Committee Meeting

of

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

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

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

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

MEMBERS OF COMMITTEES PRESENT:

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

ALSO PRESENT:

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

Jason Redd
Senate Majority
Kate McDonnell
Assembly Majority
Committee Aides

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

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

Thank you very much.

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

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

This hearing today is not--

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

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

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

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

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

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

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

Assemblywoman.

ASSEMBLYWOMAN VALERIE VAINIERI HUTTLE (Chair): Thank you, Senator.

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

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

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

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

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

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

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

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

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

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

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

Thank you.

SENATOR VITALE: Thank you, Assemblywoman.

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

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

Ken, thank you for coming.

ASST. COMM. KENNETH W. RITCHEY: Thank you very much.

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

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

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

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

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

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

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

Our continuing examination of the future of New Jersey's institutions has been in the context of the experience we gained when we most recently closed North Princeton Developmental Center in 1998. Our development centers are home to 2,722 fragile individuals with multiple disabilities, many of whom have lived in those centers for decades. Moving them into the community is a complex undertaking that cannot be accomplished overnight or without careful consideration of each person's needs.

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

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

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

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

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

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

SENATOR VITALE: Thank you, Ken.

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

ELOISE E. HAWKINS: Good afternoon, and thank you for the opportunity to present comments on behalf of the developmental centers.

As Assistant Commissioner Ritchey has already stated, Vineland Developmental Center was the first facility to open, in 1888, so we have well over a hundred years of experience in providing services to people with disabilities. Our campus consists of two campuses, and also 20 group homes and supervised apartments housing about 140 women. We have been participating in the ICF/MR program for the last 30 years. At the time we began that participation, our census at the facility was upwards of 2,000 people. Since that time, our census has dropped by almost 1,600 people primarily going into community living arrangements. So we had much success in that process. Our census currently now is down to 421 people.

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

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

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

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

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

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

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

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

Thank you. (applause)

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

SENATOR ALLEN: Thank you. (applause)

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

Really? That will move things along.

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

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

Tom and Liz, are you both coming up?

Oh, just Tom.

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: That's fine, Katie.

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

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

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

By the early 1970s though, parents had started to think about other alternatives. They had some success in setting up schools, and work programs, and camps in the community. And they began to realize that they could develop residential options, as well, that would be closer to home and in the neighborhoods where their sons and daughters had grown up.

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

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

So the question is: If the community has come so far, why do people still end up in developmental centers? And the answer is very simple: it’s resources. New Jersey has not built a community infrastructure with adequate resources to meet all the needs. By this I don’t mean that the community agencies are not willing and don’t have the expertise. But what I do mean is that there aren’t enough beds, enough staff, enough professionals because those resources have not been put into the community over the years. And as a result, when a family goes into crisis and there isn't an appropriate bed available in the community, they do end up in the developmental center.

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

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

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

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

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

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

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

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

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

MS. WALSH: This is my end. Absolutely.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

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

Thank you. (applause)

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

Thank you.

Lowell.

LOWELL ARYE: Yes.

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

ABCD represents agencies throughout the state serving people with complex behavioral, as well as neurological and medical, physical, developmental disabilities. More than 10,000 people are served by ABCD member agencies.

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

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

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

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

Let me tell you one of the things that plan lays out. It includes how many -- who's in the developmental centers. On average, they're 50 years old, 57 percent have psychiatric diagnoses, 24 percent have cerebral palsy, 18 percent have autism, 39 percent have visual impairments. I'm not going to go through the list, but what I'm telling you is that those are the same people who my member agencies serve with quality and safety in the community.

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

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

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

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

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

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

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

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

Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Lowell.

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

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

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

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

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

In addition to my own children, and being a parent, and looking into the future, I am also the guardian of my 64-year-old aunt who lived in Vineland Developmental Center for 50 years. At the age of 12 years old, my grandfather had a massive heart attack and almost died. And at that point, he and my grandmother had to make the very difficult decision to place her in a developmental center or, as we knew it, an *institution* -- which we later referred to as her *school* -- because he was a wonderful provider and caretaker, and he did not want to leave my grandmother, should he have another heart attack, to be the sole provider of three small children and then have to get a job. And, obviously, my aunt had extremely significant needs, because she is severely developmentally disabled.

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

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

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

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

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

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

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

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

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

Thank you for your time. (applause)

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

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

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

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

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

We do have one question.

Assemblyman Coutinho.

ASSEMBLYMAN COUTINHO: Thank you, Madam Chair.

It's for Lowell, just one question.

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

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

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

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

Right, Mr. Malone?

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

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

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

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

ASSEMBLYMAN COUTINHO: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

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

I'm sorry, Assemblyman Malone.

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

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

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

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

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

ASSEMBLYMAN MALONE: Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman McHose.

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

Assemblywoman McHose.

ASSEMBLYWOMAN McHOSE: Thank you very much.

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

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

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

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

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

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

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

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

MS. ROSATI-PRATICO: I agree.

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

Thank you. (applause)

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman Wagner.

ASSEMBLYWOMAN WAGNER: Thank you, Madam Chair.

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

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

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

ASSEMBLYWOMAN WAGNER: It really is a question that--

MR. ARYE: That's exactly it.

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

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

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

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Before we call up the next panel, we have Committee Room 6 available. If any of you who are standing would like to be more comfortable, in Committee Room 6 we are streaming that as well. So if anyone would-- If you're in the hallways, if you're standing, if you'd like to move into Committee Room 6, it is available.

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

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

THOMAS BAFFUTO: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

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

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

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

One of our core driving principles at The Arc is to empower people with developmental disabilities with choice. We recognize that some people would prefer to remain at a developmental center rather than move into the community, especially those who have lived there most of their lives. We respect that choice. But at the end of the day, the reality is, we simply do not need seven large institutions anymore. The vast majority of people in our service system (applause) are more appropriately served in the community. And every dollar we invest into developmental centers is one less dollar we spend building up our community infrastructure.

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

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

Debbie.

DEBORAH LEGUTKO: Good afternoon.

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

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

My younger son Frank turned 23 on April 9. He has been living at Hunterdon Developmental Center for almost 14 months. Prior to that he was living at home with 24-hour nursing care for 22 years. Frank is autistic, on a ventilator and oxygen, and has had aggressive behaviors for many years. Early last year we became -- we were unable to manage his behaviors at home, and he became a constant danger to his caregivers and himself. Our only option was to find a nursing home or an emergency developmental center placement.

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

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

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

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

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

Thank you. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Todd.

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

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

ADELAIDE DASKAM: Hi.

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

I have a brief story to tell you and everything.

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

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

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

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

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

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

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

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

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

Thank you very much. (applause)

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you, Adelaide.

And please, folks, hold your applause.

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

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

Todd, she's a tough act to follow.

TODD LeROY EMMONS: Thank you very much, Assembly.

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

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

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

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

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

My family and my case manager helped me get out of there. I am now living in a wonderful, supervised community (indiscernible) with the Bancroft group. I love living there. I've been living there for 28 years now, and I love them. They're my family. Now my day is-- I can go anywhere I want to go, I do everything I want to do. I used to-- I was employed for awhile, now I'm not. I am able to take the Transit buses. I have friends. I now even have a girlfriend that I love very much. And I'm also, thanks to Governor Corzine, who was our former Governor, I am now the newest member of the New Jersey Council on Developmental Disabilities. I can't thank him enough for that.

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

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

Thank you very much. (applause)

SENATOR BUONO: Thank you, Todd.

Any questions for our panel?

Senator Allen.

SENATOR ALLEN: Thank you.

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

MR. EMMONS: Thank you.

MS. DASKAM: Thank you.

SENATOR ALLEN: You've been very helpful.

I would like to know-- Todd, you said that you left the center because your caseworker and your family helped you do that. Did you initiate that? Did you tell them, "I really want to get out of here?" How does it work? And also, are there -- does everybody know how to make that work?

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

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

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

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

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

MR. EMMONS: Thank you, Senator Allen.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman Wagner.

ASSEMBLYWOMAN WAGNER: Thank you, Madam Chair.

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

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

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

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

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

ASSEMBLYWOMAN WAGNER: Thank you.

MR. EMMONS: You're welcome.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you very much.

SENATOR VITALE: Thank you. (applause)

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

Mr. York.

THOMAS B. YORK, ESQ.: Yes.

SENATOR VITALE: You just flew in from Arkansas?

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

SENATOR VITALE: Oh, close enough.

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

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

MR. YORK: Sure.

SENATOR VITALE: Thank you.

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

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

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

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

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

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

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

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

SENATOR VITALE: Thank you.

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

Mr. York.

MR. YORK: Thank you, Senator.

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

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

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

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

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

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

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

And another important point I feel compelled to make was that there were allegations of abuse that were, of course, very old allegations. Unfortunately, I cannot testify as to the individuals -- probably outstanding individuals who work at your developmental centers here in New Jersey, because I have not had the good opportunity to visit with them. But if they are typical of the workers that I have found in most -- the vast majority of state facilities across the country, I would say that it is highly unlikely that these people are committing that kind of abuse here today. (applause) And I think it's a shame that these people-- If there was any implication that the current employees of your developmental centers are committing those kinds of abuses, I would say they are probably false. And I think-- I feel bad that these people have been tarnished in that way if that's what the implication was meant to be.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Outcomes for many mildly disabled individuals leaving institutions for community settings may be truly positive for them and result in an improved quality of life. However, that's not the population you're generally looking at here in the current developmental centers. However, severely and profoundly disabled individuals receiving highly professional, complex ICF/MR-level professional services within institutions, who are then placed in HCBS Waiver settings, may have difficulty gaining access to these services, especially medical care, psychiatric care, and behavioral supports which are often difficult to access or sometimes simply unavailable.

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Please hold your applause.

Thank you, Mr. York.

Any members have questions for Mr. York?

Senator Allen.

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

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

UNIDENTIFIED SPEAKER FROM AUDIENCE: What state?

MR. YORK: What state?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Yes.

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

SENATOR ALLEN: I asked about it being New Jersey-- As it happens, I served on the board of an organization that runs many group homes here in New Jersey and deals with many folks with developmental disabilities on many levels. And they do offer wonderful care and these sorts of things. I know many other groups that do. I honestly don't know of any that don't. I'm not saying that they don't exist, I just don't know of them in New Jersey. And it just concerns me that we would be thinking that there were so many groups in New Jersey, if we can't point to them, that are doing such a poor job that they would have these problems occur.

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

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

MR. YORK: That's very fair.

SENATOR ALLEN: Thank you.

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

SENATOR ALLEN: Thank you very much.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblyman Malone.

ASSEMBLYMAN MALONE: Thank you.

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

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

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

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

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

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

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

MR. YORK: That's true.

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

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

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

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

ASSEMBLYMAN MALONE: Thank you very much.

MR. YORK: Thank you, Senator.

ASSEMBLYWOMAN VAINIERI HUTTLE: Assemblywoman McHose.

ASSEMBLYWOMAN McHOSE: Thank you, Madam Chairwoman.

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

Thank you for being here today.

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

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

ASSEMBLYWOMAN McHOSE: Thank you very much.

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

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

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

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

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

ASSEMBLYWOMAN McHOSE: Thank you for that.

Thank you, Madam Chairwoman.

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

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

SENATOR VITALE: Thank you. (applause)

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

Welcome to you both.

Is Dr. Conroy here with you as well?

DEBORAH M. SPITALNIK, Ph.D.: I don't know. I haven't seen him, and he is about 6'2, so I assume--

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

DR. SPITALNIK: Thank you.

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

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

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

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

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

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

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

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

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

Assistant Commissioner Ritchey talked about the individuals served by the Division of Developmental Disabilities. And I want to point out that 70 percent of those on the Division's caseload live with their families, and that's in contrast to the national percentage of 57 percent. Additionally, we have a larger number of people living out-of-home in New Jersey, 22 percent.

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

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

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

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

As Commissioner Ritchey pointed out, in 1980 we had 7,262 people in New Jersey's developmental centers, which we then called *State schools* and *hospitals*. Between 1980 and 2008, we decreased the population by 59 percent. At the same time, the rest of the country decreased its institutional population by 72 percent. Our neighboring state of Pennsylvania, who started out with the same level of population that Mr. York referenced, decreased its large congregate settings by 82 percent in contrast to our 59 percent. Our pace of reducing the size of institutions is slower than the national average.

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

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

One is positive outcomes. There was no evidence associated with increased mortality or other negative consequences -- New Jersey-specific data. And despite initial opposition, there was eventual support for community living by a clear majority of North Princeton Developmental Center families.

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

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

The Intermediate Care Facility program that people mentioned -- Title 19, which both provided Federal funding, and standards, and improvements-- By 1977, 40 states had one ICF/MR. We did not, in New Jersey, enter this program until 1978. But when we did, it became the impetus for reducing the institutional population by over 1,500 individuals, 21 percent of the population, in the five-year period between 1980 and '85. And Kathy Walsh, in her earlier testimony, talked about how The Arc of Bergen and Passaic, and many others, developed services for those individuals.

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

DR. SPITALNIK: Sure.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

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

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

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

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

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

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

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Any questions from the Committee?

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

DR. SPITALNIK: Thank you.

SENATOR VITALE: There's been a lot of discussion today about choice, and that's appropriate. But respecting choice is certainly important. What kind of effect would-- If it is that the majority of individuals who currently reside in developmental centers -- their choice, the choice of the families -- for them is to remain there, how difficult would it be to then close a developmental center or two in this state if the choice was to stay for most people?

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

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

Many of these families who are ill or aging are hanging on and continuing to provide care not only out of their love and devotion for their family member, but because the alternative to them of their family member going to a developmental center is the complete abrogation of their life-long choice. I mean, there is a range of abilities and needs, both in the centers and at home. But I have recently been reading -- and I think it will be available to you -- the list of things that families who have their family member -- their daily to-do list of what families are doing at home. And there are families who are providing continence care, diapering, feeding, feeding tubes, cleaning ventilators -- whatever it is. And there are other families who can't leave their family member alone because of their need for supervision. We have to find a way to honor choice but to consolidate and/or close so that we can appropriately balance the resources in the community, and so that we can assure choice for all families. (applause)

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

DR. SPITALNIK: Thank you very much.

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

DR. SPITALNIK: I'm sorry.

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

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

ASSEMBLYMAN MALONE: Okay.

DR. SPITALNIK: But the question is--

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

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

ASSEMBLYMAN MALONE: Okay. Thank you.

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

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

Thank you.

DR. SPITALNIK: Thank you for your time.

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

Thank you.

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

Is Joe here? (affirmative response)

Joe, there you are.

Is Sue here? (no response)

Elaine Buchsbaum?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Alison Lozano.

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

JOSEPH B. YOUNG, ESQ.: Alison Lozano from the Council is speaking for Sue.

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

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

Thank you.

ALISON M. LOZANO, Ph.D.: I'm not Elaine Buchsbaum. Elaine had to leave to take care of a family matter.

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

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

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

In addition, DDD maintains waiting lists of over 8,000 people who want community residential services or other supports that will enable them to live outside the developmental centers. Thousands of families who care for a loved one at home do not get much in the way of family support dollars or self-directed service dollars to make their situations manageable.

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

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

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

Attached to the written testimony that you have been given is the Council's response to information being circulated by an organization known as Advocates for New Jersey Developmental Center Residents. We believe that the group's claims that 96 percent of guardians and family members prefer continued ICF/MR services over community services is inaccurate, and we demonstrate its inaccuracy in the attachment that you received.

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

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

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

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

SENATOR VITALE: Joe.

MR. YOUNG: Good afternoon.

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

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

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

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

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

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

Thank you.

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

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

UNIDENTIFIED SPEAKER FROM AUDIENCE: They are.

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

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

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

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

Cindy, are you--

MS. BARTMAN: I can talk pretty loud.

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

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

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

Good afternoon everybody.

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

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

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

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

During Commissioner Velez's Senate Judiciary confirmation hearing this past March, she was asked to explain why providers of community group homes were not required to rebid their contracts on a yearly basis. Ms. Velez replied, and I quote, "With respect to those served in the DD world, it is hugely disruptive for families to come to learn that the place where their son or daughter has been for a very long period of time, by a provider agency that is working well, may now lose a bid to the lowest bidder. That would be hugely disruptive to the system." I actually took some pain in explaining this to the Comptroller's office that, in this instance -- that if somebody is residing at a provider agency, and has done so for decades, to uproot that person because of a lower bid would be very disruptive for that family, for all families. And I still maintain that position. The disruption -- it's very unlike almost any other system. The continuity for families really is paramount.

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

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

SENATOR VITALE: We have all of that testimony.

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

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

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

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

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

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

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

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

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

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

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

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

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

Maria A.

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

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

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

Thank you.

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

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

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

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

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

SENATOR VITALE: Take your time.

CAROL MASTROPOLO: It takes me a while.

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

MS. MASTROPOLO: I'm sorry.

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

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

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

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

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

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

Thank you. (applause)

You don't know how hard that was.

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

MS. BARTMAN: Yes, we have--

JOANNE R. St. AMAND: Yes, my name is Joanne St. Amand.

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

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

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

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

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

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

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

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

John P. writes: "If you read my brother's Individual Habilitation Plan, you will see references that say that he would like to be put in a group home. There is a simple problem with that comment. My brother has never spoken a word in his life, nor would he be able to understand group homes or communicate his desires in any other non-spoken way. I raise the point because it makes me wonder how many other residents' files contain similar statements that may cause decisions to be made that are not in the best interests of these individuals."

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

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

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

Thank you. (applause)

WINNIE SEKELA: Can you hear me?

SENATOR VITALE: Yes.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay. Thank you.

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

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

Thank you so much.

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

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

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

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

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

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

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Okay, thank you.

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

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

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

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

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

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

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

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

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

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

We have 246 workers up there. They're going to demand unemployment compensation. Now, Governor Christie is very clear on that. "I've got no money left. We have so much unemployment, I have no more unemployment compensation." So their answer to him is, "Do what Christie Whitman did, and Jon Corzine. Go borrow it and add it to the deficit. We don't want to know that. We want to get paid." And look what they're going to get paid: $7.9 million. He's pulling out $800,000. He's going to save $800,000, but this is what it's going to cost him when he closes us down. When he closes us down it's going to cost this much money. I'm a magician. Do you want to see this ugly thing go away? Put this back in there, open us up, by God, and this disappears. (applause)

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

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

ASSEMBLYMAN MALONE: The question is--

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

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

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

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

MR. METTA: No, no more.

ASSEMBLYMAN MALONE: Maybe Mr. Ritchey can confirm that.

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

Second panel, if you want to introduce yourselves again.

Thank you.

And after this panel, we have three more panels.

Welcome.

VITO COLLETTI: My name is Vito Colletti. I'm here as a representative of the Vineland Developmental Center. I'm going to read you excerpts from the letters that were sent to this group today. It is spoken from the hearts and minds.

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

Now, from the excerpts: Barbara A., "Our daughter has been in Vineland DC since January 22, 2010. She was having major behavior problems with elopement, and hurting of staff in her day program with her efforts to get out of the door. At home she had been constantly running out of the door and down the street to the point where safety was a major concern. She went to Trinitas Hospital and then was admitted to Vineland. A group home had been identified to take her, but not for a month at least. At Vineland she has received excellent care. The staff is great. There are enough people available when she attempts to elope. She is a big girl, so it takes a couple of people to get her back into the building, sometimes with her fighting all the way. She has been attending a day program and is doing well enough. She had previously failed out of the four day programs in Ocean County due to her behavior. Thank God for the availability of Vineland. Where else are you going to go for a emergency placement of a developmental disabled person when it is needed fast? As a parent, I feel secure knowing that there are developmental centers available for my child and others when they are needed. I also know there are individuals who could not thrive in a community setting. The centers are there to serve them. What if my daughter fails in her group home? At least she has Vineland to fall back on. The mental staff is also great. They are able to get exams and lab work done on my daughter that, in the past, had to be done in an emergency room with her medicated and strapped down with six people to hold her. I guess you have to have the right people with the right training. Keep the DCs open and do not cut their budgets. They need every penny to continue caring for the developmentally handicapped in a respectful, careful manner, giving them the lives they deserve."

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

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

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

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

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

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

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

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

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

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

Thank you.

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

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

ANNIE ESPOSITO: You can hear me, right?

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

MS. ESPOSITO: How is that?

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

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

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

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

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you.

SISTO CAPONERA: My name is Sisto Caponera. I'm representing Green Brook Regional Center.

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

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

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

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

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

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

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

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

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

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Thank you very much, Sisto.

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

Next panel: we have Kim Todd.

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

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

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

We have Cindy and John--

KIM TODD: We have more.

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

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

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

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

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

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

JUDITH A. GRAN, ESQ.: Thank you.

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

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

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

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

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

Most of the people who moved to the community had severe and profound intellectual disabilities. Many of them had multiple physical disabilities, many of them had complex medical needs, all of the disabilities that people have talked about here -- tube feeding, tracheotomies, seizure disorders, brittle diabetes, cardiac conditions, cancer. Whatever it might be, those people moved to the community and flourished there. People with extremely challenging behavior moved to the community and did better there because they were able to live a desired life, which reduced the challenging behavior. People with significant psychiatric needs moved and did well.

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Actually, may I just interrupt?

Kim, we have a list of speakers. I don't know if you are on the list. I want to give those who submitted their list. I don't have her on the list. I apologize. So I just want to give time to those who have prepared their time for the list to come up.

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

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

Thank you.

MS. TODD: Perfect.

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

PATRICIA DAVIS JOHNSON: Good afternoon.

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

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

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

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

Thank you. (applause)

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

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

Thank you.

Can you introduce yourself please.

CINDY HAYES (phonetic spelling): Yes, my name is Cindy Hayes. I'm a parent of a 19-year-old son with autism.

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

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

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

We finally ended up at Hunterdon Developmental Center. And I will tell you that I do appreciate everything they've done for him. They probably saved his life. But about two months into that visit we got behavioral support. And I have been trying for over a year -- about a year and two months on Mother's Day -- to get him out of that Center, which is where we're spending over two times as much money on him for less appropriate services.

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

Thank you. (applause)

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

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

HEARING REPORTER: Excuse me, sir.

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

ANN C. MARTINELLI: Good afternoon, everyone.

Thank you for this opportunity.

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

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

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

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

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

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

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

Thank you. (applause)

MONIQUE DUJUE WILSON: Good afternoon.

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

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

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

I remember 15 hearings held throughout the state. Forty hours of transcribed, archived testimony from people with developmental disabilities and their families telling their stories to New Jersey legislators and leaders in the disability community. The message: keep us together. We thought you understood. We thought you finally heard us after years of dwindling family supports, and the increase of more and more families choosing to support loved ones at home and wanting different choices in the community other than just centers and group homes.

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

These are actually the copies of the petitions.

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

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

Without needed supports, our family members-- The majority of funding was going to the residential and community placements, out of sync for families growing up in an educational system full of expectation and the promise of fulfilling adult lives for our family members, regardless of their disability. Without needed supports, our family members were not living. And now, most families involved in that pivotal movement have joined the wait-listers, needing transition and adult services so that they can continue to go to school, to volunteer or work.

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

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

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

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

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

ASSEMBLYWOMAN VAINIERI HUTTLE: Are you wrapping up?

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

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

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

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

MS. TODD: Okay.

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

MS. DUJUE WILSON: I have one paragraph.

SENATOR VITALE: Go right away.

MS. DUJUE WILSON: Can I continue?

SENATOR VITALE: Yes, you may.

MS. DUJUE WILSON: Thanks.

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

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

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

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

JOHN VEGA: My name is John Vega.

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

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

This is my friend Reggie Davis.

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

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

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

MS. TODD: Thank you, John.

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

SENATOR VITALE: Thank you, John.

MR. VEGA: You're welcome.

GARY RUBIN (phonetic spelling): Hello, my name is Gary Rubin.

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

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

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

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

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

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

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

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

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

Thank you. (applause)

SENATOR VITALE: Jenelle Blackmon.

Is Jenelle here? (no response)

You're not Jenelle.

DONALD L. KLEIN: And I'm not Carolyn Wade either.

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

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

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

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

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

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

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

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

But several years ago, $1 an hour was allocated by the Legislature and signed by the Governor for direct care salaries to be increased in the community. Well, as a Union, we had to fight for that dollar to go into the hourly rate of staff. They wanted management-- Management wanted that buck-an-hour. We have to fight for our people who work in community care centers for $10 an hour. We can't get a $0.25 raise.

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

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

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

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

SENATOR VITALE: Thank you.

Jenelle.

JENELLE BLACKMON: Again, we want to thank you all for allowing us to speak before you today. I just want to reiterate Don's point that CWA's position is that we're not against community placement, we are for the care of these residents and choice. And this is a community that we need to address as that.

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

MICHELLE BRITO: Thank you.

I will be quick.

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

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

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

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

Thank you.

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

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

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

Thank you.

Welcome, Robin.

ROCCA A. MAZZA: I believe my testimony was written and distributed to everyone on the panel, so I am not going to read my testimony.

SENATOR VITALE: That's when we clap.

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

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

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

ROBIN SIMS: Thank you.

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

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

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

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

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

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

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

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

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

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

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

When the DD Act was drafted, Congress made sure -- and this is, again, a Federal Act that needs to be reauthorized. It hasn't been reauthorized in 10 years. But when the Act was drafted, Congress made sure that it was clear that programs under the Act understood that individuals with developmental disabilities and their families are the primary decision makers regarding services and supports -- and such individuals and their families -- that they receive, including regarding choosing where the individuals live from available programs -- and play decisions -- which is what Tom talked about before -- in making roles (*sic*) in policies and programs that affect the individuals.

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

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

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

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

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

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

The lobbyists and some community parents are trying to make our loved ones the scapegoats for their lack of movement from the waiting list. Our Federal reimbursement rate, as has been said here today, from the ICF/MRs is greater than those in the community care waiver. So our loved ones who move into the community will cost more in State dollars when moved into community settings when they get the same or better services. And the waiting lists will grow, and no emergency placements will then be available. People will die with inappropriate care, and this has been proven time and time again. It was mentioned, when Senator Allen was here -- was talking about the mortality study and asked about it -- if it had been done in New Jersey. The fact of the matter is, it has been done by the Developmental Disability Planning Institute at NJIT. They did this at the closing of North Princeton Developmental Center. But what did they say? They said, "If the time period was extended" -- and they only looked at this for 27 months -- "more persons would have died in the final model, and the final model might have been different." So we are now asking: Why are we not doing a 10-year look-back and see how many of the folks who left in the same study are still alive? We had Dr. Katzman (phonetic spelling) here. I don't know if he's still here. But he volunteered to do this for the State at no charge. He would do the research, we would do a look-back, and we would know 10 years down the road where these people are. DDD refuses to do the follow-up study. What are they afraid of? Did they lose the former residents of North Princeton? Can this Joint Committee please compel them to do it? We need to know what happens to those who are leaving today. And it's important to track how many homes and other placements they go to once they leave the center. How many die? How many return to centers in damaged condition? And how many move to more than one home?

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

SENATOR VITALE: Robin, thank you.

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

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

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

MS. SIMS: I will.

SENATOR VITALE: Thank you.

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

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

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

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

Thank you all very, very much.

SENATOR VITALE: Thank you, Robin.

MS. SIMS: Thank you.

SENATOR VITALE: Thank you.

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

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

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

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

Clearly we will have, on occasion, problems in either setting. Neither should paint that setting with a bad brush. I think that the families that I've heard -- and I've spoken to many of these people since I've been here over the last three-plus years -- believe strongly in where their son or daughter is, or where their son or daughter should be.

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

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

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

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

Thank you.

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

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

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

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

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

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

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

And I really want to commend Assistant Commissioner Ritchey, because you sat through all the testimony. And I know that together with Commissioner Velez and our Committees here, that we can really now address this within a timeframe. Because I think what I heard today is the waiting list and the resources needed to reallocate into the community and to keep providing for our vulnerable population.

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

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

Thank you so much. (applause)

(MEETING CONCLUDED)

APPENDIX

Testimony of Kathy Walsh, CEO, The Arc of Bergen & Passaic Counties
Before the Assembly & Senate Human Services Committees
May 7, 2010

Senator Weinberg, Assemblywoman Huttle and members of the joint committees, thank you for the opportunity to participate in the conversation on this very important issue. My name is Kathy Walsh and I am the CEO of The Arc of Bergen and Passaic Counties.

The Arc in New Jersey had its roots in Bergen and Passaic Counties back in 1947. In the early days of The Arc movement one of the top issues for parents was the expansion of Developmental Center beds. At that time there were no other alternatives and families needed a safe place where their children would be well cared for. The Arc fought hard to secure additional beds throughout the state. On the weekends The Arc ran bus trips down from Bergen and Passaic Counties to the Centers which were far away. The buses would bring parents and siblings down to visit their loved ones at Vineland, Woodbine or New Lisbon.

By the early 1970's parents were starting to think about other alternatives. They had had some success in getting school, work and camp programs going in the community and they began to see that residential supports could also be provided closer to home. From this idea the Arc opened the first community residence in NJ, in Paterson, in the early 70's followed by the first in Bergen County, in Hackensack in 1980. I moved into the home in 1981 as the manager. Both the home and I are still at the Arc all these years later.

The Arc and organizations like it developed many homes in the 1980's and early 90's spurred on by parents who wanted their children closer to home. These homes all had a mix of individuals who came from the Developmental Centers and those from the community. They were successful and we all became better equipped to support individuals with greater and greater challenges. The Developmental Centers originally housed very capable individuals, many of whom are now living fairly independently in the community, however over time, the Centers have come to serve individuals with greater challenges. So too has the community. We are both light years ahead of where we were back in the 70's and 80's when I was starting out in the field.

So if the community has come so far, why do people still end up in the Developmental Centers? The answer is resources. New Jersey has not built a community infrastructure with adequate resources to meet all the needs. By this I do not mean that community agencies don't have the willingness and the expertise, what I mean is that the community doesn't have enough beds, enough professionals or enough staff to meet the need. As a result families go into crisis, there are not beds available and their loved one ends up in a Developmental Center.

So what is the solution? New Jersey needs to invest in the community and this can only be done, given the resources, by closing some of the Developmental Centers and ensuring that the funds that were tied up in those Centers are NOT diverted elsewhere. That they are used to develop the programs and resources needed so that when a family does have a crisis the resources are available in the community to meet that need. And the resources to ensure that individuals who move out of the Developmental Center receive equal or better care.

Studies have linked community living with better quality of life in the areas of community participation, family contact, self-care, freedom, utilization of mental health care, productivity, personal choice and autonomy and safety of the person and their possessions. We need to take a moderate and rational approach to community transition and the subsequent closure of a facility. We need to allocate the proper time and funds to do it right, but we must do it. We need to give people the opportunity to live full lives.

Back in the 80's one of my Arc responsibilities was visiting the Developmental Centers to meet individuals and facilitate their transition to our Arc's community residences.

Every year around the middle of February, I receive a call from the staff at our Teaneck Group Home simply saying "Andrea wants to talk to you" at which point Andrea gets on the phone. She is a woman of few words so the conversation goes something like this "me, you, dinner, no more old school." And so we set up dinner for sometime around mid March which is Andrea's anniversary. It is the anniversary of when she moved from North Jersey Developmental Center to our Teaneck Group Home back in the early 80's. Ever year since that time Andrea and I go out to dinner to celebrate her anniversary. And while we are at dinner, usually after we order, Andrea points at my cell phone and says "call" which means I need to dial the number for Mary, who was the other staff member involved in transitioning Andrea from North Jersey. Mary hasn't worked at Arc Bergen-Passaic since about 1987, but every year we call Mary and Andrea gets on the phone and thanks her for the group home. It is over 20 years since Andrea moved to the group home, yet the anniversary is something she doesn't forget, it is the date her life changed.

And mine too, because Andrea reminds me every day that we all, each of us, can help someone change their life for the better. It is well within our grasp, we just need to collectively take that first step.

Thank you.

ABCD Alliance for the Betterment of Citizens with Disabilities

Empowering People: Providers Shaping Policies

Testimony of Lowell Arye, Executive Director

To

Joint Hearing on the Care Options for People with Developmental Disabilities

Senate Committee on Health, Human Services and Senior Citizens

And

Assembly Committee on Human Services

May 7, 2010

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ABCD Alliance for the Betterment of Citizens with Disabilities

Empowering People: Providers Shaping Policies

Testimony of Lowell Arye, Executive Director at the Joint Hearing on the Care Options for People with Developmental Disabilities

I want to thank the Chairs, Senator Weinberg and Assemblywoman Huttle, and the other members of the Senate Health, Human Services and Senior Citizens and Assembly Human Services Committees for providing me with the opportunity to testify today. Discussion about the future options of care for people with developmental disabilities, including the future of the Developmental Centers, is an important issue to people with developmental disabilities, families, and providers.

My name is Lowell Arye and I am the Executive Director of the Alliance for the Betterment of Citizens with Disabilities (ABCD). ABCD is an association of non-profit organizations in New Jersey whose mission is to affect the development and implementation of public policy and to support the member organizations whose specific purpose is to improve the lives of people with multiple physical and neurological developmental disabilities so that they have the opportunity to attain the highest level of purpose and dignity. ABCD's member agencies provide a broad array of community-based services to more than 10,000 people with complex developmental disabilities and their families.

ABCD's vision is for people with complex developmental disabilities to have significant relationships, access to full participation, and inclusive options in their communities, with quality supports. ABCD is committed to empowering people with complex developmental disabilities through the advancement of beneficial public policy and successful supports. Our core values demonstrate that we are here to serve the best interests of the individuals and their families who do not always have a voice in the policy development process. ABCD's core values are: 1) Person-Centered Thinking: Persons with complex developmental disabilities will continue to develop personal competencies, gain and maintain satisfying relationships, and have opportunities to fulfill valued roles and live with dignity; 2) Inclusion: Individuals with complex developmental disabilities will be present and fully participate in community life; and 3) Choice: Persons with complex developmental disabilities will express preferences and make choices in everyday life.

The individuals served by ABCD's member agencies in the community have similar or more complex disabilities than people who currently reside in the State's Developmental Centers. Specifically, most of the individuals served by ABCD members in community-based settings are in wheelchairs, need assistance in bathing, feeding and toileting, many of these individuals are unable to communicate verbally and have behavioral and complex medical issues such as trachea tubes. Later in my testimony I will provide specific information related to assessments which were done on behalf of the Division of Developmental Disabilities (DDD) on the people who live in the Developmental Centers. As you will see, the people served by ABCD member agencies have needs as complex as those living in the Developmental Centers.

For more than 30 years, federal and state disability policy changes have been implemented that break down the barriers of exclusion, dependency, and segregation. The 1999 Olmstead Supreme Court decision interprets the most recent of these changes, the Americans with Disabilities Act, and provides a framework for developing comprehensive plans for community integration for people with disabilities. The goal of community integration is that no one should have to live in an institution if they can live in the community with the proper supports. According to the Supreme Court, people with disabilities have the right to receive benefits and supports in the most integrated settings appropriate to their needs. By issuing this decision, the Court gave legal weight to accelerating policy and systems changes to expand opportunities for people with disabilities to live with dignity and on an equal basis with others in their homes and communities.

New Jersey continues to serve more people with developmental disabilities in state institutions than almost every other state in the country. Studies show that, proportionate to its population, New Jersey serves more individuals with developmental disabilities in large, state institutions than all but three states. Approximately 2,800 individuals with developmental disabilities live in seven Developmental Centers in New Jersey. New Jersey needs to move forward on ensuring the rights of individuals to live in the most integrated setting appropriate to their needs.

With this in mind, ABCD calls upon the Governor to announce that a Developmental Center will be closed within the next two years. We look forward to working with the Administration and Legislature to adequately fund a plan, build the necessary community infrastructure, and fully utilize all federal funds to ensure that people may move into the community.

Background

In 1999, the US Supreme Court ruled in *Olmstead v. L.C.* that people had the right to live in the most integrated setting appropriate to their needs. The decision provides a process that a state can take if it does not wish to be sued for violating an individual's rights to live in the community. The process includes having a "comprehensive, effectively working plan for placing qualified persons in less restrictive settings…".

Path to Progress

ABCD joined with The Arc of New Jersey to propose, draft and advocate for a bill that mandated the State move forward on a plan in compliance with the Olmstead Supreme Court decision.
In 2006, P.L. 2006, C. 61, was enacted into law in New Jersey, and mandated that the Division of Developmental Disabilities (DDD) develop an Olmstead plan. The plan, entitled *Path to Progress*, established benchmarks to ensure that any individual wishing to move from a Developmental Center into the community would have the right and access to do so within eight years.

In May of 2007, *Path to Progress* was published by DDD, with public input, which explained how the Division would take more than 1,850 individuals out of the Developmental Centers over an eight-year period, ending by Fiscal Year 2015. The plan called for moving 250 people per year out of the Developmental Centers, beginning in Fiscal Year 2009. Despite the calls from ABCD and others within the community, the plan did not call for closure of any of the Developmental Centers. Given the costs associated with maintaining seven large Developmental Centers and the civil rights issues, it is critical that New Jersey decide to close and consolidate the Developmental Centers. The plan did provide an implicit acknowledgement that every two years 500 people would move into the community, in effect the size of one Developmental Center, but an explicit statement to close these institutions is needed.

As I explained earlier in my testimony, the characteristics of the individuals in the Developmental Centers are identical to the individuals already served by ABCD members in the community. According to the plan, the individuals left in the Developmental Centers have the following characteristics: on average 50 years old, 57% with a psychiatric diagnosis, 24% with cerebral palsy, 18% with autism, 39% with visual impairment, 40-60% with health conditions; 39% using a behavioral specialist, 45% using a wheelchair, 40% taking psychotropic medication; 14-21% could benefit from environmental modification.

The plan has never been fully funded. In FY'09, there was only funding for 125 individuals. In FY'10, funding was included in the budget for 62 individuals. In the Governor's proposed FY'11 budget there is again funding for 62 individuals. ABCD believes that the State simply needs to commit to providing the funding for moving 250 people out each year and then follow the Plan.

Need for Community Infrastructure

In 2007, the Developmental Disabilities Planning Institute at the New Jersey Institute of Technology (NJIT) performed a study for DDD. The study demonstrated that community infrastructure must be increased significantly in order to advance the rights of people with developmental disabilities and enhance their ability to live in the community.

For many of us in the community one issue of particular concern is that the front doors of the Developmental Centers remain open. Continuing to admit people into the Developmental Centers on an emergency basis cancels out the positive gains made when moving people into the community. The primary reasons for individuals from the community being admitted for non-respite purposes into the State's Developmental Centers are: 1) lack of barrier-free housing opportunities; 2) significant behavioral and psychiatric problems; and 3) medical needs that are not currently being met in the community. Clearly the NJIT study showed that rather than increasing admittance rates among individuals into the Developmental Centers, the State should expand community resources and create alternatives and other living options, including emergency options, for consumers with significant mental and physical needs or other profound disabilities.

From 1997-2007, on average, there were more individuals admitted into Developmental Centers from the community than people moving out of the Developmental Centers. Fortunately there has been a significant change in the past few years. In FY 2009 only 43 people were admitted into the Developmental Centers and as of March of this year only 28 people were admitted in this fiscal year. In this fiscal year alone, if the Plan had been fully funded to move 250 people there would have been a net reduction of 222 people in our Developmental Centers. If there had been full funding of the Plan since FY2009, we would have had a net reduction of 429 individuals in the Developmental Centers. That means that the net number of people moving out of the Developmental Centers would have equaled to or been close to the number of people in either Woodbridge (410 residents), North Jersey (400 residents), or New Lisbon (440 residents) Developmental Centers.

For years, ABCD has been at the forefront of advocating that funds from the Community Care Waiver must be reinvested back into community services. Literally millions of dollars of federal funds from the Community Care Waiver have been used by the State for other purposes. For example, in FY 2007, the State received more than $194 million in retroactive funds from the federal government. Over a three year period, only $50 million of those funds were provided for the Division of Developmental Disabilities; meaning that $144 million were used by the State for other purposes.

Last year, the Division of Developmental Disabilities amended the federal Home and Community-based services Waiver, called the Community Care Waiver, to allow the State to claim for federal funding for additional services. The Division assumed approximately $6-$9 million in additional federal funds. The Treasury sequestered these funds for governmental purposes other than community services to people with developmental disabilities.

Budget language has been in place for the past six years which caps the amount of funds from the Community Care Waiver that the State can use for community services. This budget language must be eliminated and replaced with language that reinvests all federal dollars from the waiver and any savings from consolidating/closing Developmental Centers (including the selling of the land of the Developmental Centers) back into community services.

Closure of A Developmental Center in Two Years

Earlier in our testimony we stated that ABCD calls upon the Governor to announce that a Developmental Center will be closed within the next two years. This request is based upon our view that New Jersey should support the civil rights of individuals with developmental disabilities as expressed in the Supreme Court's decision on Olmstead and in ABCD's core values of Person Centered Thinking, inclusion and choice.

The request for the Governor to announce that a Developmental Center will be closed within the next two years is also based upon an ABCD analysis of how long it has taken other states to close Developmental Centers as well as New Jersey's history with North Princeton Developmental Center.

Based upon this analysis we believe that it will take approximately two years to close Developmental Centers with 400 to 500 residents. For example, we learned from discussions with the provider association in Maryland that it took approximately 17 months from the date of announcement to closure of a facility with 153 individuals eligible to live in the community. Massachusetts is estimating that it will take approximately five years to close four institutions with a total of 476 residents. California estimated that it will take 5 years to move 350 people into the community from one of its Developmental Centers. Indiana took 18 months to move 120 residents from its Developmental Center into the community. The announcement to close North Princeton Developmental Center with approximately 488 people was in 1995 and its doors did not close until 1998. Announcing that a Developmental Center will close within the next two years falls well within these estimated and documented timeframes of already closed or closing Developmental Centers.

Conclusion

ABCD supports the right of all individuals with developmental disabilities to live in the most integrated setting appropriate to their needs, as laid out in the U.S. Supreme Court decision.
ABCD's member agencies serve some of the most medically and neurologically complex individuals with developmental disabilities in the community. We believe that individuals currently living in the Developmental Centers, all of whom have similar characteristics to those already served in the community, can and should live in the community.

We urge the Governor to announce that a Developmental Center will be closed within the next two years.

Thank you for the opportunity to testify. I am happy to answer any questions which you may have.

Testimony before the Senate and Assembly Human Services Committees

May 7, 2010

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Good afternoon. Thank you for the opportunity to speak with you today and share my story.

As a parent of two children with Down syndrome, it seems like a lifetime away that I will have to concern myself with where they will live as adults. However, my son will soon be 17. The past 16 years have gone by in a flash, meaning the reality of his adult life is around the corner. My son makes no bones about the fact that he "is looking forward to living on his own". To simplify his enthusiasm, when asked why he wants his own apartment he confidently answers: "so I can walk around in my underwear." Who can argue with that!? Thank God, my daughter is five years behind!

I am also the guardian for my 64 year old aunt with severe developmental disabilities. Community living has recently become a reality for her after 49 years of living in an institution. When she was 12 and still living at home, my grandfather had a massive heart attack and almost died. As a result, he and my grandmother made the very hard decision to place my aunt in a developmental center. In the 60's, there were no other options. There was no such thing as community-based supports and services. My grandfather, being a wonderful provider and protector, did not want to leave my grandmother as sole caregiver and provider for three young children, one with significant needs. The day they made that extremely difficult decision - a piece of them was gone forever.

I can remember as a child driving with my pop-pop to pick her up from "school" and take her back after her long weekend's home several times a year. I would sit quietly in the back seat of the car with tears running down my face hiding them from him because I did not want to make his heartache any heavier. Sadly, the environment of the developmental center had changed drastically over the past several decades. The effects were wearing and I saw my aunt's spirit begin to diminish.

Initially she seemed happy, but being apart from her family must have left a void. It certainly would for me. When I was given the opportunity to explore a move for her, I was nervously excited. Was it the right thing to take her from the place she knew as her home for the majority of her life? But her visits home and my visits there had a sobering effect that left my heart in turmoil. What may have worked in the past, and may have been the only option, no longer measured up. The frenzied atmosphere of the developmental center had no harmony. I began to realize she would hold her ears while curled up on the couch as a comfort zone which she created to cope. This was not the home I wanted for her; nor what my grandparents would have wanted. She was entering her golden years and deserved peace and tranquility to enjoy that last stage of life. We decided to take a leap of faith and community living has brought many positive changes for her. I know they were looking down with tearful smiles as my aunt transitioned over the past year and a half to an apartment in our home town.

Today, there needs to be only one option. My children do and will continue to live in the community. The concerns I have are more about the practical aspects. Who will provide their care? Will they be trained professionals? Know how to administer medications correctly? Obtain proper medical care? Provide an appropriate diet? Continue to maintain their hygiene? Make sure they dress appropriately? Encourage them to stand up for themselves? Encourage them to be involved in their community and establish relationships? Make sure they keep their job? Manage their money correctly? Take a vacation? Will they even understand them and take the time to really get to know their needs? The list would be infinite if I included all my concerns.

Although I believe community living is the answer, there is a perception that a developmental center offers an additional layer of protection from the outside world. Transitioning to the community has many challenges and community living doesn't look the same for every person. The real dilemma is finding security in the supports offered to be able to live comfortably and safely in the community. The answer is establishing stable support structures in the community that families can trust and rely on. This is what my children will need as they become adults. This is what people like my aunt need to successfully transition out of developmental centers into community living. This is what families need – *what I need* – in order to have peace of mind and know that when I am gone, my family will be okay.

The
Arc
of New Jersey

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Testimony before the Joint Human Services Committees
Thomas Baffuto, Executive Director
The Arc of New Jersey
May 7, 2010

Good Afternoon. My name is Tom Baffuto and I am the Executive Director of The Arc of New Jersey. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and other developmental disabilities and their families. We advocate on behalf of, and alongside, the more than 160,000 individuals with developmental disabilities living in New Jersey and their families. I would first like to thank Chairwomen Weinberg and Vanieri-Huttle, as well as the other members of the Committees, for the opportunity to testify today on this critically important issue. We are particularly grateful that you have taken such a strong interest in these issues and we thank you for your ongoing commitment to people with developmental disabilities throughout the state.

At the outset, it is important to be clear: The Arc of New Jersey believes in community services. We work tirelessly to ensure that individuals with intellectual and other developmental disabilities in New Jersey are provided with the necessary supports and services to live as independent a life as possible in their communities. We want people to have the same opportunities as everyone else- living, working and recreating with their families, friends and neighbors. In fact, we are constantly reminded by our members, some of whom are here today, about how important it is to them to have social interactions and proximity to their friends and relatives.

With that said, one of the core principles at The Arc of New Jersey is empowering people with developmental disabilities with <u>choice</u>. To that end, we respect that some people will choose to continue to reside in developmental centers and some people will choose to move into the community. At the end of the day, we see it as our job to make sure that people with developmental disabilities are given the appropriate information to make informed choices about their own lives.

While we certainly respect our institutional partners, there is absolutely no doubt that our service system is imbalanced. The state is continually investing large amounts of funding into seven large developmental centers ***rather*** than building community infrastructure that is sorely needed to serve people – particularly people with complex medical and behavioral needs – in community-based settings. If we are going to make sure that individuals and their families really have a choice, we absolutely have to invest in the community too. We need to do more for those who want community options, and for their families.

The reality is clear: we just simply do not need seven large institutions anymore. People with developmental disabilities – even those with complex needs – absolutely can be served safely and happily in their communities. We see it done every day. We must begin to reduce the excessively large number of developmental centers and reinvest that money into community-based supports and services. This will create a more balanced services system where consumers will still have the choice to reside in a developmental center or to choose community placements.

Along with my written testimony, I have included a copy of a white paper that we recently drafted, which lays out the background and our specific recommendations on this issue. I hope this will be helpful to you in your deliberations and I encourage you to reach out to us if we can answer any additional questions you may have.

I want to again thank you for holding this hearing and thank you for the opportunity to testify. I'd like to turn it over now to the families and the self advocates to tell you first-hand about their experiences with institutional and community-based supports.

The Arc of New Jersey

Walter Bender
President

Thomas Baffuto
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The Future of Individuals with Developmental Disabilities and New Jersey's Developmental Centers

Executive Summary

The Arc of New Jersey believes that all individuals with intellectual and other developmental disabilities have a right to live, and be fully included, in communities of their choosing. There must be an array of diverse, high quality community resources available to ensure the opportunity for community living, as well as a spectrum of residential options from which individuals with developmental disabilities can choose. Adults with developmental disabilities, in conjunction with their families, should have the opportunity to self-direct and individualize their services to the extent possible and should not be "placed" into a program or facility. The Arc of New Jersey also holds that any individual currently residing in a developmental center who has an expressed desire and ability to move into the community must be given that opportunity without further delay. Resources must be made available to ensure that individuals experience a smooth transition from developmental centers to community living, and large congregate facilities should eventually be eliminated. While they continue to exist, however, the health and welfare of the residents and the quality of services delivered, including staffing ratios, must remain priorities. This white paper outlines the key issues relevant to institutional closure and makes specific recommendations regarding the successful closure of five of New Jersey's developmental centers.

Over the past several decades, there has been an abundance of national and state-specific planning, legislation and litigation geared toward significantly reducing the number of individuals with developmental disabilities served in large congregate institutional settings. Unfortunately, New Jersey has lagged seriously behind national trends in providing community-based supports and services to individuals with developmental disabilities. For most other states, it is not a matter of "if," but "when and how" they will close their institutions. While New Jersey has made some efforts to begin changing the way supports and services are provided, there has not yet been a true philosophical or fiscal commitment to eliminating state-operated institutions.

The Arc of New Jersey calls upon the state to immediately implement the following recommendations:

1. Review and strengthen the *Path to Progress* plan (see page 6) and fully fund its implementation to ensure that individuals can continue to move out of institutions without delay if they desire to do so.
2. Ensure that a full array of medical, mental health, behavioral and related services are available to those leaving institutions by implementing the recommendations from The Arc of New Jersey's white paper, *Community Infrastructure Needs for People with*

Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and Ancillary Service Areas (see Appendix A).

3. Create a bridge fund to cover the dual costs that will exist prior to actual closure.
4. Reform case management to ensure continuity and support as individuals transition from developmental centers to community living.
5. Fully fund The 10% Solution (see page 9) to ensure no new admissions to developmental centers occur unless absolutely necessary.
6. Collect, update and disseminate critically-necessary data on people with developmental disabilities in New Jersey.
7. Form a task force to develop and oversee the implementation of a plan to close five of New Jersey's seven developmental centers over the course of 12-15 years. Two developmental centers should remain open to ensure that individuals who have lived in an institutional setting for many years and prefer to remain there can choose to do so. The task force's plan should include:
    - a. A plan to close two of the five centers over the course of the first four years, followed by one every three years until all five have been closed.
    - b. An individual plan for each developmental center closure.
    - c. Well-planned and targeted placements for individuals currently residing in developmental centers.
    - d. An order of developmental center closures based, at least in part, on the age and condition of the structure.
    - e. The examination and monitoring of community infrastructure.
    - f. A system for evaluating each closure.
8. Assist developmental center staff to become Medicaid qualified providers to ensure their ability to continue to provide services after an individual transitions into the community.
9. Reinvest all savings realized from developmental center closure into community-based services for people with developmental disabilities.
10. Direct all federal funds received through the Community Care Waiver and the ICF/MR program back to the New Jersey Division of Developmental Disabilities.
11. Ensure an appropriate annual cost of providing care increase for community providers based on the CPI-Urban Wage Earner Index for the Northeast.

The Future of Individuals with Developmental Disabilities and New Jersey's Developmental Centers

Background

Institutions for individuals with intellectual and other developmental disabilities are known in New Jersey as developmental centers. While any facility housing more than 16 individuals with developmental disabilities is considered an institution, most of New Jersey's developmental centers house closer to 500 individuals.

The first state-operated institutions for individuals with developmental disabilities in the United States were opened in the 1850s.[1] New Jersey's first developmental center was Vineland State School which was established in 1892. The national trend toward the institutionalization of individuals with developmental disabilities increased after World War II and throughout the 1950s.[2] In 1967, the nation's institutional census peaked with 240 state facilities serving 195,000 residents.[3] Since 1968, however, the number of individuals served in state institutions has declined nationally by an average of 4% each year for 39 consecutive years.[4]

Current trends promoting community-based services over institutional settings evolved out of parent advocacy movements in the 1950s and 1960s.[5] In the 1970s and 1980s, segregating individuals with developmental disabilities in large institutions became a national civil rights issue.[6] By 1980, many states had begun implementing community services initiatives involving the development and funding of group homes, supervised apartments, family support programs and supported employment in an effort to integrate individuals with developmental disabilities into their communities and support their independence.[7] In 1981, the part of the Social Security Act dealing with Medicaid was amended, creating the 1915 (c) option for states. This option allowed states to apply to the federal government for "waivers" of some of the Medicaid rules and gave states the option to provide Medicaid services in community settings rather than institutions. The waiver program for individuals with developmental disabilities, known in New Jersey as the Community Care Waiver, caused a substantial push toward the development and utilization of community-based services in New Jersey during the 1980s.

In this day and age, it is widely believed that institutions enforce an unnatural, isolated and regimented lifestyle that is neither appropriate nor necessary. Studies show that community living increases the quality of life of individuals with developmental disabilities. Furthermore, two of New Jersey's developmental centers, New Lisbon and Woodbridge, were investigated in 2002/2003 by the Department of Justice and found to have patterns of abuse and neglect, as well as conditions and services that did not meet generally accepted professional standards of care.[8] Finally, while the cost of providing services to individuals with developmental disabilities is not always less expensive in the community than the cost of providing services in an institutional setting, national data shows that when an institution is closed there is a savings of anywhere from 9% to 45%.[9]

National Efforts to Move Individuals out of Institutions

The nation's reliance on the use of residential settings for 16 or more persons has been declining since 1968.[10] The trend toward closing institutions for individuals with developmental disabilities gained momentum during the recession of the early 1980s and has continued since then.[11] The creation of the Medicaid waiver program in 1981 as well as strong advocacy from the developmental disabilities community resulted in developmental center depopulation during the 1980s through present day. From 1990-2006, the number of residents in institutions housing 16 or more people declined 41% from 171,821 people to 101,416.[12] Dr. David Braddock, the Executive Director of the University of Colorado's Coleman Institute for Cognitive Disabilities and a nationally recognized expert in the field of developmental disability research and policy, predicts that this trend will continue, "As the nation's institutional census continues to fall and average daily costs increase, there will be continued pressure on states to close institutions."[13]

States continue to close developmental centers each year and there are only ten states left that have never closed an institution, with five of those states operating only one institution.[14] The majority (70%) of the 7% decline in the national census of state institutions from 2004-2006 occurred in ten states: California, Indiana, Wisconsin, Louisiana, Georgia, Missouri, Ohio, Florida, Illinois, and North Carolina.[15] In 1991, New Hampshire became the first state to provide services to individuals with developmental disabilities exclusively in community settings.[16] Now New Hampshire, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, Maine, Indiana and the District of Columbia provide services to individuals with developmental disabilities without utilizing any state-operated institutions.[17]

Currently, three states are in the process of closing institutions: Florida, Massachusetts and Tennessee. The most recent developmental center closure was that of the Fort Wayne Developmental Center in Indiana in April of 2007, making Indiana the most populous state in the nation without any institutions for people with developmental disabilities.[18] Fort Wayne Developmental Center had 120 residents at the time its closure was announced in October 2005.[19] It took Indiana one year and six months and $95 million to close Fort Wayne Developmental Center.[20]

Developmental Center	**Location**	**Date of Closure**	**Number of Residents**	**Cost**	**Length of time from announcement to closure**
Fort Wayne	Indiana	2007	120	$95 million contract to manage transition	October 2005 – April, 2007 1 ½ years
Agnews	California	2009	350	$170 million*	July1, 2004 – March, 2009 5 years
Gulf Coast Center	Florida	2010*	306	Unknown	January 1, 2005 – present > 4 years

Rosewood Center	Maryland	2009	153	$14.4 million*	January 2008 – June 30, 2009 1 ½ years
1. Fernald 2. Monson 3. Templeton 4. Glavin	Massachusetts	2010* 2012* 2013* 2013*	162 136 123 55 Total of all four developmental centers is 476	$40 million for all four developmental centers*	December 2008 – present Estimated 5 years for all four developmental centers
Arlington Developmental Center	Tennessee	June 30, 2010*	128	Unknown	June 30, 2007 – present > 2 years

* Projections according to state plans

David Braddock was also commissioned to do a study for North Dakota in 2006 where he reported on the possible closure of Grafton Developmental Center. In this report, Dr. Braddock estimated "dual costs" of $10.4 million for a three-year implementation period to move the 150 residents of Grafton and close the center.[21] Dual costs are the costs of maintaining an institution while at the same time serving individuals from that institution in the community as the institutional population is reduced prior to closure.

New Jersey Efforts to Move Individuals out of Institutions

Unfortunately, New Jersey lags significantly behind national trends in rates of community placements of individuals with developmental disabilities from institutions. New Jersey continued to develop additional institutional capacity through 1969, with the opening of Hunterdon Developmental Center, and the state's institutional census did not peak until 1980 with 7,317 individuals living in developmental centers throughout the state.[22] While there has been some improvement, New Jersey still falls seriously behind national progress and currently ranks 49th nationally in terms of utilization of state-operated institutions to serve people with developmental disabilities.[23] In FY 2006 New Jersey's average daily spending per person in state-operated institutions reached $494, an increase of 9% from FY 2004.[24]

There are currently 2,747 individuals with developmental disabilities living in seven developmental centers throughout New Jersey.[25]

Developmental Center	Location	Date Founded	Number of Residents[26]
Green Brook Regional Center	Green Brook Somerset County	1981	83
Hunterdon Developmental Center	Clinton Hunterdon County	1969	553

New Lisbon Developmental Center	New Lisbon Burlington County	1916	414
North Jersey Developmental Center	Totowa Passaic County	1928	392
Vineland Developmental Center	Vineland Cumberland County	1892	427
Woodbine Developmental Center	Woodbine Cape May County	1921	477
Woodbridge Developmental Center	Woodbridge Middlesex County	1965	381

The Division of Developmental Disabilities is attempting to implement the *Path to Progress* plan, a State plan to move 1,850 individuals out of developmental centers and into community placements by state FY 2015. However, no developmental center closure or consolidation is currently proposed in the *Path to Progress* plan. Additionally, *Path to Progress* has not been fully funded and is not being fully implemented.

State Fiscal Year	**Total cost (per *Path to Progress*)**	**Dollars allocated**	**Number of people to move (per *Path to Progress*)**	**Actual Number of people moved out of developmental centers**	**Number of people admitted to developmental centers**
2008	$33.6 million	$30 million	100	121	47 (from January 2008 - June 2008)
2009	$61.8 million	$30 million	250	112	41 (in calendar year 2009)
2010	$44.3 million	$9.3 million	250	42 (thus far)	

The *Path to Progress* plan calls for $44.3 million in FY 2010 to move 250 people into the community. The Governor's proposed FY 2010 budget provides $9.3 million to move 62 people from developmental centers into the community. Currently, New Jersey faces significant fiscal problems in the face of the global economic crisis. It is unclear how this will affect individuals with developmental disabilities in the FY 2010 budget and future state budgets.

Another obstacle in reducing the number of individuals with developmental disabilities residing in developmental centers is that individuals are continuing to be admitted. The current policy of the Division of Developmental Disabilities is that admission to the developmental centers is permitted only when an emergency exists, as defined in Division regulations N.J.A.C. 10:46B 3-3, and no community placement is available. Unfortunately, due to the lack of funding for residential supports and services for people living at home with aging caregivers, the unmet support needs of individuals living in the community and the lack of infrastructure to serve individuals in the community, the only placements that occur are emergencies. In an emergency, with no community placements available, individuals are being admitted to developmental centers from the community. Without funding to begin serving the over 8,000 people in the community on a waiting list for services, there will continue to be emergency placements and New Jersey will never be able to truly close the front door to its developmental centers.

Developmental Center Closures in New Jersey

Only three developmental centers have been closed in New Jersey: Edison, Johnstone and North Princeton.[27] In 1988, New Jersey closed Edison developmental center, with a population of 70 residents at the time the closure was announced.[28] In 1992, New Jersey closed Johnstone Training and Research Center, which had 229 residents at the time its closure was announced in 1991.[29] Most recently, in 1998, New Jersey closed North Princeton Developmental Center, which had 512 residents at the time its closure was announced and took three years to shut its doors.[30]

There has been significant follow-up on the quality of life of the former residents of North Princeton, including three reports by the Developmental Disabilities Planning Institute (DDPI) at the New Jersey Institute of Technology (NJIT). According to these reports, nearly 75% of those who left North Princeton are residing in community settings including group homes, supervised apartments and skill development homes while about 25% ended up in a developmental center, nursing home, or other institutional setting.[31]

The studies done by the DDPI show no evidence of an increase in mortality or any other negative consequences of deinstitutionalization.[32] Despite opposition to the closure of North Princeton by some family members, the DDPI studies show that there is now strong support for community living by a clear majority of family members.[33] Additionally, the DDPI reports show that consumers living in the community are doing "equal to or better than" their institutional counterparts, with strong empirical evidence linking community living with a better quality of life in the areas of community participation, family contact, self-care, freedom via lower social controls, utilization of mental health care, productivity, personal choice and autonomy, and safety of the person and their possessions.[34]

Olmstead v L.C.

On June 22, 1995, the United States Supreme Court issued a landmark decision for individuals with developmental disabilities, recognizing community living as a civil rights issue. In *Olmstead v. L.C.*, the Court determined that the unjustified institutionalization of people with disabilities violates the Americans with Disabilities Act of 1990 (ADA). Specifically, the Court ruled that states are required to provide community-based services for individuals with disabilities who are residing in institutions if the appropriate professionals determine that the individual is capable of residing in the community, the individual does not oppose community living, and the placement can be reasonably accommodated by the state.

Governor's Task Force

In November 2001, a Governor's Task Force on the *Olmstead v. L.C.* Decision was convened to guide New Jersey's efforts to shape a comprehensive plan for the community integration of people with disabilities. In December 2002, the Department of Human Services, in conjunction

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with the Governor's Stakeholder Task Force on Olmstead issued a report titled "Achieving Community Integration for People with Disabilities." This report contained 62 recommendations addressing issues and barriers to community integration, and emphasized the need for a sustained commitment in the State budget to support the diversion of people with disabilities from institutions and the transition of people with disabilities from these settings to their communities with appropriate supports. Unfortunately, the recommendations contained in this report were not implemented and many of the issues identified by the Task Force, and the recommendations contained in its report, reappear in the 2007 *Path to Progress* plan.

Public Law 2006, Chapter 61

On August 2, 2006 Governor Corzine signed into law Senate bill 1090/Assembly bill 2947, now P.L. 2006, c.61. This law required the Division of Developmental Disabilities to develop a plan with established benchmarks to ensure that within eight years (State FY 2008 through State FY 2015), each resident in a developmental center who expresses a desire to live in the community and whose individual habilitation plan so recommends, is able to live in a community-based setting. In developing the plan, the Division of Developmental Disabilities was required to 1) establish criteria to identify those who are appropriate candidates for community-based living 2) identify the resources needed to provide those individuals with community-based services and supports and 3) set forth how the necessary funding, services and housing are to be provided.

Additionally, this law required the Division of Developmental Disabilities to solicit public input in developing the plan, including four public hearings which were held throughout the state in January, 2007. This plan was completed and released by the Division of Developmental Disabilities under the direction of Assistant Commissioner Kenneth Ritchey on May 2, 2007, and is called Olmstead Plan "Path to Progress." Public involvement continues through an Olmstead Implementation and Planning Advisory Council that includes a variety of stakeholders who advise the Division of Developmental Disabilities on various aspects of the *Path to Progress* plan and its implementation.

Path to Progress

The DDPI has already assessed all individuals living in New Jersey's seven developmental centers and the Division of Developmental Disabilities has a statewide database which includes information regarding the abilities, preferences and support needs of each resident of the seven developmental centers. The Division of Developmental Disabilities has identified 2,303 individuals who are eligible to move from a developmental center into a community placement. This includes 1,005 individuals whose families/guardians do not oppose such a move, and 1,298 whose families/guardians do oppose a move even though the interdisciplinary team and the individual do not. *Path to Progress* proposes moving the 1,005 individuals whose move is unopposed first, while providing education and preparation to the families of the other 1,298 individuals for movement thereafter.

The *Path to Progress* plan outlines the individual planning and transition process, methods for assessing and expanding community infrastructure and capacity, and the cost of implementing the plan. The *Path to Progress* plan covers State FY 2008 through State FY 2015 and involves moving 100 individuals the first year and 250 individuals each of the following seven years, for a total of 1,850 individuals in eight years. It is important to note that *Path to Progress* does not discuss the closure of any developmental centers.

Litigation

In 2004, Disability Rights New Jersey (formerly New Jersey Protection & Advocacy) filed suit against the New Jersey Department of Human Services, charging that the State has long failed to provide community-based services or to develop an adequate assessment tool for identifying individuals who are appropriate for living in non-institutional settings. The complaint further charges that the State has unnecessarily and illegally segregated individuals with developmental disabilities in institutional settings such as developmental centers. The lawsuit cites violations of mandates and requirements of the Americans with Disabilities Act (ADA), the Rehabilitation Act (Section 504) and the Social Security Act Title XIX (Medicaid).

With the lack of full funding and implementation of the *Path to Progress* plan, Disability Rights New Jersey has amended and re-filed the complaint. The purpose of the lawsuit is to get a permanent injunction that stipulates that community residential services will be provided within a reasonable timeline and that places a stringent burden of proof upon anyone seeking to commit and retain an individual to a developmental center. This case is ongoing and has not yet been heard by the court.

Conclusion & Recommendations

As evidenced by the above discussion, there has been a great deal of national and state level litigation, legislation and planning in an effort to begin significantly reducing the number of individuals with developmental disabilities served in institutional settings, and toward the elimination of institutions altogether. The *Olmstead* decision and subsequent state efforts to comply have moved us into an era where services can, and should, be provided in one's community. Unfortunately, New Jersey has not yet made the philosophical and fiscal commitment required to ultimately eliminate the need for large congregate institutions. **The Arc of New Jersey believes that the time for this change is long overdue, and calls upon the state to immediately implement the following recommendations to ensure that individuals with developmental disabilities in New Jersey have the opportunity to be full participants in their communities:**

1. **Review and strengthen the *Path to Progress* plan and fully fund its implementation** to ensure individuals can continue to move out of institutions without delay if they desire to do so. This means moving no less than 250 individuals into the community each year at an average cost of $150,000 per person. This will require allocating at least $37.5 million in New Jersey's FY 2011 budget. *Path to Progress* explicitly states that "It is important to note that the ability to properly execute this plan is contingent upon the availability of appropriated funding over its lifetime." (p. 58)

2. **Ensure that a full array of medical, mental health, behavioral and related services are available to those leaving institutions** by implementing the recommendations from The Arc of New Jersey's white paper, *Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and*

Ancillary Service Areas (see Appendix A). In order for developmental center closure to occur safely and effectively, medical, mental health, behavioral and ancillary service infrastructure must be developed in the community. We have detailed information on the support needs, and preferences which clearly shows the need for additional infrastructure and community-based supports and services to serve individuals from developmental centers in the community. For example:

	All People Living in the Developmental Centers[35]
Average age (years)	49.2
% female	40
% with a psychiatric diagnosis	53
% tube fed	8
% with catheters	4
% who use wheelchairs	47
% needing physical therapy	52
% needing speech therapy	60
% needing occupational therapy	70
% needing a behavioral specialist	56
% needing counseling	27
% needing nursing	95
% receiving special food preparation	65
% fed by staff	23
% with intensive behavioral supports	31.6
% who bang their head	12
% who run away/wander	15
% who hit others	32

Given these needs, the lack of professional infrastructure in the community to meet the medical, mental health, and behavioral support needs of the individuals currently living in New Jersey's developmental centers is a critical problem and there must be substantial efforts to expand these vital services in order to ensure the health and safety of individuals as they move into the community. A robust community support system with a wide array of supports and services is needed in order to appropriately and successfully serve individuals with developmental disabilities in the community. In May, 2006 The Arc of New Jersey released a white paper titled *Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and Ancillary Service Areas.* This paper provides a series of health-related recommendations that should be implemented in order to adequately serve individuals from developmental centers in the community.

3. **Create a bridge fund** to cover dual costs that will exist prior to actual closure. Additional funding will be needed to maintain an institution while at the same time serving individuals from that institution in the community as the institutional population is reduced prior to closure. Advocates believe that dual costs will be approximately $15 million per year per institution

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leading up to closure. Once the first two institutions are closed, assuming the savings are reinvested, there should be sufficient funds available to cover the dual costs of the remaining institutional closures.

4. **Reform case management** to ensure continuity and support as individuals transition from developmental centers to community living. Case managers should be the lifeline of information and services from the Division of Developmental Disabilities. Currently, the Division of Developmental Disabilities has caseloads of hundreds of individuals being served by one case manager. This is unacceptable. Individuals transitioning out of developmental centers need their case manager to be an active presence in brokering and linking them to the services they need. The support of a case manager is paramount to the individual's achievement of his/her desired outcomes and the safety and success of his/her transition into the community. In addition, quality case management could serve to prevent many of the emergency admissions to developmental centers by assisting individuals in obtaining the supports and services needed to avoid an emergency, as well as plan for foreseeable life changes in a way that keeps individuals supported in their communities even when their circumstances change. Knowledgeable case managers with suitable case loads and the time to understand and meet the individual needs of their clients are key to the implementation of any initiative of the Division of Developmental Disabilities. Specifically, The Arc of New Jersey recommends that the Division of Developmental Disabilities: 1) clearly define and communicate the role of case managers, 2) utilize adequate, up-to-date information technology (IT), 3) put in place clear guidelines for case management, 4) put in place mechanisms for evaluating the success of case management, and 5) where feasible, allow consumers choice in determining their case manager. More detailed information on this issue and these recommendations can be found in The Arc of New Jersey's fact sheet on reforming the Division of Developmental Disabilities' system of case management.

5. **Fully fund The 10% Solution** to ensure no new admissions to developmental centers occur unless absolutely necessary. The only way to prevent future admissions to developmental centers is if there is capacity in the community to serve not only individuals with significant medical, mental and behavioral health needs, but also those needing emergency placements. New Jersey must develop the capacity to deal with emergencies by utilizing community services rather than developmental center placements, and the waiting list for the Community Care Waiver must be addressed in order to *prevent* emergencies. There are currently 8,170 individuals in New Jersey on the Community Care Waiver waiting list for services because there is neither the funding nor the capacity to provide these individuals with services. Additionally, in 2006 there were an estimated 22,658 individuals in New Jersey with intellectual and developmental disabilities living with a caregiver age 60 or older.[36] For many of these individuals waiting for services and/or living with aging caregivers, it is simply a matter of time before their situation becomes an emergency. The Division of Developmental Disabilities consistently places approximately 350 individuals each year who are in emergency situations. When there is truly a crisis (such as the primary caregiver dying or a situation of neglect) and someone needs a place to go, they will be placed in a developmental center if there are no services available for them in the community. In 2007, The Arc of New Jersey proposed The 10% Solution to address the Community Care Waiver waiting list and increase the community capacity to serve individuals with developmental disabilities. The 10% Solution proposes

serving 10% of the priority category of the waiting list each year; in FY 2011 this would mean providing services to 499 individuals at an approximate cost to the State of $20.6 million.

6. Collect, update and disseminate critically-necessary data on people with developmental disabilities in New Jersey. It is impossible to create any sort of successful plan without accurate and up-to-date data. There should also be an ongoing review of the current assessment tool used for data collection to ensure that it accurately reflects the support needs of the individuals being assessed. In 2007 the DDPI released a report "Descriptive Characteristics of All Consumers Residing in New Jersey's DD Centers." This report contains very specific data on the needs and preferences of every individual living in a developmental center in New Jersey. Unfortunately, as far as we know this data is not being tracked over time or updated as individuals move in and out of the developmental centers. Also, while *Path to Progress* states that there has been an assessment of available community resources, including the quality of those resources and their capability for meeting the demand, we have been unable, despite requests, to obtain this data. This information is critical in order to create and implement a responsible, fact-based plan for developmental center closure. It is also imperative that aggregate data be easily accessible and available to the public so that planning can be done, progress can be monitored, and stakeholders can provide informed input with regard to the process and outcomes.

7. Form a task force to develop and oversee the implementation of a plan to close five of New Jersey's seven developmental centers over the course of 12-15 years. Two developmental centers should be identified at the outset as the ones that will remain in operation at the end of the 12-15 year period. Leaving two developmental centers open will ensure that individuals who have lived in an institutional setting for many years and prefer to remain there, can choose to do so. The task force developed to oversee and implement a plan for closure should include:

- Chair, or designee, of the Senate Budget and Appropriations Committee
- Chair, or designee, of the Senate Health, Human Services and Senior Citizens Committee
- Chair, or designee of the Assembly Budget Committee
- Chair, or designee of the Assembly Human Services Committee
- The State Treasurer, or designee
- The Commissioner of Human Services
- The Assistant Commissioner of Human Services in charge of the Division of Developmental Disabilities
- Two self-advocates
- A representative from a developmental center family organization
- Two family members of people who have transitioned to community living from a developmental center
- A representative from a labor union
- A medical consultant/expert
- A national expert on developmental center closure
- A behavioral consultant/expert
- The Arc of New Jersey
- The New Jersey Council on Developmental Disabilities
- The Boggs Center on Developmental Disabilities
- Disability Rights New Jersey
- Two appointees of the Commissioner of Human Services' choosing
- Alliance for the Betterment of Citizens with Disabilities (ABCD)
- The New Jersey Association of Community Providers

The task force's plan for developmental center closure should include:

a. **A plan to close two of the five centers over the course of the first four years, followed by one every three years until all five have been closed.** This is in line with national timeframes for developmental center closures when the number of residents is taken into account. David Braddock suggests a conservative timeframe and a date range for closure because it eliminates or invalidates a significant amount of the opposition to closure.

b. **An individual plan for each developmental center closure.** Every developmental center is slightly different. Because of this, there needs to be an individualized plan for closure for each developmental center. These individualized plans need to take into consideration the residents and their needs, the staff, the services provided by the developmental center, the community capacity to serve individuals from the developmental center, the physical structure and the community where the developmental center is located. The task force should develop and oversee the implementation of these individual developmental center plans for closure.

c. **Well-planned and targeted placements for individuals currently residing in developmental centers.** There must be 250 <u>community placements</u> from developmental centers each year. All those eligible for community placement in the developmental center targeted for closure next should be moved into the community first. If there are not 250 or more individuals remaining in the developmental center targeted for closure who are eligible for community placement, individuals from one of the two developmental centers that will remain open at the end of the 12-15 year period who are eligible for community placement should be served next. Those not currently eligible for community placement should be transferred to one of the two developmental centers slated to remain open after the 12-15 year closure period. Every person who moves, regardless of where they are moving to should have an individualized transition plan outlining when and where they will be moving and how their transition will be supported. If the individual chooses, current developmental center staff serving that individual should be a part of the transition plan and process and continue to be a regular part of the individual's life for a period of time after they move into the community. The amount of disruption of individuals' lives should be minimized to the extent possible and no individual should have to move more than once. As much as it is practicable, resident groups, friends, and staff should be kept intact when an individual moves.

d. **An order of developmental center closure based on, at least in part, the age and condition of the structure.** In determining which developmental centers to target next for closure, the task force should consider the necessity for capital improvements, cost of maintenance, needed repairs, and any other foreseeable building or grounds maintenance and repair costs. Developmental centers with greater repair needs should be considered for closure first to avoid sinking additional money into institutional infrastructure costs.

e. **The examination and monitoring of community infrastructure** to ensure that the supports and services needed by those transitioning out of developmental centers are available and appropriate. The community infrastructure and its ability to support individuals leaving developmental centers should be consistently monitored to make certain that the development of community supports and services keeps pace with the needs of individuals moving into the community. There should be a reassessment of the community infrastructure after each closure to ensure that there is the capacity to continue moving individuals into the community and a plan to create additional capacity

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in areas where insufficient capacity is anticipated. The availability of community services to meet the support needs of those leaving developmental centers is imperative to the health, safety and successful community living for all individuals transitioning out of developmental centers.

f. **A system for evaluating each closure.** Each closure should be evaluated systematically and longitudinally as was done with the closure of North Princeton Developmental Center. The evaluation of developmental center closures should include the perspectives of residents, their families, impacted staff, and the local community. Evaluation should begin at the time the closure is announced and continue for at least two years after the last resident has moved out. The evaluation and assessment information should be utilized by the task force to modify the plan or implementation as appropriate based on this data.

8. Assist developmental center staff to become Medicaid qualified providers to ensure their ability to continue to provide services after an individual transitions into the community. Currently, those leaving developmental centers are given an individual budget which they can use to purchase services and supports from any Medicaid qualified provider, whether that is an individual or an agency. If staff of the developmental centers become Medicaid qualified providers, they can be hired using the individual budgets of those transitioning into the community from developmental centers. This would allow individuals who have developed a close relationship to their staff to bring them into the community and would allow staff to maintain their employment and relationships.

9. Reinvest all savings realized from developmental center closure into community-based services for people with developmental disabilities. These funds are desperately needed to expand services to individuals with developmental disabilities and their families. The developmental disabilities community has a wide range of unmet needs due to lack of funding. The overall lack of community-based medical, behavioral and psychiatric supports is a consistent impediment to individuals with developmental disabilities in New Jersey being able to move out of large institutions and off long waiting lists. Any savings realized from developmental center closures should be used to strengthen and expand the infrastructure in place to ensure the needs of individuals with intellectual and other developmental disabilities are appropriately met and to develop capacity to serve additional individuals and support future developmental center closures.

10. Direct all federal funds received through the Community Care Waiver and the ICF/MR program back to the New Jersey Division of Developmental Disabilities. Currently, when surplus federal matching funds are received by the State of New Jersey under the Community Care Waiver or the ICF/MR program, those funds are allocated to the State's General Fund. This allows the State to utilize these funds for other areas of the state budget that do not necessarily benefit people with intellectual and other developmental disabilities. Given the dire needs of the developmental disabilities community in New Jersey, all federal revenue brought in under the Community Care Waiver or the ICF/MR program must be reinvested into community based supports and services and used to expand community infrastructure and serve additional individuals from developmental centers and the waiver waiting list.

11. Ensure an appropriate annual cost of providing care increase for community providers based on the CPI-Urban Wage Earner Index for the Northeast. The only way that the community infrastructure can fully support people moving out of developmental centers with quality supports and services is if there is an annual cost of providing care increase built into the funding for community based supports and services. Although the costs associated with providing services, such as health insurance, transportation, utilities, and worker's compensation, have increased dramatically; community provider agencies have not received an adequate contract increase in nearly 15 years. New Jersey gives its State Departments increases every year to address the mandatory increase in costs associated with providing services; however community providers, which provide the actual community services on the State's behalf, do not receive an annual increase. In order to sustain and grow the community infrastructure to serve additional individuals with developmental disabilities in the community, the cost of providing care must be fully funded with mandatory yearly increases commensurate with the CPI-Urban Wage Earner Index for the Northeast.

Notes

1. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines.*
2. *Ibid.*
3. *Ibid.*
4. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
5. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines.*
6. *Ibid.*
7. *Ibid.*
8. The Department of Justice began their investigations of the New Lisbon and Woodbridge developmental centers in March, 2002 and April, 2003 respectively. In their investigations into the conditions and practices of the two developmental centers they reported that the conditions and services did not meet generally accepted professional standards of care. Specifically, that the residents were not adequately protected from harm or appropriately supervised, that there was a pattern of abuse and neglect, that restraints were being used unnecessarily in lieu of proper mental health and behavioral supports and services, and that residents were not provided with adequate medical care or nutritional, medication and physical management.
9. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines.*
10. *Ibid.*
11. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
12. *Ibid.*
13. *Ibid.*
14. *Ibid*
15. *Ibid*
16. *Ibid.*
17. *Ibid.*
18. Indiana Family and Social Services Administration. Retrieved April, 2007 from www.fwsdc.com.
19. *Ibid.*
20. *Ibid*
21. Braddock (March 7, 2006). *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines.*
22. New Jersey Department of Human Services, Division of Developmental Disabilities (May2, 2007). *Olmstead Plan "Path to Progress."*
23. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
24. *Ibid.*

25. New Jersey Division of Developmental Disabilities, Records Custodian (February 2, 2010). Obtained via OPRA Government Records Request, #W48348.
26. *Ibid.*
27. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.
28. *Ibid.*
29. *Ibid.*
30. *Ibid.*
31. Hall Apgar, Lerman, Jordan, Carter, Christenberry, Gaboda, Hessler, Lee, Madden, Shresta, Siligato, and Tansug (November 2003). *Life After North Princeton Developmental Center: Final Outcomes, A Follow-up of Former Residents.* New Jersey Institute of Technology, Developmental Disabilities Planning Institute.
32. *Ibid.*
33. *Ibid.*
34. *Ibid.*
35. New Jersey Institute of Technology, Developmental Disabilities Planning Institute (April, 2007). *Descriptive Characteristics of All Consumers Residing in New Jersey's DD Centers.*
36. Braddock, Hemp, and Rizzolo (2008). *The State of the States in Developmental Disabilities.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.

Appendix A

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The Arc of New Jersey

Thomas Baffuto
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Community Infrastructure Needs for People with Developmental Disabilities Who Are Leaving Developmental Centers: Medical, Mental Health, Behavioral and Ancillary Service Areas

The Arc of New Jersey Planning White Paper

May, 2006

I. HEALTH CARE AND MEDICAL NEEDS

Research, current experience in New Jersey, and a recent U.S. Surgeon General's Report demonstrate that access to health care, especially specialized primary health care, is restricted for individuals with developmental disabilities. Additionally, extreme access problems exist in relation to various specialty practitioners (such as dentists, psychiatrists, gynecologists, cardiologists, and others) as well as for ancillary services such as occupational, physical, and speech therapies. The barriers to care are many and can be considered together as deficiencies in the professional *infrastructure* that exists in community settings. To begin to address these issues, The Arc of New Jersey has identified a number of actions designed to enhance and expand this service infrastructure.

Recommendations:

1. ***Discharge Planning Process.*** A comprehensive, interdisciplinary, and documented pre- and post-discharge process needs to be established to provide appropriate transition services to individuals leaving New Jersey developmental centers (DCs). This process should begin well before discharge and continue well after initial placement. Transitional waiver funding should be explored (see # 5, next page).
2. ***Medical Records.*** As individuals leave DCs, they should be accompanied by a complete medical record and medical history that includes: (1) a comprehensive, standardized summary document, (2) necessary original source documents, (3) a history of specific procedures and illnesses and (4) complete information on current medication/therapies, as well as on-going health care needs. The process of compiling the record should be integrated with the discharge planning process; the Division should empanel an expert committee, including community providers, to develop the format of this record.
3. ***Integrated Nursing-Health Care Specialist Model.*** Workable, community-based, provider-centered, DDD-funded nursing/health care specialist or support models and/or networks should be developed to provide residential support for health care. Nurses and similarly credentialed providers need to be made available as staff positions in residential providers of size and through other network arrangements as needed for groups of small providers or skill home providers. Nurses working in this model should be included in the discharge planning process to link with health care managers in Medicaid managed care.

4. ***Service Expansion.*** The Division needs to promote efficient, broad-based, and entrepreneurial primary health care delivery models by providing market analyses, technical assistance, training assistance, business planning, access to Division of Medical Assistance and Health Services (Medicaid) expertise and programs and, possibly, pilot project support to enhance the capabilities of existing providers and engage new providers. The Division should avoid purchasing services that are available through Medicaid.
5. ***Transition Waiver and Strategic Planning.*** The Division needs to explore "transition waiver" possibilities for the discharge and placement of DC individuals into adequate community settings. Furthermore, the Division needs to develop and formalize interdisciplinary, expert, strategic planning groups that include appropriate constituent representatives, in order to develop integrated, long-term, appropriate, efficient, and effective health care networks and system components for individuals with developmental disabilities. These efforts need to include assessment and re-examination of existing funded models, opportunities for pilot programs with needed start-up funding, and potential for integration into current Medicaid managed care market structures.

II. MENTAL HEALTH AND BEHAVIORAL SERVICES

It is well known that 30% to 40% of individuals with developmental disabilities also exhibit mental health disorders according to DSM criteria. Furthermore, studies in New Jersey have shown that up to 50% of individuals remaining in developmental centers live in so-called "behavioral cottages." Unfortunately, in community settings there have never been sufficient numbers of mental health professionals with experience in co-occurring disorders (i.e., "dual diagnosis"). This problem will be exacerbated in future transfers of DC individuals to community settings. Additionally, there is no well-established system of mental health supports that welcomes and well-serves adults with developmental disabilities and even fewer supports for children with developmental disabilities. Medicaid fee-for-service mental health providers have been generally unresponsive to this population.

Recommendations:

1. ***Integrated MH Service Delivery Teams.*** Develop multidisciplinary, community-based mental health teams (e.g., mental health practitioner, behaviorist, health care manager) with 24/7 responsiveness that are integrated into the developmental disabilities community (i.e., DDD providers) as well as existing mental health structures (via DMHS providers). Explore existing reimbursement structures and potential inclusion under Home and Community Based Services (HCBS) waiver (e.g., as service alternative under traditional targeted case management program) and/or as part of other services under the waiver (e.g., family support).
2. ***Integrated Behavioral Model.*** The Division needs to explore and establish workable, community-based, provider-centered behavioral models and/or networks to provide residential supports for behavioral plan development and implementation. Behaviorists need to be made available as staff positions in residential providers of size and in other network arrangements as needed for groups of small providers and skill home providers. Behaviorists working in this model need to be included on integrated teams as well as in the discharge planning process for former DC residents, and need to link with health care managers in Medicaid managed care.
3. ***CPST Linkage.*** The Division should explore the potential linkage between above teams and existing CPST program consultants with the goal of adapting CPST as required to allow it to function seamlessly with integrated teams (#1 above) and integrated field behaviorists (#2 above).

.30x

4. ***Service Expansion.*** The Division needs to explore service expansion strategies in this area including additional contracting and/or network development opportunities, expanded training supports, and personnel development. To the extent possible, services should be funded under waiver structures. Services need to include specialized therapy and counseling opportunities in addition to traditional psychiatry and behavioral interventions.
5. ***Highly Specialized Settings.*** A limited number of highly specialized, time-limited placements need to be developed, outside of traditional mental health settings, for complex mental health and behavioral cases (often with co-occurring mental health disorders) and those inpatient mental health discharges that require step-down transition. These settings need to have system components that foster integration with general DDD community residential and health care providers.
6. ***Strategic Planning.*** The Division needs to develop and formalize interdisciplinary, expert strategic planning groups including appropriate constituent representatives to develop integrated, long-term, appropriate, efficient, and effective mental health care and behavioral support networks and system components for individuals with developmental disabilities. These deliberations need to include assessment and re-examination of existing funded models, opportunities for pilot programs, and potential for integration into current or expanded HCBS waivers or Medicaid managed care.

III. ANCILLARY SERVICES NEEDS

As a group, people with developmental disabilities exhibit more co-occurring disabilities than the general population and often have specialized treatment needs even in typical services. For example, people with developmental disabilities exhibit proportionally more sensorimotor and ambulation problems and more speech and hearing and visual disabilities. Additionally, this group requires more complex dental procedures than the general population with many procedures needing to be accomplished in surgical settings. Additionally, some ancillary service needs are either not available in fully integrated settings or difficulties are encountered in adapting the settings to serve this group because of the dearth of providers or complex system and payment barriers. Thus, in developmental center settings some of these services are routinely available through the ICF/MR (intermediate care facility) model, but are exceedingly difficult to access in community settings under current waiver and/or Medicaid provisions, a problem perhaps exacerbated in New Jersey due to the lack of numerous small ICF/MR settings.

Recommendations

1. ***Service Continuity.*** Ways must be found to duplicate the range of ancillary services (such as occupational therapy, physical therapy, speech therapy, counseling, nutritional services) that were available to individuals in developmental center settings. Although the current Community Care Waiver is intended to provide such needed services, it has fallen short. Regardless, the levels of needed services should be identified in the integrated discharge planning process to assure service continuity for all individuals.
2. ***Service Expansion.*** The Division needs to explore service expansion strategies in these areas including additional contracting opportunities and/or network development, expanded training supports, and personnel development. To the extent possible, services should be funded under waiver structures. Services need to include specialized therapy and counseling opportunities in addition to traditional psychiatry and behavioral interventions. The Division needs to empanel an expert, interdisciplinary workgroup to explore these models, including possible inclusion or adaptation of the current CPST program. A critical goal of such a work group is to provide

31x

financial and other business incentives to expand the market to attract providers to work with individuals who have developmental disabilities.

3. ***Waiver Review.*** The Division needs to seek competent waiver consultants with unique capabilities who are able to bring fresh ideas to current New Jersey developmental disabilities waiver programs. One focus would be to identify waiver-funded opportunities to enhance the delivery of ancillary therapies and services (including, for example, clarifying rules and definitions *vis a vis* habilitation vs. rehabilitation).

IV. Conclusion

In its advocacy role, The Arc of New Jersey has identified and collected information and perspectives from a diverse group of providers across the state in regard to the upcoming so-called Olmstead initiatives to move individuals from state-run developmental centers to community-based settings. The consensus of expert opinion is that the present programs of the NJ Division of Developmental Disabilities are not sufficient to assure the success of this relocation process going forward. Of concern in this white paper is the level, or general lack of, professional *infrastructure* to provide adequate health care, mental health care, behavioral services, and ancillary support services as well as competent individuals to carry out such services. It is the position of The Arc of New Jersey that the Division must directly address infrastructure issues at the time it embarks on the relocation of individuals from developmental centers. In doing so, The Arc of New Jersey urges the Division of Developmental Disabilities to consider the recommendations contained in this white paper.

Testimony before the Senate and Assembly Human Services Committees
May 7, 2010
Deborah Legutko

Good afternoon. Thank you for the opportunity to share my story with you today. My name is Debbie Legutko and I am the mother of two young men, Frank and Derek, both with developmental disabilities. My older son Derek, who has autism, is now 24. He works 20 hours a week at two different part time jobs. He is very verbal, and extremely knowledgeable about sports, music, and movies. Derek has been on DDD's priority waiting list for over 9 years.

My younger son Frank turned 23 on April 9, 2010. He has been living at Hunterdon Developmental Center for almost 14 months. Frank had been living at home with 24-hour nursing for 22 years. Frank is autistic, on a ventilator and oxygen, and has had aggressive behaviors for many years. Early last year, we became unable to manage his behaviors at home and he became a constant danger to his caregivers and himself. Our only options were to find him a nursing home or an emergency developmental center placement.

Before our situation became an emergency, he had been on the waiting list for residential services for over 5 years. In fact, you may remember me testifying before you in March of 2008 about the waiting list and how much we needed help. That help never came and when our situation finally became an emergency, a developmental center or nursing home were the only options. After spending 21 years in the community it was very upsetting for Frank and our family to see him be admitted to Hunterdon Developmental Center. I cannot even consider what might happen to Derek should our family face another emergency situation.

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

For 21 years, Frank enjoyed being a part of the community. We gave him every opportunity to be out and about just like anyone else. He has traveled to Disney World, seen Broadway shows, and tried his luck on the slot machines in Atlantic City. He loves amusement parks and the excitement of the Jersey Shore Boardwalks. He is always "talking" about fire trucks and Santa Clause.

His life now is not what I envisioned for him, but at the time we really had no other choice. I always hoped he could live in a community

with other people needing the same level of care. People in our state are living longer with complex medical conditions, and its time to be innovative. I really want to see Frank in a community placement.

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

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Testimony of Adelaide Daskam
Developmental Center Hearing
May 7, 2010

My name is Adelaide Daskam; I was in North Jersey training school for five years. I didn't like the way I was being treated by the staff. I was told what to eat and what time to go to sleep. I had to stand at the back of the line in order to eat.

I am very happy living in the community. I have my own apartment, a cat and a boyfriend. I also work as a secretary assistant and I get a pay check every two weeks.

I would choose the community over an institution any day because I have FREEDOM, I have PRIVACY and I have RIGHTS! I am active in my self- advocacy group and I own a business that help people with DIFFERENT ABILTIES advocate for themselves

The institution was the WORST years of my life and no human being should have to live there! I am asking you to give them their FREEDOM.

Testimony of Todd Emmons
Joint Human Services Committee Hearing
May 7, 2010

Hello, my name is Todd LeRoy Emmons. I am here to talk to you about my experiences living in the developmental center and living in the community. Back in 1972 I was placed by my family to New Lisbon State School – Home for Boys. Which everybody said that this would help me with my living skills.

My day at the DC center was planned out for me:

- They decided what time I woke up and what time I went to Bed
- They decided what time my meals where and what I was going to eat
- They decided how I was going to spend my free time and what activities I was going to do.
- I did make some friend but I was not able to make any friends outside of the DC center
- Many times I was treated unfair and not kind at all. The staff was very abusive. They would ridicule me and call me names over and over again like "Retarded Boy" And this hurt me extremely bad and made me very upset.

This made me feel like I didn't have choices in my life time and that I did not matter. I was very sad. And did not know at that time all the things I could do for myself. I felt helpless and very alone. I did manage to leave the DC center with help from my family and case manager. They believed in me and agreed that I did not need to be in there. So we looked for a place for me to live in the community. Thankfully I gained an opportunity to live in a Community based program with Bancroft.

Now my days go like this:

- I decide what time I wake up and what time I go to bed
- I purchase and prepare all my meals independently.
- I chose the places I want to go and who I want to go there with me or sometimes I go by myself.
- I have been employed and made my own money which I control.
- I travel independently on New Jersey Transit
- I decide who my friends are and now I even have a girlfriend that we spend a lot of time together. She is very special to me.

◊ I am now on the New Jersey Council On Developmental Disabilities, a chairperson for Monday Morning Network. Our own Self Advocacy group Chairperson and many other groups.

I feel very, very happy to be a valued and contributing citizen. I vote in all elections. I live in a wonderful townhouse in the great community with a roommate. We get along very well. My family and I are very proud of all my many accomplishments so far and I am looking forward to so many more achievements.

Everybody needs to live in the Community and be giving a chance for Happiness. Thank You.

WRITTEN PUBLIC TESTIMONY SUBMITTED TO:

THE SENATE HEALTH, HUMAN SERVICES AND SENIOR CITIZENS COMMITTEE AND THE ASSEMBLY HUMAN SERVICES COMMITTEE

Friday, May 7, 2010 at 1:00 PM
Committee Room 4, 1st floor,
State House Annex, Trenton, New Jersey

Testimony of:

Thomas B. York, Esquire

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Introduction

Good afternoon committee members, thank you for this opportunity to offer testimony on these important issues. I was formerly a Deputy Attorney General with the Office of Attorney General in Pennsylvania, and subsequently the Chief of Litigation for the Pennsylvania Department of Public Welfare, although I am now in private practice. For nearly 20 years I have been assisting states in designing and defending comprehensive systems of services and supports for persons with developmental disabilities, including preserving a choice for those who feel that they are best served in an ICF/MR.

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

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

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

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

Problems arise when individuals from developmental centers are moved to the community without sufficient supports. For example, one state recently moved 47 individuals to the community with little planning with the result that half had died within 15 months. Community services must be able to address the medical, psychiatric, and behavioral needs of the residents of ICF/MRs if these individuals are to be successfully relocated to the community. New Jersey is fortunate, and set apart from other states, because it has access to provider organizations such as Developmental Disabilities Health Alliance, which specializes in meeting these needs. DDHA operates a medical home for persons with developmental disabilities, providing primary health care, mental health and other services on a statewide basis.[1] However, DDHA does not offer behavioral services, which seem to be in dire need in New Jersey.

Critical Facts

In addition, I believe there are some very good reasons why we should be *very* cautious in calling for the closure of developmental centers. Here are some points that I think your committee should carefully consider.

1. Heterogeneity of the Population. **Individuals with intellectual and other developmental disabilities (IDD) vary more than the general population, more than most people understand or realize, ranging from individuals little different from the general population to individuals who need constant care.**

People with mild intellectual disabilities who need only minimal supports to live in community settings are barely distinguishable in the general population. The vast majority of such individuals, if not all of them, who are often thought of as having mild cognitive disabilities, already live in community settings. They are our co-workers, friends and neighbors and need only minimal services and supports to succeed in community settings. In the distant past, many of these individuals were inappropriately placed in state institutions; for the most part, unless they have associated mental health or behavioral problems or were placed in such settings by court order following criminal behavior, these individuals are *no longer residing* in large state facilities.

However, people with severe and profound disabilities are far different in their needs. These individuals are quite different from the general population, often consisting of individuals who have no self-help or adaptive skills, who require personal assistance for all areas of their life, who have associated multiple disabling medical conditions, and who are often quite fragile and in need of constant and pervasive services and supports (that is, round-the-clock care). These are the individuals who, by far, make up the bulk of individuals in the remaining developmental centers in America, including the seven in New Jersey.

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[1] **Kastner, T.A. & Walsh, K.K. (2006).** Medicaid managed care model of primary care and health care management for individuals with developmental disabilities. *Mental Retardation, 44,* 41-55.

2. ***Facility Residents are a Tiny Percent of the IDD Population.*** **Although many people do not realize it, only about .76%, or three quarters of 1%, of individuals with IDD continue to reside in state-run institutions of 16 or more beds. This is a very small fraction of the population of individuals with intellectual and other developmental disabilities.**

As noted, the vast majority of individuals who continue to reside in ICF/MR developmental centers and/or state-operated facilities are those who can be said to have severe and profound disabilities. At present there are just under 40,000 such individuals residing in large (16+ bed) state-operated facilities. What is often *not* fully understood is the scope of this figure with respect to the larger population of individuals with IDD. Standard estimates of the population of individuals with intellectual disabilities (that is, *not* including other developmental disabilities) are that this group makes up between 1% and 3% of the American population. [2]

Using the middle figure of 2%, there are 6 million such individuals based on a general United States population of nearly 300 million (US Census Bureau estimate, July, 2003). Using these estimates only .66% (or less than three-quarters of 1%) of individuals with IDD currently reside in institutions. Because estimates also show that approximately 5% of people with cognitive disabilities, or about 300,000 (using the two percent estimate), could be considered to have severe and profound disabilities, only one in more than seven individuals with this level of disabilities is institutionalized. It does not seem reasonable that such a small percentage of individuals results in such a contentious and continuing debate relative to their care. Thus, it is likely that the issue has been kept in the public eye more by the ideology of pro-community advocacy groups than by professional decisions about service locations.

3. ***Costs Savings Are Not Assured in Facility Closures.*** **A recent review of selected literature did not validate the firm conclusion that cost comparisons between institutions and group homes showed cost savings in community settings.**

An important published research study conducted by individuals from your own state of New Jersey[3] reviewed selected cost comparisons between institutions and community settings. One of the conclusions reached by this study was that cost savings, in the shift from institutions to community settings, were not necessarily assured, other things being equal. More on these findings and conclusions can be found in the published report – in general it was found that costs are shifted from one area of state government (i.e., the health care costs in developmental centers would be shifted, in your case from DDD to Medicaid).

4. ***Pervasive Supports Are Needed.*** **Because of the small number of individuals (#2 above) and the lack of obvious cost efficiencies (#3 above), it is likely that the current level of institutional use is reasonable.**

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[2] That is, "intellectual disabilities" is the current term of preference for individuals that were formerly known as "mentally retarded."

[3] **Walsh, K.K., Kastner, T.A., & Green, R.G. (2003).** Cost comparisons of community and institutional residential settings: Historical review of selected research. *Mental Retardation, 41*, 103-122.

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

It is likely that the *positive* goals of deinstitutionalization (e.g., removing individuals from institutions when they do not belong in them) has largely been achieved in nearly all states, including New Jersey. It is possible, because of the larger number of institutions in New Jersey, that there still may be some individuals who desire to leave such centers and may benefit from community placement. By all means, these individuals should be given the opportunity to live in community settings. However, for individuals who do not want to move, they should not be forced to.

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

5. Individuals and Families Have Choices. **The Social Security Act, Medicaid regulations, and the Supreme Court Olmstead Decision all provide for choice of ICF/MR settings or institutional placements.**

It would be erroneous to interpret the growth in Medicaid HCBS Waivers in comparison to the contraction of institutional services as signaling the lack of efficacy of the ICF/MR model. First, many families, especially those with family members who have pervasive needs and complex disabilities, *desire* ICF/MR level services. Second, specific Medicaid regulations [42 CFR §441.302(d)] assure such a choice, as follow:

> When a recipient is determined to be likely to require the level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded, the recipient or his or her legal representative will be
> (1) Informed of any feasible alternatives available under the waiver, and
> (2) <u>Given the choice of either institutional or home and community-based services</u>
> (emphasis added)

Similarly, the Supreme Court decision in Olmstead, contrary to the belief of many, does *not* provide a mandate for deinstitutionalization. Rather it clarifies the definition of "discrimination" under provisions in Title II of the Americans with Disabilities Act. As stated in the CMS Guidance on Olmstead[4]: "there is no requirement under the ADA that community-based services be imposed on people with disabilities who do not desire it" and community services are only appropriate when the "person does not oppose such placement."

6. Positive Outcomes Are Not Always Assured. **When individuals with severe and profound disabilities are moved from ICF/MR facilities the positive outcomes of increased integration, community involvement, and exercise of free choice, are not always observed.**

Outcomes for many *mildly* disabled individuals leaving institutions for community settings may be truly positive for them and result in an improved quality of life. However, severely and profoundly disabled individuals receiving highly professional, complex ICF/MR level professional services within institutions who are then placed in HCBS Waiver settings, may have difficulty gaining access to these services, especially medical care, psychiatric care, and behavioral supports which are often difficult to access or sometimes simply unavailable.[5]

When adequate health and other professional services are not as readily available as they are in ICF/MR settings, research and practice shows that individuals run increased risk of death, mental health crises, inappropriate placement in nursing homes, lack of access to needed services, and so forth. It would seem most appropriate at present to retain complex individuals in ICF/MR settings (if they choose them), in which these services are available and accessible, until such time as the service infrastructure for these individuals can be sufficiently developed in community settings. It does not appear, in my opinion and from my experience litigating cases in several states, that any state has been able to fully develop all the networks of such services (i.e., comprehensive medical, behavioral, psychiatric, and ICF/MR-like habilitative services) in community settings that are reliably responsive to individuals with complex disabilities at a severe, and especially, profound level. In fact, it is likely that this is becoming more difficult as economic difficulties continue to plague most state budgets, including New Jersey.

Conclusion

In my opinion, it would be rash to close IDD facilities in New Jersey that are certified to provide ICF/MR services when substantial numbers of individuals with severe and profound disabilities are currently benefiting from such services and appear to require them. I do recognize that some consolidation may become possible among your developmental centers. However, in my view it would be wrong to begin on a program designed to close all developmental centers in favor of community-based services. The heterogeneity of the population is such that the simple message of anti-institutional ideologues that all facilities need to be closed is simply erroneous considering the overall facts. Furthermore, such facilities (i.e.,

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[4] CMS. (2002). Olmstead Fact Sheet Enclosures: *(1) Developing Comprehensive Effective Working Plans Initial Technical Assistance Recommendations and (2) Assuring Access to Community Living for the Disabled.* Washington: CMS Office of Public Affairs; attachments to letter of Timothy M. Westmoreland, CMS, January 14, 2000 (website accessed: 10/24/03: www.cms.hhs.gov/states/letters/ smd1140a.asp); last modified, October 30, 2002.

[5] Surgeon General of the United States. (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. Washington, DC: US Department of Health and Human Services, Public Health Service.

ICF/MR settings) are part of the Medicaid entitlement to individuals, the choice of which is assured to families and individuals receiving services, in both the Medicaid regulations and in the Olmstead Decision. The law on parental rights and guardianship rights, along with the history and tradition of our great country, further supports the rights of parents/guardians to make residential decisions for their loved ones, who are too disabled to decide for themselves. The good judgment of these caring, informed, and involved parents/guardians should not be easily supplanted by others.

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THE ELIZABETH M. BOGGS CENTER
ON DEVELOPMENTAL DISABILITIES
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Where New Jersey Stands in Services to People with Developmental Disabilities and National Policy Trends

Testimony
to the
New Jersey Senate Health, Human Services and Senior Citizens Committee and the
New Jersey Assembly Human Services Committee
May 7, 2010

by
Deborah M. Spitalnik, Ph.D.
Professor of Pediatrics
Executive Director of The Boggs Center
University Center for Excellence in Developmental Disabilities
Education, Research and Service

Senate Vitale, Assemblywomen Huttle, Distinguished Members and guests, I am honored to have the opportunity to testify before you today at this joint meeting of the Senate Health, Human Services and Senior Citizens Committee and the Assembly Human Services Committee.

My name is Deborah M. Spitalnik, Ph.D. and I am a Professor of Pediatrics at UMDNJ-Robert Wood Johnson Medical School, where I am also Executive Director of The Elizabeth M. Boggs Center on Developmental Disabilities. The Boggs Center as New Jersey's University Center for Excellence in Developmental Disabilities Education, Research and Service, is a third party reviewed program, funded under the Developmental Disabilities Assistance and Bill of Rights Act.

One of our federal mandates is to advise policy makers on issues of importance to individuals with developmental disabilities, their families and service systems. It is in that capacity that I come before you today. My goal is to place our experience, our concerns and our opportunities for supporting individuals with developmental disabilities in New Jersey in a national context.

The information I am sharing with you today comes from national data bases and state sources, and is referenced. There may be slight variations in actual numbers due to variations in the time frames of the data bases, but all the trends are constant.

It is also my deeply felt goal to contribute to a dialogue that acknowledges and affirms that we are all people of goodwill with a shared commitment to the well being and opportunities for individuals with developmental disabilities and their families.

The Direction of Federal and State Policy

There is, and has been for over 30 years, a clear direction in federal and state policy toward community living for individuals with developmental disabilities. The first major movement in deinstitutionalization occurred under President Nixon, although the nature of data gathering at that point did not make these shifts visible until later. It is been clear over time that these issues and the needs of people with developmental disabilities are bipartisan concerns.

This orientation towards community is apparent in the DD Act, in that

> Individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in home and communities, and make contributions to their families, communities, and States, and the Nation; [1]

The thrust of national policy toward the community is also seen in the evolution of Medicaid funding for long term services, as reflected in the growth of Home and Community Based Services waivers (HCBS). The findings of the US Supreme Court in Olmstead *v* L.C. that "unnecessary institutionalization is a form of discrimination", the activities of the Office of Civil Rights and the federal declaration in 2009 of "The Year of Community Living" in recognition of the 10th anniversary of the Olmstead decision, lend further evidence to the strength of this policy trend.

The long term care enhancements that are part of health care reform, embedded in the Patient Protection and Affordable Care Act, P.L. 111-148, unequivocally support increased development and reliance upon community services. These provisions (referenced in the final section of this testimony) also hold the promise of increased federal funding for New Jersey, but only for community based services and supports.

Where Do People with Developmental Disabilities in NJ and the US live?

The majority of the 41, 645 individuals, [2] 70% of the caseload of the Division of Developmental Disabilities, live at home with their families. The number of individuals who live at home with their families significantly exceeds the 57.4% of individuals who live with their families nation-wide.[3] Also of note is New Jersey's Waiting List, comprised of 8,170 individuals living with their families. The Waiting List is classified by the following categories: "Priority" 4,994 individuals; "Priority Deferred" 249 individuals; and "General" 2927 individuals.

As demonstrated in Table 1, more NJ citizens with developmental disabilities live in out-of-home placements (22.1%), compared to their peers nationwide (16.1%). Fewer NJ citizens with developmental disabilities live in homes of their own, apart from the family home. [3]

Table 1

Where People with Developmental Disabilities in NJ Live

Percentage of Individuals Receiving
Residential Services by Living Arrangement
New Jersey and USA [3]

	Out of home	In own home	In family home
New Jersey	22.1%	7.8%	70.1%
United States	16.1%	26.5%	57.4%

For people who utilize residential placements in New Jersey, in contrast to the US as a whole, we have a smaller percentage of people who live in smaller community living arrangements of 1-6, such as group homes: 60.4% compared to 74.5%.[3] In New Jersey, 2,725 individuals live in state operated developmental centers.[2] In NJ, 32.2% of residential service utilization is in settings of 16+ people, in contrast to 13.2% nationally.

Table 2

Utilization of residential settings by size
New Jersey and USA [3]

	Percentage of residents in 1-6 sized residential settings	Percentage of residents in 7-15 sized residential	Percentage of residents in 16+ sized residential settings
New Jersey	60.4%	7.4%	32.2%
United States	74.5%	12.2%	13.2%

New Jersey also has the largest number of individuals in out-of- state residential placements of any of the states. Seven-hundred and thirteen (713) individuals, 2% of the DDD caseload, are placed out of state.[2]

Of additional concern, as we look at the range of service settings, is the 500 person increase over the past ten years of individuals with developmental disabilities living in nursing homes.[3] DDD reports that there are 984 individuals who are clients of the Division, who are in Skilled Nursing Facilities.[2]

New Jersey and the National Trends in Large State Institutions

The clear nationwide trend is to decrease reliance on large state institutions for the provision of residential services. There are now 11 states that no longer have any state operated large institutional settings: Alaska, the District of Columbia, Hawaii, Maine, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont and West Virginia. [3] Eleven states now have only one state institution.[4]

New Jersey is one of only ten states that have over 2,000 people living in public institutions. [4] In New Jersey, 2,725 individuals live in state operated developmental centers. [2] Proportionately, this represents three times the percentage of individuals who reside in large state-run facilities across the country.

Table 3

Percentage of total residents in 16+bed state-run facilities
New Jersey and USA[3]

	Number of residents in 16+ state-run	Total residents	Percentage of residents in 16+ state-
New Jersey	2,897	11,485	25.2%
United States	35,035	436,866	8.0%

In addition to having a large number and high percentage of individuals residing in state facilities, New Jersey has a high rate of institutionalization from a population perspective: 33.4 persons per 100,000 of population, in contrast to 11.8 persons per 100,000 nationally.[5]

The level of intellectual disability of the residents in New Jersey's developmental centers is generally comparable to the level of intellectual disability of individuals in large state institutions nationwide. There are a larger percentage of individuals, 65.6%, classified in the profound range of intellectual functioning, which is higher than the US average of 51%, but comparable to Pennsylvania's population at 68%. Functionally, the group of individuals in NJ's developmental centers has similar needs and abilities in understanding verbal requests, toileting, and transferring [from wheelchair] compared to the institutional population nationally. A smaller percentage of NJ residents in developmental centers cannot communicate verbally or who need assistance with walking or eating compared with the national averages, but the percentage in NJ who need assistance or supervision with dressing is higher.[3] There is a slightly higher percentage (36.5 %) of individuals age 55years or older in NJ's developmental centers, compared to the US as a whole (30.6%). [3]

The Experience with Deinstitutionalization in NJ and the US

In 1980, 7,262 resided in New Jersey's developmental centers, [3] then called "State Schools and Hospitals". In the period between 1980 to 2008, the population living in developmental centers decreased by 59.4% while the population in large state facilities nationally, decreased by 72.8%. Our neighboring state of Pennsylvania, whose institutional population in 1980 was comparable to ours at 7, 290 people, from 1980 to 2008 decreased the number of people in large congregate settings by 82.4%, while we in New Jersey only in decreased our population by 59.4%.[3] New Jersey's pace of reducing the numbers of people living in state run institutions has consistently been below the national rate. In the period 2005-2008, New Jersey decreased its institutional population by 4.8%, while nationally, the institutional population decreased by 11.8%.

Of the three state institutions closed by the Department of Human Services, North Princeton Developmental Center, which closed in 1998, was the largest with 512 residents. (Edison which opened in1981 and closed in 1988, housed 70 individuals; Johnstone Training Center, closed in 1992, housed 239 individuals). Extensive documentation of the impact of the closing of North Princeton Developmental Center (NPDC) was conducted by the Developmental Disabilities Planning Institute at NJIT. Through measurement of individuals' status prior to closing, at regular intervals up to two and a third years after closure, and in comparison to individuals continuing to reside at other developmental centers, the Planning Institute demonstrated: 1) positive outcomes; 2) no evidence associated with increased mortality or other negative consequences; and 3) despite initial opposition, eventual strong support of community living by a clear majority of NPDC family members. For psychiatric and behavioral needs, often identified as areas of concern about community living, important positive findings were demonstrated. The increased numbers of individuals who received a psychiatric diagnosis, the increased use of antipsychotic medication and decreased use of medication to control behavior, suggest a pattern of more appropriate and individualized, person centered address of needs and treatment upon movement to the community.[7]

How We Utilize Available Resources in New Jersey

Medical Assistance (Medicaid), Title XIX of the Social Security Act, is the federal financial underpinning for Developmental Disabilities services in New Jersey and for all other states. How we utilize Medicaid for long term care services has both a unique history in New Jersey, and is reflective of how our state has structured supports and services for individuals with developmental disabilities. In 1971, the Intermediate Care Facilities program of Title XIX was amended to serve individuals with mental retardation/intellectual disabilities and became the ICF/MR program. By 1977, 40 states had one ICF/MR certified facility,[3] which enabled the state to draw down partial federal reimbursement for institutional services. New Jersey did not enter the ICF/MR program until 1978, considerably later than most other states. Entrance into the ICF/MR program was the impetus for New Jersey's significantly reducing its institutional population by 1,557 individuals (21%) in the five year period between 1980 and 1985, and developing a system of community residential and day services.

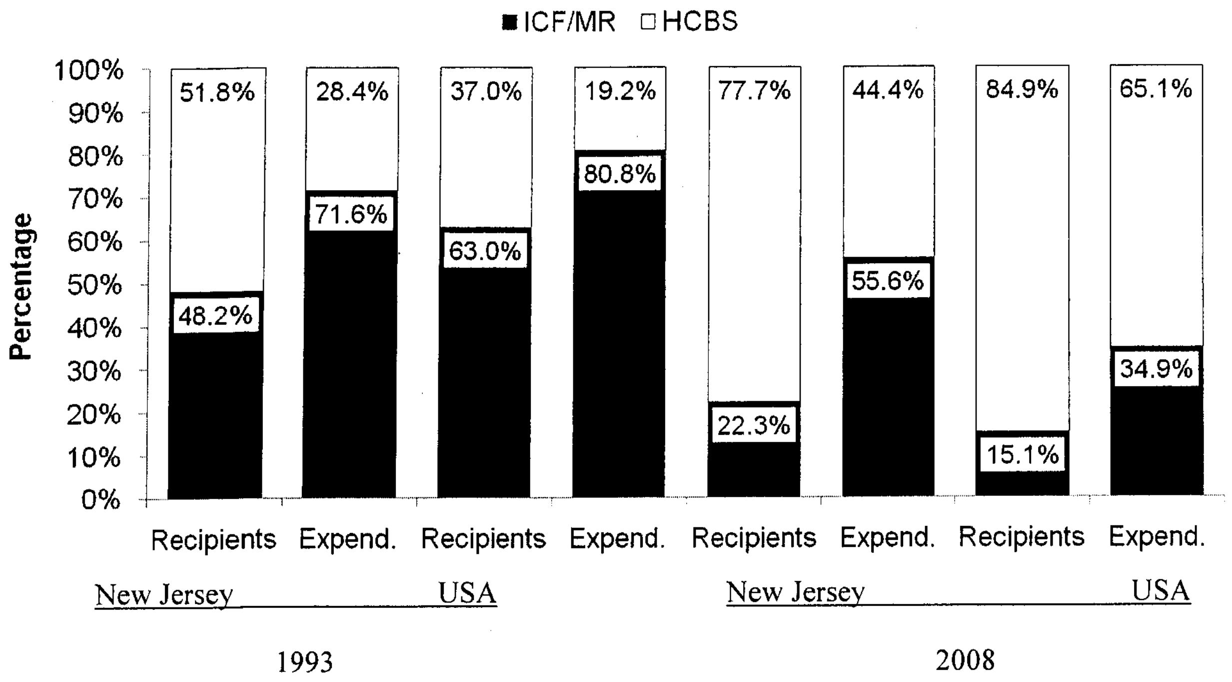
Home and community based services(HCBS) waivers came into being through the 1981 Omnibus Budget Reconciliation Act which gave the "Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow state to finance 'non-institutional' services for Medicaid eligible individuals".[3] HCBS waivers were designed to provide community services to people with ID/DD, "[W]ho, in the absence of alternative non institutional services, would remain in or would be at risk of being placed in a Medicaid facility [i.e. a Nursing Facility or an ICF-MR](p.87).[3]

The national trend toward community supports is powerfully demonstrated by the historical changes in Medicaid expenditures. From 2002 to 2008, ICF-MR expenditures increased nationally by only 5%, while HCBS waiver expenditures increased 70%.[8]

In the 15 year period between 1993 and 2008, there was a decrease in the number of Medicaid recipients served in large institutions (ICF-MRs) and an increase in those served through HCBS waivers. In New Jersey the DDD Home and Community Based Services waiver is often referred to as the "Community Care Waiver" or "CCW". Although this shift is seen in both New Jersey and nationally, as presented in Table 4, significant disparities persist in the rate of change, as well as the pattern of expenditures for community services and for large institutions, between New Jersey and the rest of the nation. The change in the percentage of Medicaid recipients receiving HCBS nationally increased more than the percentage of Medicaid recipients receiving HCBS services in New Jersey. The percentages of expenditures for community (HCBS) services also increased more nationally than in New Jersey.

Table 4

Percentage of Total Medicaid ICF/MR and HCBS Recipients and Expenditures in HCBS and ICF/MR, 1993 and 2008 New Jersey and USA [3]

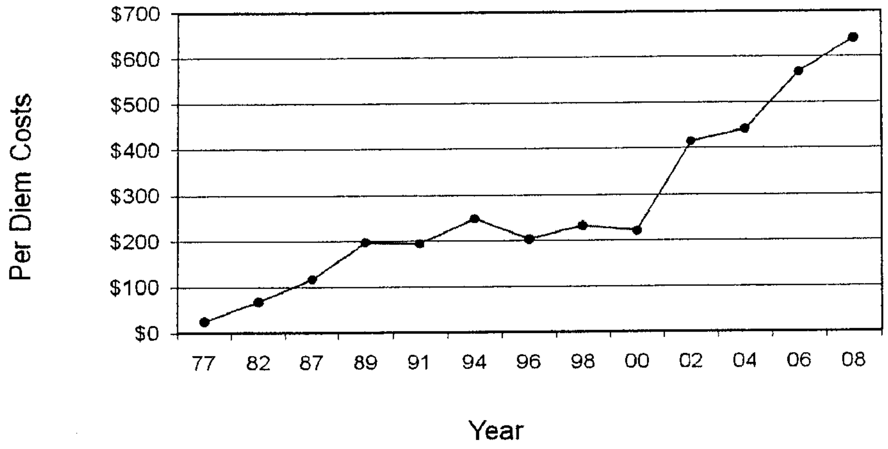


The decrease in the percentage of Medicaid recipients served in large institutions (ICF/MRs) was more dramatic for the nation than in New Jersey. New Jersey's expenditures for ICF-MR services continued to remain higher.

In New Jersey, per diem costs in developmental centers have risen dramatically, especially since FY 2001, as demonstrated in Table 5.[3] New Jersey's per diem costs in FY 08 were $641 as compared with the US weighted average of $514.35.[3] It is noteworthy that there is a significant variation in costs across NJ's developmental centers, from Hunterdon Developmental Center's cost of $390 per diem, to Woodbridge Developmental Center's cost of $803 per diem.[3]

Table 5

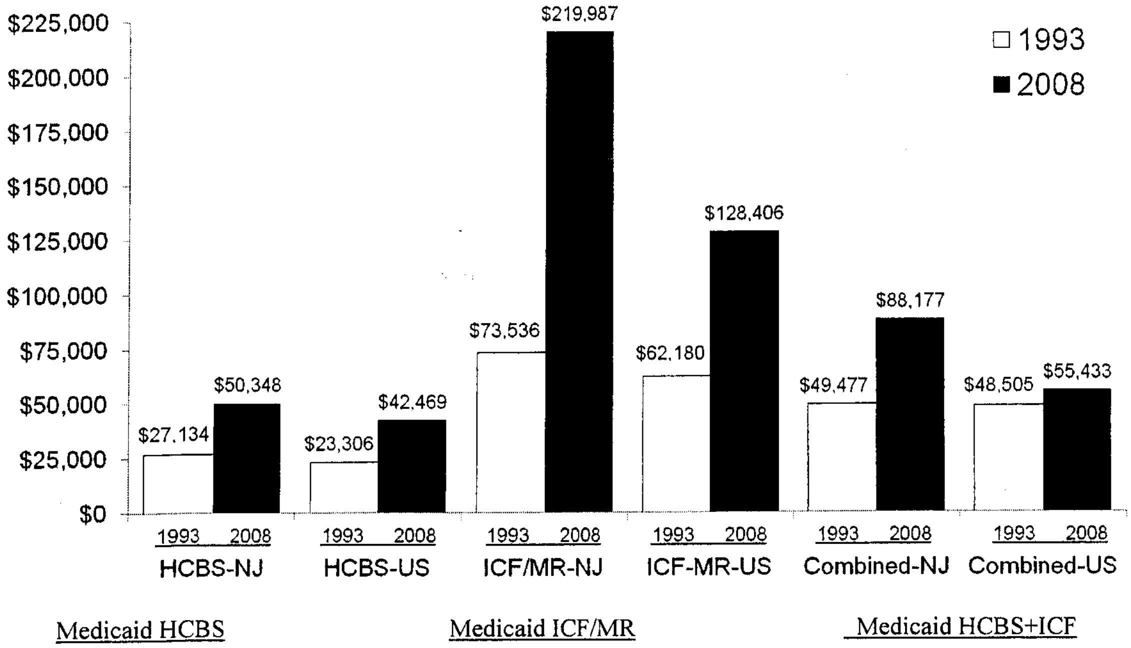
Average Per Diem of NJ State Institutions [3]



There are significant disparities in our spending in New Jersey for Medicaid recipients depending upon whether they are receiving ICF/MR services or HCBS services, as demonstrated in Table 6. Average annual spending for ICF/MR recipients in New Jersey is $219,987; for HCBS recipients it is $50,348.[3] ICF/MR per recipient spending has tripled in the past 15 years while HCBS spending has less than doubled. Our costs in each category of Medicaid long term care expenditures are higher than the US average costs, with New Jersey's ICF/MR spending being dramatically higher.

Table 6

Changes in Per Recipient Expenditures for HCBS, ICF/MR and combined HCBS and ICF/MR Recipient Between 1993 and 2008, New Jersey and the USA [3]



The Challenge of Waiting Lists and Choice Across the System

The DDD Waiting List, formerly a "Waiting List for Residential Services" has now become a "Waiting List for Waiver Services", with the HCBS Waiver, now providing in-home supports in addition to community residential and other services. A "supports" waiver, an additional HCBS waiver, is being planned by the Division of Developmental Disabilities. The increased reliance on HCBS waivers to provide services to individuals living with their families, especially those on the waiting list, creates a more urgent imperative to address the disparities in the availability and utilization of Medicaid funds for services to individuals with developmental disabilities in New Jersey.

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The issue of choice and its importance to and for individuals with developmental disabilities and their families is an issue of import to all families, independent of the services they have or want or need ,and is also an issue of equity. Families of individuals who live with their family, who are on waiting lists have long been deeply concerned about the wait for community service. For these families their long term interest and their deepest fears are that community services will not be available for their family member when they are no longer able to provide care, when the family ages, becomes ill or dies.

These concerns were addressed by the New Jersey legislature through P.L. 1997, Chapter 17 which required the Department of Human Services to develop a "plan to eliminate the waiting list for community residential services from the Division of Developmental Disabilities (DDD) by the year 2008".[9] The resulting plan recognized the need to realign the use of resources to address the disparity in access to community services. A compromise, reached through the dedicated efforts of the late Leila Gold- a parent leader in the developmental center parents group with community parent leaders, was the proposal to close three developmental centers in order to utilize those resources more broadly in the community. That recommendation was embedded in the 1998 "Plan to Eliminate the Waiting list".[9]

The issue of choice is resonant for all individuals and families across the system: for those who choose HCBS services as well as those who choose ICF/MR services.

Moving Forward: The Possibilities for Enhanced Federal Resources

Of great benefit to individuals with developmental disabilities, to states and service systems, are the provisions of the federal Patient Protection and Affordable Care Act, P.L. 111-148, which address long term care.

These include:

- **The New State Balancing Incentives Payments Program, Section 10202,** to be in effect 10/1/11 – 9/30/15.

  This will provide a temporary increase in the federal Medicaid matching rate for states that make structural reforms to increase community services over ICF services

  New Jersey should be eligible for a 2% increase, given that our level of Medicaid expenditures for HCBS is 44%, below the minimum federal target of 50%.

- **Community First Choice (CFC) Option, Section 2402**, will take effect 10/1/11.

  A new Medicaid state plan option for comprehensive home and community based services for people eligible for an institutional level of care (including ICF)

  This could provide a 6% additional federal match for CFC services

- **Extension of Money Follows the Person Rebalancing Demonstration Program, Section 2403** through 2016

  Provides an increased Federal Medical Assistance Percentage (FMAP) for individuals moving to the community from an institution

  This allows states to cover institutionalized individuals 90 days before they move to the community

It is essential that New Jersey monitor the implementation of these provisions to ensure that the state is prepared and well positioned to comply with the requirements of these funding sources, and to aggressively pursue these federal resources.

It is also essential that there be continued reinvestment of federal resources drawn into the state to permit the expansion of services to individuals with developmental disabilities who are on the waiting list.

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The Elizabeth M. Boggs Center
on Developmental Disabilities

Annual Report

Programs & Projects

July 1, 2008
June 30, 2009
Fiscal Year 2009

THE ELIZABETH M. BOGGS CENTER
ON DEVELOPMENTAL DISABILITIES
Department of Pediatrics

UMDNJ

ROBERT WOOD JOHNSON
MEDICAL SCHOOL
University of Medicine & Dentistry of New Jersey

A University Center for Excellence
in Developmental Disabilities Education, Research, and Service

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For more information about The Boggs Center,
please call 732-235-9300 or visit our website at http://rwjms.umdnj.edu/boggscenter.

Upon request, this material will be made available in alternative formats to accommodate the needs of individuals with disabilities. This report is funded by grant #90DD0552 from the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities.

Contents

Welcome

From the Executive Director

Friends,

I always appreciate welcoming you to this report, and the opportunity this letter provides to reflect on the past year and look towards the future.

It is a source of great sadness that all of us lost two irreplaceable friends with the deaths of Eunice Kennedy Shriver and Senator Edward Kennedy. Mrs. Shriver's tireless efforts helped families transcend the historical stigma of having a family member with intellectual disability, and move early onset disability into the arena of federal policy. She had a deep conviction about the importance of training personnel to work with individuals and their families. This vision helped create University Affiliated Facilities, which have now become University Centers for Excellence in Developmental Disabilities, the designation The Boggs Center is proud to hold for New Jersey. Senator Kennedy was central to federal health and human services legislation for the past four decades - improving the lives of all of us, especially the more vulnerable among us. In his life, and in his death, Senator Kennedy reminds all of us that policy and government can be the vehicle by which we hold each other dear.

In the past year, we have worked to find enhanced ways to utilize the expertise and perspectives of our Consumer Advisory Council. The impact of this deeper involvement and the generosity of spirit and time given by our CAC members is reflected in our redesigned website, program evaluation strategies, and many other aspects of The Boggs Center program. As we look toward the New Year, we are excited to be part of the Alliance for Full Participation and the national goal of enhancing employment for people with developmental disabilities, especially those with significant disabilities. We draw energy from teaching our student trainees and their contributions to creating more valued futures for people with disabilities, their families, and those who work on their behalf.

The economy continues to create great suffering for so many people and make it so much more difficult for individuals with disabilities and their families to receive the services and supports they need. In our education, research, and service roles we have always worked to provide state of the art information, contribute to a vision of full community life, and support the development of capacity to realize that vision. As we continually learn from individuals and their families, these times challenge us to find ways to innovate, to preserve what is essential, and together, find new ways create a more just society.

Thank you for your support of The Boggs Center.

Warm regards,

Deborah M Spitalnik

Deborah M. Spitalnik, Ph.D.
Executive Director
Professor of Pediatrics

Mission

Mission of The Elizabeth M. Boggs Center on Developmental Disabilities

New Jersey's University Center for Excellence in Developmental Disabilities

The Elizabeth M. Boggs Center, as a University Center for Excellence in Developmental Disabilities, values uniqueness and individuality and promotes the self-determination and full participation of people with disabilities and their families in all aspects of community life.

As a catalyst and resource, The Boggs Center, through partnerships and collaborations, builds capacity in organizations, systems, and communities in a culturally competent manner. The Boggs Center prepares students through interdisciplinary programs, provides community training and technical assistance, conducts research, and disseminates information and educational materials.

About the Center

Elizabeth M. Boggs, Ph.D.
April 5, 1913 - January 27, 1996

Elizabeth Monroe Boggs, Ph.D., parent and internationally renowned policy maker, was New Jersey's foremost scholar and advocate for people with developmental disabilities. To honor her contributions, the University of Medicine and Dentistry Board of Trustees designated The University Affiliated Program of New Jersey as "The Elizabeth M. Boggs Center on Developmental Disabilities" in late 1997.

Elizabeth Monroe Boggs was born in Cleveland, Ohio. In 1941, Elizabeth married Fitzhugh Willets Boggs (1911-1971). Their son, Jonathan David Boggs, was born in 1945 and it was recognized soon after birth that he had developmental disabilities. He eventually resided at the Hunterdon Developmental Center in Clinton, near were Elizabeth lived in Hampton, New Jersey. David passed away in 2000.

In 1935, Elizabeth graduated from Bryn Mawr College, summa cum laude, with distinction in Mathematics. She earned a Ph.D. in Theoretical Chemistry from Cambridge University, England, in 1941. Subsequently, Elizabeth was awarded honorary degrees from the University of Medicine and Dentistry of New Jersey, Kean College, and The Ohio State University.

With David's birth in 1945, Elizabeth shifted her focus, from the career in Mathematics for which she had prepared, to advocacy and the development of public policy for people with disabilities. A founder of the National Association for Retarded Children, Elizabeth served as the Association's first woman President. Throughout her career, she had continually been involved with The Arc's Governmental Affairs Committee and its activities.

Elizabeth's involvements and contributions were far-ranging. They included serving on the President's Panel on Mental Retardation and as Vice-Chair of The Task Force on the Law, 1961-1963, and on the President's Committee on Mental Retardation. Working with the International League of Societies for the Mentally Handicapped, she was a principal author of the United Nations Declaration of General and Special Rights of the Mentally Retarded. With Justin Dart, Elizabeth co-chaired the congressionally appointed Task Force on Rights and Empowerment of People with Disabilities, an important impetus to the passage of the Americans with Disabilities Act. Elizabeth served on the SSI Modernization Project and, at the time of her death, was serving on the Social Security Administration's Task Force on Representative Payees.

Elizabeth's many national awards and recognitions include the Kennedy International Award for Leadership, the Distinguished Public Service Award from HEW, the Distinguished Service Award from UCPA, the Wallace Wallin Award from CEC, and the N. Neal Pike Prize for Service to People with Disabilities. She was also recognized by the American Association of University Affiliated Programs, The Arc-US, and the President's Committee on Employment of People with Disabilities. Elizabeth was a Life Fellow of AAMR (now AAIDD), and an Honorary Fellow of the American Psychiatric Association and the American Academy of Pediatrics.

National Network of University Centers for Excellence

The Boggs Center is part of a national network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service sponsored by the Administration on Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services.

The purpose of University Centers in Developmental Disabilities, as outlined in the Developmental Disabilities Assistance and Bill of Rights Act, is to provide a leadership role in the promotion of independence, productivity, self-determination, and opportunities for full participation in community life for people with developmental disabilities and their families.

University Centers in Developmental Disabilities implement their purpose through these mandated activities, delivered in a culturally competent manner:

- Interdisciplinary education of students and fellows at the graduate, postgraduate, and undergraduate levels
- Continuing education for individuals who support or assist individuals with developmental disabilities and their families
- Community and family education, technical assistance, and model demonstration activities
- Applied research and policy analysis
- Dissemination of information and research findings and policy analyses

NJ ADD Network

The federal Developmental Disabilities Assistance and Bill of Rights Act establishes three distinct entities that complement each other's efforts in promoting "self-determination, independence, productivity, and integration and inclusion in all facets of community life" for individuals with developmental disabilities and their families.

In each state, the Administration on Developmental Disabilities (ADD) Network, as these three entities are known, is comprised of:

- University Center of Excellence for Developmental Disabilities Education, Research, and Service, which provides community and student training and technical assistance, conducts research, and disseminates information to a wide variety of stakeholders
- Council on Developmental Disabilities, which engages in advocacy and capacity building
- Protection and Advocacy system, which protects the legal and human rights of individuals with developmental disabilities

The three partner agencies that make up the New Jersey ADD (NJ ADD) Network are The Elizabeth M. Boggs Center on Developmental Disabilities, the New Jersey Council on Developmental Disabilities (NJCDD), and Disability Rights New Jersey (DRNJ). The NJ ADD Network is working collaboratively to address the shared priorities of cultural competence (coordinated by The Boggs Center), self-advocacy (coordinated by NJCDD), and emergency preparedness (coordinated by DRNJ) for people with disabilities and their families.

University of Medicine and Dentistry of New Jersey

Created by the State Legislature in 1970, the University of Medicine and Dentistry of New Jersey (UMDNJ) is a statewide network of academic health centers that includes eight schools on five campuses. UMDNJ is dedicated to the pursuit of excellence in the education of health professionals and scientists, the conduct of research, the delivery of health care, and service to the people of New Jersey. UMDNJ is the largest institution of its kind in the nation. (UMDNJ 2007-2008 University Report).

The Boggs Center, an integral component of the UMDNJ-Robert Wood Johnson Medical School Department of Pediatrics, works with the Robert Wood Johnson Medical School Department of Family Medicine and other UMDNJ departments to address the needs of children and adults with disabilities. Based within the medical school, The Boggs Center promotes a community-based, capacity-building approach to the delivery of health care and community supports for people with developmental disabilities. The Boggs Center represented 38% of the grant support funding of the Department of Pediatrics in FY 2008.

History

History of The Elizabeth M. Boggs Center on Developmental Disabilities

As New Jersey's federally designated University Center on Developmental Disabilities (UCEDD), The Boggs Center has played an important role in accessing federal and other external resources to address the needs of people with developmental disabilities and their families throughout the state. Since 1985, these resources have helped to both inspire innovative thinking and build the statewide capacity necessary for people to live fully integrated, meaningful, and valued lives in their communities.

❖ Student training is one of the core functions of UCEDDs that is mandated by the federal Developmental Disabilities Act. Since its inception, The Boggs Center has provided intensive, year-long traineeships for students from a variety of disciplines, including social work, education, pastoral care, and psychology. Regardless of their chosen professions, students who complete these traineeships have brought to their work a deeper understanding of, and commitment to addressing, the challenges confronting people with developmental disabilities and their families. In addition, Boggs Center faculty members reach students from a range of disciplines by teaching courses and serving as guest lecturers for a number of New Jersey universities.

❖ Since 1984, The Boggs Center's Developmental Disabilities Lecture Series (DDLS) has provided a unique venue for bringing nationally renowned leaders in the field of developmental disabilities to New Jersey. The DDLS is free and open to the public, and has become common ground for the sharing of new information, collaborative problem solving, and a forum for the development and refinement of state disability policy.

❖ The Boggs Center has long recognized the critical importance of Direct Support Professionals to the lives of people with disabilities. Over twenty years ago, with funding from a federal Administration on Developmental Disabilities Training Initiative Project, The Center developed the New Jersey Statewide Training Network. This network has continued to provide a vehicle for active collaboration between The Boggs Center, the state, and provider agencies. In addition, for the past two years, with a grant from the NJ Council on Developmental Disabilities, The Center has facilitated the use of the College of Direct Support (CDS), in combination with onsite mentors, in a unique Career Path pilot program with agencies.

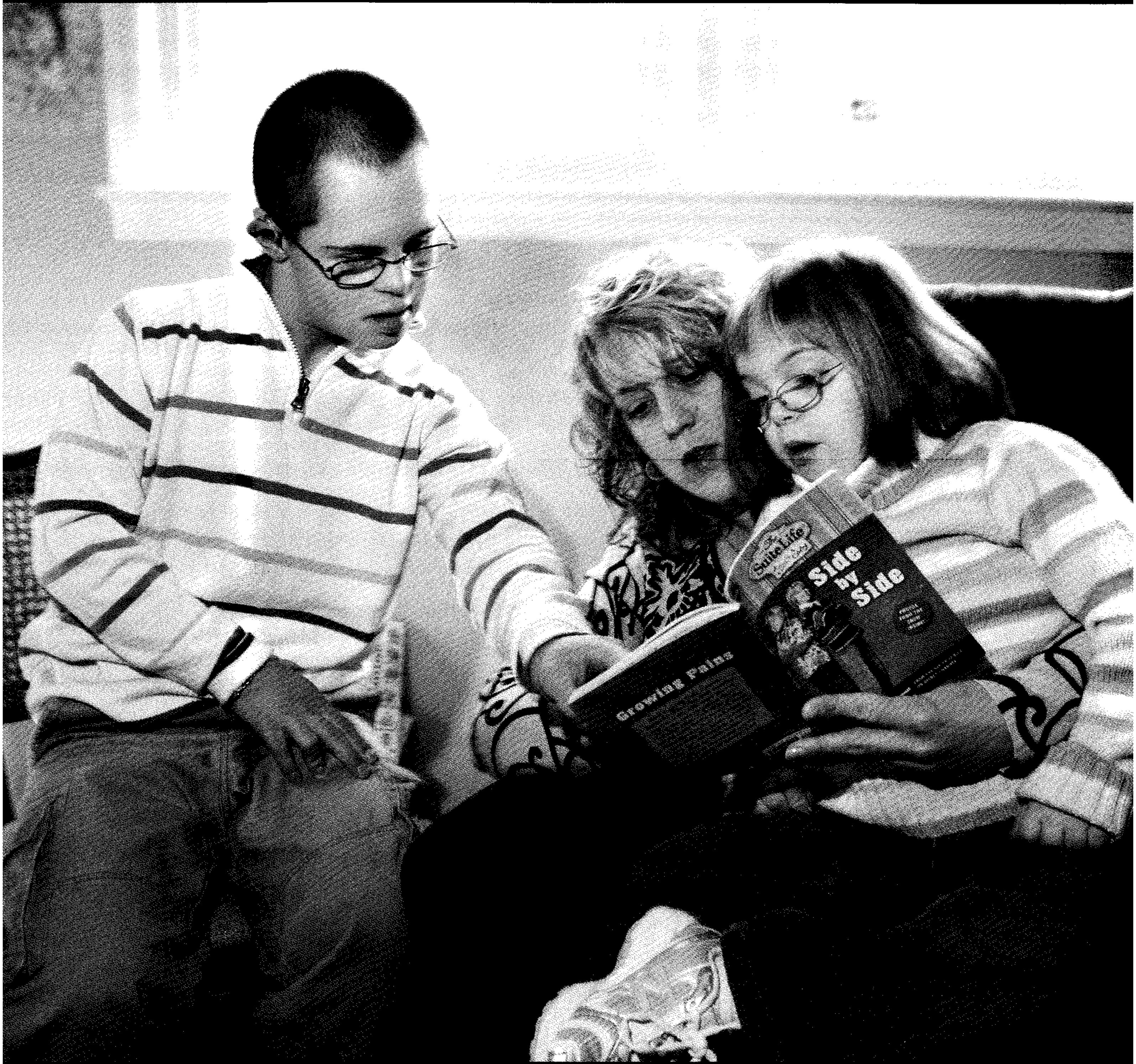
❖ In the early 90s, in a program that was also funded through a federal Training Initiative Project, The Boggs Center introduced Person-Centered Planning (PCP) to New Jersey. Since then, The Center has provided ongoing training and technical assistance on person-centered approaches for the closure of North Princeton Developmental Center, the Self-Determination Initiative, and New Jersey's current efforts in Self-Directed Supports with funding from the NJ Division of Developmental Disabilities. In addition, with funding from the NJ Division of Disability Services' federal Real Choice Systems Change grant, The Boggs Center developed and disseminated *Keeping It Real: How to Get the Support You Need for the Life You Want*, a curriculum designed to teach young adults how to advocate for, and manage their own disability-related supports.

❖ Community building activities have grown over the years, with an increased focus on faith-based groups as a source of community support. The Boggs Center's efforts in this area include the national accreditation of our unique Clinical Pastoral Education program, which – in collaboration with community provider agencies – provides chaplaincy students an opportunity for education and experience in the field of developmental disabilities. The Boggs Center also facilitates the New Jersey Coalition of Inclusive Ministries, and has published several guides related to faith-based supports, including *When The Call Comes* (funded through a federal Traumatic Brain Injury grant) *and Autism and Faith: A Journey Into Community* (funded by the Daniel J. Fiddle Foundation).

❖ Employment has been a high priority for The Boggs Center for many years. In addition to our training courses for employment specialists, faculty and staff have been involved in a number of initiatives that aim to raise awareness about the importance of employment for people with disabilities, as well as to build the statewide capacity for providing employment supports. A five-year federal System's Change Grant to the Department of Labor and a partnership with the NJ Division of Developmental Disabilities initially funded The Boggs Center's supported employment work. Boggs Center faculty and staff serve on the board of the state chapter of national APSE: The Network on Employment, and The Center has co-sponsored 17 state conferences on supported employment with NJ APSE. The Boggs Center is also a consortium partner in the National Technical Assistance and Research Center to Promote Leadership for Increasing Employment and Economic Independence for Adults with Disabilities with the Heldrich Center on Workforce Development, and is also coordinating New Jersey's efforts for the national Alliance for Full Participation, an Alliance of national disability organizations that has made employment its top priority.

- With initial funding from the Department of Education's federal System's Change and State Improvement Grants, The Boggs Center has worked for many years to build the capacity of schools to include students with disabilities through such initiatives as the training of paraprofessional educators, the Inclusion Facilitators Network and, most recently, the Positive Behavior Support in Schools (PBSIS) project. PBSIS has provided more than 70 New Jersey schools the opportunity to learn and implement national best practices for addressing behavioral challenges throughout the school.
- The Boggs Center has worked in partnership with the New Jersey Department of Education, Office of Special Education Programs; the Division of Vocational and Rehabilitation Services; and the Division of Developmental Disabilities to address transition to adult life. Efforts were initially funded through a federal System's Change in Transition Grant and then the State Improvement Grant to the New Jersey Department of Education. Current efforts focus on teaching school personnel how to provide effective Community-Based Instruction.
- For 25 years, through the Developmental Disabilities Lecture Series, ongoing training courses, technical assistance, and statewide conferences, The Boggs Center has promoted the underlying philosophy and skills for implementing Positive Behavior Support (PBS) in community settings. Currently, through Division of Developmental Disabilities' Children's Placement Enhancement Project (CPEP), Boggs Center faculty and staff are providing PBS training and technical assistance so that provider agencies are better able to serve children with behavioral challenges within the state and closer to home.
- In collaboration with the UMDNJ-Robert Wood Johnson Medical School Department of Family Medicine, the Family Practice Center, and with initial support from the Robert Wood Johnson Foundation, The Boggs Center created a program that 20 years later continues to ensure that all Family Practice resident physicians provide health care to people with disabilities as part of their training. In addition, every graduate of UMDNJ-Robert Wood Johnson Medical School in New Brunswick receives training in family centered care and developmental disabilities that includes individual visits to the homes of families with children with developmental disabilities.
- The Center helps facilitate a statewide Cultural Competence Collaborative of the Administration on Developmental Disabilities programs in NJ, the Division of Disability Services, the Division of Developmental Disabilities, SPAN, and other organizations. The Collaborative organized a Latinos and Disabilities Conference and a South Asians and Disabilities Conference, and is planning similar events for the future. In addition, The Boggs Center is involved in cultural competency efforts through the national Association of University Centers on Developmental Disabilities, and in 2002, organized a training of state personnel by the Georgetown University's National Center for Cultural Competence.
- Boggs Center efforts in the area of health care include the development and dissemination of the *Managed Health Care Curriculum: Supporting People with Disabilities to Utilize Managed Health Care* funded through a federal Project of National Significance grant. *Children with Early Hearing Loss and Existing Comorbid Conditions in New Jersey: State Data and The Experience of Families* is a research partnership between The Boggs Center and The NJ Department of Health and Senior Services, Division of Family Health Services, Early Identification and Monitoring Program. The project is funded by the Center for Disease Control's National Center on Birth Defects and Developmental Disabilities, under a cooperative agreement with the Association of University Centers on Disabilities.

For 26 years, through all these and many other activities, including service on committees, presentations, and research, The Boggs Center has worked to promote a system of supports that is responsive to both the dreams and challenges of people with disabilities and their families. It is this vision, along with an unwavering commitment to the right of every individual to be fully included in their community, that continues to guide all of The Boggs Center's efforts.


Suite Life
Side by Side
Growing Pains

Core Functions

Training, Technical Assistance, Information Development and Dissemination, and Research and Evaluation

The federal Developmental Disabilities Act, which designates the Boggs Center as New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD), mandates that we perform the core functions of training, technical assistance, research and evaluation, and information development and dissemination. The Boggs Center, in planning projects and activities, utilizes these core functions as the modalities to address our state context and needs.

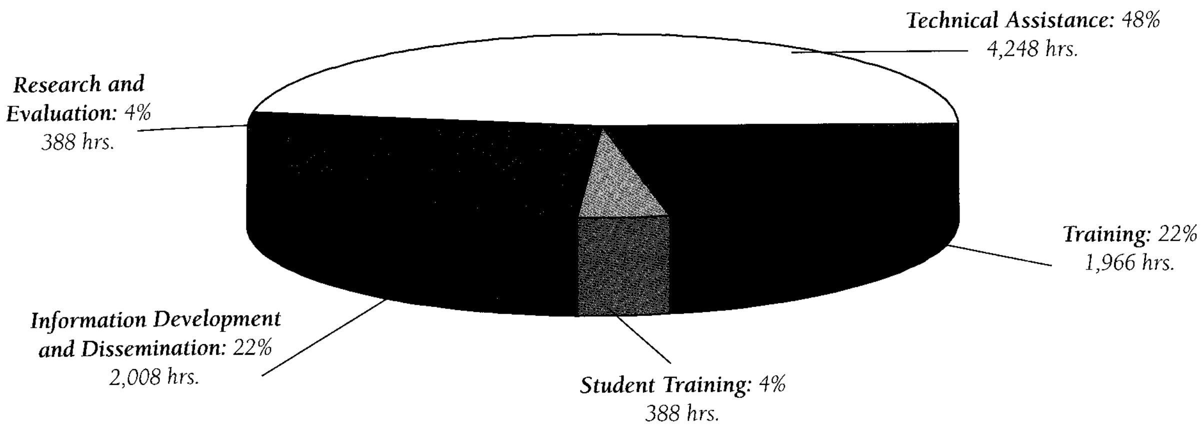
This pie chart, while presenting the hours of activity in each core function and the percentage of our overall efforts they each represent, does not fully convey the depth and the interconnections of The Boggs Center program. There is a constant interplay between core functions – they are not performed in isolation.

Boggs Center training programs prepare students and resident physicians and provide continuing education and in-service training to professionals, paraprofessionals, people with disabilities, and family members. Through a broad array of training activities, The Boggs Center builds capacity to support people with disabilities in full community living.

Technical Assistance, representing nearly half of our efforts, reflects how we work to ensure that the benefits of training programs are transferred to the settings where those trained work, so that these new skills and approaches have an impact on life quality and opportunities for people with disabilities and families. Technical Assistance is also the modality through which we contribute to the development of public policy, provide consultation and bring people together in partnerships to solve problems.

As research efforts at The Boggs Center and across the field contribute to the evidence base, we incorporate new knowledge and state-of-the-art information into training and technical assistance, and disseminate that information to enhance practice and services.

Core Function Level of Effort



Training

Training activities include training courses, workshops, and conference presentations. Continuing education recognition for many training courses and conferences is available to participants.

❖ Over 14,779 participants attended Boggs Center training courses, workshops, and presentations during Fiscal Year 2009.

❖ The Boggs Center presented 366 training events throughout the state of New Jersey as well as nationally and internationally. Faculty and staff presentations are listed on page 19.

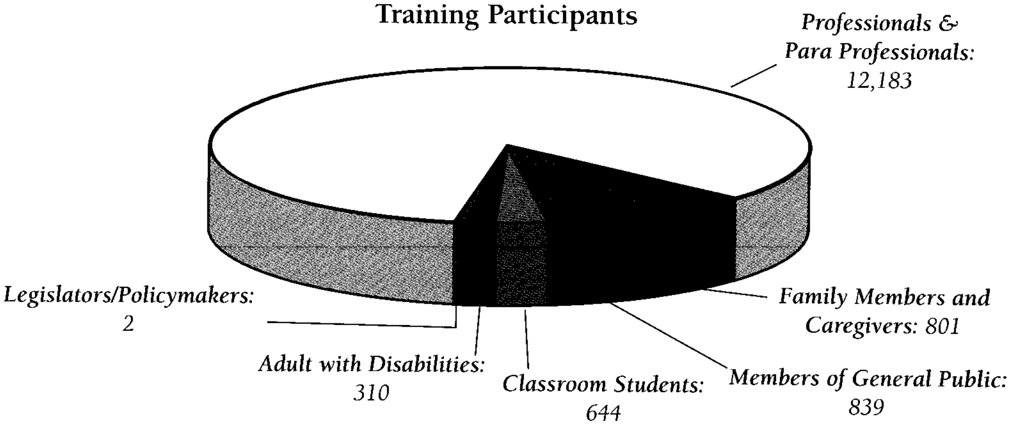
❖ The Boggs Center taught ongoing courses for community provider agencies as part of our quarterly training calendar, including Employment Specialist, Person Centered Thinking, Essential Lifestyle Planning, Positive Behavior Support, and Management. See **http://rwjms.umdnj.edu/boggscenter/** for our current schedule and online registration.

❖ During Fiscal Year 2009, eight sessions of the Developmental Disabilities Lecture Series (DDLS), were presented. More than 1,600 people attended the series.

❖ The Boggs Center conducted extensive training in Positive Behavior Support in Schools and Community-Based Instruction for school districts as part of a Memorandum of Understanding with the NJ Department of Education, a continuation of efforts begun with a Statewide Improvement Grant.

❖ Two major conferences were coordinated by The Boggs Center, including the 17th Annual Facing the Future Conference, focusing on employment for people with disabilities, and the 8th Annual Self-Directed Supports Conference.

Training Participants



Technical Assistance

Technical assistance (TA) activities involve helping organizations in planning, policy, and program development. The Boggs Center's faculty and staff contribute to systems change efforts at all levels throughout New Jersey through the extensive provision of technical assistance.

❖ In Fiscal Year 2009, The Boggs Center conducted 927 technical assistance activities, including consultations and advisory meetings with state and community agencies, school districts, and families. Boggs Center service on boards and committees is listed on page 24.

❖ The Boggs Center joined other UCEDDs from New York, Puerto Rico, and the Virgin Islands at a regional Act Early Summit sponsored by the Centers for Disease Control and Prevention and the Association of University Centers on Disabilities. Hosted by the New York UCEDDs, the Summit addressed the development of state plans to enhance systems for identifying and serving young children with Autism Spectrum Disorder (ASD), and related developmental disabilities

❖ The Boggs Center coordinates the Career Path Pilot Project funded by the NJ Council on Developmental Disabilities, which utilizes the online College of Direct Support in combination with onsite mentors and tiered, competency-based salary increases.

❖ The Boggs Center provided extensive technical assistance to community provider agencies serving individuals with challenging behaviors as part of the Community Positive Behavior Support and Children's Placement Enhancement Project of the NJ Division of Developmental Disabilities.

❖ In an effort to promote person-centered services in the community service system, The Boggs Center, under contract with the Division of Developmental Disabilities, has provided significant technical assistance in the area of Self-Directed Supports, as described on page 30.

❖ The Boggs Center works extensively with the NJ Office of Special Education Programs and local districts on positive behavior support in schools, and the transition from school to adult life, as illustrated on page 31.

❖ Two recent films were aided by technical assistance from The Boggs Center. *Praying with Lior* tells the story of a young man with Down Syndrome preparing for and going through his Bar Mitzvah. *Unlocking Autism* on Discovery Health presents conversations with researchers and families of individuals with autism.

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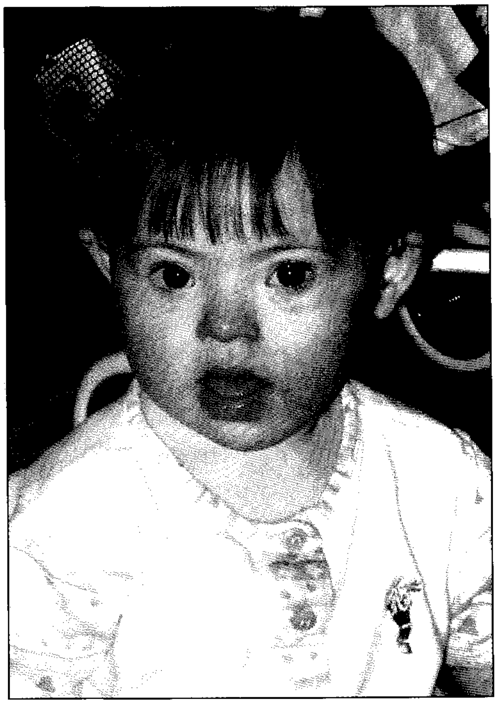
Research and Evaluation

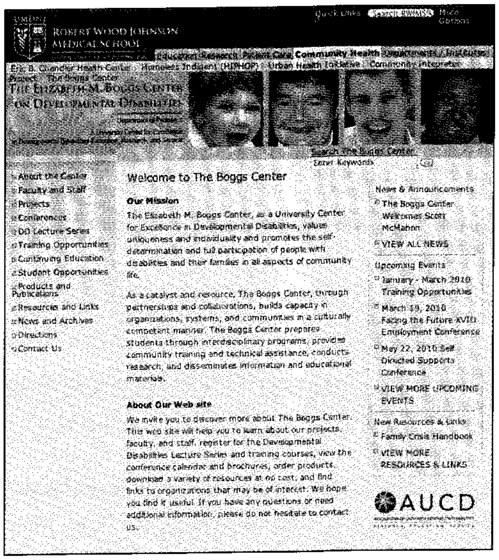
Research and Evaluation activities include research projects and program evaluation.

- Utilizing a Participatory Action Research approach, The Boggs Center is studying the experience of Children with Early Hearing Loss and Existing Comorbid Conditions in NJ: State Data and The Experience of Families, a partnership between The Boggs Center and the NJ Department of Health and Senior Services.
- The Boggs Center is studying the factors associated with school personnel adopting Positive Behavior Support as an intervention approach to behavior support in school settings.
- The Boggs Center continued to refine its capacity to collect and analyze consumer satisfaction across all training, dissemination, and student activities. As part of continuous efforts to refine its services, follow-up surveys of in-service training participants are now a standard part of the Center's program evaluation efforts. The web-based surveys assess the usefulness of the training and materials, and aid in the improvement of training offerings. A technical assistance evaluation instrument is being piloted with agencies participating in the CPEP initiative



Information Development and Dissemination

Information Dissemination includes the development and production of curricula, training guides, reports, and other educational materials in addition to community outreach and responding to requests for information.



Welcome to The Boggs Center

Our Mission

The Elizabeth M. Boggs Center, as a University Center for Excellence in Developmental Disabilities, values uniqueness and individuality and promotes the self-determination and full participation of people with disabilities and their families in all aspects of community life.

As a catalyst and resource, The Boggs Center, through partnerships and collaborations, builds capacity in organizations, systems, and communities in a culturally competent manner. The Boggs Center prepares students through interdisciplinary programs, provides community training and technical assistance, conducts research, and disseminates information and educational materials.

About Our Web site

We invite you to discover more about The Boggs Center. This web site will help you to learn about our projects, faculty, and staff, register for the Developmental Disabilities Lecture Series and training courses, view the conference calendar and brochures, order products, download a variety of resources at no cost, and find links to organizations that may be of interest. We hope you find it useful. If you have any questions or need additional information, please do not hesitate to contact us.

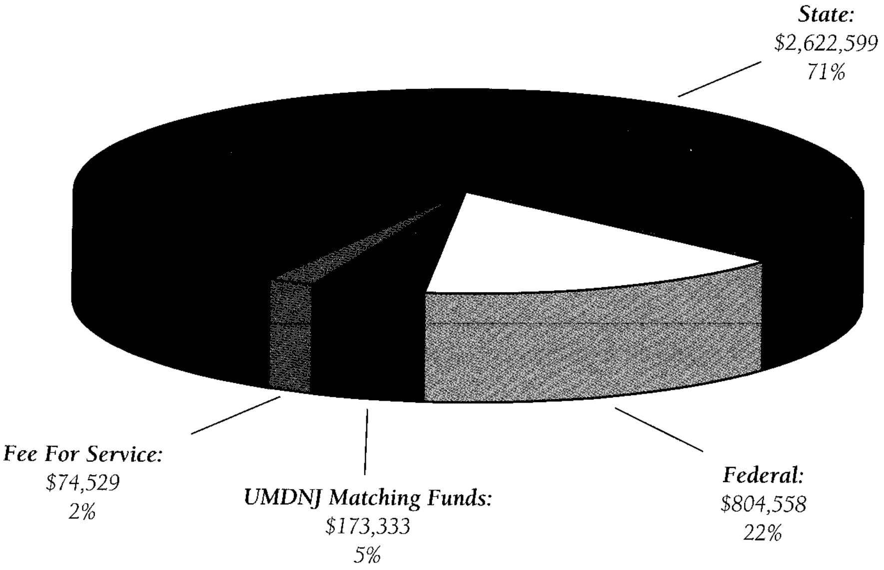
- The Boggs Center's web site **http://rwjms.umdnj.edu/boggscenter**, was dramatically re-designed during FY 2009 with input from the Consumer Advisory Council. The new design, which uses the Robert Wood Johnson Medical School template, features numerous photos of people with disabilities. Particular attention was paid to the accessibility of the site. The new web site contains Boggs Center news and announcements; faculty and staff information; training opportunities and upcoming events; student opportunities; descriptions of all of our projects; products and publications; and links to national and state disability resources.
- In July 2008, The Boggs Center started a Writers' Group for Family Caregivers, to give family caregivers of individuals with developmental disabilities an opportunity to tell their own stories, in their own words. A selection of stories is posted on The Boggs Center web site at **http://rwjms.umdnj.edu/boggscenter/projects/Writers_Group.html**.
- A total of 270,131 copies of 40 products were disseminated in Fiscal Year 2009. In addition to the new publications listed on the next page, many prior publications continued to be disseminated, including *Autism and Faith: A Journey into Community; Brain Injury: When the Call Comes;* and *Dimensions of Faith and Congregational Supports Resource Guide.*
- The Boggs Center also responded to information requests and provided resources to state and community agencies, people with disabilities, family members, university students and clergy.

Funding Sources

Funding Sources Fiscal Year 2009

The Boggs Center has particular expertise in developmental disabilities and a strong network of relationships with other components of the disability community. The Boggs Center provides services to federal and state agencies, community provider agencies, school districts, and other entities, through core funding, funded projects, and fee-for-service, including per diem consultations.

Total = $3,682,387



Boggs Center Grants and Contracts Fiscal Year 2009

Administration on Developmental Disabilities, Administration for Children and Families, US Department of Health and Human Services
University Center for Excellence in Developmental Disabilities Core Grant

Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities/ Association of University Centers on Disabilities
Children with Early Hearing Loss and Existing Co-Morbid Conditions in New Jersey: State Data and The Experience of Families Research

National Institute of Child Health and Human Development/ University of British Columbia
Transforming Coercive Relationships in Family Routines Research

New Jersey Council on Developmental Disabilities
Reducing Direct Support Professional Turnover in New Jersey: Career Path Pilot

New Jersey Department of Human Services
Division of Developmental Disabilities contract

New Jersey Department of Education - Office of Special Education Programs
Department of Education Memorandum of Understanding

Pennsylvania Council on Developmental Disabilities
Faith Community Leadership: A Collaborative Project between New Jersey and Pennsylvania

University of Medicine and Dentistry of New Jersey Foundation
Adoption and Intervention to Improve The Social Condition of School Settings Research

US Department of Labor, Office of Disability Employment Policy/ Rutgers University, Heldrich Center on Workforce Development
National Technical Assistance and Research Center


ShopRite

Faculty & Staff

FACULTY

Deborah M. Spitalnik, Ph.D.	*Executive Director* *Professor of Pediatrics* *Associate Professor of Family Medicine*
Michael Knox, Ph.D	*Deputy Director* *Assistant Professor of Pediatrics*
Daniel J. Baker, Ph.D.	*Director, Community Positive Behavior Support, Transition, and Supported Employment Projects* *Associate Professor of Pediatrics*
William C. Gaventa, M.Div.	*Director, Community and Congregational Supports* *Associate Professor of Pediatrics*
Sharon Lohrmann, Ph.D.	*Director, Positive Behavior Support in Schools* *Assistant Professor of Pediatrics*
Nancy Razza, Ph.D	*Adjunct Assistant Professor of Pediatrics*
Philip Smith, Ph.D.	*Assistant Professor of Pediatrics*

PROGRAM STAFF

Ziba Arjmand, B.S	*Data and Technology Coordinator*
Robyn Carroll, M.S.W.	*Communications Manager*
Melissa Cheplic, M.P.H.	*Training and Consultation Specialist*
Caroline Coffield, M.S.	*Project Coordinator*
Shellyann Dacres, M.A.	*Training and Consultation Specialist*
William Davis, M.Ed.	*Training and Consultation Specialist*
Joyce Jelley, B.A.	*Training and Consultation Specialist*
Wendy Kuziemski	*Event Coordinator*
Bret Li-Vaks, M.B.A.	*Training and Consultation Specialist*
Mary Malieckal, B.A.	*Financial Analyst*
Kathi Morley, A.S.	*Management Assistant*
Colleen McLaughlin, M.Ed.	*Training and Consultation Specialist*
Scott McMahon, M.S.W.	*Training and Consultation Specialist*
Kathy Roberson, M.S.W.	*Policy and Information Coordinator*
Sunne-Ryse Smith, Psy.D.	*Training and Consultation Specialist*
Michael Steinbruck, M.A.	*Program Administrator*
Ina White, M.A.	*Community Outreach Coordinator*
Alice Walsh, M.Div.	*CPE Supervisory Candidate*

PROGRAM SUPPORT

Gail DiPane	*Office and Project Support Staff*
Ann Marie McVay	*Project Support Staff*
Elizabeth Ong, B.S.	*Project Support Staff*
Carole Ramirez, B.S.	*Project Support Staff*

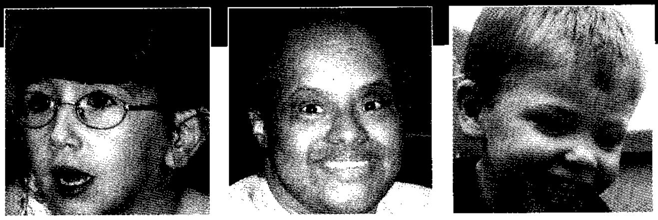
AFFILIATED FACULTY AND PROGRAM ASSOCIATES

Linda Breen	*Secretary, Department of Family Medicine*
Kathy Gabry	*Parent Advocate, Medical Student Seminar on Family Centered Care and Developmental Disabilities*
Cathryn Heath, M.D.	*Clinical Associate Professor, Department of Family Medicine*
Dolores Matlock, L.P.N.	*Primary Care Manager, Department of Family Medicine*
Uday Mehta, M.D	*Clinical Associate Professor, Department of Pediatrics;* *Associate Medical Director, Children's Specialized Hospital*
Kapila Seshadri, M.D.	*Associate Professor, Department of Pediatrics;* *Section Head, Section of Developmental Behavioral Pediatrics, Division of Child Neurology and NeuroDevelopmental Disabilities;* *Program Director, Developmental Behavioral Pediatrics Fellowship Program*

INTERDISCIPLINARY TRAINEES

Boone Clayton, M.Div.	*Master of Social Work Intern*
Nikki Hasandras, B.A.	*Master of Social Work Intern*
Joanne Van Sant, B.A.	*Master of Pastoral Care Intern*

Consumer Advisory Council



Ellie Byra, Chair	Parent Advocate
Lowell Arye	Alliance for the Betterment of Citizens with Disabilities (ABCD)
Diana Autin	Statewide Parent Advocacy Network (SPAN)
Thomas Baffuto	The Arc of New Jersey
Virginia Bryant, Esq.	Parent Advocate
Elaine Buchsbaum	Parent Advocate, Chair, NJ Council on Developmental Disabilities
Barbara Coppens	Advocate, Disability Rights New Jersey
William A.B. Ditto	NJ Division of Disability Services, NJ Department of Human Services
Lorraine D'Sylva-Lee	Parent Advocate
Chin-Lin Fong, Ph.D.	Parent Advocate, Chinese Autism Resource Center
Gail Frizzell	Parent Advocate
Harold Garwin, Esq.	Community Health Law Project
Barbara Geiger-Parker	Brain Injury Association of New Jersey
Jeanne Hoffner	Parent Advocate
Jane Horowitz	Parent Advocate
Rabbi Evan Jaffe	Flemington Jewish Center; Professional Consultation Committee, Boggs Center CPE Program
Samuel Jenkins	Advocate, NJ Self-Advocacy Project
Eric Joice	Family Resource Network
Rose Kardashian	Multi-Lingual Center, Catholic Family and Community Services
Sandra Lopez	Parent Advocate
Alison Lozano, Ph.D.	NJ Council on Developmental Disabilities
Julia McConnell	Spina Bifida Resource Network
Joanne McKeown	Parent Advocate, Statewide Parent Advocacy Network (SPAN)
Uday Mehta, M.D., M.P.H.	Parent Advocate, Children's Specialized Hospital, Robert Wood Johnson Health System
Linda Meyer, Ed.D., M.P.A.	Autism New Jersey
Jack M. Mudge	Advancing Opportunities
Safiyyah Muhammad	Parent Advocate
Hazeline Pilgrim	Parent Advocate
Sandra Pinkerton, Ed.D.	Advocate, Special Educator
Kenneth Ritchey	NJ Division of Developmental Disabilities, NJ Department of Human Services
Carrie Schepisi	Advocate, Arc of Morris
Sarah Vazquez	Advocate
Michele Wernsing	Our House, Inc.
Derrick Williams	Advocate
Roberta Wohle, Ph.D.	New Jersey Office of Special Education Programs, NJ Department of Education
Celeste Andriot Wood	Division of Family Health Services, NJ Department of Health and Senior Services
Jane Ye	Parent Advocate
Joe Young, Esq.	Disability Rights New Jersey

Awards

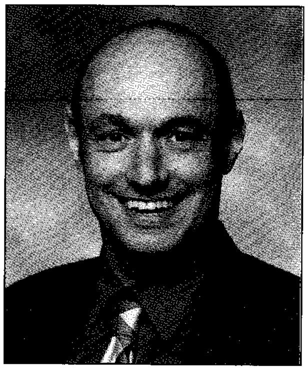
Awards Fiscal Year 2009

The Boggs Center

The Boggs Center, along with New Jersey Administration on Developmental Disabilities Network partners (NJADD), the NJ Council on Developmental Disabilities and Disability Rights New Jersey, were each honored with **Partners in Advocacy Awards** by The Arc of New Jersey. The Partners in Advocacy Awards to the members of NJ ADD Network and other honorees were presented at The Arc of New Jersey's 60th Anniversary on June 19, 2009 in Princeton, NJ.

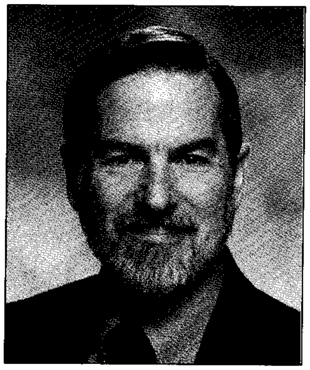
Dan Baker, Ph.D.

Dr. Dan Baker was presented with the **Rebecca McDonald Leadership Award** by NJ APSE-The Network on Employment in March 2009 in Somerset, NJ. The award recognized Dan Baker's leadership and The Boggs Center as a center of excellence in the field of supported employment.



Bill Gaventa, M.Div.

Rev. Bill Gaventa was honored by the **Union Theological Seminary Alunmni/ae Council with the Unitas Distinguished Alumni Award** for outstanding ministry for 2008 on October 17, 2008 in New York, NY. Stetson University awarded Rev. Bill Gaventa the **Distinguished Alumni Award** for 2009 for his outstanding achievements in his profession and life, which has brought distinction and special recognition to Stetson University. The award was presented on March 21, in DeLand, FL.



Sharon Lohrmann, Ph.D.

The New Jersey Association of School Psychologists awarded Dr. Sharon Lohrmann the **Dr. Irwin A. Hyman Service to Children Award**. The award was presented at the The New Jersey Association of School Psychologists' 50th Anniversary on June 6, 2009 in Jamesburg, NJ.

Presentations

Selected Faculty and Staff Presentations

Faculty

Deborah Spitalnik, Ph.D.

Spitalnik D. (2008, November). "Disability Policy Issues" (Workshop) Rutgers School of Social Work, Certificate Program in Developmental Disabilities, Piscataway, NJ.

Spitalnik D. (2009, March). "Autism in New Jersey: A Brief State of the State" (Presentation). Association of University Centers on Disabilities Act Early Summit, Bronx, NY.

Spitalnik D., & Lewis-Day, L. (April, 2009). "The DDD Community Care Waiver: What it Means for Services and Supports" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Spitalnik, D. (May, 2009). "Trends and Challenges" (Closing Keynote). Community Options "I Matter" Conference, Princeton, NJ.

Spitalnik D. (2009, June). "The Evolution of University Centers for Excellence: Some History and Some Essential Challenges" (Keynote). Federal Administration on Developmental Disabilities Technical Assistance Institute, Washington, DC.

Spitalnik D. (2009, June). "Supports, Social Capital, and People with Developmental Disabilities: Some Antidotes to Deadly Medicine" (Keynote). Oklahoma Science Museum in conjunction with the US Holocaust Memorial Museum traveling exhibit, co-sponsored by The Jewish Federation of Greater Oklahoma City and The Oklahoma Health Sciences Center, Oklahoma City, OK.

Daniel Baker, Ph.D.

Baker D. (2008, July). "Positive Behavior Support" (Workshop). National APSE Conference, Louisville, KY.

Baker D. (2008, September). "Positive Behavior Support" (Keynote). School to Work Transition Conference, Nashville, TN.

Baker D. (2008, September). "Stress Management" (Workshop). The Boggs Center Conference for Direct Support Professionals, Somerset, NJ.

Baker D. (2008, October). "Positive Behavior Support" (Keynote). Intergenerational Management. Northwest Conference on Disability, Portland, OR.

Baker D. (2008, October). "Mental Health and Intellectual and Developmental Disabilities" (Workshop). New Jersey Association of Mental Health Agencies Conference, Princeton, NJ.

Baker D. (2008, October). "Supporting Youth with Disabilities in the Transition to Adult Life" (Workshop). Rutgers School of Social Work, Certificate Program in Developmental Disabilities, Piscataway, NJ.

Baker D. (2008, November). "Positive Behavior Support: Therapy and Positive Support" (Workshop). National Association for Dually Diagnosed National Conference, Niagara Falls, Canada.

Baker, D. (2009, April). "Positive Behavior Support: Fitting into Public Settings" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Baker, D. (2009, April). "How to Help Students Find a Way from School to a Work Life" (Guest lecture). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work, New Brunswick, NJ.

Baker, D. (2009, June). "Positive Behavior Support: Sexual Health Instructions from a Positive Behavior Support Perspective" (Workshop). American Association on Intellectual and Developmental Disabilities Conference, New Orleans, LA.

Baker D. (2009, June). "Understanding and Managing Problem Behaviors." (Workshop). Rutgers School of Social Work, Certificate Program in Developmental Disabilities, Piscataway, NJ.

Gaventa W. (2008, July). "Spiritual Supports and Developmental Disabilities" (3 Keynotes). North American Faith and Light Network Conference, St. Paul, MN.

Gaventa W. (2008, August). "Aging and End of Life: Strategies for Addressing the Spiritual Needs Near the End of Life and the Challenges for Service Providers" (Workshop). The International Association for the Scientific Study of Intellectual Disabilities 13th World Conference, Capetown, South Africa.

Gaventa. W. (2008, September). "Building Community Connections With the People You Support" (Workshop). The Boggs Center Conference for Direct Support Professionals, Somerset, NJ.

Gaventa. W. (2008, September). "Spiritual Supports and Developmental Disabilities" (Keynote). Inclusive Ministries Conference, Holland, MI.

Gaventa. W. (2008, September). "Spiritual Supports and Developmental Disabilities" (Workshop). National Health Ministries Conference, Lake Junaluska, NC.

Gaventa. W. (2008, October). "Spiritual Supports and Developmental Disabilities" (Keynote). Lutheran Conference, Minneapolis, MN.

Gaventa. W. (2008, October). "Clinical Pastoral Education Program: Integrating Disability Issues in CPE Programs" (Workshop). Association for Clinical

Pastoral Education National Conference, Richmond, VA.

Gaventa. W. (2008, October). "Cultural Competence and Diversity: The Stone Game" (Workshop). Association for Clinical Pastoral Education National Conference, Richmond, VA.

Gaventa. W. (2008, October). "Inclusive Ministries: Hospitality and Sanctuary in Faith Community" (Keynote). Presbyterian Conference, Stony Point, NY.

Gaventa. W. (2008, October). "Inclusive Ministries: Biblical Themes and Issues Related to Disability" (Workshop). Presbyterian Conference, Stony Point, NY.

Gaventa. W. (2008, October). "Inclusive Ministries: Creative Strategies for Inclusion" (Workshop). Presbyterian Conference, Stony Point, NY.

Gaventa W. (2008, October). "Aging, End of Life, and Developmental Disabilities: An Opportunity to Walk the Talk" (Keynote). Aging and Developmental Disabilities Conference, Wilmington, DE.

Gaventa. W. (2009, January). "Ministries with People with Disabilities and Their Families" (Seminary Course). Princeton Theological Seminary, Princeton, NJ.

Gaventa, W. (2009 February). "Ethics and Inclusive Ministries: Where Professional and Personal Meet" (Workshop). Kenney Center, Nashville, TN.

Gaventa, W. (2009, February). "Ethics and Faith" (Guest lecture). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work. New Brunswick, NJ.

Gaventa, W. (March, 2009). "Workforce Development" (Keynote). MAX Conference for Developmental Disability and Behavioral Health Professionals, Blue Bell, PA.

Gaventa, W. (March, 2009). "Inclusive Ministries: Day of Respect, Welcoming People with Disabilities" (Keynote). Connecticut Developmental Disabilities Council Conference, Hartford, CT.

Gaventa, W. (March, 2009). "Inclusive Ministries: Making Inclusion Real" (Keynote). Ecumenical Conference, Birmingham, MI.

Gaventa, W. (April, 2009). "Instructions and Invitations: Keys to Community Connections" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Gaventa, W. (May, 2009). "Inclusive Ministries" (Keynote). Katy Autism Support Group Conference, Katy, TX.

Gaventa. W. (2009, May). "Cultural Competence, Diversity, and Spirituality" (Guest lecture). UMDNJ-School of Health Related Professions, Scotch Plains, NJ.

Gaventa W. (2009, June). "Community Building" (Workshop). American Association on Intellectual and Developmental Disabilities Conference, New Orleans, LA.

Gaventa W. (2009, June). "Multicultural Perspectives in Developmental Disabilities" (Workshop). Rutgers School of Social Work, Certificate Program in Developmental Disabilities, Cherry Hill, NJ.

Sharon Lohrmann, Ph.D.
Lohrmann, S. (2008, October). "Functional Behavioral Assessment for the LDT-C" (Workshop). The Association of Learning Consultants Fall Symposium, Bridgewater, NJ.

Lohrmann, S. (2008, December). "Designing Individualized Behavior Support Strategies: Applications for K-12 Students" (Pre-Conference Workshop). TASH Conference, Nashville, TN.

Lohrmann, S. (2008, December). "Supporting Change: Lessons Learned About Overcoming Barriers Encountered Implementing PBS In Schools" (Workshop). TASH Conference, Nashville, TN.

Lohrmann, S. & Martin, S. (2009, March). "The Process of Change: Resolving Barriers to Universal Intervention Implementation" (Workshop). International Conference on Positive Behavior Support, Jacksonville, FL.

Lucyshyn, J., Fosset, B., Binnendyk, C., Cheremshynski, C., Khan, S., Miller, L., *Lohrmann, S.*, & Elkinson, L. (2009, March). "Transforming Coercive Processes in Family Routines: Experimental Analyses of Family Centered PBS" (Workshop). International Conference on Positive Behavior Support, Jacksonville, FL.

Borgmeier, C., & *Lohrmann, S.* (2009, March). "Open Session for Network: Coaching Systems" (Workshop). International Conference on Positive Behavior Support, Jacksonville, FL.

Bambara, L., *Lohrmann, S.*, Nonnemacher, S., & Goh, A. (2009, March). "Moving Beyond Buy-In: Helping Team Members Adopt Individualized Student Practices" (Workshop). International Conference on Positive Behavior Support, Jacksonville, FL.

Lohrmann, S., Davis, W., Martin, S., Smith, S.R., Berk, B., Muscott, H., Mann, E., & Richter, M. (2009, March). "Coaching the Coaches: Activities and Strategies to Build Strong and Effective Coaches" (Workshop). International Conference on Positive Behavior Support, Jacksonville, FL.

Lohrmann S. (2009, March). "Positive Behavior Support in Schools" (Guest lecture). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work. New Brunswick, NJ.

Michael Knox, Ph.D.
Knox, M. (2008, September). "Adult Medicaid Beneficiaries with Developmental Disabilities and Epilepsy: Profiles of Service Use and Costs" (Presentation). Pediatrics Case Conference, UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ.

Knox, M. 2009 (January – May). "Current Perspectives in Developmental Disabilities" (Course). Rutgers School of Social Work, New Brunswick, NJ.

Nancy Razza, Ph.D.
Razza, N. (2008, October). "Overview of Developmental Disability and Psychotherapy" (Guest lecture). William Paterson University, Wayne, NJ.

Razza. N. (2008, December). "Overview of Developmental Disability and Psychotherapy" (Guest lecture). Monmouth University, West Long Branch, NJ.

Razza, N. (2009, February & March). "Psychopathology and Intellectual Disability" (Guest lectures). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work, New Brunswick, NJ.

Razza. N. (2009, May). "Overview of Developmental Disability and Psychotherapy" (Presentation). Monmouth Medical Center, Long Branch, NJ.

Phil Smith, Ph.D.
Smith, P. (2009, May). "Positive Behavior Support: Psychopathology and Intellectual Disability" (Presentation). Monmouth Medical Center, Long Branch, NJ.

Smith, P. (2009, June). "Positive Behavior Support" (Workshop). Statewide Clinical Consultation and Training Conference, Edison, NJ.

Staff

Carol Britton, M.S.W.
Britton, C. (2008, September). "Addressing Workforce Development Issues Through the College of Direct Support and the Career Path: What Agency Administrators Need to Know" (Workshop). The Boggs Center Conference for Direct Support Professionals, Somerset, NJ.

McLaughlin, C., *Britton, C.* (2008, November). "Direct Support Workforce Development" (Workshop). Association of University Centers on Disability Conference, Washington, DC.

Britton, C. (2009, January). "The Truth About Sexuality and Adults with Developmental Disabilities" (Guest lecture). UMDNJ-Robert Wood Johnson Medical School Sexual Awareness in Caring for Underserved Populations, New Brunswick, NJ.

Britton, C. (2009, February). "Person-Centered Thinking" (Guest lecture). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work, New Brunswick, NJ.

McLaughlin, C., *Britton, C.* (2009, March). "Statewide Rollout of the Career Path and the College of Direct Support" (Workshop). American Network of Community Options and Resources Conference, San Francisco, CA.

Britton, C. (2009, March). "Sexuality and People with Developmental Disabilities" (Guest lecture). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work, New Brunswick, NJ.

Britton, C. (April, 2009). "Take Me Out to the Ball Game: The Role of the Direct Support Professional as a Community Connector" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Britton, C. (June, 2009). "Exploring the Myth of the Perpetual Child: Understanding Sexuality and Developmental Disabilities" (Workshop). Rutgers School of Social Work, Certificate Program in Developmental Disabilities, Piscataway, NJ.

Anthony Camuso, B.A.
Camuso, A. (2008, July). "Hiring the Right People for the Right Jobs" (Workshop). National APSE Conference, Louisville, KY.

Camuso, A. (2008, September). "Communication Skills for Effective Teambuilding" (Workshop). The Boggs Center Conference for Direct Support Professionals, Somerset, NJ.

Camuso, A. (2009, March). "Customized Employment for People with Challenging Behaviors" (Workshop). Facing the Future XVII: NJ APSE and Boggs Center Conference on Employment, Somerset, NJ.

Camuso, A. (2009, April). "Community Connections: Keep the Fire Burning" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Melissa Cheplic, M.P.H.
Cheplic, M., Li-Vaks, B. (2009, April). "Tell Me How You Really Feel: Finding Your Own Voice in the Community, at Work, and in Relationships with Others" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Bret Li-Vaks, M.B.A.
Li-Vaks, B. (2009, March). "Top 10 Business Topics for Non-Profits to Survive the Economy" (Workshop). Facing the Future XVII, NJ APSE and Boggs Center Conference on Employment, Somerset, NJ.

Li-Vaks, B. (2009, March). "Methodologies to Support Students & Adults on the Autism Spectrum" (Course). Bergen County College, Hackensack, NJ.

Cheplic, M., *Li-Vaks, B.* (2009, April). "Tell Me How You Really Feel: Finding Your Own Voice in the Community, at Work, and in Relationships with Others" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

Li-Vaks, B. (2009, May). "Autism Awareness: Where is it for our Adults with Autism?" (Workshop). YAI National Institute for People with Disabilities Conference, New York, NY.

Colleen McLaughlin, M.Ed.
McLaughlin, C. (2008, September). "The Career Path – Skills, Recognition, and Relationships" (Workshop). The Boggs Center Conference on Direct Support Professionals Conference, Somerset, NJ.

McLaughlin, C., Britton, C. (2008, November). "Direct Support Workforce Development" (Workshop). Association of University Centers on Disability Conference, Washington, DC.

McLaughlin, C., Britton, C. (2009, March). "Statewide Rollout of the Career Path and the College of Direct Support" (Workshop). American Network of Community Options and Resources Conference, San Francisco, CA.

McLaughlin, C. (2009, March). "Supports Intensity Scale" (Guest lecture). Current Perspectives in Developmental Disabilities Course. Rutgers School of Social Work, New Brunswick, NJ.

McLaughlin, C. (2009, April). "Don't Just Sit There, Do Something!" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

McLaughlin, C. (2009, June). "Supporting Enviable Lives through Great Direct Support: New Jersey's Career Path" (Workshop). American Association on Intellectual and Developmental Disabilities Conference, New Orleans, LA.

Kathy Roberson, M.S.W.
Roberson, K. (2008, November). "Keeping it Real Transition Curriculum" (Workshop). Down Syndrome Conference. Princeton, NJ

Roberson, K. (2008, November). "Families in a Person Centered System: Beyond the Money" (Workshop). Association of University Centers on Disabilities Annual Meeting, Washington, DC.

Michael Steinbruck, M.A.
Steinbruck, M. (2008, July). "New Edition of PCT Trainers manual" (Workshop). The Learning Community for Person Centered Practices Conference, Portland, OR.

Steinbruck, M. (2008, July). "Graphic Facilitation and Recording" (Workshop). The Learning Community for Person Centered Practices Conference, Portland, OR.

Steinbruck, M. (2008, September). "Sharing What You Know: Tapping DSP Knowledge to Improve Person Centered Supports" (Workshop). The Boggs Center Conference for Direct Support Professionals, Somerset, NJ.

Steinbruck, M. (2009, April). "Third Places: Find and Create Opportunities to Move from Presence to Contribution in our Communities" (Workshop). The Boggs Center Conference on Self Directed Supports, Somerset, NJ.

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Publications

Selected Faculty Publications Fiscal Year 2009

Baker, D.J. (2009). *Identity Development, Intellectual or Developmental Disabilities, and Person-First Language. The NADD Bulletin, 12, 3-8.*

Baker, D.J., Nicholas, R., & **Spitalnik, D.M.** (In press). *Utilizing Generic Community Supports for People with Intellectual or Developmental Disabilities. Systems Advocacy and Social Change.*

Gaventa, W. (2008). *Children with Disabilities and Poverty: Breaking Free of Limiting Conditions. The Christian Citizen, 2, 4-5.*

Gaventa W. (2008). *Creative Ministries Before the Big Bang! The Arc Insight, 2, 3-4.*

Gaventa W. (2008). *Families and Faith Communities: The Promise and Power of the Pastoral Role. Frontline [Ireland], 73, 20-22.*

Gaventa W. (2008). *Meeting the Spiritual Needs of Children with Special Needs. The Children's Corner, Fall/Winter 2008, 13.*

Gaventa W. (2008). *Rekindling Commitment: Reflections from a Pastoral Counselor Enmeshed in Direct Support Professional Workforce Development and Person Centered Supports. Journal of Intellectual Disability Research, 57 (7), 598-607.*

Gaventa W. (2008). *Transformers: The Lived Experience. Journal of Religion, Disability, and Health, 12 (1), 1-3*

Gaventa W. *(2008). The Unity in Diversity, Complexity and Disability. Journal of Religion, Disability, and Health, 12 (2), 101-104.*

Gaventa, W. (2009).*Hearing the Call: Discovering Vocation Through Inclusive Ministries. The Arc Insight, 3, 6.*

Gaventa, W. (2009). *Spirituality and Spiritual Connections. Assess it, Train it, and Practice it. National Alliance of Direct Support Professionals, Frontline Initiative, 8-2.*

Gaventa, W. (2009). *Spirituality, Honoring the Heard and the Call of Direct Support. National Alliance of Direct Support Professionals, Frontline Initiative, 8-2.*

Gaventa, W. (2009). *Top Down and Grassroots Up: Two Initiatives in Cultural Competence. TASH Connections, Spring 2009, 19-21.*

Gaventa, W. *(2009). When Spirituality Does Not Equal "Get me to the Church on Time." Spirit Brief, 4-5.*

Razza, N.J. (2008). *Meeting the Mental Health Needs of People with Intellectual Disabilities. New Jersey Psychologist, 58 (2), 36-38.*

Razza, N.J. (2009). *Mental Health and Intellectual Disability: Toward a Therapy for All. Healthy Times, 20 (2), 1-2.*

For information or to obtain copies of Boggs Center educational materials and publications, please visit http://rwjms.umdnj.edu/boggscenter or call The Boggs Center at 732-235-9317

Publications

Boggs Center Editorial Positions Fiscal Year 2009

Daniel Baker, Ph.D.

- *College of Frontline Supervision (Board of Editors). University of Minnesota*
- *Intellectual and Developmental Disabilities (Consulting Editor). American Association on Intellectual and Developmental Disabilities*
- *National Association for the Dually Diagnosed Bulletin (Editor). NADD*
- *Research in Developmental Disabilities (Consulting Editor). Elsevier*

William Gaventa, M.Div.

- *Exceptional Parent Magazine, Spiritual and Religious Supports Series (Advisor)*
- *Insight Newsletter (Columnist). The Arc of the United States*
- *Religion and Spirituality Newsletter (Editor). American Association on Intellectual and Developmental Disabilities*
- *Intellectual and Developmental Disabilities (Consulting Editor). American Association on Intellectual and Developmental Disabilities*
- *Journal of Religion, Disability, and Health (Editor). Taylor and Francis*

Sharon Lohrmann, Ph.D.

- *Journal of Positive Behavior Interventions (Editorial Board Member). Hammill Institute on Disability*
- *Research and Practice for Persons with Severe Disabilities (Editorial Board Member). TASH*
- *TASH Connections (Editor and Chair, Editorial Committee). TASH*

Nancy Razza, Ph.D.

- *Mental Health Aspects of Developmental Disabilities (Editorial Board Member). Psych - Media of NC Inc.*

Kathy Roberson, M.S.W.

- *People and Families (Editorial Board Member). NJ Council on Developmental Disabilities*

Deborah Spitalnik, Ph.D.

- *Intellectual and Developmental Disabilities (Consulting Editor). American Association on Intellectual and Developmental Disabilities*

Service

Public Policy

The Boggs Center actively influences public policy at national and state levels. Through education and outreach, The Boggs Center helps to ensure that people with disabilities, family members, service providers and policy makers have the information they need to shape policy at the state and national levels in ways that will improve the lives of people with disabilities.

Faculty and Staff Appointments and Committees

Active participation on boards and committees provides a mechanism for Boggs Center faculty and staff to share best practices information and work collaboratively with the larger community to build capacity and create systems change

NATIONAL APPOINTMENTS AND COMMITTEES

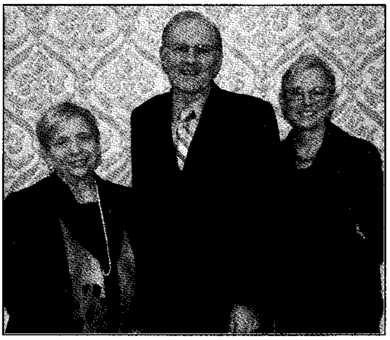
- American Association on Intellectual and Developmental Disabilities, End of Life Action Group; Religion Division (Executive Committee)
- Association for the Scientific Study of Intellectual Disability, Quality of Life Special Interest Research Group; Aging/End of Life Affinity Group
- Association of University Centers on Disabilities (Past President), Annual Report Template Workgroup; Council of Community Education Coordinators, Dissemination Committee; Council on Research and Evaluation; Data Coordinators; Dissemination Coordinators; Health Care Workgroup; Legislative Affairs Committee; Multicultural Affairs Council
- Coalition on Ministries in Specialized Settings/The Network
- College of Direct Support National Advisory Board
- Council on Quality and Leadership (Vice Chair)
- National Alliance for Direct Support Professionals, Education and Training Committee
- National Association for the Dually Diagnosed (Board of Directors); Training and Conference Committee; Professional Certification Committee; Direct Care Staff Certificate Subcommittee
- National Council of Churches, Committee on Disabilities; Task Force on Genetics
- TASH (Board Member); Training and Outreach Committee
- The Learning Community for Person Centered Practices (Board Member); Community Connections Training Curriculum Workgroup (Chair); Conference Agenda and Planning Committee; Material Development Committee (Chair); Plan Facilitation Training Curriculum Workgroup (Chair)
- World Council of Churches, Ecumenical Disability Advocacy Network

NEW JERSEY APPOINTMENTS AND COMMITTEES

- ❖ Alliance for the Betterment of Citizens with Disabilities, Staff Day Conference (Planning Committee)
- ❖ Autism New Jersey and The Boggs Center, Autism and Faith Task Force
- ❖ Boggs Center Clinical Pastoral Education Program, Professional Consultation Committee (Chair)
- ❖ Cultural Access Network of New Jersey
- ❖ Cultural Competence Collaborative, Steering Committee
- ❖ Developmental Disabilities Coalition
- ❖ Disability Rights New Jersey, Protection and Advocacy for Developmental Disabilities Advisory Group; Assistive Technology Advocacy Center Advisory Committee (Co-Chair)
- ❖ Family Support Coalition (Vice President)
- ❖ Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities (Gubernatorial Appointment)
- ❖ Interagency Transition Group
- ❖ Middlesex Educational Services Commission Transition Advisory Committee
- ❖ NJ Advisory Council on Traumatic Brain Injury (Gubernatorial Appointment)
- ❖ NJ Aging and End of Life in Developmental Disabilities Network (Coordinator)
- ❖ NJ Alliance for Full Participation (State Team Co-Chairs)
- ❖ NJ APSE – The Network on Employment (Board of Directors, Vice President, Conference Co-Chair); Conference Planning Committee
- ❖ NJ Coalition for Inclusive Ministries Steering Committee
- ❖ NJ Coalition for the Advancement of Rehabilitation Technology (Board of Trustees)
- ❖ NJ Council on Developmental Disabilities, Member (Gubernatorial Appointment); Education Committee; Public Policy Committee; Planning Committee
- ❖ NJ Department of Community Affairs, Barrier-Free Subcode Committee
- ❖ NJ Department of Education, Office of Special Education Programs, Stakeholders Group
- ❖ NJ Department of Human Services, Dual Diagnosis Task Force, Member; Adult Best Practices and Crisis Response Subcommittee; Adult Collaborative Services Subcommittee
- ❖ NJ Direct Support Professional Workforce Development Coalition Leadership Council
- ❖ NJ Division of Developmental Disabilities, Dialogue Group; Family Support Task Force; Individual Budget Assessment Committee; Olmstead Implementation and Planning Advisory Council; Olmstead Self Advocacy and Family Partnership Workgroup; Olmstead Quality Improvement Workgroup; Olmstead Service Delivery Workgroup-Employment; Olmstead Service Delivery Workgroup-Housing; Olmstead System Redesign Workgroup (Co-Chair); Quality Management Steering Committee; Self Directed Supports Conference and Training Workgroup; Self Directed Supports Health and Safety Workgroup; Self Directed Supports Policy Committee; Self Directed Supports Provider Qualification Training Subcommittee; Service Plan Outcomes Training Curriculum Workgroup; Statewide Training Advisory Committee; Systems Transformation Grant, Access and Public Awareness Workgroup (Facilitator); Systems Transformation Grant, Assessing Family Education Efforts Subcommittee (Chair); Systems Transformation Grant, Nursing Facility/Intermediate Care Facility Transitions and Diversions Workgroup; Trainers Network
- ❖ NJ Division of Medical Assistance and Health Services, Medical Assistance Advisory Committee (Chair)
- ❖ NJ Partners in Justice Healthy Sexuality Training Advisory Committee (Co-Chair)
- ❖ NJ Sexual Assault Task Force
- ❖ NJ Statewide Independent Living Council (Gubernatorial Appointment)
- ❖ NJ Transit ADA Task Force
- ❖ Robert Wood Johnson Medical School, Community Oriented Primary Care Summer Assistantship (Co-Director)
- ❖ Robert Wood Johnson Medical School, Distinction in Service to the Community Advisory Committee
- ❖ Robert Wood Johnson Medical School, Department of Pediatrics, Neurodevelopmental Disabilities Collaboration Committee; Strategic Planning Committee
- ❖ Rutgers School of Social Work, Field Education Committee; Gerontology Consortium
- ❖ Rutgers School of Social Work, Institute for Families, Office of Continuing Education, Certificate Program in Developmental Disabilities Advisory Council (Chair); Non-Profit and Public Management Advisory Council
- ❖ Small Business Development Center-Entrepreneurial Achievement Center (Board Member)
- ❖ Social Security Alliance
- ❖ State Special Education Advisory Council
- ❖ Statewide Network for Cultural Competence, Steering Committee
- ❖ Statewide Parent Advocacy Network, Family to Family Health Information Resource Center/Family Voices-NJ Parent to Parent Leadership Team Advisory Committee
- ❖ The Greater Raritan Workforce Investment Board Disability Committee
- ❖ Union County, Advisory Board on Persons with Disabilities; Senior Citizens and Disabled Persons Transportation Advisory Board
- ❖ YMCA Stand Against Racism Task Force
- ❖ United Methodist Church, Greater NJ Annual Conference, Special Needs Committee; Compassionate Advocates Team; Mental Health Task Force

Projects

Community Supports



DEVELOPMENTAL DISABILITIES LECTURE SERIES

The lecture series is a community and continuing education program provided for Division of Developmental Disabilities staff, community provider agencies, people with disabilities, and family members to enhance their knowledge and skills in innovative approaches and state-of-the-art practices for people with developmental disabilities. Eight sessions are held each year, four in the fall and four in the spring. Nationally known speakers with expertise in their field serve as faculty for the program, each conducting a morning presentation and providing technical assistance in an afternoon forum.

- ❖ Following the October 10, 2008 morning session, The Boggs Center coordinated the Dual Diagnosis Task Force Report Presentation with the NJ Department of Human Services.
- ❖ The 200th session of the Developmental Disabilities Lecture Series was celebrated at the November 18, 2008 lecture by Nancy Thaler.
- ❖ The Developmental Disabilities Lecture Series was attended by 1,600 people during Fiscal Year 2009.

> **Very informative – I appreciate all of the 'thinking outside the box' to create meaningful living spaces for all people – BRAVO."**

> **"The seminars are so valuable to parents with a DD family member. We need ongoing directions and ways to advocate for our family members"**

The Fall 2008 and Spring 2009 Developmental Disabilities Lecture Series sessions and afternoon technical assistance forums included:

Fall 2008

- ❖ Engineering Independence presented by George Braddock
- ❖ From Diagnosis to Treatment Planning: Where Does the Diagnostic Manual – Intellectual Disability Fit In? presented by Jarrett Barnhill, M.D.
- ❖ The Future is Now: Improving Job Outcomes for People with Disabilities presented by Dale DiLeo, M.Ed.
- ❖ Building a New Paradigm: A Values-Based Response to Demographic and Economic Realities presented by Nancy Thaler, M.S.

Spring 2009

- ❖ Planting Two Trees with One Seed: Communication Supports for Problem Behavior presented by Pat Mirenda, Ph.D.
- ❖ The Dance of Change in a Perfect Storm presented by Renee Pietrangelo, Ph.D.
- ❖ A Delicate Balance: Supporting Choice While Minimizing Risk presented by Sharon Krevor-Weisbaum, Esq.
- ❖ Lessons, Issues, and Next Steps in Healthcare Decision Making: Care at the End of Life presented by Leigh Ann Kingsbury, M.P.A.

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DIRECT SUPPORT WORKFORCE DEVELOPMENT

In initiatives to enhance the Direct Support Workforce, The Boggs Center collaborates with a number of public and private provider agencies and networks on a variety of strategies to strengthen recruitment, retention, and supports for direct support professionals. The Boggs Center provides primary coordination for the New Jersey Direct Support Professional Workforce Development Coalition. With the Coalition, The Boggs Center developed and coordinates the Career Path Pilot Project. The Boggs Center provides technical assistance to and facilitates quarterly meetings with the participating agencies, administers the College of Direct Support, and collaborates with stakeholders in the DSP Coalition on the development of a sustainable plan. The Boggs Center facilitates and provides technical assistance for the New Jersey Training Network, a statewide network of trainers who lead preservice training for direct support professionals in agencies serving people with developmental disabilities. The Boggs Center offers a series of three training courses for managers: Survival Skills for Managers in Community Supports, Leadership Skills for Managers in Community Supports, and Personal Skills for Managers.

- The Boggs Center staff continued to coordinate the pilot and statewide rollout of the College of Direct Support (CDS), funded by a grant from the New Jersey Developmental Disabilities Council. Nine agencies across New Jersey are in the pilot. More than 179 Direct Support Professionals participated in the Career Path, with 180 additional agency staff taking CDS courses on a lesson by lesson basis.
- The pilot agencies have developed a variety of financial and other rewards for successful completion of the certificate levels, including pay raises, bonuses, and employee recognition.
- DSPs have many positive things to say about their participation in the Career Path. In DSP meetings held throughout the state, many DSPs affirmed their appreciation for the opportunity to learn more, their increased ability to provide better supports, and for recognition of their hard work and dedication to the field.
- **Making a Difference: A Direct Support Professionals Conference** was held on September 25, 2008 and offered skill building workshops for DSPs across the state and a recognition ceremony for the 64 direct support professionals who have completed Level 1 of the College of Direct Support.
- As a result of the Career Path pilot and work conducted by the NJ Direct Support Professional Workforce Development Coalition, the NJ Division of Developmental Disabilities has started the process for implementing use of the College of Direct Support and the Career Path statewide.
- Project Coordinators have been invited to present at multiple national conferences to present the NJ Career Path as an example of best practice in workforce development for direct support professionals.
- The Boggs Center conducted 24 training sessions for more than 600 participants in the Management series.

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CULTURAL COMPETENCE

The Boggs Center initiated the development and continues to provide coordination of the New Jersey Statewide Network on Cultural Competence. The Network's mission is "to strengthen culturally competent services in the state of New Jersey for people with diverse needs, and to facilitate access by individuals, families, providers, and professionals to these services."

- The collaborative has begun to develop relationships with Middle Eastern communities in New Jersey. The Center has begun to prepare for a conference on issues of concern to Middle Eastern communities in New Jersey.
- The Boggs Center continued to support the New Jersey Statewide Network on Cultural Competence (http://www.state.nj.us/njsncc/index.shtml) by serving as coordinator of the statewide listserv, which has continued to expand.
- The Boggs Center taught a three-hour class on Diversity and Spirituality for the UMDNJ-School of Health Related Professions Psychosocial Rehabilitation Program.

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FAITH BASED SUPPORT

Faith Based Supports include activities related to the New Jersey Coalition for Inclusive Ministries, coordinated by The Boggs Center, to encourage congregations to include and support members with disabilities, and other efforts to promote spiritual supports. Activities of the New Jersey Coalition for Inclusive Ministries include coordination of training and technical assistance events; sponsorship of Conferences in cooperation with New Jersey organizations; educational events in congregations; distribution of resources to clergy and lay leadership; educational opportunities for seminarians; and quarterly forums for the Coalition.

- In a project funded by the Pennsylvania Council on Developmental Disabilities, The Boggs Center is working with seminaries to integrate disability issues and perspectives in their curricula.
- Boggs Center faculty taught a course in Ministries with People with Disabilities and Their Families at Princeton Theological Seminary.
- Boggs Center faculty conducted 32 presentations on congregational supports for people with disabilities and their families, including plenary sessions in Connecticut, Georgia, Michigan, New York, Tennessee, Texas, Virginia, and Wisconsin.
- Nearly 1,500 copies of the *Autism and Faith: A Journey into Community* were disseminated to congregations in New Jersey and around the country. More than 7,000 copies of the guide have been disseminated since its publication in May 2008.
- Rev. Bill Gaventa continued to serve as Editor of the *Journal of Religion, Disability, and Health.*

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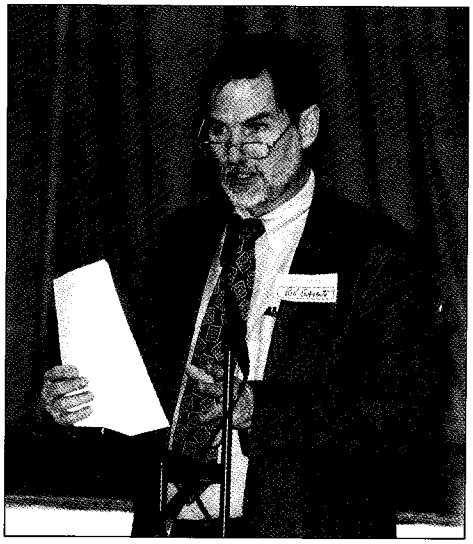

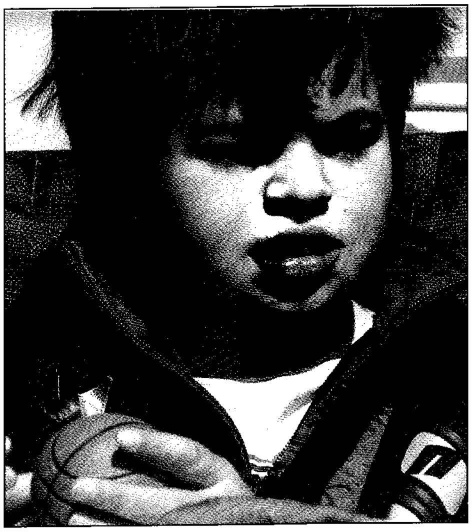

POSITIVE BEHAVIOR SUPPORT IN THE COMMUNITY

Problem behaviors are often an ongoing and severe challenge for care providers of children and adults with intellectual or developmental disabilities. Positive Behavior Support (PBS) is an evidence-based practice for addressing problem behavior among persons with intellectual or developmental disabilities. PBS is a problem solving approach that focuses on improving the quality of life for individuals with challenging behavior instead of just reducing the frequency of the undesired behaviors. The Boggs Center provides extensive training and technical assistance for community provider agencies to support people with challenging behaviors who are participating in the Child Placement Enhancement Project (CPEP). The CPEP project is funded by the NJ Division of Developmental Disabilities to increase community capacity to support children who present extremely challenging problem behaviors who either are currently placed out of state, or are at-risk for placement out of state.

Faculty and staff from The Boggs Center complete an evaluation of each child participating in CPEP. The assessment includes the relevant and critical information for designing an environment in which the child will be successful, and recommendations for support strategies that should be used with the child.

The Boggs Center offers three training courses in Positive Behavior Support: Basic Positive Behavior Support, Applied Positive Behavior Support, and Mental Health Supports. The Boggs Center's extensive activities in Positive Behavior Support in Schools are described on page 31.

- The Boggs Center conducted training for community agency staff in Positive Behavior Support. More than 700 people participated in 31 training sessions in Fiscal Year 2009. The five day training series addressed Basic Positive Behavior Support, Applied Strategies for Implementing Positive Behavior Support, and Mental Health Support for Individuals with Intellectual or Developmental Disabilities.
- In Fiscal Year 2009, The Boggs Center provided more than 1,300 hours of training and technical assistance to agencies participating in CPEP.
- The Boggs Center provided extensive training and technical assistance to CPEP agencies serving 50 children in New Jersey who were at risk of being placed out of state, at greater distance from their families and at greater cost to the State.
- The success of CPEP provides a demonstration of the efficacy of individualized PBS for the most challenging children and youth with intellectual or developmental disabilities. It is anticipated that this model will be used for other children and adults with intellectual or developmental disabilities.

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SELF-DIRECTED SUPPORTS

The Boggs Center provides the Training and Technical Assistance component of New Jersey's Self-Directed Supports efforts. Under contract with the Division of Developmental Disabilities, The Boggs Center conducts training for families, people with disabilities, agency staff, and others who are interested in the self-directed supports and self-determination processes. The Center provides training in Person Centered Thinking and Essential Lifestyle Planning, the planning process being used by families, individuals, and support coordinators in the development of a plan of care.

- The Boggs Center conducted 22 training sessions in Person Centered Thinking and Essential Lifestyle Planning for 333 agency staff, individuals with disabilities, and family members.
- In April 2009, The Center coordinated New Jersey's 8th annual **Self-Directed Supports Conference, Together is Better: Connecting to the People and Places in the Community for the Life You Want**. One hundred and eighty-eight people with disabilities and their families participated in the event.
- The Boggs Center provided extensive technical assistance in person-centered approaches and self-directed supports to the Division of Developmental Disabilities, provider agencies, individuals with disabilities, and families and disseminated information about Person Centered Thinking and Self-Directed Supports.
- The percentage and number of families with children aging out of school services, who request self directed options continues to increase. A growing number of agencies are asking The Boggs Center for customized training and technical assistance to support their capacity to offer self directed supports.
- Staff from The Boggs Center have played a key role with the Learning Community in updating national curricula in Person Centered Thinking and Essential Lifestyle Planning and in developing a new course on community inclusion.

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> ***...the constant yearning for acceptance and communities that will make room at last for those we love; this is a language we can all comprehend***

WRITERS' GROUP FOR FAMILY CAREGIVERS

In July 2008, The Boggs Center started a Writers' Group for Family Caregivers. The purpose of the group is to give family caregivers of individuals with developmental disabilities an opportunity to tell their own stories, in their own words. The group meets every other month, and a listserve provides group members who are unable to make it to meetings an opportunity to share their work with one another.

- *Writing Our Journey: Poems and Essays by Family Givers* may be found on The Boggs Center's website at **http://rwjms.umdnj.edu/boggscenter/projects/Writers_Group.html**

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NEW JERSEY POSITIVE BEHAVIOR SUPPORT IN SCHOOLS

New Jersey Positive Behavior Support in Schools (NJPBSIS) is a collaboration between the New Jersey Department of Education, Office of Special Education Programs and the Elizabeth M. Boggs Center on Developmental Disabilities. NJPBSIS is funded through I.D.E.A. Part B Funds. The NJPBSIS initiative supports the inclusion of students with disabilities within general education programs. This initiative develops the capacity of schools to address school-wide, classroom, and individual student problem behavior using current research-validated practices in Positive Behavior Support. The Boggs Center also developed and maintains The New Jersey Positive Behavior Support in Schools website, **www.njpbs.org**, which explains PBSIS, offers resources to parents and school personnel, and lists upcoming events.

- The PBSIS project team provided intensive training and technical assistance to the 28 participating schools in urban and suburban districts across the state in FY 2009. Since the inception of the initiative, more than 70 schools have received training.
- In Fiscal Year 2009, nearly 1,200 administrators, specialized staff, special education teachers, and general education teachers participated in PBSIS training. Nearly 500 hours of technical assistance was provided to schools.
- Curricula on topics including functional behavioral assessment and classroom management were disseminated to school personnel in Fiscal Year 2009.
- Following implementation of Positive Behavior Support, school personnel report a number of positive outcomes including: reductions in office referrals and suspension; reduction in special education referral rates; increases in positive student behaviors; increases in staff and student perception of school climate; and greater openness to the inclusion of students with disabilities.

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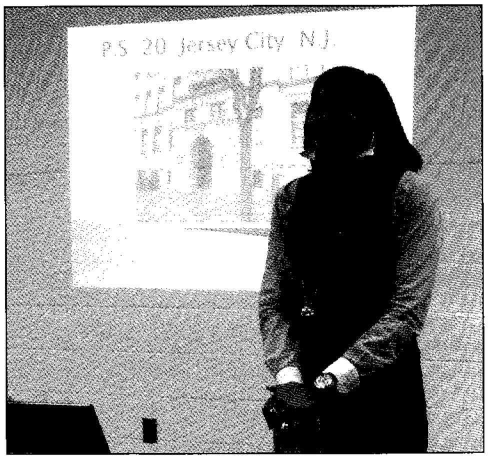

POSITIVE BEHAVIOR SUPPORT IN EDUCATIONAL SETTINGS

The Boggs Center conducts research, contractual and community fee-for-service training and technical assistance on the implementation of Positive Behavior Support practice in educational settings for children and youth.

- With funding from the UMDNJ Foundation, The Center conducted a study on understanding the practices that help schools adopt intervention approaches to improve the social condition of school settings for children and youth.
- The Boggs Center conducted fee-for-service training on Functional Assessments and Behavior Intervention Planning for organizations such as Long Branch School District in NJ and Fairfax School District in VA.

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COMMUNITY-BASED INSTRUCTION

Community-Based Instruction is a critical component of a successful transition from school to adult life for many students with disabilities. With funding from the NJ Department of Education, Community-Based Instruction (CBI) training and technical assistance efforts assist school districts in providing instruction for students in community-based settings. These efforts include: providing training and information to districts through workshops, sharing successful efforts currently occurring in New Jersey school districts, and offering direct technical assistance to school districts addressing CBI strategies, training needs, and necessary administrative supports. All activities are designed to create positive, observable outcomes for students.

- The Boggs Center conducted a series of regional one and two-day workshops; 1,047 personnel from school districts across the state participated in the training. Seventy one hours of technical assistance in community-based instruction was provided for 629 school personnel.
- Districts participating in these efforts report a tremendous number of positive outcomes from their participation. These outcomes include establishing and expanding CBI Programs in their schools/districts, for example, increasing the number of community sites for CBI and increasing numbers of students participating or broadening areas of instruction. Participants are funding these service expansions from a variety of different sources, including the American Reinvestment and Recovery Acts (ARRA).
- During this year, The Boggs Center dramatically increased local school and district administration involvement in the CBI training and technical assistance efforts by including the use of mandatory administrator teleconferences for all participating schools and districts and the requirement for administrator presence at onsite technical assistance sessions.

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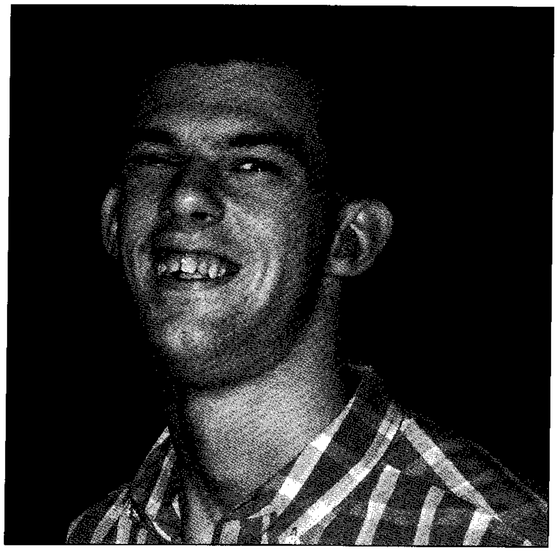

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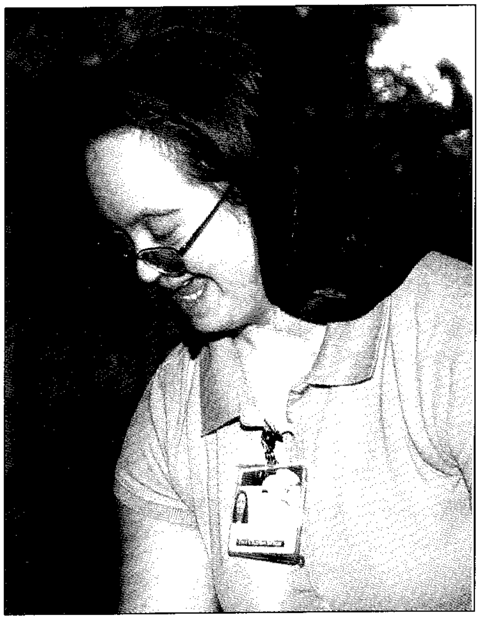

NATIONAL TECHNICAL ASSISTANCE AND RESEARCH CENTER (NTAR)

The Boggs Center is a consortium partner in the National Technical Assistance and Research (NTAR) Center to Promote Leadership for Increasing Employment and Economic Independence for Adults with Disabilities led by Rutgers University's Heldrich Center for Workforce Development. The consortium also includes the Delaware University Center for Excellence in Developmental Disabilities. The purpose of the NTAR Leadership Center is to promote better connections for people with disabilities to educational opportunities and work in the mainstream labor market.

- The Boggs Center provided technical assistance to the states selected for the State Leadership Development Institute in Fiscal Year 2009.
- The Center collaborated on the development of a literature review of employer initiated and market driven approaches to recruiting, hiring, and retaining employees with disabilities.
- Three participating states, Connecticut, Maryland, and Minnesota, have made substantial improvements in their connection of workers with disabilities into generic workforce systems.
- The NTAR Center's research efforts focus on identifying means for effective business-led collaborations with disability supports, with significant dissemination of the findings in 2010.

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SUPPORTED EMPLOYMENT TRAINING AND TECHNICAL ASSISTANCE

Boggs Center Supported Employment Training and Technical Assistance activities increase employment opportunities for people with disabilities by developing competence among service providers in all areas related to assisting people with disabilities to choose, obtain, and maintain employment. The Boggs Center offers two levels of supported employment training: Employment Specialist Introduction and Employment Specialist Advanced. Both courses are two days in duration.

- The Boggs Center provided 16 two-day training sessions in Fiscal Year 2009. The Center trained more than 427 individuals in its introductory and advanced employment specialist courses.
- The Center provided training sessions requested by individual agencies. Presentations included 2 workshops at the national APSE conference, a NJ Council on Developmental Disabilities Partners in Policymaking session, and a guest lecture in a Special Education class at The College of New Jersey.
- In collaboration with NJ APSE - The Network on Employment, The Center coordinated the 17th annual **Facing the Future Conference**, a two-day conference focusing on employment and transition. Two hundred employment service providers attended the conference, even with the economic challenges of the time.
- The new Boggs Center *Supported Employment Training Manual* was completed and disseminated. The new manual was designed for enhanced readability and interest, and contains both established practices and cutting edge strategies to support greater rates of employment.
- The Boggs Center is coordinating the state team for the national Alliance for Full Participation, which will focus on employment.

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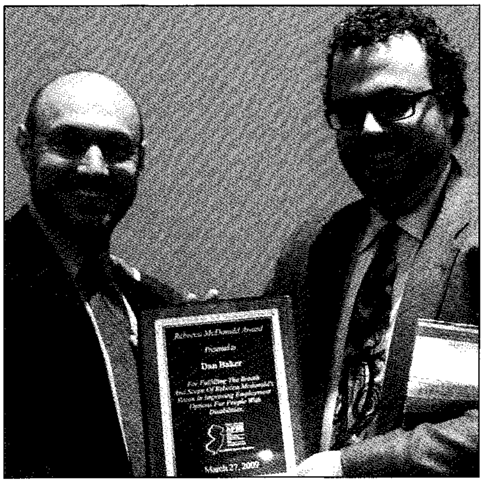

CHILDREN WITH HEARING LOSS AND EXISTING COMORBID CONDITIONS IN NJ

With funding from the Centers for Disease Control and Prevention- National Center for Birth Defects and Developmental Disabilities' Cooperative Agreement with the Association of University Centers on Disabilities Research Topics of Interest, The Boggs Center is conducting the study "Children with Early Hearing Loss and Existing Comorbid Conditions in New Jersey: State Data and The Experience of Families," in collaboration with the NJ Department of Health and Senior Services.

The project will identify the prevalence of early hearing loss in children with existing comorbid conditions and who fail newborn/initial hearing screening, identify the impact of existing comorbid conditions on follow-up of failed initial hearing screenings, describe the experience and needs of families of children with early hearing loss and comorbid conditions, and determine the knowledge and experience of audiologists in evaluating and providing services to children with early hearing loss and co-occurring conditions.

Within a Participatory Action Research design, a family advisory committee, comprised of parents of children with a hearing loss and another disability, participated in the creation of a survey instrument that reflects the issues they identified as being of greatest importance to families.

- During Year Two of the project, the initial family survey was approved by the NJ Department of Health & Senior Services and UMDNJ Institutional Review Board (IRB), and approximately 350 surveys in English and Spanish were mailed. Another 87 will be sent to families of children born in 2007.
- The survey of audiologists regarding services to children with multiple disabilities is near completion and will be submitted for IRB approval early in FY 2010.

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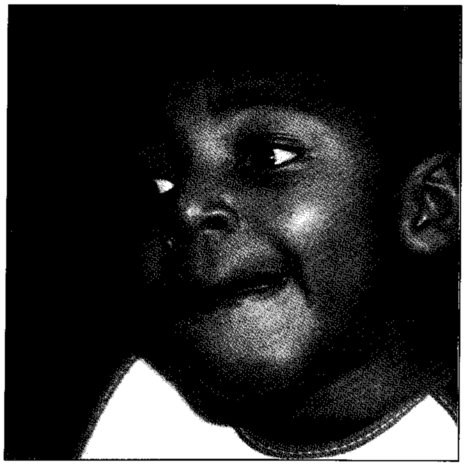

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AGING AND END OF LIFE ISSUES WITH ADULTS WITH DEVELOPMENTAL DISABILITIES

With support from the Division of Developmental Disabilities, The Boggs Center provides customized training and technical assistance and presents workshops on coping with grief and end of life issues for agencies and people supporting adults with developmental disabilities.

- In collaboration with UMDNJ-University Behavioral Healthcare's Comprehensive Services on Aging and Statewide Clinical Consultation and Training, The Boggs Center coordinated a one day workshop, Aging Well: Supporting the Physical, Emotional, and Spiritual Needs of Adults with Developmental Disabilities and Their Caregivers.
- The Boggs Center presented two workshops for New Jersey provider agencies on Aging, Grief, and Loss and Developmental Disabilities.
- A keynote for a conference in Wilmington, Delaware was presented on End of Life Issues.
- A workshop was presented on Aging: Spirituality at the End of Life: Strategies for Addressing the Spiritual Needs Near the End of Life and the Challenges for Service Providers at the International Association for the Scientific Study of Intellectual Disabilities (IASSID) Conference in Capetown, South Africa.
- The afternoon technical assistance forum following the Developmental Disabilities Lecture Series session on End of Life Planning led to a major expansion of the New Jersey Aging and End of Life listserv.

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PRIMARY HEALTH CARE PROJECT

In collaboration with the UMDNJ-Robert Wood Johnson Medical School Department of Family Medicine, The Boggs Center facilitates a medical home for adults with developmental disabilities by supporting care coordination for adults with developmental disabilities at the Family Practice ambulatory care site in New Brunswick. A resource unit provides care coordination and supports faculty and resident physicians in caring for patients with developmental disabilities.

- Care coordination was provided for 133 adults with disabilities at the Family Medicine Resource Unit.

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Student Program

The Boggs Center provides a variety of educational experiences for students, fulfilling the federally mandated Core Function of interdisciplinary education of students and preparing future generations of professionals. In addition to the student programs described below, Boggs Center faculty and staff teach courses; serve as guest lecturers; supervise practica, student projects, internships and field placements; and advise on papers, theses, and dissertations.

COMMUNITY ORIENTED PRIMARY CARE

The Center co-sponsored the Summer 2009 Assistantship in Community Oriented Primary Care with UMDNJ-Robert Wood Johnson Medical School, Department of Family Medicine. Community Oriented Primary Care (COPC) provides an interdisciplinary opportunity for medical, physician assistant, and graduate social work students to gain experience in providing basic services in healthcare and education to underserved communities in central New Jersey. Through the Center's efforts, the COPC program's didactic sessions and field placements included content and opportunities in developmental disabilities.

❖ Five students had internships and conducted health education projects at agencies serving people with developmental disabilities, including The Arc of New Jersey, The Arc of Monmouth County, and the Statewide Clinical Consultation and Training program.

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MEDICAL STUDENT SEMINAR ON FAMILY CENTERED CARE AND DEVELOPMENTAL DISABILITIES

All medical students at UMDNJ-Robert Wood Johnson Medical School in New Brunswick receive an introduction to family centered care and developmental disabilities through the Developmental Disabilities Seminar, a required component of the pediatrics rotation. The Boggs Center coordinates the seminar 8 times each year in collaboration with the Department of Pediatrics at UMDNJ-Robert Wood Johnson Medical School. A key component of the seminar is visits to families in their homes, to increase awareness of and sensitivity to the strengths and needs of families who have a child with a developmental disability.

❖ The Boggs Center continued to coordinate the Developmental Disabilities seminar for all third-year medical students in the pediatrics rotation One hundred and five students participated in the seminar in Fiscal Year 2009.

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> "I love this program for what it allows my family to demonstrate to the upcoming medical community...It allows us to be us – nothing more and nothing less."

CLINICAL PASTORAL EDUCATION

The Clinical Pastoral Education (CPE) Program is a unique preservice training program initiated by the Center, in collaboration with three seminaries in New Jersey and community based provider agencies, which serve as placement sites for chaplaincy students in the program. The goals of the CPE program are to enhance the skills of seminarians, clergy, and laypersons in the delivery of spiritual supports to people with disabilities and their families and to strengthen their skills in advocacy and developing community supports. The CPE program is accredited by the national Association for Clinical Pastoral Education, Inc. The Boggs Center is the only University Center for Excellence in Developmental Disabilities with an accredited CPE program and the only CPE program based in community agencies serving people with disabilities.

- ❖ Seven chaplaincy students graduated from the Clinical Pastoral Education Program in Fiscal Year 2009.
- ❖ In Fiscal year 2009, The Center expanded its CPE capacity by adding a supervisor in training position. Rev. Alice Walsh is participating in the Eastern Pennsylvania Institute for Clinical Supervision in Philadelphia, PA and is being mentored by Rev. Bill Gaventa.

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INTERDISCIPLINARY TRAINEESHIP

The Interdisciplinary Traineeship provides opportunities for students to learn about developmental disabilities through participation in traditional scholarly activities, research, and training. The Traineeship is open to all undergraduate or graduate students including, but not limited to, those majoring in the following disciplines: education, nursing, physical therapy, psychology, public health, and social work. The traineeship typically spans an academic year, Fall through Spring. Often students are able to obtain academic credit through their home academic institution for work completed during the traineeship. Students are paid a quarterly stipend to support their activities, and receive a certificate of completion at the end of the academic year.

- ❖ In Fiscal Year 2009, a doctoral student in Divinity graduated from the Interdisciplinary Traineeship program at The Boggs Center.

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Rutgers School of Social Work
Current Perspectives in Developmental Disabilities Course

During FY 09, Boggs Center faculty taught a graduate social work course in developmental disabilities, Current Perspectives in Developmental Disabilities. The course will be one component of a new disability area of emphasis, developed through the collaboration of The Boggs Center and the Rutgers University School of Social Work.

❖ Seven students completed the course in FY 09. Self advocates and parents as well as other Boggs Center personnel were guest lecturers.

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Rutgers School of Social Work, Institute for Families, Office of Continuing Education, Certificate Program in Developmental Disabilities

The Certificate Program in Developmental Disabilities is co-sponsored by the Rutgers University School of Social Work Institute for Families and The Boggs Center. It is intended to enhance the skills and knowledge of professionals working in the field of developmental disabilities and professionals working with people with disabilities in a variety of settings. The Boggs Center chairs the Certificate Program Advisory Council. Boggs Center faculty teach the workshops on cultural competence, disability policy, transition, positive behavior support, and psychotherapy.

❖ In Fiscal Year 2009, 124 students participated in 5 day-long workshops conducted by The Boggs Center.

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Strategic Preservice Initiatives for Mental Health Clinicians to Serve People with Intellectual and Developmental Disabilities

In 2007, The Boggs Center initiated a project to improve the education of graduate students in psychology, social work, and counseling with regard to the mental health needs of people with Intellectual and Developmental Disabilities (IDD). Rarely do academic programs for clinical professionals include coursework or practica regarding the unique vulnerabilities of people with IDD. Similarly, advances in therapeutic techniques for people with IDD have not been incorporated into graduate curricula. Through this project, lectures are provided, free of charge, to university programs, thus addressing a longstanding gap in education, and ultimately, service provision, to people with IDD in need of mental health treatment.

❖ In FY 09, The Boggs Center guest lectured for graduate students at William Paterson University; Monmouth University, taught Clinical PsyD students at the Rutgers University Graduate School of Applied Psychology, and presented to staff of Monmouth Medical Center;

❖ Articles on the mental health needs of people with Intellectual and Developmental Disabilities (IDD) were written for *New Jersey Psychologist* and The Arc of New Jersey's *Healthy Times.*

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Our thanks to the individuals and families whose photos are featured in this report and also our colleagues at the NJ Council on Developmental Disabilities for contributing some of the photographs.

UMDNJ

THE ELIZABETH M. BOGGS CENTER
ON DEVELOPMENTAL DISABILITIES
Department of Pediatrics

ROBERT WOOD JOHNSON
MEDICAL SCHOOL
University of Medicine & Dentistry of New Jersey

A University Center for Excellence
in Developmental Disabilities Education, Research, and Service

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Joseph B. Young, Executive Director

TESTIMONY SUBMITTED

ON BEHALF OF

DISABILITY RIGHTS NEW JERSEY

TO THE

NEW JERSEY

SENATE HEALTH, HUMAN SERVICES, AND SENIOR CITIZENS COMMITTEE

ASSEMBLY HUMAN SERVICES COMMITTEE

ON

DEVELOPMENTAL CENTERS AND

COMMUNITY-BASED SERVICES

FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Joe Young

Executive Director

May 7, 2010

Advocating and advancing the human, civil and legal rights of persons with disabilities

New Jersey's designated protection and advocacy system for individuals with disabilities | Member, National Disability Rights Network

Senator Weinberg, Assemblywoman Huttle, and Committee Members:

Disability Rights New Jersey (DRNJ) is the designated protection and advocacy system for people with disabilities in New Jersey, which includes the Protection and Advocacy for Individuals with Developmental Disabilities program (PADD), 42 U.S.C. § 15041 to 15045.[i] Services provided to individuals with developmental disabilities under the PADD program include: (1) information, referral, and advice; (2) individual and family advocacy; (3) legal representation; and (4) assistance in self-advocacy. The federal protection and advocacy system was established by Congress in the mid-1970s in response to the reported abuses of persons with developmental disabilities living in state-operated institutions. DRNJ's staff, which includes a former developmental center resident, makes regular visits to New Jersey's developmental centers and responds to allegations of neglect, abuse, and discrimination in both the developmental centers and the community.

Today's hearing is an opportunity to focus on the future of services for people with developmental disabilities in New Jersey. This requires us to ask not whether we should keep what we've got, but how do we get to where we want to go. When we focus on the future, there is no question that New Jersey must develop a comprehensive continuum of services that is firmly anchored in the community.

Internationally, the expectation that people with disabilities have the right to live in the community was first formally voiced in the United Nation's Declaration on the Rights of Disabled Persons in 1975 and has been reaffirmed in the 2008 Convention on the Rights of Persons with Disabilities, which seeks the recognition of "the equal rights of all persons with disabilities to live in the community, with choices equal to others" and calls upon governments to "take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community . . . by ensuring that . . . [p]ersons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." Convention on the Rights of Persons with Disabilities, Art. 19 (2008).

Nationally, the legal expectations are also clear. The United States Supreme Court's 1999 decision in *Olmstead v. L.C.,* 527 U.S. 581 (1999), as important to people with disabilities as *Brown v. Board of Ed.,* 347 U.S. 483 (1954), was to African Americans forty-five years before, declared that unjustified institutionalization and segregation of persons with disabilities was discrimination and violated Title II of the Americans with Disabilities Act. *Id.* at 597.

The Court did us no favors, however, by muddying the waters between declaring the right to integration and enforcing it. Within the Third Circuit, which has jurisdiction over New Jersey, the expectations are a bit clearer than in other parts of the country. Here, the federal courts require the states to develop a plan that "at a bare minimum should specify the time-frame or target date for patient discharge, the approximate number of patients to be discharged each time period, the eligibility for discharge, and a general description of the collaboration required between the local authorities and the housing, transportation, care, and education agencies to effectuate integration into the community." *Frederick L. v. Dep't of Pub. Welfare of Pa.,* 422 F.3d 151, 160 (3d Cir. 2005). But, developing and publishing a plan is simply not enough. The states "must be prepared to make a commitment to action in a manner for which it can be held accountable by the courts." *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 364 F.3d 487, 500 (3d Cir. 2004).

It is here where New Jersey falls short. After some struggle, New Jersey ultimately published a plan. New Jersey's goal of moving 250 persons a year out of developmental centers is relatively modest, particularly when compared to the recent order in New York requiring that state to develop 1,500 new supported housing units a year for the next three years to move its residents with mental illness out of large institutional adult homes. *Disability Advocates v. Paterson*, 03-CV-3209, Memorandum and Order (E.D.N.Y. Mar 1, 2010).

However, New Jersey's "commitment to action" has not kept pace with its promise, currently progressing at only 25% of its promised rate; while simultaneously continuing to admit more persons to the developmental centers. Virtually none of the new admittees chose to live in a developmental center. Rather they find themselves in an institution after years of community living because of the current absence of an appropriate community-based program.

The extended delay in rebalancing New Jersey's system of services for persons with developmental disabilities has also contributed to a waiting list for community-based services more than three times greater than the census of the developmental centers, while causing considerable anguish for aging parents and siblings, fearful that there will be no community program for their loved one when the family can no longer maintain their heroic effort to retain the individual at home.

Of even greater concern to me are the hundreds of individuals currently residing in developmental centers who have experienced decades of delays and disappointments. Individuals who, despite their perceived disabilities and isolation, are fully aware that there is a world beyond the boundaries of the developmental centers of which they are not a part. Every time staff from DRNJ go to a developmental center at least one resident will approach them and ask when will they be able to leave. I recently received a letter from some twenty individuals who have been living in developmental centers from a few months to more than twenty years asking me to come to meet with them to explain why they have not moved to the community. I have no acceptable answer. New Jersey must do better, starting by fully committing to meet its promises to these individuals.

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[i] Other programs incorporated within the protection and advocacy system include:

- Protection and Advocacy for Individuals with Mental Illness (PAIMI), 42 U.S.C. §§ 10801 to 10851
- Protection and Advocacy of Individual Rights (PAIR); 29 U.S.C. § 794e
- Client Assistance Program (CAP); 29 U.S.C. § 732
- Protection and Advocacy for Assistive Technology (PAAT); 29 U.S.C. § 3004
- Protection and Advocacy for Beneficiaries of Social Security (PABSS); 42 U.S.C. § 1320b-21
- Protection and Advocacy for Individuals with Traumatic Brain Injury program (PATBI), 42 U.S.C. § 300d-53
- Protection and Advocacy for Voter Access (PAVA); 42 U.S.C. §§ 15461 and 15462.

NJCDD
New Jersey Council on Developmental Disabilities

Elaine Buchsbaum, *Chair*
Alison M. Lozano, Ph.D., M.P.A., *Executive Director*

Comments of the NJ Council on Developmental Disabilities

Submitted before the Joint Legislative Meeting on Developmental Centers and Community Care Options

May 7, 2010

The New Jersey Council on Developmental Disabilities (Council) thanks Chairwomen Weinberg and Vanieri Huttle and the members of the committees for this opportunity to contribute to today's discussion about how to best design and deliver services to people with developmental disabilities in New Jersey and their families.

The Council's statutory mission includes the responsibility of informing government decision-makers about the lives of people with developmental disabilities and advocating for services and supports that remove barriers to self-directed, included, safe and rewarding lives as participating members of their neighborhoods and communities.

The Council appreciates that, particularly this year, the state has insufficient fiscal resources to fully provide all residents with developmental disabilities the services and supports they need. This persistent shortage of funds and personnel requires us to question the wisdom of continuing to support a system in which nearly 35% of the Division of Developmental Disabilites (DDD) budget is used to maintain seven large institutions that serve only 7% of the state's more than 40,000 eligible people. Indeed, DDD maintains a waiting list of over 8,000 people who want community residential services or other supports that will enable them to live outside of developmental centers. The Council believes that the resources used to support seven large institutions could be more effectively used to meet the needs of DDD's caseload, the vast majority of whom want services in a community setting.

I am the parent of a 35 year old man with autism, intellectual disabilities and a seizure disorder. I used to say I was the parent of a young man but that is no longer so. Matt continues to live with his father and me long past when he should do so for his well being. He needs to have a place of his own, separate from his parents, to ready him for the day when we are no longer able to care for him. I would like to be around while he makes that change, to help make it a smooth and positive transition.

The most important message families want you to hear today is that we live with the constant fear that our children will end up in emergency developmental center placements, exactly where we have sworn they will never go. Any state approach to services that fails to provide real community alternatives to institutional placement violates all that we families have spent our lives working for: to ensure that our sons and daughters continue to have a place to live and thrive in their community as they have always had while living in our homes.

The majority of NJ families prefer to keep their loved one with developmental disabilities at home or in a community setting with appropriate supports. The thousands of families who care for a loved one at home do not get much in the way of Family Support dollars or Self-Directed Services dollars to make their situations manageable.

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An organization known as Advocates for New Jersey Developmental Center Residents has advised us that they collected mailed-in responses to a single question from family members of institutional residents. The group claims that their survey demonstrates that "96% of guardians and family members prefer continued ICF/MR services over community services." There are several issues with this report that make this claim completely inaccurate.

Based on information in the group's own publication, only roughly half of the total number of DC residents at the time the survey was completed (1,417 out of 2,819) had a family member or guardian respond to the survey at all. A summary of the Council's concerns about the accuracy of this survey is attached to this testimony.

By way of contrast to arguments against the redistribution of resources to the community, New Jersey, like most other states in the nation, has direct experience demonstrating the positive outcomes of closing large institutions for people with developmental disabilities. A study of the results of the 1994 closing of North Princeton Developmental Center in New Jersey, published by the American Association on Mental Retardation in 2005,[1] found that the individuals who transitioned out of the institutional setting:

- had more friends
- exhibited less challenging behaviors
- perceived their life to be better
- demonstrated significant increases in self-care skills over time

The study also reported "convincing evidence" that the multi-cognitive scores of people who remained in institutional settings, including social skills, significantly decreased from 1994-2001.

There are many other peer-reviewed studies showing the benefits of less restrictive settings. Indeed, the Unites States Supreme Court, in the landmark *Olmstead* decision, observed:

> Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment... [Moreover,] segregation perpetuates unwarranted assumptions that institutionalized people are incapable or unworthy of participating in community life.

Given the research, experience and legal requirements, how can we continue to maintain a system of residential services where the vast majority of eligible children and adults remain in their family home without sufficient funds to meet their service and support needs, where thousands of adult children live with aging parents who can no longer properly care for their children, and where the only foreseeable future for families is to have a son or daughter ripped out of a family home when the parents die and placed in a restrictive, institutional "Center".

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[1] "Longitudinal Changes in Adaptive Behavior of Movers and Stayers;" Lerman, P., Apgar, D., Jordan, T. Mental Retardation Journal, American Association on Mental Retardation. February 2005, pp. 25-42.

The Council, along with the broader DD community of self-advocates, family members, providers and organizations, stands ready to work with the Legislature and other stakeholders to ensure the safety and quality of community services and supports and to resolve the economic concerns of institutional employees, vendors and other institutional stakeholders about the possible closing of some of the state's seven developmental centers.

Please feel free to contact our offices for further information about these critical matters from staff and from affected individuals and families. Thank you.

Respectfully submitted,

Elaine Bucshbaum

Elaine Buchsbaum
Chair

NJCDD
New Jersey Council on Developmental Disabilities

Elaine Buchsbaum, *Chair*
Alison M. Lozano, Ph.D., M.P.A., *Executive Director*

NJCDD Comments on "Report on Residential Choice Survey"
Published by Advocates for New Jersey Developmental Center Residents

There are several issues with this report that make the findings unreliable.

Claim:
"96% of guardians and family members prefer continued ICF/MR services over community services."

Fact:
Only roughly half of the total number of DC residents at the time the survey was completed (1,417 out of 2,819) had a family member or guardian respond to the survey.

Fact:
In three developmental centers, less than half of the residents had a family member or guardian submit a response to the survey. One center, Woodbine, was not included in the survey.

Percent of Residents for whom a Response was Received
Green Brook – 70% (65 responses out of 91 residents)
Hunterdon – 91% (516 responses out of 561residents)
New Lisbon – 48% (218 responses out of 432 residents)
North Jersey – 46% (195 responses out of 403 residents)
Vineland – 36% (168 responses out of 441 residents)
Woodbine – not part of survey
Woodbridge – 59% (255 responses out of 404 residents)

Claim:
The survey is an accurate assessment of family preferences.

Fact:
The questionnaire is not anonymous and it looks as if it is an official document.

- Across the top in capitals are the words "NOTICE OF CHOICE.".
- It gives the impression that the document is a formal decision
- It asks for the name, address and contact information for the person completing the form and for the name and DC of the resident.
- It states that the person filling out the form will provide written notification if they change their mind.

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Fact:
The survey's single yes or no question, "I am opposed to community placement for my family member/ward" was embedded in information that could be expected to have influenced the responses to the survey:

> "YOUR IMMEDIATE RESPONSE IS NEEDED!"
> "While we realize that some families may be currently seeking community placement, we believe that the majority of families feel that their loved ones are best and appropriately serviced in their current home at ___ Developmental Center……we are attempting to get a more accurate count so that the myth of the 2,400 requesting community placement will finally be dispelled. We would like to show that plans to downsize and / or close the developmental centers are not based on what our families want."

Fact:
The letter accompanying the questionnaire used value laden language vilifying DDD (Division of Developmental Disabilities.) "Over the last 8 years the Division of Developmental Disabilities (DDD) has aggressively and purposely overstated stated (sic) the number of individuals residing in developmental centers who want community placement."

Fact:
Families at the Hunterdon DC were given the survey at a family meeting at which the issue of closing institutions was discussed. This group had the highest percentage of responders indicating their opposition to community placement.

Claim:
Residents of state run ICF/MR's would be denied their rights to an individualized treatment plan if they live in the community.

Fact:
All individuals living in the community are required to have an IHP (Individual Habilitation Plan) that is an extensive plan for treatment and life in the community.
See N.J.S.A. 30:6D-10 (every agency, organization or institution providing DDD services must prepare written IHP for persons served); N.J.S.A. 30:6D-12.4(b) (DDD must prepare written IHP for all individuals receiving self-directed supports).

The concern that all community residents may not have an IHP is a programmatic problem not a policy issue.

Claim:
Developmental Center staff members who evaluated residents for community placement were given "the misleading impression that community placement is an appropriate option for all residents of New Jersey's Developmental Centers."

Fact:
The memo relied on to support this claim recognizes that not all residents of developmental centers are eligible for community placement. Attachment A is a memo from Hunterdon DC administration to staff. There is no indication that staff in other DCs was similarly instructed.

The memo instructs staff to list an individual as "eligible for community placements unless they represent a serious danger to others." There follows instructions that if the individual is deemed a serious danger to others for other than specified examples there must be a notation as to why they individual is not eligible for community placement

Research Demonstrates the Benefits of Life in the Community

The arguments for community living and the closure of institutions are based on decades of evidence about what works in the real world.

A study of the results of the 1994 closing of North Princeton Developmental Center in New Jersey, published by the American Association on Mental Retardation in 2005,[1] found that people who transitioned out of the institutional setting:

- had more friends
- exhibited less challenging behaviors
- perceived their life to be better
- demonstrated significant increases in self-care skills over time

The study also reported "convincing evidence" that the multi-cognitive scores of people who remained in institutional settings, including social skills, significantly decreased from 1994-2001.

The study compared individual's who transitioned to the community to individuals who remained in the center, and matched them according to age, gender, cognition, social-emotional functioning, self-care, mobility, and challenging behaviors.

Numerous other peer reviewed studies are available from across the country with similar findings.

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[1] "Longitudinal Changes in Adaptive Behavior of Movers and Stayers;" Lerman, P., Apgar, D., Jordan, T. Mental Retardation Journal, American Association on Mental Retardation. February 2005, pp. 25-42.

NJCDD
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NJ COUNCIL ON DEVELOPMENTAL DISABILITIES POSITION STATEMENT ON DEINSTITUTIONALIZATION

BACKGROUND

Legal Mandates

The Developmental Disabilities Assistance and Bill of Rights Act establishes "the policy of the United States that ... individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life."

Consistent with this vision, the guiding principle of the United States Supreme Court decision in *Olmstead v. L.C.*, 527 *U.S.* 581 (1999), is the inherent right of an individual to be free from unnecessary segregation from the general public. The Court made it clear that unnecessary institutionalization is a form of discrimination under the Americans with Disabilities Act (ADA), and explained that "segregation perpetuates unwarranted assumptions that institutionalized people are incapable or unworthy of participating in community life."[1]

The Justices also concluded that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[2] Accordingly, the Court reasoned that people with disabilities cannot be required to give up the benefits of full participation in their communities in order to obtain needed medical services and supports.[3] Therefore, states must make services available in inclusive, community based settings.

New Jersey Facts

Nearly 3,000 people with developmental disabilities live in our seven large State-run developmental centers, which are referred to under Medicaid law as Intermediate Care Facilities for the Mentally Retarded[4] (ICFs-MR). In many respects, this practice leaves New Jersey significantly out of step with the nation:

- Half of the states in the country (25) have a total statewide institutional population of less than 1,000.
- Nearly half of the states in the country (24) have two or fewer such institutions.
- Nine states have no state institutions at all.[5]

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[1] Id. at 597, and 600-01.
[2] Id. at 600-01.
[3] Id. at 601.

[4] The Council recognizes that this term, found in federal Medicaid statutes, is outdated and offensive. It is only included here to identify the specific provisions of the federal Medicaid statute that govern New Jersey's developmental centers.

[5] As of 2008, the following states reported no large residential institutions for people with developmental disabilities: Alaska, Hawaii, Indiana, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia.

COUNCIL FINDINGS AND RECOMMENDATIONS

The Council finds as follows:

1. New Jersey continues to rely on large institutions as a default placement and has not committed sufficient resources to free people with developmental disabilities from unnecessary confinement in large restrictive institutions.

2. The National Conference of State Legislators correctly concluded that, "[a]s long as states continue to operate large public facilities, state funds will be used to support those facilities, per capita costs of operating facilities will continue to increase, and expansion of community services will decline. [6]

3. New Jersey's over-reliance on institutional settings for emergent and long-term care significantly hinders the State's ability to develop the resources needed to provide quality community-based services and supports.

4. The State has a legal and social imperative to act immediately to develop a community infrastructure of housing, health care, direct care, transportation, along with behavioral, recreational, educational and vocational supports to ensure that our State has the capacity to serve all DDD-eligible individuals who seek home- and community-based services and supports.

Based on all of the above, the Council calls upon the State to:

1. Develop the capacity to provide persons with developmental disabilities with self-determined, safe and effective services in community settings.

2. Develop a plan and timetable to:
   a. close developmental centers
   b. reduce the population in developmental centers that remain open
   c. prevent new admissions to developmental centers
   d. redirect some of the funds currently used to maintain seven large developmental centers to the development of safe and effective self-directed, home- and community-based services and supports

3. Immediately allocate federal and State funds to meet the following goals:
   a. stop new admissions to developmental centers of people who could be served in the community by, among other things, meeting emergency requests for services in less restrictive settings

   b. increase the pace of transitioning to the community the more than 2,000 developmental center residents whom the State has identified as waiting for less restrictive settings

   c. annually meet the needs of at least 10% (400) of the current number of people on the State's growing priority waiting list for community based services and reduce the presently unacceptable length of time people remain on the priority waiting list for community services.

REVISED POLICY ADOPTED: March 20, 2009
This revised policy replaces all previously adopted policies on deinstitutionalization.

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[6] Davis, DeWayne Fox-Grage, Wendy and Gehshan, Shelly. Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators. National Conference of State Legislatures. May 19, 2000.

ADVOCATES FOR NEW JERSEY DEVELOPMENTAL CENTER RESIDENTS

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REPORT ON RESIDENTIAL CHOICE SURVEY

CINDY BARTMAN- PRESIDENT

ASSOCIATION FOR HUNTERDON DEVELOPMENTAL CENTER

SISTO CAPONERA – ADVOCACY REPRESENTATIVE

GREEN BROOK REGIONAL CENTER

VITO COLLETTI – ADVOCACY REPRESENTATIVE

VINELAND DEVELOPMENTAL CENTER

CAROL MASTROPOLO – PRESIDENT

NEW LISBON DEVELOPMENTAL CENTER FAMILY AND FRIENDS

JOANNE R. ST. AMAND – PRESIDENT

PARENTS ASSOCIATION AT WOODBRIDGE DEVELOPMENTAL CENTER

KATHY TOTH – PRESIDENT

NORTH JERSEY DEVELOPMENTAL CENTER ASSOCIATION OF FAMILY AND FRIENDS

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ADVOCATES FOR NEW JERSEY DEVELOPMENTAL CENTER RESIDENTS

REPORT ON RESIDENTIAL CHOICE SURVEY

EXECUTIVE SUMMARY

The Supreme Court has found that Title II of the federal Americans with Disabilities Act requires that states serve persons with disabilities in community settings rather than in institutions only when three conditions are met: (1) the State's treatment professionals have determined that community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

The State of New Jersey operates seven public intermediate care facilities for persons with mental retardation (ICF/MRs), also called developmental centers, as an option under its State Medicaid Plan. These centers serve more than 2,819 of New Jersey's most fragile citizens.

During the past several years, the New Jersey Division of Developmental Disabilities the state agency that oversees services for the Developmentally Disabled wherever they live, instructed its treatment teams to state that all current residents of developmental centers can live in community settings, thereby denying residents of the state run ICF/MR's their right to individualized treatment planning. As a result of this memo (Attachment A) the Division then stated "There are 2,457 individuals who have a recommendation for Community Placement in their IHP." (Attachment A1"The Path to Progress," page 11). These statements give the misleading impression that community placement is an appropriate option for all residents of New Jersey's developmental centers. However, the Division has never surveyed parents, family members and guardians regarding their preferences for services and have disregarded the recommendations of those who directly provide for the care and treatment of those individuals

The "Advocates for New Jersey Developmental Center Residents" undertook a study of the opinions of developmental center residents' guardians and family members in order to determine treatment preferences. Three findings are made:

(1) 96% of guardians and family members preferred continued ICF/MR services over community services;
(2) the conduct of the Division of Developmental Disabilities in requiring treatment professionals to recommend community living, violates the requirement for individualized treatment planning; and
(3) the use of state employees in the Bureau of Guardianship Services as "advocates" for persons receiving ICF/MR services is a conflict of interest and should be suspended immediately.

The findings of this study suggest that ongoing investments will need to be made in order to maintain federal certification of New Jersey's ICF/MRs. In addition, the conduct of the Division who requires its treatment professionals to recommend community living violates the right for individualized treatment planning. Also, these recommendations do not consider the wishes of the individuals' family as the primary decisionmaker. This practice jeopardizes federal financial participation and should be suspended. Finally, the use of state employees in the Bureau of Guardianship Services as "advocates" for persons receiving ICF/MR services is a conflict of interest and should be suspended immediately.

The Parents/Families Associations at each developmental center is pleased to offer its assistance to the Division in identifying family members and alternative guardians to address this need.

ADVOCATES FOR NEW JERSEY

DEVELOPMENTAL CENTER RESIDENTS

REPORT ON RESIDENTIAL CHOICE SURVEY

BACKGROUND:

The 'integration mandate' of the Americans with Disabilities Act requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." In 1999, the United States Supreme Court affirmed the right of individuals with disabilities to live in their community in its 6-3 ruling against the state of Georgia in the case *Olmstead v. L.C and E.W.*

The Court found that Title II of the federal Americans with Disabilities Act requires that states serve persons with disabilities in community settings rather than in institutions when three conditions are met: (1) the State's treatment professionals have determined that community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

The high court upheld that mandate, ruling that Georgia's Department of Human Resources could not segregate two women with mental disabilities in a state psychiatric hospital long after the agency's own treatment professionals had recommended their transfer to community care.

The State of New Jersey operates seven public intermediate care facilities for persons with mental retardation (ICF/MRs), also called developmental centers, as an option under its State Medicaid Plan. In choosing to do so, New Jersey is required to offer ICF/MR services to all Medicaid-eligible individuals who qualify for services. The hallmark of ICF/MR level of care is Active Treatment. Active Treatment refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. Active Treatment does not include services to maintain generally independent clients who are able to function with little supervision or in the absence of a continuous Active Treatment program. (42 CFR 483.440(a))

Each client in an ICF/MR receives an annual program plan, called an Individual Habilitation Plan (IHP), which serves as a guide to treatment planning. In contrast, services in community settings funded by the Home and Community-Based Waiver are not required to meet the Active Treatment standard. In many instances the individuals living in group homes or other settings under the Home and Community Based Waiver (HCBW) do not even have an IHP as seen in recent audits of DDD contracts.

STATEMENT OF NEED:

The overwhelming majority of the families and guardians of individuals receiving ICF/MR services are concerned that the New Jersey Division of Developmental Disabilities has embarked on a process which will result in its meeting the three Olmstead criteria for all persons currently receiving ICF/MR services but without attention to their continued need for individualized treatment services (Active Treatment program).

Fundamental Alteration:

Over the past ten years, the New Jersey Division of Developmental Disabilities has expanded the capacity of the Home and Community-Based Waiver. However, most of this new capacity has been given to moving current residents of developmental centers into the community. In fact, during the past 10 years the number of persons receiving ICF/MR services in New Jersey has decreased by about 1,000. At the same time, however, the Division did not make any significant headway in addressing the lengthy waiting list for waiver services among persons with developmental disabilities living in the community. During the same period, the waiting list has grown to more than 5,000 persons. This practice creates tension between families of individuals living in ICF/MRs and those on the waiting list for community services.

Treatment Professionals:

In 2001, the New Jersey Division of Developmental Disabilities instructed treating professionals in its developmental centers to include a statement in each client's individual habilitation plan that the resident could be served in the community. The only exceptions to this statement were for individuals who are considered dangerous to others (by virtue of having a criminal record) or individuals who could verbalize their desire to remain in their placement. Having exterminated independent professional judgment at its developmental centers, the Division promulgates the belief that no treating professionals support continued placement in an ICF/MR. In its publication "The Path to Progress, page 11" the Division notes "There are 2,457 individuals who have a recommendation for Community Placement in their IHP." Obviously, this statement reflects the influence DDD has to advance their agenda by ignoring the federal requirement for individualized treatment planning and family choice.

Consent of the Individual:

Many individuals living in New Jersey ICF/MRs do not have family guardians and are instead, served by employees of the New Jersey Division of Developmental Disabilities through the Bureau of Guardianship Services (BGS). As per instructions from the New Jersey Division of Developmental Disabilities, individuals served by BGS and those without a guardian were listed as not opposing community placement in their IHPs regardless of level of need or mental capacity. See Attachment A

In fact, within the last two years, the Division changed the IHP documents to further push the alleged community preference. The IHP was changed to a person centered plan (PCP), a planning document now written in first person language. The PCP contains a template for language expressing such a choice so that all of the PCPs read the same. As a result, the PCPs contains an explicit statement of the client's preference in what appears to be the client's own words, for community or ICF/MR services, regardless of whether the client has been deemed competent to makes such a determination. In reality, many of the clients who have allegedly made statements regarding their preference are non-verbal or unable to make such a determination. This procedure is coercive and denies guardians of their legal right to make treatment decisions on behalf of their loved ones.

Based on these changes in state policy some community advocates with the tacit support of the Division, have argued that the entire population of individuals served in ICF/MRs, that is more than 2,400 individuals, is being inappropriately served through the program and that, as a result, all ICF/MRs in New Jersey should be closed. In direct contrast, many parents and guardians oppose community placement, and believe that the ICF/MR continues to be the most appropriate setting for providing care to their loved ones. There was a petition distributed to the friends and families of the residents of the Hunterdon Developmental Center in late 2006. Over 2,300 signatures were collected, bound and presented to the Governor and State Leaders indicating their overwhelming opposition to the forced removal of residents from the Developmental Centers and a request for legislation that would review the policies of DDD and resume admissions to the centers when the individuals needs required the level of care available only at an ICF/MR (SEE Attachment B).

Unfortunately, no survey of guardians and family members has ever been undertaken by the Division and requests to read the IHP or PCP documents to see what the family's preferences are have been ignored. The current proposals to move all developmental center residents into the community do not take into account the actual level of services required for each individual. This in turn represents a challenge to policy makers and state government because they cannot adequately determine the level of financial support required to provide an appropriate level of funding for New Jersey ICF/MRs nor to those who will be moved when federal transition dollars disappear under the Money Follows the Person. MFP dollars are federal dollars that increase an individual's budget for 12 months after leaving and ICF/MR. The Center for Medicare and Medicaid (CMS) requires the states assurance that those dollars will be available through state resources when the federal dollars expire.

This study represents the first systematic effort to assess the opinions of guardians and family members regarding the need for ICF/MR services in New Jersey.

METHOD:

Each of the seven ICF/MRs operated by the State of New Jersey maintains an active parents/family group. In order to ascertain the preference of parents and non state guardians for ICF/MR versus community services, the presidents or representatives for each parent/family group convened a Task Force to conduct a survey of all parent and non state legal guardians of residents at the centers. The Task Force, named Advocates for Developmental Center Residents, designed a survey with a single question: "Are you in favor or opposed to community placement for your loved one?" The survey was mailed to all of the families at six of the seven centers, which comprised the membership of the parent/family group at each facility (Attachment D1 and D2). The seventh center, Woodbine Developmental Center was unable to participate due to the failing health of their parent/family group leadership. The center would not allow the Task Force to prepare the mailings in an effort to protect confidentiality.

The Task Force contacted Kim Friend, Director of the Bureau of Guardianship Services with a request to send the survey to the state-employed workers at BGS in an attempt to have state-appointed guardians participate in the process. As of the writing of this report she has not responded.

Funding for the mailing was obtained through donations from the parent/family group associations.

RESULTS:

Data were collected from parents and guardians at six of seven facilities. We will revise this report when data for the Woodbine Developmental Center are collected.

Results show survey responses are overwhelmingly in favor of continued ICF/MR (developmental center) services (Table 1). We received a total of 1,417 responses. Of these, 1,359 responses are in support of continued ICF/MR services and 58 responses are in favor of community placements and services through the HCBW. In percentage terms, this represents 96% in support of continued ICF/MR services and only 4% in favor of community placements.

TESTIMONY
MAY 7, 2010

Representative of Hunterdon Developmental Center- Cindy Bartman

Census at HDC 561

I am here as the representative of the Hunterdon Developmental Center families. I am going to read you excerpts from the letters that were sent to this group today. It is spoken from the hearts and minds of families. Thank you for allowing our voices to finally be heard.

For the Survey for Choice that was compiled by the Advocates for Developmental Center Residents our return of responses to the survey was 516 from a census of 561. All but 8 responses favored having their loved one stay at Hunterdon.

Anne M – the developmental centers are needed and should not be closed

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

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

James H- my son is at HDC and the people working with him do an amazing job. They always include me in decision making with everything he needs.

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

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

Tom B- Most of the clients now in our developmental centers have the mental functioning of a two year old or less. During the mass exodus from the centers in the 90's and staff recommended those who could benefit from waiver services. The providers then came and "cheery picked" the least difficult clients leaving others behind. There are eyewitness accounts of residents leaving and then returning to the centers after failed experiences in the community. Of the past 7 clients that staff were recently pressured into sending out into waiver services, 5 have returned to the center in far worse medical shape than when they were initially discharged from HDC. One girl only lasted 12 days before coming back on a feeding tube because she did not eat anything for the entire 12 days that she lived in the group home. Another girl who was very active at HDC came back confined to a wheelchair. Another person came back with multiple fractures. Two others came back with feeding tubes. We also know of a number of deaths.

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

Maria A- I have gone to visit without announcing my visit in advance and I have not been disappointed in the condition I found my daughter in. They treat her like a human being, a child, a special child that she is.

Joe and Anne B- When my twin boys entered HDC 40 years ago they were promised that this would be their home for their lifetime. How can you break a promise to a child?
Maximus continues to provide inaccurate bills. We need to constantly call and check the bill. Can't NJ do this billing themselves and not take our children's Social Security money away from them to pay for this made company?

Gail S – We are telling you loud and clear to let us make the decisions for the people we love who are unable to voice and opinion.

Teresa M. – The families of the residents of HDC are the primary decision makers. Aren't you the primary decision makers for your young children?

Nancy g- This is not the first time we have had this major stress in our lives. We as a family do NOT want our sister moved to a group home or what you may call community placement. We do not want her to leave the center.

Alexander T. – My daughter is 55 years old and functions like a child of 16 months. She is vision impaired and needs constant assistance in all daily living tasks. She also has a tendency to wander off. She only has one kidney and the remaining kidney has stones in it. She needs professional attention and close supervision, plus medical monitoring on a daily basis.

Testimony Against the Closing of Developmental Centers (ICF/MR)
MAY 7, 2010

Representative of Woodbridge Developmental Center – Joanne St. Amand
Census at Woodbridge 404

My name is Joanne St. Amand. I am the sister of Rosemary, a profoundly retarded woman whose home has been Woodbridge DC for 35 years. She was not expected to live past puberty. Rosemary turned 55 last month. A tribute to her excellent care at WDC. Rosemary cannot walk or talk; she cannot feed herself, nor take care of any of her most personal needs.

I am also the president of the Woodbridge Developmental Center Parents Association. I am here today as a representative of the Woodbridge families. I am going to read to you excerpts from some of the many letters sent to me for today's hearings. They are written from the hearts and minds of our WDC families. Thank you for allowing our voices to finally be heard.

First, the results for our "Survey for Choice", conducted by the Advocates for Developmental Center Residents are, for a census of 404, we received 255 returned responses. <u>All</u> but 15 responses favored having their loved ones stay at Woodbridge Developmental Center.

The following excerpts are taken directly from the letters received from families of WDC:

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

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

Joanne St. Amand
Woodbridge Dev Center
May 7, 2010

Barbara S - My daughter cannot walk, has seizures, cannot speak and needs around the clock care. She also has a tumor the size of a watermelon in her uterus and it cannot be operated on. … Why is it that the government always wants to take from the most innocent and needy and give to the most greedy?

Thomas, Kathleen, Brandon, Ian and Chelsea C- Most of the patients at WDC are not fortunate to still have family and relatives to advocate for them. As a result they have no voice, no advocate and no protector. There is an opportunity here for all involved to make clear, that here in NJ we are our brother's keeper.

Gerry S and 25 family members - We the undersigned recognize that the waiting list crisis in NJ demands the expansion of community based options. However, we are against any expansion at the expense of the ICF/MR residents. One size does not fit all.

John P- If you read my brother's Individual Habilitation Plan you will see references that say that he would like to be in a group home. There is one simple problem with that comment- my brother has never spoken a word in his life! Nor would he be able to understand questions about group homes or communicate his desires in any other non-spoken way. I raise the point because it makes me wonder how many other residents' files may contain similar statements that may cause decisions to be made that aren't in the best interests of these individuals.

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

Louis and Teresa M- Our son has been in one- to- one care for years at Woodbridge due to his history of self abuse, but we just heard that he is being taken off the one- to- one service due to the efforts of those at WDC.

Elizabeth W. – My daughter is 45 years old. She takes a while to get comfortable with her caregivers and will not eat for too many people. She is in good hands at Woodbridge.

Please, I ask for all the residents and their families - keep all of our Developmental Centers open. Thank- you

Joanne St. Amand
Woodbridge Dev Center
May 7, 2010

Woodbridge Developmental Center **April 22, 2010 1:30 -3:00pm**

Woodbridge Tour by Assembly Women Huttle, Tucker, McHose, & Guests

A. Welcome and Introduction to Woodbridge

The Woodbridge Developmental Center was founded in 1965 as the Woodbridge State School. The design of the Center won awards. Twenty-one buildings were residential dorms and the Center had approximately 500 staff. By the 1970's, Woodbridge had a population of nearly 1000 people (with most being young children and teens with moderate to severe medical issues and physical deformities).

In the past 40 years, there have been many changes and improvements at Woodbridge. Woodbridge became a Developmental Center and it began to participate in the federal ICF-DD program in the 1980s. We provide residential supports in 16 buildings and have 5 buildings assigned to programming. Our individuals have aged (avg. age: 50 years) and we no longer provide services to children. The current census is about 380 people who require 24/7 supervision and intensive supports (Services which are not readily available in the community). We have approximately 1260 permanent employees on payroll.

Given the acute needs of the individuals now living at Woodbridge, we have a full compliment of professional staff who provide on-site specialty services. Some of the services and programming provided at WDC include: Adaptive Seating & Positioning, Behavioral Services, Dental Services, Hearing and Vision evaluations, Nutritional Services, Primary and Specialty Medical Care, Psychology Services, Recreation Activities, Wheelchair Maintenance, Vocational and Prevocational Training, etc. In addition, we provide extensive training to our staff in every area of care.

B. Other Facts about Woodbridge:

WDC Census:	378 people, 232 (61.4%) Men & 146 (38.6%) Women (Age Range 27 to 68)
Ambulation:	275 people are non-ambulatory and require custom wheelchairs (highest in DDD) 40 use transport wheelchairs for long distances 103 are ambulatory but require supervision to ensure traffic and medical safety
Cognitive Level:	340 (90 %) have IQs in the Profound and Severe range (total care & supervision) 38 (10%) have IQs in the Mild or Moderate (behaviors & constant supervision)
Communication:	80 (21.1%) with moderate communication impairments 297 (99.8 %) with moderate or profound communication impairments 326 (86.2 %) with severe or profound hearing impairment (43 people are deaf)
Eating:	53 (14%) have G-tubes for nutritional support 300 (79.6%) have special mealtime programs and/ or supervision needs
Vision:	210 (55%) people with significant Visual Impairments 50 (13%) people who are blind
Seizures:	307 (81.2%) people with epilepsy and 167 (44.1%) receive Anti-Epileptic drugs
Psychiatric Care:	60 (15.8%) people receive psychiatric medications (lowest in DDD)


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NJACP Testimony
Joint Hearing of the Assembly Human Services Committee
Senate Health, Human and Senior Services Committee
The Future of Developmental Centers and the Community Services System
May 7, 2010

NEW JERSEY ASSOCIATION OF
COMMUNITY PROVIDERS, INC.
NJACP
Advancing Quality Services for
People with Developmental Disabilities

On behalf of our board of directors, member agencies and the thousands of people we support, thank you for the opportunity to testify today. My name is Kim Todd and I serve as the CEO of the New Jersey Association of Community Providers. We welcome the opportunity to discuss the important and challenging future of the system that supports people with developmental disabilities in these difficult times. We hope as we move forward that decisions are based, first and foremost' on what works for people with developmental disabilities. We ask you to consider the wealth of scientific research and successful and innovative approaches that have been implemented in other states. We ask you to take the necessary actions to enable all people with developmental disabilities to live quality engaged lives in the community and to craft an array of services and supports that meets their needs.

As New Jersey struggles with meeting the needs of the people it is intended to support with scarce resources, we find ourselves balancing the State's budget next fiscal year with the SSDI Personal Needs Allowance of people with developmental disabilities. Next year's budget looks equally grim. Staying the course is not a viable option as less and less resources become available to address the challenges of the Developmental Disabilities system and the window to use federal support to transition our system closes.

While New Jersey studies and debates, if and how, the rest of the nation has moved forward leaving New Jersey at 49th in the nation, with one of the highest rates of institutionalization in the country.

When compared to other states in national benchmarks including the following studies, New Jersey languishes in the bottom tiers:

- "Residential Services for People with Developmental Disabilities: Status and Trends Through 6/2007," edited by Prouty, Smith and Lakin: University of Minnesota, August 2008
- "The State of the States in Developmental Disabilities: 2008 Study Summary," by Braddock et al at the University of Colorado: January 2008 and
- "The Case for Inclusion 2010," by Tarren Bragdon, United Cerebral Palsy, Washington, D.C.

The public policy agenda on the role of institutions was determined long ago, shifting to one of community inclusion. We are debating an issue that has been decided.

- Justice Ginsberg delivered the opinion of the Supreme Court in Olmstead v. L.C. and concluded that States are required to place individuals with developmental disabilities in the most integrated setting appropriate to their needs as determined by themselves and their treatment professionals. Justice Ginsberg and the Court maintained isolating and segregating those living with developmental disabilities in institutions violates Title II of the Americans with Disabilities Act of 1990 and constitutes discrimination based on a disability. (Olmstead, 1999);

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L.106-42 stated:

- "The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities and support to make informed choices and decisions about their lives; live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens; achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual".

The Assistant Attorney General for Civil Rights, Thomas E. Perez at his Installation Ceremony in 2009 said "Civil Rights in 2009 means working to create services, programs and public facilities that are accessible to individuals with disabilities, recognizing that they have a vast contribution to make to our society and our communities that can only be maximized if they have equal access. It means recognizing that segregating people with disabilities in institutions is every bit as bad and illegal as segregating children of color in inferior schools. "

The national agenda of inclusion was reaffirmed by President Obama on the 10th anniversary of the landmark Supreme Court decision in the case of Olmstead v. L.C. President Barack Obama celebrated that anniversary by launching "The Year of Community Living. He said " The Olmstead ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently". "I am proud to launch this initiative to reaffirm my Administration's commitment to vigorous enforcement of civil rights for Americans with disabilities and to ensuring the fullest inclusion of all people in the life of our nation" he added.

While other states have moved forward to organize services and supports for people with developmental disabilities in the community, New Jersey, at 49th in the nation is clearly out of step with the rest of the nation.

The Division of Developmental Disabilities devotes 1/3rd of its $1.3B budget to support 8% of the population it serves at a rate of $710 per person, per day for care. According to the NJ Department of Human Services, the level of care exceeds need for 81% of those in institutions. Our continued support and overreliance on institutional care has outpaced our ability to ignore this issue. With costs escalating 9% annually, they will approach $1,000 a day, per person in

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four years. We will be forced to continue to allocate millions of dollars in costly upkeep and maintenance offering less and less for those who wait for community services.

We can no longer afford to continue this course of action at the expense of the thousands who continue to wait, often for decades for community services. This includes young adults transitioning from the education system with little or no options and the generations to come.

Solutions, successful approaches, and the expertise clearly exist as well as offers of assistance. At one step from last place, we are hardly pioneers, vanguards or trendsetters in transitioning systems serving people with developmental disabilities. Our challenges are not unique. Although we recognize the concerns that change presents, we can avoid the missteps of those that have gone before us by utilizing the successful approaches, the wealth of scientific research and the experiences of other states to implement change safely and successfully.

We encourage New Jersey to embrace a positive new direction in step with the rest of the nation by fully supporting community options for people with developmental disabilities and their families. We respectfully ask you to consider the price they pay each day we delay. New Jersey asks them to wait patiently while New Jersey continues to debate a course of action that maintains the status quo, and its place at 49th in the nation.

NJACP is a statewide association committed to ensuring continuing progress toward the development of a consumer driven system and greater quality of life for people with 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 developmental disabilities in agency residences, at home with their families and in their own homes.

Bernard Krakowsky

Opening Doors

by Brenda Considine

The name "Krakowsky" is engraved in script on a brass knocker mounted to the door of a first-floor garden apartment.

For the last 12 years, the man who answers that door is Bernard Krakowsky.

Krakowsky, 53, is proud of his home. With his playful, dry wit, he offers a tour of his two-bedroom condo, stepping slowly and deliberately through each room. He stops to comment on his coffee maker, which has been adapted so he can use it easily every morning.

"I just pop the Folgers one-cup filter right here, and then—coffee. It's that easy."

Outside his spare bedroom where he keeps his treadmill and exercise bike, he jokes about not working out as much as he should. And then, in his bedroom, he points out the new flat-screen television:

"Got that last summer when the other one went kafluie."

Finally, he makes his way to an overstuffed chair in his living room:

"And this is where I lounge around." Then he stops and smiles. "And it's all *mine*."

When the E.R. Johnstone Training and Research Center closed in 1992, it became the first large institution in New Jersey to be shut down by the state. At the time, many of the 225 residents were expected to go to community-based programs, but Bernard Krakowsky was not among them.

The staff of the developmental center had identified a list of men who where deemed to be too disabled to live anywhere but another institution. Krakowsky was on that list.

Robert Nicholas, former director of the state Division of Developmental Disabilities (DDD) and currently a Senior Visiting Fellow at the John J. Heldridge Center at Rutgers University, remembers Krakowsky.

"I was told it was just not possible for Bernard to live in the community," said Nicolas. "Everyone said he was 'too this,' or 'too that.' I did not get it. I kept asking: 'Why?'"

Another person who asked "Why?" was Robert Stack, CEO of Community Options. Stack convinced Nicholas to let his fledgling agency serve Krakowsky and several others leaving Johnstone who were slated to go to other developmental centers.

Initially, Krakowsky lived in a group home in Mercer County, but soon after, moved to a supervised apartment in the complex where he now owns his home. Today, he continues to receive support services, 20 hours a week through Community Options.

Once Krakowsky landed a full-time job, the staff approached him with a question: "How would you like to own your own place?"

Bernard at work at the DDD, with co worker

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"I couldn't believe it," Krakowsky recalled. "I worked and saved up enough to buy my own place and now, I pay the mortgage!" With a quick clap in the air, he smiles and adds. "Yep! That's right! I pay the mortgage!"

When asked about the 18 years he spent at Johnstone, Krakowsky's demeanor softens and is less animated. He recounts stories of working in a small workshop, taking trips and classes, and learning to use public transportation. As he rattles off the names of people who worked there, he adds:

"The staff were very kind to me. I remember the good stuff. That's all.

"But every night, we would go to bed at 10 o'clock. Lights out. Even on Friday and Saturday. 10 o'clock, lights out. Now I stay up till one in the morning if I want. I watch TV. I like to sleep in sometimes. I'll sleep till 10 o'clock on Saturday."

But sleeping in for Krakowsky is strictly limited to the weekend. Monday through Friday, he has arranged for Access Link to drive him to and from work, commuting the 10 minutes it takes to get to his job.

"I have them scheduled to come at 7:40," he says. "That way, if they are late, I am still on time."

Since 1994, Krakowsky has worked full time as a receptionist at the central office of DDD, where he answers the phone, and attends the door, buzzing in guests and visitors. As part of his job he knows everyone who works there and their telephone extensions.

Robert Nicholas recalls hiring Krakowsky for the position. "About a year after Stack first approached me about Bernard, we had a job opening at the division for a receptionist. Who shows up to interview but Bernard, dressed in his three-piece suit, with a red tie and wing tip shoes.

He would be doing a complex clerical job—the same work and the same salary as anyone else," said Nicholas. "Because Bernard is blind, there were issues around accommodations to consider. How would he dial the phones, and handle the doors? But in the end, it was not a problem."

Krakowsky had done receptionist work in the past. His résumé showed volunteer experience as a receptionist at the Stony Brook Watershed in Pennington, and later, a part-time paid position at a condo association.

Bernard is the receptionist at the central office of the DDD.

"I knew I could do it," he recalled. "I remember when I got the job. It was like, Woooo Hooo—YES! I did it."

Barbara Booth is one of Krakowsky's co-workers. She has known him for more than 6 years and although the relationship began at work, a friendship has spilled well beyond the walls of the office.

"We go to concerts at Christmas, out to dinner. He even likes to spend time with my kids," said Booth.

"Bernard is an awesome guy who is always kind. If you tell him something he never forgets," she adds. "He is always asking about me and my family. He even knows my pets."

Booth says the friendship is very mutual.

"We always celebrate birthdays, so we threw him a huge party when he turned 50. And he takes me out on my birthday!"

Nicholas reflects on his experiences and views Krakowsky as one of his teachers. "For years, every day when I came to work the first person I would see was Bernard. He was a daily reminder that we must never say "can't." P&F

QUICK FACTS ON NEW JERSEY'S DEVELOPMENTAL DISABILITY SERVICES

New Jersey, in comparison to other states, has lost ground as it continues to rely on historical approaches depressing our ability to replicate the positive outcomes of other states. Across the United States the trends in public spending over the past forty years have shifted away from funding large public institutions, with a total of 140 closures having taken place in the nation since 1969. New Jersey has closed two institutions, E.R. Johnstone Training and Research Center in 1992 with a census of 239, that became a correctional facility; and North Princeton Developmental Center in 1998 with a census of 512 people. New Jersey is not one of the 40 states with planned additional closures.

The following studies describe the trends in large public institutions over the last two decades and provide data for comparisons between states including benchmarks for New Jersey:

- "Residential Services for People with Developmental Disabilities: Status and Trends Through 6/2007," edited by Prouty, Smith and Lakin: University of Minnesota, August 2008 (cited as "Prouty, 2008") and
- "The State of the States in Developmental Disabilities: 2008 Study Summary," by Braddock et al at the University of Colorado: January 2008 (cited as "Braddock, 2008").
- "The Case for Inclusion 2010," by Tarren Bragdon, United Cerebral Palsy, Washington, D.C. (cited as "UCP, 2010").

Drawing on the findings of these researchers, work one can conclude that:

- **Nationally, large state facilities continue to downsize and close.** Between 2000 and 2007 the population of large public institutions nationally had dropped from 47,329 to 36,650, a decrease of 22.5% (Braddock, 2008). During the same period, New Jersey's institutional population dropped from 3,514 to 2,995, a decrease of 14.8% (Prouty, 2008), *two-thirds of the national effort.* In New Jersey, this is an overall decrease of 519 people, which includes 490 individuals who died while residing at the state run developmental centers, indicating a passive reduction due to mortality (NJ DDD, 2008). The resulting net discharge over those seven years of 29 people. New Jersey was ranked 49th in the nation for having one of the highest rates of utilization of state institutions at 34.9 people per 100,000 in population. The national utilization rate over this same period was 12.9 people per 100,000.
- **It *is* possible to operate a state Developmental Disabilities Services and Supports System without large state operated facilities.** On June 30, 2007 nine states did not operate any large (over 16 people) state facilities (AK, HI, ME, MN, NH, NM, RI, VT, and WV) (Prouty, 2008). Since then, two more states have closed their final developmental center (OR and IN), and the District of Columbia closed all of its state-operated institutions.
- **The cost per person in large state facilities continues to rise.** In 2007 costs reached a national average of $483 per day (Prouty, 2008). At that same point in time the average cost per day of service in New Jersey's large state institutions was $612 (Prouty, 2008). According to NJ DHS this figure rose to $710 per day in FY 2009. The average increased cost per year in New Jersey has been 9% over the last six years. Our fiscal

climate is unable to continue to support these increased costs. At the present rate of growth, at the end of the present administration's first term, costs will approach $1,000 per day, per person for institutional care.

- **The amount of spending on New Jersey's state institutions, as compared to statewide personal income, places us 6th highest among the states, yet our community spending places us in 40th place**. New Jersey's spending, per $1,000 of personal income, on institutional care is among the highest in the nation, while our spending on community services is less than 4/5th of all states. When compared to our neighboring states, New York and Pennsylvania, New Jersey is behind in our effort to fund and prioritize community services. New Jersey is more comparable to the nation's poorest state, Mississippi, in how they fund services to people with developmental disabilities.
- As of June 30, 2007, **more than two-fifths (41.9%) of the total number of large state facility residents in the country lived in five states** (California, Illinois, New Jersey, New York and Texas), each with more than 2,100 residents in such facilities (Prouty, 2008). Since that time:
    - California closed one developmental center (Agnews with 327 residents) and projects that it will close another of its large state facilities (Lanterman with 393 people) in the next two years.
    - The Western New York Developmental Center is scheduled for closure in 2010-11 and will be fully decommissioned by 2011-12, and according to FY 2010-11 state budget documents it is expected that the remaining DCs will be fully decommissioned by 2012-13.
    - Illinois is in the final stages of closing Howe Developmental Center.
    - While Texas continues to oversee the state's 13 developmental centers (or as they call them, Supported Living Centers), in the last two legislative sessions, lawmakers have made a concerted effort to fund more community living options.
- On June 30, 2007, **twenty of the forty-two states** (including DC), **still operating large institutions, had 375 or fewer individuals in their entire state operated institutional systems** (AL, AZ, CO, DE, ID, IN, KS, KY, MD, MI, MN, MT, NE, NV, ND, OK, OR, SD, UT, and WY) (Prouty, 2008). On that same date, six of the seven state operated institutions serving individuals with development disabilities in New Jersey *each* housed more than 375 people. *"Operating Data for New Jersey Developmental Centers SFY '06-'09," shows the 2007 average daily census of each of the seven developmental centers (the year for which comparable national data is available) one center served 103 people, while each of the other centers was above 394 (the range being 394 – 589).*

Of the 49 responding states responding to a survey by the *National Association of State Directors of Developmental Disabilities Services* (NASDDDS), 11 (22%) states reported that they had closed all state operated institutions for persons with intellectual and developmental disabilities (IDD).

Of the 38 states still operating institutional programs that responded to the survey (unduplicated count):

- 4 (11%) states are planning to close one or more facilities and not downsize other programs or facilities.

- 14 (37%) states are planning to downsize existing facilities but not close any institutions.
- 5 (13%) states are planning to close one or more institutions and downsize additional facilities.
- 15 (39%) states have no plans to close or downsize state operated institutional programs.

Summarizing the results of the data from these 38 states reveals that:

- 9 states (24%) have plans to close one or more institutions.
- 19 states (50%) have plans to downsize programs, reducing the census of existing facilities.

Financial Impact

- 10 states (26%) made the decision to close and/or downsize IDD facilities due to financial reasons.
- Of the 4 states with plans to close some facilities but not downsize others, three states are closing the facilities for financial reasons.
- Of the 14 states with plans to downsize but not close facilities, three states are downsizing for financial reasons.
- Of the 5 states with plans to both close and downsize existing facilities, three states made the decision for financial reasons.

According to Braddock (2008), Person's with I/DD in Out-of-Home Residential Settings, By Size of Setting: for FY-2006. New Jersey had:

- 7,621 people, or 59% of the people served in Out-of-Home Residential Settings lived in setting of 1-6 people, the national average for that year was 70%;
- 791 people, or 6% of the people severed in Out-of-Home Residential Settings lived in setting of 7-15 people, the national average was 11%;
- 4,539 people, or 35% of the people severed in Out-of-Home Residential Settings lived in setting of 15+ people, the national average was 19%.

The utilization rate by individuals with I/DD in settings for six individuals or fewer, in FY-2006, found that **New Jersey ranked 38th**, by state, with a utilization rate of 87 people per 100,000 in population as compared with a national average of 126 people.

According to the findings of Bragdon (UCP, 2010), New Jersey's usage of "Large State Facilities," ranked us toward the highest in all three categories noted.

- Percentage of the service population who are being supported in Large State Facilities; New Jersey, as of the end of FY 2009 was supporting 7.7% of the people in DCs, while the national average was 3.7%. **This ranked NJ 47th** among states.
- The number of residents in Large State Facilities, New Jersey had 2,897 people in DCs at the time of reporting. **Ranking NJ 50th** out of 51 (including Washington DC).
- Regarding the number of Large State Facilities, New Jersey has 7, ranking it 43rd.

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The Home and Community-Based Services (HCBS) Waiver (which provides access to federal matching dollars): I/DD Participants and Spending in FY-2006 in New Jersey:

- There were 9,611 participants in the Waiver;
- Waiver spending as a percentage of total I/DD spending was 29%, as compared with the national average of 45%;
- Waiver dollars per capita were $50, as compared with a national average of $66;
- New Jersey ranked 34th on spending per capita.

The Home and Community-Based Services (HCBS) Waiver data reported by Bragdon (UCP, 2010), shows a continuation of these same patterns:

- New Jersey 77.7% of its service recipients on the HCBS Waiver, whereas the national average was 84.9%, ranking New Jersey 42nd among the states.
- The percent of DDD expenditures New Jersey had on the HCBS Waiver was 44.4%. The national average was 65.1%, ranking New Jersey 45th.
- The percent of DDD expenditures New Jersey had on community-based services and supports was 60.7%, with the national average being 76.8%. This ranked New Jersey 48th.

Supported Living Programs, I/DD Participants and Spending in New Jersey in FY-2006:

- There were 1,865 participants in Supported Living programs;
- This was a utilization rate of 21 people per 100,000 in population; as compared with a national average utilization rate of 64 people per 100,000;
- Spending per capital on Supported Living Programs was $6.39 in New Jersey, as compared with a national average of $16.36.

Family Support Programs and Spending in New Jersey for I/DD:

- New Jersey had 20,013 participants in Family Supports programs (Braddock, 2008):
- There were 228 family supported per 100,000 in population, which above the national average of 144. These figures were reconfirmed for FY-2009 (UCP, 2010);
- 81% of people being supported in either in their own home, family home, foster care (1-3 people) or congregate care (1-3 people) (UCP, 2010). This is at the national average and ranks New Jersey 16th among states.
- The average spending per family was $2,954, whereas the national average was $5,376 (Braddock, 2008);
- This rate of spending ranking New Jersey 31st among states (Braddock, 2008).

Residents with I/DD in Nursing Facilities in New Jersey – FY 2004-06:

- In FY 2004, 714 individuals with I/DD were being supported in Nursing Facilities;
- By FY 2007, this number had increased to 741 people;
- This was an increase of 4%. The national percent of change over that same period was 1%.

Ranking among states of New Jersey's spending on I/DD services per $1,000 of aggregate personal income:

- In total I/DD spending, New Jersey ranked 35th in FY 2004, and rose to 31st in FY 2006;
- In spending on community services and supports, New Jersey ranked 42nd in FY 2004 and 40th in FY 2006;
- In institutional spending, New Jersey ranked the 6th highest in both FY 2004 and 2006.

NJ Developmental Centers 1999-2010

Thirty six of the 42 states supporting institutions are reducing their census, including New Jersey. However, mortality has played a major role in the reduction of the census (NJ Division of Developmental Disabilities, 2010). Over the last twelve years, the census has been reduced by 904 people across all institutions of which 787 have been deaths. At the same time 882 people were admitted from the community and 999 people moved to the community. This represents a net decrease of 117 people when the statistics are adjusted for mortality across the twelve year period. This is an average net decrease in census (adjusted for mortality) of 6 people per year, over twelve years. *See Chart Below*

Developmental Centers Census in New Jersey

	State Fiscal Year												
	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010 [7]	**11-Year Totals**
Census at the start of the Fiscal Year	3,672	3,596	3,514	3,433	3,296	3,169	3,121	3,070	3,051	2,995	2,897	2,788	**3672**
Admitted from the Community	73	81	66	20	58	105	121	96	101	85	52	24	**882**
Moved to the Community	82	90	60	87	107	93	98	59	102	116	69	36	**999**
People who Died in the D/C	67	73	87	70	78	64	79	57	55	67	55	35	**787**
Net Decrease in Census during the Fiscal Year including mortality	76	82	81	137	127	52	56	20	56	98	72	47	**904**
Census at the end of the Fiscal Year	3,596	3,514	3,433	3,296	3,169	3,121 [1]	3,070 [2]	3,051 [3]	2,995	2,897	2824 [4]	2,727	**2727**
Discharges who moved to nursing homes	n/a	n/a	9	11	6	3	8	15	14	7	5	11 [8]	**78**
Census Change during each year, *not including death.* [5]	*Down by* 9	*Down by* 9	*Up by* 6	*Down by* 67	*Down by* 49	*Up by* 12	*Up by* 23	*Up by* 37	*Down by* 1	*Down by* 31	*Down by* 17	*Down by* 12	*Down by* **117**
Net *Community* Placements [6]	9	9	-6	56	43	-12	-23	-37	-13	24	12	6	**68**

North Princeton Developmental Center closed at the end of April FY-1998.

"Moved to the community" includes individuals discharged from DDD services and those moved to nursing homes.

1 - reflects a net increase of 4 individuals moving between developmental centers; DC census decreased by 48 people overall.

2 -reflects net increase of 5 individuals moving between developmental centers; DC census decreased by 51 people overall.

3 - reflects net increase of 1 individual moving between developmental centers; DC census decreased by 9 people overall.

4 - There was one individual discharged in this year that was not tracked in the statistics made available by DDD as to where that person was subsequently supported.

5 - **Total Census Change over eleven years, not including deaths has been 78 people.**

6 - **This is the Net Community Placements, which is the total discharges, less deaths and nursing home placements.**

7 - **Fiscal year 2010 data contain 7-months of data. DDD's reported Census at the beginning of FY 2010 does not match the previously reported ending Census for FY 2009.**

8 - **Discharges have been unspecified by DDD**

All data provided by the Division of Developmental Disabilities FY-2007, FY -2008 and FY-2009

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Elliott Naishtat,
Texas State Representative
Room GW 16, Capitol Building
Austin, TX 78701

Patrick M. Rose,
Texas State Representative
Capitol Extension Room E2.602
Austin, TX 78701

March 27, 2010

Dear Representatives Rose and Naishtat,

I am not a constituent in your counties, however I have followed with interest your legislative work on behalf of children and adults with developmental disabilities and their families. I'm retired now, but have a long history in that field. I was Deputy Commissioner of Mental Retardation in Texas in the early eighties, and State Director of Developmental Disabilities in Kentucky and Minnesota. But more importantly, I was step father to Michael, who had multiple severe disabilities and lived with my wife and me in Minnesota. He died at age 24, but the years that he and I lived together gave me insight into the challenges faced by him and others. You have been very involved in providing advocacy for our state's institutional residents (I realize they are now called state supported living centers) and I applaud your work on their behalf. As I read different newspaper articles on the problems at Corpus Christi, Lubbock, Denton and elsewhere I was struck by a sense of déjà vu, that we are still discussing the need to close institutions in this day and age. I was particularly interested in the Austin-Statesman article today, March 27, 2010, referencing statements made by Thomas Perez, Assistant Attorney General for Civil Rights in the U.S. Justice Department. He articulates a view that is long overdue here in Texas.

I apologize in advance for the length of this letter but as you know this is a complex subject that can't be synopsized easily. In fact, that's been one of the problems over the years. Legislators and public officials used their common sense to create the system we now have. Unfortunately it turns out that the assumptions that underpin the current system aren't supported by science and experience. Everyone seems to think the argument for closure of institutions is just an ideological issue, with two equally valid sides, but there aren't always two sides to every issue. The arguments for closure of institutions are not simply philosophical or legal or even moral positions. They are based on a body of knowledge that has evolved…on what works in the real world.

Texans have struggled for decades with the question of how best to serve their children and adults who have developmental disabilities. I use the terms developmental or intellectual disabilities and mental retardation interchangeably, for simplicity sake, although I know the definitions are distinct for each term. Parents and professionals sincerely wanted to do the right thing for their sons and daughters…they wanted Texas to lead the nation in its demonstration of compassion and to provide what was considered "state of the art care." In the seventies and eighties, with help from legislators, state officials and an oil rich economy, we built beautiful new buildings in Corpus Christi, Lubbock, Amarillo and elsewhere to provide a protective environment that would let parents rest easy, knowing that their sons and daughters would be cared for in a sheltered community, served by caring professionals and direct care staff. Experts in different architectural styles of institutions were used in advising Texans on the construction of these buildings. Now, after years of debate, federal intervention, lawsuits alleging abuse and neglect, and watching most other states move away from congregate care to smaller, dispersed community services, doubt exists about the service delivery system we've created.

At its peak these newly developed service systems were headed up by the Texas Department of Mental Health and Mental Retardation (TDMH-MR), which in turn was led by Commissioners (e.g., David Wade, Gary Miller) whose professional training was Psychiatry, i.e., mental health. Community Centers serving people with mental health and developmental disability needs were also growing, but the lion's share of state resources was centered in the institutional system. The community centers were also, usually, headed up by people whose background was in mental health rather than developmental disabilities. Those from the field of mental health who were charged with implementing policies on behalf of people with mental retardation were sincere, dedicated people who did their best to carry out the mandates from the Executive, Legislative, and Judicial Branches of Government in Texas. This is not a criticism of their intentions or their deeds. In the sixties and seventies the field of mental health, (and mental retardation as well) was plagued with exposes of horrible conditions, warehousing of people with little or no meaningful treatment or training and violations of basic rights. The field of mental health began moving toward de-institutionalization of residents…which sometimes had unintended, negative consequences for the field of developmental disabilities.

In the field of mental health there existed a bedrock assumption, held by some professionals and policy makers, that all mental illness could be cured. The introduction of medications to reduce or eliminate symptoms was hailed by mental health professionals and their patients. The success of psycho-pharmacology aided the belief that moving people out of institutions was the most humane thing that could be done. Unfortunately, the mental health model with its belief in the ability to cure people, to make them normal again, resulted in a failure to develop a comprehensive array of community supports. That failure to assume some people would have lifelong dependency and therefore would need continued support resulted in what came to be known as "dumping," and that in turn became the argument used by institution supporters against closure of congregate mental retardation facilities. This was especially true in Texas.

The assumption in the field of developmental disabilities was the exact opposite, that the needs of the people we served were lifelong, While parents and professionals knew that kids and adults who had mental retardation, epilepsy, autism, cerebral palsy and other

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problems were capable of much more independence than had been previously assumed there nevertheless was a recognition that these conditions could not be "cured." People would need varying levels of support, depending on the severity of their disability…in most cases for their lifetime. Thus, when community service systems for this population were developed they spanned the life cycle, with programs that mirrored stages of development from birth to old age. The spectre of homeless, vulnerable or fragile people with severe disabilities almost never occurred in the field of developmental disabilities.

Why did professionals in most states abandon the institution or medical model for people with developmental disabilities? The answer to that question requires an analysis of the assumptions that drive public policy in this field:

Assumption: Congregation is necessary for people with complex needs. The theory was that we can cluster specialized professionals together to focus on the "special" needs of people who have disabilities. This is the medical model of service delivery. But the reality is that the needs of this population are not usually acute and intense. They are more often chronic or episodic. They are less in need of a hospital crash cart than they are of consistent responses to the person's needs. Talk with parents who have children with multiple, severe disabilities, especially when their child can't communicate their needs with words. What you learn is that if you live with someone you eventually learn to observe cues that can help you recognize moods, comfort level, happiness or sadness …even if the child can't talk, can't control muscle movement, or has no self help skills. Anyone who has done the "rumor" experiment in a communication class knows how difficult it is to control information when it passes through large numbers of people. And, mistakes in the case of people who are medically fragile can be deadly. So the rule of thumb is that the more involved the person's needs are, the fewer the number of people interacting with them, consistent with respect for the needs of caregivers as well. Conversely, shift patterns of staffing such as those that exist in institutions, almost guarantee that there won't be consistency over a 24 hour day. With staff vacations or sick time, holidays, and covering three shifts for each living unit, getting to an intense, personal relationship with each person is almost impossible. The same principle applies with people who have severe destructive behaviors…changing those requires that there be absolute consistency in programming.

Assumption: Families will have a major role in the lives of their loved ones. Even with regularly scheduled team meetings, with family involvement mandated, experience has shown that with few exceptions it's difficult for families to stay in contact when someone doesn't live in the same community. This is true for all of us. "Absence (doesn't necessarily) make the heart grow fonder." At first, despite the best of intentions, our contacts are frequent but life intrudes and over time they become less and less frequent. This is especially true when family members have to travel long distances to visit. It's more accurate to say "out of sight, out of mind." Conversely, when people live in the same community, it's easier to stay in touch, to know what's going on in each others' lives. Institution supporters argue that this estrangement is the exception….it isn't the norm…but most facility employees know it is.

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Assumption: Institutions serve people community programs can't serve, i.e., people with severe or profound mental retardation, who are medically fragile, who have severe mental illness/behavioral problems. A corollary assumption is that there is something so remarkably different about this population that they require the services of uniquely qualified "mental retardation" professionals. The reality is that community programs throughout the country have been serving people who are virtual twins of institution residents since the early 1970's. Our neighbors in Oklahoma have some of the most successful programs in the country, and the residents in those programs were all moved out of the Sand Springs Hissom Memorial Center which was subsequently closed. Oklahoma's programs for people with medical/behavioral issues are among the best in the nation. Professional schools of medicine, psychology, social work, etc. rarely offer any training in this field. And, why would they? The needs of this population are no different than those of the rest of us. What happens when a person becomes seriously ill in our institutions? They are transferred to tertiary care hospitals in the community. It isn't surprising, given the location of many of our facilities, that recruitment and retention of competent, skilled professionals has always been a major problem.

Assumption: People are safer and more protected in institutions. Let me be clear. This letter is in no way a criticism of institution employees. I worked in an institution (Glenwood, Iowa) for five years. The people who work in institutional settings are no different than people who work in community programs. They're just people doing the best that they can, given the cards they were dealt. By and large we get a lot more heart and soul from direct care staff than we deserve given their level of pay. Having said that, there are at least two reasons institutions are not as safe as community residences. First, institutions are often located in rural areas or relatively small towns. The community depends on the facility for much of its revenue. The people who work in them are often related. When abuse or neglect occurs there is a higher likelihood that it will be hidden or ignored. Reporting one's brother in law or neighbor for abuse is more difficult than reporting a stranger. Second, dispersed, integrated, community homes/programs are mistakenly assumed to be more anonymous, hidden away and therefore less likely to be subject to scrutiny. The reverse is true. Strangers have no problem blowing the whistle when they see a child or adult with disabilities being abused. Neighbors, people in grocery stores, medical personnel, fellow workers, church members, and involved family members are much more likely to see and report suspected abuse or neglect than the closed community of congregate care personnel. During the past two decades the public have become much more aware and sympathetic to the needs of people with disabilities. Thanks to films like Rain Man, My Left Foot, and countless others, as well as television shows that use people with disabilities in their casts (e.g., Corky, in Life Goes On) along with high profile programs like Special Olympics and celebrity involvement, there has been an outpouring of support from the general public. We've gone from a "there but for the grace of God go I," to seeing people as people, first and foremost. In the field, advocates try to use "People First" language which reflects this view. There's less concern with what makes someone "different" or "special," and more concern with our shared humanity.

Assumption: Institutions are tried and true, and have been around forever, but Community programs are new and untested. Actually, the reverse is true. Institutions are a relatively new experiment. They didn't exist in the U.S. until the mid to late 1800's. At that time they were small schools, however they grew in size and number, becoming less concerned with education and more custodial in nature, until the exposes in the mid twentieth century. Even at their peak they never served more than about 2 or 3% of all people with developmental disabilities. Families have always been the main support for this population. Community programs started in the 1950's because parents couldn't bring themselves to place their children in institutions and, unlike the institutions, they were unable to access state or federal funds, so they started their own schools and vocational programs. Longitudinal studies like the Pennhurst Study (following people who left the Pennhurst institution in PA), have shown virtually incredible improvement, using any measure, when people move into community programs. Family satisfaction, weight gain, self help skill development, etc. all demonstrate the power of moving people into the community. States like Oklahoma (Hissom Memorial Center), Nebraska (ENCOR), Connecticut(Southbury), and others have done similar studies which yield the same positive results. The University of Minnesota has tracked trends and produced numerous research reports describing the past forty years of growth in community programs. The MN Governor's Council on Developmental Disabilities website (www.mnddc.org) has links to most of the significant research done during that time.

Assumption: "They need to be with their own kind." It's impossible to generalize about kids and adults with disabilities. In fact, it's the very uniqueness of their special needs that makes them even more diverse, if that's possible, than the population at large. But perhaps the most important reason for not subscribing to this common misconception is understanding how people learn, especially children and adults with cognitive problems. It's been said that people with mental retardation have difficulty understanding abstract concepts, that they're more receptive to concrete, functional ways of learning. We know that it's easier to learn in a real environment than a fabricated one. We know that the most powerful way for any child to learn is through imitating others. As parents we might not always like what our children learn from imitating us (or their friends, or brothers, or sisters) but there can be little doubt that that is the way they learn much of what they come to practice as adults. So, if our goal is to teach someone to talk, to walk, to be toilet trained, or any of the other skills humans need to exist, why would we surround them with people who can't talk, who don't walk, who aren't toilet trained, and on and on? But that's exactly what we do in congregate environments. We put people with the most severe disabilities together and expect a good outcome. Why? If it can be said that what we want in terms of training/education is for this group to be "more normal" then it makes sense to surround them with "normal" role models, not people who share their disabilities. This underlies the current practice in special education of "inclusion" (presence and participation) of children with disabilities side by side with non-disabled children.

Assumption: By congregating people together we can serve them more cheaply. While the principle of economies of scale and assembly line production might work with Henry Ford, it doesn't work with people who have special needs. The reality is that "per diem

144x

(per day)" costs for congregate environments are much more, often two to three times as much, as community alternatives. The average cost per person per day for institutions is more than $400 (about $146,000 per year). This difference in cost between community and institutions was always true, even when the institutions had residents with less severe disabilities. Supporting people in normal housing in typical neighborhoods has always been far less expensive than institution construction and maintenance, even with adaptations made for people who have severe physical disabilities. It means we don't have to replicate resources. We don't have to build gyms, swimming pools, parks, schools and the like because they're already there. If a son or daughter lives with his/her parents there is no need to provide any of the elements that make up a home....in-home support is the least expensive way to serve. From a taxpayers point of view it always makes sense to support, not supplant, the natural home, whenever possible.

Assumption: We can train or educate people better in a congregate environment. If there's one organizing theme in this letter it is that institutions don't work for this population because they are fundamentally flawed service delivery models. They are structurally not set up to educate or train because they don't provide opportunities for imitation of "normal" behavior, non-disabled role models. They aren't set up to educate or train because, by definition, people with intellectual disabilities have trouble transferring from artificial settings to real ones....they need concrete experiences in real life situations. You learn to work on an assembly line in a factory on the actual assembly line. You learn to order at McDonald's by actually going to McDonald's.

Stephanie Goodman, from the Health and Human Services Commission says that "In Texas we support choice." But the choice she refers to is parental/familial choice not necessarily what is in the best interests' of those institutionalized. And, no, parents don't always know what's best for their children. Sometimes public policy pits the rights and needs of people who may be adversely affected by those policies against what is considered the inviolate rights of parents. Whether it's Child Protective Services or Developmental Disabilities, when that happens policy makers like you become the Solomon's.

You didn't solicit this letter but I have felt the need to express these views for a long time. Thanks again for your work on behalf of people with developmental disabilities and their families. If I can be of assistance please let me know.

Sincerely,

Ed Skarnulis, Ph.D.
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Bastrop, TX 78602
eskarnulis @austin.rr.com
512-985-5527

The state of community-based care
services to people with intellectual
developmental disabilities shows
results according to the 2010 Case
report. This year's report, based la
most states' fiscal year ending Jun
2008, when states began feeling
recession and before state [illegible]
boosts in federal stimulus funding.

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Case For Inclusion

2009

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2010 2009 2008 2007

2010 New Jersey Report

Overall Ranking (among all 50 states and Washington, DC, 1=best): **24**

Promoting Independence

***Community-based* Data**	**Value**	**Subrank (1=Best)**	**US Average**	**Source**
Percent of Recipients with ID/DD on HCBS	77.7%	42	84.9%	Research and Training Cer Living
Percent of ID/DD Expenditures on HCBS	44.4%	45	65.1%	Research and Training Cer Living
Percent of ID/DD Expenditures on non-ICF-MR	60.7%	48	76.8%	Coleman Institute

***Individuals Served by Size of Residence* Data**	**Value**	**Subrank (1=Best)**	**US Average**	**Source**
Percent in own home, family home, family foster care (1-3 residents) and congregate care (1-3 residents)	81.1%	16	80.8%	Research and Training Cer Living
Percent in community settings (1-6 residents)	89.8%	28	88.6%	Research and Training Cer Living
Percent in Large Settings (16+ residents)	7.9%	37	5.8%	Research and Training Cer Living

***Large State Facilities* Data**	**Value**	**Subrank (1=Best)**	**US Average**	**Source**
Percent in Large State Facilities (16+ residents)	7.7%	47	3.7%	Research and Training Cer Living
Number of Large State Facilities	7	43	168	Research and Training Cer Living
Residents at Large State Facilities	2,897	50	35,035	Research and Training Cer Living

***Waivers that Can Promote Self-Determination* Data**	**Value**	**Subrank (1=Best)**	**US**	**Source**

- 2008
- 2007
- 2006

Independence Plus Waiver	Yes	19	Centers for Medicare and Med
Other Self-Directed - 1115 or 1915(c) Waiver for ID/DD	Yes	15	PAS Center
Money Follows the Person - Award or Apply	Yes	28	Centers for Medicare and Med

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Quality and Safety

***Quality Assurance* Data**	**Value**	**Subrank (1=Best)**	**US**	**Source**
Council on Quailty and Leadership participant	Yes		24	Council on Quality and Le
National Core Indicators (HSRI) participant	Yes		28	Human Services Researc
Noteworthy State QA Initiatives			13	Quality Mall

***Safety* Data**	**Value**	**Subrank (1=Best)**	**US Average**	**Sou**
Percent of all those served receiving protection from abuse services	0.3%	8	1.1%	Cole

Keeping Families Together

***Family Support* Data**	**Value**	**Subrank (1=highest)**	**US**
Families Served	20,013	6	428,803
Total Spending	$59,123,073	8	$2,305,149,428
Spending per Family	$2,954	31	$5,376

Promoting Productivity

***Medicaid Buy-In* Data**	**Value**	**Subrank (1=highest)**	**US**	**Source**
Enacted	Yes		43	Centers for Medicare and
Enrollment	3,232	9	83,424	Centers for Medicare and

***Supported or Competitive Employment* Data**	**Value**	**Subrank (1=Best)**	**US**	**S**
Participants	1,363	23	110,539	(
Spending	$10,643,135	19	$708,872,399	(
Percent of all Individuals Served in Competitive Employment	14%	38	21%	(

Reaching Those in Need

[illegible]

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***Waiting Lists* Data**	**Value**	**Subrank (1=Best)**	**US**	**Source**
Waiting List for Residential Services	4,649	39	98,622	Research and Training Center
Percent Growth in Residential Services Required to Meet Waiting List	40%	34	23%	Research and Training Center
Waiting List - ID/DD HCBS - Kaiser	NA	N/A	253,306	Kaiser Family Foundation
Percent Growth in HCBS Services Required to Meet Waiting List	NA	N/A	49%	Kaiser Family Foundation

***Prevalence* Data**	**Value**	**Subrank (1=highest)**	**US Average**	**Sou**
Percent of Children with Mental Disability	4.2%	45	5.1%	US (
Percent of Adults with Mental Disability	3.3%	50	4.8%	US (

***Individuals with ID/DD served per 100k of population* Data**	**Value**	**Subrank (1=Best)**	**US Average**	**Sou**
		11		Cole

***Ratio of Prevalence to Individuals Served* Data**	**Value**	**Subrank (1=Best)**	**US Average**
	13.2%	7	6.6%

Serving at a Reasonable Cost

***ICF-MR* Data**	**Value**	**Subrank (1=highest)**	**US**	**Source**
Total Expenditures	$633,120,5435		$11,962,854,423	Research and Community Liv
Residents	2,921	11	94,846	Research and Community Liv
Cost per Resident	$216,785	6	$126,130	Research and Community Liv

***HCBS* Data**	**Value**	**Subrank (1=Best)**	**US**	**Source**
Total Expenditures	$505,880,00012		$22,310,392,935	Research and Tra Community Living
Residents	9,986	17	513,304	Research and Tra Community Living
Cost per Resident	$50,661	14	$43,464	Research and Tra Community Living

***Unmatched State ID/DD Funds* Data**	**Value**	**Subrank (1=Best)**	**US**
Total Expenditures	$470,012,206	12	$17,220,293,554
Percent of total ID/DD Spending	29%	22	33%

***Overall Spending* Data**	**Value**	**Subrank (1=Best)**	**US Average**	**Sou**
ID/DD Spending per $1,000 personal income	$3.85	31	$4.12	Cole
ID/DD Spending per capita	$189	16	$171	Cole

DNF = Did not furnish.

*Note: For more information on the actual source of the data presented,
printed report or sources.*

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United Cerebral Palsy Releases 2010 Case For Inclusion

5th Annual Report Ranks 50 States & DC on Medicaid Services for Individuals with Disabilities

The 2010 Case for Inclusion report (medicaid.ucp.org), ranks all 50 states and the District of Columbia (DC) for Medicaid services provided to intellectual and developmental disability (ID/DD) populations. The fifth annual rankings reveal:

1. Despite significant progress, all states have room to improve outcomes and services for individuals with ID/DD, particularly in the current economic climate.
2. Too many Americans with ID/DD still do not live in the community, although real and notable progress have been made since last year.
3. Certain states are making substantial progress.
4. Too much money is still spent isolating people in large institutions, with nominal change since 2009.
5. Waiting lists have increased dramatically, but performance is quite mixed by state; most are not serving everyone in need.

Top/bottom ten states in terms of quality of Medicaid service provided:

1) Arizona; 2) Vermont; 3) New Hampshire; 4) Washington; 5) California; 6) Massachusetts; 7) Michigan; 8) Connecticut; 9) Colorado; 10) Hawaii; 42) Virginia; 43) Ohio; 44) Indiana; 45) Tennessee; 46) Utah; 47) DC; 48) Illinois; 49) Texas; 50) Arkansas; 51) Mississippi

Seventeen states shifted by at least five places in the rankings from 2009 to 2010, and 21 states shifted at least six places in the rankings from 2007 to 2010. Highlights include:

- An impressive 22 states Ã± up three from 2009 and an increase from 16 states in 2007 Ã± have more than 80% of those served living in home-like settings.
- From 2005 to 2008, an impressive 13 states reduced the number of Americans living in large institutions by 20% or more.
- Overall the number of Americans with ID/DD on waiting lists for residential services has increased 56% from 2005 to 2008.

This report focuses on what is being achieved; not how much or how little money is pressures at the state level to a large extent, Medicaid shortfalls are projected to come roaring back in 2011, if the temporary increase in Medicaid funds run out.

THE CASE FOR Inclusion

2010

An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities

UCP United Cerebral Palsy™

Life without limits for people with disabilities

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About UCP

United Cerebral Palsy (UCP) is one of the nation's leading organizations serving and advocating for the more than 54 million Americans with disabilities. Most UCP consumers are people with disabilities other than cerebral palsy. Through its nationwide network, United Cerebral Palsy assists more than 176,000 individuals, as well as their families and communities each day, with services such as job training and placement, physical therapy, individual and family support, early intervention, social and recreation programs, community living, state and local referrals, and instruction on how to use technology to perform everyday tasks. For more information, visit www.ucp.org or call (800) 872-5827.

About the Author

Tarren Bragdon has been involved in healthcare policy research and analysis for over a decade. His work has been featured in dozens of newspapers and media outlets nationwide including the *Wall Street Journal, New York Post, New York Sun* and PBS. Past and present clients include United Cerebral Palsy; the MELMAC Education Foundation; the Maine Heritage Policy Center; the Heritage Foundation in Washington, DC; the Manhattan Institute; the Home Care Alliance of Maine; and the National College Access Network. He has testified before the US Senate's Committee on Small Business and Entrepreneurship and presented to numerous legislative committees and physician, hospital, Medicaid, business, social service and policy research organizations. He served two terms in the Maine House of Representatives on the Health and Human Services Committee. He served as chair of the board of directors of Spurwink Services, one of the largest social service providers in Maine with over 850 employees.

Introduction

We release this report in the context of a nation struggling with the worst economic conditions since the Great Depression. States have been challenged to close unprecedented budget deficits over the past two years and are projected to have similar enormous budget deficits for the next two to three years.

Given these factors, this 2010 report needs to be taken in context. Data for this year's report is mostly from state fiscal year 2008 - for most states ending in June 2008 and before the most significant budget deficits. Therefore, this year's report is a look back of where states stood before the current recession and before states received significant boost in federal stimulus funding. The challenge for elected officials, families and advocates is to maintain the progress that has been achieved over the past three decades. We must not let the current economic crisis be an excuse to turn back the clock on Inclusion.

The United Cerebral Palsy (UCP) annual ***Case for Inclusion*** is so important to benchmark states actual performance in improving lives for individuals with intellectual and developmental disabilities. More than how much or how little is being spent, the ***Case for Inclusion*** shows what is being achieved.

As the University of Minnesota's Research and Training Center on Community Living, concisely states: "The promise of access to and support for integrated community lives and roles for persons with [intellectual and developmental disabilities] is clearly expressed in national legislative, judicial, administrative and other sources that make four basic commitments:

- People with disabilities will live in and participate in their communities;
- People with disabilities will have satisfying lives and valued social roles;

- People with disabilities will have sufficient access to needed support, and control over that support so that the assistance they receive contributes to lifestyles they desire; and
- People will be safe and healthy in the environments in which they live.

These commitments have been articulated in a number of legislative, administrative and judicial statements describing national policy."[1]

Medicaid is the safety net program that can assist in supporting individuals with intellectual and developmental disabilities with their acute and long term care service needs. Other state programs can assist in providing other comprehensive supports to individuals. However, some Medicaid long term care policies and state programs can play a negative role by promoting isolation and seclusion.

Beginning in 2006, UCP annually releases rankings of the 50 states and the District of Columbia to show what states are actually achieving. Too often the goals of independence, productivity and community inclusion are at odds with reality. The 2010 rankings use the same methodology and core data sets as the 2007, 2008 and 2009 rankings, allowing readers to appreciate how individual states have improved, regressed or remained the same.

United Cerebral Palsy conducts this holistic analysis to chart each state's ranking and progress in creating a quality, meaningful and community-inclusive life for those Americans with intellectual and developmental disabilities served by that state's Medicaid program.

Nationwide, Medicaid served 608,000 individuals with intellectual and developmental disabilities in 2008, up 72,000 (13.4 percent) from 536,000 in just three years. Medicaid spending rose to $34.3 billion or about $56,400 per person for 2008, up from $29.3 billion in 2005 (17.0 percent increase in 3 years). Although this is a tiny portion of the 58.7 million individuals enrolled in Medicaid and the estimated $339 billion spent in 2008, Americans with intellectual and developmental disabilities are some of the most vulnerable Medicaid recipients. Individuals with intellectual and developmental disabilities make up one percent of all Medicaid recipients, but a generous 10 percent of Medicaid spending.

In addition to the noted Medicaid spending, states collectively spend an additional $17.2 billion to support individuals with intellectual and developmental disabilities in the community.

Although this report is a set of statistics, it is a collective summary of the impact and outcomes of Medicaid services to over half a million unique individuals with intellectual and developmental disabilities. Ideally such assessments should not be considered in the aggregate, but at the individual person level.

As always, the state rankings in this report are a snapshot in time. Most data is from 2008, although all data is the most recent available from credible national sources. Unfortunately, the data sourced is only as good as that provided directly by the states to the federal government or in response to surveys.

Although some states rank better than others, every state has room for improvement. The ***Case for Inclusion*** uses data and outcomes to clearly show where states' Medicaid programs are performing well and where improvement is needed.

What We Don't Know but Should

Unfortunately, some of the most important outcome data is not nationally collected or reported regularly. For example, to more completely assess key outcomes, states should report regularly and be scored on:

- Are services self-directed and how many individuals are participating in self-directed services?
- Are individual budgets used?
- What is the pay and turnover rate of direct support staff?
- What school-to-work transition programming exists for this population?
- What are the detailed results of standard client satisfaction surveys?
- What is each state's long term plan to close large institutions (public and private), if any?

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[1] The University of Minnesota Research and Training Center on Community Living. "Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities - Interim Report." September 26, 2005. Page 3. Available at: http://www.cms.hhs.gov/reports/downloads/UnivOfMinn.pdf

But advocates should always be looking at quality of life for the individual, irrespective of rankings and overall scoring. Aggregate data is important, but the true key to a state's performance is what quality of life each individual is living. The ideal is for outcomes to be reviewed at the individual level.

Hopefully, these ***Case for Inclusion*** reports, coupled with other advocacy initiatives, will encourage national groups to begin collecting and reporting on the above data measures so that a more complete picture can be presented and scored in future rankings.

Using This Report

This report is intended to help advocates and policymakers understand:

- How their state performs overall in serving individuals with intellectual and developmental disabilities
- What services and outcomes need attention and improvement in their state
- Which states are top performers in key areas, so that advocates and officials in those top performing states can be a resource for those desiring to improve

This report puts into a national context how each individual state is doing. Advocates should use this information to educate other advocates, providers, families and individuals, policymakers and their state administration on key achievements and areas needing improvement within their own state. These facts and figures can support policy reforms and frame debates about resource allocation for this population. Advocates can also use these facts to prioritize those areas that need the most immediate attention. Lastly, advocates can use these facts to support adequate and necessary ongoing funding and increasing resources in order to maintain their high quality outcomes, eliminate waiting lists, and close large institutions.

Elected officials should use this report as a guiding document on what needs time and attention and, possibly, additional resources or more inclusive state policies in order to improve outcomes for individuals with intellectual and developmental disabilities.

Those within federal and state administrations should use this report to put their work and accomplishments in context and to chart the course for the next focus area in the quest for continuous improvement and improved quality of life. The state should replicate this data reporting in more detail at the state and county level to identify areas of excellence and target critical issues needing attention.

What the Rankings Revealed – More Work Needs to Be Done but Improvements Still Being Made over the Past Year

1) All states have room to improve outcomes and services for individuals with intellectual and developmental disabilities and must be particularly vigilant in the current economic climate.

2) Too many Americans with intellectual and developmental disabilities still do not live in the community, although real and notable progress have been made over the last year:

- Now four states (up from two just two years ago) have more than 95 percent of individuals served living in home-like settings (at home, in their family's home or in settings with three or fewer residents) – Arizona, Nevada, New Hampshire and Vermont.
- An impressive 22 states – up three from last year and an increase just 16 states in 2007 - have more than 80 percent of those served living in home-like settings.
- Positively, there are 1,140 fewer Americans living in large state institutions (more than 16 beds). However, there still remain 168 large state institutions (only one closed since last year's report) housing 35,035 Americans. From 2005 to 2008, 4,063 fewer Americans were living in these large state institutions marking real –but unfortunately slow - progress.
- Now 10 states (up from nine last year) report more than 2,000 residents living in large public or private institutions – California, Florida, Illinois, Mississippi, New Jersey, New York, North Carolina, Ohio, Pennsylvania & Texas.
- Overall, the number of Americans with intellectual and developmental disabilities living in large institutions (more than 16 beds, public or private) has decreased an impressive 8,113 from 2005 to 2008, with 57,462 still living in these institutions. Inclusion is still the trend, significantly so in some states, as noted below.
- The number of Americans with intellectual and developmental disabilities served in their own home or in a family home has skyrocketed by about 70,300 (to 704,500 in 2008 from 634,200 three years prior).
- Nine states – Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia, and the District of Columbia - have no large state institutions. Thirteen states have only one large state facility remaining. No change since last year.

3) Certain states are making substantial progress toward inclusion:

From 2005 to 2008, an impressive 13 states reduced the number of Americans living in large institutions by 20 percent or more – Washington (-91%), Minnesota (-50%), Wisconsin (-46%), Oregon (-42%), Indiana (-37%), Nevada (-36%), Wyoming (-32%), Kentucky (-29%), Maryland (-29%), Louisiana (-23%), Maine (-22%), West Virginia (-20%) and Delaware (-20%). This is in addition of the 4 states and Washington, D.C. reporting no individuals living in large institutions – Alaska, Hawaii, New Mexico and Vermont.

4) Too much money is still spent isolating people in large institutions, with nominal change from last year:

- Nationally, 15.6 percent (down from 19 percent in three years) of those living in institutions consume 36 percent of all Medicaid funding spent on those with intellectual and developmental disabilities.
- Eleven states – Alaska, Arizona, Colorado, Hawaii, Maryland, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, and Vermont-- direct more than 90 percent of all related funds to those living in the community rather than in large institutions.
- Nationally, 28 states direct more than 80 percent of all related funding to those living in the community.

5) Waiting list have increased dramatically overall, but performance is quite mixed by state. Most states are not serving all those in need:

- Overall the number of Americans with intellectual and development disabilities on waiting lists for residential services has increased 56 percent from 2005 to 2008 (to 115,000 from 74,000).
- Only seven states – California, D.C., Hawaii, Idaho, Massachusetts, Rhode Island, and Vermont - report maintaining a waiting list with no one waiting for residential services.
- Yet, eighteen states report having a residential services waiting list so large that their programs would have to grow by at least 25 percent to accommodate the need.
- There is a real divide among states – those meeting the need and those documenting the unmet need through a waiting list.

It is important to note that a state may have improved in some specific categories but may drop in the overall ranking. This is primarily due to two factors: 1) A state's performance may have not improved as greatly as the national average and this would cause that state to fall in relation to other states as a whole. 2) A state may improve in one area but decline in another area. The weighted impact of that mixed performance may cause a state to fall in the rankings as well.

How the Rankings Were Developed

These rankings were developed through a broad, data-driven effort. Demographic, cost, utilization, key data elements, and outcomes statistics were assembled for all 50 states and the District of Columbia. Ninety-nine individual data elements from numerous governmental non-profit and advocacy organizations were reviewed. Dozens of Medicaid, disability and intellectual and developmental disability policy experts, were consulted as well as members of national advocacy and research organizations. They were asked to consider the attributes of top performing Medicaid programs and offer opinions and recommendations on the project in general.

To comprehensively determine the top-performing states, a weighted scoring methodology was developed. Twenty key outcome measures and data elements were selected and individually scored in five major categories on a total 100-point scale. If a person is living in the community, it is a key indicator of inclusion; therefore the "Promoting Independence" category received a majority of the points, as noted in the table on page 10.

In general, the top-performing state for each measure was assigned the highest possible score in that category. The worst-performing state was assigned a zero score in that category. All other states were apportioned accordingly based on their outcome between the top and worst-performing.

As noted, most data is from 2008, but all data is the most recent available from credible national sources. Therefore, these state rankings are a snapshot in time. Changes and reforms enacted or beginning in 2009 or later have not been considered. When reviewing an individual state's ranking, it is important to consider action taken since 2008, if any, to accurately understand both where that state was and where it is presently. Also, it is important to note that not all individuals with disabilities were considered. To limit the scope of the effort and to focus subsequent initiatives on meaningful, achievable improvement, only individuals with intellectual and developmental disabilities served were considered.

A note of caution: Although over 60 points separate the top performing state from the poorest performing state, less than 12 points separate the top ten states, about 19 points separate the top 25 states but only 10 points separate the 25 states in the middle. Therefore, minor changes in state policy or outcomes could significantly affect how a state ranks on future or past ***Case for Inclusion*** reports.

Movers and Shakers

More than the change from year to year, it is important to look at trends over time. Twenty-one states shifted at least six places in the rankings from 2007 to 2010 Case for Inclusion rankings. As previously noted, the variation in scoring among most states is very small. Therefore, small changes in outcomes can mean a significant change in rankings.

In total, 21 states had a sizable change in rankings over last four years. These states include:

State	*2010*	*2009*	*2008*	*2007*	*Change from 2007 to 2010* *(positive=improved)*
Alaska	27	3	3	2	-25
Delaware	30	13	14	14	-16
Florida	37	18	16	18	-19
Georgia	17	31	32	30	13
Idaho	16	15	18	25	9
Indiana	44	42	41	37	-7
Iowa	33	39	39	39	6
Kentucky	31	38	38	40	9
Maryland	18	32	33	33	15
Missouri	25	29	28	41	16
Nevada	13	34	34	27	14
New Hampshire	3	4	9	11	8
Oklahoma	41	30	36	35	-6
Pennsylvania	15	16	15	29	14
Rhode Island	38	19	27	28	-10
South Carolina	35	17	17	15	-20
Utah	46	37	37	36	-10
Washington	4	25	20	20	16
West Virginia	22	23	24	16	-6
Wisconsin	20	22	23	31	11
Wyoming	29	28	25	17	-12

Why? The answer is different for each state.

Alaska- dropped so dramatically due to the number of people being served in a family home was previously estimated (by the state) at over 3,000 but for this year was reported as actually being just 79. This dramatic change illustrates the problems with using estimated data compared with hard facts.

Delaware – dropped primarily due to the state no longer participating in a national quality assurance effort. Delaware in the past participated in the National Core Indicators quality assurance program.

Florida – similar to Delaware, Florida dropped as a result on no longer participating in a national quality assurance effort. Florida in the past participated in the Council on Quality and Leadership program.

Georgia – improved almost in most areas by serving more individual in home-like settings and directed more resources to the community. Georgia also added a Medicaid Buy-in program.

Idaho - directed more people and resources to the community. Idaho also added a Medicaid Buy-in program.

Indiana – dropped due to the large increase in the number of individuals served in residential setting with 7-15 individuals and a large reduction in the number served in settings with fewer than 7 residents. Also, the percent of individuals in competitive employment dropped by more than half – to 22% in 2006 from 48% in 2004.

Iowa – improved due to its participation in a national quality assurance effort, the Council on Quality and Leadership program for numerous Iowa agencies.

Kentucky – improved performance in almost every measure – dramatically increased the portion of residents served in home-like settings to 90% from 83% and added a Medicaid Buy-in program.

Maryland – improved dramatically due to serving more people in the community and directing more resources to the community, began having private agencies participating in the Council on Quality and Leadership quality assurance program, and added a Medicaid Buy-in program.

Missouri – improved dramatically as a result of a striking increase in the portion of resources being directed at community services (to 82% in 2008 from 50% in 2005) and beginning to participate in a noteworthy quality assurance program, the National Core Indicators.

Nevada – improved as a result of an impressive increase in the portion of resources being directly at community services (to 86% in 2008 from 68% in 2005) and having providers begin to participate in a noteworthy quality assurance program, the Council on Quality and Leadership.

New Hampshire – improved due to beginning to participate in a noteworthy quality assurance program, the National Core Indicators, and a drop in the number of individuals served having a reported abuse complaint

Oklahoma – dropped as a result of serving fewer people in home-like settings (from 75% of those served in 2005 to just 68% in 2008) and an increase of 2,700 people on their waiting list

Pennsylvania – improved dramatically due to substantial improvement in several areas including a significant increase in the number of individuals served (to 55,000 from less than 30,000), a substantial shift in more individual in community settings (less than 7 residents per setting, to 92% from 85%), a drop in population in large settings of 350, the closure of one state institution, and a reduction in its waiting lists

Rhode Island – dropped as a result of no longer participating in a quality assurance program, the National Core Indicators, but, positively, did add a Medicaid Buy-in program

South Carolina – dropped as a result of no longer participating in a quality assurance program, the National Core Indicators, but, positively, are directing more resources to the community (to 73% in 2008 from 55% in 2005)

Utah – dropped as a result of no longer participating in a quality assurance program, the Council on Quality and Research

Washington – improved in the rankings as started reporting the size of their waiting list and its being relatively small

West Virginia – dropped in rankings mostly due to not keeping pace with the rest of the country

Wisconsin – improved in rankings due to a substantial increase in the number and overall portion of individuals served in the community and a higher share of spending directed toward community services.

Wyoming – dropped in ranking as a result of modest change in overall score among a group of tightly clustered states.

Subrankings of States in Four Key Outcomes And Data Elements

Allocating Resources to Those in the Community (Non-ICF-MR)

% of ID/DD Expenditures on non-ICF-MR		Rank
100%	Alaska	1
99%	Vermont	2
99%	New Hampshire	3
99%	Michigan	4
98%	Oregon	5
98%	Arizona	6
97%	Rhode Island	7
95%	Colorado	8
94%	Hawaii	9
94%	New Mexico	10
93%	Maryland	11
90%	Minnesota	12
90%	Montana	13
89%	Alabama	14
88%	California	15
87%	Kansas	16
86%	Nevada	17
86%	Wisconsin	18
86%	Wyoming	19
84%	Maine	20
84%	Georgia	21
84%	South Dakota	22
83%	West Virginia	23
82%	Missouri	24
82%	Connecticut	25
82%	Massachusetts	26
82%	Washington	27
82%	Delaware	28
80%	Florida	29
78%	Pennsylvania	30
78%	Idaho	31
75%	Ohio	32
75%	Nebraska	33
75%	Oklahoma	34
75%	Tennessee	35
74%	Dist. of Columbia	36
73%	Indiana	37
73%	South Carolina	38
72%	Utah	39
70%	Kentucky	40
70%	New York	41
70%	Virginia	42
70%	North Carolina	43
66%	North Dakota	44
66%	Arkansas	45
63%	Iowa	46
61%	Illinois	47
61%	New Jersey	48
59%	Texas	49
53%	Louisiana	50
30%	Mississippi	51
77%	US Average	

Supporting Individuals in the Community and Home-like Settings

% Living in Settings with 1-3 Residents		Rank
98%	Nevada	1
98%	Vermont	2
95%	Arizona	3
95%	New Hampshire	4
93%	Idaho	5
90%	California	6
90%	Kentucky	7
89%	Washington	8
89%	New Mexico	9
89%	Alaska	10
88%	Hawaii	11
87%	Georgia	12
85%	West Virginia	13
85%	Colorado	14
81%	Delaware	15
81%	New Jersey	16
81%	Florida	17
81%	Ohio	18
80%	South Carolina	19
80%	Maryland	20
80%	Tennessee	21
80%	Montana	22
79%	Alabama	23
79%	Oregon	24
79%	Virginia	25
78%	North Carolina	26
78%	Michigan	27
78%	Massachusetts	28
77%	Missouri	29
76%	Iowa	30
76%	Utah	31
74%	Connecticut	32
73%	Maine	33
73%	New York	34
72%	Kansas	35
71%	Louisiana	36
71%	Indiana	37
69%	Pennsylvania	38
68%	Oklahoma	39
67%	North Dakota	40
67%	Nebraska	41
66%	Wisconsin	42
66%	Dist. of Columbia	43
65%	South Dakota	44
65%	Minnesota	45
63%	Texas	46
62%	Rhode Island	47
59%	Wyoming	48
54%	Arkansas	49
50%	Illinois	50
44%	Mississippi	51
81%	US Average	

Keeping Families Together through Family Support

Families Supported with Family Support per 100k of Population		Rank
537	New Mexico	1
348	New Hampshire	2
309	Arizona	3
308	Montana	4
261	South Dakota	5
228	Alaska	6
228	New Jersey	6
227	Connecticut	8
224	California	9
216	Massachusetts	10
216	New York	10
214	Vermont	12
213	Hawaii	13
211	South Carolina	14
206	Delaware	15
199	Wisconsin	16
199	Wyoming	16
185	Pennsylvania	18
181	Louisiana	19
157	Minnesota	20
139	Maryland	21
139	Mississippi	21
131	Oklahoma	23
129	Kansas	24
129	Missouri	24
123	West Virginia	26
117	Washington	27
113	Florida	28
113	Michigan	28
105	Ohio	30
105	Tennessee	30
103	Nevada	32
100	Texas	33
95	North Dakota	34
87	Illinois	35
76	Georgia	36
74	Colorado	37
69	Rhode Island	38
67	Iowa	39
66	Indiana	40
62	Alabama	41
52	Utah	42
50	Idaho	43
49	North Carolina	44
42	Kentucky	45
41	Maine	46
38	Virginia	47
35	Oregon	48
32	Nebraska	49
28	Arkansas	50
0	Dist. of Columbia	51
144	US Average	

Supporting Meaningful Work

% in Supportive or Competitive Employment		Rank
77%	Oklahoma	1
61%	Washington	2
51%	Connecticut	3
48%	Vermont	4
45%	Louisiana	5
44%	Massachusetts	6
38%	Maryland	7
38%	Pennsylvania	7
35%	Alaska	9
35%	Colorado	9
34%	New Mexico	11
34%	Oregon	11
32%	Utah	13
30%	South Dakota	14
29%	Nebraska	15
29%	New Hampshire	15
28%	Iowa	17
26%	Delaware	18
26%	Georgia	18
24%	Michigan	20
23%	Virginia	21
22%	Florida	22
22%	Indiana	22
22%	Ohio	22
21%	Kentucky	25
21%	Maine	25
21%	Wyoming	25
20%	Rhode Island	28
20%	Tennessee	28
20%	Texas	28
19%	North Carolina	31
16%	Nevada	32
16%	Wisconsin	32
15%	Idaho	34
15%	Minnesota	34
15%	Mississippi	34
15%	North Dakota	34
14%	Arizona	38
14%	Montana	38
14%	New Jersey	38
13%	California	41
13%	Illinois	41
12%	New York	43
12%	South Carolina	43
11%	West Virginia	45
10%	Dist. of Columbia	46
10%	Kansas	46
9%	Missouri	48
8%	Hawaii	49
5%	Alabama	50
2%	Arkansas	51
21%	US Average	

States' Ranking of Medicaid for Americans with Intellectual and Developmental Disabilities

Best performing state ranks #1

State	*2010*	*2009*	*2008*	*2007*
Alabama	32	33	31	32
Alaska	27	3	3	2
Arizona	1	2	1	1
Arkansas	50	50	46	46
California	5	7	5	5
Colorado	9	9	7	8
Connecticut	8	10	10	6
Delaware	30	12	14	14
Dist. of Columbia	47	48	48	49
Florida	37	18	16	18
Georgia	17	31	32	30
Hawaii	10	8	8	12
Idaho	16	15	18	25
Illinois	48	47	49	47
Indiana	44	42	41	37
Iowa	33	39	39	39
Kansas	23	24	23	22
Kentucky	31	38	38	40
Louisiana	40	46	45	44
Maine	28	35	30	24
Maryland	18	32	33	33
Massachusetts	6	5	4	4
Michigan	7	6	6	9
Minnesota	12	13	12	7
Mississippi	51	51	51	51
Missouri	25	29	28	41
Montana	21	27	26	19
Nebraska	39	44	42	43
Nevada	13	34	34	27
New Hampshire	3	4	9	11
New Jersey	24	21	22	23
New Mexico	11	11	11	13
New York	14	14	13	10
North Carolina	34	36	35	34
North Dakota	36	40	43	38
Ohio	43	45	44	48
Oklahoma	41	30	36	35
Oregon	19	20	19	21
Pennsylvania	15	16	15	29
Rhode Island	38	19	27	28
South Carolina	35	17	17	15
South Dakota	26	26	29	26
Tennessee	45	43	40	42
Texas	49	49	50	50
Utah	46	37	37	36
Vermont	2	1	2	3
Virginia	42	41	47	45
Washington	4	25	21	20
West Virginia	22	23	20	16
Wisconsin	20	22	24	31
Wyoming	29	28	25	17

Scoring of States

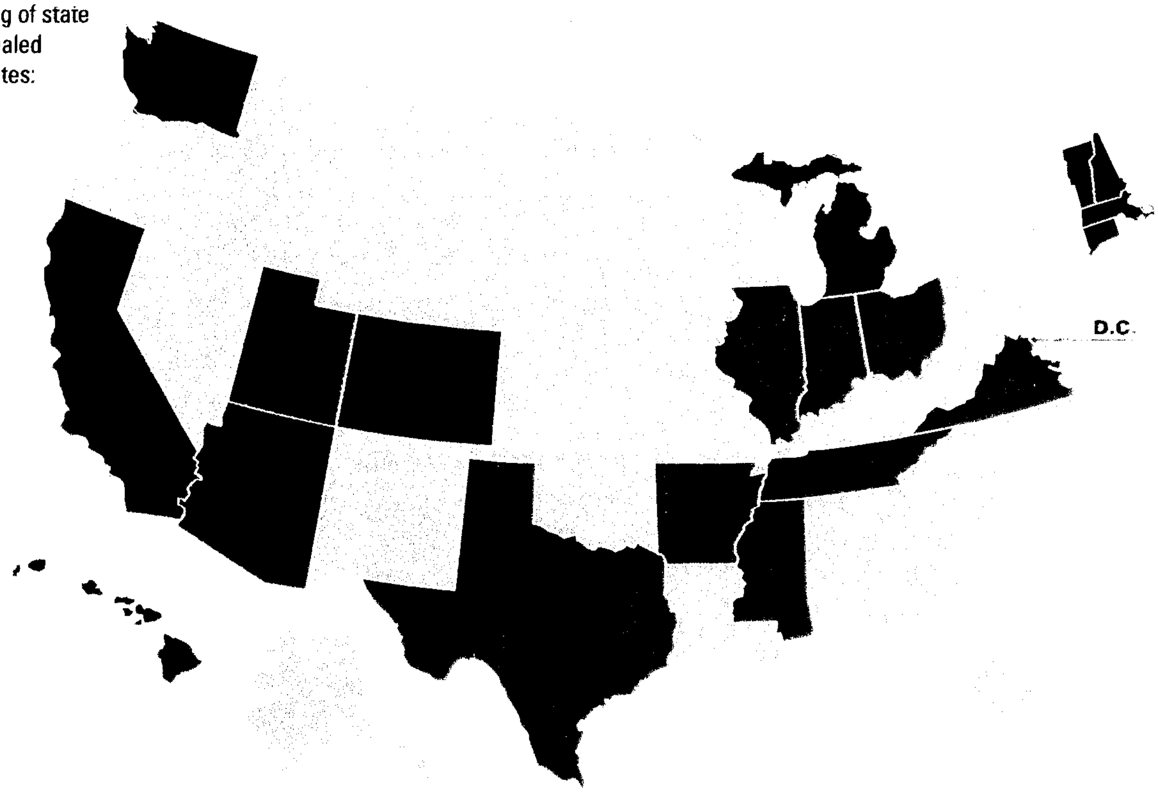
Map of Best and Worst Performing States

The results of this scoring of state Medicaid programs revealed the following Top Ten states:

1. **Arizona**
2. **Vermont**
3. **New Hampshire**
4. **Washington**
5. **California**
6. **Massachusetts**
7. **Michigan**
8. **Connecticut**
9. **Colorado**
10. **Hawaii**

. . .and Bottom Ten:

42. **Virginia**
43. **Ohio**
44. **Indiana**
45. **Tennessee**
46. **Utah**
47. **Dist. of Columbia**
48. **Illinois**
49. **Texas**
50. **Arkansas**
51. **Mississippi**



Facts about the Top Ten States

Further examining the top 10 states shows that a state does not need to look a certain way in order to best serve individuals with intellectual and developmental disabilities through Medicaid.

What matters is how a state acts and what is achieved.

In fact, the top 10 states are quite diversified. Consider these facts about the top ten states:

Large and Small Population

- Includes the most populous - California (#1), and Michigan (#8) – as well as the least populous states –Hawaii (#42), New Hampshire (#41) and Vermont (#49)

Rich and Poor

- Includes some of the wealthiest states in median household income –Connecticut (#4), Hawaii (#5), Massachusetts (#9) and New Hampshire (#1)– and less affluent states – Arizona (#33) and Michigan (#25)

High and Low Tax

- Includes high tax burden states – Connecticut (#9), Hawaii (#7), and Vermont (#1) – and low tax burden states –Arizona (#32), Colorado (#31), Massachusetts (#29), and New Hampshire (#50)

High and Low Spenders (spending per individual with intellectual and developmental disabilities served)

- Includes states with some of the highest spending per person served by the HCBS waiver – Connecticut (#10), Massachusetts (#10), and Vermont (#13)– as well as some that spend considerably less –Arizona (#45), California (#50), Colorado (#31), Hawaii (#33) and Washington (#38)

Ranking Methodology

Major Category	***Data Element***		***Weight***	***Total Weight of all Measures in the Category***
Promoting Independence	Community-based	Percent of recipients with ID/DD on HCBS	9	24
		Percent of ID/DD expenditures on HCBS	7	
		Percent of ID/DD expenditures on non-ICF-MR	8	
	Residential services in the community (includes all types)	Percent living in 1-3 residents settings	13	24
		Percent living in 1-6 residents settings	11	
		Percent living in 16+ residents settings (negative)	-4	
		Percent living in large state facilities (negative)	-3	
	Waivers promoting self-determination		2	2
Tracking Quality and Safety	Noted quality assurance program		6	12
	Percent of clients with abuse or protection report		6	
Keeping Families Together	Family support per 100,000 of population		6	12
	Percent served living in a family home		6	
Promoting Productivity	Medicaid buy-in program operating		2	10
	Percent in supported or competitive employment		6.5	
	Vocational rehab	per 100k of population	1	
		Percent VR wages to state average	.25	
		Mean weekly hours worked	.25	
Reaching Those in Need	Average percent growth of program for residential and HCBS waiting list		9	16
	Individuals with ID/DD served per 100,000 of population		3	
	Ratio of prevalence to individuals served		4	
TOTAL	20 measures			100

Appendix I

Key Data on States' Medicaid Programs for Those with Intellectual and Developmental Disabilities

		Promoting Independence														
		Community-based			Residential											
	State	% of Recipients with ID/DD on HCBS	% of ID/DD Expenditures on HCBS	% of ID/DD Expenditures on non-ICF MR	Own Home	Family Home	Family Foster Care				Congregate Care (includes ICF-MR)					
ABBR					1	1	1-3	4-6	7-15	Total	1-3	4-6	1-6	7-15	16+	Total
AL	**Alabama**	[illegible]	88%	89%	205	3,497	223	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
AK	Alaska	100%	100	100%	127	[illegible]	202	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		78
AZ	Arizona	[illegible]	98%	98%	165	25,123	971		[illegible]	[illegible]	[illegible]	195	[illegible]	[illegible]	[illegible]	[illegible]
AR	Arkansas	[illegible]	[illegible]	66%	650	1,476	[illegible]	0	16	[illegible]	196	[illegible]	[illegible]	[illegible]	12	[illegible]
CA	California	[illegible]	[illegible]	88%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
CO	Colorado	[illegible]	[illegible]	95%	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
CT	Connecticut	[illegible]	[illegible]	82%	[illegible]	1,688	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
DE	Delaware	[illegible]	[illegible]	[illegible]	16	[illegible]	162	[illegible]		162	268	[illegible]	[illegible]		[illegible]	[illegible]
DC	Dist. of Columbia	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
FL	Florida	[illegible]	[illegible]	80%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	66	[illegible]	[illegible]	[illegible]
GA	Georgia	[illegible]	[illegible]	[illegible]	[illegible]	11,263	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]
HI	Hawaii	[illegible]	[illegible]	94%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		68	[illegible]	[illegible]		[illegible]
ID	Idaho	[illegible]	[illegible]	78%	[illegible]	12,080	[illegible]	[illegible]	0	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
IL	Illinois	[illegible]	41%	61%	[illegible]	[illegible]	[illegible]	28	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
IN	Indiana	[illegible]	59	73%	[illegible]	[illegible]	283	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
IA	Iowa	86	51	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
KS	Kansas	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	53		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
KY	Kentucky	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
LA	Louisiana	[illegible]	[illegible]	[illegible]	[illegible]	10,262	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
ME	Maine	[illegible]	[illegible]	84%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
MD	Maryland	[illegible]	[illegible]	93%	[illegible]	2,390	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
MA	Massachusetts	[illegible]	[illegible]	82%	[illegible]	21,220	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
MI	Michigan	[illegible]	[illegible]	99%	5,703	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
MN	Minnesota	87	84	90%	2,020	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
MS	Mississippi	13	12	30%	87	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	131	54	[illegible]	[illegible]	[illegible]	[illegible]
MO	Missouri	[illegible]	73	82%	2,824	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	357	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
MT	Montana	[illegible]	86	[illegible]	621	[illegible]	200	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
NE	Nebraska	[illegible]	68	[illegible]	[illegible]	471	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
NV	Nevada	[illegible]	78	86%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
NH	New Hampshire	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
NJ	**New Jersey**	8	[illegible]	61%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
NM	New Mexico	[illegible]	[illegible]	[illegible]	536	1303	[illegible]	12	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
NY	New York	[illegible]	[illegible]	[illegible]	7,651	78,342	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	13,789	[illegible]	[illegible]	[illegible]
NC	North Carolina	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	82
ND	North Dakota	[illegible]	52	66%	[illegible]	715	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	39	[illegible]	[illegible]	[illegible]	[illegible]
OH	Ohio	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
OK	Oklahoma	[illegible]	[illegible]	[illegible]	1,594	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
OR	Oregon	[illegible]	[illegible]	98%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
PA	Pennsylvania	85	68	[illegible]	[illegible]	30,488	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
RI	Rhode Island	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		[illegible]	251	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
SC	South Carolina	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
SD	South Dakota	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]			[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
TN	Tennessee	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	791	[illegible]	[illegible]
TX	Texas	52	[illegible]	39	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
UT	Utah	[illegible]	[illegible]	[illegible]	[illegible]	2,015	241	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
VT	Vermont	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]
VA	Virginia	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
WA	Washington	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
WV	West Virginia	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	258	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
WI	Wisconsin	[illegible]	[illegible]	86%	[illegible]	[illegible]	[illegible]			[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
WY	Wyoming	[illegible]	[illegible]	86	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	34	[illegible]		[illegible]	[illegible]
	United States	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
	United States - Est				[illegible]	588,591	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

Source [illegible]

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Appendix I *Continued*

State	Promoting Independence														
	All Individuals by Size of Residence									Large State Facilities					
	Totals (includes own home, family home, family foster care and congregate care)									% in Large State Facilities	Residents in Large State Facilities per 100,000 population	Number of Large State Facilities	Residents of Large State Facilities	FY2008 Aver per diem	Persons with ID/DD in Non specialized Nursing Facilities
	1-3	%	4-6	1-6	%	7-15	16+	%	Total	16+					
Alabama	5,556	79%	421	5,977	85%	826	198	3%	7,001	2.8%	4.2	1	198	$167	998
Alaska	878	89%	104	982	99%	10	0	0%	992	0.0%	0	0	0	NA	[illegible]
Arizona	27,874	95%	1,190	29,064	99%	40	160	1%	29,264	0.5%	[illegible]	1	126	$520	47
Arkansas	2,741	54%	35	2,776	55%	852	1,420	28%	5,050	21.1%	[illegible]	6	1,082	$279	55
California	165,002	90%	12,365	177,367	97%	1,293	4,724	3%	183,384	1.4%	6.9	7	2,530	[illegible]	[illegible]
Colorado	7,096	85%	652	7,748	92%	543	105	1%	8,396	1.3%	2.1	[illegible]	105	$529	[illegible]
Connecticut	10,823	74%	2,570	13,393	92%	388	760	5%	14,541	5.2%	21.[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Delaware	2,508	81%	436	2,944	96%	0	138	4%	3,082	2.6	[illegible]	[illegible]	[illegible]	$412	[illegible]
Dist. of Columbia	1,294	66%	529	1,823	92%	151	0	0%	1,974	0.0%	0	0	0	NA	[illegible]
Florida	11,453	81%	5,370	16,823	92%	1,186	1,128	6%	19,137	3.2%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Georgia	14,187	87%	963	15,150	93%	0	1,070	7%	16,220	5.9%	[illegible]	[illegible]	960	[illegible]	[illegible]
Hawaii	2,883	88%	392	3,275	100%	15	0	0%	3,290	0.0%	0	0	0	NA	6
Idaho	14,995	93%	169	15,164	94%	507	483	3%	16,154	0.5%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Illinois	17,052	50%	3,663	20,715	61%	7,179	6,041	18%	33,935	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Indiana	10,804	[illegible]	1,436	12,240	80%	2,576	464	3%	15,280	0.9%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Iowa	10,748	76%	391	11,139	79%	2,070	851	6%	14,060	3.9%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Kansas	5,941	72%	1,478	7,419	89%	476	412	5%	8,307	4.3%	[illegible]	2	[illegible]	[illegible]	[illegible]
Kentucky	5,666	90%	36	5,702	90	112	499	8%	6,313	2.7%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Louisiana	12,430	71%	1,870	14,300	82%	1,275	1,906	11%	17,49[illegible]	5.6%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Maine	2,800	[illegible]	80	3,580	94	192	38	1%	3,810	0.0%	0	0	0	NA	[illegible]
Maryland	7,849	80%	1,380	9,229	95	257	279	3%	9,765	3.3%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Massachusetts	21,885	78%	8,043	29,928	94%	1,134	929	3%	31,991	2.9%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Michigan	23,679	78%	4,621	28,300	93%	1,412	666	2%	30,378	[illegible]	1.2	[illegible]	[illegible]	[illegible]	[illegible]
Minnesota	17,040	65%	8,326	25,366	96%	569	415	2%	26,350	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Mississippi	2,174	44%	81	2,255	45%	714	2,025	41%	4,994	26.3%	[illegible]	[illegible]	1,311	[illegible]	[illegible]
Missouri	11,493	77%	1,140	12,633	84%	1,131	1,195	8%	14,959	3.9%	[illegible]	[illegible]	802	[illegible]	521
Montana	3,430	80%	383	3,813	89%	402	67	2%	4,282	1.6%	6.9	[illegible]	[illegible]	[illegible]	704
Nebraska	2,481	67%	615	3,096	84%	100	501	14%	3,697	[illegible]	[illegible]	1	261	[illegible]	[illegible]
Nevada	4,611	98%	43	4,654	99%	0	69	1%	4,723	1.1%	2	2	51	$542	[illegible]
New Hampshire	2,227	95%	85	2,312	98%	19	25	1%	2,356	[illegible]	0	0	[illegible]	NA	89
New Jersey	30,570	81%	3,278	33,848	90%	855	2,971	8%	37,674	[illegible]	33.[illegible]	[illegible]	2,89[illegible]	[illegible]	[illegible]
New Mexico	3,210	89%	279	3,489	97%	121	0	0%	3,610	0.0%	0	[illegible]	[illegible]	NA	[illegible]
New York	91,042	73%	11,436	102,478	82%	18,672	3,132	3%	124,282	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
North Carolina	19,657	78%	2,549	22,206	88%	699	2,201	9%	25,106	6.6	18.[illegible]	[illegible]	[illegible]	[illegible]	300
North Dakota	1,837	67%	219	2,056	75%	501	168	6%	2,725	1.4%	16.7	[illegible]	[illegible]	[illegible]	[illegible]
Ohio	32,921	81%	1,140	34,061	84%	2,445	4,233	10%	40,739	3.7%	13.[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Oklahoma	4,760	68%	750	5,510	79%	397	1,046	15%	6,953	4.2%	8.1	[illegible]	[illegible]	$525	102
Oregon	9,626	79%	2,113	11,739	97%	331	83	1%	12,153	[illegible]	0.8	[illegible]	[illegible]	[illegible]	28
Pennsylvania	38,025	69%	12,779	50,804	92%	1,296	2,871	5%	54,971	2.3%	10.2	[illegible]	1,275	[illegible]	1,685
Rhode Island	1,918	62%	973	2,891	93%	182	23	1%	3,096	[illegible]	0	[illegible]	[illegible]	NA	13
South Carolina	14,876	80%	1,878	16,754	91%	885	841	5%	18,480	4.6%	18.8	[illegible]	841	[illegible]	[illegible]
South Dakota	2,017	65%	349	2,366	77%	559	166	5%	3,091	[illegible]	[illegible]	[illegible]	156	[illegible]	[illegible]
Tennessee	7,269	80%	355	7,624	84%	781	656	[illegible]	9,061	[illegible]	[illegible]	[illegible]	312	$962	[illegible]
Texas	8,313	63%	14,257	22,570	[illegible]	625	5,041	21%	29,23[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Utah	3,950	76%	319	4,269	82%	150	770	15%	5,189	[illegible]	8.5	[illegible]	[illegible]	[illegible]	21
Vermont	2,951	98%	55	3,006	100		0	0	3,006	0.0	0	[illegible]		NA	[illegible]
Virginia	13,038	79%	1,449	14,487	88%	564	1,420	9%	16,471	[illegible]	16.8	[illegible]	1,303	[illegible]	[illegible]
Washington	17,478	[illegible]	1,877	19,355	[illegible]	[illegible]	[illegible]	[illegible]	19,6[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	83
West Virginia	3,943	[illegible]	[illegible]	[illegible]	88%	508	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Wisconsin	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Wyoming	[illegible]	[illegible]	[illegible]	1,985	92%	97	82	4%	2,164	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
United States	[illegible]	[illegible]	[illegible]	[illegible]	89	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
United States Avg.	[illegible]	[illegible]	[illegible]	[illegible]	89	53,42[illegible]	57,462	5	[illegible]						[illegible]

Sources

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State	Promoting Independence			Ensuring Community Involvement and Safety				
	Waivers that Can Promote Self-Determination			Quality Assurance			Abuse	
	Independence Plus Waivers	Other Self Directed 1115 or 1915(c) Waiver for ID/DD	Money Follows the Person Award or Apply	Council on Quality and Leadership	National Core Indicators (HSRI)	Noteworthy State QA Initiatives	Protection and Advocacy Clients	[illegible] of all those served
Alabama				Yes	Yes		38	[illegible]
Alaska						Yes	[illegible]	[illegible]
Arizona		Yes			Yes		34	[illegible]
Arkansas		Yes	Yes		Yes		[illegible]	[illegible]
California	Yes	Yes	Yes		Yes	Yes	1,517	[illegible]
Colorado	Yes	Yes		Yes		Yes	50	[illegible]
Connecticut	Yes		Yes		Yes	Yes	15	[illegible]
Delaware	Yes		Yes				36	[illegible]
Dist. of Columbia			Yes				78	[illegible]
Florida	Yes	Yes					580	[illegible]
Georgia	Yes		Yes	Yes	Yes		36	[illegible]
Hawaii			Yes		Yes		105	[illegible]
Idaho	Yes						85	[illegible]
Illinois			Yes	Yes	Yes		106	[illegible]
Indiana			Yes	Yes	Yes		42	[illegible]
Iowa			Yes	Yes			[illegible]	
Kansas			Yes	Yes			46	[illegible]
Kentucky			Yes	Yes	Yes		59	[illegible]
Louisiana	Yes	Yes	Yes	Yes	Yes		105	[illegible]
Maine	Yes				Yes		166	[illegible]
Maryland	Yes	Yes	Yes	Yes			[illegible]	[illegible]
Massachusetts	Yes				Yes		136	[illegible]
Michigan	Yes	Yes				Yes	35	[illegible]
Minnesota		Yes		Yes		Yes	149	[illegible]
Mississippi							162	[illegible]
Missouri	Yes		Yes	Yes	Yes		113	[illegible]
Montana	Yes						35	[illegible]
Nebraska			Yes	Yes			[illegible]	[illegible]
Nevada				Yes			117	[illegible]
New Hampshire		Yes			Yes	Yes	16	[illegible]
New Jersey	Yes	Yes	Yes	Yes	Yes		130	[illegible]
New Mexico				Yes	Yes	Yes	250	[illegible]
New York		Yes	Yes	Yes	Yes	Yes	35	[illegible]
North Carolina	Yes		Yes	Yes	Yes		44	[illegible]
North Dakota	Yes	Yes	Yes	Yes			40	[illegible]
Ohio	Yes		Yes	Yes	Yes		916	[illegible]
Oklahoma			Yes		Yes		337	[illegible]
Oregon		Yes	Yes				[illegible]	[illegible]
Pennsylvania			Yes	Yes	Yes	Yes	1,127	[illegible]
Rhode Island							13	
South Carolina	Yes						[illegible]	[illegible]
South Dakota				Yes	Yes		63	[illegible]
Tennessee							76	[illegible]
Texas			Yes	Yes	Yes		[illegible]	[illegible]
Utah							236	[illegible]
Vermont		Yes			Yes	Yes	56	[illegible]
Virginia			Yes				46	[illegible]
Washington			Yes		Yes		[illegible]	[illegible]
West Virginia					Yes		156	[illegible]
Wisconsin			Yes	Yes		Yes	15	[illegible]
Wyoming					Yes	Yes	114	[illegible]
United States	19	15	28	24	28	13	[illegible]	
United States - Est								
Source	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	
Table / Page			[illegible]	[illegible]		[illegible]	[illegible]	
Year of Data	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	

Appendix I *Continued*

State	Keeping Families Together								
	Family Support				Cash Subsidy		Other Family SSI		
	Families	Spending	Spending per Family	Families Supported per 100k of Population	Families	Spending per Family	Families	Spending per Family	Individuals Living in Family Home
Alabama	2,800	$ 648,389	$ 232	62	0	N/A	2,800	$ 232	50%
Alaska	1,516	$ 1,668,000	$ 1,100	228	1,516	$ 1,000	0	$ [illegible]	[illegible]
Arizona	18,361	$ 213,935,759	$ 11,652	309	573	$ 1,826	17,788	$ 11,968	86%
Arkansas	790	$ 578,10[illegible]	$ 732	29	92	$ 1,555	698	$ 623	29%
California	31,096	$ 157,010,816	$ 5,389	320	0	N/A	31,096	$ 5,389	[illegible]
Colorado	3,432	$ 6,235,187	$ 1,817	74	0	N/A	3,432	$ 1,817	75%
Connecticut	7,984	$ 45,121,283	$ 5,651	227	4,525	$ 931	3,459	$ 9,384	53%
Delaware	1,735	$ 1,657,[illegible]	$ 955	206	126	$ 1,850	1,255	$ 82[illegible]	67%
Dist. of Columbia	0	$	$		0	N/A	0	N/A	34%
Florida	20,035	$ 321,925,659	$ 16,068	113	210	$ 2,257	19,825	$ 16,21[illegible]	[illegible]
Georgia	6,801	$ 23,244,49[illegible]	$ 3,418	76	0	N/A	6,801	$ 3,418	69%
Hawaii	2,739	$ 31,276,613	$ 11,419	217	0	N/A	2,739	$ 11,419	66%
Idaho	709	$ 302,723	$ 427	60	0	N/A	709	$ 427	75%
Illinois	11,114	$ 62,531,939	$ 5,626	87	2,611	$ 1,581	8,503	$ [illegible]	[illegible]
Indiana	4,130	$ 28,515,681	$ 6,905	66	0	N/A	4,130	$ 6,905	30%
Iowa	2,002	$ 30,565,329	$ 15,267	67	378	$ 1,23[illegible]	1,624	$ 17,831	37%
Kansas	3,549	$ 43,291,821	$ 12,198	129	1,418	$ 2,406	2,131	$ 18,712	32%
Kentucky	1,735	$ 3,324,247	$ 1,916	42	0	N/A	1,735	$ 1,916	38%
Louisiana	8,211	$ 118,768,849	$ 14,465	181	1,705	$ [illegible]	6,506	$ [illegible]543	39%
Maine	545	$ 1,100,000	$ 2,018	[illegible]	545	$ [illegible]	[illegible]	$ [illegible]	[illegible]
Maryland	7,846	$ 38,235,667	$ 4,873	159	0	N/A	7,846	$ 4,873	23%
Massachusetts	4,113	$ 38,711,80[illegible]	$ 2,[illegible]	216	0	N/A	4,113	$ 2,[illegible]	56%
Michigan	11,539	$ 54,108,014	$ 4,689	113	6,722	$ 2,620	4,817	$ 576	[illegible]
Minnesota	8,185	$ 182,768,480	$ 22,33[illegible]	15[illegible]	2,346	$ [illegible]	5,839	$ 19,0[illegible]	50%
Mississippi	4,052	$ 20,615,920	$ 5,093	139	0	N/A	4,052	$ 5,093	33%
Missouri	7,463	$ 13,531,785	$ 1,813	129	0	N/A	7,463	$ 1,813	55%
Montana	2,885	$ 11,066,166	$ 3,836	308	0	N/A	2,885	$ 3,836	56%
Nebraska	566	$ 4,634,959	$ 8,189	32	0	N/A	566	$ 8,189	[illegible]
Nevada	2,451	$ 6,640,537	$ 2,709	103	454	$ 1,136	1,997	$ 2,385	56%
New Hampshire	4,605	$ 6,881,345	$ 1,494	348	0	N/A	4,605	$ 1,494	23%
New Jersey	20,013	$ 59,123,073	$ 2,954	228	7,851	$ 1,329	12,162	$ 3,874	[illegible]
New Mexico	10,262	$ 34,058,910	$ 3,319	537	164	$ 3,468	10,098	$ 3,317	36%
New York	41,571	$ 56,317,000	$ 1,355	216	0	N/A	41,571	$ 1,355	63%
North Carolina	4,255	$ 27,304,416	$ 6,417	49	0	N/A	4,255	$ 6,417	58%
North Dakota	604	$ 5,607,743	$ 9,282	95	142	$ 3,27[illegible]	462	$ 10,823	26%
Ohio	12,067	$ 10,182,128	$ 869	105	0	N/A	12,067	$ 869	[illegible]
Oklahoma	4,615	$ 43,682,678	$ 9,465	133	2,077	$ 2,394	2,538	$ 16,253	39%
Oregon	1,275	$ 4,554,818	$ 3,572	35	0	N/A	1,275	$ 3,572	53%
Pennsylvania	22,990	$ 61,882,837	$ 2,822	185	0	N/A	22,990	$ 2,822	55%
Rhode Island	753	$ 10,343,464	$ 13,736	69	50	$ 3,402	703	$ 14,47[illegible]	76%
South Carolina	8,989	$ 34,606,072	$ 3,850	211	1,151	$ 2,809	7,838	$ 4,003	74%
South Dakota	2,019	$ 3,161,365	$ 1,566	264	0	N/A	2,019	$ 1,566	26%
Tennessee	6,285	$ 11,563,100	$ 1,840	105	2,018	N/A	4,267	$ 1,796	40%
Texas	22,980	$ 50,174,833	$ 2,183	100	2,674	$ 1,870	20,306	$ 2,225	[illegible]
Utah	1,268	$ 14,548,828	$ 11,474	52	5	$ 3,181	1,263	$ 11,50[illegible]	59%
Vermont	1,354	$ 15,819,422	$ 11,683	231	0	N/A	1,354	$ [illegible]	[illegible]
Virginia	2,917	$ 2,480,413	$ 850	38	0	N/A	2,917	$ 850	58%
Washington	7,292	$ 38,577,20[illegible]	$ [illegible]	[illegible]	3,51[illegible]	$ 2,0[illegible]	4,302	$ [illegible]	[illegible]
West Virginia	2,232	$ 20,057,794	$ 8,986	123	0	N/A	2,232	$ 8,986	58%
Wisconsin	11,064	$ 23,235,49[illegible]	$ 2,10[illegible]	192	0	N/A	11,064	$ 2,10[illegible]	[illegible]
Wyoming	1,010	$ 13,037,112	$ 12,908	199	0	N/A	1,010	$ 12,908	33%
United States	438,80[illegible]	$ [illegible]	$ [illegible]	[illegible]	40,886	$ [illegible]	393,685	$ [illegible]	[illegible]
United States - Est									

Source: [illegible]

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Year of Data [illegible]

16580

Promoting Productivity

State	Medicaid Buy-In		Supported or Competitive Employment				Voc Rehab			
	Has?	Enrollment 12/08	Participants	Utilization	Spending	-	Total Number in Competitive Employment	per 100k of population	% VR Wages to State Avg	Mean Weekly Hours Worked
Alabama			215	5	$ 2,101,982	5%	7,553	163	70%	33
Alaska	Yes	239	316	48	$ 3,812,415	55%	568	86	65	33
Arizona	Yes	4944	1,138	19	$ 5,738,945	[illegible]	1,925	30	56	33
Arkansas	Yes	17	130	[illegible]	$ 368,882	2%	2,11[illegible]	8	51	36
California	Yes	5,303	8,302	23	$ 62,219,000	15%	13,880	38	49%	32
Colorado			1,982	43	DNA	35%	2,611	54	51%	31
Connecticut	Yes	4,940	3,061	116	$ 61,055,054	51%	1,335	42	67%	33
Delaware			373	14	$ 1,461,695	26%	905	105	15	33
Dist. of Columbia			151	28	$ 3,080,477	10%	576	98	13%	38
Florida			5,156	30	$ 9,009,[illegible]	12%	12,316	67	43%	31
Georgia	Yes		3,202	36	$ 14,897,715	26%	4,668	[illegible]	50%	34
Hawaii			111	9	$ 496,800	8%	589	48	62%	31
Idaho	Yes		898	63	$ 3,356,575	15%	2,083	138	62%	33
Illinois	Yes	647	3,518	28	$ 19,662,872	11%	5,640	45	42%	30
Indiana	Yes	4,609	2,317	37	$ 13,062,679	22%	4,393	70	58%	32
Iowa	Yes	12,376	2,825	95	$ 5,611,855	28%	2,346	[illegible]	64%	32
Kansas	Yes	1080	408	15	$ 1,965,000	30%	1,643	61	51%	30
Kentucky	Yes		1,164	28	$ 2,883,581	21%	3,949	117	50%	34
Louisiana	Yes	1032	1,641	36	$ 8,144,098	45%	[illegible]	61	83%	36
Maine	Yes	850	1,001	76	$ 3,442,578	21%	730	56	51	28
Maryland	Yes	530	3,564	63	$ 47,467,713	38%	2,390	42	17%	31
Massachusetts	Yes	6,476	4,769	80	$ 6,990,802	14%	3,446	54	46%	28
Michigan	Yes	1141	4,554	44	$ 25,130,550	24%	7,543	76	57%	32
Minnesota	Yes	7,205	2,940	57	$ 13,161,136	15%	2,620	52	69%	29
Mississippi	Yes		400	14	$ 1,068,841	15%	4,553	157	[illegible]	36
Missouri	Yes		368	6	$ 1,917,211	[illegible]	4,365	[illegible]	[illegible]	31
Montana	Yes		235	25	$ 1,744,979	14%	913	96	56%	30
Nebraska	Yes	109	1,018	58	$ 1,625,561	29%	1,54[illegible]	[illegible]	[illegible]	33
Nevada	Yes	20	288	12	$ 2,871,686	16%	1,060	41	53%	33
New Hampshire	Yes	1,391	324	25	$ 1,307,676	29%	1,213	[illegible]	51	29
New Jersey	Yes	3,232	1,363	16	$ 10,643,135	14%	3,385	51	44%	32
New Mexico	Yes	419	1,221	64	$ 8,533,696	34%	1,697	85	64%	32
New York	Yes		8,265	43	$ 15,547,000	12%	13,236	69	56%	31
North Carolina	Yes	20	1,854	21	$ 9,209,328	9%	6,442	70	48%	32
North Dakota	Yes	526	306	48	$ 2,121,796	15%	903	140	66%	33
Ohio	Yes		9,526	85	$ 12,946,000	32%	[illegible]	45	59%	33
Oklahoma			3,029	86	$ 23,408,414	7%	2,249	64	51%	36
Oregon	Yes	1063	1,264	35	$ 15,358,399	14%	2,444	65	78	31
Pennsylvania	Yes	9,002	9,118	3	$ 30,587,914	38%	7,321	75	56%	33
Rhode Island	Yes	2	622	[illegible]	$ 3,749,529	20%	[illegible]	[illegible]	52%	28
South Carolina	Yes		847	20	$ 5,832,103	12%	5,667	126	55%	36
South Dakota	Yes	101	675	87	$ 1,827,[illegible]	30%	567	109	56	[illegible]
Tennessee			1,211	20	$ 7,418,800	20%	2,984	51	57%	37
Texas	Yes	[illegible]	2,956	13	$ [illegible]4,446,292	29%	[illegible]	[illegible]	[illegible]	35
Utah	Yes	639	735	30	$ 3,196,124	12%	[illegible]	122	64	33
Vermont	Yes	624	931	131	$ 212,383	8%	1,523	197	58%	29
Virginia	Yes	22	2,464	37	$ 11,670,027	23%	3,017	[illegible]	52%	33
Washington	Yes	1790	3,130	66	$ 26,376,698	31%	[illegible]	30	49	38
West Virginia	Yes	803	417	23	$ 1,012,567	11%	1,773	99	58%	33
Wisconsin	Yes	13,150	2,736	49	$ 16,450,720	26%	[illegible]	64	72	29
Wyoming	Yes	107	250	49	$ 2,125,386	21%	690	134	58%	32
United States	43	53,124	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	
United States - Est.		100,000								

Source [illegible]

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Year of Data [illegible]

Appendix I *Continued*

State	Reaching Those in Need: Waiting Lists — Waiting List for Residential Services	% Growth in Residential Services Required to Meet Waiting List	Waiting List ID/DD HCBS Kaiser	% Growth in HCBS Services Required to Meet Waiting List	Waiting List Average	Prevalence — % Children with Mental Disability	% Adults with Mental Disability	Individuals w/ ID/DD served per 100k of population	Ratio of Prevalence to Individuals Served
Alabama	136	12%	NA	NA	12%	6.1%	6.8%	159	[illegible]
Alaska	[illegible]	68%	1,500	145%	106%	4.5	5.2%	156	[illegible]
Arizona	80	2%	NA	NA	2%	4.6%	4.1%	353	[illegible]
Arkansas	870	21%	870	26%	25%	6%	7%	180	[illegible]
California	[illegible]	[illegible]	NA	NA	[illegible]	3.6%	[illegible]	504	2%
Colorado	1,390	30%	NA	NA	30%	3.5%	[illegible]	[illegible]	[illegible]
Connecticut	560	8%	1,730	22%	15%	[illegible]	[illegible]	122	[illegible]
Delaware	180	18%	NA	NA	18%	6.0%	[illegible]	358	[illegible]
Dist. of Columbia	0	0%	NA	NA	0%	6.8%	3.3%	33	[illegible]
Florida	5,683	31%	22,639	73%	52%	[illegible]	4.6	28	6%
Georgia	6,393	29%	10,364	101	15%	[illegible]	[illegible]	[illegible]	[illegible]
Hawaii	[illegible]	0%	NA	NA	0%	3.3	[illegible]	266	8
Idaho	0	0%	NA	NA	0%	5.0%	5.1%	1,073	21%
Illinois	10,446	19%	NA	NA	19%	4.6	[illegible]	368	[illegible]
Indiana	17,919	168%	35,753	334%	251%	5.9%	4.9%	244	[illegible]
Iowa	90	1%	1,646	13%	[illegible]	5.5	4.8%	172	10%
Kansas	1,163	21%	1,631	22%	22%	5.1%	4.5%	307	[illegible]
Kentucky	293	[illegible]	2,753	89%	18%	[illegible]	5%	149	2
Louisiana	DNF	DNF	9,151	133%	133%	6.6%	6.3%	411	[illegible]
Maine	59	2%	98	3%	3%	[illegible]	6.8%	291	[illegible]
Maryland	10,743	146%	NA	NA	146%	5.2%	[illegible]	176	5%
Massachusetts	[illegible]	0	NA	NA	0%	5.8%	4.4%	502	11
Michigan	45	0%	NA	NA	[illegible]	6.4%	5.6%	308	[illegible]
Minnesota	2,640	20%	NA	NA	20%	4.9%	[illegible]	312	[illegible]
Mississippi	DNF	DNF	NA	NA	DNF	6.1%	7.2%	173	[illegible]
Missouri	469	[illegible]	NA	NA	[illegible]	5.9%	5.8%	257	[illegible]
Montana	190	26%	1,372	61%	43%	5.3%	5.4%	139	[illegible]
Nebraska	1,914	59%	NA	NA	59%	[illegible]	4.8	210	[illegible]
Nevada	541	33%	540	36%	35%	3.2%	4.4%	184	[illegible]
New Hampshire	15	2%	NA	NA	2%	6.5	4.5%	18	[illegible]
New Jersey	4,649	16%	NA	NA	47%	4.2%	5.3%	442	13%
New Mexico	4,330	188%	1,141	30%	109%	4.5	5.6%	185	[illegible]
New York	1,201	9%	NA	NA	9%	4.8%	4.1%	648	16%
North Carolina	1,355	13%	NA	NA	13%	5.8%	5.3%	27	[illegible]
North Dakota	DNF	DNF	NA	NA	0%	5.2%	3.8%	441	12%
Ohio	DNF	DNF	50,679	294%	294%	5.4%	5.4%	366	[illegible]
Oklahoma	4,060	96%	12,207	225%	160%	5.7%	6.4%	197	5%
Oregon	2,260	56%	3,528	35%	45%	[illegible]	5.5%	321	[illegible]
Pennsylvania	2,074	8%	20,460	39%	11%	6.1%	5.0%	440	9
Rhode Island	[illegible]	[illegible]	NA	NA	[illegible]	5.6%	5.4	298	[illegible]
South Carolina	1,284	0%	1,296	24%	32%	4.0%	3.7%	418	[illegible]
South Dakota	[illegible]	0%	23	[illegible]	0%	4.4	4.3%	393	[illegible]
Tennessee	1,572	29%	2,316	31%	30%	5.9%	6.7%	148	2
Texas	DNF	DNF	58,140	337%	337%	5.1	4.5%	122	1
Utah	[illegible]	6%	1,654	41%	24%	4.7%	4.3%	192	4%
Vermont		0%	NA	NA	[illegible]	5.6%	5.6%	19	[illegible]
Virginia	5,976	71%	3,354	107%	90%	5.7	3.9%	216	6%
Washington	DNF	DNF	82	[illegible]	[illegible]	5.6	5.6	30	[illegible]
West Virginia	33	7%	303	8%	[illegible]	6.5%	5.8%	266	3%
Wisconsin	3,632	36%	3,936	30%	33%	5.6%	4.2%	32	[illegible]
Wyoming	53	8%	113	5%	4%	5.6	4.2%	116	[illegible]
United States	58,622	25%	253,306	49%	36%	[illegible]	4.8	51	[illegible]
United States - Est	114,916	26%							
Source	[illegible]		[illegible]			[illegible]			
Table/Page	[illegible]		[illegible]			[illegible]		[illegible]	
Year of Data	2008		2008			[illegible]			

16.7

Serving at a Reasonable Cost

State	ICF-MR			HCBS			Other I/DD Community Spending			Overall Spending	
	Total Expenditures 2008	Aver. Residents	Aver. Cost per Resident	Total Expenditures 2008	Aver. Residents	Avr. Cost per Resident	Total Community 2006	Total Non HCBS Community Expenditures (2006 total community 2006 HCBS)	% of total ID/DD Spending	ID/DD Spending per $1K personal Income	ID/DD Spending per capita
Alabama	[illegible]	240	$ 139,750	$ 267,362,500	5,450	$ 19,057	$ 267,716,330	$ 18,673,093	[illegible]	[illegible]	[illegible]
Alaska	$	0	$	$ 76,806,107	1,036	[illegible]	$ 95,262,063	$ 28,319,709	[illegible]	[illegible]	[illegible]
Arizona	[illegible]	[illegible]	$ 78,625	$ 638,167,289	19,610	31,589	$ [illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Arkansas	147,860,176	1,609	91,924	$ 97,103,703	3,351	28,978	[illegible]	193,650,620	[illegible]	[illegible]	[illegible]
California	$ 610,[illegible]	9,489	$ 64,342	$ 1,709,007,000	74,446	22,956	$ 4,000,548,336	$ [illegible]	[illegible]	[illegible]	[illegible]
Colorado	$ 22,289,048	127	176,198	$ 311,354,728	,212	43,175	$ 312,796,642	159,613,942	[illegible]	[illegible]	[illegible]
Connecticut	$ 236,99[illegible]	1,132	209,362	$ 475,540,000	7,799	60,978	$ 1,040,106,925	$ 619,642,5[illegible]	[illegible]	[illegible]	[illegible]
Delaware	$ 29,8[illegible]	140	213,861	$ 83,576,381	805	101,115	[illegible]	$ 48,325,6[illegible]	[illegible]	[illegible]	[illegible]
Dist. of Columbia	$ 82,09[illegible]	587	$ 139,955	$ 54,469,781	1,147	$ 47,510	$ 199,270,45[illegible]	181,7[illegible]	[illegible]	[illegible]	[illegible]
Florida	338,609,399	3,167	106,917	$ 945,063,12	31,187	30,308	1,166,109,[illegible]	505,018,019	[illegible]	[illegible]	[illegible]
Georgia	[illegible]	1,409	$ 102,609	$ 381,689,803	10,245	37,256	$ 398,712,[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Hawaii	9,027,307	82	110,089	$ 101,462,336	2,506	11,685	$ 133,115,676	$ 48,115,676	[illegible]	$ [illegible]	[illegible]
Idaho	$ 62,009,912	539	$ 115,046	$ 68,119,007	2,124	$ 32,07[illegible]	$ 201,236,40[illegible]	151,869,[illegible]	[illegible]	[illegible]	[illegible]
Illinois	$ 659,781,238	9,118	$ 72,360	$ 161,700,000	13,648	$ 33,829	$ 972,605,586	571,181,456	[illegible]	$ [illegible]	[illegible]
Indiana	$ 304,804,854	4,056	$ 75,158	$ 443,949,814	10,312	$ 43,003	$ 778,788,798	$ 385,252,718	[illegible]	[illegible]	[illegible]
Iowa	$ 288,092,999	2,129	135,350	303,613,019	12,928	23,394	438,579,354	182,59[illegible]	24	[illegible]	[illegible]
Kansas	$ 63,193,294	592	$ 106,836	$ 274,843,524	7,251	37,732	561,951,956	$ 132,328,71[illegible]	[illegible]	[illegible]	[illegible]
Kentucky	[illegible]	581	191,820	126,551,47[illegible]	3,089	[illegible]	$ 208,170,944	[illegible]	[illegible]	[illegible]	[illegible]
Louisiana	$ 480,841,731	5,190	$ 92,651	$ 322,451,876	6,875	$ 46,900	$ 472,558,648	220,227,046	[illegible]	[illegible]	[illegible]
Maine	$ 65,103,006	261	244,748	$ 248,956,942	2,824	38,158	425,604,979	101,38[illegible]	[illegible]	[illegible]	[illegible]
Maryland	$ 55,118,163	308	$ 179,344	$ 517,677,510	10,563	$ 49,001	629,823,163	$ 180,18[illegible]	[illegible]	$ [illegible]	[illegible]
Massachusetts	234,838,072	927	$ 253,468	$ 583,547,891	11,6[illegible]	49,098	$ 1,160,808,876	689,721,61[illegible]	[illegible]	$ [illegible]	[illegible]
Michigan	$ 56,728,240	116	$ 544,209	$ 381,731,216	7,851	48,625	$ 1,126,803,857	$ 791,185,032	[illegible]	$ [illegible]	$ [illegible]
Minnesota	178,358,058	2,173	$ 82,098	$ 925,198,681	14,5[illegible]	63,165	1,308,592,108	$ 659,499,082	[illegible]	[illegible]	[illegible]
Mississippi	$ 285,877,979	2,612	$ 109,448	$ 38,013,057	1,977	$ 19,233	$ 120,778,391	$ 83,329,3[illegible]	[illegible]	[illegible]	[illegible]
Missouri	129,143,915	993	130,121	$ 392,751,282	8,567	45,869	$ 525,249,812	215,142,72[illegible]	[illegible]	[illegible]	[illegible]
Montana	$ 13,044,028	55	$ 239,340	78,281,028	2,255	$ 34,714	$ 98,958,785	33,954,150	[illegible]	$ [illegible]	[illegible]
Nebraska	68,217,164	546	$ 124,940	$ 147,500,14[illegible]	3,447	42,7[illegible]	$ 188,013,07[illegible]	$ 51,087,28[illegible]	[illegible]	[illegible]	[illegible]
Nevada	$ 18,993,803	112	$ 170,548	$ 65,416,400	1,482	$ 44,156	$ 106,149,850	$ 44,970,55[illegible]	[illegible]	[illegible]	[illegible]
New Hampshire	$ 3,005,3[illegible]	25	$ 120,215	155,129,108	3,360	45,015	$ 185,205,628	53,173,196	25	[illegible]	[illegible]
New Jersey	$ 633,120,543	2,921	$ 216,785	$ 505,886,000	9,986	50,661	$ 908,822,206	$ 170,012,206	[illegible]	[illegible]	[illegible]
New Mexico	$ 23,171,893	182	$ 127,669	$ 267,982,051	3,744	71,576	378,088,29[illegible]	71,389,[illegible]	30[illegible]	[illegible]	[illegible]
New York	$ 2,675,003,359	7,874	$ 339,748	$ 3,825,876,515	57,481	$ 66,560	5,617,227,656	1,159,350,9[illegible]	[illegible]	$ [illegible]	[illegible]
North Carolina	461,931,336	4,150	111,309	157,750,000	3,505	$ 48,167	979,328,3[illegible]	$ 609,861,50[illegible]	[illegible]	[illegible]	[illegible]
North Dakota	$ 76,722,578	589	$ 130,0[illegible]	$ [illegible]	3,598	$ 21,57[illegible]	$ 126,355,8[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Ohio	691,77[illegible],985	6,533	105,766	$ 813,795,681	7,274	[illegible]	976,330,13[illegible]	567,626,25[illegible]	[illegible]	$ [illegible]	218
Oklahoma	$ 126,917,256	1,558	$ 81,462	$ 36[illegible],651	3,628	[illegible]	547,260,715	139,037,86[illegible]	[illegible]	$ [illegible]	346
Oregon	$ 12,240,527	[illegible]	335,35[illegible]	138,532,58[illegible]	10,583	[illegible]	532,997,31[illegible]	167,578,40[illegible]	[illegible]	[illegible]	[illegible]
Pennsylvania	$ 578,710,845	3,844	150,569	1,224,627,946	27,958	$ 43,805	$ 1,981,698,385	978,527,131	33	$ [illegible]	$ [illegible]
Rhode Island	$ 8,737,800	41	215,748	$ 251,268,605	3,172	79,233	275,358,205	44,543,95[illegible]	[illegible]	[illegible]	[illegible]
South Carolina	$ 174,255,458	1,546	$ 99,77[illegible]	213,200,000	5,415	$ 39,343	$ 369,031,[illegible]	$ 149,031,119	[illegible]	$ [illegible]	[illegible]
South Dakota	$ 22,366,55[illegible]	153	145,237	86,921,676	2,6[illegible]	32,54[illegible]	105,274,098	26,659,687	[illegible]	[illegible]	[illegible]
Tennessee	$ 241,918,741	1,202	$ 200,598	$ 553,899,151	7,356	$ 75,304	$ 621,831,2[illegible]	[illegible] 59,920,30[illegible]	[illegible]	[illegible]	[illegible]
Texas	$ 850,443,032	11,312	[illegible]	698,358,386	[illegible]	[illegible]	1,056,73[illegible]	459,206,666	[illegible]	$ [illegible]	[illegible]
Utah	$ 59,862,716	796	$ 37,747	$ 126,595,282	4,035	$ 31,394	$ 156,616,950	$ [illegible]	[illegible]	$ [illegible]	[illegible]
Vermont	$ 979,108	6	163,167	$ 31,270,835	1,237	[illegible]	120,115,119	[illegible]	[illegible]	[illegible]	[illegible]
Virginia	$ 273,332,795	1,656	$ 165,106	$ 143,732,502	1,815	56,787	$ 550,076,17[illegible]	$ 106,089,45[illegible]	[illegible]	[illegible]	[illegible]
Washington	$ 150,334,181	763	197,033	352,556,595	7,252	38,068	[illegible]	335,580,01[illegible]	[illegible]	[illegible]	[illegible]
West Virginia	$ 60,128,913	477	$ 126,056	$ 222,657,003	5,87[illegible]	$ 37,512	$ 236,28[illegible]	$ 66,936,61[illegible]	[illegible]	$ [illegible]	[illegible]
Wisconsin	126,508,008	1,003	$ 128,188	924,231,866	[illegible]	58,924	[illegible]	293,[illegible]	[illegible]	[illegible]	[illegible]
Wyoming	$ 18,312,242	88	$ 209,283	93,770,241	2,151	43,567	95,085,47[illegible]	$ 15,058,17[illegible]	[illegible]	[illegible]	[illegible]
United States	11,962,853,427	[illegible]	[illegible]	[illegible]	[illegible]	43,404	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
United States - Est.											

Source [illegible]

Table/Page [illegible]
Year of Data [illegible]

Report Data Sources

Organization	**Link for Data Referenced**
Council on Quality and Leadership	map.c-q-l.org/about
Research and Training Center on Community Living	rtc.umn.edu/misc/pubcount.asp?publicationid=186
Administration on Children and Families	www.acf.hhs.gov/programs/add/reports/Clients06.html
Centers for Medicare and Medicaid Services	www.cms.hhs.gov
Coleman Institute	www.colemaninstitute.org/
Department of Education	www.ed.gov/rschstat/eval/rehab/2005-tables
Human Services Research Institute	www.hsri.org/nci/
PAS Center	www.pascenter.org/demo_waivers/demoWaiverTable_2006.php
Kaiser Family Foundation	www.statehealthfacts.org
US Census Bureau	www.Census.gov
Quality Mall	www.QualityMall.org

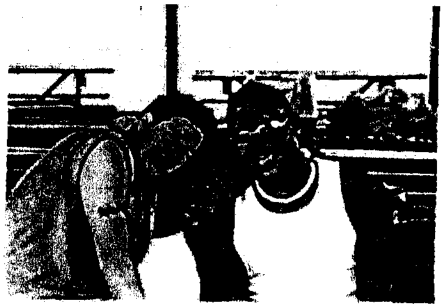
UCP United Cerebral Palsy
Life without limits for people with disabilities

United Cerebral Palsy
1660 L Street NW, Suite 700
Washington, DC 20036

Phone: (800) 872-5827
Web: www.ucp.org

Khary Wilson

Written by: Monique DuJue Wilson



My son's life experiences expanded outside of home and school only within the last 6 years of his life; he is 22. I have seen an amazing young man emerge!

Six years ago I was told I needed to place Khary in a developmental center due to his challenging a strong personality. There would be the supports he needed to address his need or personality, and he would be "safe". Instead I chose to create a personal plan specific for him and all about him, and hired people to assist him in discovering the world outside of school, home, and me.

Today Khary is leading an active and engaged life in the community, sometimes challenging, but we face each obstacle or change head on as we all must do in life, figure it out or move on to something else.

My son's life and so many other people throughout New Jersey deserve the opportunity to live life like everyone else, by rebalancing the current system and supporting this plan that calls for strong investments in community supports and by placing value on the people who assist our family members each and every day and help develop the characters of our sons and daughters, we expand the opportunity of thousands of people to live everyday lives such as you and I side by side.

It's huge, It's about freedom, it is about living for all of us!

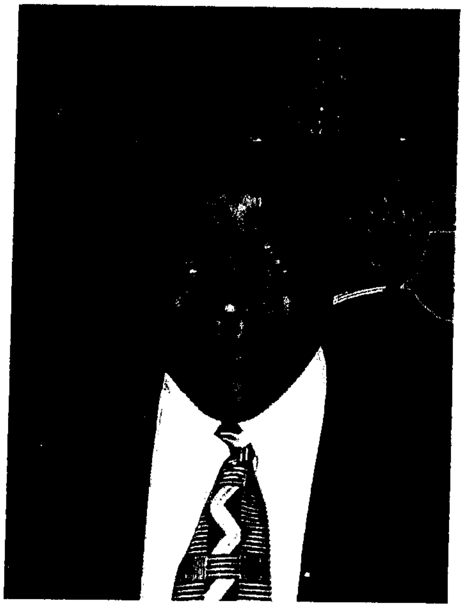
Ari Ne'eman

Ten years ago, the Supreme Court of the United States of America ruled that it wasn't a crime to have a disability. Today, we launch an effort to make the reality in New Jersey match that ruling. New Jersey's current overuse of institutions has left thousands of individuals with developmental disabilities locked away and thousands more on waiting lists. As a self-advocate running an organization of adults and youth on the autism spectrum, the Autistic Self-Advocacy Network, I feel this issue is one of great personal importance. Our people have been locked away for ages in conditions that often challenge the very idea of civilization. The history of disability policy over the last thirty years has been a story of constant struggles for greater inclusion, greater support, greater access, greater rights and greater opportunities for our people. We need to take a step forward in the spirit of that history to end a system whereby individuals have no choice but to live apart from their families, their homes and their communities.

Every major group in the disability community: parents, providers and people with disabilities ourselves all understand the importance of freeing our people from unnecessary and all too often abusive institutional settings. Let us be clear: action is needed to achieve a realization of one of the most crucial human rights issues of our time: the right of individuals with disabilities not to be segregated and marginalized but instead to be included and supported throughout society. The message that we send is that people with disabilities can, with the right support, succeed in being recognized as full members of our communities and citizens in our society.

FREE OUR PEOPLE!

Reggie Johnson
Written by: Mrs. Patricia Davis Johnson



Initially Reggie was admitted to New Lisbon via a court ordered evaluation. This evaluation should have taken approximately 30 days. Reggie remained there for approximately 18 and half years, because I was not aware of the availability of an alternate community based program.

I was comfortable with the developmental center and I thought Reggie was comfortable as well. I did not want to deny Reggie the opportunity to grow, to exist in the community to go to work, to bring home a paycheck, to go to Wawa in his own community.

Now that we (not just Reggie but my daughter and I) have transitioned into the group home under the wings of a community provider, our lives have truly been enhanced. I am so very proud of Reggie because he now exudes his individualism as well as his manhood and I respect him all the more.

The most impressionable extension of a community agency and the members of its staff is at Reggie's home is not just their professionalism in caring for the needs of the guys in the home but the uniqueness of the depth of their concern for the clients. I perceive a down pouring of love that is not just external but genuine. It doesn't only exist 8 hours a day but 24/7.

It would be selfish of me to want to keep such a wonderful thing to myself. Don't be afraid of transition when you are being guided down an unfamiliar path, do your homework, but above all things trust in your spiritual guide.

Joe Martinelli
Written by: Ann Martinelli

Joe Martinelli is a 24 year old young man who loves the New York Yankees, Bruce Springsteen's music, hanging out with friends, going out to eat and watching the thoroughbreds and trotters at the local racetracks in Monmouth County. He volunteers at a local non-profit agency in the resource library, delivers gift cards to employees of a large telecommunications company and is on the air at a local university's radio station one hour a week. Joe, with the help of his family, directs his supports and services based on his needs, with an individual budget and person-centered plan. Joe needs support to safely secure his wheelchair, drive him where he wants to go, and additional assistance at his direction. Joe has chosen who he wants to support him and how he wants to be supported. Segregated settings would not allow Joe to live his life his way, something we all take for granted.

Developmental Centers Census in New Jersey

	State Fiscal Year												
	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010[7]	11-Year Totals	
Census at the start of the Fiscal Year	3,672	3,596	3,514	3,433	3,296	3,169	3,121	3,070	3,051	2,995	2,897	2,788	**3672**	
Admitted from the Community	73	81	66	20	58	105	121	96	101	85	52	24	**882**	73.5 Avg./yr.
Moved to the Community	82	90	60	87	107	93	98	59	102	116	69	36	**999**	-87.5 Avg./yr.
People who Died in the D/C	67	73	87	70	78	64	79	57	55	67	55	35	**787**	-2.1% Avg./yr.
Net Decrease in Census during the Fiscal Year including mortality	76	82	81	137	127	52	56	20	56	98	72	47	**857**	-2.4% Avg./yr.
Census at the end of the Fiscal Year	3,596	3,514	3,433	3,296	3,169	3,121[1]	3,070[2]	3,051[3]	2,995	2,897	2824[4]	2,727	**2824**	
Discharges who moved to nursing homes	n/a	n/a	9	11	6	3	8	15	14	7	5	11[8]	**78**	8.7 Avg./yr.
Census Change during each year, *not including death.* [5]	*Down by* 9	*Down by* 9	*Up by* 6	*Down by* 67	*Down by* 49	*Up by* 12	*Up by* 23	*Up by* 37	*Down by* 1	*Down by* 31	*Down by* 17		*Down by* **105**	Down by 9.5 Avg./yr.
Net *Community* Placements [6]	9	9	-6	56	43	-12	-23	-37	-13	24	12		**62**	5.6 Avg./yr.

Developmental Centers Census in New Jersey

North Princeton Developmental Center closed at the end of April FY-1998.

"Moved to the community" includes individuals discharged from DDD services and those moved to nursing homes.

1 - reflects a net increase of 4 individuals moving between developmental centers; DC census decreased by 48 people overall.

2 -reflects net increase of 5 individuals moving between developmental centers; DC census decreased by 51 people overall.

3 - reflects net increase of 1 individual moving between developmental centers; DC census decreased by 9 people overall.

4 - There was one individual discharged in this year that was not tracked in the statistics made available by DDD as to where that person was subsequently supported.

5 - **Total Census Change over eleven years, not including deaths has been 78 people.**

6 - **This is the Net Community Placements, which is the total discharges, less deaths and nursing home placements.**

7 - **Fiscal year 2010 data contain 7-months of data. DDD's reported Census at the beginning of FY 2010 does not match the previously reported ending Census for FY 2009.**

8 - **Discharges have been unspecified by DDD**

All data provided by the Division of Developmental Disabilities FY-2007, FY -2008 and FY-2009

RESIDENTIAL SERVICES SYSTEM GROWTH NEEDS

	# of Paid Residential Service Options	# of Individuals moving from a D/C to the Community [1]	% of service system growth to accommodate these moves	# of Individuals Moving from the Priority Waiting List to Community Services [2]	% of service system growth to accommodate these moves	Total % of service system growth needed to accommodate these all of these moves
Year 1	8,525	400	4.7%	999	11.7%	**16.4%**
Year 2	8,925	541	6.1%	999	11.2%	**17.3%**
Year 3	9,466	508	5.4%	999	10.6%	**15.9%**
Year 4	9,974	430	4.3%	999	10.0%	**14.3%**
Year 5	10,404	306	2.9%	999	9.6%	**12.5%**

1 - To accommodate transition from the D/C's to the community at 80% of census, based on IHP recommendations. Actual growth will be determined by number of individuals who choose to move to the community in each year.

2 - To provide residential services to the individuals on the Priority Waiting List

COMMUNITY AGENCY PARTICIPATION RATES

	# of Residential Service Providers	% of Provider Participation in the D/C Transition Process*	Average # of new people needing to be supported per agency	% of Provider Participation in the Priority Waiting List Transition Process	Average # of new people needing to be supported per agency	Average # of new people to be served by each participating agency.
Year 1	280	30%	4.8	30%	11.9	**17**
Year 2	280	30%	6.4	30%	11.9	**18**
Year 3	280	30%	6.0	30%	11.9	**18**
Year 4	280	30%	5.1	30%	11.9	**17**
Year 5	280	30%	3.6	30%	11.9	**16**

*The agencies participating in the transition process in each of the five years may not be the same agencies.

These numbers are based on full participation rate with 80% of D/C census, based on IHP recommendations. Actual growth will be determined by number of individuals who choose to move to the community in each year.

OLMSTEAD QUALIFIED CAPACITY

	# of Olmstead qualified providers*	% of Provider Participation in the D/C Transition Process*	Average # of new people needing to be supported per agency
Year 1	112	30%	11.9
Year 2	123	30%	14.6
Year 3	136	30%	12.5
Year 4	149	30%	9.6
Year 5	164	30%	6.2

*With the current open enrollment process for Olmstead quality providers, we have estimated a 10% annual increase in capacity, resulting in 59% of the total residential capacity in the fifth year.

26lx

Evidence Concerning the Proposed Rate of Movement of People from Developmental Centers to Community Homes in New Jersey

Rates of Capacity Building in Past State Institution Downsizings and Closure Efforts

James W. Conroy, Ph.D.
Center for Outcome Analysis
Havertown, PA
www.eoutcome.org

March 2009

The Center for Outcome Analysis

The Center for Outcome Analysis, is a non-profit firm founded in 1985. Its mission is to perform evaluation, research, and training projects in the human services that will lead to improvements in the quality of life of people receiving services and supports. The company has performed extensive work in the developmental disabilities field, including research and policy-relevant evaluation in all 56 states and territories. COA is a national leader in research on the impacts of Self-Determination initiatives, the effects of deinstitutionalization, and the cost-effectiveness of Medicaid Waiver services. Over the years, COA has tracked more than 7,000 people individually from institution to community living – measuring dozens of qualities of life for each.

COA has also completed successful and widely publicized studies in the fields of AIDS, preschool and early intervention, aging, child welfare, housing, nursing homes and long term care, health care and health care reform, children's health screening, special education and inclusion, criminal justice, and market research. The company's primary specialty is the accurate measurement of outcomes, such as quality of life assessment, and the results of human service interventions.

The President of COA, James W. Conroy, Ph.D., is a 1970 *cum laude* graduate of Yale University with a BA in Physiological Psychology. Dr. Conroy began his career doing research on the impacts of the Developmental Disabilities Act of 1970, and went on to become Director of Research and Program Evaluation at Temple University's Institute on Disabilities.

After directing the Pennhurst Longitudinal Study, the largest study of its kind ever performed, he received his MA in Sociology/Program Evaluation and Ph.D. in Medical Sociology from Temple University in 1992. He left the University in that year to concentrate fully on creating the Center for Outcome Analysis. Dr. Conroy has directed more than a dozen longitudinal studies of the impacts of moving from institutional to community living. He headed the national impact evaluation on the individual outcomes of self-determination for the Robert Wood Johnson Foundation. He has been responsible for more than 280 formal research reports to government agencies and foundations, as well as more than 30 articles in scholarly journals and 10 book chapters.

His full C.V. can be seen at the company website:
http://www.outcomeanalysis.com/DL/CVs/CV-Conroy-Long-2006-10-31a.pdf

The recent introduction of Bill A3625, by Assembly Budget Chairman Louis Greenwald (D-Camden), would close five of seven Developmental Centers for people with intellectual and developmental disabilities over five years. There are currently 2,900 people in the State Centers. Approximately 2,100 people would move from institutions to small community homes.

The question has arisen: can New Jersey really accomplish this? Can the community service providers really absorb so many people in five years? This is a genuine concern, and must addressed carefully and early. Systems that grow too rapidly can, in some situations, experience disorganizing stress.

New Jersey did close two of its institutions during the 1990s – Johnstone and North Princeton. We tracked and monitored the people who left Johnstone, and found very good outcomes. For people who went to community homes, the outcomes were better than those for people who were transferred to other institutions.[1] Later, 570 people left the North Princeton in a two year period, and it closed in 1998. Scientists at Rutgers monitored that closure, and found the same kind and magnitude of good outcomes our team has found in its past studies.[2]

There may be several ways to examine this question, including anecdotal stories of past deinstitutionalization that were both rapid and successful. (For example, California, Indiana, and Oklahoma, all of which this author studied

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[1] Conroy, J., & Seiders, J. (1994a). ***1993 Report on the Well-Being of the Former Residents of Johnstone***. Project Report Number 5 of the New Jersey Strategic Planning Project. Wynnewood, PA: Conroy & Feinstein Associates.

[2] Hall Apgar, D., Lerman, P., & Jordan, T. (2000). ***Moving on: Life after North Princeton Developmental Center: A follow-up of former residents*** (Progress Report #2). Newark, NJ: New Jersey Technical Institute. Also see Lerman, P., Apgar, D., & Jordan, T. (2005). ***Longitudinal changes in adaptive behaviors of movers and stayers: Findings from a controlled research design***. Mental Retardation, Vol. 43, No. 1, pp. 25-41.

scientifically for system issues and quality of life of the people. These three, in spite of large numbers and rapid change, displayed strongly positive outcomes: the people involved were much better off in the community, and the entire system changes were fiscally conservative.)

Right now, nine states and the District of Columbia have closed *all* of their public institutions. This fact calls into serious question the very idea that "some people" actually "need" institutional settings. Ten jurisdictions have decided that this is not the case. And those systems, according to multiple studies and analyses, are healthy and sound, with people enjoying good outcomes and qualities of life. The ten are states, and the year the last institutional bed was emptied, are shown below.

State	***Year***
District of Columbia	1991
New Hampshire	1991
Vermont	1993
Rhode Island	1994
New Mexico	1995
Alaska	1997
West Virginia	1998
Hawaii	1999
Maine	1999
Minnesota	2000

The present author and colleagues have performed scientific studies of the outcomes of people moving from institution to community in four of those states, and also in seven others. The findings have been remarkably consistent:

2650

- The people are "better off" in terms of the majority of qualities of life and service;

- The dimensions of "better off" include independence, self-control of behavior, integration, productive activity, feeling safe, making choices, getting needed services, and more;
- Those who can communicate on their own are overwhelmingly pleased and never want to go back;
- Their families are also overwhelmingly pleased with their relatives' new lives in community homes, and many are surprised;
- The total cost, when all public dollars are tracked down and counted, are significantly lower in the community living model than in institutions.[3]

A broader and equally objective method is to review all the states' records of depopulation and prepare a table of some of the best known state downsizing efforts, along with some of the most rapid. Comparing these to the proposed New Jersey community relocation proposal will enable direct comparison. That will shed considerable and unbiased light on recently expressed questions about the capacity of New Jersey to do what is called for in A3625 – and do it well.

A careful analysis of the "capacity issue" is complex, but it begins with comparing how many people moved out of institutions, in how many years, into what size of population base.[4] The following table does that. For New Jersey, about 2,100 people would move under A3625, into a population base of almost 9 million over a 5 year period. The table shows that that this can be described as moving 48.2 people per million of general population in each year.

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[3] However, this is primarily due to lower staff salaries and benefits in the community homes, a situation which deserves attention and remedy.

[4] Moving 1000 people into community homes would be a different matter in California, with 35 million people, than in Wyoming, with 500 thousand - and this must be taken into consideration.

Reducing Reliance on Institutions For People with Intellectual and Developmental Disabilities: Review of State Accomplishments and Rates

State	Number Moved	Years	Population Base	Ratio: Movers Per Million General Population Per Year	Era *
New Jersey (Proposed)	2100	5	8,717,925	48.2	
DC	351	7	550,521	91.1	90s
New Hampshire	663	6	1,309,940	84.4	80s
Oklahoma	1100	4	3,547,884	77.5	90s
Connecticut	900	4	3,510,297	64.1	80s
New Mexico	700	7	1,928,384	51.9	90s
Delaware	200	5	843,524	47.4	90s
Indiana	700	5	6,271,973	22.3	90s
Kentucky	450	5	4,173,405	21.6	2000+
Alabama	450	5	4,557,808	19.7	2000+
Alaska	58	5	663,661	17.5	2000+
North Carolina	450	3	8,683,242	17.3	90s
Wisconsin	410	5	5,536,201	14.8	2000+
California	2400	5	36,132,147	13.3	90s
Georgia	600	5	9,072,576	13.2	2000+
Pennhurst	1200	10	12,429,616	9.7	80s
Nevada	102	5	2,414,807	8.4	2000+

Note: States in italics are ones in which the Center for Outcome Analysis conducted independent scientific studies of the deinstitutionalization process and outcomes.

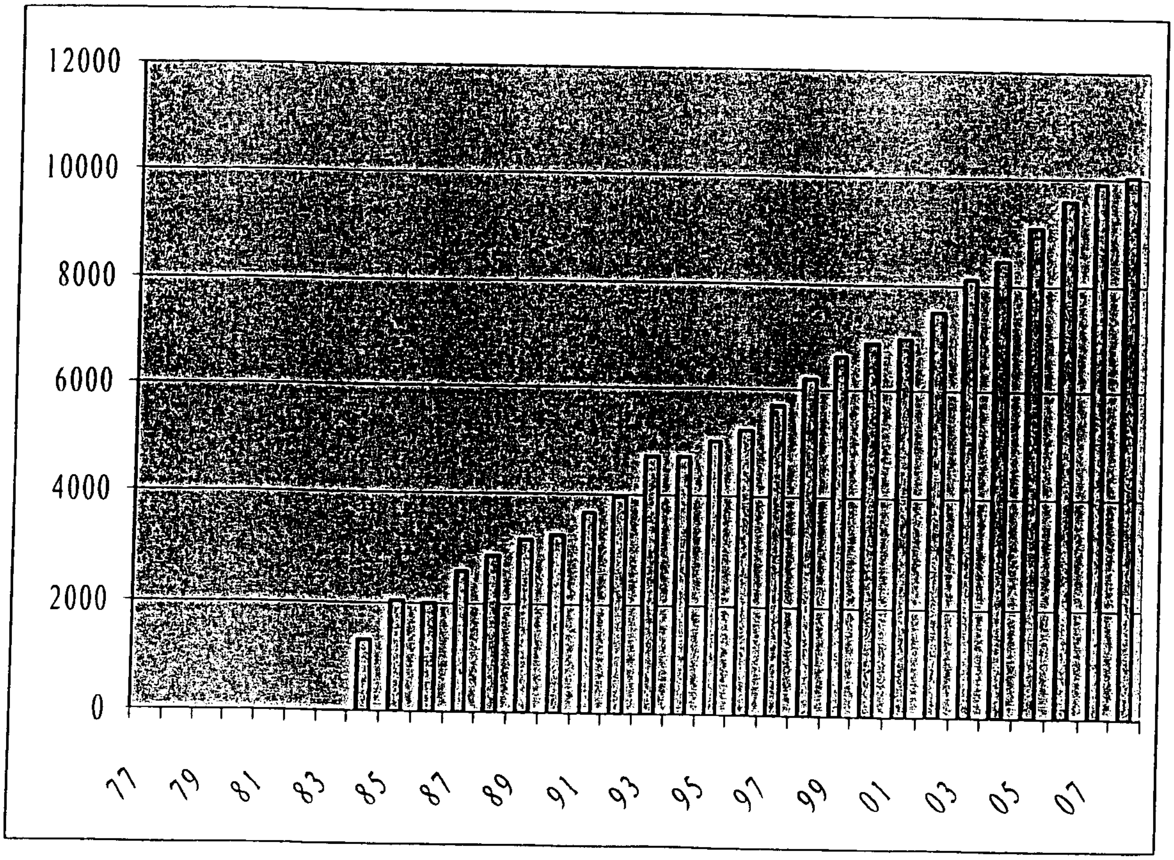
* *Era is included because more recent efforts have learned from earlier ones. The Pennhurst downsizing was one of the nation's first, and took a full 10 years. Later processes were able to move more quickly because of all that had been learned.*

The table offers ample evidence that movements of this scale have been done before. In five states, the process has been done *faster* than 48.2 per million in the population. In Delaware, the rate was about the same as projected for New Jersey.

Now that it has been established that this level of increased community support capacity is not only possible, but has been done before, the next question concerns the "maturity" of the community service system.

Does New Jersey have the community residential infrastructure necessary to absorb a rapid increase of people moving into community homes? Part of the answer to that question is provided in the graph below.

Number of People in New Jersey Community Residential Homes
1977 to 2008



268x

Over the past two decades, New Jersey has created community residential capacity that now supports more than three times the number of people remaining in Developmental Centers. And this graph only includes the people who are in settings that qualify for Federal assistance (under the Home and Community Based Services, or "Waiver" amendments to the Social Security Act). There are actually more people than shown in this graph.

Adding roughly 400 people to this 10,000 person service system each year does not seem impossible.

Moreover, the total size of the New Jersey community service and support system, including those receiving non-residential supports (day activities, case management, in-home supports, and more) is approximately 35,000 people and their families. The fact is that New Jersey, by all the evidence, has a mature and very large, well-established community service system.

Other states have announced plans for facility closures, as well. California has announced the intention to close one of its facilities, as have Georgia and Maryland. Michigan is in the process of closing its last state institution, which will make it the 11th jurisdiction to be completely free of institutions.

On these bases, we find little or no support for fearing that the proposed Bill's movement of people from institutions to communities in New Jersey would be too many or too fast. The evidence suggests that, given five years, New Jersey's community supports infrastructure will be capable of accepting, supporting, and integrating 2,100 people from the state's Developmental Centers.

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Simple Facts About Medicaid in New Jersey: Institutional and Community Care for Citizens with Developmental Disabilities

James W. Conroy, Ph.D.
President, Center for Outcome Analysis, Havertown, PA
www.eoutcome.org

1. Under the Medicaid program, the Federal government will reimburse New Jersey for 50 cents of every dollar spent on residential services for people with Developmental Disabilities.[1]

2. There are two major Medicaid programs in the Developmental Disabilities area:
ICF/MR – Intermediate Care Facilities for [people with] Mental Retardation (Institutions)
HCBS – Home and Community Based Services (Waiver)

3. ICF/MR = Developmental Centers (large institutions)
HCBS = Waiver programs – small group homes and life sharing situations

4. There are about 2,900 people in Developmental Centers (institutions)
There are about 10,100 people in Waiver program settings

5. The average cost per person in a Developmental Center is $233,965
The average cost per person in a Waiver setting is approximately $90,000

6. In either case, the Federal government pays 50% of the cost. That is New Jersey's FMAP (Federal Medical Assistance Percentage).

7. This rate, 50%, applies whether the person is in an ICF/MR or a community HCBS home.

8. So, to support a person, here is what New Jersey has to pay and what the Feds pay:

Type of Service	**Total Cost**	**Fed Medicaid Pays**	**NJ State Pays**
Institutional ICF/MR	$233,965 710	$116,982	$116,982
Community HCBS Waiver	$100,000	$50,000	$50,000

9. The table above should make it abundantly clear that HCBS Waiver Community services will require fewer NJ tax dollars per person.

10. Because dozens of rigorous research studies have demonstrated conclusively that qualities of life and service are better in HCBS Waiver Community settings than in Developmental Center Institutional ICF/MR settings, the cost/benefit ratio strongly favors HCBS Waiver Community support models.

11. For people moving out of institutions, the Feds are currently offering 80% FMAP under the "Money Follows the Person" program. States should aggressively take advantage of this one-time opportunity to reduce reliance on the costly and ineffective institutional models.

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[1] As long as service quality standards are met.

Background Information About
The Center for Outcome Analysis

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    ICF/MR – Intermediate Care Facilities for [people with] Mental Retardation (Institutions)
    HCBS – Home and Community Based Services (Waiver)

3. ICF/MR = Developmental Centers (large institutions)
    HCBS = Waiver programs – small group homes and life sharing situations

4. There are about 2,900 people in Developmental Centers (institutions)
    There are about 10,100 people in Waiver program settings

5. The average cost per person in a Developmental Center is $233,965
    The average cost per person in a Waiver setting is approximately $90,000

6. In either case, the Federal government pays 50% of the cost. That is New Jersey's FMAP (Federal Medical Assistance Percentage).

7. This rate, 50%, applies whether the person is in an ICF/MR or a community HCBS home.

8. So, to support a person, here is what New Jersey has to pay and what the Feds pay:

Type of Service	Total Cost	Fed Medicaid Pays	NJ State Pays
Institutional ICF/MR	$233,965 710	$116,982	$116,982
Community HCBS Waiver	$100,000	$50,000	$50,000

9. The table above should make it abundantly clear that HCBS Waiver Community services will require fewer NJ tax dollars per person.

10. Because dozens of rigorous research studies have demonstrated conclusively that qualities of life and service are better in HCBS Waiver Community settings than in Developmental Center Institutional ICF/MR settings, the cost/benefit ratio strongly favors HCBS Waiver Community support models.

11. For people moving out of institutions, the Feds are currently offering 80% FMAP under the "Money Follows the Person" program. States should aggressively take advantage of this one-time opportunity to reduce reliance on the costly and ineffective institutional models.

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[1] As long as service quality standards are met.

Background Information About
The Center for Outcome Analysis

The Center for Outcome Analysis is a non-profit firm founded in 1985. Its mission is to perform evaluation, research, and training projects in the human services that will lead to improvements in the quality of life of people receiving services and supports. The company has performed extensive work in the developmental disabilities field, including research and policy-relevant evaluation in all 56 states and territories. COA is a national leader in research on the impacts of Self-Determination initiatives, the effects of deinstitutionalization, and the cost-effectiveness of Medicaid Waiver services. Over the years, COA has tracked more than 7,000 people individually from institution to community living – measuring dozens of qualities of life for each.

COA has also completed successful and widely publicized studies in the fields of AIDS, preschool and early intervention, aging, child welfare, housing, nursing homes and long term care, health care and health care reform, children's health screening, special education and inclusion, criminal justice, and market research. The company's primary specialty is the accurate measurement of outcomes, such as quality of life assessment, and the results of human service interventions.

The President of COA, James W. Conroy, Ph.D., is a 1970 *cum laude* graduate of Yale University with a BA in Physiological Psychology. Dr. Conroy began his career doing research on the impacts of the Developmental Disabilities Act of 1970, and went on to become Director of Research and Program Evaluation at Temple University's Institute on Disabilities.

After directing the Pennhurst Longitudinal Study, the largest study of its kind ever performed, he received his MA in Sociology/Program Evaluation and Ph.D. in Medical Sociology from Temple University in 1992. He left the University in that year to concentrate fully on creating the Center for Outcome Analysis. Dr. Conroy has directed more than a dozen longitudinal studies of the impacts of moving from institutional to community living. He headed the national impact evaluation on the individual outcomes of self-determination for the Robert Wood Johnson Foundation. He has been responsible for more than 280 formal research reports to government agencies and foundations, as well as more than 30 articles in scholarly journals and 10 book chapters.

His full C.V. can be seen at the company website:
http://www.outcomeanalysis.com/DL/CVs/CV-Conroy-Long-2006-10-31a.pdf

An Opportunity Plan: Same Dollar More Value

Rebalancing Resources to Promote Community Living for People with Developmental Disabilities

NJACP

New Jersey Association of Community Providers

www.njacp.org

December 2008

INTRODUCTION

New Jersey's fiscal climate presents an opportunity to revise our continued investment in large public institutions to better meet the needs of people living with developmental disabilities, enabling them to live quality lives in the community. Rebalancing the allocation of fiscal, human, and capital resources within the Department of Human Services through the consolidation and downsizing of the number of developmental centers is a critical step that must be taken in a restrained fiscal climate and addressing spiraling costs for institutional care. Rebalancing fiscal and staff resources are intrinsic to shifting the historical investment from institutional care to promoting community living for people with developmental disabilities consistent with their assessed level of need. Consolidating and closing developmental centers offers opportunities not only for efficiencies, but will align services with need and address the deficits of the current system. These deficits are evidenced by our continued inappropriate reliance on developmental centers, our inability to significantly reduce the Community Services Waiting List and our inability to provide a seamless transition for young adults entering the developmental disabilities system from the educational system. This course of action will create the long awaited opportunities for people to live quality engaged lives in the community and create fiscal resources to allow New Jersey to move forward with systems change.

With the additional support of temporary bridge funding to develop and expand community services and supports consistent with the direction that has been taken across the country over the last four decades, New Jersey will be able to right size the system.

Rebalancing resources from the developmental centers will align public resources with national trends and address the unmet needs of people in the community while serving significantly more people with the same fiscal resources. Establishing a moratorium on future admission to developmental centers coupled with a temporary allocation of bridge funding repaid from the net proceeds of the liquidated properties, additional federal financial participation and other cost savings, minus the cost of the development and expansion of community based services and supports we can:

- avert costly inappropriate institutional care for 2,457 people,
- address the needs of 8,065 consumers and families awaiting services and supports of the growing community services waiting list, and
- support young adults transitioning from the educational system to the adult system who aspire to achieve the opportunities that life offers.

"The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities and support to make informed choices and decisions about their lives; live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens; achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual" (The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L.106-42).

Our investment in costly institutional care restrains and compromises an ability to respond to the growing unmet need for community based services and supports for people with developmental

Reliance on costly institutional care limits our ability to make significant progress in addressing the legal challenges New Jersey faces and to realize:

- the intent of the federal Supreme Court in the Olmstead Decision - Justice Ginsberg delivered the opinion of the Supreme Court in Olmstead v. L.C. and concluded that States are required to place individuals with developmental disabilities in the most integrated setting appropriate to their needs as determined by themselves and their treatment professionals. Justice Ginsberg and the Court maintained isolating and segregating those living with developmental disabilities in institutions violates Title II of the Americans with Disabilities Act of 1990 and constitutes discrimination based on a disability. (Olmstead, 1999);
- and address the legal challenges of a consent decree with the Department of Justice addressing Woodbridge Developmental Center and New Lisbon Developmental Center (Complaint - United States of America v. The State of New Jersey, 2004) (Boyd, 2003); and
- the present Community Services Waiting List litigation by New Jersey Protection and Advocacy (Complaint for Declaratory and Injunctive Relief, 2008).

COMPARISON OF OTHER STATES

New Jersey, in comparison to other states, has lost ground as it continues to rely on historical approaches depressing our ability to replicate the positive outcomes of other states. Across the United States the trends in public spending over the past forty years have shifted away from funding large public institutions, with a total of 140 closures having taken place in the nation since 1969. New Jersey has closed two institutions, E.R. Johnstone Training and Research Center in 1992 with a census of 239, that became a correctional facility; and North Princeton Developmental Center in 1998 with a census of 512 people. New Jersey is not one of the 40 states with planned additional closures.

The following studies describe the trends in large public institutions over the last two decades and provide data for comparisons between states including benchmarks for New Jersey:

- “Residential Services for People with Developmental Disabilities: Status and Trends Through 6/2007,” edited by Prouty, Smith and Lakin: University of Minnesota, August 2008 (cited as “Prouty, 2008”) and
- “The State of the States in Developmental Disabilities: 2008 Study Summary,” by Braddock et al at the University of Colorado: January 2008 (cited as “Braddock, 2008”).

Drawing on their work one can conclude that:

- **Nationally, large state facilities continue to downsize and close.** Between 2000 and 2007 the population of large public institutions has dropped from 47,329 to 36,650, a decrease of 22.5% (Braddock, 2008). During the same period, New Jersey’s institutional population dropped from 3,514 to 2,995, a decrease of 14.8% (Prouty, 2008), *which is only 2/3 of the national effort.* In New Jersey, this is an overall decrease of 519 people, which includes 490 individuals who died while residing at the state run developmental centers, indicating a passive reduction due to mortality (NJ DDD, 2008). The resulting net discharge over seven years of 29 people. New Jersey was ranked 49th in the nation for

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having one of the highest rates of utilization of state institutions at 34.9 people per 100,000. The national utilization rate over this same period was 12.9 people per 100,000.

Average Daily Residents of State –Operated 16+ I/DD Institutions FY 2004-2006

(Utilization in 2006 per 100,000 citizens of the general population in the state and states' ranking, lowest to highest, on institutional utilization)

State	2006	2004	% Change 2004 -06	Rate 2006	Rank 2006
New Jersey	**3064**	**3145**	**-3%**	**34.9**	**49**
New York	1605	1634	-2%	8.3	22
Pennsylvania	1416	1473	-4%	11.4	28
Mississippi	1377	1363	1%	47.1	51

Source: Braddock, D., Hemp, R., & Rizzolo, M.C. (2008). *The State of the States in Developmental Disabilities 2008.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, the University of Colorado.

- **Large state facility average daily populations decreased** by more than half (26.5%) in the U.S., and in most states between 1999 and 2007 (Prouty, 2008). In this same period, the average daily population in New Jersey's large state facilities decreased by 18.4% (Prouty, 2008). *During the ten years between 1999-2008, New Jersey discharged 894 individuals from its developmental centers, admitted 806 people, and 697 residents of the developmental centers died. The net change in census over ten years, not including mortality represents a decrease of 78 people.* (NJ DDD, 2008)

Developmental Centers Census in New Jersey

	Fiscal Year										10-Year Totals
	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008^	
Census at the start of the Fiscal Year	3,672	3,596	3,514	3,433	3,296	3,169	3,121	3,070	3,051	2,995	**3672**
Admitted from the Community	73	81	66	20	58	105	121	96	101	85	**806**
Moved to the Community	-82	-90	-60	-87	-107	-93	-98	-59	-102	-116	**-894**
Died	-67	-73	-87	-70	-78	-64	-79	-57	-55	-67	**-697**
Census at the end of the Fiscal Year	3,596	3,514	3,433	3,296	3,169	3,121^^	3,070*	3,051**	2,995	2,897	**2897**
Decrease in Census during the Fiscal Year	-76	-82	-81	-137	-127	-48	-51	-19	-56	-98	**-775**
Number "moved to the community" to nursing homes	n/a	n/a	9	11	6	3	8	15	14	7	**73**
Census Change during each year, *not including death.*	-9	-9	6	-67	-49	16	28	38	-1	-31	**-78**

Sources: Adapted from New Jersey State Budget FY 2008-2009 (2008). New Jersey Department of Treasury, Office of Management and Budget. Retrieved on August 20, 2008 at http://www.state.nj.us/treasury/omb/

^New Jersey Division of Developmental Disabilities, August 20, 2008.

North Princeton Developmental Center closed at the end of April FY-1998.

"Moved to the community" includes individuals discharged from DDD services and those moved to nursing homes.

^^reflects a net increase of 4 individuals moving between developmental centers; DC census decreased by 48 people overall.

*reflects net increase of 5 individuals moving between developmental centers; DC census decreased by 51 people overall.

**reflects net increase of 1 individual moving between developmental centers; DC census decreased by 9 people overall.

- **It *is* possible to operate a state system without large state operated facilities.** On June 30, 2007 nine states did not operate any large (over 16 people) state facilities (AK, DC, HI, ME, NH, NM, RI, VT and WV) (Prouty, 2008).
- **The cost per person in large state facilities continues to rise,** and in 2007 reached a national average of $483 per day (Prouty, 2008). At this same point in time the average cost per day of service in New Jersey's large state institutions was $612 (Prouty, 2008). The average increased cost per year in New Jersey has been 8.1% for each of the last five years. Our fiscal climate is unable to continue to support these increased costs.
- **The amount of spending on New Jersey's state institutions, as compared to statewide personal income, places us 6th highest among the states, yet our community spending places us in 40th place**. New Jersey's spending, per $1,000 of personal income, on institutional care is among the highest in the nation, while our spending on community services is less than 4/5th of the states. New Jersey's total spending on services to people with developmental disabilities is also less than 4/5th of the states. When compared to our neighboring states, New York and Pennsylvania, New Jersey is behind in our effort to fund and prioritize community services. New Jersey is more comparable to the nation's poorest state, Mississippi, in how they fund services to people with developmental disabilities.
- As of June 30, 2007, **more than two-fifths (41.9%) of the total number of large state facility residents in the country lived in five states** (California, Illinois, New Jersey, New York and Texas), each with more than 2,100 residents in such facilities (Prouty, 2008). California projects that it will close another of its large state facilities in 2008.
- On June 30, 2007, **twenty of the forty-two states** (including DC), **still operating large institutions, had 375 or fewer individuals in their entire state operated institutional systems** (AL, AZ, CO, DE, ID, IN, KS, KY, MD, MI, MN, MT, NE, NV, ND, OK, OR, SD, UT, and WY) (Prouty, 2008). On that same date, six of the seven state operated institutions serving individuals with development disabilities in New Jersey *each* housed more than 375 people. *"Operating Data for New Jersey Developmental Centers SFY '06-'09," shows the 2007 average daily census of each of the seven developmental centers (the year for which comparable national data is available) one center served 103 people, while each of the other centers was above 394 (the range being 394 – 589).*

Thirty six of the 42 states supporting institutions are reducing their census, including New Jersey. However, mortality has played a major role in the reduction of the census (NJ Division of Developmental Disabilities, 2008). Over the last ten years, the census has been reduced by 775 people across all institutions of which 697 have been deaths. At the same time 806 people were admitted from the community and 894 people moved to the community. This represents a net decrease of 78 people when the statistics are adjusted for mortality across the ten year period.

Thirty-six of the 42 states that still finance large public institutions have reduced their census during 2004-06, with the greatest reductions in Indiana (-42%), Delaware (-33%), Wisconsin (-28%), Nevada (-23%), Michigan (-22%), and Oregon (-20%) (Braddock, 2008). Achieving actual reduction of the census through deinstitutionalization, coupled with a moratorium on new admissions while investing in community services, has been undertaken by 46 other states. Implementing these actions will help move New Jersey from 49th in a national ranking of states in average number of residents in large state institutions on a daily basis (Braddock, 2008).

COMPARATIVE COSTS

Fiscal resources clearly cannot address individuals' unmet needs with the continued incremental approach to deinstitutionalization and the lack of a moratorium on future developmental center placements. As evidenced by the net decrease in developmental center census of only 78 people over the last ten years when adjusted for mortality, our costs will continue to outpace our ability to retain the present number of developmental centers. The comparative costs of services in New Jersey's Developmental Centers, living in the community, and through the self-directed Real Life Choices program, shows the variation in costs between these different types of services. The cost of care in developmental centers continues to escalate representing a 9% increase from 2004 to 2006 with an annual cost per person of $223,914 or $641 a day per person (New Jersey State Budget FY 2008-09). Eighty-one percent of the developmental center population does not require an institutional level of care. This pattern of spending limits the ability of the system to meet the growing need for community based services, to satisfy the mandate of the Olmstead decision, along with the Department of Justice and Community Services Waiting List Lawsuits, and to address the Department of Human Services' benchmarks.

Division of Developmental Disabilities

Summary of FY'08 Overtime and FY'09 Appropriations Act

	FY 2009 Appropriations Act					FY 2008				
Description	State	Federal	% Fed	Other	Total	Overtime	Total Cost	Staff	Resi-dents	Cost Per Resident
Administration	$3,310,000	$7,651,000	69.80%	$0	$10,961,000			190		
Community	$589,122,000	$317,011,000	33.30%	$45,979,000	$952,112,000			708		
Dev. Centers										
Greenbrook	$18,522,000	$11,257,000	37.80%		$29,779,000	$671,831	$30,450,831	245	95	$320,535
Vineland	17,684,000	46,298,000	72.36%		63,982,000	7,374,155	$71,356,155	1,570	474	$150,540
North Jersey	$13,716,000	$40,879,000	74.88%		$54,595,000	$5,439,500	$60,034,500	951	383	$156,748
Woodbine	7,747,000	37,116,000	82.73%		44,863,000	7,324,711	$52,187,711	1,238	485	$107,604
New Lisbon	$17,015,000	$61,883,000	78.43%		$78,898,000	$8,098,248	$86,996,248	1,442	403	$215,872
Woodbridge	15,995,000	44,424,000	73.53%		60,419,000	7,488,916	$67,907,916	1,398	405	$167,674
Hunterdon	$13,659,000	$38,248,000	73.69%		$51,907,000	$11,525,443	$63,432,443	1,376	571	$111,090
Sub Total	$104,338,000	$280,105,000	72.86%		$384,443,000	$47,922,804	$432,365,804	8,220	2,816	$153,539
Total DDD	**$696,770,000**	**$604,767,000**	44.88%	**$45,979,000**	**$1,347,516,000**	**$47,922,804**		**9,118**		

* Other Funds are made up of Contributions to Care

Source: New Jersey Department of Human Services, 2008

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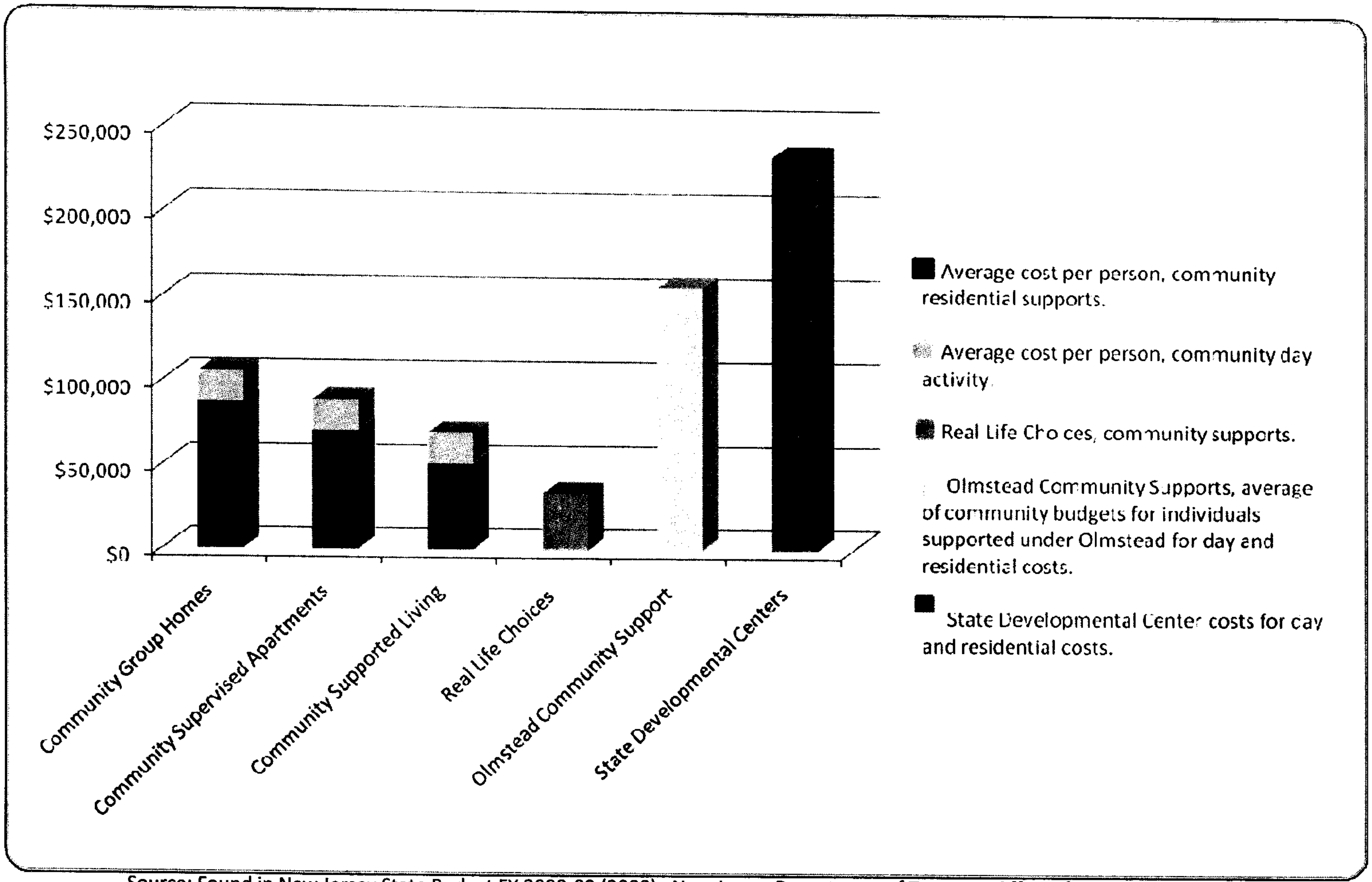
STATE ICF/MR FACILITIES
RECOMMENDED REVISED INTERIM RATES
FISCAL YEAR ENDING 2008

FACILITY	Daily Rate per person	Annual Cost per person	Number of people	TOTAL ANNUAL COST
GREENBROOK	$622.00	$227,030	99	$22,475,970
HUNTERDON	$582.00	$212,430	582	$123,634,260
NEW LISBON	$720.00	$262,800	479	$125,881,200
NORTH JERSEY	$645.00	$235,425	395	$92,992,875
VINELAND	$656.00	$239,440	474	$113,494,560
WOODBINE	$555.00	$202,575	505	$102,300,375
WOODBRIDGE	$716.00	$261,340	436	$113,944,240
Average	**$642.29**	**$234,434.29**		
Total			**2,970**	**$694,723,480**

Source: New Jersey State Budget FY 2008-09 (2008). New Jersey Department of Treasury, Office of Management and Budget. August 20, 2008 at: http//www.state.nj.us/treasury/omb/publications/09budget/pdf/54.pdf

Adapted from NJ DHS

COMPARATIVE COSTS PER PERSON FOR SERVICES - FY-2008



Source: Found in New Jersey State Budget FY 2008-09 (2008). New Jersey Department of Treasury, Office of Management and Budget. August 20, 2008 at: http//www.state.nj.us/treasury/omb/publications/09budget/pdf/54.pdf

Adapted from: Office of Reimbursement, Division of Medical Assistance

Adapted from: DDD Olmstead Budget Matrix, 2008

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COMPARISON OF COSTS
BY PROGRAM TYPE
FISCAL YEAR ENDING 2008

SERVICE TYPE	Number of people served	Total Annual Cost	Average annual cost per person	Cost per Person Residential/ Community Supports	Average Cost per Day
Community Group Homes	4,485	$389,262,310	$86,792	$105,183	$288
Supervised Apartments	1,184	$83,428,591	$70,463	$88,855	$243
Supported Living	755	$38,473,986	$50,959	$69,350	$190
Real Life Choices	656	$21,981,931	$33,509		$92
Community Day Services Only	8,990	$165,338,000	$18,391		$50
State Developmental Centers	2,970	$694,723,480	$233,914		$641

Source: New Jersey State Budget FY 2008-09 (2008). New Jersey Department of Treasury, Office of Management and Budget. August 20, 2008 at: http//www.state.nj.us/treasury/omb/publications/09budget/pdf/54.pdf

CONTROLLING INSTITUTIONAL ADMISSIONS

Large public institutions (developmental centers) are unduly restrictive and are an inappropriate level of care for 81% of the current residents who have been assessed as ready for community placement (Ritchey, K., 2007). New Jersey's continued investment in developmental centers consumes a disproportionate percentage of the Division's approximately 1.34 billion dollar budget (New Jersey State Budget, FY 2008-09) and utilizes state and federal funding to support an inappropriate level of care. The current Olmstead Plan shows a projected reduction at state institutions of 1,850 people over nine years. However, the SFY'09 budget climate permits the movement of 125 people, not the benchmark of 250 and as institutional costs have increased 20% over the last three years (NJ State Budget FY 2008-2009). This is indicative of the budgetary constraints limiting the projected decrease in developmental center census in the Olmstead Plan. When the additional costs are included in the equation, we cannot continue the present course of action of ongoing admissions, and hope to achieve the intended census reduction and cost redirection needed to develop community capacity.

With continued admissions, the developmental center census continues to fall principally due to mortality (Developmental Centers Census in New Jersey). Over the last ten years, based on a review of New Jersey's Division of Developmental Disabilities developmental center census data (DDD August 20, 2008 and NJ State Budget 2008-09), 894 people were moved into the community. However, these gains were offset by the admission of 806 people admitted to the developmental centers during that period with a net reduction of 78 people when the census data is adjusted for mortality.

In 2007, admissions were due to medical, accessibility, behavioral health needs that have resulted in recent costly institutional placements. The reasons for these admissions could be successfully addressed in a well developed system of care:

- Medical Issues – 16 (27%)
- Behavioral Issues – 13 (22%)
- Psychiatric Problems – 11 (19%)
- Needs Accessible Residence – 8 (14%)
- Court Order – 6 (10%)
- Consumer Protection – 5 (8%)

Source: New Jersey Division of Developmental Disabilities January 25, 2008.

Successful reduction of the developmental center census is predicated upon the establishment of a moratorium on future developmental center placements, with the concurrent development and access to community based services, supports and residential options to meet emergency needs and avert out of home placement. Our continued approach mitigates any gains that have been achieved in placing people into the community. If the necessary development of the community based infrastructure does not occur with a concurrent moratorium on future admissions, we will continue to rely on institutional care for many years. Court ordered placements and short term emergency placements due to circumstances presenting imminent peril, where no immediate appropriate community service/ support is available, should be the exception to the moratorium.

Comparison of Characteristics between All People at New Jersey Developmental Centers and the People without Opposition to Community Placement

	All People Living in the Centers (%)	1,005 People Where IDT, Consumer and Family Do Not Oppose Community Placement (%)
■ Average Age (Years)	49.2	47.8
■ % Female	40%	42%
■ % with a Psychiatric Diagnosis	53%	57%
■ % with Cerebral Palsy	25%	24%
■ % with History of Epilepsy	52%	49%
■ % with Active Epilepsy.	21%	18%
■ % with Visual Impairment	43%	39%
■ % with Health Conditions involving the cardiovascular/circulatory, digestive, muscular/skeletal or epidermal systems.	40 – 62%, depending	40 - 60%, depending
■ % Using a Behavioral Specialist	29%	39%
■ % with special dietary requirements or special food preparation.	65 – 71%, depending on supports needed.	61 – 74%,
■ % needing regular assistance turning or positioning the body.	20%	18%
■ % using a wheelchair.	47%	45%
■ % using physical therapy.	24%	23%
■ % taking antipsychotic medication.	37%	40%
■ % who could benefit from environmental adaptations in lighting, cabinets, closets, faucets or doors.	19 – 25%, depending on the environmental adaptation.	14 – 21%,
■ % with personal preferences, such as living with someone of the same sex or age, having their own room, a smoke free home or a calm/quiet home.	36 – 53%, depending on the preference.	32 – 47%,

Source: Ritchey, K. (2007). *Olmstead Plan "Path to Progress".*
http://www.state.nj.us/humanservices/ddd/publications/JSOlmPlanFinal.pdf.

Comparison of Support Needs between All People at New Jersey Developmental Centers and People without Opposition to Community Placement

Self Care Support Need

	All People Living in the Centers (%)	1,005 People Where IDT, Consumer and Family Do Not Oppose Community Placement (%)
■ Lowest Level of Need (Level 1)	10.1%	13.6%
■ Low Level of Need (Level 2)	16.8%	16.3%
■ Medium Level of Need (Level 3)	34.4%	30.9%
■ High Level of Need (Level 4)	38.7%	39.0%

Medical Support Levels

	All People Living in the Centers (%)	1,005 People Where IDT, Consumer and Family Do Not Oppose Community Placement (%)
■ Ambulatory Level 1	19.8%	21.6%
■ Non Ambulatory Level 2	1.2%	1.5%
■ Ambulatory Level 3	39.4%	37.0%
■ Non Ambulatory Level 4	28.8%	27.1%
■ Ambulatory Level 5	1.6%	2.3%
■ Non Ambulatory Level 6	7.4%	8.4%

Behavioral Support Levels

	All People Living in the Centers (%)	1,005 People Where IDT, Consumer and Family Do Not Oppose Community Placement (%)
■ No Special Behavioral Supports - Level 1	21.9%	21.5%
■ Minimal Behavioral Supports – Level 2	1.4%	1.9%
■ Formal Behavioral Supports – Level 3	45.1%	43.2%
■ Intensive Behavioral Supports – Level 4	31.6%	33.2%

Source: Ritchey, K. (2007). Olmstead Plan "Path to Progress". http://www.state.nj.us/humanservices/ddd/publications/JSOlmPlanFinal.pdf.

COMMUNITY SERVICES WAITING LIST

The need for community services in New Jersey continues to grow from serving 34,983 people in 2007, to a projection of 38,263 in 2009 (Community/Developmental Center Census - Developmental Center Profiles table). New Jersey is home to 2.9% of the American population and 2.7% of the American population with disabilities. Yet we have a disproportionate percentage of Americans with developmental disabilities, 9.5% whose needs are inadequately serviced (State and County Quickfacts, 2008).

The Community Services Waiting List has grown from approximately 5,000 in 1998 (ARC, 2008) to 8,065 in 2007 (DDD, 11/2007). People on the growing community services waiting list continue to require additional services and supports. Of the 8,065 total, 3,932 people are on the priority segment of the community services waiting list and are determined to be at significant risk and require residential options, or risk admission to a developmental center. The list grows at a rate of 800-900 people per year, evidencing that the current approach of addressing 10% of the priority list will allow the list to continue to expand, at best, at a 10% increase per year.

New Jersey requires 34.3% growth in the system of community services to meet the needs of the people on the priority waiting list (Prouty, 2008). This number does not include the other 4,221 people on the waiting list who also require community services. Our neighboring states of New York and Pennsylvania have greater capacity in their community systems and require between 8 and 9% growth to meet their waiting list needs (Prouty, 2008).

Community Services Waiting List by County

WAITING LIST CATEGORY

COUNTY	PRIORITY	PRIORITY DEFERRED	GENERAL	TOTAL
ATLANTIC	182	11	110	303
BERGEN	452	46	252	750
BURLINGTON	298	21	175	494
CAMDEN	330	18	177	525
CAPE MAY	58	6	31	95
CUMBERLAND	98	9	92	199
ESSEX	376	33	158	567
GLOUCESTER	175	4	174	353
HUDSON	185	24	93	302
HUNTERDON	77	4	49	130
MERCER	194	5	75	274
MIDDLESEX	386	15	241	642
MONMOUTH	422	15	165	602
MORRIS	238	30	180	448
OCEAN	377	20	217	614
PASSAIC	228	23	127	378
SALEM	29	0	40	69
SOMERSET	176	19	100	295
SUSSEX	104	8	110	222
UNION	229	38	160	427
WARREN	78	3	68	149
OUT OF STATE	136	7	18	161
UNKNOWN	33	2	31	66
TOTAL	**4,861**	**361**	**2,843**	**8,065**

Source: New Jersey Division of Developmental Disabilities, November 30, 2007

Persons on the Developmental Disabilities Residential Waiting List for New Jersey

State	Total Persons on Waiting List	% Growth Needed
New Jersey	**3,844***	**34.3%**
New York	4,130	9%
Pennsylvania	2,023	8.6%
Mississippi	N/A	N/A

Source: Robert W. Prouty, R.W., Alba, K., & Lakin, K.C., (2008). *Residential Services for Persons with Developmental Disabilities: status and trends through 2007.* Research and Training Center on Community Living, Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota.

This number represents the priority waiting list. The total waiting list population is 8,065 (NJ DDD, 11/2007).

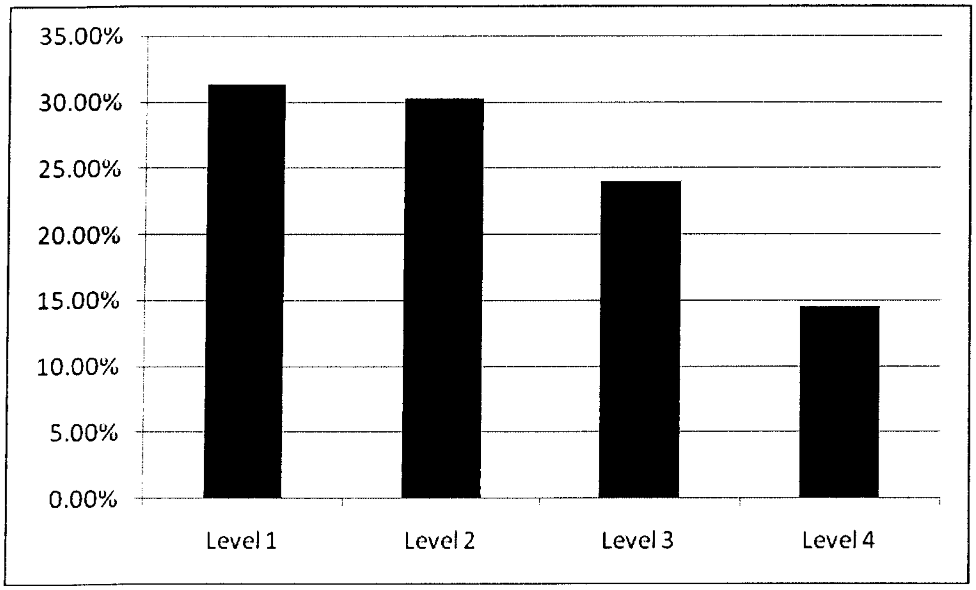
New Jersey's Waiting List Compared to National and State Populations

	National	New Jersey	**NJ Percentage**
General Population[1]	299,398,484	8,724,560	**2.9%**
Population w/disability[1]	49,746,248	1,389,811	**2.7%**
Waiting list for DD services[2]	84,523	8,065	**9.5%**

Sources: [1] *State and County Quickfacts (2008). http://quickfacts.census.gov/qfd/states/34000.html.*

[2] New Jersey State Budget FY 2008 – 2009 (2008). New Jersey Department of Treasury, Office of Management and Budget. August 20, 2008 at http://www.state.nj.us/treasury/omb/publications/09budget/pdf/54.pdf . (D-214).

Percentage of People on the Priority Waiting List Assessed for Self Care Needs



Level 1- the lowest level of self care support need.

Level 2- the low level of self care support need.

Level 3- the medium level of self care support need.

Level 4- the high level of self care support need.

Source: New Jersey Department of Human Services – Division of Developmental Disabilities

There were 8,087* people on the waiting list as of March 31, 2007 (DDD Initiative Update June 27, 2007) of which:

- 3,764 individuals were in the priority category, living with their families waiting for services from the division. *Priority* status references people at "significant risk" that is, the primary caretaker is over the age of 55 or has a chronic physical or psychiatric condition which limits their ability to care for the individual, or there is a risk to the health or safety of any individual living in the home, or a clear risk of abuse, neglect, or exploitation of the individual.
- 214 individuals were in the priority category and part of a current placement initiative.
- 898 individuals were in the priority category living outside the family home, often in a DDD funded placement.
- 373 individuals were in the priority deferred category. These individuals had been offered placement that was not appropriate in the past and declined. A person on the priority list, who was offered a placement but declined that placement because it was not an appropriate placement for the person, is placed on the *Priority Deferred* list.
- 2,838 individuals were in the general waiting list category. These individuals have expressed an interest in receiving residential services sometime in the future. If a person is not deemed to be Priority status, then they are placed in the *General* category of the waiting list.

YOUNG ADULTS TRANSITIONING FROM THE EDUCATIONAL SYSTEM TO THE ADULT SYSTEM

Millions of dollars are spent each year on educating and training children with developmental disabilities, but after graduation there are no entitlements similar to those that supported their education. Graduation for most people is the beginning of an adult life filled with hope and promise, while graduation for many students with developmental disabilities may be looked at as the beginning of sitting at home with endless days and nights of nothing to do and no hope for a meaningful future. In some cases, graduates with developmental disabilities may feel they have no alternatives, become apathetic and eventually lose their hard earned skills and miss the opportunity to become productive members of society.

CONTROLLING DEVELOPMENTAL CENTER ADMISSIONS

Successful reduction of the developmental center census is predicated upon the establishment of a moratorium on future developmental center placements, with the concurrent development and expansion of access to community based services, supports and residential options to meet emergency needs and avert out of home placement. Our continued approach mitigates any gains that have been achieved in placing people into the community. If the necessary development of the community based infrastructure does not occur with a concurrent moratorium on future admissions, we will continue to rely on institutional care for many years. Court ordered placements and short term emergency placements due to circumstances presenting imminent peril, where no immediate appropriate community service/support is available, should be the exception to the moratorium.

CAPACITY BUILDING

Access to existing conventional community resources, tailored to include expertise in addressing the needs of people with developmental disabilities, will promote utilization of existing community inclusive health and behavioral health care rather than the development of more costly segregated care. This approach capitalizes on the use of the resources existing within the community infrastructure and requires education, awareness and cross training to address the particular needs of people with developmental disabilities, ensuring services are adequate to respond to the need for care in particular areas of specialty care, such as dental and mental health care.

Building community capacity to meet the needs of individuals moving from developmental centers into the community will require the investment of bridge funding for a five year period to build the community capacity. The bridge funding will be repaid from the net proceeds, minus the cost of the development and expansion of community based services and supports and any life safety enhancements required at the remaining developmental centers.

Potential Sources of Funding to Support Bridge Funds:

- State FY-2009 appropriated capital improvement funding targeted for the developmental centers that can be deferred, plus previous unspent capital improvement funding from prior years.
- Appropriated SFY-09 overtime expenditure reductions achieved through first year, and each subsequent year's consolidation.
- State FY-09 community care waiver federal financial participation received in excess of the bookmarked amount, and amounts over and above the '09 bookmarked ceiling in subsequent years, while maintaining the current state share. As systems reform takes place, a review of other states may indicate approaches to increase federal financial participation and alternative waiver plans. Some promising approaches, such as the Wisconsin Family Care, have utilized long term care waivers offering increased consumer choice, streamlined the complexity of the system and yielded consumer satisfaction.
- Reductions in developmental center operational costs achieved through consolidation in the first year, and each subsequent year.
- Proceeds achieved through liquidation of the developmental center real estate property.
- Any unspent funds from the Division of Developmental Disabilities 2009 budget, and going forward four years (for a total of five years).
- Identify services that can be reimbursed to initiate federal claiming in compliance with the two yearly timely filing requirements to maximize federal financial participation for out of state purchase of care.
- Identify agency housing equity opportunities to support agency based capacity building utilizing agency group home equity.

These funds are necessary to strengthen and expand the existing community based services, the creation of supports, services and linkages which will have the capability of fulfilling the unmet need of people waiting in developmental centers, those on the community services waiting list and absorb the projected growth in the system.

The areas in which supports, services and linkages must be afforded through use of existing resources and expansion include, at a minimum:

- ***Timely and flexible housing options that maximize choice, fiscal and personal independence, incorporating demonstrated best practices and market availability; including the provision for individuals who can and wish to move on from existing group homes to create additional capacity:*** A variety of community-based residential options replicating the successful approaches to creating sustainable and affordable housing practices that have been demonstrated across the country, notably in Virginia, Oregon, Maryland and to a lesser extent New Jersey itself. These approaches have led to timely and efficient access to housing consistent with need and promote fiscal independence through consumer purchase or rentals via agency acquisition and/or federal or state subsidy programs.
- ***Ensure a seamless transition to services and supports for young adults transitioning from the educational system*** are readily available to pursue vocational/educational training, employment/career opportunities or other meaningful day activities including transportation, family supports and linkages to appropriate state and county services including, but not limited to, the Divisions of Vocational Rehabilitation, Disabilities Services and Developmental Disabilities.

- ***Employment and skills training to meet the changing job market:*** Community based agencies will partner with the business community to identify and incorporate training, supports and skills sets that will be responsive to job market needs and changing trends in the employment sector. Agreements will be forged with the Department of Labor and Workforce Development to ensure accessibility to supports and employment assistance programs, including One Stop Career Centers and linkages with business leaders through the State and local Chambers of Commerce to access to competitive employment and promote job retention. Agencies providing supports to individuals with developmental disabilities should be encouraged to set an example for the community by becoming employers of individuals with disabilities.

- ***Providing access to the full range of healthcare supports and professionals within the community including cross training and regulatory and/or policy changes to promote community access and quality care:*** Access to health care will be supported by linkages with community health clinics, HMO enrollment and the support of outsourced developmental center medical physicians, dentists and other allied healthcare professionals including nurses, occupational therapists, nutritionists, physical therapists, speech therapists, etc. Relationships will be facilitated with community health practitioners through the Department of Health and the state and local medical associations to increase and develop continuing education/training opportunities to enhance the skill sets and expertise of the medical, dental and behavioral health community of practice. State, region, and county DDD personnel, as well as provider agency staff and family members will advocate for greater involvement of the medical and dental community in the provision of service to individuals with developmental disabilities.

- ***Ensure access and availability of assistive and adaptive technology, including vehicle and environmental modifications to promote independence.***
- ***Provision of access to behavioral health services and supports to individuals and their support teams within the community***: Linkages with community based mental health services and supports including acute care and step down options and the children's behavioral health system will be developed to facilitate access. Expanded capacity will be developed, including in-home therapeutic support, behavioral supports, mobile response and crisis intervention and emergency crisis beds to respond across community settings, to avert inappropriate out-of-home placements. Support of outsourced developmental center mental health professional and allied behavioral support staff will provide additional resources to agencies, as well as those in self direction or at home with their families. The recommendations of the Dually Diagnosed Task Force Report released in September of 2008 should be fully supported to respond to the behavioral health needs of people with mental health challenges.
- ***Flexible respite care;***
- ***Flexible case management and support services responsive to need;***
- ***Salary parity, education/training to enhance staff skills;***
- ***Social, recreational and meaningful day activities including the need for programs that are responsive to people throughout their lifespan;***
- ***Peer and family supports, and in-home and family preservation services.***

WORKFORCE TRANSITION

It is essential to rebalance the system to support people living with developmental disabilities in the community and utilize the substantial resources that the developmental centers consume, not only from a fiscal standpoint, but within the workforce itself. Employing a "staff without walls" approach will facilitate the redeployment of staff to address the needs of the workplace, either working in the community or in the developmental centers as downsizing and consolidation takes place while retaining state benefits. It offers opportunities to redeploy staff to fill vacant positions, thereby reducing overtime costs in developmental centers and address the growing need for community based county resources. This approach permits the use of the skilled workforce:

- to assist in the transition of people from developmental centers into the community by addressing transition issues, emergency services and enhance gap areas, such as case management, facilitating transition, training, and continuous quality improvement in the community while ensuring the health and safety standards are sustained in the developmental centers.
- to assure continuity of service, protect the valuable resource, expertise and commitment of this dedicated workforce and to protect and to ensure the ongoing certification of the facilities throughout the implementation of the downsizing plan.

It is essential to rebalance the system to support people living with developmental disabilities in the community and utilize the substantial resources that the developmental centers consume not only from a fiscal standpoint but within the workforce itself.

Current developmental center employees offer a valuable resource in the development and implementation of an efficient transition plan that promotes employee stability and provides opportunities for employees to help determine their own future.

Options can be employed to reduce staff through attrition, transfers, early retirement and offset the need for professional services and direct care staff in the community while retaining state status and benefits. In state fiscal year '09, there are projected to be 8,220 employees in the seven developmental centers, representing an increase from 6,954 in SFY '06.

Personnel Data from New Jersey Developmental Centers

Position Data	Actual FY '06	Actual FY '07	Revised FY '08	Budget Est. FY '09
Institutional Total				
Filled positions				
State Supported	4,735	4,774	4,721	4,702
Federal	3,397	3,495	3,518	3,518
All Other	1	0	0	0
Total Positions	**8,133**	**8,269**	**8,239**	**8,220**
Filled positions by Program Class				
Res. Care and Habilitation Services..	6,954	7,093	7,083	7,077
Admission and Support Services	1,179	1,176	1,156	1,143
Total Positions	**8,133**	**8,269**	**8,239**	**8,220**

Source: New Jersey State Budget FY 2008 – 2009 (2008). New Jersey Department of Treasury, Office of Management and Budget. August 20, 2008 at http://www.state.nj.us/treasury/omb/publications/09budget/pdf/54.pdf.

As the implementation of the plan for rebalancing resources to promote community living for people with developmental disabilities begins to take shape, more developmental center employees will be in a position to examine alternate workplace opportunities within the state and community based system, including options available through intra and intergovernmental staff transfers. To be proactive with these employees, the implementation team will offer a variety of supports to help staff take best advantage of the options available:

- ***Retirement:*** An early retirement plan may be presented. It would be particularly beneficial to this plan if these offerings were made to staff that work through until the closing of the facility to which they have been assigned and/or until their position has become phased out, due to the decrease in developmental center census.

- ***Transfers:*** Staff will be afforded the option of filling appropriate vacancies through inter and intra departmental transfers.
- ***Retraining:*** Orientations and training and retraining opportunities will be offered to Direct Service Professionals (DSP) working in the developmental centers who are interested in transitioning into the community-based service system.
- ***Redeployment***: Consolidation within developmental centers to offset staff deficits will reduce overtime. Redeployment to positions in the community could support the system, fill gaps in specialty care, (OT, PT, Medical, Dental, other allied services), and address gaps in professional care and direct care positions, thereby, addressing the significant vacancy turnover issues in the community utilizing a staff without walls approach that will retain state status and union participation by assigning staff to division regional or county based regional offices to support the need for professional services and direct care needs.

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NATIONAL
DISABILITY RIGHTS
NETWORK
Protection & Advocacy for Individuals with Disabilities

December 2009

Re: A Decade of Little Progress Implementing Olmstead

In 1999 the U.S. Supreme Court, in *Olmstead v. Lois Curtis and Elaine Wilson*, stated loud and clear that it is a violation of the civil rights of Americans with disabilities to require a person to be institutionalized in order to receive necessary disability supports and services, if these services are more appropriately provided in the community. It is simply unacceptable, that 10 years later, there has been almost no progress reducing the numbers of Americans with disabilities, nationwide, who live in institutions. This report, "*A Decade of Little Progress Implementing Olmstead: Evaluating Federal Agency Impact After 10 Years*," evaluates the efforts of key federal agencies to enforce the *Olmstead* decision over the past decade. We found next to no federal oversight of enforcement efforts and no repercussions for states who fail to make reasonable efforts to end unnecessary institutionalization. This approach is an affront to the people with disabilities. NDRN calls for more urgent federal enforcement of the *Olmstead* mandate.

With every year that passed in the last Administration, it appeared that federal efforts to spur *Olmstead* enforcement waned. This report highlights problematic trends like this and recommends a more effective, aggressive federal approach to bring about community integration. The research for the report was largely completed in September 2009. Since that time new leadership has been appointed to the U.S. Department of Justice (DOJ) and we've seen a renewed focus on *Olmstead* enforcement. Some welcome signs include:

- DOJ has been more proactive to reach out to members of the disability community to identify potential *Olmstead* cases where their participation might advance the law and help to clarify questions that remain unsettled after the Supreme Court's decision. Questions which, if resolved, may remove barriers to individuals transitioning to the community.

- Recent DOJ investigations and filings under the Civil Rights of Institutionalized Persons Act (CRIPA) have made clear that *Olmstead* issues are deeply intertwined with problems of inadequate conditions, and solving these problems must look at whether the people in the facility belong there and whether the institution is complying with laws governing discharge planning and transition.

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Hopefully, we will see a similar sense of urgency at the new HHS, Office of Civil Rights; and this aggressive commitment to enforcement of the Olmstead mandate will continue throughout the full Obama Administration and beyond. The ebbs and flows of budgets may pressure DOJ and the U.S. Department of Health and Human Services (HHS) to slow their commitment. However, America can't afford to slow down community integration. We have a generation of baby boomers facing disabilities as a result of aging, and thousands of recently wounded Iraq and Afghanistan veterans who deserve a future outside of institutions.

Sincerely,

Curtis L. Decker
Executive Director

NATIONAL
DISABILITY RIGHTS
NETWORK
Protection & Advocacy for Individuals with Disabilities

A Decade of "Little Progress" Implementing *Olmstead*: Evaluating Federal Agency Impact After 10 Years

September 30, 2009

NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States. NDRN provides legally based assistance to P&As and works at the national and state levels to create a society in which people with disabilities are afforded equality of opportunity.

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NDRN calls for more urgent federal action to compel compliance with the civil right to live in, work and enjoy the community.

EXECUTIVE SUMMARY

A decade ago, the U.S. Supreme Court ordered States to stop unnecessarily segregating individuals with disabilities in institutions in order to receive long term services.[1] Yet, ten years later, there has been little national progress moving people with disabilities out of nursing facilities and public institutions and into communities with supports.[2] People who want to live with their families and neighbors are still needlessly confined in large public and private institutions. NDRN calls for more urgent federal action to compel compliance with this civil right.

The National Disability Rights Network (NDRN) reviewed the efforts of the U.S. Department of Justice (DOJ) and the U.S. Department of Health and Human Services (HHS) -- two agencies charged with enforcing the Supreme Court's mandate. At HHS, we found a reliance on short-term voluntary financial incentives to encourage state compliance, coupled with a lack of monitoring and data collection about the effectiveness of these efforts. At DOJ, we found a lack of attention to enforcement of the ADA's integration mandate and many missed opportunities. Particularly when compared to DOJ's heavy focus on the need to fix up those crumbling old institutions that have a history of failing to keep its residents safe from abuse and neglect, this approach is an affront to people waiting – often for decades -- in inappropriate institutions for the opportunity to return to the home communities.

The Obama Administration has announced that 2009 will be the "Year of Community Living."[3] This is a hopeful sign of a renewed federal commitment to ending unnecessary institutionalization. There is no more time to waste. Our society is aging and more people are in need of community supports to remain employed and at home. Neither must we fail the hundreds of recent veterans who may return home to face institutionalization because of an inadequate community supports.

This report offers stories of individuals who are unnecessarily institutionalized and recommends practical strategies for HHS and DOJ to do more to spur compliance with

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[1] *See Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581(1999) holding that it is a violation of the Americans with Disabilities Act (ADA) to unnecessarily segregate an individual in an institution to receive care when these supports could be provided in the community.

[2] *See* Braddock *et al.*, State of the States in Developmental Disabilities, University of Colorado 2008 at 101-305. (Some states have made significant progress moving individuals into appropriate community settings. However, a handful of states have actually increased their institutional populations.)

[3] http://www.ich.gov/readmore/THE_YEAR_OF_COMMUNITY_LIVING.htm

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Americans' civil right to remain living and working in the community. Americans waiting to leave institutions include both adults and children. For example:

Dan Smith (not his real name) is in his thirties and has Down Syndrome resulting in a mild intellectual disability. He successfully lived with his family in the community until 15 years ago when both his parents passed away, then he was moved into a 96-bed institution. He is capable of taking care of his needs, and can read, knows how to balance a checkbook, and held a job at a video store until the store closed. He is known as friendly with an engaging sense of humor. Mr. Smith would very much like to move to a small community-based group home in a setting closer to one of his siblings. He is frustrated after living so many years in an institution with very little privacy and severe limits on his choices, including those as basic as when to get up in the morning or when to turn out his reading light at night. His doctors at the institution have determined that the community would be more appropriate for Mr. Smith, but he remains needlessly confined in the institution.

David (not his real name) is 8 years old and has intensive mental health needs. He is eligible for Medicaid and his mother has asked for the therapeutic home-based mental health services that his doctor has prescribed. Medicaid has denied these medically necessary home based services and as a result, on numerous occasions, David has been forced to leave his family and go to the state hospital in order to obtain limited, episodic mental health treatment. At his young age removal from his family adds to the trauma he already experiences from his psychiatric impairment. David is at a critical period of development in his life. Denial of the services he needs like case management, crisis intervention, and in-home supports is causing long-term damage that can affect his later ability to live successfully in the community.

NATIONAL
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A Decade of "Little Progress" Implementing *Olmstead*: Evaluating Federal Agency Impact

The *Olmstead* Decision: A Mandate for Community Integration

A decade ago, In *Olmstead* v. *Lois Curtis and Elaine Wilson* the U.S. Supreme Court ruled that unjustified institutional isolation of people with disabilities is a form of discrimination under the Americans with Disabilities Act.[4] To remedy or avoid such discrimination, States are required to provide community-based services for persons with disabilities, who are otherwise entitled to institutional services, when:
1) the State's treatment professionals reasonably determine that community placement is appropriate;
2) the person does not oppose such placement; and,
3) the placement can reasonably be accommodated, taking into account resources available to the State and the needs of others receiving state-supported disability services.[5]

The ADA's reasonable accommodation regulation does not require states to make "fundamental alterations" in its services or programs.[6] However, just what constitutes a fundamental alteration has been the subject of much litigation over the past decade.[7] Significantly, however, the Court said that States can show that they are reasonably accommodating persons with disabilities if they develop a comprehensive, effectively working plan for placing qualified individuals in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by a State's efforts to keep its

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[4] *Olmstead*, 527 U.S. at 597.
[5] *Id.* at 607
[6] *Id.* at 595
[7] *See e.g.: Radeszewski v. Maram*, 383 F.3d 599, 613-14 (7th Cir. 2004); *Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175, 1182-83 (10th Cir. 2003); *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003);*Pennsylvania Protection and Advocacy, Inc. v. Pennsylvania Dept of Public Welfare*, 402 F.3d 374 (3d Cir. 2005); *Frederick L. v. Dept of Public Welfare*, 364 F.3d 487 (3d Cir. 2004), and *Sanchez v Johnson*, 2005 WL 1804195.

institutions fully populated.[8]

Data Shows Little National Progress Providing Disability Supports in the Most Integrated Settings Appropriate to the Individual

The data over the past 10 years shows only a modest 11% reduction, nationwide, in the numbers of persons with intellectual disabilities living in public or private institutions (with 7 or more beds). In 1998, the number was 182,490 and in 2006, the number was 159,909.[9] The data for individuals with mental illness living in state hospitals is similarly disappointing. Twenty years of national state hospital census data (1984-2003) were used to assess trends in the rate of declines from pre- to post-*Olmstead* periods. The data shows a steady decline in census over 20 years, but the decline has slowed significantly during the post-*Olmstead* period.[10]

On a state level, the level of progress varies greatly. Some States have made dramatic progress reducing the number of individuals with intellectual disabilities (the data is not available for individuals residing in state hospitals) residing in institutions, while a few states have made no progress.[11] As of 2006, the states with the fewest amount of individuals with intellectual disabilities living in their own homes or small group homes (homes with 6 or fewer persons) are: Alabama, Arizona, Georgia, Illinois, Kentucky, Mississippi, South Carolina, Texas, Utah, and Virginia.[12] Another way of measuring progress is to look at the percentages in which States have lowered their spending on institutions. Unfortunately, seven States failed to lower their level of spending on institutions for individuals with intellectual disabilities[13] in the decade between 1996 and 2006, including: Connecticut, Iowa, Kentucky, Louisiana, Mississippi, Nebraska, and New Jersey.[14]

Statistics also show that, nationwide, America continues to spend a greater percentage of its Medicaid long-term-care dollars in institutions rather than on community supports and services. According to a report by Thompson/Reuters, in FY 2007, nationally, only 42% of all Medicaid long term care costs where spent on community-based services, including, home and community-based (HCBS) waivers, the personal care option, and the home health services option. During the same period, 58% if all Medicaid long term care dollars were spent on institutional care, including nursing facilities and intermediate care facilities (ICF) for individuals with intellectual disabilities.[15]

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[8] *Olmstead,* 527 U.S. at 605-606.

[9] State of the States in Developmental Disabilities, at 308.

[10] PSYCHIATRIC SERVICES ♦ ps.psychiatryonline.org ♦ October 2006 Vol. 57 No. 10, p. 1. *State Psychiatric Hospital Census After the 1999 Olmstead Decision: Evidence of Decelerating Deinstitutionalization*, Mark S. Salzer, Ph.D., Katy Kaplan, M.Ed. and Joanne Atay, M.A.

[11] Braddock,at 101-305 (state profiles)

[12] *Id.* at 19.

[13] The author could not find information on level of spending for state hospitals for individuals with mental illness by state.

[14] *Id.* at 9. .

[15] Medicaid Long-Term Care Expenditures in FY 2007, September 26, 2008, By Brian Burwell, Kate Sredl, and Steve Eiken, Healthcare Thomson Reuters, 1 (http://www.ancor.org/issues/Data-Statistics/Data-Statistics.html).

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The data can be broken out differently to reveal that the shift to community-based care is particularly slow for elderly persons and persons with disabilities other than intellectual disabilities. Specifically, if funding for ICFs is removed, 69% of Medicaid long term care services were spent in state hospitals and nursing facilities and only 31% on community-based services.[16]

The slow shift of funding towards community services for the elderly and persons with mental or physical disabilities is in sharp contrast to an AARP survey showing that "89% of people 50 years and older intend to remain in their own homes rather than go to nursing facilities."[17] The failure to shift dollars to the community also makes no fiscal sense, as demonstrated by a recent AARP study which showed that "[O]n average, Medicaid dollars can support nearly three older people and adults with physical disabilities in Home and Community-Based Services (HCBS) for every person in a nursing home."[18]

So why have some States made significant progress complying with the ADA's integration mandate and others made none? Generally, it is due to a lack of leadership, a lack of responsiveness to the requests or demands of persons with disabilities, and a lack of compliance with federal law. Sometimes, there is opposition to downsizing or closure of an institution among some family members of those in institutions or by unions whose members work in institutions. In addition, legislators representing districts where institutions are situated can be protective of the economic and other benefits they derive from the institutions. The Illinois P&A, known as Equip for Equality, studied this phenomenon in their State and learned

> that it is possible to address the concerns of parents of institutional residents, unions, and political representatives without reneging on the state's responsibilities to people with disabilities and their right to live in the least restrictive setting. Common strategies for overcoming opposition to community living included having parents and guardians of family members in the institutions meet with parents whose children have successfully transitioned into the community. Additionally, parents and guardians were sometimes apprised of the many longitudinal studies that show that, despite initial opposition to deinstitutionalization, parents of individuals in institutions had come to view the experiences of their family members in the community as positive, affording a better quality of life than the institution. In the case of unions, their concerns have often been addressed by finding jobs for their members in state-operated community residences or elsewhere in state government.[19]

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[16] *Id.* at Table I Medicaid expenditures for long-term care services FY 2007.

[17] Across the States Profiles of Long Term Care and Independent Living" (http://assets.aarp.org/rgcenter/il/d19105_2008_ats.pdf), 3

[18] *Id.*

[19] SEGREGATION OR COMMUNITY INTEGRATION: ENSURING THE CIVIL RIGHTS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES IN ILLINOIS (2004) 4 HTTP://WWW.EQUIPFOREQUALITY.ORG/PUBLICATIONS/CIPPREPORT.PHP

The Federal Government Has A Key Role In Ending Unnecessary Institutionalization

In 2001, recognizing the leadership role that federal agencies can have to facilitate *Olmstead* implementation, then President Bush signed Executive Order 13217, which required all federal agencies to evaluate their regulations, policies, and programs to determine whether any should be revised or modified to improve the availability of community-based services for individuals with disabilities.[20] The two federal agencies we are reviewing in this report, the U.S. Department of Health and Human Services; and the U.S. Department of Justice completed this evaluation and identified numerous steps they could take to facilitate community integration.[21]

A. U.S. Department of Health and Human Services

The Department of Health and Human Services (HHS) Office of Civil Rights (OCR) is primarily responsible for ensuring that HHS policy promotes access to home and community-based services for individuals with disabilities. As part of that effort, the HHS Centers for Medicare and Medicaid Services (CMS) also has a role to ensure that Medicaid policy is administered in a manner that does not lead to unnecessary institutionalization. Both of these agencies have focused on enforcement but could be much more aggressive and transparent in their efforts.

Office for Civil Rights, U.S. Department of Health and Human Services

OCR is the agency primarily responsible for ensuring that state HHS agencies comply with Olmstead. In this role they immediately began educating states about *Olmstead*'s requirements and the possible implications for HHS programs. In particular, OCR advised states concerning development of a comprehensive effectively working plan for moving unnecessarily institutionalized persons into the community.[22] On January 14, 2000, OCR and CMS issued a joint letter to state Medicaid Directors indicating that state plan development would be an initial focus of OCR's enforcement efforts. It reads:

> Our intent in this enclosure is to identify some of the key principles, including the involvement of people with disabilities throughout the planning and implementation process. These principles also will be used by the Office for Civil Rights as it investigates complaints and conducts compliance reviews involving "most integrated setting" issues. We strongly recommend that States factor in these principles and practices as they develop plans tailored to their needs.

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[20] See: http://www.presidency.ucsb.edu/ws/index.php?pid=61498

[21] For the DOJ and HHS responses to EO 13217 *see* http://www.namiscc.org/newsletters/December01/hhs-report.htm

[22] *Olmstead* at 605-606 (The Supreme Court had ruled that such a plan would provide states with a fundamental alteration defense to a judicial finding that the state is in violation of the ADA integration mandate).

This letter also signaled to states that OCR would be investigating complaints and conducting compliance reviews. This program guidance from HHS was a standard against which states and advocates could monitor and assess *Olmstead* compliance. The other component of OCR's enforcement efforts was to encourage disability advocates to file complaints with their office on behalf of individuals who were unnecessarily institutionalized. Unfortunately, neither OCR's intent to hold states accountable to Olmstead plans, nor its outreach to citizens to file *Olmstead* complaints, was implemented effectively.

For example, OCR's push for disability advocates to file *Olmstead* complaints, was followed up by an investigation process that frequently excluded the individuals who filed complaints. While not universal, many OCR regional offices failed to acknowledge receipt of complaints or follow-up regarding the outcome of the investigation. The "closed" investigation process also meant that, with a few exceptions, OCR has not consulted with protection and advocacy agencies (P&As) or other advocates when investigating a complaint. P&As could provide OCR investigators with information to help them determine whether the violation is restricted to one resident or is evidence of a systemic failure within the institution.

OCR's non-transparent approach to its investigations persists at the national level as well. The Office has released only raw data and minimal details about investigations and compliance reviews conducted. In the future, we urge OCR to release more information about the process used and specific outcomes of its *Olmstead* complaint investigations. Better data would help states and advocates to assess state compliance efforts, and tell us if OCR is resolving complaints on a systems level. For example, releasing data on the particular settings that are the subject of *Olmstead* complaints, would allow P&As to identify which facilities are frequent settings of Olmstead complaints. With this information P&As and advocates would know to reach out to these facilities with training and information on best practices for conducting community needs assessments and discharge planning.

OCR efforts to monitor state *Olmstead* plan development and implementation has also been less aggressive and transparent than what is needed to ensure *Olmstead* compliance. HHS's January 2000 guidelines for state plans seemed promising, but there is no evidence that, after 2002, states plans were reviewed to ascertain compliance with these guidelines.[23]

At a minimum, OCR needs to begin, on an annual basis, tracking whether states are making progress reducing their institutional census or decreasing institutional spending. States that are not making noticeable progress ending inappropriate institutionalization should be feeling public pressure from OCR to make changes or face a DOJ lawsuit. OCR could also track which states have applied for the federal grants made available

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[23] In 2002 the US DOJ did issue a letter of corrections that cited Olmstead and referred to the guidelines for "state Olmstead plans" that were set out in the January 2000 letter, *See* http://www.usdoj.gov/crt/split/documents/laguna_honda_hosp.pdf

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over the past decade to incentive state spending on home and community-based services. Those states that did not apply for any of these programs could be prioritized for OCR technical assistance and assessment of Olmstead compliance. OCR should also put the U.S. Department of Justice on notice that these states may be violating the *Olmstead* mandate.

Data shows that seven states have failed to decrease their spending on institution services, [24] Yet, OCR does not appear to have questioned these states *Olmstead* compliance efforts. If OCR has done so secretly, it is time to break the silence. Reprimanding a state secretly is not nearly as effective an enforcement tool as if the state is publically warned to increase its compliance efforts.

On a funding level, OCR's ability to enforce *Olmstead* aggressively over the past 10 years has been hamstringed. In the year of *Olmstead*'s passage, a Commission report stated that:

> OCR operates under severe budgetary constraints . . . OCR's responsibilities and workload have increased over the past several years, yet its funding and staffing have decreased. OCR's budget has fluctuated around $20 million since 1981, and has not kept up with inflation.[25]

Three years later the Annual budget for OCR was not significantly increased[26] and yet OCR enforcement responsibilities had greatly expanded to include not only oversight of Olmstead, but also of the Health Insurance Portability and Accountability Act. Happily, this funding trend is beginning to change. The 2008 -2009 budget contained a six million dollar increase, and the 2009-2010 budget has a slight one million dollar increase. A tight budget however, does not excuse a failure to approach Olmstead enforcement more systemically and to reach out to P&As and disability advocates as a component of its enforcement reviews. Neither should it mean so few compliance reviews are conducted, nor effect whether details of these reviews are made known to the public.

Centers for Medicare and Medicaid Services (CMS), Department of Health and Human Services

CMS can provide the regulatory framework for States to rebalance Medicaid long-term care funding to facilitate community integration. Unfortunately, over the past 10 years, CMS has not appeared aggressive in its efforts to look for policy changes that would promote community integration. First let's switch from what CMS could have done to what the U.S. could have done to promote compliance with the Olmstead mandate. The U.S. Congress has not been as helpful as it could be to advance movement from institutions to the community. Specifically, Congress has passed mainly short term

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[24] Braddock at 9.

[25] U.S. Commission on Civil Rights - Funding Federal Civil Rights Enforcement: 2000–2003, published April 2002 available at: http://www.usccr.gov/pubs/crfund02/report.htm

[26] Budget of the United States Government, Fiscal Year 2003, at 466.

financial incentive programs that states can voluntarily apply for in order to receive funding to promote movement from institutions to the community. Some of the major financial incentives Congress has passed over the past decade include:

- Congress in 2000 created the Real Choice Systems Change grant program. Between June 2001 and June 2008, over 8 funding cycles, 342 Real Choice Systems Change grants have been issued awarding approximately $270 million to the 50 states, the District of Columbia and two U.S. territories[27].
- Section 6071 of the 2005 Deficit Reduction Act, created the Money Follows the Person Rebalancing Demonstration, which makes it easier for states to apply for home and community based waivers. The program authorized $1.7 billion in grants to states and lasts from 2007-2011.
- Another section of the Deficit Reduction Act established a demonstration program so people with disabilities will receive a single comprehensive assessment on the date of discharge from a hospital. The purpose of the "comprehensive assessment" is to "determine the appropriate placement of such patient in a post-acute care site. The "assessment instrument" establishes a presumption for community-services, and a hospital protocol that focuses on home and community-based services.
- the Health Insurance Flexibility and Accountability Initiative, one aspect of which is to make it simpler and easier for states to submit waiver requests and to have those requests promptly considered.

These programs have been vital to some states that have moved individuals out of inappropriate institutions and into the community with supports[28]. However other states applied and did not receive funding or never even applied for funding. Another big problem with Congressional reliance on short-term grants to re-balance Medicaid is the constant threat that as the *Olmstead* decision becomes a distant memory Congress will shift their funding to newer priorities and *Olmstead* grants will dry up.

It would be much quicker if Congress facilitated Olmstead compliance by changing the Medicaid statute. Current Medicaid law makes it mandatory for all states that participate in the Medicaid program to provide institution based care for those who need it. On the

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[27] http://www.cms.hhs.gov/RealChoice/

[28] The largest of these grants is the Real Choice Systems Change grants, which include: the Money Follows the Person Initiative; the Independence Plus Initiative; a national state-to-state technical assistance program for community living at Rutgers University; family-to-family health care information and education centers; community-based treatment alternatives for children; respite care for children; and technical assistance for consumer task forces; respite care for adults; and 2 demonstration projects, including, one to assess a new definition of homebound for purposes of Medicaid coverage; and the second, to attract and retain home health workers.

other hand, there is no requirement for states to provide home and community based services for those who need it, provision of these services is optional. This is known as Medicaid's institutional bias and it is a statutory requirement that hinders compliance with the Olmstead mandate. For nearly a decade, some members of Congress have introduced bills attempting to correct the institutional bias in Medicaid law. 29 Unfortunately, these bills have not passed.

Switching from what Congress to do, back to what CMS can do to enforce Olmstead, there are many ways CMS can promote *Olmstead* enforcement without needing Congressional action. Over the past decade CMS has done some work in this area, but with national data still showing that more funding goes to institutions than to the community, it is clear more needs to be done. Some examples of CMS *Olmstead* related efforts in the past decade include:

- clarifying that Medicaid waiver funds can be used to cover one-time transition costs associated with moving and to purchase medical equipment for nursing facility residents in the process of transitioning to the community;

- providing guidance on how to use existing CMS Medicaid data (known as minimum data set) to identify individuals who are in nursing facilities and have indicated an interest in moving to the community with supports. The guidance also discussed the reasonable accommodation requirements of Title II of the ADA.

- working with HUD to coordinate Medicaid HCBS transition programs with HUD housing. Collaboration is vital because Medicaid does not pay for room and board. Some examples of CMS coordination with HUD over the past decade, include: the Access Housing initiative which targeted 2000 vouchers over 5 years for persons transitioning out of nursing facilities; awarding funds to housing authorities to improve accessibility in public housing; and removing policy barriers that made it difficult for people with disabilities to utilize housing vouchers.

CMS policy has not always supported community integration, however. For example, on December 4, 2007, CMS issued an interim final rule on case management services. The rule restricted payment for transitional case management, a vital support for individuals with disabilities. Advocates and providers submitted comments to CMS arguing that the rule would make it more difficult for community providers to offer individuals with mental illness coordinated mental health, substance abuse, and primary care.30 Despite knowledge of its negative impact, CMS went forward with the rule.

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29 Examples of allowing individuals eligible for skilled nursing facility care to receive community based attendant services, include: The Medicaid Community Attendant Services and Supports Act (S. 971); the Community Choice Act (CCA) (S683/HR1670) and the Community First Choice Act included in a 2009 Senate health reform proposal.

30 http://www.ncd.gov/newsroom/publications/2009/pdf/ProgressReport.pdf at 33.

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CMS has also failed to accept advocates recommendations on low-cost, simple ways to remove administrative barriers to community integration. For example: broadening state authority to cover "nurse delegated" services (nursing services that a nurse can legally delegate under state law to a lower level qualified provider – thus reducing the cost and increasing the possibility that an individual can find a community-based provider of the needed service); and prohibiting states from requiring that beneficiaries be homebound before they can receive home health services. This reluctance to remove known regulatory barriers to community integration – perpetuates the feeling that *Olmstead* compliance is not taken as seriously as a civil right.

The good news is that the current Administration was willing to partially rescind the harmful rule on Medicaid coverage of targeted case management, May 6, 2009. Also that summer, the Administration broadened state authority to cover "nurse delegated services" and loosened Medicare's homebound requirements. Another positive step forward is the recent draft regulations which would eliminate the diagnosis based criteria for Medicaid waivers, and replace it with the more encompassing "needs based" criteria. Hopefully, these long awaited regulatory fixes will continue.

One area ripe for HHS program guidance relates to the connection between Pre-Admission Screening and Resident Review (PASRR) and *Olmstead* enforcement. PASRR is a provision of federal Medicaid law.[31] It requires states to screen individuals with intellectual disabilities or mental illness prior to placing them in a nursing facility, to determine whether the individual requires nursing facility level services or whether their needs can be met in the community. PASRR is designed to prevent inappropriate placement of people with intellectual disabilities or mental illness in a Medicaid certified nursing facility when community living is appropriate. PASRR also requires states to provide people with these disabilities living in nursing facilities with the therapy and health care that would assist them to be able to move to the community.

In 2006 The HHS, Substance Abuse and Mental Health Services Administration, issued a report on PASRR implementation in nursing facilities and found that 34 states have "some consideration of PASRR within the broader context of their Olmstead planning"[32]. HHS went on to recommend that CMS "Increase guidance to States, clarify/modify certain regulations."[33]

CMS should fulfill this recommendation and issue guidance clarifying that: 1) a PASRR determination that a nursing facility is needed should only be made by a staff member adequately trained in meeting mental illness needs; and 2) If an individual is found to require specialized services to treat their mental illness, the State Medicaid agency ultimately is responsible for providing or arranging for provision of those specialized

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[31] Nursing Home Reform Act under the Omnibus Reconciliation Act (OBRA) of 1987, as amended by OBRA 1990, 42 USC 1396r (e) (7), later revised by the Balanced Budget Act of 1996.
[32] "PASRR Screening for Mental Illness in Nursing Facility Applicants and Residents" at: http://nasmd.aphsa.org/medicaid_mental/docs/PASRR_Screening_for_Mental_Illness_in_Nursing_Facilities.pdf page 35.
[33] *Id.* at 37.

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services.. The guidance would also encourage states to: 1) have a policy linking people found eligible for "skilled nursing facility level of care" to appropriate community based services to support these needs; 2) request permission from CMS to obtain and use Medicaid data to identify people in nursing facilities who have indicated they wish to leave; and 3) expand PASRR reviews to include individuals with brain and spinal cord injuries.

B. The U.S. Department of Justice (DOJ)

Civil Rights Division, U.S. Department of Justice

The DOJ Civil Rights Division (CRD) has enforcement authority for the ADA Title II, and the "integration mandate" regulation. Yet, a CRD October 2008 report to Congress on DOJ enforcement of the Americans with Disabilities Act "*Access for All: Five Years of Progress Enforcing the ADA*" includes no mention of the *Olmstead* decision or any Division efforts to enforce the integration mandate of Title II. This is not to say that the DOJ has not enforced *Olmstead*, it has done so, but it has never brought a suit primarily to ensure *Olmstead* compliance.

As of the time this research was completed, in September 2008, DOJ *Olmstead* enforcement has been a secondary outcome of DOJ's main focus which is squarely on enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA). CRIPA allows the DOJ to investigate conditions in public residential facilities and to take appropriate action if they see a pattern or practice of unlawful conditions, such as abuse or neglect that deprives persons confined in the facilities of their constitutional or federal statutory rights. DOJ indicates in its 2008 *Report of Activities to Enforce CRIPA* that one aspect of CRIPA enforcement is to "ensure that public officials operating healthcare facilities are taking adequate steps to provide services to residents in the most integrated setting appropriate to their needs"[34]

From January 20, 2001 through September 30, 2008, the Division opened 94 CRIPA investigations, issued 71 findings letters, filed 32 cases, and obtained 69 substantial agreements.[35] As is the case with U.S. HHS, data available concerning DOJ enforcement of ADA integration mandate is available but is not comprehensive. This National Council on Disability spoke of this problem in a 2005 report stating that:

> In short, DOJ's annual reports make it impossible for Congress or other interested parties to monitor DOJ's work. More important, the absence of strong annual reports undermines DOJ's ability to leverage its work through voluntary compliance and serves to discourage people in institutions from reporting illegal conditions in institutions to DOJ. .. [NCD] *Recommendation:* DOJ should improve its CRIPA enforcement reports to Congress by including the full range of data required under the statute.

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[34] Department of Justice Activities Under the Civil Rights of Institutionalized Persons Act Fiscal Year 2008 http://www.usdoj.gov/crt/split/documents/split_cripa08.pdf , 19).
[35] *Id.* at 2

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> Doing so will increase accountability and enable the public to better understand the Federal Government's enforcement of the rights of people who reside in institutions.[36]

The data we have shows that over the past 10 years CRIPA activities have not focused on integration mandate compliance with the same commitment as it does whether the state plans to fix up institutions that have failed to keep residents safe from abuse and neglect.

A particular frustration documented by NDRN is the DOJ's willingness to sign settlements affecting individuals living in institutions without ensuring that residents will receive services in the most integrated settings appropriate and a failure to collaborate with the P&A systems when completing CRIPA investigations. These frustrations were also expressed by NCD in 2005 in a report to Congress that recommended:

> [CRIPA] Department staff should err on the side of being more, rather than less, prescriptive in case settlements. Department staff should insist on specific outcomes rather than more general policies and procedures to remedy violations and guard against regression when monitoring ends [and] DOJ should make better use of local protection and advocacy agencies charged with investigating abuse and neglect in institutions, and other nonprofit advocacy organizations with well-established records of protecting the rights of people in institutions."[37]

DOJ CRIPA settlements can be an important vehicle for ensuring state *Olmstead* compliance. Yet, an NDRN review of several proposed and approved CRIPA settlement agreements reached by the DOJ between 2005 - 2009 with states and municipalities, revealed that the focus of these settlements was heavily tilted toward improving conditions at facilities and little on ensuring residents will be receiving services in the most integrated settings appropriate to their needs.[38]

In considering the essential provisions for a DOJ CRIPA settlement, minimum requirements for any agreement should include adoption of the principal of providing services in the most integrated setting and the recognition and acceptance that all individuals can be served in the community. A settlement should ensure: individual involvement; informed decision-making and choice; person-centered planning; transition planning; implementation of plans; developing and expanding community capacity; monitoring of community placements; and quality assurance. Until future DOJ settlements focus on community integration, instead of just improving services in already failing institutions, the Department is virtually guaranteeing that institutions remain the *status quo* for individuals with disabilities.

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[36] The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise??, by the National Council on Disability August 8, 2005http://www.ncd.gov/newsroom/publications/2005/personsact.htm#appendixiii
[37] *Id.* at "Executive Summary."
[38] This report and press release, "National Disability Rights Network Applauds "Year of Community Living", Continues to Question Department of Justice Pouring Millions into Preservation of Failed Institutions," is available at http://www.ndrn.org/media/default.htm

In addition, DOJ should clarify some oft litigated ADA integration mandate questions. One method of clarification is to issue "DOJ findings letters." Excerpted below is an April 2003 DOJ "letter of findings" regarding an agreement entered with San Francisco in July 2001 under its CRIPA authority. The DOJ and HHS, OCR conducted a joint review of the California Laguna Honda Hospital and Rehabilitation Center (LHH) and issued these findings related to the City's compliance with Title II of the ADA. It is one of very few good examples of DOJ clarification of *Olmstead* requirements:

> [DOJ and OCR] have identified several areas of deficiencies that contribute to the unnecessary isolation of qualified residents at LHH. These areas include inadequate assessments, inadequate discharge planning, and inadequate capacity in the community to meet the needs of LHH residents for whom community placement is appropriate[39].

The letter goes on to list specific actions that "at a minimum" LHH and San Francisco must take to remedy including:

> Allocate adequate funding for, or otherwise provide home and community-based services to ensure that LHH residents are not unnecessarily isolated at LHH; and 2) Develop and implement a system-wide assessment of various subcontracted community programs to identify network gaps as well as areas of highest demand, and to provide a basis for comprehensive planning, administration, and resource targeting in San Francisco.[40]

Another mechanism for clarifying integration mandate requirements is by filing or intervening in cases that raise questions about the scope of the legal mandate. As the National Council on Disability (NCD) noted in its 2000 report "Promises to Keep: A Decade of Federal Enforcement of The Americans with Disabilities Act":

> The Department of Justice's ability to enforce ADA is not restricted to waiting for individuals with disabilities to file complaints of violations. Compliance monitoring refers to proactive measures to assess and ensure conformance with the requirements of a law in advance of the report of a violation.[41]

The NCD report further explains that:

> Title II of the ADA ... is subject to the same remedies, procedures, and rights set forth in Section 505 of the Rehabilitation Act of 1973. [which]... is subject to the same remedies, procedures, and rights

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[39] *See*,http://www.usdoj.gov/crt/split/documents/laguna_honda_hosp.pdf Page 3.
[40] *Id.* at 25.
[41] " at: http://www.ncd.gov/newsroom/publications/2000/promises_2.htm
[*See* section 2.4 Compliance monitoring]

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> set forth in title VI of the Civil Rights Act of 1964. Under the Department of Justice's regulations implementing Title VI, the Department shall conduct periodic compliance reviews of recipients to determine whether they are complying with Title VI. (28 C.F.R. § 42.107(a).) Thus, through this chain of references, the Department has authority to conduct compliance reviews under [ADA] Title II.[42]

The Obama Administration has indicated that it intends to move in this direction. Hopefully, future reports will show examples of DOJ cases brought to enforce the Olmstead mandate; DOJ intervention to support plaintiffs in Olmstead cases brought by private attorneys; strong community integration requirements in all relevant CRIPA settlements; and a focus on the importance of person-centered transition planning; and Olmstead compliance in all relevant CRIPA investigations.

Other methods of DOJ *Olmstead* guidance need to continue. For example, it is vital that DOJ clarify the meaning of the language in *Olmstead* which states that, "Nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings."[43] A few courts have held that states must maintain institutions just so that individuals living in an institution can remain in their current institution.[44] The majority of courts, however, have held that there is nothing in *Olmstead* that suggests that a state has to provide institutionalized care at the facility of the resident's choosing. The integration mandate is simply the right to be transferred to a community placement, if medically appropriate and if the State can reasonably accommodate the placement.[45]

Just as vital is the need for DOJ advice on what constitutes a fundamental alteration in the context of the *Olmstead* decisions. This could include guidance on the interplay between Medicaid waiver cost caps and the integration mandate and re-iteration of the necessary components for a comprehensive effectively working state plan for moving individuals into the most integrated settings.

INDIVIDUALS WAIT NEEDLESSLY IN INAPPROPRIATE SETTINGS

P&As hear from dozens of people each year seeking assistance to avoid or move out of nursing facilities, intermediate care facilities and state hospitals, and return to their own homes, neighborhoods and communities with supports. The stories of just some of these individuals follow.

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[42] *Id.*
[43] *Olmstead v L.C. and E.W.* at 601-602.
[44] These arguments have been presented most powerfully and consistently by the Voice of the Retarded
[45] *See, Richard C. ex. Rel. Kathy B. v. Houstoun,* 196 F.R.D. 288, 292 (W.D. 1999) aff. *sub. nom, Richard C. v. Snider*, 229 F. 3d 1139 (Table) (3d Cir. 2000). By its specific terms, the integration mandate requires movement from more to less restrictive settings, not the reverse. *See, Richard C. v. Houston,* 196 F.R.D. 288, 291-92 (W.D. Pa. 1999).

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A 55 year old client with mild intellectual disability and anxiety disorder had been living in a state-operated residential facility since 1969. Because of her anxiety, the client was afraid of the extensive dental work she needed. In 2008, a PADD advocate of the Office of Protection and Advocacy for Persons with Disabilities (the Connecticut P&A) helped the client try an anti-anxiety medication and begin a desensitization process of regular dentist visits. As a result, the client had several successful dental appointments, has made positive strides, and is making a plan for community placement.

A 16 year old girl lived at a state hospital for approximately 8 months due to self-inflicting, harmful behaviors. The client lived in one particular foster home in her home county where she wished to return upon discharge. The hospital agreed she was no longer a suicide risk, but had made no plans for her release. The client's former foster parent called Disability Rights Wisconsin (the Wisconsin P&A) to get her out of the hospital. P&A staff attended discharge planning meetings and helped to prepare an appropriate plan of services. She now lives with the foster family of her choice and is doing well in the community.

Indiana Protection and Advocacy Services (the Indiana P&A) helped a 23-year-old man with quadriplegia from a spinal cord injury who wished to remain in his temporary home, given to him through community placement. The client was happy with the fully-accessible home in which he had a spacious room, roll-in shower, and private deck. However, his insurance company and case manager informed him that the placement was only temporary. The client's provider determined he could stay if he received more hours of personal care assistant (PCA) supports. At the client's request, PAIR staff helped him complete and submit a PCA appeal to the Department of Human Services (DHS), which determined he needed a higher number of PCA hours for proper care. The increased PCA hours enabled the client to remain in his chosen home where he is currently enjoying freedom to date his girlfriend, investigate post-secondary school options, and maintain his health.

A 41 year old female with traumatic brain injury, intellectual disabilities and substance abuse, contacted DisAbility Rights Idaho (the Idaho P&A) while residing at a state facility. The client requested assistance to enter into a community outpatient addiction recovery rehabilitation program she was told was necessary prior to a discharge from the facility. PAIMI staff ensured that her discharge was planned and helped facilitate transportation in the community. As a result of PAIMI intervention, the client completed appropriate programming, was discharged, and is living independently in the community with community supports.

Ohio Legal Rights Service (the Ohio P&A) helped a client who lived in a nursing facility for more than a year and wanted to live in a home or apartment. PAIMI staff attended team meetings and negotiated with staff and the client's guardian to permit discharge to a home of the client's choice. However, the manager denied her application based on presumptions about her ability to succeed in independent housing because of her mental illness. PAIMI staff represented the client at an informal hearing to challenge the denial of her application. The management reversed its decision and accepted the client's application for residency. PAIMI successfully protected the client from discrimination based on disability, as well as her fair housing rights and right to accommodations.

South Dakota Advocacy Services (the South Dakota P&A) assisted a 67 year old male with severe depression and diabetes. The client's treating physician considered placing him at the state inpatient psychiatric hospital because he feared the client lacked the ability to take care of his medical needs at home. PAIMI staff contacted the state's adult services department regarding funding and home health care service options. PAIMI staff also contacted several of the client's support systems in the community. A civil commitment hearing was scheduled, and PAIMI staff met with the client's court appointed attorney and the qualified mental health professional conducting an evaluation to determine whether to recommend long-term psychiatric care. Because of PAIMI involvement, the petition for commitment was dismissed and the client was discharged with more services and supports in place to continue living independently in the community.

Disability Rights Oregon assisted a 12 year old with autism and bi-polar avoid institutionalization and obtain appropriate community supports. The child's mother called requesting assistance accessing services for son. The school had told her that the child was not welcome to return to any of the schools in the rural district. The district told the mother that in order to get needed services she should sign over her parental rights and make her son a ward of the state. The district said that if client hurts his sister then the state would take both of the son and daughter away from their mother. The client has episodes where he is emotionally distraught, kicks, throws himself, shakes his head, etc and he can sometimes hurt others in the process. These episodes are part of his disabilities. The district refused the mother's requests for an aide. The P&A helped the mother fight institutional placement. Instead appropriate services were found in a day treatment program. The child is receiving services and still able to return home with his family in the evenings.

RECOMMENDATIONS FOR THE OBAMA ADMINISTRATION

In fulfillment of this Administration's commitment to "The Year of Community Living" HHS and DOJ must move beyond use of voluntary incentives, and spur on stubborn states with mandates. States have had 10 years to beef up their community integration infrastructure. For a handful of states the voluntary approach has been effective – populations and funds are shifting. For the other states the time for voluntary action has expired. In these states people are not moving off of community support waiting lists at a reasonable pace; Olmstead plans have not been implemented and institution censuses have barely declined. This is the Year for Community Living – the time in which civil rights are taken seriously. NDRN urges the following recommendations:

A. <u>Department of Justice</u>:

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- File and intervene in cases to support full enforcement of the ADA Integration mandate.
- Strengthen the community integration aspects of all future CRIPA settlements.
- Clarify some questions regarding the integration mandate on which federal courts are split

B. Health and Human Services, Office of Civil Rights:

- Prepare an annual report of state institutional census. This would include tracking whether states are making progress reducing their institutional census. States that are not make noticeable progress ending inappropriate institutionalization should be under public pressure from OCR to make changes or face a DOJ lawsuit.
- Work collaboratively with P&As and disability advocates to supplement *Olmstead* compliance reviews.
- Conduct annual reviews in selected states which have failed to implement plans that met the basic components identified in the January 14, 2000 HHS letter to state Medicaid Directors.
- Communicate with DOJ regarding state efforts, or lack thereof, to ensure that individuals receive services in the most integrated settings appropriate to their needs. Issues to report on could include: States which have reduced home and community based programs; States that have not reduced populations in either state hospitals, ICF's, or nursing facility populations; and states that have not applied for Medicaid community integration incentive programs.

C. Health and Human Services, Center for Medicare and Medicaid Services:

- Continue to collaborate with HUD, including announcing an expectation that State Medicaid Agencies will coordinate funding and programs with state housing finance departments, and state community development agencies;
- Issue guidance to clarify PASRR requirements focusing on its role in promoting community integration and preventing unnecessary placement in a

nursing facility. Coordinate with DOJ to facilitate better enforcement of PASRR requirements.

- Issue guidance clarifying that EPSDT can cover teenagers from 18 to 21 and explaining promising practices in transition services.
- Issue guidance offering best practices in short-term mental health crisis services. States that increase their crisis service capacity can minimize costly and disruptive hospitalization.

CONCLUSION

This report has highlighted problematic trends in the federal approach to enforce the *Olmstead* decision over the past decade. It is simply unacceptable, that after ten years there has been little progress in reducing the numbers of Americans with disabilities, nationwide, who live in institutions. The National Disability Rights Network offers this report and recommendations with the hope that federal enforcement of the Olmstead mandate by the U.S. Department of Justice and the U.S. Department of Health and Human Services -- the two agencies charged with enforcement – will turn the promise of the *Olmstead* decision into a reality for all individuals languishing needlessly in institutions.

NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities

Press Release **July 2, 2009**

National Disability Rights Network Applauds "Year of Community Living", Continues to Question Department of Justice Pouring Millions into Preservation of Failed Institutions

The National Disability Rights Network (NDRN) applauds President Obama's proclamation of the "Year of Community Living," but decries the Department of Justice's continued support of segregation of persons with disabilities. The recent proclamation of the "Year of Community Living" from President Obama and the follow-up of specific programs from the Department of Health and Human Services are important steps to the full integration of people with disabilities into the community. However, across the Washington Mall at the Department of Justice (DOJ), actions by the Special Litigation Section of the Civil Rights Division continue to force states to funnel millions of precious state dollars into maintaining outmoded, discriminatory, and dangerous facilities that will warehouse people with disabilities for generations to come.

On June 22, 1999, the U.S. Supreme Court, in *Tommy Olmstead v Lois Curtis and Elaine Wilson,* ruled that unnecessarily segregating an individual into an institution when community supports exist is a violation of the American with Disabilities Act (ADA) Title II. Specifically, the regulations covering Title II of the ADA, 42 U.S.C. § 12131, *et seq*., and its implementing regulations at 28 C.F.R. § 35.130(d) contain what is commonly called "the integration mandate," requiring states to provide community-based services for persons with disabilities who are otherwise entitled to institutional services, when certain factors are met.

Despite the ruling in *Olmstead*, the Department of Justice continues to carry out the Bush Administration practice of forcing states to "fix up" facilities that many states have abandoned as unworkable and unsafe settings for people with disabilities to live. A review by NDRN of proposed and approved settlement agreements negotiated by DOJ under the Civil Rights of Institutionalized Persons Act (CRIPA) clearly shows the failure of the DOJ to creatively work to move people into the community in a planned and safe manner, in opposition to the will of a vast majority of disability advocates. DOJ's settlements stand in stark contrast to the litigation brought by Protection and Advocacy agencies and others that have used the dreadful conditions in these facilities to move to a more humane community based system.

If the Administration is serious about its commitment to community integration, it is critical that DOJ CRIPA settlement agreements, including those pending in Texas, Georgia, and other states, be directed toward improving community integration. By wasting hundreds of millions of dollars in taxpayer money on segregated institutions, DOJ is virtually guaranteeing that these failed institutions remain the *status quo* for individuals with developmental disabilities in Texas and elsewhere.

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COMPARISON CHARTS OF DOJ CRIPA SETTLEMENTS
VS. P&A SETTLEMENTS
(in cases involving ICF/MR or SNF)

In April 2001 President Bush signed Executive Order 13217, requiring all federal agencies to evaluate Department regulations, policies, and programs to determine whether any should be revised or modified to improve the availability of community-based services for individuals with disabilities. The Department of Justice (DOJ) identified 33 actions that the Civil Rights Division would take to help implement the decision, including enforcement of the ADA integration mandate (Title II) at issue in the Olmstead decision. Sadly, the data shows that the Civil Rights Division has not focused on integration mandate compliance with the same commitment as it has other provisions of the ADA.

A 2006 Department of Justice report to Congress on the department's enforcement in the prior five years of the Americans with Disabilities Act, *"Access for All: Five Years of Progress Enforcing the ADA,"* includes no mention of the *Olmstead* decision or any Civil Rights Division efforts to enforce the integration mandate of Title II. This is not to say that the DOJ has not enforced *Olmstead*, it has done so, but it has never brought a suit primarily to ensure *Olmstead* compliance. DOJ *Olmstead* enforcement has remained a secondary outcome of DOJ's main focus, which is squarely on enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA).

CRIPA allows the DOJ to investigate conditions in public residential facilities and to take appropriate action if it sees a pattern or practice of unlawful conditions, such as abuse or neglect, that deprives persons confined in the facilities of their constitutional or federal statutory rights. While DOJ indicates in its 2008 *Report of Activities to Enforce CRIPA* that one aspect of CRIPA enforcement is to "ensure that public officials operating healthcare facilities are taking adequate steps to provide services to residents in the most integrated setting appropriate to their needs,"[i] this often becomes too insignificant an aspect of CRIPA settlements.

NDRN has reviewed several proposed and approved settlement agreements reached by the U.S. Department of Justice (DOJ) between 2005 - 2009 with states and municipalities under their CRIPA authority. The purpose of the review is to highlight the provisions that address community integration for individuals with disabilities versus the provisions focused on improving institutional conditions. Similarly, we have looked at settlement agreements negotiated by several Protection and Advocacy (P&A) agencies and compared the P&A agreements against the DOJ agreements on community integration and institutional conditions provisions.

The two charts attached show the emphasis placed on community integration versus the improvement of institutional conditions in these settlements. These charts are for illustrative purposes only and include a randomly selected sample of settlement agreements. However, **NDRN** believes these charts illustrate our concern, as we commemorate the ten year anniversary of the *Olmstead v. LC* decision, and as the Administration launches the "The Year of Community Living," that the promise of *Olmstead* and the rights of individuals with disabilities to live independently and enjoy the fullest inclusion in our society are not being recognized nor facilitated by the DOJ in its settlement agreements. The focus of the DOJ settlement agreements continues to be on improving conditions at facilities, despite the tremendous costs, both human and financial.

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The DOJ CRIPA settlements reviewed are *U.S. v. Texas (proposed, ICF/MR, 2009); U.S. v. Nebraska* (ICF/MR, 2008); *U.S. v. City of San Francisco* (SNF, 2008); *U.S. v. Kentucky* (ICF/MR, 2006); and *U.S. v. New Jersey* (ICF/MR 2005).

The P&A settlements reviewed include *Capitol People First v. Department of Developmental Services* (CA 2008, ICF/MR); *Chambers v. San Francisco* (CA 2007, SNF); and *Travis D. v. Eastmont Human Services Center* (MT 2004, ICF/MR).

In considering the essential provisions for facilitating a community integration mandate, minimum requirements for any agreement should include adoption of the principal of providing services in the most integrated setting and the recognition and acceptance that all individuals can be served in the community; individual involvement; informed decision-making and choice; person-centered planning; transition planning; implementation of plans; developing and expanding community capacity; monitoring of community placements; and quality assurance. We consider these elements essential for any agreement.

The community integration provisions charted are: principle of most integrated setting; individual involvement and choice; individual transition planning; informed decision-making and consent; education for individuals and families on community integration options; person-centered planning; developing and expanding community capacity; community housing; community healthcare/services; enhanced case management; employment and vocational services; transportation; money management; monitoring of community placements; and quality assurance.

The improvement of institutional conditions provisions included in the chart are: integrated treatment plans; comprehensive needs assessments; psychiatric services; neurological services; psychological and behavioral services/PBS; general healthcare; nutrition; restraint/seclusion; related services (speech, occupational therapy, physical therapy, etc.); risk management/safety; daily activities/habilitation; increased staffing; implementation and monitoring of agreement; and quality assurance.

By way of visual comparison we have also included an approximation of the pages dedicated to community integration versus institutional conditions.

The simple exercise of charting the provisions reveals that the DOJ settlements heavily focus on improving institutional conditions, while the P&A settlements emphasize aspects of community integration. However, in settlement agreements reached in *U.S. v. San Francisco* (6/13/08) followed by *U.S. v. Nebraska* (7/2/08), the DOJ negotiated what we consider to be two of its strongest agreements, thus far, that include elements of community integration. We believe that this emphasis on community integration by DOJ was prompted by the active involvement of Disability Rights California, Disability Rights Education and Defense Fund, and other disability rights advocates in the San Francisco, California case. Yet, in 2009 DOJ has reversed this movement toward community integration, as illustrated in the settlement agreement proposed by DOJ in *U.S. v. Texas.*

Instead of embracing *Olmstead* and focusing on moving people into the most integrated living settings appropriate to their needs, the Texas agreement emphasizes changing institutional conditions and calls for the hiring of 1,160 additional staff at the Texas State Schools (ICFs/MR).

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The enormous costs of institutions, both financial and human, are largely avoidable. It actually costs less to serve people in community settings than it does in ICFs/MR.[ii] For example, by focusing on ending the unnecessary institutionalization of people with developmental disabilities and embracing community integration, the Nebraska legislature has estimated the cost of compliance with the DOJ settlement agreement to be $2.5 million per year[iii], while the Texas agreement with its greater emphasis on improvement of institutional conditions requires $112 million over a five-year period.[iv]

This is particularly troubling, given the lack of progress Texas has made with regard to community integration. According to the 2008 *State of the States in Developmental Disabilities*[v], a whopping 57% of federal intellectual and developmental disabilities (I/DD) Medicaid spending in Texas is on institutional care and only 31% on home and community-based services (HCBS). In contrast, Nebraska spends 25% of its I/DD Medicaid funds on institutions and 56% on HCBS.

If the Administration is serious about its commitment to community integration, it is critical that DOJ CRIPA settlement agreements, including those pending in Texas, Georgia, and other states, are directed towards improving community integration. By pouring over $100 million into segregated institutions, DOJ is virtually guaranteeing that ICFs/MR remain the *status quo* for Texans with developmental disabilities and this is true in other states.

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[i] *See,* http://www.usdoj.gov/crt/split/documents/split_cripa08.pdf at page 19.

[ii] *See,* Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007 at page 72, http://rtc.umn.edu/docs/risp2007.pdf

[iii] *See*, State Of Nebraska FY2009-10 / FY2010-11 Biennial Budget at page 49, http://www.nebraskalegislature.gov/pdf/reports/fiscal/2009budget.pdf

[iv] *See*, "State Reaches Settlement with DOJ on State Schools Investigations," http://www.txddc.state.tx.us/resources/publications/fyi/fyijun09/fyistate06-09.asp

[v] Braddock et al., *State of the States in Developmental Disabilities*, University of Colorado, 2008.

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7-1-09

COMPARISON OF DOJ AND PROTECTION AND ADVOCACY SETTLEMENT PROVISIONS RE INSTITUTIONAL CONDITIONS

INSTITUTIONAL CONDITIONS ELEMENTS	U.S. v. Texas (proposed 2009) Tx State Schools ICF/MR	U.S. v. Nebraska (2008) Beatrice State School ICF/MR	U.S. v. San Francisco (2008) Laguna Honda SNF	U.S. v. Kentucky (2006) *Oakwood ICF/MR*	U.S. v. New Jersey (2005) Woodbridge ICR/MR		Capitol People First v. Dept of Develop Services (CA 2008) ICF/MR	Chambers v. San Francisco (CA 2007) Laguna Honda SNF	Travis D. v. Eastmont Human Services Ctr (MT 2004)	Jackson v. New Mexico (1997) ICF/MR	Arnold v. Arizona Department of Health Services (1995) MH Facility
Integrated treatment plans	X	X		X					X	X	X
Comprehensive needs assessment	X	X	X	X	X		X	X	X	X	X
Psychiatric Services	X	X	X	X	X						X
Neurological Services	X	X		X	X						
Psychological & Behavioral services/PBS	X	X	X	X	X		X	X	X	X	X
General Medical Care	X	X	X	X					X		
Nutrition	X	X		X	X						
Restraint/ Seclusion	X	X	X	X	X						
Related Services (Speech, OT, PT, etc)	X	X	X	X	X						
Risk management/Safety	X	X	X	X	X		X		X	X	X
Quality Assurance	X	X		X	X			X		X	X
Implementation & Monitoring of Agreement	X	X	X	X	X			X			
Activities/Habilitation	X	X	X		X					X	
Increased Staffing	X	X					X	X			
Approximate Pages Dedicated to Conditions	25+	21+	9	5+	5+		3	2	3	3	5+

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7-1-09

COMPARISON OF DOJ AND PROTECTION AND ADVOCACY SETTLEMENT PROVISIONS RE COMMUNITY INTEGRATION

COMMUNITY INTEGRATION ELEMENTS	U.S. v. Texas (proposed 2009) Tx State Schools ICF/MR	U.S. v. Nebraska (2008) Beatrice State School ICF/MR	U.S. v. San Francisco (2008) Laguna Honda SNF	U.S. v. Kentucky (2006) *Oakwood ICF/MR*	U.S. v. New Jersey (2005) Woodbridge ICR/MR	[redacted]	Capitol People First v. Dept of Develop Services (CA 2008) ICF/MR	Chambers v. San Francisco (CA 2007) Laguna Honda SNF	Travis D. v. Eastmont Human Services Ctr (MT 2004)	Jackson v. New Mexico (1997) ICF/MR	Arnold v. Arizona Department of Health Services (1995) MH Facility
Principle of Most Integrated Setting	X	X	X	X	X	[redacted]	X	X	X	X	X
Individual Involvement and Choice		X	X		X	[redacted]	X		X	X	X
Individual Transition Planning	X	X	X	X	X	[redacted]	X	X	X	X	
Informed Decisionmaking & Consent		X	X			[redacted]	X	X	X	X	X
Education on Options for Individuals & Families	X	X	X	X	X	[redacted]	X		X	X	X
Person-centered Planning		X	X			[redacted]	X	X	X	X	X
Developing & Expanding Community Capacity		X	X	X		[redacted]	X	X	X		X
Community Housing		X	X			[redacted]	X	X	X		X
Community Healthcare/Services		X	X			[redacted]	X	X	X	X	X
Enhanced Case Management		X	X			[redacted]	X	X	X	X	X
Employment & Vocational Services		X	X			[redacted]			X	X	X
Transportation			X			[redacted]		X	X		
Money Management						[redacted]					
Monitoring of Community Placements	X	X	X	X		[redacted]		X	X	X	X
Quality Assurance	X	X	X			[redacted]		X	X	X	X
						[redacted]					
Approximate Pages Dedicated to Community Integration	3+	6+	8+	1	3	[redacted]	13	16	17+	10+	5+

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ANCOR WASHINGTON INSIDERS CLUB *Live*

National Issues

TUESDAY, NOVEMBER 3, 2009

NASDDDS Survey on State Plans to Close or Downsize

In late October 2009, NASDDDS conducted a brief email survey of member state agency officials regarding the existence of plans to close or downsize large state-operated institutional programs in their respective states. Respondents were additionally requested to indicate whether or not their current plans were being implemented in response to financial considerations.

Total NASDDDS member state agencies: 51

Total number of states responding to the survey: 49 (96%)

Of the 49 responding states, 11 (22%) states reported that they had closed all state operated institutions for persons with intellectual and developmental disabilities (IDD).

Of the 38 states operating institutional programs that responded to the survey (unduplicated count):

4 (11%) states are planning to close one or more facilities and not downsize other programs or facilities.

14 (37%) states are planning to downsize existing facilities but not close any institutions.

5 (13%) states are panning to close one or more institutions and downsize additional facilities.

15 (39%) states have no plans to close or downsize state operated institutional programs.

Summarizing the results of the data from the 38 states reveals that:

9 states (24%) have plans to close one or more institutions.

19 states (50%) have plans to downsize programs, reducing the census of existing facilities.

Financial Impact

10 states (26%) made the decision to close and/or downsize IDD facilities due to financial reasons.

Of the 4 states with plans to close some facilities but not downsize others, three states are closing the facilities for financial reasons.

Of the 14 states with plans to downsize but not close facilities, three states are downsizing for financial reasons.

Of the 5 states with plans to both close and downsize existing facilities, three states made the decision for financial reasons.

Newer Post Home Older Post

VIEW ARTICLES BY TOPIC

- 1915c Waiver (1)
- a (1)
- Advocacy (3)
- Alliance for Full Participation (1)
- Around the States: Budget Roundup (17)
- Around the States: Medicaid (38)
- Around the States: State Health Policy (25)
- Budget (32)
- Card Check (2)
- CLASS Act (8)
- CMS (12)
- Community Choice Act (1)
- Congress (2)
- Congressional Hearings (2)
- Data and Statistics (2)
- debt commission (1)
- Did You Know? (1)
- Disability Rights (3)
- DRA (1)
- Economic Recovery 2009 (27)
- Economic Recovery 2010 (4)
- Emergency Preparedness (20)
- Employment (16)
- Federal Legislation (3)
- federal regulations (1)
- FMAP (17)
- HCBS (6)
- Health Care Reform (88)
- HIPAA (3)
- Housing (17)
- ICF/MR (1)
- Labor Issues (1)
- Legislation (4)

NAC Corner

YOU NEED TO KNOW ME

H.R 868 Co-Sponsor List

ASK WORKFORCE BILL CO-SPONSORS FROM THE 110TH CONGRESS TO CO-SPONSOR IN THE 111TH!

Use ANCOR's Action Center to contact your Representative and ask them to co-sponsor H.R 868! Respond to this alert if your Representative co-sponsored the Direct Support Fairness and Security Act in the 110th Congress, but has not yet co-sponsored the bill in the 111th Congress. (See also the current co-sponsor list) Using the Action Center is easy and also provides us feedback on your outreach. Check out ANCOR's Workforce Shortage webpage for more information.

NEW H.R.868 CO-SPONSORS

Rep. Paul Hodes(D-NH) and Rep. Tim Waltz (D-MN) recently signed on to the Direct Support Professional Fairness and Security Act! Thank you to ANCOR members in for reaching out to these members.

See all 59 members of Congress supporting the bill so far!

- Litigation (15)
- lobbyist revisions (1)
- Long Term Supports and Services (15)
- Medicaid (29)
- Medicaid Integrity (1)
- Middle Class Task Force (1)
- Money Follows the Person (1)
- Olmstead (2)
- OSHA (1)
- Provider Rates (2)
- Recess Message (3)
- Regulations (1)
- Reports (2)
- SCHIP (1)
- Self Direction (1)
- Sick Leave (1)
- Social Security (6)
- Spotlight Resources (4)
- State Budgets (42)
- State Issues (54)
- State Medicaid Programs (39)
- Ticket to Work (1)
- Vocational Rehabilitation (1)
- wage and hour (1)
- Waiting List (1)
- Workforce Crisis (23)

BLOG ARCHIVE

- ► 2010 (95)
- ▼ 2009 (356)
  - ► 12/20 - 12/27 (4)
  - ► 12/13 - 12/20 (26)
  - ► 12/06 - 12/13 (8)
  - ► 11/29 - 12/06 (3)
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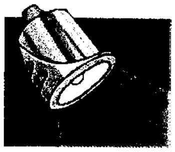
  - ► 11/08 - 11/15 (6)
  - ▼ 11/01 - 11/08 (22)
    - House Vote on Health Reform May Be as Soon as Tomo...
    - Medicaid Audits Got Down? ANCOR is Offering a Two...
    - FDA Fights False Claims About H1N1 Treatments
    - New H.R. 868 Co-Sponsors
    - NASDDDS Survey on State Plans to Close or Downsize...
    - Updated House health care bill section-by...

2009 DIRECT SUPPORT PROFESSIONAL OF THE YEAR

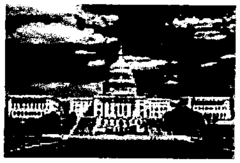
Darlene Ricco
Carson City, Nevada
Dungarvin Nevada, LLC

Learn More about 2009 Award Winners

Spotlight Resources

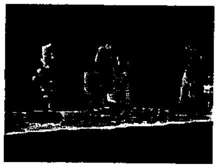


***Fiscal Survey of the States* from NGA and the National Association of State Budget Officers (NASBO)**



Advocacy Tool Kit

ANCOR PHOTOS



section

WICS Live: Around the States

WICS Live: Around the States

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New York: 500 Show Up At Hearing to Protest More P

New Mexico: Special Legislative Session Ends with

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WICS Live: Around the States

WICS Live: Around the States Blog

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WICS Live: Around the States

- ▶ 10/25 - 11/01 **(12)**
- ▶ 10/18 - 10/25 **(7)**
- ▶ 10/11 - 10/18 **(7)**
- ▶ 10/04 - 10/11 **(18)**
- ▶ 09/27 - 10/04 **(11)**
- ▶ 09/20 - 09/27 **(10)**
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- ▶ 08/02 - 08/09 **(16)**
- ▶ 07/26 - 08/02 **(10)**
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- ▶ 07/12 - 07/19 **(7)**
- ▶ 07/05 - 07/12 **(11)**
- ▶ 06/21 - 06/28 **(9)**
- ▶ 06/14 - 06/21 **(5)**
- ▶ 06/07 - 06/14 **(6)**

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- ▶ 05/31 - 06/07 (6)
- ▶ 05/24 - 05/31 (2)
- ▶ 05/17 - 05/24 (3)
- ▶ 05/10 - 05/17 (3)
- ▶ 05/03 - 05/10 (14)
- ▶ 04/26 - 05/03 (12)
- ▶ 04/19 - 04/26 (3)
- ▶ 04/12 - 04/19 (11)
- ▶ 04/05 - 04/12 (6)
- ▶ 03/29 - 04/05 (14)
- ▶ 03/22 - 03/29 (11)
- ▶ 03/15 - 03/22 (8)
- ▶ 03/01 - 03/08 (1)
- ▶ 02/08 - 02/15 (1)
- ▶ 01/18 - 01/25 (1)

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May 7, 2010

Testimony for Senate Health, Human Services and Senior Services Committee and Assembly Human Services Committee Joint Hearing

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

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

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

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

Ann C. Martinelli

A Good Life

Joe Martinelli is known for his sense of humor, his attention to details, his memory and his love of the New York Yankees. In fact, his chair has a name, "Bernie". (For the uninformed, Bernie Williams was the center fielder for the Yankees for many years!)

Joe graduated high school in 2005 and accepted a Real Life Choices Transition individual budget and completed an Essential Lifestyle Plan. Joe and his family visited a non-traditional day program and he decided to attend two days a week. Joe also spent a lot of time putting together questions he wanted to use when he interviewed for a support person. The agency he used encouraged him to write the newspaper ad himself and ran it for a short time. Joe and his family interviewed and hired a young woman. She began taking him to the day program and supported him there. She also began to hang out with Joe at his home and take him out shopping.

Joe soon realized he didn't like the day program and stopped going. Joe's support person began asking Joe to stay home more and more and he acquiesced. Joe's family thought it was what he wanted to do and didn't push him. That was a huge mistake because inside, Joe was upset and angry. He began arguing with his parents, especially his mom. It was very much out of character and disrupted his whole life. Joe began taking medication which did not help and caused side effects. Joe had always been a polite, respectful young man and once he started talking about how he felt, his family realized he didn't want to speak badly about his support person. He told his mom "I like her as a person, but she's no fun." Joe and his mom let her go and began a new journey.

Joe and his family connected with an agency and contracted with them to do job development and provide support staff. Joe's next support person was Steve, who was as fun-loving as Joe. They immediately connected and once a volunteer position was developed, Steve accompanied Joe weekly. Steve was creative, too, and this proved to be the impetus Joe needed. One day, he and Joe drove past an assisted living facility and stopped in, introduced themselves, and asked if they could visit on a regular basis. Joe is still there today. Joe and his Mom asked the agency to locate another support person and they found Carrie. Carrie was creative, too. She was a recent graduate of Monmouth University and as she got to know Joe, learned that he liked music. She approached a communications professor at MU who coordinated the radio station and asked if she and Joe could hang out during a broadcast. Not only did Furg (aka Dr. Aaron Furguson) allow them to visit "the booth", he invited them to do a one hour show with him each week. Joe is currently participating in his eighth semester on the air and last spring, the show was extended to two hours.

Unfortunately, Steve moved to Florida three years ago. But Carrie is still part of Joe's team. She will be graduating from the Monmouth County Police Academy this month and has invited Joe to her graduation. Carrie introduced Joe to Brian and Jenna. Brian accompanies Joe to his volunteer position at Vonage where he delivers gift cards to employees on the anniversary of their employment, assists him at his weekly bowling league, walks at local parks, haircuts, shopping, visiting Monmouth Park during racing season, movies and anywhere else "the wind takes them" (as Brian and Joe like to tell me). Brian introduced Joe to Chris who began supporting him over a year ago. Chris accompanies Joe to his weekly visits with the "old folks" (as Joe calls his friends at the assisted living facility). They play bingo and pokeno with them. One of the gentlemen they befriended does not come to the community room any longer, and Joe and Chris visit him in his room. Another friend introduced him to Ben, who accompanies Joe weekly to his volunteer position at a local non-profit organization in their resource library. Ben also accompanies Joe to Chris' softball games, the local pool hall and basketball games with Ben's friends. Joe has also supported Ben during talks he gives to his congregation. Jenna supports Joe by accompanying him to local high school plays, Monmouth University basketball and baseball games and walks on the boardwalk. During the past five years, these five people have introduced Joe to so many more people that his cell phone continually rings with a call or buzzes with a text message. It's a good life.

Ann and Joe Martinelli

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Senate Health Human Services and Senior Citizens Committee
and the
Assembly Human Services Committee

Friday, March 7, 2010

Thank you Senator Weinberg and Assemblywoman Vanieri Huttle for hearing testimony today.

I remember 15hearings held throughout the state, 40 hours of transcribed and archived testimony from people with developmental disabilities and their families telling their stories to New Jersey legislators and leaders in the disability community. The message: "Keep us together!" We thought you understood, we thought you finally heard us, after years of dwindling family supports and the increase of more and more families choosing to support loved ones at home and wanting different choices in the community other than just centers and group homes.

In 2006 families and people with disabilities rallied testified b the hundreds, wrote letters, sent pictures, thousands signed petitions! to make it clear that people were thinking differently, families wanted resources available to keep their families together rather than making a choice of group homes or institutional care. The majority of funding was going to residential and community placements, out of sync for families growing up in an educational system full of expectation and the promise of fulfilling adult lives for our family members regardless of their disability. Without needed supports our family members were not living, and now most families involved in that pivotal moment have joined the "waitlisters" needing transition and adult services so that they can continue to go to school to volunteer or work, to be When waiting becomes impossible unwanted placements out of the home became inevitable and common. Not by choice. Crises led to placements development centers **because there were no other choices given** .the overwhelming cry of information shared by families to the decision makers, to the DD system and to the providers who support people within that system that people and families with developmental disabilities were moving in a different direction of thinking was hear loud and clear. In 2006, New Jersey moved towards self directed services and began to recognize people wanted to be supported differently than in the past.

2010 the lists have grown ...the disproportion and the dis-appropriation of where people live and where the money goes continues to be wickedly unbalanced. The climate within the disability community is tense and mistrusting. It is sad to see that the real issue of people and families having choice has been forgotten and lost in an ugly mesh of politics, selfishness, special interests, and egos that have nothing to do with the voice of the people. I cannot understand how such a documented event in 2006,that created a historical shift in the thinking of the expectation of people with disabilities, where they choose to live, go to school and play, can be ignored? The information is not new! Why do we continue to play this game of surprise? While people wait and die to live.

What the majority of people in the state want cannot be disputed. It is to live within the community wit0h supports and services available to sustain a productive and happy life. There should not be an exclusion of the choice to remain in a development center, but today, that option is not the majority: made clear for so many years. People are being born with disabilities, surviving, growing up in families that challenge them to live life. The numbers grow, yet the supports and the resources cannot keep up. Why do you continue to support this archaic way of thinking??

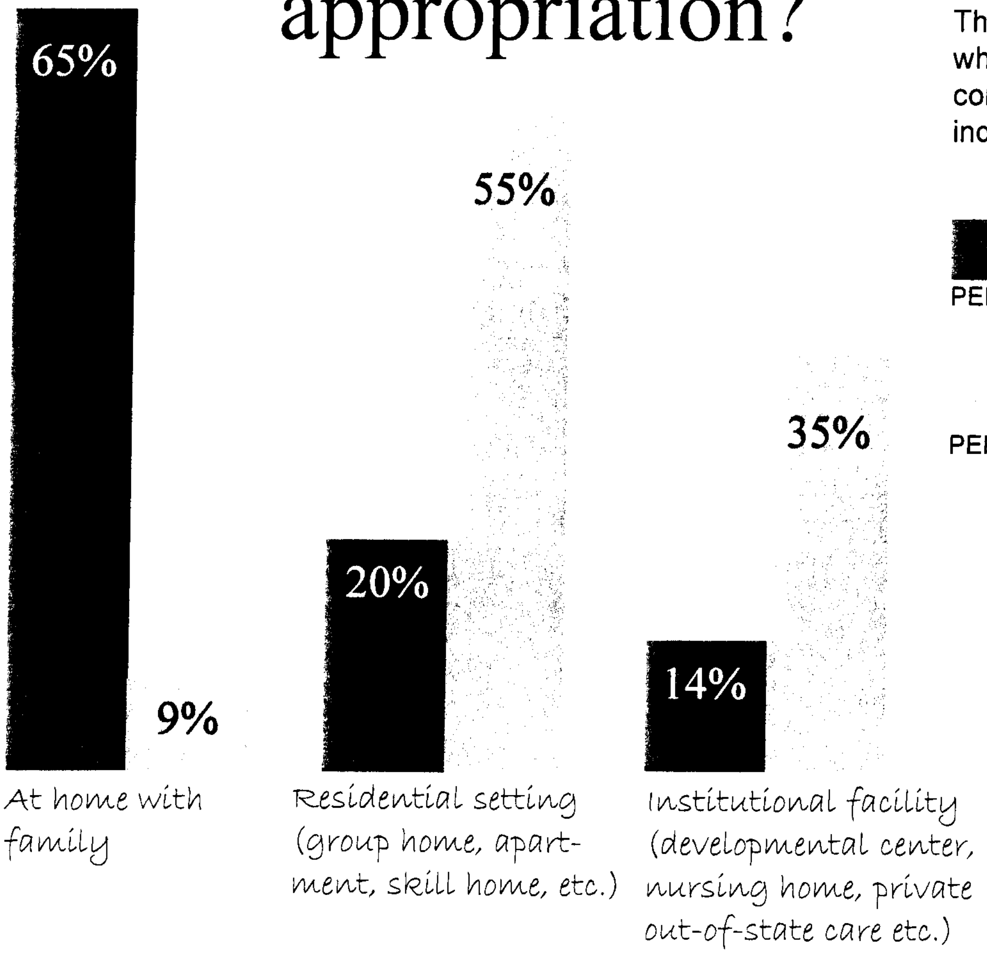
Who are we supporting? Please rebalance this system so that we can support a plan that allows opportunity for choice. I do not want to find myself here four years from now having the same stagnant conversation. We cannot continue to wait.

Monique Dujue Wilson
Parent of Khary Dominique Wilson
23 years old....striving to live!

dis

appropriation?

The total budget of the Division of Developmental Disabilities is just over $1 billion to serve a caseload of 36,622 individuals. The graphic below illustrates where the money goes compared with where individuals reside.



■ where individuals reside
PERCENTAGE OF DDD CASELOAD

where the money goes
PERCENTAGE OF DDD BUDGET

FACT *60 % of the 3,300 people on the state's priority waiting list for residential services want in-home supports to stay together, because they are not ready for out-of-home placements.*

Keep Us Together
Public Hearings

Testimony From Families

After 15 public hearings in nine locations throughout the state, families have told their stories to New Jersey legislators and leaders in the disability community. Their message was powerful, yet simple: "Keep us together!"

Public Hearing Sites
April 24 - May 23, 2006
Parsippany
Newark
Hamilton
Pemberton
Atlantic City
Gibbstown
Mt. Holly
Neptune
Paramus

> "I urge you to listen to families who are testifying and writing to you all, and to hear their stories, because they're far more powerful than any stories I can tell you. They need you to understand and represent them when it comes down to fighting for money in the family support budget."
>
> —KATHI LENTZ
> *Atlantic City Hearing*

“I ask you to demand DDD immediately begin changing its funding priorities from institutional supports and out-of-home placements to a model that will permit my daughter to live with the family she chooses, in the home she chooses and in the inclusive community of her choice.”

—Frank Tetto
Parsippany Hearing

“The day is coming that this family is going to need help, and I have no idea what the future holds for us.”

—Fay Wilson
Pemberton Hearing

“Caring for family members with a developmental disability in the home with family supports in place is still cheaper than the cost of institutionalizing that person ... Increasing the budget for family support is a win-win situation.”

—Verna Bullock-Lewis
Gibbstown Hearing

“Because (our daughter) is in Real Life Choices, my husband and I are able to work full-time jobs without having to resort to government assistance.”

—Gail Furrer
Mt. Holly Hearing

“I will be 82 in September and (my son) is 43 ... I was very pleased in 2002 when I heard about Real Life Choices because for the first time in my life, I was going to ask for something from the state to help me and that would be some respite care.”

—Jean Manogue
Parsippany Hearing

“I'm here and there's a hundred other people who are behind me who can't be here because they don't have the services. They don't have anyone to sit with their child at home. I couldn't leave Tiffany home alone. I had to bri her with me ...We don't complain about our children. It's just that we need little help, you know, to keep us going.”

—Ms. Smith
Newark Hearing

“They told us if (our daughter) was in a group home, there would be more money allocated ... I don't think it's fair. She loves being home, she loves being with her sister ... We don't want to take that away from her but we need more suppport at home.”

—Cecelia Bertonaschi
Parsippany Hearing

“Being a parent of a special needs child, we had to fight to keep her alive and we have to fight afterwards just to get her the things that she needs in order to function to the best of her ability. ...I'm going to need help with her for the rest of her life, and I will battle as long as I can to get her what she needs.”

—Michele Harps
Mt. Holly Hearing

“I try not to focus, as you know, scared out of your mind, but I don't know what the future brings. And obviously, you know, I'm relatively youn and so as I get older and I know my children won't become independent in the sense of independence, they'll always be my responsibility. I don't want to place my kids, I want my kids to be with me. There is no place for my kids.”

—Stephanie Rosati
Hamilton Hearing

“The reality for me as a young woman with a disability is that I want to contribute just like I want to live a very ordinary life in a very ordinary community doing ordinary things. If warehousing people in institutions is the way that our government decides to handle this increase of people with disabilities, I think that's a very, very sad statement.”

—Colleen Roche
Newark Hearing

“Our days were filled with feeding and caring for both babies. Our nights involved one of us staying in the girls' room to ensure their safety and look after the complicated feedings. We became totally exhausted, both physically and emotionally. Fortunately, both (my wife) and I are healthy, stable individuals, deeply committed to each other and to providing all our children with a loving home. I do not know how long we could have continued in t situation without professional assistance.”

—Robert Hage
Pemberton Hearing

(Note: Transcripts from the Paramus and Neptune hearings were not available as we went to press. Those transcripts will be posted on our website: www.njddc.org/familysupport.htm)

“(They asked,) ‘Why don’t you just place them in residential settings?’ The response was immediate and unequivocal: ‘Because we love them, and no matter what, they are part of our family.’”

—**Kathy Roberson**
Hamilton Hearing

“I turned to DDD and then was told there’s no money ... I’m doing all I can to keep my child out of an institution, to not be put in a special school, to make her a contributing person in the community. It’s not easy.”

—**Donna LeFevrre**
Pemberton Hearing

“Physically we were unable to handle (our son) anymore So we decided to put him in a group home. Which, I hate to say, was the worst thing I have ever done in my life. The care that he got was so below what I expected, and he deteriorated so badly that I don’t even want to think about it. I would have preferred keeping him at home if I had had the support that I needed.”

—**Nata Florentine**
Atlantic City Hearing

“The number of families in our communities that are living with a person with a developmental disability is growing each year. These families must be seen. These families must be acknowledged. These families want to stay together and they need the community-based programming and family supports to do so. Funding family supports is not only cost-effective, it is the right thing to do for the citizens of New Jersey.”

—**Abby Jaroslow**
Hamilton Hearing

“I want to keep my child home as long as I can. I don’t want to think about putting her in a group home. I want her to be home where I know she’s going to get the love, the nourishment she needs.”

—**Michelle Archie**
Atlantic City Hearing

“Our children are the most needy and the families receive little or no support. Families are the very fabric of our society. We’re not asking for handouts. We’re not asking for free passes, only assistance in this monumental task of raising a child with a disability. My family is a part of my community ... I’m asking for support to afford my children the same opportunities you’re able to afford and offer your own.”

—**Kim Elphick**
Parsippany Hearing

“I’m a parent fighting for my child with everything I have ... I’m asking for three hours a week. Give me two. I even offered to compromise. You know, I’m not asking for any out-of-home placement.”

—**Regina Farus**
Pemberton Hearing

“I stopped working full time, so I can provide the service (my son) needs. And, now, we’re like in another area with bills and things. And I want very much to keep him home. He has a home, he has a family that loves him, and we want to keep him home.”

—**Anna Tosen**
Newark Hearing

“We’re still taking care of our children in our 70s. Thank God we’re able to do it. It’s getting a little rough now. (our daughter) needs help with needing a lift into the bed and bath, everything. So it’s a little rough. We do our best.”

—**Josephine Cronen**
Hamilton Hearing

“Those 15 hours a month (of respite service) were an absolute God-send to me. It gave me an opportunity even if I wanted to go take a walk around the block. ...I want to try to keep (my daughter) in my home. I’m her number one advocate. I have devoted my entire life to my child and I know her best. ...I really hope that the government or whoever is making the decisions hears the outcry of parents and does provide some more money for family support. I think it is so urgent.”

—**Tara Lang**
Gibbstown Hearing

“I’m very stressed. I’m very strapped, I have no child support. I have nothing. I relate to everything about what they’re saying about putting (my son) in an institution. It will never happen. I’ll die first.”

—**Danielle Holden**
Atlantic City Hearing

> "Frankly, I don't understand how, in a very wealthy society such as ours, people who need these kind of services have to go and come up against all kinds of red tape. I don't understand that kind of thing. ...You're not asking for any kind of luxurious thing. You're asking for what I think you're entitled to."
>
> —**Assemblyman William D. Payne**
>
> *Newark Hearing*

Dear New Jersey Senate and General Assembly members,

You have just read a few excerpts, taken from more than 40 hours of testimony from 15 public hearings. We thank those of you who participated or sent a representative. As you can tell, these are families who want to stay together. They have chosen to keep their loved ones with developmental disabilities at home, instead of in residential settings that are more costly to the state. You can hear in the transcripts the frustration they feel because they cannot receive even a fraction of the services they need. Over and over again, they wanted to know why more of you were not present to hear their stories. We promised that we would get their message to you.

There needs to be an ongoing funding mechanism in the Division of Developmental Disabilities' annual budget for in-home support and transition services, and for expanding the "Real Life Choices" program. Assemblyman William Payne told the families at the hearing in Newark, "You're not asking for any kind of luxurious thing. You're asking for what I think you're entitled to." We applaud that statement. And we hope it and this publication serve as a working thesis when you consider keeping families together.

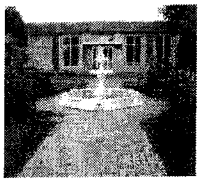
—Susan Richn
Deputy Director
NJ Council on Developmental Disabilities

Public hearings were planned by a coalition of agencies concerned about support to families
The Alliance for the Betterment of Citizens With Disabilities (ABCD)
The Arc of New Jersey
Brain Injury Association of New Jersey
Center for Outreach and Services for the Autism Community (COSAC)
The Family Resource Network
Family Support Center
Family Support Coalition
Neighbours, Inc
NJ Association of Community Providers (NJACP)
NJ Council on Developmental Disabilities (NJCDD)
Regional Family Support Planning Councils
Spina Bifida Association of the Tri-State Region
Statewide Parent Advocacy Network (SPAN)
United Spinal Association

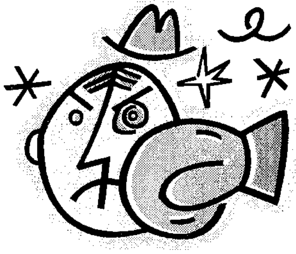
Testimony to the Senate Health, Human Services, and Senior Citizens Committee and the Assembly Human Services Committee by John Vega, on May 7, 2010

My name is John Vega and I live in Voorhees with my friends.

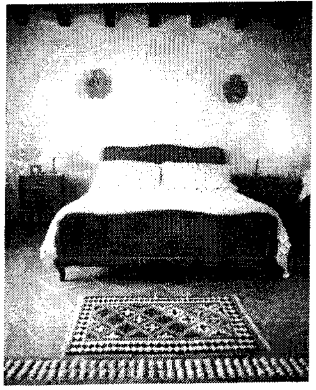
I used to live at New Lisbon for a long time and I don't want to back there.

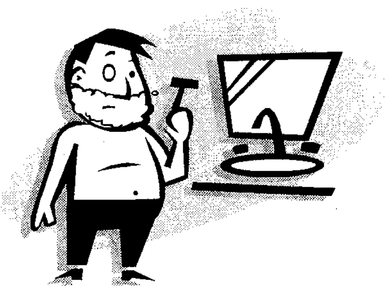


There were too many problems when I lived there. Too many people, stealing, hitting.



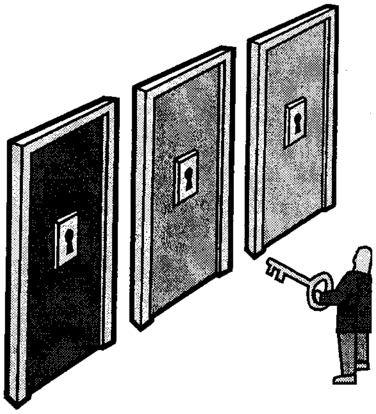
Now I have my own bedroom and my own bathroom. I like the privacy.





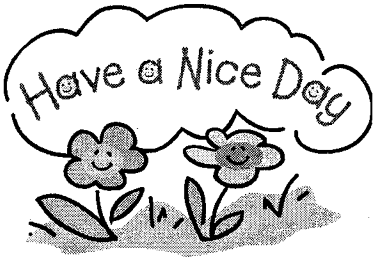
I live with my best friend, Reggie.

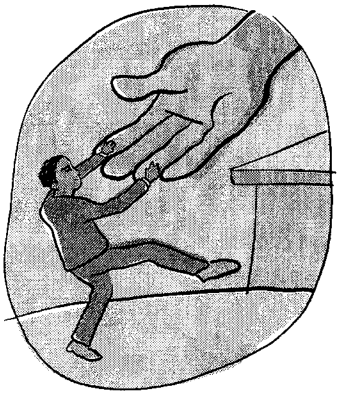
I can do what I want to do now and make my own choices.



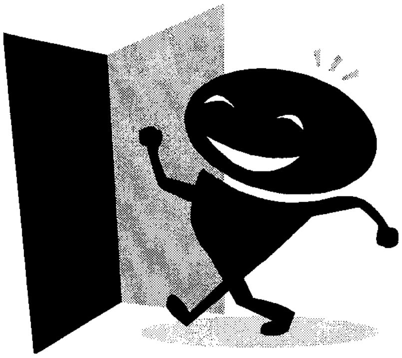
I can go where I want to go.

I like the staff who work at my house. They treat me nice and they help me.





I think everyone should be able to leave New Lisbon if they want to .



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Testimony of Rocco A. Mazza
Coalition of Families Advocating for Developmental Centers

Joint Hearing
Senate Health, Human Services and Senior Citizens and
Assembly Human Services

May 7, 2010

My brother has successfully resided in the same state developmental center for the last 36 years. He is currently 50 years old, diagnosed from birth as having severely profound mental retardation with the intellectual capacity of about a 2 year old. He suffers from cerebral palsy and has very limited to nearly no verbal ability. When my parents admitted my brother into that developmental center nearly four decades ago, they believed they were entering into a compact with the State of New Jersey that would guarantee the stability of his long term care for the rest of his life. Since then, our family has been fully satisfied with the loving care and service he has received.

I believe that many of the community based providers, some of whom are here today, are well intentioned and have a willing heart to serve our developmentally disabled. But, nevertheless, the philosophical trend toward diminishment and eventual closure of state developmental centers is a dangerous one. What we are looking at is nothing less than the wholesale privatization of care for *the most vulnerable* population among us.

It was less than a month ago when a statewide newspaper splashed a story across its front page about two disturbing incidents that occurred in 2008/2009 where two developmentally disabled women died from brutal neglect at the hands of a state-licensed private sponsor in the community. Innocent, fragile and vulnerable Tara O'Leary was sent to a private home in the community after her parents passed away. Lydia Joy Perry was under the same privatized care after she lost her parents.

Their horrible deaths are the result of a core belief that privatized care with little oversight, minimal regulatory standards and no accountability is perfectly suitable for our developmentally disabled loved ones.

New Jersey's Developmental Centers are federally certified ICF/MRs (Intermediate Care Facilities for the Mentally Retarded), adhering to very, very strict federal standards of care that include a detailed Active Treatment program, an Individual Habilitation Plan, multiple layers of oversight and on-site 24 hour medical supervision. None of which are required in community based settings. My brother suffers from periodic mild brain seizures. He is on medication and is supervised by medical personnel at his developmental center around the clock. Sometimes it is necessary for the dosage of his medicine to be adjusted. This requires constant monitoring by medical personnel. In contrast to the seven state-run facilities, there is only one privately run ICF/MR in the entire state. No other community based group home is a certified ICF/MR. By very definition, the private community provider's standards of care and regulatory oversight pale in comparison to that which is mandated upon our state-run developmental centers.

Privatization may be a logical choice for municipal garbage disposal. Privatization of sewerage services or water supplies may be the economically viable alternative on a local level. I am sympathetic to the belief that government may have grown too expensive for many of us to afford with property taxes skyrocketing. But let's be clear about this. Our developmentally disabled are the most delicate and fragile human beings among us. They are our children, our brothers and sisters and our friends. Their lives must not be contracted out to the lowest bidder.

We have a moral imperative to provide access to the best possible services for these medically needy and intellectually impaired people. With federal Medicaid subsidies based on ICF/MR

standards, the cost of care for each of our residents in developmental centers to the state treasury is minimal. The community providers cannot match the state in cost effectiveness for the extensive care that most of our residents require.

You can be sure that I am keenly aware that a developmental center may not be the most appropriate residential setting for everyone, particularly those who are blessed with a higher functioning disability. But the reality of life within some of these community settings gives me serious pause, nonetheless.

I've recently heard from a social worker in one of the seven state developmental centers who told me of an individual on the list for community placement. This individual had very specific needs for their care and it was incumbent upon the community provider to ensure that the proper equipment for this individual meet the criteria necessary for the resident's needs. The resident was released to the group home where they failed to provide the specific bed that was necessary for this individual. That resident fell off an inappropriate bed and landed in the hospital with a broken leg within the first 48 hours of their move into the community.

I've learned of a community group home in Bergen County that neglected their developmentally disabled so badly that the private provider had to eventually be removed from its operation but only after numerous complaints by neighbors who were appalled by the mistreatment they witnessed day after day after day. This is what you get with a lack of accountability and lack of federal standards.

Privatization may work for some of the developmentally challenged in our state but certainly not for many others. Closing any one of the seven developmental centers will result in not only disorienting the developmentally disabled residing in a place they call "*home*" but will also remove these vital facilities and their specialized Active Treatment programs from our choice of options. We need to protect our ability to choose the residential care setting that is best for our

loved ones. Closure of developmental centers is nothing less than a gradual elimination of that choice.

This movement toward private community providers as the dominant option for this sensitive population is troubling. Those providers who do it well deserve our applause and gratitude. But our loved ones' lives and living arrangements should not be the product of a grand community social experiment. We either do it right or don't do it at all. Lives are at stake. Community placement is a precarious choice that should be reserved for those families who willingly choose that option and who know their developmentally challenged loved one best.

Let's rethink this process. Developmental Center care should not be used as an emergency backstop but instead as the central hub of active treatment services, the level of care required in ICF/MRs, for the disabled in both state facilities and in the community.

With nearly 8,000 people on a high priority urgent waiting list for residential placement, we do not have the luxury of eliminating any residential options. I would strongly recommend the state reinvest in capital improvements to the existing seven developmental centers. Let's update and modernize them. Reopen admissions and allow families on the waiting list to exercise their right to an option of choosing developmental center placement if they so wish. We are recommending real choice for everyone.

For years, admissions to these centers have been closed by the state DDD with emergency situations and court order the only exceptions. That is an outrageous policy when you're operating under an 8,000 person urgent waiting list that will only continue expanding. It is immoral and unlawful by federal standards to deny ICF/MR services in the assessments for these individuals. Why not allow these potential new residents the option of choosing the best environment for medical care, active treatment, socialization and safety? Each center is a safe and secure community unto itself

providing all the socialization you can ask for. My brother and most other developmental center residents enjoy regular off campus recreation by attending activities in the community including camping, trips to amusement parks, ice cream parlors, sports venues and more.

Let us not only continue to use the resources that our seven developmental centers provide but let's expand them.

Developmentally challenged individuals residing in the community should be able to avail themselves of activities at the developmental centers, and within federal guidelines, the centers could offer off-campus services to those out in the community. How about forging a partnership instead of this attempt by some community providers to dismantle the developmental center infrastructure?

There is a misrepresentation of truth being peddled that you can somehow solve the waiting list problem by closing the centers and using the money saved to establish more community living opportunities. That is patently false and anyone honest enough to look at the difference in federal Medicaid reimbursement rates between ICF/MRs and community waiver programs will understand this. This is a divisive argument that only foments a deepening rift between families and advocates on both sides of this issue. We simply need to look at the long term prospects of a reality that includes a constantly growing waiting list. I promise you the waiting list will grow longer turning into a worse crisis even if you close all the centers.

Privatization is not a panacea for the needs of this *<u>most vulnerable</u>* population. Private community care is but one piece of a large puzzle. The unique expertise and federally mandated services of state-run ICF/MRs is the central anchor to this broad continuum of care. A recommitment to and reinvestment in our state's developmental centers will ensure that the growing numbers of

developmentally impaired individuals in New Jersey will always be provided for.

Allow me to conclude by briefly quoting from our survey of developmental center families on residential choice: "Our hope is that we can finally understand that the majority of those who are living at the developmental centers are happy in their homes and need to have their choices acknowledged. There is no mandate to close any centers in any law including the Supreme Court decision in the Olmstead case. The representatives of those living in our developmental centers should be respected in the same way that those who represent those living at home or in other community placements are. We all love our children and want what is best for them."

Thank you.

Rocco A. Mazza
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Lyndhurst, NJ 07071
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VOR
Speaking Out for People
with Mental Retardation

The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act

The Need for Immediate Reforms

Robin Sims, VOR President
Rev. April 2010

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A Message from VOR's Immediate Past President

My daughter, Mary Elizabeth, has profound mental retardation, with significant physical and medical disabilities. She functions at the level of less than one year old and needs fulltime help for all her daily needs, from toileting to dressing to eating. Mary Elizabeth resides in a community group home, but each and every day returns to her former home – a state-operated ICF/MR – for physical therapy, swimming in a therapeutic pool, socialization, community outings with facility residents, and nursing care. Mary Elizabeth's successful community living is due in large part to her continued interaction with the ICF/MR's nurses, direct care staff and residents – people she has known most of her life.

Mary Elizabeth is not alone in terms of her level of disability and her reliance on ICF/MR care for continued health, safety and happiness. She represents thousands of others whose lives depend on the continued existence of ICF/MR options for people with severe and profound mental retardation, who also have chronic medical conditions and/or severe behavioral challenges.

In addition to being Mary's Elizabeth's mother, I am also the Immediate Past President of VOR. I agreed to serve VOR because this organization supports residential and service choice. VOR is a national advocacy organization that speaks for all individuals with mental retardation and their families. We recognize that the availability of a full array of quality residential services and supports for people with mental retardation, through all stages of life, based on choice and need, with full family involvement, is a common sense policy that leads to good outcomes.

We respectfully request your consideration of VOR's position on behalf of our nation's most vulnerable citizens and the proposed reforms to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). We submit that some DD Act funded programs are violating some of the key purposes and policies of the Act and, as a result, are doing harm to people with severe and profound mental retardation.

Thank you for your thoughtful consideration. Remember, Americans who can't help themselves due to no fault of their own are dependent upon the good will of the Congress.

Mary E. McTernan, Ph.D.

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Speaking Out for People
with Mental Retardation

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Rev. April 2010

Executive Summary

The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act: The Need for Immediate Reforms

For the first time in ten years, Congress will be considering the reauthorization of programs receiving federal funding under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

While the DD Act's policy endorses residential choice and individual decisionmaking, some DD Act programs, through legislative lobbying, class action lawsuits and other tactics, act to eliminate one of those choices – Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). These practices force the transfer of thousands of individuals from specialized ICFs/MR that are uniquely suited to meet their extreme needs. Protection & Advocacy (P&A) lawsuits, for example, have been filed without regard to the choices of the people affected and their families/guardians. The resulting closures of some ICFs/MR have led to higher incidences of abuse, neglect and death of people with severe and profound developmental disabilities, who also have other debilitating physical, medical and/or behavioral disabilities. What's more, when P&A (funded by the U.S. Department of Health and Human Services (HHS), as authorized by the DD Act) sues to close an ICF/MR (funded and certified by HHS), the lawsuit could be titled HHS v. HHS – an absurd use of federal dollars.

VOR urges Congress to adopt the following reform proposals aimed at assuring that DD Act program recipients carry out the Act's mandate to respect choice in residential settings and family decisionmaking:

A. Level fund DD Act program funding to give Congress time to review the programs and consider reforms.

B. Pass H.R. 1255 to require that federally-funded organizations, including P&A, notify residents of Medicaid-funded and certified ICFs/MR before a class action is filed, and provide a time limited opportunity for residents, or where one has been appointed, their legal guardians, to opt out of the lawsuit.

C. Secure an HHS audit of how all DD Act programs are working and whether they are respecting family choice and the *Olmstead* Supreme Court decision, to be submitted to relevant House and Senate committees within one year.

D. Limit the reauthorization to three years so that the Congress can more closely monitor the effectiveness of DD Act policy and DD Act program activity and how HHS is overseeing it.

VOR also calls on Congress to require that CMS conduct a study of whether states are offering people freedom of choice between an ICF/MR and Home and Community Based Services (HCBS) waiver settings, as required by Medicaid law and regulation (42 U.S.C. §1396n(c)(2)(C), 42 C.F.R. §441.302, and 42 C.F.R. §441.303(d)).

Thank you for your thoughtful consideration of VOR's DD Act reform proposals.

About VOR: VOR is a national organization advocating for the right of individuals with intellectual and developmental disabilities and their families to choose from among a full array of high quality residential and other support options. For more information, please contact Tamie Hopp, Director of Government Relations and Advocacy at 605-399-1624 (direct); or Tamie327@hotmail.com.

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The Need for Immediate Reforms

I. INTRODUCTION

For the first time in ten years, Congress will be considering the reauthorization of programs receiving federal funding under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The DD Act needs to be reauthorized, but it also needs to be amended to make sure its purposes are being carried out.

VOR is a national organization that advocates for the right of individuals with mental retardation and developmental disabilities and their families to choose from among a full array of high quality residential and other support options.

While the DD Act's policy also endorses residential choice, some federal funds allocated to implement the DD Act are used to eliminate one of those choices: Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). ICFs/MR are often the best way to meet the needs of the most vulnerable of the population with mental retardation and developmental disabilities.

So far, a volunteer VOR task force has identified over 90 examples in 20 states of the DD Act programs' disregard for Congressional intent, often with tragic consequences to the displaced individuals.

The reauthorization process will allow Congress a rare opportunity to review DD Act funding streams. There is a clear disservice being done to some of our most vulnerable, least able citizens under the auspices of DD Act programs.

With this presentation, VOR documents for Members of Congress federal law as it relates to residential choice, the people being served by ICFs/MR, the services they receive, the disconnect between DD Act policy and practice, and the sometimes tragic outcomes that result. The presentation concludes with suggestions for much needed reform to be written into the 2010 DD Act reauthorization (*see* page 12).

II. LACK OF CONGRESSIONAL AND AGENCY OVERSIGHT

In 2000, when the Congress last reauthorized the DD Act, it amended the Act to extend the reauthorization period from three years to seven. *The long reauthorization period resulted in little or no congressional oversight regarding the effectiveness of DD Act programs for this extended period of time.* VOR believes that, as a result, the purposes of the DD Act and the interests of a highly vulnerable population have been seriously compromised. In many cases these programs have undermined the structured care which many individuals with complex, severe disabilities require for their well-being and survival.

For More Information

Developmental Disabilities Assistance and Bill of Rights Act (DD Act): →
http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

More information about VOR: →
http://www.vor.net

For a summary → **of the full Task Force Report, see,**
http://www.vor.net/images/stories/pdf/DDActAbuseReport.doc

The full Task Force Report is here:
http://www.vor.net/images/stories/pdf/TaskForceReport.doc.

Since 2000, the House Energy and Commerce Committee's membership has changed by at least 51%; the Senate Health Education Labor and Pensions Committee has changed by at least 57%. Reauthorization in 2010 provides an opportunity for the reconstituted Senate and House committees to scrutinize how effective the DD Act programs are in carrying out their congressional mandate for people with mental retardation and developmental disabilities. In particular, Congress should assess the impact that the programs are having on people with severe and profound mental retardation. Following this review, Congress needs to adopt meaningful reforms.

Section III, which follows, provides background information supporting our case for immediate reform to key provisions within the DD Act.

Section IV (p. 12) sets forth VOR's recommendations for immediate reform.

III. THE NEED FOR IMMEDIATE REFORMS

A. The people served in ICFs/MR
B. The services people receive in ICFs/MR
C. An overview of federal law in support of choice
D. Abuse and neglect in community settings
E. Protection & Advocacy lawsuits: Questionable results and a demonstrated lack of family involvement

A. The people served in ICFs/MR

Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need support in every aspect of life including walking, communicating, bathing, eating and toileting. 74.5% of all ICFs/MR residents experience severe and profound mental retardation; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many of these people also have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions.

Currently, 6,381 ICFs/MR are home to 93,164 people.

For More Information

VOR Position – Our Family Members: People with Severe and Profound Mental Retardation: →
http://vor.net/images/MedicaidMR.doc

Characteristics of Residents of Large Facilities: →
http://rtc.umn.edu/docs/risp2008.pdf (pages 33-39)

For More Information

Background and Milestones –ICFs/MR:
http://www.cms.hhs.gov/CertificationandComplianc/downloads/ICFMR_Background.pdf →

ICFs/MR: Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with MR/DD:
http://www.ihca.com/consumer/ddcare.htm#Meeting

Characteristics of Residents of Large Facilities: →
http://rtc.umn.edu/docs/risp2008.pdf (pages 33-39)

ICFs/MR as Permanent Homes: →
http://vor.net/images/stories/ICFsMR_are_home.pdf

B. The services people receive in ICFs/MR

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

Medical	**Dental**	**Behavioral psychology**	**Clinical social work**	**Dermatology**
ENT	**Gastroenterology**	**Gynecology**	**Neurology**	**Nursing**
Nutrition	**Occupational therapy**	**Physical therapy**	**Orthopedics**	**Opthalmology**
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**	**Respiratory 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**

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

C. An overview of federal law in support of choice

Federal law is consistent with common sense: Like any other citizen, people with mental retardation and their families/guardians have the right to choose where to live.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000

Nothing in the DD Act mandates or supports removing people from the facilities in which they choose to live. Indeed, the Act validates the role of the individual and family:

> "Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000) (*Findings, Purposes and Policies*).

Congressional intent further confirms support for the provision of facility-based care based on individual choice and need:

> "[T]he Committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system" (House Energy and Commerce Report No. 103-378, Nov. 18, 1993, pages 7-8 (to accompany H.R. 3505, Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1993, Section-by-Section Analysis, Section 3, adding Purposes and Policies to Findings)).

For More Information

DD Act, 42 U.S.C. 15001: →
http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

Visit http://www.vor.net/DDAct2007.html for additional DD Act resources, including:

- ✓ Link to DD Act
- ✓ 1993 House Committee report language re: Purposes and Policies
- ✓ "Deinstitutionalization is not mandated by the DD Act," August 2006.

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The Olmstead decision

Contrary to some advocates' representations, Olmstead does **NOT** mandate deinstitutionalization of every disabled person. The Supreme Court in Olmstead very clearly supports choice in residential options, finding that the decision of where someone is served must be grounded on need, choice and available resources:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." Olmstead v, L.C, 119 S. Ct. 2185, 2187 (1999).

Consistently, the plurality opinion noted:

> "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's *Amici Curiae* brief]." 119 S. Ct. at 2189 (*plurality opinion*)

Justice Kennedy concurred:

> "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." 119 S. Ct. at 2191 (Kennedy, *Concurring*).

According to the Supreme Court, institutionalization is "unjustified" and community placement is required and only appropriate when:

> (a) "The State's treatment professionals have determined that community placement is appropriate;
>
> (b) The transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
>
> (c) The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." Olmstead v. L.C., 119 S. Ct. 2185, 2181 (1999).

For More Information

Olmstead decision resources: →
http://www.vor.net/olmstead_resources.htm

Justice Ginsburg, →
majority opinion:
http://supct.law.cornell.edu/supct/pdf/98-536P.ZS

Justice Kennedy,
***concurring opinion*:**
http://supct.law.cornell.edu/supct/pdf/98-536P.ZC1 →

Justice Ginsburg,
majority opinion:
http://supct.law.cornell.edu/supct/pdf/98-536P.ZS
→

Visit http://www.vor.net/olmstead_resources.htm for additional Olmstead information, including:

- ✓ VOR Olmstead Amicus Brief
- ✓ Olmstead and Choice – Outline
- ✓ What Olmstead is Not
- ✓ Olmstead and Guardianship

For More Information

To read Judge Payne's decision in Arc of Virginia v. Kaine, see, http://www.vor.net/images/SEVTCDecision.pdf

Code of Federal Regulations, Part 441 Services: Requirements and Limits Applicable to Specific Services; Subpart G, Home and Community Based Services: Waiver Requirements (*see*, http://www.gpoaccess.gov/cfr/index.html) →

Compliance with State Plan and Payment Provisions, 42 U.S.C. §1396n (*see*, http://www.gpoaccess.gov/uscode/search.html) →

Very recently, a U.S. District Court Judge for the Eastern District of Virginia cited "personal choice" as key principle in the Olmstead decision. In Arc of Virginia v. Kaine, the Virginia Office for Protection & Advocacy (VOPA), claimed that renovations to a state-operated ICFs/MR violated Olmstead because rebuilding and resizing the facility could force the plaintiff's members to be served at the renovated facility. Judge Robert Payne dismissed the lawsuit finding that plaintiffs failed to establish a "case or controversy" ripe for judicial review and, thus, the court lacked jurisdiction to hear the case. Recognizing that deinstitutionalization was the plaintiff's central motivation in this case, Judge Payne cited Olmstead, stating:

> Thus, the argument made by Arc [*represented by P&A*] and the United States [*Amicus in support of plaintiffs*] who filed regarding the risk of institutionalization fails to account for a key principle in the Olmstead decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it." (citation omitted)

Medicaid law

The receipt of federal Medicaid funding is contingent upon ***a state*** offering the choice of ICFs/MR or Home and Community Based Services (HCBS) waivers.

A Medicaid HCBS waiver shall not be granted unless the state provides satisfactory assurances that –

> "such individuals who are determined to be likely to require the level of care provided in a hospital, nursing facility or intermediate care facility for the mentally retarded are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital, nursing facility services or services in an intermediate care facility for the mentally retarded." 42 U.S.C. §1396n(c)(2)(C).

When a recipient is determined to be likely to require the level of care provided in an ICF/MR, the recipient or his or her legal representative will be –

> "(1) Informed of any feasible alternatives available under the waiver, and (2) Given the choice of either institutional or home and community-based services." 42 C.F.R. §441.302

The State agency ***must*** furnish CMS with sufficient information to support the assurances required by §441.302, including its "plan for informing eligible recipients of the feasible alternatives . . . institutional services or home and community-based services." 42 C.F.R. §441.303(d).

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Many states ***routinely*** do not follow the law with regard to advising eligible individuals or their legal guardians the choice between HCBS waiver and ICF/MR services. Furthermore, CMS has not held states accountable to upholding the choice law, despite citizen complaints. In addition to DD Act program reform, VOR also requests that Congress put in place reforms that help ensure that established law with regard to the provision of choice is followed. ICF/MR and HCBS-eligible individuals must be advised of their right of choice under Medicaid law.

D. Abuse and neglect in community settings

Sadly, abuse and neglect of people with mental retardation continues to occur in both institutional and community settings. Simply residing in the community is no guarantee of quality care. Quality care is not a function of where one lives but of the skills and commitment of the staff and of proper oversight.

The cause of compromised quality in community-based settings for people with mental retardation and developmental disabilities is generally linked to the rapid expansion of community programs over the past decade; inadequate access to health care; the lack of adequate staff training and competency (attributed to low wages and qualifications); the lack of state and federal oversight; and the lack of adequate funding.

These concerns are widespread. In at least 30 states and the District of Columbia, reports of ***systemic*** abuse, neglect and death have appeared in newspapers, state audits, and scholarly journal articles. Congress, the U.S. Surgeon General, the General Accountability Office and CMS have also cited serious concerns regarding compromised quality in community settings. For example, citing lack of access to necessary health care, the U.S. Surgeon General noted in 2002, "Compared with other populations, adults, adolescents, and children with mental retardation experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care." Financial exploitation was the subject of a 1993 House Committee on Small Business, released by then-Chair Ron Wyden: "Increasingly, millions of Americans with these life-long handicaps are at risk from poor quality care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies." While similar problems occur in ICFs/MR, state and federal scrutiny regarding ICF/MR care guards against long-term, systemic problems. ICFs/MR are held to 378 specific standards ("Conditions of Participation") annually. In contrast, HCBS waiver programs are reviewed only every 3-5 years and are **not** subject to uniform quality assurance standards. So, while there are good community programs, there are many others that fail to provide high quality care. The current system of oversight often fails to identify these "bad apples" until tragedy occurs.

ABUSE AND NEGLECT IN COMMUNITY SETTINGS: RESOURCES

VOR's Abuse and Neglect document: http://vor.net/abuse_neglect.htm (rev. March 2010)

Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, U.S. Surgeon General (2002): http://www.surgeongeneral.gov/topics/mentalretardation/

Bibliography of 72 peer reviewed studies about the abuse of children with developmental disabilities (2001): http://www.cfrc.illinois.edu/biblio.pdfs/abuseofdisabled.pdf

Special Olympics Health Research: Research studies conducted by Special Olympics found disturbing evidence that individuals with ID face widespread health problems, while health professionals are not receiving adequate training in order to treat them: http://vor.net/images/SOHealth.pdf

Quality Oversight Compared: A comparison between ICFs/MR and HCBS Waivers (2004): http://vor.net/images/ICFvHCBSQuality.doc

Federal Oversight of Growing Medicaid HCBS Waivers Should be Strengthened, GAO-03-576 (June 2003), http://www.gao.gov/new.items/d03576.pdf.

Letter from Senators Grassley and Breaux, re: poor HCBS quality: http://grassley.senate.gov/releases/2003/p03r07-07a.htm

E. Protection and Advocacy lawsuits: Questionable results and a demonstrated lack of family involvement

Statement of the problem

The activities of some federally-funded DD Act programs have contributed to higher abuse, neglect and death of some individuals with severe and profound mental retardation. Foremost among these activities are class action lawsuits brought by Protection and Advocacy (P&A) that eliminate specialized services needed by many of our nation's most vulnerable citizens, forcing the transfer of these individuals over the wishes of their parents and guardians to community programs that are often unprepared to safely serve their specialized needs. Many of these problems could be avoided if P&A consulted with and secured the approval of the families and guardians of people living in large facilities before they filed class action suits on their behalf. Instead, P&A's routinely ignore family/guardian input and choice.

P&A systems' mandate

State-based P&A systems receive federal funding to "protect the legal and human rights of individuals with developmental disabilities" by "pursuing legal, administrative, and other appropriate remedies or approaches." Some P&A's have interpreted their charge to include class action lawsuits against ICFs/MR (42 U.S.C. §15041 and 42 U.S.C. §15043(a)(2)(A) (2000) (http://www.acf.hhs.gov/programs/add/adddocs/act.pdf).

P&A funding since the last reauthorization

P&A Funding, FY 2000 – FY 2010 (in millions)

2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
$28.11	$33.0	$32.34	$36.263	$38.416	$38.107	$37.928	TBD	$39.024	$40.0	$41.0

Class action lawsuits: HHS v. HHS

Since the late-1970s, there have been 30 P&A-initiated class action lawsuits against ICFs/MR with the express or implied purpose of closure. Since 2000, the date of the last reauthorization, at least nine such lawsuits have been filed. In the last five years (since 2005), there have been four lawsuits filed. At least seven lawsuits are pending, either as active cases or with court oversight of a settlement agreement. As a result of all these lawsuits, at least 21 ICFs/MR have closed, resulting in the forced transfer of thousands of individuals from their homes.

P&A class action lawsuits against ICFs/MR are funded by the U.S. Department of Human Services (HHS) through grants from the Administration on Developmental Disabilities, an agency within HHS. Most if not all residential facilities targeted by P&A class action lawsuits are funded and certified by CMS, also an agency within HHS. In these lawsuits, HHS is both plaintiff and defendant – a waste of taxpayer funds!

PROTECTION & ADVOCACY LAWSUITS

Admin on DD
http://www.acf.hhs.gov/programs/add/states/pas.html.

DD Act, 42 U.S.C. 15041 and 15043(a)(2)(A):
http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

P&A Class action lawsuits against ICFs/MR:
http://vor.net/images/PAClassActions.doc

Protection and Advocacy Agencies: Involvement in Deinstitutionalization Lawsuits, GAO-03-1044:
http://www.gao.gov/new.items/d031044.pdf

Tragic consequences

The closures of ICFs/MR as a result of P&A class action suits have often had tragic consequences, with both mortality studies and media stories documenting systemic abuse, neglect and death (see e.g., Robert Shavelle, David Strauss and Steve Day, "Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999," Journal of Data Science 3(2005), 371-380: Following a class action lawsuit by California's P&A agency, more than 2,000 persons with developmental disabilities transferred from California institutions into community care during 1993 to early 1996. Researchers found a "corresponding increase in mortality rates by comparison with those who stayed behind . . . a 47% increase in risk-adjusted mortality over that expected in institutions.")

In the meantime, the number of people on waiting lists for services continues at high levels. When a facility is closed, the service system often loses the largest, most experienced provider, exacerbating a state's waiting list problem.

Lack of communication with families

The policy provisions of the DD Act state that the individuals with developmental disabilities and their families – not the P&A's – are the primary decisionmakers regarding the services and supports they receive, including residential options:

> "Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000) (*Findings, Purposes and Policies*).

On its face, this policy makes good sense. It is based on the premise that the power of informed decisionmaking best rests with individuals and their families and not with the DD Act funded entities. Many people with severe and profound mental retardation benefit from having a loved one who knows and cares about them serve as a legally-appointed guardian. The law appoints guardians to make fundamental decisions on behalf of their family members, recognizing that families often know best when the individuals are not able on their own to make life and death decisions.

Despite this common-sense notion and the clarity of Congressional intent, P&A programs routinely do not consult with families and guardians *before* filing suit. Generally, P&A's only comply with the notice requirements of the federal rules of civil procedure, which require notice to families and guardians only *after a proposed settlement* has been reached. Here are some examples.

For More Information

VOR's Abuse and Neglect document: →
http://vor.net/abuse_neglect.htm.

Shavell, Strauss, and Day Mortality Study,
http://www.lifeexpectancy.com/articles/jds.pdf. →
Note: The 2005 Shavelle, et al., study is one in a series of comparative mortality studies involving people with DD and deinstitutionalization (*see*, http://www.lifeexpectancy.com/articles.shtml - link, "Comparative Mortality").

DD Act, 42 U.S.C. 15001(c)(3):
http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

Family → **testimonials** from **California**, **Kentucky**, **Ohio**, **Florida**, **Illinois**, **Arkansas**, **Pennsylvania**, **Maryland**, and **Utah** speaking to state P&A's' lack of respect for the parents, families and guardians, along with fervent efforts to close large ICFs/MRs, are available at http://www.vor.net/legislative-voice/additional-dd-act-reauthorization-resources/summary-of-family-testimonials

For More Information

Family testimonials from **California**, **Kentucky**, **Ohio**, **Florida**, **Illinois**, **Arkansas**, **Pennsylvania**, **Maryland**, and **Utah** speaking to state P&A's' lack of respect for the parents, families and guardians, along with fervent efforts to close large ICFs/MRs, are available at http://www.vor.net/legislative-voice/additional-dd-act-reauthorization-resources/summary-of-family-testimonials. →

- In **California**, P&A brought suit irrespective of the fact that 98% of the developmental center family/guardian survey respondents opposed P&A representation of their family members (Coffelt v. Department of Developmental Services, No. 91-6401 (Ca. Super. Ct. Jan. 1994).

- In **California**, in *"Coffelt II"* (Capitol People First, et al. v. California Department of Developmental Services, 2002), P&A challenged intervention efforts by parent/guardian representatives, arguing, "As a matter of substantive law, parents and guardians of institutionalized persons have different and potentially conflicting interests on matters pertaining to their child's or ward's constitutional or statutory rights to liberty and due process." The Court rejected P&A's challenge.

- In **Kentucky**, families and guardians filed a lawsuit to oppose a settlement agreement between P&A and the State that called for transferring individuals from state ICFs/MR, and then closing those beds to future admissions.

- In **Ohio**, more than 31,000 people, including families and guardians, successfully opposed a proposed settlement between the P&A (OLRS) and the State to eliminate entirely the ICF/MR program. "For the past sixteen years, families of individuals who chose to live in state-operated and private ICFs/MR wrote to OLRS asking that their loved ones be removed as part of the class . . . Shouldn't families and guardians be allowed a more active voice in litigation involving their family members with mental retardation?" (Ohio League for the Mentally Retarded (OLMR), a statewide family/guardian association, comments on OLRS state plan, June 2006).

- In **Florida,** families sought intervention in a P&A lawsuit that expressly calls for the closure of public ICFs/MR. Shortly after filing the lawsuit in 1998, the Florida P&A responded to a family's concern that their loved one may be transferred from a Florida facility by saying in a letter, "Florida's Developmental Services Institutions, constitute a despicable way for government and society to treat people who happen to have a developmental disability."

- In **Illinois** in 2010, family guardians, on behalf of their family members, successfully sought intervention after several years of trying in a P&A lawsuit that threatens the closure of private ICFs/MR with more than 9 beds. Illinois' P&A agency has opposed efforts by families to intervene. In July 2009, more than 2,000 objectors, mostly families, successfully blocked a proposed settlement advanced by P&A and the State.

For more Information

Family → **testimonials** from **California**, **Kentucky**, **Ohio**, **Florida**, **Illinois**, **Arkansas**, **Pennsylvania**, **Maryland**, and **Utah** speaking to state P&A's' lack of respect for the parents, families and guardians, along with fervent efforts to close large ICFs/MRs, are available at http://www.vor.net/legislative-voice/additional-dd-act-reauthorization-resources/summary-of-family-testimonials.

- In **Arkansas**, families successfully intervened and challenged a P&A legal attempt to make admissions to state ICFs/MR more onerous for families by requiring court hearings for all admissions and annual court hearings to consider whether state-center residents should be discharged. This proposed process would have undermined the role of families and guardians, an apparent P&A objective in this case.

- In **Pennsylvania**, families of state operated facilities are seeking to intervene in a lawsuit filed by P&A that alleges all facility residents can and should be served in community settings. Families object to the lawsuits allegations and objectives and are seeking to intervene.

- In **Pennsylvania**, families of Western Center residents filed a lawsuit following the center's closure due to a P&A lawsuit. In addition to other claims, the families challenged the manner in which the center was closed – families were separated from their relatives by 20-30 state police as the remaining 49 residents were loaded into vans and transported to places unknown to them or their families. About a month after this incident, and in response to 30 complaints filed by family members, the Executive Director of P&A insisted that "the behavior of Office of Mental Retardation and center staff during those three days was exemplary" (Source: *OMR Planning Advisory Committee Meeting Summary*, May 22, 2000).

- In **Maryland**, P&A testified before the state legislature that "No one should have to live in an institution . . . The model of warehousing people with developmental disabilities in institutions is an outdated relic of history" (February 16, 2006). At this same hearing, family members and guardians testified in support of facility care for those who need specialized supports.

- In **Texas**, P&A intervened in the Lelsz lawsuit. Families spent over $500,000 and intervened in the Lelsz lawsuit in attempt to preserve choice. Following the lawsuit, legislative action led to the closures of Travis and Fort Worth State Schools in 1995 and 1996

- In **Utah**, in response to a P&A lawsuit settlement, families retained legal counsel to prevent community placements of their family members, counter to choice and need. Despite assurances by P&A that these residents will not move, P&A has renewed its call for the developmental center's closure.

Examples of state P&A's using their federal funds to eliminate the ICF/MR option, through legal and legislative means, are abundant. The need for immediate reform is clear.

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IV. REFORM PROPOSALS FOR THE REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

VOR submits the following reform proposals to redress the problems of DD Act funding recipients not complying with the purposes of the Act, most specifically with the provisions supporting choice in residential settings and family decisionmaking.

Reform is needed because the result of DD Act program abuse has often been the elimination of the public safety net for the nation's most vulnerable persons with developmental disabilities: ICFs/MR. The reform proposals are designed to assure that the purposes of the Act's mandate to respect choice in residential settings and family decisionmaking is carried out.

VOR urges Congress to amend the DD Act as followed:

A. Level fund DD Act program funding to give Congress time to review the programs and consider reforms.

B. Pass H.R. 1255 to require that federally-funded organizations, including P&A, notify residents of Medicaid-funded and certified ICFs/MR before a class action is filed, and provide a time limited opportunity for residents, or where one has been appointed, their legal guardians, to opt out of the lawsuit.

C. Secure an HHS audit of how all DD Act programs are working and whether they are respecting family choice and the *Olmstead* Supreme Court decision, to be submitted to relevant House and Senate committees within one year.

D. Limit the reauthorization to three years so that the Congress can more closely monitor the effectiveness of DD Act policy and DD Act program activity and how HHS is overseeing it.

VOR also calls on Congress to require that CMS conduct a study of whether states are offering people freedom of choice between an ICF/MR and Home and Community Based Services (HCBS) waiver settings, as required by Medicaid law and regulation (42 U.S.C. §1396n(c)(2)(C), 42 C.F.R. §441.302, and 42 C.F.R. §441.303(d)).

V. CONCLUSION

Thank you for your thoughtful review and compassionate support of VOR's concerns and recommendations for changes to the DD Act. Remember, Americans who can't help themselves because of no fault of their own are dependent upon the goodwill of Congress.

ADVOCATES FOR DEVELOPMENTAL CENTER RESIDENTS

THE THINGS WE KNOW

1. The State of NJ has no law on the books that orders the closure of any Developmental Center.
2. There is no Federal Law that mandates the closure of any developmental center.
3. The survey was conducted by Family Representatives from 6 of the 7 Developmental Centers in NJ.
4. There has been no such survey done by DDD or any other agency in NJ.
5. 96% of those responding to the survey stated that they wanted their family member/ward to remain in their current home at the Developmental Center
6. The guardians employed by the Bureau of Guardianship Services do not act as independent representatives of those clients but make their recommendations based on mandates from DDD.
7. The Bureau of Guardian Services refused to participate in this study.
8. The use of state employees as "advocates" are therefore in direct conflict of interest of the persons receiving ICF/MR services and their actions should be suspended immediately.
9. Parents who may have asked for BGS services have done so in many cases out of fear that when they die their loved one will not be protected. They are not however in favor of their loved one being moved out of their placement at their Developmental Center.

10. The treatment professionals are being forced to recommend a community placement against their professional opinions of the need for ICF/MR services for their clients.

11. The contracts between NJIT (DDPI) and DDD show a pattern of targeting people to move rather than to allow them their choice.

12. Assembly bill A1673 will deprive the most vulnerable citizens of NJ the proper care and treatment they need.

13. Assemblyman Greenwald is not considering the overwhelming majority of family members who oppose community placement for their loved one.

14. Many on the urgent waiting list are eligible for the ICF/MR services offered in the Developmental Centers and are being denied access.

VOR
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April 2010

SUPPORTING COMMON SENSE and LAW: INDIVIDUALS and FAMILIES AS "PRIMARY DECISIONMAKERS":

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) creates and authorizes appropriations for federal funding of three primary programs: state Developmental Disabilities Councils (**DD Councils**), state Protection and Advocacy (**P&A**) systems, and state University Centers for Excellence in Developmental Disabilities (**UCEDD**).

Among other federal legislative directives, funding for DD Act programs is conditioned upon adherence to the following policy requirement:

> (3) individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision making roles in policies and programs that affect the lives of such individuals and their families; (42 U.S.C. 15001(c)(3)).

The "primary decisionmaking" policy language was added by then-Health Subcommittee Chairman Henry Waxman in 1993 after hearing from families of individuals with profound developmental disabilities. These families expressed concern about DD Act programs ignoring their need for specialized care for their loved ones with severe cognitive disabilities and, worse, actively working to eliminate these specialized residential programs. The accompanying **House Energy and Commerce Committee Report** expanded on the meaning of the primary decisionmaking language as follows:

> **"[T]he Committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system."** [H.Rpt 103-378 (to accompany H.R. 3505, the Developmental Disabilities Act Amendments of 1993)].

Despite this clear language in favor of residential choice, some DD Act-funded programs have engaged in activities that have resulted in the loss of facility-based care for persons with MR/DD, over the wishes of the residents and their parents and guardians and to the detriment of many former residents. In its report, VOR's DD Act Task Force documents over 90 examples from 20 states of DD Act programs' anti-facility bias. (see, http://www.vor.net/images/stories/pdf/DDActAbuseReport.doc)

Congressional support for families as primary decisionmakers makes good common sense. Involved families, many of whom are also court-appointed legal guardians, are in the best position to make care decisions on behalf of their family members with profound developmental disabilities. Specialized residential settings – federally licensed, Medicaid-funded ICFs/MR – often provide the best environment for individuals with significant cognitive, physical, medical and behavior challenges.

Congress will soon consider the reauthorization of the DD Act. When it does, **please STRONGLY SUPPORT individuals and their families as PRIMARY DECISIONMAKERS**, as well as consider other reforms that will put a stop to DD Act activities which ignore this important policy directive.

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Rev. April 2010

The Need for Immediate Reforms:
The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act

For the first time in ten years, Congress will be considering the reauthorization of programs receiving federal funding under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

While the DD Act's policy endorses residential choice and individual decisionmaking, some DD Act programs, through legislative lobbying, class action lawsuits and other tactics, act to eliminate one of those choices – Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). These practices force the transfer of thousands of individuals from specialized ICFs/MR that are uniquely suited to meet their extreme needs. Protection & Advocacy (P&A) lawsuits, for example, have been filed without regard to the choices of the people affected and their families/guardians. The resulting closures of some ICFs/MR have led to higher incidences of abuse, neglect and death of people with severe and profound developmental disabilities, who also have other debilitating physical, medical and/or behavioral disabilities. What's more, when P&A (funded by the U.S. Department of Health and Human Services (HHS), as authorized by the DD Act) sues to close an ICF/MR (funded and certified by HHS), the lawsuit could be titled HHS v. HHS – an absurd use of federal dollars.

VOR urges Congress to adopt the following reform proposals aimed at assuring that DD Act program recipients carry out the Act's mandate to respect choice in residential settings and family decisionmaking:

A. Level fund DD Act program funding to give Congress time to review the programs and consider reforms.

B. Pass H.R. 1255 to require that federally-funded organizations, including P&A, notify residents of Medicaid-funded and certified ICFs/MR before a class action is filed, and provide a time limited opportunity for residents, or where one has been appointed, their legal guardians, to opt out of the lawsuit.

C. Secure an HHS audit of how all DD Act programs are working and whether they are respecting family choice and the *Olmstead* Supreme Court decision, to be submitted to relevant House and Senate committees within one year.

D. Limit the reauthorization to three years so that the Congress can more closely monitor the effectiveness of DD Act policy and DD Act program activity and how HHS is overseeing it.

VOR also calls on Congress to require that CMS conduct a study of whether states are offering people freedom of choice between an ICF/MR and Home and Community Based Services (HCBS) waiver settings, as required by Medicaid law and regulation (42 U.S.C. §1396n(c)(2)(C), 42 C.F.R. §441.302, and 42 C.F.R. §441.303(d)).

Thank you for your thoughtful consideration of VOR's DD Act reform proposals.

About VOR: VOR is a national organization advocating for the right of individuals with mental retardation and developmental disabilities and their families to choose from among a full array of high quality residential and other support options. For more information, please contact Tamie Hopp, Director of Government Relations and Advocacy at 605-399-1624 (direct); or Tamie327@hotmail.com.

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New Jersey Association of Mental Health Agencies, Inc.

May 7, 2010

Senator Loretta Weinberg
Assemblywoman Valerie Vainieri-Huttle
Members of the Senate Health and Human Services Committee and the Assembly Human Services Committee

Dear Senator Weinberg, Assemblywoman Vainieri-Huttle and Committee Members:

On behalf of the New Jersey Association of Mental Health and Addiction Agencies (NJAMHAA), I would like to share with you concerns and recommendations related to A-1673/S-811. However, I would like to first announce that our members voted in favor of making the strategic change in our name to NJAMHAA, which we believe reinforces our commitment to addressing issues that affect providers and consumers of treatment and support services to address mental illnesses, addictions and co-occurring disorders.

In addition, many of our members also serve individuals who have developmental disabilities, in addition to mental illnesses and/or addictions. This leads me to the first point I would like to make regarding A-1673/S-811.

The state must recognize that many individuals with developmental disabilities also have underlying mental illnesses, as evidenced by emotional and behavioral symptoms. Therefore, the need for adequate funding for psychiatric services to address mental health disorders, as well as developmental disabilities, must not be overlooked when providing community placements for individuals who are being discharged from institutions. In addition, as much of the system is already overburdened with demand, before individuals are discharged to the community, there must be sufficient access to services to address this need.

NJAMHAA has always believed that individuals should have the opportunity to live in the least restrictive, most appropriate environment that meets both their needs and their preferences. Therefore, choices must be made available to enable them to live most successfully in the settings of choice.

Not only is it imperative that each individual be placed in the most suitable environment, but it is equally crucial that sufficient funding be provided to ensure adequate, high-quality, treatment and other support services in these settings. State dollars for these services must follow the individuals into the community.

In addition, for those whose families prefer continued stays in developmental centers, adequate bed space is required – and, naturally, sufficient funding for these beds and the needed services is necessary.

Funding must also include "bridge funds" to cover the simultaneous costs of continuing to operate the developmental centers while building up community resources to ensure everyone's needs can be met.

Furthermore, to ensure a seamless transition from developmental centers to the community, the state needs to develop a more realistic time frame for the closing of institutions. The proposed schedule is very aggressive, especially considering the state's limited resources.

Intensive resources and careful planning are essential to ensure that individuals will receive the services they need, whether they are moving into the community or staying in an institutional setting.

Thank you very much for your time and consideration regarding this important matter. If you need additional information, please do not hesitate to contact me. I can be reached at 609-838-5488, ext. 292, or dwentz@njamha.org.

Sincerely,

Debra L. Wentz

Debra L. Wentz, Ph.D.
Chief Executive Officer