

State of New Jersey
Department of Human Services

Developmental center residents share their stories about
moving to the community...

*moving
forward*



Chris Christie, Governor

Kim Guadagno, Lt. Governor

Jennifer Velez, Commissioner

Introduction

Moving Forward features personal profiles about individuals who have moved from New Jersey's developmental centers into the community. These transitions have occurred due to the closure of North Princeton Developmental Center, the proposed closure of Vineland Developmental Center, and the ongoing advancement of *Olmstead*, a US Supreme Court ruling that affirms the civil rights of individuals with disabilities to move out of institutions (DCs).

Disproving the myths surrounding DC to community moves, the people highlighted in this publication have conditions which are severely disabling that have not impacted their ability, or desire, to live happy and fulfilling lives, with the necessary service support they need to thrive outside of an institution. Their stories should serve to motivate, enlighten, and inspire individuals currently living in a DCs and their families or guardians to inquire about community-living opportunities.

One account in particular may resonate among concerned families. A gentleman, who angrily opposed his son's placement in a group home when it was announced his Developmental Center was closing, writes a very moving letter of regret for underestimating Michael's strong spirit and potential for developmental growth. His change of heart, because of his son's successful transition, shows the promise of what is possible.

According to *The State of the States in Developmental Disabilities in 2008*, New Jersey ranks 49th in the country with the second highest number of DCs per-capita. At its peak, there were 11 facilities, housing over 7,000 individuals with developmental disabilities. Today, there are only 2,400 residents statewide and the last Developmental Center closure occurred in 1998. The decrease in census reflects the growing number of community placement opportunities available, and the preference of families to support their relatives with developmental disabilities at home.

This publication is dedicated to individuals who may be thinking about *Moving Forward* and to those who have preceded them...

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Eddie

“There’s a big difference, and I never thought I would say it. I never thought I would see the difference.”

– Gloria, Eddie’s mother

North Princeton Developmental Center closed in 1998.

One of the last residents to leave was **Eddie**. This is his story:

At age 21, Eddie was taken to live at North Princeton Developmental Center when his parents could no longer care for him at home. The developmental center was his home for 35 years, until the center closed and he moved into a group home.

At the developmental center, Eddie lived in a building with 35 other men, sharing a bedroom with three individuals. Today, Eddie has his own bedroom and enjoys spending time with five other housemates.

When Eddie’s parents learned that North Princeton would be closing, Eddie’s mother, Gloria, and his now deceased father, Edward, were concerned. Even though life at the institution was not perfect, “it was all we knew,” and “my husband and I had heard rumors about the group homes being even worse,” Gloria said. “We were so upset and frightened of the unknown.”

Eddie’s parents visited group homes and talked to community providers about what life was like in group homes. When they first saw Eddie’s future home, operated by Cerebral Palsy of Middlesex County, “we fell in love with it,” said Gloria.

“I was always more positive about it, and my husband eventually realized that this was better. Before he died, he was happy with the change,” Gloria recalls.

To Eddie’s family, the group home has been very beneficial. Eddie is unable to speak, but others observe how deeply Eddie cares about his family and how social he has become since moving to the group home.

“It’s more family-oriented, and Eddie gets more one-on-one attention. It’s definitely improved his life,” says Eddie’s brother, Gary, a police officer. “His ability to interact is better,” he adds.



“He’s calmer now. He has a routine,” Gloria said. She added that North Princeton was very noisy, which affected his behavior.

Gloria believes the move to the group home became the landmark moment in her son’s life. “There’s a big difference, and I never thought I would say it. I never thought I would see the difference.”

Freddreana

Freddreana is a new person, with a new home of her own, a new healthier lifestyle - and a new name.

Freddreana, a confident, outgoing woman was already excited about the new beginning she had been planning. After living for almost nine years in North Jersey Developmental Center, she was moving to a one-bedroom apartment and a life of more independence.



During the transition and planning process in 2009, Freddreana learned that the name she had been called, “Fredrena,” was not the name on her birth certificate. Her name is really “Freddreana.” Freddreana loves her independence and worked hard for it, with the support of staff who helped her prepare and make her move.

“Monica helps me out a lot,” referring to a counselor with Partnerships for People (PFP), an agency that provided support services to help Freddreana adjust and thrive in the community. She also is grateful to Trace, a support coordinator with Caregivers of New Jersey, who helped her navigate the transition and develop an Essential Lifestyle Plan (ELP) before she left the developmental center. Trace started working with Freddreana in April 2008. Trace met with Freddreana often at North Jersey Developmental Center and helped navigate her transition process. Trace says that he worked hard to get to know Freddreana in order to make sure the right options were available for her

in the community. After researching her health records and talking with Freddreana and her Developmental Center staff, Trace developed Freddreana’s Essential Lifestyle Plan (ELP) with valuable information about her behavioral,

medical, and self-care needs as well as important descriptions of her preferences and dreams.

Shonnette, the provider coordinator, says the ELP provided helpful information about Freddreana’s behavioral, medical and self-care needs and preferences. Shonnette and Monica said they worked with Freddreana on compromise, appropriate public behavior, nutrition, and a variety of skills.

Freddreana likes to decorate and clean her apartment, shop, play bingo, and go to church, restaurants and the hair salon. “Every day she wakes up with a purpose,” Shonnette adds.

Freddreana proudly holds up the key to her home, showing it to Trace. “I worked really hard,” said Freddreana. “I got my freedom back.”

Trace tells her now that she has fully transitioned, “I used to be your support coordinator, but I’m not going to be that anymore. Now I am just going to be your friend.”

John, Francis, Joseph & Alphonso

John, Francis, Joseph and Alphonso

had been friends for more than 20 years, residing together at New Lisbon Developmental Center. When the opportunity arose to move to a home in the community, the people closest to them felt that the four men would be perfect housemates.

The transition process from a developmental center to a community home is thoughtful and thorough. Many people work together to support individuals in developing a successful life in the community. Russ, a support coordinator from Values Into Action worked with John and Alphonso in designing their transition, and Stacy, a support coordinator for Caregivers, Inc., worked with Joseph and Francis. The support coordinators collaborated with each other and with each gentleman's Transition Team to plan for the four friends to stay together.

Northwestern Human Services was chosen as the agency to serve the four friends. NHS found a spacious ranch-style home and then converted it for handicap accessibility. In 2010, the home was ready, with hardwood floors and walls painted in soft colors.

Each of the men spent two weeks in the home to decide if this was the house that they wanted to call home. Francis and John moved in on August 26, and Joseph and Alphonso moved in on November 10.

The house is staffed 24-hours a day, seven days a week. There is an accessible van available for transportation. They attend the NHS day program and go to the mall or other community sites. Since it is a self-designed program and the men are senior

citizens, they choose what they want to do. When they stay in, they like to watch movies and do arts and crafts.



Joseph lived at NLDC for more than 42 years and moved to his new home on his 80th birthday. He is very independent and active.

Francis lived in the developmental center for 28 years. Francis and Joseph enjoy socializing and listening to music.

John lived in the developmental center for 52 years. He is independent and organized and assists his housemates by pushing their wheelchairs when they leave the house.

Alphonso lived there for 24 years. Alphonso's nickname is "The Boss" because he keeps everyone "in line" and "keeps tabs on" everyone.

Living in the community "gives them an opportunity to show what they know," said Aneesah, a direct support professional. The staff members are like family to the gentlemen and the gentlemen are like family to the staff.

4 Michael

"I underestimated Michael. He does things I never thought he could do."
- Lee, Michael's father

In 1995, with the announcement that North Princeton Developmental Center would close, **Michael's** father, Lee strongly opposed the plan. This is Michael's story and the story of his father's change of heart.

"I did what I could to stop them from closing North Princeton. I wrote letters and talked to people. But they still closed it. And I was concerned," said Lee.

After all, when Michael was seven, Lee had moved Michael into an institution, knowing that his son needed much more intensive care than Lee could possibly provide at home. "I thought the care at North Princeton was good; I had no complaints," said Lee. He visited his son every week and was pleased with the activities at the center.

When Michael moved into his group home operated by The Arc, Ocean County Chapter, Lee noticed quickly that Michael became more social. He even liked participating in Friday night dances at The Arc. "I underestimated Michael. He does things I never thought he could do."

Michael now resides with four other men and women with similar disabilities, and who share chores around the house. Michael has his own room and participates in community-based activities in small group settings, which helps him with his ability to socialize and provides the personalized support that he needs.

Michael participates in vocational and recreational programs, such as gardening or doing puzzles and crafts. In the evenings, Michael and his housemates may go bowling, to the movies or to a dance or other social activities.

Michael is not able to speak, but communicates in other ways that people who know him understand. "I am quite pleased with his care. I am glad Michael is out of North Princeton. He is a lot happier where he is," Lee said. "And so am I."



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Michael...continued

April 16, 1998

To Recipients of These Letters:

The first letter is a reprint of an article written by me that expresses my fears about my son Michael's transfer from North Princeton Developmental Center to a community based facility. Please read this letter first.

On December 16, 1997 Michael was transferred to a Group Home operated by the Ocean Arc. Please read this letter after digesting the first.

The second letter shows my joy and enthusiasm for the care my son is receiving from the Ocean Arc.

The old adage that it takes a big man to admit he was wrong certainly fits here.

Lee's Letters

Lee Wieder
1000 Drive

APRIL 1998

A FOLLOW-UP

In the Spring 1997 issue of the Torch there was a story by me about my fears for my son.

My son, Michael, was a resident at North Princeton Developmental Center. The facility was in the process of being closed and the residents were to be transferred to community-based facilities.

This concept had surfaced from time to time and its very thought filled me with fear. Michael has been in facilities for the developmentally disabled for thirty-two years. The thought of his being in an environment that was not totally protected, in all ways, made me wonder how he could accept the transition.

Well, on December 16 Michael came to the group home in Brick.

The staff of The Arc and the group home took great pains to introduce my son to his new residence. He was brought from North Princeton to Brick several times to acquaint him with the surroundings. I cannot begin to talk about the great patience and great love shown to ease the transfer.

He was also taken to The Arc to see where he would be spending most of the week.

Well, let me not belabor the point. The transition has gone well and Michael seems to be happy. I visit weekly and we go out as we have been doing for 32 years.

I cannot begin to thank all the wonderful people that contributed to the smooth transition. I would name all the people but I would be afraid of missing someone. Therefore, let me extend my congratulations and deepest thanks to Lil Gallagher and her highly capable staff for putting this father's fears to rest.

God Bless You All,

Lee Wieder

MAY 1997

New Frontiers: A father's view...

By
Lee Wieder

The most difficult decision of my life was the day I decided I could no longer cope with my son Michael at home and that institutionalization was the answer.

My wife and I thought long and hard. We prayed, we cried, we tried to come up with an alternative, but none came. We had to evaluate what we were doing to our other child, Barbara, and the torment we were going through.

Our decision at that time was to commit Michael to a state facility for the mentally retarded.

We thought we were right then and I still think I am right, now.

Current philosophy is that the care can best be attained in a community setting. While in my heart of hearts I disagree, maybe I am bucking the tide. Perhaps, the current thinking is an idea whose time has come.

I don't think anyone can understand the ambivalent emotions I am experiencing.

I am willing to try what many states are doing now, that is, to move the mentally retarded out of the large congregate facilities and into the community.

I am told that this will be best for my son. I hope so. If the planners and providers are wrong, it is Michael who will suffer the trauma and upset.

Conversely, if all is successful and Michael's life has the better quality predicted, I'll be thrilled for him.

I find that now in my golden years, I am being challenged once again to face new frontiers. I must take on the system for yet another battle. This time it is to ensure that all of the services and programs promised are in place for my son and countless others returning to the community.

In order for the movement to be successful, a well planned community-based system of follow along support must be in full operation. Our children deserve no less.

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Reggie

Reggie's smile is as reflective of his joy as the bright colors on the walls of his home.

Reggie's smile is as reflective of his joy as the bright colors on the walls of his home. Three years after moving out of the New Lisbon Developmental Center, Reggie is happy with his new home and his life in the community.

He has a job he loves and supportive family and friends. But Reggie's transition from the developmental center to his current residence did not happen overnight.

The transition began several years ago when Reggie's mother, Patricia, attended a meeting conducted by the Community Living Education Project (previously known as the Family Support Project) and met Maggie from Quality Management Associates (QMA).

Reggie's family and the QMA instantly liked each other and began working together to help Reggie live the more independent life they thought he deserved. His transition from the developmental center to the four-bedroom house he shares with three housemates was made slowly, with Reggie eventually making visits that gradually increased from one to several nights.

Now he lives in a home with a family room, living room, dining room, spacious kitchen where he cooks for his housemates, and an outside deck where they entertain friends and family. "It's good to live here because it's quiet," Reggie says.



"Reggie is blessed," Patricia says. "He has a lot of independence and is a proud man who does not frown upon doing things for himself and encouraging others to do the same. He loves maintaining his home by disposing of trash, raking leaves, and keeping the property immaculate."

Reggie works in recycling at the Arc of Camden. He previously worked at QMA in janitorial services. Before he left for the Arc, he made sure his replacement was properly trained.

Reggie splits holiday time with people at QMA and his relatives. He also remains friends with many current and former residents of the developmental center, where he returns for visits, donning a jazzy suit for special parties.

When asked for advice for other parents of people transitioning out of developmental centers, Patricia says, "Let them grow."

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Sharon

Sharon lived at Vineland Developmental Center for almost a decade until she moved out last fall. Now, she has her own place, a mother-in-law suite attached to a larger group home.

Sharon sets her own schedule, which is very precise, and cherishes her much desired privacy.

“It feels lovely,” says Sharon.

Her bedroom is arranged exactly the way she wants it—including an impressive five-shelf doll collection. This arrangement is off-limits to anyone else.

In the kitchen, she has a microwave.



It's the one appliance she's become comfortable using—so far. In the mornings, she can make her own oatmeal. She's also learning how to adjust the settings to get her tomato soup just the right temperature.

Private and independent-minded, Sharon has thrived in the community. The group home provides her with her own full-time staff member.

Sharon has a routine she follows rigidly: She attends a day program in the mornings. Two nights a week, she goes on outings with staff. Her favorite pastime is to window shop to add to her doll collection, of which she has close to 200.

Sharon also likes to keep up with current events. She spends two hours a night watching television news. She follows foreign affairs, national politics, and the tabloids.

Living on her own with support, Sharon is gaining more skills of independence. She sets the menu, helps with the cooking and pitches in with the clean-up.

“I don't like washing dishes,” she says, flatly. But then, who does?

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To receive the full version of the stories about Freddreana, John, Francis, Joseph, and Alphonso, and Reggie, please contact the Community Living Education Project at 800-500-0448 for a copy of the My Life Now April 2010 and April 2011 magazines.

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