You are certainly the champions for your families. We have to keep our voices together. Your voices are heard through us. And we will continue to champion on your behalf.

Thank you. Thank you for staying over five hours.

For those of you who did not have an opportunity to speak, you know how to reach us. And I know either by e-mail and by phone-- And we're here to assist you.

Thank you again. (applause)

SENATOR VITALE: Thank you very much.

I want to thank the members for being here, for being so patient, and for staying so long, especially the Assembly -- Senate, a little weak-- But thank you very much.

And to the families who are here, and who spent so much time before and have now left -- for your commitment to your family, to your loved ones, to your sisters, your brothers, your sons, your daughters, your grandchildren, or just a friend. There is nothing more important than that, and you are a real example of what it means to be family and to love people and care about them at their most vulnerable time.

Thank you for doing that. We'll be talking to you again soon.

Thank you. Meeting adjourned.

ASSEMBLYWOMAN VAINIERI HUTTLE: I want to thank the staff too.

SENATOR VITALE: Yes, very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: They've been very helpful.

Thank you, all. (applause)

**(MEETING CONCLUDED)**