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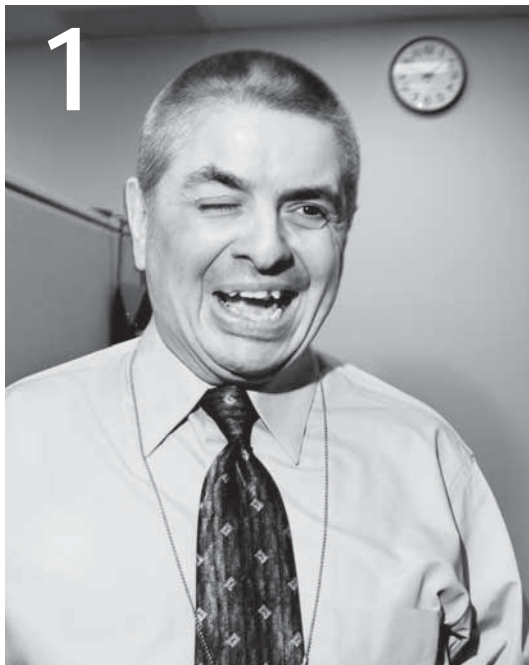
Frank Caragher, The Arc of Union County

The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building and systemic change that contribute to a coordinated, consumer and family-centered, consumer- and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

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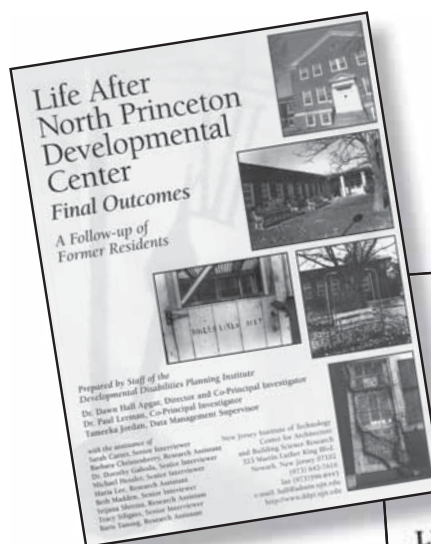
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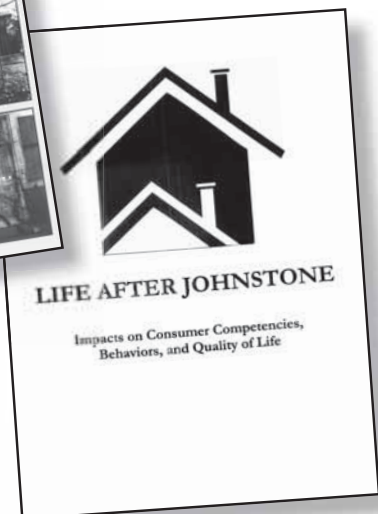
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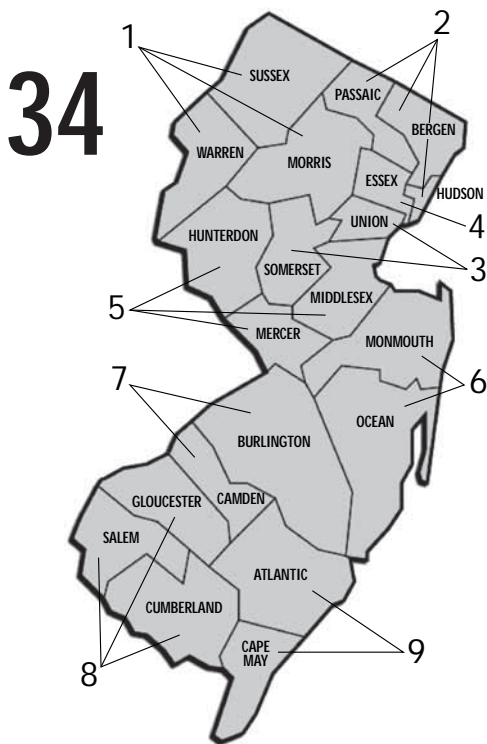
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from the EXECUTIVE DIRECTOR ■

Several times over the past month I have had the occasion to discuss a topic that continues to plague people with developmental disabilities. The issue is discrimination. One of the ways discrimination is exhibited against people with developmental disabilities is NIMBY, or “not in my back yard” syndrome. Although the phenomenon is not as prevalent as it was 25 years ago, it still remains a concern for those people with developmental disabilities who wish to live in the community.

Over the past 20 plus years, more and more individuals with developmental disabilities have moved into local communities and neighborhoods. Most residents of those neighborhoods would agree these individuals with developmental disabilities should become part of their local communities, but a few would say “not their neighborhood.”

As recently as January, the San Diego News reported some residents of an “upscale community” in Carlsbad, California, were outraged at the city for their support of a non profit agency’s purchase of a million dollar home in their neighborhood. The intended residents of this home were to be individuals with developmental disabilities. Those who attended a meeting with officials of the city stated they lived in the neighborhood because it was an “inviting family neighborhood,” and “it only takes one time for my child to see something obscene and the damage is done.” In addition they stated it would “reduce property values, increase crime and erode the quality of the neighborhood.”

A similar sentiment was described last month on the NBC Today

show. It was reported that a young lady had been hired by the BBC (British Broadcasting Company) as a host for a daily children’s show. As a result of the hiring, a viewer wrote in to the BBC to say she did not want her children to watch the show the young actress hosted “because I know it would have played on my eldest daughter’s mind and possibly caused sleep problems.” The reason for the anticipated sleep problems is that the young host was “born with an incomplete arm that ends in a stump below her elbow.”

Those of us who are self advocates, family members and advocates should be outraged that this type of behavior is still evident in our society and our world. We know these reasons for discrimination and prejudice cannot be supported by the facts. Housing prices do not plummet when people with developmental disabilities move into a neighborhood. I have yet to read of a child having nightmares due to another person having a partial amputation of a limb. Most often this bad behavior is fueled by fear of the unknown. That is, those people who express these concerns have never known a person with a developmental disability, or any type of disability.

The only way to resolve the issue of prejudice against people with developmental and other disabilities is to make them part of our every day world. We cannot hide them away in institutions, or even hide them in their own homes. We must see them on the street and in stores and places of worship.

Prejudice is learned, so the best place and time to learn about developmental disabilities is during child-



hood. We must offer the opportunities for children without disabilities to share their space and their lives with children with developmental disabilities. For most children, the chance to learn about each other can be naturally accomplished through integrated school settings. Realistically, this is a complicated topic, but it should be our ideal to have all children learn in close proximity of each other, regardless of their individual capabilities.

In the meantime, let us work together to make sure people with developmental disabilities are fully a part of all our communities. Then people who still think there is something “scary” about disability will see that their neighbors with developmental disabilities are just the same as they are. We must not hide behind real or imagined walls, but must insist that we all have an opportunity to be full participants in the joys and challenges that life in the real world offers.

—Alison Lozano, Ph.D., MPA
Executive Director

PARTNERS REGROUP TO LEARN ABOUT FEDERAL UPDATES

Mike Brogioli, chief executive officer of the National Association of Councils on Developmental Disabilities, provided a detailed look at what's happening at the federal level to nearly 100 graduates of the Council's Partners in Policymaking advocacy training program last month.

Brogioli explained how the council's national organization works with federal officials to keep them informed about issues vital people with developmental disabilities and their families. He talked about the federal law governing the councils and their sister agencies, the university centers for excellence, and the protection and advocacy programs.

Following Brogioli's presentation, Leslie Potter from Congressman Rush Holt's office gave a preview of the federal stimulus package just signed by President Barack Obama. Although at the time the details of the three-day-old package were still being reviewed, Potter outlined a number of areas in health care, education and financial supports where people with developmental and other disabilities would see funding increases.

Potter said that for the most part existing federal and state guidelines, agreements and formulas would remain the same. Funding increases would follow those existing guidelines.

Mike Brogioli, Lowell Arye and Krystal Odell discuss federal and state funding issues at Partners' meeting.



Amy Meyers (foreground) listens to presenters at Partners' meeting.

To close the program a panel that included Brogioli, Lowell Arye (executive director of the Alliance for the Betterment of Citizens with Disabilities—ABCD), and Krystal Odell (founder and CEO of Allies, Inc.) discussed a broad range of public policy issues guided by questions submitted by the PIP graduates.

The session was part of an annual re-gathering of graduates of the PIP program to continue the public policy advocacy skills training begun during the original sessions.

AUTISM STUDY FINDS PARENTS WORRIED ABOUT THE FUTURE

Below are the details of a study released in December by Easter Seals, funded by Mass Mutual Financial Group, to measure the degree of concern parents of children with autism have about their children's future.

Easter Seals worked with Harris Interactive, in cooperation with the Autism Society of America, to survey 1,652 parents of children who have autism and 917 parents of children who don't (age 30 and under) about daily life, relationships, independence, education, housing, employment, finances and healthcare. The survey was conducted on-line.

According to The Study Findings:

Nearly 80 percent of the parents of children with autism who responded said they're "extremely or very" concerned about their children's independence as an adult, compared to 32 percent of parents responding who have children without autism.

Fourteen (14) percent of parents of children with autism believe their off-spring will be able to make their own decisions, compared to 65 percent of the other group of respondents.

Seventeen (17) percent of parents of children with autism feel that their children will have friends in the community, compared to 57 percent of the other parents. Nine (9) percent believe that their children will ever have a spouse, compared to 51 percent of other parents.

Seventy four (74) percent of the parents of children with autism fear that their off-spring will not have enough financial support when they die, while 18 percent of the parents of children without autism share this worry.

More than 50 percent of the parents of children with autism said that "the cost of caring for my child drains my family's current financial resources," compared to 13 percent of parents from the other group.

Half of the parents whose children have autism said that caring for their autistic children "will drain my family's future finances," compared to only 10 percent of the group whose children do not have autism.

Finally, more than three-quarters (76 percent) of the parents responding whose children have autism worry about their offspring's future employment. A third (35 percent) of the other respondents have this fear.

The study's findings weren't "surprising to a lot of people in the field of autism," said Patricia Wright, Easter Seals national director of autism services. "But all this anecdotal information that we have, we didn't have strong data to support it."

"We needed data, particularly, around the needs of adults," Wright said. "We feel that there's not enough attention being paid to adults with autism. More attention is paid to children. We've got some

good information about the effectiveness of early intervention, but autism is a life-long disability."

NEW JERSEY PROTECTION & ADVOCACY BECOMES DISABILITY RIGHTS NEW JERSEY

Disability Rights New Jersey is the new name for New Jersey Protection and Advocacy, Inc., the state's designated protection and advocacy agency for persons with disabilities.

According to Acting Executive Director, Joseph B. Young, "Our new name reflects our identity as part of the disability rights movement. It is part of an effort among the protection and advocacy agencies, represented in all 50 states and the U.S. territories, to make our mission readily recognizable by people with disabilities and the general public."

DRNJ continues its mission to advocate and advance the human, civil and legal rights of persons with disabilities and currently administers ten disability rights programs statewide, offering individual and systems legal and non-legal advocacy, outreach, education and training, and information and referral services.

For more information visit: www.DRNJ.org

MARY KAY WEBER CHOSEN AS COUNCIL VICE-CHAIR:



Mary Kay Weber



Lorraine D'Sylva-Lee

Long-time Council member Mary Kay Weber has been chosen to serve as Vice-Chair. Weber, of Tinton Falls, will take over for Lorraine D'Sylva-Lee whose term on the Council expired.

FEDERAL STIMULUS PACKAGE ADDRESSES DISABILITY ISSUES: INCLUDES INCREASED FUNDING FOR MANY PROGRAMS

President Barack Obama has signed a comprehensive spending bill to authorize his economic recovery package. The American Recovery and Reinvestment Act (ARRA) includes \$787 billion in tax cuts and program funding, among them, a number of disability-related provisions.

The following summary describes the disability specific programs and the amount of increased spending they will receive through 2010:

Health

The bill authorizes \$87 billion to increase the federal government's share of Medicaid spending. Sixty-five per cent of the funds will be given to all states; the remaining thirty-five per cent will be used for additional payments (in the form of a decrease in a state's match) for states with high unemployment rates. Each state will receive a "base" 6.2% increase.

A "maintenance of effort" requirement in the bill prohibits states from changing eligibility requirements, but there is no such provision for benefits or services, allowing states to shift funding within their Medicaid plan.

There is an additional \$19 billion for health information technology to jumpstart computerized health records; \$1 billion for prevention and wellness to prevent chronic diseases and to increase immunization programs; \$100 million in competitive grants to localities and nonprofits to remove lead paint in low income housing; and \$10 billion to the National Institutes of Health for Biomedical Research.

Education

In the area of education, the bill authorizes an additional \$11.3 billion for the IDEA State Grant Program; \$500 million for the IDEA Part C Early Intervention Program; and \$400 million for the pre-school program.

Social Security

The bill includes a one-time emergency payment of \$250 to people who receive Supplemental Security Income (SSI), Social Security, disabled veterans, and other selected benefits; \$500 million to help the Social Security Administration reduce the processing time for claims and appeals decisions; and \$500 million to replace the antiquated National Computer Center to modernize the Social Security Administration.

Employment

The bill includes \$540 million for State grants for Vocational Rehabilitation; funding to modernize the unemployment compensation program, and increase benefits to workers; as well as \$500 million in job training for adult and another \$1.2 billion for youth services.

Independent Living & Housing

The Centers for Independent Living will see an additional \$140 million to assist people with disabilities to live in their communities.

The bill contains a number of provisions aimed at addressing the housing crisis including \$4 billion in Public Housing Capital for building repair and modernization; \$250 million for a new program to fund energy retrofits of Section 811 Supportive Housing for Persons with Disabilities, Section 202 for the Elderly and Project Based Section 8 units to make them energy efficient; and \$2.25 billion for the HOME Investment Partnership, with \$2 billion targeted to fill gaps in approved Low Income Housing Tax Credit projects.

There is \$1 billion in Community Development Block Grants to support housing and services to help hard pressed localities; \$1 billion for housing, food, employment and healthcare to serve areas hardest hit by the recession; \$2 billion for Neighborhood Stabilization to help communities purchase and rehabilitate foreclosed, vacant properties to create more affordable housing; and \$5 billion to weatherize homes of low-income households to reduce energy costs.

Early Childhood

The bill includes new money for childcare and head start. \$2 billion in Child Care Development Block Grants will be made available to states to serve an additional 300,000 children in low income working families; \$93.6 million of that is targeted to improve infant and toddler care.

An additional \$2.1 billion is earmarked for Head Start to provide services to 110,000 additional children. States are now scrambling to understand the bill and maximize benefit from it.

Many questions remain about the stimulus package, including when the funding will be released and how much of it will be subject to regulation or other procedures.

LETTER TO THE EDITOR

In her comment in the November issue (*People & Families* vol. 3 #1 Winter 2008), Dr. (Alison) Lozano asks “What are we waiting for?” calling on New Jersey lawmakers and advocates to downsize and close New Jersey’s developmental centers.

It is past time for us to set the record straight.

First, our loved ones receive exemplary care.

Our developmental centers are all licensed as Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). That means they are subject to an annual survey to ensure they meet eight federally required conditions of participation in areas ranging from active treatment (habilitation), health care and staffing.

Second, our loved ones are not “segregated.” Many residents go to “work” outside the center, visit restaurants, shops, friends and family, and go on vacations. Some centers host other organizations’ offices and/or events.

Third, developmental centers are cost effective.

Our loved ones have expensive needs. Think of the centers as the “intensive care units” of the service system. Imagine the costs of serving (safely and professionally) intensive care unit patients in locations scattered across a city.

Moving our family members to the community simply will not cost less and could cost even

more. Costs associated with community-based care almost always exclude basic costs of care such as room and board, health care, transportation, and day programs. Developmental center costs are all inclusive.

Finally, there are not 2,400 people, as has been reported in New Jersey’s *Path to Progress*, clamoring to get out of our developmental centers. In reality, there are very few families dissatisfied with developmental center care, and many informed families would welcome the opportunity for their loved ones to be served in these specialized settings (now or in the future).

We have much in common with the readership of *People & Families*. We are staunch supporters of the developmental center option, but we also support the need for expanding community-based options.

Carol Mastropolo—President, New Lisbon Developmental Center Family and Friends

Cindy Bartman—President, Association for Hunterdon Developmental Center

Dolores Thomas—President, Family and Friends of Woodbine Developmental Center

Joanne St.Amand—President, Parents Association at Woodbridge Developmental Center

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.

Bernard at work at the DDD, with co worker



The staff of the developmental center had identified a list of men who were 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 Nicholas. “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?”

“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



Bernard is the receptionist at the central office of the DDD.

Pennington, and later, a part-time paid position at a condo association.

“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.”

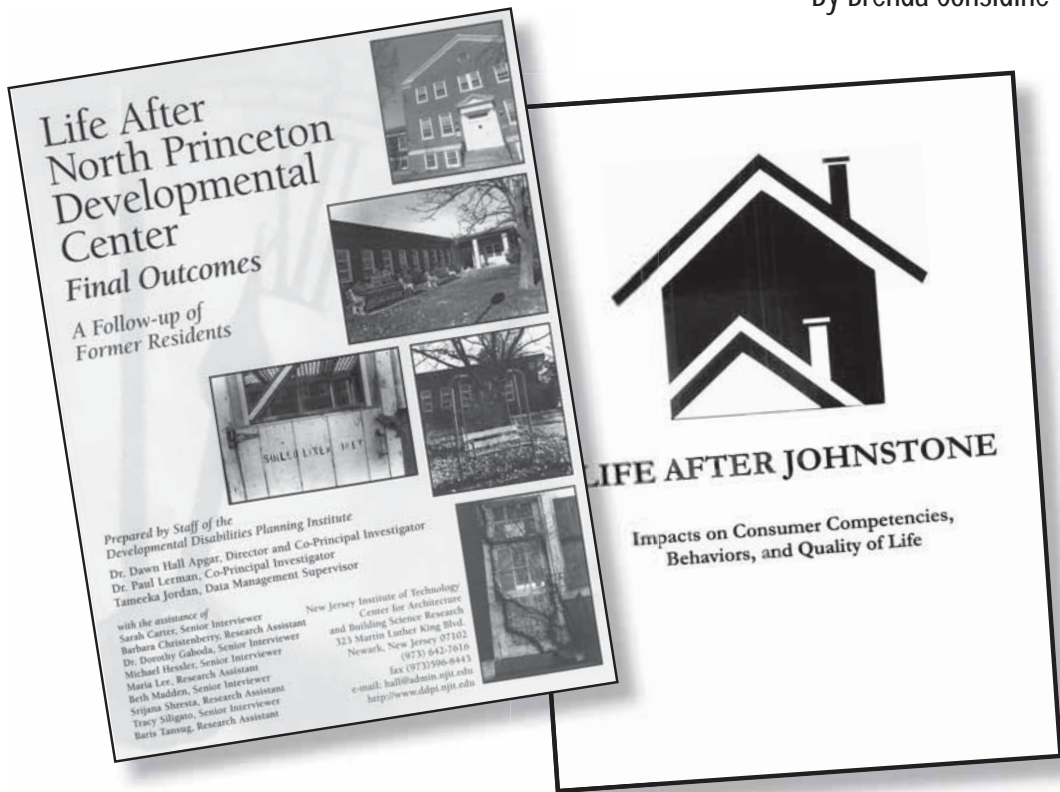
Booth says the friendship is very mutual.

“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**

Challenging the Notion of "Too Disabled"

By Brenda Considine



In the early 1970s, images depicting the conditions in Willowbrook State School in Staten Island galvanized a nationwide movement to close institutions serving children and adults with developmental disabilities.

But even as other states began to consolidate and close institutions, New Jersey continued to place people into them. Today, New Jersey is among a small handful of states with more than 2,000 adults with intellectual disabilities, physical disabilities and autism living in state institutions.

Many say that has to change.

Robert Nicholas, former director of the Division of Developmental Disabilities, is the only division director to oversee the closure of a New Jersey developmental center. He says that throughout his long tenure with the Department of Human Services, he always wanted to do something to help people move out of institutions, but found it difficult to get the support needed to actually close a developmental center.

In 1991, he got the chance.

“It was presented initially as a money saving effort,” said Nicholas. “I put forth the proposal to close Johnstone - I was actually surprised when they said ‘yes’”

It would not be that simple, however. The closure of the E.R. Johnstone Research and Training Center in Bordentown was marked with public outcry and controversy. Throughout the spring, lawmakers held public hearing, with tearful parents and impassioned union employees predicting the harm that would come to the residents of Johnstone if the facility closed.

Nicholas recalled the unflinching support for the closure from the New Jersey Council on Developmental Disabilities, and grassroots advocacy support from leaders at the Arc of New Jersey. That support, he said, was vital to the closure efforts.

“Many thought it would never happen,” Nicholas said. “It was the first time we had ever done this in New Jersey, so we really needed the support of the advocacy community.”

Johnstone eventually closed in 1992, and the 155 residents moved on, many to community settings. The Council funded a number of follow-up studies to examine the quality of their lives and other outcomes, all of which found favorable changes, both for former residents and for their families.

“It was not a perfect process,” admitted Nicholas. “We had never done this before and we really did not have a road map.”

Three years later, in 1995, the Commissioner of Human Services announced the closure of a second institution, North Princeton Developmental Center (NPDC). After the announcement, DDD staff, families, community providers and residents began developing transitional living plans.

“This time, the process was very different,” said Nicholas. “It was much more consumer-driven.”

Indeed, the tables were totally turned. Rather than allow provider agencies to select those residents they would serve, residents and their families selected a provider. Community providers hosted fairs and invited residents out to lunch to help them understand life in the community.

“A lot of it was consumer to consumer,” said Nicholas, referring to the very personal connections that were made during the closure process.

One of those was Eileen DiMaio. DiMaio selected Community Options, a Princeton-based non-profit, to provide her with the residential and employment supports she would need to live in the community.

According to Lisa Smith, Director of Training and Quality Assurance at Community Options, DiMaio had been in and out of several state institutions and had been served in a community-based program that did not work.

“She did not want to leave North Princeton because she was really afraid to fail again,” said Smith.

Smith recalled how, week after week, DiMaio would ride with staff from Community Options to visit her friends from NPDC who had since moved into supported living arrangements in the community. One day, after months of visits, Smith says Eileen simply announced she was ready to move in—and she wanted to move that day!

“The move had to be on her terms,” said Smith. “She needed to see the house all put together – and to see an empty room, ready and waiting, that could be hers—then she could move.”

Robert Stack, founding Director and CEO of Community Options, is unwavering in his support of efforts to close developmental centers.

“I think it is morally reprehensible that we have not closed more of these facilities,” he added. “Eighteen other states have no institutions at all,



Robert Stack and Lisa Smith of Community Options

or fewer than 100 people living in one. Only Texas has more than we do.”

Stack’s 20-year-old agency was instrumental in debunking the notion that some Johnstone residents were, in the words of critics of the closure, “too disabled” to make it in the community.

“Stack does not believe anyone is ‘too disabled’ to work,” said Nicholas. “He knows first hand that when you challenge people—and respect them—they will blossom.”

Like the closure of Johnstone 18 years ago, it may once again be a financial crisis that prompts the closure of New Jersey’s next developmental center.

“In light of the financial crisis, it is hard to ignore the fact that a significant portion of the DDD budget is funding less than 10% of its caseload—those living in the state’s developmental centers,” said Alison Lozano, Ph.D., executive director of the Council.

“Even if we ignore the moral and ethical arguments, there is an obvious discrepancy in the way in which resources are allocated,” Lozano added.

Stack agrees. “There is a need for rebalancing in New Jersey,” said Stack. “It used to be cheap to run institutions—today it is not.”

Assemblyman Louis Greenwald (D-Camden) has proposed legislation to close five developmental centers in the next five years, redirecting resources to community based support services. He says there are compelling moral and economic reasons to “radically restructure” the way the state spends money on people with developmental disabilities.

“We need to bring the way we care for the developmentally disabled into the 21st century,” said Greenwald. “By investing in community-based programs rather than traditional institutionalized models, we can both save taxpayers money and provide higher-quality care.”

Greenwald has said that the closure of developmental centers would allow resources to be redirected toward reducing the waiting for community housing.

“In the economic crisis, we face an opportunity to change failed public policy,” Greenwald said. “The state can no longer afford to support seven institutions, where it costs about \$227,000 to house each of their 2,900 residents.” He estimated community care would cost less than half of that amount.

A number of New Jersey newspapers have come out in support of the closure effort. **P&F**