

medicaid and the uninsured

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Medicaid Disease Management: Issues and Promises

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Executive Summary

More than half of all adult Medicaid enrollees have a chronic or disabling condition, according to some estimates. Many states are adopting Medicaid disease management programs as a way to improve health care quality and reduce costs for these enrollees. This issue paper presents information from nine states that have developed and implemented disease management programs for adult Medicaid enrollees with chronic conditions such as asthma, diabetes, and congestive heart failure, or who are trying to manage these populations through capitated managed care. We examine the motivations, goals, strategies and impact of these state efforts, in addition to describing the details of their initiatives. These findings have important implications for Medicaid and Medicare policy, including strategies for addressing the needs of dual eligibles.

The target states – Colorado, Florida, Indiana, Maryland, Missouri, New York, North Carolina, Oregon and Washington – were chosen to provide a diversity of geographical location and size of Medicaid programs and to include several states with established stand-alone disease management efforts. In-depth phone interviews were conducted with Medicaid officials and other stakeholders in the nine target states in the first quarter of 2004. Overall, this research indicates that, if carefully designed, disease management programs can address many underlying health system issues affecting the disabled and chronically ill. However, program savings and improved quality of care are more difficult to demonstrate, though preliminary indications appear promising. While some states have promoted real health system reforms through disease management programs, most have pursued more limited objectives. Other key findings from this work include:

Program Goals and Structures

Many states want to achieve immediate cost-savings from their disease management initiatives and see outsourcing as the only viable option. The cost-savings targets established for disease management programs are frequently developed by legislators who are under acute pressure to resolve budget problems and have been lobbied by pharmaceutical industry officials on the potential impact of disease management programs. The decision on whether to build or buy the disease management program is also driven by states' budget problems and time pressures to show cost savings. States often outsource disease management so that they can get their programs initiated and show results quickly.

Programs have evolved away from pharmaceutical management and implementation disease-by-disease. They now focus on multiple diseases and improving self-care. Early programs like Florida's contracted with multiple vendors, each responsible for disease

management for a single disease. Concerned that the single-disease approach fragments care and does not address the needs of enrollees with multiple conditions, most states that outsource now contract with a single vendor. The vendor develops disease management interventions for multiple diseases (often diabetes, congestive heart failure and asthma) and creates approaches and interventions to address patient comorbidities. Programs have also evolved from a primarily pharmaceutical-focused approach – working with physicians and pharmacists to improve enrollee compliance with pharmaceutical regimens – to a more enrollee-focused approach using nurse care-managers to help participants identify and work on behavior-change goals and improve self-management skills.

Mental health issues and dual eligibles are generally not targeted by Medicaid disease management programs. While mental health problems are among the most prevalent chronic conditions for Medicaid enrollees, most disease management programs do not target these conditions, perhaps because there are not yet tested models for improving patient self-care. And although dual eligibles – people with both Medicare and Medicaid coverage – represent a large proportion of the adult Medicaid population with chronic illnesses, they are generally not included in states' disease management programs because most of the cost savings would benefit Medicare not Medicaid.

Commercial disease management approaches need to be adapted for Medicaid enrollees who tend to be more difficult to contact and have a more complex array of problems than the commercially insured population. States have asked disease management companies to devote more resources to identifying and contacting potential enrollees, making multiple contacts and using a mix of mailings and phone calls. States have also asked for a more intensive and local care management approach, especially for enrollees with more complex conditions.

Most programs operate fairly independently of physicians, but some have developed innovative approaches to engage providers. Disease management companies are all too aware of the potential resistance from physicians who might view disease management as burdensome or interfering. Disease management programs operate largely at an arm's length from providers, underscoring the potential limitations of this approach for addressing underlying health system problems of practice variation, fragmentation of care and lack of evidence-based medicine. A few states, though, including Colorado, Indiana, Washington and New York have developed alternative approaches to more fully engage physicians.

Chronic care management is not a focus of most states' managed care contracting – but states are interested in learning and doing more. States say they have not asked their managed care organizations (MCOs) to develop tailored approaches to manage the care of their chronically ill enrollees, although many have done so as part of their overall care management strategies. Some states are beginning to ask what more they should or could be doing to ensure that managed care enrollees with chronic illnesses are appropriately managed.

Key Findings

Initial savings and quality results from stand-alone disease management programs are promising, but by no means conclusive. States report both savings and improved outcomes from their programs, but these promising results are preliminary. Some states, including Indiana and Washington, are planning rigorous external evaluations but the results will not be available for a year or two. It is not possible to reach a definitive conclusion about the impact of disease management programs based on available preliminary data largely because studies did not have the necessary rigor or the results are incomplete.

States are having a hard time reaching potential enrollees. Once contacted, participation in disease management is voluntary, and take-up rates vary. A significant obstacle for all programs is difficulty contacting potential enrollees. Factors explaining these low rates of contact include frequent moves by Medicaid enrollees, lack of phones and outdated or incomplete information in state eligibility systems.

Issues of enrollee turnover and low payment rates hamper potential scope and impact of chronic disease initiatives. Developing and maintaining enrollee and provider participation has been challenging for states due to enrollee turnover – in part due to eligibility rules – and provider dissatisfaction because of low payment rates. Both these issues will dampen the success of disease management initiatives. Without consistent eligibility and stable relationships with physicians, chronically ill enrollees cannot hope to benefit from states' chronic disease efforts. With these elements in place, states may be able to pursue more creative strategies.

If carefully designed, disease management programs can help address underlying health system issues affecting the chronically ill. While some states have made genuine efforts to promote health system reforms through disease management, most have not focused on this objective, instead working to improve patient skills to manage their own care. These skills are needed, but states are potentially missing a chance to address underlying problems of poor coordination and communication, lack of quality improvement infrastructure and the lack of attention to helping people avoid – rather than treat – chronic diseases.

Clearly, these issues are larger than the Medicaid program, and costs savings, not fundamental health system reforms, were the objective of most states as they launched disease management programs. However, disease management can play a fundamentally positive role in helping to address these deeper issues and some states have seized this opportunity. As shown by the examples of Indiana and Washington, states can work towards these objectives even if they outsource all or large parts of their programs, but doing so will require broad thinking, hard work and creativity.

I. Overview and Study Approach

Facing unprecedented budget crises, many states are considering or have implemented substantial cuts to their Medicaid programs. State cost-cutting efforts first focused on provider payments and controls for pharmacy spending. As state budget crises persisted, states have considered more substantial cuts to eligibility and benefits. Reviewing their options, many states are now considering how to better address the needs and manage health care spending for high-cost populations, whose care accounts for a large proportion of total Medicaid spending. A major question for states is whether they can improve health care quality and reduce costs for this population.

This is not a new issue for states, but they are turning to it more urgently given current and projected budget problems. This issue paper presents information from nine states that have developed and implemented disease management programs for adult Medicaid enrollees with chronic conditions such as asthma, diabetes, and congestive heart failure, or who are trying to manage these populations through capitated managed care. In this report we examine the motivations, goals, strategies and impact of state efforts, in addition to describing the details of state initiatives. These findings have important implications for Medicaid and Medicare policy, including strategies for addressing the needs of dual eligibles.

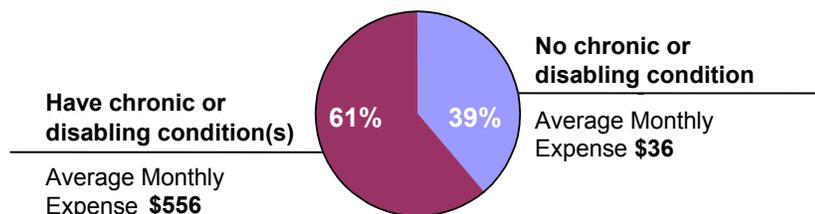
Nine target states – Colorado, Florida, Indiana, Maryland, Missouri, New York, North Carolina, Oregon and Washington – were chosen for this analysis. We selected states providing a diversity of geographical location and size of the Medicaid program and included several states with established stand-alone disease management efforts. For comparison, we included two states, Maryland and New York, which do not have stand-alone disease management initiatives but enroll a portion of the SSI population in capitated managed care. In-depth phone interviews were conducted with Medicaid officials and other stakeholders in the nine states (see interview protocol in Appendix Two) in the first quarter of 2004. While not the focus of this report, several states also have initiatives to manage the care of very high-cost enrollees through intensive case management. Enrollment in these programs is usually triggered by very high health care spending or the presence of a rare and expensive condition.

II. Background: Chronic Disease in Medicaid

More than sixty percent of adult Medicaid enrollees have a chronic or disabling condition.

According to the results of one study, more than 60 percent of adult Medicaid enrollees have a chronic or disabling condition (Figure 1), most commonly diabetes, hypertension, asthma, psychoses and chronic depression.¹ These chronically ill enrollees require far more medical care than do their healthier peers. Average monthly medical expenses for enrollees with chronic or disabling conditions in this study were \$556 (\$6,672 annually) compared to \$36 (\$432 annually) for people without these conditions.

Figure 1. Percentage of Adult Medicaid Enrollees in Four States with a Chronic or Disabling Condition, 1995



Source: HCFA State Medicaid Research Files for California, Georgia, New Jersey and Kansas, 1995

Recent research has shown that nearly half (48%) of adults with Medicaid report having at least one physical or cognitive limitation, and that 2001 spending for these Medicaid enrollees averaged more than \$711 per month (\$8,535 annually), whereas spending on those not reporting such conditions averaged only \$146 per month (\$1,752 annually).²

Most adult Medicaid enrollees with one chronic condition have another.

Allen et al. also showed that almost half (46 percent) of enrollees with one chronic or disabling condition had another – often a mental health problem. (According to MEPS survey data, one quarter of the entire Medicaid population has a mental disorder.)³ People with multiple conditions have much more complex health problems resulting in more intensive health care and higher costs (Figure 2).⁴

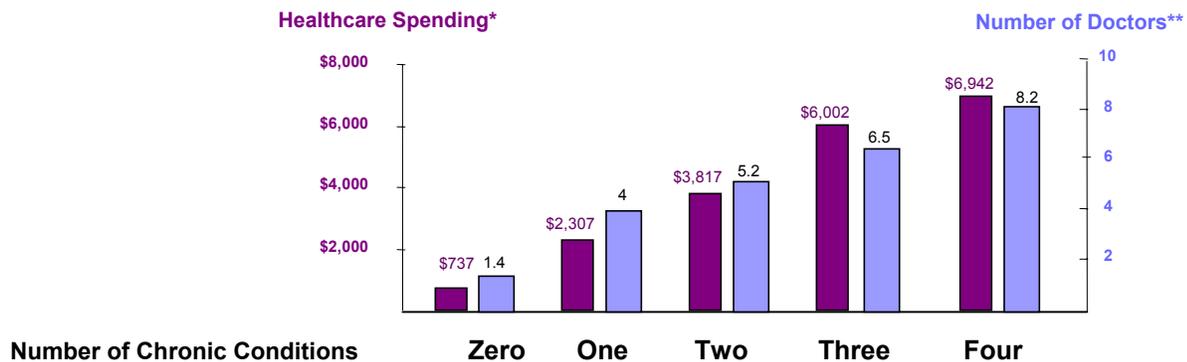
¹ Susan M. Allen, et al. *The Faces of Medicaid: The Complexities of Caring for People with Chronic Illnesses and Disabilities*. The Center for Health Care Strategies, 2000.

² Kaiser Commission on Medicaid and the Uninsured estimates based on MEPS data as presented in Jack Hadley and John Holahan, "Is Health Care Spending Higher under Medicaid or Private Insurance?" *Inquiry*, Vol. 40, No. 4, Winter 2003/2004.

³ Gerard Anderson. *States Confront Multiple Chronic Conditions*. Partnership for Solutions, April 12, 2003.

⁴ Table adapted from Anderson, 2003.

Figure 2. Average Annual Per Capita Healthcare Spending and Number of Doctors, by Number of Chronic Conditions for Medicaid Enrollees, 1998



Source: Medical Expenditure Panel Survey, 1998. Data for all Medicaid enrollees.

*Mean cost per capita

**Average number of unique physicians

Despite the large amounts of money spent for their medical care, people with chronic conditions often do not get the care they need.

Despite high health care spending, there is widespread evidence that people with chronic conditions do not get the health care they need and have poor health outcomes as a result. For example, a national study of adults with medical conditions showed that only 45 percent of people with diabetes get the care they need and only 25 percent of diabetics receive recommended testing to monitor their condition.⁵ Like other purchasers, Medicaid officials believe that improved management of care for the chronically ill could result in better health outcomes and possibly lower costs as the serious medical problems resulting from unmanaged chronic conditions are eliminated.

III. Medicaid Disease Management Programs: Motivation and Design

Applying disease management to fee-for-service Medicaid is a new concept.

Traditional managed care models offer structures and systems to address the needs of the chronically ill. But many if not most of the affected Medicaid enrollees are enrolled in fee-for-service or Primary Care Case Management (PCCM) programs, where these management structures do not exist. The state of Washington found that most Medicaid enrollees with chronic illnesses were in fee-for-service Medicaid, and that these enrollees were faring worse than other populations (especially Medicare fee-for-service enrollees) in terms of getting the preventive care and medications they needed.⁶

Disease management programs have been part of managed care organization (MCO) care management approaches for years. Today's innovation is implementing disease management programs in fee-for-service or PCCM Medicaid programs, outside the managed care framework. This model is new and as yet largely unproven. Some states implement stand-alone disease management because they have little or no capitated Medicaid managed care. Other states, including Oregon, have substantial Medicaid managed care programs but are implementing

⁵ Elizabeth A. McGlynn et al. "The Quality of Health Care Delivered to Adults in the United States." *New England Journal of Medicine*, Vol. 348, No. 26, 2003.

⁶ Personal communication with Alice Lind, February 2004.

disease management for populations not enrolled in managed care. The rapid adoption of stand-alone Medicaid disease management programs by states – the number of states with programs increased from 11 to 21 from fiscal year 2001 to fiscal year 2003 – has been driven by states’ desire to manage care and reduce costs of chronically ill enrollees who are not enrolled in capitated managed care.⁷ The growth in Medicaid disease management mirrors the overall expansion of the disease management industry, whose revenues grew from \$85 million in 1987 to \$600 million in 2002, an average annual growth rate of 40 percent.

Disease management, whether within managed care or implemented on a stand-alone basis, is a response to the following:

- A small portion of the population is responsible for a large portion of costs. For example, recent research indicates that four percent of Medicaid enrollees are responsible for 53 percent of Medicaid spending.⁸
- Health care for the chronically ill is often fragmented and poorly coordinated.
- Care for the chronically ill does not follow evidence-based guidelines.

The premise of disease management is that by better coordinating health care services and improving patients’ and physicians’ adherence to evidence-based best practices, health care costs for this group will decline as quality improves. Disease management usually involves identifying enrollees with a target condition, developing behavior and treatment plans based on practice guidelines and patient assessments, and developing processes and resources to support enrollees and providers as they try to change both individual and treating behaviors (Figure 3).

Figure 3. Definition of Disease Management

Disease management (DM) is a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant. DM:

- Supports the physician or practitioner/patient relationship and plan of care.
- Emphasizes prevention of exacerbations and complications utilizing evidence-based practice guidelines and patient empowerment strategies.
- Evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health.

Disease management components 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
- Routine reporting/feedback loop (may include communication with patient, physician, health plan and ancillary providers, and practice profiling)

Source: The Disease Management Association of America

⁷ Vern Smith et al. *Medicaid Spending Growth: Results from a 2002 Survey*. Kaiser Commission on Medicaid and the Uninsured, September 2002.

⁸ Urban Insitute analysis of 2000 Medicaid Statistical Information System (MSIS) Data. 2004, forthcoming.

The overall approach to disease management adopted by Washington State is similar to those developed by many states:

- A 24-hour call center is available to all enrollees identified as having target diseases.
- The vendor follows up by phone to schedule an assessment with enrollees identified as having more acute needs.
- The vendor sends an information packet to the primary care physician. For asthmatics, the primary care doctor is generally easily identifiable from medical claims. The state reports that it is much more difficult to identify primary care providers for enrollees with diabetes, perhaps because these patients are more likely to be treated by multiple physicians.
- A nurse care-manager completes an initial assessment, clarifying the identity of the primary care physician if necessary. Approximately 10-20 percent of these assessments are completed in person, using Washington-based nurse care managers under a contract with the vendor, *Specialty Disease Management*. These on the ground care managers make contact with the primary care physician before the assessment.
- A summary of the assessment (and of the reassessment every six months) is sent to the primary care physician.

Many states want to achieve immediate savings from their disease management initiatives and see outsourcing as the only viable option.

Most states are hoping to realize rapid savings from their disease management programs. The cost-savings targets established for disease management programs are frequently developed by legislators who are under acute pressure to resolve budget problems and have been lobbied by pharmaceutical industry officials on the potential impact of disease management programs. The decision on whether to build or buy the disease management program is also driven by states' budget problems and time pressures to show cost savings. States often outsource disease management so that they can get their programs initiated and show results quickly. Many states think the time and effort needed to develop programs internally would not be acceptable to legislatures wanting to see almost immediate cost-saving impacts.

In addition to time pressure to show results, other factors lead many states to outsource rather than build their own programs. One is the reluctance to build new government functions, demonstrated by widespread hiring freezes and staffing limits. Another is states' lack of cash to invest up-front in building new programs.

Outsourcing can ease financial constraints because disease management companies advance resources for the start-up costs and place their own fees at risk (fees are reimbursed if agreed-upon outcomes are not achieved). Pharmaceutical companies have gone one step further and actually fund Medicaid disease management programs in Florida and Colorado. One reason pharmaceutical companies back these arrangements is that disease management tends to increase pharmaceutical spending, while decreasing other costs.

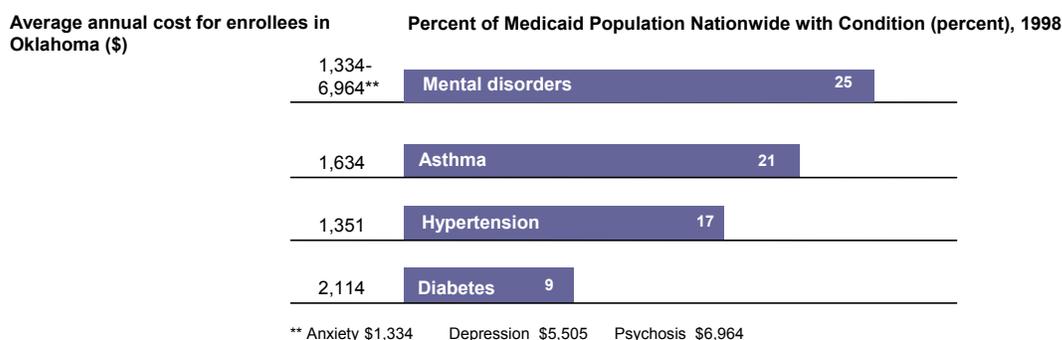
Pharmaceutical companies fund Florida's disease management initiatives as part of a program of "value-added" contracts. The pharmaceutical products of companies making these "value-added" investments are included on Medicaid's preferred drug list without the provision of supplemental rebates, as normally required. News reports indicate that pharmaceutical companies lobbied hard for this provision. Some analysts argue that supplemental rebates are worth much more than the value of investments and cost savings from disease management programs. The state's Office of Program Policy Analysis and Government Accountability estimates that eliminating these value added contracts and replacing them with supplemental rebates might save the state \$64.2 million in FY 2003-2004, although it is not clear whether this

figure is net of the guaranteed savings for value-added contracts totaling \$36.2 million in FY 2002-2003.⁹

Disease management programs focus on diseases with the greatest potential for savings.

Logically, disease management programs have focused on diseases that are prevalent, high-cost, where there is evidence of a gap between existing practice and evidence-based guidelines and where improved patient self-care might improve quality and reduce costs (Figure 4). Diabetes, asthma and congestive heart failure (CHF) meet these criteria and are the most commonly targeted diseases for Medicaid disease management programs. States also report they are developing programs for end-stage renal disease, sickle cell disease, high-risk pregnancies, hemophilia, hypertension, depression and HIV/AIDS. States have mixed views on the appropriateness of disease management for some of these more complicated and costly conditions. The Medicaid agency in Indiana, for instance, convinced its legislature not to include HIV/AIDS on the disease management list, concerned that a cost-savings goal was not appropriate for this population. Although mental health conditions are among the most prevalent and costly chronic conditions for adult Medicaid enrollees, they have not been the focus of early state disease management efforts, perhaps because there are not yet tested models for improving patient self-care for people with these conditions.

Figure 4. Cost and Prevalence of Chronic Conditions for Medicaid Population



Source: Percent of Medicaid population with conditions – MEPS 1998.
Average cost for enrollees in Oklahoma – Medicaid enrollees in the state with a single chronic condition from Robert Garis. “Examining the Costs of Chronic Conditions in a Medicaid Population”. *Managed Care*. August, 2002.

States select target diseases based on whether they are expected to produce savings over a short one to three year period, while also sometimes working to develop disease management for other costly diseases that may show results only after a longer period. State legislatures frequently dictate which diseases will be addressed by Medicaid disease management initiatives.

Programs have evolved away from pharmaceutical management and implementation disease-by-disease. They now focus on multiple diseases and improving self-care.

Early programs like Florida’s contracted with multiple vendors, each responsible for disease management for a single disease. Concerned that the single-disease approach fragments care and does not address the needs of enrollees with multiple conditions – who might have multiple

⁹ Florida recently decided to eliminate their pharmaceutical company-sponsored disease management programs after they expire in 2005. The state indicated it plans to continue using disease management, though not through drug-company sponsored programs. See Theresa Agovino, “Florida fails to renew drug company-sponsored programs to reduced health care costs,” Associated Press, July 26, 2004.

care managers each working with them on a single disease – most states that outsource now contract with a single vendor. The vendor develops disease management interventions for multiple diseases (often diabetes, congestive heart failure and asthma) and creates approaches and interventions to address patient comorbidities.

Working with a single vendor is a first step to a more integrated approach to addressing enrollees' multiple conditions. This approach works if the multiple conditions are all included in the disease management program but does not if the comorbidities are not targeted. States are interested in addressing these comorbidities as well, but most have not yet developed effective strategies to do so. For example, Indiana's interventions currently focus only on the diseases its legislature selected for the program's focus, but they are tracking the most common comorbidities with the goal of developing strategies to address these as the program develops.

Programs have also evolved from a primarily pharmaceutical-focused approach – working with physicians and pharmacists to improve enrollee compliance with pharmaceutical regimens – to a more enrollee-focused approach using nurse care managers to help participants identify and work on behavior-change goals and improve self-management skills. States are still trying a variety of approaches, however, some reflecting new models and some with the original single-disease structure and focus on pharmaceutical management. Colorado's five disease management initiatives are each run by a separate vendor, for example, and are funded by eight pharmaceutical companies. Virginia and Missouri's programs, meanwhile, still focus primarily on pharmaceutical management.

Washington was initially interested in developing a more holistic and integrated alternative to standard disease management offerings. The state asked vendors to propose strategies to address the broad health care patterns and needs shown in the extensive data it released on the Medicaid fee-for-service population's diseases, comorbidities and health care utilization. One vendor responded with an innovative strategy bringing together a variety of interventions – managed behavioral care, pharmacy management, and care management – essentially proposing traditional managed care but without risk. Finding it could not cost-out this approach or compare it to other vendors' proposals, the state eventually contracted for a more typical disease management program focusing on asthma, diabetes, congestive heart failure and end-stage renal disease.

Other states are targeting the underlying problems of overweight and smoking, which may contribute to morbidity for a chronic condition but also contribute to other diseases. Indiana has incorporated messages targeting smoking and overweight into its disease management program while Washington has added a flu vaccine measure to the assessment of its disease management approaches for asthma, diabetes and CHF.

By supporting and reinforcing improved patient self-management and use of evidence-based guidelines, disease management programs reflect certain elements of the *Chronic Care Model* developed by researcher Edward Wagner and widely regarded as a benchmark approach for chronic illness care (Figure 5).¹⁰ However, most disease management programs do not address other key elements of the Chronic Care Model including fundamental delivery system change and development of clinical information systems that can be used by providers.

¹⁰ Edward H. Wagner. "Improving Chronic Illness Care: Translating Evidence into Action." *Health Affairs*, Vol. 20, No. 6, November/December 2001.

Figure 5. Gaps Between Wagner’s Chronic Care Model and State Disease Management Programs

Elements of the Wagner Chronic Care Model	State Disease Management Programs:	
	Generally Address	Usually do not Address
Support for patient self-management	√	
Use of evidence-based guidelines	√	
Reforms to delivery system		√
Development of clinical information systems		√

Source: Williams, 2004

A number of states, including New York, Indiana and Washington are implementing chronic disease collaboratives – the main intervention strategy of the Chronic Care Model – either as a component of their disease management initiatives or more broadly through the health department.¹¹ Indiana, for instance, has implemented several chronic disease collaboratives in its disease management program. The development of Washington’s disease management program followed years of work by the health department to improve chronic care throughout the state. The Department of Health had sponsored a series of collaboratives focusing on both asthma and diabetes.

Building infrastructure for chronic disease management motivated two states to “build” instead of “buy” their programs.

Although state officials seem generally satisfied with the services of disease management vendors, some wish they could have built programs internally to shape them more closely to state needs and develop lasting care management infrastructure. With these issues in mind, Indiana has developed a hybrid solution. By outsourcing components of its initiative but not the whole program – a so-called “assembling” model – Indiana has been able to retain strong control over its program without the need to build substantial additional state infrastructure.

Indiana’s Medicaid agency was initially directed by its legislature to develop a disease management program for specified diseases using an outside vendor. However, after meeting with chronic disease experts and spending months in negotiations with a vendor – discussions which focused largely on how to measure savings and not on intervention and quality improvement strategies – the state decided to cancel the planned procurement and instead build the program internally. In designing the interventions and the evaluation approach, the state agency has focused on the following objectives:

- Emphasize health outcomes, not just cost-savings.
- Focus energy on developing interventions, not developing cost-savings formulas.
- Build on the skills and infrastructure of existing local institutions.
- Make efforts to strengthen the state’s public health infrastructure, support sustainability and health system change and improve chronic care for all residents, not just Medicaid enrollees.

¹¹ This description of chronic care collaboratives is taken from the *Improving Chronic Illness Care Web Site—www.improvingchroniccare.org*: “The regional collaboratives bring together 10 to 30 organizations in a year-long effort to improve care of patients suffering from asthma, depression, congestive heart failure and other chronic conditions. The region may be a city, county, state or even larger area. Participating organizations may range from small clinics to large managed care plans and are coordinated by a central sponsor organization. As with the Breakthrough Series, teams from each organization meet for periodic ‘learning sessions’ to examine proven improvement strategies and refine plans for incorporating such strategies within their organizations using the Chronic Care Model. In between meetings, they consult core faculty and submit monthly reports to their senior leaders, gathering for a final meeting to showcase results.”

Figure 6. Characteristics of Select State Disease Management Programs

Medicaid Program		Disease Management Program							
State	Enrollees	Start	Asthma	CHF	Diabetes	Other	Build or Buy	Agent	Description
CO	347K	2002-2003	✓		✓	✓	Buy	Care Managers	Outsource series of pilot programs funded by drug companies. Use education and phone counseling.
FL	2.04M	1999	✓	✓	✓	✓	Buy	Pharmacists	Began as DM program with separate vendors for each disease (PCCM only). Now run by two pharmaceutical companies: Pfizer and Bristol, Meyers, Squibb. Automatic enrollment with opt out.
IN	610K	2003	✓	✓	✓			Care Managers	Cancelled procurement for an outside vendor to build own program. Use Chronic Care Model. Physician support and care management through call center and case managers. Building registry. Also target those at risk of chronic disease.
MO	773K	2002	✓	✓	✓	✓	Buy	Pharmacists & Physicians	Outsource DM to Heritage. Fee-for-service enrollees only. Physician-pharmacist provider teams make 4 visits/year to each patient.
NC	1.20M	1998	✓		✓	✓	Build	Physicians & Care Managers	In-state program for PCCM. System of community health networks organized by doctors (2,000 participating). Networks get \$2.50 per enrollee.
OR	537K		✓	✓	✓		Buy	Care Managers	Outsource to McKesson. Fee-for-service enrollees. Education/assessment (phone) by nurse managers. Individual management by case managers.
WA	915K	2002	✓	✓	✓	✓	Buy	Care Managers	Outsource DM to McKesson & Renaissance. Education and counseling by nurse care managers. Target fee-for-service enrollees. Trained physicians on education, protocols, and quality. Complete evaluation pending (2004). Using Chronic Care Model.

Source: Williams, 2004

- Examine results for a comparable control group and for entire target population, not just people “touched” by the program.

Indiana has pioneered this “assembling” model of disease management, contracting out many of the functions but retaining control of strategic decision-making for the program, which is jointly managed by the Medicaid agency and the Department of Health. For example, the disease management initiative uses the Indianapolis-based call center also used for the Medicaid eligibility determinations, ensuring that patient contact and eligibility information is up-to-date. In addition, the state contracts with two existing local organizations – the Indiana Minority Health Coalition and the Indiana Primary Health Care Association – to provide nurse care managers.

Interested in building a community-based approach, North Carolina has structured its disease management program around regional networks of primary care case management (PCCM) providers. (More than 75 percent of the state’s Medicaid enrollees are in the PCCM program). Each network hires nurse care managers and other staff who work with physicians, local health and social service departments and patients in the local area. A single case manager (with an office often located in one of the participating physician’s practices) is assigned to work with each provider and her patients on care management for asthma, diabetes, reducing ER utilization and nursing home polypharmacy.

The state currently has 13 networks with 2,000 or more physicians participating. The state provides resources, information and technical support and is responsible for coordinating the development of evidence-based protocols and guidelines used by all of the networks. The state pays both the network and the participating primary care provider \$2.50 per enrollee. If not in a network, PCCM providers get only \$1.00 per enrollee, creating a clear incentive to participate.

Initially, each network was allowed to develop its own care management strategies and approaches. Over time, however, the program recognized the need for more standardization. The program has retained its local community- and physician-led structure, but uses standard target diseases, guidelines, processes and measures developed by a state-wide board made up of the clinical directors of each of the networks. Physicians use disease-specific tool kits in managing the care of patients with target conditions. Although the program’s care managers only work with Medicaid enrollees, physicians can use these toolkits with any of their patients. Physicians and hospitals report they are using the action plans and guidelines in the care of all patients.

Within each network, the medical director convenes the lead physicians of each practice periodically to talk about medical management and discuss performance in meeting clinical targets. As will be discussed later in this report, provider profiling is at the heart of this effort. These meetings are also used to discuss overall health care system concerns. Issues raised at the network level can result in statewide Medicaid policy changes. For instance, the Medicaid program recently announced that providers will be able to bill for time they spend training patients in inhaler and peak-flow techniques. This change in policy was based on feedback from network physicians.

The networks also provide an organizational framework for addressing community-wide public health and health care system issues. Individual networks have developed initiatives focused on bike safety, child-development, ADHD, developmental services and developing clinical pathways and screening for depression and substance abuse. One network has developed an electronic patient medical record while another has a grant to apply care management

approaches to all patients, not just Medicaid enrollees. Networks have also been used to disseminate public health alerts.

The desire for a sustainable approach also motivated New York, which has developed statewide chronic disease initiatives for diabetes and asthma, with a focus on chronic care collaboratives and disseminating evidence-based guidelines and information, rather than traditional disease management. Still, some in the state are pushing for a more formal Medicaid disease management program. A recent Medicaid task-force report called for the development of disease management initiatives, which observers say pharmaceutical companies have been advocating as an alternative to supplemental rebates.

Establishing cost-savings formula is complicated and contentious.

The amount and timing of projected cost-savings is an almost singular focus for states' contract negotiations with disease management companies, especially when fees are at-risk. Negotiations about how to calculate cost-savings are difficult and time-consuming because the two sides must come to agreement on a range of specifics:

- How to define the baseline for measuring the impact of the program
- How to address issues of “regression to the mean” – a phenomenon by which this year’s high cost users will on average experience lower costs in the following year even without an intervention
- Which groups or populations should be excluded from the cost-impact analysis
- What constitutes an appropriate control group
- What measures of cost or savings will be used

Because of difficulties negotiating contracts when fees are at-risk, Florida removed the risk component of its contracts. Meanwhile, the complexity and time required to negotiate guaranteed cost-savings was one factor in Indiana’s ultimate decision to “assemble” rather than “buy” disease management services.

Despite the efforts, the formulas initially developed by states do not anticipate all issues. Washington, for example, belatedly realized it needed to download and transfer three years of data to fully evaluate the impact of its program and adequately control for “regression to the mean.” Cost-savings formulas can also be subjective and not sufficiently explicit, even when negotiated in advance. Because of disagreements over how to apply the cost-savings formulas, one of Florida’s vendors refused to make a refund in excess of \$7 million the state said was due because cost savings goals were not met. The issue is still not resolved.

Most states do not enroll dual eligibles in disease management.

Although dual eligibles – people with both Medicare and Medicaid coverage – represent a large proportion of the adult Medicaid population with chronic illnesses, they are generally not included in states’ disease management programs. That is because most of the cost savings resulting from disease management would benefit Medicare, which pays for acute care services for this population, not Medicaid. Washington reports that not covering duals creates programmatic issues for states, not only at the front end – when these needy enrollees are screened out – but also mid-stream when they are disenrolled from disease management upon becoming eligible for Medicare. This is a substantial issue for people with end-stage renal disease, who convert quickly to Medicare, but is less of a problem for other disease categories. The federal government has agreed to consider developing a mechanism for states to share in these savings, but so far, no plan has been developed. Some states such as Indiana have

decided to extend their disease management programs to duals despite these issues. Colorado has included duals in its disease management programs for diabetes and schizophrenia and has developed a dedicated care management program for duals receiving home and community-based services (involving innovative use of daily patient monitoring using touch-pad phones).

IV. Medicaid Disease Management Programs: Implementation

DM companies use claims data to identify potential enrollees.

Medicaid agencies contract with outside vendors (often the disease management companies) to identify candidates for disease management programs using diagnosis codes and utilization data for inpatient and outpatient care, procedures and use of particular drugs. Enrollees identified by this analysis are then often divided into high- and low-risk groups, usually according to the resource intensity of their care. State officials report that this process can be difficult because the data used in analyses are often not complete or definitive, creating both false positives and false negatives. Laboratory results, for instance, are usually not available through claims data. An initial phone-based enrollee assessment, to confirm both the presence and severity of the chronic condition and to identify potential co-morbid conditions, is part of most disease management programs.

Many states have a two-level intervention, targeting mailed information, call center access or lower-intensity care management to the lower-risk group and providing scheduled calls, home visits or biometric monitoring for the higher risk groups (Figure 7). For example, lower-risk disease management enrollees in Indiana and Washington receive telephonic care management, while those with higher severity are targeted for more intensive care management through local nurse care managers who can make in-person visits.

Figure 7. Example of Two-level Intervention in Medicaid Disease Management Program

Low-intensity disease management (targeted to enrollees with lower risk scores)	High-intensity disease management (targeted to enrollees with higher risk scores)
Telephonic or limited duration care management	Intensive care management
Health education materials	Home visits
Access to call center	Biometric monitoring

Source: Williams, 2004

Data can be a powerful driver for changing physician practice in disease management programs.

Most disease management programs share individual patient information with physicians, but not data on practice patterns. By not including provider profiling in their efforts, some observers argue that disease management interventions are missing a key opportunity to change provider behaviors. North Carolina credits its provider profiling for success to date in improving asthma staging documentation and use of asthma action plans. Chart audits are used to assess provider performance for asthma and diabetes care. The regional provider networks are responsible for sharing and disseminating data about practice patterns for target diseases in their regions, comparing results to protocols established by the program. These results are used to produce profiles of each physician practice showing performance against evidence-based clinical benchmarks. Virginia used a similar approach in its stand-alone program. Physicians were given frequent feedback about the ER use of their patients. The ER use rates

for physicians receiving these data declined 41 percent compared to 23 percent for physicians not receiving these notices.

Commercial disease management approaches need to be adapted for Medicaid.

Disease management strategies need to be adapted for Medicaid enrollees who tend to be more difficult to contact and have a more complex array of problems than the commercially insured population. States have asked disease management companies to devote more resources to identifying and contacting potential enrollees; making multiple contacts and using a mix of mailings and phone calls. States have also asked for a more intensive and local care management approach, especially for enrollees with more complex conditions. Some states require disease management companies to hire nurse care-managers living in the same area as the target population, facilitating visits to physicians and to patients in their homes.

Despite modified disease management design for Medicaid, states are having a hard time reaching potential enrollees. Once contacted, participation in disease management is voluntary, and take-up rates vary.

States do not need federal waivers to implement disease management if they make participation voluntary and statewide. All states in this study have voluntary programs, although some promote participation rates by enrolling people automatically then allowing them to opt out of programs. States using an opt-out approach say that very few participants – perhaps fewer than five percent – choose not to participate once contacted.

A significant stumbling block for all programs is difficulty contacting potential enrollees. Colorado found that only about 50 percent of the potential enrollees are “contactable,” although once people are contacted most (about 75 to 80 percent) want to participate. Factors explaining these low rates of contact include frequent moves by Medicaid enrollees, lack of phones and outdated or incomplete information in state eligibility systems. Missouri also reports that some Medicaid enrollees do not want to participate because they do not want complete information about their health status, prescriptions or health care utilization shared with their primary care provider.

Washington was initially optimistic their program would grow quickly once established, but enrollment has not increased as expected. Several factors explain the slower than expected enrollment increases including a high level of client turnover (enrollees lose Medicaid eligibility or drop out of the program because they become eligible for Medicare) and a large core of hard-to-reach enrollees. To address these issues, the state is looking for ways to get more up-to-date eligibility information and the disease management vendor is making six to seven attempts to contact and enroll each person they identify. Missouri indicates that challenges contacting potential enrollees, as well as effort needed to gain participation of physicians and pharmacists, have produced higher start-up costs than were initially anticipated.

Florida’s enrollment data system did not include phone numbers, so the state worked with the department of social services and the social security administration to obtain phone numbers for potential enrollees. One of the disease management companies, LifeMasters, provided prepaid phone cards or mobile phones to the approximately 20 percent of the participant population lacking phones.¹²

¹² Ben Wheatley. *Medicaid Disease Management: Seeking to Reduce Spending by Promoting Health*. State Coverage Initiatives Issue Brief, August 2001.

Program design can also affect take-up rates. In Missouri, only an estimated five to seven percent of eligibles sign up for the program. Under the Missouri program both enrollees and their doctors must sign up to participate in the program. One reason for the low participation rate is that doctors are unwilling to participate and enrollees do not want to switch doctors. In its initial program, Florida also found that participation rates were relatively low mainly due to difficulty locating clients. Participation varied considerably from six to 58 percent depending on the disease (the state implemented separate initiatives for different diseases). In its current program, once potential enrollees are contacted, opt-out rates are quite low (about three percent). Colorado also found that participation rates varied by disease, with the lowest participation by people with schizophrenia, and higher participation by asthmatic clients than by diabetics. In Missouri, people with asthma and diabetes were more likely to participate than people with depression and heart failure.

Programs rely on nurse care managers.

Nurse care managers are the backbone of most disease management programs. They use computerized tools and “scripts” to complete initial assessments of enrollees, establish goals for each patient based on the results, and conduct periodic follow-up calls. Although early state programs relied on nurse care managers located outside the state, disease management companies are increasingly being asked by states to recruit nurses living in local communities. States see this as especially important for people in the higher cost/need categories, who generally have a more intensive interaction with the care managers. While most interactions are by phone, some programs have experimented with conducting home visits, especially to complete the initial assessment. Understanding the patient’s home environment can help the nurse care manager develop more effective and appropriate strategies to support the patient in making behavior change.

Washington’s disease management RFP indicated to bidders that in-person visits might be required and asked bidders to outline how they would coordinate with other case managers involved in the enrollee’s care and to work with local community organizations and providers. Approximately 10-20 percent of the enrollees in Washington have in-person contacts with the local nurse care managers.

Most disease management programs operate fairly independently of physicians, but some have developed innovative ways to engage providers.

Most disease management programs operate fairly independently of physicians, although they relay critical information about the patient’s health status or adherence to treatment protocols through faxed alerts. Disease management companies are all too aware of the potential resistance from physicians who might view disease management as burdensome or interfering. The focus on patient self-care in disease management programs – and not on changing provider treating or prescribing behavior – reflects emerging concepts of chronic care but is also an attempt to avoid interfering with the patient/provider relationship. Disease management programs operate largely at an arm’s length from providers, underscoring the potential limitations of this approach for addressing underlying health system problems of practice variation, fragmentation of care and lack of evidence-based medicine.

Even when programs are designed to engage physicians they are not always successful. Although some programs had hoped to get a portion of enrollees from provider referrals, few referrals have materialized. North Carolina found that the first wave of participating providers was enthusiastic, but it has been increasingly difficult to attract new providers to the program.

Physicians in states like Washington, already complaining of low reimbursement rates, say that funding used for disease management should have been spent stabilizing reimbursement rates and improving physician participation, rather than creating a new stand-alone program. Low physician participation in Medicaid could ultimately have a dampening effect on disease management programs if enrollees are unable to find a stable medical home.

Financial incentives have been proposed as one technique to engage physicians. New disease management models under development for the commercially insured population mirror managed care in offering providers incentives in the form of a percentage of savings achieved or preference in auto-assignment. None of the states in this study had these mechanisms in place, although North Carolina is exploring using such incentives.

A few states have developed alternative approaches to engaging physicians. One of Colorado's pilot programs, implemented by National Jewish Medical Center, sends primary care physicians a summary of every client contact by fax. Meanwhile, Indiana has spent considerable time thinking about how best to involve the primary care physicians in the disease management process. Care managers for the higher-severity enrollees in Indiana visit the primary care provider before contacting the enrollee, seeking recommendations on priority areas for patient self-care improvements. Care managers then try to coordinate at least one of their follow-up sessions to coincide with a doctor's appointment, giving the enrollee, primary care provider and care manager a chance to meet face-to-face. Physicians are provided with patient tool kits, flow sheets and consensus protocols, which they are free to use with any of their patients. In addition, Indiana sees its internet-based patient record as a key way to involve providers in the disease management process. The electronic medical record and information system will be a repository for claims information, health assessment information, individualized care plans and some other patient information.

In Washington, McKesson is trying to support and not duplicate providers' own care management efforts. McKesson hired a local physician with extensive experience working on chronic care initiatives in the state to work closely with providers serving a large share of chronically ill Medicaid enrollees – mostly community health clinics and other safety net providers. He meets with provider groups to identify the initiatives, protocols and infrastructure they already have in place to address chronic care needs and to review the status of their chronically ill Medicaid patients. McKesson then develops a customized set of approaches and interventions building on the providers' existing assets and quality goals. These might include developing a patient registry for the provider using the medical and pharmacy claims data McKesson uses to identify disease management participants. A single case manager is identified to work with the provider and the provider's patients, streamlining communication and decision-making. One of the original disease management vendors in Florida, *Positive Healthcare*, similarly hired a full-time medical director to work with physicians throughout the state.

The Missouri legislature asked the state to develop a program targeting pharmaceutical spending. The state rejected a nurse care manager approach because this model made no one person or team accountable for the patient and for coordinating care. The state developed a program based on a partnership of the primary care provider and the pharmacists, who develop individualized care plans focusing on drug treatment and behavior change for chronically ill enrollees.

The state currently has about 130 trained provider and pharmacist teams who meet with each other and face-to-face with enrollees to develop and implement care plans. Lacking capitated

managed care in the Medicaid program, the state has considered building on this base by giving providers a monthly payment in return for serving as enrollees' medical home – much in the same way that PCCM programs operate. However, program leaders note that physicians may not want to take on these additional responsibilities given low reimbursement rates in Medicaid.

V. Medicaid Managed Care: Approaches to Chronic Care

Only a few states enroll the SSI population (who probably represent most Medicaid adults with chronic conditions) in capitated managed care.

States report that most – although certainly not all – adults with chronic illnesses qualify for Medicaid because they are disabled and part of the SSI eligibility group. Only a handful of states (Arizona, Maryland, New Mexico, Oregon, South Dakota and Tennessee) enroll more than three quarters of beneficiaries with disabilities in managed care.¹³

Some states have either not implemented or have retreated from managed care for the SSI population because of health plan withdrawals or difficulties enrolling this more care-intensive population. Oregon launched a substantial enrollment effort six or seven years ago when five plans were enrolling the SSI population. Since then, all but one plan has withdrawn.

States enrolling the SSI population in managed care have devoted considerable resources to developing risk-adjustment for plan payments so that plans are not penalized for attracting sicker enrollees. One Maryland plan developed specialized services for enrollees with HIV/AIDS – which would not likely have occurred if plans felt they would be penalized for attracting higher need enrollees – demonstrating the success of the risk adjustment efforts.

Chronic care management is not a focus of most states' managed care contracting – but states are interested in learning and doing more.

States say they have not required their managed care organizations (MCOs) to develop tailored approaches to manage the care of their chronically ill enrollees, although, as discussed below, many plans have done so as part of their overall care management strategies. Some states are beginning to ask what more they should or could be doing to ensure that managed care enrollees with chronic illnesses are appropriately managed. In an effort to learn more about MCO activities and determine if contracting requirements should be more specific, New York is conducting a survey of what MCOs are doing in case management, asking how they target and identify enrollees. With a grant from the CDC, New York has also convened health plans to develop a state-wide treatment guideline for asthma that could be used by all plans. The state is now implementing these guidelines.

Many states ask Medicaid managed care plans to report HEDIS measures to track quality of care in Medicaid managed care plans. The HEDIS measurement set includes several measures related to managing chronic illness:

- Comprehensive diabetes care
- Appropriate medications for people with asthma
- Controlling high blood pressure
- Cholesterol management after acute cardiovascular events
- Follow-up after hospitalization for mental illness

¹³ Center for Health Care Strategies. *Adults with Disabilities in Medi-Cal Managed Care: Lessons from other States*. September 2003.

- Antidepressant medication management

New York uses five of these HEDIS measures, tracking both plan performance and overall trends for enrollees in managed care. Among its Medicaid managed care enrollees, New York found that about 40 percent with asthma did not have appropriate medication of their disease and about 50 percent of diabetics had poor control of their Hemaglobin A1c. The state has shown an improving trend for both conditions.

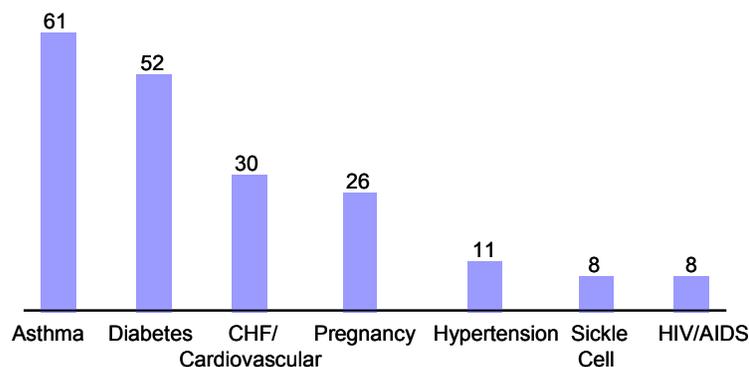
Maryland tracks quality of diabetes care using HEDIS measures and has also developed an approach to provide financial incentives and disincentives to plans based on their quality performance on eight measures, including one chronic care measure – eye exams for diabetics. The incentive and disincentive approach was put on hold before any were paid, however, after the legislature redirected resources that were set aside to pay for the incentives.

While most states do not focus on chronic care management in their managed care requirements or negotiations with plans, some states report that chronically ill enrollees get better care from MCOs than from fee-for-service Medicaid because care is better coordinated and the financial incentives facing plans encourage them to keep chronically ill members healthy.

Medicaid managed care organizations also use disease management.

Participating MCOs generally have disease management programs of some sort – usually involving management of conditions such as pediatric asthma, high-risk pregnancies and diabetes (figure 8).¹⁴

Figure 8. Percent of Medicaid Managed Care Plans Enrolling SSI Population Who Report Having Disease Management Programs, by Disease, 2000



Source: Tobias, 2000

States know MCOs have disease management programs in place, but do not know much about these initiatives including their disease focus, number of enrollees or impact. The elements of MCO disease management programs are quite similar to programs run by states on a stand-

¹⁴ Figure based on Carol Tobias, et al. *How Health Plans Identify and Serve Medicaid Special Needs Populations*. Health and Disability Working Group, Boston University School of Public Health, 2000.

alone basis, and some MCOs contract with disease management vendors, in the same way that states do, to provide these services. Managed care organizations develop and operate these initiatives on their own as part of their overall care management approach, often pairing them with intensive case management for very high-cost enrollees.

VI. Outcomes

States report that initial results of stand-alone disease management programs are promising, but by no means conclusive.

Disease management programs are expected to decrease inpatient and ER costs, increase pharmacy costs, and produce a net decline in total costs. Health outcomes – or at least measures of appropriate care – are expected to improve as both patients and providers follow evidence-based practice. Both cost-savings and health-outcome figures have been released by some disease management vendors and states (Figure 9). Most states consider the evidence promising but preliminary. Some states, including Indiana and Washington, are planning rigorous external evaluations but the results will not be available for a year or two.

Figure 9. Preliminary Outcomes of State Disease Management Programs

	Savings	Health Outcomes
Asthma	<p>Colorado: Costs for participants declined by 37.4 percent. Costs for control group declined by 23.8 percent in the same period.</p> <p>North Carolina: Average cost of an asthma episode was 24 percent lower for children in disease management. Rate of pediatric hospitalization for asthma and ER use was 8.2 and 242 (per 1,000 member months) respectively for non-participating providers compared to 5.2 and 158 respectively for participating providers.</p> <p>Florida: Reductions in inpatient stays (2 percent), ER use (3 percent) and office visits (1 percent).</p> <p>Virginia: Projected \$3 to \$4 savings for every dollar on disease management support.</p> <p>Washington: \$250,000 in first year of the program*</p>	<p>North Carolina: Proportion of enrollees with documentation of staging increased from 47 to 63 percent.</p> <p>Proportion of enrollees (with II-IV staging) on inhaled corticosteroids increased from 49 to 95 percent.</p> <p>Washington: Percentage of asthma clients receiving flu shots increased from 45 to 65 percent. Percentage of clients with an action plan increased from 12 to 24 percent. Percentage of clients with daily preventative medications increased from 63 to 80 percent. Percentage of clients who are not a current smoker increased from 61 to 70 percent.</p>
Diabetes	<p>Washington: \$900,000 for first year of the program*</p>	<p>Nationally: Based on a systemic review of 27 studies, the Guide to Community Preventive Services strongly recommends disease management for improving diabetes care – findings apply to community clinics or managed care.</p> <p>North Carolina: Six out of eight process measures improved.</p> <p>Washington: Percentage of diabetics taking daily aspirin or anti-platelets increased from 41 to 64 percent. Testing rate for HbA1c increased from 40 to 59 percent. Percent of clients with a lipid profile increased from 72 to 88 percent. Percentage with a flu vaccine increased from 51 to 69 percent.</p>
CHF	<p>Washington: \$375,000 for first year of the program*</p>	<p>Washington: Percentage of CHF clients weighing themselves daily increased from 32 percent to 64 percent. Percentage using an ACE inhibitor increased from 60 to 72 percent. Percentage with a flu vaccine increased from 51 to 66 percent.</p>
Other	<p>Washington: \$680,000 for ESRD*</p> <p>Florida: Guaranteed savings of \$18 million for FY 2002</p>	

*First-year savings (totaling more than \$2 million) are guaranteed by contract.

Source: Author's analysis of state reports and documents

It is not possible to reach a definitive conclusion about the impact of disease management programs based on available preliminary data largely because studies did not have the necessary rigor and some of the results are incomplete. Many analyses do not include or use inadequate control groups, making interpretation of the results difficult. Some analyses net out the operating costs of the program, while others do not. A few analyses track changes in certain cost classes, without examining total costs. Finally, some states have released “cost-savings” which do not reflect changes in health care costs, but are simply a report of guaranteed savings established in vendor contracts.

A Colorado asthma study illustrates the importance of comparing study results to results for an appropriate control group. The study population showed a promising decline in total costs of 37 percent (net of program costs). However, total costs for the control group also declined 24 percent, even without an intervention. This parallel improvement is likely due to regression to the mean – the tendency of people with high health care spending one year to have lower costs the next. The Colorado study also illustrates the difficulty of defining a comparable control group without randomization. In order to select a group that was comparable in health care spending and acuity, the program composed the control group of people who were eligible for the program but either declined to participate or could not be reached. However, the factors that might have made these people less likely to participate – rural location, transience, low-income – are also associated with the factors the study was trying to evaluate: health behavior and utilization.

Many observers predict that actual cost savings will fall below the ambitious savings goals set by some states. Florida’s initial program, for instance, was expected to save \$112.7 million in four years (1997-2001) by providing disease management for nine diseases. A review by the Office of Program Policy Analysis and Government Accountability found that the initiative had cost the state \$24.1 million, and it was not clear it had saved any money.

VI. Conclusions

Disease management programs can help enrollees navigate the health care system and obtain the preventive care they need.

Disease management programs are generally seen as a relatively low-cost way to improve health care for people with chronic health problems. They should not be seen as a cure-all, however, as most initiatives do not address the underlying delivery system issues which lower quality and sometimes raise costs for people with chronic conditions.

High enrollee turnover and low payment rates hamper the potential scope and impact of chronic disease initiatives.

Developing and maintaining enrollee and provider participation has been challenging for states due to enrollee turnover – in part due to eligibility rules – and provider dissatisfaction because of low payment rates. Both these issues will dampen the success of Medicaid disease management initiatives. Without consistent eligibility and stable relationships with physicians, chronically ill enrollees cannot hope to benefit from states’ chronic disease efforts. With these elements in place, states may be able to pursue more creative strategies. Officials in North Carolina believe that strong support from the medical community – buoyed by adequate payment rates – permitted the development of an innovative provider-based strategy. States lacking this strong and supportive provider base will not be able to pursue a similar approach.

New disease management programs are tailored to the needs of Medicaid programs and their enrollees. Still, programs are limited by excluding duals and people with mental health problems.

Vendors and states have developed new disease management models that invest more in outreach to potential enrollees, are more integrated (offering programs for multiple chronic conditions), and provide more intensive services for higher-need enrollees. However, because programs are still “siloed,” they may not address the complex and multi-faceted needs of people with chronic conditions. In addition, dual eligibles and people with mental health problems are often excluded, limiting the potential impact of the programs.

If carefully designed, disease management programs can help address underlying health system issues affecting the chronically ill.

While some states have made genuine efforts to promote health system reforms through disease management, most have not focused on this objective, instead concentrating on improving patient skills to manage their own care. These skills are needed, but states are potentially missing a chance to address underlying problems of poor coordination and communication, lack of quality improvement infrastructure and the lack of attention to helping people avoid rather than treat chronic diseases.

Clearly, these issues are larger than the Medicaid program, and cost savings, not fundamental health system reforms, were the objective of most states as they launched disease management programs. However, disease management can help to address these deeper issues and some states have seized this opportunity. As shown by the examples of Indiana and Washington, states can work towards these objectives even if they outsource all or large parts of their program, but doing so will require broad thinking, hard work and creativity.

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APPENDIX ONE DESCRIPTIONS OF SELECT STATE DISEASE MANAGEMENT PROGRAMS

States	Year Started	Diseases	Legislative Mandate	Financial Arrangements	Vendor	Program Model	Evaluation
Colorado	2002	Asthma Breast and cervical cancer Chronic obstructive pulmonary disease (COPD) Diabetes Neonatal intensive care Schizophrenia	Legislature mandated the development of disease management program	Fully funded by pharmaceutical companies: Pfizer, Abbott, Eli Lilly Astra Zeneca, Novartis, GlaxoSmithKline, Johnson and Johnson (Eli Lilly contributed more than half of total amount)	Specialty Disease Management: clients with schizophrenia and medical comorbidities McKesson: high-cost case management Asthma: National Jewish Medical Center	<ul style="list-style-type: none"> Pilot program is not state-wide ROI calculation will include vendor costs, client satisfaction, quality of life status and physician satisfaction Care Management Organization: Telephonic triage and health counseling (for all disease management) Schizophrenia and medical comorbidities: Colorado based nurse care managers make home counseling initial visit followed by telephonic management. Have formed self-help groups. Clients have access to 24/7 call center (clients with claims from \$2,400 to \$102,000) Diabetes: (over \$500/year) Asthma: Baseline assessment, care plan, telephonic counseling, fax summaries to providers, 24/7 call center. Three proactive phone calls over six-month treatment period. (\$500 to \$35,000 a year) 	<ul style="list-style-type: none"> Outside evaluation by University Health Sciences Center (diabetes and schizophrenia) Baseline and post intervention health and functional status measurement (SF12 and SF36)
Florida	1999	Asthma Congestive heart failure Diabetes Hypertension	Legislature mandated development of disease management program Medicaid budget reduced each year in anticipation of savings	Guaranteed savings and investments of \$40.5 million for 2003-2005 Pfizer funds the efforts	McKesson for call center and hospital systems for care management	<ul style="list-style-type: none"> Informational mailing and access to call center for all enrollees identified as having disease Pfizer contracts with 10-hospital system to manage higher risk enrollees with intensive case management (about 12 percent of total) provided by 50 care managers. After an initial assessment, the care managers develop a care plan 	<ul style="list-style-type: none"> Results have been released – but not a rigorous evaluation Evaluation by Medical Scientists

States	Year Started	Diseases	Legislative Mandate	Financial Arrangements	Vendor	Program Model	Evaluation
Indiana	2003	Asthma (not yet launched when interviews conducted) Diabetes Congestive heart failure <i>Other diseases will be introduced later</i>	Indiana has a legislative mandate to develop disease management program for asthma, diabetes, CHF, stroke, hypertension and HIV/AIDS. The legislature did not establish a cost-savings mandate	Paid on a fee basis.	Americhoice: call-center Indiana Minority Healthcare Coalition: high-severity nurse care-management Indiana Primary Care Association: high-severity nurse care-management	<ul style="list-style-type: none"> Enrollees divided into low- and high-severity. Initial assessment completed for everyone. The program includes a home-based assessment for the higher-risk enrollees. Low-severity have access to call center and quarterly follow-up. High-risk work for 4-6 months with case manager to identify specific self-care goals. These enrollees transition back to call-center at end of 4-6 month period. Indiana is also implementing several chronic care collaboratives throughout the state. 	Regenstrief Institute will evaluate – will include randomized controlled clinical study in one county including medical record review
Missouri	2002	Asthma Depression Diabetes Heart failure		Both PCPs and pharmacists can bill for disease management: <ul style="list-style-type: none"> \$75 per individual assessment \$35 for problem follow-up or new problem assessment \$25 for follow up assessment Heritage is paid based on the number enrolled	Heritage	<ul style="list-style-type: none"> Program for fee-for-service enrollees. Patients identified using enrollee risk index. Enrollees with low- or very high-risk are not eligible. Heritage completes the risk assessment. The program “backward recruits” providers to match patients in program. PCPs and pharmacists (provider team) must complete training. Patients can only get target-disease related care from assigned PCP/Pharmacist team. Provider team completes an initial assessment and develops an individualized care plan and completes a six-month assessment. This is presented in a face-to face meeting with enrollee. Patients are asked to bring in all medications for each visit. Outcomes include drug utilization changes, changes in drug related problems, changes in medical utilization, provider/patient satisfaction. 	

States	Year Started	Diseases	Legislative Mandate	Financial Arrangements	Vendor	Program Model	Evaluation
North Carolina	1998	Asthma Diabetes	Legislature cut the budget by \$29 million based on early cost-saving results	Participating providers and networks each get \$2.50 per month for each enrollee	12 community networks of PCCM doctors and other providers (over 2,000 physicians)	Regional networks of PCCM physicians are paid by the state to hire care managers and work together to address target chronic conditions. Provider profiling is a cornerstone of the effort.	
Oregon	2002	Diabetes Asthma Heart Failure		McKesson is paid on a population basis for the interventions	McKesson	Education and assessment by phone with nurse managers Case managers work with individual patients (120 patients each)	
Washington	2002	Asthma Diabetes Congestive heart failure End-stage renal disease	Legislative mandate to develop program and save \$600 thousand in two years (5% of total costs).	Fees are \$30 per month based on population identified for asthma, diabetes and CHF and \$300 per month for ESRD. Fees are 100 percent at risk – 20 percent for quality and 80 percent for cost (for asthma, diabetes and asthma based on decreased costs of 5 percent, for ESRD based on decreased utilization of 1.5-2 percent)	McKesson For asthma, diabetes and CHF Renaissance For ESRD	McKesson: Telephone case-management for asthma, diabetes and CHF <ul style="list-style-type: none"> Initial phone contact and assessment Follow-up based on client's risk status. About 10 percent receive home visits Send initial packet and alerts to physicians Patient care protocols built into communication with client Opt-out for enrollees Renaissance: In-person case management for ESRD	University of Washington will evaluate

Disease Management Design

- What are the overall characteristics of Medicaid enrollees with chronic conditions?
 - Are they generally in fee-for-service Medicaid, PCCM or managed care?
 - What distribution across eligibility groups?
 - Are they concentrated in particular providers/MCO's?
 - How expensive are they and how does cost compare to other enrollees?
 - What are most expensive/prevalent conditions?
 - What services do they use most intensively?
 - What are their enrollment patterns?
 - How are they different from other Medicaid enrollees?

- Have you had recent changes or cuts in the Medicaid program affecting enrollees with chronic illness?
 - Benefits
 - Eligibility
 - Cost-sharing
 - Changes in managed care program
 - Pharmaceuticals (restrict number, PDL, etc.)

- What opportunities do you see in developing specialized approaches to serve these populations? What are the risks and challenges?
 - How address duals?
 - Interest from legislature?
 - Able to make investments given current budget environment?

- What are the considerations and tradeoffs for focusing on particular diseases vs. high cost populations in general?
- Does your program focus on chronic disease prevention or at-risk populations?
- What are your state efforts to:
 - Identify and track users with chronic conditions
 - Manage care or reduce costs for these enrollees (probe for the various approaches)
 - Measure the impact of these efforts

- Which groups or populations have been the focus of your efforts? Why were these groups selected?
- What was the impetus and motivation for these initiatives? What are the goals? What is the degree of focus on cost vs. quality?
- How did you decide whether to build programs internally, contract with DM companies or integrate into managed care contracting?
 - If build, what services did you purchase or assemble to support program?
 - If buy, how approach procurement?
 - If MCO's, do you enroll ABD population and do you risk-adjust payments?

- What partnerships have you developed to design or implement these initiatives (with providers, MCOs, DM companies, PBMs, consumer groups, etc.)
- Did you need to get waivers from CMS to implement these programs?
- What have been the operational and implementation experiences of these efforts? Lessons learned?
- What impact have you seen on cost, access and quality?
- What are your plans for the future?
- What are the lessons for other states? For Medicare?

Disease Management Implementation

- Please describe the basic structure and design of your initiatives. Why did you select these approaches? What are your successes, issues and challenges?
 - Identification and enrollment process (is enrollment automatic?)
 - Involvement of physicians, case managers, patients, pharmacists
 - Financial relationships
 - Data and information systems
 - Monitoring, communication and feedback
 - Incentives
- What changes or improvements are you focusing on? Does your initiative mostly target provider or patient behavior? Why did you select this approach? What are your successes, issues and challenges?
 - Physician performance
 - Patient self-care
 - Communication and coordination
 - Prescribing patterns
- Please describe roles of different partners. Why was this structure selected? What are your successes, issues and challenges?
- Did existing disease management approaches/products meet your needs?
- If you use case managers, how do they communicate and interact with enrollees and physicians?
 - Face to face
 - Telephone
 - Electronic devices
- What are the financial structures and arrangements in your programs? Why were these structures selected? Issues and challenges?
 - Savings guarantees
 - Fees at risk
 - Provider incentives
 - “Private” funding from pharmaceutical companies
- What costs and investments did you have to start and run the program?
- What have been your experiences and lessons learned with the following approaches and interventions?
 - Call centers
 - Case management
 - Reminders and alerts
 - Protocols and clinical guidelines
 - Physician feedback

- Predictive modeling
- Electronic communication
- How do chronic disease programs dovetail with other health care services for chronically ill enrollees?
 - What is interaction and engagement with primary care and specialty providers treating these patients?
 - Were physicians involved in establishing initiative?
 - What is the involvement of enrollees?
 - How do you address needs of enrollees with multiple conditions?
- How have stakeholders reacted?
 - Providers
 - Patients
 - Advocacy groups
- Have you adapted the approach to meet the needs of the Medicaid population?
 - Literacy and health literacy
 - Frequent moves or lack of phone
 - Care seeking patterns
 - Cultural competence
- What have been the operational and implementation experiences of your efforts? Lessons learned? Changes you would like to make?
- What successes have you had? Challenges?
- What are your savings and quality goals?
 - Basis for savings goals?
 - Time horizon for savings goals?
- What is the impact of your programs on costs, access or quality? How do you measure ROI? Any external evaluation?
 - Look at total costs or just certain costs?
 - Include costs to run program?
 - How define baseline?
 - How track results?
 - Address regression to the mean?
 - What are quality measures?
 - Patient satisfaction?
- What are your plans for the future?
- What are the lessons learned?

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