Promising Practices in Long Term Care Systems Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation

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PENNSYLVANIA'S TRANSFORMATION OF SUPPORTS FOR PEOPLE WITH MENTAL RETARDATION

As home and community-based support systems continue to grow and evolve, states are examining whether their current systems reflect fundamental participant and community values. A number of states are concluding that they need to put in place systemic reforms to ensure that their home and community-based support systems promote dignity, independence, individual responsibility, choice, and self-direction.

Systemic reforms are simultaneously addressing multiple aspects of community long term support systems in order to improve responsiveness to participants' needs and preferences. These initiatives are developing entirely new ways of designing, organizing, and managing community-based supports as a system rather than as a random collection of uncoordinated individual supports. In some cases, this has required states to make fundamental changes to the administrative infrastructure of their home and community-based support programs.

Two design features in particular have repeatedly emerged as essential components of systemic reform initiatives:

- *Single Entry Points*, which provide people with a clearly identifiable place to get information, advice, and access to a wide variety of community supports; and
- *Person-Centered Services*, which place participants, not services or providers, as the central focus of funding and service planning.

The Centers for Medicare and Medicaid Services contracted with Medstat to examine approaches ten states took to developing Single Entry Points and Person-Centered Services to assist people with disabilities to live productive and full lives in integrated community settings. We conducted on-site interviews with state officials, advocacy organizations, and local program administrators, and extensively reviewed written documents on policy proposals, administrative rules, and program evaluations. The emphasis of the resulting ten case study reports is on identifying transferable models that can be adapted for replication in other states and communities across the country, while acknowledging that some aspects of state systems may be unique to each state's culture, history, and traditions.

Overview of Pennsylvania's Transformation Project

The Commonwealth of Pennsylvania's Office of Mental Retardation (OMR) is implementing a system-wide reform of its supports for people with mental retardation. The objective of this Transformation Project is to improve the quality of life of people who use publicly funded supports by providing them with more choices and greater control over these supports.

Like most states, Pennsylvania's mental retardation program has evolved in recent decades from a primarily facility-based system to a more flexible and responsive program of community-based supports. That process started in earnest with the enactment of the Mental Health and Mental Retardation Act of 1966 (MHMR Act). At the time that the MHMR Act was debated, the state had over 13,000 individuals with mental retardation living in large state-operated centers. Another 1,500 individuals with mental retardation were living in large, privately run facilities. Few had any viable options for community-based supports tailored to their needs and wishes.

The MHMR Act established county-based departments of Mental Health and Mental Retardation (MHMR) to administer community supports on the local level. Pennsylvania's 67 counties formed 46 departments of MHMR, including several that serve multiple counties. The Office of Mental Retardation (OMR) monitors the counties' performance and licenses facility-based supports. OMR is part of the Department of Public Welfare, the Commonwealth's Medicaid agency. The counties have had a high level of discretion in designing supports for individuals with mental retardation, and the system was viewed by many as provider-driven rather than driven by the goals of individuals with mental retardation.

The Transformation Project that is currently underway preserves the basic structure put in place in 1966. Counties will continue to operate the HCBS system with state oversight, but participants now have—and will continue to have—a greater choice of supports, providers, and methods of service delivery. OMR also is improving its effectiveness in meeting federal requirements for Medicaid HCBS waivers to ensure people with mental retardation have freedom of choice and receive quality supports. In addition, the information management processes and business practices and procedures that backstop the system are being upgraded and standardized.

The Transformation was organized into three phases for planning and implementation purposes:

- Phase I – Quality
- Phase II – Consumer Support
- Phase III – Financial Processes

Phase I is complete, and OMR is currently implementing several components of Phase II in a four-county pilot project. The rest of Phase II, as well as Phase III, will be implemented later. Many of these changes are detailed in this report. In addition, Appendix A contains a comprehensive list of the changes being carried out in each phase.

Pennsylvania's System for People with Mental Retardation

Unlike many states, Pennsylvania has adopted separate systems for people with mental retardation and those with other developmental disabilities. The latter include autism, developmental disabilities resulting from traumatic brain injuries, and physical

disabilities that manifest before age 21. The Department of Public Welfare's Office of Social Programs provides supports for people with developmental disabilities who do not have mental retardation.

Although the Office of Mental Retardation operates a number of programs for people with mental retardation, participants approach the system from the perspective of multiple options stemming from a single funding source. In the state fiscal year ending in June 2001 (fiscal year 2001), OMR funding totaled $1.8 billion, including nearly $15 million in matching funds from the counties, and provided supports to 80,230 participants. OMR spent $1 billion for community supports, with most of these expenditures supporting the 21,000 participants served under OMR's three Medicaid HCBS waivers: the Consolidated Waiver for Individuals with Mental Retardation, the Person/Family Directed Support Waiver, and the Infants, Toddlers, and Families Waiver.

The Consolidated Waiver for Individuals with Mental Retardation provides supports to eligible people with mental retardation over age 3 so they can remain in their communities. Supports include environmental adaptations, habilitation, permanency planning, respite, specialized therapy, transportation, and visiting nurse services. Many people using this waiver live in group homes or other settings apart from their natural families. Pennsylvania had federal approval to serve 15,493 people in 2002, and the waiver served 13,597 participants in May, 2002.

The Person/Family Directed Support Waiver is also available to eligible people with mental retardation over age 3. This waiver requires the person, or his or her family, to exercise self-direction by hiring his or her providers. People using this waiver must live at home, either by themselves or with family members. This waiver offers adaptive and environmental supports, habilitation, homemaker/chore supports, personal support, respite, therapies, transportation, and visiting nurse services. Pennsylvania had federal approval to serve 7,361 people in 2002, and the waiver served 6,217 participants in Mary, 2002.

The Infants, Toddlers and Families Waiver provides supports to children from birth to age three who need early intervention services defined in the Individuals with Disability Education Act, Part C. Families are required to direct their children's supports, as they are for children receiving the Person/Family Directed Support Waiver. Pennsylvania has federal approval to serve 3,730 children in 2002, and the waiver currently served 3,102 participants in May, 2002.

Pennsylvania intends to apply the Transformation Project's information technology and many of the accompanying system changes to all of its waiver programs. OMR's parent agency, the Department of Public Welfare, offers several additional HCBS waivers that provide supports to people with disabilities to live independently in their homes and communities. The OBRA waiver currently serves 285 people with developmental disabilities, and is approved to serve 356 people. Pennsylvania also offers a waiver for people with AIDS; the Attendant Care and Independence waivers for people with

physical disabilities; the Michael Dallas Waiver for technology-dependent individuals; and the CommCare Waiver for people with traumatic brain injuries. In addition, the Elwyn Waiver was established in response to the closure of a specific nursing facility.

Pennsylvania's supports for older people are administered by a separate cabinet-level department, the Department on Aging. This department offers an Aging Waiver for people age 60 and older. It also provides state-funded home and community-based supports with proceeds from the state's lottery, and a Long Term Capitated Assistance Program that is an alternative to nursing facility care for qualified older Pennsylvanians.

Evolution of Pennsylvania's Transformation Project

Impetus for Reform

Pennsylvania's current path can be traced back to 1991, when the Planning Advisory Committee to the OMR, a state-sponsored group comprising individuals, families, advocates, providers, and county MHMR employees, set forth a vision of having people with mental retardation live mainstream lives within their communities. Called *Everyday Lives*, the document became the cornerstone of OMR's efforts to give individuals and families a more decisive voice in shaping individual and systemic goals. It also has guided the state's allocation of public funds to nurture reform. In addition to freedom of choice and the availability of quality supports, the document's central tenets include giving people with mental retardation the freedom to live the lives they want and to negotiate risk; the opportunity to contribute to the community; and the right to be safe at home, at work, at school, and elsewhere in the community.

A few years later, in 1995, a new administration invited the Planning Advisory Committee to develop a strategic plan for the states' supports for people with mental retardation. In 1997, the committee published an ambitious plan designed to make the vision laid out in *Everyday Lives* into a reality. Known as *A Multi-Year Plan for Pennsylvania's Mental Retardation Service System*, the strategic plan called for participants and their families to have more choices and greater control over resources. The *Multi-Year Plan* also called for an expansion of community resources for people in institutions and on waiting lists; better integration of OMR's quality management efforts; improvements to management information processes to make the system stronger; and a restructuring of OMR's system of supports from a provider/county-driven entity into one guided by the needs of participants and their families. Because of the Planning Advisory Committee's work, OMR and its stakeholders concluded that major reform was needed to make the system truly responsive to people with mental retardation.

In 2000, a few years after the release of the *Multi-Year Plan,* the Centers for Medicare and Medicaid Services (CMS) conducted a quality review of one of Pennsylvania's waiver programs for people with mental retardation. CMS expressed concern about the state's operation of the Medicaid waiver programs. According to state staff, its key findings concerned the lack of consistency among the 46 county-based departments of

MHMR, the lack of a statewide quality assurance system, inadequate case management to ensure people's health and safety, and the lack of free choice among qualified providers.

Guided by the *Multi-Year Plan*, and concerned about losing federal funding in the wake of the CMS review, the state embarked on a multi-year restructuring project to develop a seamless system of person-centered supports for people with mental retardation. As a first step, Pennsylvania committed $850 million over five years to fund people with mental retardation who were waiting for supports.

OMR brought in Braxton (formerly Deloitte Consulting) to help retool the existing management information system to support implementation of the *Multi-Year Plan*. Braxton recognized that revising the management information system alone would only solidify the existing provider-driven system. Instead, they recommended that OMR concurrently restructure its policies, procedures, and business practices in order to achieve its goal of creating a participant-driven system. This comprehensive effort became known as the Transformation Project.

To be successful, the Transformation Project would require a considerable financial commitment from the state—and the timing could not have been better for OMR. The governor of Pennsylvania at the time was committed to improving the state's information technology infrastructure. As a result, when OMR asked for funding to revamp its management information system, the governor was receptive to the department's request.

Once the funding was secured, the Office of Mental Retardation established a Transformation Management Office. Individuals and teams from across the Commonwealth were given the task of designing a system-wide restructuring strategy, including a master plan to create new, standardized practices to support a participant-centered approach to supports and use information technology to support these new practices.

Stakeholders Roles in Program Implementation

OMR has become a leader in bringing individuals and families to the planning table and involving them in formulating policies affecting individuals with mental retardation who receive community supports. As a result of this stakeholder involvement, self-determination has evolved from being a state goal into a reality for many participants.

From the onset of the Transformation Project, OMR committed to having broad-based stakeholder involvement in the process. Experience from previous initiatives to improve supports had taught OMR that the results of the initiatives improved if individuals with mental retardation, their families, providers, and representatives of county departments of MHMR were involved. Although on occasions consensus has not been reached—particularly in the area of quality improvements—stakeholder participation was invaluable. OMR is working with its long-standing Planning Advisory Committee – the group of individuals with mental retardation, families, advocates, providers, and county

MHMR employees that developed the *Multi-Year Plan* – during the Transformation, and OMR has created additional forums for stakeholder input.

OMR established a *requirements team* – made up of some mix of OMR staff and county staff, providers, participants, and families – for each component of the Transformation. Each team is co-chaired by an OMR manager and a Braxton consultant. The requirements teams' mandate was to develop appropriate new policies and procedures, and then to determine how the new information system, the Home and Community Services Information System (HCSIS), could implement and support them.

Individuals with mental retardation and their families were members of the requirements teams for several new processes, including the individual support plan and the incident reporting system. In addition to participating on some of the requirements teams, individuals with mental retardation and their families were involved in frequent meetings regarding the Transformation with OMR staff at both the state and county levels, including senior management. They also helped guide the creation and distribution of a number of brochures and other program documents targeted to individuals and their families.

County departments of MHMR were also fully involved in designing the new system. OMR established a 12-member county advisory committee to participate in making final decisions, and OMR's leadership met frequently with county administrators to ensure clear and collaborative communication. Each county also had a designated County Transformation Manager; these managers met monthly to plan and coordinate activities. In addition, OMR conducted county readiness reviews and helped each county to develop its own action plan to handle the Transformation. OMR also developed a Transformation guidebook specifically to help counties make the many changes necessary to prepare for the Transformation, ranging from upgrading information systems to establishing an independent quality monitoring program to helping providers and participants in their county prepare for the changes.

A Provider Transformation Council, consisting of leaders of the statewide provider associations, met regularly. A provider readiness assessment and guidebook were developed to facilitate provider involvement in planning activities, and a variety of reports and other written materials were developed and disseminated to give providers details about the Transformation.

Single Entry Points: Facilitating Individuals' Access to Needed Supports

Pennsylvania has for some time, and with mixed results, operated a single entry point for supports. Under the old system, county MHMR departments conducted assessments, processed enrollments, determined how the waiting list for Medicaid waivers should be prioritized, and provided support coordination. The problem, however, was that many people did not know the offices existed. In addition, participants needed to call or visit an

office in order to receive supports. They also needed to visit a *separate* office in order to determine Medicaid eligibility.

Online Application for Supports

One goal of the Transformation Project is to improve access to supports by providing a clearly identifiable place—a single entry point—where the public could obtain information on a wide array of community supports available to individuals with mental retardation and their families. To achieve this, OMR is using a Web-based tool that its parent agency, the Department of Public Welfare, is developing under a separate information technology project.

This tool, called Commonwealth of Pennsylvania Application for Social Services (COMPASS), provides a single entry point for screening and applying for a wide variety of social service programs, including Medicaid, Temporary Assistance for Needy Families, Food Stamps, and energy assistance. COMPASS eliminates the lengthy and cumbersome paper application process of old, as well as the need to go to a county office for assistance. As a result, counties, private social service agencies, and providers can quickly help individuals apply. This "no wrong door" approach will enable people to learn about and apply for a host of publicly funded supports immediately from any computer terminal with Internet access.

Through COMPASS, people can apply for publicly funded health care coverage, food stamps, and cash assistance benefits. People can now also use COMPASS to apply online for Medicaid HCBS Waivers and other OMR supports. People can enter information in COMPASS for both financial eligibility and functional eligibility. The financial eligibility information is then transferred to the local Medicaid financial eligibility staff, and the functional eligibility information is transferred through HCSIS to people at county department of MHMR, who then conduct the in-person assessment described in the next section. Many families will likely continue to utilize the county department of MHMR to apply for waiver supports; for these families the support coordinators will use COMPASS to record eligibility information.

Individuals with mental retardation and their families are the first to use COMPASS to apply for HCBS waivers and other OMR supports; soon, all applicants for home and community-based supports will be able to apply on-line. People and families now have instant on-line access to detailed information about OMR supports and step-by-step guidance through the application process. There is also a pre-screening module to guide individuals to any supports for which they are qualified, including HCBS waivers.

COMPASS has been designed for ease-of-use, and an informational brochure about the tool is being broadly disseminated to individuals through local social service agencies and several stakeholder groups that represent people who may use COMPASS. For the component of COMPASS that enables people to apply for OMR supports, DPW and OMR sent information to the county departments of MHMR, individual and family

advocacy groups, and provider associations. COMPASS can be accessed by people with visual, hearing, physical, and/or cognitive disabilities, and is available in ten other languages to assist non-English-speaking individuals. In addition, families can call a toll-free customer-service number to receive assistance in accessing the COMPASS system.

Assessment Process

After applying for supports on COMPASS, an intake worker at the county department of MHMR meets with the participant and/or a family member to complete a Priority of Urgency of Need for Services for Persons with Mental Retardation (PUNS) form. Pennsylvania uses three categories to rank an individual's need for supports, including HCBS waiver supports and state-funded supports funded by OMR: emergency (needs supports immediately), critical (needs supports within one year), or planning (support needs are more than a year away). The relative intensity of supports needed is also determined according to the following criteria:

- Case Management—only case management needed.
- Low Intensity Service—ancillary supports and case management needed.
- Medium Intensity Service—vocational/day supports needed possibly in addition to ancillary supports and case management.
- High Intensity Services—residential supports needed, possibly in addition to vocational/day supports and ancillary supports.

Depending on the results of the PUNS assessment, the person may not be able to receive all necessary supports right away, but may be eligible to receive some supports to meet immediate needs. The data in the seven-page PUNS assessment form are reviewed annually or as needed until supports are available.

Individual Estimated Resources (IER)

OMR originally planned to calculate an individual budget, called the Individual Estimated Resources (IER), based on each person's specific characteristics and needs. OMR staff considered an individual budget a critical component of OMR's shift to an individual/family-driven system. OMR planned for the individual budget to give individuals and families the maximum control over how support dollars are spent. An individual or family could choose any combination of supports within the budget. In addition, it would be portable, allowing a participant to maintain the approved level of support if he or she moved to a new county. Under the current system, such continuity is not guaranteed.

The IER process sought to support some of the OMR's major goals, including:

- having a person-centered process for matching funding to participants' needs;
- removing bias and unfairness from funding decisions;
- ensuring equity and consistency across the state; and

- allowing individuals to determine which supports will best meet their needs.

During a pilot stage in 2002, OMR used the IER process for new applicants only, with plans to expand it in 2003. OMR suspended the IER in January, 2003, in response to concerns that will be described below.

During the pilot, the amount of a person's IER was based on information from a second assessment, called the Situational Assessment. Once a person is determined eligible for supports, a support coordinator conducted a Situational Assessment to collect the information necessary to plan a person's supports. The Situational Assessment tool contained 62 questions related to the person's needs and circumstances. The Home and Community Services Information System (HCSIS) calculated the IER based on the Situational Assessment. Information in the assessment determined the amount of funding necessary to support the person, and provided consistency across the pilot counties in determining support levels.

The Situational Assessment and the IER were developed by the Office of Mental Retardation after extensive research and review of individual budget estimations across the country. In the end, the DOORS model, developed in Wyoming, served as the foundation for Pennsylvania's approach (A description of this model is available at http://www.cms.gov/promisingpractices/wyib.pdf.). OMR used stepwise regression analysis in creating the tool, and struggled with the issue of preventing financial bias as they established a baseline from existing individuals who were being fully served. A cost-of-living study was also conducted in each of Pennsylvania counties, and the results led to inclusion of a cost-of-living factor in the allocation formula. The tool has shown high validity in the pilot projects conducted thus far, and will soon be ready for a reliability study.

If implemented, the IER would represent a guideline dollar amount and not a cap. If an individual, a family member, or a support coordinator believed the IER amount was not enough to provide necessary supports, he or she could request an Exceptional Case Review through OMR. This process would be completed within 30 days and would be conducted by credentialed experts. If a person then disagreed with the outcome of the Exceptional Case Review, he or she could request a formal hearing at the Department of Public Welfare level. Alternatively, people could bypass the Exceptional Case Review and immediately request a formal hearing.

The Situational Assessment, the IER, and the Exceptional Case Review are the most controversial components of the Transformation. Some individuals, families, and advocates do not have confidence that the cost of providing supports to someone can be predicted based on that person's characteristics and circumstances. Some are concerned that participants and their families will come to view the IER as a cap, and will thus not receive adequate supports. Others challenge whether the Exceptional Case Review process will indeed be timely.

OMR responded to these concerns in January 2003 by suspending the application of the IER. OMR has since established a work group of state and county officials and stakeholders to review the proposed approach and to explore possible accommodations to allay participants' fears. In the meantime, OMR will continue to use the Situational Assessment on a pilot basis. OMR will also calculate the IER for each individual enrolled, but not use the IER in support planning. OMR will study the impact the current tool would have if applied. Until a decision about how to proceed is made, however, the expenditures for an individual's supports will be determined according to county policies, with considerable county variance.

Person-Centered Services

This series of case studies on state long term supports initiatives focuses on two primary components of systemic reforms. The first, as described in the previous section of this report, is a single entry point designed to provide an identifiable place where people can get information, objective advice, and access to a wide range of community supports. The other essential component is a system of person-centered services that places participants, not supports or providers, at the center of funding and support planning.

Person-centered services systems, as discussed in the following sections of this report, have three key features. First, by providing a wide range of support options and a person-centered planning process to facilitate choice among these options, these systems enable people to make meaningful choices about their living arrangements, the types of supports they receive, and the manner in which supports are provided. Second, by designing person-centered management systems, the state's ability to achieve intended participant and program outcomes is enhanced. Third, by coordinating person-centered services with community resources, residents of institutions have enhanced assistance in transitioning to community living.

Person-Centered Support Options

The integration of person-centered support options marks a significant change in practice for OMR, and is designed to enable participants to make meaningful choices about their living environments, the types of supports they receive, and the manner in which supports are provided.

Support Coordination—After the PUNS assessment and, in pilot areas, the Situational Assessment, individuals choose a support coordinator and begin planning their supports. If individuals do not choose a support coordinator, one is assigned to them. Counties either hire support coordinators or contract with an agency that employs them. Before the Transformation, some organizations that provided support coordination also provided direct supports. OMR no longer allows this conflict of interest.

OMR has also established a new person-centered individual support plan (ISP) process, currently in a pilot stage, that offers a consistent format to assess the person's health and

safety needs, to identify the person's preferences and needs, and to promote outcomes such as the kind of work the person wants to do. The new system is designed to make it easier for participants to choose the supports they need, the providers they use, and their preferred home and work environments. In the new system, the individual and his or her family can select additional people to participate in the planning process, in addition to themselves and the support coordinator.

To aid their decisions, participants will have access to a Web-based Services and Support Directory. This directory will allow each participant to choose from a listing of all qualified providers, see the supports they provide, and compare their rates. DPW standardized definitions for all home and community-based supports to provide clarity and consistency, which will be particularly important for people who may qualify for more than one of Pennsylvania's eleven waivers.

Support coordinators will have a redefined role under the new, more self-focused system. They will have new statewide standards for conducting needs assessments; assisting in developing ISPs; ensuring that each ISP meets the participant's needs; assuring that quality supports are delivered, coordinated, and monitored to ensure the participant's health and safety; assisting the participant in accessing community resources; and providing support to the individual during the decision-making process.

To help support coordinators and their supervisors adapt to their new roles, OMR undertook a major core competency training initiative during state fiscal years 2001-2002. OMR committed $2 million for training in the first year. OMR expects to continue extensive training, focusing on four or five central themes each year. The purpose of the training is to create a standardized approach to support coordination, a switch after many years of local control. Topics covered in the initial program included family/person-centered planning, using the individual support plan, strategies for linking person-centered planning to positive individual outcomes, and leadership development/supervision. The next training program will focus on utilizing HCSIS effectively in supporting self-determination, ensuring quality supports, and implementing and monitoring individual support plans. Training exercises were designed with input from individuals and families.

Self-Directed Supports—Currently, individuals three years old or older can receive supports from one of two Medicaid HCBS waivers: the Consolidated Waiver or Person/Family Directed Supports Waiver. People using the Consolidated Waiver receive supports from traditional provider agencies, while people using the Person/Family Directed Supports Waiver – or their families – direct their support and can hire their own direct support workers.

Under the Transformation, people who direct their own support and their families will have more support in doing so. OMR will require counties to contract with at least one intermediary service organization to assist people and families who direct a person's supports. These organizations will provide financial services like preparing workers'

paychecks and withholding taxes and supportive services such as helping a person arrange for back-up support and advising a person about how to hire a provider. People can currently receive this assistance in some, but not all, counties.

OMR has also contracted with a group of individuals and family members to train individuals and families throughout the state to direct their own support. The Pennsylvania Self-Determination Consumer and Family Group developed training and informational materials on self-determination and is training families throughout the state. One family member involved with the group is now working full time on self-determination training, in partnership with other participants and family members.

Person-Centered Systems Management

Pennsylvania's Transformation Project is changing the state's entire system of community supports for people with mental retardation, rather than just discrete parts of the system. An important part of the Transformation is creating statewide standards for the management of person-centered supports. For example, the statewide information system enables OMR to standardize enrollment, assessment, support planning, and quality assurance processes throughout the state. These statewide processes are essential to the Transformation Project, which is planned to improve people with mental retardations' supports, regardless of where they live in the state. In addition, by strengthening statewide quality requirements and measurement, OMR increased its capability to provide supports that safely meet each person's needs and reflect each person's goals.

At the same time, the Department of Public Welfare integrated the management of community supports for different population groups. The increased communication and cooperation within the department, and with the Pennsylvania Department of Aging, allows people with mental retardation to benefit from department-wide initiatives like the application system (COMPASS) and allows people with other disabilities to receive the benefits of improved choice and control planned under the Transformation.

Home and Community Services Information System—OMR's Transformation Management Office developed a system-wide strategy for restructuring the information management system that included the creation of new, standardized practices to support a person-centered approach. A key objective of the Transformation Management Office is to streamline management processes across funding streams in order to achieve both:

- seamless continuity of supports; and
- accountability for the quality of supports provided and for public expenditures.

The Home and Community Services Information System (HCSIS), includes all implemented and planned components of the Transformation, except for the application system, which was developed separately for all social services (COMPASS). The Web-

based HCSIS allows the state to collect information from the counties about support planning, individual outcomes, quality monitoring, and program expenditures.

Applying System Changes Across Populations—HCSIS is one of several information technology improvements the Department of Public Welfare is implementing. DPW created a department-wide strategy to implement these changes, minimize duplication of effort, and ensure the systems are compatible with each other. The strategy includes standards for all information systems, such as a common means to identify participants and providers. The strategy also includes a department-wide team responsible for planning information technology projects, which includes representatives from all DPW Offices. DPW also has an Office of Information Systems, which supports the integration of DPW's information systems and ensures these systems fit into Pennsylvania's statewide information technology strategy.

As part of this strategy, DPW established a process to implement information technology improvements in one office and apply them to the rest of the department. DPW initially assigns one office, called a champion, to implement a project. That office first implements the project to meet its own needs, with input from the other offices. Then the champion office helps other offices in the department adopt the change.

For HCSIS, DPW established a department-wide governance structure for HCSIS that includes all DPW program offices that manage Medicaid HCBS waivers and the Pennsylvania Department of Aging, a separate department that manages a waiver for older people. All these offices will eventually use HCSIS. The governance structure provides forums for the other agencies to provide input into the system so the Transformation to a person-centered system can occur for people with disabilities other than mental retardation.

Quality Assurance and Improvement—The first improvements to OMR's system were quality improvements. OMR management chose to implement these changes first to ensure participants' health and safety and to quickly address concerns raised during a CMS review of one of OMR's waivers. During Phase I of the Transformation, OMR developed a framework for a person-centered approach to improving the quality of the supports that individuals receive. Phase I included the design and implementation of three new processes—an Incident Management system, Health Care Quality Units, and Independent Monitoring for Quality (IM4Q)—along with improvements in OMR's Monitoring of Counties by its regional offices.

The Incident Management System establishes a timely, consistent, Web-based process for reporting and investigating unusual incidents involving people with mental retardation, including incidents that may indicate abuse or neglect. The system tracks corrective action counties and providers take in response to incidents; and gathers information that state and county staff analyze to identify ways to prevent future incidents. The system applies to participants who receive supports authorized by a county department of MHMR and/or who receive supports from licensed facilities.

OMR developed the statewide system to respond to problems that arose from having individually designed, county-level incident management reporting systems. The degree to which incidents were reported and investigated varied widely when counties had their own systems, and the state exercised little oversight over this process to ensure appropriate investigation and corrective action after incidents of possible abuse and neglect.

Under the Incident Management System, OMR requires providers to have standardized practices for responding to and investigating certain types of incidents that providers must report (reportable incidents), according to OMR requirements. A provider must submit:

- an initial electronic notification to the county and OMR of all reportable incidents within twenty-four hours;
- an incident report within five days;
- and a final report, which includes the investigation's findings and a corrective action plan, within 30 days of when the incident is finalized by the provider, unless OMR grants an extension.

OMR policy designates what types of incidents are reportable incidents, which require investigation by one of 2,200 trained and certified investigators. All investigators must have been certified according to OMR specifications. Investigators must have taken the course *Conducting Serious Incident Investigations*, offered by Labor Relations Alternatives, Inc., and have passed a certification test. These investigators may be employed by the provider, the county, or OMR. Investigators must be recertified every three years.

Most reportable incidents may be investigated by the provider, the county, or OMR, according to the provider's policy on incident management. Providers must submit this policy, as well as other quality management policies, to OMR for its approval. The county department of MHMR must review the investigations of all reportable incidents, and must approve the investigation and the provider's corrective action plan. Using the Web-based system, the county notifies the person's support coordinator and OMR regional staff, who also review the incident. The county or OMR may choose to conduct their own investigation on any incident, based on the initial circumstances of the incident or upon review of a provider investigation. In addition, county- or OMR-employed investigators must investigate injuries resulting from restraints; injuries that require hospitalization, emergency room treatment, or treatment beyond first aid; abuse involving improper or unauthorized use of restraints; deaths; and any reportable incident in which the provider, its CEO, or its Board of Directors, is the target of the investigation.

The Incident Management System gives OMR the capacity to immediately access all incident-related information. This offers a level of oversight and management that was not possible under the previous system. OMR regional staff are responsible for reviewing

incidents as part of their licensing duties and their oversight of counties' performance. Each provider, county, and OMR region also has an ongoing risk management responsibility; staff meet regularly to review incidents and ensure corrective action plans are implemented and that areas of risk are addressed. In addition, staff at OMR's central office analyze trends in these incidents to identify possible quality improvement initiatives.

The Incident Management system and new incident management policy became effective in the spring of 2002. Later that year, OMR collected information about the Incident Management system's performance through a Web-based survey of frequent users, twelve statewide focus groups, and meetings with provider associations and advocacy organizations. OMR has received many positive statements about the system and recommendations for enhancement. OMR is working with a group of stakeholders to revise the incident management policy and the information system based on the recommended changes.

Health Care Quality Units (HCQU) are regional, nonprofit organizations formed by coalitions of counties and accountable to the counties. OMR has established eight HCQUs across the state that employ county-funded physical and behavioral healthcare professionals who assist county program staff and providers in improving the overall health status of individuals receiving supports. The HCQUs have also provided training and technical assistance; undertaken data collection and trend analysis; authored clinical and medical reviews; participated in health system and policy development; and participated in health care advocacy activities.

HCQUs play a role in the OMR quality management structure by compiling Health Risk Profiles (HRP), which are completed annually for a sample of individuals receiving OMR residential supports. The HRP's primary purpose is to provide information about systemic health-related trends for people supported by OMR. The HRP screens for physical and behavioral health risk factors and measures a participant's healthcare access and participation in wellness promotion and disease prevention. Each Health Risk Profile also identifies areas that may require further evaluation and/or intervention by the participant's primary healthcare provider.

OMR plans to analyze the data from the Health Risk Profiles, but that analysis has not been conducted yet. After the analysis, OMR plans to use this data to guide decisions about quality improvement activities related to participants' physical and behavioral health. Health Risk Profile results will be reviewed at the provider, county, and regional levels as part of ongoing risk management activities. Data from the HRP will also be compared to data from Independent Monitoring for Quality and the National Core Indicators Project, as well as other national health measures for people with mental retardation.

Independent Monitoring for Quality (IM4Q), a cornerstone of OMR's quality management framework, originated as a recommendation in *A Multi-Year Plan for*

Pennsylvania's Mental Retardation Service System. Volunteer IM4Q review teams – consisting of individuals with disabilities, family members, and other stakeholders without a link to the support providers being reviewed – interview selected participants and their families about the quality of supports within the context of their daily lives. The review teams are trained and supported through local independent monitoring programs contracted by each of the counties. OMR has set an objective to offer independent monitoring to each participant in a residential community program once every three years.

IM4Q measures a number of aspects concerning the quality of supports being provided to participants. These quality measures are organized around the guiding principles from *Everyday Lives – Making it Happen,* a 2001 document by OMR's Planning Advisory Committee that examined the degree to which people could live the lives envisioned in the 1991 *Everyday Lives*. The interview tool, called *Essential Data Elements*, was developed by an IM4Q requirements team, which included participants and family members.

In addition to being informed by the *Everyday Lives – Making It Happen* principles, the interview tool incorporates the *National Core Indicators Consumer Survey.* This survey is part of the National Association of State Directors of Developmental Disabilities Services' Core Indicators Project for assessment of quality in MR/DD systems across the country. The Core Indicators Project provides outcome data from other states, which OMR uses for comparison with Pennsylvania's outcomes. Interview information is entered through HCSIS and results are tabulated and analyzed by Temple University's Institute on Disabilities. A full IM4Q report was published for fiscal year 2001.

<u>OMR Monitoring of Counties</u> is the state's formal process for monitoring each county's administration of the HCBS waivers, its adherence to waiver requirements, and the health and welfare of the county's waiver participants . Starting in January 2002, OMR changed its process for monitoring county performance to use a standard process to ensure quality supports, regardless of the county in which a person resides.

Teams of OMR monitors, based on the regional offices, annually visit and interview a five-percent sample of waiver participants in each county. The teams also complete a record review at the county and at the sample participants' providers. They then provide counties with a monitoring report, which is reviewed by subject experts at OMR's central office, who may recommend further review or revision. The team then submits the final report to the counties and, if necessary, the teams ask the counties to develop a corrective action plan. The teams subsequently review the counties' corrective action plans to ensure that identified issues are adequately addressed. Depending on the severity of the identified issues, an on-site validation of corrections may be required.

The monitoring teams use HCSIS to prepare for the visits. They review trends identified in the Incident Management system and Independent Monitoring for Quality interviews.

They will also be able to use HCSIS to identify any administrative, fiscal, or licensing issues specific to the five-percent sample of waiver participants under review.

Quality Improvement Plan. OMR established a process to use information from the above initiatives in a systematic way to plan how to improve supports for people with mental retardation. The Commonwealth uses a Plan, Do, Check, Act (PDCA) methodology for Continuous Quality Improvement, with steps to plan improvement, perform data collection, analyze data and process information, and interpret findings to identify further improvement opportunities.

Each year, starting in 2002, OMR staff create a draft action plan based on information in HCSIS. The draft plan also incorporates recommendations from organizations that analyze data from the Independent Monitoring for Quality: Temple University's Institute on Disabilities, which publishes a statewide report, and Human Services Research Institute, which analyzes data for the National Core Indicators Project.

The draft quality improvement plan identifies recommended interventions, which are defined and prioritized. Interventions include examples such as: additions to annual support coordinator training to provide more information on a particular issue, additional information or training for participants and families, and providing examples of best practices regarding a particular issue to counties, providers, and participants. The Subcommittee on Quality of OMR's Planning Advisory Committee reviews the draft plan and revises it during a series of all-day meetings. The whole Planning Advisory Committee provides additional input and approves the plan before OMR approves the plan.

OMR's Quality Assurance and Improvement System: Next Steps. An upcoming initiative is implementation of a set of provider standards called the Invitation to Quality (ITQ). ITQ will establish new quality standards in order to receive funds from OMR. These standards are more stringent than current standards, including licensing criteria. ITQ will apply to all licensed and non-licensed providers, except those employed by participants under self-direction.

Once ITQ is implemented, providers must answer a series of questions in order to enroll as OMR providers. Providers answer most of these questions—mostly yes/no questions—on a module of HCSIS. Providers must also send hard copies of several documents to the OMR Provider Relations Office, including financial information and quality improvement plans, to verify that they have met the ITQ requirements. OMR then compiles a summary page on HCSIS that describes the findings and identifies any required actions the provider must take to be in compliance. The provider must then use HCSIS to submit a formal action plan to OMR's Provider Relations Office.

After the initial ITQ review is complete, providers must update their information annually. Updated information may include responding to new ITQ questions, as well as providing new financial information and a new quality management plan for the

upcoming year. If, at any time, serious problems are uncovered, the county must conduct a focused review of problem areas and report the results of that review in HCSIS. Every four years, the county must conduct a mandatory on-site review for each provider and report the review's results in HCSIS.

Invitation to Quality will initially be a voluntary process; regulatory changes are needed to require providers to meet these standards. OMR plans to include a requirement to meet ITQ standards into state regulations, giving OMR authority to apply sanctions up to and including disqualification if the new standards are not met.

Coordination of Person-Centered Supports with Community Resources

The Office of Mental Retardation has taken steps to meet its goal of enabling individuals with mental retardation to participate actively in the life of the community. In particular, OMR has placed a high priority on transitioning people from the state's five mental retardation facilities, and has included the state intermediate care facilities into the Transformation Project. As a result, any participant opting to move from a state facility into the community will have access to and use the same planning tools as everyone else. OMR also developed a wide array of written materials for individuals and their families to use during the transition planning process, including a comprehensive brochure that is a guide for the process.

In the four counties that are piloting parts of Phase II of the Transformation (consumer support changes), facility residents are working with the same support coordinators who assist people in the community. The resident will be able to work with the same support coordinator once he or she has made the transition from the state facility into the community. To ensure continuity during the transition, either the facility's Qualified Mental Retardation Professional or its Social Worker will work in tandem with the person's support coordinator before, during, and afterwards. The Home and Community Services Information System has been designed to allow two sets of documentation during the transition to ensure facility staff and support coordinators both are fully informed when they assist facility residents.

Lessons Learned

Pennsylvania's Transformation Project is far from complete, but Pennsylvania's experience can yield valuable lessons for other states as they undertake major systems reform. The people interviewed for this report identified a number of critical elements that contributed to the Transformation, including the system-wide nature of the reforms and the involvement of multiple stakeholders.

A system-wide reform process—From the onset, the leadership of the Office of Mental Retardation (OMR) understood that the multiple processes involved in providing home and community-based supports were interrelated. As a result, they repeatedly stressed that any successful transition to greater self-determination had to involve reform of the

whole system—and they were committed to overhauling the existing system. While recognizing the interrelatedness of system components, OMR is implementing the project in phases, rather than changing the entire system at once. By implementing a few components first, OMR was able to show tangible results of the Transformation early in the project, and these early successes may build momentum for the project.

A vision—State officials, participants, and other stakeholders shared a vision of a more person-centered system, and have kept that goal front-and-center as the Transformation Project has evolved. People interviewed for this report stressed the need to ensure that this goal drive the design of system processes and procedures, including the information system.

Create a sense of urgency—The concerns CMS expressed in its quality review of one of OMR's Medicaid waivers created an additional impetus for the project. If OMR did not correct these concerns, CMS could, in a subsequent review, impose sanctions on OMR like limiting new participants' access to waivers. This possibility contributed to a widely perceived need for change, even among stakeholders that may experience more costs than benefits from the Transformation, such as providers.

Stakeholder participation—The involvement of participants, their families, advocates, providers, and representatives from county-based departments of Mental Health and Mental Retardation, is invaluable. OMR's commitment of time and resources to solicit input from various stakeholders, and the processes they set up to facilitate that process, has reduced the potential controversy over the changes toward the new system. The various stakeholder groups also helped to communicate information about the Transformation Project to their respective audiences.

Identify champions—The establishment of requirements teams for the various components of the Transformation Project helped to build a sense of pride and ownership among the group of people working on each specific issue.

Evaluate system changes—After components of the system reform were implemented, OMR considers it important to collect input from participants, family members, advocates, provider staff, and county staff to identify what additional improvements can be made.

Appendix A

Pennsylvania's Transformation Project: Implementation Phases

Phase I – Quality (completed in 2002)

Health Care Quality Units
Health Risk Profile
Incident Management
Independent Monitoring Interviews
Office of Mental Retardation (OMR) Monitoring of Counties

Phase II – Consumer Support

Phase 2.1, pilot started August 2002

Participant Registration
Individual Support Plan
Services and Supports Directory
Support Coordination functions

Suspended in January 2003 for further review, after piloted with Phase 2.1

Individual Estimated Resources (individual budget)
Situational Assessment (to collect information to determine individual budget)
Exceptional Case Review (to review individual budgets)

Phase 2.2, pilot started January 2003

Invitation to Quality provider standards
Provider Monitoring
Fiscal Intermediary Services

Phase III – Financial Information

Provider Rate Setting
Provider Invoicing
Provider Payments
Allocations to Counties

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