Olmstead Overview - Pennsylvania’s Efforts

On June 22, 1999 the US Supreme Court issued its decision in *Olmstead v. L.C.* This lawsuit against the state of Georgia questioned the state’s continued confinement of two individuals after state hospital physicians had determined that they were ready to return to the community. Both of the *Olmstead* plaintiffs, identified as L.C. and E.W. to protect their privacy, were diagnosed with mental retardation and mental illness. Both women voluntarily admitted themselves to Georgia’s state mental hospitals. Eventually, they and their treatment team decided that they were ready for “community based care.” However, they remained in the hospital because Georgia had no available community-based housing or services for them and no funding to generate more housing and services to accommodate them.

The lawsuit was based on the Americans with Disabilities Act (ADA), stating this law required mental health programs to be administered in the most integrated setting appropriate to the needs of qualified individuals with disabilities. The court rejected the state’s argument that the hospitalization continued due to funding decisions, not a decision to discriminate. They interpreted the ADA to mean that states could not legally require people with disabilities to remain institutionalized in order to receive health care services and this unjustified isolation was a form of discrimination.

**Pennsylvania’s Efforts to Date**

1. Development of an *Olmstead* Task Force known as the Stakeholder Planning Team (SPT). In 2003, the SPT developed a comprehensive document on the issues of home and community-based services. SPT subcommittees include the Workforce Development Subcommittee and the Quality/Data Subcommittee.

2. Governor Edward G. Rendell created the Office of Health Care Reform (OHCR) that has implemented three county pilot projects intended to streamline the Medicaid waiver eligibility process to persons in nursing care facilities in moving to home and community-based services. This office coordinates efforts for the system change grants (*An overview of OHCR grants is available on the association web site at [www.paproviders.org](http://www.paproviders.org)*).
   - **Quality Assurance and Quality Improvement in HCBS** grant for $498,650 concentrates on ways to gauge and assure consumer satisfaction as well as corrective actions and development of a back-up support staff system so a person will not be left without needed help.
   - **Money Follows the Person** grant for $698,211 helps determine ways government funds can follow the person from one service setting to another as their needs and desires change.
   - **Aging and Disability Resource Center** grant of $764,000 will operate four demonstration resource centers to assist consumers and families with information, counseling, assessment, and assistance in applying for long-term care services.
   - **Cash and Counseling** grant (see details below).
3. In 2002 Pennsylvania received a Real Choice Systems Change grant to address barriers to long-term home and community-based care. Part of the grant supports the Stakeholder Planning Team (SPT) to develop the state's Olmstead plan.

4. In 2004 Pennsylvania applied for a Cash and Counseling grant ($350,000) from the Robert Wood Johnson Foundation which would allow people of all ages with disabilities to live in the least restrictive and most integrated setting appropriate to their needs and to receive consumer-centered services. Pennsylvania would use this model for its Aging waiver and in many of the existing 1915(c) home and community-based waiver programs. Programs to be included in the demonstration are three waivers for adults with physical disabilities, the Michael Dallas Waiver for technology dependent, and the 60+ waiver; and programs for persons with mental retardation age three and older. Flexible allowances will be used to design and purchase goods and services including hiring friends and family, becoming the employer, using a fiscal intermediary for tax and payroll functions, home modifications, vehicle alterations, etc. Self-directed support corporations (groups of family/friends) can form non-profit corporations to assist consumers with long-term care services.

5. Beginning in 2002, Pennsylvania began implementation of a federal Medicaid Infrastructure Grant (MIG) based on the Ticket to Work and Work Incentives Improvement Act of 1999. The purpose of the 1999 act was to eliminate barriers faced by persons with disabilities to obtain and maintain employment. Ticket to Work focuses on employment training, placement services, and provides new options for healthcare coverage for Medicare and Medicaid recipients. The project works directly with the one-stop career centers (CareerLink) to improve linkage between the centers and disability services.

Funding for this grant came from the President’s New Freedom Initiative and President George W. Bush’s Executive Order 13217 of 2001 that led to the nationwide effort to remove barriers to community living for people of all ages with disabilities and long-term illnesses. The grants are administered by the Centers for Medicare and Medicaid Services (www.cms.hhs.gov).

The state addressed healthcare coverage through Medical Assistance for Workers with Disabilities (MAWD), which provides health care coverage to workers with disabilities who meet certain eligibility standards. Details are available by calling 800-692-7462 or accessing www.dpw.state.pa.us and selecting Office of Income Maintenance.

The MIG grant has four major components:
- An Advisory Committee on Employment (ACE) to oversee the implementation of the grant and make programmatic and policy decisions regarding employment barriers.
- One urban and one rural demonstration project to establish a one-stop service model for persons to learn about and obtain information on services related to employment.
- One urban and one rural demonstration project to develop a back-up delivery system for attendant care services.
- Educational and outreach efforts regarding MAWD, Ticket to Work, and one-stop options.

Agencies working together on this effort include the Departments of Labor and Industry Office of Vocational, the CareerLink system, and the Department of Public Welfare home and community-based programs. Court and federal recommendations for the Olmstead
planning process should include stakeholders planning groups, public forums for stakeholder input, draft plans for public review, plans developed for accountability and outcomes, and a statewide advisory committee.

The plan breakdown must focus on short-term activities such as revamping assessment tools for identification and assessment of service recipients, quality assurance efforts, and integrated data collection and analysis. Barriers to state action focus on budget shortfalls (some due to declining state revenues) delaying plan implementation, workforce development, and staff retention and recruitment issues.

It was determined that community-based services must provide informed choice and be consumer-driven. These services must also provide physical, social, political, educational, and economic integration for individuals served.

Pennsylvania’s Latest Action

The Office of Mental Retardation (as of 2007 called Office of Developmental Programs) Planning Advisory Committee (OMR PAC) Community Integration Subcommittee developed the state’s Olmstead Plan in 2005. Stakeholders, including PCPA, addressed the various issues, topics, and criteria needed in this plan. Work groups were formed to develop plans for all aspects of community living in the most integrated, least restrictive environment. The work groups addressed guiding principles; public and private intermediate care facilities for the mentally retarded (ICFs/MR), children, large state-funded facilities, other residential facilities, non-residential services, and persons at risk. Each group addressed barriers to implementation of desired outcomes.

In 2006 OMR requested revisions to the draft plan based on the US Court of Appeals for the Third Circuit decision in Frederick L. v. Department of Public Welfare. The court decision stated that the department must develop a “viable integration plan” that at a minimum specifies:

- Time-frame or target date for patient discharge,
- Approximate number of patients to be discharged each time period,
- Eligibility for discharge, and
- A general description of the collaboration required between local authorities and housing, transportation, care, and education agencies to effectuate integration into the community.

Olmstead Subcommittee Budget Request (FY 2005/06)

The OMR PAC Community Integration Subcommittee developed a list of Olmstead Plan-related budget recommendations for OMR to consider as it developed its FY 2005/06 budget request to the state. These included:

- That the ICF Assessment for FY 2003/04 FY be used to fund one-time Olmstead initiatives,
- Allow money to follow the person from congregate facilities to integrated supports,
- Sufficient one-time funds to support movement of residents of a selected state center to waiver programs,
- One-time funds to cover costs of 35 people to move from large state funded facilities to waiver programs,
- Funds to support the conversion of large ICFs/MR to small ICFs/MR with conditions of no more than four residents in smaller program, not require day services to be facility-based and must convert to waiver within one year,
- $300,000 to support persons in real work, and
• Funding to assure the children placed out of home are identified and have a plan developed for community integration.

During FY 2005/06 OMR used “Money Follows the Person” principles in its closure of Altoona Mental Retardation Center and movement of residents into community living or other institutional settings, based on the individuals request. Individuals moving into the community were funded by the Medicaid waiver and served by the appropriate selection of services.

Litigation, Complaints and Trends

1. A January 2006 update by the Center for Personal Assistance Services (www.pascenter.org/olmstead/index.php) notes that national trends of Olmstead implementation have occurred by litigation to create reforms.
   • The state with the most reported lawsuits is Pennsylvania with 14; 11 are closed and two are open, four are classified as Olmstead cases;
   • There have been 58 lawsuits in 27 states;
   • By 2004, 29 states had published Olmstead plans and four states were developing plans. Fourteen states had developed alternative responses to Olmstead.

2. The US Office of Civil Rights (OCR) is responsible for investigating complaints alleging a violation of the Americans with Disabilities Act “integrated regulation,” which requires that persons with disabilities receive public services in the most integrated setting. These violations are set in the Olmstead decision. In Pennsylvania, an advocacy group alleged that the state failed to provide services in the most integrated setting. After the OCR investigation, the state developed a long-term plan to address the waiting list for persons with mental retardation, regional planning groups to address community mental health for adults, and reduction of state mental institution populations including transferring funds to the community. The Department of Public Welfare implemented a “Stakeholder Planning Team” to examine services. (OCR Docket #99-07183).

3. Nationally, barriers to action have included state budget shortfalls which have lead to hiring freezes and high rates of staff turnover. Many community service providers rely on state and federal Medicaid funding to implement programs and provide supports to individuals with disabilities. As business costs increase but funding sources do not, the issue of providing safe and healthy living environments for individuals when providers have high staff turnover and vacancy rates becomes more real. This does not address the emotional impact on persons with disabilities that have to deal with many new staff to assist them in their daily living.

Many staff shortages are for paraprofessionals or direct service workers that provide daily care and assistance to individuals. The issues of worker vacancies and turnover relate to low wages, poor benefits, and limited opportunity for job advancement. PCPA enacted a turnover and vacancy survey to determine drug and alcohol, mental health, and mental retardation provider issues regarding staffing for services in 2006. A copy of the results is available from Policy Specialist Linda Drummond (linda@paproviders.org).

4. Some states have opted to take cost-neutral or low-cost solutions such as consumer-directed care, transition from institutions to community services, and consumer education on choices. The Centers for Medicare and Medicaid Services Real System Change grants are providing opportunities to implement these options. Pennsylvania began one effort in 2000...
for individuals with mental retardation with the development of Intermediary Service Organizations which offer consumers more control over selection of services and providers of these supports.

5. The 2005 State of the States in Developmental Disabilities looking at FY 2004 statistics indicates some progress has been made in the movement toward community services, but much still needs to be done. National statistics show:
   - Nearly 500,000 persons with developmental disabilities are in out-of-home residential placements; 21 percent are in institutions with 16 or more persons, 11 percent are in institutions with 7-15 persons, and 68 percent are in 1-6 person settings.
   - 36 percent are in institutions (state centers, private or public ICF/MR, or nursing homes.
   - In Pennsylvania, 6,685 of 24,415 (or 27 percent of persons) are still in institutions as described above.
   - The average cost for larger state-operated institutions is $146,000 per person, per year and $68,000 for private ICFs/MR. Smaller, private ICFs/MR (15 persons or less) average $75,000 per person, per year and small, public ICFs/MR average $86,000 per person, per year.
   - Medicaid Home and Community Based Waivers average costs are $38,000 per person, per year and Supportive Living/Personal Assistance averages $21,000 per person, per year.

Resources
A variety of web sites which provide information regarding the Olmstead Decision including details on the litigation, national and state efforts, updates on initiatives, and impact on individuals are available. These include those listed below.
   - Judge David L. Bazelon Center for Mental Health Law, www.bazelon.org
   - Center for an Accessible Society, www.accessiblesociety.org
   - US Department of Health and Human Services Office for Civil Rights, www.hhs.gov/ocr
   - University of Pennsylvania Collaborative on Community Integration, www.upennrrtc.org