

Revisiting North Princeton

In this issue of People & Families we mark the 10-year anniversary of the closing of North Princeton Developmental Center. The closure was announced in 1996 and the last people moved out in 1998.

By any measure the closure of the first and only large institution for people with developmental disabilities in New Jersey was an unqualified success.

People who lived there are now living in community settings and overwhelmingly are more satisfied with that arrangement than with institutional life. Families too—even those vehemently opposed to the closure when it was announced—are positive about where and how their loved ones are living.

Funds used to support people at the center were shifted into supporting them in the community and about \$10 million additional dollars were pumped into the community services infrastructure to help support their needs and the needs of other state residents with developmental disabilities living in communities throughout New Jersey.

The closure was so successful that in 1998, in response to the demands of legislators concerned about the growing Waiting List for state services for people with developmental disabilities, a 10-year plan to end that List included plans to further restructure the state's DD system by closing three more centers.

So why now, nearly 10 years after the closure of

NPDC and the end of the timeline for the “Plan to End the Waiting List,” is no one talking much about either? Could it be that opposition to the closure by workers and families—who are understandably heavily invested in institutions both emotionally and financially—has had a third rail effect on future discussions? I believe so.

We have talked about moving people out of developmental centers. And we continue to talk about the urgent need to modernize the state system to respond to the growing and changing needs of its constituents. At the time we even talked about how a developmental center option should remain available for those living at the centers if that's what they and their families continued to choose.

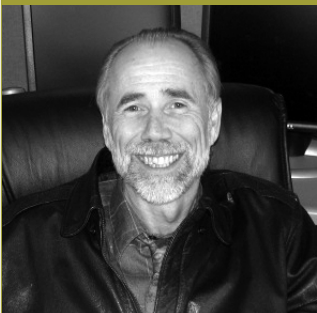
But any serious discussion—not to mention action—that includes closing additional centers and redirecting that money into community-based supports has been taboo. “We can talk about moving people out of the dcs” a number of officials have said privately over these past 10 years, “but don't use the word ‘closure.’”

Major restructuring is difficult and messy. People's lives are involved and there is always much more to major public policy changes than statistics and the bottom lines. It impacts thousands of people and throws many of their lives into uncertainty—most acutely those who live there and their families; and those who work there. Those are very good reasons to be cautious and deliberative, and respectful of those whose lives will be most immediately affected.

However, both the closure and the Plan were done with a good deal of caution and a great deal of deliberation, as well as a tremendous amount of effort to address the concerns of institutional workers and families connected to the centers. Still, political will faltered and as a result, resources-vs.-needs pressures are building and threaten to send this system into crisis.

A recent state Supreme Court ruling said the state Division of Developmental Disabilities could not make rules that limit eligibility for services that were not codified in state law. That ruling could mean that thousands more people are eligible for services from an already overburdened system—a system that is increas-

editor's note



The comments here are my own and have not been endorsed by the New Jersey Council on Developmental Disabilities, or by any of its members. There is nothing here that is contrary to the Council's mission or policies, but the statement as a whole is not in any way an official Council statement.

ingly showing the strains of a “tinkering around the edges” approach.

People with developmental disabilities living in their families’ homes make up nearly two-thirds of the division’s caseload. Those families get less than 10 percent of public funds available to help support people with developmental disabilities. They need and are increasingly asking for more help to keep their family member at home while they wait for the state to offer a broader range of flexible support services that meet individual needs and individual choices. (Services that are, by the way, more cost effective as well as being more appropriate)

Numbers vary, but undoubtedly there are hundreds of people—approximately 1,000 were identified in the state’s recent Olmstead Plan—living at the state’s six large developmental centers who have been identified as ready for community living, who want to move, and who have no opposition to their moving from their families. Again, estimates of the savings of providing supports to those people in the community vary, but everyone agrees they would be significant.

National percentages applied to New Jersey’s population figures show that there could be more than 100,000 people with developmental disabilities in New Jersey. A significant portion of those who have not

applied for services might benefit from some help through publicly funded support services and may ask for that help in the future.

Each new budget cycle shows a system with increasing demands and nearly stagnant resources. Public support for people with developmental disabilities has always been generous. Even so, there will never be enough resources to meet the demand, especially if those resources are spread thin between current models of service provision—such as individual and family choice of naturally integrated community supports—and antiquated options, such as institutions and other congregated care facilities.

So what to do? That’s not easily answered, obviously. But before another task force or blue ribbon panel works for another year or so developing another report to burden another set of shelves, maybe we should look at some of the lessons of the past—like the North Princeton closure, the Plan to End the Waiting List, the Long Term Care Exploration Report, the DDD Community Living Plan Part I Residential Facilities Closure Process, etc.—and move on.

Ten years ago we talked long and hard about how to restructure the DD system for the future. And we’ve been talking ever since. Isn’t it past time for some action?
—Norman Reim

N J C D D N E W S & N O T E S

NAME THE MAGAZINE CONTEST

Come on, folks! We know you creative people are out there. Come up with a name for this publication that reflects the modern image of people with developmental disabilities. Please, do not use the words “special,” “challenged” or “disabilities” in your title. Send your submissions to Norman Reim, editor, NJCDD, PO Box 700, Trenton, NJ 08625-0700, or send an e-mail to gregory.mizanin@njddc.org and use the word “Magazine” in the subject box. The winner will receive a \$50 gift card, courtesy of the editor.

TRAINING SUPPORT FUND

NJCDD has funding available to help people with developmental disabilities and their families attend conferences, seminars and other advocacy training and information building activities they may not otherwise

have the opportunity to attend.

The annual fund is available on a first come first serve basis and is for in- and out-of-state activities. Individuals apply directly to the Council and must meet certain criteria in order to receive funding. The purpose of the fund is to support the expansion of training and information gathering opportunities to broader numbers of advocates with developmental disabilities and their immediate family members. Contact Norman Reim, 609.633.8280, or e-mail norman.reim@njddc.org.

LETTER

Just a short note to congratulate you on the “new” magazine. The layout is superb and I greatly enjoy the stories of those with disabilities showing the whole world their abilities. I look forward to future issues.

—Jerry Caprio
Verona, NJ