

Special "Path to Progress" Update

Jon S. Corzine, Governor

Jennifer Velez, Commissioner

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Today's Quotes: *"Life is change. Growth is optional. Choose Wisely"*

Karen Kaiser Clark, American Motivational Speaker

Olmstead - Where are we now?

An update -Olmstead turns 10 and "Path to Progress" turns two

June marked the 10-year anniversary of the landmark **Olmstead vs. L.C. & E.W. decision**, in which the U.S. Supreme Court affirmed the right of individuals with disabilities to live in the community. Based on a case brought by two Georgia women who resided in psychiatric hospitals for decades, the Olmstead decision has served both as a rallying cry for people with disabilities and a challenge to the states committed to serving them.

In New Jersey, we are also marking an anniversary, as it has been a little more than two years since DDD responded to the challenge of Olmstead by issuing its own Olmstead Plan, the "*Path to Progress*." In this issue of *DDD Today*, we mark both of these significant anniversaries by reporting on New Jersey's progress along the path of its Olmstead Plan.

Before going forward, however, let's take a quick look back at the path. At the time of the Olmstead decision, June 10, 1999, New Jersey (NJ) had spent more than 20 years

working to develop and expand services in the community for individuals with developmental disabilities. NJ took its first formal steps to address the Supreme Court ruling through the Governor's Stakeholder Task Force on the Olmstead Decision, which was convened in December 2002. This resulted in a formal report called, "Achieving Community Integration for People with Disabilities."

Although the report was greeted very positively, NJ continued to face rapid growth in the number of people living in the community who were eligible for and in need of DDD-funded services. As a result, NJ also continued to be challenged by its ability to meet the needs of individuals who wished to leave the residential developmental centers DDD administers.

In 2005, New Jersey Protection and Advocacy, Inc. (NJP&A), which last year changed its name to Disability Rights New Jersey, said in essence, that the state was not meeting that challenge.

NJP&A alleged within an Olmstead lawsuit that thousands of New Jersey citizens continued to be forced to live in large institutions, "unlawfully and unnecessarily."

In 2006, the Governor signed legislation requiring DDD to publish an Olmstead Plan. Consequently, one year later, in May, 2007, DDD released the Olmstead Plan "Path to Progress," or simply, "the Plan," which outlined a blueprint for moving 1,850 individuals from its seven residential developmental centers to the community while also transforming the entire system that serves New Jersey residents with developmental disabilities.

On June 22, 2009 the federal government acknowledged the anniversary of Olmstead through a press release: "Statement by HHS Secretary Kathleen Sebelius on the 10th Anniversary of the U.S. Supreme Court Decision *Olmstead v. L.C.*" <http://www.hhs.gov/news/press/2009pres/06/20090622a.html>

Olmstead by the Numbers

Since New Jersey's Olmstead Plan was released on FY-2007, 319 individuals have transitioned from a developmental center (DC) to the community. One could easily – and mistakenly – assume that this number indicates DDD is not on pace to achieve the goal set forth in the Plan of placing 1850 individuals by Fiscal Year (FY) 2015. DDD, however, feels very confident about its ability to continue to successfully transition DC residents who want to move to the community, and not too concerned with trying to hit a target set in 2007. DDD recognizes that the projections in the Plan were always intended to be fluid, based on a number of changing variables.

One of the most important variables, for example, is the wishes and desires of the individuals who are to do the transitioning and the families that act as their guardians. (The Olmstead decision says that individuals who are both able and aren't opposed to living in the community should move from the institution, and that the State has to have a plan to address how to move those individuals. Olmstead does not say a state can force an individual to leave an institution if that is where they want to live, and this is not a part of the Plan.)

At the time the Plan was released, it projected that DDD would transition 100 individuals in FY2008 and 250 each year afterwards through FY2015. These numbers were based on best estimates available at the time of individuals who were both deemed able to move and had indicated they wanted to move.

DDD understands that some individuals and families may change their minds over time. In order to get a sense of where DC residents and their families stand now, the Division is about to conduct a survey in order to ask them. The survey should take two months to complete, and the results should be available in the fall. The survey will help DDD refine the Plan so that everyone who should be planned for will be, and so that education and other efforts that will support their transition can be developed.

Another important variable, recognized at the time the Plan was released, was the fact that DDD's ability to move individuals into a community placement depends on funding the state legislature allocates to support its efforts. Clearly, this is a challenge during difficult economic times, as New Jersey is now experiencing. Even in the difficult economy, however, the Governor and the Legislature recognize the importance of the Plan, and are committing resources. DDD continues to use the resources it has to keep the Plan moving forward.

A third variable relates to the amount of time it takes to help someone transition successfully. At the time the Plan was released, it was estimated individuals could be transitioned in six months. Today, after two years' experience, DDD has learned that on average, one placement takes 12 to 15 months to complete.

While DDD continues to look for ways to make the process move more efficiently, the Division will not rush the process along and compromise an individual's safety or fail to listen to the individual and family throughout the transition process. (More on this in "Why does Placement Take a Year?" on Page 5)

30 60 90 Follow-up is Important

After helping individuals transition from a developmental center to the community, DDD is responsible for making sure they succeed in their new homes. One important way to do this is to give them a visit, and then visit again and again, so that any issues that could undermine a placement are quickly recognized and addressed.

For DDD, this happens through a process generally referred to as “30 60 90,” a reference to the face-to-face visits DDD staff makes 30, 60 and 90 days after an individual leaves a developmental center. The Division also makes face-to-face visits on the 180th day, and then annually for up to three years after the individual moves to the community.

DDD’s commitment to this process is reflected by its completion rate measured over the last year: 99 percent. This high visit completion rate, which is measured quarterly, means that DDD is doing just about the most effective monitoring job possible, even as more visits must be made because the number of individuals leaving the developmental centers continues to grow.

Monitoring visits are made by staff from DDD’s Community Services Offices in conjunction with staff from the developmental center who know the individual well. As a result of the visits, DDD has been able to address concerns shortly after they have been identified by modifying individuals’ plans and details of the services they receive. DDD finds that when concerns are identified and addressed early, the individual’s community placement is much more likely to be a success. The visits are DDD’s best method for ensuring the health, safety and well-being of each individual who transitions to the community.

Redesign of DDD’s Case Management Services began July 1st

One significant goal outlined in the Olmstead Plan, “Path to Progress,” was redesigning DDD’s operations in the community. The purpose was to allow the Division to better address the widely varying needs of all individuals who are eligible for its services, including those who are transitioning out of the developmental centers.

The Division has just launched one of the most significant aspects of that redesign: the transfer of approximately 20,000 individuals from DDD case managers to nationally certified Information and Referral Specialists at DDD’s sister agency, the Division of Disability Services (DDS). DDS is the author of the indispensable DDS Resource Directory that catalogs all types of services throughout the state. DDS also has many years of experience in efficiently connecting individuals with disabilities and their families to those services that can address their needs.

The moves will be done in phases to ensure a successful transition. Individuals in the first phase were notified and transferred on July 1, 2009.

The individuals being transferred are those whom DDD has determined do not need specialized case management services at this time. Instead, their need is for assistance with issues such as insurance, benefits, transportation, education and employment, which are provided by entities outside the Division. DDS can more easily link individuals to these services.

Once assigned to DDS, individuals will have easy access to all types of information, education and support, including DDD’s Family Support Services. They will have the added assurance that if needs related to their developmental disability increase significantly, they will be referred back to DDD for more traditional, DDD-specific, case management services.

Most of the individuals who will be transferred to DDS through this process are under the age of 22, in school and live at home with their families. Approximately 45 percent of the more than 40,000 individuals who are eligible for DDD funded services fit this description, and their number is growing at a rate of approximately 154 per month.

The next steps in the redesign process will involve DDD being able to redistribute the work handled by its case managers, many of whom today have as many as 500 or 600 individuals on their case load. The specifics of the redistribution are being developed, but the aim is to allow DDD case managers to provide timelier case management services for individuals with the most significant needs. This likely will include individuals transitioning out of the developmental centers.

DDD expects to complete the process of transferring individuals to DDS sometime next year. The result will be a system better able to provide case management services for all individuals with developmental disabilities, regardless of their level of need.

Training and Education are Critical for the Plan to succeed

Training and education – for everyone involved - are key if the Division of Developmental Disabilities' Olmstead Plan, "Path to Progress," is to succeed.

The process of transitioning an individual to the community can take at least a year or more. Professional, paraprofessional and direct service staff, as well as individuals and families, all need to be well-informed about everything involved in the process including:

- The growing number and diversity of opportunities for individuals in the community
- How to do person-centered planning for individuals who are moving to the community
- The transition process and what the experience is like for individuals and their families, and
- How to best support individuals and their families as they plan for the future

When staff is involved, it is equally important that training never stop. Direct support staff members need continuous training opportunities, to assure they have the necessary skills and competencies to address both the day-to-day needs of the people they serve as well as the more challenging aspects of their care.

A small sample of available training and education efforts for direct support staff include:

- Ongoing training in "Person Centered Thinking," "Essential Lifestyle Planning," "Community Connecting," "Mental Health Supports" and "Management Skills for Community Supports" is provided by the Elizabeth M. Boggs Center on Developmental Disabilities at UMDNJ-Robert Wood Johnson Medical Center. The Boggs Center is New Jersey's federally designated University Training Center for Excellence.
- The first-ever statewide Conference for Direct Support Professionals, sponsored by the Boggs Center, was held in September, 2008. More than 300 direct support professionals from across the state attended and more than 60 received a certificate for completing the first part of a pilot Career Path Process.
- A pilot program is testing the viability of a user friendly, web-based training curriculum called the College of Direct Supports. It was developed by the University of Minnesota with courses developed and reviewed by national development disability experts and based on a national set of skill standards. If the pilot is successful, the goal is to use the College of Direct Supports to provide consistent training to direct support professionals throughout the state. The promise of the College is that it could be used both by staff in agencies and those working in self-directed services and supports, as well as those working in developmental centers when appropriate.
- The New Jersey Direct Support Professional Workforce Development Coalition and its Leadership Council are working to develop and implement a competency-based Career Path for Direct Support Professionals that will lead to higher skill levels for staff and ensure better quality of care in the community. A pilot phase is currently testing the viability of such a program, and as of April 2009, 181 Direct Support Professionals (DSPs) from eleven agencies had enrolled. More DSPs continue to enroll in the project every quarter, and pilot agencies report much interest among staff. Coalition members include Direct Support Professionals, staff from The Boggs Center, staff from DDD, representatives from the three provider networks (ABCD, Arc of NJ, and NJACP), a representative from NJ Community Colleges and community agency representatives.
- Trinitas Hospital's State Wide Clinical Consultation and Training (SCCAT) provides a six-session training program on various mental health topics for mental health providers and developmental disabilities service providers, care coordinators and case managers. Work is being done to offer this training more broadly.

For more information about training and education programs related to the Plan, please contact the Family Education Project - Telephone: Toll-free: 800-500-0448, Email: johnsoas@umdnj.edu

Why Does a Placement Take a Year?

DDD has learned many lessons since it began to turn the goals of its Olmstead Plan, “Path to Progress” (the Plan) into action. One of the most important has been that it takes longer (than first thought) to successfully transition an individual from a developmental center (DC) to the community.

When the Plan was released on May 7, 2007, it reflected a best faith estimate that an individual could be transitioned to the community within six months. Today, DDD knows from experience that the process is more likely to take from 12 to 15 months. There are many reasons why this is so, which all come out of the essential aspects of the Plan. These including protecting the health and safety of people in the community, and allowing individual choice to be a centerpiece of any transition.

Most importantly, DDD is responsible for protecting the health and safety of people moving to the community. Consequently, transitioning for individuals is much more than simply finding them a place to live. DDD must be sure that wherever they go, they continue to be healthy and safe. This requires careful planning and preparation, especially since many individuals leaving the DCs require support with behavioral, medical and accessibility issues.

A key part of transition is selecting a qualified team of people who will help provide that support in the community. DDD continuously looks at how to more efficiently build the individual plans and teams that will

support each individual, but no one moves until health and safety needs are appropriately addressed.

In addition, these moves reflect a major shift in the system that serves New Jersey residents with developmental disabilities. As a result, everyone, from staff at the DCs to provider agencies in the community to the individuals who will move and their families, is learning new ways of thinking about the system and their roles in it.

For example, individuals leaving the DCs and their families are learning for the first time how to make decisions about their own supports and services. Individuals obtain these services through a budget provided by DDD, based on an assessment of their needs.

A key part of transition is selecting a qualified team of people who will help provide that support in the community.

In the past, these decisions have all been made by staff in the Division and provider agencies. The change in this process requires individuals and their families, as well as the DC staff and community providers, to grow and change. One of the aims of the Plan is to increase individuals’ ability to self-direct their services, and as such, the process needs to accommodate the time it takes to grow.

There are also emotional issues to consider and address. Many individuals who will move to the community in a DC for years, some for decades. Even those who most want to move can find that they need time to adjust to this major change in their lives. The emotions of individuals, and their families, can, and do, alternate from excitement to anxiety and back again.

At the DCs, staff is affected emotionally as they watch people they have cared for, and cared about, for years move on to new homes. Individuals in transition, and their families, are aware of their staff’s emotions and can react to those too. These emotions are normal and healthy, but they need to be acknowledged and addressed if the individual’s transition is going to be successful.

DDD has instituted an extensive and ongoing family education program through the DC’s to help all those involved with these issues. This is another area where rushing the process would undermine the goal of successful community transitions.

The provider community also has faced challenges. Most significantly, the infrastructure to support a six-month timetable for helping an individual transition to the community did not exist at the time the Plan was released.

Placement (Continued from page 5)

For a provider agency, “building infrastructure” often means finding an apartment or house in the right location and price range to serve as a group home or supported apartment. Then, the housing must be made appropriate and accessible for the people who will live in it. If renovations are required, additional time is needed to work with local officials regarding any municipal codes and requirements.

Agencies also must find, hire and train the staff that will be providing the services and supports the people who live in the housing will need. As mentioned above, the move to a system in which individuals, families and support teams take a very active roll in selecting all supports and services has meant a significant change and adjustment for many community agencies. The community system is adapting to the new system, but this too, is a growth experience.

Finally, both the agencies and the Division are being challenged by new business rules that have come into play as a result of the Plan. One example is individual budgets, another essential aspect of the Plan, which are part of a larger move the Division is making toward a fee-for-service system in which providers will be paid for the services they provide, as they provide them.

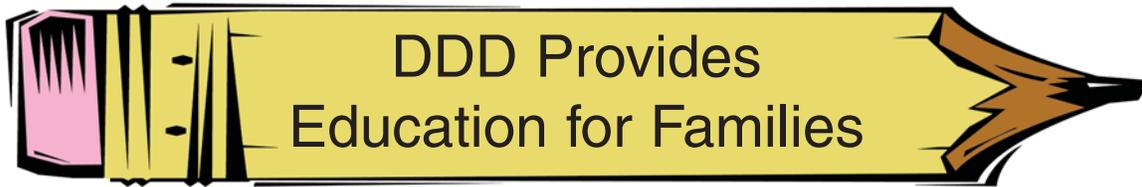
This is very different from the way providers have been paid in the past. Historically, the Division has paid all providers a percentage of their total contract amount on a monthly basis, without tying the payment to the actual delivery of services. The move to individual budgets is necessary if individual choice is to truly be at the center of the Plan, but it requires DDD and community agencies to change many different business systems.

Even with so much change and growth, DDD has made efforts in the past two years to appropriately speed the transition process. DDD has an advisory committee that continually looks at these issues, and many staff whose full time is devoted to this effort. DDD will continue to refine the transition process, and foster the growth and change necessary to do so, until the Plan achieves its goal.

ANNOUNCEMENTS

Spina Bifida Resource Network of New Jersey and Metro New York (SBRN) recently announced that Julia McConnell has been appointed to the position of Executive Director, effective April 15, 2009. Ms. Jane Horowitz is retiring from the position after 25+ years of service to the individuals and families of who live with spina bifida. Congratulations to Ms. Horowitz on her future endeavors, and good luck to Ms. McConnell and the SBRN.

DDD Presents County-Based Forums: DDD is inviting individuals who are in Real Life Choices, Self-Determination or at the top of the priority and priority-deferred categories of the Waiting List for Waiver Services (WLWS) – formerly known as the Community Services waiting List (CSWL) or Residential Waiting List – to attend a county-based family forum. The forums are geared toward the family’s need to plan and prepare for the well-being of their adult child/children with developmental disabilities. Forums are being held in each of the state’s 21 counties. For information, contact Janice Delorenzo at 609-689-1794 or janice.delorenzo@dhs.state.nj.us. The Ocean County Planning Meeting is scheduled for Wednesday, July 1, 2009 from 9:00 AM – 12:00 PM. It will be held at the Ocean County Library, Mancini Hall. (101 Washington St., Toms River, NJ 08753) The Ocean County Family forum is scheduled for Tuesday, August 4, 2009 from 6:30 PM – 9:00 PM. It will be held at the Arc of NJ (985 Livingston Ave., North Brunswick, NJ 08902).



DDD Provides Education for Families

DDD understands that families of individuals who reside in New Jersey's developmental centers (DCs) have many questions and concerns about watching their loved one's transition to the community. To address this need for information and support, DDD is funding an extensive network of family educational programs through the UMDNJ Family Education Project.

The Family Education Project (FEP) is intended to help families of people who live in the DCs explore all the possibilities of community living. This happens both through education about those possibilities, and by offering families of people in the DCs the opportunity to meet and talk about the transition with individuals who have already moved from a DC.

The FEP also provides training for DC and Community Services staff about the transition process and their role in it as part of the team of people who will help support individuals moving to the community.

- **New Beginnings Family Meetings**, which allow families an opportunity discuss community living and the support coordination community transition process.
- **Pictures of Community Living Learning Events**, which bring families together with representatives of community provider agencies to talk about services and supports in the community.
- **Family visits to community living settings**, which FEP arranges upon request.
- **The New Beginnings in Community Living Quarterly Newsletter**, which is distributed now to about 2400 family contacts of individuals living in the DCs.
- **The FEP website**, www.umdj.edu/linkweb, which provides access to all project publications and links to community information and resources related to Olmstead.
- **The New Beginnings Family Guide Services**, a series of guides, each corresponding to a different phase of the transition process, written for families of individuals living in the DCs.
- **The FEP Family to Family Advisory Group**, which comes together to brainstorm and share ideas with the FEP on issues of concern to families and ways to increase informed decision making.
- **The FEP Toll Free Number for Family Inquires is 800-500-0448.**



How many people have recently moved to the community from developmental centers?

July 2007 - June 2008 = 121

July 2008 - June 2009 = 112

Singing A New Song

Joe Ripley's Transition Story

By Natalie Trump and Dave Wright - UMDNJ, Family Education Project

Joe Ripley, 71, grew up in Montclair, NJ. Joe's family experienced challenges and it became difficult for Joe to be supported at home. Joe eventually moved to New Lisbon Developmental Center, where he lived for 25 years.

In the fall of 2008, Joe was recommended for consideration for community transition. The support coordination transition process is driven by a core team composed of the individual, family and staff, in some instances a state guardian, and those who know the individual well and want him/her to have a successful move.

The transition process is facilitated by a support coordinator; in Joe's case this was Sue Henshaw of Caregivers of New Jersey. Sue has spent a lot of time planning with Joe and when she talks about him she says that he's a "real character." She says that Joe is a polite guy who loves to sing.

The planning process revealed that Joe starts to yell when he becomes frustrated or impatient, and there was some concern about how this would affect Joe's housemates or neighbors. The team members proceeded to brain storm on this issue because they knew it would be important to find the right match in a housemate for Joe.

It happened that another individual, Bob, was also in the planning process and looking for a housemate. Sue got together with Bob's support coordinator, Russ Burger from Values Into Action, to see if a roommate situation could potentially work for them. By discussing and understanding the particulars in each man's life, the teams agreed that this could work. Additionally, both teams interviewed and selected Quality Management Associates of NJ (QMANJ) as the community provider that will support them.

The QMANJ home chosen for Joe and Bob is located in Marlton, NJ, and has a yard and a deck. It is staffed by two full-time people during the day and one person at night, who remains awake.

Before he moved in, Joe made extended visits to the home to get comfortable with the setting. These visits helped Joe and the staff members become acquainted. During these visits, for example, the staff learned that riding in the van to the shore and other places did not work for Joe. He would become impatient and want to return home.

Joe moved into the home in February, 2009. Joe and Bob are now housemates and will be joined in July by George. QMANJ staff said that the trio is a great family unit and the house has a nice rhythm to it.

It has been noted that Joe's yelling has gradually diminished as staff has learned to do things that help Joe not become frustrated. For instance, due to Joe's vision problems, the staff learned to state who comes in or leaves the room, and who they are addressing when talking in the room where Joe is located.

Joe has become close to the staff at his home. He is especially attached to two staff members, Ali and Kristen.

After a period of adjustment, Joe is now living a calm quiet life. He enjoys and looks forward to attending his day program and has not missed a day since he started. Joe has also become more patient and accepting of explanations for delays. Anyone who will visit these gentlemen should be prepared to be serenaded by Joe as he sings one of his favorite country western songs or his rendition of "Singing in the Rain."

