

medicaid
and the uninsured

MEDICAID MANAGED
CARE FOR PERSONS
WITH DISABILITIES:
A CLOSER LOOK

Prepared by
Marsha Regenstein
Christy Schroer
Jack A. Meyer
Economic and Social Research Institute
for
The Kaiser Commission on
Medicaid and the Uninsured

kaiser
commission on

medicaid

and the uninsured

The Kaiser Commission on Medicaid and the Uninsured serves as a policy institute and forum for analyzing health care coverage and access for the low-income population and assessing options for reform. The Commission, begun in 1991, strives to bring increased public awareness and expanded analytic effort to the policy debate over health coverage and access, with a special focus on Medicaid and the uninsured. The Commission is a major initiative of the Henry J. Kaiser Family Foundation and is based at the Foundation's Washington, D.C. office.

James R. Tallon
Chairman

Diane Rowland, Sc.D.
Executive Director

MEDICAID MANAGED CARE FOR PERSONS WITH DISABILITIES: A CLOSER LOOK

April 2000

Prepared by

Marsha Regenstein, Ph.D.¹
Christy Schroer, M.H.A.
Jack A. Meyer, Ph.D.

The Economic and Social Research Institute
Washington, DC

Preparation of this report was supported by a grant from the Kaiser Commission on Medicaid and the Uninsured. The views expressed in this report are those of the authors and do not necessarily reflect those of the Commission or The Henry J. Kaiser Family Foundation. A companion paper, *Medicaid Managed Care for Persons with Disabilities: A Closer Look, Descriptions of Programs in Florida, Kentucky, Michigan, and New Mexico* (publication # 2163), provides in-depth descriptions of the four case studies. Both documents are part of a larger study on Medicaid managed care for individuals with disabilities that includes a national survey of state practices and focus groups of low-income disabled individuals.

¹ Ms. Regenstein is currently director of the National Public Health and Hospital Institute.

Contents

ABOUT ESRI	ii
ABOUT THE AUTHORS	ii
ACKNOWLEDGMENTS	ii
EXECUTIVE SUMMARY	iii
OVERVIEW	1
INTRODUCTION.....	1
ORGANIZATION OF THE REPORT.....	4
BACKGROUND	5
FINDINGS FROM THE LITERATURE.....	5
STATE SURVEY FINDINGS.....	10
CONSUMER PERSPECTIVES.....	13
CASE STUDY FINDINGS	16
OVERVIEW OF THE FOUR STATES.....	17
Florida.....	17
Kentucky.....	18
Michigan.....	19
New Mexico.....	19
ENROLLMENT/AUTOENROLLMENT.....	23
QUALITY ASSURANCE PROGRAMS.....	24
SPECIAL FEATURES FOR PERSONS WITH DISABILITIES.....	26
BEHAVIORAL HEALTH.....	27
RATE-SETTING AND ADVERSE SELECTION.....	28
LESSONS LEARNED	30

About ESRI

The Economic and Social Research Institute (ESRI) is a nonprofit organization that conducts research and policy analysis in health care and in social services reform. ESRI specializes in studies aimed at enhancing the effectiveness of social programs, improving the way health care services are organized and delivered, and making quality health care accessible and affordable.

About the Authors

Marsha Regenstein, Ph.D., formerly vice president of ESRI, is the director of the National Public Health and Hospital Institute. Dr. Regenstein has analyzed how changes in the health care market affect vulnerable populations, especially persons with disabilities. She has written on coverage policy within Medicare and Medicaid, long-term care, welfare reform, and models for financing early childhood education.

Christy Schroer, M.H.A., is a research associate at ESRI. Ms. Schroer has conducted research on Medicaid managed care, hospital outpatient services, laboratory safety and health regulations, and physician issues.

Jack A. Meyer, Ph.D., is the founder and president of ESRI. He is also an Adjunct Associate of the Center for Health Policy at Stanford University. Dr. Meyer has conducted policy analysis and directed research on frontline issues in health care reform and social policy. He is the author of numerous books, monographs, and articles on topics including health care, labor market and demographic trends, and policies to reduce poverty.

Acknowledgments

The authors would like to acknowledge the contribution of Medicaid staff, advocates, program enrollees, health plan administrators and medical directors and many others who were generous with their time during our site visits. We are particularly grateful to Charles Corley, Charles Kight, Wendy Smith and Jayne Parker in Florida; Jay Dowds, Dr. Richard Heine and Mary Walker in Kentucky; Richard Murdock and Jane Finn in Michigan; and Charles Milligan and Marise McFadden in New Mexico. The authors would also like to acknowledge Linda Cummings, Ph.D., for her assistance on this project. We gratefully acknowledge the support of the Kaiser Commission on Medicaid and the Uninsured.

Executive Summary

Throughout the 1990s, states have been turning to managed care in an effort to improve access to care and control costs for Medicaid enrollees. The proportion of Medicaid enrollees in capitated or primary care case management (PCCM) programs has increased from only one in ten at the beginning of the decade to over half today. At first, states were primarily moving young parents and their children enrolled in the Temporary Assistance to Needy Families (TANF, formerly AFDC) program into managed care. More recently, states have been attempting the more difficult task of finding managed care options for people with disabilities and chronic illnesses. This population includes children with special health care needs, non-elderly adults with physical impairments, functional limitations, and severe mental or emotional problems, and the frail elderly.

Proponents of managed care assert that such programs have considerable potential to improve the health and functional status of people with disabilities by improving access to primary and preventive care, coordinating and integrating health and social services, and encouraging the use of home and community-based alternatives to institutional care. Nevertheless, if not properly designed and monitored, managed care can pose serious threats to the health and well-being of people with disabilities. For example, managed care may sever patients' long-standing relationships with physicians who understand their special needs and problems. It may create incentives for providers to block access to specialty care and ancillary services that are required to meet the complex needs of children and adults with disabilities. It may also exacerbate the adverse risk selection in the health insurance market, furthering incentives facing health plans to sidestep enrolling people whose anticipated medical costs are high.

In December 1998, the Kaiser Commission on Medicaid and the Uninsured published the results of a nationwide study of state initiatives to enroll children and non-elderly adults in managed care conducted by the Economic and Social Research Institute (ESRI). This study found 36 states with Medicaid managed care programs that enroll children and/or adults with disabilities. These programs cover about 1.6 million people

with disabilities, or about 27 percent of the nearly 6 million children and non-elderly adults with disabilities covered by Medicaid in 1998.

Following the survey, four in-depth case studies were conducted of managed care programs in Florida, Kentucky, Michigan, and New Mexico. This report presents the results of these case studies, while also drawing on the findings from the national survey of state practices referenced above, focus groups of persons with disabilities currently enrolled in Medicaid managed care programs, and a review of the relevant literature. This report tries to address the issue of how persons with disabilities fare under managed care arrangements. It describes ways that managed care is affecting overall health care delivery for some of our nation's most vulnerable citizens, and describes the lessons learned for policymakers who enroll – or plan to enroll – persons with disabilities in their managed care programs.

Key Findings

- Little evidence exists within the published literature to suggest that Medicaid managed care actually helps or harms children and adults with disabilities. While there are countless references to the care of this population and concerns about how they fare in managed care arrangements, very few studies have looked at utilization of services, outcomes, coordination of care, or overall satisfaction among persons with chronic conditions and disabilities in Medicaid managed care arrangements. Consequently, states wishing to include these populations in their managed care programs have little in the way of published research to guide their efforts.
- Results from our nationwide survey of state practices show that most managed care programs for people with disabilities are “mainstream” programs that include disabled Medicaid beneficiaries in the same design that is used to serve people with occasional acute care needs. Often, these programs follow a “one size fits all” approach that fails to identify and address the unusual challenges facing people with disabilities in gaining timely access to a wide array of services. However, the case studies highlight two programs specifically designed for children with special health care needs.
- States are using a mix of mandatory and voluntary arrangements for enrollment in Medicaid managed care, although the majority of persons with disabilities enrolled in managed care are in mandatory, capitated arrangements (approximately one-third of disabled Medicaid beneficiaries in managed care are in PCCM plans). Voluntary programs preserve a “safety valve” for beneficiaries, but could lead to adverse risk selection. Voluntary arrangements may also result in low take-up rates, which could make it difficult for states to achieve their cost management goals in a reasonable time period.
- Most states are using “auto-assignment” to select a managed care arrangement for people who do not voluntarily choose a health plan or primary care provider.

Our case studies revealed some controversy surrounding the auto-assignment process. Some patient advocates believe that companies contracting with states to assign beneficiaries are placed under pressure to “steer” patients to tighter forms of managed care (e.g., HMOs instead of PCCM models).

- Health plans are paid through capitation rates that frequently do not reflect the widely varying risk profiles of different categories of enrollees, or are not adequately increased over time to account for rising costs. States most frequently adjust rates using age, sex, eligibility categories and geography. Additional adjustments, such as health status and prior service utilization, have been used infrequently and remain poorly refined. Inadequate rates for people with chronic health needs have resulted in incentives for health plans to “cream skim” and avoid “expensive” patients as well as to freeze enrollment or withdraw entirely from the Medicaid program. Consequently, some states may lose or have already lost plans or provider delivery systems that had good performance records.
- States have generally not held managed care plans strictly accountable for implementing basic features of a good managed care model such as requiring health plans to identify enrollees with special health care needs and provide such people with a comprehensive health care needs assessment within a reasonable period. Although the survey results and the case studies show that some states do require the participating plans to provide these special features, the studies also found that these states do not always use these tools to account for the special needs of persons with disabilities
- Focus groups with Medicaid enrollees with disabilities, conducted in conjunction with this study, reveal serious difficulties in accessing specialty care, prescription drugs, dental care, home health, durable medical equipment, and a variety of other services. Behavioral health is another important area where impediments to access can pose serious problems.
- In areas such as quality assurance standards, grievance and appeals procedures, and other “safety valves,” states typically combine people with disabilities with the general Medicaid population. States have not designed special features to account for the special challenges facing children and adults with disabilities. The case studies provide examples of how some states are handling quality assurance standards.

Lessons Learned

Even at these early stages of enrollment, it is possible to identify certain characteristics or features of Medicaid managed care programs to help persons with disabilities obtain high-quality health care that tries to facilitate their access to health services. The experiences in Florida, Kentucky, Michigan and New Mexico, as well as the survey and focus group data, are extremely instructive and provide lessons for policymakers who may be considering enrolling persons on SSI in their Medicaid managed care programs.

These lessons are also relevant for programs that are already up-and-running to help develop ways to safeguard the care of persons with disabilities. The following lessons are based on the national survey of state practices, the focus groups, and case studies.

1. ***Move steadily, but not swiftly to managed care, enrolling persons with disabilities in the program only after it has been operational for some period of time.*** States should phase in managed care requirements in stages, rather than leaping from old to new models without a period of trial and adjustment. During the early phases some measures may be used that will later be abandoned, such as allowing enrollment to be voluntary rather than mandatory and maintaining a PCCM model as an alternative to HMO enrollment. People with disabilities could be phased in at later stages of enrollment. Our studies found that the states that waited to enroll persons with disabilities – after an open planning process that involved consumers and advocates – generally had smoother transitions, better designed programs, and less resistance over the long run from opponents and advocacy groups.
2. ***Involve consumers, involve consumers, involve consumers.*** All states that we spoke with touted the involvement of consumers and advocacy groups, but few built consumer representation and involvement into all stages of program development, quality assurance, and oversight and monitoring of the program. Ultimately, if the goal is to design a system that works well, saves money, and responds to client needs, consumer involvement is an absolute necessity. Moreover, if family-centered care is to be more than a slogan, enrollees and their families must be involved in program design and mid-course corrections throughout the process.
3. ***If the program is a mainstream model, identify a population with special needs and develop specific provisions for their enrollment and ongoing care.*** Some of the mainstream programs have developed a “program within a program,” at least for enrollment efforts, to make certain that special health needs are appropriately addressed. This helps to focus attention on the needs of this group and acquaints the health plan with these enrollees.
4. ***Special attention to the care of the general Medicaid population also translates into special care for persons with disabilities.*** Florida’s requirement for primary care physicians to see all new enrollees within a certain time period means that persons with disabilities will be assessed shortly after enrollment. Systems that respond to each and every complaint or grievance work well for all enrollees in a plan. Well-designed features to improve care for all enrollees will have derivative benefits for persons with disabilities.
5. ***Set up systems to monitor the availability and utilization of prescription drugs, durable medical equipment, home health and physical therapy.*** Information from the focus groups in Florida and New Mexico and other sources identifies the types of services that persons with disabilities commonly have problems accessing. Health plans should have flexibility in determining how to use resources cost-efficiently, but there appears to be a bias against equipment and services designed to improve the physical and functional well-being of persons with disabilities. States should take steps to assure persons with disabilities access to these vitally important equipment and services.

6. ***Don't underestimate the ability of Medicaid staff to influence care delivery.*** Providers in several states are acutely aware of the extent to which they are monitored by their state Medicaid offices. Though they complain about the oversight, health plans respond to it and are likely to exercise extra care when it comes to vulnerable populations.
7. ***HCFA should work with and encourage states to set standards for health plans to facilitate the protection of people with chronic conditions and disabilities as they move into Medicaid managed care.*** For example, HCFA and the states could set standards requiring health plans to: 1) identify people with chronic illnesses and disabilities; 2) conduct timely assessments of their health and functional status and the health and social services they need; 3) track progress in quality of care and outcomes; and 4) report on the performance of health plans in meeting the needs of people with disabilities. Where shortfalls in quality or performance occur, plans should be required to develop strategies for improving the situation. Over time, if plans do not correct deficiencies in quality of care, states should consider whether contracting with those plans is in the interest of the Medicaid beneficiary.
8. ***Until risk-adjusters are developed to even the playing field, monitor adverse selection carefully and develop ways to measure for it.*** Health plans in competitive markets are likely to claim that they experience adverse selection, but there are few mechanisms in place to measure this or adjust for it in the absence of sophisticated methodology. Even in the absence of such sophisticated methodology, however, states can improve the current rudimentary adjustments that are limited to categorical eligibility, age and gender. For instance, states can investigate methods for compensating plans for caring for more costly enrollees through withholds or “bonuses” for more complex case loads. In addition, HCFA could support further refinement of risk adjustment mechanisms and permit states to either adopt a “HCFA model” or implement their own comparable version.
9. ***Think through managed behavioral health care to determine ways to make the system work better.*** Virtually all of the state behavioral health programs are plagued with coordination problems within and across managed care plans. With no clear model yet designed to address these issues, states should try to develop safeguards to minimize these problems. In the meantime, a lot more consumer involvement could help identify the most vulnerable gaps in service delivery and try to shore those up through a combination of managed and fee-for-service arrangements.
10. ***Be sensitive to the cultural and political realities of the state.*** What may work in one region of the country may be a disaster in another. States that have been successful from the planning stages have been sensitive to provider needs and anxieties about managed care, historical turf issues, population diversity, and other local concerns. There are examples of managed care programs that were hotly contested by their communities and others that were cautiously accepted. States that worked through the issues before enrollment began had many fewer problems in implementing Medicaid managed care.

11. *It may be easier to “keep an eye on the program” in smaller Medicaid states.*

Medicaid staff in Kentucky and New Mexico keeps a close watch on their programs, but it would be hard to imagine Florida or Michigan staff keeping similar tabs on their much larger Medicaid programs. If the model of close oversight by Medicaid staff works well for people with disabilities, though, it might be useful to determine ways to develop smaller, more manageable regional programs. HCFA should work with states to identify models of excellence for the care of chronically ill and disabled populations. The field needs careful, objective, critical reviews of managed care arrangements for adults and children with chronic conditions and disabilities to develop an understanding of what works and what does not.

Overview

Introduction

Over the past several years, children and adults with chronic conditions and disabilities¹ have been enrolling in managed care organizations in increasing numbers. By 1998, nearly 1.6 million individuals covered by Medicaid – one of every four non-elderly persons on SSI – were enrolled in a managed care plan or program, with the majority of these individuals enrolled in capitated arrangements.² Much of this growth is a result of geographic expansions of currently existing programs, as well as phase-ins of previously approved plans under Medicaid waivers. The growth has occurred in the absence of a clear understanding of how to manage persons with serious and complex conditions in a managed care environment. Medicaid managed care plans are forging new ground, attempting to apply managed care principles – developed and honed on relatively healthy populations – to persons who often require heavy doses of chronic, costly, and specialized services. Due to changes under the Balanced Budget Act (BBA) of 1997, however, it is unclear whether the growth in Medicaid managed care will continue to accelerate.³

¹ For the purpose of this report, the term “persons with chronic conditions and disabilities” is used interchangeably with persons on SSI enrolled in the Medicaid program. Also, the report focuses exclusively on children and adults who are not enrolled in Medicare. It does not address the concerns of the elderly or those dually eligible for Medicaid and Medicare.

² Regenstein M. and Schroer C. *Medicaid Managed Care for Persons with Disabilities: State Profiles*, prepared for the Kaiser Commission on Medicaid and the Uninsured, December 1998.

³ The BBA allows states to implement mandatory Medicaid managed care programs without first obtaining a waiver from the Health Care Financing Administration. Under this new rule, it is not necessary for state Medicaid managed care programs to operate on a statewide basis; benefits can differ across the state and within eligibility groups; and administrators can restrict enrollees’ choice of providers. Nonetheless, the BBA exempts children with special health care needs (i.e., those on SSI children who qualify for services under the maternal and Child Health block grants, children in foster care or adoption assistance, and certain others) who may enroll in managed care only on a voluntary basis. The law also requires states to develop and implement quality assessment and improvement strategies and external independent reviews of an MCO’s performance.

The overwhelming majority of Medicaid managed care programs have opted for a health care “melting pot” where persons who qualify for Medicaid on income-related grounds only – who may require mostly primary care and preventive services – are mixed in with an extremely diverse set of people whose health needs could challenge even the most sophisticated integrated care model.⁴ Yet architects of Medicaid managed care programs, health plan medical and administrative leadership and many others maintain that the mainstream model can work well for all enrollees, as long as the requisite talent and expertise is available and accessible. Furthermore, they argue that the model offers the added benefits of better coordinated care, improved continuity of care, and the ability to tailor resources to need in a way that is not feasible under an unmanaged fee-for-service style of medicine.

Persons with disabilities are facing the challenges presented by Medicaid managed care with varying degrees of success. Children and adults on SSI currently enrolled in these arrangements are among the early graduates of what has become a national policy of inclusion for health care. This policy has its benefits – for example, many Medicaid managed care programs have improved access to primary care services and some specialty care. But reports from persons with disabilities in managed care arrangements also point to serious impediments to care. Their stories describe how they must now maneuver through a maze of cost-management rules and incentives to maintain what can sometimes amount to an army of health workers involved in varying degrees with their care. For them, managed care plans can thwart rather than facilitate access to care.

One of the most obvious roadblocks to understanding how persons with disabilities and chronic conditions fare in Medicaid managed care arrangements is the persistent lack of encounter data from participating MCOs. As early as 1992, in testimony before a subcommittee of the House Committee on Energy and Commerce, the General Accounting Office recommended that states use “utilization data to determine if the appropriate amount of services are being provided” among four safeguards of care to assure adequate protection for clients.⁵ State Medicaid programs and health plans alike have produced inadequate information about how well these delivery arrangements are serving the needs of persons with chronic conditions and disabilities. As the state study presented in the next section demonstrates, while all states require health plans to provide data, few state representatives are prepared to embrace their encounter data as truly representative of the delivery of health services in their state.

⁴ The majority of individuals on Medicaid qualify based on income. Prior to the welfare reforms of 1996, welfare and Medicaid eligibility were linked, so that persons who qualified for welfare were automatically enrolled in Medicaid. Under the new welfare program, Temporary Assistance for Needy Families, eligibility based on income generally also qualifies someone for Medicaid, although enrollment is no longer automatic.

⁵ U.S. General Accounting Office, *Medicaid Factors to Consider in Managed Care Programs*, Testimony of Janet Shikles, Director of the Health Financing and Policy Issues before the Subcommittee on Health and Environment, House Committee on Energy and Commerce. GAO/T-HRD 92-43 (Washington: GAO, 1992).

Little evidence exists within the published literature to suggest that Medicaid managed care actually helps or harms people with disabilities. While there are countless references to the care of this population and concerns about how they fare in managed care arrangements, very few studies have looked at utilization of services, outcomes, coordination of care, or overall satisfaction among persons with chronic conditions and disabilities in Medicaid managed care arrangements. Consequently, states wishing to include these populations in their managed care programs have little in the way of published research to guide them.

In an effort to develop useful information for policymakers regarding how managed care is affecting the structure and approach of health care delivery for low-income disabled people and how this vulnerable group is faring under these new programs, the Kaiser Commission on Medicaid and the Uninsured supported three recent studies:

1. A nationwide survey of all 50 states and the District of Columbia to document the number and size of Medicaid managed care programs that enroll non-elderly people with disabilities conducted by the Economic and Social Research Institute (ESRI);
2. A series of focus groups of non-elderly people with disabilities conducted by Lake Snell Perry & Associates to learn about their experiences with Medicaid managed care; and
3. A more in-depth case study of the managed care programs undertaken by four states – Florida, Kentucky, Michigan and New Mexico – also conducted by ESRI.

Detailed results of the first and second studies are available from the Kaiser Commission on Medicaid and the Uninsured.⁶ The third project is the main focus of this report wherein we present a composite analysis of the four case studies. Also available from the Kaiser Commission is a companion paper, which provides in-depth descriptions of the four case studies.⁷

⁶ Marsha Regenstien and Christy Schroer. *Medicaid Managed Care for Persons with Disabilities: State Profiles*, prepared for the Kaiser Commission on Medicaid and the Uninsured, December 1998. Michael Perry and Neil Robertson. *Individuals with Disabilities and Their Experiences with Medicaid Managed Care: Results from Focus Group Research*, prepared for the Kaiser Commission on Medicaid and the Uninsured, July 1999. www.kff.org.

⁷ Marsha Regenstien, Christy Schroer, and Jack A. Meyer. *Medicaid Managed Care for Individuals with Disabilities: Case Studies of Programs in Florida, Kentucky, Michigan, and New Mexico*, prepared for the Kaiser Commission on Medicaid and the Uninsured, April 2000.

Organization of the Report

Following this introduction, we present a review of the relevant literature on Medicaid managed care for disabled populations, as well as the highlights from the national survey of state practices and the focus groups. Next, we move into the major focus of this report, a discussion of the four case studies. This section first provides an overview of each state's Medicaid program, followed by an analysis of the structure and impact of various program features such as whether capitated and/or PCCM programs are offered; whether the programs are mandatory or voluntary for people with disabilities; criteria for autoenrollment, if any; rate-setting criteria for capitated programs; whether disabled people are covered by "mainstream" managed care or by a separate specialized program; and whether behavioral health is offered under a managed care arrangement or an alternative approach. Finally, this report concludes with a series of "lessons learned" for policymakers, drawing from all three studies.

Background

Findings from the Literature

Overview

An article written in 1993 by Fox, Wicks and Newacheck on state Medicaid HMO policies and their adequacy for children with special health needs began with the following statement:

Little research has been done to ascertain what enrollment in a health maintenance organization may mean for the care of Medicaid beneficiaries who regularly require specialty health services.⁸

Now, seven years later, there is still relatively little information available in the published literature about the experiences of adults and children with chronic conditions and disabilities in Medicaid managed care arrangements and the ways that these arrangements affect their overall health or access to care.

While there has been an enormous amount of interest in managed care in the private and public sectors, there have been relatively few studies over the past several years that can help policymakers, providers, consumers and researchers answer certain fundamental questions. For example, has Medicaid managed care helped adults and children with chronic conditions and disabilities get better care, more appropriate care, or better access to certain kinds of services that are important to their overall health and well-being? In other words, is Medicaid managed care a better vehicle for the care of these populations than fee-for-service Medicaid? How are these individuals better off under managed care? What tradeoffs – in terms of actual health care delivery or health outcomes – are associated with the movement away from fee-for-service medicine and toward managed care?

⁸ Fox HB, Wicks LB, Newacheck PW. State Medicaid Health Maintenance Organization Policies and Special-Needs Children. *Health Care Financing Review* 1993, 15(1):p. 25.

Most researchers would likely agree, from a review of the available literature, that these questions have not yet been resolved, or even adequately addressed. There are, however, a number of studies that inventory, chronicle or otherwise detail various features of Medicaid managed care programs that could be of particular importance or interest to persons with chronic conditions and disabilities and their families. The goal of these studies is generally to make some inferences about quality of care and access to services, in the absence of encounter data or other utilization or quality indicators. For example, an earlier report collected information through a targeted telephone survey about many program features that we believe could be most helpful to adults and children with chronic conditions and disabilities.⁹

A more extensive survey of Medicaid managed care programs is conducted periodically by the National Academy of State Health Policy. The most recent survey, published in 1999, provides detailed information about Medicaid managed care programs and enrollment, payment methodologies, quality assurance features, and many other elements.¹⁰ While this survey does not focus exclusively on persons with disabilities, it describes the key features that pertain to this population, as well as the general Medicaid population, and separately identifies certain features that are of particular importance to persons with special health care needs.

Other reports have also looked at these and other program features to get an early indication of whether managed care is appropriately caring for persons with special needs. A 1996 report by Horvath and Kaye detailed Medicaid managed care ombudsman and grievance procedures in Delaware, Minnesota, Missouri, Oregon and Tennessee. According to the authors, "Grievances and complaints, whether lodged formally or informally, can serve as an early warning system that all is not well within a particular health plan or can highlight flaws in the design of the overall administrative system."¹¹ Not surprisingly, the authors found considerable variation across state systems of receiving complaints from Medicaid managed care enrollees.

Several reports have also suggested ways to safeguard care for children with chronic conditions and disabilities in managed care arrangements. A Commentary published by Newacheck, Hughes, Stoddard and Halfon in *Pediatrics* in 1993 identified three "essential programmatic elements" that must be incorporated into managed care programs to safeguard the care of chronically ill children: 1) the rates paid to plans and

⁹ Regenstein and Schroer, 1998. We included information about: whether persons with chronic conditions and disabilities could choose to participate in the managed care program; how autoassignment worked for this population; the existence of lock-in provisions and guaranteed eligibility; the extent to which capitation payments were adjusted according to the individual's conditions or use of health services; the existence of special program or enrollment provisions designed to improve access or quality for persons with special needs; and whether the plan was required to assign a case manager or perform a health assessment within a specified period of time.

¹⁰ National Academy for State Health Policy. *Medicaid Managed Care: A Guide for the States. 4th Edition.* Portland, ME, 1999.

¹¹ Horvath J, Kaye N. *Snapshot of Medicaid Managed Care Ombudsman and Grievance Procedures.* 1996. Portland, ME: National Academy for State Health Policy, p. 14.

providers for the care of chronically ill children; 2) the availability of services and providers needed by chronically ill children; and 3) the quality of care chronically ill children receive.¹² A 1994 report on low-income children with disabilities by Regenstein and Meyer also suggested that health plans make “special provisions” for improved access to primary and specialty care when dealing with children with disabilities and their families.¹³

Tanenbaum and Hurley, in a Commentary published in *Health Affairs* in 1995, urged the proponents of managed care to move cautiously when even thinking about moving persons with disabilities into managed care arrangements.¹⁴ Listing some of the structural and practical impediments to the task, the authors stated: “No matter how well intended, the actual practice of managed care for persons with disabilities at best will test the patience and ingenuity of all involved.”¹⁵

In a 1995 study, McManus and Fox outlined some of the design elements that can facilitate care for “high-risk” children in HMO arrangements.¹⁶ While their findings do not apply exclusively to low-income children, their recommendations apply to any child with special health needs in an HMO environment. Among their recommendations are ways HMOs can improve needs assessments, access to care, preventive interventions and primary care. In their 1996 report, Fox and McManus described current state Medicaid managed care policies and plan practices affecting children with chronic or disabling conditions and suggest six “essential state elements” and nine “essential plan elements” to safeguard care for children with special health care needs in Medicaid managed care arrangements.¹⁷

According to a 1996 literature review by Newacheck and colleagues on the effects of managed care on children with chronic conditions and disabilities, assessing outcomes that result from enrollment in managed care for children with chronic health programs presents a “formidable challenge.”¹⁸ Acknowledging that a comprehensive monitoring

¹² Newacheck PW, Hughes DC, Stoddard JJ, Halfon N. Children with Chronic Illness and Medicaid Managed Care. *Pediatrics* 1994; 93(3). 497-500.

¹³ Regenstein M, Meyer JA. *Low-Income Children with Disabilities: How Will They Fare Under Health Reform?* 1994. Portland, ME: National Academy for State Health Policy, p. 28.

¹⁴ Tanenbaum SJ, Hurley RE. Disability and the Managed Care Frenzy: A Cautionary Note. *Health Affairs* 1995; 14(4): 213-219.

¹⁵ *Ibid.*, p. 214.

¹⁶ McManus MA, Fox HB. *Strategies to Enhance Preventive and Primary Care Services for High-Risk Children in Health Maintenance Organizations*. 1995. Washington, DC: The Child and Adolescent Health Policy Center.

¹⁷ Fox HB, McManus MA. *Medicaid Managed Care for Children with Chronic or Disabling Conditions: Improved Strategies for States and Plans*. Washington, DC: Maternal and Child Health Policy Center, 1996. One essential state element, for example, concerns the specificity of pediatric benefits. Here, the authors suggest that when developing contract language for plans serving children with chronic or disabling conditions, “all states need to list and describe pediatric benefits as distinct from those for adults...”

¹⁸ Newacheck PW, Stein REK, Walker DK, Gortmaker SL, Kuhlthau K, Perrin JM. Monitoring and Evaluating Managed Care for Children with Chronic Illnesses and Disabilities. *Pediatrics* 1996; 98(5):952-958.

and evaluation strategy to understand how enrollment has affected chronically ill and disabled children would likely involve a significant commitment of resources on the part of foundations, government and health plans, the authors state:

Given the paucity of existing information and the stakes for children with chronic conditions and their families, investment of added resources in a comprehensive monitoring and evaluation strategy is essential. [p. 952]

Access and Utilization

One of the most important questions concerning access to care for persons with disabilities is the extent to which gatekeeping arrangements – which are commonly incorporated into managed care strategies – can limit access to specialty care. Hurley, Freund and Gage used data from Medicaid primary care gatekeeper programs in California and New Jersey to determine their effect on referral patterns.¹⁹ The study found that beneficiaries enrolled with gatekeepers were significantly less likely to see specialists when compared with unenrolled beneficiaries in comparison groups. Likewise, a 1988 survey of pediatricians collected information about referral patterns and access to specialty services in managed care and fee-for-service arrangements.²⁰ This study found that pediatricians referred patients in managed care systems somewhat less frequently than in traditional pay systems. Also, more than 20 percent and 10 percent of pediatricians with patients in managed care systems had at least one referral to subspecialist care and inpatient care, respectively, denied in the previous year. Pediatricians experienced more barriers in preferred provider organizations than in health maintenance organizations.

There are some studies that have looked at utilization of services or various outcomes of individuals with chronic conditions in Medicaid managed care and other care arrangements. In a study comparing utilization of health care services by children with asthma, attention deficit disorder, diabetes, epilepsy, and sickle cell anemia who were insured by Medicaid or an employer group in 1992 and 1993, Shatin, et al. found not only that children in Medicaid tended to be sicker,²¹ but also that children with chronic health conditions who are enrolled in Medicaid managed care use more services than children with similar conditions who are insured through employers.²² Another study by Mauldron and colleagues compared care between managed and fee-for-service

¹⁹ Hurley RE, Freund DA, Gage BJ. Gatekeeper Effects on Patterns of Physician Use. *J Fam Pract* 1991; 32(2):167-174.

²⁰ Cartland JDC, Yudkowsky BK. Barriers to Pediatric Referral in Managed Care Systems. *Pediatrics* 1992; 89(2):183-192.

²¹ Five percent of the Medicaid population had one of these conditions compared to 3 percent of children insured through the employer group.

²² Shatin D, Levin R, Ireys HT, Haller V. Health Care Utilization by Children with Chronic Illnesses: A Comparison of Medicaid and Employer-insured Managed Care. *Pediatrics* 1998:102(4).

Medicaid and concluded that a Medicaid HMO provided appropriate and necessary care to children with chronic conditions (in this case, diabetes and allergies).²³

Several studies on Medicaid managed care have focused on the delivery of managed mental health services. A 1992 study by Lurie, et al., that looked at the effect on various health outcomes of enrollment of chronically mentally ill Medicaid beneficiaries in prepaid plans versus traditional fee-for-service Medicaid found no consistent evidence of harmful effects of enrollment in prepaid plans, at least in the short run.²⁴ Christianson et al. also studied the effect of Medicaid managed mental health care on community-based mental health treatment programs and found, again in the short run, that the use of such community-based programs was not necessarily affected by enrollment of Medicaid beneficiaries in prepaid plans.²⁵ David Mechanic, in a commentary on that study, urged careful interpretation of those findings, suggesting, for example, that since there is much “defective” in traditional Medicaid patterns of care, simply showing that access does not worsen under managed care is not necessarily a reason for satisfaction.²⁶

A 1996 study by Dickey, et al. described changes in utilization of mental health services for patients with schizophrenia who were enrolled in a Medicaid managed mental health program in Massachusetts from 1991 to 1994.²⁷ Through a retrospective, multiyear cross-sectional study that used administrative data from over 16,000 disabled adult patients from the Massachusetts Division of Medical Assistance and the Department of Mental Health, the authors found that inpatient admissions decreased during the study period from 29 percent to 24 percent, as did lengths of stay. There was a small increase in the fraction of patients readmitted within thirty days of discharge, as well as a small decrease in health expenditures per treated beneficiary. Other reviews of the Massachusetts managed mental health program also found cost savings associated with the move to managed mental health care.²⁸

Other studies have looked at the delivery of services to persons with HIV and AIDS. For example, a 1994 study of the Oregon Health Plan and its effect on Medicaid coverage for outpatients with HIV looked at the changes in the number of persons eligible for

²³ Mauldron J, Leibowitz A, Buchanan JL, Damberg C, McGuigan KA. Rationing or Rationalizing Children's Medical Care: Comparison of a Medicaid HMO with Fee-for-service Care. *Am J Public Health* 1994; 84:899-904.

²⁴ Lurie N, Moscovice IS, Finch M, Christianson JB, Popkin MK. Does Capitation Affect the Health of the Chronically Mentally Ill? *JAMA* 1992; 267(24):3300-3304.

²⁵ Christianson JB, Lurie N, Finch M, Moscovice IS, Hartley D. Use of Community-Based Mental Health Programs by HMOs: Evidence from a Medicaid Demonstration. *American Journal of Public Health* 1992; 82(6): 790-795.

²⁶ Mechanic D. Editorial: Managed Care for the Seriously Mentally Ill. *American Journal of Public Health* 1992; 82(6): 788-789.

²⁷ Dickey B, Normand ST, Norton EC, Azeni H, Fisher W, Altaffer F. Managing the Care of Schizophrenia: Lessons from a 4-Year Massachusetts Medicaid Study. *Arch Gen Psychiatry* 1996; 53:945-952.

²⁸ See, for example: Callahan JJ, Shepard DS, Beinecke RH, Larson MH, Cavanaugh D. Mental Health/Substance Abuse in Managed Care: The Massachusetts Medicaid Experience. *Health Affairs* 1995; 14(3):173-184.

Medicaid and the types of services no longer available under the program.²⁹ In reviewing patient care at two HIV outpatient clinics, the study found that while only about one-fifth of patients were Medicaid-eligible, nearly three-quarters would have been eligible under the Oregon Health Plan. According to the authors, while a small percentage of these patients' visits were for conditions listed below the plan's coverage threshold, none was for HIV-specific conditions.

State Survey Findings

In this nationwide study of state practices, ESRI relied on a comprehensive interview guide and numerous follow-up telephone calls to program administrators in all 50 states and the District of Columbia to develop profiles of state Medicaid managed care programs that enroll non-elderly persons with disabilities. ESRI collected information on key enrollment and quality assurance features, and the "special program features" that are designed to facilitate the enrollment of persons with disabilities or support their health care needs. The report also provides estimates of state-by-state enrollment of non-elderly persons with disabilities in Medicaid managed care.³⁰

The report found that 36 states together operate 58 managed care programs with a total enrollment of nearly 1.6 non-elderly disabled persons. This represents roughly 27 percent of the nearly 6 million non-elderly Medicaid beneficiaries with disabilities. Moreover, of these 58 programs, 36 are capitated and 22 are PCCM programs. Approximately two-thirds of all persons with disabilities enrolled in Medicaid managed care programs are in capitated arrangements, with the remaining one-third in PCCM programs. These facts shatter the common perceptions that relatively few persons with disabilities are in Medicaid managed care, and that those who are have been placed essentially in managed fee-for-service programs.

Florida has the highest *number* of persons with disabilities enrolled, with 205,000 individuals – or 66 percent of this population in the state – in its capitated and PCCM programs. Indiana has the lowest number enrolled, with 70 individuals – or 0.1 percent of the state's population of persons with disabilities enrolled in a voluntary capitated program. When ranking the states by the *percent* of disabled persons enrolled in managed care, Tennessee heads the list, with 100 percent enrolled in a mandatory capitated program – estimated at 200,000 in 1996 – enrolled in TennCare, a capitated

²⁹ Conviser R, Retondo MJ, Loveless MO. Predicting the Effect of the Oregon Health Plan on Medicaid Coverage for Outpatients with HIV. *American Journal of Public Health* 1994; 84(11):1994-1996.

³⁰ The survey findings and methodology used to estimate enrollments are explained in detail in the companion report by Regenstein and Schroer, referenced above. In brief, the study team contacted all state Medicaid programs to determine whether persons on SSI were enrolled, either on a voluntary or mandatory basis, in capitated or PCCM programs. If the states met ESRI's criteria for enrolling persons on SSI in managed care, we administered a lengthy questionnaire to several Medicaid staff members to identify key features of the programs and to estimate current enrollments. The results of these questionnaires were summarized on a shorter survey form that was sent for verification to all of the Medicaid managed care programs as well as to states that did not meet the eligibility criteria. In several cases, we worked with state Medicaid personnel to try to estimate the number of non-elderly SSI beneficiaries who were enrolled in a managed care program.

managed care program. Eleven more states enroll at least half of their disabled Medicaid populations in managed care arrangements. In order of ranking, these states are: New Mexico, South Dakota, Arizona, Oregon, Maryland, Florida, Michigan, Georgia, Virginia, Utah, and Massachusetts.

Only five of the 58 programs exclusively enroll persons on SSI or who are otherwise disabled: the District of Columbia's Health Services for Children with Special Needs; Indiana's Voluntary Risk-Based Managed Care for Persons with Disabilities; Michigan's Children's Special Health Care Services; Ohio's Accessing Better Care; and Wisconsin's Independent Care.³¹ Each of these programs is voluntary and enrolls persons with disabilities only. Two of the programs (the District of Columbia and Michigan) are for children only.³² Together, these five programs represent less than 1 percent of total enrollment of persons with disabilities in Medicaid managed care programs.

Because most of the programs are mainstream by design, it should not be surprising that the majority of enrollment and program features for persons with disabilities are identical or similar to those for persons without chronic conditions and disabilities. Nevertheless, it is noteworthy that these programs have designed relatively few special features to address a much more complex and challenging group of enrollees.

Most of the Medicaid managed care programs that enroll persons on SSI on a mandatory basis use an enrollment broker and employ enrollment practices that apply to all prospective enrollees, irrespective of their disability status.³³ Likewise, most of the programs apply their autoassignment criteria evenly across disabled and non-disabled groups. Persons with disabilities in PCCM arrangements are commonly autoassigned to current or former primary care physicians (PCPs), and those in capitated care are frequently assigned to managed care organizations affiliated with current or former providers. They can also be assigned randomly, based on geography, or according to proportions by the "choosers" – those individuals who select their plans or PCPs.

Although there are generally few special features tailored to the needs of persons with disabilities, some programs include an enhanced outreach component that works more closely with persons with disabilities who are having difficulty choosing a health plan or provider. In a few cases, persons with disabilities are either enrolled voluntarily in an

³¹ These programs are for persons with disabilities only, although they enroll others who are ineligible for SSI. For example, Michigan's program enrolls children who qualify for SSI or for Title V services, or both. Wisconsin's program targets the frail elderly, and includes enrollees who are eligible for both Medicaid and Medicare. The enrollment figures that appear in Tables 1 and 2 include only children and adults under age 65 who are on Medicaid and receive SSI. They exclude individuals on Medicare.

³² In Florida, children on SSI can enroll in the Children's Medical Service Network that specializes in the care of children with special needs. This program is an option within the state's primary care case management program.

³³ In two cases – Alabama's *Better Access for You*, and Kentucky's *Health Care Partnerships* – enrollment brokers are not necessary for plan assignment, because all enrollees become part of the same regional health plan. In certain other cases, Medicaid staff or fiscal agents assume a broker role and help enrollees choose plans or providers, or assist in the autoassignment process.

otherwise mandatory program (New Jersey and Texas) or are autoassigned only to the PCCM option (Massachusetts). Once enrolled, however, most programs appear to rely on mainstream provisions for care and quality assurance. On the other hand, the five programs that are designed exclusively for persons with disabilities include many special features for their care including a broad range of wrap-around services (District of Columbia and Michigan) and health assessments for all enrollees that form the basis of a detailed care plan (Wisconsin).

Many managed care programs indicate that they routinely assign case managers to children and adults with chronic conditions and disabilities, though few states require participating health plans to do so. Fewer than half of the programs require plans to see enrollees within a specified period of time – when there is the requirement, they commonly must see a new enrollee within 45 to 120 days. Only about one-third of the programs require providers to conduct health assessments on new enrollees.

While many of the states have some features that apply to persons with disabilities, the basic program requirements, elements and care patterns generally apply to all enrollees within the programs. In addition, many of these features may exist as policy but they are often applied or implemented unevenly. Indeed, as is discussed in more detail below, and in the companion report referenced above, focus groups with persons with disabilities in Medicaid managed care plans revealed that they were generally unaware of these features.

Almost all managed care programs set payment rates for enrollees based on categorical eligibility; in this way, MCOs receive higher capitated payments for individuals on SSI than for those in the general Medicaid population. Some programs also vary rates according to age and gender. Eleven states use additional factors to set payment rates for persons enrolled in managed care. Very few programs, however, currently employ what can be considered a sophisticated risk-adjustment methodology based on prior resource use, diagnosis, health status, or some combination of these factors.

Five states – Indiana, Maryland, Massachusetts, Michigan and Wisconsin – are setting rates based on pre-determined diagnostic groupings. In Michigan, for example, the Children’s Special Health Care Services Program has set five rate categories, based on ICD-9 diagnosis groups, that correspond to the severity of chronic condition or disability, and the type or amount of resources that are likely to be needed by the child. Most of these “risk-adjustment” methodologies are relatively new and are likely to need refinement as they are implemented in various settings across the country.

Finally, the ESRI survey collected information about the ways that persons on SSI and others enrolled in the managed care programs receive mental health and substance abuse services. Several models appear to have emerged for managed behavioral health, although there is little consensus about the best way of delivering and managing these services, or coordinating them with physical health care. The survey found

significant variation across the states, and even within certain states, in the delivery of behavioral health services.

Persons in capitated arrangements receive behavioral health services through their MCOs, through separate (although perhaps affiliated) behavioral health organizations, or through the fee-for-service system. Persons in primary care case management services often receive care via the fee-for-service system, although there are exceptions to this rule. In Massachusetts and in a five-county pilot program in Florida, for example, PCCM enrollees receive all behavioral health services from behavioral health organizations (BHOs) under contract with the state Medicaid programs. Still other states, such as California and Colorado, are beginning to develop county or regional mental health boards or systems to manage their behavioral health care.

Consumer Perspectives

As part of this study, the Kaiser Commission on Medicaid and the Uninsured commissioned a series of focus groups with non-elderly persons with disabilities in Medicaid managed care arrangements in Florida and New Mexico. The purpose of these focus groups was to go directly to disabled consumers of managed care services and ask them how well they believe managed care is serving their needs.

The focus groups were conducted by Lake Snell Perry & Associates (LSPA), a national opinion research firm located in Washington, D.C.³⁴ LSPA worked closely with the ESRI study team to design the focus group questions and identify participants. Seven focus groups were conducted in February 1999 in Tampa, Florida and Santa Fe and Albuquerque, New Mexico.³⁵ The focus groups consisted of the following individuals: adult consumers of mental health services; parents of developmentally disabled children; children with chronic physical conditions and their parents; and adults with physical or functional disabilities.

Focus group participants – all of whom (other than parents or guardians of participating children) qualified for Medicaid through the Supplemental Security Income (SSI) program – have spent years and even decades trying to access services from the health care system. Several of them complained that managed care presents a new level of challenges. They speak of a system that is at times inflexible – despite the need for even more flexibility in their lives. This sense of inflexibility is surprising, since managed care should be able to develop a more flexible approach to health care delivery, and certainly one that is tailored to the specific needs of its enrollees. However, persons with disabilities are facing a new layer of management that, in their estimation, is a waste of

³⁴ For a report on the focus groups, see: Perry, Michael and Neil Robertson, *Individuals with Disabilities and Their Experiences with Medicaid Managed Care: Results from Focus Group Research*, prepared for the Kaiser Commission on Medicaid and the Uninsured, July 1999.

³⁵ LSPA planned to conduct four groups in each of the states for a total of eight focus groups. Recruitment in New Mexico proved extremely difficult for adults with physical or functional disabilities. In lieu of a focus group, LSPA conducted one in-depth interview.

precious time and money and only delays their ability to get the services and treatments they need. If they expend the time to battle the system, they often get approval for the contested services. At times, however, they say they pay out-of-pocket for (covered) services or tap into advocacy organizations or other groups for help.

Focus group participants across categories and sites mentioned difficulties accessing specialty care, prescription drugs, transportation services, dental care, home health, durable medical equipment, and a variety of other services. They also feel the lack of choice associated with capitated care and miss the fee-for-service system for its flexibility in choosing providers. They mentioned feeling “rushed” under managed care and say they are very interested in finding providers who will spend the necessary amount of time with them during an appointment and during their period of care.

Focus group participants found the enrollment process confusing and also did not feel that their care was being managed adequately. Some felt they did not have a good understanding of their options. In Florida, where Medicaid enrollees can choose between the capitated and PCCM options, participants seemed to be unaware that they had this choice. Most said that they asked a physician, nurse, or friend to recommend a health plan. Most say they are unlikely to switch because of the “hassle” involved in moving to another care arrangement. Participants also reported they did not trust that their primary care physicians (PCPs) were familiar enough with their histories – they found themselves repeating information to physicians – and again, this would result in delays in treatments or services. Furthermore, many focus group participants felt that case managers were providing little help in coordinating care.

Persons with disabilities also have difficulty accessing specialty care and getting the prescriptions, equipment, home care and therapy that they need. When they get appointments with specialists, they find the logistics involved in getting to multiple appointments scattered throughout their areas to be complicated and time-consuming. They also say the referral process is confusing, especially when there are multiple specialists involved. Even when transportation to and from appointments is available, it is frequently unreliable and inflexible. All of the participants told stories of unfilled prescriptions, missed appointments, and delayed services because of problems with transportation services.

These individuals also share common concerns about access to prescription drugs. It seems that while MCOs commonly develop formularies, some physicians continue to write prescriptions for non-formulary drugs. When enrollees try to fill the prescriptions they are often denied. Some of these physicians try to finesse the system by writing a prescription for a 15-day supply of drugs. Pharmacists are instructed, at least in New Mexico, to fill these shorter prescriptions even if they are off-formulary, but this results in enrollees’ needing to go back to the pharmacy more frequently, creating significant barriers to compliance.

Health plans also construct barriers to obtaining costly durable medical equipment and parents again find themselves waging a battle for equipment for their children. Wheelchairs appear to be an especially contentious issue and the source of frequent battles between families and health plans, with health plans refusing to pay for customized chairs, motorized chairs, and newer chairs to accommodate a child's growth.

One of the major differences across the two states centered on the participants' impressions of mental health services. Focus group participants in New Mexico were much happier with their experiences with their behavioral health organization than those in Florida, who were extremely dissatisfied with their behavioral health organization. Despite these differences, both groups complained that they had too little time with their mental health professionals and felt rushed during appointments. They were frustrated that from visit to visit they are often unable to see the same mental health professional and therefore cannot develop bonds of trust that are so important to patient care. Individuals in Florida also said they have difficulties getting an appointment in the first place.

The focus group results are consistent with some, but not all, of the information gathered through the national survey and, as will be presented in the next section, the case studies. It is too early in most state managed care programs for meaningful encounter data, and few states are conducting external or internal reviews to develop information about how managed care affects enrollees' experiences with the health care system, and therefore, the focus groups offer our only glimpse into the realities of managed care for persons with disabilities.

Case Study Findings

Building on the nationwide survey, the ESRI project team selected four states for in-depth study and analysis. The states – Florida, Kentucky, Michigan and New Mexico – were selected for several reasons. First, we wanted states that had enrolled relatively high numbers of persons on SSI in PCCM or capitated arrangements. As was learned from the national survey, New Mexico has enrolled over 90 percent of its non-elderly SSI population in its Salud! program, while Michigan and Florida have each enrolled more than 50 percent of their non-elderly SSI beneficiaries. Kentucky’s enrollment is much lower, reflecting the fact that the Health Care Partnership program is currently operational in only two regions of the state. Within those regions, however, nearly all persons on SSI are enrolled in the program.

Second, we looked for geographic and program diversity. Florida has large PCCM and capitated programs, and Michigan has a very large capitated option plus a smaller specialized program for children with special health care needs. Kentucky offers one managed care option per region, New Mexico has three managed care organizations that each must operate statewide, and enrollees in Florida and Michigan can choose among a myriad of participating plans. The four states also offered various features that could affect care for persons with disabilities.

The site visits took place between September and December 1998. At least two members of the study team participated in each of the visits and met with several members of the Medicaid staff, managed care organizations, behavioral health organizations, enrollment brokers, advocates, physicians, and other interested parties. A great deal of information was gathered by listening to Medicaid staff explain the details of their programs; to health plan administrators describe the challenges of delivering care to Medicaid enrollees; and to advocates provide opinions about the strengths and weaknesses of the various program options. While the study tried to capture the mission, programmatic features and spirit of these programs, the principal goal was to develop information about how persons with disabilities are faring in Medicaid managed care arrangements and to analyze the genesis, implementation and effectiveness of the programs. In many cases, however, the program features for persons with disabilities are identical to those for persons in the general Medicaid population. Consequently, the

study included many of the details about the basic program elements despite the fact that they may not be designed specifically for persons with disabilities.

The discussion below first provides an overview of the program(s) in each of the four study states, followed by a comparison and analysis of various programmatic features. The next section of this report presents a series of key findings and lessons learned for policymakers based on data gathered from the case studies, as well as the national survey of state practices, and focus groups. Additional detailed information on each of the individual case studies is available in a separate report from the Kaiser Commission on Medicaid and Uninsured.

Overview of the Four States

We begin with an overview of the general structure and size of each state's Medicaid managed care program(s). Table 1 provides background information on the four case study states and lists Medicaid and other statistics for comparison purposes. As can be seen from this display, the states vary quite a bit in terms of size of population, extent to which they are urban or rural, poverty level, and use of health services. New Mexico, for example, is a very poor state that is challenged to deliver health services across a vast and rural state. Yet, New Mexico spends nearly five times as much on adult, blind and disabled Medicaid beneficiaries as it does on the general adult Medicaid population. Kentucky spends about two and one-half times as much. Table 2 summarizes various program features of the managed care programs in Florida, Kentucky, Michigan and New Mexico.³⁶ Detailed descriptions and analyses of the Florida, Kentucky, Michigan and New Mexico Medicaid managed care programs that enroll persons with disabilities are provided below.

Florida

Two programs in Florida enroll non-elderly persons on SSI – the Medicaid Provider Access System (known as MediPass) – a PCCM program, and a full-risk, capitated program known as the HMO Program. Both programs are mainstream and are not designed specifically for persons with chronic conditions and disabilities. Florida is one of four states that require most individuals with disabilities to enroll in Medicaid managed care, but allows them to choose between a PCCM or a capitated program. Although Florida has been enrolling its Medicaid population in managed care programs since the 1980s (including persons on SSI), it was not until 1996 that the state began to require beneficiaries eligible for managed care to enroll in either the MediPass program or in the state's capitated option, the HMO program.

MediPass is a traditional PCCM model, with participating physicians providing care or referring members for nearly all covered services, and creating a “medical home” for

³⁶ We have included only those programs that enroll persons with disabilities. Kentucky's KenPAC program, for example, is not discussed, because persons on SSI are ineligible for the program. As individuals enroll in the Partnership, KenPAC is being phased out throughout the state.

Medicaid Managed Care for Individuals with Disabilities: A Closer Look

program enrollees. The program was designed in the early 1990s to help reduce inappropriate utilization and control Medicaid expenditures. It was developed as a result of Medicaid beneficiaries' limited interest in the voluntary capitated program and the state's desire to move more individuals into managed care arrangements. An estimated 484,880 people are enrolled in MediPass. Approximately 27 percent of those enrolled (or about 135,000) are non-elderly persons with disabilities.

The requirement to enroll in either MediPass or the HMO program applies to adults with disabilities in Florida who do not qualify for one of the waiver programs and who are ineligible for Medicare. Children with chronic conditions and disabilities are not eligible for the HMO program; instead, they are assigned to MediPass. Once enrolled in MediPass, they can choose to stay in that program or take advantage of an added feature exclusively for children with special health care needs. Interested parents can enroll eligible children in the Children's Medical Service (CMS) Network, a Title V/Maternal and Child Health Bureau program that specializes in the care of children with disabilities and other chronic conditions.

Florida has enrolled Medicaid beneficiaries in full-risk, capitated care since 1982, allowing all health plans that meet the terms of the contract to participate in the Medicaid HMO Program. In September 1998, there were 14 participating health plans in the program, with total enrollment at 373,300 people. Nearly 19 percent of those enrolled (or about 70,000) are non-elderly persons with disabilities.

Kentucky

Kentucky has one Medicaid managed care program that enrolls persons with disabilities – the Health Care Partnerships Program (commonly referred to as “the Partnerships”). The program is mainstream and not designed specifically for persons with chronic conditions and disabilities. The Partnerships Program was conceived, in part, as a way to include persons with chronic conditions and disabilities in Medicaid managed care, and is replacing the former KenPac, a PCCM that enrolled only non-disabled populations. Under the Health Care Partnerships program, the state established eight regions for Partnership development. By design, each MCO functions as a “Partnership” among the local hospitals, physicians and health plans, including safety-net providers that have traditionally served the Medicaid population. The Partnerships are required to include individuals receiving Supplemental Security Income (SSI), foster care children, children in the Special Needs Adoption Program and in psychiatric residential treatment facilities, and medically fragile recipients. All providers in a region have to agree on the specific structure of their MCO, which is run by the Medicaid Administration.

All providers in a region must come to a formal agreement on the specific structure of the MCO. As of January 1999, two Partnerships were operational and serving clients. Passport serves 16 counties in the Louisville area and Kentucky Health Select serves 21 counties in the Lexington area. An estimated 175,280 people are enrolled in the program; approximately 20 percent of these (or about 35,000) are non-elderly persons with disabilities.

Michigan

Michigan is one of only five states that has a program developed exclusively for non-elderly persons on SSI. The Children's Special Health Care Services Program (CSHCS) is a specialized Medicaid managed care program caring for children (0-21 years of age) with special health care needs only.³⁷ The CSHCS is not entirely a Medicaid program as it also serves eligible children in the Maternal and Child Health Block Grant (Title V) program and in Michigan's CHIP program, "MIChild."

The CSHCS program has existed for some time on a fee-for-service basis. In the fall of 1998, the state launched a capitated option within the CSHCS program. It is currently enrolling participants (voluntary or mandatory) and was offered statewide by the end of 1999. Currently, two MCOs participate in the CSHCS managed care program.

Despite the existence of this specialized program, most persons with disabilities in Michigan are enrolled in a mandatory, mainstream capitated managed care program. The Michigan Department of Community Health implemented a full-risk mainstream capitated model called the Comprehensive Health Care Program (CHCP) – in part to address the rise of Medicaid expenditures in the 1990s. The CHCP is mandatory for persons receiving TANF and those on SSI who do not receive Medicare (among others); individuals dually eligible for Medicare and Medicaid may enroll on a voluntary basis. Currently, an estimated 748,750 people are enrolled in CHCP; this includes approximately 140,600 (or about 19 percent) non-elderly persons with disabilities.

New Mexico

New Mexico operates one Medicaid managed care program, known as Salud!, for all Medicaid enrollees, including non-elderly persons with disabilities. New Mexico's move to Medicaid managed care came about in large measure because of a desire to slow rapidly growing Medicaid expenditures during the period from 1986 to 1996. In 1996, the governor of New Mexico proposed conversion to a mandatory, capitated, all-inclusive program. Despite strong sentiments against managed care on the part of advocates, consumer groups and the press, the Salud! program was implemented in 1997. Prior to this time, New Mexico had operated a PCCM program that did not enroll persons with disabilities.

Salud! is a full-risk, capitated managed care program for the majority of Medicaid enrollees in New Mexico. Currently, an estimated 191,600 people are enrolled in Salud!; this includes approximately 35,000 non-elderly persons with disabilities (or about 18 percent of enrollment). Three MCOs provide care to most Medicaid enrollees: Presbyterian Salud, Lovelace Community Health Plan and Cimarron Salud. Each MCO is required to provide Medicaid services to residents throughout the state, regardless

³⁷ Individuals with cystic fibrosis or certain hereditary coagulation disorders are eligible for the program for life.

of their location or particular needs.³⁸ Because of the rural nature of the state, and the associated shortages of health care professionals, providers are permitted and even encouraged to affiliate with all three MCOs.

New Mexico also runs four waiver programs. One program, which is for persons with developmental disabilities, has an enrollment of about 1,650 people. Another waiver program serves about 1,300 disabled and elderly persons. There is a medically fragile program with approximately 130 enrollees; this program targets children who are severely disabled and who are generally technology dependent. The fourth waiver program provides care to about 50 persons with HIV/AIDS. All four programs provide case management, homemaking, and personal care services. Waiver enrollees receive non-waiver services from Salud! and are therefore considered part of the Salud! program.

³⁸ There are certain services that are provided outside of the MCOs through waiver programs. These are explained in greater detail in the companion case study report .

Table 1: Characteristics of Case Study States

	Florida	Kentucky	Michigan	New Mexico	United States
Sociodemographic					
Population (In Thousands –1998) ^a	14,916	3,936	9,817	1,737	270,299
Percent of Residents Living Inside Metropolitan Areas (1996) ^a	92.90%	48.20%	82.40%	56.70%	79.80%
Economic					
Percent of Population Below the Poverty Level (1996) ^a	14.20%	17.00%	11.20%	25.50%	13.70%
Personal Income Per Capita (1997) ^a	\$22,409	\$18,329	\$22,680	\$17,380	\$22,713
Median Household Income (1996) ^a	\$30,641	\$32,413	\$39,225	\$25,086	\$35,492
Health					
Doctors per 100,000 Civilian Population (1995) ^a	227	195	213	204	239
Rate of New AIDS Cases (per 100,000; 1996-1997) ^b	46.7	10.4	9.9	13.4	23.6
Smoking Prevalence (Adults Ages 18 and Older; 1995) ^c	23.1	27.8	25.7	21.5	22.4
Medicaid					
Percent of Population Covered by Medicaid (1994-1995) ^d	13.20%	13.70%	11.50%	16.00%	12.20%
Percent of Medicaid Beneficiaries in Managed Care ^e (June 1997)	63.55%	50.87%	77.55%	57.47%	47.82%
Percent PWDs in Medicaid Managed Care Programs (1998) ^h	66.4%	22.0%	58.9%	91.5%	26.9%
Percent in Managed Care who are PWDs (1998) ^f	24% ^g	20% ^h	18.7% ⁱ	18.3% ^j	N/A
Spending per Blind and Disabled Beneficiary ^k	\$6,920	\$5,571	\$8,701	\$8,488	\$8,784
Spending per Average Adult Beneficiary (Ages 21-64) ^k	\$2,419	\$2,198	\$2,036	\$1,794	\$2,080
Ratio of Blind and Disabled to Average Adult Beneficiary	2.9	2.5	4.3	4.7	4.2
Federal Medicaid Assistance Percentages (1998) ^l	55.65%	70.37%	53.58%	72.61%	60.66% ^m
Medicaid as a Percent of State Budget (1995) ⁿ	15.80%	18.60%	19.70%	13.40%	N/A

Sources

^aU.S. Bureau of the Census, see <http://www.census.gov/www.states>

^bCenter for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997, Vol. 9 (1). Atlanta, GA. Center for Disease Control and Prevention, U.S. Department of Health and Human Services.

^cCenter for Disease Control and Prevention. Morbidity and Mortality Weekly Report, Vol. 45 (44). 1996.

^dThe Urban Institute. Unpublished estimates from the TRIM-adjusted March 1995 and 1996 Current Population Survey (CPS) data. Washington, DC. 1997.

^eHealth Care Financing Administration, see <http://www.hcfa.gov/Medicaid/mcsten97.htm>

^fPWD = non elderly persons with disabilities. Source: M. Regenstein, and C. Schroer, *Medicaid Managed Care for Persons with Disabilities: State Profiles*. The Kaiser Commission on Medicaid and the Uninsured, 1998.

^gMediPass and the HMO Program combined.

^hHealth Care Partnerships Program only.

ⁱComprehensive Health Care Program only.

^jSalud! only.

^kD. Liska, B. Bruen, A. Salganicoff, P. Long, and B. Kessler, *Medicaid Expenditures and Beneficiaries: National and State Profiles and Trends, 1990-95*, 3rd ed. Kaiser Commission on the Future of Medicaid, 1997.

^lOffice of the Assistant Secretary of Planning and Evaluation, see <http://aspe.os.dhhs.gov/health/fmap98.htm>

^mAverage of 51 States' FMAP

ⁿNational Association of State Budget Officers. 1995 State Expenditure Report. Washington DC. National Association of State Budget Officers, 1996.

Table 2: Features of Medicaid Managed Care Programs in Case Study States

State Program	MICHIGAN			FLORIDA		KENTUCKY	NEW MEXICO
	Physician Sponsored Program (PSP)	Comprehensive Health Care Program (CHCP)	Children's Special Health Care Services Program (CSHCS)	MediPass	HMO Program	Health Care Partnerships Program (HCPs)	Salud
Type of Program	Mainstream, PCCM	Mainstream, Capitated	Specialized, Capitated ^a	Mainstream, PCCM	Mainstream, Capitated	Mainstream, Capitated	Mainstream, Capitated
Participation	Mandatory ^b	Mandatory	Voluntary	Mandatory ^c	Mandatory ^c	Mandatory	Mandatory
Population Served	Majority of Medicaid enrollees	Majority of Medicaid enrollees	Children up to 21 who meet medical and financial criteria ^d	Majority of Medicaid enrollees	Majority of Medicaid enrollees	Majority of Medicaid enrollees	Majority of Medicaid enrollees
Estimated Enrollment of PWD^e	N/A	140,600	100 ^f	135,000	70,000	35,000	35,000
Percent PWD in Total Enrollment	N/A	18.7%	100%	27.8%	18.8%	20.0%	18.3%
Waiver	1915 b	1915 b	Voluntary	1915 b	1915 b	1115	1115
Enrollment Broker	Yes	Yes	Yes	Yes	Yes	No	Yes
Services Carved Out	BH, LTC	BH, LTC	BH	BH	BH ^g	BH	None
Health Assessment Required	No	No	Yes	No	No	Yes	No
Case Manager Required for PWD	No	No	Yes	No	No	No	Yes
PCP Required to See New Enrollees	No	No	Yes	No	No	Yes ^h	No
Number of MCOs	N/A	30	2	N/A	16	2 ⁱ	3

^aA fee-for-service product is also available.

^bCurrently being phased-out and replaced by the CHCP.

^cEligible Medicaid enrollees may choose between the MediPass and HMO Program.

^dSome children eligible for Michigan's CHIP program or Title V services are also served by the CSHCS program. Individuals with cystic fibrosis or certain hereditary coagulation disorders are eligible for the program for life.

^eRegenstein and Schroer, December 1998.

^fProgram began enrolling children in September 1998.

^gIn the Tampa area, behavioral health services are covered by the health plans as part of a demonstration project.

^hCertain conditions require case management.

ⁱThe Partnership program is currently still being implemented. Once the program is phased-in statewide, eight MCOs will participate. Each MCO will serve all eligible Medicaid beneficiaries in eight different regions of the state.

Many states enroll disabled Medicaid beneficiaries in mainstream managed care programs designed for the general Medicaid population. These programs may or may not have special features designed to facilitate the enrollment of individuals with disabilities. The following section describes commonly used features and discusses whether the four case study states have adopted them when providing care to the disabled.

Enrollment/Autoenrollment

The four case study states closely mirror the national distribution of persons with disabilities in managed care arrangements in that their enrollments are largely mainstream and more likely to be in capitated arrangements. Of the states, Florida is the only one with an active PCCM program. (Michigan's is being phased out.) Its PCCM enrollment remains high, in part because of autoenrollment procedures that for years favored PCCM over HMO care, and in part because all enrollees may choose to enroll in the PCCM program. While overall more enrollees choose PCCM care, the proportions are even greater for persons with disabilities.

All four states operate large, mainstream managed care programs. One state – Michigan – offers a highly specialized program for children with chronic conditions and disabilities on a capitated or fee-for-service basis. This program is voluntary (as are all other specialized programs for non-elderly persons with disabilities in the country) and, while it has been in existence for several years as a fee-for-service option, it recently added a capitated “track” that is beginning to enroll children. Florida does not operate a separate specialized program, per se, but rather runs a voluntary “program within a program” via the Children’s Medical Services Network – an option within the MediPass program for children with specialized needs.

Most of the programs use an enrollment broker (or other agent) to handle all aspects of the enrollment process. Kentucky does not require the use of a broker because enrollees do not choose among competing health plans for their care. Kentucky’s model is unique in that it requires a consortium of providers to form a Partnership that becomes the sole source of care for all persons eligible for Medicaid managed care in the region. Once enrolled, individuals must designate a provider as their PCP or be autoassigned to one, except that the Kentucky Partnerships are not permitted to autoassign persons with chronic conditions and disabilities to a PCP. Instead, Partnership staff must work with the enrollee to help that person select a PCP.

In Florida, Michigan and New Mexico, persons with disabilities are autoassigned if they do not choose a health plan (or program), and again if they do not choose a PCP. Florida’s autoassignment practices have changed over the years; now all new enrollees who do not select an option are autoassigned to the HMO Program. Once assigned to that program, persons with disabilities (like other enrollees) are autoassigned based on the proportions designated by those individuals selecting health plans. In the MediPass program, Florida’s PCCM option, persons with disabilities are autoassigned based on

geographic area, with children assigned to pediatricians or family physicians and women assigned to obstetricians/gynecologists.

Michigan uses a formula derived through the competitive bidding process to autoassign enrollees in the Comprehensive Health Plan Initiative. New Mexico also uses this autoassignment strategy if it cannot autoassign to a previous provider who is currently participating in the Salud! program.

From our discussions with Medicaid officials, health plan representatives and advocates, it appears that the enrollment and autoassignment of persons with disabilities went relatively smoothly. In most cases, persons with disabilities were included in a subsequent round of enrollment; they were not included in the first group to enroll in managed care. In Kentucky, the enrollment of persons on SSI was delayed by only a few months, but this delay – in the longer run – provided an extremely helpful period of time for additional outreach and education activities that proved quite successful and well-received.

Delaying or staggering enrollment also has a “psychic” benefit, especially for persons with disabilities who may be concerned about the change to managed care and disruptions in their care patterns. These individuals know that their needs for health services are greater than those of the general population. For many of them, management of their own health conditions takes up an enormous amount of their time, energy, and resources. They do not want to be part of an experiment; on the contrary, they want assurances that the program will be relatively “glitch-free” if they are going to hand over control of their health care to a third party. Allowing some time for the program to operate before requiring persons with disabilities to join can alleviate certain fears on the part of persons with disabilities.

In practice, too, it can provide time for some of those glitches that are bound to occur in the start-up phase of a program to be resolved. Several of the states had administrative difficulties associated with moving large numbers of enrollees from one Medicaid system to another. In Kentucky, because of the delay, persons with disabilities were spared the anxiety and frustration surrounding these problems. Persons with disabilities in New Mexico, however, were not as lucky. They were included in the earliest enrollments in urban parts of the state, and advocates and consumers alike complained of enormous confusion and anxiety in the beginning months of the program.

Quality Assurance Programs

One of the benefits of managed care, at least in theory, is that accountability for health outcomes and quality is intertwined with fiscal accountability at the provider level. If managed care were designed exclusively to control costs, providers could use a variety of methods to curtail benefits or limit care – especially to persons who require costly services over long periods of time.

The appeal of managed care, however, is that it assumes accountability for costs and quality as a joint responsibility. In the Medicaid program, the shift to fiscal accountability is clear and rather simple to facilitate. States pay managed care organizations a fixed amount for each individual who enrolls in the organization, and it is up to the MCO to determine the appropriate mix of services (under a predetermined set of criteria concerning benefits, provider availability, and the like). States have a much more predictable set of outlays for the Medicaid population and can shift the burden of figuring out where to cut costs to the health plans – which may be a more appropriate group to make this decision since they are ones providing care on a day-to-day basis.³⁹

The delegation of accountability for quality, however, is less clear. All Medicaid managed care programs have quality standards and require participating MCOs to have written quality assurance provisions. MCOs must monitor quality and report to their state Medicaid offices on a variety of indicators of quality care. Some MCOs are required to survey their enrollees to find out whether they are satisfied with their care. All have mechanisms for enrollees to file concerns, complaints, and grievances – terms that are taking on different meaning and being debated in Medicaid offices throughout the country.

All of these provisions are extremely important to ensure that Medicaid enrollees are treated appropriately and fairly by managed care organizations and their affiliated providers. Surprisingly, however, there are few (if any) formal quality assurance provisions that apply to persons with chronic conditions and disabilities. Quality assurance has followed the mainstream model, with basic prescriptive and proscriptive provisions that apply to all enrollees. Little emphasis is placed on looking specifically at the group of people who are driving health care costs and utilization and whose care could benefit most – or be damaged most – by aggressive gatekeeping and care management.

In the absence of formal measures are varying degrees of informal oversight and monitoring on the part of Medicaid staff to make certain that MCOs are looking out for vulnerable clients. In Kentucky and New Mexico, Medicaid staff are monitoring health care delivery closely and staying in frequent contact with providers. Some of Kentucky's Medicaid staff appear to be making the Partnership program a personal challenge – there is a level of oversight and involvement from the Medicaid office that transcends the written requirements governing the program. There is also a resolve to incorporate consumers in the process that goes beyond standard practice in other communities.

Kentucky's program also defines a “medically fragile” group and requires Partnerships to take greater care in enrolling these individuals and linking them with necessary services. These front-end efforts have served several purposes: all persons with disabilities choose their PCPs after, in some cases, lengthy discussions with Partnership clinical

³⁹ Of course, they are also the ones that can benefit directly from these cuts, and this conflict requires that Medicaid and other payers continue to pay close attention to how funds are allocated across services and enrollees.

staff; and Partnership clinicians become familiar with the health status and health needs of the client populations – especially ones who need chronic and specialized care. Although the Partnerships are not required to see new enrollees within any specified time period, Medicaid officials say that this requirement is likely to be added as Partnerships become operational in other regions of the state.

Kentucky's program currently operates in only two regions – and they are the ones located in urban areas with academic health centers and a critical mass of primary and specialty care. As the program expands, Kentucky Medicaid staff may find it more difficult to maintain this same level of oversight in their relationships with the newer Partnerships.

Both of Florida's managed care programs require new enrollees to be screened by a primary care physician within 90 days of enrollment. This feature is extremely helpful for persons with disabilities, especially in a large state with many competing health plans, where Medicaid staff are less likely to keep a watchful eye over all managed care organizations. Michigan is also a large state with many competing plans; in that state, however, only the specialized children's program requires new enrollees to be seen within a set time period (in this case, 60 days). There are no requirements for providers to see new enrollees in Michigan's Comprehensive Health Care Program, despite the fact that most persons with disabilities enrolled in Michigan managed care are in the larger program.

Medicaid managed care is a highly regulated industry, with scores of requirements concerning benefits, providers, capital, hours of operation and the like. It is disconcerting that so few of these provisions require MCOs to monitor carefully the experiences of persons with disabilities. Even Kentucky's efforts, which are in some ways extraordinary, rely on front-end efforts on the enrollment side and informal (individual staff-driven) efforts to assure quality for persons with special needs. More targeted quality assurance measures specifically for persons with disabilities might provide a consistent and stable source of information that, over time, could be used to determine how persons with different types of disabilities and chronic conditions fare in managed care arrangements.

Special Features for Persons with Disabilities

As the national survey of state practices indicated, there are relatively few special features for persons with disabilities. In our discussions with the states, we probed for details about enrollment, autoassignment, covered services, case management, requirements to see new enrollees, use of a specialist as PCP, quality assurance, and coordination with advocacy groups in an attempt to identify variations in the programs for persons with disabilities.

As was noted above, only five programs across the country target children and/or adults with chronic conditions and disabilities only – all of their features, by definition, are specialized. Yet their collective enrollments come to less than 1 percent of total

enrollment of persons with disabilities in managed care. Clearly, specialized programs are not the model of choice for Medicaid managed care at this point in time.

Of the mainstream programs, only a few special features for persons with disabilities are included to manage or monitor their care post-enrollment. Several states modify their enrollment practices for persons on SSI but, once enrolled, appear to rely on mainstream provisions for their care and quality assurance. Of the states under review, Kentucky stands out again for its identification of medically fragile individuals and its proscription against autoassignment to a PCP for persons on SSI.

Behavioral Health

States continue to face challenges providing managed behavioral health services to their enrolled populations. Each of the states, though proud of their efforts in managed care and believing their programs are improving quality and access, are reluctant to claim the same level of success on the behavioral health side.

Medicaid officials cite a number of reasons why behavioral health can be such a difficult program to manage well. First, many of the states have significant shortages of mental health and substance abuse professionals – especially ones who will see Medicaid patients. Second, there are issues of care coordination and turf; mental health services have never been well-coordinated with physical health services, and serious inequities remain in payment for mental health versus other health services.

States are also struggling with the basic design of the delivery of managed behavioral health services, and remain torn between including behavioral health within the total capitated payment and carving it out for payment to a separate BHO. New Mexico has taken a blended approach by requiring its MCOs to partner with a separate behavioral health organization (BHO). In this way, care is linked to the MCO (which, technically, is ultimately responsible for the provision of services) but provided by a separate entity that is expert in the provision of behavioral health services. This arrangement has its opponents who question, among other issues, the way that risk is shifted from the MCO to the BHO to intermediaries and then to community-level providers. In practice, however, it appears to be working relatively well, and access to a variety of behavioral health services has improved significantly within Salud!.

Kentucky is in the process of setting up Partnership-like entities under its new Kentucky Access Program to provide behavioral health services through a program that is separate – but linked programmatically – to its Partnership program. Liaisons on the physical health and behavioral health side will work together to try to coordinate service delivery. All parties say, however, that the process has been more challenging than originally envisioned. Nevertheless, they remain optimistic about their ability to improve behavioral health care delivery in the state.

Florida is experimenting with a capitated pilot in the Tampa region – the Prepaid Mental Health Program – that involves the use of Community Mental Health Centers as many of the providers of core services, and partners with Value Options to provide administrative and management leadership. All MediPass enrollees in a five-county region enroll in the program for mental health care and continue to receive substance abuse services on a fee-for-service basis.⁴⁰ Florida Medicaid appears to be pleased with the pilot, although advocates have concerns about care coordination and access to psychotropic drugs.

In Michigan, health plans are required to provide up to twenty outpatient mental health visits and all mental health-related medications, although they do not manage the care of most persons needing mental health services. Most behavioral health is provided through the Managed Specialty Services program. The principal providers for this program have been 49 county-sponsored Community Mental Health Service programs; however, the state plans to develop a competitive bidding process which may “shake up” the provision of services over the next several years.

Rate-Setting and Adverse Selection

With one exception, the programs in the four states use relatively simple rate-setting criteria to pay health plans for Medicaid enrollees. Most adjust rates by categorical eligibility (in this case, whether the enrollee receives SSI), age, gender, and sometimes geographic area. Only one program, Children’s Special Health Care Services in Michigan, incorporates additional risk-adjusters based on diagnosis-related categories.

Risk-adjustment is complicated. Though previous work has indicated that the health costs of persons with disabilities are actually more predictable than the costs of the general Medicaid population,⁴¹ it is nevertheless a complex and challenging undertaking to develop and implement meaningful risk-adjusters in Medicaid managed care.

It should not be surprising, then – given what we know about the extent to which programs that enroll persons with disabilities rely on a mainstream model – that most states have moved forward with mandatory enrollment of most persons on SSI without first developing risk-adjusters to reduce the likelihood of adverse selection and provide some financial safeguards for their care. Florida, Michigan and New Mexico have each heard from plans that insist they are experiencing adverse selection. Empirical analysis could support or refute these contentions but Medicaid staff in these states have not conducted such analyses.⁴²

⁴⁰ At the time the program was developed, substance abuse providers did not want to participate.

⁴¹ Kronick R, Zhou Z, Dreyfus T. Making Risk Adjustment Work for Everyone. *Inquiry*, 1995;32:41-44.

⁴² Medicaid staff in New Mexico looked at payments to plans following claims of adverse selection. The state concluded that there was not adverse selection, despite the fact that certain types of enrollees were favoring certain plans. The state claimed that total costs associated with these patients were distributed evenly across the plans (in proportion to their total enrollees). The methodology used in the analysis was very simple and would have identified only the most obvious patterns. The question about adverse selection is still very much an open one.

Nevertheless, Florida and Michigan plan to incorporate more sophisticated risk-adjusters into payment methodologies in the future. Kentucky officials, on the other hand, prefer a relatively simple rate-setting structure – in part because they have a non-competitive model and are not experiencing adverse selection at the plan level.

The children’s specialized program in Michigan offers a very interesting example of one state’s attempts to risk-adjust based on diagnosis and develop financial incentives and safeguards for providers who participate in the capitated option. The program is in its very early stages, however, and enrollment has been lower than originally anticipated. Over time, it will be interesting to watch how these diagnostic groupings distribute resources across the two participating MCOs and to see whether they redress the problems associated with adverse selection.

Lessons Learned

Proponents of managed care assert that such programs have considerable potential to improve the health and functional status of people with disabilities by improving access to primary and preventive care, coordinating and integrating health and social services, and encouraging the use of home and community-based alternatives to institutional care. Nevertheless, if not properly designed and monitored, managed care can pose serious threats to the health and well-being of people with disabilities. For example, managed care may sever patients' long-standing relationships with physicians who understand their special needs and problems. It may create incentives for providers to block access to specialty care and ancillary services that are required to meet the complex needs of children and adults with disabilities. It may also exacerbate the adverse risk selection in the health insurance market, furthering incentives facing health plans to sidestep enrolling people whose anticipated medical costs are high. As states design programs for their disabled population, they will need to consider these issues and decide how or even whether managed care can serve the needs of this vulnerable population.

Even at these early stages of enrollment, it is possible to identify certain characteristics or features of Medicaid managed care programs to help persons with disabilities obtain high-quality health care that tries to facilitate their access to health services. The experiences in Florida, Kentucky, Michigan and New Mexico, as well as the survey and focus group data, are extremely instructive and provide lessons for policymakers who may be considering enrolling persons on SSI in their Medicaid managed care programs. These lessons are also relevant for programs that are already up-and-running to help develop ways to safeguard the care of persons with disabilities. These lessons are based on the findings from the national survey of state practices, focus groups, and case studies and are offered with the hope that states will continue to explore managed care models of care for persons with disabilities before returning to costly and fragmented care under fee-for-service models.

1. ***Move steadily, but not swiftly to managed care, enrolling persons with disabilities in the program only after it has been operational for some period of time.*** States should phase in managed care requirements in stages, rather than

leaping from old to new models without a period of trial and adjustment. During the early phases some measures may be used that will later be abandoned, such as allowing enrollment to be voluntary rather than mandatory and maintaining a PCCM model as an alternative to HMO enrollment. People with disabilities could be phased in at later stages of enrollment. Our studies found that the states that waited to enroll persons with disabilities – after an open planning process that involved consumers and advocates – generally had smoother transitions, better designed programs, and less resistance over the long run from opponents and advocacy groups.

2. ***Involve consumers, involve consumers, involve consumers.*** All states that we spoke with touted the involvement of consumers and advocacy groups, but few built consumer representation and involvement into all stages of program development, quality assurance, and oversight and monitoring of the program. Ultimately, if the goal is to design a system that works well, saves money, and responds to client needs, consumer involvement is an absolute necessity. Moreover, if family-centered care is to be more than a slogan, enrollees and their families must be involved in program design and mid-course corrections throughout the process.
3. ***If the program is a mainstream model, identify a population with special needs and develop specific provisions for their enrollment and ongoing care.*** Some of the mainstream programs have developed a “program within a program,” at least for enrollment efforts, to make certain that special health needs are appropriately addressed. This helps to focus attention on the needs of this group and acquaints the health plan with these enrollees.
4. ***Special attention to the care of the general Medicaid population also translates into special care for persons with disabilities.*** Florida’s requirement for primary care physicians to see all new enrollees within a certain time period means that persons with disabilities will be assessed shortly after enrollment. Systems that respond to each and every complaint or grievance work well for all enrollees in a plan. Well-designed features to improve care for all enrollees will have derivative benefits for persons with disabilities.
5. ***Set up systems to monitor the availability and utilization of prescription drugs, durable medical equipment, home health and physical therapy.*** Information from the focus groups in Florida and New Mexico and other sources identifies the types of services that persons with disabilities commonly have problems accessing. Health plans should have flexibility in determining how to use resources cost-efficiently, but there appears to be a bias against equipment and services designed to improve the physical and functional well-being of persons with disabilities. States should take steps to assure persons with disabilities access to these vitally important equipment and services.
6. ***Don’t underestimate the ability of Medicaid staff to influence care delivery.*** Providers in several states are acutely aware of the extent to which they are monitored by their state Medicaid offices. Though they complain about the oversight, health plans respond to it and are likely to exercise extra care when it comes to vulnerable populations.

7. ***HCFA should work with and encourage states to set standards for health plans to facilitate the protection of people with chronic conditions and disabilities as they move into Medicaid managed care.*** For example, HCFA and the states could set standards requiring health plans to: 1) identify people with chronic illnesses and disabilities; 2) conduct timely assessments of their health and functional status and the health and social services they need; 3) track progress in quality of care and outcomes; and 4) report on the performance of health plans in meeting the needs of people with disabilities. Where shortfalls in quality or performance occur, plans should be required to develop strategies for improving the situation. Over time, if plans do not correct deficiencies in quality of care, states should consider whether contracting with those plans is in the interest of the Medicaid beneficiary.
8. ***Until risk-adjusters are developed to even the playing field, monitor adverse selection carefully and develop ways to measure for it.*** Health plans in competitive markets are likely to claim that they experience adverse selection, but there are few mechanisms in place to measure this or adjust for it in the absence of sophisticated methodology. Even in the absence of such sophisticated methodology, however, states can improve the current rudimentary adjustments that are limited to categorical eligibility, age and gender. For instance, states can investigate methods for compensating plans for caring for more costly enrollees through withholds or “bonuses” for more complex case loads. In addition, HCFA could support further refinement of risk adjustment mechanisms and permit states to either adopt a “HCFA model” or implement their own comparable version.
9. ***Think through managed behavioral health care to determine ways to make the system work better.*** Virtually all of the state behavioral health programs are plagued with coordination problems within and across managed care plans. With no clear model yet designed to address these issues, states should try to develop safeguards to minimize these problems. In the meantime, a lot more consumer involvement could help identify the most vulnerable gaps in service delivery and try to shore those up through a combination of managed and fee-for-service arrangements.
10. ***Be sensitive to the cultural and political realities of the state.*** What may work in one region of the country may be a disaster in another. States that have been successful from the planning stages have been sensitive to provider needs and anxieties about managed care, historical turf issues, population diversity, and other local concerns. There are examples of managed care programs that were hotly contested by their communities and others that were cautiously accepted. States that worked through the issues before enrollment began had many fewer problems in implementing Medicaid managed care.
11. ***It may be easier to “keep an eye on the program” in smaller Medicaid states.*** Medicaid staff in Kentucky and New Mexico keep a close watch on their programs, but it would be hard to imagine Florida or Michigan staff keeping similar tabs on their much larger Medicaid programs. If the model of close oversight by Medicaid staff works well for people with disabilities, though, it might be useful to determine ways to develop smaller, more manageable regional programs. HCFA should work with states to identify models of excellence for the care of chronically ill and disabled

populations. The field needs careful, objective, critical reviews of managed care arrangements for adults and children with chronic conditions and disabilities to develop an understanding of what works and what does not.

1450 G STREET NW, SUITE 250, WASHINGTON, DC 20005
PHONE: 202-347-5270, FAX: 202-347-5274,
WEB SITE: WWW.KFF.ORG

Additional free copies of this publication, Medicaid Managed Care for Persons With Disabilities: A Closer Look, (#2179) are available by calling our publications request line at 800 656-4533.