



# THE DEVELOPMENTAL DISABILITIES

by Maryann B. Hunsberger

The Developmental Disabilities Family Education Project is based at the University of Medicine and Dentistry New Jersey (UMDNJ) School of Public Health, Health Systems and Policy Department, in Piscataway. Susan Hammerman is the project director.

Initially, project members worked with people on DDD's waiting list who lived at home and wanted out-of-home residences. In 2005, DDD invited the project to organize informational activities for families of people living at Woodbridge Developmental Center and New Lisbon Developmental Center.

Due to complaints about safety issues, the Justice Department signed a settlement agreement with the state in August 2004 regarding conditions at New Lisbon, an institution with about 600 residents. The agreement required the state to serve New Lisbon residents in the most integrated setting appropriate to their individual needs, which in many cases means community-based settings.

The Justice Department and the state signed a similar agreement in

Since North Princeton Developmental Center (NPDC) closed in 1998, the Developmental Disabilities Family Education Project, with the support of the Division of Developmental Disabilities, has been reaching out to families of people transitioning to community living

November 2004 about Woodbridge, home to more than 500 people with developmental disabilities.

In October 2006, DDD expanded the range of options now available to people who will move from developmental centers. "They've included opportunities that are available to all DDD clients," said Hammerman. "People in developmental centers will now be able to self-direct their own services and supports, or to receive services and supports in a traditional way. DDD based these choices on what they learned from developing Real Life Choices."

(Ed. Real Life Choices is a community supports effort from the state designed to provide the supports people want and need in their family homes and reduce and delay the need to out-of-home placements in community-based residencies or developmental centers; these types of flexible, self-directed supports can also be used if and when individuals move to other

living arrangements.)

"The options will be wide open," said Hammerman. "The expansion just occurred, so it is still in the planning and development stage. Support coordinators will develop plans to link individuals to the services and supports that they need. The support coordinators will work for independent provider agencies chosen by DDD through a request for proposal process. They are working out all of the details now."

Hammerman has been working with Dave Wright, Director of Family Education and Lois Grau, chair of the Health Systems Policy Department, who serves as the principal investigator for the project. Wright explained that the project has four avenues of information for families, including forums, small group meetings, a workbook and a website at [www.umdj.edu/linkweb](http://www.umdj.edu/linkweb).

They are revamping the New Beginnings Workbook to fit the new process and available options. The family meetings take place as indi-

# FAMILY EDUCATION PROJECT

vidual meetings with families or forums that are open to more than one family. "We talk to the families about the person-centered model that the division is following," said Wright.

The state's developmental centers have alerted families that invitations to forums and other informational activities will be arriving. "Over the years, families haven't had much opportunity to get new information. Clear-cut information is important, especially with the new options. Some families hadn't thought about their family member living in the community before. Some tried a community setting, but came back because of ill-matched community services and the lack of options. The services weren't tailor-made and individualized to the person. With DDD now using an individualized, person-centered plan to get the right match for each person, it's their challenge to allow families to see the full picture of current possibilities," said Hammerman.

Hammerman said they have found families who want to give community living a chance. "Some of these families have been waiting a long time for community living options. Over the next month, we will start to see more of these fami-

lies. We hope to find even more families wanting information about community placement, so we can clarify what is available and help them make informed choices."

The first forum took place in Cherry Hill in December 2006 with about 40 people present. Some families and friends present had family members in Woodbridge and New Lisbon, but others had family members in different developmental centers. Community agencies gave presentations, as did staff from DDD. Some individuals, who left North Princeton Developmental Center, spoke about their lives in the community. "It was a very interesting and good first discussion. Barry Griffith (an extremely articulate man), explained his life in the community very well."

The project is choosing the forum locations based on where interested families live. They hope to have a spring forum in central New Jersey.

Hammerman said that their experiences have shown that family involvement in planning and shaping the life of the family member in the community results in better outcomes. "We see this as a way to achieve a very positive outcome with the

person's health, safety and life quality."

Wright said the partnership between the family, DDD and the community helps make the transition as easy and successful as possible. "Because this is so new, it's an opportunity for everyone to learn together."

The next step for the families who attend the forums is to decide if they want to move forward with this. Then, they can start working on a plan for their family member. The developmental center and DDD will help plan with the individuals and their families and refer them to support coordinators. "Our job is to provide the information and then DDD will take it from there."

DDD expects the process to move more quickly this year, once they identify additional interested families. "In those two centers, there are about one thousand people. The total in developmental centers in New Jersey is three thousand, so this funding includes people wanting to leave any developmental center. The funding covers 180 people over the next two years. This is really a first step. It's a beginning. It's just a beginning," said Hammerman. **P&F**

# DDD's OLMSTEAD PLAN

by Jonathan Jaffe

On a cold winter night, an auditorium at Union County College in Cranford played host to a state Department of Human Services (DHS) forum designed to gather public comments about how to best transition people with development disabilities from developmental centers to community settings.

Hundreds of seats lined the college's Roy Smith Theater, yet only about 25 people attended the hearing, which was the first of four public hearings in January the state agency was required to hold as part of a law signed by Gov. Jon Corzine.

DHS, through its Division of Developmental Disabilities (DDD), is developing a plan to assist some of the more than 3,000 people who live in the state's seven developmental centers to move into community homes. The plan will be implemented over an eight-year period.

The effort comes on the heels of a 1999 Supreme Court decision, known commonly as "Olmstead," which mandates that people with disabilities should receive services "in the most integrated setting possible."

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.

"Each developmental center resident who wants to live in the community and whose needs can be met in a community setting should have the opportunity to move," said then Acting DHS Commissioner Clarke Bruno. "We should also respect the wishes of residents who want to remain in a developmental center. Our goal is to provide opportunities and options for people with developmental disabilities."

The sparse audience in Cranford was informed that 33,000 people with disabilities are on the caseloads of DDD. Two-thirds live with their families. Most of the remainder of those not at the developmental centers live in community settings, such as group homes and supervised apartments, throughout New Jersey

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

a desire to live in the community—and whose individual habilitation plan recommends it—the opportunity to live in a community-based setting.

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.

Patricia Merk, Olmstead project director for the DDD, who attended the hearing in Cranford, said her agency will use the input from the hearings to help establish objective criteria for candidates interested in moving, identify the needed resources and determine how the funding, services and homes will be provided.

The plan is due in May and will be submitted to Corzine, the Senate Health, Human Services and Senior Citizens Committee and the Assembly Human Services Committee, she notes.

During the hearing in Cranford, DDD officials heard from family

members of people with disabilities and other advocates. While those providing testimony were able to comment on any topic they deemed relevant, DDD officials said they were looking specifically for answers to these three questions:

■ What services and supports do you (or your family member) need to transition from the developmental center to the community, in order to prepare all parties (you, your family member, the development center, agency staff and the community) for a successful move?

■ What services and supports, including housing, do you or your family member believe are needed in the community setting, to help you, or your family member to live as independently and safely as possible?

■ What concerns do you have regarding getting services and supports in the community? Do you have any recommendations to address your concerns?

Jacquelin Crator of Roselle, whose daughter lives at Hunterdon Developmental Center in Clinton, said her daughter is not eligible to move into a community setting.

Yet she used the venue as an opportunity to recommend ways to improve life at the developmental center. She told DDD officials that the Hunterdon facility needs to provide better workshops and medical care for consumers. She believes the staff turnover is high and there needs to be more oversight of consumers. She also claimed that activity reports are tampered with to paint a rosy picture and that there is a chronic

waste of funds.

"My daughter does not need two sets of curtains for her room," Crator said. "She doesn't need six bras. Three is enough to go around."

Meanwhile, Takeena Thomas, Executive Director of New Jersey Self-Advocacy Project in Piscataway, told DDD representatives that she is "excited to see the state making an effort to develop a plan" to expand community living programs.

"Many individuals are self-advocates who have stated publicly the desire to live in the community," Thomas said. "These advocates want

told officials. "The state Department of Human Services needs to allow flexibility in the process and back off the growing bureaucracy."

Caragher added that community providers will play a major role in this transition and the DHS must consider them as "equal partners."

DDD officials note that each individual who chooses to move into the community will have an individual plan that will include all services and supports they need to ensure their health and well being, including transportation.

Each plan will be developed by an Independent Supports Coordina-

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—Takeena Thomas, executive director  
New Jersey Self Advocacy Project

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Frank X. Caragher, executive director of The Arc of Union County in Springfield, described the effort to open community living opportunities to people in developmental centers as "a long time coming."

"We need to make sure that people want to leave and that they have the supports to succeed," he

tion Team, created and funded by DDD, and will include the individual and their family as part of the team. DDD will be responsible for assuring that providers are qualified, monitoring them to ensure that services and supports are provided effectively.

Public hearings also took place at the New Lisbon Developmental Center in New Lisbon, Middlesex County College in Edison and the North Jersey Developmental Center in Totowa. **P&F**