



by Jonathan Jaffe

It was 1995 when a debate erupted over the future of institutions for people with developmental disabilities in New Jersey.

After much planning, state officials announced a 32-month process to close the North Princeton Developmental Center (NPDC) in Montgomery Township. Discussion centered on a controversial three-phase plan, in which approximately 150 residents at a time would be removed from the 535-bed institution and relocated to community settings.

Such news created shockwaves in the developmental disabilities

community. Institutionalization had been the status quo to serve people with such disabilities as severe mental retardation for 100+ years. That began to change after the overcrowding and substandard care revealed through the Willowbrook scandal created its own shock waves. States throughout the country reduced populations and closed institutions, pumping money into community-based residential services.

New Jersey also reduced its institutional census and created a community-based system. But its institutional system remained robust, leaving it with the highest per capita institutional population in the nation. And it had only closed two facili-

ties—both relatively small—at the time of the NPDC decision.

Parents and friends of NPDC residents were skeptical that such a move by Gov. Christie Whitman's administration would be a benefit, as their loved ones were familiar with institutional living and seemed to thrive there. Some claimed in anger that the state was callously turning its back on its most vulnerable population and openly feared the state would not have the financial muscle to provide adequate community care.

Union officials also blasted the plan, as they represented many of the caregivers at NPDC whose future as state employees suddenly was in doubt. There was much at

AN HISTORIC CLOSURE, 10 YEARS AFTER



stake for the unions, as about one-sixth of the state workforce at the time – about 10,000 people – were employed through the state’s developmental centers.

Union heads, along with the rank-and-file, argued that state workers who went to the private group homes would be paid less and offered fewer benefits. They also expressed strong doubt that—given Whitman’s emphasis on reducing the state work force—jobs would be waiting for them at other state facilities.

For the Whitman Administration, closing NPDC was a risky political move. The upstart mayor of Woodbridge, James E. McGreevey, who was gearing up to run against Whitman for Governor in 1997,

called the developmental centers “successful” and “responsive to the needs of the client population.” The mayor of Montgomery at the time, Ted Maciag, also called for the status quo.

Such political opposition stoked union members and the families of residents of NPDC and other developmental centers, adding fuel to the debate.

Yet, with such obstacles at hand, the state Department of Human Services moved forward with the plan, which called for the developmental center to officially become “surplus property” by May 1998.

Whitman, in an interview for this article, recalled her administration was determined to move forward with the closure, as it was

widely believed that many of the 531 clients at North Princeton had the ability to thrive in the community.

“Yes, families were scared,” Whitman said. “We told them we want their loved ones to be all they can be. Independent living is real and we had the support to make it happen.”

WHY NORTH PRINCETON?

At the time of its closing, North Princeton’s dark history was well-known. Founded in 1898 as the New Jersey State Village for Epileptics, it originally housed a population lumped together as a “dependent, defective, and delinquent class.”

By the 1930s, the thousand-plus-acre village housed more than 1,500 patients and staff in more than 100 buildings. Many spent their entire lives at the Village and, upon their deaths, were buried in a makeshift graveyard that still exists on the site.

As understanding of epilepsy and its treatments improved, the Village lost its mission. Its change in 1952 inaugurated several decades of decline, during which the institution served patients with severe psychiatric or developmental problems. Many of the buildings fell into disrepair, as the developmental center sputtered into the 1990s.

(In April 2005, the remaining 250 acres of the NPDC property was sold to the Township of Montgomery for \$5.95 million.)

Robert Nicholas, who headed the state Division of Developmental Disabilities (DDD) from 1989-1998, was charged with deciding which developmental center would be phased out as part of Whitman’s initiative. He was the ideal person to

lead the effort, as he coordinated the closure of the Johnstone Training and Research Center in Bordentown Township just three years prior.

"In drafting a closure plan, we looked at all of the developmental centers in the state," Nicholas recalled. "We couldn't close the center in Vineland, as it was one of the major employers in the area. We kept coming back to North Princeton, which had plenty of substandard buildings."

And, as it was the goal of the state to find other state jobs for displaced workers, North Princeton was located near the Trenton Psychiatric Hospital and other state facilities that could use the talents and experience of NPDC employees, Nicholas said.

A DECISION IS MADE

Nicholas, at the time, said most of the residents of NPDC were determined to be ready to live in the community through a study conducted by a Rutgers University assessment team. Others, he said, might be transferred to more structured settings with some form of intensive supervision. The remaining individuals might need to be relocated to another center.

"Certainly, all the people in those units do not need security. In fact, on a day-to-day basis, they are out and unsupervised around campus. They are out in the community going to movies (with supervision similar to that in community-based homes)," Nicholas said.

As state officials ironed out their strategy, union members vowed to

remain a road block, arguing that people who had lived in institutions for many years would not do well on the outside.

Carolyn Wade, who was president of the Communications Workers of America Local 1040 representing 9000 workers, said at the time that some clients who have exhibited violent or aggressive behavior are segregated into four housing units.



**Former Division Director
Robert Nicholas**

"Many of them have serious behavioral problems; many of them are not aware of their immediate surroundings," said Don Klein, another CWA official, at the time.

Eager to get the support of families, state officials tried to calm the unions, who painted a bleak picture of group homes. Nicholas said NPDC workers would be given priority for transfer to other state jobs. They also said any bids by private operators who would operate the community programs would be required to give the NPDC employees first crack at new jobs.

THE PLAN GOES PUBLIC

DHS made the long-anticipated announcement in January 1995 to move 531 residents with developmental disabilities into community-based programs. The announcement met with immediate—and expected—wrath.

"Much of the staff is like family to the residents and the families of the residents," said Larry Quinlan, who served as president of the North Princeton Developmental Center Friends and Family Association, at the time. "Some residents consider certain staff members as their second mothers and fathers... The development center is the residents' home."

Quinlan now lives with his brother Richard in the community, also serving as his support staff. According to Larry, the situation is working well for both brothers.

William Waldman, who served as DHS commissioner, said community placement would be paid for by "redirecting" the state funds provided to operate the center—\$39 million in 1995. The money, he said, will be used to contract agencies to run "individually tailored" programs for each client.

"Nothing we are going to do here is going to endanger the public safety," said Waldman, as quoted at the time by the *Trenton Times*. "No one will be placed unless we have an equal or better opportunity. No facility will be closed unless we are convinced we have the capacity to accomplish that."

He also took the opportunity to announce a series of scheduled public hearings to receive input from family and friends of the residents, as well as care providers and the community as a whole.

EXAMINING THE EXODUS

State officials needed to track the landmark effort, as its success was expected at the time to pave the way for the closure of other developmental centers through the 1990s. Researchers from Rutgers who had developed early data of residents of the center were called on by DDD to establish the Developmental Disabilities Planning Institute, now located at the Center for Architecture and Building Science Research, New Jersey Institute of Technology in Newark.

Members of the non-partisan group also were used a few years earlier at Johnstone to study the outcome of residents who moved into the community and to other developmental centers during the phase-out of that much smaller institution.

Dawn Hall Apgar, the institute's director, said her group was asked in 1995 to design and implement a detailed research study for NPDC. The group was asked to evaluate the planning process involved, checking if the consumers' preferences were presented as viable options.

The group then followed 150 randomly selected individuals for two years, as they adjusted to life in a community setting. The group also tracked 150 NPDC residents who were moved to other developmental centers in New Jersey.

Study participants were based on gender, age and abilities to ensure similar populations in both study groups. As part of the process, the NJIT researchers interviewed consumers, their families and staff.

"Overall, we found that consumers were doing as well or better than they had while living in the

developmental centers," said Apgar, a Clinton resident who has led the institute for nine years. "We found individuals received more training in how to do everyday tasks while living in the smaller community homes. Meanwhile, those who stayed in the development centers had a loss in cognitive functioning over time."

The researcher said her group's findings were not a surprise. She referred to a study that was completed in California prior to the closure of NPDC that showed the institutionalization of people with disabilities caused higher death rates among the population.

"We followed that and found community living had no association with higher death rates when you controlled the existing medical conditions, such as seizure disorders," she added.

Apgar said the successful closure of NPDC was due to "political will, strong support from community-based facilities and advocates of people with disabilities and was, eventually, backed by the Olmstead court decision." (Olmstead is the landmark US Supreme Court decision of 1999 mandating that people with disabilities receive services "in the most integrated setting possible.")

Since the conclusion of the NPDC study, the institute has continued its mission to study this population. Researchers have had access to the people living in all seven remaining developmental centers in the state.

"We've created a statewide database of their support needs, abilities, medical conditions, behaviors, et cetera, to assist the state in planning for these individuals in a systematic way," Apgar

said.

MOVING FORWARD

While it was widely expected in 1995 that developmental centers would go the way of 8-track cassettes by now, DHS has been unable to close any more institutions.

Why more centers have not closed is a political question, not a policy one, said Ethan B. Ellis, who served as executive director of the New Jersey Council on Developmental Disabilities through the closure of NPDC and up until last year. During the first half of Ellis' tenure, the Council played a key role in advocating for the state to close developmental centers and redirect resources into community-based supports and services.

"There is a small, but very vocal group of parents, who continue to advocate for the institutions," Ellis said. "They represent about 200 of the 3,100 people now living in the developmental centers. And they have formed an unholy alliance with the unions, who see their jobs depending on the developmental centers staying open."

He added that communities throughout the state whose economies rely on the developmental centers remaining open have also fought for institutional living, creating a strong alliance with certain parents and the unions.

Ellis said opponents of institutional closures and resources redirection are ignoring or downplaying some key facts in their public discourse. He notes that some residents of NPDC went into supportive living arrangements and, today, are living independently. Many are working, and are no longer a drain on taxpayers, he noted.

"It costs \$135,000-160,000

per each person in a developmental center every year," Ellis said.

"Group homes costs \$80,000; supportive living costs \$40,000 per person."

That means, he concluded, that if people in developmental centers were phased into the community, the DHS could provide services for double the amount of people at the same price as it is paying now.

"The outrageous part of this is that DDD in 1999 offered parents a lifetime guarantee for their children to remain in the developmental centers so long as they do not oppose the closing of other developmental centers," Ellis said. "The parents turned it down. Two hundred parents are keeping 1,500 people in prison."

Sherryl Gordon, executive director of the American Federation of State, County and Municipal Employees, which represents state employees working in the institutions, said she remains concerned about the level and continuum of care that people receive in group homes.

"The money is not flowing into group homes to match the level of care that we think patients receive in the larger institutional settings," Gordon said. "This state is providing less financial support for the patients; the dollars are not flowing."

Gordon said she also remains concerned about regulations in group homes, such as fire safety. In addition, she contends there is a "revolving door" among the staff at these facilities, as they are paid lower than care providers who have state jobs, working in the institutions.

Whitman said the experience

with NPDC shows that group homes work. She said she hopes the successful experience of North Princeton consumers now living in the community will demonstrate a continuum of care, as well as ongoing connections with family. "I'm hoping that family members will be more comfortable with the idea that their family members can function in this kind of atmosphere."

The former Governor acknowledged that not all consumers who have moved to the community have thrived, but described that as "inevitable. But to the largest extent, this has been a positive experience," she said.

Leila Gold, whose 41-year-old son lives in a cottage with 28 other people at the Hunterdon Developmental Center in Clinton, said there is a specific need for institutions in New Jersey. She said her son, David, whose IQ hovers at about 25, would not survive living in the community.

"The same staff is there when David goes to sleep and when he wakes up," Gold said. "The staff becomes parents to our children. The group homes are known for their high turnover. But at Hunterdon, staff members spend their entire careers working there. The care is much higher than in the community."

Leo Gold, David's stepfather, agrees, adding that institutional living has "given my son a good life. It gives him protection against bad things and makes sure he is in top condition, with the best medication and a good education, he said, adding "I am pleased what they do for my son."



Leila Gold doubts group homes would ensure that David gets his medicine at the same time every day, and also questioned if he would receive the regular medical evaluations he requires.

"I'm not saying community living is bad; it can work for many, many people who should never have been in a developmental center," said Leila Gold, noting her son is autistic and has brain damage. "The centers are only for people like my son who can't make it in the community."

Leo Gold said there are many misperceptions about the state's developmental centers, as many assume that people with developmental disabilities are just thrown in there. He described Hunterdon as "a community," where residents go to various programs and events in the community. People come there each day for medical check-ups and other treatments, and it is a complex, professional operation to

serve a population of people who can not care for themselves.

NEXT STEPS

Carol Grant, state director of developmental disabilities (at the time this article was written), noted that the total population in the state's developmental centers has reduced by 653 people since NPDC closed its doors.

When asked why no other developmental centers have closed, Grant said, there needs to be specific appropriations of state money allotted to transition people from developmental centers to the community. She said state officials were wary to close another center because they didn't like the idea of not giving residents the choice to stay or go.

"The plan we are putting together now is not about closure of

express a desire to live in the community - and whose individual habilitation plan recommends it—the opportunity to live in a community-based setting. (This plan was recently published on the state's web site.)

Grant said Gov. Jon Corzine has earmarked \$40 million in this "very difficult" budget year to move 180 people out of institutions, as well as for infrastructure improvements to support the shifting populations.

DDD officials stress the state law does not require a specific number of people to move, nor does it mandate the closure of any of the developmental centers. DDD is now developing a plan to assist more than 3,000 people who live in the state's seven developmental centers and want to move into community homes. The plan will be implemented over an eight-year period.

Since 1980, the DDD has been moving people from state-run developmental centers into the community. About 100 people leave the developmental centers and transition to the community each year, state officials said.

"We are now working with people with disabilities and their families as they make their choice," said Grant. "There is no deadline here for when people need

to make a choice. We expect 180 people to move from the developmental centers to the community over the next three years."

Robert Nicholas, the former DDD director, said he is pleased that the state is now offering people with

disabilities a choice of where to live. He is also pleased to see the Corzine Administration financially supporting the effort.

But, he asked, what about the people on the waiting list for services?

"The money follows the person out of the institution; there is no new money to serve people on the list," he said. "There are people on waiting lists for community programs. But the people coming out of the institutions are being served in these slots with the new money.

"The new money is helping people who are already being helped," Nicholas said. "The people on the waiting list need to wait until the next pot of money. It's a dilemma."

Grant noted the state's fiscal 2007 budget includes \$10 million to help address the community services waiting list, both residential and self directed, as well as family support. "As Dr. Nicholas has indicated, it is always important to invest in the waiting list, which is the front door of the developmental disabilities system," she said.

Even with the effort to reduce populations in the developmental centers, Grant noted, she expects there will always be a need for the care provided through the institutions, which offer highly-structured, around-the-clock care. Some states offer this service through nursing homes, rather than institutions, which, Grant said, is a topic for future discussions.

"There are no magic answers, as long as services are delivered in the least restrictive setting," she said. "Every state has unique solutions. The main concern is the civil rights of individuals, and the choices that they and their families now have in New Jersey." **P&F**



developmental centers, but about the civil rights of individuals to live where they want to live," she said.

Under a law passed in August 2006, the DDD must develop a plan by May 2007 to give residents living in developmental centers who