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"

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

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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,
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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)

SUSAN A. COLE, 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 Huttle 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.

ASSEMBLYMAN PATRICK J. DIEGNAN JR.: 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 Huttle 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 HUTTLE: 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 Huttle 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.

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.

JOANNE R. ST. AMAND: 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--

KEVIN TREMBLE: 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.

CINDY BARTMAN: 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 Huttle, 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 there 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 met 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 it's 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)

ASSEMBLYMAN CRAIG J. COUGHLIN: 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 Huttle, 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.

DENISE SUSSINA: 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 Zonegran, 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 where 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.

THOMAS BAFFUTO: 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.

DEBORAH GOOD: 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.

CAROLYN C. WADE: 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)

REX REID: 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.

MARTHA CRAY: 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)

DAVID DAYYA, 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.

ROBERT RUTLAND: 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.

JUANA MITCHELL: 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.

MARIE WHITE: 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.

BRENT T. SJAARDEMA: 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.

THOMAS R. HINES 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.

SUSAN MASON: 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 publish 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

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)

CHERYL YACONO: 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.

STEVE HAZEN: 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.

CARL V. HAZEN: 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)

BARBARA COCKEFAIR: 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 basketballs 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.

MARIE REID: 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.

ALAN FERRER: 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.

FRANCES FINKELSTEIN: 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.

DONNA VACCA: 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 Zetkulic, Mr. and Mrs. Fred Maier, Tom Damiano, Gary Mortoro, William Holy, Debra Trepkau, Patricia McMillan, and last name is Urion.

DEBRA TREPKAU: 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.

WILLIAM G. HOLY: 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.

KIRSTEN SCHENK: 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 as 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)

APPENDIX

My name is Carolyn Fontanella and I am a councilwoman in the Borough of Totowa. I am here today in order to ask for your support regarding the residents, their families, and the employees of the North Jersey Developmental Center.

While some people refer to the individuals who reside at NJDC as clients, I prefer to refer to them as "residents". Some other people may even refer to the residents of NJDC as "special needs" individuals – I, on the other hand, would simply say they are "SPECIAL." These men and women reside at the North Jersey Developmental Center,

169 Minnisink Road, Totowa, NJ. Not only is this is 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 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 here. 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

should their relatives be transferred to another facility. Please keep in mind that spending this valuable time with their relatives, who are diagnosed with developmental disabilities, is not a luxury – it is 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 provides so much more than a "service" to the residents of NJDC. While it is true they assist the residents in all of their activities of daily living, let it also be said 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 all 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 all of 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 some might describe as an ordinary everyday "JOB" into a 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 first hand, and I commend each and every one of these employees.

I would like to take this opportunity to personally and publicly thank all of the employees 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 the 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.

Testimony Against Closure

Presented to the Joint Committees
of
Health, Human Services and Senior Citizens
And
Human Services
February 13, 2013

Montclair State University
Montclair, New Jersey

Submitted by
Joanne R. St. Amand
Sister of Rosemary Sciarrillo, Cottage 18
and
President, Woodbridge Developmental Center Parent Association

Distinguished members of the Joint Committees, I thank you for the opportunity to speak to you today on such an important and critical subject. My name is Joanne St. Amand. I am a resident of Cranford. I am the sister of Rosemary Sciarrillo, a 57 year old profoundly intellectually disabled (ID) resident of Woodbridge Developmental Center (WDC). I am also the president of Woodbridge Developmental Center Parents Association. I am here today not only on behalf of my sister but for all the residents of WDC.

There are many very important issues to address such as the quality of care, the choice of families, the civil rights of individuals, the Olmstead decision, cost comparisons between the centers and the community. To keep within the guidelines of this hearing, I will focus my comments on care.

I agree with Drs. Kevin Walsh and Ted Kastner, two prominent experts in the field of Developmental Disabilities, that New Jersey must continue to provide Intermediate Care Facilities / Mental Retardation (ICF/MR) level services in developmental centers. The majority who receive ICF/MR care have profound or severe intellectual disabilities and are among the neediest, most disabled and medically fragile[1].

This is true for my sister and the other residents at WDC. These residents are not the typical ID individuals that most of us are familiar with. They are not the typical client supported by the ARC and other non-profits, nor are they typical of the majority of individuals on the waiting list for services. WDC residents are truly the most intellectually, medically, and physically compromised of the entire population with intellectual disabilities.

About My Sister Rosemary

Ro's disabilities are typical of the other women in her cottage. She is profoundly intellectually disabled. She is 57 years old but looks about 20 years younger. She is physically smaller in statute and her back is twisted from severe scoliosis (curved spine) so she cannot sit in a regular chair and need 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 cannot walk or talk. She cannot roll over by herself. She won't make eye contact for more than a second or two. She has to be lifted and carried from her bed, to her wheelchair or to a 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 dysphagia (difficulty swallowing) and all of her liquids need to be thickened so she does not choke, aspirate her food and develop pneumonia. She dehydrates quickly when she is sick so her liquid intake needs to be monitored.

She suffers from severe constipation and needs help to have a bowel movement. Rosemary has epilepsy which has been well controlled by the doctors at WDC. She cannot tell you when she is not feeling well and depends on her 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 because her veins are very small and a catheter must be used to collect her urine. Rosemary made two trips to the ER last month. I made sure I was there when she arrived and I stay at her side until she returns back to her home at the center.

About the Residents of WDC

The census of Woodbridge Developmental Center is about 330. According to the OPRA information, 307 (90%) are classified as profoundly intellectually disabled (the most extreme case), and 21 are severely intellectually disabled. All have some level of verbal impairment and 75% cannot talk.

Over 70% cannot walk and require customized wheelchairs, essentially all have moderate to profound communication impairment, over 85% have severe or profound hearing impairment and over 50% have significant visual impairments. Over 80% have seizure disorders, and over 80% need to be feed, have mealtime programs, and require supervision for dysphasia. The average age of residents at WDC is in the low 50s. There are approximately 80 individuals over the age of 60 and a handful in their 70s[2].

A report entitled "Descriptive Characteristics of All Consumers Residing in New Jersey's DD Centers", was prepared by NJIT, DD Planning Institute, in April 2007 and presented as Testimony to the Task Force on Closure. It compared the residents from each of the 7 developmental centers and clearly shows that residents at Woodbridge Developmental Center to be the most disabled among the 7 centers. They have:

1. the lowest cognition competencies (along with Hunterdon),
2. the lowest score for communication skills of all centers,
3. the lowest self-care skills relating to eating, drinking, dressing and toileting (along with Vineland).
4. the lowest social, emotional functioning such as sociability, friendliness and caring of others (with Hunterdon),
5. the lowest mobility among all centers,
6. the highest proportion of active epilepsy / seizures (with Hunterdon),
7. Only 4% of the consumers at Woodbridge were thought to want to move by staff.
8. Regarding special medical treatments, 93% of the consumers at Woodbridge required increase fluids, which is significantly above the overall population (30%).

This means almost all have the cognitive ability of an infant or toddler requiring **total care** and supervision.

Why is it important to keep Developmental Centers Open: ICF/MR vs. CCW?

All developmental centers follow the ICF/MR Medicaid program which is fundamentally different than the Home and Community Based Services (in NJ it is known as the Community Care Waiver, CCW) (see Table 1). The ICF/MR model requires comprehensive interdisciplinary planning and treatment services according to federal guidelines. That is, federal law requires ICF/MR facilities to provide individualized "**active treatment**" programs administered on site by licensed professionals. Clinical professional and active treatment services are "bundled" and 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, psychology, neurology, dermatology, gynecology, pharmacology, pulmonology, orthopedics, ophthalmology, and nursing. There are respiratory therapists, nutritionists, dieticians, OT, PT, speech therapists, audiologists. There are wheelchair maintenance and steam cleaning services, assistive technology, and direct care assistance for all aspects of daily living such as eating, bathing, toileting, hygiene and mobility (see Table 2). Our ICF/MR residents require this onsite comprehensive assortment of healthcare for their very survival. For instance, staff have years of experience and are trained to recognize the need and recommend appropriate adaptive equipment, to properly feed residents with dysphagia so they don't aspirate, prevent dehydration, to monitor constipation, to provide inhalation therapy, and quickly identify the signs of a problem, which can easily lead to a serious, even fatal situation if left unchecked. At the centers, we have an on-site pharmacy. Medicines can be ordered and filled within hours. Now think of how impatient we are to get our scripts fill for cold meds or a UTI's.

Developmental Center residents will have to "waive" their rights to the ICF/MR program when they transition to the Community Care Waiver. The CCW does not provide anywhere near this level of programing nor onsite specialized support. In contrast, their program services and supports are "unbundled". Individuals funded by CCW must locate services in community settings and access them through regular Medicaid programs and providers [3]. Individuals could have appointments with doctors who rarely see someone with their disabilities. Just last week we had an individual who went into respiratory distress easily recognized by a respiratory therapist who called a code. Our doctor arrived immediately, inserted in a breathing tube and stabilized him before the ambulance even arrived. We all have a good idea what the outcome would have been in the community.

In order to maintain receipt of federal payments, ICF/MR facilities are held to 378 specific standards reviewed annually (Conditions of Participation). Home and Community Care Based Services (CCW) has no body of federal guidelines and is only required to provide "assurances" as a condition of approval. CCWs are reviewed every 3 to 5 years, and the state has the option to renew, not renew, or change the terms of its waiver program. The flexibility of the CCW can actually work against those requiring ICF/MR level care because the stability from year to year may not be there[3].

One can compare an individual needing the care of an ICF/MR to someone requiring the services of an Intensive Care Unit (ICU) in a Hospital. It serves only a small fraction of the individuals in the hospital, operates with a highly specialize team of professionals, may appear to be most costly department to run but if you were to try and duplicate those exact same services outside the ICU, it would be cost prohibitive and difficult at best to have the collective specialists located at one site. For the simple concept of economies of scale, the services in an ICF/MR cannot be duplicated with such efficiencies in the community for the same cost, nor at equal or better services, a condition needing to be met according to the Olmstead decision.

It is well documented that moving into the community can be a life-ending environment for our ICF/MR residents. 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% higher in the community than in the institutuion[4].

This trend of higher mortality is again seen in the findings from the North Princeton Developmental Center closure. There were 22 (63%) deaths among the 150 who moved out of NPDC and 13 (37%) among the 150 who stayed in an institution[5]. This study was ended after a short time of 27 months after closure. Where are they now? How did they fair 3 years out, 5 years out?

According to Dawn Apgar[6], the Deputy Commissioner of DDD, "Four characteristics measured in 1994, prior to the closure of North Princeton Developmental Center were the best statistical predictors of death. They included: (1) being 60 years or older in 1994; (2) having epilepsy / a seizure disorder in 1994; (3) having low self-care abilities in 1994; and (4) having one or more medical conditions in 1994."

These criteria describe both our Woodbridge and North Jersey DC populations. As is well documented by experts in the field, we will be putting their lives in danger by moving residents out of WDC. The

ICF/MR model assures that our 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 the locations of our current centers so residents remain geographically close to their families (and so family members like me can be at my sister's side for any situation!!) We need to maintain the experienced staff and professional services which already exist at these sites.

It's time be morally responsible to our ID residents in the centers. It's time to stop the bullying by government employees, misguided ideologists and organizations who continually favor their clients who are much less impaired.

We need to all work together for what is right for everyone. We need to look at other models like the Community Resource Center, already used in several states [7, 8]. We have components of this model at some of our centers already.

The lives of our family members are in your hands. Please find a way to not close both Woodbridge and North Jersey Developmental Centers.

Respectfully submitted,

Joanne R. St. Amand
Sister of Rosemary Sciarrillo
President, Woodbridge Developmental Center Parents Association
e-mail: jrst.amand@verizon.net

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1. New Jersey Legislative Review Panel on State Psychiatric Hospitals and Developmental Centers, Testimony of K. Walsh and T. Kastner, Oct 17, 2011.
2. From information received through OPRA as of 03-27-2012
3. Written testimony submitted by VOR for consideration by the Legislative Review Panel on State Psychiatric Hospitals and Developmental Centers, Oct 13, 2011.
4. Mortality of adults with developmental disabilities living in California institutions and community care, 1985-1994, Strauss, D. Kastner,T. and Shavelle, R. (1998) Mental Retardation, 36, 360-371.
5. Deinstitutionalization and mortality: Findings of a controlled research design in New Jersey, Apgar, D.H., Jordan, T., and Taylor, S. J. (2003) Mental Retardation, 41, 225-236.
6. Life after North Princeton Developmental Center, Final Outcomes, A follow-up of Former Residents, Apgar, D.H., Lerman, P., and Jordan, T.
7. Examples of Community Resource Centers can be found in Virginia, Massachusetts, Kentucky, Washington State, Missouri and Florida.
8. VOR Testimony to the Task Force on Closure, Mar 9, 2012.

Table 1

Home and Community Based Services Waivers: An overview

The Home and Community-Based Services (HCBS) waiver program was established in 1981 as part of Medicaid in the Social Security Act (1915(c)). Under the HCBS waiver program, states can elect to furnish a broad array of services (excluding room and board) that may or may not be otherwise be covered by Medicaid, including case management, homemaker, home health aide, personal care, adult day health care, habilitation, and respite services. States can request permission to offer additional services. The Centers for Medicare & Medicaid Services (CMS) must grant approval of all waiver applications. The intent of the waiver is to give states the flexibility to develop and implement alternatives to institutional care for eligible populations. Eligible populations include Medicaid-eligible elderly and disabled persons, physically disabled, persons with developmental disabilities or intellectual disabilities, or mental illness. Individuals must be shown to be eligible for institutional services (such as an Intermediate Care Facility for Persons with Intellectual Disabilities (ICFs/ID, a/k/a ICFs/ID) to be eligible for HCBS. (Source: Duckett, M.J. & Guy, M.R., *HCBS Waiver*, Health Care Financing Review (Fall 2000). Vol. 22, Number 1, pp 123-125).

Quality Assurance: ICF/MR and HCBS Compared

ICF/MR	HCBS
To be federally certified, ICFs/MR must meet 8 conditions of participation: (CoPs): Management; Client Protections; Facility Staffing; Active Treatment; Client Behavior and Facility Practices; Health Care Services; Physical Environment; and Dietetic Services. The eight CoPs comprise 378 specific standards and elements. State surveyors conduct annual onsite reviews. CMS is currently conducting "look behind" surveys of every state and public ICFs/MR to "double check" the state surveyors' findings. Serious deficiencies must be corrected within 90 days; other deficiencies must be corrected within a year. Failure to correct deficiencies results in loss of certification and loss of Medicaid funding. The Department of Justice (DOJ) also has a role in overseeing public (not private) ICFs/MR. DOJ does not have jurisdiction over community programs.	Although there is no standard HCBS program, all are required to provide CMS with the following assurances, as a condition of waiver approval: health and welfare of waiver participants; plans of care responsive to waiver participant needs; only qualified waiver providers; State eligibility assessment includes need for institutionalization; State Medicaid Agency retains administrative authority; and the State provides financial accountability **(the waiver must cost less than the institutional program).** HCBS waivers are reviewed every 3-5 years. In 2004, CMS refined its method of quality oversight, initiated with the release of *The Protocol* in 2000. In January 2004, CMS made mandatory the use of the *Interim Procedural Guidance* as the method for federal waiver review. The *Guidance* requires CMS staff to solicit evidence from the states as to their quality management strategy and implementation, including evidence that the statutory and regulatory assurance have been met. CMS also requires an annual report form ("372 form"), submitted electronically, to gather additional information about how states assure and improve quality.

Note of caution: The "flexibility" catch-22

The cornerstone of the HCBS waiver – state flexibility – is also its catch 22 for participants. Every 3-5 years a state has the option to renew, not renew, or change the terms of its waiver program. HCBS services must be delivered pursuant to the development of a plan of care and based upon assessed individual needs. However, because the HCBS program is an optional benefit and states have the flexibility to determine the service package, number of persons to be served, target group, etc., a participant may find themselves cut from the program or with a different mix of services than in prior years. In Mississippi, for example, an approved waiver resulted in 48,000 people being cut from the waiver program. In nearly every state, Governors are considering changes to the Medicaid program.

There is no question that the HCBS waiver program has allowed thousands of individuals to be adequately served in community-based settings. The residents remaining in our nation's ICFs/ID, however, are the most fragile and most in need of consistent, high quality, services. When considering the waiver option, individuals, families and guardians are cautioned to weigh the benefits with the costs.

Table 2

The services people receive in ICFs/MR

ICFs/MR: A sampling of the comprehensive services provided to residents

This comprehensive assortment of federally-certified professional therapeutic, dietary, health care, recreational, and residential services is required by the neediest, most fragile, and most disabled members of our society. Group homes – even those homes that are certified by the Centers for Medicare and Medicaid Services (CMS) – do not provide the same level of programming, with the same assortment of onsite, specialized services, as ICFs/MR. For some ICF/MR residents the provision of professional support and health care is required for their very survival.

Medical	**Dental**	**Behavioral psychology**	**Clinical social work**	**Dermatology**
ENT	**Gastroenterology**	**Gynecology**	**Neurology**	**Nursing**
Nutrition	**Occupational therapy**	**Physical therapy**	**Orthopedics**	**Ophthalmology**
Pharmacology	**Psychiatric**	**Podiatry**	**Pulmonology**	**Lab work**
Speech/ language therapy	**Therapeutic recreation (e.g., swimming, equestrians, etc.)**	**Vocational assessment, training and opportunities (on and off campus)**	**Wheelchair clinics/Rehab engineering**	**Assistive technology/ communication augments/ switch activation**
audiology	**Respite Services**	**Habilitation**	**Staff and Student Training (classroom/on-the-job).**	**Residential, including dormitory, group homes, private rooms, cottages, apartments.**
Direct care for activities of daily living (eating, dressing, bathing/ hygiene, toileting, mobility, etc.)	**Sensory integration/ Stimulation Room**	**Pet therapy**	**Respitory therapist**	**QMRPs**
Family Support and Advocacy Organizations	**Active Treatment Services**	**Transportation**	**Library**	**Nutritionist/ Dieticians**
Religious services/ chapel	**Human Rights Committee**	**Cafeteria, private kitchens, Canteens**	**Restaurants and stores open to public**	**Other services not noted here**

An invitation to visit an ICF/MR

To fully appreciate the people served, their extreme needs, and the professional and compassionate care and training they receive, I encourage and invite our legislators and their staffs to visit ICFs/MR in New Jersey. I would be happy to arrange for a tour of Woodbridge Developmental Center and introduce you to families and their family members with intellectual disabilities, or you can arrange a tour directly with the facility. You will be warmly welcomed.

Testimony
submitted by Cindy Bartman
for
New Jersey State Legislative Committee
of the
Assembly Human Services Committee
Senate Health, Human Services and Senior Citizens Committee

on the
Closures of the North Jersey and Woodbridge Developmental Centers

February 13, 2013
Montclair State University
Montclair, New Jersey

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 am a life-long New Jersey resident. 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 NJ 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 the past 5 years.

Thank you again for holding this hearing today and taking the time to listen to us. I want to reemphasize some of the points you have heard from our families today.

You have heard 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 have heard from a family member that Home and Community Based Services do not work for everyone. You have also heard 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 means 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 building 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 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 the 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% higher for residents transferred into the community than if they had remained in the larger centers. Ohio experienced similar results.[1]

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. This 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[2]. But again, this level of care is <u>critical</u> to the day-to-day survival of our family members.

You have heard today from a family member who has told you that family guardians and developmental center interdisciplinary team members are being strong-armed by the state to acquiesce to the pre-determined 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.

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[1] The Alternative Press. Dr. Salvatore Pizzuro, September 3, 2012

[2] What the Community Care Waiver Means for Your Family Member: A Guide to Understanding the Division of Developmental Disabilities' Community Care Waiver. June 2010

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 died soon 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 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 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. We 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 there geographical locations so the family members can continue to visit and preserve their family life.

Testimony
of

Sam Friedman

Co-Guardian of Jacqueline Friedman

before the

New Jersey State Legislature
Joint Meeting
of the
Assembly Human Services Committee
Senate Health, Human Services and Senior Citizens Committee

on the

Pending Closures of the North Jersey and Woodbridge Developmental Centers

at

Montclair State University Conference Center
Montclair, NJ
February 13, 2013

Chairman Vitale and Chairwoman Huttle, thank you for the opportunity to testify. My name is Sam Friedman. I'm a long-time New Jerseyan. I grew up in Westfield, and once tutored the Rahway Fire Chief's son. I now live in Englewood. You're my representative, Assemblywoman Huttle, and I thank you for taking the time to listen to us and consider our point of view.

I'm co-guardian of my younger sister Jacqueline. Jackie had two strikes against her before she was born -- Down syndrome, and severe brain damage when her umbilical cord broke, cutting off her oxygen. Her heart stopped, she was virtually stillborn, and survived only due to medical heroics. And so, Jackie's fate was essentially sealed in 1964. She will never utter a word or even an intelligible sound; or play with a toy; or look anyone in the eye; or show facial recognition of anyone or thing upon which she on occasion trains her eyes for an instant. Nor will she learn any new skills, and of course, she can't take care of herself or control any of her own bodily functions. Taught to walk, her gait is rigid due to Harrington rods implanted in her spine to arrest worsening scoliosis; but like a docile pony, she is only led, never venturing on her own. Taught to feed herself by rote, she doesn't see the pureed food she spoons from the bowl and jams into her mouth. Determined to have the I.Q. of a two-month-old, Jackie's reality is that of a two-month-old who's got nigh on a half-century's life experience.

And Jackie most certainly does have a life – a being, a presence, a personality, a soul, if you will -- 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 and nursing care at the ready, which she needs; structured recreation, which she needs, on occasion therapeutic intervention, which she needs and which she'll need more of as she declines with age; and just as importantly, human love, which she needs. This she gets from staff, most of whom have known her for decades; from a rookie on staff who's fallen for Jackie like others before her and who visits Jackie on her own time; from her foster-grandmother Eleanor, whose infirmities now make it hard for her to get there from nearby Paterson; and from me, her brother. Once or twice a month, I'm there for an afternoon or evening, helping feed her, and maybe adding a soft chocolate treat, for she has the family sweet tooth; getting her out for fresh air, so as to keep her walking; and taking her to her childhood favorite gondola swing – knowing full-well that 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 down into my shoulder or lap to have me cuddle her. But my commute is from Englewood to Queens, and I've got years to go, and I've got a family. So I get there when I can. <u>When Jackie is in the hospital, I stretch myself so as to get there</u>, as her advocate, just as any relative needs – *and just as you would do for yours*. Only Jackie, of course, needs that more so: She can't say, "It hurts," and, sad to say, some clinicians can't read the signs.

There's no nice way to put this: I'm here now to beg you to use whatever clout you have to stop the State from delivering strike three to Jackie, and to many hundreds who are more like her than not. Eviction from North Jersey will tear her from all that sustains her: the staffing, care, medical and therapeutic inputs, and oversight inherent in the federally-prescribed level of care required at Developmental Centers; the surrogate family who loves and cares for her; *and my loving presence in*

21x

her life. These elements cumulatively have kept her alive and relatively well, long past what might reasonably be expected.

To 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 will not be able to get there, even when there's a medical crisis, and I'm decades younger and fitter than many, indeed most, of the family members being forced into this untenable circumstance. Geography, Chairman Vitale and Chairwoman Huttle, is determinative, *and the State knows it.* Jackie -- more cognitively limited than some, not yet as medically complex as others -- is in turn representative of many, indeed most, of the residents of North Jersey and Woodbridge – severely impaired in body and brain, inveterately frail, and, above all, vulnerable in the extreme, utterly helpless in the face of bureaucratic forces.

When the State Division of Developmental Disabilities Assistant Director – as recently quoted in the Bergen Record – states that Jackie and her fellow Developmental Center residents do <u>not</u> have unique needs, that – quote -- "thousands" like her are being well cared for "in the community," and that it is really just a matter of educating the families[so that we see things right], I promise you, Senator and Assemblywoman, that she is either lying, or is willfully ignorant, or some combination of the two.

In the past few months, as a representative of the Coalition that seeks to save these residents' homes, I *have* studied up. Here, in sum, is what I've learned, and what nearly all of our families have come to know:

First, it is the very most severely impaired iceberg-tip of New Jersey's disabled persons who reside at the Centers. Their conditions are more complex and extreme, and consequently their needs are more intensive and wide-ranging, than are other disabled persons'.

Second, the closures have likely been ordered so as to shift funding, to shift it away from New Jersey's most severely disabled, and instead toward the needs of other disabled folks whom the State has thus far failed -- and perhaps also toward other Gubernatorial priorities not having to do with the disabled at all. Hence, the only two Centers in the northern third of the State have been ordered closed in a political deal among the Governor and south Jersey legislators, while those in the central third of the State are for all intents and purposes full.

Third, the evictions -- with our loved ones being pushed *en masse* into so-called community placement consisting of yet-to-be-created group homes -- owe to a political wind that is undeniable, *but have literally nothing to do with the needs of our helpless loved ones.* The mass relocation certainly has nothing to offer the ones, like Jackie, who cannot benefit in any way from any of the advantages that community placement might afford some folks who are less cognitively- and medically-impaired. But Jackie and those like her do stand to lose much in the transition from the federal ICF-MR (Intermediate Care Facility – Mentally Retarded) level of care that applies to Developmental Center residents to the Community Care Waiver level of care that applies to group home residents.

And that, Chairman Vitale and Chairwoman Huttle, is why some 184 out of 195 North Jersey family members who are guardians – 94 percent, an overwhelming majority -- chose continued Developmental Center placement over community placement. This was in a survey conducted relatively recently, in 2009, in which they were given a choice that was not inherently coercive.

Fourth, I learned this: With respect to guardians' choosing the appropriate placement for their wards – again, there's no nice way to say it – *the fix is on*.

Pressure on guardians to choose group home placement has been ongoing, beginning with our first contact with the State regarding the closures: At the get-go, we were called to meetings where high-level State reps who won't normally talk to us made a personal appearance, making sure to get it through our heads that community placement came with 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* up north, for any but a lucky few. Second, it wouldn't matter much anyway, because, notwithstanding our role as guardians, we'd have *zero* choice with respect to where our loved ones would go. The rare exceptions to this "no choice" rule, we were told, would be the *frequent visitors* – those few who because of some combination of geography, private wealth, and non-working status, could afford to visit their loved one all the time. As for working people, like me? *Fugheddaboutdit.* So-called "survey forms" distributed to us, which we were directed to fill out, pronto, incorporated this Hobson's choice into their wording and graphics. Then, a kindly group-home pitchman, courtesy of a State contract, promising us it would all be O.K., rounded out the proceedings. He brought with him his wares -- Exhibits A and B, if you will -- slick publications depicting, respectively, 13 community South Jersey placements, and nine more 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 community models with respect to the well-being of our loved ones – who are, simultaneously, severely and profoundly retarded *and* medically complex and fragile disabled persons.

And finally, Senator Vitale and Assembly Member Huttle, I learned this fifth lesson, a most bitter one: *Guardians are not the only ones being pressured.* The professionals – the social workers, therapists, case coordinators and managers and other care-givers -- who assess fitness for community placement in the development of our loved ones' annual Individual Habilitation Plans – are being pressed by their higher-ups to enforce the fix -- that is, to push community placement over Developmental Center placement 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 statements in the assessments that favor Developmental Center placement that were ordered to be purged or re-written. This *State* pressure on the staff who treat, who are *State* employees, is not just inappropriate and not just a rotten deal – it is by definition unprofessional, it is plainly immoral, and it is perhaps even illegal in serving to interfere with 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 the deck the trump cards -- no matter how honestly come by -- that might contribute to a "winning hand" for some residents. That is how politically committed State is to minimizing numbers of residents who are officially sanctioned for continued care under the federal level of care. It's almost Soviet, is it not?

Senator Vitale and Assembly Member Huttle, I have a combined health science and journalism background and am innately curious. Because care and treatment of the disabled is not my area of expertise – outside of what I know about Jackie -- I've sought out the expert knowledge of top developmental disability professionals elsewhere, who are not directly involved in any way in the present conflict, to hear what they have to say. What they've told me makes me tremble. One director, who has both run facilities akin to our Developmental Centers and directed group homes, and who has even presided over the emptying of an institution for the disabled in another state – pretty good credentials for weighing in, I would think -- said this to me: She frankly would be *very concerned* for what she termed the "low-functioning" residents who have been cared for in the Centers for many decades, even were their physical well-being to be well-attended-to in their new settings. "I expect that a great many will die soon," she said.

Chairman Vitale and Chairwoman Huttle, I implore you. Use all of your powers, all of your capital, all of your leverage, to inveigh upon your colleagues to undo this palpable wrong. If you do not, the State will variously disperse, and bus south, our loved ones. Any follow-up study that might evidence likely connection between these forced evictions and fatal outcomes will be years in the making, if ever -- too late for most or all of some 700 disabled residents. If you do not, the calls that I or others make to you to report the declines and demises of our loved ones will be labeled "anecdotal." But we will know, and, hence, you will know. Please, spare us, and as well yourselves, the fate of knowing that we did not stop our most vulnerable citizens from being done in -- in the final analysis -- by the forces of cynical political expedience. In return for your going the full distance for our loved ones, we can promise you only these things: our votes; our inscribing your good deeds in the hearts and minds of our families, friends and communities, for the rest of our lifetimes, and for future generations; and one thing that isn't ours to give -- you will sleep better at night.

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 me out.

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KEEP WOODBRIDGE DEVELOPMENTAL CENTER OPEN

February 13, 2013

Committee Members:

My daughter Catherine will be 52 in March and is classified as profoundly retarded at a seven 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 i.e. 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% 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 states political agenda. The state is affecting not only these 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 2 or 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 these individuals and not on what seems to be cheaper and more expedient.

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 are not capable of providing the necessary quality of care?

I know why 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 that 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 also has 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.

Respectfully,

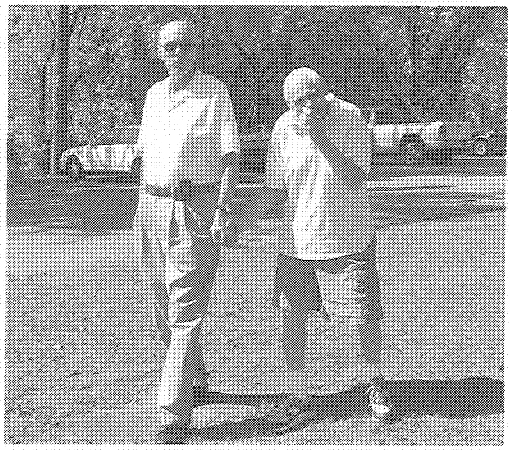
Virginia O'Brien
Parent of Catherine O'Brien
Resident of Woodbridge Developmental Center

Catherine and her parents Don & Virginia O'Brien

Catherine is 51 years old, is classified as profoundly retarded and functions at a 7 month age level. She has lived at WDC since it opened in 1965.
Don and Virginia live in South Plainfield. They are in their late 70s and visit their daughter Cathy every week.

Bobby and his brother Len Lorensen

Bobby is 68 years old and has lived in a developmental center for 60 years, and at WDC since it opened in 1965. He is non-verbal and functions on the level of an 18 month old, yet Bobby has led a contented and healthy life at Woodbridge. Since their parents died many years ago, Bobby's guardian is his older brother Len.



Peter and his mother Eileen Canale

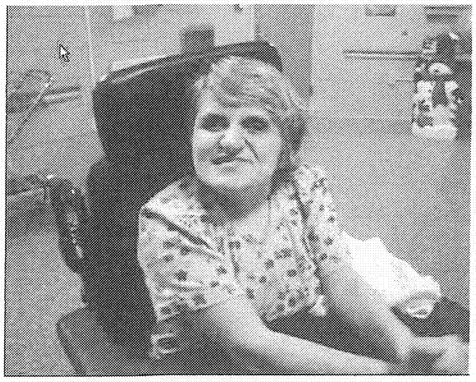
Peter has lived at WDC for 49 years, since he was 5 years old. Peter is blind, deaf, wheel chair bound with the cognitive ability of an infant and weighs a mere 60 pounds. His mother Eileen Canale is 84 years old and it would be very difficult for her to visit Peter if he was moved to a developmental center in South Jersey.

Woodbridge Developmental Center

Woodbridge Developmental Center

Rosemary and her sister Joanne St. Amand

Rosemary is 57 and has lived at WDC for more than 37 years. Rosemary has never spoken and cannot move on her own. She has the cognitive age of a 3 month old. Rosemary's sister Joanne lives in Cranford. Since their mother died a year ago, Joanne and her brother are Rosemary's co-guardians.



Joyce and her brother Peter Banos

Joyce has lived at WDC more than 40 years. Her brother and guardian Peter Banos lives in Mendham. Joyce was born with a multiple, severe birth defects. She has never spoken a word, needs to be spoon fed, is in diapers and has many severe medical issues. Her parents although they have passed away expressed their intent that Joyce remain at Woodbridge for the remainder of her life.

Kerr and his mother Juana Mitchell

Kerr has lived at WDC for many years. His mother Juana takes public transportation to see Kerr several times a week. From her home in Bloomfield it takes a couple of hours each way, with 4 connections (each way). But at least public transportation is available to Woodbridge! Kerr expects to see his mother and Juana is distressed at the thought that she might not be able to reach him if he is moved to a developmental center in South Jersey. The emotional impact on both is incalculable.

Salvatore Pizzuro, Ed.D., LL.M., P.D.
Testimony Before the Senate Health and Assembly Human Services Committees
2/13/2013

Chairman Vitale, Chairwoman Vanieri Huttle and members of the Senate Committee on Health, Human Services and Senior Citizens and the Assembly Human Services Committee, my name is Sal Pizzuro. Thank you for the opportunity to address you during this hearing on the closing of Developmental Centers in New Jersey.

It is interesting that, back in August, I was contacted by an individual who said that he had been the Deputy Director of the New Jersey Division of Developmental Disabilities for 32 years. His name is Bernie White, and he said that he was contacting me to discuss the high rate of mortality that arose when residents were transferred from the large developmental centers to the community.

He explained that while he served as a State official, California attempted to do what we are doing in New Jersey: "Closing some of the State's Developmental Centers". He cited numbers and indicated that he tried to do the same thing in New Jersey many decades ago, but indicated that other States experienced a rise in mortality rates when such a transfer is attempted.

I did not have time to verify his facts and figures, but he mentioned that there was a variable that was closely associated with the mortality rates: "Whether the transfer to the community or another developmental center precluded the residents from seeing their families". He also indicated that other factors, such as whether or not the resident was ambulatory, figured into long term survival. I did learn soon afterward that the residents of Totowa and Woodbridge had a significantly higher proportion of non-ambulatory individuals than the population of people with DD who reside in New Jersey's group homes.

A few years ago, NJ DDD listed the necessary components for a successful transfer to the community. Those components included

- "accessible housing for people with physical limitations
- Appropriate healthcare
- Appropriate nursing services
- Appropriate mental health services
- Appropriate physical, speech and occupational therapies
- social and recreational activities, and
- opportunities for employment"

Sources have indicated that virtually no prospective community placements have all of these components, and the plan for such transfers does not include the guarantee that the residents will live closer to their families, which is considered a necessary ingredient for survival and success.

I did not come to recommend whether the Totowa and Woodbridge Developmental Centers should close, but I would like to suggest that proper preparations should be completed in advance of the closings.

When White contacted me, he also cited the results of California's transfer of residents from developmental centers to community settings in which, according to White, the death rates were 47 percent higher than if the residents remained in the larger centers. White also indicated that an attempt by Ohio to transfer residents to the community had similar results. Although I had no further conversations with White, and my insane daily schedule did not allow me to verify all of his claims, I was struck by the concept that the issue must be carefully evaluated before such a move is made.

New Jersey must consider the possibility that the plan to close the Woodbridge and Totowa Developmental Centers may be premature. We are already engaged in a battle to protect New Jersey's citizens with developmental disabilities from abuse, neglect and exploitation that has resulted in many deaths and lifelong injuries. We must consider whether there are an adequate number of reasonable community settings available. Given that there is currently a long waiting list for housing among individuals with developmental disabilities who currently live with their families, we must consider the fate of the current residents of the developmental centers. Would they be added to the current waiting list, where individuals wait for years or, in some cases, even decades for housing? Would they be placed in a part of the State where their families could not visit them? Would they have access to the services necessary for a reasonable quality of life? Will the residents of the two aforementioned developmental centers be leaving willingly or against their will?

In my opinion, the current move to close the developmental centers exemplifies the concept that these vulnerable citizens are without rights and their very lives and physical and emotional welfare are considered to be without value.

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 Development Center since 1965. Woodbridge is her home. She is very comfortable there and gets excellent care from the competent staff. She is happy, 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 and 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 setback 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, 1979-2001, 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. 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 OPEN.

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 (LCSW). A social worker who for the past ten 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. This is my younger daughter Lori Ann who for the past 15 years has been successful at paper shredding, envelope stuffing and gardening. I am equally proud of both of them.

Lori cannot speak for herself, she cannot lobby for the healthcare she desperately needs and deserves. She would never be able to be at a forum such as this, but while we are here telling her story she is in the safe care of her "other family" the health care 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 "Pervasive developmental disorder." An atypical form of autisms 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, Zonegran, Haldol, Topramax and Zyprexa used the Dr's say to decrease physical aggression, decrease overall agitation which has many times lead Lori to hurt herself and others and often included property destruction.

Before being placed in NJDC Lori's first 15years where spent home going to a variety of special Ed schools, multiple Dr's 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 care and 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 or environment for Lori. Watching her pain and remorse after each crisis is what finally lead me to the realization 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 care givers. She is not a candidate for a group home with limited staff and should not have to move a hundred miles away from the only life she knows. If there was any way for Lori to reside anywhere other than the most closely supervised psychiatric setting she would live home with me. For many years Lori has required an aid just for her needs, the aids were great. With the state no longer wanting to provide that additional care even though her moods and effects are liable it seems the state is still preparing to move her and others like her to lower level of care facilities.

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 the intensive care unit for 32 years and part time as an acute dialysis nurse. I work alternating 12 hour shifts, yet I have always found time to visit with Lori everyday for the past 15 years. NJDC is close enough to me where I could bring her dinner and help with her PM care "tub time" before going to a long night of work taking care of 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 hard to let her go, but in hind sight is 20/20 and after 15 years of care at NJDC I know in my heart they were right. Lori is happy in her home and 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 happen to her and I 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 residents.

I feel that this decision is brutally unfair. You are asking me to choose between the care of my daughter needs and being able to see her regularly and to be the stable part of her life. Please keep NJDC open and don't allow it to close. Help to let Lori and I live the rest of our lives safely on close proximity of each other.

Thank you for holding this hearing today and listening to the families.

The Arc of New Jersey

Achieve with us.

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Testimony on Developmental Center Closures
Joint Legislative Hearing at Montclair University
Tom Baffuto
February 13, 2013

Good Morning,

My name is Tom Baffuto and I am the Executive Director of The Arc of New Jersey, the largest statewide advocacy organization for individuals with intellectual and developmental disabilities and their families. We have 20 affiliated local chapters providing services in all 21 counties in New Jersey. Our mission is to enhance the quality of life of children and adults with intellectual and developmental disabilities and their families through advocacy, empowerment, education and prevention.

Thank you for the opportunity to speak with you today about the very important issue of developmental center closures and New Jersey's capacity to serve people from its developmental centers in community settings. First off, I want to commend the Legislature for establishing the Task Force on the Closure of State Developmental Centers. We support the Task Force's binding ruling to close North Jersey and Woodbridge Developmental Centers. The Arc of New Jersey stands ready to assist the residents and family members going forward and we are happy to serve as a resource for them as they navigate through this process.

With that said, one of the core principles at The Arc of New Jersey is empowering people with developmental disabilities with choice. To that end, we understand that some people will choose to keep their son or daughter in a developmental center and we support that choice. We also recognize that those selecting that option will be faced with a great burden and increased distance to visit their loved one. Ultimately, our hope is that suitable community homes can be identified to ease that burden and to keep families figuratively and geographically closer together.

As we look at the 340 residents of North Jersey Developmental Center and the 321 residents at Woodbridge Developmental Center, it is critical that every person receive an individualized plan. All 661 individuals leaving these centers have unique needs and moving forward it is imperative to create a comprehensive outline for their next phase of life.

The Department of Human Services (DHS) is aggressively developing community housing. The Division of Developmental Disabilities (DDD) and the New Jersey Housing and Mortgage Finance Agency (HMFA) have partnered on housing needs and since the start of the current fiscal year, more than 200 beds have been brought on line in different geographic regions in the state. They are also working to develop 100 more beds this year. We applaud this partnership and the rapid development and we are encouraged by the progress being made. We believe that if the current pace continues, we can meet the needs of those seeking homes in the community. It should also be noted that presently, the housing infrastructure is operating efficiently with less than a 2% vacancy rate in the community.

When talking about housing it helps to look at the 11 states that have completely eliminated developmental centers and the additional 11 states that only operate one developmental center. These 22 states have found success using a small housing model to transition former DC residents to group homes of 4 people or less. Group homes and supported living arrangements that house and serve people with intellectual and developmental disabilities in the community are licensed and highly regulated by the Department of Human Services, with safety and accountability being top priorities. Individuals can count on continuity of care. A high-quality level of support is available outside of the developmental center. Providers are willing and able to handle the influx of people and they embrace the closing of these centers. We are also excited by the welcoming response of local municipalities to bring people with developmental disabilities into the folds of the community.

Fortunately, individuals and families are not without resources. The Community Living Education Project (CLEP), housed at UMDNJ, provides education to individuals and families about the full range of resources that are available in community living for people with developmental disabilities. CLEP serves as a liaison and helps individuals and their family members learn more about what is available in their area. In addition, chapters of The Arc stand ready to assist families in any way they need. Staff members are happy to provide families with a firsthand look at local group homes and assisted living facilities. Families should know that there are a number of options for their child or loved one, including traditional day programs and self-directed options. Notwithstanding support needs, there are available programs and employment opportunities in North Jersey. We welcome and encourage families to visit and explore services to obtain a true understanding of what is really available for their loved one.

It should also be noted that the Governor has promised reinvestment of all funds realized from the two DC closures into community-based services for people with I/DD. These funds can help build up the existing infrastructure and enhance the disability service system.

In addition to housing and day programs, access to mental health services is a vital need for individuals exiting the developmental centers. We must remember that 31.6% of people living in developmental centers receive intensive behavioral supports and 53% have a psychiatric diagnosis. We need to work with the Legislature to ensure that there are sufficient, well-trained mental health professionals for those moving into the community programs. Access to psychiatrists and other specialty practitioners, such as dentists and gynecologists, are key to this population's success. In addition, we encourage DHS to conduct a thorough analysis of individuals living in the developmental centers to categorize needed services, identify current resources and create new resources moving forward. Individuals leaving DCs should be accompanied by a complete medical history that includes a comprehensive, standardized summary document, necessary original source documents, a history of specific medical procedures and illnesses, complete information on current medication and therapies received, as well as ongoing health care needs. This data should be included in the individualized transition plan that accompanies each resident.

We also implore DDD to communicate often and effectively with families during this transitional period. It is imperative that families are provided clear information so they understand what is to come and when it will occur. The state should develop meaningful ways to involve families in the transition process. Involving them and connecting them with other families and community agencies will help with the relocation process.

An exact date for the developmental centers closing is still being determined. We must use the time that remains to identify and develop resources for individuals transitioning to the community. Success will include a combination of residential facilities, behavioral and medical health services, available day programs and employment opportunities. The Arc of New Jersey believes that the community will be ready when the first developmental center closes.

I want to thank you again for holding today's hearing and for the opportunity to testify.

ABCD Alliance for the Betterment of Citizens with Disabilities

Empowering People: Providers Shaping Policies

Testimony of Dan Keating, PhD
Executive Director
Joint Legislative Committee Meeting on DC Closure
Montclair University
February 13, 2013

Good morning Chairman Senator Vitale and Chairwoman Assemblywoman Vainieri – Huttle. We thank you for the opportunity to speak before your committees today in this joint session. We also appreciate the attendance and attention of the members of the Senate Health, Human Services and Senior Citizens and the Assembly Human Services Committees and recognize the commitment and support that members of both committees routinely show to the citizens of New Jersey with intellectual and developmental disabilities. It is much appreciated.

My name is Dan Keating. I am the Executive Director of The Alliance for the Betterment of Citizens with Disabilities (ABCD). ABCD is a statewide organization representing member agencies that provide an array of community –based supports for more than 10,000 people with complex physical and neurological developmental disabilities and their families. ABCD members provide services and supports to individuals with significant medical and behavioral challenges.

ABCD supports the closure of two Developmental Centers as recommended by the Task Force on the Closure of Developmental Centers. Furthermore, we believe that community providers are capable and skilled in providing quality supports and services to those who will be moving from the DCs. Community providers are ready to meet the challenge of providing quality experiences for those looking for new relationships in their communities.

Our providers know that all individuals, regardless of the severity of their disability can grow and develop. The movement toward community options for individuals with intellectual and developmental disabilities was reaffirmed in 2000 with the reauthorization of the DD Act. In part the act proposes that: Individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and states, and the nation. NJ's provider community can accomplish this vision for those who want to move from the Development Centers. We start from the premise that all individuals can learn and develop. If we start from the premise that one can't do something, they never will. If we do not believe that people can develop and we tell them that they can't, they never will. They will never be given the chance. Rather than "they can't" we say "why not?"

That is not to say that all develop to the same level or accomplish the same things. Everyone is given the opportunity to grow and develop at their own pace. The support network is always there. Providers create situations that minimize the risk. None of us know the ultimate level that anyone will reach. We cannot predict the future. However, we can allow people the opportunity. If we say they can't they won't! If, on the other hand we say they can go further, they will develop and grow. Limiting people's experiences out of fear takes away opportunities for growth. We need to address the sources of fear and minimize risk so as to give people the opportunity to grow and develop.

Closing two developmental centers will give many individuals in NJ the opportunity to experience success and friendships in the community. In testimony before the Task Force on the Closure of Developmental Centers Deborah Spitalnik of the Boggs Center testified that although 90% of the individuals served by the NJ Division of Developmental Disabilities live in the community, only 66% of DDD's resources go to those residing in the community. If the savings accrued from closing the DCs is reinvested in the community we can create a more balanced system of supports. More people with intellectual and developmental disabilities will have access to supports and resources that will enable them to more fully participate in the community. The opportunity for establishing relationships with people other than other individuals with disabilities will be enhanced.

We understand and appreciate the concerns of those who are skeptical about this approach and do not see the individuals who reside in the DCs as being able to live in the community. Yet, for every person in the Developmental Centers there is an individual already living, participating and included in the community with the same level of need for supports.

In testimony before the Task Force on the Closure of Developmental Centers Patricia Carlesimo, the Executive Director of LADICIN, an ABCD member agency, shared the following story: "Winnie was born in 1959...She was diagnosed with cerebral palsy in early childhood. She has three sisters and one brother. She grew up in her family home until the age of 16 when she moved to Vineland Developmental Center....'When we first met Winnie, she was in the Vineland Hospital, attached to the Developmental Center, weighing...less than 50 pounds, non-verbal, but with talking eyes, and a communication device that was not readily available to her. We spent some time talking with her – she responded quickly and intelligently with yes or no signals. She indicated her desire to be in the community. We were told that she could not live in a community setting because of her medical needs....When she came to us, therapists immediately began to work with her to properly position her in a power chair and to position her communication device so that she could reach it easily and with a reduction in postural stress. ...she became her own payee on Social Security.'

Winnie has spastic quadriplegia and is dependent on others for assistance with all activities of daily living including: toileting, bathing, positioning, transfers, feeding, and communication. At LADACN she has access to an array of services delivered through a transdisciplinary team...She uses a power wheelchair with an individualized seating system... and an eye gaze system and communication book for communication purposes. She is at risk for aspiration due to dysphagia; however, she is followed by our speech pathologist with experience in this area and with proper positioning, adapted equipment, spooning techniques and food textures she has not had any aspiration pneumonias. In fact she has doubled her weight since she moved into the community. She now weighs 110 pounds and has been able to maintain this weight. Our therapists work in tandem with the group home staff to ensure that she is positioned properly...that transfers are safely done, that she is fed correctly at mealtimes and that she is able to express herself to staff and friends.

Winnie has thrived living in the community....In her day program she receives occupational, physical and speech therapy and works on basic education, life skills training, computers, art, music, adapted recreation, vocational training, social skills and community integration. She is on 8 medications a day and sees her primary care physician, a gastroenterologist, a dentist and eye doctor. She has been hospitalized 8 times since she came to us with some very serious conditions; but, she has successfully recovered each time and returned to her community home. She has a long term friendship with a man who lives in Ocean County. She is basically healthy and happy at 53. In November 2010 Winnie met a significant long-term goal. Through her persistence and patience and with ... assistance ... Winnie became her own guardian. She is very proud of this accomplishment as we are of her."

Here is a woman with what most would agree are significant disabilities who preserved her family relationships, became much healthier, developed long term friendships, learned to be increasingly independent, including managing her money, becoming her own payee, and after 18+ years of living with an assigned guardian, assuming personal guardianship against many odds. She shops, she dines, she participates in community activities and she enjoys the enrichment opportunities offered through her day program.

LADACIN said "why not," instead of "you can't" to Winnie.
If we hold that people can learn and grow and the upside is worth the value of giving individuals the opportunity to try, more is possible. Supports are available. The providers of community supports are skilled and capable of supporting individuals with significant disability in the community. It is happening now. With the closure of two DCs the savings, if reinvested in the support system, will enable more people on NJ's extensive waiting list to obtain services and supports.

ABCD supports the closure of two developmental centers as recommended by the task force on the Closure of Developmental Centers. Furthermore, we encourage that the savings from the operation of those Centers be reinvested into the community. We need to invest in the people who work in the community, the Direct Support Professionals who consistently provide quality experiences for the individuals that they support. One additional suggestion would be to use the closed facilities to provide centers for medical, dental and other therapeutic supports. These centers could provide training for medical and dental school students and other health professionals. Individuals with intellectual and developmental disabilities could have access to the medical supports that they need.

Thank you for the opportunity to share the thoughts of the members of ABCD with you today. We look forward to on-going dialogue with the legislature and the administration to continually focus upon the provision of quality supports to individuals with intellectual and developmental disabilities in the community.

Respectfully submitted,

Daniel J. Keating, PhD

NJACP
New Jersey Association of Community Providers
Advancing Quality Services for People with Intellectual and Developmental Disabilities

Testimony
Deborah Good, NJACP Board of Directors and Past President
February 13, 2013
Senate Health and Human Services Committee Joint Legislative Hearing on the Closures of North Jersey Developmental Center and Woodbridge Developmental Center

On behalf of the New Jersey Association of Community Providers, our Board of Directors and the thousands of people with intellectual and developmental disabilities our agencies support, we appreciate the opportunity to share our thoughts on the community's capacity to serve individuals with intellectual and developmental disabilities. My name is Deborah Good and I am on the NJACP Board of Directors and am a Past President of the organization. Thank you for the opportunity to be part of the proceedings today.

NJACP is a statewide association committed to ensuring continuing progress toward greater quality of life for people with intellectual and developmental disabilities. Our organization is comprised of community based organizations that provide an essential foundation of services and supports including group homes, supported living and a full range of community services to support individuals with intellectual and developmental disabilities both in agency residences, at home with their families and in their own homes.

We support The Task Force on the Closure of Developmental Center's recommendation to close North Jersey Developmental Center and Woodbridge Developmental Center as a first step toward realigning the system to meet the needs of people and to promote community inclusion. NJACP has been a vocal advocate in the effort to support community inclusion in New Jersey and to position our system to support the growing need for community services for people with intellectual and developmental disabilities.

For many people living in institutions that may have been waiting decades, closure is an opportunity for the public system to allow people the choice to live in the community. We also recognize that with change comes uncertainty for people and their families. The provider community stands as a strong partner with the State to meet people's needs and wants and help people achieve their hopes and dreams. We are committed to providing quality supports and services that promote independence and provide for health, safety and well-being.

NJ has a wealth of community resources to support this change from our renowned medical facilities, behavioral health systems, today's advances in technology, the affordability of the current housing market and over 300 committed community based providers. The public private/partnership has demonstrated that we have the expertise and commitment to support the varied needs of people including those with complex medical and behavioral health needs. With community development, reinvestment of institutional savings and the support of federal funds targeted to support community inclusion; New Jersey can realign its system to support community living successfully.

The closure of North Jersey and Woodbridge also presents an opportunity to strengthen the system by reinvesting any savings from institutional closure back into the community system. The provider system moves forward with a strong foundation, and, as institutional census declines, targeted savings to the community will support growth and ready access to services and supports. This is an opportunity to embrace new technologies, quality improvements, and expand services.

We look to work together with the people who rely on this system to make choice a reality for all people with intellectual and developmental disabilities and meet the growing community based needs of New Jersey residents.

Joint Committee Hearing Testimony

February 13, 2013

Carolyn C. Wade
President
CWA Local 1040
230 Parkway Avenue
Trenton NJ 08618
609-538-8899

Good morning members of the Committee. Let me thank you for this opportunity to speak before you today. My name is Carolyn Wade and I am the President of CWA Local 1040. We represent about 9,000 members in our Local and a little more than 800 of those members are in North Jersey and Woodbridge Developmental Centers. I have come before you today to discuss our concerns about the closure of these two facilities. If the closures proceed it will have a devastating effect on the services the State provides to its developmentally disabled community as well as the diminishing of the quality of care. We have been through many closures before, including those of Johnstone Training and Research Center in 1991, North Princeton in 1998 and Marlboro Psychiatric Hospital also in 1998, Hagedorn in 2012. We have seen it all with deinstitutionalization, from people living under bridges on the Jersey Shore once released; to DHS not knowing where clients are years later; to client abuse because their behaviors were far too aggressive for the community, and constant recidivism of clients back into the developmental centers because they were never suited for community residential living in the first place. Local 1040 represents not only developmental center workers, but also community providers such as Mercer ARC, Community Care and Respite Providers who care for this population in their very own homes. So we see the whole spectrum of care that is out there for this population and have become acutely aware of their needs and the services that are provided.

In the developmental centers you have well trained staff with full time doctors, nurses, dentists, psychiatrists, occupational and physical therapists, dieticians, social workers and Para -professionals on the job daily. This is not the case in community group homes. The developmental centers have licensed professionals whereas in the group homes, the community providers are not required to do much more than a two week training session before they can begin working. Is this the type of care that should be provided to the most profoundly and severely disabled? Former Deputy Commissioner of NJ's Division of Developmental Disabilities, Bernie White stated that if NJ were to go through with these closings and place these individuals into the community there would be a 47% death rate of those that are moved. Even NJ's own Institute of Technology study on the North Princeton closure would show if carried out one more month farther, that there would have been a significant increase in mortality of those that were moved into the community. This plan is ill-conceived and does not take the severity of these individuals' conditions into consideration.

It has been established that there are not enough well trained physicians in the community according to the American Academy of Developmental Dentistry and Medicine (AAMD). Numerous published studies and reports have documented that community physicians, dentists, and nurses are not experienced or well-trained regarding the evaluation and management of health conditions frequently encountered in adults with severe medically complex developmental disabilities. (Yale / Special Olympics Report, Surgeon General's Report of 2002, US Health and

Human Services Task Force Report, American Academy of developmental Medicine and Dentistry report, American Medical Association Resolution Council On Medical Service (Resolution 805-1-10); CMS (Centers for Medicare and Medicaid Services) Reports 3-1-11).

The AAMD states in their Health Disparities Consensus Statement released in 2011 by Steve Edielman (from the University of Delaware, H. Rodney Sharp, Professor of Human Services Policy and Leadership) that this population is 'medically underserved'. Many physicians just do not know how to treat this population. The AAMD further states 'The majority of newly graduated physicians and dentists (despite an interest in patients with Neuro-developmental Disorders and Intellectual Disabilities) do not feel competent to treat this category of patients. Training and education must be a necessary component for physicians in order to ensure the livelihoods of this medically vulnerable population. Unfortunately, this is not currently available in NJ. I hope this will not be the cause of the demise of many of those the State will be moving.

Additionally, more than half of the residents we care for in the developmental centers are medically complex adults with developmental disabilities. This means that they suffer from multiple issues, including but not limited to: 1) motor dysfunction, 2) seizures, 3) destructive behavior due to poor impulse control which may or may not categorize into a true psychiatric diagnosis, and 4) severe cognitive dysfunction. In addition, there are often oral or swallowing dysfunctions, aspiration pneumonia (lung or airway inflammation due to foreign materials like food, liquids, vomit, or fluids from the mouth being breathed in), reflux disease, recurrent pneumonia, osteoporosis, fractures, and multiple drug toxicities. These conditions occur in various combinations. Our doctors in the developmental centers have to be a fundamental part of the team that care for these individuals and constantly monitor the treatment plan, medications and services their clients receive.

This type of comprehensive care given in the developmental centers goes beyond fragmented treatment from isolated professionals in group homes. A medically complex client's life often depends on this holistic approach which is not provided in the community.

I raise all of these issues before you today to ask you to reconsider the State's plan to close these centers. We represent excellent and proficient staff in all our seven developmental centers and know this population best. It is inhumane of this State to recommend closure without taking a closer look at the bigger picture, putting our most vulnerable citizens' lives at stake. I speak for those individuals without a voice so that they may be heard because we are their family too. I ask you, members of this committee to help us in our fight to keep these developmental centers open. Thank you.

REPORT OF THE COUNCIL ON MEDICAL SERVICE

CMS Report 3-I-11

Subject:	Designation of the Intellectually Disabled as a Medically Underserved Population (Resolution 805-I-10)
Presented by:	Thomas E. Sullivan, MD, Chair
Referred to:	Reference Committee J (Barbara J. Arnold, MD, Chair)

At the American Medical Association's (AMA) 2010 Interim Meeting, the House of Delegates referred Resolution 805-I-10, which was introduced by the International Medical Graduates Section and calls for the AMA to "lobby Congress to work with the appropriate federal agencies, such as the Department of Health and Human Services, to classify intellectually disabled persons as a medically underserved population." The Board of Trustees referred Resolution 805-I-10 to the Council on Medical Service for study.

This report provides background on intellectual disabilities, discusses how the federal government currently designates a group as a medically underserved population, highlights Patient Protection and Affordable Care Act (ACA, PL 111-148) provisions that are likely to impact individuals with intellectual disabilities, reviews relevant AMA policy, and presents policy recommendations.

BACKGROUND

Approximately seven to eight million Americans of all ages experience some level of intellectual disability (American Association on Intellectual and Developmental Disabilities, 2009). An intellectual disability – sometimes referred to as a cognitive disability or "mental retardation" – is an impairment that manifests before adulthood and limits mental functioning indefinitely. The degree of disability can vary greatly and be categorized as mild, moderate, severe, or profound based on the ability to communicate, socialize and perform activities of daily living. Some of the most commonly known causes of intellectual disability may be attributed to genetics, infections during pregnancy and problems at birth or factors during childhood.

Over the past 50 years, care for those with intellectual disabilities has shifted from institutions to the mainstream community. Individuals with intellectual disabilities are more likely to receive fewer routine health examinations, fewer immunizations and less prophylactic oral health care than do other Americans. As noted in Resolution 805-I-10, employment and low-income status are key barriers to health care access for individuals with intellectual disabilities. Lower socioeconomic standing, related to poor employment prospects, results in a greater reliance on government-funded programs (e.g., Medicare, Medicaid, the Children's Health Insurance Program, local community clinics, county medical centers, federally qualified health centers and safety net clinics).

HEALTH RESOURCES AND SERVICES ADMINISTRATION

The Department of Health and Human Services (HHS) oversees the Health Resources and Services Administration (HRSA), which is the primary federal agency designed to administer the primary care Health Professional Shortage Area (HPSA) designation system. Since the 1970s, the HPSA designation system has expanded to nearly 30 programs that can be divided into four broad categories: 1) primary care service grants; 2) health professionals training and recruitment support; 3) Medicare and Medicaid payment enhancements; and 4) support for international health professional graduates. HPSA designations are specifically used by programs such as the J-1 Visa waiver program and the Federally Qualified Health Care (FQHC) program to address health care access and physician payment barriers. The J-1 Visa program allows international medical graduates to qualify for a waiver of the two-year foreign residency requirement if they commit to serve in a medically underserved area or population or in a HPSA facility for at least three years. The primary care FQHC program directs primary care physicians to medically underserved areas, populations and facilities.

There are three types of HPSA used to prioritize the distribution of federal and state funds based on medical need: geographic, population-group, and facility. Geographic HPSAs, designated as medically underserved areas (MUAs), include entire counties, a portion of a county, or a group of contiguous counties. Population-group HPSAs, designated as medically underserved populations (MUPs), include groups, such as migrant farm workers, low-income urban populations, or federally recognized Native American Tribes or Alaska Natives, within particular geographic areas. Facility HPSAs include federal or state correctional institutions, health centers, and certain rural health clinics.

To receive HPSA designation, the requesting agency or individual must provide HRSA with information demonstrating that the area, population group, or facility meets applicable criteria (General Accounting Office, "Health Professional Shortage Areas," 2006). Developed over 30 years ago, policymakers and patient advocates have periodically questioned the designation methodology. Congress has been hesitant to initiate changes that may be technically and politically complex and would affect the financing of more than 30 federal programs.

THE MEDICALLY UNDERSERVED POPULATION (MUP) DESIGNATION

To designate individuals with intellectual disabilities as a "medically underserved population," HRSA would need to specifically identify the group in its definition. The formula for MUP designation is comprised of four variables, that when added together, represent the extent to which a population is underserved. These four variables are: (1) the ratio of primary care physicians to 1,000 individuals in the population with incomes at or below 100 percent of the federal poverty level in a specific area, (2) the percentage below the federal poverty level, (3) the percentage aged 65 and older, and (4) the infant mortality rate. In 2004, the American Academy of Developmental Medicine and Dentistry (AADMD) used these four variables to determine that the intellectually disabled population should be designated a medically underserved population. Although the request was submitted to HRSA, the AADMD reports no formal response to the request.

The ACA requires HRSA to replace the medically underserved designation methodology through the negotiated rulemaking process. Accordingly, in 2010, HRSA convened the Negotiated Rulemaking Committee on Designation of Medically Underserved Populations and Health Professional Shortage Areas to initiate a review of MUP designation criteria. As part of its review, a subcommittee was established to focus on the health care access issues of populations with special needs. The subcommittee has considered changing the designation process by separating the criteria into three groups: regular, simplified and streamlined. Individuals with intellectual disabilities would potentially meet the simplified criteria designation process based on existing federal legislation (i.e., the Americans with Disabilities Act of 1990 amended by the American with Disabilities Act of 2008, PL 110-325, the Combating Autism Act of 2006, PL 106-426, the

Developmental Disabilities Act of 2000, PL 106-402, and the Traumatic Brain Injury Act of 2008, PL 110-206). Individuals with intellectual disabilities are already assumed to meet the criteria related to health status, access to care and poverty, and would only need to demonstrate low provider availability at local levels. The HRSA Negotiated Rulemaking Committee's final report is expected in the fall of 2011, and HHS is projected to publish an interim-final regulation during the spring of 2012.

THE IMPACT OF ACA

Several key provisions of the ACA address coverage, access, underlying population health and investments in workforce, all of which are likely to benefit individuals with intellectual disabilities. These provisions include:

- Preventing health plans from limiting or denying enrollment of children under the age of 19 due to a pre-existing condition;
- Preventing health plans from setting lifetime dollar limits;
- Requiring health plans to cover wellness and preventive services;
- Requiring health plans to make coverage available to children up to age 26;
- Expanding health insurance coverage to 32 million Americans;
- Investing in innovations such as medical homes and care coordination demonstrations in Medicare and Medicaid with the goal of preventing disabilities from occurring and progressing;
- Creating temporary high-risk pools and health insurance exchanges; and
- Authorizing $50 million to integrate primary and specialty care services in community-based mental and behavioral health settings.

The Council is hopeful that these provisions, taken together, will improve the health care of those with intellectual disabilities.

RESOLUTION 805-I-10

During testimony on Resolution 805-I-10, speakers expressed concerns about how "intellectually disabled" would be defined for the purposes of identifying a new MUP. As noted, several laws have attempted to address access to care for individuals with intellectual disabilities and a HRSA Negotiated Rulemaking Committee is reviewing its designation process.

The resolution also highlights several socioeconomic barriers that can prevent individuals with intellectual disabilities from obtaining appropriate access to care. During testimony, questions were raised about whether a MUP designation would actually improve access. The Council believes that while a MUP designation could focus resources on individuals with intellectual disabilities, it is unlikely that a new designation alone would foster optimal health care access.

An equally salient concern is whether there are adequate educational opportunities for those who care for the intellectually disabled. A 2005 survey conducted jointly by the American Academy of Developmental Medicine and Dentistry and the Special Olympics found that 52 percent of medical school deans, 56 percent of students, and 32 percent of medical residency program directors responded that graduates were "not competent to treat people with neurodevelopmental disorders or intellectual disabilities." In addition, 81 percent of medical students surveyed reported receiving no clinical instruction in treating individuals with neurodevelopmental disorders and intellectual disabilities, and 66 percent reported that they were not receiving adequate classroom instruction.

The study also indicated that the lack of training is not linked to discrimination or unwillingness to treat individuals with intellectual disabilities; most medical students are interested in providing care as part of their career (Special Olympics, 2005; Wolff, Waldman, et al., 2004).

AMA POLICY

Several key AMA policies promote the goals of Resolution 805-I-10. For example, the AMA supports health system reform alternatives that are consistent with AMA policies concerning universal access for patients, insurance market reforms that expand choice of affordable coverage and eliminate denials for pre-existing conditions or due to arbitrary caps, and investments and incentives for quality improvement and prevention and wellness initiatives (Policy H-165.838, AMA Policy Database).

The AMA also has several policies that specifically advocate for improving care to those with intellectual and developmental disabilities. The term "developmental disability" encompasses both intellectual and physical disabilities. Policy H-90.975 advocates for the highest quality medical care for persons with profound developmental disabilities; encourages support for health care facilities whose primary mission is to meet the health care needs of persons with profound developmental disabilities; encourages medical school faculty and trainees to deliver care to persons with profound developmental disabilities and multiple co-morbid medical conditions; encourages medical schools and graduate medical education programs to train medical students and residents in caring for the developmentally disabled; and encourages the use of available resources related to profound developmental disabilities.

Policy D-270.997 advocates for funding for training physicians in the care of "mentally retarded"/developmentally disabled individuals, increasing the reimbursement for the health care of these individuals; and advocates that insurance industry and government reimbursement reflect the true cost of health care of "mentally retarded"/developmentally disabled individuals. In addition, Policies D-90.996 and H-290.982[16] similarly refer to "mentally retarded" individuals.

Policy H-200.992 urges the federal government to consolidate the federal designation process for identifying areas of medical need; coordinate the federal designation process with state agencies to obviate duplicative activities; and ask for state and local medical society approval of said designated underserved areas.

DISCUSSION

Resolution 805-I-10 highlights the need for a robust effort to increase the number of physicians and other health care professionals able to provide care to individuals with intellectual disabilities. Using the HRSA designation criteria to designate individuals with intellectual disabilities as an MUP is a potential avenue to increase the supply of physicians providing care among those individuals who are uninsured. Previous attempts to revise the designation process to recognize individuals with intellectual disabilities as medically underserved have been slow, and the success of current efforts to modify the designation methodology had not been finalized at the time that this report was written.

The Council is aware that special populations including individuals with intellectual disabilities are being considered by the HRSA Negotiated Rulemaking Committee for designation as a "medically underserved population." Extending the designation of MUPs may provide incentives to physicians who care for individuals with intellectual disabilities. Given that the Committee's formal proposal will not be available until the fall of 2011, the Council recommends that the AMA support a simplified process across appropriate federal agencies to designate individuals with intellectual disabilities as a medically underserved population.

In the broader context of improving access to care for individuals with intellectual disabilities it is unlikely that a population-based designation alone would significantly increase access to needed health care. Consistent with Policy H-165.838, the AMA advocates health system reform principles that support providing health insurance coverage for all Americans, enacting insurance market reforms that expand choice of affordable coverage, eliminate denials for pre-existing conditions or due to arbitrary caps, provide investments in incentives for initiatives that improve quality and enhance prevention and wellness – all of which are principles included in the Affordable Care Act. The Council is hopeful that such a comprehensive approach will improve health care for the sickest and poorest Americans.

The absence of professional training on disability competency and poor provider payment are barriers that prevent individuals with intellectual disabilities from receiving appropriate medical care. Policy D-270.997 advocates for funding for training physicians in the care of "mentally retarded" individuals and also advocates for increase provider payments to reflect the true cost of providing health care. The Council believes that Policy D-270.997 addresses these barriers and recommends that it be editorially revised to use the term "individuals with intellectual disabilities," instead of "mentally retarded."

The Council notes that Policies H-290.982[16] and D-90.996 similarly identify individuals with intellectual disabilities as "mentally retarded," and recommends that all policies be editorially revised to reflect the more culturally sensitive terminology of "individuals with an intellectual disability" or "intellectual disability."

RECOMMENDATIONS

The Council on Medical Service recommends that the following be adopted in lieu of Resolution 805-I-10, and that the remainder of the report be filed:

1. That our American Medical Association support a simplified process across appropriate government agencies to designate individuals with intellectual disabilities as a medically underserved population. (New HOD Policy)

2. That our AMA editorially revise Policies D-90.996, D-270.997 and H-290.982[16] by insertion of the term "individuals with intellectual disabilities" and deletion of the term "mentally retarded." (Modify Current HOD Policy)

Fiscal Note: Staff cost estimated to be less than $500 to implement.

References are available for the AMA Division of Socioeconomic Policy Development.

DREDF
Advocating for
disability civil rights
since 1979

June 9, 2010

Health Resources and Services Administration
Department of Health and Human Services
Attention: HRSA Regulations Officer
Parklawn Building, Room 14A-11
5600 Fishers Lane
Rockville, MD 20857

Re: #HRSA-1

To Whom It May Concern,

We strongly urge you to appoint several individuals with broad knowledge and awareness of health and health care disparities, barriers to care, and health outcomes experienced by individuals with diverse disabilities to the Negotiated Rulemaking Committee (NR) that will establish a comprehensive methodology and criteria for designation of Medically Underserved Populations (MUPS) and Health Professions Shortage Areas (HPSA).

We also specifically support the recommendations of Dr. Matt Holder and others who have called for identification of individuals with neurodevelopment disorders as a Medically Underserved Population and the call by the Justice for All Action Network (JFAAA), Schwab Rehabilitation Hospital and Access Living (Chicago, Illinois), and others for recognition of disability status as the basis for inclusion in the MUPS and HPSA designation.

According to HRSA's sixth annual report on training primary care physicians, "Vulnerable individuals and populations often have a greater risk for poor health outcomes than the general population because of the interplay of disparate health care access; health care quality; and genetic, personal, behavioral, environmental, socioeconomic, and community risk factors." [1] For people with disabilities, these interrelated and crosscutting determinants of health are especially relevant.

Disability status, although not yet recognized by HRSA as a MUP or HPSA, is nevertheless pervasive among underserved populations that are defined by race, poverty and age. While individuals with disabilities are already de facto members of these populations, Federal agencies concerned with health, health care and related research have devoted little attention to addressing the specific health care inequities and barriers to care people with disabilities face, so practically speaking, they remain not only underserved, but also invisible.

In the United States an estimated 54.4 million (18.7 percent) people have some level of disability, and 35.0 million (12.0 percent) have a severe disability.[2] The incidence of disability is

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significantly higher among working-age African Americans (17 percent) and among Native Americans (22.5 percent) as compared with 12.6 percent among whites. [3]

Rates of disability also increase with age; 41.9 percent of individuals over the age of 65 report disability, compared with18.6 percent of people who are younger. [4] More than two thirds of adults who have vision impairments are over age 65, and the leading causes of vision impairment in the United States are age-related. [5] Among adults over 65, 11.1 percent report deafness or a lot of trouble hearing. [6] Disability affects women more significantly as they age. Among women aged 16 to 64, a little over 17 percent have one or more disabilities, compared with 43 percent of women who are 65 or older. [7]

Poverty and Disability

The impact of poverty on health has been well documented. Disability status is both a cause and an outcome of poverty, thus disability and poverty in the United States are inextricably entwined. For people with disabilities, the rate of poverty is between two to three times the rate for people who do not have disabilities. About half of all working-age adults who experience poverty have a disability. Moreover, almost two-thirds of adults experiencing long-term poverty also have a disability. [8]

Poverty limits access to adequate and effective health care and disease prevention services, and increases the probability of living in neighborhoods that contribute to poor health or of being homeless. [9] The US health care system further exacerbates the connection between poverty and disability. [10] For example, recent research indicates that rates of uninsurance can be as high as 28 percent for people with certain conditions such as mental health disabilities. [11] Moreover, according to a recent report, "People with disabilities account for a larger share of those experiencing income poverty than people in any single minority or ethnic group (or, in fact, all minority, ethnic and racial groups combined)…" [12] Disability, along with poverty, therefore are overlapping identities for underserved individuals who experience systemic health and health care inequality.

Health Disparities and Barriers to Care

The impact of various interrelated and crosscutting determinants of heath affect people with specific impairments differently, yet virtually every group experiences barriers to care and health disparities that affect health status and health outcomes. Barriers to care can include limited medical facility accessibility; lack of accommodations such as Sign Language Interpreters and print materials in formats that are accessible to people who are blind or have vision impairments; and lack of accessible diagnostic and exam equipment.

Identified by the Institute of Medicine, one of the most significant barriers to care is lack of provider education and disability awareness needed to counter disability stereotypes and misconceptions held by health care providers. [13] Other barriers include lack of insurance or insurance coverage limits, and lack of care coordination.

The Current State of Health Care for People with Disabilities, published in 2009 by the National Council on Disability, reports the following examples of health disparities, barriers to care, and health status for specific groups:

- People who are deaf or experience significant problems hearing report a higher prevalence of “fair” or “poor” health status, and hypertension and diabetes is more prevalent than among people who do not have hearing difficulties. Communication barriers compromise care for people who are deaf or hard-of-hearing and inadequate communication can cause reluctance on the part of the person to seek care, medication errors, misdiagnoses, and a significant danger before and after anesthesia and surgery.

- Income, education, and membership in certain racial and ethnic minority groups are significantly associated with vision impairment. For example, 16 percent of adults in poor families had vision difficulties, compared with 9 percent of adults in families that were not poor. People who are Hispanic have higher rates of vision impairment than people who are African American, and both groups have higher rates than those for people who are white. Approximately 30 percent of people over age 18 who have vision impairments rate their overall health status as either “fair” or “poor,” compared with 8 percent of the population that does not have vision impairments. They also experience a greater prevalence of obesity.

- Women with disabilities experience poorer health than women who do not have disabilities, despite the fact that both groups report the same types of health problems. Nearly a third of women with extensive functional limitations rate their overall health as poor compared with less than 1 percent of women with no limitations. Women with disabilities are also less likely to receive mammography services and pap tests than women without disabilities.[14]

As a practical matter, health care clinics and offices that serve primarily low income individuals have significant budget constraints that make it difficult for them to take proactive steps to accommodate patients with diverse disabilities by removing architectural barriers, providing Sign Language interpreters, providing additional exam time for people with cognitive or speech disabilities, and acquiring accessible examination and diagnostic equipment. The lack of such accommodations therefore profoundly influences the quality of care individuals with various disabilities receive in the forums where they are most likely to seek care and contributes to their underserved status.

A growing body of research by renowned health policy experts including the Institute of Medicine, the Surgeon General of the United States, the National Council on Disability, the Centers for Disease Control and Prevention, and by leading public health research centers and institutions indicates that people with disabilities are both underserved and poorly served by the current health care system and that medical professionals, especially primary care practitioners, lack even basic training and disability awareness required to provide culturally appropriate care.

HRSA’s proposed interest groups and categories from which the NR Committee will be composed do not possess knowledge and expertise about the healthcare gaps and barriers people with disabilities face or the extent to which such individuals meet existing criteria for MUPS designation. Consequently, they cannot be expected to adequately represent these important, and thus far unrepresented issues, during the NR deliberations. Since one of the foundational purposes of the committee“...is to determine whether the proposed rule might significantly affect additional interests not adequately represented by the list of proposed participants," representatives from these possible additional affected interests must be selected. Therefore, we reiterate our strong recommendation that several experts with cross-disability experience in the diverse field of health and disability be appointed to the NR Committee that will establish criteria for both MUPS and HPSA. In light of the small size of the final committee, we also recognize that one individual may be called on to represent a variety of interests. As an alternative, we recommend that at least one expert and an alternate, each of whom represents groups with closely associated cross-cutting and cross-disability perspectives, be appointed.

Thank you for your consideration.

Sincerely,

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Endnotes

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American Academy of Developmental Medicine and Dentistry

CONCEPT/POSITION PAPER

MOVING TOWARDS "MAINSTREAMING" MEDICAL CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES, BY INTEGRATION OF INSTITUTIONAL PHYSICIAN SERVICES WITH SERVICES PROVIDED BY PHYSICIANS IN THE COMMUNITY AND AT MEDICAL SCHOOLS.

A. INTRODUCTION

Numerous studies have identified inadequate health services as a major factor preventing successful community experience for people with developmental disabilities. In 2001 the US Surgeon General convened a conference in Georgetown, DC to address this problem of health disparities and unmet health needs encountered in persons with developmental disabilities. The Surgeon General's Report in 2002 pointed out that lack of physician and dentist training and experience was a major deficiency that contributed to the problem Subsequently, in May 2002, a small group of concerned physicians and dentists established the American Academy of Developmental Medicine and Dentistry (AADMD) to "give legs" to the Surgeon Generals report.

Part of the problem has been that physicians who practice in the community or at academic medical centers have had relatively little training and/or experience with the complex health problems frequently encountered in adults with severe developmental disabilities. Consequently, there is a general lack of medical literature to guide the practitioner. Furthermore, physicians who practice in institutions and who have had the most clinical experience with the medically fragile/complex adult disabled patient have little interaction or communication with their physician colleagues in the community and/or academic medical centers. This results in a chronic state of discontinuity of care and non-transfer of medical knowledge and expertise for the patients who need it most, i.e. the medically complex developmentally disabled adult.

Policies which create fragmentation of health services for the medically complex disabled adult need to be reconsidered. Initiatives and leadership designed to promote integration (not isolation) of institutional health services with those of community and academic medical centers should be developed. The following objectives listed below would begin to move us towards this goal.

B. INITIATIVES DESIGNED TO INTEGRATE INSTITUTIONAL, COMMUNITY, AND MEDICAL SCHOOL BASED HEALTH SERVICES

1.The sponsorship of Academic Medical Symposia by Developmental Center Medical/Educational Departments.

2. Collaboration of Developmental Center physicians with Academic Medical Center physicians in clinical research projects designed to enhance physician ability to provide effective health services to developmentally disabled adults with complex health problems.

3. Participation of Developmental Center Physicians in the teaching of medical students and physicians-in-training regarding health problems frequently encountered in developmentally disabled adults.

4.The creation of medical lectures to be presented by Developmental Center physicians to physicians located at community and Academic Medical Centers regarding health problems frequently encountered in the developmentally disabled adult.

5. The assignment of medical school faculty appointments to physicians who work in Developmental Centers and who are prepared to make a committment to teaching, clinical research, and community health service.

6. The acquisition of "admitting privileges" to community hospitals and academic medical centers by physicians who work in Developmental Centers.

7. Development and implementation of administrative policy and procedure which creates the opportunity for Developmental Center Physicians to admit and attend to their Developmental Center patients while they are hospitalized in community hospitals and/or academic medical centers.

8. Provision of health services to developmentally disabled patients who live in the "community" by Developmental Center physicians, either as an outpatient in a Developmental Center "Clinic" setting or inpatient in the community hospital and/or academic medical center.

SUMMARY: Initiatives designed to promote communication, collaboration, and eventually integration of health services for developmentally disabled adults with complex medical /behavioral problems should be undertaken. Attainment of the objectives outlined above would "set the stage" for the formation of a "network" of physicians which would function to 1) teach physicians-in-training, 2) contribute to the general medical literature, and 3) provide state of the art clinical care to these most vulnerable individuals.

D. SUMMARY AND CONCLUSIONS

In order to improve quality of health services provided to persons with developmental disabilities, there needs to be better collaboration between primary care physicians who provide service to persons with developmental disabilities, but who practice in different settings (Medical School, Community, Institution). None of these categories of primary care physicians possess all the necessary skills to effect system-wide changes on DD health service quality. Those coming from "academic" and "community" medicine will need to interact with developmental center physicians in order to become familiar with the clinical problems frequently encountered in patients with complex disabilities in need of study, while those coming from community hospitals/offices and developmental centers will need to develop "faculty skills" such as teaching, lecturing, clinical research design, publication, symposia production, and grant writing. This interdisciplinary approach will result in a cadre of physicians which will not only know the issues, but will also have the ability to learn more about them and disseminate findings to their medical colleagues. With "Developmental Medicine" taught in medical schools and incorporated into the "data base" of the average physician, better medical "supports" will become available in the community. This will translate into increased likelihood of a successful community experience, especially for those individuals with complex disabilities.

Finally, Harold L. May MD, in his chapter entitled "Changing Conditions and the Provision of Care" (from Rubin and Crocker, 1989) commented on the advantages of "links" between developmental centers and medical centers. Dr. May observed that **"cooperating institutions can benefit, learning from each other while teaching each other. Piece by piece, they can dismantle the walls of separation that previous generations have mistakenly built."**

ADVISORY COMMITTEE ON TRAINING IN PRIMARY CARE MEDICINE AND DENTISTRY

THE ROLE OF TITLE VII, SECTION 747 IN PREPARING PRIMARY CARE PRACTITIONERS TO CARE FOR THE UNDERSERVED AND OTHER HIGH-RISK GROUPS AND VULNERABLE POPULATIONS

Sixth Annual Report to
the Secretary of the
U.S. Department of Health and Human Services
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November 2006

62x.

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ADVISORY COMMITTEE ON TRAINING IN PRIMARY CARE MEDICINE AND DENTISTRY

Section 748 of the Health Professions Education Partnerships Act of 1998 authorizes the establishment of an Advisory Committee on Training in Primary Care Medicine and Dentistry. The Act directs the Secretary to establish an advisory committee to be known as the Advisory Committee on Training in Primary Care Medicine and Dentistry. The Advisory Committee was constituted to:

1) Provide advice and recommendations to the Secretary concerning policy and program development and other matters of significance concerning the activities under section 747.
2) Not later than 3 years after the date of enactment, and annually thereafter, prepare and submit to the Secretary, the Committee on Health, Education, Labor and Pensions of the Senate, and the Committee on Energy and Commerce of the House of Representatives, a report describing the activities of the Advisory Committee, including findings and recommendations made by the Advisory Committee concerning the activities under section 747.

Congress created the Advisory Committee to obtain insight and objectives from primary healthcare providers, educators, and trainees who work on the front line. The members include such health professionals as physicians and physician assistants, as well as general and pediatric dentists, from the disciplines of primary care medicine and dentistry.

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ABSTRACT

Vulnerability is the increased susceptibility for poor medical, mental, and oral health outcomes. Vulnerable individuals and populations often have a greater risk for poor health outcomes than the general population because of the interplay of disparate healthcare access; healthcare quality; and genetic, personal, behavioral, environmental, socioeconomic, and community risk factors. All of these factors can operate at the individual, family, community, and population levels.

Traditionally, healthcare providers have considered biomedical conditions as primary determinants of poor health. Since poor health along one dimension can be compounded by poor health along others, health needs are considerably greater for those with multiple health problems than for those with single health problems. Likewise, when non-biomedical health determinants converge in an individual, vulnerability may dramatically increase.

As our population, society, and environment change, so does the constellation of vulnerability factors that healthcare providers must be competent to address. The U.S. population has also significantly changed over recent years, including dramatic increases in racial and ethnic minorities and new immigrant groups, many of whom are non-English-speaking and with differing cultural beliefs; children living in poverty; and individuals who have no healthcare insurance or who are underinsured.

The Nation's 100 million persons from racial and ethnic minority groups are a critical vulnerable population. Persons from minority groups have well-documented barriers to essential healthcare services and suffer a great burden of preventable disease. These individuals must be the focus of healthcare, educational, and research initiatives to reduce unacceptable disparities. In particular, healthcare providers must develop the knowledge, skills, and competencies necessary to address this large vulnerable population. These goals are important in all programs that train medical and dental providers, but they are a special focus of programs for primary care physicians, physician assistants, and dentists who assume an even greater role in the care of vulnerable populations.

However, there are other groups of vulnerable populations who have, to date, been overlooked in discussions about patients with special needs and greater risks of adverse outcomes. Advancements in medical technology and specific treatment interventions, for example, have significantly increased longevity for many persons with developmental disabilities. As a result, there is a growing population of adult patients with developmental and intellectual disabilities who are unable to find appropriate health and dental care providers experienced in caring for their special healthcare needs. Persons with intellectual and developmental disabilities are an emerging vulnerable population, as are prisoners and survivors of terrorism, war, and natural disasters. These groups must be added to the list of those with traditional risk factors, such as homelessness, substance abuse, mental illness, poverty, and poor access to healthcare.

Clinicians must develop an expanded set of clinical skills in order to address the complex problems of vulnerable patients. They must learn to identify factors that contribute to vulnerability and to work with patients and communities to bolster factors that promote good health. This work requires clinicians to be able to perform effectively across lines of difference in culture, class, race, and ethnicity, as well as with persons with intellectual and physical disabilities.

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) commissioned six experts to provide a detailed written description of vulnerability and vulnerable populations and the challenges facing an evolving healthcare system attempting to remedy identified disparities. These six papers, found in Appendices A through F of this report, highlight a multi-factorial approach to defining vulnerable populations and individuals in the United States. At the same time, the papers provide a guide for interdisciplinary workforce approaches and clinical innovations and training competencies through Title VII, section 747 programs directed toward this ever-changing epidemiology among the Nation's citizens.

The U.S. Department of Health and Human Services should promote educational programs for primary care dentists, physicians, and physician assistants that contribute to the development of these competencies and clinical innovations in caring for vulnerable populations.

CONCLUSION

Vulnerability is the increased susceptibility for poor medical, mental, and oral health outcomes that is influenced by conditions such as disparate healthcare access; healthcare quality; and genetic, personal, behavioral, environmental, socioeconomic, and community risk factors. Current educational training available in the Nation's medical and dental schools and residency programs does not adequately train students to be competent to provide comprehensive and preventive healthcare for the Nation's most vulnerable populations. Title VII, section 747 programs are uniquely positioned to provide the leadership to change a healthcare system that has often neglected its most vulnerable citizens. Adoption of the recommendations in this report will significantly expand healthcare services to all vulnerable individuals, including those with special health needs.

RECOMMENDATIONS

Consistent with its stated purpose:

To educate and train physicians, pediatric and general dentists, and physician assistants to enhance the quality, capacity, and diversity of the Nation's primary care workforce, giving special consideration to the healthcare needs of underserved populations and other high-risk groups.

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recommends the following:

1. To prepare future primary healthcare providers with the training to meet the emerging challenges to the health of the public, the Title VII, section 747 grant program requires reauthorization and an appropriation at a minimum level of $215 million.
2. The Title VII, section 747 grant program should address the identified curricular and clinical instruction inadequacies relating to the management of vulnerable and high-risk individuals in the Nation's medical and dental predoctoral and postgraduate training programs.
3. In order to address health disparities as outlined in *Healthy People 2010*, the recruitment, education, and training of a larger and more diverse primary care workforce of physicians, physician assistants, and pediatric and general dentists are necessary to address the Nation's critical healthcare needs, specifically those of vulnerable individuals and populations.
4. The Title VII, section 747 grant program should encourage the educational accreditation, licensure, and certification organizations for physicians, physician assistants, and general and pediatric dentists to mandate policies and procedures that ensure that the healthcare workforce is prepared to provide competent care to vulnerable individuals and populations.
5. The Title VII, section 747 grant program should review and expand the definition of underserved and high-risk populations to include all aspects of vulnerability. Title VII, section 747 proposals that address primary care education and training to serve vulnerable populations should be prioritized. The Title VII, section 747 grant program should encourage programs to provide their trainees with the means to know the basic demographics about their patient populations and to understand the implications for the care of those patients.

THE ROLE OF TITLE VII, SECTION 747 IN PREPARING PRIMARY CARE PRACTITIONERS TO CARE FOR THE UNDERSERVED AND OTHER HIGH-RISK GROUPS AND VULNERABLE POPULATIONS

INTRODUCTION

Vulnerability is the increased susceptibility to poor medical, mental, and oral health outcomes. Vulnerable individuals and populations have 1) greater health needs; 2) more difficulty accessing appropriate care; and 3) even with care, suffer worse outcomes (Shi, 2005). Some persons are at increased risk for poor health outcomes because of the interplay of disparate heathcare access; healthcare quality; and genetic, personal, behavioral, environmental, socioeconomic, and community risk factors. All of these factors can operate at the individual, family, community, and population levels.

Traditionally, healthcare providers have considered biomedical conditions as primary determinants of poor health. Since poor health along one dimension can be compounded by poor health along others, health needs are considerably greater for those with multiple health problems than for those with single health problems. Likewise, when non-biomedical health determinants converge in an individual, vulnerability may dramatically increase.

As our population, society, and environment change, so does the constellation of vulnerability factors that healthcare providers must be competent to address. For example, primary care for children with chronic medical problems requires different skills from well child care. With the rising prevalence of chronic illness in the pediatric population, primary care will increasingly mean providing services for children with chronic disorders and complex medical needs in local community settings (Wise, 2005).

The U.S. population has significantly changed over recent years, including increases in racial and ethnic minorities and new immigrant groups, many of whom are non-English-speaking and with unique cultural beliefs; children living in poverty; and individuals who have no healthcare insurance or who are underinsured. The number of elderly individuals, particularly those over 85 years of age, has significantly increased, and many fragile elderly are not mobile enough to present for regular care (Lurie, 2005). (See sidebar on page 2: "Assessing Vulnerability at the Community Level" (Frey, Pandhi, et al., 2005—now Appendix B in this document)).

Advancements in medical technology and specific treatment interventions have increased longevity for many persons with developmental disabilities. As a result, there is a growing population of adult patients with developmental and intellectual disabilities who are unable to find appropriate health and dental care providers with the expertise to care for their special healthcare needs. Persons with intellectual and developmental disabilities are an emerging vulnerable population, as are prisoners and survivors of terrorism, war, and natural disasters. These groups must be added to the list of those with traditional risk factors, such as homelessness, substance abuse, mental illness, poverty, and poor access to healthcare.

Vulnerability is dynamic; the aftermath of the Gulf Coast hurricanes of 2005 demonstrated that environmental and geographic conditions can rapidly create vulnerable populations (Frey, Pandhi, et al., 2005; see Appendix B). Some persons who were vulnerable in the days after the hurricanes remain so, while others are again robust. Individuals and communities also possess factors that confer resiliency. The resilience created by these factors can offset some of the contributors to vulnerability. (See sidebar on page 4: "The Gulf Coast Hurricanes of 2005" (Frey, Pandhi, et al., 2005; see Appendix B also)).

Clinicians must develop an expanded set of clinical skills in order to address the complex problems of vulnerable patients. They must learn to identify factors that contribute to vulnerability and to work with patients and communities to bolster factors that promote resiliency. This work requires clinicians to be able to perform effectively across lines of difference in culture, class, race, and ethnicity, as well as with persons with intellectual and physical disabilities.

The U.S. Department of Health and Human Services (HHS) should promote educational programs that contribute to the development of these competencies in caring for vulnerable populations among primary care dentists, physicians, and physician assistants. Toward this end, faculty must be prepared to teach and model appropriate assessment and care of vulnerable patients. Training institutions should undertake faculty development initiatives, design model curricula, and implement educational programs on caring for vulnerable patients and populations.

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) commissioned six experts to provide a detailed written description of vulnerability and vulnerable populations and the challenges facing an evolving healthcare system attempting to remedy the identified disparities. These six papers can be found in Appendices A through F of this report.

CURRENT STATUS

Historically, Title VII, section 747 programs have played a significant role in helping to train future primary care medicine and dentistry professionals who are capable of responding to changing demands and emerging healthcare needs of the U.S. population. This training has included addressing the health outcome disparities in underserved, high-risk, vulnerable groups such as the elderly, individuals with HIV/AIDS, substance abusers, the homeless, racial and ethnic minorities, economically and/or educationally disadvantaged, and other individuals with special health needs (ACTPCMD, 2005).

Recent information requested by ACTPCMD of Title VII, section 747 grantee programs, and received from

Assessing Vulnerability at the Community Level

New Mexico is one of the poorest states in the United States and has many of the worst health-related outcomes. As a largely rural state, New Mexico has issues of access to care that are compounded by the very high levels of uninsured and Medicaid recipients in the state. Rio Arriba County, one of the most rural counties in New Mexico, has an all-cause mortality rate of two and a half times that of the rest of the state. Between 1990 and 2000, death from accidents was over three times, and death from motor vehicle accidents was four times that of the state as a whole.

Rio Arriba County, like many rural counties in the United States, has few jobs available beyond agriculture or farming and related services. Citizens are forced to drive long distances for almost any job.

Factors that increase this county's vulnerability largely come from low levels of human capital, with high levels of alcohol and drug abuse also being factors and consequences of the problem. Forty-three percent of children in the county have had their first drink of alcohol by age 12, and 40 percent of students in grades 9–12 have participated in binge drinking in the previous 30 days (New Mexico Department of Health, 2003). In a county with a high level of poverty and inadequate housing, the educational level of citizens is particularly low and the educational system significantly challenged. The majority of the primary and secondary schools in the county are on the state watch list for low performance. Attendance at schools is low, and the drop-out rate for Rio Arriba County is one of the highest in the United States.

The county, particularly the youth in the county, suffers from low resiliency factors that, if higher, could increase human capital. County youth have lower levels in their families, schools, and communities of the setting of boundaries and expectations, and they report lower levels of a caring adult in the home or community. Positive peer influence, commitment to learning, life skills, and social competencies are all essential aspects of individual and group coping with the adversities of geography and poverty, but Rio Arriba County youth have significantly lower measures of resilience, compared to other youth in the state. Lack of resiliency relates to higher levels of smoking, alcohol and drug use, and drinking and driving.

The combination of low human capital—education, life skills, and resilience—and the geography and poverty that require driving long distances for work have created a culture of risk in Rio Arriba County that has a profound effect on the young people who live there.

131 responders, demonstrates that grantee programs serve these and other defined populations. Title VII, section 747 grantees were asked to describe what their programs were doing to prepare primary care practitioners to care for the underserved; other high-risk groups (defined as the elderly, individuals with HIV/AIDS, substance abusers, the homeless, and victims of domestic violence); and vulnerable populations (due to factors such as racial and ethnic minority status, economic and/or educational disadvantage, language barriers, poor health literacy, neurodevelopmental disorders, intellectual disabilities or mental illness, or other special health care needs). The percentage of total programs providing training for these underserved and other high-risk groups and vulnerable populations is as follows:

- Racial and ethnic minority status – 54.8%
- Economic and/or educational disadvantage – 53.1%
- Elderly – 43.5%
- Language barriers – 33.3%
- Intellectual disabilities or mental illness – 31.1%
- Individuals with HIV/AIDS – 29.4%
- Special healthcare needs – 28.2%
- Victims of domestic violence – 26.0%
- Substance abusers – 22.0%
- Homeless – 20.3%
- Poor health literacy – 16.4%
- Neurodevelopmental disorders – 7.9%

This information highlights that each category above is served by at least 20 percent of the programs, with the exception of those with poor health literacy and neurodevelopmental disorders.

Recent studies, however, have identified that certain high-risk groups that have been significantly overlooked, such as individuals with intellectual disabilities, mental illness, or neurodevelopmental disorders, continue to have difficulty accessing medically necessary comprehensive healthcare in their local communities because of an inadequate number of physicians and dentists trained to provide those needed services. For example, individuals with intellectual disabilities experience a higher prevalence of adverse conditions, inadequate attention to care needs, inadequate focus on health promotion, and inadequate access to quality healthcare services (Krahn, Hammond, et al., 2006). In addition, individuals with intellectual disabilities have four times more preventable mortality than the general population, suggesting that medical care may alter health outcomes for persons with intellectual disabilities (Horwitz, Kerker, et al., 2000).

As one example, an analysis of health data collected from 3,531 Special Olympian athletes in 2003 by Special Olympics International revealed the following findings: 1) 30 percent of the athletes reported never having received an eye exam; 2) only 32% of the athletes reported an awareness regarding sun protection needs; 3) 40 percent scored above normal on the Body Mass Index (BMI); 4) 50 percent of the athletes presented with one or more types of skin or nail conditions; 5) 32 percent did not pass the auditory pure tone test at the 2,000-Hz level; and 6) 53 percent of all athletes had obvious signs of gingival infection (Special Olympics, 2005).

The 2001 Surgeon General's Conference on Health Disparities and Mental Retardation concluded that insufficient didactic and clinical instruction in U.S. medical and dental predoctoral and postgraduate training programs was a significant cause of the health disparities identified for individuals with mental retardation. The subsequent report encouraged curricular changes in the Nation's professional schools and residency programs to address this problem (U.S. Public Health Service, 2002).

The American Academy of Developmental Medicine and Dentistry jointly with Special Olympics International examined the level of curriculum focused on the management of individuals with neurodevelopmental disorders and intellectual disabilities (ND/ID) using a survey instrument. The results of this study indicated that 52 percent of the medical school deans, 53 percent of dental school deans, 56 percent of students, and 32 percent of medical residency program directors responded that graduates were "not competent to treat people with neurodevelopmental disorders or intellectual disabilities." In addition, 58 percent of the medical school deans and 50 percent of the dental school deans reported that clinical training in managing individuals with ND/ID is not a high priority. Eighty-one percent of the medical school students reported not getting any clinical instruction in treating individuals with ND/ID, and 66 percent noted that they were not receiving adequate didactic instruction (Special Olympics, 2005). An earlier study reported that 60 percent of dental school deans cited "lack of curriculum time" and "lack of faculty expertise" for training deficiencies in the area of managing individuals with ND/ID. Fifty-one percent of the dental students noted that they did not receive any specialized clinical training, whereas 68 percent reported an inadequate level of didactic instruction regarding individuals with ND/ID (Wolff, Waldman, et al., 2004). Although physician assistant educators were not included in this survey, physician assistants compose an expanding sector of the U.S. healthcare system and will require similar skills to provide care for persons with disabilities.

Encouraging signs for change, however, were identified. Nearly three-quarters of the medical and dental students surveyed reported an interest in treating people with intellectual disabilities as part of their professional career, whereas 100 percent of the medical school deans, 90 percent of the medical residency program directors, 97 percent of the dental school deans, and 94 percent of the dental residency program directors indicated they would implement a specific curriculum regarding treatment for people with ND/ID in their facilities if one were provided to them (Special Olympics, 2005; Wolff, Waldman, et al., 2004).

Another major area leading to health disparities is race and ethnicity and socioeconomic status. A recent

The Gulf Coast Hurricanes of 2005

The differences in the ability of individuals to cope with the consequences of the hurricane that struck the U.S. Gulf Coast are a recent, highly visible example of vulnerability. Because of geographic factors, all those living in the area were vulnerable, but differences in levels of financial, human, and social capital for neighborhoods and individuals created very different levels of vulnerability.

Low-lying parts of New Orleans and surrounding areas were vulnerable, and water-retaining systems were in a state of disrepair. These conditions created an area of geographic risk. Many of the most severely affected populations in the Gulf Coast were at increased risk because they lived in areas with a high-density of non-permanent housing, such as trailer parks and housing lacking foundations.

Differential access to human resources was evidenced by the vivid racial inequality depicted in the aftermath of the flooding. Of those living in the most vulnerable geographic communities, most were African-American. The historic lack of access to higher quality housing in the African-American population compounded this problem.

Differential socioeconomic resource access also contributed to vulnerability, as some families and neighborhoods were less able to evacuate because of lack of public or private transportation. Low-income populations throughout the region also had difficulty accessing medical care because of the closing of healthcare facilities and the lack of portable health insurance coverage.

Finally, age and disability were factors for individuals vulnerable from other causes. Many of the deaths that took place after the initial storm were among elderly or disabled people who either could not or would not evacuate their homes or institutions. The loss of electricity and of access to medications or home health nursing had tremendous effects on an already-sick population with little reserve to deal with an overwhelming natural event.

Tracking the course of two hypothetical individuals with differential vulnerability may further elucidate individual aspects of vulnerability. Person A and Person B are both from similar racial backgrounds, achieved similar education, live in the same neighborhood, are employed, and do not own a car. Person A lacked a local social support system and remained in his house until he was evacuated after the flood. He now has an uncertain future in a new area of the country and is having difficulty finding employment. Person B had developed close friends through his workplace and was able to leave the area with a friend during the recommended evacuation period. His friend's family has helped him find a new job and a new home. Person B's increased social capital offset some of his vulnerability to this catastrophe.

In an examination of the Gulf Storm disaster, individuals and populations most affected suffered from a confluence of individual, geographic, community, age, racial, and health risk factors that produced terrible and divergent outcomes.

National Healthcare Disparities Report (Agency for Healthcare Research and Quality, 2006) noted that "disparities related to race, ethnicity, and socioeconomic status still pervade the American health care system. While varying in magnitude by condition and population, disparities are observed in almost all aspects of health care...." The report showed that minorities in 2004 rated their health status less positively than Whites, with 13.3 percent of Hispanics; 14.5 percent of African Americans, Non-Hispanics; and 16.5 percent of American Indians/Alaska Natives reporting fair or poor health status while only 8 percent of Whites/Non-Hispanics did so. The study compared minority groups to Whites on a number of quality care measures, finding that 53 percent of Hispanics, 43 percent of African Americans, and 38 percent of American Indians/Alaska Natives received worse care than Whites. In terms of access to care, 88 percent of Hispanics, 50 percent of African Americans, and 50 percent of American Indians/Alaska Natives had worse access to care than Whites. The study further examined the variable of "no usual source of health care" for adults between the ages 18 and 64 at various poverty levels. At less than 100% poverty, 39.8 percent of Hispanics had no usual source of health care as compared to 22.7 percent of Whites. Similar results were found for people between 100 percent and 200 percent poverty. At greater than 200 percent poverty, 22.7 percent of Hispanics had no usual source of health care while the figure for Whites was 12.4 percent. Disparities of health care are clearly related to race/ethnicity and poverty.

Title VII, section 747 training programs should continue their efforts to reduce healthcare disparities for all vulnerable high-risk groups through appropriate and innovative training, research, and service provision. In particular, programs should expand the scope of their didactic and clinical instruction to include growing vulnerable populations, spanning from groups that are well-recognized to those that have had less attention, including persons with neurodevelopmental disorders. Additional emphasis could be put on prevention and wellness through creative health literacy projects to significantly improve health outcomes and quality of life for all underserved high-risk populations and especially those individuals with ND/ID while further reducing the health disparities that currently exist. Health-promoting education programs, for example, could address smoking cessation, weight control, exercise and fitness regimens, safe sex practices, recognition of and intervention for alcohol and drug abuse, and early treatment for emerging mental illness.

RECOMMENDATIONS

Consistent with its stated purpose:

To educate and train physicians, pediatric and general dentists, and physician assistants to enhance the quality, capacity, and diversity of the Nation's primary care workforce, giving special consideration to the healthcare needs of underserved populations and other high-risk groups.

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recommends the following:

1. **To prepare future primary healthcare providers with the training to meet the emerging challenges to the health of the public, the Title VII, section 747 grant program requires reauthorization and an appropriation at a minimum level of $215 million.**

    - **Rationale**: Title VII funds are essential to support major primary care training programs that train the providers who work with vulnerable populations. It is critical that funds not only be restored to 2005 levels, but that funding be increased, as the need for healthcare of the public, including those high-risk groups identified in this report, increases. It is critical that funds offset the acknowledged rate of inflation. This additional funding is also necessary to prepare current and future primary care providers for their critical role in responding to healthcare challenges including demographic changes in the population, increased prevalence of chronic conditions, decreased access to care, and a need for effective first-response strategies in instances of acts of terrorism or natural disasters.

2. **The Title VII, section 747 grant program should address the identified curricular and clinical instruction inadequacies relating to the management of vulnerable and high-risk individuals in the Nation's medical and dental predoctoral and postgraduate training programs.**

    - **Priority must be given to programs that develop and implement curricula to care for vulnerable patients and populations.**

- **Programs must develop faculty capable of teaching best practices for the care of vulnerable populations.**
- **Priority must be given to support innovative models of physician, physician assistant, and pediatric and general dental faculty development that enhance the quality and capacity for the effective and efficient delivery of primary healthcare for vulnerable populations.**
- **Rationale**: Current medical, physician assistant, and dental school faculty in many academic institutions do not have the necessary expertise and/or training materials to provide an adequate level of education and clinical exposure for their students and residents in the area of ND/ID or other high-risk groups. Title VII, section 747 training programs can serve as the training ground for future academicians with the clinical skills and professional judgment to reduce or eliminate these well-documented educational deficits. Eligibility for Title VII faculty development should be extended to include dental faculty.

  Vulnerable, high-risk individuals often require an interdisciplinary approach to treatment because of the complexity of concomitant medical conditions, emotional and behavioral issues, and chronic disabilities. Title VII, section 747 programs are uniquely positioned to provide the impetus for best-practice changes to a healthcare system that has often neglected its most vulnerable citizens.

3. **In order to address health disparities as outlined in *Healthy People 2010*, the recruitment, education, and training of a larger and more diverse primary care workforce of physicians, physician assistants, and pediatric and general dentists are necessary to address the Nation's critical healthcare needs, specifically those of vulnerable individuals and populations.**

   - **Rationale**: As the demographic composition of the U.S. population changes, so should the demographics of trainees and faculty of training programs. Race and ethnicity remain intricately linked to vulnerability status in the United States. Racial and ethnic minorities tend to receive lower quality of healthcare than non-minorities, even when access-related factors such as patient insurance status and income are taken into account. Cultural differences between providers and patients can affect provider-patient relationships and may contribute to disparities in quality of healthcare provided to racial and ethnic minorities (Pamies, 2005; Institute of Medicine, 2003).

     As our country becomes more ethnically diverse, we need to train providers who are more reflective of the persons needing care in this new America. Since minority and immigrant populations bear a disproportionate share of disease burden and health risk, the healthcare needs of these populations exceed their proportionate representation in the U.S. population. At the same time, our health professional provider diversity remains low, with only 5 percent of dentists, 9.5 percent of physicians, and 11 percent of physician assistants identifying themselves as Hispanic or African American (U.S. Census Bureau, 2000; Pamies, 2005; American Academy of Physician Assistants, 2006). To address the disparity between the ethnic and racial diversity of the U.S. population needing care and the ethnic and racial diversity of the health workforce, Title VII funds should be used to support recruitment and retention of minority health and dental providers. This is the primary work of the Health Career Opportunities Program (HCOP; authorized in Title VII, section 739 of the Public Health Service Act [PHSA]) and the Centers of Excellence (COE; authorized in Title VII, section 736 of the PHSA). We strongly support adequate funding of these programs. It should be noted that Title VII, section 747 has supported increased diversity of the healthcare workforce and that many of our programs work in collaboration with the HCOP and COE programs.

     Dower et al. published a report, entitled "From Affirmative Action to Health" in 1999, which reviewed the literature regarding the impact of affirmative action and the health status of communities. One of the findings was that the literature supports "a positive relationship between health professions diversity and improved access to health care for traditionally underserved populations." In their study, Cantor et al. (1996) found that "minority and women physicians are much more likely to serve minority, poor, and Medicaid populations." Similarly, Moy and Bartman (1995) found that "nonwhite physicians are more likely to care for minority, medically indigent, and sicker patients."

In 1997, Xu et al. reported study results supporting the hypothesis that "underrepresented minority physicians are more likely to care for medically underserved patient populations." The authors speculated that "underrepresented minority physicians are more willing to care for underserved patients because they are sensitive to the unmet needs of this population. Such an attitude, brought to medical school and reinforced by educational experiences, might lead to their ultimate decision to enter primary care and provide care to medically under-served patients. Conversely, underrepresented minority patients may prefer and seek out physicians of similar background." Grumbach et al. (1999) reviewed surveys of medical school graduates conducted by the Association of American Medical Colleges in 1998. Fifty-eight percent of underrepresented minority graduates from California medical schools intended to practice in an underserved area, compared to 19 percent of non-Latino white graduates and 19 percent of other minority graduates.

In addition to insufficient numbers of minorities enrolled in the health professional schools, training of providers in cultural competency at these institutions is also lacking. According to recent studies, 9 percent of the Nation's medical schools offer a course to address cultural competency, and fewer than half of the schools offer coursework in health disparities (Pena, Munoz, et al., 2003; Pamies, 2005; Betancourt, Green, et al., 2005). Title VII funds should support programs designed to improve cultural competency among medical and dental health providers so that these providers will be able to work effectively with a diverse population.

Vulnerable populations often have difficulty obtaining medical and dental care because of a variety of factors, including low socioeconomic status, lack of medical and dental insurance, and lack of providers trained to address their complex medical and social problems. As health provider shortages develop over the next decade, vulnerable populations will be disproportionately affected. Title VII should support the training of physicians, dentists, and physician assistants to prevent a shortage. In particular, Title VII should fund programs to train providers with the inclination and skills to care for vulnerable populations.

Since team models of care may improve outcomes of care for persons with chronic diseases (Wagner, 2000), Title VII programs should educate providers to work in effective teams that optimally use the skills of various providers to extend care to underserved and vulnerable patients. Because the needs of vulnerable patients are multi-dimensional, they will be better addressed by a team of providers with a wide range of assessment and treatment skills.

4. **The Title VII, section 747 grant program should encourage the educational accreditation, licensure, and certification organizations for physicians, physician assistants, and general and pediatric dentists to mandate policies and procedures that ensure that the healthcare workforce is prepared to provide competent care to vulnerable individuals and populations.**

   - **Rationale**: Good health is essential to ensuring quality of life for all American citizens, including those with special healthcare needs, and also for the strength of the Nation. Medical and dental trainees must be prepared to promote health across the full range of vulnerable populations.

     Americans with intellectual disabilities and their families face significant obstacles in access to basic healthcare. One major barrier is the lack of healthcare providers with adequate training to treat persons with intellectual disabilities. In 2002, the Surgeon General's Report on Health Disparities and Mental Retardation recommended the development and implementation of criteria for accreditation and certification of health professions schools and training programs, based on the inclusion of mental retardation in their curricula. As a result of the Surgeon General's report and with the support of organized dentistry including the American Dental Association and the American Academy of Developmental Medicine and Dentistry, the Commission on Dental Accreditation (CODA) adopted new language in accreditation standards for predoctoral dental programs and dental hygiene programs. As of 2006, graduates of U.S. dental schools and dental hygiene programs must be competent in assessing the treatment needs of patients with special needs.

Other organizations responsible for granting accreditation, licensure, or certification should follow the lead of CODA in order to reduce the healthcare disparities of individuals with intellectual disabilities and other vulnerable populations. The Title VII, section 747 programs are poised to help develop, implement, and advocate for the education and training of healthcare professionals to care for vulnerable populations. Furthermore, Title VII, section 747 programs can further serve as catalysts for the professional accreditation process regarding the management of individuals with special healthcare needs.

5. **The Title VII, section 747 grant program should review and expand the definition of underserved and high-risk populations to include all aspects of vulnerability. Title VII, section 747 proposals that address primary care education and training to serve vulnerable populations should be prioritized. The Title VII, section 747 grant program should encourage programs to provide their trainees with the means to know the basic demographics about their patient populations and to understand the implications for the care of those patients.**

   - **Rationale**: In order to promote the health of our society, physician, physician assistant, and dental trainees must be prepared to assess vulnerability among patients and communities and provide competent care to vulnerable populations. These vulnerable populations include those who have been previously recognized, such as persons from racial and ethnic minorities, and those with mental illness, poor health literacy, low socioeconomic status, multiple chronic health problems, and poor access to care. In addition, the definition of vulnerable populations must be expanded to incorporate emerging high-risk groups such as victims of terrorism or natural disasters, prisoners, immigrants, and those with intellectual and developmental disabilities.

     Currently, several high-risk vulnerable populations are not recognized as medically underserved populations by Federal agencies, although they actually could qualify for such a designation utilizing the current Health Resources and Services Administration (HRSA) guidelines. These guidelines establish criteria for the Designation of Medically Underserved Populations (MUPs), based on the Index of Medical Underservice (IMU), published in the Federal Register on October 15, 1976, and provisions of Public Law 99-280 enacted in 1986. The IMU involves four variables: 1) the percentage of the population with incomes below the poverty level (V1); 2) the percentage of the population age 65 or over (V2); 3) the infant mortality rate for the population (V3); and 4) the ratio of primary care physicians per 1,000 of the population (V4). The IMU weighted-value scale ranges from 0 to 100, in which 0 represents a population completely underserved and 100 represents a population best served or least underserved. According to HRSA, a population is considered to be a MUP if it receives an IMU score of less than 62.0.

     The HRSA formula for establishing the MUP designation involves the application of the IMU to data on an underserved population group within an area of residence to obtain a score for the targeted population group. Population groups requesting a MUP designation should be those with economic barriers (low-income or Medicaid-eligible populations) or with cultural and/or linguistic access barriers to primary medical care services (*http://bhpr.hrsa.gov/shortage/muaguide.htm*).

     Although several studies, for example, have well-documented the inability of individuals with neurodevelopmental disorders and/or intellectual disabilities (ND/ID) to access necessary and appropriate medical and dental services, the current Federal definition of underserved populations does not recognize people with ND/ID as underserved. The American Academy of Developmental Medicine and Dentistry (AADMD) has calculated an IMU score for the ND/ID population based on the published criteria:

     - **V1=5.6**
       Thirty-three percent of children and adults with intellectual disabilities live in poverty (Parish, 2003).

     - **V2=19.8**
       Ten percent of the ND/ID population is over the age of 65 (Kochanek, Murphy, et al., 2004).

- **V3=0.0**

  Infant mortality within this group is recorded as 47-94/1,000 (Kochanek, Murphy, et al., 2004).

- **V4=28.7**

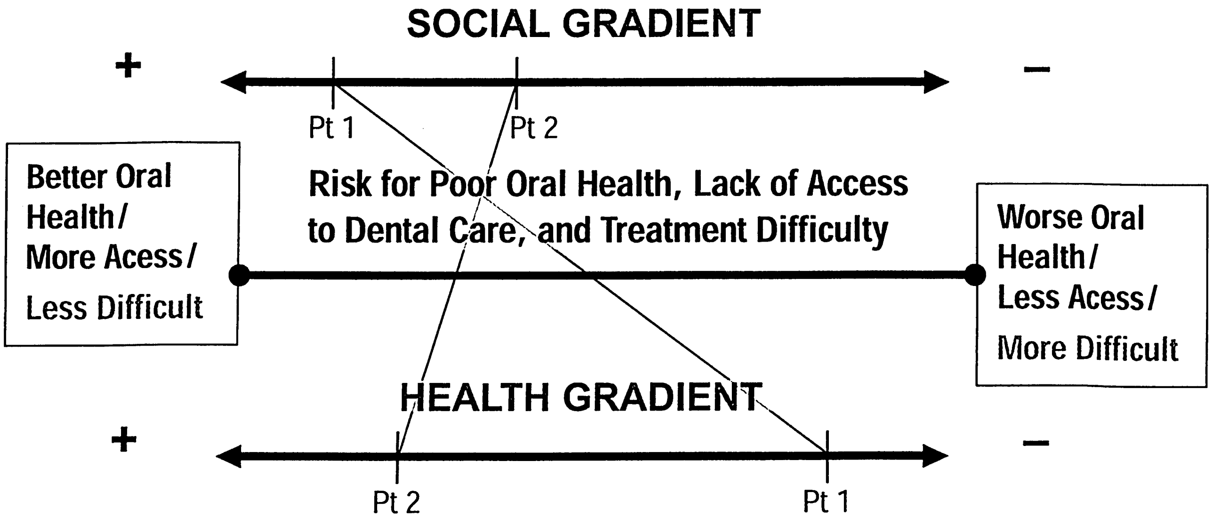
  The number of primary care physicians willing and capable of caring for the

  ND/ID population is very difficult to estimate, although anecdotally the presumed number is fairly low. By default, a V4 maximum score of 28.7 was utilized to calculate the IMU. Using the HRSA guidelines for establishing eligibility for a targeted MUP, the IMU score (V1+V2+V3+V4) for the ND/ID population would be equal to 54.1, which is less than the 62.0 score needed to determine eligibility. Recent graduates from medical and dental schools typically have student debt ranging from $120,000 to over $200,000. Designating individuals with ND/ID as a MUP would allow new physicians, physician assistants, and dentists who choose to provide healthcare services for a significant number of patients with ND/ID in their practices to apply for Federal student loan forgiveness, thereby potentially increasing the access to medically necessary services by this most vulnerable population and reducing the health disparity that currently exists.

Title VII, section 747 proposals that address primary care education and training to serve vulnerable populations such as individuals with ND/ID should be prioritized. In this way, medical, physician assistant, and dental students who want to provide healthcare services to these high-risk populations can be given the necessary didactic and clinical instruction to assume this professional responsibility upon graduation.

Healthcare training programs must better prepare our students to understand the needs of the populations that they will serve. New providers should understand how to access and utilize resources available to them when they join a new community. Such resources would allow them to appreciate the demographics of that community and recognize the special needs which that particular community might have. After this assessment, providers can then determine how they can better provide services within each unique community, recognizing that each has diverse needs and issues.

Providers also need the tools to understand how to assess for a variety of vulnerabilities within their service population. Edelstein (2005) provides an oral health example that can be extrapolated to other types of healthcare. In the graphic below, Edelstein demonstrates how two dimensions relate to poor oral health and limited access to healthcare for vulnerable populations. The intersection of where an individual falls on a "gradient of social advantage/disadvantage" and where that individual falls on a gradient of "health advantage/disadvantage" designates a



resultant "treatment difficulty" level that is associated with lack of access to dental care.

This poor access results in part from a lack of competency and confidence of healthcare providers in treating vulnerable individuals.

The role of Title VII programs is to better position primary care providers to improve their competencies and confidence in working with and for vulnerable populations through appropriate training. Title VII programs should encourage the development of educational strategies designed to equip trainees with specific skills needed to assess aspects of vulnerability in patient populations. Medical, dental, and physician assistant training programs should incorporate a curriculum that teaches trainees about vulnerability, the complex interplay of multiple risks for vulnerability, and community vulnerability assessment.

CONCLUSION

Vulnerability is the increased susceptibility for poor medical, mental, and oral health outcomes that is influenced by a plethora of possible circumstances or conditions such as disparate healthcare access; healthcare quality; and genetic, personal, behavioral, environmental, socioeconomic, and community risk factors. The current educational training available in the Nation's medical and dental schools and residency programs does not adequately train students to be competent to provide comprehensive and preventive healthcare for the Nation's most vulnerable populations and high-risk groups. Title VII, section 747 programs are uniquely positioned to provide the leadership to change a healthcare system that has often neglected its most vulnerable citizens. The Committee believes that adoption of the recommendations herein will facilitate these necessary changes and significantly expand healthcare services to all vulnerable individuals, including those with special needs.

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CLOSING THE GAP:

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U.S. Department of Health and Human Services • 2002

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Message from Tommy G. Thompson

Secretary of Health and Human Services

Good health is essential to quality of life, and the health and well-being of its people are essential to the strength of the Nation. At a recent White House dinner honoring the Special Olympics, President Bush eloquently stated that "America at its best upholds the value of every person and the possibilities of every life." He went on to say that "the story of our country is an ever-widening circle, a society in which everyone has a place and everyone has something to give."

Yet there is a segment of our population that too often is left behind as we work to achieve better health for our citizens. Americans with mental retardation, and their families, face enormous obstacles in seeking the kind of basic health care that many of us take for granted. Unfortunately, societal misunderstanding of mental retardation, even by many health care providers, contributes to the terrible burden. Too few providers receive adequate training in treating persons with mental retardation. Even providers with appropriate training find our current service system offers few incentives to ensure appropriate health care for children and adults with special needs. American health research, the finest in the world, has too often bypassed health and health services research questions of prime importance to persons with mental retardation.

Individuals with mental retardation are more likely to receive inappropriate and inadequate treatment, or be denied health care altogether. Children, youth, and adults with mental retardation receive fewer routine health examinations, fewer immunizations, less mental health care, less prophylactic oral health care, and fewer opportunities for physical exercise and athletic achievement than do other Americans. Those with communication difficulties are especially at greater risk for poor nutrition, overmedication, injury, and abuse.

In issuing this Blueprint for improving the health of those with mental retardation, the Surgeon General has drawn the attention of the Nation to the longstanding health disparities experienced by a group of Americans who deserve our full attention and support in their efforts to get the health care they need. By identifying these needs and outlining concrete action steps for addressing them, this community has created an unprecedented opportunity to narrow the gap between the health needs and health services for this special group. The Surgeon General's national Blueprint, which complements the suggestions contained in the President's *New Freedom Initiative*, takes the essential first steps needed to bring together self-advocates with mental retardation and their families with the scientists, health care providers, professional training institutions, advocacy organizations, and policymakers who can make a difference in the lives of individuals with mental retardation.

Our national commitment to the health of every American is demonstrated most clearly in efforts to reach those whose circumstances in life are most difficult. In this important new report, the Surgeon General articulates how the health of people with mental retardation can be significantly strengthened in the years ahead.

Foreword from the Surgeon General

As Surgeon General I have focused on identifying and addressing some of our Nation's pressing unmet health needs and disparities in health and health care. These efforts have dealt with issues such as mental health (especially children's mental health), suicide, oral health, and obesity. By learning more about these issues and focusing the country's attention on them, the process has begun to develop broad support for specific steps that can be taken to improve them.

Over the last year, we undertook an effort to examine the health of persons with mental retardation, especially the health disparities they suffer. It became apparent that as our system of care for those with mental retardation evolved, our attention to their health lessened. Even a quick glimpse at the health status of persons with mental retardation, both children and adults, reveals glaring deficiencies that must be addressed. To better understand, we sought to listen, not just to the experts in this field, but directly to individuals with mental retardation, to their family members, and to their other caregivers—those who live and struggle every day with the wide spectrum of issues that affect the health of these individuals.

This dedicated community can teach us a great deal. They can help us all to better understand and face their unmet needs, which are significant and all too common. Perhaps the greatest lesson is that as a society we have not really been listening and paying attention to them. We have been too likely to expect others, without mental retardation, to speak to their needs. We have found it too easy to ignore even their most obvious and common health conditions. Just as important, we have not found ways to empower them to improve and protect their own health. No one who cares would suggest that this is acceptable. Nothing, however, will follow from this effort unless we help our society better understand and appreciate that these persons are an integral part of the American people, with much to give if they, too, enjoy proper health.

Each person reading this report has an opportunity to learn more about these individuals' lives and needs, and to work together to improve their health. As the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation, held in December 2001, this national Blueprint identifies goals and action steps set forth by this community as its priority needs.

The goals and action steps should be considered for implementation at all levels, in all sectors of our society, from single individuals acting in their own communities to the largest national organizations or government agencies acting on state- and nation-wide issues. Each of us must accept the responsibility to do our part to improve the health of all persons with mental retardation.

Reports don't have arms and legs. Like many others, this report will just sit on shelves unless we turn it into action. It is important to listen to those affected to learn what needs to be done, but to listen and not respond with determined action will only heighten the injustice this community has too long endured. I ask everyone reading this report to do your part to achieve our noble objective of improving the health of all persons with mental retardation. If we do, together we will make a significant difference in the lives of these important individuals.

David Satcher, M.D., Ph.D.
Surgeon General
January 2002

CLOSING THE GAP:
A National Blueprint to Improve the Health of Persons with Mental Retardation

REPORT OF THE SURGEON GENERAL'S CONFERENCE ON HEALTH DISPARITIES AND MENTAL RETARDATION

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The Surgeon General expresses sincere appreciation to all who contributed their time, experience, and knowledge to support the development of this report and national Blueprint to improve the health of individuals with mental retardation. The Surgeon General would especially like to acknowledge the following:

THE PUBLIC

Among the most valuable contributions were those from members of the public who participated in many ways:

- Approximately 8,500 comments were received at the Surgeon General's dedicated website and at the Surgeon General's Listening Session on Health Disparities and Mental Retardation, October 10, 2001.
- The participants and speakers at the five sites included in the Surgeon General's Listening Session—Civitan International Research Center at the University of Alabama, Eunice Kennedy Shriver Center at the University of Massachusetts Medical School, Oregon Institute on Disability & Development at the Oregon Health & Science University, Waisman Center at the University of Wisconsin, and the National Institutes of Health.
- The participants, speakers, and moderators at the Surgeon General's Conference on Health Disparities and Mental Retardation, especially the self-advocates and family members who shared their perspectives on the day-to-day challenges of enabling persons with mental retardation to achieve good health.

NATIONAL ORGANIZATIONS

Many national organizations of advocates, patients, and health care professionals supported the Surgeon General's effort by sharing their expert knowledge, and by participating in the Listening Session and the Conference. In particular, the Surgeon General would like to recognize the major efforts contributed by the following organizations:

American Academy of Pediatrics
American Association on Mental Retardation
American Dental Association
American Osteopathic Association
American Psychiatric Association
Association of University Centers on Disabilities
Child Neurology Society
Joseph P. Kennedy, Jr. Foundation
Special Olympics, Inc.
The Arc of the United States

The support and continued interest of the following national organizations also are appreciated:

American Academy of Child and Adolescent Psychiatry
American Academy of Neurology
American Association of Physician Assistants
American Association on Health and Disability
American College of Obstetricians and Gynecologists
American Medical Association
American Neurological Association
American Nurses Association
American Physical Therapy Association
American Psychological Association
The Council on Quality and Leadership
Developmental Disabilities Nurses Association
Family Voices
Federation of Families
Intertribal Voices for Children's Mental Health
National Alliance for Caregiving
National Association for the Dually Diagnosed
National Association of Developmental Disabilities Councils
National Association of Qualified Mental Retardation Professionals
National Association of Protection and Advocacy Systems
National Association of State Directors of Developmental Disabilities Services

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National Dental Association
National Down Syndrome Congress
National Hispanic Medical Association
National Indian Child Welfare Association
National League for Nursing
National Medical Association
Oglala Sioux Tribe
People First
Self Advocates Becoming Empowered
Special Care Dentistry
TASH – The Association for Persons with Severe Handicaps
Voice of the Retarded

GOVERNMENT AGENCIES

The Surgeon General's Conference on Health Disparities and Mental Retardation was sponsored by the following Government agencies:

Department of Health and Human Services

Office of the Surgeon General, Office of Public Health and Science
National Institute of Child Health and Human Development, National Institutes of Health
National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention
Agency for Healthcare Research and Quality
Center for Mental Health Services, Substance Abuse and Mental Health Services Administration
Indian Health Service
National Institute on Aging, National Institutes of Health
National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health
National Institute of Dental and Craniofacial Research, National Institutes of Health
National Institute of Mental Health, National Institutes of Health
Office of the Assistant Secretary for Planning and Evaluation

Social Security Administration

Office of Disability

in collaboration with the following agencies:

Department of Health and Human Services

Administration for Children and Families
Administration on Developmental Disabilities
Centers for Medicare & Medicaid Services
Maternal and Child Health Bureau, Health Resources and Services Administration
National Center for Health Statistics, Centers for Disease Control and Prevention
National Center on Minority Health and Health Disparities, National Institutes of Health
National Institute of Environmental Health Sciences, National Institutes of Health
National Institute of Neurological Disorders and Stroke, National Institutes of Health
National Institute of Nursing Research, National Institutes of Health
Office of the Director, National Institutes of Health
Office of Public Health and Science
President's Committee on Mental Retardation

Department of Defense

Office of the Assistant Secretary of Defense, Health Affairs, TRICARE

Department of Education

Office of Special Education and Rehabilitative Services

The Surgeon General would especially like to recognize Duane Alexander, M.D., Director of the National Institute of Child Health and Human Development, and the staff of the Institute for their assistance in conceptualizing the effort, organizing the Listening Session, conducting the Conference, and preparing this report.

Introduction

> *"Individuals and their families should be equal partners [with providers] in making health care decisions. . . ."*
>
> Conference participant*

Like other Americans, persons with mental retardation (MR) grow up, grow old, and need good health and health care services in their communities. But people with MR, their families, and their advocates report exceptional challenges in staying healthy and getting appropriate health services when they are sick. They feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs. They struggle with unwieldy payment structures that were designed decades ago when people with MR often died in childhood or lived out their lives in residential institutions (U.S. Senate Appropriations Committee, Hearing Report No. 107-92).

Today, the life expectancy of people with conditions associated with MR has lengthened into adulthood and middle age. People with MR are remaining in their communities. In ever-increasing numbers, people with MR either do not enter institutions, or they leave them to live with their families or in other community settings, and they are determined to understand and take charge of their health. But in most cases, neither the education and training of health professionals nor other elements of the Nation's health system have been updated to reflect their progress. Especially as adolescents and adults, people with MR and their families face ever-growing challenges in finding and financing primary and specialty health care that responds both to the characteristics of MR and to the distinctive health care needs of each stage of life.

Terms in This Report

Environments refers to the characteristics of residential, work, educational, and community sites that may have positive or negative impacts on the health of people with MR. "Environment" includes family members and other caregivers, employers, teachers, and others at community sites, whose attitudes and treatment may support or impede people with MR in maintaining their health.

Family and other caregivers. "Family" refers to parents (including foster parents), siblings, and other family members who are primary caregivers for individuals with MR. "Caregiver" refers to personal care assistants, job coaches, housing counselors, volunteer "buddies," and others who assist individuals with MR in diverse ways.

Persons with MR or self-advocates refers to individuals with MR. The Surgeon General is aware that there is a controversy around the use of the term "mental retardation" and that self-advocacy groups and professional associations are currently discussing alternatives. Until a consensus is reached, with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as "mental retardation," that term has been used in the Surgeon General's effort on health disparities and mental retardation.

Providers or health care providers refers to physicians, dentists, nurses, physician assistants, dental hygienists, physical/occupational/speech-language therapists, behavioral health specialists, and all other health care providers.

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*Statements quoted in the Blueprint were made by Conference participants.

As health needs and service systems change over a lifetime, transitions are reported to be exceptionally difficult. Medicaid recipients speak of "falling off a cliff" when they graduate from the program's expansive pediatric coverage to more constricted adult benefits. Many may spend years on a waiting list to gain access to the more flexible service packages that are available only through Medicaid waivers to limited numbers of adults with MR.

Planning health care services, allocating sufficient resources, and monitoring the health and quality of care for people with MR are major policy challenges because needed data are not sufficient for the task. For example, for a majority of people with MR, their condition is relatively mild, and once they leave school, they disappear into larger communities, untracked in major national data sets.

Disparities and Diversity—Compared with other populations, adults, adolescents, and children with MR experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care. These challenges are even more daunting for people with MR from minority communities with many cultures and languages and whose culture and primary language may not be reflected in available health services. As with many other disabling conditions, the multiple disorders associated with MR are found disproportionately among low-income communities that experience social and economic disparities when they seek health care. Mental retardation compounds these disparities because many health care providers and institutional sources of care avoid patients with this condition. Without direct clinical experience, health care providers may feel incapable of providing adequate care. They may not value people with MR and their potential contributions to their own health and to their communities.

Identifying the Problems—This report presents a national Blueprint to improve the health of persons with MR. The Blueprint identifies problems and solutions proposed by the community of people with MR and those who care about their health. It consists of multiple action steps that were developed by work groups at the Surgeon General's National Conference on Health Disparities and Mental Retardation, December 5–6, 2001, in Washington, DC. The action steps are organized under six broad goals that emerged from Conference discussions and analysis of work group recommendations. (Appendix A is a summary of data presentations at the Conference. Appendix B is a list of Conference participants.)

Setting the Agenda and Realizing the Goals—The purpose of this Blueprint is to set forth an agenda from the community for national, State, and local action, in both public and private sectors, to improve the health of individuals with MR and to include them fully in health systems that meet their needs. Realizing the goals of this Blueprint calls for partnerships at all levels of public and private endeavor, from government agencies, legislatures, corporations, foundations, research and health care organizations, universities, and accreditation boards for health professions schools and training, to self-advocates, their families, local businesses and schools, voluntary, civic and faith-based organizations, individual clinical practices, and community-based health care services for other vulnerable populations. (Appendix C illustrates the diversity of potential partners, as suggested by participants in the December Conference.)

Goals to Improve the Health of People with Mental Retardation

- Health Promotion and Community Environments
- Knowledge and Understanding
- Quality of Health Care
- Training of Health Care Providers
- Health Care Financing
- Sources of Health Care

Dual Diagnosis Research Agenda—A separate national Workshop, held days before the Surgeon General's Conference, developed a detailed agenda for research on emotional and behavioral disorders and mental illness in people with MR and developmental disabilities. These coexisting conditions ("dual diagnosis") are among the most common and least understood aspects of health and MR because people with MR are commonly excluded from research on mental illness (as well as other types of disorders) on the basis of IQ rather than specific safety or other

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considerations in a research protocol. This type of disparity also is seen in the organization of health care services. For example, mental health programs and providers may exclude individuals on the basis of low IQ.

The Workshop, supported by the National Institutes of Health and the Joseph P. Kennedy Foundation, developed research recommendations on epidemiology, diagnosis and assessment, and interventions in emotional and behavioral disorders of people with MR. The agenda also addressed ethical considerations, research design, and research training needs. (National Institutes of Health, *Workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities*, November 29–December 1, 2001, http://draft.ninds.nih.gov/news_and_events/Emotional_Behavioral_Health_2001.htm).

Federal Initiatives on Disabilities—This report is published at a time when other Federal initiatives also are seeking to enable individuals with disabilities to live in their communities and receive appropriate services, including health care. These initiatives address some of the same problems that action steps in this report address and, in certain cases, propose the same or similar responses. For example, in a preliminary report to the President on his *New Freedom Initiative*, Federal agencies addressed structural changes in Medicaid, family support services to avert caregiver "burnout," and better training for personal care attendants and other direct service providers (U.S. Department of Health and Human Services, *Delivering on the Promise: Preliminary Report of Federal Agencies' Actions to Remove Barriers and Promote Community Integration—New Freedom Initiative*, December 21, 2001).

Shortly after the Conference, the Health Resources and Services Administration (HRSA), in partnership with the March of Dimes, the American Academy of Pediatrics, and Family Voices, held a national conference to promote a ten-year plan for appropriate community-based services for children and youth with special health care needs (HRSA, *All Aboard the 2010 Express: A 10-Year Action Plan to Achieve Community-Based Service Systems for Children and Youth with Special Health Care Needs and Their Families*, December 2001).

In conjunction with the Surgeon General's Conference on Health Disparities and Mental Retardation, the National Institute of Child Health and Human Development supported a national study describing diverse programs and creative strategies for providing community-based health care and supportive services for people with MR. (Appendix D is a summary of programs included in this study, which was provided to Conference participants.)

Most, if not all, of the content of this Blueprint is generally applicable for any population with disabilities. In fact, individuals with MR also may experience physically disabling conditions and disabling mental illness. The special role of this Blueprint is to set an agenda reflecting the distinctive implications of MR for health and disabilities policy and practice.

A National Blueprint to Improve the Health of Persons with Mental Retardation

This Blueprint resulted from a multistep process designed to identify and address the health-related concerns and recommendations of the community of individuals, families, and providers who are concerned with health and MR. The first step occurred at a March 5, 2001, Senate Appropriations Subcommittee hearing, called by Senator Ted Stevens (R-AK), to receive a literature review of the health and health status of adults, adolescents, and children with MR. Authors of this study and other witnesses reported that people with MR had poorer health and far less access even to basic screening and corrective treatment for vision, hearing, and oral health problems than others and that diagnosis and treatment of mental illnesses and other serious disorders in this population were often delayed, inadequate, or not provided at all.

At the hearing, the Surgeon General announced his intention to focus the attention of the Nation on the health needs of adults, adolescents, and children with MR. Subsequently, the community of people concerned with health and MR were invited to help plan a national conference on health disparities and MR by communicating their experiences, concerns, and ideas to a dedicated website and at a national Listening Session held on October 10, 2001. The estimated 8,500 comments and suggestions sent to the website and expressed at the Listening Session formed the basis for planning the national Conference. (Appendices E and F are a summary of the Listening Session and a list of speakers at the Listening Session, respectively.)

The National Conference—The purpose of the national Conference, held December 5–6, 2001, in Washington, DC, was to identify important issues in health and MR and to develop action steps to address these issues. In inviting Conference participants, every effort was made to reflect the broad diversity of people with MR and others concerned with their health. Officials of Federal agencies attended the Conference as observers and as "resources," providing information requested by participants.

Eight Conference work groups identified priority issues from those proposed during the planning process and from their own experiences. Work group topics ranged from provider attitudes and health care financing, to appropriateness of services across the lifespan and health promotion. Before the work groups began their deliberations, plenary session presentations provided background information on what was currently known about each group topic, and described examples of diverse programs providing health care and related services to adults, adolescents, and children with MR.

Drafting the Blueprint—To draft the Blueprint, it was necessary to consolidate nearly 50 issue areas and 200 action steps recommended by the Conference work groups. All records of the work of the groups were reviewed, including plenary session presentations of highlights of the work group decisions and written notes and audiotapes of group deliberations. An informal discussion among work group moderators as well as review of these records enabled drafters of the Blueprint to array the action steps under six broad goals that reflect priorities shared among the work groups. Action steps shown under the goals have been distilled from multiple group deliberations and reports.

"Potential strategies," also derived from group deliberations, have been added to provide examples of activities, topics for research, and the like. These action steps and strategies should not be considered the only ways to achieve the six goals. The resulting Blueprint presents a consolidation of the problems identified and solutions proposed by participants from the website, the Listening Session, and the Conference. It is intended for multiple audiences, from the community of people who live with MR on a daily basis, to the health care providers, researchers, agencies, and others that can contribute to a more inclusive health care system. Each partner and combination of partners will bring their own priorities and ideas to the task of improving the health of people with MR.

Core Values for All Aspects of the Blueprint—Throughout the Conference, certain core values permeated the deliberations of the work groups and the general Conference discussions at plenary sessions. As expressed by several Conference participants, these values include the following:

"We ought to be about keeping people healthy...."

"For things to change, we must change the stigma [of MR] to understanding and respect."

"[Every action must fully include]...people with MR,...family involvement, and...people telling us what they need, as opposed to our telling them what they want."

"Providers have to look beyond the disability and see the person—talk to us!"

"...If we do all [of the action steps], and we don't do it in a person's first language, and we don't do it showing respect...for their culture, it means nothing...."

"[There must be] coordinated, community-based services that [are] integrated, available, and accessible. Let's not make it all so difficult."

GOALS AND ACTION STEPS

GOAL 1: Integrate Health Promotion into Community Environments of People with Mental Retardation

> *"Health promotion programs should accommodate people with MR. Examples include smoking cessation, weight control, fitness, safe sex, drugs, and alcohol."*

As with other populations, health promotion and disease prevention are multifactorial for individuals with MR. They need to be empowered with adequate and understandable information and reinforcement to avoid health risks and maintain healthy personal habits. Their health care providers and the environments where they live, work, learn, and socialize should offer opportunities to inform, support, and reinforce healthy lifestyles. Routine preventive services, from periodic oral prophylaxis and restoration, to cancer screening, immunizations, and early intervention with emerging mental illness are critical to prevention of more serious conditions and secondary disability. Because of the potential for modeling behaviors, health-promoting knowledge and habits of personal care attendants and family members, co-workers, and others can help individuals with MR to protect and maintain their health.

Action Steps:

- ***Wellness:* Educate and support individuals with MR, their families, and other caregivers in self-care and wellness.**

Potential strategies: Adapt self-care and wellness programs designed for general populations and cultural, ethnic, and socioeconomic minorities to the needs of individuals with MR. When proven effective, replicate existing programs for individuals with MR, especially peer-designed programs for wellness, self-care, and mental health. Evaluate the use of assistive technology and different media in educating and reinforcing healthy behaviors in individuals with MR, their families, and their caregivers. Develop and disseminate models for health care provider counseling and reinforcement of wellness and healthy behaviors in individuals with MR, their families, and caregivers.

Potential topics: Nutrition and weight control; exercise; oral health; family planning; safe sex; strategies for protection from rape, domestic violence, and sexual abuse; maintaining treatment regimens; avoiding medication errors; recognizing and seeking care for emerging disorders; and age-related changes in, and risks to, health status.

- ***Caregiver support:* Develop and implement strategies for reducing care burdens for families of individuals with MR, and reducing high rates of turnover in nonfamily caregivers.**

Potential strategies: Identify stressors and sources of resilience in individuals with MR, their families, and their caregivers, and support strategies to enhance resilience. Support respite care, case management, advance (lifetime) planning for transitions to different stages of life and age-associated health needs. Provide assistance in caring for individuals with dual diagnosis, including family and caregiver training in behavior management and advance planning for behavioral crises. Provide technical assistance to families in information technologies, including how to use the Internet. Explore compensation, including basic health coverage, for family caregivers whose care responsibilities prevent them from working outside the home.

Additional strategies: Provide training in health care, including supporting healthy habits, for personal care attendants and other caregivers. Create career tracks leading to certification of caregivers with regard to health-related competencies. Support basic health care coverage and increased compensation, commensurate with demonstrated health competencies, for caregivers.

- ***Workplace:* Protect the health of individuals with MR from occupational hazards.**

Potential strategies: Develop and disseminate modules to educate and train individuals with MR, their employment counselors and job coaches, their families and caregivers, their employers and potential employers, and occupational health and safety inspectors, in recognizing and eliminating hazardous working conditions that may require special accommodations for employees with MR. Potential accommodations include ensuring that employees

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with MR work in safe and healthful environments and understand how to avoid repetitive motion disorders and other occupational hazards.

- ***Assessment:*** **Assess the effects of health promotion and wellness activities for individuals with MR on their morbidity, secondary disability, mortality, life satisfaction, independent living, achievement of life goals, and cultural and ethnic identity.**

GOAL 2: Increase Knowledge and Understanding of Health and Mental Retardation, Ensuring that Knowledge Is Made Practical and Easy to Use

> *"We're invisible in the data. We can't make people believe we need more services if we don't have data to back us up."*

Credible scientific knowledge is considered essential to all goals in this Blueprint, from establishing appropriate standards of health care, to training health care providers, to revising financing structures, and improving the capacity of individuals and their families to protect and maintain their health. For example, the lack of population-based data on prevalence of MR and the health status and service needs of this population impedes planning and allocating resources for their care. Failure to monitor the quality of their care hampers detection of prejudicial or inadequate treatment. Recent advances in neurosciences, genetics, psychopharmacology, and other fields of research could improve the diagnosis and treatment of individuals with MR and emotional, behavioral, or psychiatric disorders (dual diagnosis).

At the same time, individuals, family members, and health care providers need easily accessible, scientifically accurate, culturally relevant, and understandable information for prevention and health promotion, as well as for diagnostic and treatment decisions. All aspects of health-related research, from biomedical and epidemiologic to health services and ethics, offer multiple opportunities to increase and improve the utility of scientific knowledge on health and MR.

Action Steps:

- ***Participation:* Enable individuals with MR, their families, and their health care providers to partner with professional investigators in identifying health research priorities, and in designing and implementing research relating to health and MR.**

Potential strategies: Include individuals with MR, family members, and their primary and specialty health care providers in research advisory committees and planning groups to provide input into the development of research proposals and grant submissions. Offer training to lay advisors in identifying research questions and other technical matters. Encourage federally funded health researchers to develop partnerships in which persons with MR, their family members, and other caregivers, including health care providers, are consulted and participate in the planning and conduct of research relevant to MR.

- ***Research agenda:* Develop a national research agenda that identifies gaps in existing scientific knowledge related to health and MR, including methodological challenges, priorities, feasibility, and timetables for achieving priority research.**

Potential strategies: Develop specific agendas for basic, clinical, and translational research; for studies of the efficacy of wellness and treatment services and service models for people with MR; for legal and ethical issues, health care financing, and its relationship to outcomes; and for other matters identified by the community. Implement the December 2001 research agenda of the Workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities (National Institutes of Health, Workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities, November 29–December 1, 2001). Enhance research collaborations across multiple research agendas and disciplines.

- ***Data collection:* Collect data on the health status of persons with MR in relation to the utilization, organization, and financing of their health services.**

Potential strategies: Identify and evaluate existing data on health and MR. Add MR to population-based data collection on health status, health risks, health services utilization, and health care costs. Test methods of identifying patients with MR on Medicaid and other third-party payer claims for purposes of collecting data, while also protecting patient confidentiality. Conduct market research to determine attitudes toward MR of health care providers, and how to change negative attitudes. Survey individual practices, managed care

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organizations, and localities and States to better understand the experiences of individuals with MR when they seek health care.

- ***Research subject protection:*** **Review current ethical and legal rules for protection of human research subjects as they relate to individuals with MR. Revise these rules as necessary to facilitate the participation of persons with MR in clinical trials and other types of research, with full protection of their autonomy, health, and safety. Ensure that individuals, their families, their health care providers, and their advocates participate as partners in reviews and revisions of these rules. Ensure their participation in Institutional Review Board (IRB) reviews of research proposals relating to MR.**

Potential strategies: Provide training in legal and ethical rules for protection of human research subjects to lay participants in review and the revision of these rules. Provide training in IRB standards and procedures.

- ***Understanding and use:*** **Provide assistance for individuals with MR, their families, and their health care providers in finding, evaluating, and using health research findings to help in the prevention, diagnosis, and management of medical (including psychiatric), psychological, and oral health conditions, and to inform treatment decisions by individuals and their families.**

Potential strategies: Establish, and keep current, a national clearinghouse, a website, and a list-serve to guide users in identifying and evaluating research, and to promote their exchange of information and opinions. Design science-based continuing education curricula for licensed health care providers. Translate peer-reviewed journal information, reports of evidence-based best practices, and other findings for lay consumption, and disseminate information to provider groups, and State agencies that serve persons with MR, and provider trade journals.

- ***Research capacity: Increase the number of investigators trained in health and MR research.***

Potential strategies: Fund undergraduate training and postdoctoral research fellowships at medical, dental, and other health professions schools and training programs targeted specifically at issues relevant to MR. Solicit proposals for multidisciplinary research. Solicit proposals from centers and programs that provide health care to individuals with MR, especially those living in their communities. Solicit joint proposals from these providers and investigators at medical, dental, and other health professions schools and programs.

- ***Visibility:*** **Enhance the visibility of health and MR research.**

Potential strategies: Increase and ensure appropriate use of funds to support research on health and MR, including expansion of studies on dual diagnosis and other disorders for which individuals with MR are at elevated risk. Create prizes and other awards for excellence in health and MR research. Endow chairs for health and MR research at health professions schools. Establish special interest sections in health research organizations. Support special plenary lectures on health and MR at national medical, dental, and other health professions meetings. Publish health and MR research findings in peer-reviewed medical (including psychiatric), dental, psychological, nursing, physician assistant, dental hygienist, and other health-related journals, as well as in health services research and policy journals.

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GOAL 3: Improve the Quality of Health Care for People with Mental Retardation

"Encourage agencies and health care professionals to treat people with MR according to age and health needs, not just for their disability."

The quality of health care for individuals with MR depends on the knowledge and skills of individual providers, particularly their capacity to engage these patients in their own health care, and on systemic factors. Such factors include monitoring the utilization of health care services and outcomes for people with MR, and correcting deficiencies in the quality of their care, such as medication error, underutilization of services, and failure to interact effectively with patients and family members.

At both the individual provider and health systems levels, credible standards of health care, based on scientific evidence, are essential to improving the quality of health care for people with MR. Until an adequate science base is available, however, consensus standards that reflect the knowledge and experience of recognized experts (including the community of people concerned with health and MR), and are formulated in standardized procedures, are an important interim step. The potential for MR-specific standards to contribute to stigmatization must be balanced against the need for health care services that fully meet the needs of this population.

Action Steps:

- ***Priorities:* Identify priority areas of health care quality improvement for persons with MR.**

Potential strategies: Consult with individuals with MR, their families, and their primary and specialty health care providers and researchers to identify priority areas for ensuring and improving the quality of their health care. Identify existing best practices that may be used systemwide to improve the quality of care, and those areas in which better practices may be needed. Use these consultations, together with evaluations of existing and needed scientific knowledge, to establish priorities for improving the quality of health care for people with MR.

- ***Standards of care:* Identify, adapt, and develop standards of care for use in monitoring and improving the quality of care for individuals with MR.**

Potential strategies: Work with associations of health professionals that develop consensus and science-based standards of care for populations with disabling conditions, for people with MR, and for general populations. Identify and adapt standards developed with the support of the National Institutes of Health, the Centers for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, and other Federal agencies; consult with the National Committee for Quality Assurance and with contractors that develop health care standards for quality assurance in managed care. Identify existing strategies for adapting and developing additional standards of care for use with culturally diverse populations.

Additional strategies: Develop science-based standards on topics for which sufficient scientific knowledge exists. Develop interim, consensus standards on topics for which scientific knowledge must be developed. Replace consensus standards, to the extent feasible, with science-based standards. Review and update standards to reflect new knowledge, as it becomes available.

Potential priority topics for standards: Responsiveness to distinctive cultural values of diverse communities; self-care and maintenance of health-promoting activities; diagnosis and treatment of emotional and behavioral disorders and mental illness; provider screening; and prevention and early intervention in medical, psychiatric, behavioral, and oral health conditions for which individuals with MR are at heightened risk, such as premature aging, and for coexisting conditions, such as diabetes and mental illness.

Other potential priority topics: Recognition and treatment of emergency conditions, including sexual, physical, and psychological abuse and their sequelae; prevention, diagnosis, and treatment of substance abuse; development of plans of care, including self-care, to achieve health goals of individuals and their families; development and revision of lifetime health plans for individuals with MR; age-appropriateness of health services (including pediatric, adolescent, adult, geriatric, palliative, and end-of-life care); and age-related transitions, including pediatric to adult health care.

- *Use:* **Ensure that the practice, organization, and financing of health care services for individuals with MR promote improvement in their quality of care.**

Potential strategies: Determine whether and how existing standards for care of people with MR are used. Integrate standards of care for MR into the following: clinical practice guidelines; curricula for health professions training; guidance for individuals, their families, their other caregivers, and their primary and specialty care providers; organized health services (including managed care organizations, hospitals, community health centers, and others); and quality assessment and performance improvements in organized health services and individual provider practices.

Additional strategies: Explore methods of linking health care financing to appropriate standards of care for people with MR. Methods could include health care quality requirements in managed care contracts and oversight of such contracts by private and public purchasers, and projects to test such linkage in behavioral health, maternal and child health, family planning, oral health, and comprehensive health care services programs.

- ***Recognizing excellence:*** **Establish local, regional, and national awards that recognize excellence in providing health care to individuals with MR.**

Potential strategies: Work with individuals, their families and caregivers, academic institutions, medical, dental, and other health professions societies, and national associations and other interested parties and groups to recognize excellence in providing health care for individuals with MR. Recognition could include financial prizes and nonmonetary awards.

GOAL 4: Train Health Care Providers in the Care of Adults and Children with Mental Retardation

"The number one issue is lack of training to support healthy lifestyles [for individuals with MR] across the lifespan."

The challenges and rewards of treating individuals with MR are rarely addressed in the training of physicians and other health care professionals. However, anecdotal evidence and limited data indicate that opportunities for clinical experiences with these patients, early in medical and other health professions training, increase the capacity of providers to value and accept these patients into their practices.

Action Steps:

- ***Professional education:*** **Integrate didactic and clinical training in health care of individuals with MR into the basic and specialized education and training of all health care providers.**

Potential strategies: Evaluate existing health professions training curricula that address health and MR and disseminate those found to be efficacious. Partner with families and individuals with MR to develop and implement training modules. Use providers experienced in the care of individuals with MR and family members to mentor health professions students, residents, and fellows in the care of this population. Develop and implement criteria for accreditation and certification of health professions schools and training programs, based on inclusion of mental retardation in their curricula.

Potential curriculum topics: Dual diagnosis; health risks and expression, in people with MR, of age-related conditions found in other populations; direct interactions with these patients, such as history-taking, including cultural practices, diagnosis, treatment, and counseling and supporting individuals in wellness and in adherence to treatment regimens; appropriate use of medications and alternative behavior management techniques; working with individuals and their families to develop and update goal-oriented health care plans, including lifetime plans and plans for transition points; and use of augmentative communications devices and other specialized equipment.

- ***Interdisciplinary education and training:*** **Support development and dissemination of effective training modules in interdisciplinary practice. Design modules to include social workers, family members, individuals with MR, and others, when relevant, such as teachers, personal care attendants, job counselors, and frontline office staff.**

- ***Provider competence:*** **Develop methods of evaluating and improving health provider competence in the health care of individuals with MR. These methods should be based on appropriate standards of care, including care that reflects understanding and respect for diverse cultures, and should be used to evaluate the competence of students and practicing providers, and to provide feedback and reevaluation of their performance.**

- ***Continuing education:*** **Develop, evaluate, and disseminate continuing education curricula for health care providers at all levels of practice in the care of individuals with MR. Such curricula should be based on appropriate standards of care and include training opportunities that reflect understanding and respect for diverse cultures.**

GOAL 5: Ensure that Health Care Financing Produces Good Health Outcomes for Adults and Children with Mental Retardation

> *"Let's develop reimbursement that is respectful of the diverse lifestyles of people with MR and their families and that is tied to outcomes they value, [but] be careful...that we don't develop policies that will cover more people, with more flexibility, without ensuring the basic level of care that we know our people need."*

High rates of poverty among adults and children with MR mean that a large proportion of them rely on publicly financed health care insurance, which is not always well-adapted to serving their needs. People with MR find that many providers avoid the program, citing low reimbursement rates, administrative burden, and fear of being inundated with underfinanced patients. Providers who are committed to treating individuals with MR report that restrictive Medicaid rules on which services are covered, in which settings, can limit use of innovative service models.

Families with private-sector coverage encounter gaps in coverage, unaffordable premium payments, and little flexibility in designing packages of services to meet their children's needs. Cost-avoidance and cost-shifting by both public and private payers force families to try to mediate between special education programs and third-party payers and between long-term and acute care systems. Research and understanding of financing structures, to better accommodate service needs of individuals with MR, are hindered by lack of critical utilization and reimbursement data.

Action Steps:

- ***Outcomes and financing:*** **Determine relationships among diverse financing mechanisms, service packages, and health outcomes for individuals with MR. Use findings to ensure accountability of flexible arrangements for financing services.**

Potential strategies: Test effects on health outcomes, for people with MR, of diverse models for providing health care services, service packages, and financing mechanisms. Identify factors in varying combinations that affect outcomes. Determine effects of adjunct services, including respite care, transportation, child care, and case management, in combination with medical, dental, and other health services, on outcomes. Support longitudinal studies of portability of health services packages as educational, employment, and residential circumstances change. Develop methods of ensuring accountability for sufficiency and quality of health care services, including accountability for outcomes, in models for flexible health service financing.

- ***Definitions:*** **Use appropriate definitions of "effective," "cost-effective," and "health outcomes" in research, organization, and financing of health care for individuals with MR.**

Potential strategies: Explore expanding definitions of terms used in measuring the effects of health care financing and service models to include wellness, functionality, patient and family understanding of health maintenance and treatment regimens, capacity for consumer choice among services, and satisfaction and individualization of service packages. Calculate health care costs across all systems with responsibility for health care of individuals with MR, such as special education, and third-party payments for behavioral therapy. Support development of methods to determine cost-effectiveness of services over the lifespan, taking into consideration cost offsets among long-term, preventive, and acute care, and other factors.

- ***Services:*** **Identify a package of health care services for individuals with MR that will produce good outcomes in terms of health maintenance, management of illness, functionality, and life goals across the individual's lifespan.**

Potential strategies: Review currently available public and private packages of health care and supportive services for cost, quality, and consumer satisfaction. Test models of comprehensive lifetime coverage to better meet the needs of persons throughout their lives and avoid age-related disruptions of financing and services. Assess the use of criteria, including acquiring and maintaining functionality for making decisions on coverage.

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- ***Leveraging:* Evaluate models for leveraging health dollars to maximize purchasing power by and for individuals with MR. Ensure that individuals' coverage and access to primary and specialty health care and support services are not eroded by revisions in purchasing practices and policies.**

Potential strategies: Evaluate models for coordinated funding of pediatric, adolescent, adult, and geriatric care, including acute and long-term care, primary care, specialty services, and school-based services, through use of pooled funds, complementary financing from multiple funding streams, and other innovations. Evaluate models for tying funding mechanisms to good outcomes, as defined in the first action step. Evaluate models that enable individuals with MR and their families to choose needed health services on an individualized basis and to monitor outcomes and service utilization. Encourage third-party payers to reimburse for health care services in carefully monitored clinical trials and other studies at academic centers of excellence.

Additional potential strategies: Provide technical assistance to States, tribes, and health care programs and providers in using Medicaid authorities to finance innovative models for providing health care, and identify and eliminate financial disincentives for such models. For example, payer rules limiting reimbursements to one visit per patient per day may mean that families must make multiple appointments with multiple providers to complete multidisciplinary assessments. Evaluate and replicate the use of incentives, such as enhanced Medicaid reimbursement rates, to encourage States to develop and/or replicate effective models that meet the needs of individuals typically not covered.

- ***Cost offsets:* Explore strategies to offset financial costs to providers and health services programs that are associated with meeting specialized needs of patients with MR.**

Potential strategies: Assess the relationship between different rates of Medicaid and Medicare provider reimbursement and any impact on access to health care for individuals with MR. Identify sources and amounts of costs to providers that are associated with meeting specialized needs of individuals with MR. Assess the effect of offsetting such costs on provider acceptance of individuals with MR. Assess combined and separate effects of cost-offsets and nonfinancial provider supports, described elsewhere in the Blueprint, on provider acceptance.

GOAL 6: Increase Sources of Health Care Services for Adults, Adolescents, and Children with Mental Retardation, Ensuring that Health Care is Easily Accessible for Them

> *"Services can be wonderful and high quality, but if there aren't enough, or if you can't get to them, or if you don't know about them, [they're of] no help to you...."*

Like other Americans, especially those who are poor and disabled, people with MR are confronted with a fragmented health care system in which primary and specialty sources of care are often poorly distributed, inadequate in number, and ill-equipped to respond to their needs.

Action Steps:

- ***Diversity:* Increase the number of physicians, dentists, clinical psychologists, and allied health care professionals who have appropriate training and experience in treating adults, adolescents, and children with MR, including those from socioeconomically and linguistically diverse communities.**

Potential strategies: Recruit students, residents and fellows, and practicing providers from diverse communities, and train them in providing health care to individuals with MR. Establish health professions curricula and continuing education modules in cultural competence in relating to patients with MR. Work with spiritual and other leaders who know the cultural and ethnic beliefs, values, and primary languages of individuals and families in diverse communities to plan and provide health care services, develop health professions training curricula, and otherwise ensure responsiveness to diverse ethnic, cultural, and linguistic needs in all aspects of health care for individuals with MR and their families.

- ***Easier access:* Make access to health care services less complicated for individuals with MR and their families and caregivers, whether in urban, rural, or remote communities.**

Potential strategies: Ensure that independent service coordinators who work on behalf of clients to locate and ensure access to and coordination of services are available for individuals with MR who wish such assistance. Co-locate primary and specialty medical, psychiatric/psychological, and dental services. Support multidisciplinary teams, including mobile teams to bring services to individuals' homes, schools, and other nonclinical sites. Ensure that individuals with MR receive assistance in care coordination and transportation to health care services. Ensure that individuals and families in various community settings receive usable information about available health care in their communities.

Additional strategies: Review eligibility to reduce the need for multiple applications and multiple determinations of eligibility for services. Promote the use of presumptive eligibility, once initial eligibility is established, for services through Medicare or Supplemental Security Insurance (SSI)/Medicaid.

- ***Community-based care:* Integrate health care services for individuals with MR into diverse community programs.**

Potential strategies: Incorporate preventive health education and interventions into early intervention and special education plans. Support development of protocols and dissemination, for care of individuals with MR and coexisting conditions, at community and migrant health centers, community mental health services, addiction disorder services, family planning programs, rape/sexual abuse and family violence services, public health clinics, and other publicly funded, community-based health services and programs. Prohibit such programs and services from excluding individuals solely on the basis of IQ.

- ***Health professionals:* Expand the types of health professionals used in providing health care to individuals with MR, including geriatric, pediatric, and other nurse practitioners and nurses, physician assistants, dental hygienists, and behavioral therapists.**

Potential strategies: Identify and remove disincentives and barriers in Medicaid, Medicare, and private third-party payer reimbursements to expand the use of a wide variety of health professionals to care for persons with MR.

- ***Supporting providers:* Support supplementary services to help physicians, dentists, psychologists, and other providers and organized health services in providing care to individuals with MR.**

103x

Potential strategies: Work with providers to identify nonfinancial "costs" in including individuals with MR in their practices and programs. Support needed services that could offset such "costs." Such services could include technical assistance with Medicaid and other types of claiming, case managers, preliminary health screening and referrals, completing informed consent procedures, and assembling complete and current medical and dental histories (including family histories) of individuals with MR. Explore the use of "health passports" (copies of up-to-date health histories, including family history) that "travel" to health services with individuals with MR.

- ***Special equipment:* Ensure that adaptive equipment and assistive technologies are available in urban, rural, and remote communities for use at clinical sites where individuals with MR receive health care.**

Potential strategies: Provide support to health care providers to finance the costs of purchasing and installing special equipment and modifications to practice sites, such as installation of automatic doors, specialized examining tables and chairs, and wheelchair-accessible bathrooms. Evaluate and support the use of overhead allowances, direct subsidies, cost- and time-sharing among providers, and other mechanisms for offsetting costs of acquiring (and, as necessary, training in the use of) specialized equipment.

- ***Lifetime health:* Ensure continuity of health care services throughout the life of an individual with MR.**

Potential strategies: Develop and implement State plans for providing age-appropriate, comprehensive, and continuous health services for individuals throughout their lives. Develop and disseminate models for individual lifetime health care plans, with periodic review and updates.

Appendix A: Surgeon General's Conference on Health Disparities and Mental Retardation Summary of the Plenary Session of December 5, 2001: Background Presentations

The plenary session on the first day of the Surgeon General's Conference on Health Disparities and Mental Retardation provided important background information for the work groups held later that day. Starting with the opening remarks, the presentations set the tone and provided the foundation for the eight separate work group discussions.

For each work group, a moderator introduced the key issues to be addressed, and another expert presented the current state of knowledge. To complement the facts, an individual representing a service program that creatively addressed the issues discussed the program, challenges, and achievements. Brief summaries of the opening remarks and presentations follow.

OPENING REMARKS

Duane Alexander, M.D., Director, National Institute of Child Health and Human Development (NICHD)

Dr. Alexander noted that because the NICHD was established by President John Kennedy to lead the Nation's research effort to improve the health of individuals with mental retardation (MR), he welcomed the Surgeon General's request to convene the conference. He expressed appreciation to all who would help develop recommendations and to the many Government agencies that supported the effort. Dr. Alexander introduced Dr. Satcher as the moving force behind the Nation's efforts to address the many health disparities faced by different population groups across the country.

David Satcher, M.D., Ph.D., Surgeon General of the United States

Dr. Satcher described the conference and its outcome as an important example of efforts to move forward in the best interests of the American people following the tragedies of September 11. After recognizing the NICHD and other agencies involved, he pointed out that Surgeon Generals' reports have enjoyed great credibility with the American public because they are based not on opinion, politics, or religion, but on the best public health science.

This conference complements several top priorities of the Surgeon General's Office, including health disparities and meeting the health needs of our most vulnerable, the role of the community health system in the struggle for access to care, and identifying and addressing common problems and experiences within our global health community.

The genesis of this conference was the March 2000 field hearing of the Senate Appropriations Subcommittee on access to care for individuals with MR, at which families and self-advocates testified convincingly about the problems they face. The Conference and the Blueprint for action reflect the Surgeon General's efforts to not only listen but respond with effective programs. The Conference report and its implementation are key to achieving this goal. Noting the caveat with the use of the term "mental retardation," he asked all participants to judge each other not by the words used to describe the condition but rather by the actions taken to help improve the lives of those with the condition.

Loretta Claiborne, Athlete and Self-Advocate

Ms. Claiborne thanked the Surgeon General for listening to individuals with MR, and expressed her hope that her experiences seeking health care as a child would not happen to others. She credited the Special Olympics with recognizing the urgent health needs of many of their athletes, and pointed out that this conference, with its high rate of involvement by people who have never been listened to before, was different and important.

PRESENTATIONS

Bonnie Kerker, Ph.D., Overview Presentation on the Prevalence of Mental Retardation

Dr. Kerker noted that accurate and consistent prevalence data on MR are essential for developing health policies and health care services, and for allocating public funds to address the needs of children and adults with MR.

Current data show that approximately 0.3 to 3.1 percent of the general population, and about 1.1 percent of all children, have MR. Of these individuals, most are classified as having mild MR. Other developed countries report a lower and narrower range of MR than the U.S. Some of the discrepancy in prevalence estimates is due to differences in the way MR is defined and in the types of data used. For instance, MR is commonly defined in three basic ways—on the basis of intellectual functioning alone, intellectual functioning with adaptive behaviors, or intellectual functioning with an identifiable etiology of MR. Likewise, prevalence data may be population-based, including counts of people with MR in an overall population, or the data may be drawn from clinical or administrative sources, meaning that it is based on individuals who access services. Most U.S. prevalence data come from the latter sources; however, such data usually provide less accurate counts because many adults and children with MR may be unable to access care.

Another difficulty lies in the timing and ease of identifying individuals with MR. For example, because of naturally occurring but subtle differences in early developmental patterns, children may not be diagnosed early in life. Those children diagnosed later through the school system, especially those with mild MR, are often lost in followup as adults.

In summary, despite wide ranges in prevalence data, many people in the U.S. and abroad must confront the challenge of MR. The challenge for our Nation begins with more accurately estimating the prevalence of these conditions. This requires using a standardized definition of MR, increasing the use of population-based data that emphasize participation of individuals with MR, and encouraging and helping health care providers to identify both adults and children with MR.

Work Group One: Attitudes of Health Care Professionals

David Coulter, M.D., Moderator

Referring to comments made at the Surgeon General's Listening Session on Health Disparities and Mental Retardation, Dr. Coulter noted that many family members and self-advocates continue to encounter poor attitudes among health care providers.

Our society assumes health care professionals should provide accessible, comprehensive, family-centered care that is also coordinated, continuous, culturally competent, and respectful of a patient's choices. Meeting the needs of individuals with MR, however, also requires developing new ways to incorporate the concept of self-determination and patients' own goals for a healthy life into their care. This requires better training for providers to improve their attitudes and their knowledge of the needs of those with MR.

Listening Session participants also noted that health care providers may reluctantly accept Medicaid recipients or individuals with MR as patients. Provider attitudes also may influence the quality of care delivered to people with MR and reduce direct communication with these patients. For patients who come from different ethnic and cultural groups, provider attitudes may lead to misunderstandings concerning the values and perceptions of health or concerning MR itself.

K. Charlie Lakin, Ph.D., Scientific Presentation

Dr. Lakin discussed the wide range of intellectual ability and health needs of children and adults with intellectual disabilities. Poverty is a key issue for those with intellectual disabilities: adults with these disabilities are three times more likely to live in poverty than other adults in the U.S. Similarly, children with intellectual disabilities are twice as likely to live in poverty as other children. In addition, people with intellectual disabilities are less likely to be insured than the general population.

Despite these facts, data from the National Health Interview Survey show that a majority of people with intellectual disabilities, or their proxies, report their doctor's thoroughness, respect and attention to privacy, interest in them and their condition, and availability in an emergency to be either "good" or "excellent."

However, other literature shows that if health care providers lack the experience or specific knowledge, they are reluctant to treat people with intellectual disabilities. Likewise, providers may hesitate to treat patients with intellectual disabilities because of poor experiences in past encounters or because providers are inadequately compensated for the additional time that may be required to care for these patients.

Provider training is key to influencing these attitudes. Research shows providers (or other professionals working directly with patients in a clinical setting) who took a structured training course concerning the health care of individuals with intellectual disabilities had an increased desire or willingness to treat these patients. The attitudes of providers who were trained with only reading or course work did not change.

In summary, the literature reveals that provider attitudes influence access to services. A provider's willingness to treat people with intellectual disabilities is influenced by public, private, and advocacy groups; access to technical support and professional allies; and evidence that it is financially viable to treat people with intellectual disabilities. In addition, transportation, communication, and other problems commonly experienced by persons with disabilities only increase the challenges faced by providers.

Sharon L. Ramey, Ph.D., Creative Program Presentation

Dr. Ramey shared findings about a unique research program at the Alabama Mother and Family Specialty Center in Birmingham, Alabama. Originally developed to determine whether providing good prenatal care could decrease the rates of low-birthweight and premature babies, the program faced the challenge of caring for many women with intellectual disabilities. In a previous study, about one-third of the mothers with low-birthweight or premature babies had low IQs themselves.

The researchers carefully documented the amount and quality of care each of the 600 women enrolled in the program received during her pregnancy. Mothers received highly tailored prenatal care provided by the same nurse over the course of the program. Instructional videotapes, educational materials, flexible clinic hours, transportation to the clinic, child care during office visits, and participation in a talk show to discuss common questions during pregnancy complemented the care the mothers received.

An evaluation revealed that the tailored program of prenatal care failed to reduce significantly the incidence of low-birthweight or premature babies; however, the program improved the health of the mothers and their knowledge of their bodies, promoting healthy lifestyles and healthy behaviors. In the end, the program and its many components helped to prepare these women, many with low IQs, for the challenging task of motherhood.

Work Group Two: Quality of Health Services

Roxanne Dryden-Edwards, M.D., Moderator

Dr. Dryden-Edwards noted that individuals with intellectual disabilities need specific approaches to health care treatment. Most importantly, to give quality care, providers will need to spend more time with these patients and take advantage of opportunities to learn about a broad range of their needs. Current and future health care professionals will need to be better trained. It will be important that they learn how to provide comprehensive care respectfully, prevent the inappropriate use of medications, and ensure that children receive appropriate followup care as they make their transition into adolescence and adulthood.

K. Charlie Lakin, Ph.D., Scientific Presentation

In reviewing the literature, Dr. Lakin noted that much research concerning the quality of care for individuals with intellectual disabilities targets those living in institutions. In these settings, a wide range of health needs are generally met in a satisfactory manner. However, as the needs of this population become more complex, the need for additional professional training increases.

Interesting data from the National Health Interview Survey also show that children with intellectual disabilities were just as likely to see a doctor within the past year as children without these disabilities. In fact, adults with intellectual disabilities were more likely to see a doctor within the past year than those without such disabilities. One fact also was clear—people with intellectual disabilities have a greater need for specialized health care.

Despite these promising findings, anecdotal evidence suggests that many people with intellectual disabilities fail to have their basic health needs met. Unfortunately, no comprehensive study documents this fact or the technical quality of health services provided. Such studies, with outcome-oriented approaches, must be conducted. These studies, in turn, will provide the foundation for developing quality-of-care guidelines for people with intellectual disabilities. These guidelines should address access to health professionals, health promotion and nutrition, routine monitoring of health care, dental and oral health, and commonly associated health problems. The role and training of support staff also must be addressed.

Nancy N. Cain, M.D., Creative Program Presentation

Dr. Cain discussed Rochester Community-Based Crisis Intervention Services, a program to increase access to psychiatric care for people with intellectual disabilities. The Rochester program has two main components, including a crisis intervention team and a specialized psychiatry clinic. During a crisis, the intervention team works with families and group homes on a short-term basis to help find appropriate care for the adult or child with intellectual disabilities. Program staff are on call for emergency room consultations 24 hours a day, and may be asked to evaluate an individual in the emergency room to determine whether the problem is psychiatric in nature. If so, the team member facilitates a psychiatric admission.

Although the crisis intervention team evaluates both children and adults, currently, only adults are seen in the specialized psychiatry clinic. Adults with intellectual disabilities may be followed on a long-term basis in the clinic. Both medical students and psychiatry residents may train with either the crisis intervention team or in the specialized psychiatry clinic.

A program review revealed that the crisis intervention team and specialized psychiatry clinic have prevented unnecessary hospitalizations, enhanced appropriate community placements, maintained behavioral health, enhanced the expertise of providers working in the community, and increased collaboration between the developmental disability and mental health systems.

Work Group Three: Finding and Getting to Health Care Services

Sheryl White-Scott, M.D., Moderator

Dr. White-Scott discussed what was learned about finding and getting to health care services at the Surgeon General's Listening Session on Health Disparities and Mental Retardation. Participants highlighted a lack of information concerning the types and location of services, and a definite shortage of appropriately trained health providers. Transportation and access problems exist in both urban and rural settings. Often people face cultural and language barriers, and patient education materials are not geared to individuals with cognitive impairments. Complicating matters, few formal health care standards exist for treating these individuals. Multidisciplinary experts, working across systems, must develop these standards.

Deborah Spitalnik, Ph.D., Scientific Presentation

Dr. Spitalnik discussed key factors influencing an individual's ability to obtain needed health services. These factors include "access, affordability, availability, and acceptability." Research in this area is complicated by difficulties in collecting data, lack of comparability across studies, lack of good measures of access, and imprecise definitions of MR.

Unfortunately, poverty is an access issue for many people with MR, who often depend on public support for health care. A recent study of children on Supplemental Security Income (SSI) showed that they frequently received care from a general practitioner without pediatric experience. In addition, children with MR often failed to receive subspecialty care. Additional disparities are related to race, geographic location, and SSI status.

Another problem is that individuals' health needs are frequently interpreted only in reference to their MR and not in regards to broader issues. Beyond negative perceptions and issues involving stigma, this "diagnostic overshadowing" continues to limit access to appropriate and quality care. Ironically, adults with mild MR may have trouble accessing care because they often have a normal appearance but may have difficulty with compliance, authority, behavioral challenges, and abstract thinking. Together, these characteristics pose significant barriers to care.

Transportation and financing also pose access problems for many individuals with MR. In particular, Medicaid fee-for-service programs may provide financial disincentives for treating individuals with a disability, based on the inherent health care needs of these patients. Medicaid's managed care programs, however, may offer more protections than these and commercial managed care programs. Many States are moving towards such Medicaid systems.

Ronald Lindsay, M.D., Creative Program Presentation

Dr. Lindsay presented the Ohio Rural Developmental and Behavioral Clinic Initiative. The program was developed in 1995 in response to a needs assessment completed by the Ohio Department of Health. The study identified gaps in coverage, lack of service coordination, lack of information, and unmanageable systems as constraints for individuals with MR to access comprehensive care. Urban counties were also found to have more resources to care for children than rural counties. In response, the State created a new rural initiative. Although the program started with two rural health clinics in two separate counties, the program currently has 37 clinics in eight counties and receives evaluations of children living in 18 other counties.

A key goal is to decrease health disparities for children with suspected MR and developmental disabilities. To accomplish this, two evaluation teams were created: a developmental team for children up to age six and a behavioral team for school-age children. The interdisciplinary teams conduct comprehensive evaluations; both teams have local public health nurses who serve as liaisons between the teams and local communities. The nurses receive referrals from parents and providers, obtain appropriate records, conduct home visits after a child is evaluated, and help to implement the teams' recommendations. Families play an important role in both the child's evaluation and treatment.

A program evaluation assessed the first two years of activities, during which 120 children were seen. Children's clinical charts were reviewed, and parents were interviewed. The evaluators assessed how diagnoses were formed, team recommendations, and the outcome of these recommendations, including whether services were obtained or pursued. The study found that few system barriers exist for families once children are evaluated. In addition, a family's refusal to pursue services is the chief reason for not obtaining care. Of families that did pursue services, 98 percent successfully obtained the needed care.

While the evaluation showed that the program improved access to diagnostic evaluations, identified previously undiagnosed conditions, aided access to followup care, and met family needs, it also highlighted the need for more outcome and population-based data and ways to improve the acceptance of social recommendations by families.

Finally, the program's primary challenge remains sustaining a program that is community-based and integrated, providing a seamless system of care. This challenge entails collaborating with local agencies that must share a vision, work together, and integrate their services. The primary challenge is to integrate service delivery, training, technical assistance, consultation, and research.

Work Group Four: Paying for Health Care Services

Daniel Bier, M.P.A., M.S.W., Moderator

Mr. Bier discussed how health care services work in a marketplace, and how reimbursement can promote the best value. The work group would address the relevant themes developed at the Surgeon General's Listening Session. These include (1) what services should be covered by insurance, (2) the

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preauthorization process and the definition of medical necessity, (3) co-insurance, and (4) the cost of premiums.

Deborah Spitalnik, Ph.D., Scientific Presentation

Dr. Spitalnik discussed how methodological issues can influence research concerning the financing of care for individuals with MR. These issues include the lack of precise diagnoses and the failure to record diagnoses, as well as the instability of diagnoses within the billing systems and clinical claims data.

For example, Medicaid files were not designed to identify populations with special health needs; however, most people with MR pay for health care through public insurance, whereas only 7.1 percent of adults with MR have insurance through their employer. The inadequate design of Medicaid files means that Medicaid datasets often lack important utilization and reimbursement data concerning the services provided to individuals with MR. These deficiencies hinder research and our understanding of the financing and use of services by this population.

Although children with MR may be insured through their parents' coverage, commercial insurance often has coverage gaps, high premiums, and no mandate to provide benefit packages to meet their needs. Nonetheless, given the scarcity of good coverage, parents of children with MR frequently will not move or change jobs for fear of losing their health insurance coverage.

Medicare covers 480,000 people with MR, but these beneficiaries differ from the average elderly beneficiary because they are poorer and less likely to be connected to health care providers. Approximately 70 percent of Medicare beneficiaries with MR are also enrolled in Medicaid, which has become the largest financial funding source for health care for people with disabilities. Medicaid covers 1.5 million noninstitutionalized adults with MR and 246,000 institutionalized ones. It provides acute and some long-term care benefits. Although individuals with MR make up only 4.9 percent of the beneficiaries, they use 15.7 percent of Medicaid's dollars. To reduce health costs, States have a keen interest in switching beneficiaries to Medicaid managed care programs.

Complicating matters, Medicaid has two parts, including mandatory and optional services. Unfortunately, many services deemed optional are critical for people with disabilities and include items such as dental coverage, prescription drug coverage, and long-term care services. States also vary as to whether they mandate that Medicaid beneficiaries enroll in managed care programs. Many Medicaid managed care programs lack claims data and diagnostic information concerning people with MR.

Theodore Kastner, M.D., M.S., Creative Program Presentation

Dr. Kastner presented some general issues related to the provision of primary care and mental health services in Medicaid managed care, and discussed the creation of Developmental Disabilities Health Alliance, Inc., a company providing health care services to persons with developmental disabilities under contract with several health maintenance organizations (HMOs) in New Jersey's Medicaid managed care system.

Premised on providing high-quality, comprehensive health care to individuals with MR, the program seeks to overcome the limitations of scale by creating a statewide integrated system of care. Several key business assumptions also are built into the program, starting with the notion that the use of capitation helps to better predict future cash flow. In addition, a successful for-profit program will increase choices and competition, improve accountability, and align the business goals with the clinical needs of the patients.

To market the package of services to private HMOs, program officials used familiar business terminology and discussed ways that the new system could better manage disease by providing comprehensive care. Several HMOs were enlisted to broaden the range of payers and to help establish market-based reimbursement for their unique managed care systems. Although obtaining capital was a hurdle, capitation payments proved to be very helpful.

Although relatively young, the company represents an effective way to provide an array of managed care services to individuals with MR, relying on Medicaid reimbursements. Success also is related

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to developing the talents of staff and being flexible in the face of market changes. Compromise is also essential as is the need to be opportunistic, to add value to the services provided, to leverage funds effectively, to use capitation effectively, and to develop a good business plan.

Work Group Five: Age-Appropriate Health Services

Timothy Kowalski, D.O., Moderator

Dr. Kowalski highlighted the transition points all individuals encounter as they advance through the developmental stages of life. The work group was asked to focus on the transition points and how they may interact with the special needs of individuals with MR.

Marsha M. Seltzer, Ph.D., Scientific Presentation

Dr. Seltzer noted that the health of approximately one-third of individuals with MR is reported to be fair or poor. About 60 percent of people with MR and developmental disabilities live with their families, who often serve as their brokers for health services; however, as children and adults with MR live longer, the role of their parents and siblings in brokering health care services changes.

To plan for care, it is important to merge the life course perspective with the special needs of individuals with specific diagnoses related to MR. For instance, individuals with Down syndrome often experience the early onset of aging. Similarly, individuals with MR versus those with developmental disabilities must be treated differently because they have such heterogeneous needs. At the same time, each stage of life, such as adolescence, early adulthood, and advanced age, offers unique challenges that must be considered in relation to factors such as gender, poverty, barriers to health services, and lack of trained providers.

Paul Glassman, D.D.S., M.A., M.B.A., Creative Program Presentation

Dr. Glassman discussed the Center for Oral Health for People with Special Needs at the University of the Pacific (UOP) School of Dentistry. Historically, as individuals with MR moved from institutions to community settings, their untreated dental problems worsened in response to the lack of community resources. This situation had significant implications for the well-being of this population; research shows that oral health strongly correlates with systemic disease as well as nutrition.

Established to create the "ideal" community-based system for dental care, the Center is a coalition of dental professionals, faculty from the UOP School of Dentistry, regional centers, hospitals, agencies, and individuals, linked by a dental services coordinator. The coordinator, who is usually a dental hygienist, serves as a liaison between the individual and people in the community, often working with general dentists to help them become more comfortable treating individuals with MR. In addition, the Center has a triage and referral system and training programs for all personnel levels. Prevention programs and treatment resources also have been developed. Among others, these include educational materials for dental hygienists, an online resource directory, and a hands-on training program for dentists.

The increased awareness of the importance of oral health and the new coalitions that have been formed highlight the Center's success. For example, a statewide task force on oral health for people with special needs was formed, in addition to a new effort, the California Endowment for Oral Health Care Program. Going beyond local and State impact, a national forum, Special Care Dentistry, has been established to bring together dental professionals for training, advocacy, and coalition-building to work on common problems.

Work Group Six: Continuity of Health Services Throughout Life

George Jesien, Ph.D., Moderator

Dr. Jesien noted that as individuals move from one health care system to another throughout life, continuity of care is often disrupted. Each system tends to operate under different rules and various eligibility requirements that hinder efforts to obtain needed care. Starting with children, school and the health care systems fail to communicate well with each other, and many services are dropped for various reasons as the child becomes an adult. The goal is to

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provide systems of care that are easier to navigate, with agencies and key stakeholders coordinating services more efficiently.

Marsha M. Seltzer, Ph.D., Scientific Presentation

Dr. Seltzer suggested that participants consider an interesting paradox—that as communities develop more "age-specialized health care services for individuals with MR," the specialized care may "become a barrier to continuity of services across the life course."

The barriers start with health care specialists. If individuals with MR must seek the care of numerous specialists to meet a broad range of health needs, this situation automatically increases discontinuities in care. The specialty needs may change as a patient gets older (e.g., geriatrics) and may require specialty care based on gender (e.g., women's health services). In this situation, family practice physicians, or having a particular point of service, may play a special role in the care of people with MR.

Fragmentation of the service system also poses barriers to receiving continuous care. Most often, this fragmentation occurs as individuals move from early interventions into public education and then into adult services. Changes in policies and services also pose unexpected barriers. For example, changing the definition of MR and the terminology used can easily affect eligibility requirements. In addition, significant State-to-State variability exists in the availability of services.

Finally, another barrier often arises depending on whether individuals with MR choose to live in family situations. Nearly 60 percent of individuals with MR live with their parents throughout their life course, but disruptions in care can occur when parents die. By contrast, individuals living in nonfamily licensed settings have greater access to health care. This situation occurs because many settings are affiliated with larger efforts to provide at least minimal access to care.

Joel Levy, D.S.W., Creative Program Presentation

Dr. Levy discussed the Young Adult Institute (YAI) Premier Health Care Program, which provides comprehensive health care to individuals with MR and developmental disabilities. Specially trained medical professionals provide both acute and chronic medical, dental, psychiatric, and in-home nursing care services to children and adults. With more than 50 percent of clients being minorities, cultural competency is essential to the program's success.

Other Program goals include providing continuous care and offering a wide range of services. The Program's philosophy is that treatments should be integrated, provided in the least restrictive manner possible, and based on the individual and family's unique needs. To achieve this goal, the Program coordinates its services with those offered by local agencies. This coordination allows individuals with MR to receive care in their communities. At the same time, the Program has contracts with academic hospitals around the State to provide any services that are unavailable locally.

Work Group Seven: Promoting Health: Providers

Sanford Fenton, D.D.S, M.D.S., Moderator

Dr. Fenton introduced several issues raised at the Surgeon General's Listening Session. These issues included providers not screening individuals with MR for dietary and nutritional status, tobacco or alcohol use, cancer, or domestic violence. Participants in the Listening Session also mentioned that some health care providers have little or no specialized training or equipment needed to care for individuals with MR. Specialized providers also may miss opportunities to ensure that needed immunizations are obtained and to educate clients and their families concerning a range of primary care and prevention topics. These problems are exacerbated by the high turnover rate of personal care attendants and by frequent gaps in the medical record.

On the basis of these trends, recommendations could be devised to help improve preventive screening, provider training, provider coordination, the rate of turnover in personal care attendants, and the use of health promotion techniques.

David Braddock, Ph.D., Scientific Presentation

Dr. Braddock discussed the history of institutionalization of people with MR. Today, States vary in the range of services they offer to individuals, particularly to those in community-based settings. Any effort to develop new health promotion programs must be tailored to this reality. Although the number of small residential homes serving six or fewer clients has increased, health promotion in these settings poses problems. A British study comparing health promotion for individuals with MR in community versus residential settings found inadequacies particularly in community settings. This situation must be corrected, given the importance of health promotion and the number of individuals with MR living in a community setting. Activities could include developing recreation and fitness programs in the community, providing counseling for individuals in the community, working with mental health centers to address the behavioral and mental health needs, collaborating with special education programs to teach children healthy habits, training health professionals about health promotion, training and supporting staff members in residential settings, collaborating with provider and parent organizations to make health promotion a national priority, and working with new technology to promote health.

Jill Morrow, M.D., Creative Program Presentation

Dr. Morrow discussed the Pennsylvania Health Care Quality Units (HCQU) Program and the specific health care issues affecting people with MR in the State. Most notably, health care professionals and others working with this population lack indepth knowledge about specific health care needs. Health promotion is also an issue.

The HCQU Program was created to respond to these problems and to help people with MR become better consumers of health care, to expand their choice of health care providers, and to help deliver a higher quality of care to people with MR. The Program targets individuals with MR and their families, providers of MR services, community medical providers, and county staff (including "support coordinators" who served as case managers). The emphasis is on providing support but not direct care services.

The Office of the Medical Director in the State's Office of Mental Retardation coordinates the Program's activities. The activities are implemented by a consortium of counties and are staffed by different clinicians and data personnel. To reach its goals, staff members identify gaps in health care services and health care knowledge and then develop professional training and technical assistance programs to address these needs. Staff members also identify systemic problems and work closely with other offices and agencies to address these issues.

The Program has been effective at the individual and community levels. For example, recently Program staff worked with a young diabetic man who was interested in learning more about his diabetes and how to give himself insulin injections. To meet the man's needs, HCQU staff contacted a local nurse educator and shared specific educational techniques for working with individuals with MR. The local nurse then was able to teach the young man about his diabetes and show him how he could take better care of his own diabetic needs.

Work Group Eight: Health Promotion: Individuals and Caregivers

Jackie Golden, Moderator

Ms. Golden identified key issues raised at the Surgeon General's Listening Session. Self-advocates reported that people often talk about them and not to them. Similarly, society often tries to "do for them," instead of teaching them how to do for themselves. In addition, neither caregivers nor individuals are valued for the potential role they can play in health promotion. Adding to this complexity is that direct care staff in group homes are often impoverished and lack heath care themselves. Therefore, enhancing health promotion for individuals with MR requires training and provider support for direct caregivers, families, and children and adults with MR.

David Braddock, Ph.D., Scientific Presentation

Dr. Braddock discussed some of the difficulties associated with promoting health for individuals with MR in community settings. Self-advocacy organizations can play an important role in launching new health promotion projects, working closely with family members who significantly influence the adoption of healthy lifestyles. To encourage such activities, Developmental Disability Councils should be encouraged to use their authority to give grants within the State for health promotion projects.

Gloria Krahn, Ph.D., Creative Program Presentation

Dr. Krahn discussed the Oregon Healthy Lifestyles for Persons with Developmental Disabilities Program. The Program was developed to address the fact that persons with disabilities (1) often experience poorer health status and narrower margins of health, (2) may be more susceptible to illness, (3) have limited access to treatments, and (4) may be excluded from health promotion opportunities.

The Program is currently developing two new intervention efforts. The first project is the Healthy Lifestyles Workshop for adults with developmental disabilities. The two-and-a-half-day workshop uses a peer training model that emphasizes empowerment training. This training includes understanding the importance of assessing one's own health and establishing personal health goals. The workshop also targets self-determination and motivation and describes wellness as a lifelong journey that encompasses balance across life activities. To ensure continued success, each participant is paired with a mentor who works with the individual for up to six months following the workshop.

In the past, the workshops were presented in six locations across Oregon, and have included 33 participants with cognitive limitations. Feedback on the project shows that followup is very difficult, but participants report increased awareness of healthy lifestyle choices and of self-empowerment.

Another project, called "Health and Wellness for Teens with Disabilities: Getting Sensitized," targets health care providers who are in training. This newly developed effort is trying to increase awareness of the special problems that teens with disabilities encounter and to improve provider skills in meeting these needs and in supporting the teens' overall health and wellness. The project consists of three two-hour modules, and includes didactic teaching, video presentations, and hands-on exercises. The modules, which will soon be field-tested, cover general wellness, relationships and sexuality, and mental health and substance use.

Appendix B: Participants List

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Appendix C: Potential Partners in Realizing the Blueprint

Conference participants were asked to identify potential partners that may help to diminish the health disparities for people with MR. The names that appear below should not be interpreted in any way as a commitment by a specific agency or organization. Instead, this list is intended to illustrate the potential partnerships on many levels. Furthermore, this list is not exhaustive but includes some of the specific examples that were offered during the Conference.

Academic Institutions and Organizations

- Accrediting Bodies
  - Residency Review Committees
- American Dental Educators Association
- Association of American Medical Colleges
- Association of University Centers on Disabilities
- Deans of Medical, Dental, Nursing, and other Allied Health Schools

Civil Rights, Minority Health, and Health Disparities Organizations

- NAACP

Employers and Other Purchasers of Health Care

Families

Federal and State Regulatory Agencies

- State Insurance Commissioners

Federal Government Agencies

- Department of Education
  - Office of Special Education and Rehabilitative Services
- Department of Health and Human Services
  - Administration for Children and Families
    - Administration on Developmental Disabilities
  - Agency for Healthcare Research and Quality
  - Centers for Disease Control and Prevention
    - National Center for Birth Defects and Developmental Disabilities
    - National Center for Health Statistics
  - Centers for Medicare & Medicaid Services (formerly HCFA)
  - Health Resources and Services Administration
    - Bureau of Maternal and Child Health
    - Bureau of Primary Health Care
  - Indian Health Service
  - National Institutes of Health
    - National Center on Minority Health and Health Disparities
    - National Institute of Child Health and Human Development
    - National Institute of Dental and Craniofacial Research
    - National Institute of Mental Health
    - National Institute on Aging
    - National Institute on Alcohol Abuse and Alcoholism
  - Office of Minority Health
  - Office of Public Health and Science
    - Office of the Surgeon General
  - Office of the Assistant Secretary for Planning and Evaluation
  - Substance Abuse and Mental Health Services Administration
    - Center for Mental Health Services
- Department of Labor
- Social Security Administration
  - Office of Disability

Federal, State, and Local Government Groups

- National Association of Counties
- National Governors Association
- State Developmental Disabilities Councils
- State Medicaid Directors
- State Protection and Advocacy Agencies

Federal, State, and Local Policymakers

- State Legislatures
- U.S. Congress

National, State, and Local Professional Health and Allied Health Organizations

- American Academy of Pediatrics
- American Dental Association
- American Medical Association

Pharmaceutical Companies

Philanthropic Groups and Foundations

- Joseph P. Kennedy, Jr. Foundation
- Kaiser Foundation
- Robert Wood Johnson Foundation

Public and Private Third-Party Payers

- Insurance Companies
- Medicaid
- Medicare

Self-Advocate, Parent, and Other Advocacy Groups

- American Association on Mental Retardation
- National Committee for Quality Assurance
- Self Advocates Becoming Empowered
- Special Olympics, Inc.
- The Arc of the United States

State and Local Public Health Departments

Tribal Community and Health Organizations

Appendix D: Health Disparities and Mental Retardation: Programs and Creative Strategies to Close the Gap

Kathleen Braden, M.D.[1]

I. INTRODUCTION

Individuals with mental retardation[2] experience poorer health, shorter lifespans, and less access to professional health care than people without this condition (Horowitz et al.). Many factors are thought to contribute to these disparities. Physicians and other providers often lack training and experience in treating individuals with mental retardation and are reluctant to assume clinical responsibility for them. Cultural sensitivity may be lacking. Financing for health care services is often inadequate, and scientific knowledge about the efficacy of care for this population is far from complete. Services may be poorer in quality because of societal assumptions that people with mental retardation cannot participate appropriately in their own health care (Surgeon General's Listening Session and Senate Appropriations Committee Report). For years, families, providers, and these individuals have sought, with varying degrees of success, to improve their health and health care.

This report is designed to provide information about service programs that have developed creative strategies to provide health care to people with mental retardation living in their communities. The report is not a comprehensive catalogue of all health care programs that use creative strategies to serve this population. There is no attempt to evaluate individual programs or to assess the merits of one program over another. Instead, the report illustrates a variety of responses to the distinctive challenges of providing primary and specialty medical, dental, psychiatric, and wellness services to children, adolescents, and adults with mental retardation. The programs described vary in scale, geographic location, populations served, services offered, service models, and funding. Some programs are inclusive, offering services to a broader population and making special accommodations for individuals with mental retardation. Other programs specialize in care for this population.

Following a review of the origins of this report and the author's method, individual program descriptions are presented, with contact information for readers wishing to learn more about their activities. The programs are grouped in four major sections that reflect reported disparities in health care for individuals with mental retardation: medical services, mental health services, oral and dental health care services, and health and wellness programs. Within these sections, programs are shown in subcategories that relate to different strategies in program design. This scheme is flexible because certain programs could fit into more than one category.

The National Institute of Child Health and Human Development supported the research and preparation of this report. Certain programs described

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[1] Associate Clinical Professor of Pediatrics, Eunice Kennedy Shriver Center for Developmental Disabilities, University of Massachusetts Medical School, Worcester, MA. The programs and strategies summarized in this paper are described in more detail in a forthcoming report by the author. The author would like to thank the many people who helped her understand their programs and strategies for providing health care for people with mental retardation. For the most part, these people are identified as "contacts" in the summary program descriptions. The author particularly thanks Ms. Joan Beasley, formerly with the Robert D. Sovner Behavioral Health Research Center, for her help in understanding the history and scope of the Center's START Program.

[2] The author is aware that there is a controversy around the use of the term "mental retardation" and that self-advocacy groups and professional associations are currently discussing alternatives. In preparing her report, she has sought to retain the terminology used by the programs she describes. In the title, however, she has adopted the usage of the Surgeon General's effort on health disparities and mental retardation. Until a consensus is reached, with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as "mental retardation," that term is used in official information on the other elements of the Surgeon General's effort on health disparities and mental retardation.

in the report were presented at the Surgeon General's Conference on Health Disparities and Mental Retardation, December 5–6, 2001, in Washington, DC.

II. ORIGINS OF THE REPORT

This report is part of recent national initiatives to highlight and improve the health and health care of individuals with mental retardation who live in their communities. Until deinstitutionalization began in the 1970s, large numbers of children and adults with mental retardation lived in residential institutions. Although the institutions were identifiable entities responsible for the health of their residents, they were typically underfunded and understaffed.

Deinstitutionalization brought important benefits. These benefits included newly established rights for individuals with disabilities, for example, the right to public education in the least restrictive environment, and for low-income individuals, the right to publicly financed health care coverage. Supported living and other types of programs were created to help individuals living in their communities. Staff-to-resident ratios in group homes typically improved compared with ratios in the older institutional care sites.

With the inclusion of people with mental retardation in local communities, public attitudes have started to change—but slowly. Severe shortages in financial and human resources that characterized institutional care have not been resolved. In addition, when individuals move into community settings, responsibility for their health care often remains diffused. This situation means that individuals, their families, and their caregivers continue to face difficult challenges finding adequate sources of health care, getting to them, and paying for the service.

Many of these challenges were addressed at a March 2001 special hearing of the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Resources. U.S. Senator Ted Stevens (R-AK) convened the hearing to take testimony from self-advocates, researchers, and Federal officials on the health and health care needs of individuals with mental retardation (Senate Appropriations Committee Report). The focus of the hearing was a report prepared by a research team at the Yale University School of Medicine for Special Olympics, Inc. (Horowitz et al.). On the basis of its literature review, the team reported critical deficiencies in physical, mental, vision, and dental health of people with mental retardation. But the team also reported that health data on this population are "scarce," and that public resources for persons with mental retardation have been devoted primarily to their deinstitutionalization, housing, education, and employment.

At the Senate Appropriations Subcommittee hearing, Surgeon General David Satcher called for better health-related surveillance, community-based health systems, targeted research, and other steps to improve the health status of individuals with mental retardation. The Surgeon General subsequently launched a national effort on health disparities and mental retardation, beginning with an invitation to individuals with mental retardation and others concerned with their health to help him plan a national conference the following December.

More than 600 comments and suggestions sent to a special website helped to structure a Surgeon General's national Listening Session on October 10, 2001. Self-advocates, family members, and other participants in the Session spoke to the Surgeon General in person and by live, interactive video from five sites around the country. E-mail messages and written comment cards were also submitted. Participants reported multiple challenges, from dismissive and inexpert health care providers, to shortfalls in services, insurance coverage (Medicaid and private), transportation, coordination among multiple service systems, and a lack of programs promoting healthy lifestyles and disease prevention. Providers described the poor fit between their clinical training and the distinctive needs of patients with mental retardation. Family members said that their ongoing responsibility for children and adults with mental retardation meant that they were often unable to hold paying jobs and to carry health insurance for themselves. Poverty was reported to be high in this population (Surgeon General's Listening Session).

Finally, family and provider advocates for people with mental retardation urged the Surgeon General to promote research into the prevalence of mental retardation and the efficacy of care for this condition.

Some individuals said that people with mental retardation were "lost" in larger studies of people with disabilities, and they urged collection of data that could provide the basis for documenting the need for improved funding and better allocation of health care resources to serve this population. Others sought research that could be used to establish evidence-based clinical standards and provide training curricula. Researchers wrote to the Surgeon General noting that their task was complicated by the current use of three different diagnostic criteria for mental retardation.

The issues and concerns described to the Surgeon General formed the agenda for the December conference to develop a national action plan on health disparities and mental retardation. This report was prepared to provide conference attendees with examples of local and State programs that address some of their concerns.

III. METHODOLOGY

To identify programs using creative strategies to address health disparities in people with mental retardation, the author queried key informants, including self-advocates and families, health care and social service providers, schools of dentistry and medicine, national organizations (medical, social service, and advocacy), and researchers and other experts in the health care needs of people with mental retardation. To collect information about the programs, the author conducted semistructured telephone and e-mail interviews with individuals who had established and who currently administer the programs. Respondents were asked to describe their programs generally and to identify populations served, services provided, and sources of funding. Respondents also were queried about providing training and evaluations or research associated with a program. Finally, respondents were asked to reflect on challenges encountered in creating and maintaining their programs, and to provide advice to others who may consider replicating their strategies.

Several factors determined the selection of programs included in the report. The first factor was whether one or more key informants viewed a program as a thoughtful response to one or more health care gaps that commonly affect individuals with mental retardation. A second factor was the willingness of administrators to have their programs included in the report and to provide the author with requested information. A third factor was selection of programs that illustrate many different types of service models and strategies, populations served (urban, rural, ethnic, and cultural and racial minorities), financing mechanisms, geographic distribution, and other characteristics.

The following descriptions are based on information provided by program administrators.

IV. PROGRAMS AND CREATIVE STRATEGIES (SUMMARY DESCRIPTIONS)

A. MEDICAL SERVICES

1. Comprehensive Health Care Integrated with Social Services

*a. **New York City Premier Health Care Program, New York, NY**—Citywide program providing primary and subspecialty care and dental and mental health services to culturally and socially diverse population of individuals with developmental disabilities, including mental retardation. Provides case management and family care services; maintains outreach to schools, residences, day programs, and homes.

Funding: Fee-for-service from insurers of all types (Medicaid, Medicare, private insurance). State pays a special rate for recipients with developmental disabilities.

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* Denotes programs presented at the Surgeon General's Conference on Health Disparities and Mental Retardation, December 5–6, 2001, Washington, DC.

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***b. Developmental Disabilities Health Alliance, Inc., (DDHA), Bloomfield, NJ**—Statewide health care company providing primary and mental health care, interdisciplinary assessments, health promotion and disease prevention, and other services for two groups of Medicaid managed care enrollees: children and adults who qualify for services of the State Division of Developmental Disabilities (DDD), and individuals who qualify for Medicaid and Medicare. DDD arranges needed consultations with local "safety-net" providers. Providers are trained in the company's service model. A five-year planning process including all stakeholders preceded establishment of the company.

Funding: Medicaid, under DDHA contracts with Medicaid managed care plans.

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c. Northern Virginia Training Center's Regional Community Support Center, Fairfax, VA—Regional Center of Excellence providing specialized medical, behavioral, dental, and respite services for individuals with mental retardation and complex medical and behavioral needs. Program evolved from residential training center and includes inpatient services. Provides training for staff of community residential services and vocational providers, also to university students in health and other professions. Evaluates consumer satisfaction.

Funding: Primarily State and Federal funds for Intermediate Care Facilities for Mental Retardation (ICF/MR). Additional revenue sources, primarily Medicaid and private insurance, are being explored. Steering committee includes facility and community stakeholders. State is expanding service model to other State training centers and to geriopsychiatric centers.

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2. Inclusive Health Services

a. Vermont Rural Medical Home, Northfield, VT—A program based in a primary care physician's office, for children with developmental disabilities and their families. A steering committee composed of the physician, head nurse, and three families of the children designed special office procedures based on a survey of the parents. Procedures include a script for the receptionist to identify patients with special needs, parking and other special accommodations for office visits, and queries during visits about nonmedical needs. Other elements are a resource parent/care coordinator position and a family network that advocates on medical and educational concerns. Currently exploring expansion to other physicians' offices.

Funding: Initial Robert Wood Johnson Foundation grant; additional grant and Medicaid funding for care coordinator position.

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***b. Alabama Mother and Family Specialty Center, Birmingham, AL**—Demonstration project at university research clinic providing prenatal care to multirisk, African American, inner-city clients. Estimated 30 percent of women were mildly to moderately cognitively impaired. Provided prenatal care (medical, nursing, social work, nutrition, education) using evidence-based practices. Clinic

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nurse-practitioners trained to recognize potential problems in patient comprehension, communication, and understanding. Videotape and other client supports developed; transportation and onsite child care offered. Study results indicated positive effects, including participants' knowledge of risk conditions and perceived mastery in their lives.

Funding: Grant from Federal Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality). Research demonstrated that costs could be funded through Medicaid.

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3. Specialty Outreach Services

*a. **Ohio Rural Developmental and Behavioral Clinic Initiative, Columbus, OH**—Regional outreach clinic serving children with mental retardation and developmental disabilities in Appalachian counties in southeastern Ohio. Provides onsite, multidisciplinary evaluations for infants and children up to age six with developmental delays and for school-age children with developmental disabilities and mental health/behavioral disorders. Assessment teams are clinic staff and the local public health nurse; teams also may include local school personnel, primary care and mental health providers, and county juvenile justice systems. Program also provides referrals, coordination by a local public health nurse, and health professions training in clinics. Program is evolving from one that provides direct services to one that trains local program personnel to evaluate and care for the children.

Funding: Primary funder is State Department of Health (Title V agency); other support includes Healthy Tomorrows and Leadership Education in Neurodevelopmental Disabilities (LEND) grants (Federal Maternal and Child Health Bureau, Health Resources and Services Administration), also private foundations and financial and in-kind support from participating agencies and local programs, such as early intervention, county health departments, schools, Head Start, county mental retardation/developmental disability boards, and physicians.

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b. **South Dakota Rosebud Developmental Clinic, Sioux Falls, SD**—Interagency program providing developmental screening at reservation WIC clinics for infants and children up to age five; also screening followup, referral for evaluations at reservation clinic for children, and linkages to services for families of children with health and/or developmental concerns. Trains local providers and university graduate students. "Uses best available practices."

Funding: Three-year startup funding from the Federal Bureau of Indian Affairs and State Office of Special Education; currently supported by the tribe.

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c. Rose F. Kennedy Children's Evaluation and Rehabilitation Center Mobile Team, Bronx, NY— Mobile team providing multidisciplinary evaluations to children of clients at a methadone maintenance clinic. Transportation to and medication at the evaluation site were offered to clients of other methadone clinics. Team services on site included family counseling, short-term speech therapy, nutritional counseling, and behavior management training; referrals provided for educational, therapeutic, and medical services. Training in child development, for substance abuse clinic staff, provided.

Funding: Medicaid; but reimbursement is limited to one clinician visit per client per day; limited ability of program to finance multiple clinician services needed to complete evaluations during a client's visit.

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4. Specialized Provider Training

a. New Mexico Continuum of Care Project, Albuquerque, NM—Statewide program that trains health care professionals in care of deinstitutionalized individuals and trains direct care staff and case managers to provide medical support for clients. Program also includes specialty consultation clinics; specialized clinics at several primary care clinics; consultations for physicians, nurses, caregivers, case managers, interdisciplinary teams, and families; and consultations on policy for State agencies. Mediation provided for team or agency conflicts affecting delivery of services. Program maintains a website (http://star.nm.org/coc).

Funding: State Department of Health, also some Medicaid and Federal Maternal and Child Health Bureau funds.

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***b. Pennsylvania Health Care Quality Units (HCQU) Program, Harrisburg, PA—**Data collection, training, and technical assistance organizations working with health care and residential services providers in multicounty areas. HCQUs housed in parent organizations, such as nursing schools and mental health services, but administered independently. No direct services; program focus is on improving communication between residential care and medical systems and on increasing capacity of both systems. Future goals include collecting and analyzing data related to management of health care incidents to aid counties providing services, and expanding data collection to include individuals living outside a residential system to assess their quality of care.

Funding: Medicaid (Medicaid waiver administrative funds and funds for individuals other than those eligible for waiver funding).

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B. *MENTAL HEALTH SERVICES*

1. Tertiary Care Psychiatric Outpatient Clinic/Training Strategies

***a. Rochester Mental Retardation/ Developmental Disabilities Psychiatric Disorders Outpatient Clinic, Rochester, NY—**University-based outpatient clinic offering therapy for individuals aged 18 and older, diagnosed with mental retardation and mental illness (dual diagnosis). Provides training for psychiatry residents, providing therapy for caregivers as well as for individual clients. Housed in university psychiatry department; works with pediatric department's developmental disabilities center and its crisis intervention team. Mission includes providing a service model for professional training (all disciplines, all levels) and research to increase knowledge of dual diagnosis.

Funding: State Funding for first eight years of clinic; current funding from third-party payers.

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b. Nebraska Neuro-Developmental Psychiatry, Omaha, NE—University-based program providing psychiatric outpatient care for older adolescents and adults with developmental disabilities and mental health needs, living in State and in parts of Iowa. Program also trains psychiatry residents. Services include testing and evaluations, psychotherapy, behavioral interventions, medication management, and consultations. Clients are primarily from rural communities.

Funding: University Department of Psychiatry in College of Medicine and third-party payers.

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2. Specialty Care and Service Linkages

a. START Program at Robert D. Sovner Behavioral Health Resource Center, Danvers, MA—The Systemic, Therapeutic, Assessment, Respite and Treatment (START) program for individuals with developmental disabilities and behavioral/mental health care needs (dually diagnosed) in region, links developmental disabilities agencies and mental health providers serving the general population. Program also provides crisis intervention services, and specialized outpatient psychiatric services for dually diagnosed individuals. Services include a mobile emergency crisis team, emergency meetings involving inpatient units or an emergency respite facility, emergency and "planned" respite services, and short-term psychiatric inpatient care (community mental health and general hospitals). Program focus is planning and coordination by mental health crisis and developmental disabilities service teams, working with individuals, families, and caregivers. Specialty interventions provided as needed.

Funding: State Department of Mental Retardation; also insurance.

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***b. Rochester Community-Based Crisis Intervention Services, Rochester, NY**—University-based crisis intervention program aids communication and cooperation between community providers serving individuals with mental retardation and challenging behaviors. Services include establishing formal and informal communications and agreements among various providers, educating families and agency staff (e.g., psychiatric emergency room social worker and psychiatric residents), conducting skilled behavior assessments, and employing management techniques.

Funding: State Office of Mental Retardation and Developmental Disabilities.

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C. ORAL HEALTH CARE AND DENTAL SERVICES

1. Health Care and Training in Academic Settings

a. Dental Education in Care of Persons with Disabilities (DECOD) Program, Seattle, WA—Clinical service and training clinic at the University of Washington dental school, providing care for adults with special health care needs resulting from developmental, physical, medical, and emotionally disabling conditions. Services include diagnostic assessments, preventive care, primary dental care, emergency services, and rehabilitation for individuals with complex oral problems. Services provided in clinic and at affiliated clinics in a residential school, at other sites, and in individual residences for those who are homebound. Emphasis is on use of patient management techniques and avoiding use of sedation whenever possible. Clinic trains dental school students in care of individuals with special needs. Patient surveys indicate a high degree of satisfaction with quality of care.

Funding: Startup funding from the Robert Wood Johnson Foundation; currently supported by dental school Department of Oral Medicine with additional support from State Department of Health and Social Services, which pays a special rate to cover specific dental services and costs from increased treatment time.

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2. Linkages Between Developmental Disabilities Service Systems and Dental and Oral Health Providers

a. Butler County Dental Care Program, Hamilton, OH—Countywide program coordinating care, through case management, for adults participating in the State mental retardation/developmental disabilities system. Program developed network of providers, hospitals, case managers, caregivers, and guardian agencies. Dental hygienist serves as care coordinator; provides comprehensive assessments of individuals' oral health and extent of disability, obtains medical and dental histories, and accompanies clients to participating dentists' offices. Dentists are offered professional education credits in care of this population. Program also arranges transportation to dental appointments and counsels caregivers and providers on potential sources of payment for services. Consumers are visited periodically to ensure that the health promotion plan is understood and followed.

Funding: Support from the Health Foundation of Greater Cincinnati and county Board of Mental Retardation and Developmental Disabilities. Some startup funds came from ARC.

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***b. The University of the Pacific School of Dentistry California Center for Oral Health for People With Special Needs, San Francisco, CA**—County-based program providing a dental coordinator for individuals with developmental disabilities in local social service agencies in rural communities. Services include community assessments of existing oral health resources, triage and referrals by a coordinator, prevention training and materials for caregivers and parent groups, recruitment of dentists and provision of in-office social supports, continuing education courses for oral health professionals, hands-on training, and educational materials. Program established a statewide task force that developed a State action plan and continues to have input on legislation. Program working with State Department of Developmental Services to integrate oral health training into health and other professional education programs.

Funding: Initial grant funding; social service agencies now fund a dental coordinator. Program expected to be replicated in eight communities with foundation support.

Contact:
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3. Dental Care Provided by an Inpatient Intermediate Care Facility (ICF/MR)

a. Hazelwood Center ICF/MR Dental Services Clinic, Louisville, KY—Program at an intermediate care facility providing dental care to individuals with severe to profound mental retardation residing at the facility and to clients from three outlying community homes. Services include general dentistry, periodontal and oral surgery, endodontics, biopsy, and emergency dental care. Conducts research on improving quality of care (protocols reviewed by University of Louisville Institutional Review Board). Reports very low rate of referrals to inpatient operating room for treatment under general anesthesia. Program developed procedures for low-dose digital radiography and reduction of gingival hyperplasia with maintenance of seizure control.

Funding: State mental retardation/developmental disability agency; expected new State funding will permit treatment of individuals with mental retardation living in group homes or with their families.

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b. Tufts Dental Facilities (TDF) Serving Persons with Special Needs, Waltham, MA—Statewide, university-based program providing comprehensive oral health care for individuals with developmental disabilities. Multipart program includes a Special Needs Community Dental Health Program, which is a partnership of individuals with developmental disabilities, special education personnel, parents, social workers, and service coordinators. Provides oral health evaluations and referrals for treatment by dental hygienists, also case management and oral health education in classrooms, adult day activity centers, sheltered workshops, and community residences. Other program components include dental clinics at developmental disability centers and elsewhere, and postgraduate training for general dentists concerning care for individuals with developmental disabilities and for other special populations.

Funding: State departments of health and mental retardation and revenues from third-party payers. Dental clinic clients funded through the State's managed care plan for low-income residents. Additional funds are needed to continue the program.

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D. HEALTH AND WELLNESS PROGRAMS

1. Wellness Training for Individuals with Mental Retardation

***a. Healthy Lifestyles for Persons With Developmental Disabilities Program, Portland, OR**—Program provides workshops in health promotion, with peer trainers, for individuals with developmental disabilities. Curriculum reflects needs identified in six geographic and culturally diverse focus groups of individuals with developmental disabilities and discussions with care providers. It also teaches principles of self-determination, development of individual support systems, and healthy lifestyles. Programs include recruitment of mentors from participants' communities and collection of followup data to monitor and determine the impact of training.

Funding: Federal Administration on Developmental Disabilities grant (Project of National Significance) and partnership with State Office on Disability and Health.

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***b. Rehabilitation Research and Training Center (RRTC) on Health and Wellness for Persons With Long-Term Disabilities, Portland, OR**—Program trains students who will become care providers for children and adolescents with neurodevelopmental and related disabilities. The center has developed a pilot-tested professional training curriculum in health promotion and wellness for adolescents with neurodevelopmental and related disabilities. Curriculum developed for use by master's level and predoctoral students and by individuals in medical fellowship programs who will provide care to children and adolescents with neurodevelopmental and related disabilities. Curriculum is adapted from materials for persons without developmental disabilities and reflects data from focus groups of adolescents with developmental disabilities, consultations with adolescents with physical and learning limitations, consultations with other LEND programs, and the literature. Curriculum modules address general concepts of wellness and disability, sexuality and mental health, and substance abuse. Data collected to monitor and to determine impact of training; field-testing planned at three other LEND programs, with further data collection to assess overall program impact.

Funding: Federal Administration on Developmental Disabilities grant (Project of National Significance); National Institute on Disability and Rehabilitation Research, Maternal and Child Health Bureau (LEND), and partnership with State Office on Disability and Health.

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/2v

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107th Congress, United States Senate Committee on Appropriations, Report on Special Hearing, March 5, 2001, S. Hearing Report No. 107-92. (Includes a reprint of paper by Horowitz et al.) Link to website: http://frwebgate.access.gpo.gov/cgibin/getdoc.cgi?dbname=107_senate_hearings&docid=f:71288.wais.pdf

Appendix E: Summary of the Surgeon General's Listening Session on Health Disparities and Mental Retardation

October 10, 2001

National Institutes of Health
Bethesda, MD
Civitan International Research Center, University of Alabama
Birmingham, AL

Eunice Kennedy Shriver Center, University of Massachusetts Medical School
Worcester, MA

Oregon Institute on Disability & Development, Oregon Health & Science University
Portland, OR

Waisman Center, University of Wisconsin
Madison, WI

INTRODUCTION

On October 10, 2001, Surgeon General David Satcher, M.D., Ph.D., held the first-ever Surgeon General's Listening Session on Health Disparities and Mental Retardation. The Listening Session was a major component of the Surgeon General's effort on health disparities and mental retardation, a national dialogue to better understand and address the many severe and often unmet health needs of people with mental retardation. The keystone of the effort is reaching out to individuals with mental retardation,* their families and providers, advocacy groups, and community-based organizations that are on the front lines daily, trying to protect and promote the health and well-being of people with mental retardation.

This summary provides an overview of comments to the Surgeon General during the Listening Session. It also reflects written comment cards collected during the Session and e-mail messages to a special Surgeon General's website received before, during, and one week following the Listening Session.

The purpose of the Listening Session was to learn directly of health-related concerns and experiences of individuals with mental retardation and others concerned with their health. Participants were invited to share their thoughts regarding the unmet health needs of people with mental retardation, and to suggest possible solutions.

The major themes that emerged from the Listening Session were used to develop the agenda for the Surgeon General's Conference on Health Disparities and Mental Retardation on December 5–6, 2001. At that Conference, individuals and families will work with leading experts, researchers, and representatives of professional and other health care organizations to develop a national action plan addressing health disparities and mental retardation. This grassroots approach reflected the Surgeon General's commitment to an action plan addressing the issues of most importance to individuals with mental retardation and others concerned with their health. Conference participants will discuss what is currently known concerning the science, practice, and

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* In this summary, "individual" refers to an individual with mental retardation. The Surgeon General is aware that there is a controversy around the use of the term "mental retardation" and that self-advocacy groups and professional associations are currently discussing alternatives. Until a consensus is reached, with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as "mental retardation," that term will be used in official information on the Conference and other elements of the Surgeon General's effort on health disparities and mental retardation.

other aspects of health care services for individuals with mental retardation, identify priority issues, and draft recommendations for action.

This summary of the Listening Session reflects comments presented by more than 40 individuals during the Session as well as comments of an additional 800 individuals, including nearly 600 who had sent comments to the Surgeon General's website before the Listening Session. Analysis of the issues described in these comments indicated that they cluster under four themes, which formed the agenda of the Listening Session. The themes were as follows:

Understanding special health care needs. Examples of issues were attitudes of health professionals towards individuals with mental retardation, and provider knowledge and understanding of special health care needs of these individuals.

Getting health care services. Examples of issues were finding and getting to appropriate health care, and paying for needed services.

Growing up and living with disabilities. Examples of issues were age-appropriateness of health care services, and transitions as individuals' health care needs change with their age.

Healthy lifestyles. Examples of issues included roles of health professionals, individuals with mental retardation, and their caregivers in maintaining health and preventing illness and secondary disability.

During the three-hour Listening Session, speakers at five sites described their concerns and ideas for improvement to Dr. Satcher, Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development, other participants at the sites, and a national audience viewing a live videocast of the Session. The archived videocast can be viewed at http://videocast.nih.gov/PastEvents.asp?c=4&s=11. Representatives of 29 different Federal agencies and more than 70 nongovernment organizations participated in the planning and implementation of the Listening Session.

The summary begins with a discussion of several themes that recurred throughout the Session in many different comments, both verbal and written. The many specific issues described for the Surgeon General are summarized in bulleted lists under eight topical headings (two for each of the four Listening Session themes). To convey the tone of the Listening Session, selected remarks of participants are shown in italics.

COMMON THEMES

Throughout the Listening Session and in written comments, providers, caregivers, and especially self-advocates spoke of their determination to be treated by health care providers as "real people," with the same interest in good health and functioning as people without mental retardation. As one self-advocate told the Listening Session:

"I am who I am, and I can be the best of who I am. All I'm trying to do is make a living, and the only way I can do that is to have good health care."

At the same time, speakers described distinctive characteristics that indicated the need for specialized approaches to health care. One health care provider wrote:

"...Disability impacts the way people experience medical, social, and psychological problems. Learning ability and health may be affected by medication, complicated by challenging behaviors, or impacted by anxiety or fear...."

A second common theme was the individualized nature of the health care needs of individuals with mental retardation. The types and intensity of services an individual may need vary with the individual's age, the coexisting conditions, the etiology of his or her mental retardation, and the environment in which the individual lives. Some participants spoke primarily of the same types of preventive, acute, and chronic health care needs that people without mental retardation experience. Others reported the challenges of managing exceptionally complex coexisting conditions. One family member, describing a child with Down syndrome, said:

"...The medical issues are more paramount. [The child] has had open heart surgery, two pacemakers, asthma, [tracheomalacia], four sets of ear tubes, four eye surgeries,...RSV [respiratory syncytial virus], Candida albicans infection, reflux, Sjogren's syndrome, JRA

[juvenile rheumatoid arthritis], scoliosis, 47 pneumonias, upper right lobe lung damage (resulted in 14 months of supplemental [oxygen]), dental health issues, strabismus, and nystagmus."

A third common theme was the need for more information—both science-based knowledge that could improve the health of individuals with mental retardation, the quality of their care, and their access to services, and also specific information on how to understand a family member's condition and how to find and pay for health care. In particular, difficulties in recognizing and treating behavior disorders, depression, and other mental illness were often described. Family members wanted to understand what behavior in a child is developmentally appropriate and what may be a behavior disorder that would benefit from early diagnosis and treatment. A health care professional wrote:

"Many academic physicians/dentists are bewildered by the health problems of mentally retarded people [sic] with severe complex disabilities and will acknowledge that clinical research-based medical data necessary for optimal treatment of frequently occurring medical/dental conditions in this population is lacking...."

A family member said she felt both overwhelmed by information available on the Internet, yet underinformed about day-to-day issues in the health of a family member with mental retardation. Another told the Listening Session:

"No one seemed to be able to help us find what we wanted or needed."

Finally, certain participants described personal strategies that they considered helpful, as well as existing services and programs that seemed successful. One-self advocate said:

"People advocated for me and helped me learn advocacy skills so that I could personally help medical professionals know my needs."

Among existing programs that individuals described as helpful were health promotion activities that focused on obesity in a special education setting; a Medicaid-financed waiver program that trained minority personal assistance staff to work with adolescents with disabilities; medical curricula that included parents of individuals with disabilities as teachers of medical students; and a one-stop diagnostic, treatment, and resource center for families.

Some participants also suggested changes that could reduce health disparities experienced by individuals with mental retardation. For example, they urged priority attention to research and care for individuals with mental retardation and mental illness (dual diagnosis). Collaborations between academic medical and dental centers and physicians and other providers with experience in institutional care of people with mental retardation were suggested as a means of improving both care and the quality and use of research.

Other suggestions included development of standards of clinical practice and standards for evaluation of services for individuals with mental retardation; professionalization of personal care attendants; changes in the organization and financing of health care; and addressing public misperceptions of mental retardation. One of the most common suggestions was revisions in curricula of health professions schools and training programs. One family member said:

"As [my daughter] gets older, [the] doctor's appointment becomes even more challenging. Since she is nonverbal and not able to express herself in meaningful ways, finding out what has been bothering her has been the job of my instinct....I really think the medical schools should somehow incorporate curriculum on dealing with or treating persons with disabilities, particularly with mental retardation, into their existing course of study. Being a member of an immigrant community, I think there has to be more diverse medical personnel to effectively treat patients whose English proficiency is limited...."

Many participants summed up their concerns as lack of access to the type of care they needed, when they needed it. In grouping examples of these concerns under the topical headings below, an effort was made to highlight underlying factors that could be addressed in a national action plan.

1.38x

SUMMARY EXAMPLES OF LISTENING SESSION TOPICS

Understanding Special Health Care Needs

Attitudes of Health Care Professionals

"Whenever I go into the doctor's office,...they talk to the people that bring me. But it's my life and it's my illness.... Can you respect me enough to talk to me?" (Self-advocate)

"Doctors need to be educated by families...." (Health care educator)

- A physician or other health care provider may be reluctant to accept an individual as a patient.
- A provider may not accept Medicaid recipients as patients.
- A provider may provide or recommend a lower level of care for an individual with mental retardation than would be recommended for a person without this condition.
- A provider may not interact directly with the individual with mental retardation but may instead talk only with a family member or other person with the individual.

A provider may not respond to or understand values and perceptions of health and mental retardation of African Americans, Native Americans, Alaska Natives, Hispanics, Southeast Asians, and other distinctive ethnic and cultural groups; a provider may not speak the primary language of an individual with mental retardation and his or her family.

The Quality of Health Services

"... [Individuals with these disabilities] may need increased time, different treatment methods, and more frequent learning opportunities...." (Health care professional)

"Where is research currently conducted and/or compiled that addresses (a) epidemiology of health statistics of persons with MR, (b) access to health care, (c) effectiveness of training programs for providers, families, and self-advocates, and (d) impact of Federal and State funding policies in health care access and health statutes?" (Listening Session comment card)

- Multiple gaps in the scientific knowledge base impede improvements in the health care of individuals with mental retardation. Data collection and analyses typically fail to specifically identify individuals with mental retardation.
- More translation of the existing science base into forms usable by individuals, caregivers, and health care providers is needed.
- Clinical practice guidelines and methods of measuring quality of care for individuals with mental retardation are needed. The experience of individuals with mental retardation in using a health care service should be considered when that service is being evaluated.
- Health providers often lack specialized knowledge and training in treating individuals with mental retardation.
- Health care providers may not be knowledgeable about specific clinical issues, such as diagnosis and treatment of mental illness and recognition of abuse and neglect.
- A provider may use medication inappropriately to control challenging behaviors, instead of using therapies to assist the individual and caregiver with managing such behaviors.
- Health care providers may be more likely to extract teeth than to provide ongoing preventive oral health care for individuals with mental retardation.
- An individual's medical history, diagnosis, and treatment may be substandard because the provider does not communicate effectively with the individual. For instance, diagnostic and treatment procedures that are inadequately explained may be refused. A provider may be reluctant to accept clinical responsibility when an individual refuses recommended procedures.

Getting Health Care Services

Finding and Getting To Health Care Services

> *"We drive 200 miles to get specialized health care because doctors here have no understanding of [our daughter's] needs, mostly because she has Down syndrome, besides other conditions many 'normal' people get." (Family member)*

- Individuals, families, and providers lack information about the types, locations, and availability of health care services.
- There are shortages of appropriately trained and experienced providers at all points of contact in the health care system: primary care and specialist physicians, including psychiatrists, dentists, nurses, psychologists, ancillary health care professionals such as radiograph technicians, emergency department providers, and administrative staff of health care providers and services. Shortages are particularly acute in rural and low-income urban areas.
- Clinical sites may not be physically accessible, such as not being accessible for individuals with visual and/or hearing impairments.
- Professional equipment, from scales to dental chairs to diagnostic and treatment equipment, may not be appropriate for individuals with disabling conditions, including mental retardation.
- Shortages of appropriate health care services exist across community settings, including in homes of individuals, in schools, and in supported living arrangements.
- Mental health programs lack models of care that are appropriate for individuals with mental retardation.
- A provider may not be knowledgeable about working cooperatively with families, special education programs, community living arrangements, or other systems providing health and other types of care for an individual. This lack of knowledge concerning existing, appropriate health and related services makes these resources less accessible to individuals who require them.

Paying for Health Services

> *"...I needed to navigate a very complex medical assistance system and even find loopholes so that my dentures would be replaced sooner than the allocated time for replacement due to early breakage (from seizures)." (Self-advocate)*

- Needed services may be excluded from insurance coverage (Medicaid or private, including managed care). For example, Medicaid typically does not cover routine adult dental, vision, or hearing services or preventive care. Private insurers typically exclude long-term therapies, developmental assessments, nutritional products, and customized durable medical equipment.
- Mental retardation may be characterized as a mental illness, excluded from medical coverage, or as a neurologic condition, excluded from psychiatric coverage.
- An insurer may refuse to provide coverage for an individual with mental retardation.
- Insurance premiums may be exceptionally costly; out-of-pocket costs of services not covered by an insurer may be unaffordable for middle-class families.
- An insurer (including Medicaid) and school system may each refuse coverage for occupational, speech-language, or physical therapies, and other services provided in the educational setting. Each may consider the other program to be financially responsible.
- Service authorization procedures (Medicaid, managed care, and special education plans) are too complicated, too time-consuming, and too delayed. Services may be inappropriately denied as not "medically necessary."
- Insurance personnel responsible for authorizations may not understand mental retardation or other conditions associated with mental retardation.

- Routine administrative practices may be inappropriate for an individual with mental retardation. For example, the individual may not understand a mail notice to choose a primary care physician, and may be automatically assigned to a physician who does not understand the individual's needs.

Growing Up and Living with Disabilities

Age-Appropriate Health Services

"Just because people get older doesn't mean their disabilities disappear...." *(Self-advocate)*

"Many [persons] with cognitive limitations become parents and fall through the cracks [as they focus on getting health care for their own child]....There is a need for specific programs...with a commitment to help these families...." *(Health care professional)*

- Pediatricians and pediatric dentists have historically continued to provide care for individuals after childhood; however, improved lifespans mean that these individuals need practitioners knowledgeable in primary adult care, in specialist care for conditions found in other adult populations, such as obesity and cardiovascular conditions, and in conditions occurring at elevated rates in certain individuals with mental retardation (e.g., dementia associated with premature aging).
- Age-related conditions, such as changes in medication needs, mobility, or arthritis, may be seen as part of an individual's disability and may be inadequately recognized or treated.
- Existing service models for end-of-life conditions, such as hospice or institutional care for Alzheimer's disease, may not be appropriate or acceptable for an individual and his or her family.

Continuity of Health Services Throughout Life

"...It is so hard to have your head in the trenches...day to day...and still be able to look ahead and find possibilities for the future...." *(Family member)*

- The extent of Medicaid coverage may depend on age, not medical need, of an individual. For example, coverage for home care may end at age 21 for a ventilator-dependent individual.
- Coordination among medical specialists and with early intervention services for care of a medically complex person may work during the first years of life; however, when the medical condition is stabilized and the person's needs become more intensive and diverse as he or she grows, finding and coordinating multiple services may be left to the family.
- Transition from adolescent to adult care is especially complex.
- Care for an individual with multiple conditions may be fragmented. For example, different specialists may be managing an individual's seizures, gastrointestinal disorder, and abnormal destructive behaviors, resulting in adverse drug interactions or chronic drug toxicity. Age-related changes in health care needs may further complicate care if more or different providers are needed.
- There are severe shortages in care coordination services.

Healthy Lifestyles

Promoting Health: Providers

"To prevent injuries, we need the same precautions as for the elderly who are less coordinated, less stable, less able to hear and see well, and less able to make quick decisions; health conditions [associated with employment] are not monitored, and it is hard for the individual to associate it to their job site or activity...." *(Health care professional)*

"Current [substance abuse] intervention and treatment programs are completely unsuitable for [individuals with mental retardation] since they often require communication and discussion. However, opportunities for abusing substances are abundant. They become a form of release and self-medication when there are no more suitable outlets...." *(Health care professional)*

- Providers may not screen individuals with mental retardation for dietary and nutritional status, exercise habits, oral disease (e.g., periodontal disease), tobacco and alcohol use, depression and other mental illness, cancer (mammograms, Pap smears, prostate cancer), abuse or neglect, domestic violence, and occupational hazards.

- Providers may not have the specialized training and equipment needed to provide preventive interventions, such as oral prophylaxis and applications of protective materials to tooth surfaces. Providers may overlook the need for immunizations and opportunities to educate individuals and families in health-promoting behaviors such as exercise.

- High rates of turnover in personal care attendants may mean that an attendant does not know the medical history and concerns of an individual with mental retardation. Thus, the attendant may not be able to help either the individual or the provider in communications, maintaining needed courses of treatment, recognizing symptoms that need attention from a health care professional, and other matters.

- Gaps in, or unavailability of, medical records of an individual with mental retardation may compromise continuity of health care services.

Promoting Health: Individuals and Caregivers

"I would like to see programs for the whole body...." (Self-advocate)

"People with disabilities need help to know about diet...." (Self-advocate)

- Training and education in self-care may not be offered to individuals with mental retardation. Opportunities to provide such training and education in community settings, such as special education programs, may be overlooked.

- Preventive interventions may not be designed to enable an individual to understand or participate in health-promoting behaviors, such as management of diabetes and routine oral hygiene.

- Personal care attendants may not be trained and may not help an individual maintain appropriate diet and nutrition, regular exercise, or good oral hygiene, and avoid tobacco use and other health risks. Attendants may allow or unintentionally encourage unhealthy lifestyles by their own example if they are not knowledgeable about health promotion.

- Job coaches and employment counselors may not be trained to identify and advocate against unsafe workplace conditions, such as exposure to toxic substances, repetitive motion injuries, and others. Occupational hazards may be viewed as a lower priority than securing employment for an individual with mental retardation.

Appendix F: Surgeon General's Listening Session on Health Disparities and Mental Retardation

October 10, 2001

Speakers

Welcome and Opening Comments

Surgeon General David Satcher, M.D., Ph.D.,
U.S. Department of Health and Human Services
Duane Alexander, M.D., Director,
National Institute of Child Health and Human Development, National Institutes of Health (NIH)
Ms. Loretta Claiborne, Self-Advocate

Panel Moderators, NIH Site

Elin Cortijo-Doval, M.Ed.
George Jesien, Ph.D.
Deborah Spitalnik, Ph.D.
Sheryl White-Scott, M.D.

Participating Sites

Civitan International Research Center, University of Alabama at Birmingham
Judy Barclay
Matthew Foster
Alvin Garvin
Wendy Hardy
Elouise Woods
Patsy Wright

Oregon Institute on Disability & Development, Oregon Health & Science University, Portland, Oregon
Judy Cunio
Michael Geheb
Trent Minor
Julie Quaid
Sidney Stuller
Sharon Turner
Judy Wiley

Eunice Kennedy Shriver Center, University of Massachusetts Medical School, Worcester, Massachusetts*
Ana Arango
Sandy Blanes
Billie Chan
David Coulter
Kim Daniels
Yvette Johnson
Ann Ligums
John Morgan
Reginald Raphael
Cindy Smith
Charlotte Spinkston
Bersford Wilson

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* Due to technical difficulties, the speakers at the Massachusetts site were unable to participate at the time of the actual Listening Session. However, their recorded remarks have been added to the archived videocast of the session and are part of the official record. The entire Listening Session can be viewed at the following site: http://videocast.nih.gov/PastEvents.asp?c=4.

Waisman Center, University of Wisconsin, Madison, Wisconsin
Cindy Bentley
Barbara Katz
Lynne Schauls
Bill Schwab
Nancy Shook
Jayn Wittenmyer

National Institutes of Health, Bethesda, Maryland
Sally Atwater
Sue Badeau
Renee Bedieux
Robert Bergner
Susan Clark
Jose Cordero
Roxanne Dryden-Edwards
Jackie Golden
Julie Hacker-Yannes
Katrina Johnson
Wanda Jones
Guy Leif
Maureen Mitchell
Liz Oppenheimer
Victor Robinson
Jamie Rutman
Tim Shriver
Irvin Silverman
Ginny Thornburgh

Good morning Assemblywoman Huttle. I rise to speak on State actions to close developmental centers in California, Illinois, Kansas and Virginia that have impacted the developmentally disabled.

These are the reasons for closing:

California - sited budget saving and activism by ARC and United Cerebral Palsy.
Illinois - Budgetary reasons.
Kansas - To balance states budget, cost savings and better and less restrictive care.
Virginia - state cites cost savings and better and less restrictive care.

Opposition to closure:
Illinois:
Bipartisan legislative over sighted body commission on Government forecasting and accountability expressed doubts that insufficient time had been given for closure and recommended the decision to close both developmental centers be reversed until a plan for closure is presented and guardians are on board.

This is very similar to what we are going through with the decision to close both our centers as you know came from the Task Force which started with one center in the South Jersey but came out with two (2) centers in the North. Just to let you know the legislature did budget to keep developmental centers open but Governor Quin pushed his budget through and there was insufficient votes to veto.

Kansas: Economic study conducted by third party and funded by Local Chamber of Commerce found its center closing would have a $37 million impact on the local economy, the cost savings from closing center would be wiped out with lost tax revenue.

California and Virginia: as well as all other states are supporting and lobbying for H.R. 2023 currently in the U.S. House of Representatives, this bill which currently has 90 cosponsors from both parties, would give guardians of persons with developmental disabilities the right to opt out of class action suits that result in closing developmental centers also establish that residents and guardians choice of residency be respected.

The most compelling reasons to keep centers open is studies on the mortality rates of persons with developmental disabilities after transfering into community care.

In a report in 1999 by Robert Shavelle, David Stratus and Steven Day, Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities After Transfer Into Community Care: A very interesting and informative report. In its introduction it starts with budgetary constraints as being the driving factor that forced a re-examination of policies for caring for the developmentally disabled.

And concludes with the overall community death rate being 47% higher than expected for comparable persons living in institutions. The report reasons that lower mortality rates in institutions compared to other residence types are continuity care, centralized record keeping and immediate access to medical care.

We know that we cannot stand by with a clear conscience when knowing that in other states the mortality rate was 47% higher in group homes than in developmental centers, yet we are closing centers here also.

Let's do what is in the best interest of those who can't help themselves by keeping these centers open. They do the job and they do them better. Let's not rush into a decision that will cost us more than we can pay.

Thank you for your time and effort.
Gerald Newsome, Vice President, Local 195, IFPTE

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Testimony before Joint Meeting of Senate Health, Human Services and Senior Citizens Committee and The Assembly Human Services

By Rex Reid

Phone Number (609) 888-5500 **FAX NUMBER: (609) 888-5335**

Testimony before Joint Meeting of
Senate Health, Human Services and Senior Citizens Committee and
The Assembly Human Services

By Rex Reid

Good morning, my name is Rex Reid and I am the Political and Legislative Representative for the American Federation of State, County, Municipal Employees (AFSCME) in New Jersey and I represent the AFSCME workers at Woodbridge Developmental Center (WDC) and North Jersey Developmental Center (NJDC). And I'm here to ask you the members of the Senate Health, Human Services and Senior Citizens Committee and The Assembly Human Services Committee to help the families /guardians and works to keep WDC and NJDC open. The Residents of WDC and NJDC are your citizens; they need your help; they are the least able to care for themselves and that is why we are here asking you to help them save their homes. Some of them have lived at WDC and NJDC for decades and know no other home. The States' plan to move the residents into community group homes is ill conceived and deadly, as stated by a former Deputy Director of the Division of Developmental Disabilities for 32 years, Bernie White. He said that moving the residents from Woodbridge into the Community settings would result in a 47% higher death Rate than them remaining in the center. These statistics are gathered from the states where this has been done like California and Ohio. And if that were not reason enough the AFSCME, IFPTE and CWA workers live in the Cities of the districts you represent, and they pay taxes, and vote in your districts and spend most if not all of combined Developmental Center income of approximately 91 million dollars in your districts of the year. Some 166 of them in the 28th District for $8,460,356; 356 of them in the 35th District for $18,143,896; in the 20th District 193 of them feed $9,836,438 into that community this on an averaged median income of $50,966. I won't read the other 33 districts that the workers of NJDC and WDC come from but they are from across the state. I say that because the Governor's Task Force determined that finances lost to the cities would not hurt. But, I ask you can your districts stand to lose any part of 91 million dollars in these hard economic times.

The task force looked at the unemployment rates of Middlesex County at 8.2% and Passaic County's at 10.8% and compared it to Cumberland County's rate of 12.9% and came to the conclusion that these two counties with a combined unemployment rate of 19% could fair better if their centers were closed because of the density of the population. I would say to you that is part of the flaw with the task Force report .First the workers of WDC and NJDC 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 vs. the population density of Cumberland County were looking at a 3/1 difference in the numbers of unemployed and a 2.5/1 difference between Passaic County and Cumberland County. I say this not to say that keeping Vineland Developmental Center open was wrong but to say 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 declining census. The census could only decline because admissions to all the developmental centers are closed. The Task force ignored the Family's input and denied them the choice Olmsted gives them. If you close the developmental centers there is no choice. The Residents that live in the Developmental centers need to be where they are because of the care and attention they receive.

We are asking you to find a way to save the Developmental centers, the homes of the residents. Thank You For Hearing me.

	Employee's	Average maiden income
District 1	1	$50,966.00
District 7	4	$203,864.00
District 8	1	$50,996.00
District 9	2	$101,932.00
District 10	2	$101,932.00
District 11	15	$764,490.00
District 12	14	$713,524.00
District 13	11	$560,626.00
District 14	3	$152,898.00
District 15	2	$101932.00
District 16	3	$152,626.00
District 17	9	$458,694.00
District 18	18	$917,388.00
District 19	111	$5,657,226.00
District 20	193	$9,836,438.00
District 21	5	$254,830.00
District 22	161	$8,205,526.00
District 23	8	$407,728.00
District 24	3	$152,626.00
District 25	3	$152,626.00
District 26	9	$458,694.00

	Employee's	Average maiden income
District 27	28	$ 1,427,048.00
District 28	166	$ 8,460,356.00
District 29	158	$ 8,052,628.00
District 30	2	$101,932.00
District 31	8	$407,728.00
District 32	2	$101,932.00
District 33	2	$101,932.00
District 34	130	$6,625,580.00
District 35	356	$18,143,896.00
District 36	14	$713,524.00
District 37	15	$764,490.00
District 38	6	$305,796.00
District 39	2	$101,932.00
District 40	22	$1,121,252.00

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Unemployment

Develop. Center	County	Rate of Unemploymt (not seasonally adjusted	County Population	No of People Unemployed	Area Sq Miles	No of Unemployed per Sq Mile
Woodbridge	Middlesex	8.2%	786,971	64,531	321	201
North Jersey	Passaic	10.8%	497,093	53,686	191	279
New Lisbon	Burlington	8.7%	450,627	39,204	819	48
Green Brook	Somerset	6.9%	324,186	22,368	307	73
Vineland	Cumberland	12.9%	154,823	19,972	500	40
Hunterdon	Hunterdon	6.5%	130,783	20,120	438	46
Woodbine	Cape May	14%	97,724	13,681	267	51

Testimony / February 13, 2013

Martha Cray
137 Charlotte Terrace
Roselle Park, NJ 07204
(908) 380-2515
Martynj001@aol.com

Good Morning Senator Vitale, Assemblwoman Huttle & committee members and the viewing audience.

I am sitting here in dis-belief 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 of so many which was acted as a safety-net to those who just cannot thrive out in the community.

My heart goes out to all the families that now have to re locate their loved ones

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 NJ

With that being said, I am talking about "better oversight", "transparency" and "accountability". It is time that abuse and neglect, and death among the developmentally disabled must stop being the front page of newspapers, and the top story on the 6:00 news. The time to change is now.

My son, Billy Cray 28 yrs old, lived residential care since he was 10yrs due to his challenging behaviors. . My son endured 3 sexual assaults, and numerous amounts of physical assaults, black eyes, knocked out teeth, and bruised bodies

God gave me this precious and loving child, so as parents, we may protect him from what he thinks is a trusting and safe world, from the bad and ugly that lurks about.

Not ALL direct care workers, are abusive. My son has had many great heart felt direct care workers in his life. I am so grateful, and thank them all the time for the care they gave and continue to give.

These are my recommendations :

- **Surveillance Camera's**

Safeguarding those with developmental disabilities from abuse and neglect is a lot more important than " the right to confidentiality." There are camera's in so many

places of business's, even when we go through an intersection, some have camera's. Camera's give transparency

- **Certifying and Educating The Direct Care Staff:**

Educating and Certifying direct care staff is so important, especially working with the developmentally disabled. They face challenges everyday, such as challenging behaviors, medically challenged, physically challenged, and the verbally challenged (Non Verbal)

Home Health Aides- cannot enter anyone's home to work without a certificate. Why shouldn't it be the same with our loved ones with developmental disabilities? Let's increase the staff pay, $10 - $12 is not enough for some staff who are single parents and need to put food on the table..

With the Grace of God, Billy is currently in an incredible program valued, and doing very well, and it's good to see him smiling again

Thank you all for listening and God Bless..

Kind regards,
Martha Cray Mother and Advocate
Family Alliance to Stop Abuse and Neglect

Aileen Rivera
45 Hinchman Avenue
Wayne, New Jersey 07470
joe-aileen@hotmail.com
973-600-0642 – cell

Re: Testimony - February 13, 2013

Good Morning Senator Vitale, Assemblwoman Huttle & Committee Members.

I want to start off by expressing how saddened I am of the closing of North Jersey Developmental Center and Woodbridge Developmental Center. These centers are the homes of many developmentally disabled, who in many cases have lived there most of their lives. I want to tell all families that my heart goes out to them, for reversal of those decisions that severely and negatively impact lives.

I want to thank you for inviting me to testify before the committees to share with everyone my thoughts regarding changes that need to be made, and the quality of life of a loved one with developmental disabilities.

When my son was born, I remember counting ten little fingers and ten little toes, not realizing that we were going to have life-long challenges. As is the same with all families here. I have no regrets and because of my son's disability, I have learned to be a more understanding mother and I am thankful to God that I have learned to love and care for all developmentally disabled people. When they hurt, I hurt and when they get abused or neglected, I take it personally.

My son has had great and giving Caretakers, and he currently is in a program that has excellent caretakers. However, he has also suffered at the hands of abusive caretakers, in the past, as have many other disabled individuals. I want to make it very clear that I am not saying that all caretakers are abusive.

My recommendation is to acknowledge great and devoted caretakers, by incorporating an "Employee of the Month", wherein the employee of the month will receive an incentive of the choice of the agency that they work with. In speaking with families who's loved ones were in residential facilities, in NJ, families have shared that some facilities have this type of incentive program. If an employee is recognized, they generally are awarded a day off with pay. The process is, that families are given ballot cards to complete and to provide the name of the direct care staff & why they feel said caretaker has gone above and beyond their call of duty, and to give comments indicating the reasons why. Then the card is mailed to the Administrative Department of the facility. You would think that this would work, but it actually does not. Direct care staff also can fill out the cards for other direct care takers to be recognized. In speaking with other families, some have witnessed abusive staff being recognized by their peers, which in some cases abusive staff are being recognized by their peers, and in some cases bad behavior is rewarded. I believe this program would work at it's best, if a non biased party outside the facility would handle this.

Also, I strongly recommend Surveillance Cameras. There are video cameras every where and even at ATM's. I know that everyone will agree with me that the lives of our loved ones are more valuable than an ATM. We need surveillance cameras to protect our loved ones, especially with how investigations are handled in many facilities, where the developmentally disabled cannot defend themselves. Thank you for your time,

Sincerely,

Aileen Rivera Mother and Advocate
Family Alliance to Stop Abuse and Neglect

NEW JERSEY STATE AFL-CIO
106 West State Street
Trenton, New Jersey 08608
(609) 989-8730
FAX (609) 989-8734
www.njaflcio.org

CHARLES WOWKANECH
LAUREL BRENNAN

CHARLES H. MARCIANTE

February 13, 2013

Dear Members of the Senate & Assembly Joint Health Committee:

Statement in Opposition to the Closing of North Jersey & Woodbridge Developmental Centers

On behalf of the residents, resident families and caregivers employed at these facilities, the New Jersey State AFL-CIO thanks you for holding this hearing and respectfully asks for your support to keep these two facilities open.

The reasons for this are many and they are significant. Of paramount importance are the rights of the individuals that reside at these facilities. We believe that in many cases, the level of services required cannot be adequately provided in the group home setting. Furthermore, relocating disabled individuals far from their families' homes will have a significant and negative impact on the current developmental center residents. This type of separation will be devastating to these individuals because family involvement is critical to their well-being.

We would also like to bring to the attention of the committee the significant negative economic impact these closures will have on the care givers employed at these facilities and on the communities in which they live. Estimated job loss related to these closures is 1,000 employees from the North Jersey Developmental Center and 1,200 from Woodbridge Developmental Center. These caregivers are skilled, well trained employees that know the residents best. They perform their jobs with the upmost of professionalism. During this period of high unemployment in the state, it will be difficult for these workers to find comparable employment and will adversely affect them and their families that depend on them.

The New Jersey State AFL-CIO brings these issues to your attention because we would like the State to reconsider its plan to close these centers. The state needs to look at how this decision will negatively impact the lives of hundreds of residents, thousands of family members and place 2,200 workers on the unemployment lines, negatively affecting them and the families that depend on them. The representatives at this hearing have the best interests of the residents of these institutions at heart and are speaking on behalf of them because many of them can't speak on behalf of themselves. Thank you and please make your voices heard loud and clear in support of keeping these centers open.

Sincerely,

Charlie
Charles Wowkanech
President

Laurel
Laurel Brennan
Secretary-Treasurer

CW:LB:jn
OPEIU:153

"The Voice for Working Families in New Jersey"

My name is Robert Rutland, my twin brother is Doyle Rutland.

My Brother is profoundly disabled. He can not walk, talk or even feed himself.

My twin brother is both Mentally and Physically Retarded from birth.

His mind never developed. He is at a mental stage of a 4 month old and as such he needs around the clock care: Feedings, exercising, lifting him from his bed to a wheel chair and back again, dressing him, giving him baths, giving him his medications, changing his diapers etc.

MY BROTHER IS TOTALLY DEFENSELESS.

He is oblivious to most of the world and to 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.*

Do not take from those who have so little and can't help nor defend themselves and please think of the family members such as myself.

I am handicapped and can't get to see my brother nearly as much as I would like as is, but if you close the center and move my brother to Hunderton or the next nearest facilty which is 2 or 3 hours away, I fear I won't be physically able to visit him anymore.

Please understand, this is not just a facility, this is <u>HOME</u> to my twin brother and to take that away from him is paramount to stealing candy from a baby!

With all due respect, *I BEG YOU NOT TO CLOSE THE WOODBRIDGE DEVELOPMENTAL CENTER.*

Thank you for your time and consideration.

Public Hearing on Closure – Woodbridge Developmental Center

Joint Hearing of the State Health, Human Services and Senior Citizens Committee

Co-Chaired by: Senator Joseph Vitale
Assemblywoman Valerie Vainieri Huttle

Montclair State University
Wednesday, February 13th, 2013

Senator Vitale and Assemblywoman Huttle –

My name is Michael Chomicki. My brother, Henry Chomicki, is 50 years old and a resident of Woodbridge Developmental Center for 35 years.

My brother does not speak, has a seizure disorder and as a result of medications over many years has lost his teeth, which now presents a severe risk of choking. He is self-abusive, banging his head and punching his face – as he easily gets frustrated and has no means of communicating any pain or other issues afflicting him. Henry cannot make choices or decisions for himself.

Henry has a safe, structured home at Woodbridge Developmental Center. All of his medical, dental, orthopedic, dietary and behavioral issues are dealt with on a 24 hour / 7 day basis by trained professionals. He has a consistent routine to his life and he seems happy and content.

Because of my brother's lack of safety awareness and self-injurious behavior, he needs the Woodbridge Developmental Center with all of its safety nets in place to protect him and allow him to enjoy a safe life.

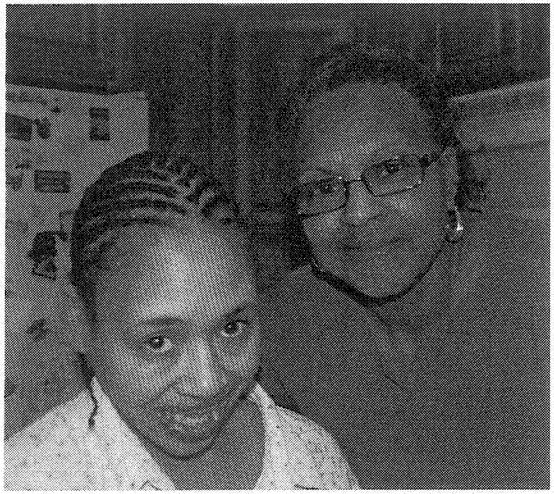
As a family we were very surprised, saddened and afraid for Henry when we heard of the decision of the Task Force to close Woodbridge Developmental Center. We are a close family and visit him twice a week. It is important we see him in person, as Henry cannot communicate with us via any other means due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

We understand that other Developmental Center placement options would be in the far south section of the State, a 2-3 hour commute from Woodbridge, which presents a hardship on our family regarding visiting options. We request that your decision would make available other Developmental Center placement options in the northern part of the State, such as Hunterdon Developmental Center.

Henry is my only sibling and with my parents advancing in age, it is important that Henry will be close to us, so that we can continue our regular visits. Please do not separate our family and other families like ours with your decision.

Respectfully Submitted,

Michael Chomicki
606 Stocker Street
Stewartsville, New Jersey 08886



My name is Deborah Smith, my daughter Kesha Smith has been a resident of North Jersey Developmental Center for twenty-seven years. I am angry and sadden over the decision to close her home, deeply concerned about her future and well-being and the possibility of her being placed 100 miles from her family, and terrified over the adverse impact that such a distance will have on my family's ability to maintain our relationship with our daughter.

Kesha is 42 years old, profoundly intellectually disabled, she has limited functional speech, aggressive behavioral issues, and she suffers from epileptic Petit Mal seizures and has experienced as many as 50 -100 per day, but thanks to the care and medical treatment she has received at NJDC, her seizure activity is 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 that would be equal to or better than the services, she currently receives at NJDC.

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 where they believe best support their wants and needs. However, not everyone living in a developmental center has that desire, or the functional ability to live in the community. My daughter would not survive in a group home. She started in community homes and those placements were not successful. Although well intended, the individuals charged with her care could not deal with her inability to express her wants and needs because of her limited speech. They could not handle her aggressive behavior, or the frequencies of the seizure activity she experienced on a daily basis. Getting her to take her mediation twice a day was even more of a challenge for them. I respectfully disagree with the state's interpretation of the Olmstead decision, and their belief that everyone regardless of their functional capabilities can be cared for in the community, or group home.

I submit to you that NJDC is Kesha's community placement. She lives in an environment that her family believes best meets her unique needs. She lives with groups of people who are much like her, and where they fellowship with each other and have a common interest, to live in a safe, secured, loving and 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, school, vocational center, hair salon, swimming pool, picnic area, basketball and bocce court, sewing, and clothing center. She can walk around her neighborhood with a sense of privacy and safety; she cannot do that in the community outside of NJDC.

My daughter needs the kind of continued care she has received for 27 years at NJDC. If the State closes NJDC, she would be transferred to another center that is over 100 miles one-way from her family. Such a distant would drastically reduce my family's ability to continue a close relationship Kesha, which may cause her to regress.

On behalf of my daughter and all of the developmental disabled living in developmental centers, I ask that you take the necessary steps to stop the closures of these two centers. I also express my sincere thanks and appreciation to you for allowing us this opportunity to share our stories. We need your help to save our loves ones homes. Please do not let them down.

Deborah Smith
NJDC Parent
Paterson, NJ

To: Honorable Members of The New Jersey State Legislature

From: Brent T. Sjaardema, Brother and Legal Guardian for John Sjaardema,
Woodbridge Developmental Center

Date: 13 February 2013

Re: Developmental Center Closings
Montclair University Hearing

Page 1 of 2

My brother, John Sjaardema, is developmentally disabled and makes his home at Woodbridge Developmental Center. Although he is able to walk, he cannot speak and psychological tests reflect his development as that of a 6 month old. He is unaware of danger and thus would not fare well in a community setting.

The case against Georgia Director of Developmental Disabilities, Tommy Olmstead, is often cited as support for the closure of developmental centers. This case involved respondents who although represented by legal guardians were able to speak and testify as to their situation. It is a disservice to cite this case to families whose loved ones have profound disabilities and where community placement would involve an undue risk. Assembly speaker Lorreta Weinburg has called for an investigation into the risk of community living, and before this is undertaken a task force decides to close the only two developmental centers in the heavily populated metropolitan North East New Jersey area.

The Division of Developmental Disabilities, in reacting to the task force position, has issued a questionnaire to affected families. If a developmental center is indicated as a preference, the Division offers no opportunity to specify a preference of location. For community placement the area of preference choice is so large as for the northern choice to stretch from the Hudson to the Delaware. Olmstead was about integration with the community. What about continued connection with loving family? What should happen is that the loved ones social worker should be involved in counseling and individual support. A callus form approach is an insult and affront to families of these loved ones.

What is really needed is for the two developmental centers in the metropolitan region to remain open. There is a need for the type of care and support these centers provide. An organization, of which I am a member, VOR (formerly known as Voice of the Retarded), campaigns to keep this option available. This is important for continued family contact and support.

Page 2 of 2 written report of Brent T. Sjaardema regarding Developmental Center Proposed Closures.

In my frequent visits to John, I have found a loving, caring and supportive staff at Woodbridge. It is my inclination that the same would be true at North Jersey. My brother has been at Woodbridge since its opening in 1965. I can remember before that long overnight trips with my parents to Woodbine. At that point, I was just a little boy. I am the only sibling and before their passing my parents impressed upon me their desire to have John remain at his home at Woodbridge Developmental Center. They also told me that it was their desire to have me secure legal guardianship following their passing so that they could rest in peace, assured that their son and my brother was cared for well. I am doing my best to honor that legacy.

Closing the homes of these defenseless loved ones is a sad situation. Assembly speaker Weinburg's formation of a study on the safety of community living is prima fascia evidence of the downside of community placement for those who lack skills in activities of daily living. This is especially true for those who, like my bother, do not have the comprehension to evaluate risk such as traffic. It is imperative that the action of the Task Force be overturned and that these defenseless loved ones be protected in the homes which they have known. Here, they are supported by a caring loving staff, who knows and is attentive to their needs. These caring, loving workers are your constituents and they and their families too depend upon your discretion to keep these centers open.

February 13, 2013

Public Hearing on Closure of Woodbridge Developmental Center

Co-Chaired by: Senator Joseph F. Vitale
Assemblywoman Valerie V. Huttle

Joint Hearing of the State Health, Human Services and Senior Citizens Committee

My name is Thomas R. Hines, Jr. My nephew, Henry Chomicki, is a resident of Woodbridge Developmental Center. Henry and I have wonderful visits once a week and enjoy a snack together. He cannot speak, so I do all the talking and he communicates through sounds and gestures. For instance, if he wants more ice cream, he points to it. We smile at each other a lot.

If you close the Woodbridge Developmental Center and move Henry out of his home he will not understand what happened to his cottage and family, his familiar surroundings, or why his daily routine has changed. I am sure this will produce stress and anxiety, and the frustration of being unable to express his feelings will lead to many behavioral outbursts that my nephew will have to endure.

The Task Force made the decision to close his home – they will not suffer. My life will go on. <u>But Henry will suffer the consequences of your decision</u>.

With the exception of the Hunterdon Developmental Center in Northwestern New Jersey, all other Developmental Centers are located in Southern New Jersey about two to three hours from Woodbridge. This will make it more difficult for me to visit my nephew every week. I cannot talk with him on the telephone – he has to see me and touch me to know that his uncle cares!

Please do not close the Woodbridge Developmental Center.

Thank you.

February 12, 2013

Dear Mr. Senator Vitale, MadameVainieri- Huttle, other Representatives, Senators, State Assembly Representatives of NJ, and Committee members of the State Health,Human Services and Senior Citizens Committee,

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

I currently reside in Florida, where a Federal Investigational Report was just published regarding the Florida State System. As a result of that report, I cannot bring my sister to Florida. If NJ is Moving ~~looking~~ to the future care of the Mentally Retarded Model from other states, then I encourage you to read the investigative report dated Sept. 2012 of the US FEDERAL GOVERNMENT on Florida. It will provide you ~~an~~ information as to where this path will lead NJ.

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 51 years in Woodbridge Developmental Disabilities 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. 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 her healthcare risks.

She is 51 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 Healthcare 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 healthcare of the most vulnerable of NJ.

The link for the Federal Investigation Report dated Sept. 2012 on Florida's Service System for Children with Disabilities with Medically Complex Conditions is here:

http://www.ada.gov/olmstead/documents/florida_findings_letter.pdf

Susan Mason, RN

Sister of Catherine O'Brien, Resident of Woodbridge Developmental Disabilities Center

To Whom It May Concern:

My son Antonio "T.J." Melero resides at North Jersey Developmental Center in Totowa, NJ. He is very happy there and he receives the very best of care from a very loving, dedicated and professional staff.

He is mute and blind and has limited mobility and is confined to a wheelchair most of the time. He is a total-care individual who requires constant monitoring and assistance. In addition to these handicaps he suffers from frequent urinary tract infections, and grand-mal seizures; I am comforted by the fact that the 24 hr. medical staff is there to administer professional care when these medical emergencies arise. After these infections and seizures TJ loses his strength which the therapy that he receives helps him resume.

I visit my son every day and he looks forward to our time together as do I. His younger brother Gary also visits 3 to 4 times a week. His extended family Aunts, Uncles and Cousins also visit him. We enjoy this family time And can do so because of the geographical closeness to our homes. We also enjoy Holiday family gatherings where TJ visits relatives which this close proximity also allows. Closing this facility impacts our family in a negative way and is extremely disheartening.

On my daily visits for the nearly 4 ½ years I have seen first hand what loving and professional employees North Jersey Developmental Center is staffed with and especially the Meese A – Wing where TJ resides.

TJ is happy and very well cared for at NJDC this is the perfect placement for him. I, his mother, his family and friends which are great in number and most of whom are registered New Jersey voters feel the same way and do not want NJDC to close.

The economic impact to Totowa and surrounding areas due to loss of jobs and business will have negative consequences as well.

Thanks,

Terry Campagna
2/12/13

February, 12th, 2013

To whom it may concern.

I am opposed to the closing of The North Jersey Developmental Center located in Totowa New Jersey. This facility provides services to the most helpless and needy people in our society. The level of care given to the residents is heart warming. Closing this facility would impose a hardship on relatives who visit residents there, some who have moved in order to be closer to the facility. Please take into consideration the people who will be adversely affected by a decision to close this center and not solely on possible financial savings.

Thank you for your consideration in this matter.

Gary Campagna

Gary Campagna
16 Mozart Ave
Little Falls NJ 07424

Attn: Craig Domalewski and other members of the NJDC task force:

I am writing today to implore that you reconsider the closing of the North Jersey Developmental Center. This institution is more than a "center", it is *home* to 400 handicapped and disabled residents, and is also a great comfort and peace of mind for their families.

After learning about this issue from NorthJersey.com and my aunt, whose nephew Antonio (TJ) relies on the excellent care provided at NJDC to meet his daily needs, I am appalled that such a serious matter has been made over budget cuts with little care as to the people this decision affects.

Not only will employees lose their jobs needlessly in a recovering economy, thereby losing a viable way to support their families (hardworking NJ residents, regardless of town residency), but this closure also emotionally, physically, and financially hurts those these institutions are established to serve. The cost to human dignity and loss of adequate residential care are not items that seemed to have been reviewed by your task force. In fact, it seems glossed over as an "individual decision" that must be made without any reflection as to what the NJDC closing realistically means to its residents, families, and staff.

First, Hunterdon Development Center, while an extensive facility in its own right, is an hour away by car from Totowa. For families and residents with little options in the way of time, quality care access, and money, this is more than an inconvenience, but raises significant barriers between them and their loved one. Further, according to the Department of Human Services: Division of Developmental Disabilities, Hunterdon DC is housed on 102 acres of land and serves 524 residents (12/31/11) with an average age of 50, whereas NJDC boasts 188 acres with a more reasonable 400 residents of various ages and needs.

As a mental health professional who has worked with many vulnerable populations in NJ and NY – geriatric residents, adolescents in therapeutic foster care, and high-need high school and college students – it is common knowledge that smaller facilities, while under pressure for funding and staffing, offer better supervised environments, which, in turn creates a safer, healthier, and more nurturing place for those served. When you increase the caseload for a residential site and/or close an institution, you are limiting public options and jeopardizing the well-being of your citizens, in this case, very fragile ones.

Plus, NJDC's mission is more inclusive and offers services catered to all without such a limited demographic as Hunterdon. To pass off our developmentally disabled loved ones to a facility with less property, fewer staff, more residents, and a limited scope of service in comparison to NJDC is neglectful, immoral, and abhorrent. It is also short-sighted and does not provide long-term, feasible solutions for those who need assistance most because "individual choice" does not really exist; it's dismissive and a way to throw several hundred New Jersey residents into an abyss without state accountability to institutions that are sub-par, too expensive, or non-existent.

Now, I know you're charged with an impossible job because being on a task force assigned to save the state money means that somewhere along the line you're going to upset someone. In this line of work, you can't make everyone happy. I also know that individually, you're just fulfilling the role assigned to you. However, other than economical factors, was the efficacy of these centers reviewed and found deficient in some way? No? Interesting. Was there a "humanity factor" or indicator scored in that rubric, whereby you placed yourself or a loved one in the shoes of one of NJDC's residents, family members, or staff before making the call? Could you imagine being in their predicament? Pretend that you are, do a little personal research, and then come back to the table with a clearer picture of what NJDC offers that is unavailable in the surrounding area. That small flicker of worry you just felt, the one before a hundred counterarguments rose to the surface, is real and only a fraction of what the families pleading with you are going through. Don't take away their child's home, their sibling's home, their parent's home, their spouse's home.

I hope that through reading this and others' stories you start to realize that these people are not liabilities that should be slashed to help balance a budget. And that there are better ways and reform options worth exploring.

Sincerely,

Rachel (Pong) Mecca, MA

Clifton, NJ

STEVEN J. CANDIDO
ATTORNEY AT LAW

425 Pompton Avenue

Cedar Grove, NJ 07009

Telephone: (973) 890-0040
Facsimile: (973) 890-9050

February 12, 2013

To Whom it May Concern:

Re: Antonio (TJ) Melero
North Jersey Developmental Center

Dear Sir/Madam:

Please accept this letter on behalf of Antonio (TJ) Melero who requires 24 hour care and resides at the North Jersey Development Center that is being considered for closure.

I have known TJ for his entire life and know that he would not thrive and/or survive in an unattended/unsupervised "group home" as is being suggested.

Please reconsider closure of the North Jersey Developmental Center for TJ and the other residents with severe handicaps that require supervised attention. These people should not be displaced from the only home that they have known for many years.

Thank you for your kind attention and consideration in this regard. I remain,

Very truly yours,

Steven J. Candido

SJC/pj

02-12-13

To whom it may concern,

My cousin T.J is currently being cared for in The North Jersey Developmental Center in Totowa. Recently I have been informed that the state of New Jersey is attempting to shut it down. With news of this unjust attempt I have no choice but to speak out. My cousin T.J needs constant care because he is not able to walk on his own, not able to speak, and is partially blind. TJ's family visits him every single day if not multiple times a day. My aunt, TJ's mother, is 100% confident in the employees of NJDC, they are kind hearted, caring, and hard working. Knowing this gives her peace of mind to know that her son is in a good environment. To take away someone's peace of mind is ludicrous. By shutting down this "Home" will not only trouble to families of the residents but also trouble the employees that will be without a job. With this being said I request that your reconsider your previous thought of shutting our "home" down.

Thank you for your time.
Steven Natoli

02/12/13

To Whom It May Concern:

I disagree with the closure of NJDC facility. My brother is there and I want him to stay where he considers his home to be. I get to visit TJ just about everyday. He is cared for on a 24/7 basis with his personal and medical needs met.

He is given great care by a wonderful and caring staff. They treat TJ with respect and understanding. He is well cared for and loved by all of them. Please keep NJDC open so I do not have to worry about him. Thank you for understanding.

Gary M.

174

13 Brookshire Drive
Cedar Grove, New Jersey 07009
February 13, 2013

TO WHOM IT MAY CONCERN:

I have recently learned that the State of New Jersey is contemplating closing down the **North Jersey Developmental Center** located in **Totowa, New Jersey**. The plan is, I believe, to move the unfortunate occupants presently residing in this facility to "group homes". This action is being considered due to lack of funds to support the NJDC.

One of the occupants of **NJDC** is Antonio Melero. Antonio is blind, unable to walk, talk or hear. He is the nephew of my neighbor. His family, naturally, is extremely heartbroken; they would be totally devastated (as others' families in this facility) should this change occur.

I, from my experience of being a care giver, believe that "group homes" are not the answer as they do not have qualified doctors on staff. If a resident should experience a "seizure", heart attack, a fall causing broken bones, concussion, etc., there, therefore, would be no immediate medical assistance which Anthony, et al, would so seriously need.

I am asking, therefore, that the State reconsider - - - keep the **North Jersey Development Center** in Totowa open for these precious human lives that need and are thriving with NJDC's special care!

You know, . . all of us are Angels, but with one wing – and, in order to fly, we need to hug one another.

Thank you.

Sincerely,

Blanche Meagher

2/12/13

To Whom It May Concern

I am writing this letter with great distress in my heart that the state of New Jersey wants to close North Jersey Developmental Center located in Totowa. As a teacher for children special needs, I know how important it is for our children to live in a stable home and environment, with people who can care for them and make each and everyone feel wanted and loved. Your facility was once that place ut now you are trying to take the only place they call there home away from them. Closing your doors would be a huge mistake. This is the only place so many lives will be made and changed. Why take it away from them? Just put yourselves in their place! Think about being pulled away from the most familiar place you know and then being sent to another facility Who Knows Where!! Please make the right choice, the only choice.

Sincerely,
T. Le Queux
Teresa Le Queux
Teacher: Clifton New Jersey

02-11-2013

To Whom It May Concern regarding:

Keeping North Jersey Developmental Center located in Totowa, NJ OPEN

I can't express enough on how important it is to keep this facility open for the clients that resident at the above location. My nephew Antonio Melero (TJ) has been at this location since Sept. 2008, and he is going to be 30 years old on March 3rd. His mother (my sister – Terry Campagna) comes to visit TJ **EVERY DAY**. I would like to give you a little idea of TJ's needs;

TJ cannot see, nor talk, which means TJ cannot express himself verbally or visually and is confided to a Wheelchair most of the day due to the fact that his ability to walk is extremely limited and due to the many other setbacks that TJ has. TJ also gets seizures from time to time which when that occurs it sets him back for days! TJ is unable to shower, dress, or feed himself. TJ is unable to take care of himself and needs 24 hour care. The other most important thing is the fact that there are Doctors and staff right on the premises when an emergency happens that they are prepared to handle the issue at hand.

I only wish you had the opportunity to meet TJ because he is such a loving human being and gives so much back to his family with his wonderful disposition that TJ has through all of his health issues. I can tell TJ is happy at this location where he resides.

One last thing I would like to mention is the fact that the staff here at North Jersey Developmental Center are one of the most caring, loving and professional teams that I am proud to have the privilege of knowing. My heart goes out to them as well because they do their jobs more than 100% and give back to their clients as they were their own. I do not know many, if any places that I truly feel the warmth when walking thru those doors to see my nephew TJ and knowing he is in the BEST place he could be.

Thank you for your time to this very important matter!

Sincerely,
Judy and Sal Natoli

Salvatore Natoli
Judy Natoli

Judy

From: John Pong 1]
Sent: Tuesday, February 12, 2013 8:52 PM
To: Judy
Subject: Re: Meeting with State of NJ regarding NJDC

TO WHOM THIS MAY CONCERN,
RE:CLOSING OF THE NJDC

I WAS RECENTLY INFORMED AND SADDENED BY THE POSSIBILITY OF THE CLOSING OF THIS CENTER . THIS IS ONE GOVT FUNDED FACILITY THAT SHOULD REMAIN OPENED. PEOPLE THAT CANNOT TAKE CARE OF THEMSELVES NOR THEIR FAMILIES SHOULD BE ABLE TO DEPEND ON THE GOVT TO TAKE CARE OF THEIR OWN PEOPLE.IT IS IMPERATIVE THAT THE PATIENTS OF THIS CENTER WILL CONTINUE TO HAVE THE 24/7 CARE THAT THE SO DESPERATELY NEED AND DESERVE. THERE IS ENOUGH STRESS AND ANXIETY WHEN YOUR LOVED ONE IS IN A FACILITY BUT WE KNOW THAT AT NJDC THEY ARE TAKEN CARE OF AND IN GOOD HANDS AND FAMILIES CAN BREATHE THE EASIER KNOWING THEY CAN TRUST THE PEOPLE THAT OVERSEE THEM.

SINCERELY, JOHN AND CARMELA PONG

On Tue, Feb 12, 2013 at 1:51 PM, Judy <judynat@verizon.net> wrote:

> *Dear Friends and Family – Please Help!!!!*
>
> *We were just notified yesterday that there will be a meeting at Montclair State University on Wednesday morning with the State of NJ for the families from*
>
> ***North Jersey Developmental Center** to discuss the closing of the facility where Antonio (TJ) Melero (my nephew) resides. We are going with other families from NJDC to speak our minds as to why we feel they need this facility to stay open. If you could take a few minutes and write a quick note/letter for TJ*
>
> *and the residents of **NJDC** to keep their HOME open we would greatly appreciate it.*
>
> *The state wants to place them in Group homes where they are not being cared for nor watched over as they need to be. Also noting that there is no*
>
> *Supervision at these group homes and the folks are unattended most of the*

From: Christinachin com]
Sent: Tuesday, February 12, 2013 8:55 PM
To:

Please take a min and help out our cousin tj please there close the place where he is and we need all the help we can get thank u so much . Out prays go out to him and his family .

179

From: Claudia Phillips [redacted]
Sent: Tuesday, February 12, 2013 9:47 PM
To: [redacted]
Subject: North Jersey Developmental Center

To Whom It May Concern:

I am writing to express my concern over the possible closing of the North Jersey Developmental Center. So many people are helped by this facility it would be a terrible loss for these people and their families. They will be losing their home and for some the only one they have ever known. Please do all you can to save this worthwhile facility.

Claudia Phillips

Judy

From: Claudia Phillips [redacted]
Sent: Tuesday, February 12, 2013 9:52 PM
To: [redacted]
Subject: North Jersey Developmental Center

Dear Sir:

My neighbor's relative is a resident of this facility. He has been greatly helped here and if it should close would cause much hardship to him and his family. Please do all you can to save this center.

Thank you,

Jennifer Phillips

181x

Judy

From: Kelly Decke[redacted]
Sent: Tuesday, February 12, 2013 9:58 PM
To: [redacted]et
Subject: Closing of North Jersey Developmental center

To Whom it may concern,

□ I am writing to you in reference to the closing of The North Jersey □Developmental Center, I am asking that you not close this facility as a lot of the tenants are doing well with the assistance that they are□receiving□ I am not so sure that they will be able to obtain the same level of health and wellness at their parents homes. Please be sure that you are considering the hardships that the closure of this facility and facilities of its kind. These are very important for many families and I would hate to see the increase of unemployment if these homes close due to family members needing to care for the residence. Again, please reconsider the option of closing this facility.

Thank you for your time,

Concerned and sincerly,
□Kelly Decker

Judy

From:
Sent: Tuesdav. February 12, 2013 8:09 PM
To:
Subject: Re: To Whom It May Concern regarding.doc

February 12, 2013

Mr. & Mrs. John Ripoli
301 Beechwood Drive
Paramus, New Jersey 07652

RE: KEEPING NORTH JERSEY DEVELOPMENTAL CENTER OPENED - LOCATED IN TOTOWA, N

To Whom It May Concern regarding:

I can't express enough on how important it is to keep this facility open for the patients that resident at the above location. Dear friends of ours, Judy and Sal Natoli, have a nephew Antonio Melero(TJ) that has been at this facility since Sept. 2008, and he is going to be 30 years old next month. His dear mother comes to visit TJ EVERY DAY. Judy and Sal LOVE their nephew very much and always talk about TJ. They have expressed TJ's needs repeatedly in our conversations. TJ's needs; TJ cannot see, nor talk, which means TJ cannot express himself verbally orvisually and is confided to a Wheelchair most of the day due to the fact that his ability to walk is extremely limited and due to the many other setbacks that TJ has. TJ also experiences seizures from time to time which when that occurs it sets him back for days! TJ isunable to shower, dress, or feed himself. TJ is unable to take care of himself and needs 24 hour care. As TJ needs care 24/7 is it of utmost importance that there are doctors on staff 24/7! TJ is such a loving human being and gives so much back to his family with his wonderful disposition that TJ has through all of his health issues. His family can tell TJ is happy at this location where he resides. Judy and Sal have expressed that the Staff at North Jersey Developmental Center is one of the most caring, loving and professional teams they have ever meet! They feel that the staff goes above and beyond in taking care of their patients especially TJ! They feel that their nephew TJ could not be in a better facility. Thank you for your time to this very important matter! Sincerely, Lauren and John Ripoli

Judy

From: Jennifer Gormley [redacted]
Sent: Tuesday, February 12, 2013 7:28 PM
To: [redacted]
Subject: N.J. D.C. in Totowa

To whom it may concern,

I don't want to see N.J. D.C. in Totowa closed. I feel that it provides a great service to the citizens in the surrounding area. Please consider keeping it open to continue this service.

Thank you,

Jennifer Gormley

Sent from my iPhone

From: Jennifer Gormley [redacted]]
Sent: Tuesday, February 12, 2013 7:30 PM
To: [redacted]
Subject: N.J. D.C Totowa

To whom it may concern,

I don't want to see N.J. D.C. in Totowa closed. I feel that it provides a great service to the citizens in the surrounding area. Please consider keeping it open to continue this service.

Thank you,

Joan and Donald Gormley

Sent from my iPhone

Judy

From: Jennifer Gormley [redacted]
Sent: Tuesday, February 12, 2013 7:31 PM
To: [redacted]
Subject: N.J. D.C. Totowa

To whom it may concern,

I don't want to see N.J. D.C. in Totowa closed. I feel that it provides a great service to the citizens in the surrounding area. Please consider keeping it open to continue this service.

Thank you,

Alice Hand

Sent from my iPhone

Judy

From: Jonathan Turner [redacted]
Sent: Thursday, February 14, 2013 2:58 AM
To: [redacted]
Subject: Developmental Center

Please place the patients in mind when deciding on closing this Center. From what I understand, this is a very good place that does a good job at helping people. Please keep the patients' best interests in mind. :)

Judy

From: [redacted]

Sent: Thursday, February 14, 2013 4:49 PM

To: [redacted]

Subject: Re: RE: Meeting with State of NJ regarding NJDC

Hi Judy, Sorry, I do not have word on my netbook. I am supposed to have a starter version of word and excel (basicaly limited vesion) but I cannot find it and don't know what the exec name is.

So, I can draft a paragraph and feel free to make it into a letter format and enhance it.

Attention --- NJDC - North Jersey Development Center

I realize times are tough in this economy but it is absolutely pitiful if you close the center. There is lots of money wasted everyday through out the state of NJ. This NJDC is very much needed. There are people who live in the center that very much need this place to live. There are many people including Anthony Melero (TJ) who currently live there and it is an excellent facilty. Please grant your resources appropriately for the areas that need it.....NJDC. Please do not close the facility.

Thank you in advance.

Janet Greene

02-11-2013

To Whom It May Concern regarding:

Keeping North Jersey Developmental Center located in Totowa, NJ <u>OPEN</u>

*I can't express enough on how important it is to keep this facility open for the clients that resident at the above location. My nephew Antonio Melero (TJ) has been at this location since Sept. 2008, and he is going to be 30 years old on March 3rd. His mother (my sister -- Terry Campagna) comes to visit TJ **<u>EVERY DAY</u>**. I would like to give you a little idea of TJ's needs;*

TJ cannot see, nor talk, which means TJ cannot express himself verbally or visually and is confided to a Wheelchair most of the day due to the fact that his ability to walk is extremely limited and due to the many other setbacks that TJ has. TJ also gets seizures from time to time which when that occurs it sets him back for days! TJ is unable to shower, dress, or feed himself. TJ is unable to take care of himself and needs 24 hour care. The other most important thing is the fact that there are Doctors and staff right on the premises when an emergency happens that they are prepared to handle the issue at hand.

I only wish you had the opportunity to meet TJ because he is such a loving human being and gives so much back to his family with his wonderful disposition that TJ has though all of his health issues. I can tell TJ is happy at this location where he resides.

One last thing I would like to mention is the fact that the staff here at North Jersey Developmental Center are one of the most caring, loving and professional teams that I am proud to have the privilege of knowing. My heart goes out to them as well because they do their jobs more than 100% and give back to their clients as they were their own. I do not know many, if any places that I truly feel the warmth when walking thru those doors to see my nephew TJ and knowing he is in the BEST place he could be.

Thank you for your time to this very important matter!

Sincerely,
Leonard de Oliveira

Good Afternoon Elizabeth Boyd, *02-14-13*

Thank you and your team for taking the time to hear from the ***HEARTS*** *of so many yesterday regarding, the North Jersey Developmental Centers possible closing. I can only* ***HOPE*** *and* ***PRAY*** *that with this latest information that you folks have received with the out poring turnout from yesterday and I counted close to 400* ***Voters*** *(by the way just think how many more that could have shown if only this was done on the Weekend instead of a Wednesday) when most people who are* ***fortunate enough to have a JOB*** *and might not have had the opportunity to take the day off for possible fear of not getting paid for the day. Maybe you and your team can* ***enlighten Governor Christie*** *to immediately reconsider his decision to close these (****what he calls facilities****)* ***we*** *call our* ***Loved ones homes.***

As I keep receiving Emails, Letters etc. regarding the above issue I will be sending them along to you. I sincerely appreciate the time, energy and care that you and your panel have demonstrated. Help us to be heard!!!

I honest to God thought that Governor Christie was a Great Leader and saw Great potential to see him run for the Presidency of the United States of America (WE THE PEOPLE are voters) but since he has brought this outrageous disheartening idea to pick on HELPLESS children of God and ***Shame on him****, he will clearly not have my VOTE for any government position that he might consider running for in the future unless he recedes the closings of these homes!*

190x

Please also keep in mind that with each and every person that has been affected by these current events (has family, friends, and relatives that live all throughout the United States of America) where if Governor Christie decides to run for President, this can and will have a major impact on these VOTERS as to if they deem him fit to be President. We now leave it all up to him.

Governor Christie, make the right choice and there is only one – Keep our Homes open for our families! (I'm sure you and your wife, Praise and Thank God every night, before you go to sleep that your children are healthy – because I know that's what I do each and every night) it breaks my heart that my sister not only has a Severely handicapped child, but the fact that she now has to fear, worry and is so heart broken as what could possible happen to her child because of ***YOU*** *is just an unjust.*

I challenge you, your wife and children to live one day (just one day) in the lives of these parents, siblings who have to deal with this heartache each and every day!!! Then let me know how you feel about closing down their homes.

Sincerely,
Judy Natoli
Cedar Grove, NJ
973-222-7786

This is the first hearing that I was made aware of despite recently reading of other hearings held by a Task Force.

Back in September of 2012 I received a phone call from a Kathy. A representative from the state of New Jersey advising me the Woodbridge Development Center was to be closed and I would be receiving a letter in the mail shortly. She explained that the Governor had compiled a task force to study this issue. When I asked her how I might be able to obtain a copy of this report via web site or hard copy Kathy informed me the task force's report was not complete but the decision to close Woodbridge and Totowa Development Centers were made. I was shocked that a major decision like this was made prior to a report and study being completed. Meanwhile, the Developmental Centers to remain open are all far south of Bergen County where my wife and I reside. I find it suspect that the southern most Development Centers such as Vineland are to remain open whereas the most densely populated section of northern NJ; is where the two centers are slated to be closed.

I was raised in North Bergen, NJ and have lived in NJ my entire life except for a short 6 months. I am extremely disheartened regarding the plans to close these developmental centers. This will have a negative effect on so many of NJ citizens who are unable to have the great fortune you and I have here today. To stand and speak up for themselves. A gift we all sometimes take for granted.

I stand here today to request that Woodbridge remain open. I ask this not for myself but for those who cannot Stand here on their own nor Speak to you on their own because of their mental and physical disabilities. Billy Blank is my step-nephew and legal guardian. A resident of Woodbridge Developmental Center. We love him very much. I have been visiting him at Woodbridge since I was 11 years old. He has been at Woodbridge Developmental Center approximately 44 of his 50 years of life. It's the only home he knows. He will think moving him is a punishment as he cannot comprehend why this would be happening after 44 years. 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 do not foreclose upon his home! 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, you know who they are and your surroundings. Billy throws kisses to his care takers and is known as a loving and loveable boy by the employees his family at Woodbridge. He receives immediate medical help and regular procedures on the premises. He needs constant supervision and caring from people such as his family, the employees at Woodbridge provide him on a daily basis. The medical assistance is immediate when he needs it as is the attention he receives and deserves from this state.

We give billions of dollars to help our citizens when a tragedy such as Hurricane Sandy blows through our state. This is just and right. Please do not allow a tragedy to happen in this state by moving these people out of their homes. I will hold this state responsible for any health problems or negative issues that may affect Billy from any move where he loses the only home he knows. I understand this may be a federal program however let us stand as one against what will have a negative effect on the very NJ citizens we should be protecting. I hope the media will make this information known to all voting and nonvoting citizens of this state and beyond.

The Record newspaper reports that there are almost no available beds at Hunterdon & Greenbrook facilities. The other two Developmental Centers slated to remain open in the more northern part of the state. Do not force older relatives and others to visit these people in Developmental Centers that are 91, 131 and 145 miles from Totowa and even further from their homes. This is a hardship on them, makes them spend more money for tolls and gas they may not have and it is not environmental sound using more fuel for their vehicles.

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 are speaking about people's lives.

I ask the legislatures of this state including the Governor who were elected to serve ALL the people of this state to do the right thing and stop and reverse this decision. Do the right thing! Stand up, open your hearts and keep these developmental centers open for those who need them.

GARY YACONO
C: 201-870-3817
278 W. PASSAIC ST., Rochelle Park, NJ 07662

My name is Carl Hazen. I am a 35 year resident of Bloomfield, New Jersey and have worked private industry and the public schools of New Jersey my entire adult life

I would like to thank the Legislators and Committee Chairs who have come to Montclair to listen to the families of the citizens whose lives will be directly affected by the consolidation of the Development Centers.

My brother, Michael John Hazen is a profoundly disabled citizen of New Jersey. He has been a resident of Woodbridge Developmental Center for nearly 40 years. Mike cannot feed himself dependably. He cannot cook or shop. He is confined to a wheelchair. He cannot speak. He cannot attend to his personal hygiene. He cannot live independently

Woodbridge Developmental Center is Mike's home. Everyone calls him by name. Everyone knows him and his personal needs. The workforce at Woodbridge Developmental Center takes care of Mike. The care he receives is excellent.

Community placement is not a viable option for Mike and his severely disabled peers who live at Woodbridge. He will never enjoy a walk to the candy store or a trip to a neighborhood park. He would have no idea how to navigate to such a trip. Such a trip would put Mike in danger. He is fortunate to live at Woodbridge Developmental Center because he is safe. Family members can easily take him for a walk safely and securely.

I visit Mike every week. Most Tuesday evenings after work I arrive in time to feed dinner to Mike. Depending on the weather and the time of year we listen to music indoors or I push his wheelchair outdoors where we can enjoy music and the warm evening air. If you move Mike to South Jersey I'll be unable to visit him weekly. One of the highlights of his week will be eliminated. How can you do this to a person who cannot speak for himself?

My Dad turned 90 this year. When myself and my siblings were grown he bought a house in Perth Amboy to be close to Mike. He visits Mike every Sunday. He cannot make a 3 hour drive to south Jersey. If you close Woodbridge Developmental Center another of the highlights of Mike's week will be eliminated. How can you do this to a person who cannot speak for himself?

I am here today to speak for my disabled brother. Woodbridge Developmental Center is Mike's home. Please do not make Mike leave his home. Please do not degrade his quality of life. Please do not move him away from his family.

Thank you.

Carl Hazen
101 Grove St.
Bloomfield, NJ 07003

My daughter is 58 years old. She has lived at NJDC 48 years. She is 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. (The cottage is two Stories) She has her own room furniture & T.V. There is a RN dispensing medications, & the Clients eat in the cottage, which is attractively decorated & changes with the seasons. She needs Specially prepared Food because She has No teeth. She has daily activities she can walk to. She attends church and goes on trips. Enjoys cottage parties and attends Camp at LeMar Penn. every June. I take her to lunch every Sunday. I live only 25 min. away. Sounds Good?

However! She can dress herself but not tie her shoes or shower independently. Her eyesight is very poor, and She is afraid of stairs that have an open railing. Most importantly – she has no speech. Her rare syndrome - Rubenstien Taybee is caused by a gene alteration in the first trimester, and no speech is one of the syndrome's Symptoms. She communicates quite well with those who know her well by gesturing & a few sounds, BODY LANGUAGE but would be Totally lost if with strangers in a new facility.

Her receptive vocabulary is good.

an example One day a substitute Nurse was on duty & when my daughter went for her meds, she kept striking the hand on the Counter. The nurse asked Staff why she did that. The answer – she wants you to crush the pills before she takes them. – (She cannot swallow lumps)

Closing NJDC & Woodbridge is wrong & poor planning. Our cottage Meese is for those clients who are also too physically handicapped to live in a cottage. [It is the only facility in the State for those clients.] They will need nursing homes. There are cir. 9–10,000 people in N.J. at home on the list for Community placement for years. Suddenly 700 Clients are ahead of them, for all these mythical GROUP homes. Those at home and their parents are all getting older. Keeping NJDC & Woodbridge open and developing Vineland into a geriatric facility, WOULD BE WISE. This will be needed soon.

Thank You

B Ms. Kathryn H. Bergin

February 13, 2013

To Whom It May Concern:

Thank you for taking the time to read this letter. I hope after reading this you will understand the importance of keeping the Developmental Center's open and will stop the closing of North Jersey and Woodbridge Developmental Center.

My daughter, Stephanie Roots, has called North Jersey Developmental Center her home for the past 28 years and this move is very upsetting to her as well as our entire family. I do not understand the logic behind this decision by Governor Christie and his task force to close these Developmental Centers, which provide the necessary level of care and supervision for each individual client. Moreover, this Governor has no idea what is best for my daughter; I do. I feel as if my daughter is being pushed out in the community which will not understand her and all the special people like her, and I know she will not get the same care and level of supervision she receives at NJDC. The caring staff of NJDC often times takes the place of family for the many clients that do not have family or someone to speak up for them. When my daughter first went to North Jersey Developmental Center in 1984 she had behavior problems and we could not keep her at home any longer. We had to go to work and it was very difficult. The center has done such a great job with her she is very happy there and has her friends and staff that she is very fond of. I know she will be very upset to have to leave there as any child would be if they have to move it is very hard for them to adjust to a change. That is there home and the Governor and his task force does not to have any compassion for them. The clients there are New Jersey's special citizens that need the most compassion and understanding. I feel that the Governor should be proud that the state has the Developmental Centers to take care of these special citizens that are unable to speak for themselves. I do not feel that community placement is the right thing for my daughter. We as parents and guardians should have the right to make that decision and not the State of New Jersey.

Thank you for your time and attention with regard to this critical issue.

Sincerely,

Marie Reid Gaylord Reid

Marie and Gaylord Reid

158 Madison Avenue

Westfield, NJ 07090

February 13, 2013

To Whom It May Concern:

I am writing on behalf of my sister, Stephanie Roots, who is currently a client at North Jersey Developmental Center in Totowa, NJ. I am appalled at the decision to close the institution, which provides an excellent and unparalleled level of care for special people like Stephanie.

It is my opinion that the impetus for the closing of this institution, and others throughout the state, are based on the self-serving interests of the state government, rather than a sincere concern for the idiosyncratic needs of the developmentally disabled clients. Moreover, I would venture to say that the governor's task force fails to fully understand the psychological impact this type of transition can have on clients, nor do they even care.

To shuffle clients like Stephanie out into the community without the same level of supervision and care is truly a poor decision which ultimately will have dire consequences on both client and community alike. I foresee problems concerning not only security and safety for developmentally disabled clients, but also a general miscommunication between clients and the community, which oftentimes does not understand the thought process and actions of clients.

I appease you to please reconsider the decision to close these institutions and instead formulate an alternative plan to maintain the developmental centers and, if necessary, acquire financial support from the public. My sister, Stephanie, is entitled to a happy, healthy, and safe life, which I do not foresee being possible in a community-based group home, which, at best, would provide a marginal level of care.

Thank you for your time.

Sincerely,

Kellie D. Reid

Kellie D. Reid

158 Madison Avenue

Westfield, NJ 07090

1 People ([illegible])

2. ~~Politicians lipservice~~

an ~~Dear~~

~~To whom IT~~

Speaking For Chucky
Ferris

To whom it may concern,

~~[illegible]~~ Our state goverment has decided to close the woodbridge developmental center within the next five years. I am apalled by this decision. First of all, vineland is another center that was suposed to be close because of abuse and neglect of their residents. All of a sudden woodbridge was chosen. Why!

My brother was a resident since he was eleven, He is now 58. He needs 24/7 care. The community cannot take care of him. Woodbridge center has an excellent staff of Doctors, Psycholigist Nutritionists, social workers, and all kinds of therapy. The place is clean The staff always meets with me every year to acquaint me with everything they are doing for my brother. Goals are always set for his well being

Hospital on campus

200x

Our state says that the Woodbridge Developmental Center meets certain criteria in order to close. What is that criteria? Our state also wants to close the Rahway Prision which has an excellent program that ~~which~~ has the prisioners interact with the residents of Woodbridge Center.

What is really behind this closure? Is there a land developer that is interested in the properties of ~~Rahway Prision~~ and Woodbridge Developmental Center. What will happen to the residents? Can they take their place in the community! Newtown CT, ~~Could the~~ Is the community equipped to handle them. In conclusion if we proceed We need to ~~answer~~ have these questions answered or we will end up regretting this closure for the rest of our live.

Yours truly
Alan Furker
Alan F

Woodbridge Developmental Center

2016

With the shocking announcement of the planned closures of North Jersey and Woodbridge Developmental Centers, the Governor and legislators of the State of New Jersey are playing Russian roulette with the lives of thousands of people involved: the disabled residents, their loving families and the caring staff members who provide critical services to these residents.

These pending closures will cause tremendous hardships for all involved. Many of the residents will lose ready access to the intensive skilled supports that only a developmental center can provide. Families will lose easy access to their loved ones. For those many parents who are aging, the proposed changes also threaten their comfort that loved ones will be safe and secure in the protective care of responsible state staff. Regrettably, these workers are now at risk of losing employment in areas already burdened by high unemployment,

Our son has multiple and profoundly complex psychiatric and developmental diagnoses. If he were to remain in a developmental center upon the closing of North Jersey, he would most likely have to be placed in the New Lisbon Developmental Center, 90 miles away. His present placement allows for weekly visits with his parents and siblings; living farther away from his family would be devastating for all concerned.

We have grave reservations about this change based on our son's disastrous past experience living in a group home despite the fact that both parents served on the sponsoring agency's board of directors. 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 services he currently receives to maintain his mental and physical equilibrium? It's as if the state is trying to sell parents/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 of fragile individuals and dubious promises of trust.

Frances and Stephen Finkelstein

3 Marble Court, #16; Clifton, NJ 07013 February 13, 2013

Samuel Friedman <shmilich@gmail.com>

February 13, 2013, meeting stateent from the Finkelsteins

1 message

Frances Finkelstein[redacted]> Sat, Feb 9, 2013 at 1:33 PM
To: Samuel Friedma[redacted]

With the shocking announcement of closures of North Jersey and Woodbridge Developmental Centers, the Governor and legislators of the State of New Jersey are playing Russian roulette with the lives of thousands of people involved: the disabled residents, their loving families and the caring staff members who provide services to these residents. This pending closure will cause tremendous hardships for all involved. Many of the residents will lose ready access to the intensive skilled supports that only a developmental center can provide. Families will lose easy access to their loved ones. Staff are at risk of losing work in an area already burdened with high unemployment.

Our son has multiple and profoundly complex psychiatric and developmental diagnoses. If he were to remain in a developmental center, he would most likely have to be placed in the New Lisbon Developmental Center, 90 miles away from North Jersey. His present placement allows for weekly visits with his parents and siblings; living farther away from family would be devastating for all concerned.

We have grave reservations based on our son's disastrous past experience living in a group home despite the fact that both parents served on the sponsoring agency's board of directors. DDD has not been able to show us group homes in this area that could presently provide him with all of the services that he requires. It's as if the state is trying to sell you a car that has yet to be designed; yet we're being told to "trust them."

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 and dubious promises of trust.

William G. Holy
69-27 53rd Avenue
Maspeth, NY 11378-1425
Phone: (718) 397-3840
Cell Phone: (347) 461-4640
E-Mail: bill.holy@rcn.com

Ladies and Gentlemen:

Thank you for your time and attention this morning. My name is William Holy. I am the brother and legal guardian of my sister, Patricia Ellen Holy, who is an adult resident of Woodbridge Developmental Center.

Where Our Focus Should Be:

My sister's photograph is the last page of this statement; and, I respectfully request that you look at it for a few seconds right now. Patricia is now 63 years old. She was brain damaged at birth, and, as you can see, is profoundly mentally incapacitated. She has lived in state institutions since she was three years old, and has been a resident of the WDC for more than 50 years. As all the rest of the residents of Cottage 1, my sister is totally non-ambulant and has no capacity for cognitive thought nor any of the normal physical capabilities that you and I take for granted. She cannot speak, walk, hold anything in her hands, nor focus her eyes. She sits belted into a wheel chair 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 there is a pained look on her face. She can no longer eat, because her digestive system is shutting down; so she is fed through a GI tube. Someone else has had to feed, bathe, change her diapers and clothe her for the entire span of her life. Her original prognosis was for a life span of less than eight years; yet she lives still there at the WDC, a living tribute to modern medical science and the loving, expert care she receives there. She is an angel waiting to happen with no ability to care for her-self at all. Every other resident of her cottage is in an analogous state 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.

Part of the Proposed Solution that Can't Possibly Work:

Group homes are not an option for people like my sister. Such facilities lack the medical and logistical capabilities to care for severely mentally challenged people like my sister, Patricia. Yet, for the last few years, I have frequently received 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 this regard. The proposed cure doesn't alleviate the financial problems, it simply transfers them to another venue, and exacerbates them because of the associated over-crowding it will cause in other institutions, and the diminution of the quality of care my Sister and her fellow residents of Woodbridge will experience. .

Effects of the Closure – Increased Costs Elsewhere:

In addition, the effects on the working population of the surrounding communities will be equally devastating. Many of the people who care daily for the residents of WDC are long-term employees of the Institution, nearby residents, and minimally compensated individuals who will lose their jobs. Because of the level of their compensation, they 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 long term living assistance benefits such as food stamps and even welfare. So, the potential cost savings of closing the WDC will be reduced by the increased costs of other social programs.

A More Cost Effective Approach to the Operating Cost Problem:

Finally, the architectural and structural condition of the WDC campus of buildings is sound, but the support infrastructure (i.e.: the electrical, heating, ventilation, air conditioning (HVAC) and plumbing infrastructure is obsolete, making the facility expensive to operate. There are extremely cost-effective approaches to resolving this problem, 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 also supports the Rahway prison, which is miles away. Because of the increased cost of utilities, central HVAC plants like this one have given way to installation of local modular HVAC systems, incorporating unitary modular chillers and modular hot water condensing boilers, which just match the variable heating and cooling loads of the individual buildings of a campus such as the WDC as those load requirements vary throughout the operating year in an extremely efficient manner. The lighting systems that incorporate obsolete high-energy light fixtures could be replaced with LED fixtures that operate at a fraction of the cost, and which would also further reduce the air conditioning costs of the facility. Finally, reduced demand plumbing fixtures would save significantly on the water and sewer costs. If such an solution were pursued 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 utility cost savings. In addition, State and Federal grant money might be available to further reduce the capital costs of such a retrofit.

Balancing Financial and Human Responsibility:

In conclusion, to paraphrase an ancient Chinese proverb – *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 life-line of those who have no other way to survive, which is what the closure of the WDC would precipitate.

Thank you for your time and consideration.

2 DEx

February 13, 2013

To: Joint Committee on Human Services

My name is John Pydyszewski. I am here today on behalf of my parents, John and Annette Pydyszewski, and my brother, Keith Pydyszewski. I am speaking today because my brother cannot, and my parents and I need to protect my brother's civil rights. Keith is a resident of the Woodbridge Developmental Center. He has lived there since he was 12 years old. Keith will be 56 this May, so he has lived there for over 40 years – the majority of his life. It is his home. I think this is an important point to consider – it is his home. A Developmental Center isn't your typical state office building where people simply go to work. This is home for individuals who cannot care for themselves. They are truly our most vulnerable citizens. In this regard, my parents and I are thankful for the caregivers at the developmental center for the care and attention they give to my brother.

No one would argue against moving qualified individuals to group homes, and if my brother could function in one, my parents and I would support that 100%. The fact is, he cannot. He is classified as "severely and profoundly handicapped," and requires a level of care that is not available in a group home.

When you read my brother's Bio on file with the Division of Developmental Disabilities, it is written in the first person. It says things like "I like this" or "I do that." This is very misleading in that it would appear that he can communicate and function independently. The fact is, my brother cannot communicate. He has never spoken a word in his life. Consequently, he is dependent on the Development Center setting for his well-being.

Keith is accustomed to frequent visits from my parents. Since they are older and no longer able to drive, moving my brother farther away would result in fewer visits by my parents, me, and my wife - the only family my brother knows. He doesn't have the capacity to understand this, and it will surely be upsetting for him.

Comments have been made about developmental centers being "warehouses" for these people. While such statements may make for good headlines, my parents have been actively involved in and monitor the care that my brother is given. If they considered the Woodbridge Developmental Center a warehouse, I can assure that you would have heard about it long before now. If you haven't already done so, I would encourage each of you to visit these developmental centers. I would be happy to put you in contact with the appropriate individuals to arrange a tour.

I have provided my contact information below if you have any questions or comments.

John J. Pydyszewski (Brother of Keith)
28 Markwood Drive
Howell, New Jersey 07731
732-364-4620
jpydysz@its.jnj.com

April 21, 2012

To Task Force & Governor Christie

I am writing this letter in regard to possible closure of our State Developmental Centers. I would like to first say I have no objection to our loved one's moving to community placement when it is appropriate. It is a very delicate decision in regard to who can or cannot handle this type of environment.

The North Jersey Dev Center has been home to our daughter for twenty one years. When my husband and I went to assess if North Jersey Dev Center would suit our daughter's needs we were relieved at what we observed. The Center reminded us of Douglass College Campus in New Brunswick, N. J. where my sister attended college.

In the twenty one years our daughter's home has been NJDC all of her needs have been available to her. They have a sheltered workshop on grounds that she requires, recreational activities with an auditorium available for such activities, a chapel, vocational building, swimming pool, most importantly medical service's.

Our loved one's have a freedom at the NJDC to move about on grounds such as to walk to the workshop, walk to food service's to buy a snack for themselves, sit outside on the swings or on the benches under the tree's and visit with one another. Our daughter and the other ladies of Cottage I are very fortunate to have this facility for their home.

I firmly believe that the member's of the Task Force should HAVE TOO spend one month at NJDC. By one month I mean a full eight hour day for Sunday, Monday, Tuesday, Wednesday, Thursday, Friday and Saturday. You CANNOT just come for a few hours and make an accurate or fair assessment . If you were to do this you will see clearly the need for both Community and Developmental Center placement for our loved one's.

Sincerely,
William & Jeanne Urion
331 Rick Road
Milford, N.J. 08848

908-735-4374

Frederick Maier
5 Wilcox Street
Dumont, NJ 07628
Tel. 201-385-9256
February 13, 2013

Re: Closing of North Jersey Developmental Center (NJDC)

To Whom It May Concern:

My name is Fred Maier. I am a concerned relative of a loved one at NJDC – my sister Marilyn. She has been at NJDC for over 9 years. She came there around 2003.

Marilyn is now 52 years old. She lived wither her family until she was 21. We could not take care of her anymore because of all her behavioral problems.

Marilyn was put in Greystone Psychiatric Hospital for about 2 ½ years. This was a horror while she was there. They put her on all different types of psychotic and behavior medications and I feel that she was not adequately taken care of. She seemed always to have poor hygiene, and the buildings of this institution were run-down.

After all of this, from the early 1980's to the late 1990's, Marilyn was kept at a nice institution called North Princeton Developmental Center. It was a little far away from the family, but we managed. This place was home for her for 15 years. It was a pleasant setting, there was a good staff, and nice cottage-sized buildings. I felt that my sister was taken care of well there. Why they decided to close *this* nice facility over 16 years ago is beyond me.

Because of this closure in 1998, Marilyn was placed in a group home for 5 years in Hasbrouck Heights, run by the Devereux Agency. It was much closer to her family home, and the first three years went well. But the last two years was like a horror story, wrought with emotional, bad behavior moods and psychotic episodes. Every other month, we would get calls late at night that Marilyn either had to go to the emergency room at Bergen Pines, or there was a police incident involving her. Other times, my sister would wander from the home, or got into fights with other patients and staff. She could not be handled well any more at this group home. I would not want this to happen to my sister anymore.

Around 2001, Marilyn was admitted to Bergen Pines for two years until they could find placement at a developmental center, because they felt that she was not capable of being in a group home setting anymore. While there, the staff overfed her, over-drugged her, and she was just "warehoused" there with people who had drug, alcohol and psychiatric problems. She gained 60 pounds while there. This institution did not take care of her well at all.

Finally, my sister was placed in North Jersey Developmental Center in 2003. Since this time, NJDC has been a very capable home for her. Marilyn knows the staff well, and all of her needs seem to be addressed at this facility. Her weight has been properly managed, and her behaviors have been kept under control. She gets good medical and dental care, and seems to be well-adjusted and happy. This place is a close drive for me compared to other developmental centers in New Jersey. I find the staff readily accessible and friendly, and they address all of her medical, psychological and behavioral issues, something she *could not get* in a group home setting. The center has a medical clinic, dentist, dieticians and physical therapist on the grounds readily available for her and all the clients. Particularly when emergencies arise, this is most valuable to individuals like my sister who requires so much individual care.

I feel NJDC has been a good home for my sister for almost 10 years. Even though group homes are worthwhile for mentally disabled and handicapped clients, the developmental centers are still needed for the more severe and profoundly disabled people in our state of New Jersey. I would like to at this time continue to call NJDC her home, and it would be terrible if this developmental center would close permanently. To close is to hurt these types of clients.

Sincerely,

Fred Maier

Fred Maier

Testimony for New Jersey Legislature – February 13,2013, Montclair State University

I would like to thank the Legislators and Committee Chairs who have come to Montclair to listen to the families of the citizens whose lives will be directly affected by the consolidation of the Development Centers. My name is Steve Hazen.

I am here to support my brother Michael Hazen and our family. Michael is a profoundly disabled person. He has been under the care of the New Jersey Development Center at Woodbridge for nearly 40 years. He needs constant care to move about, to eat, to take care of daily grooming and hygiene, to handle the normal elimination of his bowels and bladder – basically to continue to live. Michael is disabled physically and developmentally. At the peak of his abilities in his early teen years, he could communicate and act on his needs at the level of a 3 year old child. He has not spoken in his adult years.

He is, as I said, a profoundly disabled person. He relies on the state of New Jersey for support to live his life. And the dedicated staff at the Woodbridge Development Center have supported him well on behalf of the state of New Jersey. But his family, our parents who both turn 90 year old this year, and his 5 siblings, also provide support to his life by visiting him at Woodbridge as often as we can.

This connection to family members improves Michael's quality of life. Although he does not speak, he sees and hears his visitors. He can feel our touch, our hugs and our kisses. He reacts to our presence often by teasingly refusing to make eye contact or by showing his interest in a new food offering one week and ignoring that same food the next. He demands variety from us and we find that endearing. He also sheds tears when one of us who lives far away comes to visit after a long absence. Through the years, by what I believe are memories of his childhood days when we lived together as a large family, he remains connected to us and cherishes us in his way, as we cherish him.

His quality of life is not the same as the quality of our lives who can attend this hearing. Anyone who visits Michael can see that clearly. But if the consolidation plan is implemented as proposed, Michael could be moved to a Center which is much too far away for our Dad to travel to visit. Our brother Carl lives in Bloomfield and teaches science to middle school students in in Bedminister, New Jersey. He visits Michael on most Tuesdays after school. But he will not be able to travel to see Michael on a regular basis, if the consolidation plan is implemented as proposed. Michael will lose these regular, tangible connections to his family – the same kind of family connection that so many of us enjoy in our lives.

Michael will never enjoy the independence of driving a car to the grocery store to pick up some fruit or cookies, or any of the other ordinary things that we take for granted. But he can enjoy the presence of his family in his life. And that experience gives him pleasure as it gives us pleasure who are gathered in this room. If the consolidation plan is implemented as proposed, Michael could lose these regular, tangible connections to his family, and his quality of life will be severely diminished. That seems an especially cruel burden for the state of New Jersey to impose on one of its most helpless citizens.

I do not propose a specific solution to the problems that generated the consolidation plan – although I certainly hope that the Woodbridge Center can continue to provide for my brother's wellbeing. But I ask the Committee members to protect the interests of Michael and those like him. They are among the most vulnerable of our community and literally cannot speak for themselves and their best interests. It is my duty as Michael's brother to bring your attention to Michael and other residents of the Woodbridge Center and to encourage you to use your power and influence to do the right thing for them on behalf of the state of New Jersey. Their lives are in your hands.

Thank you for listening and for the help you can provide.

13 February 2013

To the Legislators and Committee Chairs present today, thank you for holding this hearing. My name is Mary Hazen Johnston; I am the older sister of Michael Hazen. I have driven here from Boston to attend this hearing. My brother has lived at Woodbridge Developmental Center for nearly 40 years, since 1973. In that time the excellent staff and medical professionals have cared for him well. Members of my family have visited once or twice every week.

Michael is severely disabled. He cannot walk or talk, and needs assistance to meet his most basic needs, from eating and drinking to bathing and personal hygiene. He has emotional needs just like we all do. As a child, Michael could walk and talk and we had a loving relationship. I used to give him rides on our tandem bicycle, walk him to his summer camp bus stop, and play in the yard with him. He used to tease me, like any little brother does. However, even at his best, he had the mental capacity of a three year old and needed constant care. Although he can't talk anymore, I am confident that my visits connect Michael to his childhood and to me. He can feel my love for him. Sometimes when I visit, a tear runs down his face. In his own way, he shows how much these visits mean to him.

I live in Boston and visit Michael several times a year. My parents chose to retire to Perth Amboy, close to Woodbridge, so they could be near Michael. My 90 year old father, George Hazen, visits weekly. If Michael were moved farther away, my father would not be able to see him often. My brother Carl lives in Bloomfield and despite his busy schedule, he visits Michael weekly as well. My other siblings, who live out of state, see Michael whenever they come to New Jersey.

In 1973, the state of New Jersey made a commitment to Michael to care for him and provide a home for him. If Woodbridge were to close, our family would not be able to visit Michael regularly. This would severely affect his quality of life. He has so few pleasures in life. Please don't limit his life further by closing the home which he has known for nearly40 years and depriving him of the family contact he has enjoyed all these years. Michael and all the residents at Woodbridge Developmental Center are among the most defenseless and vulnerable citizens in the state, and depend on you to recognize and provide for their needs, both physical and emotional. Please keep Woodbridge open!

Mary Hazen Johnston
80 Bedford St.
Lexington, MA 02420
781-861-6748

DAVID SCHLETT
106 WINTHROP RD
EDISON,NJ 08817
732-287-1233
DAVE4EVER@OPTONLINE.NET

FEBRUARY 13,2013

Hello, my name is David Schlett, I live in Edison NJ. I am brother and legal guardian to Jeffrey Schlett, he is 55 years old. Jeffrey's home is the Woodbridge Developmental Center, for the last 43 years. Government is very supportive of individuals in need. Drug addicts, alcoholics and criminals all receive financial assistance from the government. They have the ability to change, but they keep making the same wrong bad decisions. The residents at developmental centers don't have the capacity to make any decisions. Please don't make any decision to make their lives more difficult than they are. By sending them out to live in the community you're making their lives expendable. The care that they will receive won't be the same. Societies will be judged by the care that is given to the individuals that are the most vulnerable. You were elected to make responsible decisions affecting our society. Do the right thing, so that we never have to say I told you so.

Thank you

David Schlett, brother of Jeffrey

Joint Committee on Human Services
Statement submitted by Eileen Oujo
Sister of Edward, Cottage 8

My name is Eileen Oujo, and my brother, Edward, is a resident of Woodbridge Dev. Center. He has been a resident of Woodbridge since 1966. I am here today to voice my objection with the decision of the Task Force to close Woodbridge Developmental Center and North Jersey Developmental Center, and to force these residents to move to group homes. The residents of these developmental centers are the most profoundly disabled and medically fragile members of our community.

My brother is profoundly disabled, and is completely dependant on his caregivers for every aspect of his life. I would like you to think about his condition. He cannot speak. He cannot walk. He cannot feed himself. He cannot toilet himself. He cannot dress himself. He cannot eat regular food, but must eat pureed food to prevent choking. He is self-injurious, and bites his wrists when frustrated or anxious. He needs care 24 hours a day, 7 days a week. Clearly, he needs and is entitled to the ICF/ MR model of care. Under this model of care, all necessary services are provided on site at the developmental center. He has access to physicians, psychologists, dieticians, speech therapists, physical therapists, and a whole myriad of professionals experienced in the care of the profoundly disabled.

He is not a candidate for a group home, and should not be forced to move to one. Most of the people who live in group homes are ambulatory, can communicate, can dress and feed themselves. This is not the case for my brother, as well as for most of the residents remaining at Woodbridge and North Jersey. The level of care provided at group homes is much lower and does not adequately address their needs. In group homes, all services would be provided in the community, and would not be readily available.

I would urge this committee to initiate legislation that would prevent the closure of these Developmental Centers. The residents of these centers cannot and should not be forced to accept care that does not adequately provide for their special needs.

Respectfully submitted by:

Eileen Oujo
1218 Candlewood Lane
Sea Girt, NJ 08750
eoujo@aol.com

Would like testimony read but does not wish to speak.

JOSEPH R. MILBROOK
234 Warburton Avenue
Hawthorne NJ 07506

February 11, 2013

Gentlemen:

My twin brother, Gary,was first placed at North Jersey Developmental in Totowa in 1964 And then transferred to Woodbridge in 1966 which is abrut an hour's drive.

He is 53 years old..cannot walk. talk, ot feed himself, must have strained foods, and would not benefit from .community placement.

I believe his rights are being denied because he needs to be in a protective , safe environment such as Woodbridge,

When he was first placed in Totowa, my parents were about twenty minutes away. When he was transferred to Woodbridge, it is about an hour's drive. My Dad has since died.. It really is not fair to close the only two centers located in North Jersey. My mom is 81, I drive to visit Gary.

I urge you to reconsider this decision.of closing both of these centers which are located in North Jersey

Sincerely

Joseph R Milbrook

Joseph R. Milbrook

twin Brother & Guardian

Joan Butman on behalf of my parents and brother.

February 12, 2013

TO: The Joint Committee on Human Services
Senator Vitale and Assemblywoman Vainieri-Huttle

FROM: Mr. & Mrs. Louis Maresca, parents and guardians of
Thomas, C-16.

Our son has been a resident of Woodbridge Dev. Center for thirty years. Prior to that, he was a resident of Woodbine Dev. Center. We asked for relocation so that we could visit him more often plus the facility was so much newer and seemed better, which proved to be true. It has been wonderful having him in Woodbridge, and he is very happy there. I cannot emphasize enough the loving care he receives from the staff, many of whom have been there since Thomas was first admitted to Woodbridge. This is his home, and they are his family along with the other men who live in C-16. Removing him would be like splitting up any other family.

If our son is placed in any of the development centers that are slated to remain open, he will be cut off from us and his entire family because of distance. My husband is 86 and I am 80. It is hard for us, but we can manage to visit him once a week and take him for a two-hour ride in the car, which he loves to do. But when we return, he is happy to run inside and get in his recliner where he is perfectly content. All in all we drive four hours each time. If he were in Hunterdon, it would add 3 hours to our trip. Woodbine would be even further away. There is no way we could do it, and it would be much further for our children to visit.

I do not know if he would be accepted in a group home because of his behavior and eloping problems. His inability to speak would be very serious if he managed to get out which he often did when he was at home even with triple locks on the doors and triple fences around the property. He is very fast and would be hard to catch. He has no fear of traffic and could easily be struck by a car or truck.

I also worry about his health care. At Woodbridge, there is always a nurse available, and the doctor is on premises and knows how to handle patients with the behavior problems of most of the residents. There is also a dentist available with the capability of handling patients with the problems of hyperactivity and incomprehension of what is being done. Nor do we know beforehand if there would be a doctor or dentist in the vicinity of the group home who would take him on as a patient because of his behavior problems.

To add to all of this, Tom does not handle change well at all. His behavior could become unmanageable. All things considered, this move could be life threatening for our son.

Before closing Woodbridge please visit the facility and see just how good the staff is and see how well the residents are treated and how happy they are.

It is my hope that the law can be changed so that Woodbridge can remain open. I don't see any other solution to his problem and that of many others living at Woodbridge - some of whom are much worse off than our son, Tom.

The lives of many people will be affected by your decision. Please make it a good one.

Respectfully submitted,

Theresa Maresca

Testimony for Developmental Center Closure Hearing

NJ Senate Health, Human Services and Senior Citizens Committee and Assembly Human Services Committee

February 13, 2013

Our names are Dante Chrystal and Sidney Katz and we are self-advocates from the New American Movement for People with Disabilities. We appreciate the opportunity to appear before the committee today to talk about why institutions should be closed. We are testifying on behalf of people with disabilities in New Jersey.

We would like people with disabilities to enjoy the benefits of living in the community. People with disabilities should be able to recognize their rights and give back to their communities. We have to speak for them because no one else is speaking for them. In the past, parents put their child in institutions because the doctor said that their child would be better off. It is wrong for people with disabilities to be in institutions because they are treated horribly. The living conditions are also very poor. It is time to treat us like human beings rather than animals. We hear plenty of horror stories about what they do to the residents and it is unacceptable.

Nowadays, more people with disabilities are living in the community because there are more options available. As research and personal stories have shown, people with disabilities achieve more fulfilled lives in the community. Parents should look into these resources as they are very helpful. In the long run, it is cheaper for the state government to integrate people with disabilities into the community. Although the unions don't want to lose their jobs, they need to understand the life-changing burden it places on people with disabilities.

We receive services from Community Access Unlimited. Our organization believes that people with disabilities are just like everyone else. We can go out to eat with friends, we can work in the community, we can go to school, we can make choices about our daily lives, and we can choose to get married. The services we receive at CAU encourages us to make these choices. It is no shame to have a disability. Living in an institution makes people with disabilities feel ashamed about who they are and allows society to have a negative perception of the disability community.

You can't walk in our shoes, you can't step on our feet – we are proud people with disabilities. It is time for New Jersey to be completely Olmstead compliant.

Thank you for your time and consideration,

Dante Chrystal and Sidney Katz

The New American Movement for People with Disabilities

To: Whom It May Concern
From: Isabel Sly

Re: Closing of North Jersey Developmental Center

My brother is William Espejo; he is 52 years old and lives in Cottage 7 at the Developmental Center. William is epileptic, retarded, has behavior problems and is unable to take care of himself. He has lived in some type of facility since he was 10 years old because of these problems. These places have been 'home' to him.

During the late 1980's and through the 90's, William lived in the North Princeton Developmental Center. Upon its closing he was placed in a group home with the SCARC agency. The home William knew and understood was gone and going to a group home with different rules and a more lenient life style was detrimental to his behavior.

The time spent in the group home was a horrible 4+ years. The staff was kind and meant well – but they were unable to control him and many times had to call me to come and discipline him. Through that time there were many trips to the hospital, calls by the police and general havoc wreaked on the SCARC care givers, the group home neighbors, the poor police who had to respond to calls and the hospital emergency room people who had to deal with the end results. After 3 ½ years it was decided that SCARC could not keep him in the group home. It took another year+ to place him at North Jersey and lots of time on waiting lists.

Group homes are good – it's a great idea. I've had the opportunity to meet many individuals for which that type of setting works well. Unfortunately it is not for everyone. It is not a one-size-fits-all, especially as individuals have different needs – some more than others medically, emotionally, and behaviorally.

Closing North Jersey and other Developmental Centers puts those that require a very strict and controlled environment at risk. It also puts our communities at risk because the people are not equipped intellectually and emotionally to deal with people who have severe medical, emotional and behavioral problems.

Closing North Jersey will take away what is home to a great many people. The care givers are family and friends to them. Their ability to discipline those who need it, take care of individual needs and ensure that the people that are in their care receive the best care available is what makes North Jersey Developmental Center a home. Uprooting my brother and others like him, yet again, is heartless and shows a disrespect to those who cannot take care of themselves.

Margo Post Marshak
31 Sleepy Hollow Drive
Newtown Square, PA 19073-3929
610-356-2244, mmarshak@caltech.edu

October 18, 2012

For the Hearing on the plight of NJDC/WDC residents by a New Jersey Senate/Assembly Committee

Dear Members of the Senate/Assembly Committee:

In my opinion, a decision to close the North Jersey Developmental Center (NJDC), an institution for which the State of New Jersey should feel great pride, is unconscionable. It is especially cruel to clients, particularly those who are older, who have spent many years of their lives at NJDC because of their fragile physical and mental circumstances. Is New Jersey so poor and so lacking in compassion that it will make a choice to abandon the appropriate care of its most helpless citizens?

I am aghast by what closure would mean to my sister Sarah (Sally) Post, our family, and many of the residential clients and their families. Sally has lived at NJDC since 1996. She is 61 years old with marginal intelligence and multiple medical and psychological problems.

NJDC has been remarkably good for, and to, Sally. The constancy and consistency, caring, and collaboration of members of the staff should be an example to all institutions; they are extraordinarily dedicated people who day in and day out do a very difficult job and work extremely well together. Sally receives constant medical guidance and attention. Her psychological therapy has been productive, and she has gained insight into her problems. The quality of her meals appears to be the only weakness of NJDC.

Sally's siblings, and our mother when she was alive, tried multiple living arrangements for her before she went to live at NJDC. These included living with my mother, living as an adult in a house that we bought for her, living there with and without a roommate, and living in two different group homes under the auspices of the State of New Jersey. None of these worked for Sally, and we were in constant fear for her security and safety. All were inadequate, including the group homes, because there was never enough oversight and care, and she got herself into constant and serious trouble. Some years ago when Sally was offered an opportunity to move from NJDC to a third group home, she told me that it would be an unsafe environment for her and that she wanted to stay at NJDC for her lifetime. So where would New Jersey safely place Sally?

I would be pleased to answer any questions that you might have about my perceptions of NJDC. I spent 15 years as Vice President of three of our nation's greatest institutions of higher education, and I originally felt devastated that Sally's best chance for a secure life would be at NJDC. The staff there proved me to be very wrong, for which I will always be grateful.

Sincerely,

Margo Post Marshak

Margo Post Marshak

224v.

✓

[redacted]

Family Member Name: CHRISITA SINAGRIA

Relationship to Client: MOTHER / GUARDIAN

Client's Name: JOANNE SINAGRIA

Client's Age: 49

Family Member's Phone #: (609) 927-0427

Family Member's Address: 17 PRIMROSE CIRCLE,
EGG HARBOR TWP., NJ 08234

# of Years Client Has Been At the Facility: 45

Medical Background of Client: BORN WITH STURGE-WEBER DISEASE. PROFOUND BRAIN DAMAGE. SUFFERS SEIZURE MENTAL DEVELOPEMENT "2 MONTHS OLD"

Concerns of the Family: ALL SHE IS CAPABLE OF UNDERSTAN
IS PAIN, HUNGER & KNOWING THOSE WHO CARE FOR H
WHENEVER SHE HAS HAD TO BE HOSPITALIZED (OUT O
HER LIVING FACILITY) SHE BECOMES TOTALLY DISTRES
DOES NOT EAT - HAS TO BE FED WITH FEEDING TU

TO TAKE HER AWAY FROM THE ONLY "HOME" SHE
HAS KNOWN AND THE PEOPLE SHE KNOWS AR
RELATES TO WOULD BE, IN MY OPINION, LIFE
THREATENING. SHE KNOWS NO OTHER PLACE BU
NORTH JERSEY DEVELOPMENTAL CENTER. SHE I
INCAPABLE OF UNDERSTANDING WHAT IS GOING

October 13, 2012

5224 S. Birmingham Place
Tulsa, OK 75105-6616

LAURIE MASON
9-1-55   3-19-12

Dear Mr. Friedman,

I received your correspondence and want you to know how concerned I am for all the guardians and residents at the North Jersey Developmental Center. I first read about the closings of both developmental centers in a publication called *New Beginnings In Community Liv*ing and was appalled. I am no longer a part of this community as my daughter, Laurie, passed on. I give things to God for taking her when He did. I have nothing but compassion for those of you who are faced with this enormous problem and pray for all of you.

Moving residents to community living has been on their agenda for many years. Laurie was a profoundly retarded daughter who was unable to verbalize yet they continually sent mail requesting that we allow her to enter community living - even though she was a Hepatitis B carrier. We rejected the idea each time. If she were still living I do not know what I would be doing.

I will gladly fill out the forms you are requesting to be returned to you - I do not know if it will be accepted since I no longer have any relationship with Totowa.

You have my sincere respect and admiration for the task that you are undertaking and the challenge all of you face.

Sincerely,

Ruth V. Mason

Ruth V. Mason

22lox.

2/13/13

To whom it may concern,

Paul Eric Vacca is a resident of North Jersey Developmental Center in Totowa New Jersey. Paul is a non-verbal fifty-one year old profoundly retarded man who has cerebral palsy. He walks very unsteadily and needs twenty-four hour care.

Paul has lived at NJDC for the past twenty one years. Paul is very happy there, and moving him out of his home, which he knows very well, would not be a good idea. Paul will regress, which he has done in the past when there has been a change in his life.

We are at an advanced age, and we would not be able to visit him as often as we do if Paul is moved far away.

Please reconsider closing NJDC, where Paul and other clients will be out of a home where they feel safe and know their surroundings.

Thank You,

Donald N Vacca & Theresa Vacca
Parents and Guardians of Paul Vacca

227x

Hearing On WDC Closure
Feb. 13, 2013

My sister, Evelyn Ervington, lives at WDC in cottage 11.

Evelyn was placed in an institution at the age of 17 when my parents could no longer care for her at home. She is now 66 years old. For many years Evelyn was misdiagnosed as insane and treated with various psychotropic drugs that may have controlled certain behavior but left her unable to develop to her potential; and in addition medicines that had very serious and lasting side effects.

After many, many years Evelyn was accepted at WDC where she finally received the care and treatment that helped her develop and have a life worth living. Her special needs cannot be accommodated in a group home. She is now a senior, in a wheel chair and walker; is incontinent; cannot bath or dress herself without assistance; and needs regular doctor visits as well as special dietary care and physical therapy. Evelyn must have these services and round the clock care by professionals that are experienced with her needs. In my research, community placement does provide care and service that is equal and certainly not better than what my sister is receiving at WDC.

Finally, I live in North Jersey. If WDC is closed the closest developmental center to me would be Green Brook, which according to DDD, only have a few openings. The other centers are in South Jersey and approximately 2-3 hours away. It would be with great difficulty and at times impossible for me to visit my sister, attend her IHP meetings or bring her home. I know that this would be a major setback for Evelyn.

It is my hope that government will not forget that these, our most venerable citizens, are also entitled to life, liberty and happiness.

Thank You.

Georgia Van
50 Leslie St
Newark, NJ. 07108
973-399-1738 (H)

My name is Kathy Toth, and I have a sister who currently resides at North Jersey Developmental Center in Totowa. Due to work commitments I could not be here today to share with you personally, but I would like to take the opportunity to share with you through this letter.

On a personal level, speaking about Patti, North Jersey is her home. We, her family are the lucky ones though. We are able to be there for her. We see her every weekend and she can stay overnight with us. She is able to come with us to the park, bowling, long weekends, and vacations. We even enjoyed going to Disney World one year. With all that said, after the day, the weekend or the vacation away is over, Patti goes HOME. Back to her friends and the dedicated people who take care of her. Patti loves her bags and shoes, don't all girls? She has her friends who trade bags; you never know what purse she will be carrying when we go to pick her up. Is it her's or did she borrow it from Gerry? Maybe she will choose to relax in her room and watch her stories in the afternoon, she has that ability to do so, or if she feels more social today, she can gather in the common area and share with her friends. Patti has a pretty even tempered personality, and is easy going. Unless you take her magazine away while she is reading it she is usually very calm. She is known to be very stubborn though. The staff over the years has learned how to get through the stubbornness because they know her needs and know how to communicate with her.

The center has so much to offer. There is occupational therapy to put her to work and keep her active all the time. Speech therapy, so she can better express her needs and wants. Recreation gets her up and out to shoot some hoops, or participate in the walkathon. Recreation that provides bus trips to the park or to the movies. Maybe even the mall. There are nurses on duty at the cottage where she lives. When she had to go to the emergency room via ambulance, there was someone who was with her, someone she knew and trusted until we could get there to be with her. Staff who stayed on to make sure she was taken care of even after we arrived and she was admitted. There are doctors on staff at the center. Patti usually refuses to go to the doctor outside the center, even if one of her friends or sisters goes with her. Having medical staff on the campus, we know she is getting all the nursing and medical attention that she needs.

The question to answer is why do we need the center? Patti needs the services that the center can provide. She will not go out for everyday medical appointments. She will not go out on trips on her own. She will not go out and get some exercise on her own. She needs the staff to encourage her. But she is lucky that she has family that also is able to do these things with her. There are many clients that don't. It is about all of them. It is easy to listen to me and the others speak of their own family members. We need to speak for all the residents who don't have a voice here today. They need the services the centers provide. They need the staff that knows who they are and what their special needs may be. They need the home that they currently enjoy and it is all they know. The centers are able to provide the quality of life that each and every one of you enjoys. The centers provide the Family for the residents that are not lucky enough to have family close by, or family at all. We are an aging organization, as our population ages, so do their family members. Family is the other residents. Family is the direct care staff.

Family is everyone who is dedicated to the residents. So many of the staff know the residents by name, and as they walk around campus can talk to them directly by name because they care, just like we all care about our family members.

Why the Center? Because we need to stay committed to provide and maintain the quality of life that everyone in our "Family" deserves.

Thank you for giving me the opportunity to speak with you today. I urge each and every one of you here, who has never visited a center, to come out and see our homes and our residents. The center as well as the residents would love to meet you.

KAthy Toth - 201-475 8375
59 PArkview Ave
Elmwood PARK, NJ 07407

NJSHA

February 13, 2013

To: The Senate Health, Human Services and Senior Citizens Committee

The Assembly Human Services Committee

FROM: Linda Tucker, President elect

New Jersey Speech-Language Hearing Association

RE: Hearing on the Closure of North Jersey and Woodbridge Developmental Centers

Thank you for the opportunity to submit information regarding the planned closing of the North Jersey and Woodbridge Developmental Centers. The New Jersey Speech-Language Hearing Association (NJSHA) is a professional association that represents speech pathologists and audiologists in the state. addition to working on communication, including speech production and use of language, speech language pathologists are involved in managing feeding and swallowing disorders (dysphagia). Communication and swallowing are central to quality of life, health, and safety of the residents of these centers.

In the past, residents of these large residential centers have been discharged to group homes, and have done well in those new settings. The existing problem is that those who currently reside in the centers are usually the most severely involved. They are the multiply handicapped, medically fragile or dually diagnosed (developmental disability and psychiatric disorder) individuals whose conditions tend to be unstable. In the developmental disability centers these individuals have daily access to speech-language pathologists who may modify their management on short notice as the conditions change. These are individuals for whom placement in the community could be problematic. Additionally, these individuals are aging. With aging comes a decline of skills, so that those who have been eating safely up to this time can encounter more challenges when eating. Choking, malnutrition, dehydration, and pneumonia associated with aspiration of food and liquid are not uncommon in this population. Hearing loss interferes with communication. Disorders of aging may further disrupt communication and swallowing functions exposing these vulnerable individuals to harm.

Speech-language pathologists as well as physical therapists, occupational therapists, and dieticians are all involved in ongoing modifications of diet, seating, and adaptive utensils to help these individuals remain oral feeders while continuing to meet their nutritional needs in a safe manner. For those who are hospitalized and return with gastrostomy tubes, the team is involved in determining if and when the client can return to oral feeding. This team approach has been central to maintaining health and safety of these complex and severely impaired individuals.

At the present time, in the community group home setting, these critical services to maintain health and quality of life are not readily available to the clients. Additionally, the staff working in the home does not have the guidance from a team of knowledgeable health-care professionals regarding communication, feeding, and swallowing issues.

The New Jersey Speech- Language-Hearing Association encourages the committees to consider these problems in their deliberations. If in fact, more individuals are discharged to group homes it is imperative that these crucial healthcare services be available to them, on a consultation basis, to help ensure that they can meet their communication and nutritional needs in a safe and effective manner.

To Whom It May Concern regarding:

Keeping North Jersey Developmental Center located in Totowa, NJ OPEN

I am writing this letter on behalf of the residents of the North Jersey Developmental Center concerning the importance of keeping this facility open. The families of the patients who reside here have expressed to me how fortunate they are to have found such a wonderful caring staff to help them in the care and well being of their family member.

The care and treatment they receive at this facility by the healthcare professionals is truly one of a kind. They go above and beyond to make the residents life as comfortable as possible. I am the mother of three children and can only imagine the hardships that these families endure when they can no longer care for their own family member. I can not express how heart warming it is to here that such a place still exists.

I hope and pray that the funding to keep this place operational can be resolved. The North Jersey Developmental Center is worth fighting for and I hope you can see the value of keeping such an institution open for years to come. Please give this matter serious consideration for all involved.

Thank you for your time.

Sincerely,

Beatrice Miele

234x

02-11-2013

To Whom It May Concern regarding:

Keeping North Jersey Developmental Center located in Totowa, NJ <u>OPEN</u>

I can't express enough on how important it is to keep this facility open for the clients that reside at the above location. Antonio Melero (TJ) has been at this location since Sept. 2008 and he is going to be 30 years old on March 3rd.
His mother (my cousin – Terry Campagna) comes to visit TJ ***<u>EVERY DAY</u>****.*

TJ cannot see, nor talk, which means TJ cannot express himself verbally or visually and is confided to a wheelchair. TJ is unable to shower, dress, or feed himself. TJ is unable to take care of himself and needs 24 hour care.

The other most important thing is the fact that there are Doctors and staff right on the premises when an emergency happens that they are prepared to handle the issue at hand.

Thank you for your time to this very important matter!

Sincerely,
Richard & Shirley Cronen

02-11-2013

To Whom It May Concern regarding:

Keeping North Jersey Developmental Center located in Totowa, NJ <u>OPEN</u>

I can't express enough on how important it is to keep this facility open for the clients that reside at the above location.

*Antonio Melero (TJ) has been at this location since Sept. 2008, and he is going to be 30 years old on March 3rd.His mother (my niece – Terry Campagna) comes to visit TJ **<u>EVERY DAY.</u>***

TJ cannot see, nor talk, which means TJ cannot express himself verbally or visually and is confided to a wheelchair most of the day. TJ also gets seizures from time to time which when that occurs it sets him back for days! TJ is unable to shower, dress, or feed himself. TJ is unable to take care of himself and needs 24 hour care. The other most important thing is the fact that there are doctors and staff right on the premises when an emergency happens that they are prepared to handle the issue at hand.

One last thing I would like to mention is the fact that the staff here at North Jersey Developmental Center are one of the most caring, loving and professional teams that I am proud to have the privilege of knowing. My heart goes out to them as well because they do their jobs more than 100% and give back to their clients as they were their own.

Thank you for your time to this very important matter!

Sincerely,
Ruth Sanders

McMillan, Pat

From: McMillan, Pat
Sent: Wednesday, February 13, 2013 9:25 AM
To: McMillan, Pat
Subject: Statement for Community Placement Hearing February 13, 2013

I am here today to express my concern about the initiatives occurring in the State of New Jersey to close Developmental Centers and require community placement of their residents, which has the potential to seriously jeopardize the lives of New Jersey's most vulnerable citizens-those with profound developmental disabilities. This very personal issue for my family has been raised at my sister, Sherry Keating's yearly evaluations which I attend as her legal guardian and as my family's advocate. Over the last several years I have received correspondence and phone calls requesting my attendance at meetings to convince me of the value of community placement, over Sherry's continued residence in the development center environment in which she has resided for the last 50 years.

I have written and verbalized to the proponents of these plans that my family and I are adamantly opposed to community placement for my sister, Sherry, at any time in the foreseeable future. Sherry was diagnosed as being profoundly mentally retarded due to lack of oxygen at birth (hypoxia). She was afflicted with cerebral palsy and seizures, and at the age of 6, my parents made the torturous decision to institutionalize her since they were not able to meet her needs along with those of the other children in our family at that time. Due to her severe impairments, Sherry requires constant supervision to prevent her from potentially harming herself or others. She has the IQ of an 18 month old although she is 56 years of age currently. During her 50 years of institutional living, Sherry has developed some limited skills while under the care of Woodbridge Developmental Center's team of professionals. I laud the work they do and their commitment to improving the lives of its residents who cannot live independently and, in my sister's case cannot properly verbalize their needs.

Developmental Center residents who have resided in and regard the Center as their home for their entire adult lives should not be cast to the winds in the State's efforts to balance its budget off the backs of its most vulnerable citizens. To mandate community placement for my sister or anyone similarly situated is unconscionable and my family intends to rigorously fight any proposed plan to act on removal of my sister from the only home she has known for over forty years. The economic woes that our State is currently facing were not created by our developmentally disabled residents, whose lives would be severely disrupted and compromised by community placement ~~of its most vulnerable residents~~, who endure significant difficulties and hardships without the State ceremoniously closing the Centers that sustain their daily existence. There are better, more humane ways to balance budgets than to dismiss those who, through no fault of their own, depend on the care they receive in an institutional setting and instead pretend their needs and safety issues would be adequately addressed in a community based home.

I am acutely aware of the economic realities facing Americans today and the difficult decisions our elected representatives face as they struggle with balancing budgets in such a tough economy. However, I feel strongly that it is a moral imperative to minimize disruption and avoid devastation to our developmentally disabled citizens who should not bear the brunt of fiscal slashing simply because they cannot speak for themselves. Since my sister cannot independently care for herself outside of the institutional setting that has nurtured her and developed her limited skills, what reasonable mind could posture that placing her in a community based home could in any way replace the level of care she needs and has known for fifty years? I implore you to do the right thing for our most vulnerable, disabled residents of developmental facilities and discontinue pressuring them and their families to place them in community homes against their wishes and their needs for health, safety and security.

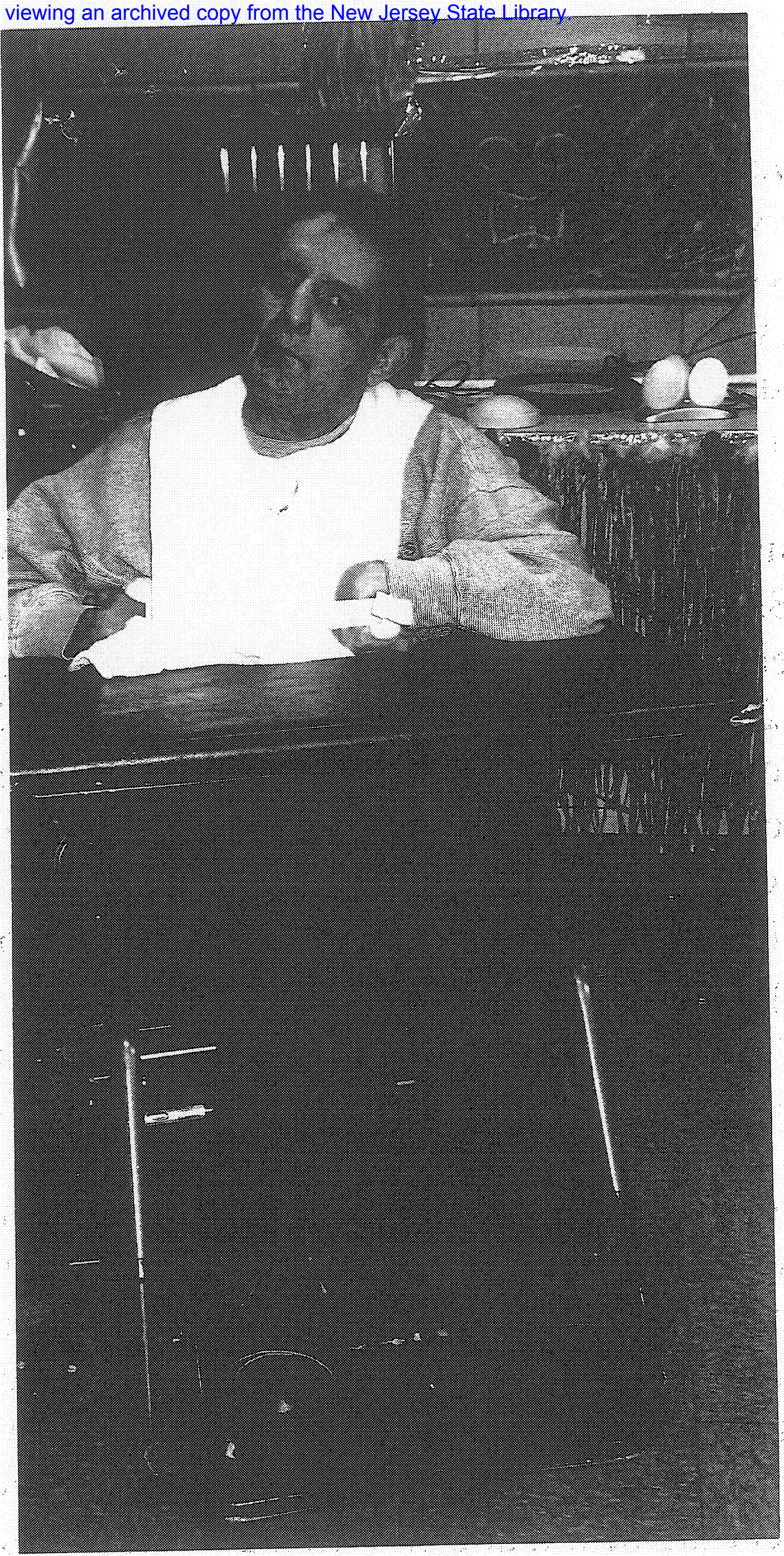
2-13-13

TO THE STATE OF N.J

I'M APPEALING TO YOUR SENSE OF DECENTCY TO KEEP THE HOMES OF THE LESS FORTUNET LIKE WOODBRIDGE DEVELOMENTAL CENTER OPEN! MY BROTHER GARY SCHWARTZ HAS SPENT MORE THAN HALF OF HIS 62 YEARS IN WDC. HE IS WELL TAKEN CARE OF, IT'S IN HIS BEST INTEREST TO STAY WITH THE PEOPLE THAT KNOW AND LOVE HIM!

Eugene Schwartz

732 349-5756



Hello, my name is Camille Senerchia Egan and I am here today to speak on behalf of my 69-year-old profoundly retarded, non-verbal brother, Michael. Michael has lived with his current WDC family since 1965. Yes, that is 48 years together in a happy, healthy, loving relationship that our parents hoped for when they had to face the reality of not being able to offer Michael all the services and care that he needed. They placed his needs above their own and found the location that they thought was the best for their eldest child and only son to live out his days. I am sure you would agree that it was not an easy decision for loving parents to make but it was THEIR decision to make.

Michael relies on the staff for 100% of his care. He is confined to a wheelchair with limited use of his arms and practically no use of his hands. He must be transferred via a mechanical lift with 2 staff members assisting to void potential injuries. He cannot attend to his personal care needs or his food preparation tasks. He cannot manage his own money, maintain his clothing or living area or move from one room to another without staff assistance.

Michael receives Occupational Therapy 3x per week. He also needs alternate positioning both in and from his wheelchair to maintain his skin integrity, as well as, hands splints to reduce the risk of skin break down. He is on a diet of pureed foods with thickened liquids because of his severe dysphasia & chocking risk due to Parkinson's diseases. Additional medical concerns are; osteoporosis, constipation, periodontitis, partial seizure disorder and GERD.

Michael has been diagnosed with a mood disorder. He is very uncomfortable with unfamiliar persons or changes in his daily routines. WDC offers him most of his medical services on-site. He would not be able to cope with stranger filled waiting rooms and multiple doctors who are not experienced in dealing with the severely retarded.

Finally, Michael is used to having frequent visits from his " Bayonne Family". We have two aunts who are both in their 80's. I drive from the Jersey Shore, pick them up and in 25 minutes we are visiting Michael. We bring him goodies from his Italian background, he is smothered with attention and kisses from ladies that I am sure remind him of our mother. Moving him from his home in WDC to an unfamiliar community in New Jersey will make it impossible for me to pick them up for these much enjoyed visits. How can anyone possibly think that this would be in his best interest?

I understand that we are living in tough economic times and budget restraints must be made. However, as a retired special education teacher I know that one-size does not fit all. While there are many who can make a good life in the community my brother is NOT one of them. In addition, as caring sister, I beg of you not to make the cuts that directly affect the health and well being of New Jersey citizens that are not able to fight for themselves. Do not tear my brother away from the family that has loved and cared for him for the last ½ a century.

Council Members at Large
Kyle Anderson
James V. Carroll
Gregg M. Ficarra
Brenda Yori Velasco

Ward Council Members
First - Charles Kenny
Second - Richard A. Dalina
Third - Michele R. Charmello
Fourth - James H. Major
Fifth - Robert Luban

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Council President
Charles Kenny

Council Vice-President
Kyle Anderson

Municipal Clerk
John M. Mitch, RMC, CMC, CMR

February 11, 2013

Senator Joseph Vitale
569 Rahway Avenue
Woodbridge, New Jersey 07095

Dear Senator Vitale:

I am writing on behalf of the Woodbridge Township Council to commend you for holding a hearing to consider the planned closing of the Woodbridge Developmental Center, and to urge the committee to take whatever action possible to reverse the State's anticipated action.

The Woodbridge Developmental Center is a special place, filled with special people and a devoted caring staff. Closing the Center will have a severely detrimental effect on the residents and will impose a real hardship on the patients' families, many of whom already travel great distances to visit their loved ones. Moving the Center further away may prevent family members from visiting patients. At a recent Council Meeting, numerous family members of patients came to our meeting to elicit the Council's support to block the Center's closure. We were all moved by their obvious love and caring for their relatives, and the universal admiration for the Center. They believe, and the Council agrees, that closing the Center will harm its patients and the Township.

Additionally, the family members who attended our meeting told of the extraordinary care and kindness of the Center's staff. They consider the staff family. Further, the closing of the Center will cause workers to be laid-off. In a State where the unemployment rate is greater than the national average by nearly two (2) points, how can we undertake measures that will only exacerbate the problem?

Whatever monetary cost savings is achieved by closing the Center will be more than offset by the human cost to the patients and their families, and the loss of jobs by dedicated and caring individuals.

Please avert what will be a human tragedy. Take the action necessary to reverse the decision to close the Center.

Thank you for your consideration.

Very truly yours,

Charles Kenny
Charles Kenny
Council President
Attachment
cc: Assemblyman C. Coughlin
Assemblyman J. Wisniewski

Michele R. Charmello
Michele R. Charmello
3rd Ward Councilwoman

ADOPTED: SEP 18 2012

I hereby certify that this is a true and exact copy of a Resolution adopted by the Municipal Council of the Township of Woodbridge at its Regular Meeting held on SEP 18 2012.

COUNCIL VOTE

	MO.	2nd	ABSENT	Y	N	NO VOTE
R.DALINA				✓		
K.ANDERSON				✓		
J.CARROLL				✓		
G. FICARRA				✓		
R.LUBAN				✓		
J. MAJOR		✓		✓		
M.CHARMELLO				✓		
C.KENNY	✓			✓		
B.VELASCO				✓		

John M. Mitch

John M. Mitch, RMC, CMC, CMR
Municipal Clerk

Sponsored by 3rd Ward Councilwoman Michele R. Charmello

January 8, 2013

State of New Jersey
Department of Human Services
Division of Developmental Disabilities
PO Box 726
Trenton, NJ 08625-0726
Attn: Rita Rigby / NJ State Senate Committee

Eileen Fralinger, MS
Supervising Community Program Specialist
Olmstead Waiting List Unit

I am responding to your letter/survey sent to me by certified mail regarding alternate placement preference for my family member Louis Caserta. It is an error for DDD to assume that if you do not hear from me that my and my spouse's preference is consistent with the recommendation of the IDT.

Our 40 year old son Louis Caserta has been in NJ state developmental centers for over twenty years and has an ICFMR level of medical care, a status that must be maintained. Eleven of the last twenty years Louis has resided at the North Jersey Developmental Center (NJDC). We have seen firsthand how those years at NJDC have benefited him tremendously. My family and I adamantly oppose his transfer to another state institution in South Jersey where he would be far away from his family and cause all sorts of life issues about which I will elaborate and about which we have already experienced in the past. Also we are not in favor of him being transferred to a group home/community placement facility as a result of past negative experiences.

Several years ago my spouse and I placed Louis into group homes in our area to try them out, as Louis was becoming difficult to care for at home, and it met with failure as Louis was constantly expressing desires to leave because he was not comfortable with the settings and the staff was not able to fulfill his medical and personal needs. Louis was and is unable to talk and in that era aside from his autism and development disorders Louis was a very aggressive individual, especially if provoked, who required special care which could not be provided to him at home nor in a group home/community placement setting and as a result his stays were short lived and/or it was determined by the homes that he was not fit to stay. The last group home that he stayed at left a horrible lasting impression on my spouse and me as Louis somehow ended up attacking staff members (to this day we do not know what provoked the attack) and was met by a police officer who handcuffed him as if he were a normal human being (without autism or a developmental disabilities) who committed assault. It took such an incident along with a series of others for my spouse and me to convince the State of NJ that Louis could not be at home nor in a group home and needed to be placed into a state developmental center. Due to what we were told by the State of NJ, which was that there were no vacancies in either northern or central NJ developmental centers, Louis was originally placed in South Jersey at the New Lisbon Developmental Center (NLDC) which was a good 82+ miles away from our home and on most days would require a 2 ½ to 3 hour car ride each way from where we reside in Morristown, NJ. It was really hard on our son to adjust to being so far away and he never really did but we were content that at least he was in a facility that was properly equipped to take care of his medical and personal needs. Nevertheless, Louis suffered because he was not able to see his family often enough due to the distance factor and busy work schedules. He would often cry, especially when his family would leave him to go back home. As the years went on we could see that Louis's mental health was affected by his medication and more so by not being able to see his family as often and as a result he showed signs of depression and withdrawal from family involvement. Moreover, Louis was getting sick a lot more often and it was difficult to schedule visits when he was constantly ill and we were limited in the days that we could see him. Simultaneously Louis was also developing epileptic seizures that caused him to collapse and injure himself quite often. Most of the times his seizures occurred on weekdays and again we were unable to go see him due to the distance and busy work schedules. Moreover we were not able to be a part of the parent counsel which again was due to the distance and busy work schedules. All of this and more is what prompted our request to transfer him closer to home which took several years to come to fruition.

Once Louis was transferred to the NJDC in the Spring of 2001 we immediately saw a change in Louis's mental health. The staff is phenomenal and they treat us and Louis with the utmost respect and handle his needs to the fullest. We are contacted quite often by his social workers, nurses and other staff members regarding his progress and family event and not just when something negative happens to him (which has occurred less often than when he was in NLDC). We see him a lot more often because we are about a 20+ mile/25 minute drive away and with each visit we are able to spend a lot more time with him and bring him home if we feel that he is healthy enough to do so. Aside from the improvements to Louis's mental health we have also seen that his seizures lessoned over time which translated into less injuries which put us at ease as we are aging seniors and feel assurance in that our son is close to home and we are able to easily visit him at the NJDC in general or whenever he has medical issues and is brought to a local hospital.

Our fear as expressed by many other guardians at the NJDC is that if our loved one is moved to another state institution that is far away from home, (because as guardians we know that he is unsuitable for community placement), that he could once again slip into depression, become ill, aggravate his existing medical issues which could ultimately result in our biggest fear (and studies have shown that it is a sound fear) that individuals such as Louis, who are subjected to such moves after becoming accustomed to a good home at a state development center with close access to loved ones, could very well suffer from mental health issues and/or worse case scenario pass away before his/her time due to his/her medical and/or psychological issues that would go along with leaving a good state developmental center and being distanced from their loved ones, especially as he/she ages. I do not believe it would be in anyone's interest, even the State of NJ, to subject itself in possibly being directly or indirectly responsible for such tragic events.

I **do not support** any movement of my loved one and have not returned the placement survey because I found it inadequate to express my needs and opinions. No planning should take place without my input.

Thank You.

Sincerely,

Pellegrino Caserta & Family / Joe Caserta
(Giuseppe)
8 ½ Center Avenue
Morristown, NJ 07960
973-984-5983
201-230-9150

DEBORAH LYNN SHENK

AGE - 43

MENTAL AGE - 6 MONTHS

REQUIRES TOTAL CARE

SEVERE RETT SYNDROME

Deborah has lived at Woodbridge for over 20 years. Woodbridge is the BEST developmental Center in New Jersey. We cannot stress enough the positive impact the staff has had on her health and well being. The kind of total care Deborah requires CANNOT be achieved in a small group setting. She requires very specific one-on-one care during all aspects of her daily life – especially eating and drinking. She cannot help herself in any way.

The planned closing of Woodbridge will impact our ability to visit and bring her home for short day trips. The idea that a group home setting is appropriate for people with Deborah's profound disabilities is just plain wrong.

Developmentally disabled people have a wide range of capabilities…….please keep the most severely impacted in mind. The closure of Woodbridge impacts many of our most disabled.

Walter Shenk Colts Neck, NJ 732 685 3061
Janice Shenk

February 13, 2013

ADDITIONAL APPENDIX MATERIALS
SUBMITTED TO THE

SENATE HEALTH, HUMAN SERVICES, AND SENIOR CITIZENS COMMITTEE
AND
ASSEMBLY HUMAN SERVICES COMMITTEE
for the
February 13, 2013 Meeting

Submitted by Virginia O'Brien, Private Citizen:
Donald and Virginia O'Brien, "A CARING COMMUNITY ESSAY: Woodbridge Developmental Center should remain open, South Plainfield couple says," *Courier News*, December 9, 2012.

Submitted by Carolyn C. Wade, President, Local 1040, Communications Workers of America:
"Health Disparities Consensus," The American Academy of Developmental Medicine and Dentistry, ©2007-2012.

Submitted by Marylyn Carr, Private Citizen:
Suzanne Russell, "Hearing on planned closure of Woodbridge Developmental Center Set for Feb. 13," *mycentraljersey.com/njpressmedia/com*, February 5, 2013.