



Pennsylvania Self-Determination for People with Developmental Disabilities Promotes Flexibility in Living Arrangements and Services

Self-Determination for Persons with Developmental Disabilities

SUMMARY

Pennsylvania's Department of Public Welfare, Office of Mental Retardation ran pilot projects in urban, rural and suburban counties—Allegheny, Blair and Lehigh—to develop and implement the first steps of county plans to give people with developmental disabilities greater choice in determining the services they receive.

The project was part of the Robert Wood Johnson Foundation's (RWJF) national program, *Self-Determination for People with Developmental Disabilities*.

Statewide Results

- By February 1998, the Department of Public Welfare, Office of Mental Retardation reported that 15 counties participated in self-determination initiatives of their own design. State officials attributed this outcome to the combination of RWJF funding and Pennsylvania's commitment to the *Multi-Year Plan for Pennsylvania's Mental Retardation Service System*, which accelerated change by prompting an examination of county policies regarding services for people with developmental disabilities.
- Pennsylvania used information gained from the three pilot projects to develop its Home and Community Based Services waiver to the federal Centers for Medicare & Medicaid that became effective July 1, 1999. It allowed Pennsylvania to provide greater flexibility in living arrangements and service delivery.

County Results

Pennsylvania reported the following county results:

- *Allegheny County*: Independent support coordination agencies designed an assessment tool to determine provider rates according to levels of need (using such factors as living arrangements and medical needs), which 33 agencies tested with 69 individuals.

- *Blair County*: The county designed and implemented a process to transfer funds from the county or from its contracted providers to create individual budgets for 21 individuals, who also utilized person-centered planning to develop support plans.
- *Lehigh County*: Through the creation of an individual purchasing process that uses vouchers, 95 individuals selected and purchased employment-related and/or day services.

Funding

RWJF awarded Pennsylvania an 18-month planning grant of \$100,000 between 1997 and 1998. To cover additional staff time in the pilot counties, the Office of Mental Retardation contributed \$166,000 to this project.

THE PROBLEM

In Pennsylvania, a state with seven major cities and the largest rural population in the United States, 45 county mental health/developmental disabilities programs administer services for people with developmental disabilities and are responsible for collecting and maintaining related data.

Counties vary in how they administer services, but adhere to policies set by the Office of Mental Retardation, a part of Pennsylvania's Department of Public Welfare. Four regional offices supervise and give technical assistance to the county administrative units.

Instead of providing services directly, most counties have purchased services through contracts with private providers. These contracts define a group of services (such as residential care, day programs and supported employment) for a fixed number of people at a certain cost, known as "bundled services."

Since bundled services are not tailored to individual need, people who function relatively well may receive unnecessary services, while others in greater need (and people waiting for any service) may receive inadequate support.

In 1995, the Office of Mental Retardation reported, Pennsylvania's mental retardation system served more than 63,000 people using a total budget of \$1.2 billion. Some 3,250 adults resided in state institutions and more than 3,000 people lived in small and large group homes.

The Office of Mental Retardation estimated, based on lists maintained by the county agencies, that 20,000 people with developmental disabilities eligible for services were waiting for services of any kind. That number was expected to peak as caregivers to the baby boom generation aged.

At the time of the grant award, Pennsylvania already had a history of working toward giving people with developmental disabilities greater control over the publicly funded services they needed. By 1989, the Office of Mental Retardation had developed a vision statement, *Everyday Lives*, which directed system change toward deinstitutionalization, consumer-directed services and natural supports (assistance provided by friends, family and community members).

Based on these principles, Pennsylvania developed its 1993 Medicaid Home and Community-based Services waiver from Medicaid regulations to facilitate individual and family choice of services, and their delivery in the individual's home community, rather than in institutional or large group settings.

In 1995, the office began planning to provide more community-based services and to free up financial resources for people on the waiting list. In 1997, soon after this grant began, the Department of Public Welfare adopted the *Multi-Year Plan for Pennsylvania's Mental Retardation Service System*.

It recommended steps to redesign services for people with developmental disabilities to make services compatible with the goals of self-determination, and aimed to restructure the system within five years to make it consumer-directed, cost-efficient and with measurable outcomes.

THE PROJECT

As part of the national program, *Self-Determination for People with Developmental Disabilities*, RWJF awarded an 18-month planning grant of \$100,000 to Pennsylvania's Department of Public Welfare, Office of Mental Retardation.

The grant funded pilot projects in urban, rural and suburban counties—Allegheny, Blair and Lehigh, respectively—to further develop and implement county plans to give people with developmental disabilities more choice in determining the services they receive.

These three counties had already tried various approaches to better tailor services to consumers. The Office of Mental Retardation also planned to continue its state-level planning of a more consumer-directed, cost-effective, long-term care system.

To cover additional staff time in the pilot counties, the Office of Mental Retardation contributed \$166,000 to this project. A statewide coordinator provided technical assistance and coordinated communication activities and state policy to support project goals.

While this grant was in progress, the state sponsored public forums, legislative hearings, presentations and training on the concepts of natural supports, self-determination and

quality in human services throughout the commonwealth as part of the *Multi-Year Plan for Pennsylvania's Mental Retardation Service System*.

Allegheny County. Allegheny County was already providing person-centered planning, individual budgets and services tailored to individual choice (funded by money left over from closing institutional facilities) to some 232 individuals. In March 1997, the county government formed a coalition to guide the pilot project. It included people who had previously worked on changing the developmental disabilities service system.

The county hired the Human Services Research Institute to assess the feasibility of using some aspects of managed care to provide services to people with developmental disabilities. The county was contemplating giving organizations some degree of management control over services rendered in exchange for a fixed fee for each person served regardless of the complexity of the services provided.

The institute staff identified the fiscal, legal and regulatory changes necessary to revise the system, and evaluated the county's readiness to make changes. To set fair provider rates, and to avoid the problem of having providers evading providing services to people with more complex needs, the county asked independent agencies that coordinate support services for individuals with developmental disabilities to design and test an assessment tool to determine levels of need (according to criteria such as living arrangements and medical needs) on which to base group rates for different levels of need.

The education and training subcommittee of the guiding coalition surveyed individuals with developmental disabilities, their families and advocacy and professional groups about their knowledge of self-determination. Based on these findings, the subcommittee drafted a primer on self-determination, and planned curricula for presentations, training and conferences on self-determination.

Blair County. Blair County adopted guiding principles (developed from the Everyday Lives vision statement of the Office of Mental Retardation), policies and procedures to foster consumer control over services and increase the inclusion of people with developmental disabilities in their communities. The county began to add to contracts basic measures of provider performance such as consumer satisfaction, maintenance of safety and service to individuals on the waiting list.

The county used community focus groups, educational sessions, open meetings and newsletters to train people with developmental disabilities, their families, advocates, service providers and county agency staff in person-centered planning. It designed and implemented a process to transfer funds from the county or from its contracted providers to create individual budgets for 21 people with developmental disabilities, whose support plans were the result of using person-centered planning. The county developed baseline data to assess the cost-effectiveness of its pilot.

Lehigh County. Lehigh County hired the Human Services Research Institute to assess the county's readiness to manage a system designed around the needs of people with developmental disabilities and their families. The institute's report outlined the existing delivery system in Lehigh County and how it might compare to a consumer-directed system, and provided options to move the existing system towards more consumer-directed services. Using the institute's recommendations, a county strategic planning committee established guiding principles and identified system issues to be addressed before a new system could be implemented.

Through the creation of an individual purchasing process using vouchers, 95 individuals with developmental disabilities selected and purchased employment-related and/or day services. The county also began using person-centered planning and explored how to combine paid and non-paid, or natural, supports to improve the availability of services. For its management information system, the county explored the availability of new database software programs that can track and connect client and provider information.

RESULTS

Statewide Results

- **By February 1998, the office reported that 15 counties participated in self-determination initiatives of their own design.** State officials attributed this outcome to the combination of RWJF funding and Pennsylvania's commitment to the *Multi-Year Plan*, which accelerated change by prompting an examination of county policies regarding services for people with developmental disabilities.
- **Pennsylvania used information gained from the three pilot projects to develop its Home and Community Based Services waiver from Medicaid regulations that became effective July 1, 1999.** Experience with the pilot projects, the project director observed, "raised issues to the top of the pile that we didn't know were issues." Issues such as whether a private nonprofit agency could manage public funds, and who would qualify to provide home-based services were worked out before the waiver application to the federal Centers for Medicare & Medicaid services was written. Without the pilot projects, these issues would have emerged only after the waiver had been written and approved.

County Results

- ***Allegheny County:* Independent support coordination agencies designed an assessment tool to determine provider rates according to levels of need (using such factors as living arrangements and medical needs), which 33 agencies tested with 69 individuals.**
- ***Blair County:* The county designed and implemented a process to transfer funds from the county or from its contracted providers to create individual budgets for**

21 individuals, who also utilized person-centered planning to develop support plans.

- **Lehigh County: Through the creation of an individual purchasing process that uses vouchers, 95 individuals selected and purchased employment-related and/or day services.** The county also began working with person-centered planning and explored how to combine paid and natural supports.

Communications

Project staff produced brochures, held conferences and workshops and gave presentations to disseminate information about the three pilot sites. Staff from Allegheny County made 26 presentations to various advocacy, provider and other professional organizations and held two conferences and three workshops on self-determination and long-term supports attended by more than a thousand people. Blair County used RWJF funding to bring nationally recognized speakers to three local workshops on self-determination, and to produce and disseminate 3,200 copies of a project newsletter. Lehigh County presented at or participated in panels at 12 local and national conferences. (See the [Bibliography](#).)

LESSONS LEARNED

1. **In contrast to state agencies in which change can be centrally mandated, county offices must be nurtured to implement change, if a state agency wishes to promote changes in county level systems.** (Project Director/Office of Mental Retardation)
2. **It is useful for project staff to speak with staff in states with similar systems who have faced similar challenges.** Such support is very effective because it is tailored to specific circumstances and provides concrete examples. For instance, in the face of early skepticism from a regional office of the Health Care Financing Administration (now the Centers for Medicare & Medicaid Services) Pennsylvania was able to point to Wisconsin's success in providing home and community-based services through a county-, rather than state-based system. (Project Director/Office of Mental Retardation)
3. **Families can be valuable training resources and may be willing to share their experience.** A family member from one county in Pennsylvania visits other counties and states to explain how family members can train and supervise staff to support their children. (Project Director/Office of Mental Retardation)
4. **When people with developmental disabilities and their families shop for consumer-directed services, they need time to educate themselves, seek out services suited to their specific needs, and make informed and prudent choices.** This is one circumstance that will require adaptation as systems make the transition from provider- to consumer-direction. (County Project Director)

5. **Consumers, providers and administrators in consumer-directed systems need a great deal of education and training to understand how the new system operates.**

In such systems, individuals with developmental disabilities and their families need to understand what resources are available and how to gain access to them. Providers need to learn to be responsive to consumer needs cost-effectively. State and county governments need to learn how to shift from processes supporting a provider-driven system to ones that support consumer control. Education and training campaigns are needed to help each group affected by changes in service delivery. (Project Director/Office of Mental Retardation, County Project Director)

6. **Public education will be needed to help communities learn, or relearn, how to understand, welcome and support people with developmental disabilities as these people become increasingly able to live again in their own communities rather than in institutions or group homes.** (Project Director/Office of Mental Retardation, County Project Director)

AFTERWARD

Pennsylvania continues to work toward consumer-directed supports for persons with developmental disabilities, and make state funding available to counties to begin local system reform. The state has projected that all counties in Pennsylvania will use individual budgets and a consumer-directed approach to serving persons with developmental disabilities by January 2004.

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BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Reports

Allegheny County Self-Determination Demonstration Project: The Fundamentals (training booklet). Pittsburgh.

Allegheny County Self-Determination Rules! (brochure). Pittsburgh.

Ashbaugh J et al. *Assessment of the Feasibility of Instituting a Customer-Driven System of Services and Supports for Adults with Mental Retardation in Allegheny County*. Cambridge, MA. Human Services Research Institute, 1998.

Human Services Research Institute. *Final Report of Lehigh County Feasibility Study*.

Sponsored Conferences

"Self-Determination: Choice and Control, Fact or Fiction?" Allegheny County Annual MR/DD Conference, May 19–20, 1998, Pittsburgh.

Sponsored Workshops

"Consumer Driven Systems of Care: A Blueprint for Change; Long Term Services and Supports: A National Perspective." May 14, 1997, Pittsburgh.

"Consumer Driven Systems of Care: A Blueprint for Change; Long Term Services and Supports: A State and Local Perspective," May 31, 1997, Pittsburgh.

"Consumer Driven Systems of Care: A Blueprint for Change; Long Term Services and Supports: A Historical Perspective," June 13, 1997, Pittsburgh. Attended by 200 persons from provider agencies and advocacy groups, self-advocates, state and county staff and family members.

"Self-Determination is not a Model. It's a Human Right," June 12, 1997, Altoona, PA.

"Self-Determination Project: Committed to Empowering People," July 24–25, 1997, Altoona, PA.

"The Future of Long Term Supports for People with Developmental Disabilities," January 21, 1998, Altoona, PA.

"The Dream of Self-Determination: What Are We Trying to Achieve?" April 16–17, 1998, Pittsburgh.