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RESOURCE PAPER

Disease Management for Chronic Behavioral Health and Substance Use Disorders

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Executive Summary

Public sector purchasers have begun to turn their attention toward the potential benefits of disease management programs for chronic mental health and substance use disorders. As is characteristic of a developing field, definitions of disease management are in flux. Nevertheless, a common understanding of some of the key characteristics and the distinctions between the newer approach of disease management and the more traditional approaches of case/care management is emerging. In this evolving field, purchasers need to be extremely clear about the precise models of care that they want to purchase and to carefully and properly qualify prospective vendors. Although the industry trade association and others have developed the capability to accredit disease management vendors, accreditation may not yet be reliable.

Disease management in the area of mental health and substance abuse shares many features with other evidence-based practices, such as Assertive Community Treatment and the Texas Medication Algorithm Project, as well as others included by SAMHSA in its National Registry of Effective Prevention and Treatment Programs.

Three trends are converging to increase the interest in disease management programs today:

1. Health care costs per patient are especially high for individuals with chronic disease; the overall number of individuals with chronic disease in the population is increasing; and thus the proportion of health care costs attributable to individuals with chronic disease is high; and
2. There is a significant gap between the existence of evidence-based practices in the treatment of individuals with mental health and substance abuse disorders and the actual deployment of these practices in the field; and
3. High quality care for these individuals with chronic disorders requires extensive coordination among a variety of entities, not all of them traditional medical care system participants.

Despite the promise and evident logic of disease management, its effectiveness in behavioral health has not yet been fully established. Nevertheless, several States have implemented disease management programs or pilots for behavioral health services. The experiences of the most significant of these programs are reviewed briefly in this Resource Paper to draw out implementation issues, lessons and implications.

Introduction

This report discusses disease management (DM) for chronic mental health and substance use disorders, offering a brief review of the current state of the art, with a particular focus on policy issues of concern to major stakeholders in the public sector. It begins by defining the disease management concept, explaining the opportunity it may offer for providers, consumers and public purchasers of care, and then distinguishes disease management from case management and from other tools that also utilize emerging evidence-based practices.

A brief review of the literature is followed by a description of the current state of development across this rapidly growing industry, which began to deal with mental and substance use disorders by focusing on depression. The next step is a summary of a series of interviews conducted over a two-year period with key stakeholders in the field, including purchasers, consumers and industry spokespersons, to identify the latest state disease management initiatives in chronic mental health and substance abuse management. The state section addresses the programs' impact to date on state and other public purchasers, on providers of existing services, and on consumers, including some of the lessons learned from disease management efforts. It concludes by presenting a set of recommendations for public purchasers and other stakeholders.

Disease Management for Mental and Substance Use Disorders

Serious mental illnesses and substance use disorders are chronic conditions and share many characteristics with chronic physical ailments. Most notably, there are specific therapies (both pharmacological and clinical) that are known to improve outcomes for specific mental illnesses and addictions; they often require coordination among numerous specialists; and their treatment tends to require extensive involvement in that care by the client or "patient" if that care is to be effective. As with physical chronic disease, the usual goal of treatment for many with these disorders is recovery - maintenance or improvement of quality of life and level of functioning. A chronic disease framework, focused on evidence based practice and consumer education with careful attention to medication management and self-care can be enormously beneficial for mental health and substance use disorders.

In an unpublished paper completed in June 2003 that is one of the bases for this inquiry, Gelber *et al.* reviewed the state of the art with regard to disease management programs for Medicaid clients with serious mental illness and/or addiction. They observed that, even very early in the development of the disease management approach, "disease management may represent a new frontier or be combined with Medicaid managed behavioral health programs or Medicaid managed care initiatives in physical health."¹ Sandra Foote, Director of the Health Insurance Reform Project at George Washington University, told *Psychiatric News* in September 2003 that there is a significant opportunity for effective management of chronic mental illnesses. This paper seeks to more broadly disseminate and update for public purchasers and other stakeholders the information obtained in the Gelber *et al* 2003 paper. We find that the field of

¹ S. Gelber, D. Rinaldo and J. Bartlett, "Disease Management Programs for Medicaid Clients with Mental Illness," June 2003, The Avisa Group.

DM has continued to grow. New programs have been offered by a number of vendors and by some States, particularly in depression and schizophrenia. Unfortunately little has occurred in disease management for serious substance use disorders though this is still developing. There is increasing attention being paid to disease management approaches in the public sector, propelled by CMS and SAMHSA's interest in this subject. This could have very positive implications for the quality of care for chronic mental and substance use disorders that the New Freedom Commission, the Surgeon General's Report, the Institute of Medicine, public and private health purchasers and the growing consumer movement continue to demand.

Definitional Issues

DMAA Definition of Disease Management

As is often the case in a developing field, definitions of disease management are in flux. According to the industry's trade association, the Disease Management Association of America (DMAA), established in March 1999, "Disease Management is a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant"². The trade organization's Web site states that a true disease management program includes all of the following components:

- 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, and practice profiling).

The DMAA definition is the definition of DM that the three disease management accrediting entities (NCQA, URAC and JCAHO) use to identify and to accredit DMO programs. However, it is clear that other definitions of disease management are also in use and that many programs that have some but not all of these components, also call themselves disease management programs.

CMS Definition of Disease Management – Medicare and Medicaid

Explicit encouragement by CMS of small disease management pilots and associated state Medicaid waivers has given increased momentum to the highly competitive private DM industry, an industry inaugurated by pharmaceutical companies in the 1990's as a way to increase medication compliance and utilization by patients and providers. However, to date much of the CMS emphasis is on physical health. On the CMS website, there is not yet a mention of chronic mental or substance use disorder disease management, even as a secondary diagnosis, despite concerns expressed by health economists such as Sandra Foote of CMS³.

² <http://www.dmaa.org/definition.html> (accessed June 21, 2004)

³ See, for example, Sandra Foote's article on disease management including mental illness posted at www.healthaffairs.org/WebExclusives/Foote_Excel_073003.

According to CMS, "Disease management is a set of interventions designed to improve the health of individuals by working more directly with them and their physicians on their treatment plans regarding diet, adherence to medicine schedules and other self-management techniques"⁴. This definition focuses on provider and patient education, medication adherence/scheduling and patient self-management. In its emphasis on diet/nutrition as well as other self-management techniques, it suggests a focus on traditional chronic physical illnesses, such as diabetes and congestive heart failure, as opposed to mental health or addictions, where diet may be an issue but it is considerably less prominent than the other clinical management issues CMS mentions.

The CMS definition is much more limited than the DMAA definition, and this has added to some confusion in the field. Disease management activities should encompass both medical conditions and chronic mental health and substance abuse conditions. In focusing primarily on patient self-management, CMS has not included the care coordination, practice guidelines and quality management components that are so central to the DMAA guidelines. However, even in defining disease management more narrowly, CMS has signaled the states, industry and provider communities that costs associated with patient education, medication scheduling and training in self-management are potentially eligible for Federal match dollars in Medicaid.

Medicare

The Centers for Medicare and Medicaid Services (CMS), made a major national policy statement when it included disease management in the set of changes incorporated in its recent Medicare reform provisions (Medicare Modernization Act of 2003, MMA). It has approved two new programs – the Voluntary Chronic Care Improvement Program and the Care Management Performance Pilot Program, to examine the potential of disease management techniques.

The Chronic Care Improvement (CCI) Program is the first large-scale chronic care improvement initiative under the Medicare fee-for-service program and it is restricted currently to three chronic physical illnesses, offering self-care guidance and support to chronically ill beneficiaries who have Congestive Heart Failure (CHF), Complex Diabetes, or Chronic Obstructive Pulmonary Disease (COPD). The chosen organizations will help Medicare beneficiaries who participate in the pilots to manage their health, adhere to their physicians' plans of care, and assure that they seek or obtain the medical care they need to reduce their health risks.⁵ Health insurers, disease management organizations (DMOs), physician group practices, integrated delivery systems, and consortia of these entities or other legal entities are eligible to apply to become CCI DM organizations. In Phase I, the pilot phase, there will be approximately ten regional CCI programs, collectively serving approximately 150,000 - 300,000 chronically ill Medicare beneficiaries. The Phase I programs operate for three years and will be evaluated through randomized controlled trials.

Phase I of the Medicare CCI program does not include any behavioral health disorders. Thus, while its evaluation will ultimately provide evidence of the efficacy of disease management for physical illnesses, it will not necessarily help to determine whether this approach is a useful one for vulnerable individuals with chronic mental and/or substance use disorders.

⁴ <http://www.cms.hhs.gov/media/press/release.asp?Counter=967>, accessed 7/28/04

⁵ <http://www.cms.hhs.gov/medicarereform/ccip>, accessed June 22, 2004.

Medicaid

CMS sent the States a letter in February 2004 about the Medicaid program, suggesting several disease management models States could adopt that CMS feels could qualify for Federal matching funds.

States were informed that DM is an initiative focused on nutrition, medication regimens and other patient “self-management” techniques in which the patients can be trained by providers or their staff. No mention was made of other specific tools of disease management, such as physician alerts, periodic patient-status reports, personalized feedback on self-care, registered nurse outreach, access to 24-hour call centers, or educational materials in many media and languages. Similarly no mention was made to the different types of providers of disease management programs, including health plans, managed behavioral health firms, pharmaceutical companies, pharmacy benefit management firms (PBMs), pharmacists themselves, or software or health care information and technology firms that may provide program components or simply care monitoring software. Finally, the CMS guidance to the states did not mention chronic mental illnesses or addictions, consumer/peer self-help groups or recovery management components, since the current model is one of physical health, not behavioral health.

States that are interested in developing Medicaid disease management programs acceptable to CMS can do so either under a new or existing Medicaid waiver or a State Plan Amendment. States can contract with a DMO that would manage the overall care of the beneficiary, paying the DMO a capped amount per capita, or they can establish a primary care case management program, working with primary care providers to deliver care to enrollees with chronic conditions. Individual providers (physicians, pharmacists or dieticians) are permitted to contract with States to provide disease management services. However, Medicaid managed care members who voluntarily join a DMO plan will be covered by the existing managed care “lock-in” provisions, according to CMS.

Disease Management vs. Case Management

In the industry and in the many programs that are emerging, Disease Management initiatives share many characteristics with earlier case management programs. However, a prototypical disease management program that meets the DMAA definition uses evidence-based treatment guidelines and reliance on protocols and standards that have not typically been incorporated in the older case/care management programs traditionally sold by managed care companies and some payors.

In order for state purchasers to be sure what it is they are paying for, the table below summarizes the key distinctions between the two approaches as of this point in time (2004):

Program Area	Case/Care Management	Disease Management
Patient Population	Numerous individuals at high risk for costly medical events and adverse outcomes	Individuals diagnosed with a specific disorder or set of disorders that typically respond positively to evidence-based treatment
Patient Education	Individualized and somewhat limited	Curricula and materials standardized for a specific disorder or target population; Materials are generally disseminated to all enrollees and available through the internet.
Reliance on Evidence-Based Treatment Guidelines	Limited and generally restricted to “level of care” or similar criteria	High
Reliance on Protocols and Standardization	Generally focused on utilization management or treatment planning	High
Provider Education	Not generally provided	Standardized curricula and materials for a specific disorder shared with providers and their patients
Outcomes	Limited, cost-based “outcomes” measurement; key objective is to reduce adverse outcomes, manage costs and generate savings	Management geared to specific desired outcomes, less emphasis on immediate cost reduction and more on longer term care management and quality improvement, as well as longer term savings
Reporting and Feedback Loop	Not a typical component	Includes communication with patients, providers and sometimes purchasers and practice profiling against accepted published protocols

Unfortunately, from the purchaser’s perspective, the distinction between the two approaches often blurs as vendors of these two types of services respond entrepreneurially to increasing market demand and to the scientific community’s increasing knowledge of the more effective care processes. During the course of this study, we identified a number of vendors who asserted that their companies were providing disease management programs for chronic mental or

physical disorders, when, in fact, they were providing case management services or they offered only a few components of disease management such as pharmacy management or provider management, both of which have been components of managed care programs in the past. Unbundling, repackaging and upward pricing of these older services as disease management services is a reality with which purchasers may have to contend. Purchasers need to be clear about precise models they want to purchase and careful to search out and properly qualify disease management programs.

Disease Management: An Evolving Field

There has been a recent and rapid emergence of a variety of disease management organizations and “products.” As with many emerging markets, the field is evolving and this is particularly true with disease management approaches to behavioral health care. There is no trademark on the term “disease management” and the many different types of vendors providing services under the rubric of disease management have developed a large variety of programs and services that they have chosen to call disease management programs.

Early efforts in disease management have frequently focused on depression⁵ due to the scope of the problem and the expenditures on depression. One major component of most behavioral health Disease Management programs is the pharmacy benefit for the specific condition(s) being managed. As a result, these programs have captured the interest of public sector purchasers looking to improve the quality and breadth of pharmacy compliance and to manage rapidly rising pharmacy costs – especially medications for mental illnesses or addictions covered by Medicaid.

Not only is the DM “movement” still evolving, with numerous variations being offered by different types of vendors, even programs that do include all six of the DMAA components tend to differ substantially from one another in terms of the relative emphasis they place on any one of them for a particular purchaser, be it a health plan or a State Medicaid program. Nevertheless, the DMAA’s definition, in conjunction with that of CMS, offers a useful starting point for a discussion of the issues.

Accreditation May Not Yet Be Reliable

While the major accrediting organizations do have the capacity to accredit vendors of disease management programs, few mental or substance use disorder disease management programs exist as yet, much less have the seal of accreditation that many public entities seek to protect themselves and their vulnerable clientele. For example, on its Web site⁶, the Joint Commission on Accreditation of Healthcare Organizations lists many organizations accredited to provide what it calls “Disease-Specific Care,” but virtually none of those organizations includes any behavioral conditions among the diseases for which they are certified. Similarly, NCQA offers disease management accreditation, and on its site⁷ lists its accredited organizations and their programs; of the 29 organizations named, only two offer programs in behavioral health, and both are for depression only. URAC names 14 companies that have been accredited to offer disease management programs, but does not specify their program areas.

⁶ <http://www.jcaho.org/dscc/dsc/dsc.htm>, accessed 7/28/04

⁷ www.ncqa.org/programs/accreditation/DM/dmaccrstatus.htm, accessed 7/28/04

In sum, disease management for chronic mental health or substance abuse conditions is a fluid and emerging area, in which new programs are being developed and aggressively marketed to states and other public purchasers, as in the early days of managed behavioral health. Most programs are small and not representative, nor have they been accredited or thoroughly externally evaluated; it is not clear who amongst evaluators knows enough about disease management to do so. This fact makes it more difficult for purchasers to properly assess what external DM vendors of all types have to offer in the area of disease management for chronic mental illnesses or addictions. If public purchasers, including States' Medicaid programs and/or CMS, want to use accreditation status as a key requirement for a chronic mental health or substance use disorder disease management program, they will have to communicate that fact jointly to NCQA, URAC, and JCAHO and see to it that the specific, public sector-relevant mental health and substance abuse criteria and accreditation teams are developed by these organizations as the current accreditation models are oriented towards behavioral health.

Relationship Between Disease Management and Evidence-Based Practices

Mental health, Medicaid, and substance abuse purchasers, consumers and other stakeholders may notice that Disease Management as defined by the Disease Management Association of America shares many features with the widely-heralded Assertive Community Treatment (ACT) and the Texas Medication Algorithm Project (TMAP). These are two of the best documented and most widely applied "evidence-based" practices in mental health. It is therefore important to distinguish disease management as a concept or intervention from each of these programs.

Assertive Community Treatment (ACT)

According to the Web site of the National Alliance for the Mentally Ill,

ACT is a service-delivery model that provides comprehensive, locally based treatment to people with serious and persistent mental illnesses. Unlike other community-based programs, ACT is not a linkage or brokerage case-management program that connects individuals to mental health, housing, or rehabilitation agencies or services. Rather, it provides highly individualized services directly to consumers. ACT recipients receive the multidisciplinary, round-the-clock staffing of a psychiatric unit, but within the comfort of their own home and community.⁸

ACT incorporates treatment (including psychopharmacology and other therapies), rehabilitation and a variety of support services provided by a multidisciplinary staff working as a team. However, it does not necessarily emphasize measurement of outcomes, a systematic feedback loop or patient education in self-management or medication/treatment scheduling; all of which are important components of Disease Management. ACT teams and services have generally been offered via the public sector rather than by commercial vendors. They have generally not been provided on a full or even partial risk basis for a full episode of care though perhaps there would be merit in this.

⁸ See http://www.nami.org/Template.cfm?Section=ACT-TA_Center&template=/ContentManagement/ContentDisplay.cfm&ContentID=8075, accessed June 22, 2004.

Texas Medication Algorithm Project

TMAP, begun in 1996, developed, implemented and evaluated not just a set of medication algorithms, but “an algorithm-driven treatment philosophy” for several major adult psychiatric disorders now being treated in the Texas public mental health system.. The TMAP emphasis is on adult disorders, not on children or adolescents and not on substance use disorders. TMAP’s objective, using funding from the public and private sectors was to improve the quality of care for Texas’ designated serious mental illnesses and to achieve the best possible patient outcomes for each dollar of resource expended.⁹ It is medication-oriented. The TMAP treatment philosophy focuses on medication management protocols and practices and has been developed to date for schizophrenia, major depressive and bi-polar disorders. It incorporates: evidence-based, consensually-developed medication treatment algorithms; the clinical and technical support necessary to allow the clinician to implement the algorithms; patient and family education programs that allow the patient to be an active partner in care; and uniform documentation of care provided and resulting patient outcomes.

Thus, TMAP (and its implementation name TIMA) indeed incorporate many elements of what a commercial vendor might call a disease management program, although it addresses primarily medication compliance and has not been implemented on a capitated basis. While it did not originally include an explicit feedback loop, the fact that it represents active care collaboration between the public sector and an academic institution, and that it was developed in four phases, strongly point to its new effort to guide practice modifications during the care process. In TMAP itself, however, the focus is on appropriate psychopharmacology; it does not yet incorporate all other tested non-medication therapies, even for the indicated diagnoses and/or supportive rehabilitative services, as a full scale disease management program might do. Instead, it has been implemented by Texas and other states/local governments as a public sector practice improvement initiative for one or more specific adult chronic mental illness diagnoses. It has a particular focus on improving physician prescribing practices and patient/client compliance, thus presumably enhancing the quality and effectiveness of services provided to patients.

Other Evidence Based Practices

SAMHSA’s rapidly developing National Registry of Effective Prevention and Treatment (NREP) programs in substance abuse and mental health, as well as CSAT’s Treatment Improvement Protocols (TIP’s) series in substance abuse, are sources of information for evidence-based programs and practices in chronic mental illness or addictions, similar to but broader than what TMAP currently provides. As yet, they are untapped by commercial disease management vendors who often are the first to serve public payors.

Although most disease management programs incorporate patient/consumer education and self-management components, they have not been managed or operated by consumers themselves as peer-run mental illness or addiction support services are sometimes managed. However DM programs could use consumer-operated services as one important and cost-effective component of care.¹⁰

⁹ <http://www.mhmr.state.tx.us/centraloffice/medicaldirector/TMAPover.html>, accessed June 22, 2004.

¹⁰ J.E.Miller, “Disease Management Programs: A New Approach in State Medicaid Cost Containment Policy,” NAMI Policy Research Institute, December 2003.

The Rationale for Disease Management

Several trends in the contemporary American health care marketplace are converging and this suggests that there is value in disease management approaches for chronic conditions including mental illnesses and substance use disorders:

- Health care costs per patient are especially high for individuals with chronic disease(s); including mental and substance use disorders, whether clients receive their care through the public or the private sectors. The overall number of persons with chronic conditions is growing rapidly in the U.S as the population ages, and the total costs of chronic disease, including or complicated by behavioral conditions, are a significant proportion of total health care costs;
- There is a significant gap between the existence of well documented “evidence-based practices” that improve outcomes for individuals with mental and substance use disorders and the actual deployment of these practices in the field; and
- For individuals with chronic physical ailments, and even more so for those with primary or secondary chronic mental health or substance abuse/dependence disorders, high quality care requires extensive coordination among a variety of funding sources and providers, not all of them traditional medical providers, and in some cases across delivery system sectors and payors. This approach is intrinsic to a comprehensive disease management program.

Continuing Care and High Costs

One expert says, “Caring for chronic illness usually features uninformed and passive patients interacting with an unprepared practice team.”¹¹ A result of this phenomenon is that, in the words of Berk and Monheit, we have had “a remarkable stability in the spending distribution over the past decade [from 1987 to 1996], despite dramatic changes in health care delivery and continuing technological change.”¹² Thus, in 1987 the most expensive one percent of the population accounted for 28 percent of all health care payments, while in 1996 they still accounted for 27 percent. In both years the top five percent of the population in terms of expenditures accounted for more than half of all payments while the top ten percent accounted for more than two-thirds.

These expenditure proportions hold true not only for the population as a whole, but also for individuals under age 65 who have employment-related health insurance and are enrolled in managed care of any kind,¹³ and, as documented by Lieberman *et al.*, for Medicare beneficiaries as well. The latter authors found that between 1995 and 1999 “the most costly 5 percent of beneficiaries in each year accounted for 47 percent of total Medicare spending,” and the most costly ten percent accounted for 66 percent.¹⁴ In describing the “high spenders,” they note that almost 90 percent of those in the top five percent had at least one of the seven chronic

¹¹ Thomas Bodenheimer, M.D., quoted in M. Sipkoff, “Health Plans Begin to Address Chronic Care Management,” *Managed Care*, December 2003.

¹² M. Berk and A. Monheit, “The Concentration of Health Care Expenditures, Revisited,” *Health Affairs*, 20:2, March/April 2001, p. 10.

¹³ *Ibid.*, p. 14.

¹⁴ S. Lieberman, J. Lee, T. Anderson and D. Crippen, “Reducing the Growth of Medicare Spending: Geographic Versus Patient-Based Strategies,” *Health Affairs*, Web Exclusive, 10 December 2003, pp. 604-605.

conditions they analyzed (which, however, did not include any mental or substance use disorders). The National Center for Chronic Disease Prevention and Health Promotion reports that, “The medical care costs of people with chronic diseases account for more than 75% of the nation’s \$1.4 trillion medical care costs.”¹⁵

This incidence of chronic diseases is not only high but rising as the U.S. population ages and lifespan increases. According to the Institute of Medicine’s 2001 report, *Crossing the Quality Chasm*, “Chronic conditions, defined as illnesses that last longer than 3 months and are not self-limiting, are now the leading cause of illness, disability, and death in this country. . .”¹⁶ Moreover, “about 44 percent of those with a chronic illness have more than one such condition.. .”¹⁷ Further, the IOM cites the increase in chronic conditions and lack of attention to those conditions despite their increasing prevalence as one of the four underlying reasons for inadequate quality of care in the U.S.

The Gap Between the Existence and Use of Evidence-Based Practices

There is also wide agreement in the field of health care quality that, “current methods of organizing and delivering care are unable to meet the expectations of patients and their families because the science and technologies involved in health care . . . have advanced more rapidly than our ability to deliver them safely, effectively, and efficiently.”¹⁸

Citing numerous articles that discuss care for hypertension, depression, diabetes and asthma, Wagner *et al.* indicate that “fewer than half of U.S. patients with [these ailments] are receiving appropriate treatment.”¹⁹

In behavioral health care specifically, the report of The President’s New Freedom Commission on Mental Health,²⁰ published in 2003, expressed considerable agreement with the similarly critical Surgeon General’s Report on Mental Health, published four years earlier:²¹

From the Surgeon General’s Report: “State-of-the-art treatments, carefully refined through years of research, are not being translated into community settings.”²²

Similarly, from the New Freedom Commission report: “... new effective practices are not being used to benefit countless people with mental illnesses.”²³

¹⁵ <http://www.cdc.gov/nccdphp/overview.htm>, accessed June 22, 2004.

¹⁶ Institute of Medicine, Committee on Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academy Press, 2001, p. 27.

¹⁷ *Ibid.*

¹⁸ See Institute of Medicine, Committee on Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academy Press, 2001, p. 25 and

http://www.rwjf.org/publications/publicationsPdfs/Chronic_Care_in_America.pdf, accessed June 22, 2004.

¹⁹ E.H. Wagner, B. Austin, C. Davis, M. Hindmarsh, J. Schaefer and A. Bonomi, “Improving Chronic Illness Care: Translating Evidence into Action,” *Health Affairs*, 20:6, November/December 2001, p. 64.

²⁰ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

²¹ U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General*, Rockville, MD: USDHHS, SAMHSA, CMHS, NIH, NIMH, 1999.

²² *Ibid.*, p. 455.

Effective disease management initiatives offer the potential of implementing new, well-tested and promising mental health and substance dependence treatment methodologies, ensuring medications are deployed appropriately by providers and clients and that ineffective treatments are diminished or avoided altogether. With its focus on specific conditions using specific treatment protocols and measures, disease management includes what these national panels advocate: use of evidence-based practices, patient involvement, as well as measurement, evaluation and management of both processes and outcomes through continuous feedback.

The Need for Coordination to Provide Appropriate Health Care for Chronic Conditions

Disease management often involves coordinating complex care and multiple providers as well. For individuals with chronic mental and substance use disorders, even more than for those with chronic physical disorders, high quality care truly requires that the interventions of numerous providers and numerous sectors and funders in the community be coordinated on behalf of each person, whether funding is blended or braided. Yet a lack of coordination of services, defined as a “poorly organized delivery system,” is identified as another of the four underlying reasons for inadequate quality of care in the Institute of Medicine’s monograph, *Crossing the Quality Chasm*. The President’s New Freedom Commission highlighted this point with regard to the mental health system by noting that, “... understandably, consumers often feel overwhelmed and bewildered when they must access and integrate mental health care, support services, and disability benefits across multiple, disconnected programs that span Federal, State, and local agencies, as well as the private sector.”²⁴ The same is true of persons with addictive disorders, who, if anything, also encounter the additional stigma of being associated with illegal behaviors.

In sum—from the perspective of cost, treatment effectiveness, quality improvement and the coordination of care—disease management approaches, if properly designed, and developed with sufficiently comprehensive, culturally appropriate and independently evaluated components appear to offer significant promise to public and private behavioral health purchasers.

Effectiveness of Disease Management

Despite the promise and the evident logic, purchasers should understand that the effectiveness of disease management in behavioral health and physical health, either clinically or fiscally, has yet not been fully established, even though the U.S. has come to recognize that the improvement of chronic care is now absolutely critical to our health care system. The CBO recently prepared an analysis (2004) that found insufficient evidence to conclude that disease management programs can generally reduce overall health spending, although they did note that such programs may have value even if they do not reduce costs²⁵.

²³ *Achieving the Promise*, p. 68.

²⁴ *Ibid*, p. 27.

²⁵ Congressional Budget Office “An Analysis of the Literature on Disease Management Programs” October 13, 2004.

Wagner *et al.* observe that,

“Regardless of age at onset, whether their etiology is known or whether their manifestations are primarily physical or psychosocial, essentially all chronic conditions present a common set of challenges to the sufferers and their families.
.”²⁶

They emphasize that “the typical acute problem-oriented visit is a barrier” to the care that these chronically ill individuals actually need.

The Robert Wood Johnson Foundation has supported development of the Chronic Care Model (CCM), with the goal of improving the care of patients with chronic illnesses. The CCM, although not defined as DM *per se*, is based on clinical experience and medical evidence, and incorporates all of the elements of disease management as defined here, with a particular emphasis on patient education and support. However, in a February 2004 article evaluating an effort to implement the CCM, Cretin *et al.* note that, “Despite its evidence-based origins and intuitive appeal, the CCM has not been evaluated in controlled studies. . . . CCM is attractive and plausible, but its effectiveness has not been adequately tested.”²⁷

In fact, Lieberman *et al.* note that their “ongoing survey of the peer-reviewed literature suggests, at best, weak empirical evidence for long-term [Medicare] savings resulting from existing disease management programs.”²⁸ While one does not know whether the models or their implementation is at fault, the skepticism they express regarding likely savings in Medicare may be equally appropriate for other public programs and payors/purchasers. In particular, they note that, “Interventions developed for workers and their families in employer-sponsored insurance could be inappropriate or infeasible for elderly or disabled Medicare beneficiaries, especially given the prevalence of dementia and multiple chronic conditions.”²⁹

In a paper published in May 2002 by the National Health Care Purchasing Institute, Mechanic cited several disease management programs that have shown promising results, but then suggested that, “Despite DM’s promise, the evidence that such programs can yield positive ROI [return on investment] is still quite limited. To be successful, DM programs must overcome physician resistance, poor patient compliance, fragmented medical information, and poor communication systems.”³⁰ In addition, we would argue that savings estimates provided to state and other public purchasers and legislators are often inflated or without any foundation in science.

²⁶ Wagner *et al.*, *op. cit.*, p. 65.

²⁷ S. Cretin, S. Shortell and E. Keeler, “An Evaluation of Collaborative Interventions to Improve Chronic Illness Care: Framework and Study Design,” *Evaluation Review*, 28:1, February 2004, p. 30.

²⁸ S. Lieberman *et al.*, *op. cit.*, p. 607.

²⁹ *Ibid.*

³⁰ R.E. Mechanic, “Disease Management: A Promising Approach for Health Care Purchasers,” Executive Brief, May 2002. <http://www.academyhealth.org/nhcpi/mechanic.pdf>, accessed 7/28/04.

The results of disease management programs show that initiatives vary in focus, components and outcomes, especially in the public sector. The jury is still out on overall effectiveness, clinically and fiscally. Rigorous and valid independent evaluations of public sector (or private sector) disease management programs are difficult to find and hard to do. This is in part due to issues such as enrollment “churn” in public managed care populations, as well as due to missing clinical data for Medicaid and SCHIP and/or the lack of enrollment (or denominators) for other public sector populations.

Three successive evaluations concluded that the Florida Medicaid disease management initiatives that began in 2001, which did not include mental health or substance use disorders, had not met the State’s cost savings or health outcomes expectations. These demonstrations programs have been allowed to expire. Other States’ analyses or vendor-sponsored studies are underway in many places. Some of these evaluations may meet scientific criteria for external evaluations; others may not, sometimes because they are provided by entities that could have conflicts of interest. More comprehensive evaluations are needed.

Disease Management in State Medicaid and Other Public Sector Program

In this section, we briefly review a number of emerging Medicaid disease management programs or pilots that have some relevance for behavioral health services. These pilots have not yet included substance use disorders, although several states and other purchasers say that they are developing such programs. In addition, as the current DM programs for serious mental illness (SMI) are small, diverse and proliferating rapidly, only some of the more prominent efforts are explored here.

As explained above, in February 2004 the Centers for Medicare and Medicaid Services (CMS) sent a letter to State Medicaid officials in which it “urged States to adopt programs to help those with chronic illnesses better manage their diseases.”³¹ It is no surprise that a number of States, beset with budget shortfalls and deficits and significant Medicaid cost increases, welcomed this as an opportunity to control costs and simultaneously improve quality of care. Most, however, have not yet focused on chronic mental disorders, other than depression secondary to chronic physical disease, or on co-occurring or primary chronic substance use.

The National Conference of State Legislatures reported that, as of April 2004, 24 States had passed legislation specifically addressing disease management, and “at least 9 other States . . . have some type of disease management program not established through legislation.”³² The vast majority of these programs are targeted at specific physical illnesses, primarily asthma, diabetes, hypertension and congestive heart failure. However, two States, Illinois and Texas, passed legislation in 2004 requiring establishment of

³¹ <http://www.cms.hhs.gov/media/press/release.asp?Counter=967>

³² <http://www.ncsl.org/programs/health/diseasemgt.htm>, accessed 7/28/04

disease management programs for serious mental health conditions. The growth of these small initiatives is rapid.

This paper is an attempt to assist purchasers to understand behavioral health disease management efforts because we believe that State Medicaid, mental health and substance abuse and pharmacy management agencies as purchasers will increasingly turn to disease management approaches, whether home-grown or obtained from a vendor. Managed behavioral health care organizations (MBHO's), health plans, pharmacy disease management companies, pharmacists and providers will increasingly offer comprehensive DM approaches for specific chronic mental disorders and substance dependence as an explicit part of their menu of services and products. Many of these organizations began to discuss such initiatives several years ago. In fact, some MBHO's now active in the public sector say that they are currently transforming themselves into what they call disease management organizations.

Unfortunately, particularly from the perspective of Medicaid behavioral health, most of the typical vendor offerings still focus solely on routine depression or on depression secondary to chronic physical disorders, rather than major depressive disorder with psychotic features or other more serious syndromes and addiction. In addition, most MBHO's, health plans, pharmacy disease management companies, PBMs and providers have not spent time thinking about substance use disorders, despite the availability of evidence-based practices and links to these and so many other conditions.

Brief State Case Studies

Selected Disease Management programs are outlined below from Missouri, Colorado, Texas, Florida, Massachusetts and other states.

Missouri

The Missouri Department of Social Services, Division of Medical Services and the Department of Mental Health have implemented or are planning to implement two different Disease Management initiatives. The Missouri Disease Management Program of the Division of Medical Services was initiated in November of 2002 and focuses on four disease states in the Medicaid fee-for-service population. These include: asthma, depression, diabetes and heart failure. The program is run by Heritage Information Systems, Inc. of Richmond, VA, a health care technology company specializing in disease management and pharmacy cost containment. No other behavioral health diagnoses are included. The program identifies individuals with these four disorders who are at high risk for adverse outcomes and asks them to enroll with physician and pharmacist teams for their care related to the specific condition. These teams are authorized to provide up to four additional primary care and educational visits for the patients that focus on illness education and lifestyle issues that can contribute to the management of their condition. Patients are free to continue to use their existing primary care physicians and pharmacists for other conditions. Patient-specific information is distributed to the providers on a regular basis for use during visits. Training is required of all provider team members.

The Department of Mental Health is also implementing a more specialized behavioral health disease management effort for providers of services to disabled individuals on Medicaid. This latter effort will be focused on providers for high cost individuals with schizophrenia, beginning late Fall 2004. This effort builds on the on-and-a-half year-old behavioral pharmacy management initiative implemented by the Missouri Department Mental Health in collaboration with Comprehensive Neuroscience Inc. (CNS) with funding from several of the major pharmaceutical companies. That pharmacy benefit management effort targeted “outlier” prescribers, intervening with them through targeted provider correspondence based upon an analysis of provider claims. More than 3,000 letters are being mailed each month to physicians to notify them of prescribing patterns that do not meet consensus standards. These standards include analysis of “non-guideline” practices such as multiple prescribers, duplicate prescriptions, possible excess dosing, multiple prescriptions for contraindicated drugs, etc. According to Missouri administrators, the program has helped to contain pharmaceutical cost growth and improved prescribing quality by reducing duplicate prescribing. It will be independently evaluated by SAMHSA.

The newest Disease Management effort that Comprehensive Neuroscience will implement for Missouri takes a similar approach to claims and utilization analysis for the fee-for-service Medicaid population. This includes individuals who are excluded from managed care such as the disabled, youth in state custody, those in more rural areas, elderly, etc. Instead of focusing on outlier provider prescribers, however, the effort will identify outlier (high cost) consumers with schizophrenia and analyze their service claims to identify opportunities for improvement. Out of a total of 550,000 Medicaid-eligible FFS individuals, 19,000 (3.5%) had a diagnosis of schizophrenia. The claims’ costs for these individuals were ranked and the 2000 schizophrenic individuals with the highest costs had an average cost of approximately \$50,000 per year. The lowest cost 12,000 individuals had an average cost of \$4, 500 for the same period. (However, these per capita costs did not include the state hospital or housing costs.)

For these identified 2,000 high cost consumers, a monthly report card will be prepared and provided to each of the physicians or providers (CMHCs) on record. The report will include all pharmacy, ER visits, inpatient hospital visits and the last outpatient visit. Each record will include diagnosis, dates of service and provider. In this way, providers will be better able to understand the full range of services that the individuals they serve are receiving. Based upon these claims, CNS will also provide an analysis of costs and service use that provides a prediction of future costs for the individuals. The factors in this analysis include items such as the number of medications received, number of people seen, age, race, etc. CNS estimates that this analysis will correctly identify 67% of the high cost individuals for the next six months. It is hoped that this early identification of individuals will help providers focus on prevention and early intervention efforts for them and their other patients. To assist with this project, the state of Missouri has hired an Advance Practice Primary Care Nurse to provide administrative case management services among primary care providers, psychiatrists and case managers. As needed, Missouri officials may expand this state care coordination staffing.

While the program has not yet been implemented, it builds on the established pharmacy management effort and could be an interesting approach to disease management. By providing critical service information to current providers, CNS and the Department of Mental Health hope to offer their providers the clinical information needed to most effectively care for their most disabled and costly schizophrenic consumers.

Colorado

Colorado Medicaid entered into a financial arrangement supported by Eli Lilly in July 2002 to implement a small pilot program to manage Medicaid patients identified through claims analysis who are suffering from both schizophrenia and additional medical co-morbidities such as diabetes. This voluntary, patient-oriented demonstration, set to wrap up in December, 2004 after being extended six months, is administered by Specialty Disease Management Services, Inc. (SDMSI), a Jacksonville, Florida disease and case management company. SDMSI is a Lilly partner that originally provided field-service nurses for HIV patients in the Florida disease management program.

For the Colorado schizophrenia pilot, registered nurses in a 24-hour call center are used to recruit, assess, provide education, care coordination and outcomes monitoring for the schizophrenia/physical disease management program participants, using evidence-based protocols when available. The program deploys the registered nurse care managers to work as field operatives, visiting with patients and clinicians to provide home counseling visits, referrals and to promote the use of clinical guidelines and ensure that treatment recommendations are followed. The nurses also work with the clinicians. Enrollment in this program grew slowly but is now over 250 clients enrolled, as was planned. The program is being monitored by Colorado's state managed care officials and is going to be evaluated externally by the University of Arizona, College of Pharmacy, under arrangements with Eli Lilly. SDMSI is scheduled to deliver its own report on the program during Fall 2004.

Based on advice from an independent academic reviewer for some of the program evaluation designs, the Department, the vendors, and third party program reviewers, are conducting a quasi-experimental "return on investment" analysis based on vendor costs for the program, client satisfaction, clinical progress and quality of life status and provider satisfaction. All funding for the pilot programs in Colorado is provided directly to the vendors of the disease management programs through a three-way agreement with the State, the vendor and Eli Lilly.

In another Colorado program, StayStat is working as a partner in the southeastern, central and south central mental health regions with those areas' Medicaid managed behavioral health vendor – SyCare, based in Alamosa, Colorado. In a subcontracted program for SyCare that covers 6 mental health centers and approximately 20,000 members in Colorado, StayStat is monitoring psychiatric medication compliance for SyCare, detecting outlier cases and allowing SyCare to intervene with Colorado practitioners whose patients appear as outliers in terms of medication compliance. Addiction medication compliance is not currently a focus of this program.

Texas - TMAP and More than TMAP

The Texas Department of Mental Health and Mental Retardation (TDMHMR) recently (2003-04) announced a major initiative to be rolled out over the next several years that combines Disease Management with protocols based on TMAP for Major Depressive Disorder, Bi-Polar Disorder and Schizophrenia, using a new benefit design created by a Texas project team (June 2003). The program will serve both public sector adults and children/adolescents and which will also be rolled out in the State's Medicaid managed behavioral health Northstar program managed by Value/Options.³³

TDMHMR, which became part of the Division of Behavioral Health Services under the newly reorganized Department of State Health Services, estimates that 90% of its service population or adults with serious mental illness are individuals with one of the three conditions noted above. The benefit design component of the innovation defines specific bundles of services within five levels of care that include specific service components. The levels are determined using a uniform screening and assessment protocol; symptom rating scales from the Texas Medication Algorithm project and functional assessment tools. Each of the components of care is based upon evidence-based practices for these specific disorders. These include medication algorithms for the diseases from TMAP; case coordination; rehabilitative case management, including supportive housing, employment, skills training and specialized services; Assertive Community Treatment and Crisis Services. A comprehensive consumer education program was also developed as a part of the TMAP/TIMA implementation, including disease specific curricula, and these are supplemented with peer support services. Outcomes measurement at an individual and system level will be implemented across the services.

In concept, the Disease Management components of the initiative are a comprehensive and well designed effort that follows the DMAA definition of disease management for the three disorders involved. They build on the extensive work that has been supported by the State, by foundations and by pharmaceutical companies for TMAP/TIMA implementation. The State expects that the full roll out, which includes tools to measure fidelity to the model, as well as individual outcome monitoring and a statewide progress evaluation, will take several years. The initiative will be evaluated by Tummy's Internal Resiliency and Disease Management Evaluation Team using aggregated individual data. It will be presented in a semi-annual publication based on five system objectives with related evaluation criteria, charting progress first from four implementation sites as baselines and then from the first six months of the fuller initiative. Like North Carolina, Arizona, Pennsylvania, Michigan and Arizona, Texas ultimately expects to rely on a combination of county-based mental health authorities (LMHA's) and its 41 community mental health centers, to provide services under this initiative.

³³ See www.mhmr.state.tx.us/CentralOffice/behavioralhealthcareservices/RDMEval.html for full details

The new benefit design dimension of the initiative limits publicly funded services for individuals to those services outlined in one of the five levels of care determined to be appropriate for the individual consumer. Furthermore, recent announcements have indicated that TDMH intends to fund full public services statewide to individuals with these three specific mental conditions only, while offering a modest, 7-day emergency benefit to individuals with other serious or more routine mental disorders who represent a threat to themselves or the community but that do not meet these diagnostic criteria; substance dependence is not an included disorder. There has been a fair amount of controversy over this benefit limitation and associated funding cutbacks, both from consumers and providers in the State. In fact, the limited diagnosis aspect of the Texas mental disorder DM program, an economic policy choice, is not a component of a disease management program for chronic mental disorders itself.

Florida

Florida was one of the first States to adopt a disease management program for its Medicaid recipients when it began its initiative in 1997, focused initially on physical illness. Florida's Agency for Health Care Administration (AHCA) and its Division of Social Services manage and oversee these efforts. By the end of 2000, the Florida State Medicaid agency had contracted with eight disease management organizations to manage six diseases³⁴. Mental illness was not included in the early phase of Florida's initiative.

In 2001, based on State legislative input and audits, Florida revised its disease management program so as to permit the State Medicaid agency to negotiate contracts with prescription drug companies to provide Medicaid disease management programs in return for placement of that company's products on the State's Medicaid Preferred Drug List. Under this program, Bristol-Meyers Squibb financed a health management program for Hispanic and African-American Medicaid beneficiaries with depression, as well as other diseases. Bristol-Myers Squibb guaranteed savings of \$16.3 million to the State of Florida between October 2001 and June 2003.

Florida also had some disease management for mental illness provided by McKesson Corporation's URAC-accredited McKesson Health Solutions disease management company, headquartered in Broomfield, Colorado where it has its CareEnhance 24-hour nurse advice line.

A set of three studies has been completed in Florida by the State Legislature's Office of Program Policy Analysis and Government Accountability (May 2001, April 2003 and May 2004), with that Office acting as an independent evaluator for the Legislature of disease management efforts of other state agencies. However, the focus was on programs for hypertension, cancer, congestive heart failure, end-stage renal disease and sickle cell anemia, not on chronic mental illness or substance use disorders. In Florida, external

³⁴ Spigel S "Florida Disease Management Program" OLR Research Report, Connecticut General assembly January 28, 2003

vendors, created by several large pharmaceutical companies who offered the State free disease management programs in lieu of providing rebates on their drugs and in exchange for listing on the State's preferred drug list, operated the early disease management programs. Following the OPPAGA reports, HB 1843 was signed into law in May 2004, which among other Medicaid reforms, allows these pharmaceutical company disease management programs to expire in 2005, although disease management programs could be offered by other players in the future.

In September 2004, Florida's AHCA announced that it had obtained the commitment of five pharmaceutical companies to guarantee a savings of \$34 million to the State's Medicaid pharmacy budget over one year. In turn, mental health drugs will be exempted from certain prior authorization requirements. State officials will develop and adopt best-practice guidelines for prescribing behavioral health-related drugs; translate the guidelines into practice; review prescribing practices and patterns, and compare them to a number of indicators that are based on national standards. Other program elements include implementing a disease management program with a model medication component for high users of behavioral health care. The commitment and role of the pharmaceutical companies is primarily financial, although they will be involved in an advisory capacity.

Massachusetts

MassHealth, the Commonwealth of Massachusetts' Medicaid program, currently includes: traditional managed care organizations (MCOs) that provide physical and behavioral health services; the Primary Care Clinician (PCC) program, with its behavioral health carve out, and; traditional fee-for-service (FFS) for enrollees exempted from managed care. With almost 40% of their enrollees, and at least half of disabled with mental illness in the PCC program and the behavioral health carve out, MassHealth has focused a great deal of attention on primary care integration with the behavioral health carve out.

Specifically, Mass Health and its managed behavioral health care vendor, the Massachusetts Behavioral Health Partnership (MBHP) run by Value/Options, have initiated numerous efforts to improve access to needed services. To support primary care clinicians by increasing the availability of specialists a team of child psychiatrists and other specialists provide support to primary care physicians. MassHealth is also working on developing a performance incentive in its contract with MBHP for FY'05 to improve access to health care for DMH clients. MassHealth has several enhanced case management and chronic care initiatives for individuals with serious health care needs.

MassHealth works with several of its MCOs on a special Robert Wood Johnson grant focused on improving access and quality in primary care screening, assessment and treatment of depression. In the MHSPY program, the one program that we could consider a disease management initiative, Massachusetts has a major initiative to improve the treatment for children with serious emotional disorders (SED). This capitated program blends multiple funding streams, including Medicaid, mental health, local school and DSS funding. Services include primary care, pharmacy benefits, specialty services, and a broad array of in-home support services that would not

traditionally by funded by Medicaid. Unfortunately only 60 youth are currently served in Greater Boston primarily because the complex funding arrangements, particularly with local schools, have slowed efforts to expand the program.

As a state, Massachusetts is a leader in purchasing health care and particularly behavioral health services; however, the state has been slow to adopt disease management approaches for chronic mental and substance abuse disorders partly because of the success of the carve-out program in controlling costs and maintaining quality. While the individual initiatives cited above focus on many of the important components of effectively managing care for individuals with complex behavioral conditions, with the exception of the MHSPY program, they do not explicitly include pharmacy benefits and the efforts generally lack an explicit focus on consumer education, self-management and wellness that is so important to disease management approaches. For individuals with serious mental illness and/or addictive disorders, understanding one's illness, recognizing and managing symptoms and the signs of relapse or adverse events, identifying the effects of medication and knowing when to seek professional treatment are essential elements of recovery and at the heart of more focused "disease management".

Other States of Interest

Tennessee

Tennessee contracts with managed behavioral health care company Magellan Health Services for behavioral health services in the three Grand Regions of Tennessee. Over the coming months, enrollment in the TennCare program will be scaled back significantly. However, the Governor has announced a new focus on the implementation of disease management programs for TennCare beneficiaries in the health plans. It is unclear at this time, whether the Disease Management programs will involve behavioral health services, since they are currently carved-out from the health plans.

Wyoming, Montana, Wisconsin, Pennsylvania, Puerto Rico and Hawaii

Wyoming, Montana, Wisconsin, Puerto Rico, and Hawaii have disease management programs administered by APS Healthcare, Bethesda, MD. APS has a disease management program for high cost medical conditions, including a single disease state management program for depression and schizophrenia and another for behavioral health/medical co-morbidity. Other public sector high risk disease management clients include several counties in Pennsylvania. The schizophrenia disease management approach is based on the Schizophrenia Consumer Outcomes Research Team (PORT) research jointly developed by AHCPR, NIMH, and Johns Hopkins in 1992 that resulted in 32 recommendations, ranging from appropriate medication use in schizophrenia to family interventions to case management. In 1998 a survey conducted by Lehman, Steinwachs, et. al. found a worldwide physician compliance rate with the PORT of less than 50%, ample justification for disease management. APS' ongoing schizophrenia disease management program focuses on medication, psychosocial, recovery and family approaches to managing this condition, as well as physician education, case management and technical assistance.

Addiction Disease Management: Illinois and Wisconsin

There are a few emerging efforts in addiction disease management that are worth mentioning even though they are not very advanced. The State of Illinois Department of Human Services Office of Alcoholism and Substance Abuse is co-sponsoring the “Behavioral Health Recovery Management Project (BHRMP)” as a joint venture between the state, the Fayette Companies and Chestnut Health Systems, two provider health system vendors. This effort emphasizes the development of evidence-based practice guidelines for mental health and substance abuse, with an orientation towards recovery rather than maintenance but as of this writing it is not yet a full blown disease management effort.

In Wisconsin the Wisconsin Physicians Service, a Medicare Part B and Tri-Care vendor, announced an initiative in 2001 for Disease Management for Addictive Disorders. No detail is currently available on this endeavor or whom it covers.

Private Sector Disease Management Capabilities and Companies

Specialized mental health and substance abuse disease management capabilities are being developed by companies in several distinct components of the private sector. In many ways these are more advanced than the State Medicaid initiatives discussed above. Vendors include the following types of public or private sector organizations:

- Managed care plans
- Managed behavioral health plans
- Specialty disease management firms
- Pharmaceutical disease management companies
- Pharmaceutical benefits managers (PBMs)
- Insurance companies
- Large physician groups

However, experience with eager private managed care vendors in the public sector over the past 15 years indicates that public and private purchasers must conduct a thorough due diligence to identify vendors who have the programs, capabilities, experience and track record they want and the information and clinical systems to support the efforts. There is a distinct tendency amongst entrepreneurial companies to present future or hoped-for capabilities as realities, as well as a record of states and legislators being overly optimistic, less than clear about what they want and not always reasonable in the savings or outcomes expectations they may have.

Implementation Issues, Lessons and Implications

The Medicaid and managed behavioral health literature and ongoing developments in Medicaid disease management programs suggest several lessons that should be taken into account in designing and implementing a disease management effort for severe mental illness and co-occurring or primary addictive disorders. Many issues such as Medicaid eligibility changes, provider turnover and client dropout that have arisen in the past in public managed care programs. They affect disease management programs equally and need to be addressed when developing and implementing these programs. In addition, vendor qualifications should assess the extent to which potential vendors offer disease management that meets the DMAA definition and whether they have successfully served diverse populations. Preference should be given to those with experience in managing Medicaid programs for beneficiaries with serious mental illness, substance use disorders and with familiarity with the public agencies that serve those populations. Prior experience is important because public behavioral health care has a distinct, politicized culture, with increasing advocacy from many (NAMI, NMHA, Faces and Voices of Recovery (FAVOR), legal advocates, etc.) that complicates the management and oversight of public programs.

Among other major program development challenges are inter-agency coordination, data requirements, provider limitations, and consumer concerns:

Inter-Agency Coordination: Most disease management programs at least have significant control over the program's administration, if not its clinical environment. But Medicaid enrollees with mental health or substance abuse problems are likely to be clients under the control of multiple State and community administrative agencies, including the Departments of Health, Mental Health, Alcoholism and Substance Abuse Services, Mental Retardation and Developmental Disabilities, Children and Family Services, Justice, Juvenile Justice, Corrections, Parole, Housing, Vocational Rehabilitation, as well as other agencies. These State and/or local agencies typically have different professional, organizational, fiscal and constituency concerns and they may complicate a client's adherence to a disease management treatment plan, even one based on sound science. Although disease management programs are often limited to a particular agency's clientele, the characteristics of the Medicaid SMI/SED population often require the ability to coordinate care and/or data with numerous other public agencies, especially the mental health and addictions agencies and programs that provide most public treatment for Medicaid clients with mental illnesses.

Solutions may include:

- Case management and other program functions might be staffed jointly or by agreement delegated to one agency, via an interagency agreement;
- Common data bases could be used by case managers across agencies with program enrollees assigned to agencies according to mutually agreed upon assignment, service and evaluation criteria and protocols;
- Alternatively, enrollees could be assigned to a contracted vendor according to established program criteria and guidelines.

Data Requirements: An SMI or addiction disease management program may require additional data content beyond that easily available in Medicaid claims files. It may also be necessary for the data to be commonly defined, in common formats, and commonly accessible (subject to HIPAA requirements) across providers within a single agency and across agencies in the event of an inter-agency effort. Existing but separate State data systems may either need to be specifically modified to support an internally run mental illness and/or addiction DM program or may need to be connected to each other in order to interface (to the program's providers and users) with a DM vendor's systems.

Solutions may include:

- Automating the collection of data from providers, including automating uniform medical charts and records;
- Establishing common databases for housing historical and current operating data and making it accessible to program staff across agencies, subject to HIPAA requirements;
- Defining program data and evaluation criteria commonly across agencies and developing evaluation strategies and methods (control groups, pre-/post-measurements, etc.) that permit reasonable comparisons to other studies or State initiatives underway or required by the Legislature.

Provider Limitations: Providers who traditionally serve an SMI Medicaid population may not be accustomed to working as closely with a demonstration program at the level of detail and scrutiny that disease management presumes. In some geographic areas, there also may be few providers who are willing or able to provide the range of services that enrollees may need or to coordinate provision of such services across multiple providers.

Solutions may include:

- Working with and operating through comprehensive hospitals that Medicaid enrollees traditionally use.
- Some DM programs have also strengthened the capabilities of community-based ambulatory providers by training and sometimes augmenting their staff.

- Implementation of these solutions is limited by State budget deficits and layoffs, which have heavily affected mental health budgets in most States.

Consumer Concerns: Medicaid mental health and/or substance use disorder consumers or their families/guardians may not understand the benefits of disease management and may not be familiar with participating in supervised treatment regimens. The culture of peer support in State and Federal departments of mental health and/or substance abuse has empowered some clients, who may reject or resent interventions they do not request, control, or fully accept. Medicaid managed care vendors who are taking care of a member's physical health may vary considerably in the quality and intensity of their care of these members and in their willingness to cooperate with or incorporate mental health and/or addiction disease management.

Solutions may include:

- Patient education and compliance by providing content and patient reminders over the Web. However, many Medicaid consumers, especially those with SMI/SED and/or addictive disorders, may not have personal computers at home or conveniently available to them, and may not read or understand English. Even those few Medicaid consumers who do have access to computers may not be able to use them during a crisis, when they may need them most.
- Providing limited use cell phones, prepaid phone cards, or toll-free phone numbers to reach those individuals without home telephones to provide continuing disease management services.
- Promotion of cultural diversity, especially with respect to the disease management field workers, the client written or other media/materials, and even the clinical case managers/physicians, if at all possible through:
 - Preparing program materials in the languages and at an appropriate reading level.
 - Assigning outreach workers to assist with program enrollment and/or follow up to assure that treatment regimens are understood, are practical and are followed. Compliance with any regimen is a big problem with SMI populations.
 - Using technology to make program participation easier by giving enrollees limited mobile phones or materials for viewing on site, at peer meeting places for SMI clients, at treatment programs or at home via video tape or DVD player.
 - Possibly providing or overseeing the coordination of supportive transportation, day care, personal assistance, transitional housing, health care or other services that SMI/SED/SA enrollees may require to participate successfully in the program and to comply with their approved treatment plans.

Other Challenges for Medicaid Behavioral Health Disease Management

Telephonic and Web-Based Disease Management

Based on our review of the evidence to date, a telephonic component (perhaps via prepaid phone cards, limited use cell phones and/or 800-numbers) can and should be part of a disease management program for Medicaid recipients with SMI/SED and/or chronic addictive disorders. However, such a program is not sufficient by itself for this population due to Medicaid recipients' frequent lack of regular telephone service. Purchasers could provide a toll-free 800 number or a prepaid phone card to permit clients to call in to a case manager but this arrangement prohibits pro-active case management. The best alternative is to augment telephone outreach and care management with in-person case management for high need recipients. The Internet may be of some use for individuals who can read well in English, if the Web site and materials are simply and clearly presented. It should be available in more than one language.

Case Manager Qualifications

Case managers used for chronic mental illness or substance use disorder care management should at a minimum have completed Master's level training, but field and peer case workers can be less educated if they are well supervised. The case managers themselves should be supervised regularly by experienced PhD clinical psychologists or MD's who are board certified in psychiatry and/or addictions' medicine and who can review compliance and the medication and treatment regimens. All staff should have a minimum of 2-3 years experience in the public sector, except for the field or peer outreach staff, who may need less experience if well supervised.

Disease-Specific Guidelines and Protocols

"Disease-specific" clinical guidelines and performance standards exist for many diagnoses including routine and severe mental illness and severe emotional disturbance, and they are fast emerging for substance use disorders. However, they are not yet well integrated with case management software. The two best known criteria sets are the American Psychiatric Association (APA) guidelines, which include some substance use disorder protocols, and the Texas TMAP guidelines, which do not. The TMAP guidelines go much further than the APA guidelines and talk about life management, not just medication management. Unfortunately, there are some fidelity problems amongst providers, especially those who either do not buy into using guidelines or who refer to them and then fail to use them. Also the two sets of guidelines currently omit the co-occurring disease issues (mental health, substance abuse and physical medical conditions); neither of the criteria sets distinguish between management during crises and management during routine periods. For the field of addictions, the ASAM (American Society of Addiction Medicine) criteria have been more level-of-care oriented than protocol-oriented until recently, but these criteria are evolving and are now available in an on-line format. None of these criteria sets specifically address themselves to disorders in culturally diverse populations or for children and adolescents.

Public Sector Partnering

Public sector partnering involves extensive collaboration between the Medicaid program, the state mental health or substance abuse agencies and other programs such as vocational rehabilitation and supportive housing. Disease management for public behavioral health needs to include outreach to public housing, transportation, schools, and other state agencies. Clubhouses and peer support should also be available for those with serious mental illnesses.

Disease Management Program Components

The six components of a disease management program specified by the DMAA appear to be necessary but not sufficient for an effective program that addresses the needs of Medicaid recipients with SMI/SED/SA. In particular, the DMAA model does not emphasize interagency coordination, or public sector partnering, and cultural and medical linkages must also be addressed in order to provide supports that are critical for program success for the Medicaid population. Purchasers will have to insist that these models become more inclusive and that programs address the Medicaid population clinically and culturally. More intensive outreach and consumer involvement is necessary to identify, reach, manage and sustain potential clients than would be required for an asthma disease management program. Program cooperation, if not collaboration, with a State's DMH/SA and Public Health Departments is essential, as is involving other key stakeholders and consumers in individuals' care and recovery.

Conclusion

Disease management programs have grown rapidly. Supported by and often delivered by traditional managed care organizations, managed behavioral health care vendors, pharmaceutical companies and others, DM programs promise cost management while significantly improving the quality of care for enrollees with substance use and/or chronic mental health disorders. One of the primary means by which this is achieved is through consumer education and peer support which the Centers for Medicare and Medicaid have strongly supported in guidance to States. Consumer education includes the management of lifestyle conditions that may contribute to or complicate the condition, managing medication schedules and the recognition and management of symptoms. This is extraordinarily relevant to behavioral health conditions and it provides a new, more patient-centered and empowering approach to care that the field is likely to rapidly adopt.

The integration of primary care, specialty behavioral health services and often pharmacy benefits requires further development and testing of standardized protocols or algorithms for care, sophisticated information management and new tools for outcome monitoring and measurement. Taken together, these are the elements of an effective disease management program. The inclusion of pharmacy benefits and primary care will require significant changes for many Medicaid behavioral health programs that have been designed as carve-outs.

The growth of DM has been extensively supported by pharmaceutical companies. Colorado's DM program and TMAP are examples of what has been achieved with the extensive support of the pharmaceutical industry, academics and foundations. To its credit, the pharmaceutical industry has recognized the importance of developing evidence-based guidelines and medication

management techniques as a part of a comprehensive intervention for specific conditions. At the same time, it is important for public purchasers and consumers alike that DM is seen as scientifically valid and unbiased.

Managed behavioral health care initiatives in the public sector include many of the elements of disease management programs. Often, however, behavioral carve-outs do not include pharmacy benefits and have not had a focus on the specific chronic condition or conditions faced by enrollees. The health care field and behavioral health have resisted efforts in the past to define these guidelines. Recent advances in the field, reports such as the Institute of Medicine Report, *Crossing the Quality Chasm*, and the impressive evidence that is emerging from medication and treatment algorithms, such as TMAP, and the SAMHSA National Registry of Effective Practices prove a readiness for change within the field. Disease management gives purchasers one more tool to achieve the goals of high quality, efficient and person-centered mental health and substance abuse care systems.