



## **The Future of Pennsylvania's Medicaid Funding for Services to Individuals with Intellectual Disability**

*Adopted April 25, 2012*

### **EXECUTIVE SUMMARY**

This document begins with a brief review of the expansion of Medicaid funded community services to individuals with intellectual disability in Pennsylvania and the current complexities that demand systems change. After a review of national trends and recent studies, the paper proceeds to identify principles that should serve as a foundation for creating a managed care delivery system for community services. The county-based behavioral health managed care system is presented as a viable option for delivery of all community based-services for individuals with intellectual disability, including under the consolidated and person and family directed services waivers. By integrating this system into the existing behavioral HealthChoices program structure, the state can achieve cost savings and build on the successes realized in behavioral health managed care while encouraging better integration of care for dually diagnosed individuals.



## **The Future of Pennsylvania’s Medicaid Funding for Services to Individuals with Intellectual Disability**

### **BACKGROUND**

In 1966 the Pennsylvania General Assembly passed one of the first state laws regarding community services to individuals with intellectual disabilities and mental health conditions: the Community Mental Health/Intellectual Disabilities Act. The 1966 Act created a foundation for community services by defining county and state responsibilities. Counties were given responsibility for creating and managing a core of services to assist individuals in their communities with state oversight. The community service system has grown in numbers and complexity since 1966:

July 1983 - Pennsylvania began to match federal funds for home and community waiver services.

July 1988 – Waiver serves approximately 2000 individuals at an approximate annual cost of \$60 million and federal oversight agency expresses concerns with initial renewal. <sup>1</sup>

1999 – Person/Family Directed Service (PFDS) waiver begins, which provides for the health and safety of individuals at a capped cost of \$20,000 per year.

2006 – New agreement implemented between state and county programs to implement waiver standards

Since 2006 a work plan was implemented that entailed: creating provider qualifications, initiating direct payment to providers by the commonwealth based upon prospective, cost-reconciling state rates and creating a statewide monitoring system to oversee processes from individual planning to provider monitoring. The implementation of payment through treasury resulted in state level management for individuals served by waivers, and a separate system for individuals who do not meet eligibility requirements or cannot receive waiver services due to limited capacity. These individuals receive supports through the county system, which is funded by state and county resources.

### **CHALLENGES**

Pennsylvania has expanded services tremendously since the inception of community services. For 2010-11, the Consolidated Waiver served approximately 17,069 individuals at a budgeted

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<sup>1</sup> Health Care Financing Administration, Philadelphia Regional Office. Special Review of the Philadelphia Portion of the Pennsylvania consolidated 2176 Waiver, Waiver Number 0147. Joseph Gaffney, Developmental Disabilities Specialist, William G. Da is, Medicaid Program Specialist. July 11 to July 22, 1988 <http://shelf1.library.cmu.edu/cgi-bin/tiff2pdf/heinz/box00007/fld00002/bdl0005/doc0002/heinz.pdf>

cost of \$1.5 billion, approximately \$88,000 per person. During the same year approximately 11,577 individuals received services under the PFDS Waiver with a budgeted cost of \$196 million, or approximately \$17,000 per person. Approximately half the funding for both waivers is provided by the state and half is matched by the federal government. The county program, which is supported by base funds, was budgeted at \$166.5 million in the same fiscal year. These dollars, plus one dollar of county match for every ten state dollars, served just over 41,000 individuals at an average cost of just over \$4000 per individual.<sup>2</sup>

The commonwealth continues to experience multiple challenges. The context includes substantial growth in the Medicaid waiver programs, greater complexity of individual needs and pressures for increased accountability for limited public dollars. The service system is impacted by all of the following factors:

- Lack of ability to ascertain assessed need and match to appropriate services
- Increased expenses associated with change in individual needs
- Continued federal oversight scrutiny to meet standards for care and consistent oversight
- Proposed federal and state cuts to community funding
- Continued demand in the number of individuals waiting for services
- Establishing meaningful outcome expectations and services to generate desired outcomes
- Meeting the conditions of the Olmstead Plan
- Sustaining a viable provider network through changes in the rate structure

These issues are not unique to Pennsylvania, as more demands are being placed on all levels of government. But many states have begun to consider significant changes to their financial models for system management.

## **NATIONAL TRENDS**

CMS is preparing for a significant increase in state interest in managed care models for managing a variety of services, including supports to individuals with intellectual disabilities. Organizations such as the Kaiser Foundation and the National Association of State Directors of Developmental Disabilities Services (NASDDS) have begun to catalogue initiatives that are underway which impact the developmental disabilities service system in various states across the country. At least three states have put forward proposals that include individuals with intellectual disability in response to CMS technical assistance offering for those who are dually eligible for Medicare and Medicaid. The National Council on Disability has offered principles to CMS which the group is recommending be used to assess the impact of managed care and identify strengths to build upon. These principles also outline the risks that must be mitigated.<sup>3</sup> National

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<sup>2</sup>Pennsylvania House Appropriations Committee. *Budget Primer: Intellectual Disability Services*. February 2011. [http://www.hacd.net/primers/BP\\_DPW\\_IntellectualDisabilities\\_Feb2011.pdf](http://www.hacd.net/primers/BP_DPW_IntellectualDisabilities_Feb2011.pdf)

<sup>3</sup>National Council on Disability. *Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities*. January 2012. <http://www.nasdds.org/pdf/CMSMANAGEDCARENCDRECOMMENDATIONS%201.pdf>

enrollment for managed care funded through Medicaid has yet to peak, but has reached 71.5 percent in 2010. This figure includes all managed care models and payment systems.<sup>4</sup>

Managed care was traditionally a model for funding medical treatment, but its use is expanding for everything from acute care services to chronic conditions. Pennsylvania began instituting a very successful managed care program for behavioral health in 1997 which is structured under a 1915(b) waiver. The program has done much to improve service quality and access for consumers while controlling costs. However other states are leading the way into managed care for individuals with intellectual disabilities. North Carolina is rolling out managed care for behavioral health and intellectual disability services statewide this fiscal year after conducting a county pilot program. New York has a voluntary managed care program for individuals with intellectual disabilities. Kansas has proposed a managed care plan for all Medicaid funded services including long term care, developmental and physical disabilities, and mental and physical health. The future path for Kansas is still being debated in the legislative and regulatory arenas.

In February 2012, the Kaiser Commission on Medicaid and the Uninsured released an issue paper entitled “People with Disabilities and Medicaid Managed Care: Key Issues to Consider”. It outlines key considerations regarding provider networks and service delivery systems, including: provider payment, beneficiary protection and oversight of managed care. Fifteen percent of Medicaid beneficiaries with disabilities account for 42 percent of total Medicaid spending for services. And, “a growing number of states have been turning to risk-based managed care, including mandatory enrollment in MCOs, for Medicaid beneficiaries with disabilities.”<sup>5</sup> Twenty-six states reported mandating managed care for some children who receive SSI, and well over half mandate managed care for some children with special health care needs (32 states) and adults with disabilities (33 states). According to NASDDS, in 2009 six states had some form of capitated managed long-term care, but as of 2011 a National Association for States United for Aging and Disabilities survey reported 50 percent of states are operating or exploring managed long-term care programs.<sup>6</sup>

## **PRINCIPLES FOR MANAGED CARE FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY**

Since managed care has been for traditional physical health services, which focus on acute and episodic care, there are critical differences for consideration in structuring managed care for intellectual disability services. Intellectual disability is a lifetime condition, and individuals have varying degrees of rehabilitative capacity. So while some individuals have the ability to increase

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<sup>4</sup>Centers for Medicare and Medicaid Services. *National Summary of Medicaid Managed Care Programs and Enrollment, July 1, 2010*. <https://www.cms.gov/MedicaidDataSourcesGenInfo/downloads/2010Trends.pdf>

<sup>5</sup>Kaiser Commission on Medicaid and the Uninsured. *People with Disabilities and Medicaid Managed Care: Key Issues to Consider: Executive Summary*. February 2012. <http://www.kff.org/medicaid/upload/8278.pdf>

<sup>6</sup>National Association of States United for Aging and Disabilities. *State of the States Survey 2011 – State Aging and Disability Agencies in Times of Change*. January 2012. [http://www.nasuad.org/documentation/nasuad\\_materials/NASUAD%20States%20Survey%202011.pdf](http://www.nasuad.org/documentation/nasuad_materials/NASUAD%20States%20Survey%202011.pdf)

their independence, others will have need for more services and supports as they age. Consequently, the needs of people with intellectual disability require that any approach to managed care be built on principles that serve the population's needs. PACA MH/DS advances the following principles as the most important considerations for constructing a new system.

#### *Everyday Lives as a Foundation*

*Everyday Lives* is a fundamental policy document for Pennsylvania's system of services to individuals with intellectual disability. The focus is to promote gaining independence to the fullest degree possible in accordance with self-determination and in a supportive and positive manner. The central tenets include: accountability, choice, collaboration, community inclusion, contributing to the community, control, freedom, individuality, mentoring, quality, relationships, safety, stability and success.

#### Stakeholder Involvement

All stakeholders, including individuals waiting for services, those participating in services, families and caretakers, providers, and administrators must be aware and involved in designing and implementing a new service system in order to be effective.

#### Cross-Disability, Life Span Focus

A managed care system serving individuals with intellectual disability should be designed to address diverse needs across all age groups and tailored to the needs of all sub-populations of Medicaid beneficiaries who will be enrolled in the plan. It should facilitate better service to the estimated 30 to 35 percent of persons with intellectual disability that have a psychiatric disorder.<sup>7</sup>

#### Support All System Resources, Including Family Caregivers

A publicly funded system of services must be able to dovetail natural resources with paid services and supports as close to where an individual lives as possible. Whether the resources are another public service agency, a health agency, a utility, an educational resource, or business, partnerships at the local level are key to engaging individuals in the community.

#### Reinvest Savings in the System

A service system should be designed to reinvest any savings gained through management or service efficiencies toward addressing the needs of individuals on the waiting list or wanting to leave state centers to live in the community. The benefit of the behavioral HealthChoices model is that it allows savings to be reinvested in services, rather than expanding the profit margin of private interests.

#### Consistent Authorization Criteria

Service definitions and their intended outcomes must be clearly stated prior to implementation. The criteria for how to receive authorization for needed services must be in accordance with federal standards and based on an individual assessment. Programmatic and budgetary oversight must be coordinated.

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<sup>7</sup>NADD National Association for the Dually Diagnosed. About Us page.  
<http://www.thenadd.org/pages/about/ddinfo.shtml>

## Participant Rights and Due Process

All consumers and their representatives must understand and have access to appeal and grievance procedures that result in timely resolution. The right to appeal is integral in maintaining and improving quality services and a quality system that supports services.

## Standards and Outcomes

Systemic and individual goals must be clearly identified and measured to assess the effectiveness and quality of services. Traditional physical health managed care frequently sets standards and outcomes in order to increase access for more eligible individuals to receive services, increase quality of consumer health and contain costs. Goals for managed care plans for individuals with intellectual disability must also measure safety, independence appropriate for the individual's level of ability, and sense of belonging in the community.

## **PENNSYLVANIA'S ASSETS FOR TRANSITIONING TO MANAGED CARE**

Pennsylvania is unique compared to many other states considering managed care for individuals with intellectual disability, because it already has local infrastructure that has demonstrated successful management in transitioning to managed care for behavioral health services. The successful conversion from a fee-for-service to managed care system began in 1997 for both physical health care and behavioral health care under HealthChoices. Counties played a key leadership role in this effort for behavioral health, and have been integral to developing a viable community service system which supports mental health consumers' recovery-oriented goals. Counties are positioned to serve the same purpose for the intellectual disability system, and to facilitate better coordination of services for individuals with dual diagnosis.

HealthChoices permitted counties "the right of first opportunity" to administer the program. The majority of counties accepted the right of first opportunity, but where they were unable or deferred this opportunity, the state contracted for managed care directly and worked closely with counties to unify their approach in addressing individual needs in the community regardless of funding source. Combining the management of the federal waiver program with counties' statutory responsibilities under the MH/ID Act of 1966 created a unified system of program and financial responsibility for mental health services that still guarantees the voice of local stakeholders, and assures that savings are reinvested in the system.

Behavioral HealthChoices met and exceeded all of its goals to improve access, improve quality of care and contain costs. The tangible benefits include:

- Expanded choice of providers and services for consumers
- Decreased use of institutional care
- Leveraging public and private resources to meet local needs
- Increasing employment opportunities for consumers and professionals
- Reinvestment of savings in service improvements
- Creation of incentives to providers to for evidenced based, promising and best practices
- Facilitating cross system collaboration through contractual arrangements
- Maintaining a high degree of consumer satisfaction
- Created consistent program standards, requirements and performance measures

- New service development driven by local needs

With infrastructure already in place and processes already developed for bids and contracting, the timeframe for creating a locally administered managed care service delivery system is streamlined. The existing managed care system for mental health meets federal standards and is responsive to consumers. In light of nationwide trends and the level of concern with the sustainability of Medicaid spending in Pennsylvania, it is prudent to begin to prepare for these discussions. The Pennsylvania Association of County Administrators of Mental Health and Developmental Services requests various stakeholders endorse an approach based on the behavioral HealthChoices program structure. It is the best managed care alternative to assure *Everyday Lives* values are preserved, family and consumer needs are kept in the forefront, and public accountability for future vision and direction of the community intellectual disability system is maintained.

## RESOURCES

Centers for Medicare and Medicaid Services. *National Summary of Medicaid Managed Care Programs and Enrollment, July 1, 2010*. <https://www.cms.gov/MedicaidDataSourcesGenInfo/downloads/2010Trends.pdf>

Health Care Financing Administration, Philadelphia Regional Office. *Special Review of the Philadelphia Portion of the Pennsylvania consolidated 2176 Waiver, Waiver Number 0147*. Joseph Gaffney, Developmental Disabilities Specialist, William G. Da is, Medicaid Program Specialist. July 11 to July 22, 1988 <http://shelf1.library.cmu.edu/cgi-bin/tiff2pdf/heinz/box00007/fld00002/bd10005/doc0002/heinz.pdf>

Kaiser Commission on Medicaid and the Uninsured. *People with Disabilities and Medicaid Managed Care: Key Issues to Consider: Executive Summary*. February 2012. <http://www.kff.org/medicaid/upload/8278.pdf>

Kaiser Commission on Medicaid and the Uninsured. *Policy Brief: Medicaid Managed Care: Key Data, Trends, and Issues*. February 2012. <http://www.kff.org/medicaid/upload/8046-02.pdf>

NADD National Association for the Dually Diagnosed. About Us page. <http://www.thenadd.org/pages/about/ddinfo.shtml>

National Association of States United for Aging and Disabilities. *State of the States Survey 2011 – State Aging and Disability Agencies in Times of Change*. January 2012. [http://www.nasuad.org/documentation/nasuad\\_materials/NASUAD%20States%20Survey%202011.pdf](http://www.nasuad.org/documentation/nasuad_materials/NASUAD%20States%20Survey%202011.pdf)

National Council on Disability. *Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities*. January 2012. <http://www.nasdds.org/pdf/CMSMANAGEDCARENCDCRECOMMENDATIONS%201.pdf>

Pennsylvania House Appropriations Committee. *Budget Primer: Intellectual Disability Services*. February 2011. [http://www.pahouse.com/HACD/series/32/BP\\_DPW\\_IntellectualDisabilities\\_Feb2011.pdf](http://www.pahouse.com/HACD/series/32/BP_DPW_IntellectualDisabilities_Feb2011.pdf)

Planning Advisory Committee for the Office of Developmental Programs, Pennsylvania Department of Public Welfare. *Everyday Lives*. 1991.