

DISEASE MANAGEMENT AND  
MEDICAID WAIVER SERVICES FOR HIV/AIDS PATIENTS

Office of Health Policy  
Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services  
April 2009

## TABLE OF CONTENTS

Executive Summary.....	1
Introduction .....	2
Background .....	3
Disease Management: Findings from the Literature .....	5
Disease Management for Complex Medical Conditions.....	7
Medicaid Disease Management .....	9
Disease Management for HIV/AIDS.....	11
Conclusion .....	13
APPENDIX A .....	15
APPENDIX B .....	17
REFERENCES .....	18

## Executive Summary

Disease management (DM) is a system of coordinated health care interventions and communications to help patients self-manage their chronic diseases and prevent complications from these health conditions. Key components of DM include population identification processes; evidence-based practice guidelines; collaborative practice models to include physician and support-service providers; patient self-management education (may include primary prevention, behavior modification programs, and compliance/surveillance); process and outcomes measurement, evaluation, and management; and routine reporting/feedback loop (may include communication with patient, physician, health plan and ancillary providers).

Demographic trends, rising numbers of Americans with multiple chronic illnesses, and unsustainable cost growth in the health care sector need to be addressed. Disease management has been marketed as a way to improve health outcomes and reduce health care costs. However, questions remain about disease management and its ability to improve cost effectiveness of care and outcomes for certain populations. The growing trend of using DM in Medicaid may yield information about how such approaches can benefit vulnerable populations with chronic conditions and possibly make the case for expanding DM as an intervention within other programs for population health improvement. A major challenge in measuring DM outcomes is the wide variation in program designs and the populations enrolled in the programs. Existing DM research examines different interventions for different diseases among different populations. Based on the current state of DM outcomes measurement, increased standardization in evaluation methodologies is needed to more accurately estimate DM programs' impact. There is no broad evidence base to support the assumption that DM significantly improves health outcomes and reduces the cost of care for populations with multiple chronic illnesses. One costly, complex chronic illness that merits more attention is HIV disease. People with HIV are living longer and experiencing chronic conditions that commonly occur with aging. Because of the growing prevalence of HIV/AIDS in the U.S., studying HIV DM programs may provide a better understanding of the impact DM can have on health outcomes, treatment compliance, cost effectiveness and overall quality of care for people living with HIV/AIDS.

## Introduction

Disease management (DM) refers to a system of coordinated health care interventions and communications to help patients self-manage their chronic diseases and prevent complications from these health conditions. DM has been touted by vendors as an effective tool to reduce health care costs. Some DM vendors have claimed that disease management programs can save as much as eight times the cost of the program. Vendor marketing materials refer to overall program savings, per member per month savings, or reduced annual health care expenses. Marketing this sort of “return on investment” has piqued strong interest in DM among private and public payers of health care services. However, it has not been conclusively determined that DM can successfully reduce the costs of care or significantly improve health outcomes, particularly among individuals with multiple chronic conditions.

DM is commonly offered in private insurance plans and employer-sponsored wellness programs, and Medicaid and Medicare have incorporated DM approaches for some enrollees. Questions remain about the elements of DM that improve patient outcomes and whether DM can effectively reduce costs of care for certain populations. When high-cost patients are targeted for DM, measuring outcomes is challenging because it is difficult to attribute the intervention with producing an effect that may have occurred even in the absence of the intervention.

This paper examines the limited evidence to date on the impact of DM for low-income populations enrolled in public insurance programs, and raises questions about the effectiveness of DM targeted to HIV/AIDS. An important question is whether DM is a useful approach for health care delivery even if it does not reduce the costs of care. The capacity for DM to reduce the costs of care for complex medical conditions like HIV disease may be limited, but more research is needed to assess the extent to which DM offers value in dimensions of quality such as improving care delivery, clinical outcomes, patient satisfaction and quality of life. The growing trend of using DM in Medicaid may yield information about how such approaches can benefit vulnerable populations with chronic conditions and possibly make the case for expanding DM as an intervention within other programs for population health improvement. In the current climate of unsustainable health care cost growth, any increased costs resulting from the adoption of DM are worth close examination.

## Background

The prevalence of chronic disease in the U.S. is a significant public health issue. About 133 million people, almost half of all Americans, have at least one chronic health condition – for example, heart disease, asthma, or diabetes. The Centers for Disease Control and Prevention (CDC) estimates that chronic diseases account for 70% of all deaths in the U.S., and the medical care costs of people with chronic diseases account for more than 75% of the nation's \$2 trillion annual medical care costs.

DM began during the 1970s with the concept of prospective medicine. Prospective medicine focuses on health risk appraisal and reduction, i.e., identifying an individual's current and potential health hazards and helping reduce those risks in order to extend life expectancy, improve quality of life, and reduce morbidity and disability. The movement progressed in the 1980s as patients with diabetes were encouraged to engage in self-care activities, or "self-management." In the 1990s, the term "disease management" was coined to describe a strategy to increase pharmaceutical sales by improving medication adherence. The industry association – formerly the Disease Management Association of America, which renamed itself DMAA: The Care Continuum Alliance – promotes disease management as a tool for evidence-based population health improvement. The goal of disease management is to reduce the costs of care while improving health outcomes. The concept of DM is grounded in the notion that chronic care, self-management of disease, and wellness promotion can reduce costly, acute medical complications. DM programs have been growing in popularity in the commercially insured market, primarily because they are advertised as a way to improve cost effectiveness of care. It is estimated that the annual revenues for the DM industry have grown from \$78 million in 1997 to about \$1.8 billion in 2008. DM is also being adopted in many Medicaid programs and tested under pilot and demonstration projects for Medicare populations with certain high-cost chronic illnesses like heart disease and diabetes.

Financing arrangements for DM services can affect the level of savings that can potentially be achieved. Two traditional forms of disease management contracts are capitation contracts and case rate contracts (Baldwin, 1999). Capitation contracts involve fixed amount per-member-per-month payments from a health plan to a disease management vendor. Case rate contracts pay fixed amounts per patient treated. Some case rate contract arrangements pay higher reimbursement rates for treating patients with advanced disease or more complications. Another risk sharing approach for DM contracts is the shared savings approach, in which the costs or revenues of the disease management vendor are subject to specific performance targets. For example, the vendor may be required to achieve a 5 percent

savings target for all services provided to the enrolled population. The financial risk involved will be affected by the population being served, patient characteristics, complications, and clinical outcomes. If predictive models used by DM vendors overestimate patient utilization needs, this can result in savings if actual service utilization is lower than projected. Such factors including patient characteristics and utilization needs must be taken into account when considering potential savings from DM programs.

Disease management has evolved into a complex and diverse industry offering comprehensive management of common chronic conditions. Some DM vendors have recently been shifting their focus from single-disease programs to an integrated approach that targets all of a patient's health problems. Many programs have expanded from targeting very high-cost and high-risk patients to addressing the needs of broader populations, with approaches ranging from mass communication technology and call-center based outreach to more intensive approaches such as recurring home visits by nurse case managers. DM can also involve feedback mechanisms for providers such as practice profiling, which is an analytic tool that uses epidemiological methods to compare physician practice patterns and process and clinical outcomes. The goal is to deliver evidence-based, high quality care to improve patient outcomes. The use of DM interventions could be considered an offshoot of the Chronic Care Model originally developed by Ed Wagner, M.D., M.P.H. as a tool to improve the care of individuals with chronic illness (including HIV/AIDS). The Chronic Care Model focuses on six elements: self-management and adherence support, decision support, clinical information systems, delivery system design, organization of health care, and community resources.

Disease management seems an intuitively plausible approach for addressing rising health care costs and the need for improved quality of care in the U.S. However, in spite of the growing use of DM in the commercially insured market, there is no conclusive evidence that DM reduces overall costs, and there is only limited evidence that it can improve quality of care for some conditions. Inherent challenges to measuring the impact of DM include regression to the mean and selection bias. Disease management programs may identify patients after they have incurred significant health care costs, such as a hospitalization, but then utilization of services can return to normal without any intervention. The decrease in utilization might be attributed to regression to the mean or to the DM program. With selection bias, patients who choose to enroll in a DM program may have underlying differences from those who do not enroll. If treatment and utilization costs are lower for DM program enrollees compared to the nonparticipating patients, it is difficult to know for certain how much of the difference is attributable to the DM program intervention. DM evaluations do not always

use randomized controlled methodology because of operational issues. For example, an employer that engages a DM vendor to provide services may not wish to use random assignment to determine which employees are targeted for intervention and which are controls. If the employees self-select for participation, then this type of situation is not a randomized controlled trial of the DM intervention, and it introduces bias. Because of limitations such as this, many existing studies using quasi-experimental designs have been criticized for their low rigor methodologies.

As the number of disease management programs has grown over the years, there has been only limited uniformity in programmatic features. Common features of disease-specific programs include an integrated approach to care and patient education through home visits or by telephone. Case management programs are characterized by intensive post-discharge monitoring by a case manager who connects patients to community-based non-medical support services (Krumholz et al., 2006). As DM programs continue to evolve, they may become useful tools in ensuring high quality, patient-centered care.

#### Disease Management: Findings from the Literature

Mixed results from studies of disease management programs in general indicate there is no conclusive evidence of the impact of the programs on cost-effectiveness and health outcomes. According to the Congressional Budget Office's 2004 analysis of disease management studies for several chronic diseases, there is insufficient evidence to conclude that disease management programs can generally reduce overall health spending. A more recent review of the disease management literature found there is some evidence of improved clinical outcomes for certain conditions (congestive heart failure, coronary artery disease, and depression) – and little or no evidence that disease management improves outcomes for asthma and chronic obstructive pulmonary disease (Chen & Au, 2008). In addition, the review found that, compared to evidence of improved clinical outcomes, there is even less evidence that disease management programs produce savings. It seems that the potential for disease management to control costs might depend on whether the populations targeted for intervention have conditions that leave little room for overall improvement in their health status. Depending on the conditions a population has – for example, frail, elderly patients with co-occurring illnesses like heart disease, lung disease, and diabetes – cost savings could result from reductions in high-cost acute care episodes, but their need for physician visits or costly prescription medications may not be affected by DM intervention. Even where there is limited return on investment or cost savings resulting from

DM, the potential for improving long-term clinical outcomes may be a reason to pursue DM and care coordination approaches.

Disease management interventions are sometimes referred to as patient self-management, care coordination, and care management. Among the problems that have been identified as major challenges to evaluation of the impact of disease management programs is the lack of a standardized taxonomy of mechanisms used in managing patients with complex conditions. DM programs are heterogeneous. Lack of standardization among DM providers regarding what DM entails makes it difficult to compare effectiveness across providers. In addition, the short-term nature of many studies cannot measure benefits that may take years to materialize (Luck et al., 2007). When the start-up costs of a program and the costs of the number of staff involved in providing DM and care coordination services are considered, the prospects for cost savings may be low in the short term. There might also be costs from greater utilization of primary care services, specialty care (depending on comorbidities), and pharmaceuticals (or increased adherence to medication regimens) that add to program costs (Billings & Mijanovich, 2007). For example, Indiana's Chronic Disease Management Program for Medicaid enrollees with diabetes and congestive heart failure used two interventions – an intensive nurse care management program and a telephonic program – both of which included patient education. An analysis of Indiana's program results, incorporating programmatic costs, found that the largest savings to Medicaid were for the low-risk enrollees offered the telephonic intervention (Holmes et al., 2008). However, the analysis covered only a 21-month follow-up period and, therefore, could not account for any possible longer term program impacts that might result among the high-risk enrollees. In theory, over the long term, there might be potential for cost savings – or alternatively, reduced growth in the cost of care – due to reduced hospitalizations or other complications associated with the chronic illnesses.

Disease management programs typically focus on managing an individual chronic illness. Many DM programs focus on single diseases and exclude people with multiple chronic illnesses, so there has been little opportunity to conduct research on the health and cost impacts of DM for individuals with multiple chronic conditions, and this is a challenge to developing effective, targeted clinical management approaches for patients with comorbidities (Vogeli et al., 2007). Due to demographic trends and the increasing number of individuals with chronic illnesses that may lead to costly hospitalizations, it is likely that states will continue to explore disease management as a way to address rising health care costs for Medicaid, especially for patients with multiple chronic conditions.



For populations enrolled in Medicaid or Medicare, the prevalence of multiple chronic conditions makes disease management complex. The impact of DM may depend on the characteristics of the population receiving the intervention. An evaluation of the Medicare Health Support programs indicated that care management interventions among beneficiaries with chronic conditions did not result in savings for Medicare (Chen et al., 2008). The Medicare Health Support programs targeted heart disease and diabetes; other Medicare disease management demonstrations included patients with cancer and chronic obstructive pulmonary disease and did not significantly improve clinical outcomes or result in cost savings.

### Disease Management for Complex Medical Conditions

In January 2008, the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) convened an expert panel to discuss outcomes measurement issues related to DM for populations with chronic conditions. The panel included researchers and clinicians, and the discussion noted that the inconsistency in methodologies used to evaluate DM programs makes it difficult to compare evaluations of program effectiveness. Based on the current state of DM outcomes measurement, increased standardization in evaluation methodologies is needed to more accurately estimate DM programs' impact. In addition, there is wide variation in program designs and characteristics of the populations served in the programs, which presents a challenge for comparing the effectiveness of different DM models. For many Medicare and Medicaid patients who face a host of social service needs as well as medical needs, certain DM models (such as telephone-based health coaching) may not adequately address all of the patient's needs. More study is needed to determine which models best respond to populations with special needs. The expert panel did not reach a conclusion about whether DM is the solution to getting health care costs under control, but they agreed that we need a better understanding of disease management's impact on clinical outcomes and utilization. The panel noted that measures need to go beyond processes (e.g., number of tests or services provided) and reflect the specific outcomes that the DM program is attempting to achieve for the patients. For individuals with multiple chronic conditions, DM may have the potential to minimize hospitalizations or other acute complications associated with those conditions by improving care coordination and facilitating patient compliance with treatment plans.

One example of a population with special needs is individuals living with HIV. CDC estimates that more than 1.1 million people in the U.S. are living with HIV, and one-fifth of them are unaware of their infection. There are no known current estimates of the insurance status of Americans with HIV. A

1997 study found that, among a sample of HIV patients in 10 U.S. cities with high HIV prevalence, about one-third had private health insurance, 40 percent had public insurance, and 27 percent were uninsured (Fleishman, 1997). Their insurance coverage depended on factors like employment status, the extent of disability due to the disease, and the public benefits available in their geographic location. In many cases, an individual might utilize more than one type of coverage, for example, Medicaid or private insurance plus Ryan White program services for certain benefits not covered by the insurance.

After the discovery of antiretroviral medications in the 1990s, treatment became widely available and significantly extended the average lifespan for HIV-infected individuals. HIV disease was the eighth leading cause of death in 1996, but no longer ranks among the top fifteen causes of death. CDC data indicate that from 1987 through 2005, the proportion of deaths due to HIV disease among people under age 35 decreased from 43 percent to 12 percent. In contrast to the early days of the AIDS epidemic in the U.S., HIV disease is now generally considered to be a chronic condition rather than a death sentence. The highly active antiretroviral therapy (HAART) "drug cocktails" used for HIV/AIDS treatment require strict adherence to prevent resistance of the virus to therapy. Adherence to antiretroviral therapy can be difficult for some because of the number of pills involved in the regimen and unpleasant side effects caused by HIV medications, such as fatigue, nausea, skin rashes, and high cholesterol.

Because of the need for ongoing treatment and the potential for acquiring co-occurring illnesses, HIV patients seem appropriate for targeted intervention through DM to prevent complications associated with the disease. HIV infection disproportionately affects individuals of lower socioeconomic status, and many with the disease are uninsured or underinsured and may have other special needs like substance abuse treatment or mental health services.

The Medicaid program is the largest federal payer of HIV/AIDS medical care in the U.S. The Centers for Medicare and Medicaid Services (CMS) estimates that there are 266,000 Medicaid beneficiaries with AIDS, or advanced HIV disease. Low-income individuals with AIDS are often automatically eligible for Medicaid if they receive Supplemental Security Income disability payments. According to the Kaiser Family Foundation, annual federal Medicaid spending on HIV/AIDS between 2000 and 2007 increased from \$3 billion to roughly \$7 billion, which is equal to half of total annual federal spending on HIV/AIDS in the U.S. In general, prescription drug expenditures are a large part of the cost of HIV/AIDS treatment.

Several states use Medicaid waiver authority under sections 1115, 1915(b), and 1915(c) of the Social Security Act to implement special programs or services for individuals with HIV infection. These waiver authorities permit research and demonstration projects, and allow states to modify health care delivery systems and care settings in their Medicaid programs. Waivers are not needed to implement disease management in Medicaid, but some states have incorporated elements of DM in their waiver programs. Considering the growing prevalence of HIV/AIDS in the U.S. and the high proportion of Medicaid enrollees with multiple chronic illnesses, additional research is needed to help determine how DM might be used to improve health outcomes, treatment compliance, cost effectiveness and overall quality of care for people living with HIV/AIDS.

CMS estimates that there are approximately 100,000 Medicare beneficiaries with HIV/AIDS, and approximately 65,000 are also covered by Medicaid ("dual eligibles"). The availability of Medicare prescription drug coverage is important for beneficiaries with HIV/AIDS due to the need for medications to manage the disease. Data on the costs associated with the prescription drug benefit among Medicare enrollees with HIV/AIDS have not yet been published; however, Medicaid programs' prescription volume decreased by almost 50 percent when drug coverage for dual eligibles moved to Medicare Part D (Bruen & Miller, 2008).

In addition to Medicaid and Medicare, HHS funds primary health care services, supportive services, and prescription medication coverage for individuals with HIV/AIDS through the Ryan White HIV/AIDS Program. The Ryan White HIV/AIDS Program administered by the Health Resources and Services Administration (HRSA) is the largest federal program specifically dedicated to providing HIV/AIDS care and treatment in the U.S., funded at \$2.1 billion annually. The Ryan White Program is a safety net grant program and the payer of last resort for HIV/AIDS care. The grants to states for the AIDS Drug Assistance Program represent 40 percent of Ryan White funding each year. Other Ryan White funds pay for primary care, dental care, supportive services (e.g., nutrition assistance), provider education, quality assurance and program evaluation, and demonstration projects targeting hard-to-reach populations affected by HIV/AIDS.

### Medicaid Disease Management

A 2003 study of three Medicaid DM programs (for all chronic conditions, not HIV-specific DM) indicated that the states' varied program designs produced short-term net savings and improved outcomes in their patient populations (Gillespie & Rossiter, 2003). Because of the variability in the programs

reviewed and the range of chronic conditions addressed by the programs, it is difficult to generalize about the overall effectiveness of DM. However, these three states' programs provide examples of how Medicaid can address the needs of low-income and elderly patients using DM. In February 2004, CMS urged states to adopt programs to help Medicaid patients with chronic illnesses better manage their diseases. In a letter to state Medicaid officials, CMS announced it would match state costs of running DM programs aimed at improving health outcomes while lowering the medical costs associated with these diseases. CMS suggested three models that states might use that would be eligible for federal matching funds:

- 1) States can contract with a disease management organization (DMO) that manages the overall care of the beneficiary but does not restrict access to other Medicaid services. A state can pay the DMO a capped amount per beneficiary with the organization being responsible for any expenses over the set amount;
- 2) States can establish a primary care case management program (PCCM), whereby the state works with PCCM providers to enhance the care it delivers to enrollees with chronic conditions; or
- 3) Individual providers (physicians, pharmacists, or dietitians) can contract with states to provide DM services.

State legislatures have shown interest in DM primarily as a cost containment tool, and according to the National Conference of State Legislatures, 26 states have passed laws specifically addressing DM. In addition to using disease management in Medicaid, some state health departments encourage their public health clinics and public hospital systems to incorporate DM approaches in their care delivery. Currently, there is only a limited amount of information available about Medicaid DM program outcomes and even less data available specifically concerning Medicaid HIV disease management. Clinical quality management is a common operational component of state Medicaid programs, but budget constraints frequently limit the amount of resources dedicated to producing rigorous, independent evaluation reports. As the interest in DM expands, more information should be made available about the models that have been used and what their impacts were.

New Hampshire, Oregon, Texas, and Washington are states that provide Medicaid disease management for common chronic illnesses such as asthma and diabetes, but not for HIV disease. The chronic diseases commonly targeted in Medicaid disease management are the same high-cost conditions most frequently targeted in commercial disease management programs: congestive heart failure, diabetes, asthma, chronic renal failure, lung diseases, and hypertension. In general, Medicaid disease management programs do not target mental illness or patients dually eligible for Medicaid and Medicare even though these individuals represent a large proportion of

Medicaid enrollees with chronic conditions (Williams, 2004). The reason may be an assumption about the degree to which these high-cost populations can realistically be managed by DM interventions, due to their need for a wide range of services; or the behavior changes needed for self-management may be more difficult among these populations.

McKesson Corporation is a vendor that has operated Medicaid DM programs for a variety of chronic illnesses in several states. Another separate branch of McKesson's business is a licensed wholesale distributor of oncology and specialty pharmaceuticals. McKesson's National Committee for Quality Assurance (NCQA)-accredited DM programs are for diabetes, asthma, and heart failure. McKesson has implemented DM for Medicare managed care populations in addition to DM for Medicaid, and has publicly reported results from only select programs. For example, New Hampshire's program for more than 4,400 Medicaid clients with asthma, diabetes, heart failure, coronary artery disease, chronic obstructive pulmonary disease, end stage renal disease and chronic kidney disease generated \$4.8 million net savings to the state over two years. McKesson also reported that the New Hampshire Medicaid DM program led to a 12 percent reduction in emergency department costs in the program's second year. Too few states have conducted independent evaluations of their Medicaid disease management programs, but perhaps as their experience with DM grows, they may publish findings about their program outcomes.

### Disease Management for HIV/AIDS

Antiretroviral treatment has extended the lifespan of people with HIV infection, and more people become infected with HIV than die from the disease each year. Since the mid-1990s, the age-adjusted HIV death rate has declined by more than 70 percent (Kaiser Family Foundation, 2008). As more people with HIV infection live longer, the demand for HIV care and treatment will continue to grow. For HIV, medication compliance is especially important in order to help prevent the virus's resistance to therapy, so this is one reason that disease management programs that offer treatment adherence support may be a useful approach for HIV patients in particular.

As of October 2008, CMS had approved Medicaid waivers specifically targeted to HIV-positive populations in Alabama, California, Colorado, Delaware, the District of Columbia, Florida, Hawaii, Illinois, Iowa, Maine, Missouri, New Jersey, New Mexico, North Carolina, Pennsylvania, South Carolina, and Virginia. Most of these Medicaid programs are Section 1915(c) home and community-based service waiver programs, which offer benefits

like case management and private duty nursing as an alternative to institutional care. The District of Columbia and Maine implemented Section 1115 waivers to enroll HIV-infected individuals in Medicaid who would not otherwise be Medicaid-eligible unless their health deteriorated to the point of disability. These waiver programs target HIV populations for Medicaid but were not established for the purpose of offering DM.

The table in Appendix A lists approved Medicaid 1915(c) HIV/AIDS waivers and the Medicaid managed care waivers that include DM or other special services for enrollees with HIV/AIDS. The 1915(c) waivers targeted to HIV/AIDS populations typically offer case management, not DM. DMAA, the disease management trade association, has defined DM as “a system of coordinated healthcare interventions and communications for populations with conditions in which self-care efforts are significant.” Case management differs from disease management because it is intended to provide assistance for both medical and social services needs. Medical case management is another term for coordination activities centered around supporting patients’ engagement with primary care services. A scientific statement from the American Heart Association noted that a comprehensive definition of DM still needs to be established. Without a standardized definition for DM and the specific interventions that DM entails, making comparisons of program effectiveness is more difficult.

Case management is offered in many Medicaid HIV waiver programs, but HIV disease management programs are not as common in Medicaid. Florida was an early implementer of Medicaid DM, beginning its program in 1997. The DM program in Florida targeted several chronic conditions and was reported to have saved the state a total of \$41.9 million in medical costs (for all conditions) during the first 27 months of operation (White et al., 2005). It was later in 1999 that Florida initiated its HIV disease management program, and it is still in operation today using a DM vendor to provide services. No recent analyses of Florida’s program have been published, but an examination of trends since the program began would be useful to show net savings achieved over time and to identify any particular features of the program that seemed to influence the positive results.

Although there is a growing trend of implementing DM in Medicaid, currently only Florida and Virginia offer targeted HIV disease management for Medicaid enrollees. California only recently began implementation of its Medicaid HIV DM pilot program. In 2004, Indiana passed a law removing HIV/AIDS from the list of conditions targeted in its Medicaid DM program because of concerns that HIV is not an appropriate condition to target for achieving cost savings – perhaps due to the fact that the high cost of HIV care is largely attributable to medications that help extend lifespan;

therefore, reducing the costs of HIV care might mean cutting lives short. HIV is unique among chronic conditions, largely because of the dramatic decrease in AIDS mortality since the 1990s and the rising utilization and high prices of new medications like fusion inhibitors to treat HIV disease. It is estimated that 73 percent of the lifetime cost of HIV care is attributable to antiretroviral medications (Schackman et al., 2006). It is unknown whether any other states besides Indiana have debated the appropriateness of implementing specialized HIV disease management in Medicaid. However, because many people living with HIV/AIDS have Medicaid coverage, it is likely that costs for HIV medications will continue to contribute to states' increasing Medicaid expenditures.

In FY 2009, ASPE is conducting case studies of two models of disease management intervention targeted to low-income patients with HIV/AIDS. The ASPE study includes a vendor-based Medicaid HIV disease management program and a clinic provider-based care coordination model for people living with HIV. Important issues such as provider staffing and coordination, patient characteristics, and measuring program impacts will be examined in the study. Lessons learned from these programs, which have been in operation for more than 10 years, will help to identify promising practices and challenges associated with financing and implementing care coordination and disease management for HIV patients.

## Conclusion

To date, there is no broad evidence base to support the assumption that disease management improves health outcomes and can reduce the cost of care for populations with multiple chronic illnesses. Most of the evidence currently available about DM is for diabetes, asthma, congestive heart failure, and chronic obstructive pulmonary disease – primarily among commercial DM programs. Research on DM has not focused specifically on HIV/AIDS in Medicaid programs. Therefore, it is debatable whether DM can be an effective cost containment tool for Medicaid populations, who often have a high prevalence of co-occurring illnesses or mental health issues that make management of their conditions more complex. The research conducted to date offers limited evidence that DM can help improve health outcomes for some conditions; more investigation is needed regarding the specific program features, infrastructure, and techniques for provider coordination that are needed to provide the most cost-effective care for patients with multiple chronic conditions. Long-term studies are needed to assess the effectiveness of DM programs for Medicaid populations overall.

Until a cure for HIV is developed, DM may be a useful approach to improve care coordination and promote treatment compliance among HIV patients. CDC's most recent estimates indicate that 1,106,400 adults and adolescents were living with HIV in the United States in 2006, an increase of 11 percent compared to 2003 HIV prevalence estimates. Considering the number of individuals living longer with HIV infection and the significant role Medicaid plays in providing HIV treatment, it will be important to monitor whether DM can help improve outcomes among enrollees with complex health conditions including HIV/AIDS. Studying DM in the HIV population may yield information about how to effectively manage combinations of comorbidities, including chronic diseases that become common with aging. Finally, studying DM for individuals with HIV may help determine the value that care coordination approaches offer beyond cost savings.



## APPENDIX A

### Approved Medicaid Waivers Offering Services Targeted to Individuals with HIV/AIDS

<u>State</u>	<u>Waiver authority</u>	<u>Date Originally Approved</u>	<u>Services</u>
<b>Alabama</b>	1915(c)	03/16/2004	Personal care, respite, skilled nursing, and companion services to individuals with HIV/AIDS.
	1915(c)	10/01/2004	Case management, homemaker, personal care, respite, companion, skilled nursing for HIV/AIDS age 21 with no maximum age.
<b>California</b>	1915(b)	12/20/1982	Primary Care Case Management (PCCM) plans are contractually responsible for the primary care, ambulatory care, case management, utilization review, and prior authorization through the fee-for-service (FFS) Medi-Cal program. The goal of PCCM plans is to reduce the over utilization of high-cost FFS inpatient hospital services through early intervention, preventive care, and outpatient referrals. Medical case management and two Disease Management programs are available (a DM pilot program beginning in January 2009 for HIV/AIDS and a DM program for six other chronic diseases).
	1915(c)	03/07/2002	Case management, homemaker, environmental modifications, skilled nursing, transportation, specialized medical equipment and supplies, attendant care, psychosocial counseling, Medi-Cal supplement for infants and children in foster care, nutritional supplements, home delivered meals and nutritional counseling.
<b>Colorado</b>	1915(c)	01/01/2004	Nursing facility and hospital level of care for homemaker, personal care, adult day health, transportation and personal care to adults with HIV/AIDS.
<b>Delaware</b>	1915(c)	01/01/1991	Case management, personal care, respite, mental health services and nutritional supplements to children and adults with HIV/AIDS.
<b>District of Columbia</b>	1915(c)	01/01/1997	Water purification systems and replacement filters to persons with HIV/AIDS who would otherwise require institutionalization in a hospital.
	1115	01/19/2001	Medicaid benefits to HIV-positive individuals who otherwise would be ineligible for Medicaid.
<b>Florida</b>	1915(b)	01/01/1990	Disease management for individuals with chronic illnesses, including HIV/AIDS.
	1915(c)	01/01/1990	Case management, homemaker, personal care, environmental access adaptations, skilled nursing, specialized medical equipment and supplies, day health, education and support, specialized personal care for foster care children, home delivered meals, therapeutic management, adult dental and nutritional risk reduction for individuals diagnosed with AIDS.
<b>Hawaii</b>	1915(c)	06/01/1992	Case management, personal care, respite, adult day health, environmental access adaptations, non-medical transportation, specialized medical equipment and supplies, personal care, private duty nursing, counseling and training, moving assistance, home delivered meals, and home maintenance to aged and disabled individuals with a diagnosis of AIDS.
<b>Illinois</b>	1915(c)	10/01/1993	Personal care, homemaker, home health, emergency home response, respite, foster care, supplemental payment and environmental modifications to persons diagnosed with AIDS, AIDS-related complex (ARC), or HIV infection.
			Disease management is available as an additional voluntary service for Medicaid and other Illinois health program enrollees with complex medical conditions, including HIV/AIDS.
<b>Indiana</b>	1915(b)	09/13/1993	The full package of Medicaid benefits is available to beneficiaries enrolled in the waiver program. Care coordination/targeted case management is available as a self-

<u>State</u>	<u>Waiver authority</u>	<u>Date Originally Approved</u>	<u>Services</u>
			referral service for Medicaid enrollees with HIV infection.
<b>Iowa</b>	1915(c)	07/1/1995	Counseling, Home Health aide, homemaker, nursing, respite and hospice, consumer directed attendant care, adult day care and home delivered meals to persons with AIDS or HIV.
<b>Maine</b>	1115	02/24/2000	Early treatment of HIV disease – a limited but comprehensive package of services, including antiretroviral therapies for individuals who are HIV-positive and at or below 250% FPL.
<b>Missouri</b>	1915(c)	07/01/1992	Personal care, specialized medical equipment and supplies, private duty nursing, and attendant care.
<b>New Jersey</b>	1915(c)	03/01/1991	Case management, private duty nursing, medical day care, personal care, narcotic and drug abuse treatment at home, intensive supervision to eligible children who reside in division of youth and family services supervised foster care homes, pediatric community transitional home services and hospice care to persons with AIDS and children up to age 13 who are HIV+ who would otherwise require the level of care provided in a nursing facility.
<b>New Hampshire</b>	1915(b)	2004	Disease management for individuals with chronic illnesses, including HIV/AIDS.
<b>New Mexico</b>	1915(c)	07/01/1994	Case management, homemaker/personal care, and private duty nursing for patients with HIV/AIDS.
<b>North Carolina</b>	1915(c)	10/01/1995	Case management, respite, adult day health, personal emergency response services (PERS), in-home aids, delivered meals, waiver supplies and home mobility aids for individuals with AIDS diagnosis (if ages 13 and older); HIV seropositivity and a CDC classification of category A, B or C (children ages 2-12); and HIV seropositivity (children up to age 2).
<b>Pennsylvania</b>	1915(c)	04/01/1995	Homemaker, specialized medical equipment and supplies, home health aide, skilled nursing, nutritional consultations, and community transitions services to individuals 21 and over with symptomatic HIV or AIDS. Targeted case management is available for Medicaid clients with HIV (not a waiver service).
<b>South Carolina</b>	1915(c)	10/01/1991	Case management, personal care aide, private duty nursing, home delivered meals, foster care, counseling services, and modified hospice care for persons with HIV/AIDS.
<b>Virginia</b>	1915(c)	07/01/1994	Case management, personal care, respite, private duty nursing, extended state plan services (nutritional supplements) to disabled individuals at the hospital or Nursing Facility level of care who have HIV and are symptomatic or who have AIDS. This waiver also provides consumer-directed personal care and respite care. Disease Management is available to waiver enrollees.

## APPENDIX B

### Reported AIDS Cases in States with Programs Targeted to HIV/AIDS

<b>State</b>	<b>Reported AIDS Cases Cumulative through 2005</b>
Alabama	8,252
California	139,019
Colorado	8,480
Delaware	3,458
District of Columbia	16,962
Florida	100,809
Hawaii	2,857
Illinois	32,595
Indiana	7,963
Iowa	1,656
Maine	1,053
Missouri	10,630
New Jersey	48,431
New Hampshire	1,032
New Mexico	2,526
North Carolina	14,915
Pennsylvania	31,977
South Carolina	12,715
Virginia	16,378

Data Source: 2007 National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention State Profiles online at <http://www.cdc.gov/nchhstp/stateprofiles/usmap.htm>

## REFERENCES

- Baldwin III, A. L. (1999). Research Report: Financial and Risk Considerations for Successful Disease Management Programs. Seattle, WA: Milliman & Robertson, Inc.
- Billings, J. & Mijanovich, T. (2007). Improving the Management of Care for High-Cost Medicaid Patients. *Health Affairs*, 26(6):1643-1655.
- Bruen, B.K. & Miller, L.M. (2008). Changes in Medicaid Prescription Volume and Use in the Wake of Medicare Part D Implementation. *Health Affairs*, 27(1):196-202.
- California Department of Health Care Services. (2008). *California DHCS Division Descriptions*. Retrieved September 22, 2008, from <http://www.dhcs.ca.gov/Documents/DHCSDivisionDescriptions070308.pdf>
- Centers for Disease Control and Prevention. (2008). *New Estimates of U.S. HIV Prevalence, 2006*. Atlanta, GA: Author.
- Centers for Disease Control and Prevention. (2008). *HIV Mortality through 2005*. Retrieved September 16, 2008, from <http://www.cdc.gov/hiv/topics/surveillance/resources/slides/mortality/>
- Centers for Medicare & Medicaid Services. (2008). *Medicaid Waivers and Demonstrations List*. Retrieved July 1, 2008, from <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/>
- Centers for Medicare & Medicaid Services. (2004). *Disease Management in Medicaid (SMDL #04-002)*. Retrieved July 1, 2008, from <http://www.cms.hhs.gov/smdl/downloads/smd022504.pdf>
- Chen, A. and Au, M. (2008). *Medicaid Evidence-Based Decisions Project (MED): Rapid Review of the Disease Management Literature*. Princeton, NJ: Mathematica Policy Research, Inc.
- Chen, A., Brown, R., Esposito, D., Schore, J., & Shapiro, R. (2008). *Report to Congress on the Evaluation of Medicare Disease Management Programs*. Princeton, NJ: Mathematica Policy Research, Inc.

- Congressional Budget Office. (2004). *An Analysis of the Literature on Disease Management Programs*. Washington, DC: Author.
- Disease Management Association of America. (2007). *DMAA Definition of Disease Management*. Retrieved September 4, 2008, from [http://www.dmaa.org/dm\\_definition.asp](http://www.dmaa.org/dm_definition.asp)
- Fleishman, J.A. (1997). Changes in insurance status among people with HIV infection. *Abstract Book Association for Health Services Research Meeting*, 1997(14): 267-268.
- Gillespie, J. L. & Rossiter, L. F. (2003). Medicaid Disease Management Programs: Findings from Three Leading US State Programs. *Disease Management Health Outcomes*, 11(6): 345-361.
- Holmes, A.M., Ackerman, R.D., Zillich, A.J., Katz, B.P., Downs, S.M., & Inui, T.S. (2008). The Net Fiscal Impact of a Chronic Disease Management Program: Indiana Medicaid. *Health Affairs*, 27(3):855-864.
- Illinois Department of Healthcare and Family Services. (2008). *Disease Management: Your Healthcare Plus*. Retrieved September 4, 2008, from <http://www.hfs.illinois.gov/dm/>
- Indiana Health Coverage Programs. (2007). *HIV-Care Coordination: EDS Indiana Title XIX*. Retrieved September 4, 2008, from <http://www.indianamedicaid.com/ihcp/index.asp>
- Luck, J., Parkerton, P., & Hagigi, F. (2007). What is the Business Case for Improving Care for Patients with Complex Conditions? *Journal of General Internal Medicine*, 22(Supp 3):396-402.
- Kaiser Family Foundation. (2006). *HIV/AIDS Policy Fact Sheet: Medicaid and HIV/AIDS*. Menlo Park, CA: Author.
- Kaiser Family Foundation. (2009). *HIV/AIDS Policy Fact Sheet: Medicare and HIV/AIDS*. Menlo Park, CA: Author.
- Kaiser Family Foundation. (2009). *HIV/AIDS Policy Fact Sheet: The HIV/AIDS Epidemic in the United States*. Menlo Park, CA: Author.
- Krumholz, H.M., Curie, P., Riegel, B., Phillips, C.O., Peterson, E.D., Smith, R., Yancy, C.Q., & Faxon, D.P. (2006). A Taxonomy for Disease Management. *Circulation* 114:1432-1445.

- McKesson Corporation. (2008). *Disease Management Fact Sheet*. Retrieved September 3, 2008, from [http://www.qa.mckesson.com/static\\_files/McKesson.com/CorpPR/Fact%20Sheets/McKessonDMFactSheet.pdf](http://www.qa.mckesson.com/static_files/McKesson.com/CorpPR/Fact%20Sheets/McKessonDMFactSheet.pdf)
- McKesson Corporation. (2007). "New Hampshire Department of Health and Human Services Renews McKesson Health Solutions Medicaid Disease Management Program" Press Release. San Francisco, CA: Author.
- National Conference of State Legislatures. (2008). *50 State Summary of Disease Management Laws*. Retrieved September 3, 2008, from <http://www.ncsl.org/programs/health/diseasemgtleg04.htm>
- Pennsylvania Department of Public Welfare. (2008). *AIDS Waiver Program Fact Sheet*. Retrieved September 4, 2008, from <http://www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance/AIDSWaiverProgram/>
- Schackman, B.R., Gebo, K.A., Walensky, R.P., Losina, E., Muccio, T., Sax, P.E., Weinstein, M.C., Seage, G.R. III, Moore, R.D., & Freedberg, K.A. (2006). The lifetime cost of current human immunodeficiency virus care in the United States. *Medical Care* 44(11):990-997.
- Virginia Department of Medical Assistance Services. (2006). *Healthy Returns<sup>SM</sup>: Virginia Medicaid Disease Management*. Retrieved September 16, 2008, from <http://legis.state.va.us/jchc/9.14.06Disease.pdf>
- Vogeli, C., Shields, A.E., Lee, T.A., Gibson, T.B., Marder, W.D., Weiss, K.B., & Blumenthal, D. (2007). Multiple Chronic Conditions: Prevalence, Health Consequences, and Implications for Quality, Care Management, and Costs. *Journal of General Internal Medicine*, 22(Suppl 3):391-395.
- White, C., Fisher, C., Mendelson, D. & Schulman, K. A. (2005). *State Medicaid Disease Management: Lessons Learned from Florida*. Washington, D.C.: The Health Strategies Consultancy LLC with Duke University.
- Williams, C. (2004). *Medicaid Disease Management: Issues and Promises*. Washington, D.C.: Kaiser Family Foundation.