

Assemblyman Greenwald's Ambitious Plan to Close 5 DC's in 5 Years

by Jonathan Jaffe

In response to ongoing calls from the community to close New Jersey's developmental centers, Assemblyman Louis D. Greenwald (D-Camden) has introduced ambitious legislation that shifts funding from the institutions toward community-based services.

Greenwald's measure (A-3625), introduced January 13, is designed to revamp the way the state cares for individuals with developmental disabilities, reducing the population of New Jersey's seven developmental centers by 80 percent within five years.

The proposal has received staunch opposition from some parent groups, as well as the unions representing employees who work in the institutions.

Under the plan, five of the seven centers would close. One center would remain open in North Jersey, the other in South Jersey, for individuals and families who prefer institutional living.

"The time has come for us to end this warehousing of human life and to give the consumers and the patients what they require, what they have asked for, what their families have dreamed of, which is the opportunity to live independently and in a way and in a means with the dignity and respect that they deserve," said Greenwald, chair of the Assembly Budget Committee.

The proposed legislation would establish a 17-member Community Services Planning Council for Persons with Disabilities. This group would



Assemblyman Louis D. Greenwald

create a plan within 180 days to phase out the five centers, relocating people to community settings.

This planning council would be comprised of these individuals or their designees: the state Department of Human Services (DHS) commissioner, the State Treasurer, the DHS assistant commissioner who heads the state Division of Developmental Disabilities (DDD), chairs of the Assembly Budget and Human Services committees and of the Senate Budget and Appropriations and Health, Human Services and Senior Citizens committees.

In addition, there would be 10 people appointed by the DHS commissioner: two advocates for persons with developmental disabilities and two family members of persons receiving services from the division who have transitioned to community living from a developmental center.

The commissioner would also appoint a representative from the Family Education Project at UMDNJ, a representative from the New Jersey Association of Community Providers, a representative from the Autistic Self Advocacy Network, a representative from Advocates for Alternatives, Inc., a representative from a labor union and a national expert on developmental disabilities.

Ari Ne'eman, president of the Autistic Self-Advocacy Network, is an enthusiastic supporter of the legislation.

"Ten years ago in a decision as landmark as any since *Brown v. Board of Education*, the Supreme Court of the United States ruled that it was not a crime to have a disability," Ne'eman said. "Today we launch an effort to make the reality in New Jersey match that ruling."

Under the proposed law, the DHS commissioner would provide quarterly progress reports to the Governor and state Legislature that details the transition.

"New Jersey's fiscal climate presents an opportunity for us to revise our continued habitual investment in these costly, outdated, large public institutions that segregate people," said Kim Todd, CEO, New Jersey Association of Community Providers (NJACP), a supporter of Greenwald's proposal.

"Our continued support of institutional care has outpaced the resources of New Jersey," Todd

added. "This year the New Jersey Division of Developmental Disabilities (DDD) will expend a third of its \$1.4 billion budget to support just 8 percent of the people, and 80 percent of them don't require this costly level of care."

Greenwald's bill, which he publicized through a press conference and YouTube video, has placed the future of the developmental centers on the State House front steps. For many, the assemblyman's bill is welcomed, long overdue and should receive some consideration among the state legislators. Others hope the bill dies in committee.

A DIFFERENT PERSPECTIVE

Groups, such as some parent groups and employee unions, have stressed the value of the intensive, 24-hour care at the institutions and are urging the state to keep them open. There are 8,115 full-time and 1,008 part-time or temporary jobs in the seven developmental centers, state officials say.

Sherryl A. Gordon, executive director of American Federation of State, County and Municipal Employees (AFSCME) Council 1, said the Greenwald legislation would be a "terrible disservice" to the institution's residents and the union members.

"Because our members care for these clients, they have become a family," Gordon said. "In this economy, it is a disservice to our members that their livelihood depends on a stroke of a pen. Assemblyman Greenwald is being extremely short-sighted."

Gordon claims that Greenwald did not meet with the union before announcing this proposed legislation. "Even if we agreed to disagree; the idea of changing services without a conversation with us is unacceptable," she said.

Gordon noted that keeping only two institutions open is insufficient, as people want to stay close to their families. "Leaving one open in the north and one in the south is less than adequate," the union head said.

Don Klein, executive vice president for Local 1040 Communications Workers of America, said the bill appears to be a stunt to save money at the expense of one of the state's most fragile populations. He said the legislation is "an assault" on those individuals who require a full range of services.

Representatives of developmental center parent groups declined the invitation to be interviewed for this article.

OTHER REACTION

Pat Davis-Johnson of Newark, whose son, Reggie, moved from the New Lisbon Developmental Center to a group home in Voorhees, supports the proposed legislation.

“In my heart 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 and purchase coffee, which he loves,” Davis-Johnson said.

She noted her son lived for 18 years at New Lisbon, and was “blessed” with quality care.

Greenwald said his proposal follows the lead of 10 other states that have largely abolished institutional care for people with developmental disabilities. He said community settings are far less expensive, costing \$300 a day per person compared with \$614 in developmental centers.

The assemblyman noted that focusing limited state resources on community living would help reduce the nagging waiting list of 7,834 people with developmental disabilities who are awaiting a slot to receive additional state-funded services and placement in a community home, independent of their families.

“We’re saying to the public that the time is now to take care of these people who cannot speak for themselves,” Greenwald said. “In these tough economic times, public policy doesn’t have to stop or freeze. We’re open to creative ideas that can change the state for the better, provide a better quality care and do so for less cost.”

Greenwald’s bill has garnered support from advocacy and legal rights groups, such as Disability Rights New Jersey—the state agency providing legal protection and advocacy services for people with developmental disabilities.

“The state has these seven, enormous developmental centers,” said R. Scott Thompson, a Roseland attorney who represents Disability Rights New Jersey. “And the state pays salaries to 8,000 employees to provide services to 2,861 people in these developmental centers. Closing five of them sounds like a perfectly good option.”

“The five developmental centers can be closed, the real estate sold and their staffs and budgets significantly reduced,” said Thompson, noting his client sued the DHS last year on behalf of the 7,834 people who are on the state waiting list for community housing and other services.

That list has grown by more than 60 percent in the last 10 years, according to Greenwald’s legislation. That list currently has 4,701 residents on a priority status because their parents are over age 55 or they have a pressing circumstance, said Pam Ronan, a DHS spokeswoman.

“Assemblyman Greenwald’s intentions are certainly good and his bill has opened a dialogue about this issue. We’re thrilled about that,” said Liz Shea, spokeswoman for the Arc of New Jersey.

“However, we’re concerned about some of the specifics, like the time frame his bill outlines,” Shea said. “The State of New Jersey has never been able to move quickly. So closing the five developmental centers in five years may be too ambitious.”

“Moving so many people into the community would require the appropriate residential, behavioral, medical and dental supports,” she added. “It may be too ambitious to think sufficient supports can be in place in five years. Ten years may be more realistic.”

The Arc of New Jersey is not convinced the savings from closing the developmental centers would be as significant as Greenwald presumes. “We want to look at how much would actually be saved,” Shea said.

Adding more services in community settings, rather than institutions such as developmental centers, is a national trend. DDD officials say every state has been working to enhance services in local communities and reduce reliance on institutions.

Over the past 30 years, the number of people with developmental disabilities living in large public institutions in the nation has decreased by 73 percent. New Jersey has reduced the number of people living in the developmental centers over that same time by 59 percent, state officials said.

Greenwald’s proposed legislation comes at a time when the state is working to relocate 1,850 people from the state’s developmental centers, as part of an eight-year plan culminating in 2015.



As part of a 1999 U.S. Supreme Court decision affirming an individual's right to live outside an institution—a case commonly known as “Olmstead”—state officials are relocating developmental center residents to homes and apartments in communities across New Jersey.

To launch this undertaking, the state earmarked \$50 million to DDD over a three-year period, ending in fiscal 2009.

According to Greenwald's legislation: “New Jersey has an obligation to make significant progress to meet the intent of the ‘Olmstead decision,’ and make a systems transformation that enables persons with developmental disabilities to receive appropriate services and supports in a timely manner. The proposed law shifts a significant investment in developmental center-based care to community-based services and support systems.”

DHS Commissioner Jennifer Velez called the Greenwald bill “complex,” adding it is “an aggressive model and timeframe distinctly different

from our current plan to help individuals ready and able to move to the community. That framework, underway now for two years, will continue to guide our efforts to best serve the consumers who reside in our developmental centers.”

Ken Ritchey, assistant DHS commissioner overseeing DDD operations, said the proposed legislation is similar in philosophy to the Olmstead plan, noting his division is actively moving people from the institutions into the community.

“We want people who want to be in the community to be in the community,” Ritchey said.

Ritchey said 176 people have been moved out of institutions under the program, including 55 in the current fiscal year. The original goal for this budget year was 250 outplacements, but it was cut to 125 in the face of state budget issues.

Most of the nearly 40,000 people with developmental disabilities served through the state live in the community—and most of those live in their family homes. **P&F**

ERIC NEVISON

Life After School

An Ongoing Challenge for Individuals and Families



by Brenda Considine

What Eric Nevison cannot easily put into words, he says clearly in other ways. When his parents talk about school, Eric turns his expressive blue eyes to the floor. “Can we change the subject?” When they talk about his future, the world of work, and what it will take to get there, Eric offers a nervous smile, fidgets in his power wheelchair, and turns his head away. “Can we PLEASE change the subject?”

Like most other teens, Eric is reluctant to talk about taking charge of his future. It is frightening and a lot of work. There are a lot of unknowns.

Since he was in pre-school, Eric attended his local public school in Hillsborough, New Jersey. Scrapbooks tracing his school career show the boy, then the young man, taking part in the school community.

Now, at the age of 19, Eric is considered a “postgrad.” His class has graduated but Eric will continue at Hillsborough High School until the age of 21. For the next three years, his full-time job is to learn more about, and prepare himself for, adult life.

“I have seen some of these adult programs and I am not impressed,” she says. “People sit in their chairs all day watching TV or doing a craft. He would be bored to death. It seems like a lot of choices. But really, we don’t have any.”

Christine Petruzzelli is the supervisor of special education at the high school. For more than 10 years, the school has operated a transition program aimed at getting students with more significant disabilities into the work force before they graduate.

According to Petruzzelli, finding the right fit for some students requires a lot of creativity.

“We have some students who use augmentative communication devices and have mobility issues. They may need someone with them at all times.

We look at the student’s strengths and interests, as well as their needs, to determine the best fit for real work.”

“It is a real family effort,” adds Petruzzelli. “Our case managers bring in outside service providers like DDD (the state Division of Developmental Disabilities) and the Arc (of New Jersey) to help us plan. Because these are the people who will likely be serving our students beyond high school.”

Transition planning began for Eric when he was 14. At that time, the school started talking about goals for when he graduated. According to Eric’s mom Lisa Nevison, things were going well until Eric turned 18. That is when Lisa said the public school “hit a brick wall.”

“They were very honest with us. They basically came to us and said they felt they were not giving Eric what he needed. They asked us what to do.” Lisa says it was a “Catch-22:” The school was asking them what to do for Eric, and they were asking the district what should be done.

The Nevisons and the district agreed that Eric needed work experiences, but, according to Lisa, the problem centered around the fact that most of the postgraduate work experience the district has arranged in the past involved either physical labor skills, like sweeping or stocking shelves; good eyesight, like filing or office work; or verbal communication skills, like greeting people in a store. These are skills Eric does not have.

To tackle the dilemma the school put together a dream team of professionals and paraprofessionals to plan Eric’s school day and work experiences. In the morning, his one on one paraprofessional provides academic support; in the afternoon, she becomes his job coach. Eric’s work experiences take him to four other schools in his district, where he delivers mail and messages, and helps in the cafeteria.

Although he looks forward to his afternoons at work, his favorite “job” is when he is invited into the grade-school classrooms, where he answers students’ questions about his disability and about issues of disability rights.

Eric is able to communicate with the 4th graders though his Dinovox, an electronic communication device that has been programmed to generate speech. Eric selects symbols, pictures,



Lisa Nevison with son Eric and his communication device

letters, words, or phrases. Using a large button positioned on his power chair at his elbow, Eric is able to move the cursor to the words and phrases he wants to use. Because his eyesight is poor, the device, about the size of a desktop telephone, also has voice prompts to help direct Eric to the right buttons.

Even though Lisa Nevison goes to every workshop, seminar, and conference she can, she still feels like they are unprepared for the transition.

She gestures to a handout given to her at a recent workshop. It is a flow chart of the adult service system. "See this?" she says. "It tells me nothing about what Eric would really get. I still don't feel like I fully understand his options."

Lisa sees the adult service system as a confusing maze of providers and state agencies, with little accountability and little responsibility.

"Right now, Eric has a host of customized services and supports built around his needs. Right now, he is entitled to services. But in three years, he is eligible for services. There is a big difference."

Alice Hunnicutt, Director of Transition Services for SPAN, the Statewide Parent Advocacy Network, sees this in her work every day.

"I talk to families who are happy with the educational supports their child is getting. They are shell-shocked when they learn that there is nothing automatically in place for them after

their child graduates. The criteria for getting adult services vary from each state agency, and funding is not guaranteed."

Lisa says she really likes the language around DDD's Real Life Choices option, but admits that she is not likely to go that route. "People who know me and know Eric are shocked that we would consider a traditional day program. After all he has been fully included every day of his school career," she says.

"When Eric is fully included at school, it is the school's job to manage services and supports. If someone doesn't show up for work, Eric still goes to school. If someone quits, they have to hire and train a new person. In Real Life Choices, all that becomes my job."

Lisa also believes that the funding offered through Real Life Choices, even at the highest level, would not be enough to support Eric full-time. "We did the math, and there would be funding to support him for two, maybe three days a week. What is he supposed to do the other day? What would we do? Quit our jobs and stay home with him?"

"And," she adds, "I have no faith that we will find job coaches and personal assistants and drivers willing to work for \$7 an hour."

The alternatives to Real Life Choices do not excite her either. Eric laughs nervously when his

mother describes what she calls “Barney Day Care,” her reference to the traditional adult day programs she has toured.

“I have seen some of these adult programs and I am not impressed,” she says. “People sit in their chairs all day watching TV or doing a craft. He would be bored to death. It seems like a lot of choices. But really, we don’t have any.”

Eric’s father works full time as a physical therapist in a nearby public school and has seen transition from the other side of the table.

“I have seen transition for the kids I work with and it scares me,” he said. “Even kids who are very able and very motivated end up sitting at home. It is not for lack of preparation. The services and supports just are not there. We don’t want to see that happen to Eric.”

“Becoming more independent will take a lot of work, and Eric is not the most motivated kid,” admits

his mother. “He has to want it. This is his future.”

Eric smiles and gestures to indicate his agreement with her concern, admitting that he prefers to have others help him.

“He likes to be doted on,” his mother jokes. “But we try to find that delicate balance between supporting his disability, and catering to him.”

In spite of his fear and reluctance, transition from school to adult life has pushed Eric to new limits.

“He has been forced to communicate with people who do not understand him,” she says. “He has been forced to use the skills he really did not want to.”

Lisa says she is doing what she can now, but believes the next three years will be the hardest she has faced. “I am putting on my seatbelt and getting ready for a bumpy ride. What we need is a road map. I know if Eric is to have a future that works for him—and for us—it has to be creative.” **P&F**

Assistive Technology (AT) and Transition Planning

Throughout the transition process, students with disabilities, their families, and school professionals need to think about the student’s life *after* graduation. They should ask: What kind of work will the student do? Will the student go to college? Where will the student live? How can the student be as independent as possible?

As the IEP (Individualized Education Plan) team considers what students with significant disabilities will do following their non-college school years they should ask how assistive technology might help.

The process begins by listing AT devices the student currently uses at home, in school and in other places in the community—low tech to high tech, specialized or “off the shelf.” For each device, they should ask: Who owns the device? Will the device be useful after graduation? What services are currently provided by the

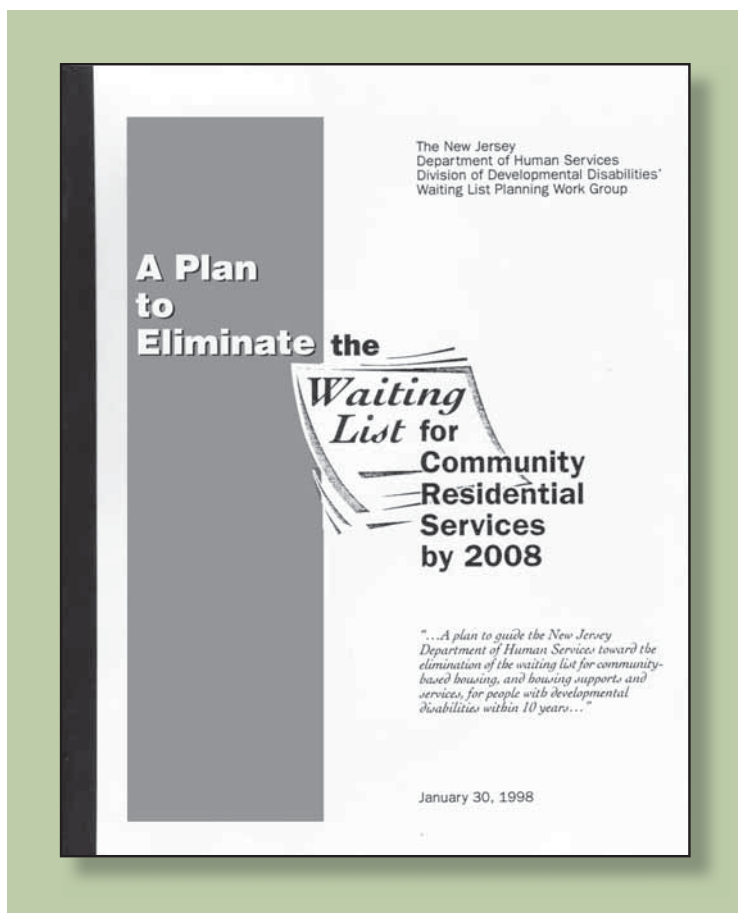
school (if any) to support the use of the device; and if these services are needed after graduation, who will provide them?

Next, the team should consider whether any additional AT devices and services might be needed after graduation. The transition years are a great time to teach the student how to use these devices, and an important time to think about using these. Often, tasks currently performed by a family member, friend, teacher, or aide, could be performed by the student with the help of assistive technology.

Students should learn how to obtain assistive technology at this time in their lives. Because funding sources change, it is important to determine who will pay for replacement devices, or other devices and services to meet changing needs in new environments and at new activities.

A Reminder About the Waiting List

by Jonathan Jaffe



Parents such as Lynn Evans say they are frustrated, disappointed and saddened. For almost eight years, Evans' daughter, Stacy, has been on New Jersey's community housing waiting list for people with developmental disabilities.

Last fall, she was one of 4,600 people to receive a letter from the New Jersey Division of Developmental Disabilities (DDD) with a progress report. Stacy had moved to number 1,343 on the list of 7,834 people with disabilities who hope for residential placement in a group home or supervised apartment.

“The state considers Stacy a priority. Her number is better than many others, but I still feel very frustrated,” Evans said. “No one ever seems to move off the list or move off very fast. And the list keeps growing.”

New Jersey separates its 7,834-person waiting list into three categories. There are 4,701 people on the “priority list,” who have parents over the age of 55. There are 282 people on a “priority deferred list,” because the families do not want loved ones with disabilities to live outside the home at this point. There is also the general list of 2,851 who will need a residential placement or are infants too young for placement.

“This is the same problem that every state faces,” said Kenneth Ritchey, an assistant commissioner for the state department of Human Services, which oversees DDD. “The waiting lists are way too long.”

Ritchey said DDD is now working with 100 families on the “priority” and the “priority deferred” lists to assess their needs. He said DDD is pushing for a community care waiver waiting list, rather than just for group home services. This gives people flexibility in the services they receive and where they receive these services, including in their own homes, in apartments or in other residential programs, Ritchey said.

Emergency placements—which are made when a parent or caregiver gets ill or dies—account for approximately 200 people moving off the waiting list annually. They are placed in vacancies in community settings or in one of the state’s seven developmental centers.

Ritchey said there are ongoing efforts to “clean up” the waiting list, noting 500 people have been removed recently because they have been served or no longer require services.

For example, the state has removed 180 people from a day service waiting list, contacting every person on it since July. People were assigned

to day programs or removed from the list, based on their request. The state also reached out to the New Jersey Association for Community Providers to learn if anyone else needs day services.

“The problem here and in many other states is that there are not enough funds to match federal funds,” Ritchey said. “We are pressured by the Olmstead ruling and emergencies, trying to get people off of waiting lists in a timely fashion.”

Ritchey said New Jersey’s waiver program is “up to speed” with those in other states, noting DDD can now accommodate people in multiple environments.

“So when we call families and say your number has come up, we want to support you and want to know if you need in-home services, or services out of the home,” he said. “Some families say they are fine and don’t currently need any services.”

“Some people out there who need services aren’t on any of our lists,” Ritchey added. “We know the demand is bigger. We want to use federal dollars to ensure movement every year and to keep expanding community capacity.”

ONLY IN AN EMERGENCY

The amount of non-emergency placements, made with state funds dedicated for that purpose, has dropped off significantly since 2002.

“The majority of the state’s resources go to emergency placements. It’s not the way the system is supposed to work,” said Liz Shea, spokeswoman for the Arc of New Jersey. “People with disabilities do not get the independent lifestyle they or their families wait and hope for.”

“I think part of the problem is people with disabilities and their families have no voice in Trenton and too little advocacy,” said Ringwood mother Debbie Legutko. She and her husband, Michael, have two adult sons on the waiting list.

“People don’t get placed unless their parents or care-givers become too old and seriously ill or die. It’s just sad,” Legutko added. “I feel like the state, which we should be able to turn to for help, turned its back on us.”

Responding to criticism that the system is too bureaucratic, DDD began in November to notify

people with disabilities and their families with their position on the waiting list. The notifications are to be sent out by letter each year.

Spurred in part by the letters, advocacy groups and families with loved ones' on the list have renewed efforts to persuade the state officials to act quicker to reduce the wait.

In the past year, Arc of New Jersey embarked on a campaign to try to reduce the waiting list by 10 percent per year. Meanwhile, Disability Rights New Jersey, a legal advocacy group, has filed a federal lawsuit against the DHS to create a list-reduction plan.

And parents like Debbie Legutko have met Human Services Commissioner Jennifer Velez, Ritchey and other state officials to address the issue, as well as to offer testimony to various legislative committees.

The state, however, says the problem remains because of dwindling funds to match federal money and a lack of space for placements. According to DHS spokeswoman Pam Ronan, DDD currently runs between 1.5 and 2.5 percent vacancy rate in its community residential programs.

It costs \$160,000 a year for a person to be placed in a group home, with a day program, health care, transportation and other services. New Jersey spends almost \$1 billion on services to individuals living in community settings, including residential, in-home supports and family supports and another \$500 million on the residential and other services provided in the seven developmental centers. The bill is mostly split between the state and federal coffers, Ritchey said.

There are 9,000 people now receiving services through the waiver program, while 2,618 are in developmental centers. A total of 40,000 people are served through DDD.

ONE FAMILY'S WAIT

A group home would be the ideal choice for one of Debbie and Michael Legutko's two sons, but they acknowledge such a placement could be years away.

One son, Derek, 24, has autism. He has two part-time jobs, is outgoing and can take care of himself with supervision. On the list for seven years, Derek's number hovers around 1,170.

"When you think about how few people get placed each year, it's going to be a long wait," his mother said.

Michael, 56, and Debbie, 54, are their sons' care-givers. But, in recent years, Debbie has survived breast cancer and heart valve surgery. "My health has made us really focus on what will happen to our sons when we grow old or die," she said.

Their younger son, Frankie, 21, also has autism, but his health is more fragile. He uses a portable ventilator to breathe because of a birth defect that prevented his lungs from fully developing.

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The
Arc
of New Jersey

Frankie's number was 2,003 after being on the list for five years. But his mother explained Frankie is in line for residential placement sooner because he has "priority" status.

The Legutkos had been told that only nursing homes would be equipped and staffed to handle Frankie's needs. He requires 24-hour nursing care and close supervision because of behavioral issues. The family is now considering placing Frankie in the Hunterdon Developmental Center in Clinton.

"Hunterdon seems receptive to accepting someone like Frankie who is on a ventilator and

needs supervision. They have a full-time respiratory therapist and seems to be making an effort to accept people with medical needs,” she said. “When we visited, we saw activities going on, the people seemed well-cared for, and the facilities and grounds were well-kept.”

“We don’t want Frankie to end up in a nursing home. We want someplace better for him. Someplace where he can have friends, activities and hopefully live a happier life,” Legutko added.

“We just want to know both our sons are settled before anything happens to us,” she said. “They’ve been on the waiting list now for years. So, their numbers make us sad and discouraged.”

HISTORY OF THE LIST

Reducing the waiting list gained momentum among New Jersey lawmakers and advocacy groups in 1994 after voters approved a \$160 million housing bond act for people with disabilities.

The state’s goal was to create more group homes or supervised apartments for people with disabilities who were ready and able to live independently or whose parents or family members were no longer able to care at home for them.

Initially, the state Legislature earmarked about \$24 million a year to pay private companies to staff group homes and apartments. With matching Medicaid money, the state hoped 400 to 500 people with disabilities could be scratched off the waiting list each year.

In 1997, the New Jersey Legislature required the DHS to devise a plan to eliminate the then 4,700-person waiting list by 2008. The state predicted that without such a plan the list could climb as high as 7,500 people within 10 years.

By 2002, a sagging economy and tighter state budgets curtailed spending on services for people with developmental disabilities. And, by last year, the number of people on the state’s waiting list for community housing and other services exceeded the state’s prediction of a decade ago, topping 8,000.

In 2007, Gov. Jon Corzine committed a modest \$2.8 million to the cause or about enough to move about 28 people off the waiting list. In the

current fiscal year that ends June 30, about \$12.5 million was set aside to reduce the waiting list.

However, Ritchey used vacancies in existing programs to help about 200 people find needed day programs. And in January, Corzine’s budget reductions whittled away \$4.5 million more from the initial allocation, bringing it down to about \$8 million.

Faced with a growing budget crisis, Corzine announced in February that another \$3.6 million will be cut, dropping the number to \$4.4 million.

DDD officials say they will be able to maintain a commitment to community placement but will not know the final number served from the Community Services Waiting List until the close of this fiscal year.

The division estimates it will be able to serve approximately 100 individuals on the waiting list this year with the \$4.4 million appropriation.

“This number is always an estimate because the cost per-person varies in meeting each individual’s needs,” said Ronan. “The total amount needed per person is based on whether a person chooses in-home services or needs residential services as well as the level of supports each person requires.”

A NATION WAITS

New Jersey is not alone. The federal Department of Health and Human Services estimates 283,000 Americans with disabilities are wait-listed for services. But, ARC of the United States believes the actual figure could be approaching 700,000.

In Texas, more than 100,000 people with disabilities remain on waiting lists for housing and other independent-living services. In Pennsylvania, the number is approaching 22,000.

In Maryland—the state with the lowest poverty rate—nearly 18,000 people are on its waiting list, half in the crisis category. Colorado has a list of 10,000 people with disabilities.

TV journalist Geraldo Rivera dubbed these waiting lists “the new institution” when he hosted an hour-long Fox News special report in January to spotlight the issue.

Peter Berns, executive director for the ARC of the United States, described the national waiting list crisis as “a multi-layered problem,”

caused in part by an “institutional bias” in the federal Medicaid system.

“Medicaid mandates that services be provided in institutional settings,” Berns said. “Community-based services are an option provided by a waiver. States have flexibility in how many dollars they commit to community-based services and how many people they will serve.

“Demand for waivers . . . demand for services provided in community-based settings have far outstripped how much states are willing and able to spend,” said Berns.

The problem is made worse by a national shortage of appropriate housing for people with disabilities, too few service providers to operate supervised group homes and apartments, and a high turnover rate among qualified support personnel needed to staff those facilities, he explained.

“The obvious solution would be to flip the Medicaid system on its head,” said Berns. Medicaid should require that services be provided in community-based settings and make it a waiver-option for them to be provided in institutions.”

THE 10 PERCENT SOLUTION

The Arc of New Jersey, a family advocacy group, started a campaign last year to garner political and public support to chop away at the state’s waiting list. The effort, dubbed the “10 Percent Solution,” is unique among state’s grappling with ever-growing waiting lists.

ARC of New Jersey estimates that moving 10 percent of priority cases off the list each year would cost the state about \$15 million and would be matched with federal Medicaid funds.

“We’re strictly interested in moving 10 percent of the 4,000 or 4,500 people in the urgent category,” said Tom Baffuto, executive director for ARC of New Jersey. “That could remove up to 450 people a year.”

Baffuto pointed out that not everyone on the waiting list needs or wants residential placement. Many simply need in-home supports or other types of necessary services.

“It’s a realistic and attainable goal. We didn’t know when we first proposed this idea how sour our state and national economy would

turn,” said Baffuto. “Our economy is in crisis, but our goal remains realistic. The people on this waiting list have been in crisis for a lot longer than our economy.”

“We think 10 percent is palatable to the community, to the taxpayers and to the people in Trenton who represent them,” he said. “We have no gimmicks or tricks to find the money. We just know that money must be appropriated. Too many families are reaching the edge of what’s reasonable.”

AND A LAWSUIT

Last spring, New Jersey Protection & Advocacy (now Disability Rights New Jersey), a legal advocacy group, filed a federal lawsuit against the DHS on behalf of the 8,000 wait-listed people with developmental disabilities. (For more information, see box on page 20)

The lawsuit says the rights of these people have been violated because they have waited so many years for government-sponsored community housing and other services. The lawsuit argues that New Jersey failed in its duty to provide housing for people with developmental disabilities who want or need to live outside of their family homes.

Attorney R. Scott Thompson, representing NJP&A, explained the lawsuit “seeks to force the state to implement a realistic plan to eliminate the waiting list. No matter what the state claims, they do not currently have a realistic plan.

“Moving 25 or 30 people off the list each year isn’t satisfactory when there’s a net gain of nearly 1,000 people each year,” said Thompson. “We think ARC’s 10 percent solution, for example, would be a perfectly realistic plan.”

While there have been similar lawsuits filed in other states, no court verdict has ordered a state to eliminate its waiting list. “But, there have been many cases which resulted in successful settlements to greatly reduce waiting lists,” Thompson said.

Berns said he knew of “eight or 10 lawsuits in recent years aimed at reducing states’ waiting lists,” noting the ARC of the United States last year asked the global legal services organization, DLA Piper, to review those lawsuits “to devise more successful legal strategies and help us come up with a more comprehensive approach.” **P&F**

UPDATE

Waiting List Litigation Continues

Disability Rights New Jersey (DRNJ), the state's designated protection and advocacy agency for persons with disabilities, is continuing litigation against the New Jersey Department of Human Services to seek elimination within three years of the waiting list for services from the Division of Developmental Disabilities and the establishment of a plan with reasonable timelines for providing waiver services in the future. DRNJ and the New Jersey law firm of Lowenstein Sandler PC filed a complaint in the U.S. District Court contending that 8,000 people with developmental disabilities have had their rights violated because they have been waiting too long—some for a decade—to receive community services, including community residential housing. R. Scott Thompson of Lowenstein Sandler says, "These individuals have been for years diverted to a so-called 'wait-list' for such services, with no guarantee, and little hope, of accessing the services they need." Few ever leave the Division's waiting list unless a parent or other caretaker becomes ill or dies.

The State petitioned the court for an extension of time to answer the complaint and in early January 2009

they filed a response claiming that the State has immunity from litigation under the Americans with Disabilities Act (ADA). According to Emmett Dwyer, Director of Litigation for DRNJ, "The state's challenge to the ADA is without merit." The State further alleged that DRNJ does not represent the interests of the 8,000 people on the waiting list. Dwyer adds, "This is an attempt to thwart significant litigation. The current challenges to the ADA and DRNJ's standing are merely litigation tactics."

DRNJ asserted its standing as an organizational representative of the 8,000 individuals on the waiting list through its status as the designated protection and advocacy system for people with disabilities in the state, the significant representation of persons with disabilities and family members of persons with disabilities on its governing board, advisory councils and staff, as well as its continual efforts to solicit public comment on the needs of and barriers affecting people with disabilities throughout the state.

(Ed. Note—Text prepared by Disability Rights New Jersey)