
MODERATOR BIOGRAPHIES

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MANAGED CARE FOR CHILDREN AND ADULTS WITH DISABILITIES: A STEP IN WHICH DIRECTION?

Brian Burwell and Sandra Tanenbaum

Introduction

Managed care financing and delivery models have considerable potential for improving the value and quality of health care and supportive services provided to children and adults with disabilities. Managed care models that encourage flexibility in benefit coverage and which coordinate care across the full spectrum of the insurance benefit package are features that are particularly attractive to persons with disabilities. At the same time, however, managed care incentives to eliminate “inappropriate care” or care that is not “medically necessary” are of great concern to people with disabilities whose experience in obtaining access to needed health care services in the fee-for-service system is already problematic.

Both positive and negative effects of managed care for persons with disabilities are similarly reflected in the limited empirical research that has been conducted to date on the impacts of managed care on disabled populations. Some studies point to improvements in outcomes, while others have found significant reductions in service levels under managed care incentives. In brief, the jury is still out on how managed care models effect the health care status of persons with disabilities, and the challenge to the health care services research community is to monitor the enrollment of persons with disabilities into managed care systems closely, and to identify those factors which contribute to improved and worsened outcomes for these vulnerable populations.

Children and Adults with Disabilities: Who Are They?

Part of the challenge in assessing the impact of managed care on persons with disabilities is that the population of children and adults with disabling conditions is extremely diverse, with broad-ranging differences in both types and levels of impairment. At the same time, managed care models are evolving into a variety of permutations that make the generalizability of managed care impact studies increasingly hazardous. In conceptualizing a research agenda for examining managed care impacts, it is critical that we begin with a fundamental understanding of the defined populations, and how the structure and incentives of managed care models may impact access, cost and quality outcomes for persons with severe and chronic disabling conditions.

Children with Disabilities

National survey data indicate that approximately one in ten children have a “severe chronic illness” (Neff and Anderson, 1995). This estimate obscures dramatic diversity in the characteristics of children with disabling conditions--many children with disabilities have conditions which do not result in health care use or costs significantly higher than the population of children without disabilities, while a significant minority of children with disabilities have severe and multiple conditions that require continuous and expert medical attention. Health care and supportive services for the population of children with special health care needs are also fragmented across a variety of financing and service settings that renders the transition from a fee-for-service framework to a managed care framework operationally cumbersome.

Importantly, within the population of children with high health care needs, there is a subset of children with extremely severe medical conditions that require continuous and highly specialized care. For example, within the target population of SSI children receiving services under the District of Columbia’s

Managed Care System for Disabled and Special Needs Children Demonstration, a Medicaid Section 1115 waiver program, children with Medicaid expenditures of over \$50,000 per year constituted less than three percent of all SSI children in the District in the year prior to implementation of the demonstration program, yet they accounted for about 54 percent of all Medicaid spending for SSI children (Blanchon, 1996).

Childhood disability differs from disability in adulthood in that the nature and extent of the disability frequently changes during the developmental process. Many children experience improvements in functioning as they develop, and the disability may become less limiting with time. Other children with extremely severe medical conditions do not survive childhood at all. Moreover, the health care needs of children with disabilities is confounded over time by the interaction of the disability with the child's normal development, such as the onset of puberty. Consequently, access to appropriate pediatric and adolescent specialists may change frequently during the developmental process.

In regard to accessing health care, parents obviously take an active role in negotiating the health care system for their children. In brief, many parents take on the "coordination of care" role that is generally lacking in the fee-for-service system. Consequently, their interactions with the care coordination function of a managed care system may require a new accommodation of respective roles in managing the care of the disabled child. Managed care organizations are generally not used to the level of advocacy and health care system knowledge exhibited by parents of children with disabilities, and may not know how to positively incorporate that energy and knowledge into their internal care coordination systems.

A common concern of parents is the ability to maintain relationships with pediatric specialists, many of which have developed over the lifetime of the child, once the child is enrolled into a managed care plan. Consequently, in some Medicaid managed care initiatives, states require participating plans to continue to pay for ongoing physician-patient relationships, even if the specialty physician is not otherwise enrolled in the plan. This issue is of obvious concern to plans who feel that they are being paid to manage the care of the enrollee, but may not be given all the requisite tools to do so.

Children with disabilities differ from adults with disabilities in one other important respect--children are more likely to receive their health care through a fragmented financing system. Expansions in SSI and Medicaid eligibility for children with disabilities in recent years has meant that there are a growing number of children who have both private health care insurance and Medicaid coverage. Since the Medicaid benefit package is more comprehensive than private health insurance coverage, children and families often use their Medicaid coverage to finance services that are supplemental to their private insurance benefits, particularly home and community-based services and extended therapies. In addition, under the Individuals with Disabilities Education Act, local school systems are required to provide children with disabilities with educationally related services that often extend into the health care arena, particularly in the case of children with severe medical conditions. Lastly, under the Title V Program for Children with Special Health Care Needs, many states provide direct care services to children with disabilities on a categorical basis, not as part of the child's health insurance benefit. Since the implementation of managed care systems generally occurs within payers, not across payers, these multiple financing streams for children with disabilities create special challenges for the managed care marketplace.

Adults with Mental Illness and Substance Abuse Problems

Purchasers of health care services in both the private and public sectors have targeted services to persons with mental illness as prime candidates for managed care financing and delivery initiatives. In the private sector, many large companies have "carved-out" mental health and substance abuse benefits from their mainstream health care benefit programs, and have contracted with specialized vendors to administer these benefits. In the public sector as well, state Medicaid programs are building upon the infrastructure that has developed in managed behavioral health care to similarly "carve-out" at least a subset of mental

health and substance abuse-related services covered under their own benefit packages to companies that specialize in the management of these services. On the research side, there is a larger body of research available on the impacts of managed mental health care than on how managed care impacts other services and/or populations.

While there has been significant penetration of managed care systems in the mental health/substance abuse market, it is important to recognize the differences in private and public markets as they relate to persons with mental health and substance abuse problems. In the private sector, purchasers finance mental health and substance abuse care for their employees, retirees and dependents. This population of workers and dependents is predominantly middle class and employed, with the concomitant array of mental health conditions that are most prevalent in this socio-demographic group. Depression and substance abuse disorders are diagnoses of high concern to private purchasers of health care, and the health care benefit programs of employers are structured to maximize value in the early identification and treatment of these conditions, with the objective of sustaining the productivity of their workforces.

In regard to coverage of mental health and substance abuse services for the dependents of employees, the goals are to provide coverage that is sufficiently attractive to recruit and retain a quality workforce (i.e. remaining competitive in the market for qualified workers) while limiting corporate expenditures for mental health and substance abuse care. Coverage of mental health and substance abuse care for adolescents with mental health conditions is often a major benefit issue for employers, since this population includes a subset of persons who account for a high percentage of total expenditures for these services.

In the public sector, the primary population of interest is persons with severe and persistent mental illnesses, particularly persons with disabilities associated with schizophrenia-related disorders. Approximately 30 percent of all adults under the age of 65 receiving SSI benefits, or about 1.5 million persons, qualified for SSI benefits on the basis of a mental disorder other than mental retardation (SSA, 1996). In addition, about 1 million persons with mental disorders received SSDI benefits, and are therefore insured under the Medicare program. As opposed to individuals receiving SSI benefits, persons receiving SSDI benefits have had a sufficient work history to obtain insured status under the Social Security disability system. On the whole, it is therefore reasonable to assume that SSDI beneficiaries have somewhat higher levels of functioning than persons receiving SSI.

Persons with severe and persistent mental illness have a broad range of medical, therapeutic, and supportive care needs, and a key issue in the application of managed care models to this population is what part of the care spectrum should be "managed." Although a number of state Medicaid programs have implemented mental health "carve-out" programs, it is important to recognize that states generally have only "carved-out" acute mental health services under these programs--inpatient care and outpatient follow-up care. Long-term supportive services, such as residential care programs, vocational training, day program services, and intensive case management services, have generally been excluded from the managed care contracts with carve-out vendors. Basic health care services are also usually provided by mainstream plans or the fee-for-service system.

The characteristics of persons with severe and persistent mental illness and their health and supportive service needs forcefully underscore the challenges of applying managed care models to the financing and delivery of services to this population. As a consequence, we are seeing a variety of managed care models emerging. Conceptually, one relatively simplistic way of classifying the service needs of this population is in three broad categories: (1) basic health care needs; (2) mental health-related services needed to deal with acute episodes of mental illness (short-term hospitalization, crisis intervention services); and (3) long-term supportive services intended to maintain individuals in independent or semi-independent community care settings.

As discussed above, most managed care initiatives for persons with severe and persistent mental illness have focused only on the management of one part of the total service continuum, i.e. the management of short-term hospitalizations and outpatient services. Basic health care services and long-term supportive services have, with few exceptions, *not* been made part of state managed care initiatives, as yet. A major reason for this segmentation of the total benefit package is related to infrastructure issues—states are building upon the infrastructure of managed behavioral health care vendors that have developed from demand created in the commercial marketplace. Another reason for this segmentation relates to the fragmentation of payments sources; Medicaid is generally the primary payer for acute mental health services for this population, while state Departments of Mental Health remain the primary payer for longer-term supportive services.

The limited scope of managed care initiatives for persons with severe and persistent mental illness has created “boundary” issues that affect the operationalization of these programs in critical ways, as well as how this population receives services. One fundamental issue is the boundary between mental health care and basic health care. Does it make sense for persons with severe mental illness to receive their primary health care through one system but have their “mental health” services managed by a separate system? If so, how is medication management coordinated across these dual systems? One major rationale for managed care is to coordinate care across a comprehensive benefit package for an enrolled population, and managed care initiatives which simply mirror the fragmentation of service delivery existent in the fee-for-service system are likely to fall short of this goal.

On the other hand, some state Medicaid programs have “carved-out” mental health services from managed care contracts for basic health care as a means to *protect* the population from the financial incentives of managed care to reduce services that may not be considered “medically necessary.” There is considerable controversy in the commercial insurance market about the “savings” that have been achieved for health care purchasers by behavioral managed care vendors, and whether these savings are affecting mental health outcomes. Thus, in the public sector, mental health carve-outs have been used as a policy tool to protect mental health benefits from the incentives of managed care plans, most of whom have little experience in providing services to persons with severe and persistent mental illness. However, another factor in states’ decisions to carve out mental health benefits has been advocacy by the specialized provider systems that serve this population to protect their market share.

Another boundary issue in designing managed care systems for persons with severe and persistent mental illness is whether to combine substance abuse programs with mental health services into an integrated managed care system. Although programmatically, there are strong reasons for bundling mental health and substance abuse benefits for this population in an integrated system, infrastructure issues and provider concerns often act to keep these services unbundled.

A final issue regarding the application of managed care models to persons with severe and persistent mental illness concerns the measurement of plan performance. What measures should purchasers (public or private) use to assess whether plans are doing a “good job?” Persons who support individuals with severe mental illness know that interventions of the highest quality can still lead to undesired outcomes in some individuals, while in other cases, people with mental illness somehow seem to get better or do okay despite inferior care or the absence of care. The relationship between good care and positive outcomes in this population is not straightforward, and the assessment of performance probably needs to measure average outcomes over sufficiently large samples of individuals, wherein the differentiation between inferior and superior care can be more reliably discerned.

Adults with Physical Disabilities and Persons with AIDS

The population of persons with severe and chronic physical disabilities, including persons with multiple sclerosis, cerebral palsy, muscular dystrophy, quadriplegia, and other conditions, encompasses a very broad range of disabilities and impairment levels. Persons with severe physical disabilities are often not well served by the fee-for-service health care system, and many experience the frustration of referrals to multiple specialists without any single physician taking overall responsibility for the oversight of their health care. If the care coordination functions of managed care models truly take hold, then managed care holds some promise for improving access and quality for persons with severe physical disabilities.

However, as with other disabled populations, many people with severe physical disabilities are skeptical that managed care organizations will provide them with access to comprehensive and coordinated medical care. Many worry that managed care organizations will be stringent in the allocation of resources in meeting their medical needs and will perceive them as “undesirable” enrollees, particularly if the cost of their care exceeds the average premium paid by their sponsor, be it an employer, Medicare, or Medicaid. For persons who require highly specialized care, many worry whether managed care plans will deny access to the most qualified specialists, and/or specialists with whom they have developed long-standing relationships.

On the purchaser side, private employers generally place little emphasis on ensuring that covered individuals with severe disabilities are adequately served in the managed care system. The disability programs of employers generally focus on short-term disability issues; the integrated management of their health insurance, workmen’s compensation, and disability insurance programs; and rehabilitation initiatives which assist injured workers’ to return to work as quickly as possible. The quality of health care provided to persons with severe and chronic conditions is generally not an issue of high concern to most private employers. Furthermore, the assessment of the performance of managed care plans by employers has largely focused on measures that are pertinent to large segments of their covered populations (e.g. prenatal care, immunizations, etc.) rather than on how plans treat individuals with rare conditions.

For persons with severe disabilities who do not have private insurance and are covered by Medicaid, it appears that mandatory enrollment in some kind of managed care system is increasingly inevitable. With completion of the enrollment of non-disabled Medicaid populations into managed care, states are now focusing their attention on the more difficult challenge of enrolling SSI recipients into managed care (Checkett, 1996). And unlike persons with severe mental illness, mental retardation and/or developmental disabilities, persons with severe physical disabilities generally do not have specific “sponsors” or “programs” within state government whose responsibility it is to look out for their welfare. Just as the needs of persons with physical disabilities often fall through the cracks in the current Medicaid system, there is equal danger that the needs of this population will be largely ignored in the headlong rush to achieve Medicaid savings through managed care approaches.

In contrast, persons with AIDS are receiving special attention in the development of Medicaid managed care models. Led by the model developed by the Community Medical Alliance in Boston, the concept of “specialized health plans” (SHPs) which target a single population type, is now being replicated in other states such as Maryland and New York. Specialized health plans are generally perceived as *voluntary* alternatives to mainstream managed care plans, rather than mandatory alternatives that persons with certain conditions would be required to enroll in. The development of specialized plans is not totally attributable to demand side factors. Another factor is that specialized provider networks with experience in providing health care services to specific populations want to be able to preserve their “product line” without having to diversify into being mainstream health plans.

The Community Medical Alliance model for managing the care of persons with AIDS places strong emphasis on the substitution of non-institutional care arrangements for institutional care, particularly during the terminal phases of the illness. The recruitment and training of medical care professionals that are

committed to the treatment philosophy and culture of the Community Medical Alliance is another key component of the model.

Areas of Commonality Across Populations

Although children with severe disabilities, persons with severe and persistent mental illness, and adults with physical disabilities possess diverse characteristics that raise unique issues in the application of managed care models, there are some common characteristics shared by all of these populations. First, persons with severe disabilities of all types require access to specialty services that may be limited under managed care approaches. Closed panel plans may have few or no physicians with expertise in the care of conditions with low prevalence rates in the general population. Point-of-Service plans may allow enrollees to seek care outside of their networks, but at a higher cost to enrollees, who may have limited financial resources to utilize out-of-network providers.

Second, the health care costs of disabled populations are more predictable than the health care costs of non-disabled populations. Not only are they more predictable at the population level, but also, in many cases, at the *individual* level. This creates opportunities for health plans to maximize profitability by adopting business strategies to limit the enrollment (or increase disenrollment) of individuals whose health care costs are predictably above the payment rate made to the plan. Risk adjustment strategies which pay plans fairly for the *expected* costs of persons with disabilities, yet which still reward plans for efficient care, are critical to the application of managed care models to these populations, as well as to ensuring that persons with disabilities are provided quality care by the plans in which they are enrolled (Kronick et al, 1996). However, alternative mechanisms, other than risk adjusted capitated rates, for financially rewarding plans which enroll higher-cost individuals and providing quality services, also need to be explored. Risk-adjusted capitation may prove *not* to be the best solution to addressing these incentive issues, particularly given the technical and operational challenges of measuring risk and adjusting payments appropriately.

Third, the development of performance measures, which reliably assess the relative performance of plans in providing medical and supportive care to persons with disabilities of all types, is an area that requires extensive work and development. Workable approaches to eliciting the perspective of consumers, many of whom may have disabilities which impede traditional survey methods, is a key issue in the development of such measures.

Fourth, it is frequently the case that people with disabilities are receiving services from multiple payment sources and programs concurrently. The development of managed care models for these populations must respond to a set of needs that are broader than the financing and delivery of medical care. If care for these populations is to be truly integrated, then models need to be developed which consolidate the financing and delivery of health care services, rehabilitative services, long term care services, family supports, respite care, occupational supports, and personal counseling within integrated organizational structures. It may not be necessary for a single organization to possess all of these capabilities, but a managed care approach to these populations must include mechanisms for effectively coordinating the full array of medical and *related* services that are needed to help persons with disabilities maintain the highest level of independence possible.

What Does the Research Tell Us About the Impacts of Managed Care?

Empirical research which directly measures the health outcomes of persons with disabilities in fee-for-service versus managed care settings is extremely limited, and the research which has been conducted does not paint a consistent picture of the impacts of managed care. Research on the impacts of targeted managed care initiatives seems to paint a more positive picture, while general population studies of

managed care impacts are more pessimistic. Also, considerably more research has been conducted of the impact of managed care on mental health populations than on populations with other types of disabilities.

Master et al (1996) describe improved outcomes among persons with severe disability and AIDS in a targeted Medicaid managed care program in Massachusetts. Positive outcomes included increased patient satisfaction, reduced inpatient hospital days, and improved decubitus ulcers and PCP. The study suggests that managed care can improve care for persons with severe disability through the use of innovative providers providing care in innovative settings, relative to the fee-for-service system. The results of this research may be questioned, however, given that the researchers also represent the senior management team of the managed care organization being studied. Similarly, Meyers et al (1987) found improved outcomes from managed care in a population of severely disabled adults in an independent living center, largely associated with increased resource allocation to care provided in the individual's home and centered around the person's individualized needs.

In an 11-year longitudinal study of persons with rheumatoid arthritis receiving care in fee-for-service settings versus prepaid group practice, Yelin et al (1996) found no evidence of differences in either the quantity of health care provided or in health care outcomes on either an annual or long-term basis across the systems of care.

Studies of populations in mainstream managed care plans seem less positive. An analysis of data from the Medical Outcomes Study (Ware et al, 1996) found that while health outcomes for the average patient did not differ between fee-for-service and managed care settings, health outcomes were decidedly poorer for patients who reported ill health at baseline. The study suggests that while managed care plans do quite well in maintaining the health of healthy patients, relative to fee-for-service, that people with higher medical needs fare less well in managed care, due to financial incentives among plans to reduce the level of resources applied to medical interventions. The findings of the Medical Outcomes Study support similar findings by the same research team ten years previously (Ware et al, 1986). Although the population of interest in the Ware study encompassed "chronically ill" persons, not persons with severe disabilities, it is reasonable to generalize the study findings to all populations with higher-than-average medical care needs. In another study of data from the Medical Outcomes Study, Safran et al (1992) found notable differences in dimensions of primary care provided to persons with chronic illness across fee-for-service plans, IPA-model plans, and traditional HMOs, but did not specifically associate these differing primary care paradigms with patient outcomes.

Research on the impacts of mental health managed care models is decidedly richer. The Medical Outcomes Study reported above found superior mental health outcomes in managed care for nonpoverty populations, but inferior outcomes in the poverty group (Ware et al, 1996). Wells et al (1990) found that one managed care network provided less intensive mental health services to their covered population but a higher quantity of services. Lurie et al (1992) found few differences in mental health outcomes among patients served in managed care versus fee-for-service with one exception--persons with schizophrenia showed superior outcomes in a fee-for-service setting. And in a study focusing on a population of persons with depression, Rogers et al (1993) reported that depressed patients declined, on average, in managed care settings, declines that were likely attributable to a drop-off in the prescription of anti-depressant drugs.

Other studies have reported more positive impacts of mental health managed care initiatives. Superior mental health outcomes under managed care, as well as reduced financial impacts on patients, were reported by Babigan et al (1992). Shern et al (1995) also reported greater reductions in problems, fewer unmet needs, and higher adherence to clinical protocols, among mental health clients in a managed care demonstration than in a comparison fee-for-service population.

A few studies have evaluated the impacts of mental health carve-out programs for Medicaid populations, and thus far, have generally reported favorable outcomes. Callahan et al (1995) conducted an evaluation of a Medicaid mental health carve-out in Massachusetts and reported that the carve-out vendor was successful in substantially lowering Medicaid costs for acute mental health services without any overall reduction in quality or access. Christianson et al (1995) also reported significant reductions in Medicaid expenditures for mental health services in the first year of a carve-out initiative, primarily due to reductions in inpatient admissions for mental health treatment, although mental health outcomes were not measured.

Studies that assess the impact of managed care on children with disabilities are very few, although a number of researchers have published on the potential dangers of managed care systems on children with disabilities. Fox et al (1993) reported findings from a survey of parents of children with disabilities, with mixed results. Parents were pleased with the reduced out-of-pocket costs associated with managed care systems, and with improved access to medical services, but at the same time reported increased difficulty obtaining access to specialty services and mental health care. The focus of managed care plans on requiring specialty care interventions to demonstrate rapid improvement was cited as a significant concern, and a barrier to care continuity.

Discussion: Is Managed Care for Children and Adults with Disabilities a Step Forward or a Step Backward?

Research on the impacts of managed care on children and adults with disabilities is decidedly mixed. The limited body of research published to date seems to suggest that the incentives of capitated financing mechanisms are not, in and of themselves, the primary determinants of outcomes. Rather, the research suggests that operational variables, i.e. how managed care models are *applied*, are equally important, if not more important, in determining how people with disabilities fare in the managed care world. Of particular interest is the nature of the managed care entity with whom the purchaser has contracted to provide care. Managed care organizations with missions to serve persons with disabilities, and organizations who provide specialized services, appear to achieve better outcomes for persons with disabilities than do mainstream plans which have no special focus on the needs of disabled populations.

As managed care models continue to evolve, and as purchasers increasingly pursue innovative managed care purchasing strategies, it will be increasingly important for researchers to help sort out *which* managed care models are associated with improved outcomes and reduced costs versus those managed care models which achieve reductions in health care costs only to the detriment of the populations they are intended to serve.

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IMPACT OF MANAGED CARE ON CHILDREN WITH DISABILITIES REACTOR BIOGRAPHIES

Ruth E.K. Stein, M.D.

Ruth Stein is Professor and Vice Chairman of the Department of Pediatrics and Director of General Pediatrics at Albert Einstein College of Medicine. She is also Pediatrician-in-Chief at Jacobi Medical Center. She has been involved in developing models of care for children with special health care needs for many years. Her research is on chronic physical disorders in childhood and their psychological and social consequences. From 1983 to 1995, she was also the Principal Investigator of the Preventive Intervention Research Center for Child Health at the Albert Einstein College of Medicine/Montefiore Medical Center. She recently spent a sabbatical at the United Hospital Fund examining issues for the pediatric population under managed care.

Nancy R. Thaler

Nancy Thaler has been Deputy Secretary for Mental Retardation in the Pennsylvania Department of Public Welfare since 1992. She served as the Director, Bureau of Community Programs, for six years prior to being appointed Deputy Secretary. Before her career in State government, she worked for 16 years in a large nonprofit agency in southeastern Pennsylvania, Ken-Crest Services. While with that agency, she served eight years as a direct care worker, including four years as a houseparent and another eight years in administrative positions.

As Deputy Secretary for Mental Retardation, Ms. Thaler is responsible for the State's services to people with mental retardation. These services affect 3,240 people in State institutions, and 63,000 people in the community.

EVALUATION OF THE DISTRICT OF COLUMBIA'S DEMONSTRATION PROGRAM: MANAGED CARE SYSTEM FOR DISABLED AND SPECIAL NEEDS CHILDREN

Carol Irvin, Ph.D.

As a Health Economist at Abt Associates, Inc., Carol Irvin has conducted numerous studies on the use, costs, and outcomes of health care services provided under managed care and fee-for-service arrangements. In current work she is analyzing enrollment patterns among applicants to the Program for All-Inclusive Care for the Elderly (PACE)--a capitated day health center program for frail elders. Dr. Irvin is also currently involved in analyzing the impacts of a new pharmaceutical product on the use and costs of health care services and labor market participation among individuals with chronic progressive multiple sclerosis. In earlier work funded by the Health Care Financing Administration, she has done comparisons of care and customer satisfaction of families in Florida, Michigan, and Maine enrolled in Medicaid managed care and fee-for-service providers. She has also analyzed the impact on health care use and economic outcomes of a national capitation demonstration project among mine workers--a high risk industry population.

Dr. Irvin has also been actively researching health care issues pertaining to the maternal and child populations. Research in this area include assessing Missouri's 1988 Medicaid expansion and its impacts on enrollment patterns of pregnant women and infants, prenatal care, birth outcomes, and infant health care. Related work includes on-going analysis of the Community Integrated Service Systems (CISS) serving women and children and a series of analyses of the Special Supplemental Food Program for Women, Infants, and Children (WIC) program.

THE DEMONSTRATION

- Eligible Population
- Plan Structure
- Provider Network
- Benefit Plan

ENROLLMENT

- Enrollment Procedures
- Challenges to the Enrollment Process
- Current Enrollment Experience

COMPONENTS OF THE EVALUATION

- Analyses of Enrollment
- Implementation of the Demonstration
- Outcome Analyses

DATA TO BE COLLECTED

- Secondary Data Sources
- MMIS
 - S Plan encounter data
 - S SSI eligibility data
- Primary Data
 - S Key informant interviews
 - S Focus groups
 - S Client survey
 - S Medical record review

PRIMARY RESEARCH QUESTIONS

- Analyses of Enrollment
 - S Which children enroll?
 - S Which children are long-term enrollees?
- Implementation of the Demonstration
 - S What can other states and managed care plans learn?
- Outcomes Analyses
 - S What are the experiences of the District, the managed care plan, the providers, and the children and their families under this type of health care system?

FAMILIES' OUT-OF-POCKET EXPENSES WHEN CARING FOR CHILDREN WITH SPECIAL NEEDS: A PRELIMINARY REPORT COMPARING CHILDREN IN MEDICAID AND A COMMERCIAL PRODUCT LINE

Elizabeth A. Shenkman, Ph.D.

Elizabeth Shenkman is the Coordinator of Research and Program Evaluation at the Institute for Child Health Policy of the State University System of Florida, and an Assistant Professor of Pediatrics at the University of Florida. Dr. Shenkman is the Principal Investigator on the following research projects: Contractual Arrangements with Physicians: Implications for Pediatric Health Care, funded by the Robert Wood Johnson Foundation; Managed Care: Implications for Families' Out-of-Pocket Expenses When Caring for Children with Special Health Care Needs, funded by the Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Health Policy; and the School Enrollment-Based Health Insurance (SEBHI) Program Evaluation, funded by the Florida Healthy Kids Corporation. In addition, she is the Co-Principal Investigator for the following project: Children with Special Health Care Needs Within Managed Care: the Department of Empirically-Based Models, funded by the Department of Health and Human Services, Maternal and Child Health Bureau.

BACKGROUND

- Concerns about children with special needs in managed care environments
- Limited data from managed care organizations about enrollees
- Strong financial burdens in fee-for-service system
- Will these burdens be greater in managed care?

PURPOSE

- Present preliminary information about families' out-of-pocket expenses when caring for children with special needs
- Two groups of children
 - S Commercially-insured through a special program
 - S Medicaid fee-for-service or primary care case management
- Continuing to collect data for both of these groups

THE THIRD PARTY PAYERS

- Commercial Product Line
 - S Insured through a special program providing subsidized premiums
 - S About 30,000 enrollees
 - S Comprehensive benefit package
 - S Private not-for-profit corporation negotiates contracts with health maintenance organizations
 - S Health maintenance organizations bear risk and maintain the provider network
 - S Currently four participating

- S Primary care provider serving as gatekeepers
- S Program enrollment is voluntary
- Medicaid Product Line
 - S About 49% of the children are enrolled in primary care case management
 - S Comprehensive benefit package
 - S Children covered varies according to Federal Poverty Level
 - S Medically Need Program available

THE BENEFIT PACKAGE

- Well child care visits and immunizations
- Primary and specialty physician office visits
- In-patient hospital care
- Surgical procedures
- Emergency services and transportation
- Prescriptions
- Vision screening and glasses
- Hearing screening and hearing aids
- Physical, occupational, speech therapy
- Mental health services

HOW WERE THE CHILDREN SELECTED?

- Identified initially from claims data from participating health maintenance organizations and Florida Medicaid
- Used International Classification of Diseases, 9th Revision
- High and low prevalence conditions included
- Screening questions used to identify those with greatest needs
 - a. Because of a physical or mental condition, does your child require more supervision than other children of his/her age?
 - b. Does your child require extra or specialized medical care, therapies, supplies, or medical equipment because of a special health care need?
 - c. Has your child had his/her special health care need for 6 months or longer?
- Must meet a or b or c

OUT-OF-POCKET EXPENSES MEASURED

- Direct expenses--medical care expenditures for diagnosis, treatment, continuing care, rehabilitation and terminal care
- Other direct expenses--expenditures items or services such as respite care, special diets or formulas, medical supplies, special or additional clothing, and others
- Indirect expenses--time spent in providing care for the child and lost employment opportunities

CAREGIVERS' OUT-OF-POCKET EXPENSE SURVEY

- Panel of reviewers
- Field testing
- 45 to 60 minutes to administer as telephone survey

WHAT WAS CONSIDERED AN OUT-OF-POCKET EXPENSE

- If the item or service was paid for entirely or in part by:
 - S A parent or guardian
 - S Another family member residing in the household
 - S The child's supplemental security income check
- Co-payments categorized according to the expense incurred

OTHER CATEGORIES MEASURED:

- Child's functioning using the Functional Status Rating Scale short form
 - S Addresses mood, interest level, communication
- Diagnostic information
- Demographic information

DIAGNOSTIC CATEGORIES

- Array of diagnoses represented
- Used diagnostic categories to group the children
- Also used scores on Functional Status Rating Scale to describe the children
- Wide variation in functioning seen both within and between diagnostic groupings

SUMMARY AND RECOMMENDATIONS

- Highest expenses for families in "Other Direct" category
- Regressive pattern of expenditures for both groups of children
- Benefit packages must consider broad array of services and items
- Significant caregiving time
- Health care cost savings can be achieved; but at what price to families?

FUTURE WORK

- Include influence of participation in State Title V Children with Special Health Care Needs Programs
- Explore unmet needs
- Explore lost employment opportunities
- Link to actual health care use data

TABLE 1. TOTAL NUMBER OF CHILDREN IDENTIFIED		
Category	Florida Medicaid	Commercially Insured
Total number of children screened for ICD-9-CM codes	307,241	27,487
Total number of children enrolled within the last three months of selecting the sample	253,562	13,591
Total number of children with at least one ICD-9-CM code enrolled in the last three months of selecting the sample	84,315	1,916
Percentage of enrollees with at least one ICD-9-CM code and enrolled within the last three months of selecting the sample	33%	14%

TABLE 2. FAMILIES SCREENED FOR STUDY PARTICIPATION AND SURVEYS COMPLETED		
Category	Florida Medicaid	Commercially Insured
Completed screening questions	112	547
Did not qualify	12 (10%)	128 (23%)
Qualified but refused to participate	24	32
Qualified and completed a survey	76	387

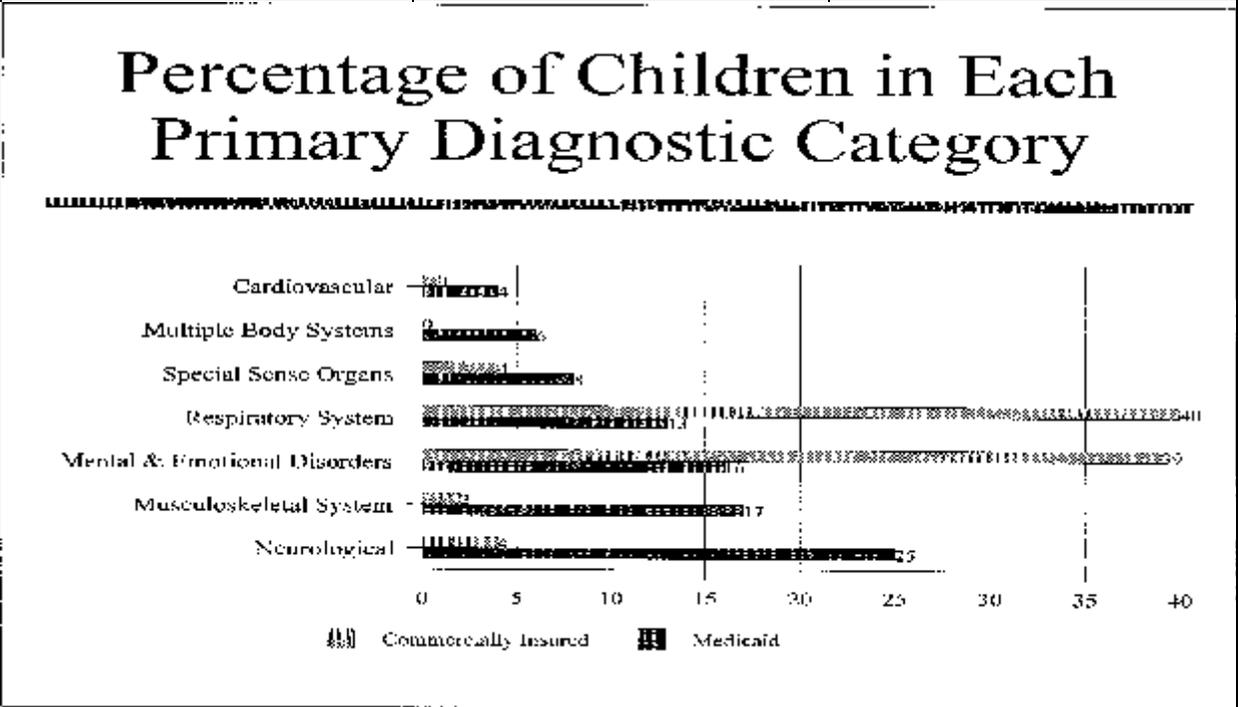
TABLE 3. DEMOGRAPHIC CHARACTERISTICS OF THE STUDY SAMPLE		
Category	Children Receiving Medicaid	Commercially Insured Children
Respondent Gender - Female - Male	97% 3%	95% 5%
Respondent Age	37.43 ± 10.90	39.55 ± 9.99
Child's Age	9.23 ± 5.23	10.48 ± 6.21
FSII (R) Score	78.53 ± 18.69 (range 17 to 100)	87.20 ± 15.33 (range 21 to 100)
Child's Racial Background - White - African-American - Other	80% 15% 5%	85% 8% 7%
Child's Ethnicity - Hispanic - Non-Hispanic	11% 89%	12% 88%
Family Income Average Family Income - less than \$9,999 - \$10,000 to 14,999 - \$15,000 to 19,999 - \$20,000 to 24,999 - \$25,000 to 34,999 - \$35,000 to 44,999 - \$45,000 or more - Don't know/refused	30% 17% 14% 12% 10% 7% 7% 2%	13% 22% 19% 15% 12% 8% 5% 7%
Cash Assistance-SSI for Child - Used actual records to respond to questions - Use an estimate of expenses	35% 35% 65%	0% 47% 53%

TABLE 4. CHILDREN'S PRIMARY DIAGNOSTIC CATEGORIES AND FSII(R) SCORES				
Category	Children Receiving Medicaid (N=76)		Commercially Insured Children (N=387)	
	Percent Children	FSII(R) Mean Core and Standard Dev	Percent Children	FSII(R) Mean Core and Standard Dev
Mental and Emotional Disorders	16%	67 ± 20	39%	75 ± 22
Respiratory System	13%	69 ± 206	40%	90 ± 15
Neurological	25%	76 ± 19	4%	82 ± 18
Musculoskeletal System	17%	86 ± 13	2%	92 ± 10
Special Sense Organs	8%	80 ± 18	4%	86 ± 15
Endocrine System	<1%	71 ± 0	3%	90 ± 12
Cardiovascular	4%	88 ± 12	<1%	88 ± 0
Digestive System	3%	88 ± 20	<1%	90 ± 0
Multiple Body Systems	6%	88 ± 09	0%	NA
Genito-Urinary System	1%	76 ± 10	1%	86 ± 18
Hemic and Lymphatic System	<1%	67 ± 0	0%	NA
Neoplastic Diseases--Malignant	<1%	100 ± 0	<1%	86 ± 0
Immune System	2%	87 ± 13	<1%	87 ± 0
Growth Impairment	2%	96 ± 7	0%	NA

TABLE 5. DIRECT AND OTHER DIRECT EXPENSES FOR THE MONTH AND YEAR IN DOLLARS				
Category	Children Receiving Medicaid		Commercially Insured Children	
	% Reporting Expense	Mean	% Reporting Expense	Mean
Direct Expenses Per Month	37%	131.89 ± 393.35	87%	28.59 ± 139.2
Direct Expenses Per Year	38%	1,072 ± 1,4629.1	86%	384.11 ± 1,582
Other Direct Expenses Per Month	89%	162.57 ± 305.93	63%	30.79 ± 69.8
Other Direct Expenses Per Year	89%	1,444.1 ± 1,779.2	63%	689.4 ± 2,502.6

TABLE 6. DIRECT AND OTHER DIRECT EXPENSES AS A PERCENT OF FAMILY INCOME				
Category	Children Receiving Medicaid		Commercially Insured Children	
	% Reporting Expense	Mean	% Reporting Expense	Mean
Direct Expenses Per Month	37%	4.87 ± 32.4	87%	2.32 ± 10.38
Direct Expenses Per Year	36%	4.33 ± 12.2	87%	2.8 ± 12.78
Other Direct Expenses Per Month	89%	12.79 ± 21.9	63%	2.11 ± 6.20
Other Direct Expenses Per Year	88%	11.25 ± 25.6	63%	2.25 ± 10.98

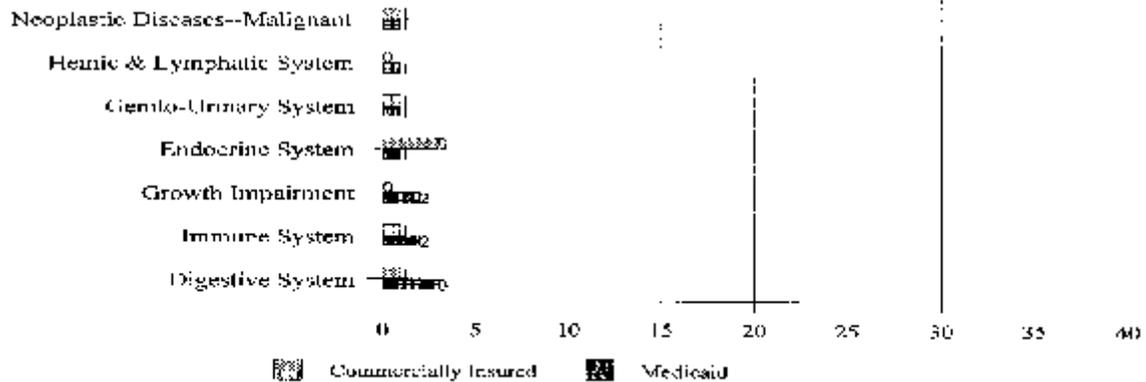
TABLE 7. CAREGIVING TIME		
Category	Percent Reporting	Mean Hours and Standard Deviation
Medicaid	85%	15.33 ± 9.19
Commercially Insured	48%	8.76 ± 3.2



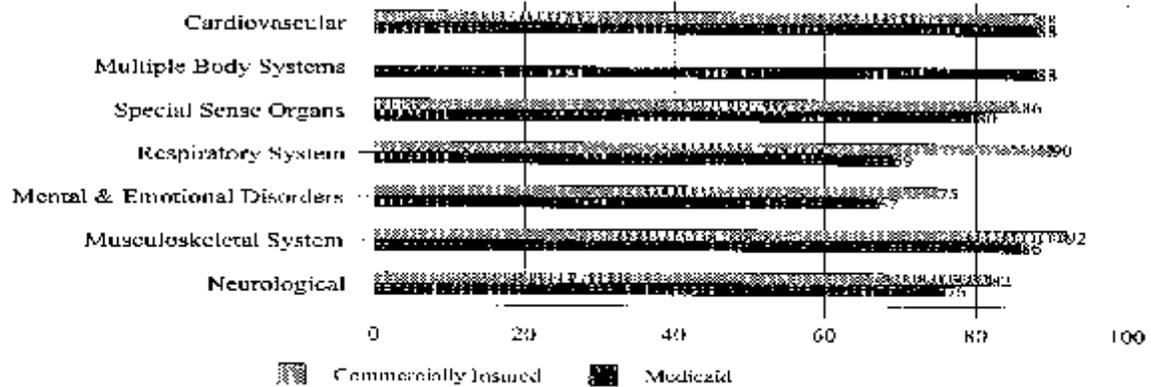
Commercially Insured	48%	8.76 ± 3.2
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Percentage of Children in Each Primary Diagnostic Category

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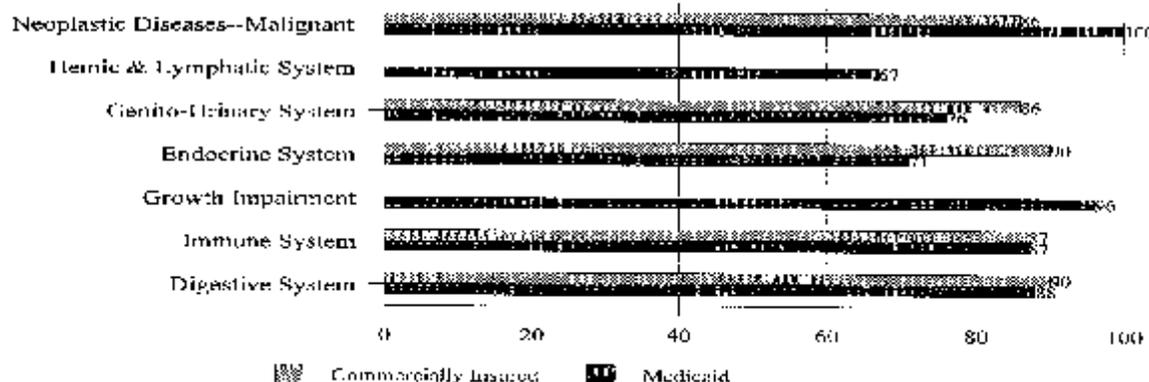


Mean Functional Status Scores by Diagnostic Category

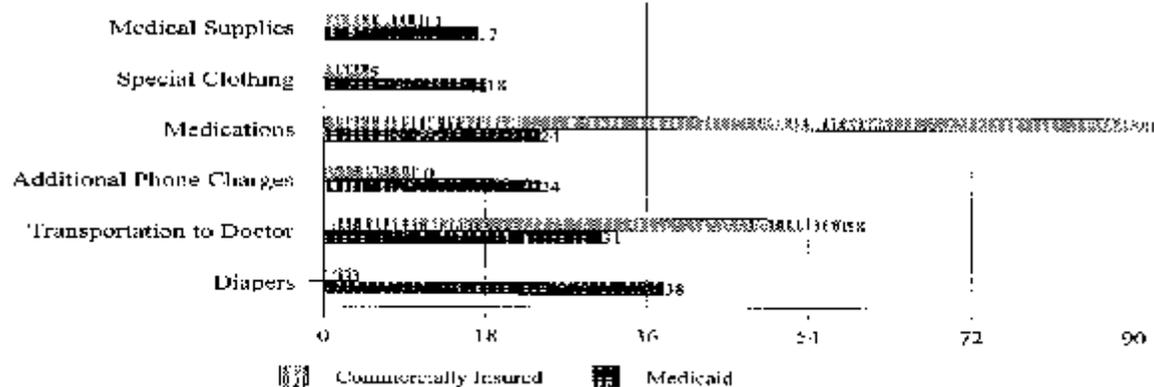


Mean Functional Status Scores by Diagnostic Category

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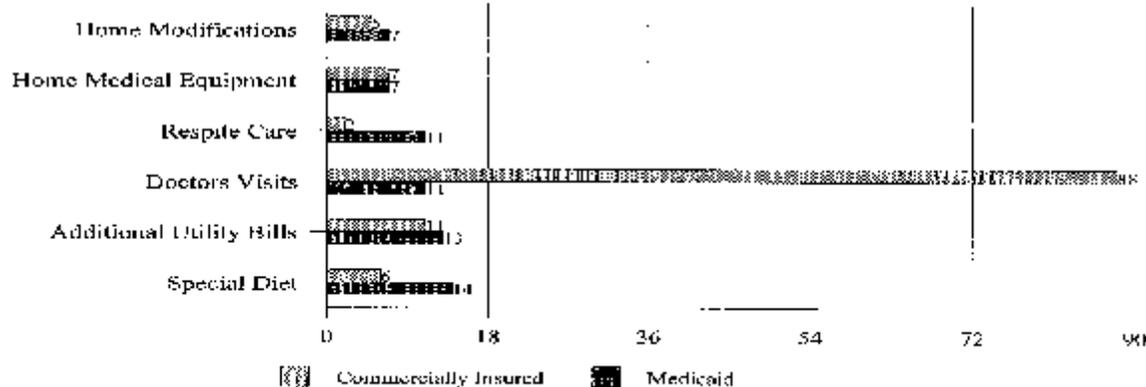


Percentage of Respondents Reporting Expense



Percentage of Respondents Reporting Expense

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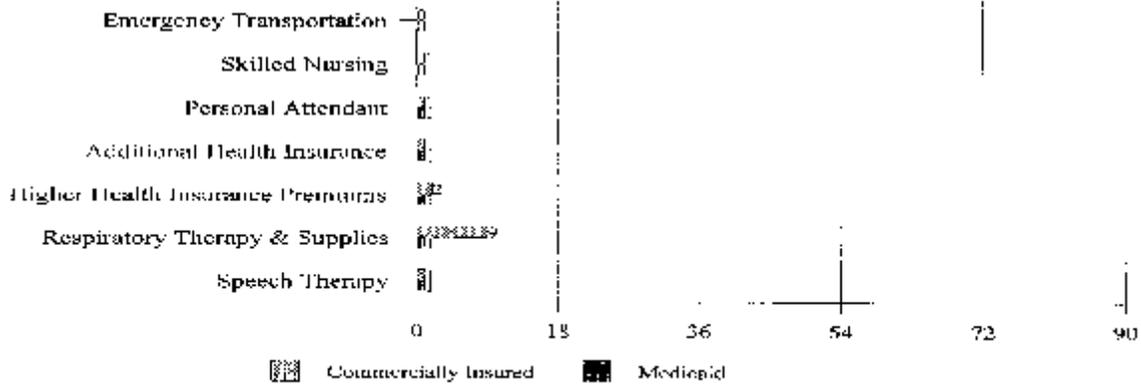
Percentage of Respondents Reporting Expense

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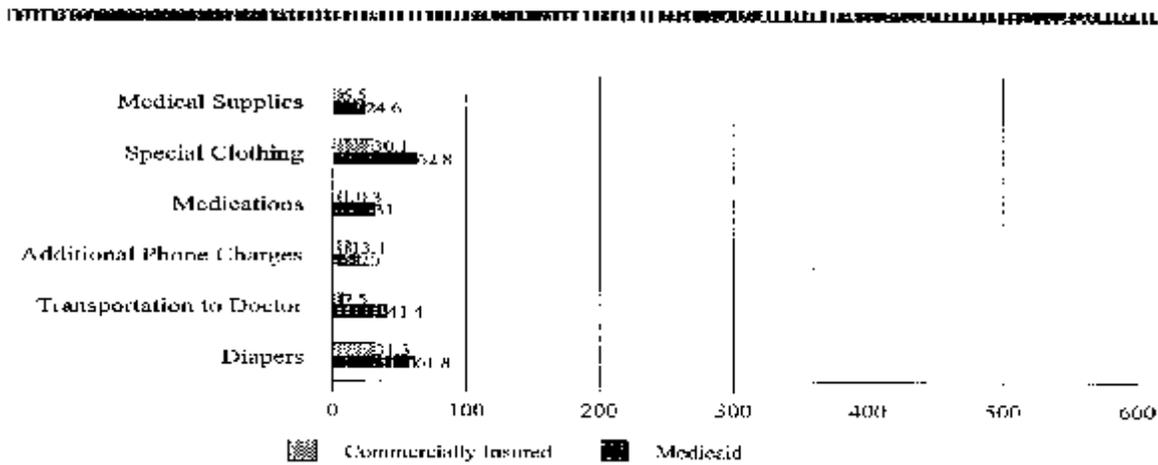


Percentage of Respondents Reporting Expense

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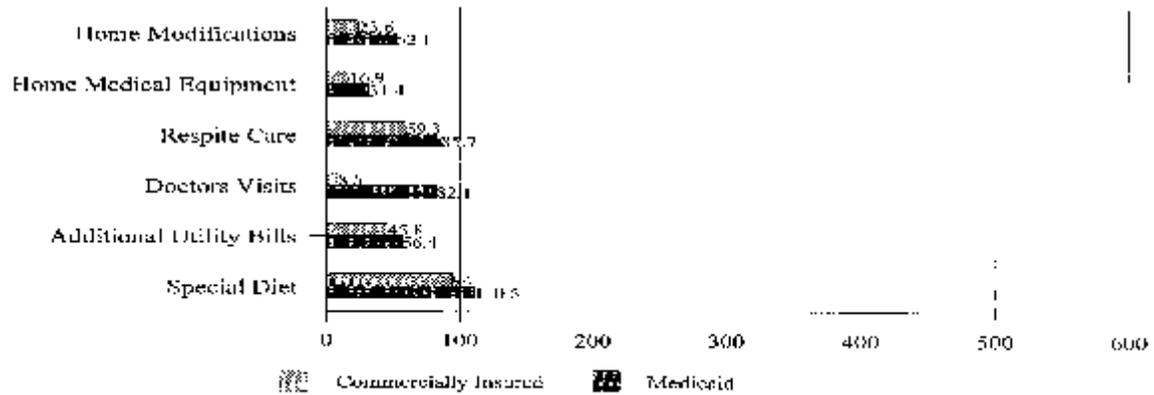


Mean Out-of-Pocket Expense by Service/Item



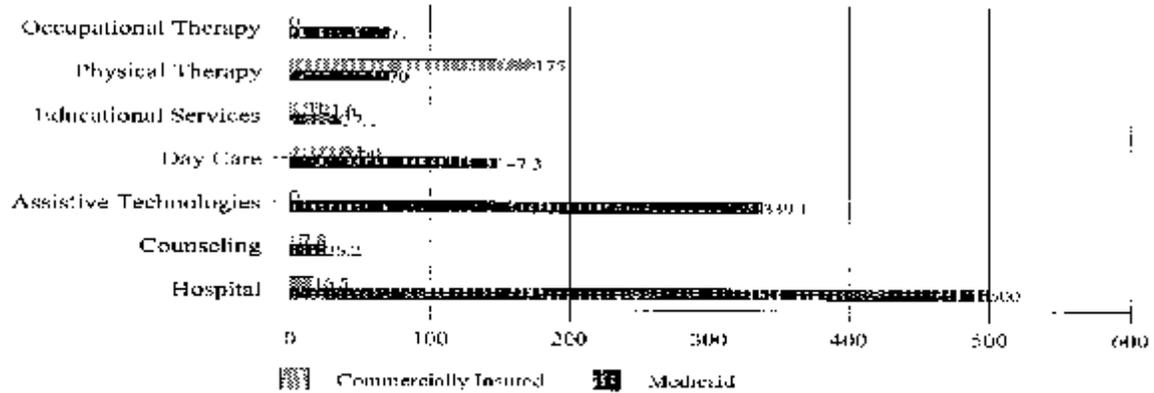
Mean Out-of-Pocket Expense by Service/Item

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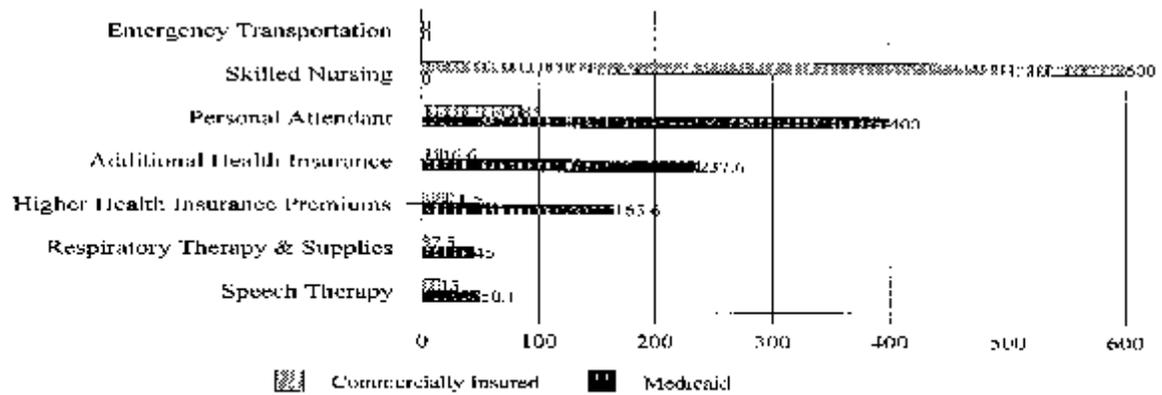
Mean Out-of-Pocket Expense by Service/Item

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Mean Out-of-Pocket Expense by Service/Item

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THE MANAGED CARE ENHANCEMENT PROJECT FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Deborah Allen

As the Director of the Division for Children with Special Health Care Needs of the Massachusetts Department of Public Health, Deborah Allen is responsible for assuring family-centered, community-based care for children with special health care needs and their families. Her division is the lead agency for implementation of Part H of the IDEA in Massachusetts and for the provision of case management services to SSI-eligible children. Ms. Allen is the Principal Investigator for the federally funded Managed Care Enhancement Project for Children with Special Health Care Needs. She is also responsible for two grants funded by Title IV of the Ryan White Care Act: MassCARE (Massachusetts Community AIDS Resource Enhancement), which focuses on pediatric and family care needs, and MCAP (the Massachusetts Women's HIV Care and Advocacy Project), which promotes identification and care of women with HIV prior to or early in pregnancy.

Ms. Allen has master's degrees in Health Policy and Management and Maternal and Child Health from the Harvard School of Public Health and is, as we speak, in the final stages of her doctoral research on "Predictors of Voluntary HIV Testing During Pregnancy," also at Harvard. She is absolutely committed to making this the last formal education she ever undertakes.

OUTLINE OF PRESENTATION

- Health care in Massachusetts
- MassHealth Managed Care
- The Managed Care Enhancement Project
- Needs assessment
- Interventions
- Evaluation
- Concluding thoughts

HEALTH CARE IN MASSACHUSETTS--A WHIRLWIND TOUR

- Extensive tertiary medical system
- Widespread influence of academic medicine
- Extensive CHC network
- Extensive HMO penetration
- No county health departments
- Limited clinical role of local health departments
- Comprehensive Medicaid program

MASSEALTH OVERVIEW

- Target population - 450,000 Medicaid recipients
- All Medicaid clients except:
 - S Individuals with private insurance and Medicaid
 - S Individuals with Medicare and Medicaid
- Enrollment started April, 1992

SSI RECIPIENTS IN MASSEALTH

- Special procedures for
 - S Outreach
 - S Enrollment
 - S Assignment
- For adults and children on SSI

MASSEALTH COMPONENTS

- Health Benefits Advisor Program
- Primary Care Clinician Program
- Mental Health/Substance Abuse Program
- HMO Program

PCC PROGRAM

- Approximately 1300 practices
- Almost 2500 physicians
- Eligible providers are:
 - S Internists
 - S Pediatricians
 - S Family practitioners
 - S Ob-gyns
 - S Nurse practitioners

PCC PROGRAM OPERATIONS

- No capitation at present
- PCC receives \$10 bonus per primary or preventive visit

- PCC responsible for:
 - S Primary care
 - S Specialty referrals
 - S Authorization of most medical services
- Mental health, substance abuse do not require PCC authorization

PCC PROGRAM ENROLLMENT

- Current enrollment approximately 290,000
- 80% of Medicaid enrollees in PCC program
- 80% of children with special health care needs in PCC program

HMO PROGRAM

- 8 vendors statewide
- 1 special contract for disabled individuals
- Enrollment is voluntary
- Current enrollment 81,000

MANAGED CARE ENHANCEMENT PROJECT OVERVIEW

- Four year grant ending Sept. 1997
- Funded by HRSA--Maternal and Child Health Bureau
- Joint Title V--Division of Medical Assistance administration
- Active, diverse advisory committee

MCEP GOALS

- Improve health status of children with special health care needs in MassHealth
- Improve quality of life for families of children with special health care needs in MassHealth
- Increase appropriate use of health resources for care of children with special health care needs while averting unnecessary costs
- Enhance understanding of optimal systems of care for children with special health care needs

MCEP NEEDS ASSESSMENT

- Utilization data
- Family survey
- Provider survey
- Family focus groups
- Provider focus groups
- National key informant interviews

FINDINGS ON UTILIZATION

- CSHCN claims reveal:
 - S Equal or greater use of primary care
 - S More use of
 - Inpatient care
 - Home health care
 - Prescriptions
 - DME
 - S Less use of
 - Dental
- Than other children in MassHealth Managed Care

FAMILY SURVEY METHODS

- Inclusion criteria
 - S SSI enrollment or at least one EI claim
 - S At least one full year of Medicaid with \leq 45 day interruption
- Sample
 - S 1,000 families chosen at random
 - S Overselection of Spanish-speaking families
- Implementation
 - S Two mailings in English and Spanish
 - S 800 number for questions or if phone administration preferred
- Response
 - S 32% response rate
 - S 254 English surveys returned or completed by phone
 - S 67 Spanish surveys returned or completed by phone

FAMILY SURVEY FINDINGS

- High level of general satisfaction
- Areas for improvement
 - S Access to information
 - S Family supports
 - S Coordination of services
- Survey also revealed weak links between primary care and
 - S Schools
 - S Discharge planning
 - S Home care

PROVIDER SURVEY METHODS

- Target population
 - S Pediatricians, family practitioners
 - S Participating in Primary Care Clinician Plan
- Sample
 - S 906 physicians
- Implementation
 - S Initial attempt at phone administration
 - S Shift to administration by mail
- Response
 - S 31% response rate
 - S 196 surveys completed by mail
 - S 89 surveys completed by phone

PROVIDER SURVEY FINDINGS

- High level of general satisfaction
- Some areas of provider concern
 - S Coordination of care
 - S Information needs
 - S Time constraints

OTHER NEEDS ASSESSMENT STRATEGIES

- Confirmed and expanded upon needs assessment findings
- Identified possible interventions

INTERVENTIONS

- Special Care Coordinator
 - S 4 sites
 - S 3.5 FTE's
- Parent manual
 - S Focus on system "how to's"
 - S Parent role in writing, editing
- Enhanced provider education
- Enhanced customer service
- Enhanced PCC/case management linkage

EVALUATION OF SCC INTERVENTION

- Parent questionnaires
 - S Two points in time
 - S Comparison group
 - S Child functional status
 - S Family functional status
 - S Parent satisfaction

- Utilization
 - S Admissions
 - S ER use
 - S EPSDT compliance
 - S Over one year relative to comparison group

- Post-implementation PCC review
 - S Qualitative interviews at 4 sites

EVALUATION OF MANUAL

- Parent survey
 - S Use
 - S Strengths and weaknesses
 - S Usefulness

- Provider survey
 - S Use
 - S Strengths and weaknesses
 - S Impact on practice

CONCLUDING THOUGHTS

- Medicaid managed care offers opportunities to change system for the better
- To seize that opportunity must have relevant players in a given state at the table listening to each other
- Key elements to make managed care work for cshcn are being to emerge
- These elements must be addressed at each stage of implementation, from early planning to final evaluation

TABLE 1. COSTS OF CARE FOR CSHCN	
Average per member per month	
CSHSN	\$360
Other children in MassHealth	\$58
Maximum per member per month	
CSHSN	\$26,519
Other children in MassHealth	\$12,769

TABLE 2. SERVICE TYPES AS PERCENT OF TOTAL COST FOR CSHCN

Home health	23%
Inpatient care	22%
Prescriptions	13%
DME	6%
Primary care visits	6%
Specialty visits	6%
ER, transportation, dental	≤2%
Other	13%

PLANNING GRANT: SERVICES FOR CHILDREN WITH CHRONIC ILLNESS AND DISEASE IN AN HMO

Barbara E. Staub, M.D.

Barbara Staub has been at the White Bear Lake Clinic for 13½ years and enjoys her practice. As a general pediatrician, she sees a wide range of illness as well as doing a lot of preventive, well-child care. Dr. Staub's special interests are in chronic illness and disability.

Dr. Staub received her medical degree at the Albany Medical College in 1980. She did her pediatric internship and residency at the University of Minnesota Medical School and was board certified in 1986. Her other professional activities have been a Clinical Assistant Professor, Department of Pediatrics, University of Minnesota Medical School; and Fellow, American Board of Pediatrics.

A COLLABORATIVE PROJECT

- PACER Center
- University of Minnesota
- HealthPartners

STUDY OBJECTIVES

- Comprehensive assessment of the needs and services, and the costs of services for a pediatric population with chronic illness and disability in a managed care environment.
- Examine the interface between our managed care system and education and social services.

STUDY COMPONENTS

- Parental Evaluation
- Cost and Utilization Data
- Primary Care Physician Survey
- Community Advisory Board

PARENTAL ASSESSMENT

- Family Advisory Board
- Family Interviews

PARENT ADVISORY BOARD

- Case Management Services Desired
- Mental Health Services Desired
- Information Source About HP Policies Desired

PHYSICIAN SURVEY

- 29 Physicians Surveyed
- Time
- Benefits
- Care Coordination

COMMUNITY ADVISORY COUNCIL

- Case Management
 - S Agency's Perspective
 - S Family Perspective
- Improved Communication Between Agencies and Health Systems
- Monitoring of Short and Long-Term Outcomes
- Monitoring of Costs

HEALTHPARTNERS PROVIDES

- Access to Subspecialist Care
- Medical Care Management by Pediatrician
- Benefits which are Supplemented by other Sources

NEXT STEPS

- Provide Family-Centered Case Management
- Address Mental Health Needs
- Provide Comprehensive Assessment of Total Costs
- Create Outcome Measures
- Provide Coordination among Agencies Involved in these Children's Lives

TABLE 1. THE SAMPLE BY CONDITION AND AGE			
Diagnoses	Ages 1-4 years	Ages 5-11 years	Ages 12-20 years
Cystic Fibrosis	2	2	2
Cerebral Palsy	2	2	2
Trisomy 21	2	2	2
Muscular Dystrophy	1	1	1
Juvenile Onset Diabetes Mellitus	1	1	1
Myelomeningocele	2	2	2
Autism	1	1	1
Blind/Deaf		2	

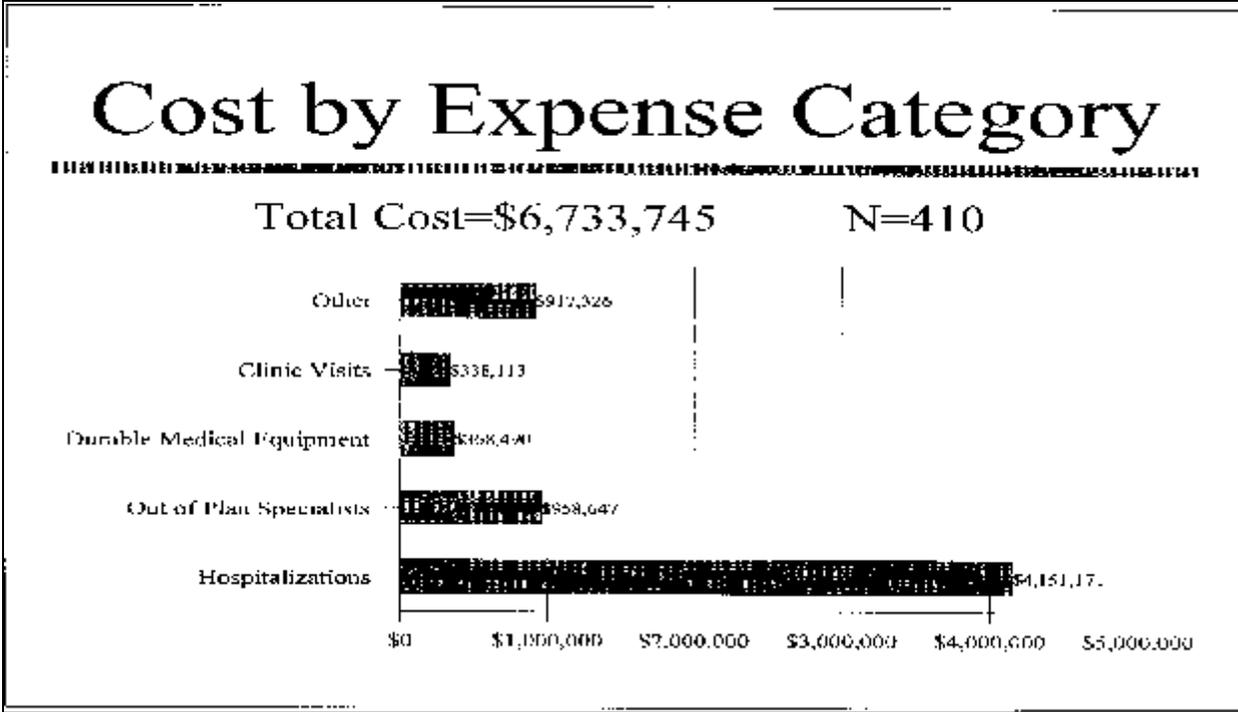
TABLE 2. DEMOGRAPHICS DATA		
Ethnicity	N	%
White	33	94.3
Hispanic	1	2.9
Other	1	2.9
Parent Education		
Vocational School	3	8.6
Some College	14	40.0
College	12	34.3
Graduate	5	14.3
Family Income		
\$20,000-40,000	13	37.1
\$40,000-70,000	15	42.9
\$70,000+	7	14.3

TABLE 3. IMPACT: DOES CHILD'S CONDITION AFFECT ABILITY OF PARENT TO BE EMPLOYED ?		
Response	N	%
No	25	71.4
Yes	10	28.6

TABLE 4. SUPPLEMENTAL FUNDING/INSURANCE SOURCE		
Funding Source	Yes (receive)	No (did not receive)
TEFRA	19 (54.3%)	16 (45.7%)
SSI	4 (11.4%)	31 (88.6%)
Medicaid	4 (11.4%)	31 (88.6%)
Vocational Rehabilitation	4 (11.4%)	31 (88.6%)
WIC	3 (8.6%)	32 (91.4%)
Family Subsidy	2 (5.7%)	33 (94.2%)
Title V	-	35 (100%)
AFDC	-	35 (100%)

TABLE 5. SERVICES RECEIVED AND PAYMENT SOURCE					
Service	# Received	Payment Sources*			
	(N)	HP	TEFRA	School	Other
OT	19	3	3	16	1
PT	15	5	4	10	1
Speech and Language	13	-	4	10	1
Skilled Nursing	3	1	2	1	1
Personal Care Attendant	12	-	7	2	4
Respiratory Therapy	6	3	2	1	-
Mental Health	2	2	-	-	-
Medication	28	24	11	-	21
DME	12	9	6	-	8

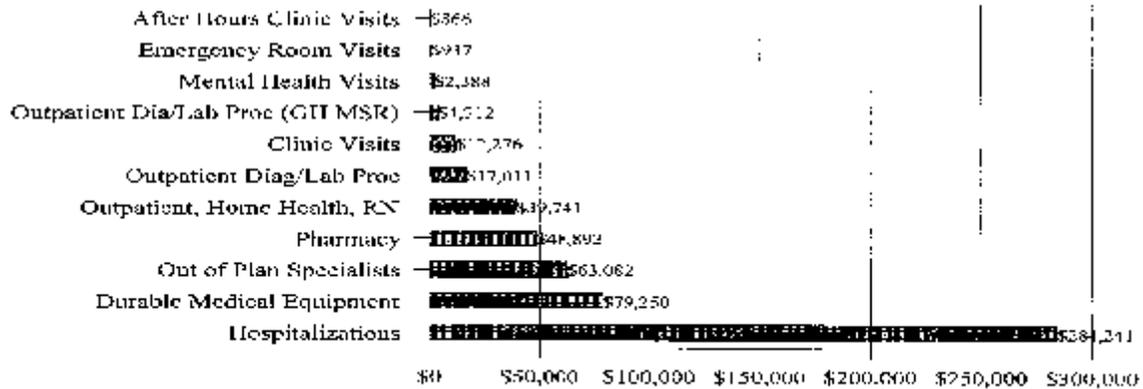
*Many families receive more than one payment source.



Cystic Fibrosis Cost

Total Cost=\$552,895

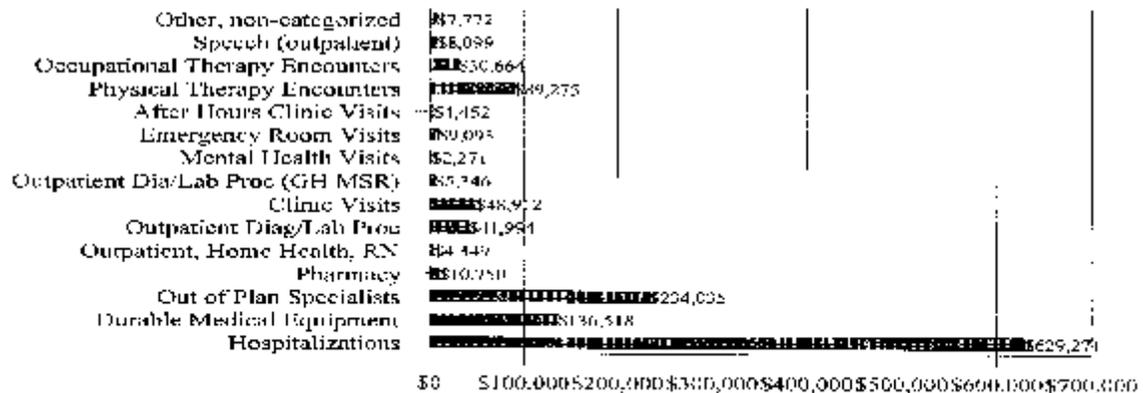
N=18



Cerebral Palsy Cost

Total Cost=\$1,262,797

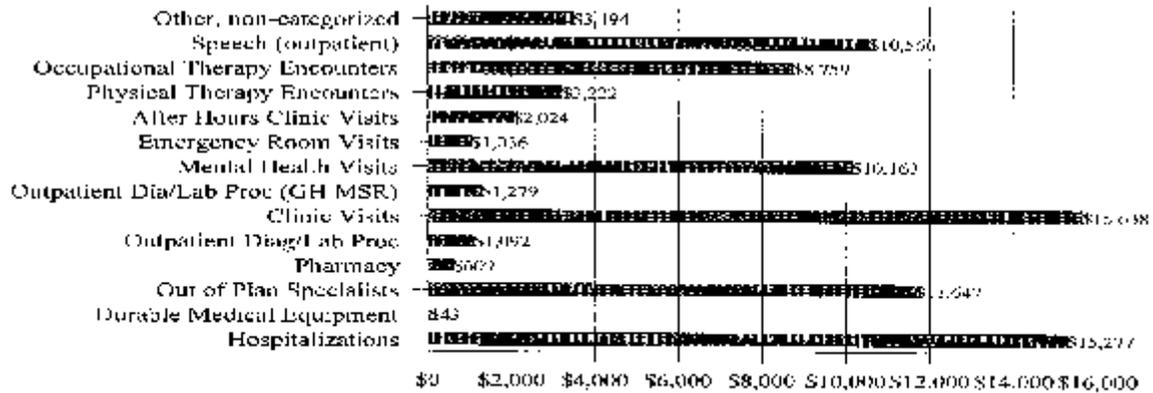
N=99



Autism Cost

Total Cost—\$84,849

N=24



STATE MEDICAID MANAGED CARE POLICIES AFFECTING CHILDREN WITH CHRONIC OR DISABLING CONDITIONS

Harriette B. Fox

Harriette Fox is the President of Fox Health Policy Consultants, a small Washington-based consulting firm specializing in the financing and delivery of maternal and child health services, and the co-director of the Maternal and Child Health Policy Research Center. She has had extensive experience managing projects examining Medicaid, private health insurance, and other financing arrangements to support services to children, with a particular focus on issues pertaining to managed care and health insurance reform. Her work has included analyses of Federal laws and policy options; evaluations of State Medicaid and maternal and child health programs; surveys of State and private industry insurance practices; and consultation to numerous State and private organizations. She has published extensively on the subject of health care financing and children. Before establishing Fox Health Policy Consultants in 1982, Ms. Fox was the Senior Program Analyst for the Select Panel for the Promotion of Child Health. She also had served as a consultant to the Institute of Medicine and the National Health Policy Forum.

Margaret McManus

Margaret McManus is President of McManus Health Policy, Inc., a small consulting firm which specializes in managed care and health insurance reform affecting children. She also co-directs a Maternal and Child Health Policy Research Center for Paul Newacheck and Harriette Fox, funded by the Federal Maternal and Child Health Bureau. For the past 15 years, Ms. McManus has consulted with the American Academy of Pediatrics' Committee on Child Health Financing and a variety of other national, State, and local organizations. She has recently assisted the Maternal and Child Health Bureau in convening a series of managed care work groups on definitions, capitation and risk adjustment, quality of care, and family participation. Ms. McManus has published extensively on the subject of health care financing and children. Most recently, with Harriette Fox, she has completed a report entitled, Medicaid Managed Care for Children with Chronic or Disabling Conditions: Improved Strategies for States and Plans.

TABLE 1. STATE MEDICAID POLICIES REGARDING CHILDREN SERVED BY FULLY CAPITATED PLANS <i>DRAFT—Not for Publication</i>				
State	Categorical Groups Enrolled	Voluntary or Mandatory Enrollment ¹	Specific Exemptions for Non-institutionalized Special-Needs Children	Pediatric Services Carved Out of Managed Care Contracts ²
Arizona	AFDC, AFDC-related, SSI	Mandatory	Children receiving developmental disability services	Mental health and substance abuse (capitated), hospice, personal care, specialty services for CSHN-eligible children
California⁴	AFDC, AFDC-related, SSI, Foster Care	Mandatory in 3 counties; voluntary in 17 counties; mandatory for AFDC only in one county	None	Mental health services for SED-eligible children, intensive substance abuse, early intervention, health-related special education, dental ⁵ (capitated), certain comprehensive case management, specialty services for CSHN-eligible children

State	Categorical Groups Enrolled	Voluntary or Mandatory Enrollment ¹	Specific Exemptions for Non-institutionalized Special-Needs Children	Pediatric Services Carved Out of Managed Care Contracts ²
Colorado	AFDC, AFDC-related, SSI, Foster Care	Voluntary	None	Intensive mental health, certain substance abuse, intensive ancillary therapies, dental, hospice, personal care
Delaware	AFDC, AFDC-related, SSI, Foster Care	Voluntary	None	Mental health, substance abuse, health-related special education, dental, prescription drugs
District of Columbia	AFDC, AFDC-related	Voluntary	None	Mental health, substance abuse, early intervention, health-related special education, dental, vision
Florida	AFDC, AFDC-related, SSI, Foster Care	Voluntary	Children receiving CSHN services	Intensive mental health, intensive substance abuse, hospice, dental ⁵ , vision ⁵ , personal care, multi-handicap assessments, specialized services for foster care children
Hawaii	AFDC, AFDC-related, Foster Care, Demonstration Eligibles	Mandatory	None	Mental health services for SED-eligible children (capitated), dental (capitated), personal care
Illinois	AFDC	Voluntary	None	Dental (capitated), vision, comprehensive case management
Indiana	AFDC, AFDC-related	Voluntary	None	Mental health, substance abuse, vision
Iowa	AFDC, AFDC-related ⁶	Voluntary	None	Substance abuse, health-related special education, dental, prescription drugs ⁵ , durable medical equipment ⁵
Maryland	AFDC, AFDC-related, SSI	Voluntary	None	Certain early intervention, certain health-related special education, hospice, personal care, certain EPSDT expanded benefits ⁷
Massachusetts	AFDC, AFDC-related, SSI	Voluntary	None	Dental, prescription drugs, vision, personal care, intensive durable mental equipment ⁵

State	Categorical Groups Enrolled	Voluntary or Mandatory Enrollment ¹	Specific Exemptions for Non-institutionalized Special-Needs Children	Pediatric Services Carved Out of Managed Care Contracts ²
Michigan	AFDC, AFDC-related, SSI, Foster Care	Voluntary	Children receiving CSHN services	Intensive mental health, health-related special education, certain dental, personal care
Minnesota	AFDC, AFDC-related	Mandatory in eight counties; voluntary in one county	Children who are determined to be seriously emotionally disturbed prior to enrollment, determined blind or disabled but not eligible for SSI, likely to be terminally ill, or receiving an adoption subsidy ⁸	Case management for SED-eligible children
Missouri	AFDC	Mandatory	None	Mental health services for SED-eligible children, intensive substance abuse, health-related special education, dental, prescription drugs, hospice, certain case management, EPSDT expanded benefits
New Hampshire	AFDC, AFDC-related, Foster Care	Voluntary	None	Intensive mental health, intensive substance abuse, intensive ancillary therapies, early intervention, health-related special education, dental, prescription drugs, intensive personal care, comprehensive case management, durable medical equipment
New Jersey	AFDC, AFDC-related, SSI, Foster Care	Voluntary	Children who have chronic debilitating conditions, language difficulties, or who have a provider relationship that would be substantially disrupted	Mental health, substance abuse, intensive ancillary therapies, health-related special education, personal care
New York	AFDC, AFDC-related, Foster Care (not in NYC)	Mandatory in one borough; voluntary elsewhere	Children receiving CSHN services, certain children who have specific medical needs that cannot be met through an HMO	Intensive mental health, intensive substance abuse, early intervention, health-related special education, dental ⁵ , vision ⁵ , hospice, personal care, comprehensive case management, durable medical equipment ⁵
North Carolina	AFDC	Voluntary	None	Mental health and substance abuse (both capitated), dental, vision, personal care
Ohio	AFDC, AFDC-related	Mandatory in two counties; voluntary elsewhere	None	Hospice

State	Categorical Groups Enrolled	Voluntary or Mandatory Enrollment ¹	Specific Exemptions for Non-institutionalized Special-Needs Children	Pediatric Services Carved Out of Managed Care Contracts ²
Oregon	AFDC, AFDC-related, SSI, Demonstration Eligibles	Mandatory in 28 out of 36 counties	Children who have an existing provider relationship that would be disrupted or who have specific medical needs that cannot be met through the HMO ⁹	Mental health in all but 3 counties, intensive substance abuse, health-related special education, dental ⁵ (some capitated), personal care
Pennsylvania	AFDC, AFDC-related, SSI, Foster Care	Mandatory in one county; voluntary elsewhere	None	Certain intensive mental health, early intervention, personal care, specialized services for foster care children ⁵ , certain services for mentally retarded and developmentally disabled children
Rhode Island	AFDC, AFDC-related, Demonstration Eligibles	Mandatory	None	Intensive mental health, mental health services for SED-eligible children, intensive substance abuse, certain early intervention, certain health-related special education, dental, personal care, comprehensive case management, EPSDT expanded benefits
Tennessee	AFDC, AFDC-related, SSI, Foster Care, Demonstration Eligibles	Mandatory	None	Intensive mental health, personal care
Texas	AFDC, AFDC-related	Mandatory	None	Intensive mental health, early intervention, health-related special education, dental, vision, prescription drugs, comprehensive case management, durable medical equipment, EPSDT expanded benefits
Utah	AFDC, AFDC-related, SSI, Foster Care	Voluntary	None	Mental health (capitated), substance abuse, early intervention, health related special education, dental ⁵ , prescription drugs ⁵ , certain services for mentally retarded and developmentally disabled children
Virginia	AFDC, AFDC-related	Voluntary	None	Intensive mental health, health-related special education

State	Categorical Groups Enrolled	Voluntary or Mandatory Enrollment ¹	Specific Exemptions for Non-institutionalized Special-Needs Children	Pediatric Services Carved Out of Managed Care Contracts ²
Washington	AFDC, AFDC-related	Mandatory	Children whose distance from delivery sites makes enrollment impractical, who have language difficulties, who have an existing provider relationship that would be substantially disrupted, or who have a significant medical need that cannot be met through the HMO ¹⁰	Most mental health (capitated in some areas), substance abuse, early intervention, health-related special education, dental, eyeglasses, personal care, comprehensive case management
Wisconsin	AFDC, AFDC-related	Mandatory	None	Dental ⁵

AFDC-related = children who qualify for Medicaid because of their poverty-level status as regular or optional Medicaid eligibles as well as children whose families meet the AFDC income criteria but do not receive AFDC benefits.

CSHN = state Title V program for children with special health care needs

SED = state comprehensive community mental health services program for children and adolescents with serious emotional disturbances

1. In some states, Medicaid-eligible children were required to choose between enrollment in a fully capitated plan or in another form of managed care, such as a primary care case management program. These states are shown as having voluntary enrollment.
2. Use of the qualifying term "inclusive" in this column means services beyond plan limits or services required by special high-need populations. The use of the qualifying term "certain" means only particular services within a category or services provided by a specific type of provider (usually a publicly-funded provider). Where the word "capitated" appears in parentheses after a service, this means that the state had developed a separate capitated arrangement for this service.
3. Arizona enrolls children in foster care in a separate fully capitated plan.
4. California is operating a number of different Medicaid managed care arrangements and policies differ across arrangements. Information in the table is correct for the geographic managed care model.
5. Plans have the option of including this service in their contracts.
6. Iowa allows AFDC and AFDC-related children who enter into foster care to continue to receive care through an HMO, if they elect to do so. In such instances, specialized services for foster care children are paid for separately.
7. A carve-out of "EPSDT expanded benefits" means that a state had carved out of its contract federally-allowable Medicaid services that would not otherwise be covered under its regular Medicaid plan or expanded coverage of services that otherwise would have limitations.
8. Minnesota also exempts children who are refugees or who have a primary care provider outside of Itasca County from HMO enrollment.
9. Oregon also exempts children who are Native Americans from HMO enrollment.
10. Washington also exempts children who are Native Americans or homeless from HMO enrollment.

SOURCE: Information was obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff during the spring and summer of 1994 and was verified by the states as being accurate as of March 31, 1995.

TABLE 2. MEDICAID SERVICES TO CHILDREN EXCLUDED FROM CONTRACTS		
<i>DRAFT--Not for Publication</i>		
Services Carved Out of Contracts	Number of States (n=29)	Percent of States
Dental services	20	69%
Health-related special education services	16	55
Personal care	15	52
Some mental health services	13	45
Early intervention services	10	34
Case management	9	31
All mental health services	9	31
Vision services	9	31
Prescription drugs	7	24
Hospice	7	28
Durable medical equipment	5	17
EPSDT expanded benefits	4	14
Some ancillary therapies	3	10
CSHN specialty services	2	7
Specialized services for foster care children	2	7

SOURCE: Information was obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in March 1995, and was verified by the states as being accurate as of March 31, 1995.

TABLE 3. EPSDT LANGUAGE IN STATE MEDICAID MANAGED CARE CONTRACTS REGARDING DIAGNOSIS AND TREATMENT						
State	Specifies and Explains the EPSDT Benefit ¹	Includes Core Elements of OBRA '89 EPSDT Language			Incorporates Federal EPSDT Law or Rules by Reference	Incorporates State EPSDT Law or Rules by Reference
		<i>Requires services to correct or ameliorate identified defects, illnesses, or conditions</i>	<i>Requires services for both physical and mental health problems</i>	<i>Requires all federally allowable diagnostic, treatment, and other health care services</i>		
Arizona	X	X	X	X		X
California	X					X
Colorado	X				X	
Delaware	X	X	X	X	X	
District of Columbia						
Florida	X			X	X	X
Hawaii	X	X	X	X	X	
Illinois	X	X	X		X	
Indiana	X				X	
Iowa	X				X	
Maryland	X	X		X		
Massachusetts	X	X		X	X	X
Michigan	X				X	
Minnesota	X				X	
Missouri ²	X			n/a	X	
New Hampshire	X	X	X	X	X	
New Jersey	X	X	X		X	
New York	X	X	X	X		
North Carolina	X	X	X			
Ohio	X					X
Oregon ³	n/a	n/a	n/a	n/a	n/a	n/a
Pennsylvania	X	X	X	X	X	
Rhode Island ²	X	X		n/a		

State	Specifies and Explains the EPSDT Benefit ¹	Includes Core Elements of OBRA '89 EPSDT Language			Incorporates Federal EPSDT Law or Rules by Reference	Incorporates State EPSDT Law or Rules by Reference
		<i>Requires services to correct <u>or</u> ameliorate identified defects, illnesses, or conditions</i>	<i>Requires services for both physical and mental health problems</i>	<i>Requires all federally allowable diagnostic, treatment, and other health care services</i>		
Tennessee	X				X	
Texas ²	X			n/a	X	
Utah	X	X	X	X		
Virginia	X	X	X	X		
Washington	X		X		X	X
Wisconsin	X	X	X	X	X	X
TOTAL	27 of 28	15 of 28	13 of 28	12 of 25	18 of 28	7 of 28
<p>1. Certain states substitute their own program names for the Early Periodic Screening, Diagnosis and Treatment benefit. For the Purposes of this analysis, these states were considered to have specified and explained the EPSDT benefit if their contracts explicitly addressed each component (screening, diagnosis and treatment) in their definition of the benefit.</p> <p>2. This state's contract excludes all expanded EPSDT benefits (services beyond those included in the state plan). However, the contractor is responsible for all other diagnostic and treatment services.</p> <p>3. Oregon has waived EPSDT requirements under a Section 1115 waiver.</p> <p>SOURCE: Information is based on an analysis of contracts in effect in December 1995, performed by Fox Health Policy Consultants. Provider manuals, administrative rules, and other documents referenced in the state contracts were included in the analysis.</p>						

TABLE 4. MEDICAL NECESSITY LANGUAGE IN STATE MEDICAID MANAGED CARE CONTRACTS

State	Medical Necessity Defined in Contract		If included in contract, Criteria Used to Define Medical Necessity						
	General	Child-Specific	Includes Services for Preventive Purposes as well as Diagnostic and Treatment Purposes	Includes Treatments for a "Condition," "Disability," or "Handicap" in Addition to an "Illness or Injury"	Qualifies Terms Such as "Disability," "Handicap" or "pain" with "severe" or "significant"	Requires Conformance with Standards of Good Medical Practice or Prevailing Community Standards	Requires the most appropriate level of services that can be provided safely	Requires the Least Costly Alternative Treatment of Equal or Reasonably Equal Effectiveness	Requires Evidence of Effectiveness or Proven Medical Value
Arizona	X		X	X					
California									
Colorado	X		X	X		X	X		
Delaware									
District of Columbia									
Florida	X		X	X	X	X	X	X	
Hawaii	X					X			
Illinois	X			X		X			
Indiana									
Iowa	X			X		X		X	
Maryland	X		X						
Massachusetts	X		X	X		X			
Michigan									
Minnesota	X		X	X	X	X			
Missouri									
New Hampshire		X	X	X					
New Jersey									
New York	X		X	X	X				
North Carolina									
Ohio	X				X	X		X	
Oregon	X		X			X	X		X
Pennsylvania									
Rhode Island	X			X					
Tennessee	X					X	X		
Texas									
Utah									
Virginia									
Washington	X		X	X		X		X	
Wisconsin	X		X	X		X	X	X	X
TOTAL	16 of 29	1 of 29	11 of 17 with definitions	12 of 17 with definitions	4 of 17 with definitions	12 of 17 with definitions	5 of 17 with definitions	5 of 17 with definitions	2 of 17 with definitions

State	Medical Necessity Defined in Contract		If included in contract, Criteria Used to Define Medical Necessity						
	General	Child-Specific	Includes Services for Preventive Purposes as well as Diagnostic and Treatment Purposes	Includes Treatments for a "Condition," "Disability," or "Handicap" in Addition to an "Illness or Injury"	Qualifies Terms Such as "Disability," "Handicap" or "pain" with "severe" of "significant"	Requires Conformance with Standards of Good Medical Practice or Prevailing Community Standards	Requires the most appropriate level of services that can be provided safely	Requires the Least Costly Alternative Treatment of Equal or Reasonably Equal Effectiveness	Requires Evidence of Effectiveness or Proven Medical Value
SOURCE: Information is based on an analysis of contracts in effect in December 1995, performed by Fox Health Policy Consultants. Provider manuals, administrative rules, and other documents referenced in the state contracts were included in the analysis.									

FAMILIES' OUT-OF-POCKET EXPENSES WHEN CARING FOR CHILDREN WITH SPECIAL NEEDS: A PRELIMINARY REPORT COMPARING CHILDREN IN MEDICAID AND A COMMERCIAL PRODUCT LINE

Elizabeth A. Shenkman, Ph.D.

INTRODUCTION

Despite the growing interest in enrolling children with special health care needs in managed care plans, remarkably little is known about the effects of managed care on this vulnerable group.^{1,2} This lack of information is due, in part, to the fact that many private managed care organizations (MCOs) are unwilling to release person level use data so that analyses can be conducted on those enrollees who have special health care needs. In addition, states with Medicaid managed care plans have exempted some or all children with special needs from enrollment in these plans. Therefore very limited data from the public sector are available.^{3,4}

Many concerns have been raised about how children with special health care needs and their families will fare within a managed care environment. It is not known whether families will be able to obtain the services their children need in an environment where health care use and expenditures are closely monitored. Within the current fee-for-service system, families often face strong financial burdens both in terms of out-of-pocket expenses and caregiving time. These financial burdens are disproportionately borne by lower-income families.⁵ Some believe that placing children with special health care needs in managed care arrangements will result in even higher out-of-pocket expenses for families as they enter a system with stringent health care utilization management and potential financial disincentives to physicians to provide care or make referrals.⁶

PURPOSE

The purpose of this paper is to present preliminary information about families' out-of-pocket expenses when caring for children with special health care needs. Families' expenses for two groups of children are

presented. The first group are commercially-insured children with special needs who are receiving care through private health maintenance organizations. The second group are children with special needs who are receiving care through Medicaid fee-for-service or primary case management programs.

The information in this paper is preliminary because we are continuing to collect data both for the Commercially insured and the Medicaid populations. In addition, we are presenting the findings from the survey data only. We have actual health care use data from the HMOs and Medicaid from their claims and encounter data bases for each child in the study. However, these data have not been completely analyzed and therefore are not included in this report.

METHODS

The Third Party Payers Participating in the Study

The Third Party Payers--Commercial: The commercially insured children participating in this study to date are insured through a special program designed to provide subsidized insurance premiums to previously uninsured children. Families with incomes below 130% of the federal poverty level (FPL) pay \$5.00 per child per month; those between 131% and 185% of the FPL pay \$15.00 per child per month; and those at 186% of the FPL or above paid the full premium of \$50.00 per child per month. Approximately 30,000 children are currently enrolled. The benefit package is the same as that offered through Medicaid (Table 1). A key program feature is the provision of care through the private sector. The program is not intended to extend Medicaid coverage or to provide health care as a variation of the current Medicaid system for children in Florida. A private not-for-profit corporation negotiates contracts with HMOs to assume the financial risk and to provide health

care services for the children. Four HMOs currently have contracts and deliver care through private physicians' offices and clinics in the children's communities. Both pediatricians and family practitioners serve as the children's primary care providers. Extensive specialty networks including tertiary care facilities are available through the HMOs. Program enrollment is voluntary.

The Third Party Payers--Florida Medicaid: The Medicaid Program in Florida offers coverage to the following children: (1) children less than one year of age and pregnant women at 134% to 185% of the FPL; (2) children one to six years of age at 101% to 133% of the FPL; and (3) children six to thirteen years at 100% of the FPL or below. Forty-nine percent of children receiving Medicaid are enrolled in the Medipass Program which is a Primary Care Case Management Program. Physicians provide care coordination for these children on a capitated basis. Any services provided beyond care coordination are reimbursed at a Medicaid fee-for-service rate. Catastrophic coverage is available through Florida Medicaid.

Sample Selection

Children were initially identified for possible inclusion in the study through the following steps:

1. Each HMO and Florida Medicaid provided child-specific health care use data including International Classification of Diseases, Clinical Modification, 9th Revision (ICD-9-CM) codes for each health care encounter.
2. In collaboration with two physicians from the University of Florida, Department of Pediatrics, we developed a list of ICD-9-CM codes that might indicate the child had a special health care need. The list was intentionally broad and included conditions of high and low prevalence (Appendix A).
3. The health care use data bases were searched to identify those children who had at least one health care visit during which an eligible ICD-9-CM code was identified. We then identified those children with an eligible ICD-9-CM code who were enrolled within three months preceding the sample selection. We wanted to include those who were recently enrolled so that the survey data and health care use data were as contemporaneous as possible.

Table 2 shows the number of children identified across each HMO and Florida Medicaid for possible inclusion in the study. As expected, significantly more children were identified as possibly having a special health care need through the Medicaid data base than through the private HMO data bases (33% versus 14%).

4. Once the commercially insured children were identified from the data bases, we contacted a census of all those potentially eligible and administered a series of screening questions to determine final eligibility into the study. The screening questions were used to ensure that we only included those children who had moderate to severe health care needs. The following screening questions were used:
 - a. Because of a physical or mental condition, does your child require more supervision than other children of his/her age?
 - b. Does your child require extra or specialized medical care, therapies, supplies or medical equipment because of a special health care need?
 - c. Has your child had his/her special health care need for 6 months or longer?

Those children whose families answer yes to question a or b and c will be included in the study. That is, a family who has a child (1) requiring increased supervision or has a child who requires specialized medical care, therapies, supplies, or medical equipment because of a special health need; and (2) the child has had the condition for 6 months or longer were included in the study.

Questions about activities of daily living (ADLS) were not used as initial screening questions because, based on our past work, a significant number of children may have special health care needs with no ADL deficits. For example, a child with mental retardation could have many needs for educational interventions and supervision resulting in additional financial and caregiving burdens on the families; yet have no ADL deficits.

Table 3 shows the number of parents with commercially insured children meeting the ICD-9-CM criteria who were contacted, the number who met the screening question criteria, and the number who participated in the survey.

5. Because so many children in the Medicaid data base had an ICD-9-CM code that might qualify them for inclusion in the study, we obtained a simple random sample of the Medicaid enrollees to contact. The same screening questions described in Step 4 also are being used to determine final study eligibility for the Medicaid population. We randomly selected 5,500 children, administered screening questions to 112 parents to date, and obtained 76 completed interviews (Table 3). We expected to find not only a greater number of children with special health care needs in the Medicaid data base, but also more children with significant health care needs when compared to the HMO population. As expected, more children in the Medicaid data base met the screening questions for

inclusion into the study when compared to the pediatric HMO population (23% versus 10%).

6. At the present time, we have completed surveys for 387 children in the commercial product line and 76 children participating in the Medicaid Program. The data for these children are presented in this report. As previously mentioned, we are continuing to conduct surveys among the Medicaid enrollees and also among children who are receiving health insurance through other commercial product lines offered by the HMOs with whom we are working.

Measures of Caregivers' Out-of-Pocket Expenses

We developed the Caregivers' Out-of-Pocket Expense (COPE) Survey to assess the following dimensions for expenses:

- Direct Expenses--medical care expenditures for diagnosis, treatment, continuing care, rehabilitation and terminal care. Expenses for the following services are included in this category: physical therapy, occupational therapy, speech therapy, skilled nursing (registered nurse/ licensed practical nurse), personal attendant, respiratory therapy, specialized day care, counseling, doctor's visits in clinic or office, hospital care, medications and home medical equipment.
- Other Direct Expenses--expenditures for the following items or services: respite care, special diets or formulas, medical supplies, special or additional clothing, diapers not normally used at the child's age, transportation costs, educational services related to the child's special health care need, assistive technologies, transportation related to the child's special health care needs, emergency transportation, purchase of a car or van related to the child's special health care needs, and home modifications.
- Indirect Expenses--time spent in providing care for the child and lost employment opportunities.

Survey items initially were developed based on a literature review of expenses families incur when caring for children with disabilities.^{7,8,9} A panel of reviewers reviewed the first two drafts of the surveys for content. Reviewers included: a generalist pediatrician from an academic health center who specializes in caring for children with special health care needs, a family economist, a health care economist, two state Title V Children with Special Health Care Needs (CSHCN) Program Directors, two families who have children with special health care needs, and two policy analysts from the former Congressional Office of Technology Assessment. Following the content reviews, the survey was revised and field tested with 60 families. Based on the field testing, a final version of the survey was developed and used in this research.

This phase of our research focuses on families reported direct and other direct expenses. Families were determined to have incurred direct or other direct out-of-pocket expenses if the respondent indicated that the child received the particular service or item and it was paid for either entirely or in part by the parent or guardian, another relative residing in the household, or the child's Supplemental Security Income (SSI) check. The respondent was asked what the out-of-pocket expense was for the preceding month and for the preceding year for each service or item the child received. He or she also was asked if the expenditure for the month was typical or not and if the dollar amount provided was based on actual records or an estimate.

If the family was required to pay a co-payment for a service and the payment was made according to the criteria described in the preceding paragraph; the dollar amount was attributed to the particular category for which the co-payment was required. For example, in the commercially insured population, families are required to pay a \$3.00 co-payment for an acute care visit to their primary care provider. The \$3.00 co-pay would be described as an out-of-pocket expense for a doctor's visit. Thus out-of-pocket expenses could represent a co-payment for a particular service or item; an expenditure for a service or item not covered in the benefit package; or a service or item that was covered by the benefit package but the maximum amount allowed for payment was exceeded and the family had to begin paying.

Measures of Child's Functional Status

We used the Functional Status Rating Scale [FSII(R)], short form, to assess the children's level of functioning. The FSII(R) assess a child's functioning in the areas of social behavior, sleeping, eating, and activities.¹⁰ The instrument also was specifically designed to detect changes in a chronically ill child's functioning across time. The short version contains 14 items and has an alpha coefficient of 0.80. An alpha coefficient measures the degree to which the items on an instrument measure the same concept.¹¹ The alpha coefficient of .80 means that the items on the FSII(R) are consistently measuring the same concept.

The instrument is scored from 0 to 100 with 100 representing the highest functioning. The developers established concurrent validity by correlating the FSII(R) measures with established measures of morbidity such as days in hospital and school absences. The correlations were moderate ranging from .24 to .47. A copy of the items are contained in Appendix B.

Demographic Measures

We gathered information about the family's race and ethnicity, respondent's age, total family income, and participation in the SSI Program for children. In addition, we

asked about the child's age and diagnosis.

Data Analysis

Descriptive data only are presented for this phase of the study. Specifically we will describe the following:

- The children's demographic characteristics.
- The diagnoses (grouped together into diagnostic categories) and the FSII(R) scores by diagnostic category of the children in the HMOs and Medicaid.
- The amount families spent on direct and other direct expenses expressed both in dollar amounts and as a percentage of family income for children in the HMOs and Medicaid.
- The amount families spent on direct and other direct expenses expressed both in dollar amounts and as a percentage of family income by diagnostic category for children in the HMOs and Medicaid.
- The dollar amount spent for specific services and items (i.e. physical therapy, supplies, medications, and others) for children in the HMOs and Medicaid.

RESULTS

The Study Sample

Children enrolled in Medicaid varied from children in the commercial program on several characteristics (Table 4). A higher percentage of children in Medicaid were African-American (15% versus 8%) and from lower income homes. Thirty percent of the Medicaid enrollees reported an average family income of less than \$9,999 per year compared to only 13% of the commercially insured. However, overall both groups had low incomes with 15% or less of the respondents reporting a family income over \$35,000 per year. In addition, children in the Medicaid program had significantly lower scores on the FSII(R) than the commercially insured children ($p < .01$). When reporting out-of-pocket expenses, it is important to note that a higher percentage of families in the commercially insured group when compared to the Medicare group used actual records rather than recall to report their expenses.

More than 70 different diagnoses are represented in this study. Given the diverse array of diagnoses, children were classified into categories (Table 5). We used the Social Security Administration's diagnostic categories that are contained in their medical listings of impairments. Children in Medicaid had a broader range of diagnoses and more severe diagnoses than children in the commercially insured group. The most striking example can be found in the respiratory category. Ninety-two percent of the commercially insured children in the respiratory category had a diagnosis of asthma compared to only 2% of the children receiving Medicaid. Children who received Medicaid and were classified in the respiratory category had diagnoses including: ventilator dependency, cystic

fibrosis, and chronic respiratory failure.

The greatest similarity in diagnoses was found in the category of mental and emotional disorders. Attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD) were the most frequently occurring conditions with 80% of the commercially insured children and 74% of the children in Medicaid in this category having one of these two diagnoses. Depression and mental retardation were also seen in this category for both groups.

In addition to classifying into diagnostic groups, we obtained FSII(R) scores on each child. Prior research has documented that there is wide variability in functioning both between and within diagnoses; therefore classifying children according to their functioning as opposed to a diagnostic label is a valuable approach. The children's FSII(R) score by diagnostic category is contained in Table 5. With the exception of neoplastic diseases, children in Medicaid had lower scores for each diagnostic category when compared to commercially insured children. For both groups, children with mental and emotional disorders had the lowest scores in functioning. However, these low scores may reflect the fact that the instrument used contains many items that could be indicative of a mental or behavioral problem such as items referring to the child's mood, cheerfulness, and crying behavior. Few of the items specifically refer to limitations in physical activity.

The Amount Families Spend on Direct and Other Direct Out-of-Pocket Expenses

Given the higher functional status scores of children in the commercially insured program, it is not surprising that families incurred less out-of-pocket expenses in both absolute dollar amounts and in terms of the amount spent as a percent of family income when compared to Medicaid enrollees. Tables 6 and 7 illustrate the amount families spent out-of-pocket on direct and other direct expenses. Cross-tabulations of families' out-of-pocket expenses by income level reveal that families with incomes below \$14,999 per year spend a disproportionate amount of their income on caring for their children when compared to families with incomes above that amount. While the average amount of out-of-pocket expenses as a percent of family income was only about 2% for the commercially insured, these expenses represented 12% of family income for those reporting incomes below \$14,999. A similar regressive pattern was noted for Medicaid recipients with families at the lowest income levels paying as much as 32% of their income to care for their children with special needs.

Families with children in the commercial insurance program spent about equal amounts of money per month on direct and other direct expenses. However, families who had children in the Medicaid program spent greater amounts of money on other direct expenses. These other

direct expenses included items and services that are not traditionally covered by Medicaid or other third party payers. Table 8 describes specific expenditures by third party payer category. Families incurred expenses for medications, special diets, assistive technologies, and respite care that are not contained in the Medicaid benefit package. Those families who received supplemental security income (SSI) reported spending this money on these and other items that were described in the "other direct expense" category. Ninety percent of families reported using the child's SSI check for one or more of the items or services in this category.

An important but often neglected area of out-of-pocket expenses to the family is that of indirect expenses or the time families spent caring for the child and lost employment opportunities. For this report, we calculated the average amount of time in hours that families reported spending in caregiving activities for their children with special needs. The number of hours spent in caregiving was obtained through the following methods:

- Obtaining a listing of each person residing in the household, the person's age and relationship to the child with special needs;
- For each person 18 years of age or older, asking if that person spent any time providing care to the special needs child, and if so the number of hours spent providing that care; and
- Summing the number of caregiving hours across all members of the household who indicated that provided care.

We obtained the following results:

- Eighty-five percent of families whose children were receiving Medicaid reported spending time in specific caregiving activities. They reported spending an average of 15.33 hours per day (\pm 9.19; range 0 to 24 hours) in care provision.
- Forty-eight percent of families whose children were commercially insured reported spending time in specific caregiving activities. On average, these families spent 8.76 hours per day (\pm 3.2; range 0 to 11 hours) providing care.

We have several more items about families caregiving activities and the impact that this has had on their employment. These data will be analyzed in future work.

SUMMARY

The data contained in this report are preliminary. We are gathering more survey data from Medicaid and from other commercial product lines. However, some patterns are noted in these data that have important implications when designing health care programs and financing mechanisms for children with special health care needs.

Families incur significant out-of-pocket expenses when caring for their children. Lower income families bear the heaviest financial burden with expenses as high as 32% of their total income. While families with children in the HMOs have less expenses than those families with children in Medicaid, they still bear out-of-pocket expenses that take the heaviest toll on the lowest income groups. Benefit packages must be designed that consider the broad array of services required by children with special health care needs including respite care and educational technologies.

Moreover, the impact on the family in terms of their time must be considered. Perhaps health care expenditures can be minimized but at great personal cost to families. Particularly for families receiving Medicaid, more than half of their day can be spent providing care to their children with special needs. The economic impact of this activity must be considered.

Often it is difficult to compare out-of-pocket expenses between different third party payers due to differences in benefit packages. In this phase of our study, all of the children received the same benefits. Although this is a preliminary report, differences in out-of-pocket spending can largely be attributed to differences in the children's health status. Children in Medicaid had much lower scores on functioning when compared to children in the commercially insured group.

Further analytic work will be conducted using regression techniques to more fully describe the factors influencing out-of-pocket expenses. In addition, we will include the children's health care use data from the claims data bases as well as measures of the time families spend in caregiving.

Notes

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TABLE 1. SUMMARY OF MEDICAID BENEFITS IN FLORIDA*	
Category	Reimbursement
Durable Medical Equipment - Limited to one per day per recipient - District service authorization required for certain orthotics, prosthetics, and other equipment for Medicaid eligible EPSDT children under the age of 21	The lesser of the amount billed or the established maximum Medicaid fee.
Home Health Care Services - Intermittent and private duty/personal care	The lesser of the amount billed or the maximum allowable
Hospice Care - Routine or continuous home care - Inpatient respite or general inpatient care	Medicaid allowable rate
Hospital Services--Inpatient	45 day limit
Hospital Services--Outpatient	\$2.00 co-payment for Medicaid
Laboratory	Medicaid allowable rate
Eye Care - Refractions - Eyeglasses	\$3.00 co-payment Covered every two years with a \$10.00 co-pay. Only Medicaid frames.
Physician Services	\$2.00 co-payment for Medicaid; \$3.00 co-payment for commercial product line.
Podiatry Services	\$2.00 co-payment for Medicaid. Certain limitations.
Prescription Drugs	31 day supply with a \$2.00 co-pay; \$3.00 co-pay for commercially insured
Occupational Therapy Services	One treatment per day; reassessments every 6 months; minimum treatment period; Medicaid allowable rate
Physical Therapy Services	One treatment per day; reassessments every 6 months; minimum treatment period; Medicaid allowable rate
Respiratory Therapy Services	One therapy per day; minimum treatment period of 30 minutes; reassessment every 6 months; Medicaid allowable rate
Speech Therapy	One therapy per day; minimum treatment period of 30 minutes; reassessment every 6 months; Medicaid allowable rate
Mental Health	20 visits per year with \$5.00 co-pay
Extended Care	Varies by type of extended care required
Transportation	Emergency transport covered in full
*Does not include all benefits offered such as special waivers, birth centers, nursing homes.	

TABLE 2. TOTAL NUMBER OF CHILDREN IDENTIFIED FROM THE HEALTH CARE USE DATA BASES USING SELECTED ICD-9-CM CODES		
Category	Florida Medicaid	Commercially Insured
Total number of children screened for ICD-9-CM codes that may reflect a special health care need	307,241	27,487
Total number of children enrolled within the last three months of selecting the sample	253,562	13,591
Total number of children with at least one ICD-9-CM code indicating a possible special health care need enrolled in the last three months of selecting the sample	84,315	1,916
Percentage of enrollees with at least one ICD-9-CM code indicating a possible special health care need and enrolled within the last three months of selecting the sample	33%	14%

TABLE 3. FAMILIES SCREENED FOR STUDY PARTICIPATION AND SURVEYS COMPLETED		
Category	Florida Medicaid	Commercially Insured
Completed screening questions	112	547
Did not qualify	12 (10%)	128 (23%)
Qualified but refused to participate	24	32
Qualified and completed a survey	76	387

TABLE 4. DEMOGRAPHIC CHARACTERISTICS OF THE STUDY SAMPLE		
Category	Children Receiving Medicaid	Commercially Insured Children
Respondent Gender - Female - Male	97% 3%	95% 5%
Respondent Age	37.43 ± 10.90	39.55 ± 9.99
Child's Age	9.23 ± 5.23	10.48 ± 6.21
FSII(R) Score	78.53 ± 18.69 (range 17 to 100)	87.20 ± 15.33 (range 21 to 100)
Child's Racial Background - White - African-American - Other	80% 15% 5%	85% 8% 7%
Child's Ethnicity - Hispanic - Non-Hispanic	11% 89%	12% 88%
Average Family Income - Less than \$9,999 - \$10,000 to 14,999 - \$15,000 to 19,999 - \$20,000 to 24,999 - \$25,000 to 34,999 - \$35,000 to 44,999 - \$45,000 or more - Don't know/refused	30% 17% 14% 12% 10% 7% 7% 2%	13% 22% 19% 15% 12% 8% 5% 7%
Cash Assistance-SSI for Child - Used actual records to respond to question - Used an estimate of expenses	35% 35% 65%	0% 47% 53%

TABLE 5. CHILDREN'S PRIMARY DIAGNOSTIC CATEGORIES AND FSII(R) SCORES								
Category	Children Receiving Medicaid (N=76)				Commercially Insured Children (N=387)			
	Percent Children	FSII(R) Mean Score & Standard Deviation	Min.	Max.	Percent Children	FSII(R) Mean Score & Standard Deviation	Min.	Max.
Mental and Emotional Disorders**	16%	67 ± 20	18	100	39%	75 ± 22	18	100
Respiratory System	13%	69 ± 206	50	100	40%	90 ± 15	46	100
Neurological	25%	76 ± 19	28	100	4%	82 ± 18	24	100
Musculoskeletal System	17%	86 ± 13	31	100	2%	92 ± 10	53	100
Special Sense Organs	8%	80 ± 18	42	100	4%	86 ± 15	44	100
Endocrine System	<1%	71 ± 0	71	NA	3%	90 ± 12	20	100
Cardiovascular	4%	88 ± 12	71	100	<1%	88 ± 0	88	NA
Digestive System	3%	88 ± 20	43	100	<1%	90 ± 0	90	NA
Multiple Body Systems*	6%	88 ± 09	67	100	0%	NA	NA	NA
Genito-Urinary System	1%	76 ± 10	64	100	1%	86 ± 18	42	100
Hemic and Lymphatic System	<1%	67 ± 0	67	NA	0%	NA	NA	NA
Neoplastic Diseases--Malignant	<1%	100 ± 0	100	NA	<1%	86 ± 0	86	NA
Immune System	2%	87 ± 13	71	100	<1%	87 ± 0	87	NA
Growth Impairment	2%	96 ± 07	85	100	0%	NA	NA	NA

* Includes Down Syndrome, multiple body dysfunction, and catastrophic congenital anomalies
** Includes mental retardation

TABLE 6. DIRECT AND OTHER DIRECT EXPENSES FOR THE MONTH AND YEAR IN DOLLARS								
Category	Children Receiving Medicaid				Commercially Insured Children			
	% Reporting Expense	Mean	Min.	Max.	% Reporting Expense	Mean	Min.	Max.
Direct Expenses Per Month	37%	131.89 ± 392.25	0	3050	87%	28.59 ± 139.2	0	2562
Direct Expenses Per Year	38%	1072 ± 14629.1	0	5780	86%	384.11 ± 1582	3.00	6200
Other Direct Expenses Per Month	89%	162.57 ± 305.93	0	3077	63%	30.79 ± 69.8	0	660
Other Direct Expenses Per Year	89%	1444.1 ± 1779.2	0	9680	63%	689.4 ± 2502.6	1.00	2890

TABLE 7. DIRECT AND OTHER DIRECT EXPENSES FOR THE MONTH AND YEAR EXPRESSED AS A PERCENT OF FAMILY INCOME								
Category	Children Receiving Medicaid				Commercially Insured Children			
	% Reporting Expense	Mean	Min.	Max.	% Reporting Expense	Mean	Min	Max.
Direct Expenses Per Month	37%	4.87 ± 32.4	0	698.0	87%	2.32 ± 10.38	0	146.4
Direct Expenses Per Year	36%	4.33 ± 12.2	0	128.95	87%	2.8 ± 12.78	.10	1698.7
Other Direct Expenses Per Month	89%	12.79 ± 21.9	0	129.8	63%	2.11 ± 6.2	0	72.0
Other Direct Expenses Per Year	88%	11.25 ± 25.6	0	487.0	63%	2.25 ± 10.98	.04	1587.6

TABLE 8. SPECIFIC EXPENSES IN DOLLARS FOR CHILDREN IN MEDICAID AND COMMERCIALY INSURED				
Category	Children Receiving Medicaid		Commercially Insured Children	
	Percent Incurring Expense	Cost/Month in Dollars Mean and Standard Deviation	Percent Incurring Expense	Cost/Month in Dollars Mean and Standard Deviation
Physical Therapy	1%	70.0 ± 98.9	<1%	175 ± 168.5
Occupational Therapy	1%	71.0 ± 97.6	0%	0
Speech Therapy	1%	50.1 ± 86.5	<1%	15.0 ± 21.2
Skilled Nursing	0%	0	<1%	600 ± 848.6
Personal Attendant	<1%	400.0 ± 0	<1%	85 ± 0
Respiratory Therapy and Supplies	1%	45.0 ± 35.3	9%	7.5 ± 26.4
Day Care	2%	147.25 ± 97.2	<1%	50.0 ± 70.7
Counseling	3%	25.2 ± 21.7	22%	7.8 ± 13.7
Doctors Visits	11%	82.1 ± 123.78	88%	8.5 ± 27.6
Hospital	4%	500.0 ± 1,110.0	9%	16.5 ± 80
Respite Care	11%	85.7 ± 226.8	2%	59.3 ± 119.2
Medications	24%	31.0 ± 52.7	90%	10.3 ± 31.5
Special Diet	14%	110.5 ± 98.7	6%	94.0 ± 132.6
Medical Supplies	17%	24.6 ± 32.7	11%	6.5 ± 10.7
Special Clothing	18%	62.8 ± 54.1	5%	30.1 ± 31.5
Home Medical Equipment	7%	31.4 ± 60.9	7%	16.9 ± 54.9
Diapers	38%	61.8 ± 66.3	3%	31.33 ± 45.7
Assistive Technologies	3%	339.1 ± 328.2	0%	0
Educational Services	2%	37.1 ± 38.9	2%	21.6 ± 41.8
Additional Phone Charges	24%	20.0 ± 25.1	10%	13.4 ± 24.0
Additional Utility Bills	13%	56.4 ± 58.7	11%	45.8 ± 48.9
Higher Health Insurance Premiums	1%	167.6 ± 143.0	2%	21.5 ± 27.7
Additional Health Insurance	1%	237.6 ± 217.2	<1%	16.6 ± 28.7
Transportation to Doctor	31%	41.4 ± 63.9	58%	7.5 ± 15.2
Emergency Transportation	0%	0	0%	0
Home Modifications	7%	52.1 ± 103.6	5%	23.6 ± 65.2

**APPENDIX A. ICD-9-CM CODES USED TO IDENTIFY CHILDREN
FROM THE CLAIMS/ENCOUNTER DATA**

Code	Condition
042	Human Immunodeficiency Virus (HIV)/AIDS (Use additional codes to identify all manifestations of HIV)
142	Malignant Neoplasm of Major Salivary Glands
142.0	Parotid gland
142.1	Submandibular gland
142.2	Sublingual gland
142.8	Other major salivary glands
142.9	Salivary gland, unspecified
147.0	Superior wall
147.1	Posterior wall
147.2	Lateral wall
147.3	Anterior wall
147.8	Other specified sites of nasopharynx
147.9	Nasopharynx, unspecified
155	Malignant Neoplasm of Liver and Intrahepatic Bile Ducts
155.0	Liver, primary
155.1	Intrahepatic bile ducts
155.2	Liver, not specified as primary or secondary
158	Malignant Neoplasm of Retroperitoneum and Peritoneum
158.0	Retroperitoneum
158.8	Specified parts of peritoneum
158.9	Peritoneum, unspecified
170	Malignant Neoplasm of Bone and Articular Cartilage
170.0	Bones of skull and face, except mandible
170.1	Mandible
170.2	Vertebral column, excluding sacrum and coccyx
170.3	Ribs, sternum, and clavicle
170.4	Scapula and long bones of upper limb
170.5	Short bones of upper limb
170.6	Pelvic bones, sacrum, and coccyx
170.7	Long bones of lower limb
170.8	Short bones of lower limb
170.9	Bone and articular cartilage, site unspecified
171	Malignant Neoplasm of Connective and Other Soft Tissue
171.0	Head, face, and neck
171.2	Upper limb, including shoulder
171.3	Lower limb, including hip
171.4	Thorax
171.5	Abdomen
171.6	Pelvis
171.7	Trunk, unspecified
171.8	Other specific sites of connective and other soft tissue
171.9	Connective and other soft tissue, site unspecified
189	Malignant Neoplasm of Kidney and other Unspecified Urinary Organs
189.0	Kidney, except pelvis
189.1	Renal pelvis
189.9	Urinary organ, site unspecified
190	Malignant Neoplasm of Eye

Code	Condition
190.0	Eyeball, except conjunctiva, cornea, retina, and choriod
190.5	Retina
191.0	Cerebrum, except lobes and ventricles
191.1	Frontal lobe
191.2	Temporal lobe
191.3	Parietal lobe
191.4	Occipital lobe
191.5	Ventricles
191.6	Cerebellum NOS
191.7	Brain stem
191.8	Other parts of brain
191.9	Brain, unspecified
192	Malignant Neoplasm of Other Unspecified Parts of Nervous
192.0	Cranial nerves
192.1	Cerebral meninges
192.2	Spinal cord
192.3	Spinal meninges
192.8	Other specified sites of nervous system
192.9	Nervous system, part unspecified
196	Secondary and Unspecified Malignant Neoplasm of Lymph Nodes
196.0	Lymph nodes of head, face, and neck
196.1	Intrathoracic lymph nodes
196.2	Intra-abdominal lymph nodes
196.3	Lymph nodes of axilla and upper limb
196.5	Lymph nodes of inguinal region and lower limb
196.6	Intrapelvic lymph nodes
196.8	Lymph nodes of multiple sides
196.9	Site unspecific
197	Secondary Maligant Neoplasm of Respiratory and Digestive System
197.0	Lung
197.1	Mediastium
197.2	Pleura
197.3	Other respiratory organs
197.4	Small intestine, including duodenum
197.5	Large intestine and rectum
197.6	Retroperitoneum and peritoneum
197.7	Liver, specified as secondary
197.8	Other digestive organs and spleen
200	Lymphosarcoma and Reticulosarcoma
200.0	Reticulosarcoma
200.1	Lymphosarcoma
200.2	Burkitt's tumor or lymphoma
200.8	Other named variants
201	Hodgkin's Disease
201.0	Hodgkin's paraganuloma
201.1	Hodgkin's granuloma
201.2	Hodgkin's sarcoma
201.4	Lymphocytic-histiosytic predominance
201.5	Nodular sclerosis
201.6	Mixed cellularity
201.7	Lymphocytic depletion
201.9	Hodgkin's disease, unspecified

Code	Condition
202	Other Malignant Neoplasms of Lymphoid and Histiocytic Tissue
202.3	Malignant histiocytosis
202.4	Leukemic reticuloendotheliosis
202.5	Letter-Siwe disease
202.8	Other lymphomas
202.9	Other and unspecified malignant neoplasms of lymphoid and histiocytic tissue
204	Lymphoid Leukemia
204.0	Acute
204.1	Chronic
204.8	Other lymphoid leukemia
205	Myeloid Leukemia
205.0	Acute
205.1	Chronic
205.2	Subacute
205.3	Myeloid sarcoma
205.8	Other myeloid leukemia
205.9	Unspecified myeloid leukemia
206	Monocytic Leukemia
206.0	Acute
206.1	Chronic
206.2	Subacute
206.8	Other monocytic leukemia
206.9	Unspecified monocytic leukemia
207	Other Specified Leukemia
207.0	Acute erythremia and erythroleukemia
207.1	Chronic erythremia
207.2	Megakaryocytic leukemia
207.8	Other specified leukemia
208	Leukemia of Unspecified Cell Type
208.0	Acute
208.1	Chronic
208.2	Subacute
208.8	Other leukemia of unspecified cell type
208.9	Unspecified leukemia
210	Benign Neoplasm of Lip, Oral Cavity, and Pharynx
210.0	Lip
210.1	Tongue
210.2	Major salivary glands
210.4	Other and unspecified parts of the mouth
210.5	Tonsil
210.6	Other parts of oropharynx
210.7	Nasopharynx
210.8	Hypopharynx
210.9	Pharynx, unspecified
213	Benign Neoplasm of Bone and Articular Cartilage
213.7	Long bone of lower limb
215	Other Benign Neoplasm of Connective and Other Soft Tissue
216	Benign Neoplasm of Skin

Code	Condition
225 225.0	Benign Neoplasm of Brain and Other Parts of Nervous System Brain
228 228.0 228.00 228.01 228.02 228.03 228.04 228.09 228.1	Hemangioma and Lymphangioma, any site Hemangioma, any site Of unspecified site Of skin and subcutaneous tissue Of intracranial structures Of retina Of intra-abdominal structures Of other sites Lymphangioma, any site
229 229.0 229.8 229.9	Benign Neoplasm of Other and Unspecified Sites Lymph nodes Other specified sites Site unspecified
237 237.70 237.71 237.72	Neoplasm of Uncertain Behavior of Endocrine Glands and Nervous System Neurofibromatosis, unspecified Neurofibromatosis, Type I [von Recklinghausen's disease] Neurofibromatosis, Type II [acoustic neurofibromatosis]
250 250.0 250.1 250.2 250.3 250.4 250.5	Diabetes Mellitus, Type I [insulin dependent type] [IDDM] [juvenile type], uncontrolled Diabetes mellitus without mention of complication Diabetes with ketoacidosis Diabetes with hyperosmolarity Diabetes with other coma Diabetes with renal manifestations Diabetes with ophthalmic manifestations
277 277.0 277.00 277.01	Other and Unspecified Disorders of Metabolism Cystic fibrosis Without mention of meconium ileus With meconium ileus
282 282.60 282.61 282.62 282.63 282.69	Hereditary Hemolytic Anemias Sickle-cell anemia, unspecified Hb-S disease without mention of crisis Hb-S disease with mention of crisis Sickle-cell/Hb-C disease Other
292 292.0 292.11 292.12 292.2	Drug Psychoses Drug withdrawal syndrome Drug-induced organic delusional syndrome Drug-induced hallucinosis Pathological drug intoxication
293 293.0 293.1 293.8 293.81 293.82 293.83 293.89	Transient Organic Psychotic Conditions Acute delirium Subacute delirium Other specified transient organic mental disorders Organic delusional syndrome Organic hallucinosis syndrome Organic affective syndrome Other

Code	Condition
293.9	Unspecified transient organic mental disorder
294 294.1	Other Organic Psychotic Conditions (Chronic) Dementia in conditions classified elsewhere
295 295.1 295.2 295.3 295.4 295.5 295.6 295.7 295.8 295.9	Schizophrenic Disorders [0=unspecified] [1=subchronic] [2=chronic] [3=subchronic with acute exacerbation] [4=chronic with acute exacerbation] [5=in remission] Disorganized type Catatonic type Paranoid type Acute schizophrenic episode Latent schizophrenia Residual schizophrenia Schizo-affective type Other specified types of schizophrenia Unspecified schizophrenia
296 296.2 296.3 296.9	Affective Psychoses Major depressive disorder, single episode Major depressive disorder, recurrent episode Other and unspecified affective psychosis
299 299.0 299.1 299.8 299.9	Psychoses with Origin Specific to Childhood Infantile autism Disintegrative psychosis Other specified early childhood psychoses Unspecified
300 300.0 300.00 300.01 300.02 300.09 300.10 300.11 300.12 300.13 300.16 300.19 300.20 300.3 300.4 300.5 300.7 300.8 300.81 300.9	Neurotic Diseases Anxiety states Anxiety states, unspecified Panic disorder Generalized anxiety disorder Other Hysteria, unspecified Conversion disorder Psychogenic amnesia Psychogenic fugue Factitious illness with psychological symptoms Other and unspecified factitious illness Phobia, unspecified Obsessive-compulsive disorder Neurotic depression Neurasthenia Hypochondriasis Other neurotic disorders Somatization disorder Unspecified neurotic disorder
301 301.10 301.20 301.50 301.51 301.59 301.7	Personality Disorders Affective personality disorder, unspecified Schizoid personality disorder, unspecified Histrionic personality disorder, unspecified Chronic factitious illness with physical symptoms Other histrionic personality disorder Antisocial personality disorder

Code	Condition
302 302.3 302.50 302.51 302.52 302.53 302.6 302.85	Sexual Deviations and Disorders Transvestitism With unspecified sexual history With asexual history With homosexual history With heterosexual history Disorders of psychosexual identity Gender identify disorder of adolescent or adult life
306 306.0 306.3 306.4	Physiological Malfunction Arising from Mental Factors Musculoskeletal Skin Gastrointestinal
307 307.0 307.1 307.2 307.20 307.21 307.22 307.23 307.3 307.40 307.41 307.42 307.43 307.46 307.47 307.50 307.51 307.52 307.53 307.54 307.59 307.6 307.7 307.80 307.81 307.9	Special Symptoms or syndromes, Not Elsewhere Classified Stammering and stuttering Anorexia nervosa Tics Tic disorder, unspecified Transient tic disorder of childhood Chronic motor tic disorder Gilles de la Tourette's disorder Stereotyped repetitive movements Nonorganic sleep disorder, unspecified Transient disorder of initiating or maintaining sleep Persistent disorder of initiating or maintaining sleep Transient disorder of initiating or maintaining sleep Somnambulism or night terros Other dysfunction's of sleep stages or arousal from sleep Eating disorder, unspecified Bulimia Pica Psychogenic rumination Psychogenic vomiting Other Enuresis Encopresis Psychogenic pain, site unspecified Tension headache Other and unspecified special symptoms or syndromes, not elsewhere classified
308 308.0 308.1 308.2 308.3 308.4 308.9	Acute Reaction to Stress Predominant disturbance of emotions Predominant disturbance of consciousness Predominant psychomotor disturbance Other acute reactions to stress Mixed disorders as reaction to stress Unspecified acute reaction to stress
309 309.0 309.1 309.21 309.22 309.23 309.24 309.28	Adjustment Reaction Brief depressive reaction Prolonged depressive reaction Separation anxiety disorder Emancipation disorder of adolescence and early adult life Specific academic or work inhibition Adjustment reaction with anxious mood Adjustment reaction with mixed emotional features

Code	Condition
309.3 309.4 309.82 309.83 309.89 309.9	With predominant disturbance of conduct With mixed disturbance of emotions and conduct Adjustment reaction with physical symptoms Adjustment reaction with withdrawal Other Unspecified adjustment reaction
310 310.2 310.8	Specific Nonpsychotic Mental Disorders Due to Organic Brain Damage Postconcussion syndrome Other specified nonpsychotic mental disorders following organic brain damage
312 312.0 312.1 312.2 312.30 312.31 312.32 312.33 312.34 312.35 312.39 312.4 312.8 312.81 312.82 312.89 312.9	Disturbance of Conduct, Not Elsewhere Classified Undersocialized conduct disorder, aggressive type Undersocialized conduct disorder, unaggressive type Socialized conduct disorder Impulse control disorder, unspecified Pathological gambling Kleptomania Pyromania Intermittent explosive disorder Isolated explosive disorder Other Mixed disturbance of conduct and emotions Other specified disturbances of conduct, not elsewhere classified Conduct disorder, childhood onset type Conduct disorder, adolescent onset type Other conduct disorder Unspecified disturbance of conduct
313 313.0 313.1 313.2 313.3 313.81 313.82 313.83 313.89	Disturbance of Emotions Specific to Childhood and Adolescence Overanxious disorder Misery and unhappiness disorder Sensitivity, shyness, and social withdrawal disorder Relationship problems Oppositional disorder Identity disorder Academic underachievement disorder Other
314 314.00 314.01 314.1 314.2 314.8 314.9	Hyperkinetic Syndrome of Childhood Without mention of hyperactivity With hyperactivity Hyperkinesis with developmental delay Hyperkinetic conduct disorder Other specified manifestations of hyperkinetic syndrome Unspecified hyperkinetic syndrome
315 315.0 315.00 315.01 315.02 315.09 315.1 315.2 315.3 315.31	Specific Delays in Development Specific reading disorder Reading disorder, unspecified Alexia Developmental dyslexia Other Specific arithmetical disorder Other specific learning difficulties Developmental speech or language disorder Developmental language disorder

Code	Condition
315.39	Other
315.4	Coordination disorder
315.5	Mixed development disorder
315.8	Other specified delays in development
315.9	Unspecified delay in development
316	Psychic Factors Associated with Diseases Classified Elsewhere
317	Mild Mental Retardation
318	Other Specified Mental Retardation
318.0	Moderate mental retardation
318.1	Severe mental retardation
318.2	Profound mental retardation
319	Unspecified mental retardation
330	Cerebral Degenerations Usually Manifest in Childhood
330.0	Leukodystrophy
330.1	Cerebral lipidoses
330.2	Cerebral degeneration in generalized lipidoses
330.8	Other specified cerebral degenerations in childhood
330.9	Unspecified cerebral degenerations in childhood
331	Other Cerebral Degenerations
331.1	Pick's disease
331.3	Communicating hydrocephalus
331.4	Obstructive hydrocephalus
343	Infantile Cerebral Palsy
343.0	Diplegic
343.1	Hemiplegic
343.2	Quadriplegic
343.3	Monoplegic
343.4	Infantile hemiplegia
343.8	Other specified cerebral palsy
343.8	Other specified infantile cerebral palsy
343.9	Infantile cerebral palsy, unspecified
344	Other Paralytic Syndromes
344.0	Quadriplegia and quadriplegia
344.00	Quadriplegia, unspecified
344.01	C1-C4, complete
344.02	C1-C4, incomplete
344.03	C5-C7, complete
344.04	C5-C7, incomplete
344.09	Other
344.1	Paraplegia
344.2	Diplegia of upper limbs
344.3	Monoplegia of lower limb
344.30	Affecting unspecified side
344.31	Affecting dominant side
344.32	Affecting nondominant side
344.4	Monoplegia of upper limb
344.40	Affecting unspecified side
344.41	Affecting dominant side
344.42	Affecting nondominant side

Code	Condition
344.5	Unspecified monoplegia
344.6	Cauda equina syndrome
344.60	Without mention of neurogenic bladder
344.61	With neurogenic bladder
344.8	Other specified paralytic syndromes
344.81	Locked-in state
344.89	Other specified paralytic syndrome
345	Epilepsy
345.0	Generalized nonconvulsive epilepsy
345.1	Generalized convulsive epilepsy
345.2	Petit mal status
345.3	Grand mal status
345.4	Partial epilepsy, with impairment of consciousness
345.5	Partial epilepsy, without mention of impairment of consciousness
345.6	Infantile spasms
345.8	Other forms of epilepsy
345.9	Epilepsy, unspecified
369	Blindness and Low Vision
369.00	Impairment level not further specified
369.10	Impairment level not further specified
369.3	Unqualified visual loss, both eyes
369.4	Legal blindness, as defined in U.S.A.
369.60	Impairment level not further specified
369.61	One eye: total impairment; other eye: not specified
369.70	Impairment level not further specified
370	Keratitis
370.0	Corneal ulcer
370.00	Corneal ulcer, unspecified
389	Hearing Loss
389.00	Conductive hearing loss
389.01	Conductive hearing loss, external ear
389.02	Conductive hearing loss, tympanic membrane
389.03	Conductive hearing loss, middle ear
389.04	Conductive hearing loss, inner ear
389.08	Conductive hearing loss of combined types
389.1	Sensorineural hearing loss
389.10	Sensorineural hearing loss, unspecified
389.11	Sensory hearing loss
389.12	Neural hearing loss
389.14	Central hearing loss
389.18	Sensorineural hearing loss of combined types
389.2	Mixed conductive and Sensorineural hearing loss
389.7	Deaf mutism, not elsewhere classifiable
389.8	Other specified forms of hearing loss
389.9	Unspecified hearing loss
394	Diseases of Mitral Valve
394.0	Mitral stenosis
394.1	Rheumatic mitral insufficiency
394.2	Mitral stenosis with insufficiency
394.9	Other and unspecified mitral valve diseases
395	Diseases of Aortic Valve

Code	Condition
395.0	Rheumatic aortic stenosis
395.1	Rheumatic aortic insufficiency
395.2	Rheumatic aortic stenosis with insufficiency
395.9	Other and unspecified rheumatic aortic diseases
396	Diseases of Vitral and Aortic Valves
396.0	Mitral valve stenosis and aortic valve stenosis
396.1	Mitral valve stenosis and aortic valve insufficiency
396.2	Mitral valve insufficiency and aortic valve stenosis
396.3	Mitral valve insufficiency and aortic valve insufficiency
396.8	Multiple involvement of mitral and aortic valves
396.9	Mitral and aortic valve diseases, unspecified
493	Asthma
493.0	Extrinsci asthma
493.1	Intrinsic asthma
493.2	Chronic obstructive asthma
493.9	Asthma, unspecified
494	Bronchiectasis
580	Acute Glomerulonephritis
581	Nephrotic Syndrome
581.0	With lesion of proliferative glomerulonephritis
581.1	With lesion of membranous glomerulonephritis
581.2	With lesion of membranoproliferative glomerulonephritis
581.3	With lesion of minimal change glomerulonephritis
581.81	Nephrotic syndrome in diseases classified elsewhere
581.89	Other
581.9	Nephrotic syndrome with unspecified pathological lesion in kidney
584	Acute Renal Failure
584.5	With lesion of tubular necrosis
584.6	With lesion of renal cortical necrosis
584.7	With lesion of renal medullary (papillary) necrosis
584.8	With other specified pathological lesion in kidney
584.9	Acute renal failure, unspecified
585	Chronic Renal Failure
586	Renal Failure, Unspecified
587	Renal Sclerosis, Unspecified
588	Disorders Resulting From Impaired Renal Function
588.0	Renal osteodystrophy
588.1	Nephrogenic diabetes insipidus
588.8	Other specified disorders resulting from impaired renal function
588.9	Unspecified disorder resulting from impaired renal function
589	Small Kidney of Unknown Cause
589.0	Unilateral small kidney
589.1	Bilateral small kidneys
589.9	Small kidney, unspecified
714	Rheumatoid Arthritis and Other Inflammatory Polyarthropathies
714.3	Juvenile chronic polyarthritis

Code	Condition
714.30 714.31 714.32 714.33	Polyarticular juvenile rheumatoid arthritis, chronic or unspecified Polyarticular juvenile rheumatoid arthritis, acute Pauciarticular juvenile rheumatoid arthritis Monoarticular juvenile rheumatoid arthritis
741 741.0 741.9 742.0 742.1 742.2 742.3	Spina Bifida With hydrocephalus Without mention of hydrocephalus Encephalocele Microcephalus Reduction deformities of brain Congenital hydrocephalus
744 744.5 744.83 744.84 744.9	Congenital Anomalies of Ear, Face, and Neck Webbing of neck Macrostomia Microstomia Unspecified anomalies of face and neck
745 745.0 745.1 745.12 745.19 745.2 745.3 745.4 745.5 745.6 745.60 745.61 745.69 745.7 745.8 745.9	Bulbus Cordis Anomalies and Anomalies of Cardiac Septal Closure Common truncus Transposition of great vessels Corrected transposition of great vessels Other Tetralogy of fallot Common ventricle Ventricular septal defect Ostium secundum type atrial septal defect Endocardial cushion defects Endocardial cushion defect, unspecified type Ostium primum defect Other (absence of atrial septum, atrioventricular canal type ventricular septal defect, common atrioventricular canal, common atrium) Cor bioculare Other Unspecified defect of septal closure
746 746.0 746.00 746.01 746.02 746.09 746.1 746.2 746.3 746.4 746.5 746.6 746.7 746.8 746.81 746.82 746.83 746.84 746.85 746.86	Other Congenital Anomalies of Heart Anomalies of pulmonary valve Pulmonary valve anomaly, unspecified Atresia, congenital Stenosis, congenital Other Tricuspid atresia and stenosis, congenital Ebstein's anomaly Congenital stenosis of aortic valve Congenital insufficiency of aortic valve Congenital mitral stenosis Congenital mitral insufficiency Hypoplastic left heart syndrome Other specified anomalies of heart Subaortic stenosis Cor triatriatum Infundibular pulmonic stenosis Obstructive anomalies of heart, not elsewhere classified Coronary artery anomaly Congenital heart block

Code	Condition
746.87 746.89 746.9	Malposition of heart and cardiac apex Other Unspecified anomaly of heart
747 747.0 747.1 747.2 747.20 747.21 747.22 747.29 747.3 747.4 747.40 747.41 747.42 747.49 747.5 747.6 747.60 747.81	Other Congenital Anomalies of Circulatory System Patent ductus arteriosus Coarctation of aorta Other anomalies of aorta Anomaly of aorta, unspecified Anomalies of aortic arch Atresia and stenosis of aorta Other Anomalies of pulmonary artery Anomalies of great veins Anomaly of great veins, unspecified Total anomalous pulmonary venous connection Partial anomalous pulmonary venous connection Other anomalies of great veins Absence or hypoplasia of umbilical artery Other anomalies of peripheral vascular system Anomaly of the peripheral vascular system, unspecified site Anomalies of cerebrovascular system
748 748.0	Congenital Anomalies of Respiratory System Choanal atresia
749 749.00 749.01 749.02 749.03 749.04 749.1 749.10 749.11 749.12 749.13 749.14 749.20 749.21 749.22 749.23 749.24 749.25	Cleft Palate and Cleft Lip Cleft palate, unspecified Unilateral, complete Unilateral, incomplete Bilateral, complete Bilateral, incomplete Cleft lip Cleft lip, unspecified Unilateral, complete Unilateral, incomplete Bilateral, complete Bilateral, incomplete Cleft palate with cleft lip, unspecified Unilateral, complete Unilateral, incomplete Bilateral, complete Bilateral, incomplete Other combinations
750 750.4 750.5	Other Congenital Anomalies of Upper Alimentary Tract Other specified anomalies of esophagus Congenital hypertrophic pyloric stenosis
751 751.0 751.1 751.2 751.3 751.4 751.5 751.6	Other Congenital Anomalies of Stomach Meckel's diverticulum Atresia and stenosis of small intestine Atresia and stenosis of large intestine, rectum, and anal canal Hirschsprung's disease and other congenital functional disorders of colon Anomalies of intestinal fixation Other anomalies of intestine Anomalies of gallbladder, bile ducts, and liver

Code	Condition
751.60 751.61 751.62 751.69 751.7 751.8	Unspecified anomaly of gallbladder, bile ducts, and liver Biliary atresia Congenital cystic disease of liver Other anomalies of gallbladder, bile ducts, and liver Anomalies of pancreas Other specified anomalies of digestive system
754 754.11	Certain Congenital Musculoskeletal Deformities Double outlet right ventricle
758 758.0 758.1 758.2 758.3 758.4 758.6 758.7 758.8 758.9	Chromosomal Anomalies Down's syndrome Patau's syndrome Edwards's syndrome Autosomal deletion syndromes Balanced autosomal translocation in normal individual Gonadal dysgenesis Klinefelter's syndrome Other conditions due to sex chromosome anomalies Conditions due to anomaly of unspecified chromosome
765 765.0 765.1	Disorders Relating to Short Gestation and Unspecified Low Birth Weight Extreme immaturity Other preterm infants
766 766.0 766.1 766.2	Disorders Relating to Long Gestation and High Birth Weight Exceptionally large baby Other "heavy-for-dates" infants Post-term infant, not "heavy-for-dates"
770 770.0 770.1 770.2 770.3 770.4 770.5 770.6 770.7 770.8 770.9	Other Respiratory Conditions of Fetus and Newborn Congenital pneumonia Meconium aspiration syndrome Interstitial emphysema and related conditions Pulmonary hemorrhage Primary atelectasis Other and unspecified atelectasis Transitory tachypnea of newborn Chronic respiratory disease arising in the perinatal period Other respiratory problems after birth Unspecified respiratory condition of fetus and newborn
771 771.0 771.1 771.2	Infectious Specific to the Perinatal Period Congenital rebecca Congenital cytomegalovirus infection Other congenital infections
800 800.0 800.1 800.2 800.3 800.4 800.5 800.6 800.7 800.8	Fracture of Vault of Skull Closed without mention of intracranial injury Closed with cerebral laceration and contusion Closed with subarachnoid, subdural, and extradural hemorrhage Closed with other and unspecified intracranial hemorrhage Closed with intracranial injury of other and unspecified nature Open without mention of intracranial injury Open with cerebral laceration and contusion Open with subarachnoid, subdural, and extradural hemorrhage Open with other and unspecified intracranial hemorrhage

Code	Condition
800.9	Open with intracranial injury of other and unspecified nature
801	Fracture of Base of Skull
801.0	Closed without mention of intracranial injury
801.1	Closed with cerebral laceration and contusion
801.2	Closed with subarachnoid, subdural, and extradural hemorrhage
801.3	Closed with other and unspecified intracranial hemorrhage
801.4	Closed with intracranial injury of other and unspecified nature
801.5	Open without mention of intracranial injury
801.6	Open with cerebral laceration and contusion
801.7	Open with subarachnoid, subdural, and extradural hemorrhage
801.8	Open with other and unspecified intracranial hemorrhage
801.9	Open with intracranial injury of other and unspecified nature
802	Fracture of Face Bones
802.0	Nasal bones, closed
802.1	Nasal bones, open
802.2	Mandible, closed
802.20	Unspecified site
802.21	Condylar process
802.22	Subcondylar
802.23	Coronoid process
802.24	Ramus, unspecified
802.25	Angle of jaw
802.26	Symphysis of body
802.27	Alveolar border of body
802.28	Body, other and unspecified
802.29	Multiple sites
802.3	Mandible, open
802.30	Unspecified site
802.31	Condylar process
802.32	Subcondylar
802.33	Coronoid process
802.34	Ramus, unspecified
802.35	Angle of jaw
802.36	Symphysis of body
802.37	Alveolar border of body
802.38	Body, other and unspecified
802.39	Multiple sites
802.4	Malar and maxillary bones, closed
802.5	Malar and maxillary bones, open
802.6	Orbital floor (blow-out), closed
802.7	Orbital floor (blow-out), open
803	Other Unqualified Skull Fractures
803.0	Closed without mention of intracranial injury
803.1	Closed with cerebral laceration and contusion
803.2	Closed with subarachnoid, subdural, and extradural hemorrhage
803.3	Closed with other and unspecified intracranial hemorrhage
803.4	Closed with intracranial injury of other and unspecified nature
803.5	Open without mention of intracranial injury
803.6	Open with cerebral laceration and contusion
803.7	Open with subarachnoid, subdural, and extradural hemorrhage
803.8	Open with other and unspecified intracranial hemorrhage
803.9	Open with intracranial injury of other and unspecified nature
806	Fracture of Vertebral Column with Spinal Cord Injury

Code	Condition
806.0	Cervical, closed
806.00	C1-C4 level with unspecified spinal cord injury
806.01	C1-C4 level with complete lesion of cord
806.02	C1-C4 level with anterior cord syndrome
806.03	C1-C4 level with central cord syndrome
806.04	C1-C4 level with other specified spinal cord injury
806.05	C5-C7 level with unspecified spinal cord injury
806.06	C5-C7 level with complete lesion of cord
806.07	C5-C7 level with anterior cord syndrome
806.08	C5-C7 level with central cord syndrome
806.09	C5-C7 level with other specified spinal cord injury
806.1	Cervical, open
806.10	C1-C4 level with unspecified spinal cord injury
806.11	C1-C4 level with complete lesion of cord
806.12	C1-C4 level with anterior cord syndrome
806.13	C1-C4 level with central cord syndrome
806.14	C1-C4 level with other specified spinal cord injury
806.15	C5-C7 level with unspecified spinal cord injury
806.16	C5-C7 level with complete lesion of cord
806.17	C5-C7 level with anterior cord syndrome
806.18	C5-C7 level with central cord syndrome
806.19	C5-C7 level with other specified spinal cord injury
806.2	Dorsal [Thoracic], closed
806.20	T1-T6 level with unspecified spinal cord injury
806.21	T1-T6 level with complete lesion of cord
806.22	T1-T6 level with anterior cord syndrome
806.23	T1-T6 level with central cord syndrome
806.24	T1-T6 level with other specified spinal cord injury
806.25	T5-T12 level with unspecified spinal cord injury
806.26	T5-T12 level with complete lesion of cord
806.27	T5-T12 level with anterior cord syndrome
806.28	T5-T12 level with central cord syndrome
806.29	T5-T12 level with other specified spinal cord injury
806.3	Dorsal [Thoracic], open
806.30	T1-T6 level with unspecified spinal cord injury
806.31	T1-T6 level with complete lesion of cord
806.32	T1-T6 level with anterior cord syndrome
806.33	T1-T6 level with central cord syndrome
806.34	T1-T6 level with other specified spinal cord injury
806.35	T5-T12 level with unspecified spinal cord injury
806.36	T5-T12 level with complete lesion of cord
806.37	T5-T12 level with anterior cord syndrome
806.38	T5-T12 level with central cord syndrome
806.39	T5-T12 level with other specified spinal cord injury
806.4	Lumbar, closed
806.5	Lumbar, open
806.6	Sacrum and coccyx, closed
806.60	With unspecified spinal cord injury
806.61	With complete cauda equina lesion
806.62	With other cauda equina injury
806.69	With other spinal cord injury
806.7	Sacrum and coccyx, open
806.70	With unspecified spinal cord injury
806.71	With complete cauda equina lesion
806.72	With other cauda equina injury
806.79	With other spinal cord injury

Code	Condition
806.8 806.9	Unspecified, closed Unspecified, open
807	Fracture of Rib(s), Sternum, Larynx, and Trachea
940 940.0 940.1 940.2 940.3 940.4 940.5 940.9	Burn Confined to Eye and Adnexa Chemical burn of eyelids and periocular area Other burns of eyelids and periocular area Alkaline chemical burn of cornea and conjunctival sac Acid chemical burn of cornea and conjunctival sac Other burn of cornea and conjunctival sac Burn with resulting rupture and destruction of eyeball Unspecified burn of eye and adnexa
941 941.0 941.1 941.2 941.3 941.4 941.5	Burns of Face, Head, and Neck (include all 5th digit code) Unspecified degree Erythema (first degree) Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
942 942.0 942.1 942.2 942.3 942.4 942.5	Burn of Trunk (include all 5th digit codes) Unspecified degree Erythema (first degree) Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
943 943.0 943.1 943.2 943.3 943.4 943.5	Burn of Trunk (include all 5th digit codes) Unspecified degree Erythema (first degree) Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
944 944.0 944.1 944.2 944.3 944.4 944.5	Burn of Trunk (include all 5th digit codes) Unspecified degree Erythema (first degree) Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
945 945.0 945.1 945.2 945.3 945.4 945.5	Burn of Trunk (include all 5th digit codes) Unspecified degree Erythema (first degree) Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
946 946.0 946.1	Burns of Multiple Specified Sites Unspecified degree Erythema (first degree)

Code	Condition
946.2 946.3 946.4 946.5	Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
947 947.0 947.1 947.2 947.3 947.4 947.8 947.9	Burn of Internal Organs Mouth and pharynx Larynx, trachea, and lung Esophagus Gastrointestinal tract Vagina and uterus Other specified sites Unspecified site
948 948.0 948.1 948.2 948.3 948.4 948.5 948.6 948.7 948.8 948.9	Burns Classified According to Extent of Body Surface Involved Burn (any degree) involving less than 10 percent of body surface (include all 5th digit codes) 10-19 percent of body surface 20-29 percent of body surface 30-39 percent of body surface 40-49 percent of body surface 50-59 percent of body surface 60-69 percent of body surface 70-79 percent of body surface 80-89 percent of body surface 90percent or more of body surface
949 949.0 949.1 949.2 949.3 949.4 949.5	Burn, Unspecified Unspecified degree Erythema (first degree) Blisters, epidermal loss (second degree) Full-thickness skin loss (third degree (NOS) Deep necrosis of underlying tissues (deep third degree) without mention of loss of a body part Deep necrosis of underlying tissues (deep third degree) with loss of a body part
995.5	Child maltreatment syndrome

APPENDIX B. ITEMS USED TO MEASURE FUNCTIONAL STATUS

Enter child number and first/last name of child with special health care needs listed in Section 1, #16.

Child Number: _____ First Name: _____ Last Name: _____

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FUNCTIONAL STATUS II (R) 14-ITEM VERSION (English)

Here are some statements that mothers have made to describe their children. Thinking about _____ (INDEX CHILD), during the last two weeks did he/she...

	PART 1			PART 2			
	Never of Rarely	Some of the Time	Almost Always	Fully	Partly	Not At All	
17. Eat well	0*	1*	2__	2	1	0__	FS1
18. Sleep well	0*	1*	2__	2	1	0__	FS2
19. Seem contented and cheerful	0*	1*	2__	2	1	0__	FS3
20. Act moody	0	1*	2*__	2	1	0__	FS4
21. Communicate what he/she wanted	0*	1*	2__	2	1	0__	FS5
22. Seem to feel sick and tired	0	1*	2*__	2	1	0__	FS6
23. Occupy himself/herself	0*	1*	2__	2	1	0__	FS7
24. Seem lively and energetic	0*	1*	2__	2	1	0__	FS8
25. Seem unusually irritable or cross	0	1*	2*__	2	1	0__	FS9
26. Sleep through the night	0*	1*	2__	2	1	0__	FS10
27. Respond to your attention	0*	1*	2__	2	1	0__	FS11
28. Seem unusually difficult	0	1*	2*__	2	1	0__	FS12
29. Seem interested in what was going on around him/her	0*	1*	2__	2	1	0__	FS13
30. React to little things by crying	0	1*	2*__	2	1	0__	FS14

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MANAGED CARE ENHANCEMENT PROJECT FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: FAMILY AND PRIMARY CARE CLINICIAN NEEDS ASSESSMENT METHODS AND DESCRIPTION OF SURVEY RESPONDENTS

METHODS

A needs assessment was conducted to gain a better understanding of the needs and concerns of families of children with special health care needs enrolled in MassHealth Managed Care and primary care clinicians (PCCs) in the MassHealth Primary Care Clinician Plan. Surveys, which focussed on issues identified by the project Advisory Committee, were utilized to identify the needs and concerns of families and PCCs. Focus groups were then held in order to clarify and enhance survey data. Focus groups also provided a forum in which participants could generate ideas and recommendations for potential interventions to address their concerns. The results of the assessment were used to guide the development of appropriate interventions to enhance the care of children with special health care needs in MassHealth Managed Care.

Criteria Used for Defining MassHealth Population of Children with Special Health Care Needs

In order to identify the population of children with special health care needs enrolled in MassHealth Managed Care, the following criteria were used: Children with special health care needs were defined as those children aged 18 and under who were enrolled continuously (with no more than a 45 day break in eligibility in FY 94) in the MassHealth Managed Care program, and who were either (1) receiving SSI or (2) receiving AFDC and had at least one Early Intervention claim in FY 94.

Surveys

Surveys were sent to a random sample of families of children with special health care needs enrolled in MassHealth and PCCs in the MassHealth PCC Plan. All families were sent both English and Spanish versions of the survey. Three hundred twenty-one family surveys (including 67 Spanish versions of the survey) and 285 PCC surveys were returned. This represents a 32% and 31% response rate, respectively. Analysis of family survey data did not reveal any significant differences in the responses of English and Spanish respondents. Analysis of PCC survey data did not reveal any significant differences in satisfaction or needs between PCCs with high and low proportions of children with special health care needs in their practice, or between PCCs in different practice types.

Focus Groups

Four family and two PCC focus groups were conducted. The family focus groups were held in Lawrence, Boston, Hyannis and Holyoke. The Holyoke focus group was conducted in Spanish. The PCC focus groups, which were comprised of PCCs from a variety of practice types and cities and towns throughout Massachusetts, were conducted as conference calls.

DESCRIPTION OF SURVEY RESPONDENTS

Family Respondents

321 families completed the family survey (32% response rate). The mean age of respondents' children was 9.7 years, with 2.5% under 3 years of age and 52% between 3 and 10 years of age. There was no significant difference in age or race between respondents and non-respondents. When asked to describe their child's current special health care needs, 6% described the need as a physical limitation only, 12.5% described the need as one that requires help with every day activities, and 33% described the need as one resulting in difficulty with social relationships only. The remaining respondents reported a combination of different types of needs.

PC Respondents

285 PCCs completed the PCC survey (31% response rate). 59% were from group practices, 17% were solo practitioners, and 24% were from outpatient departments or community health centers. Of the 285 respondents, 194 were eligible to complete the entire survey. (91 reported that they either did not provide primary care for Medicaid enrolled children under age 18 or did not provide care for children with special health care needs, and were therefore instructed not to continue beyond the first few survey questions.) Therefore, 194 surveys were used for analysis. When asked to describe their patient population by estimating the proportion of children with special health care needs that fall into various categories, the average responses were as follows:

- chronic disease or physical disability category 39.4% of caseload
- cognitive impairment category 30.0% of caseload

- mental health or behavior impairment category 32.4% of caseload

When asked to estimate the proportion of their entire caseload comprised of children with special health care needs, the mean response was 10.4% (range between 1% and 100%). 60% reported that less than 10% of their caseload was comprised of children with special health care needs.

MANAGED CARE ENHANCEMENT PROJECT FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: PRIMARY CARE CLINICIAN SURVEY-- MAIL SURVEY

This survey asks about your experience and perceptions caring for children with special health care needs. It is part of the Managed Care Enhancement Project for Children with Special Health Care Needs, a quality improvement project designed to enhance the care of children with special health care needs enrolled in MassHealth Managed Care. It is a joint project of the Massachusetts Department of Public Health and Division of Medical Assistance.

Your input is critical: It will help us ensure the MassHealth Managed Care addresses the needs of children with special health care needs, their parents, and their primary care providers in the future. Responses to survey questions are **strictly confidential**; only aggregate results will be reported.

Please return the survey in the enclosed envelope. If you have any questions about the survey of the project, please call Nicole Roos at 1-800-882-1435 or Ngoc Bui-Tong at (617) 348-5720.

For purposes of this project, **children with special health care needs are defined as** those children aged 18 and under who have:

- 12. A serious, chronic condition that is expected to last at least one year or result in death; and/or
- 13. A condition which has a cognitive, biologic or psychologic basis and results in sequelae which include the need for medical care or special services at home or school; dependency on daily medical care, special diet, medical technology, assistive device, or personal assistance in order to function; or a persistent limitation of function or activities of childhood.

APPLICABILITY: The following questions will ensure that this survey is relevant to your practice.

- Do you provide primary care for Medicaid enrolled children under age 18?**

G	Yes	→	Go to question #2
G	No	→	End here and return the survey in the enclosed envelope. Thank you very much of your participation.
G	Don't Know	→	Go to question #2
- What percentage of the children in your entire caseload has special health care needs (given the definition of children with special health care needs above)?**

Write in percent: _____% If > 0%, go to question #4
If = 0% go to question #3

3. If you do not care for children with special health care needs, what are the obstacles that prevent you from caring for children with special health care needs?

If your response to question #2 is 0%, end here and return the survey in the enclosed envelope. Thank you very much for your time. The information you have provided will help us improve access to care for children with special health care needs.

If your response to question #2 > 0%, go to question #4.

YOUR PATIENT POPULATION: The following questions ask about your patient population.

4. What is your estimate of the proportion of children with special health care needs that fall into each of the three categories: physical impairment, cognitive impairment, and mental/behavioral impairment? (NOTE: Many children have impairments in more than one domain. We are looking for a rough estimate based on your judgement of their primary or major impairment.)

What percent of the children with special health care needs that you care for would you say are in the...

- a. Chronic disease or physical disability category _____%
- b. Cognitive impairment category _____%
- c. Mental health or behavior impairment category _____%

If the percentages do not total 100%: Is there another category that should be added? If so, what is that category and what proportion of your children with special health care needs belong in that group?

- d. Category: _____ %

5. Do you provide care for any children who have ever used durable medical equipment, such as respirators, oxygen, or gastrostomy tubes, on an ongoing basis?

- G Yes → Go to question #6
- G No → Go to question #7
- G Don't Know → Go to question #7

6. Approximately how many children currently in your practice use durable medical equipment?

Write in number: _____

7. Do you provide care for any children who have ever received home health, skilled nursing, or private duty nursing because of their special health care needs?

- G Yes → Go to question #8
- G No → Go to question #9
- G Don't Know → Go to question #9

8. Approximately how many children receiving home health, skilled nursing, or private duty nursing because of their special health care needs are currently in your practice?

Write in number: _____

PROVISION OF CARE: The following questions focus on care for children with special health care needs within your practice.

9. Does your practice include any of the following types of clinical staff? If yes, do they assist you in the care of children with special health care needs? (Indicate your response by writing Y for "yes" and N for "no" on the corresponding line. If your response is "yes," indicate whether or not they assist you in care.)

<u>Types</u>	<u>Included in your practice?</u>	<u>If so, do they assist in care?</u>
	<u>Y/N</u>	<u>Y/N</u>
a. Nurse Practitioners	___	___
b. Physician Assistants	___	___
c. Clinical Social Workers	___	___
d. Registered Nurses	___	___
e. Licensed Practical Nurses	___	___
f. Medical technicians	___	___
g. Other (describe below:)	___	___

10. Some practices have made adaptations or modifications to accommodate children with special health care needs, because of the volume of such patients that they treat or for other reasons. For each of the adaptations listed below, indicate with an X whether your practice (1) already has it, or the modification is not applicable; (2) is planning to have it within the next 3 years; (3) may consider it at some point in the future; or (4) does not expect to have or consider this adaptation/modification.

<u>Adaptation/Modification</u>	<u>Already Has or N/A</u>	<u>Is Planning</u>	<u>May Consider</u>	<u>Not Considering</u>
a. Removing steps	___	___	___	___
b. Adding automatic doors or ramps	___	___	___	___
c. Purchasing adaptive medical equipment for office	___	___	___	___
d. Allocating more time per visit to children with special health care needs	___	___	___	___
e. Home visits/house calls	___	___	___	___
f. Other (describe below:)	___	___	___	___

SPECIALISTS: The following questions ask about your experience with specialty referrals for children with special health care needs.

11. Thinking about referrals you make for children with special health care needs, how often would you say they are to pediatric subspecialists?

G Always
 G Usually
 G Sometimes
 G Never

12. How often do you identify specific questions you would like the specialist to answer?

G Always
 G Usually
 G Sometimes
 G Never

13. How often do you specify a time frame for receiving feedback from the specialist?

G Always → Go to question #14
 G Usually → Go to question #14
 G Sometimes → Go to question #14
 G Never → Go to question #15

14. If you specify a time frame for receiving feedback from the specialist, what do you generally do when feedback is not received within the defined time frame?

HOME CARE: The following questions ask about your experience with home care services. (If your response to question #17 was "no," skip this section and go to question #21.)

15. When a child in your practice requires home care, how often is the referral initiated by you?

G Always → Go to question #17
 G Usually → Go to question #17
 G Sometimes → Go to question #16
 G Never → Go to question #16

16. Who typically initiates referrals for home care?

17. How often do you participate in the development of home care plans for children in your practice?

- G Always
- G Usually
- G Sometimes
- G Never

18. Do you typically have any ongoing communication with home care providers?

- G Yes → Go to question #19
- G No → Go to question #20

19. Under what circumstances do you communicate with home care providers? (Check all that apply.)

- G To sign insurance authorization requests
 - G To update information or answer medical question about the child
 - G Other (describe:)
-

20. Who typically monitors the implementation of home care plans?

COORDINATION OF CARE: The following questions address coordination of care. For purposes of this survey, **care coordination includes:** making referral appointments; following up on referrals; ensuring that different providers receive information they need regarding the child's well-being; ensuring that parents receive information they need; and other **tasks related to the organization, rather than the provision of care.**

21. Which, if any, of the following care coordination strategies do you ever rely on? (Indicate your response by writing Y for "yes" and N for "no" on the corresponding line.)

<u>Care Coordination By:</u>	<u>Strategy Relied On?</u>
	<u>Y/N</u>
a. PCC	___
b. Office Nurse	___
c. Medical Technician	___
d. Subspecialist	___
e. Clinical Social Worker	___
f. State Agency Case Management	___
g. Home Care Agency	___
h. Parents	___
i. Other (describe below:)	___

22. Of the care coordination strategies listed above (in question #21), on which one(s) do you rely most often?

INFORMATION: The following questions ask about seeking certain types of information related to the care of children with special health care needs.

23. Have you ever sought clinical information related to the care of a child with special health care needs from any of the following sources? (Indicate your response by writing Y for "yes" and N for "no" on the corresponding line. If your response is "yes," indicate whether or not the information/source was readily accessible and helpful.)

Source	Have You Sought	Was it Readily	Was it
	Information?	Accessible?	Helpful?
	Y/N	Y/N	Y/N
a. Colleagues within practice	___	___	___
b. On-line medical sources	___	___	___
c. Subspecialist that child was referred	___	___	___
d. Diagnosis related agency	___	___	___
e. Medical library	___	___	___
f. DPH/UMass FIRST Program	___	___	___
g. Family TIES	___	___	___
h. Other (describe below):	___	___	___

24. Have you ever used any of the sources listed above (in question #23) to obtain materials for parents of children with special health care needs?

- G Yes → Go to question #25
 G No → Go to question #26

25. Which source(s) did you use? (Choose from those sources listed in question #23.)

26. Have you ever sought non-clinical information related to the care of a child with special health care needs, such as information on SSI or on recreational programs, from any of the following sources? (Indicate your response by writing Y for "yes" and N for "no" on the corresponding line. If your response is "yes," indicate whether or not the information/source was readily accessible and helpful.)

Source	Have You Sought	Was it Readily	Was it
	Information?	Accessible?	Helpful?
	Y/N	Y/N	Y/N
a. Public or medical library	___	___	___
b. The Information Center (ICID)	___	___	___
c. DPH Hotline	___	___	___
d. New England Index	___	___	___
e. Early Intervention	___	___	___
f. Schools	___	___	___
g. Family TIES	___	___	___
h. Other (describe below):	___	___	___

YOUR VIEWS: The following questions ask about your satisfaction with different aspects of caring for children with special health care needs.

27. How satisfied are you with the relationships you have to parents of your patients with special health care needs?

- G Very Satisfied
 G Somewhat Satisfied
 G Somewhat Dissatisfied
 G Very Dissatisfied

28. What factors do you feel contribute to rewarding relationships with parents of children with special health care needs?

29. Do any factors particularly impede rewarding relationships with parents of children with special health care needs?

30. How satisfied are you with the relationships you have with specialists to whom you refer children with special health care needs?

- G Very Satisfied
- G Somewhat Satisfied
- G Somewhat Dissatisfied
- G Very Dissatisfied

31. What factors do you feel contribute to rewarding relationships with specialists?

32. Do any factors particularly impede rewarding relationships with specialists?

33. How satisfied are you with your role as a Primary Care Clinician for children with special health care needs?

- G Very Satisfied
- G Somewhat Satisfied
- G Somewhat Dissatisfied
- G Very Dissatisfied

34. What factors do you feel contribute to your satisfaction in providing primary care to children with special health care needs?

35. What factors do you feel make it difficult to provide primary care to children with special health care needs?

36. Do you have any further insights that you feel are important for us to understand in shaping a system of care for children with special health care needs enrolled in MassHealth Managed Care?

- G Yes → Go to question #37
- G No → Go to question #38

37. Please list as many points as you feel are important.

38. We will be preparing a report of our findings from this survey. Would you like to receive a copy? (If so, please write your name and address in the space provided on the next page.)

- G Yes
- G No

39. **Would you like to receive information on any of the programs mentioned in this survey? If so, would you like a general information packet on services for children with special health care needs, or information on a particular program?** *(Please write your name and address in the space provided on the next page if you would like to receive information.)*

- G No, I do not wish to receive any additional information at this time.
- G Yes, please send me a packet of general information.
- G Yes, please send me information on the following program(s):

41. **Would you be willing to consider participation in further efforts to gather information, such as focus groups?** *(If so, please write your name, address and telephone number in the space provided on the next page.)*

- G Yes
- G No

Thank you very much for your time. The information you have provided will be of enormous help to us in enhancing care for children with special health care needs.

If you would like to receive additional information, or are willing to consider participation in further efforts to gather information, such as focus groups, please complete the following information:

Name:

Address:

Phone:

MANAGED CARE FOR CHILDREN WITH SPECIAL HEALTH NEEDS: PARENT SURVEY

For section A, please read each statement and check **all** the boxes that apply to your child with special health care needs.

A. Questions 1-2 ask about your child's condition.

1. How would you describe your child's current special health care needs?

- My child has physical limitations such as walking.
- My child requires help with every day activities such as eating, dressing, or bathing that most children of the same age can do for themselves.
- My child has more difficulty with social relationships than most children of the same age.

2. Which of the following does your child currently use?

- | | |
|--|---|
| <input type="checkbox"/> Physical, occupational, and/or speech therapy(ies) | <input type="checkbox"/> Personal care assistance: help with bathing, preparing meals, or other personal activities from someone who is not a family member or friend |
| <input type="checkbox"/> The Early Intervention Program | <input type="checkbox"/> Mental health services |
| <input type="checkbox"/> Home health care such as home nursing | <input type="checkbox"/> Ongoing care from medical specialists |
| <input type="checkbox"/> Specialized chair or bathtubs, wheelchairs, or other durable medical equipment or assistive devices | <input type="checkbox"/> Frequent visits to doctors as compared to other children of the same age |
| <input type="checkbox"/> Regular (daily or weekly) prescription medications | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> Special diet | |
| <input type="checkbox"/> Medical technology such as G-tube, tracheostomy ventilator, or nebulizer | |

For sections B-F, check only **one** box that best describes your experience with your child's primary care doctor. This is the person you were asked to choose when your child was enrolled in MassHealth Managed Care.

B. Questions 3-8 ask about the medical care your child receives.

3. When my child has a medical need, the person that I call is my child's primary care doctor.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

4. My child's primary care doctor is easy to reach.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

5. My child's primary care doctor understands his/her special health care needs.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

6. My child's primary care doctor helps me understand how my child's development and social needs change over time.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

7. My child's primary care doctor responds to my child's health problems in a reasonable amount of time.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

8. I am satisfied with the way my child's primary care doctor provides medical care for my child with special health care needs

- | | |
|---|--|
| <input type="checkbox"/> Very Satisfied | <input type="checkbox"/> Somewhat Dissatisfied |
| <input type="checkbox"/> Somewhat Satisfied | <input type="checkbox"/> Very Dissatisfied |

C. Questions 9-18 ask about how your child's primary care doctor coordinates all the medical services (primary care, specialty care, therapies, hospitalization, home care) that your child uses.

9. My child's primary care doctor listens to me when I feel my child needs specialty care.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

My child has not needed specialty care.

10. When my child's primary care doctor determines a need for specialty care, s/he makes the referral in a reasonable amount of time.

- | | |
|----------------------------------|------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Usually | <input type="checkbox"/> Never |

My child has not needed specialty care.

11. **My child's primary care doctor makes referrals to specialists who understand my child's special health care needs.**
 G Always G Sometimes
 G Usually G Never
 G My child has not needed referrals.
12. **My child's primary care doctor does a good job coordinating referrals.**
 G Always G Sometimes
 G Usually G Never
 G My child has not needed referrals.
13. **When my child needs hospitalization, my child's primary care doctor stays involved with his/her care.**
 G Always G Sometimes
 G Usually G Never
 G My child has not been hospitalized.
14. **My child's primary care doctor plays an active role in the discharge planning while my child is hospitalized.**
 G Always G Sometimes
 G Usually G Never
 G My child has not been hospitalized.
15. **My child's primary care doctor or other office staff makes arrangements for home care when it is needed.**
 G Always G Sometimes
 G Usually G Never
 G My child has not needed home care.
16. **My child's primary care doctor or other office staff communicates regularly with home care providers about the care my child receives.**
 G Always G Sometimes
 G Usually G Never
 G My child has not needed home care.
17. **When I request it, my child's primary care doctor communicates with the staff of my child's early intervention program or school.**
 G Always G Sometimes
 G Usually G Never
 G I have not made this request.
18. **I am satisfied with the way my child's primary care doctor coordinates all the medical care that my child receives.**
 G Very Satisfied G Somewhat Dissatisfied
 G Somewhat Satisfied G Very Dissatisfied
- D. Questions 19-30 ask about the support you receive to participate in the care of your child.**
19. **The medical treatments that my child needs are explained to me by my child's primary care doctor in a way that I can understand.**
 G Always G Sometimes
 G Usually G Never
20. **My child's primary care doctor encourages me to ask questions about the care my child receives.**
 G Always G Sometimes
 G Usually G Never
21. **My child's primary care doctor takes enough time to answer my questions.**
 G Always G Sometimes
 G Usually G Never
22. **My child's primary care doctor asks my opinion on my child's health and development.**
 G Always G Sometimes
 G Usually G Never
23. **My child's primary care doctor communicates my views to others involved in my child's care.**
 G Always G Sometimes
 G Usually G Never
24. **My child's primary care doctor pays attention to my opinion of other providers to whom my child has been referred.**
 G Always G Sometimes
 G Usually G Never
 G My child has not been referred.
25. **My child's primary care doctor makes me feel that I am part of the team involved in my child's care.**
 G Always G Sometimes
 G Usually G Never
26. **My child's specialists support my role as a member of the team involved in my child's care.**
 G Always G Sometimes
 G Usually G Never
 G My child has not needed specialty care.
27. **When a decision has to be made about my child's care, my opinions are respected by my child's primary care doctor.**
 G Always G Sometimes
 G Usually G Never
28. **When a decision has to be made about my child's care, my opinions are respected by the specialists.**
 G Always G Sometimes
 G Usually G Never
 G My child has not needed specialty care.

29. I have received enough training on any medical procedures I need to do for my child at home.
G Always G Sometimes
G Usually G Never
G My child has not needed any medical procedures at home.

30. I am satisfied with the support I receive for my role in providing care for my child with special health care needs.
G Very Satisfied G Somewhat Dissatisfied
G Somewhat Satisfied G Very Dissatisfied

E. Questions 31-39 ask about information you need to make sure your child gets the best possible care.

31. I can get information on my child's conditions.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

32. I can get information on my child's developmental needs.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

33. I can get information on diagnostic procedures or tests performed on my child.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

34. I can get information on research and the latest medical discoveries related to my child's special needs.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

35. I can get information on MassHealth Managed Care enrollment procedures.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

36. I can get information on my rights within MassHealth Managed Care if I have a problem or disagree with my child's primary care doctor.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

37. I can get information on MassHealth Managed Care benefits.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

38. I can get information on other programs that might help my child or family.
G Always G Sometimes
G Usually G Never
G I have not needed this information.

39. I am satisfied with information I receive on medical care for my child with special health care needs.
G Very Satisfied G Somewhat Dissatisfied
G Somewhat Satisfied G Very Dissatisfied

F. Questions 40-47 ask about emotional and other kinds of help available to your family.

40. How easy was it to get mental health counseling for your child with special health care needs?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Easy
G Have not tried to get counseling.

41. How easy was it to get mental health counseling for yourself?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Easy
G Have not tried to get counseling.

42. How easy was it to get mental health counseling for your other children?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Easy
G Have not tried to get counseling.

43. How easy was it to find family-to-family support groups?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Difficult
G Have not tried to find family-to-family support

44. How easy was it to get help coordinating different medical appointments and therapies that your child may need?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Difficult
G Have not tried to get help

45. How easy was it to get help finding and arranging respite care?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Easy
G Have not tried to get help

46. How easy was it to get support with school enrollment or early intervention services?
G Very Easy G Somewhat Difficult
G Somewhat Easy G Very Difficult
G Have not tried to get support

47. I am satisfied with support that is available to help me provide care for my child with special health care needs.
G Very Satisfied G Somewhat Dissatisfied
G Somewhat Satisfied G Very Dissatisfied

G. Questions 48-50 ask your opinions about the care your child receives.

48. What makes you happy about the medical care your child receives?

-
-
49. What makes you upset about the medical care your child receives?

50. What would you like to improve about the way your child's care is provided?

51. How long has your child been with his/her current primary care doctor?
_____ month(s)

OVERALL FINDINGS OF NEEDS ASSESSMENT

An analysis and integration of survey and focus group data revealed overall satisfaction of families and primary care clinicians (PCCs) of children with special health care needs to be generally high. However, when satisfaction with different aspects of care is compared, both families and PCCs reported being less satisfied in some areas than in others. These areas, information, family supports, and coordination of care (in particular, coordination of care regarding home health services, hospitalization and discharge planning, and school health services) were identified by both families and PCCs as areas that present opportunities for improvement.

This summary report includes key findings of the family needs assessment, followed by key findings of the primary care clinician needs assessment.

FAMILY NEEDS ASSESSMENT

Three hundred twenty-one family surveys were completed, and four family focus groups were held. Tables I-IV describe key survey findings. Table V is a summary of the family needs assessment and incorporates key findings of both the survey and focus groups.

The family survey measured overall parent satisfaction in five different areas of care. Table I describes the responses to the five overall satisfaction questions. Most respondents reported being satisfied in most areas in most areas measured. However, when comparing the responses to the overall satisfaction questions, we see that the provision of information and the availability of supports to help parents care for their children with special health care needs stand out as areas in which fewer parents reported themselves “very satisfied.” This comparison, in conjunction with the knowledge that patient satisfaction surveys generally reflect a somewhat positive or favorable bias, suggests that the provision of information and availability of family supports are areas that may benefit from improvement.

Parents reported some types of information and supports to be more accessible than others. Tables II and III list parents’ ratings of the accessibility of different types of information and supports.

Although overall satisfaction with primary care physicians’ coordination of medical care was high (94%), respondents reported primary care physician involvement to be low in several critical areas of care coordination: discharge planning, home care, and school health services. These areas are highlighted in Table IV. These responses are in striking contrast to the responses in other areas measured regarding the primary care physician’s role in

care coordination. Other areas of care coordination measured revealed primary care physician involvement to be always/usually present for at least 87% of respondents.

One suggested explanation for parents’ high level of overall satisfaction with primary care physicians’ coordination of medical care, despite low primary care physician involvement in these areas, is that parents may not view communication and coordination with hospital discharge planning, home care, and schools as part of the role of their child’s primary care physician and therefore do not attribute them as contributing to their satisfaction (or dissatisfaction) with the way in which the primary care physician coordinates their child’s care.

In order to gain further insights regarding the problems of information, support, and care coordination, parents were asked to elaborate on these areas in focus groups. Highlights of the focus group discussions are described in Table V (on the following page), along with a summary of key findings from the parent survey.

Summary of Family Needs Assessment

Parents of children with special health care needs identified the availability and accessibility of information, family supports and care coordination, particularly coordination of care surrounding hospitalization, discharge planning, home care and school health services, as areas that could benefit from improvement. Focus group discussions confirmed these survey findings. They also provided anecdotal information from parents about concerns regarding uncovered or under-covered services. Areas in which parents felt there to be gaps in services included durable medical equipment; dental health services; mental health services; transportation; and interpreter services.

The problems of family supports and gaps in services are not unrelated to those of information and care coordination. Interventions that improve the dissemination of information to both families and primary care physicians may also address the problem of limited access to family supports and perceived gaps in services.

PRIMARY CARE CLINICIAN NEEDS ASSESSMENT

Surveys were received from 285 PCCs: 194 surveys were used for analysis. (91 PCCs were not eligible to complete the entire survey and were therefore excluded from analysis.) Two PCC focus groups were held. Table VI describes selected survey results. Table VII summarizes the PCC needs assessment by incorporating

key findings of both the survey and focus groups.

Overall PCC satisfaction in three areas measured by the survey was high. Most respondents reported being satisfied in most of the specific areas measured. In general, respondents reported that “making a difference,” and watching a patient progress, grow and develop were key factors contributing to their satisfaction. However, when probed, several areas emerged as areas in which there is room for improvement. Table VI includes a summary of these findings.

Primary Care Clinicians identified several areas of care that could benefit from improvement. The areas identified were those related to care coordination and information regarding the care of children with special health care needs. A summary of key findings of the PCC needs assessment, highlighting PCC concerns, is presented in Table VII.

Summary of PCC Needs Assessment

PCCs identified coordination of care of children with special health care needs, mostly related to the provision of home care services, hospital discharge planning, specialists, schools and parents, as an area in need of improvement. Coordination of care was described as particularly difficult for those children with multiple needs who are serviced by many agencies. PCCs also identified a lack of information--or difficulty in accessing information--regarding the care of children with special health care needs as a problem both for themselves and for parents. In addition, PCCs reported a concern that time limitations prevent them from meeting all of the needs of the child and family. Interventions that improve the dissemination of information and strategies to improve care coordination may, in fact, reduce this problem of time limitations.

TABLE 1. SURVEY FINDINGS ON OVERALL PARENT SATISFACTION				
Satisfaction with...	Very Satisfied	Somewhat Satisfied	Somewhat Dissatisfied	Very Dissatisfied
The way in which their child’s primary care physician provides medical care	71%	23%	4%	2%
The way in which child’s primary care physician coordinates the medical care their child receives	71%	23%	4%	2%
Support parent receives for their role in caring for their child with special health care needs	70%	22%	6%	2%
Information parent receives on medical care for their child with special health care needs	56%	31%	9%	4%
Support available to help parent provide care for their child with special health care needs	53%	31%	10%	6%

TABLE 2. SURVEY FINDINGS ON PARENT INFORMATION		
Type of Information: Frequency with which Parent can Obtain Information If Needed	Always/ Usually	Sometimes/ Never
Information on child's conditions	87%	13%
Information on child's developmental needs	87%	13%
Information on diagnostic procedures or tests performed on child	86%	14%
Information on MassHealth Managed Care enrollment procedures	71%	29%
Information on rights within MassHealth Managed Care if parent has a problem or disagrees with child's physician	71%	29%
Information on MassHealth Managed Care benefits	70%	30%
Information on research and latest medical discoveries related to child's special health care needs	68%	32%
Information on other programs that might help their child or family	60%	40%

TABLE 3. SURVEY FINDINGS ON FAMILY SUPPORTS		
Type of Support: Ease or Difficulty with which Parent can Find and Obtain Support If Needed	Very/ Somewhat Easy	Very/ Somewhat Difficult
Mental health counseling for other children in the family	80%	20%
Mental health counseling for parent	78%	22%
Support with school enrollment or early intervention services	78%	22%
Assistance coordinating different medical appointments and therapies that child may need	78%	22%
Mental health counseling for child with special health care needs	74%	26%
Locating family-to-family support groups	70%	30%
Assistance finding and arranging for respite care	68%	32%

TABLE 4. SURVEY FINDINGS ON COORDINATION OF CARE		
Area of Care Coordination: Frequency of Primary Care Physician Involvement	Always/ Usually	Sometimes/ Never
Communication with School or Early Intervention Program: when requested to do so by parent, primary care physician communicates with staff of child's early intervention program or school	73%	27%
Discharge Planning: primary care physician plays an active role in the discharge planning process when child is hospitalized	72%	28%
Home Care: primary care physician (or staff) makes arrangements for home care when it is needed	70%	30%
Communication with Home Care Providers: primary care physician (or staff) communicates regularly with home care providers about the care child receives	67%	33%

TABLE 5. SUMMARY OF FAMILY NEEDS ASSESSMENT		
Issue	Survey Findings	Focus Group Findings
Information	<p>Types of information parents have needed but had the most difficulty obtaining include information on:</p> <ul style="list-style-type: none"> • research and the latest medical discoveries related to their child with special health care needs • MassHealth Managed Care enrollment procedures, benefits and rights • other programs that might help their child or family 	<p>Several parents identified the need for all information to be simplified so that more parents could understand it. Types of information noted include:</p> <ul style="list-style-type: none"> • medical information • information on other services for their child or family • information on benefits
Family Support	<p>Types of supports parents have needed but have had difficulty obtaining include:</p> <ul style="list-style-type: none"> • mental health counseling services (for their child with special needs, for themselves, or for their other children) • family-to-family support groups • respite care • assistance coordinating medical appointments • support with school enrollment or early intervention services 	<p>Several parents recommended that parents have a Parent/Patient Advocate to provide support. Again, they referred to problems with school health services. The role of the Advocate would be:</p> <ul style="list-style-type: none"> • to assist parents at school team meetings in order to ensure that their child's rights are supported • to monitor the services the school provides in order to ensure that services are rendered and the recommended treatment plan is followed
Care Coordination	<p>Specific areas of care coordination that need improvement include:</p> <ul style="list-style-type: none"> • hospital discharge planning • home care • school health services 	<p>Focus group participants consistently mentioned school health services as a major problem. Problems noted included availability of services as well as parents' limited knowledge of services actually provided to their children.</p> <p>Focus group discussions confirmed that, while many parents are unhappy with coordination and information related to school health services, they do not necessarily expect their child's primary care physician to play a role in coordinating their child's treatment at school.</p>

TABLE 6. SURVEY FINDINGS ON PCC SATISFACTION					
Satisfaction with...	Very Satisfied	Somewhat Satisfied	Somewhat Dissatisfied	Very Dissatisfied	Most Common Factors Associated with Dissatisfaction
The relationships PCC has with parents of patients with special health care needs	57%	35%	7%	1%	<ul style="list-style-type: none"> time constraints poor communication uncooperative families/failure of families to keep appointments and follow through stressed parents
The relationships PCC has with specialists to whom they refer children with special health care needs	45%	49%	6%	0%	<ul style="list-style-type: none"> lack of communication inaccessibility lack of teamwork and cooperation difficulty in coordination of care
Their role as a Primary Care Clinician for children with special health care needs	36%	53%	11%	0%	<ul style="list-style-type: none"> time constraints (33% reported that time constraints made providing primary care to children with special health care needs difficult) red tape/paperwork insurance company rules and restrictions lack of services/programs lack of financial reimbursement inability to coordinate multiple providers

TABLE 7. SUMMARY OF PCC NEEDS ASSESSMENT

Issue	Key Survey and Focus Group Findings
Coordination with Specialists	<ul style="list-style-type: none"> • 27% of survey respondents reported that, when they make a referral to a specialist, they sometimes or never identify specific questions they want the specialist to answer • 42% of survey respondents reported that they never specify a time frame for receiving feedback from specialists • Lack of communication and delayed feedback by specialists were reported as problems often encountered by focus group participants • Focus group participants noted that problems arise when specialists refer their patients to other specialists without the PCC's knowledge
Coordination with Home Care and Hospital Discharge Planning	<ul style="list-style-type: none"> • 53% of survey respondents reported that they sometimes or never participate in the development of home care plans for children with special health care needs; 10% reported they always participate in home care plan development • 34% of survey respondents reported that, when a child in their practice requires home care, the referral is only sometimes initiated by them. Hospitals were reported as a common source of the home care referral. • Some focus group participants felt that the home care system works well for children with acute needs, but is more problematic for children with chronic, complex conditions. Their feeling was that these children require an exceptional amount of time to coordinate all of their various needs. • Focus group participants reported burdensome paperwork and high turnover in home care agencies as causing a large drain on PCCs' time. Turnover in home care agencies resulted in little communication between old and new caregivers, presenting PCCs with a greater challenge obtaining information about their patient
Coordination with Schools	<ul style="list-style-type: none"> • In focus group discussion, participants noted that coordination with school health services is a major challenge. Their concerns included: <ul style="list-style-type: none"> - insufficient school personnel or resources to meet the needs of children with special health care needs - difficulty contacting school providers since parents are not always aware of the name of the school provider and because school providers are usually unavailable at the times when PCCs are available to communicate with them by telephone
Information	<ul style="list-style-type: none"> • Survey results revealed that PCC's are most likely to seek information on issues related to the care of children with special health care needs from specialists (96% of respondents), colleagues within their practice (89%), medical libraries (67%) and early intervention providers (61%). • Survey respondents reported that they are least likely to seek information on issues related to the care of children with special health care needs from on on-line medical sources and programs run by public and other social service agencies. • When asked to elaborate on their information needs during focus groups, participants reported that they typically did not use state agencies as an information resource because of the difficulty in determining the most appropriate agency to contact, as well as the most appropriate person in the agency.

Issue	Key Survey and Focus Group Findings
Parent Role	<ul style="list-style-type: none"> • 87% of survey respondents reported that parents are one of the most common sources of care coordination. • 18% of survey respondents reported that parents are the ones who typically monitor the implementation of home care plans. • In focus groups, PCCs reported that they rely heavily on parents to coordinate their child's care. While some PCCs felt that this arrangement works well for some families, they believed that it is very demanding on families and not all parents have the ability, information and support to perform this difficult role well. • Focus group participants recommended that there be a centralized patient advocate case management system which would include team meetings with physicians. They reported that the most difficult aspect of caring for children with special health care needs is ensuring that full consideration is given to all of the patient's multiple health and information needs. They strongly believed that a patient advocate case manager could help physicians, patients and their families in this regard.

IMPACT OF MANAGED CARE ON ADULTS WITH MENTAL ILLNESS REACTOR BIOGRAPHIES

Howard H. Goldman, M.D., M.P.H., Ph.D.

Howard Goldman is Professor of Psychiatry at the University of Maryland, School of Medicine at Baltimore, where he is Director of Mental Health Policy Studies. From 1983-1985 he served as Assistant Institute Director at the NIMH, where he was responsible for mental health care financing policy and related research. He continues to consult to the Federal Government on health care finance, including his service in 1993 on the President's Task Force on Health Care Reform.

As Assistant Director of NIMH, he worked with the Social Security Administration (SSA) on the revision of the mental impairment standards for the disability program. Subsequently, he consulted to the American Psychiatric Association on a SSA contract to assess the reliability and validity of those standards. Dr. Goldman has written several articles in the professional literature on the SSA disability program and recently conducted a published review of measures of functional assessment. He also consulted to Westat on the design of the Disability Examination Study for SSA, and he is a member of the National Academy of Social Insurance Policy Panel on Disability.

Dr. Goldman is a frequent contributor to the professional literature in mental health services research and economics. His resume lists ten books, 20 monographs and reports, and over 150 articles and chapters. Dr. Goldman's editorial board appointments have included Health Affairs, Journal of Mental Health Administration, Psychiatric Services (formerly Hospital and Community Psychiatry), and the American Journal of Psychiatry. In addition, he has just completed the fourth edition of his textbook for medical students, Review of General Psychiatry.

Michael F. Hogan, Ph.D.

Michael Hogan has served as Director of the Ohio Department of Mental Health since March 1991. He was Commissioner of Mental Health in Connecticut from 1987-1991 and was credited with leading that State to a fourth place ranking among the State mental health systems in 1990--tied with Ohio. Previously, he served as a Regional Director and State Hospital Superintendent in Massachusetts, and was responsible for administering mental health and mental retardation programs in Western Massachusetts.

Dr. Hogan holds a bachelor's degree from Cornell University and a Ph.D. from Syracuse University. He is President of the Board of the National Association of State Mental Health Program Directors (NASMHPD) Research Institute and serves on the National Advisory Council, which approves NIH research grants. He has authored a text and numerous book chapters and papers on mental health care, with his most recent publications focussed on The Organization and Financing of Mental Health Care and Managing the Whole System Under Managed Care. He is married and has three sons.

SEVERELY MENTALLY ILL HMO MEMBERS

Bentson H. McFarland, M.D., Ph.D.

Bentson McFarland is Professor of Psychiatry, Public Health and Preventive Medicine at Oregon Health Sciences University and Adjunct Investigator at the Kaiser Permanente Center for Health Research in Portland, Oregon. He received his M.D. degree and a Ph.D. in biostatistics from the University of Washington in Seattle. He conducts research on mental health services, pharmacoeconomics, and pharmacoepidemiology.

RESEARCHERS

- Bentson H. McFarland, M.D., Ph.D.
- Richard E. Johnson, Ph.D.
- Mark C. Hornbrook, Ph.D.

BACKGROUND: MEDICAL OUTCOMES STUDY

- Depressed psychiatric patients disenrolled from HMO sooner than comparable fee for service patients
- No HMO controls

OBJECTIVES

- Enrollment duration
- Service use
- Cost of care

SEVERELY MENTALLY ILL HMO MEMBERS

- Specialty mental health users
- Diagnosis of schizophrenia or bipolar disorder
- Cohort #1
 - S Outpatient records 1986-1987
 - S Follow-up through 1990
- Cohort #2
 - S Inpatient records 1990-1991
 - S Follow-up through 1995

CONTROLS (AGE AND SEX MATCHED)

- Membership
- Pharmacy users

- Diabetic patients

SEVERELY MENTALLY ILL SUBJECTS (COHORT #1)

- N = 250
- Age = 32
- Male = 50%
- Schizophrenia = 32%
- Prior state hospital use = 41%

PREDICTORS OF LONGER ENROLLMENT FOR SEVERELY MENTALLY ILL SUBJECTS (COHORT #1)

- Prior enrollment duration (p < .006)
- Community mental health center use (p < .05)

Note: HMO costs of care not predictive of enrollment duration

CONCLUSIONS

- Severely mentally ill HMO members maintain HMO enrollment (as do other ill HMO members)
- Community mental health center use associated with longer enrollment
- HMO costs of care not related to enrollment duration

TABLE 1. UTILIZATION AND HMO COSTS DURING FOLLOW-UP (COHORT #1)		
	Severely Mentally Ill	Controls
Community mental health center	40%	5%
State hospital	12%	1%
Exceeded mental health benefit	12%	0%

TABLE 2. ENROLLMENT DURATION (COHORT #1)	
	Days in HMO
Diabetic patients	1,424
Severely mentally ill	1,263
Pharmacy controls	1,236
Membership controls	1,023

TABLE 3. ENROLLMENT DURATION (COHORT #2)	
	Days in HMO
Diabetic patients	1,256
Severely mentally ill	1,158
Pharmacy controls	861
Membership controls	175

COLORADO'S EARLY AND PRELIMINARY EXPERIENCE WITH CAPITATION FOR THE SEVERELY AND PERSISTENTLY MENTALLY ILL ADULTS

Joan R. Bloom, Ph.D.

Joan Bloom is Professor of Health Policy and Administration at the University of California, Berkeley in the School of Public Health. She received her doctorate in Sociology of Education at Stanford University. She is a Co-Investigator at the Center for Mental Health Services Research. In addition, she is an Affiliated Investigator at the Northern California Cancer Center and a Consultant for the Stanford University Medical Center. Her research interests include organizational studies and community services focused on the delivery of medical and mental health services. She has had a long-standing interest in prevention and early detection of chronic disease. She is currently the Principal Investigator of two NIH funded studies: (1) the Colorado Capitation Study in which mental health services are being capitated for the Medicaid eligible population in the State of Colorado funded by the National Institute of Mental Health; and (2) Young Women with Breast Cancer, funded by the National Cancer Institute in which ethnically diverse, newly diagnosed younger women in the greater Bay Area are assessed and provided with a psychosocial support intervention. She is also involved in a longitudinal study focused on work redesign of hospital nurses. She serves on the Board of Directors of the Northern California Cancer Center and on the editorial boards of Cancer Prevention, Epidemiology and Biomarkers and International Journal of PsychoOncology. She serves on the Breast and Cervical Cancer Advisory Committee for the State of California and is Chair of their Evaluation Committee.

Dr. Bloom's teaching interests include organizational sociology, health care management, and program planning and evaluation. She teaches courses in program planning and evaluation, and master and doctoral level courses in organizational studies plus a variety of seminars.

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 - S Neal Wallace, M.P.A.
 - S Richard Scheffler, Ph.D.
- MEDSTAT, Washington, DC
 - S Brian Cuffel, Ph.D.

COLORADO'S MENTAL HEALTH SYSTEM

- Seventeen Community Mental Health Centers (CMHCs) provide the majority of outpatient services.
- Two state hospitals provide short and long term psychiatric services.
- Additional emergency services are provided in private facilities.

FEATURES OF CAPITATION PROGRAM

- Pilot program.

- Fully capitated--inpatient and outpatient.
- Carve-out.
- Covers all Medicaid beneficiaries needing mental health services.
- August/September 1995 program began.

SPECIFIC AIMS:

- Consumer Outcomes:
S Do consumer outcomes differ?
- Access and Utilization:
S Does access and utilization of mental health services change?
- Cost:
S Does the cost of services differ?
- Cost-Effectiveness:
S Does cost-effectiveness differ?
- Implementation and Innovation:
S Does capitation facilitate innovation in public mental health systems?

SUBJECT CHARACTERISTICS

- Medicaid Eligible
- Gender (50% female, 50% male)
- Diagnosis:
S Schizophrenia OR
S Bipolar Affective Disorder OR
S Any diagnosis and 24-hour care episode in previous year
- Cost (High cost/Low cost)*

*Only for 1994 sample

ORGANIZATIONAL CHANGE MEASURES:

- Community Program Philosophy Scale
- Organizational Culture Questionnaire
- Organizational Structure Survey
- Key Informant Interviews

TABLE 1. RESEARCH DESIGN			
Targets for Each Cell	1994	1995	New to System
Model 1*	128	64	64
Model 2*	128	64	64
Comparison - FFS	128	64	64
Model 1 = Stand Alone/Alliance CMHC Model 2 = Joint venture between FP managed care firm and Stand Alone/Alliance CMHC			

TABLE 2. STATUS OF CONSUMER INTERVIEWS: 9/1/96			
	Wave 1 (Baseline)	Wave 2	Wave 3
Completed Interviews	684	521	232
Refused	116	13	3
Deceased	n/a	5	4
Unable to Locate	53	11	1
Non-Response	35	7	0
Too Ill	7	3	3
Contacted to Date	895*	560	243
Success Rate	76%	93%	95%
* An additional 361 individuals were assigned for a total of 1265, however, these potential subjects were deemed inappropriate for a variety of administrative and clinical reasons.			

TABLE 3. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF SAMPLE FOR EACH GROUP			
Characteristic	Model I (%)	Model II (%)	F.F.S. (%)
Gender			
Male	48.5	49.4	47.9
Female	51.5	50.6	52.1
Ethnicity			
White	67.7	46.9	45.8
Black	4.0	4.9	18.8
Hispanic	6.1	19.8	8.3
Age			
21-35	43.4	25.9	31.9
36-50	41.4	46.9	53.2
51-65	13.1	19.8	6.4
65+	2.0	7.4	8.5
Diagnosis			
Schizophrenic			
Bipolar-Affective Disorder			
Other			
High Cost Client	31.3	39.5	52.1

TABLE 4. UTILIZATION OF MENTAL HEALTH SERVICES FOR EACH MODEL BEFORE AND FOLLOWING IMPLEMENTATION OF CAPITATION*						
Characteristic	Model I		Model II		FFS	
	Pre-	Post-	Pre-	Post-	Pre-	Post-
Inpatient						
Outpatient						
Day Treatment						
Crisis Intervention						
Individual Therapy						
Group Therapy						
Case Management						

* 6 months prior to six months following capitation as of November 1996.

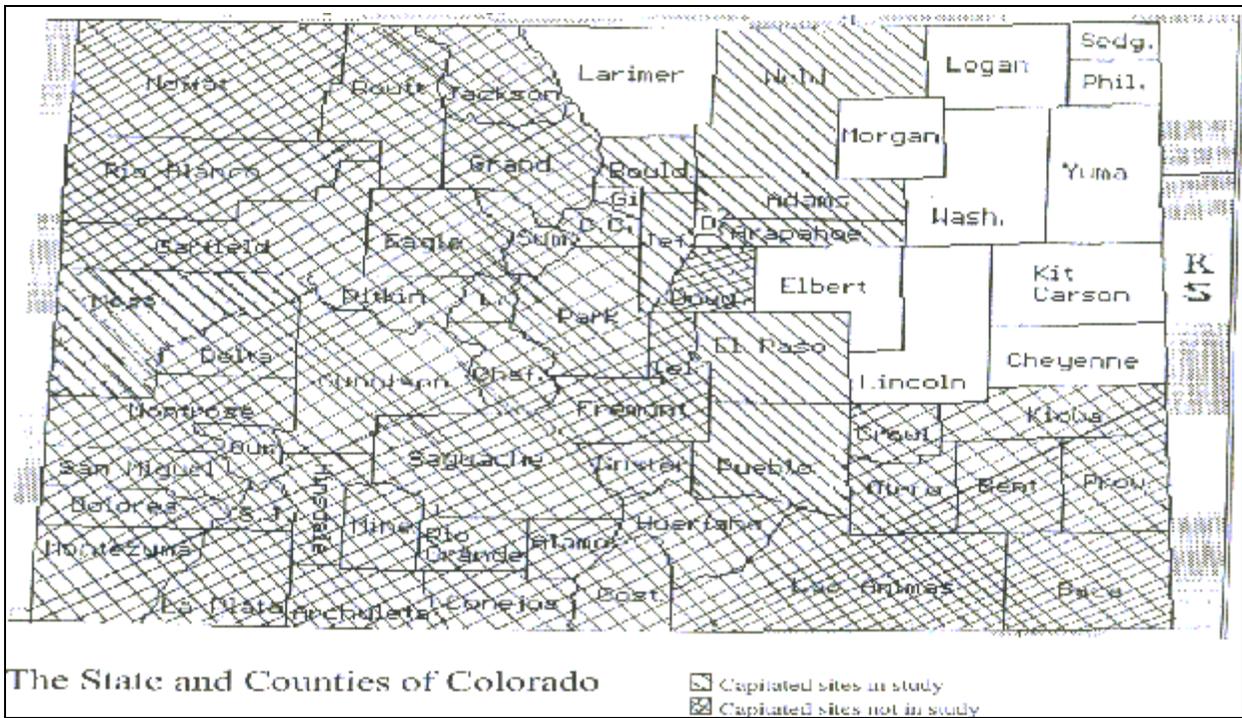
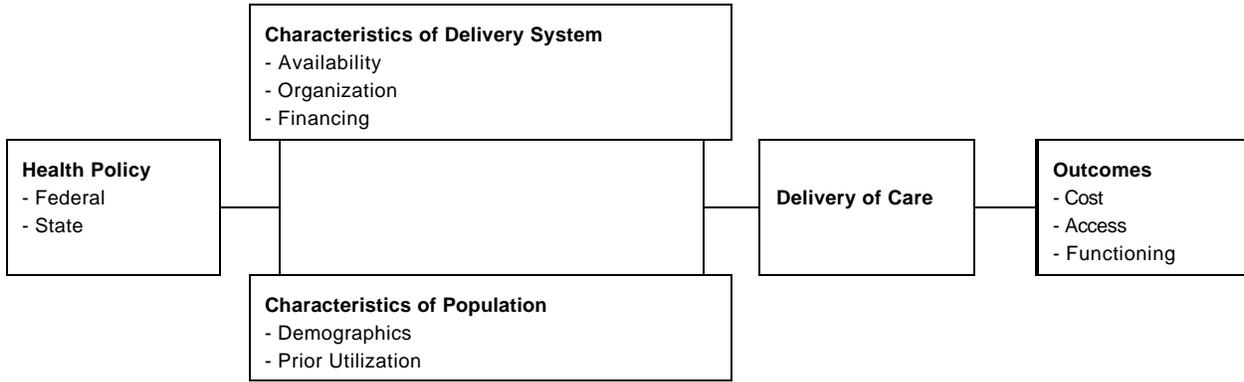
TABLE 5. COSTS PER UNIT OF PAYMENT (MEAN AND VARIANCE) FOR MENTAL HEALTH SERVICES FOR EACH MODEL BEFORE AND FOLLOWING IMPLEMENTATION OF CAPITATION*						
Characteristic	Model I		Model II		FFS	
	Pre-	Post-	Pre-	Post-	Pre-	Post-
Inpatient						
Outpatient						
Day Treatment						
Adult Treatment						
Crisis Intervention						
Individual Therapy						
Group Therapy						
Case Management						
Total Costs						

* 6 months prior to six months following capitation as of November 1996.

TABLE 6. OUTCOMES OF MENTAL HEALTH SERVICES FOR EACH MODEL SIX MONTHS BEFORE AND SIX MONTHS FOLLOWING IMPLEMENTATION OF CAPITATION*						
Characteristic	Model I		Model II		FFS	
	Pre-	Post-	Pre-	Post-	Pre-	Post-
Health Status (MOS SF36)						
Physical Functioning						
Bodily Pain						
General Health						
Social Functioning						
Mental Health						
Mental Health Symptoms (BPRS)						
Functional Status						
GAF Score						
Family Contact						
Daily Activity						
Social Contact						
Quality of Life						
Ever Homeless						
Housing Adequacy						
Finances						
Self-reported Income						
Income Adequacy						
Average Adequacy						

* Results as of November 1996.

CONCEPTUAL FRAMEWORK



Revised from Aday, et al., 1994

THE EFFECTS OF PRIVATE SECTOR MENTAL HEALTH CARVE-OUTS

Thomas G. McGuire, Ph.D.

Thomas McGuire is a Professor of Economics at Boston University. He has authored or edited three books and more than 100 published articles on health and mental health economics and policy. In 1983, his book, Financing Psychotherapy, received the Elizur Wright Award from the American Risk and Insurance Association recognizing an outstanding contribution to the literature on risk and insurance. He received the Carl Taube Award for outstanding contributions to mental health services research from the American Public Health Association in 1991. He has served as co-chair of three NIMH-sponsored conferences on economics and mental health, and has been the Research Director of a training program in economics and mental health at the Heller School at Brandeis University since 1981.

Dr. McGuire is the recipient of two sequential five-year Research Scientist Awards from the National Institute of Mental Health to study payment and financing of mental health services. Currently, he is also a recipient of an Investigator Award in Health Policy from the Robert Wood Johnson Foundation (joint with Richard Frank) to study reform of the organization and financing of mental health and substance abuse.

PRESENTATION NOT AVAILABLE AT TIME OF PRINTING. PLEASE REFER TO THE BACKGROUND PAPER COSTS AND INCENTIVES IN A MENTAL HEALTH AND SUBSTANCE ABUSE CARVE OUT.

THE MASSACHUSETTS MENTAL HEALTH SYSTEM CHANGE

Barbara Dickey, Ph.D.

Barbara Dickey is Associate Professor, Department of Psychiatry, Harvard Medical School and Director of Mental Health Services Research at McLean Hospital. She has been studying the costs and outcomes of care for the seriously mentally ill in different treatment settings for many years, including studies of hospital alternatives, community-based systems and comprehensive treatment models that integrate acute and long-term care for the psychiatrically disabled. She has been a frequent contributor to the professional literature and has recently co-edited a book on measuring behavioral health outcomes in clinical practice. With NIMH funding, she recently completed a cost-effectiveness study of housing and treatment for adults who are homeless and mentally ill and she is current the Principal Investigator of an NIMH study of managed care in Massachusetts.

PRESENTATION NOT AVAILABLE AT TIME OF PRINTING. PLEASE REFER TO THE BACKGROUND PAPER MANAGING THE CARE OF SCHIZOPHRENIA.

COSTS AND INCENTIVES IN A MENTAL HEALTH AND SUBSTANCE ABUSE CARVE OUT

Ching-to Albert Ma and Thomas G. McGuire

Draft; preliminary and unfinished

DO NOT QUOTE OR CIRCULATE

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ABSTRACT

This paper examines the overall change in costs of mental health and substance abuse services in a carve out program initiated in 1993 by the General Insurance Commission (GIC) of the Commonwealth of Massachusetts. Claims data for two years before (July 1991-June 1993) and two years after (July 1993-June 1995) the carve out were obtained from the GIC. These data were accompanied by an eligibility file for the four-year sample period. The exact financial arrangements in the vendor-payer contract are examined and described. The paper provides a full description of incentives, including multi-year contract renewals, and the payments and incentives associated with the administrative portion of the payments. We use those incentives to generate hypotheses about the effects of managed care on patterns of service use and cost.

The paper quantifies the changes in costs between the two years before the carve out and the two years after. By examining patterns of services in a population of continuously enrolled individuals, we eliminate selection-related changes in characteristics of the population.

The paper's main contribution is to describe and decompose the effect of managed care for mental health and substance abuse and to relate the observed effects to the incentives in the contract. We show the total plan and employee payments by month of service date for all major categories of expenditures, such as inpatient, other residential, and office visits. Trends in medical care prices will be used to adjust the data. Our basic decomposition therefore show impact by type of services, and show this separately for plan and employee-paid costs.

Our findings indicated significant savings after the carve out. Total and plan costs reduced by 50% to 70% over the four-year period. The pattern of cost reductions

are similar with respect to outpatient and inpatient services, as well as to mental health and substance abuse services. The estimated average price of a mental health outpatient visit increased over time in the sample period, whereas that of a substance abuse outpatient visit decreased slightly.

INTRODUCTION

Many big employers and payers have contracted with specialty management firms to administer the delivery of mental health and substance abuse (MHSA) benefits to their enrollees. This so-called MHSA "carve out" appears to be a most significant recent development, and has led to a new "behavioral healthcare" industry consisting of firms specializing in this service. Oss (1994) estimates that in 1994 over 50 million people in the U.S. are in some carve out program. "Risk-based" contracts, in which the specialty vendor (usually a for-profit corporation) bears some or all of the financial risk associated with MHSA services, are used in about half of all carve out programs. The rapidly growing use of separate carve-out contracts has been stimulated by reports of very favorable cost experience for many payers, with some savings reported to be in the range of 40 percent or more (Frank, McGuire and Newhouse 1995).

From an employer's or a payer's point of view, a carve out contract addresses the longstanding issues of moral hazard and adverse selection associated with insurance for mental health services (McGuire 1981; Frank, Huskamp, McGuire and Newhouse forthcoming; Frank, Glazer and McGuire 1996). Moral hazard is contained by the techniques associated with managed care--price negotiations, provider network selection and monitoring, prior authorization and utilization review. Adverse selection can be addressed by unification of the financial risks associated with mental health within a single contract; by pooling all persons in the same contract, no plans compete to avoid costly MHSA users.

Although the carve out approach offers these potential advantages in principle, the practical importance of this new form of insurance contract remains to be established. Favorable experience of innovative firms need not be a good predictor of what happens to the typical employer. First, if payers who first adopted carve out methods for MHSA services management are those with below average management efficiency in their previous existing plan ("low-hanging fruit" in the language

of the industry), then the effectiveness of carve outs may be much less for payers with well-run plans (Frank, McGuire and Newhouse 1995). Second, the experience of a particular payer and population is often influenced by many specific factors, some of which may not apply to other payers. Therefore, it appears important to study the diversity of payer and population characteristics, vendors' management techniques, and the actual contracts between them carefully, before generalizations are made.

We contribute to the accumulating evidence on carve outs and managed care by reporting on the experience of the MHSAs carve out of a major employer in Massachusetts-the Commonwealth itself. In this first paper in a continuing project on this case, we relate the incentives in the contract to the aggregate experience. First, we describe the MHSAs carve out contract between the Commonwealth of Massachusetts and the vendor, and identify its incentive implications. Second, we analyze insurance claims data for two-year periods before and after the carve out. We examine the association between the contract incentives and the actual cost outcomes, and use the period before the carve out as a benchmark for comparison. Before-and-after comparisons can be problematic because the underlying population can change. We have therefore selected for detailed analysis a group of enrollees who are continuously covered for the entire four-year data period, and examine the actual use and cost experience for them before and after the carve out.

BACKGROUND AND LITERATURE REVIEW

A behavioral health carve-out program was initiated in 1993 by the GIC of the Commonwealth of Massachusetts. The largest private payer in the state with an enrollment base of about 120,000, the GIC is responsible for providing health insurance to state and some local employees and their dependents. The GIC contracted with a combination of traditional indemnity insurers as well as HMOs since the middle of the 1970s. Between fiscal years 1989 and 1992, the State Hancock Plan, administered by John Hancock Mutual Life Insurance Company, was the indemnity plan for GIC enrollees. This managed fee-for-service plan included preadmission certification, utilization and concurrent reviews, second opinions and discharge planning, as well as pharmacy provider networks as managed-care features. These provisions applied to all areas of medical care, including MHSAs services. In addition, GIC contracted with 14 HMOs (staff/group and network models) and offered them as enrollment options to employees.

The GIC voted to change its health benefit plans in late 1991. The stated goal was to improve the value of services to employees given the overall expenditure level, increase enrollment in managed care, and reduce risk fragmentation and adverse selection problems (Group Insurance Commission, Request for Proposal, 1992, p.1-3). To achieve this, the GIC retained services of a management

consulting firm to assist with the evaluation of its existing benefits program, and the search for alternative benefit designs. One of the consultant's recommendations adopted by the GIC was the development of a separate MHSAs carve-out program for enrollees. By a proposal request and subsequent biddings and negotiations, GIC selected a behavioral health care firm, *Options Mental Health, Inc.*, from among five applicants, to set up a managed care mental health network of physicians and providers, and to manage mental health and substance abuse care on a partially at-risk basis.

The trade press contains many favorable reports of the experience of employers with carve out plans. Battagliola (1994) summarizes the experience of IBM which implemented a behavioral health carve out in 1991. In 1989, IBM was spending \$106 million on MHSAs benefits for its employees and dependents; this was going up at 10 percent per year, and consuming 15 percent of all health benefit costs. The carve out (with Value Behavioral Health [VBH]) consisted of a PPO with differential in-network and out-of-network cost sharing, expansion of alternative treatments, strengthening of an Employee Assistance Plan (EAP), and utilization review. By 1993, IBM's mental health costs had fallen to \$59.2 million and only 10 percent of health benefit costs. Clearly, *something* happened here! The article provides some information about enrollment changes (the number of employees was falling by 3-4 percent per year in the later years of the data), prices (inpatient cost per day fell by 40% between the pre and post periods), and benefit changes, but understanding what happened is difficult because no information is provided on the nature of the contract between IBM and VBH, or on the composition of the expenditure changes. Finally, it is worth mentioning that IBM began the initiative with a very generous plan and very high rates of spending per employee, approximately \$660 per employee per year on MHSAs, more than double the national average for the period. Reducing costs by 30 percent (in real terms) still leaves IBM far above average rates of spending.¹

The formal research literature on carve outs is just emerging. Grazier et al. (1993) examine outpatient utilization data one year before and one year after implementation of a PPO point-of-service plan with a benefit change for 4,220 continuously enrolled, active employees. Overall the rate of outpatient use went up slightly, but the visits per user fell slightly. The employer/vendor contract was "administrative services only" or ASO, so the vendor bore no explicit financial risk associated with utilization.

Frank and McGuire (1996) describe the experience of a carve out plan for MHSAs in Massachusetts Medicaid with aggregate data from one-year pre and three and a half years post institution of a behavioral healthcare carve out. Price reductions for inpatient care and the virtual elimination of inpatient treatment for substance abuse appear to have been the main mechanism generating savings of approximately 25 percent per enrollee in real terms. The

reduction in services was experienced virtually entirely by the disabled Medicaid beneficiaries. AFDC enrollees saw their costs (adjusted for medical price inflation) go up slightly over the course of the contract. The one-year contracts between the state and the vendor, Mental Health Management of America (MHMA) were almost entirely ASO contracts, and gave the vendor small incentives to reduce costs. Massachusetts began the period ranking third among the state in terms of overall health care spending for per Medicaid beneficiary. [ref]

DATA: ELIGIBILITY AND CLAIMS FILES

Data for this project come from eligibility and health claims files, covering the period July 1991 through June 1995, and provided to us by MEDSTAT. Identifying information about the contract holder was scrambled so that claims data could be merged with eligibility information without identifying contract holders. The eligibility data allow us to calculate the average number of Primary Insured Participations, or PIPs for each month. A PIP is essentially a contract holder.² Family contracts may cover more than one individual. We use relation, sex and date of birth information to identify individuals.

For some analyses we use a subsample of PIPs consisting of those covered by the GIC for the entire four-year sample period.³ The purpose of identifying this "continuously covered" population was for a better control of sample characteristics. All of these individuals have been covered by the GIC before and after the carve out. Cost outcomes of the continuously covered subsample will be compared to those of the entire sample. About 40,000 individuals are in our continuously covered population.

In the post carve out period after July 1993 we sought information about any claim for MHSA that would be covered by the carve out contract. Inpatient and other residential care was included in the sample. For outpatient care, we extracted any claim with a mental health procedure. A comparable selection criteria was used for the pre period as well, to make utilization in the pre period comparable to utilization in the post period.⁴

The claims data contain several cost related fields. The contract between GIC and Options is driven by the amount that the GIC has to pay, so some of our analysis will be based on the payments by GIC reported on the claim. Claims also contain information about payment amounts that are the responsibility of the beneficiary such as copayments and deductibles. Finally, covered charges represent the total negotiated price that Options has arrived at with the provider. Normally, the sum of GIC payments, beneficiary payments, and other payer obligations (if any) will be covered charges. Providers also report charges, but we will not use this information in this paper.

Units of services such as length of stay (LOS) and

visits on some outpatient claims are also reported on claims. Price per unit will be calculated by dividing covered charges by the appropriate units.

Claims data for the last two months in the sample period appear to be incomplete, apparently because of delays in the submission and processing of claims. We requested data as of November 1995, allowing three months past the final service date, but this was not long enough to accumulate almost all claims for the last quarter of data. For this reason, we discarded the claims data for the last three months in the sample period, and instead base the last year's figures on seasonally adjusted nine-month data.

By any standard the data show a very significant cost reduction after the carve out. Table 1 summarizes the findings for the entire enrolled population; all prices and costs are in current year dollars. For this population, the total net payment from GIC for all MHSA services was about \$9.32 million for fiscal year 94 (July 1993-June 1994), and \$7.29 million for fiscal 95. These compare to \$16.93 million in fiscal 92 and \$14.87 million in fiscal 93, the two years before the carve out. The average GIC payment per PIP per month for the four years between 1992 and 1995 were, respectively, \$20.32, \$17.84, \$9.52, and \$7.49. The average GIC payment per enrollee per month for these years were, respectively, \$13.91, \$12.22, \$6.04, and \$4.76.

Table 2 presents similar cost figures for the continuously covered population, and all price and cost figures are in constant 1995 dollars, with medical price index adjustment. Here the total GIC payment between 1992 and 1995 were, respectively, \$10.45, \$8.47, \$4.60, and \$3.89 millions. The average payments per PIP per month were, respectively, \$32.41, \$26.24, \$14.26, and \$12.08; per enrollee per month figures were, respectively, \$22.03, \$17.84, \$9.70, and \$8.22. Overall various indicators of "costs" have decreased between 50% and 70% in four years. We also find that total costs of MHSA services--the total paid by GIC, enrollees, as well as any third parties--show a similar pattern. Thus, the savings were not simply achieved by shifting costs from the GIC to enrollees or another payer.

Table 3 categorizes the plan and total costs of the continuously enrollees according to inpatient versus outpatient services: inpatient costs declined by about 50% while outpatient costs by more than 60%. The breakdown of these changes according to MHSA care are illustrated in Table 4.

THE CONTRACT BETWEEN THE GIC AND OPTIONS

To understand the contract between Options and the GIC, it is useful to provide some background about the proposal request and negotiation processes. In the

Request for Proposal (RFP), each potential bidder was provided with a summary of the plan enrollment, costs, and utilization pattern data for two years before the RFP was released. For each of the two years, the data included hospital admission and outpatient visit rates per 1,000 enrollees, number of hospital days per 1,000 enrollees, costs per hospital admission and outpatient visit, and costs per employee. These data were given for MHPA services, both separate and combined, for all employee groups.⁵ Utilization pattern data, such as distribution of admissions by diagnosis and outpatient visits, readmission rates, patterns of large claims, were also provided.

The GIC and its consultants first used the data to establish a set of benchmark projections of costs and savings. Each potential vendor was asked to provide its own set of projections, and the two sets of projections were compared and evaluated after the bids were submitted.⁶ Finally, Options was selected as the winner, and the details of the final MHPA contract were decided.

We now describe the contracts between the GIC and Options. The initial contract was for a one-year duration, and began in July 1993. It was expected at the time that the contract renewal for a second year would happen when the initial contract expired. We will briefly describe the benefit and coverage design. Detailed descriptions of the financial arrangements between GIC and Options will then be provided.

Important dimensions of the new benefit plan for MHPA were dictated by the GIC in the RFP. The MHPA carve out would be a managed care plan, nominally similar to the "managed care" in the previous Hancock plan, but expected to be more aggressive. The GIC specified the in-network and out-of-network benefits, goals for provider networks, and even the utilization levels (10, 20, 30 visits) at which the vendor should be intervening in the care process. Implementation of these features were of course to be left to the vendor. Benefits to enrollees choosing in-network care in the point-of-service plan were expanded from coverage before the carve out. Providers were to be precertified by Options before being admitted to the network. Whether an enrollee receives care from a network provider or not, precertification must be obtained from Options by calling a toll-free telephone number *before* care began (except for emergencies). A Clinical Case Manager was responsible for precertification. Options must be notified within 24 hours of any hospitalization, whether emergency (life-threatening), urgent, or routine. Complaints and grievances were reviewed by Options representatives, as are disagreements with clinical determinations.⁷

Financial aspects of the carve out that are relevant to enrollees are as follows.⁸ Generally, in-network coverage for inpatient services is complete with no deductibles; out-of-network inpatient coverage is 80% of allowed charges, with a 60 days limit per year and with a two-admission or

two-episode lifetime limit on substance abuse treatments. In-network outpatient visits are free for the first four, subject to a \$20 copayment for the fifth to twenty-fifth, and subject to a \$40 copayment thereafter. Out-of-network outpatient coverage is 50% of allowed charges, and subject to a maximum of 15 visits per year. In-network out-of-pocket expenses are limited to \$1,000 per individual and \$2,000 per family. Finally, the lifetime benefit maximum is \$1 million.

Benefits and cost sharing in the MHPA carve out program were substantially better for the enrollees than their previous plan. Before the carve out, mental health inpatient coverage at a general hospital was complete for 120 days (after a \$150 deductible), then 96% after annual deductible. But mental health coverage at a psychiatric hospital was complete for only 60 days, and at 80% thereafter with a limit of 300 days. Perhaps, the most striking difference was that before the carve out, substance abuse coverage at a substance abuse facility was at 80% and only up to \$10,000 a year after deductible. Outpatient MHPA coverages were respectively at 50% and 80%, with respective limits of \$1,500 and \$2,500 per year after deductible. The annual benefit limit was \$500,000; lifetime, \$1,000,000. The benefits after the MHPA carve out represented significant improvements, especially for in-network care.

The financial contract between the GIC and Options consisted of two main parts. First, for the fiscal year beginning July 1993, each month Options received from the GIC a fee (the ASO fee), which was calculated by multiplying the number of PIPs by \$3.43. Second, this rate would be adjusted upward by 5% in the second year unless otherwise agreed upon by the GIC and Options.⁹ The contract for fiscal 1993-4 also specified a target claims cost of \$20.72 per month per PIP. Besides serving as a benchmark to evaluate cost effectiveness of the contract, it would be used to adjust the ASO fee. In the actual implementation, for the fiscal year beginning July 1994, the ASO was revised to \$3.17 per month per PIP, and the target level lowered to \$15.39 per month per PIP.

For the fiscal year beginning July 1993, the target was established at \$20.72 per month per PIP. The \$20.72 refers to the portion of costs paid by the GIC, and does not include enrollee cost sharing. At the end of the fiscal year, the actual claims costs would be compared with the aggregate claim target (aggregate, because the rate was stated in terms of per month per PIP), and the ASO fee would be reduced by an amount equal to 20% of the excess of actual claims over the target, but this reduction would not be more than 20% of the ASO fee for the contract year. For example, if the claims cost turned out to be \$21.72 per month per PIP, then the ASO fee would be reduced by \$0.2 (20% of \$21.72-\$20.72) per month per PIP. The maximum cost overrun for which Options's ASO was reduced was $$(20.72+3.43)=-\24.15 . For fiscal year 1995-6, the target was reduced to \$11.19 per month per

enrollee, but the ASO fee was raised to \$5.18 per enrollee per month. The adjustment of the ASO fee according to the excess of claims costs over target remained unchanged.

Besides the adjustment of the ASO fee according to the discrepancy between actual claims cost and the target, Options was required to satisfy performance targets. During the first year, the set of performance guarantees consisted of five items, but expanded to sixteen in the second. The following is a sample from those in both years:¹⁰

- At least 90% of enrollees surveyed by an independent contractor should be satisfied with the services they received.
- Options should deliver reports by due dates.
- Options should guarantee claims financial accuracy to be no less than 99%; payment accuracy, 97%; procedural and coding accuracy, 95%.
- In the event that any of these guarantees was not met, Options must pay a penalty to GIC equal to 2% of the ASO fee for each guarantee violation, but the maximum of such penalty payment could not exceed 23% of the ASO fee.

It is important to keep in mind that the overall benefit package was expanded substantially after the carve out. In particular, coverage for in-network outpatient care was greatly improved. If enrollees' copayment and deductible remain unchanged, this coverage improvement must tend to increase use. Furthermore, even if use did not increase due to the benefit expansion, the improvement in coverage for in network care would tend to shift costs to the GIC from other payers who have contracts with the GIC enrollees. Thus, Options would have to implement some cost savings measure simply to be able to maintain costs to the GIC at existing levels. Indeed, the initial claims target of \$20.72 per PIP was such a level that savings by Options would just offset any cost increasing effects of the benefit expansion.

INCENTIVES IN THE CONTRACT

First consider the explicit incentives in the first year of the contract, and focus on the financial penalty and rewards associated with the claims target. Up to 20% of the ASO fee could be refunded to the GIC in case the actual cost was higher than the target level. The ASO fee to Options was the result to negotiations, and was paid regardless of the costs actually incurred in administration; thus, it was a type of prospective payment. The ASO fee included a profit allowance, but the actual profit or loss might be higher or lower depending on the costs actually incurred by Options.

Clearly, Options would attempt to economize on its own administrative expenses. If controlling MHSAs costs requires Options' resources, such resources would only

be provided if Options is properly motivated. Indeed, the carve-out contract does contain explicit incentives for Options to control MHSAs service costs. The most explicit of such incentives is associated with the claims target. The ASO fee could be reduced by up to 20% in response to costs accumulating above the claims target. To such a small company, this probably represented a significant amount of potential earnings. Nevertheless, *most of the financial risks remain with the GIC*. In spite of the fact that the contract is written in terms of a per PIP per month payment, the contract is very far from being a "capitation" contract in which risk is shifted largely to the vendor.

These points are extremely important and illustrated in different ways in Figures 1 and 2. Figure 1 shows how the ASO fee to Options, and costs to the GIC vary with the actual level of claims costs per PIP in the contract's first year. Options faces some risk, but this is quite small in comparison with the possible cost variations faced by the GIC. Given the different sizes of Options and the Commonwealth of Massachusetts, the risk sharing arrangement appears to be sensible. Although GIC does bear most of the MHSAs service costs, the remaining cost responsibility assumed by Options still seems significant for providing incentives for Options to meet the cost target. Figure 2 depicts the same risk sharing arrangement in a "proportional" way. Here, it is clear that the carve-out contract does not shift all cost responsibilities to the vendor.

As we noted above, the contract between GIC and Options was subject to renewal after the first year. The initial contract did specify an automatic adjustment on the ASO fee by 5% but other details of the contracts were open to revisions. In fact, in the second year, the same type of contract was signed by the GIC and Options, but the cost target was lowered from \$20.72 per month per enrollee to \$15.39 (or about 25%).

INTERPRETATION: INCENTIVE CONTRACTS AND PERFORMANCE

The ASO fee arrangements for Options contained a number of very interesting features. First, the contract did not allow the ASO fee to increase when Options was able to lower costs below the target level, but was subject to the risk of up to 20% of the fee for cost overruns. For a company of the size of Options, the total risk does not appear to be totally insignificant. This perhaps contrasts with the Massachusetts Medicaid behavioral health carve out (see Frank and McGuire, 1996), where the "at-risk" contract imposed a maximum penalty of \$300,000 in the first year of the contract. In contrast, if the ASO fee was \$3.43 per month per enrollee, for a population of 70,000 PIPs, Option's potential penalty in a year could be more than \$560,000. If the use of aggressive managed care to reduce claims costs meant higher administrative expenses, the incentives established by the ASO fee mechanism

would imply that costs should not be expected to fall significantly below the target level. But in actual fact, the first-year claims costs did fall significantly below the target. This brings us to the second point.

Options might have correctly anticipated that significant cost savings in the first year could have two effects. First, its superior performance might prompt the GIC to raise its expectation about cost saving potentials. A likely consequence was that GIC would lower the target rate. This phenomenon of superior contract performance resulting in more demanding terms in the future is called the "ratchet effect" in the contracting literature (see Laffont and Tirole, 1986, for example). Second, Options might think that it could convince the GIC that its value to the behavioral mental health carve out was high by demonstrating excellent performance in the first fiscal year. This could enhance Options's bargaining power in the contract renewal for the third year. In addition, it might also be a good signal to the market, so that Options's prospect of winning new contracts would be improved. We will call this the "reputation effect."

Clearly, the ratchet and reputation effects act against each other: the former induces Options to lower its performance, but the latter provides the opposite inducement. We can argue that Options in fact chose a performance level that traded off these two opposing effects. It was interesting to observe that the target rate was lowered in the second year by about 25% (in normal terms), and further reduced in the third year, but the administrative fee was reduced by a little in the second year, and then raised significantly in the third year.

From the perspective of incentives, the existence of a penalty for cost levels that are above the target does not necessarily imply that the target level will be achieved. In fact, Options might optimally choose to violate the target, incurring some penalty while saving administrative expenses. Nevertheless, the contract did not provide any incentive for Options to lower costs below the target level, since Options was unable to keep any savings. Therefore, it seems to us that what needs to be explained was the fact that Options achieved much more: in each of the years after the carve out, the actual costs were lower than the target level by a significant amount. Here, our hypothesis is that the reputation effect initially dominated the ratchet effect: for small cost reductions beyond the target level, Options's reputation began to build up, but the ratchet effect did not become important until significant savings beyond the target level was attained.

To understand the impact of the carve out, it is important to distinguish different two sets of relationship changes. First, Options was brought in to implement the provision of MHSA services by managed care. Whereas before the carve out, only those enrollees with the HMOs had their care delivered via managed care, all enrollees were under the management of Options since the carve

out. This is a form of demand-side management. Second, Options set up a network of providers for enrollees. Before the carve out, providers negotiated individually with the GIC. After the carve out, Options, on behalf of the GIC, centralized all negotiations with providers. This affects the supply side. The first change may have the effect of reducing inappropriate use of MHSA services, since preadmission authorization, utilization review, and other monitoring may deter or screen out some demands for services. The centralization of bargaining makes Options a "monopsonist" buyer with market power, and enables it to use the size of the GIC population to secure a lower price from providers.

The above arguments suggest the following *decomposition* analysis. Consider any single type of service, say an outpatient visit. By definition, the total cost of this service in a given period of time is equal to the total number of times this service is used multiplied by the average price of each service. A reduction in total cost of this service can come about through a reduction in the quantity, the price, or both. From the claims data, we calculate the total number of outpatient visits for the periods before and after the carve out. Using the data of outpatient costs, we can estimate the average price per visit. For inpatient services, we calculate LOS of each episode and obtain the average LOS by dividing by the number of inpatient episodes. Using the inpatient costs data, we then estimate the average price per inpatient day. As it turns out, after the carve out, the claims data separated out from all inpatient services an additional class: inpatient service at an alternative setting. These are inpatient services performed at a less intensive setting such as residential facility, partial facility, intensive outpatient, residential professional and partial professional settings.

Table 5 and 6 present the decomposition of MHSA outpatient services and costs. For the continuously enrolled population, we estimate the prices per MHSA outpatient visit by dividing the total outpatient plan costs (after discarding outliers that may simply reflect adjustments to previous claims) by the total number of visits. We express the estimates both in terms of current year dollars and constant 1995 dollar. Table 5 shows an upward trend for MH outpatient prices, but a downward trend for SA. Nevertheless, we should note that the outpatient coverage of MH was significantly improved after the carve out; before the carve out, MH outpatient coverage was at 50% while SA at 80%. Table 6 presents the our own analysis and that from Options on number of admissions and average LOS per admission. While the data we received from MEDSTAT gave us numbers of admissions that were comparable to those Options reported, the total number of inpatient days were higher from our own analysis. Furthermore, we were unsuccessful in decomposing from our data total inpatient days into "conventional" and "alternative setting" inpatient services. Nevertheless, there is a slight decrease in the

total of admissions as well as the ALOS in both analyses. From Table 5 suggests that the dramatic decrease in outpatient costs could be due to reduction in quantities, since "prices" either increased or remained relatively stable. On the other hand, Table 6 suggests that the reduction in inpatient plan costs mainly could be a result of price reduction, since numbers of admissions as well as ALOS did not decrease as much as the total plan costs.

CONCLUSIONS

- The anticipated cost shifting from enrollees to the plan is offset by decrease in prices. Because of the improved MHSA coverage and benefits for enrollees, expenses for the plan should tend to increase. But in the GIC experience, this increase was more than compensated by the decrease in prices that GIC had to pay providers as well as by the effect of managed care quantities.
- Both outpatient and inpatient costs decrease. Despite the general view that managed care will tend to shift the demand for MHSA services from inpatient to outpatient, the GIC experience shows a mixed result. For mental health services, the decrease in outpatient costs between fiscal 92 and 95 was significantly less than inpatient, while these costs decreases were almost in the same percentage for substance abuse.
- Both MH and SA services decrease in quantity uniformly.
- The target level in the contract must be understood in relation to the penalty. That is, the entire schedule of ASO fees must be analyzed. Although there are penalties for failing to maintain the target, there is no a priori reason to expect that the target will be maintained. The vendor may *optimally* fail to maintain costs below target, incurring the penalty while avoiding administrative costs.
- In the case of the GIC MHSA carve out, the target level is related to the ratchet and reputation effects. We find that even when Options faces no financial gains from reducing costs *below* the target, in fact that was what happened. Meeting a target is insignificant when a contract is viewed in isolation, but may have repercussions when contract renewals and bidding for new contracts are considered part of a firm's incentive. As in many other industries, a good reputation is a very valuable asset to a firm. Our finding is consistent with the "long term" perspective of contracting. Whenever a carve out program requires the contracting out of the administrative and management duties of the deliveries of medical services, the long term effects of contracting must be considered.

NOTES

1. For other examples, see Alexander Consulting Group

(1990) on McDonnell Douglas; Altman and Price (1993) on Alcan; and Umland (1995).

2. According to the contract, a PIP is a covered person who is an employee, a retired employee (of various classes), a covered student age 24 or over, an individual not part of a family unit covered under some continuation provision (see Appendix D of the Agreement for Managed Mental Health Services by and between Commonwealth of Massachusetts Group Insurance Commission and Options Inc. 1993). Thus, the total number of PIPs does *not* correspond to the total of all enrollees; rather each PIP roughly corresponds to a unique employee identification number in the enrollment records. In particular, spouses and most dependents are not PIPs.
3. We actually selected these enrollees by identifying contracts with months of enrollment of 46 or greater of a possible 48.
4. Some cost shifting between MHSA and general medical care is possible. For instance, inpatient treatment for alcohol abuse could be reclassified by a clinician as treatment for gastrointestinal problems and paid for under the general health insurance benefit. We are not in a position to evaluate how much of such cost shifting has occurred. For study of this in another context, see Norton et al. (1996).
5. Active employees, retiree and survivors, and all groups.
6. In many instances, potential vendors were asked to justify their projections, or to provide information on the basis of which those calculations were obtained.
7. It is unclear whether any outside arbitration would be allowed.
8. The benefit and enrollees' out-of-pocket payment designs for fiscal years 93-94 and 94-95 are identical.
9. An implementation fee was also paid by the GIC in the first few months. This was calculated at \$.35 per PIP per month.
10. See Merrick (1996) for more discussion of the performance targets.

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TABLE 1. MENTAL HEALTH AND SUBSTANCE ABUSE COSTS				
Entire Set of Enrollees	FY 92	FY 93	FY 94	FY 95
Average monthly PIPs (92 is est)	69,440	69,212	81,571	81,062
Average monthly enrolled	101,373	101,012	128,496	127,486
Total cost	\$22,345,087	\$20,001,460	\$12,429,902	\$9,710,747
Total plan cost	\$16,928,806	\$14,817,617	\$9,316,278	\$7,290,191
Total cost per PIP per month	\$26.82	\$24.08	\$12.70	\$9.98
Plan cost per PIP per month	\$20.32	\$17.84	\$9.52	\$7.49
Total cost per enrollee per month	\$18.37	\$16.50	\$8.06	\$6.35
Plan cost per enrollee per month	\$13.92	\$12.22	\$6.04	\$4.77

TABLE 2. MENTAL HEALTH AND SUBSTANCE ABUSE COSTS (ADJUSTED FOR INFLATION, IN 1995 \$)				
Continuously Covered Enrollees	FY 92	FY 93	FY 94	FY 95
Average monthly PIPs	26,887	26,887	26,887	26,887
Average monthly enrolled	39,541	39,541	39,541	39,541
Total cost	\$14,103,476	\$11,915,996	\$6,331,853	\$4,697,196
Total plan cost	\$10,455,369	\$8,467,091	\$4,601,074	\$3,898,639
Total cost per PIP per month	\$43.71	\$36.93	\$19.62	\$14.56
Plan cost per PIP per month	\$32.41	\$26.24	\$14.26	\$12.08
Total cost per enrollee per month	\$29.72	\$25.11	\$13.34	\$9.90
Plan cost per enrollee per month	\$22.03	\$17.84	\$9.70	\$8.22

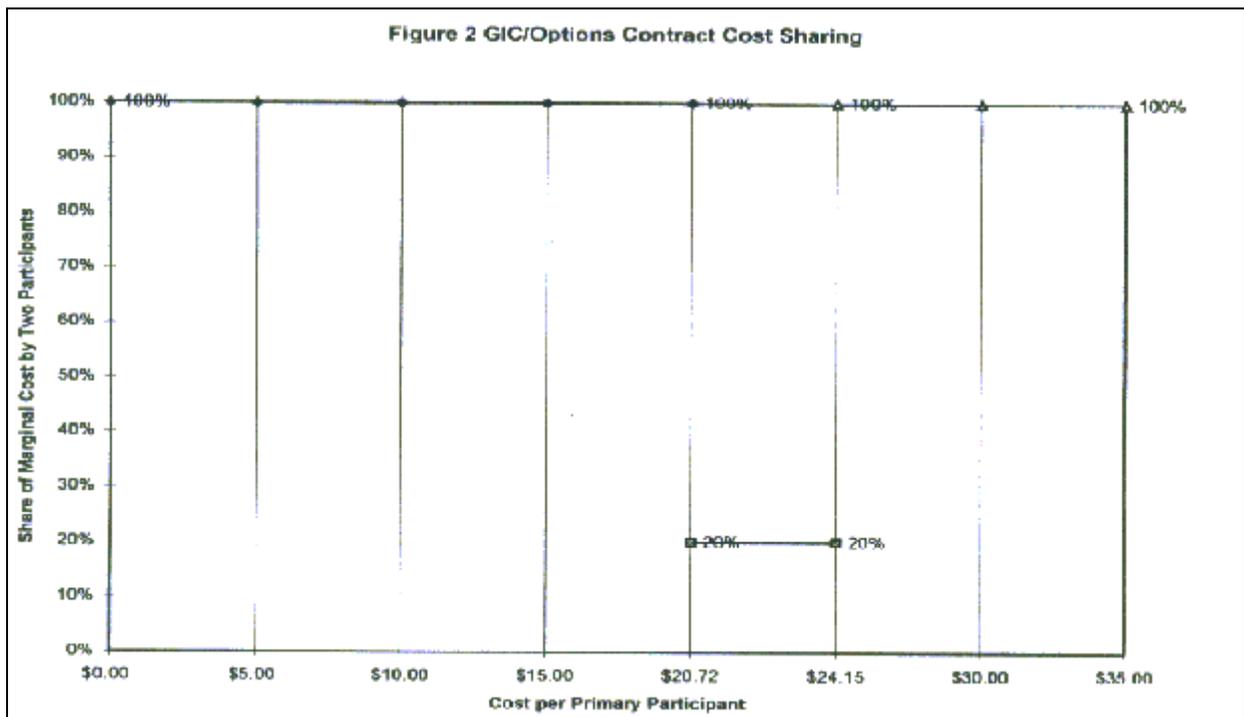
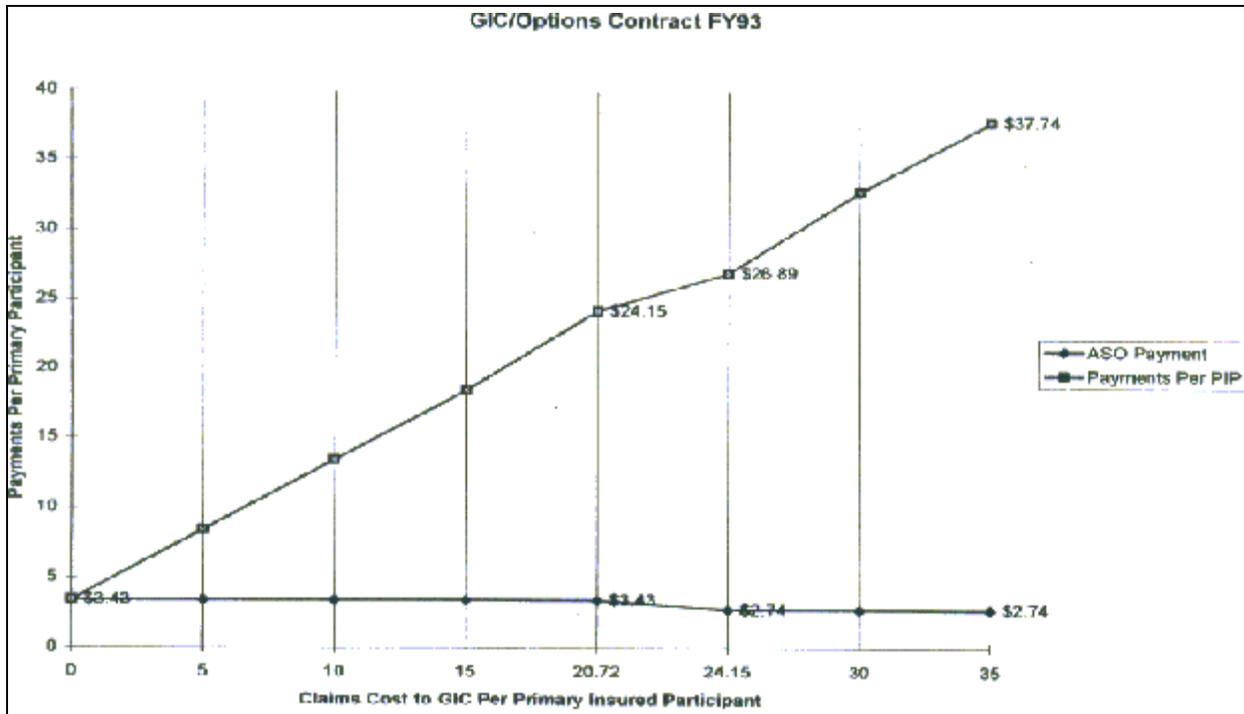
TABLE 3. INPATIENT AND OUTPATIENT COSTS					
Continuously Covered Enrollees	FY 92	FY 93	FY 94	FY 95	% Change
Total outpatient cost	\$8,120,662	\$7,714,771	\$4,187,579	\$2,983,368	0.55
Plan outpatient cost	\$4,577,179	\$4,394,690	\$2,647,443	\$2,068,618	0.47
Total inpatient cost	\$5,982,814	\$4,201,225	\$2,144,274	\$1,713,828	0.62
Plan inpatient cost	\$5,878,191	\$4,072,402	\$1,953,631	\$1,830,021	0.62

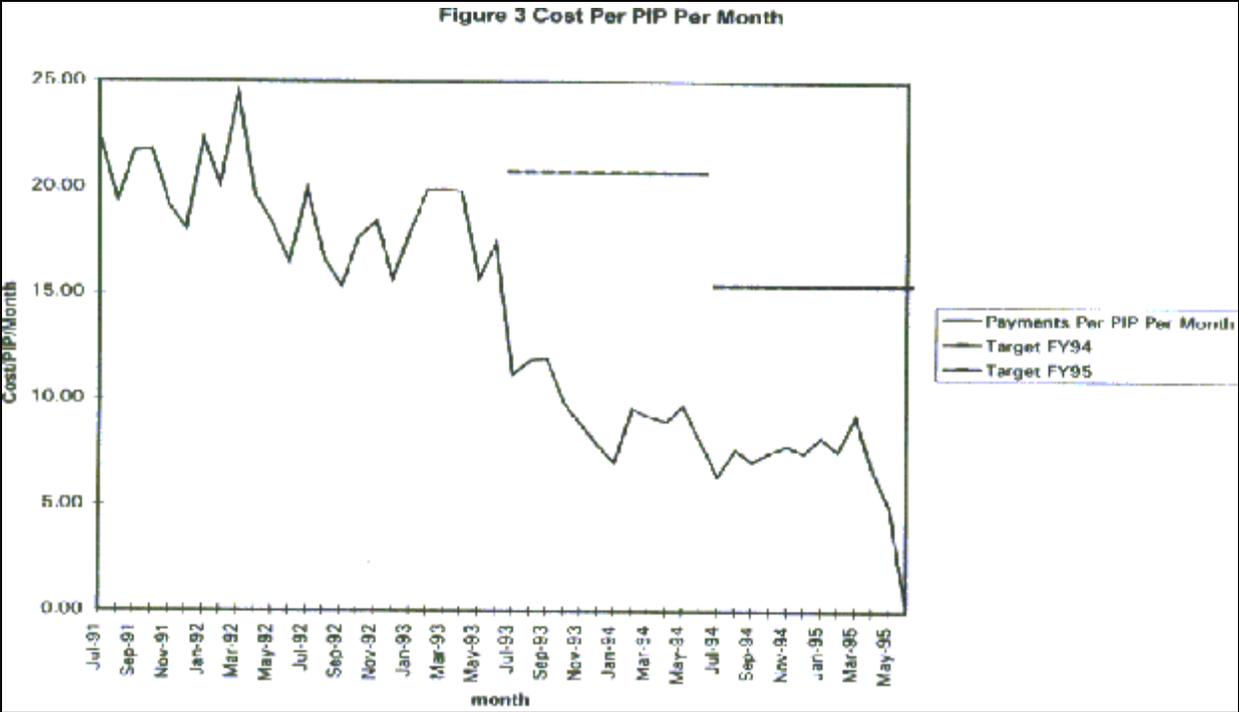
TABLE 4. BREAKDOWN OF MENTAL HEALTH AND SUBSTANCE ABUSE COSTS					
Continuously Covered Enrollees	FY 92	FY 93	FY 94	FY 95	% Change
Plan total outpatient MH cost	\$4,291,262	\$4,056,528	\$2,547,510	\$1,835,488	0.47
Plan total outpatient SA cost	\$285,917	\$338,162	\$99,932	\$71,890	0.72
Plan total inpatient MH cost	\$4,689,307	\$3,246,222	\$1,605,253	\$1,294,947	0.63
Conventional inpatient MH			\$1,425,635	\$1,112,972	
Alternative level MH			\$173,575	\$176,184	
Plan total inpatient SA cost	\$1,188,883	\$826,180	\$332,671	\$323,205	0.67
Conventional inpatient SA			\$292,813	\$276,173	
Alternative level SA			\$39,740	\$46,993	

NOTE: Inpatient MH, inpatient SA cost figures are from service claim file.

TABLE 5. PRICE ESTIMATES OF OUTPATIENT MENTAL HEALTH AND SUBSTANCE ABUSE				
Current Year Dollar	FY 92	FY 93	FY 94	FY 95
Continuous set: MH outpatient	\$40.29	\$42.68	\$54.23	\$52.95
Continuous set: SA outpatient	\$56.27	\$59.02	\$53.08	\$53.11
Contant 1995 Dollar	FY 92	FY 93	FY 94	FY 95
Continuous set: MH outpatient	\$46.52	\$46.59	\$56.49	\$52.95
Continuous set: SA outpatient	\$64.98	\$64.43	\$55.29	\$53.11

TABLE 6. INPATIENT QUANTITY OF MENTAL HEALTH AND SUBSTANCE ABUSE				
Data from MEDSTAT	FY 92	FY 93	FY 94	FY 95
Number of admissions	944	876	1,007	985
Total number of days	13,098	10,443	13,827	10,934
ALOS	13.88	11.92	13.73	11.10
Data from OPTIONS Annual Report	FY 92	FY 93	FY 94	FY 95
Number of admissions			1,079	969
Total number of inpatient days			9,121	7,031
Total number of alternative setting days			3,211	3,190
Total number of days			12,332	10,221
ALOS (counting only inpatient days)			8.4	7.2
ALOS (counting all days)			11.43	10.55





ENROLLMENT DURATION, SERVICE USE, AND COSTS OF CARE FOR SEVERELY MENTALLY ILL MEMBERS OF A HEALTH MAINTENANCE ORGANIZATION

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Background: The rapid growth of prepaid health care and the increasing enrollment of Medicaid clients in health maintenance organizations (HMOs) raise concerns about the adequacy of services for persons with severe mental illness in capitated health plans. Uncontrolled studies have suggested that enrollment of HMO members with mental illness may be prematurely terminated.

Methods: We identified 250 adult Kaiser Permanente Northwest Region (Portland, OR) members who were enrolled during 1986 or 1987 and had chart diagnoses of schizophrenia or bipolar disorder. Severely mentally ill subjects were matched by age and sex with control HMO members with and without diabetes mellitus. Records of the HMO and the state mental health agency were reviewed to determine HMO enrollment duration, private and public service utilization, and HMO costs of care during the 4-year follow-up period.

Results: The severely mentally ill subjects had 42 months of HMO enrollment during the follow-up period compared with 37 months for the controls without diabetes mellitus and 47 months for the patients with diabetes mellitus ($P < .001$). When HMO enrollment prior to the study was taken into account, the severely mentally ill subjects and those with diabetes mellitus had similar membership duration. Among the severely mentally ill subjects, community mental health service use was related to longer duration of HMO enrollment ($P < .05$) but HMO costs of care per member per month were not related to retention. The severely mentally ill subjects were high users of mental health services but their use of general medical care was similar to that of the controls without diabetes mellitus.

Conclusions: This controlled study found no evidence for early termination of HMO members with costly mental illness. Use of community mental health care was associated with longer duration of HMO enrollment.

The dramatic growth in health maintenance organization (HMO) enrollment has heightened concern about the adequacy of treatment available for persons with severe mental illness in prepaid systems.^{1,2} This topic is of particular interest to the dozens of states^{3,4} that are now in the process of replacing fee-for-service with capitated health care systems for Medicaid clients, many of whom have severe mental disorders.⁵ Indeed, Mechanic⁶ has suggested that public mental health programs should be gradually integrated into the larger, prepaid health care system while bearing in mind the many challenges involved.⁷ Conversely, Scheffler et al.⁸ have recommended that programs for persons with severe mental illness remain "carved out" of general health care. Furthermore, editorial writers have claimed that traditional HMOs "disenroll individuals who develop serious mental disorders"⁹ and have stated that "HMOs have routinely excluded any coverage of chronic mental illness."¹⁰ On the other hand, HMOs have also been described in which persons with severe mental illness "receive relative priority."¹¹ Inconveniently, there have been few empirical data with which to inform this debate.^{1,2}

One of the few pertinent studies is the 1987

Minnesota project, which included a comparison of health status for chronically mentally ill Medicaid clients who had been randomized to fee-for-service vs prepaid (HMO) health care.^{2,12-14} Unfortunately, the project ended prematurely after only a year of operation. Few if any differences were found for chronically mentally ill persons, although the subset of this group with schizophrenia may have been adversely affected by assignment to the independent practice association model HMOs that participated in the project.^{2,14}

Somewhat related to this issue is the RAND observational Medical Outcomes Study,^{15,16} which raised the possibility that during 1986 through 1988 psychiatric patients with major depressive disorder in prepaid health care may have switched insurance coverage (i.e., terminated HMO enrollment) sooner than their counterparts in the fee-for-service sector. It was suggested that the limited mental health services provided to these subjects (referred to as HMO "skipping") may have contributed to their departure from the HMO.^{16,17} However, the Medical Outcomes Study lacked a control group within the HMO.

To address these issues, we conducted a multiyear

longitudinal cohort study of HMO members with severe mental illnesses such as schizophrenia or bipolar disorder. Based on the existing literature,^{9,15} we hypothesized that the severely mentally ill HMO members would disenroll earlier than their lower-cost counterparts.^{9,10} We also wished to learn if there was a relation between HMO members' use of public mental health services and their duration of enrollment.

METHODS

Study Site

The study was conducted in the Northwest Region of Kaiser Permanente, a nonprofit, prepaid, group-practice HMO that currently serves some 385000 members in greater Portland, OR. The HMO has been in operation for over 50 years, provides comprehensive medical benefits, and includes a specialty mental health department presently consisting of about 20 psychiatrists and 80 other mental health professionals.¹⁸ The HMO's mental health and substance abuse benefits conform to those mandated by Oregon law. Since 1987, Oregon insurers have been required to cover up to \$2000 of outpatient and up to \$8500 of inpatient, residential, or day treatment mental health and/or substance abuse services every 24 months for adult beneficiaries. The HMO allows substitution of inpatient for outpatient benefits. However, the total adult mental health and/or substance abuse benefit is a maximum of \$10500 per 24 months. In addition, the vast majority of HMO members have a pharmacy benefit. A 1995 survey of the membership showed that 84% of enrollees obtain all of their prescriptions and 12% obtain some or most of their prescriptions (including those written by non-HMO clinicians) at the HMO's pharmacies. The HMO maintains a membership information processing system that records eligibility for services based on monthly premium payments. Administrative personnel attempt to contact individuals whose premiums are unpaid. For purposes of this study, disenrollment was defined to have occurred at the beginning of a 90-day or longer period of ineligibility. The project was reviewed and approved by the Kaiser Permanente Northwest Region Committee for the Protection of Human Subjects on February 16, 1995.

Selection of Subjects

The years 1986 and 1987 were chosen as a baseline period so that this project could be compared with earlier work.^{2,12-16} Because the HMO's outpatient charts were not computerized at the time, severely mentally ill subjects were selected from the 2334 persons who received an antipsychotic drug (excluding prochlorperazine and thietilperazine, which are used in the HMO only for treatment of nausea and vomiting) or lithium from an HMO pharmacy during 1986 or 1987; individuals in the original group who also received anticancer drugs or drugs used in the treatment of acquired immunodeficiency syndrome

were excluded. To minimize the numbers of subjects who might have conditions such as Alzheimer disease, the study focused on the 733 potential subjects who were between ages 10 and 46 years in 1986. Of this group, 526 had mental health department charts (indicating they had had at least 1 contact with an HMO mental health specialist at some time). Individuals were then randomly selected from these 526 persons for mental health chart abstraction. Subjects who carried chart diagnoses of bipolar disorder (including mania, manic-depression, and hypomania) or schizophrenia (including schizophreniform disorder and schizoaffective disorder) in the mental health record were retained in the study. Mental health chart abstraction proceeded through 440 charts until 250 subjects meeting these inclusion criteria were located. Persons who were excluded at this stage typically had diagnoses of substance abuse (primarily amphetamines, cocaine, and/or alcohol) or psychotic depression. Since this study was designed to be descriptive in nature, the sample size of 250 was selected so that the SEs of the mean of annualized utilization estimates (measured in office visits per person per year) would be less than 10% of the estimated mean value. As in other record review projects, diagnoses were assigned based on the majority of those found in the subjects' mental health charts.^{19,20} This group of subjects was labeled "cohort 1."

Control Members With and Without Diabetes Mellitus

The severely mentally ill subjects in cohort 1 were then matched with other HMO members. The "pharmacy" controls were taken from the population of HMO members who used the system's outpatient pharmacies during 1986 or 1987 (and had not received an antipsychotic drug or lithium). This group included some two-thirds of the HMO's membership. The "membership" controls were selected from the HMO's enrolled population during 1986 and 1987, which averaged about 290000 persons on any given day at that time. Subjects were matched for sex, year of birth, and "coverage status" (i.e., whether the subject was a subscriber or a dependent of the subscriber). For studies of the enrollment duration of cohort 1, the subjects were also matched for sex and year of birth (within 5 years) with 234 people selected from the 2140 individuals who were HMO members during 1986 or 1987 and who had been discharged by a general medical-surgical unit (in 1986 or 1987) with a diagnosis of diabetes mellitus.

Service Utilization

Cohort 1 subjects' HMO service utilization data were obtained from 1986 through 1990 record reviews and computerized databases. In addition, the names and dates of birth for all subjects without diabetes mellitus in cohort 1 were matched against state mental health agency computerized utilization data. The state agency provided information about subjects' use of community mental health programs and the state mental hospitals from 1986 through 1990. While there were extensive data on state hospital

usage (including dates of admission and discharge, diagnoses, and so forth) the community mental health data were limited to enrolled vs not enrolled during particular time periods. The Chronic Disease Score^{21,22} (based on nonpsychotropic drug dispensing) was used to gauge the severity of physical illnesses in subjects from cohort 1 without diabetes mellitus.

Costs

The HMO's accounting data and Medicare cost reports became available in 1987 and were used to calculate cost coefficients for each unit of service (e.g., outpatient visit to a provider, day in a medical-surgical unit, and so on). The cost coefficients were then multiplied by units of service for cohort 1 to determine the cost (in 1990 dollars) for each type of care.^{23,24} Billing records were used to determine the costs (in 1990 dollars) of services purchased by the HMO (e.g., general hospital inpatient psychiatric care) for members of cohort 1. Public sector costs were not available.

Secular Trends in Enrollment Duration

To address possible secular trends in enrollment duration, a second group of severely mentally ill subjects (labeled "cohort 2") was chosen from the HMO members discharged from a general hospital during 1990 through 1992 with diagnoses of schizophrenia or bipolar disorder. These people were matched for age and sex with HMO controls with and without diabetes mellitus as described for cohort 1. The enrollment duration study focused on the 165 female and 116 male (average age, 31 years in 1990) severely mentally ill subjects in cohort 2 who were between the ages of 10 and 46 years at the time of the index hospital discharge, of whom there were 139 with a diagnosis of schizophrenia and 5 who also had a diagnosis of diabetes mellitus. Follow-up for cohort 2 started with the index hospital discharge and ended December 31, 1995.

Statistical Analysis

Service utilization and cost data for cohort 1 are reported on a per member per month of enrollment basis. In 2-way analyses of variance (ANOVA), data were transformed as needed so that the residuals were roughly normally distributed. For example, the total cost per person per month was transformed by adding 1 to the cost numerator, dividing by the months of enrollment denominator, and then taking the logarithm of that ratio. To account for multiple comparisons, the studentized range test was used to compare the cohort 1 severely mentally ill subjects' utilization and costs with those of the controls.²⁵ Enrollment duration comparisons used the log-rank test and the Cox proportional hazards model stratified to account for the matching.²⁶ Changes in coverage status (subscriber vs dependent) were examined using the Miettinen method.²⁷

Cox proportional hazards models were used to examine factors associated with retention of cohort 1 severely mentally ill subjects in the HMO during the follow-up period from 1986 through 1990.²⁶ Blocks of potential predictors were planned for stepwise inclusion in the proportional hazards models. These potential predictor variables were demographics (age, sex, schizophrenia vs bipolar disorder); enrollment status at the start of the study (subscriber vs dependent, Medicare vs no Medicare, Medicaid vs no Medicaid, years of HMO enrollment prior to the start of the study); and utilization (state hospital admission at any time while an HMO member during the study period, use of community mental health services while an HMO member at any time during the study period, total HMO costs of care per member per month, and HMO mental health costs of care per member per month).

RESULTS

Demographics

In cohort 1 there were equal numbers of males and females. Subjects in cohort 1 were (on average) 32 years old in 1986, with an age range from 13 to 45 years and an SD of 8 years. The ethnicity distribution was 80% white, 5% African American, 2% Asian American, 2% Hispanic, and 12% unknown. There were no differences in the distributions of known ethnicity between the severely mentally ill subjects and the controls. Some 30% of the 250 severely mentally ill persons in cohort 1 (for whom data were available) had never married. In contrast only 12% of the controls (for whom data were available) had never married. At the beginning of the study about half (53%) of the 750 subjects without diabetes in cohort 1 were subscribers, while 44% were dependents and the remaining few were nonmembers. Only 12% of the cohort 1 severely mentally ill subjects changed coverage status from dependent to subscriber during the 4-year follow-up period, compared with 22% of the controls without diabetes mellitus (relative risk, 0.53; 95% confidence interval, 0.30-0.92). The severely mentally ill subjects in cohort 1 were much more likely to have Medicare coverage than the controls without diabetes mellitus (10% vs 0.2%, $P < .001$ by Fisher exact test). There was no difference in the prevalence of Medicaid coverage (5% vs 4%).

The 250 severely mentally ill subjects in cohort 1 had lengthy histories of mental illness. At the time of their first HMO mental health department contact, the vast majority (73%) reported having had at least 1 previous psychiatric hospitalization, with 40% of severely mentally ill subjects reporting 3 or more admissions. Many (41%) were known to have been admitted to a state mental hospital in Oregon. The majority (57%) had had contact with the HMO's emergency psychiatric service at some time during their enrollment.

Diagnoses

The diagnostic algorithm showed that 79 (32%) of the 250 severely mentally ill subjects in cohort 1 had chart diagnoses of schizophrenia, 98 (39%) had bipolar disorder, and the remaining subjects had multiple diagnoses. As expected, 92% of the 98 persons with bipolar disorder had received prescriptions for lithium, while 93% of the 79 subjects with schizophrenia had been dispensed antipsychotic drugs. Some 30% of the bipolar subjects had received antipsychotic drugs as well as lithium.

Service Use

Health care utilization data for the 1986 through 1990 study period are presented in **Table 1**. Not surprisingly, the severely mentally ill HMO members utilized greater amounts of services than did the controls without diabetes mellitus. As expected, the severely mentally ill subjects had greater per member per month use of mental health [F(2498)=120.1, $P<.001$] and substance abuse outpatient services [F(2498)=6.5, $P<.003$] as well as greater use of general hospital psychiatric inpatient services [F(2498)=86.3, $P<.001$]. During the study period, 88 (35%) of the severely mentally ill subjects in cohort 1 had 274 general hospital psychiatric admissions while the pharmacy controls had none and the membership controls had 1.

Interestingly, there were no statistically significant differences among the 3 groups without diabetes mellitus in the per member per month use of general medical outpatient services. However, differences were observed with respect to use of general medical-surgical inpatient care [F(2498)=4.5, $P=.01$]. The studentized range test indicated that the severely mentally ill subjects' use of general medical-surgical inpatient care was equivalent to that of the pharmacy controls.

The Chronic Disease Score (based on pharmacy data other than psychotropic drugs for the 665 subjects without diabetes mellitus enrolled in 1986) showed that the severely mentally ill subjects had the highest score (mean=0.48, SD=1.18), followed by the pharmacy controls (mean=0.31, SD=0.92), who were in turn followed by the membership controls (mean=0.15, SD=0.65). These differences are highly statistically significant (2-way ANOVA F[2498]=7.9, $P<.001$). Because the Chronic Disease Score was not normally distributed, we also examined the percentage of each group with a nonzero score (47 [20%] of 231 severely mentally ill subjects, 34 [15%] of 225 pharmacy controls, and 16 [8%] of 209 membership controls). These frequency differences were also highly statistically significant ($X^2=14.3$, $df=2$, $P<.001$).

During their HMO enrollment in the follow-up period, 30 (12%) of the severely mentally ill subjects in cohort 1 were admitted to a state mental hospital compared with 3 (1%) of the pharmacy controls and 1 (0.4%) of the membership controls ($X^2=48.5$, $df=2$, $P<.001$). Similarly, 101 (41%) of the severely mentally ill subjects in cohort 1 used community mental health services during the follow-up

period compared with 12 each (5%) among the pharmacy and membership controls ($X^2=152.7$, $df=2$, $P<.001$).

Costs

Table 2 and **Table 3** show the HMO costs of care per member per month for the subjects without diabetes mellitus in cohort 1. The vast majority (98% of the severely mentally ill subjects, 95% of the pharmacy controls, and 87% of the membership controls) incurred HMO costs. The severely mentally ill subjects had substantially higher HMO costs of care per member per month of enrollment than did the controls without diabetes mellitus. The average cost for the subjects with severe mental illness was \$380 (median of \$203) per member per month vs an average of \$149 (median of \$33) for the pharmacy controls and \$90 (median of \$23) for the membership control subjects [2-way ANOVA on the transformed total cost F(2419)=81.4, $P<.001$]. The studentized range test showed that the 3 groups were all statistically significantly different from one another at the $P=.05$ level.

Looking in more detail at costs per member per month for the severely mentally ill subjects showed that the median combined mental health cost (inpatient, outpatient, and pharmaceutical) was \$99 with the median, excluding psychotropic pharmaceuticals, at \$74. Median outpatient mental health cost was \$48. The 90th percentile figures were \$798 per member per month for total costs, \$544 for all mental health costs, \$492 for mental health costs excepting psychotropic medications, \$284 for inpatient care, and \$214 for outpatient mental health costs.

Enrollment Duration

The Kaplan-Meier product-limit estimates in the **Figure** show the retention of cohort 1 subjects in the HMO from the start of time under observation (in 1986 and 1987) until disenrollment or the end of follow-up on December 31, 1990. Mean enrollment duration for cohort 1 is shown in **Table 4**. The enrollment durations of the cohort 1 groups differ significantly (log-rank $X^2=40.7$, $df=3$, $P<.001$). The stratified Cox model showed that the most powerful predictor of enrollment duration was not being in the membership control group ($X^2=25.1$, $df=1$, $P<.001$), with the next most powerful predictor being years of HMO enrollment prior to entering the study ($X^2=17.8$, $df=1$, $P<.001$). Once prior years of HMO enrollment had been taken into account, there were no statistically significant enrollment differences among those subjects with diabetes mellitus, severe mental illness, and pharmacy controls in cohort 1. **Table 4** also shows that the enrollment duration of cohort 2 subjects was similar to that of cohort 1.

Retention

Among the severely mentally ill cohort 1 subjects, stepwise Cox proportional hazards modeling showed that the factors related to longer duration of enrollment in the

HMO were years of HMO enrollment prior to the start of the study period ($X^2=7.6$, $df=1$, $P<.006$); age ($X^2=5.6$, $df=1$, $P<.02$); and community mental health service use ($X^2=3.9$, $df=1$, $P<.05$).

Costs of care (total costs per member per month or mental health costs per member per month) for cohort 1 were not significantly related to retention based on the Cox proportional hazards modeling. Other factors not significantly related to cohort 1 enrollment duration in the proportional hazards models included sex, schizophrenia vs bipolar disorder, subscriber status, or use of the state hospital.

COMMENT

Results from this study need to be interpreted in light of its design. The project was not a randomized trial nor did it include a comparison group of subjects outside the HMO. Since the study was designed to take advantage of existing data, subjects were not interviewed and clinical outcomes were not measured. Consequently, there could well have been important but unrecorded differences among the groups. Furthermore, subjects' reasons for disenrollment and for use of public mental health services were not available.

The project examined "prevalent" cases of people with severe mental illness who were using HMO services. At the time of this study it was not possible to identify HMO members with newly emerging (i.e., "incident") psychosis. Certainly, the "careers" of severely mentally ill persons who do not receive treatment may well be different from those of the subjects described here. For example, persons who become psychotic and refuse HMO mental health services might be unable to maintain enrollment and quickly leave the organization. Indeed, earlier work has shown that the treated prevalence of schizophrenia within this HMO is less than what would be expected from Epidemiologic Catchment Area data, although the treated prevalence of bipolar disorder is comparable to the national estimate.¹⁸ Very recent improvements in the HMO's automated data systems may provide an opportunity to conduct an incidence study focusing on people with newly emerging psychosis.

Another issue is the degree of severity of the subjects' mental disorders. For example, some 67% of the cohort 1 severely mentally ill subjects were self-reported to be employed at the time of their first HMO mental health clinic visit. Interestingly, the Epidemiological Catchment Area project found that 43% of the persons identified in that study as having schizophrenia were employed.²⁸ The severely mentally ill HMO members may be that subset of persons with conditions like schizophrenia, who have a relatively good prognosis.²⁹⁻³⁷

Nonetheless, the frequent use of emergency and

inpatient psychiatric services for this population suggests that many of these individuals were, indeed, severely disabled. Furthermore, the Chronic Disease Score indicated that the severely mentally ill persons appeared to have had physical as well as mental health problems. These individuals were also much more likely to have Medicare coverage than the controls without diabetes mellitus. Presumably, the severely mentally ill subjects became eligible for Medicare coverage by virtue of qualifying for Social Security Disability Insurance due to their mental illness.³⁸ The relatively low rate of Medicaid participation by the severely mentally ill subjects in cohort 1 may well have been due to state policies at the time of the study, which, in effect, deemed persons receiving Social Security Disability Insurance to be "too wealthy" for Medicaid.

Relatively few of the severely mentally ill subjects in cohort 1 (compared with the controls without diabetes mellitus) changed coverage status from dependent to subscriber during the 4-year follow-up period. One explanation for these findings is that the severely mentally ill subjects who entered the study as dependents were not as likely as their matched controls to obtain competitive employment (and thereby become subscribers in their own right). Indeed, naturalistic follow-up studies of patients with mania suggest that significant disability would be expected for at least some of those severely mentally ill HMO subjects who had bipolar disorder.^{39,40}

Its limitations notwithstanding, this study showed that HMO members with severe mental illness had enrollment duration longer than that of controls without diabetes mellitus but somewhat shorter than that of members with diabetes mellitus. Furthermore, costs to the HMO were unrelated to duration of enrollment. To the authors' knowledge, cohort 1 has been followed up longer than any group of mainstream managed care beneficiaries with severe mental illness. This study is also one of the few that measured both private and public mental health service use.¹³ In contrast to the Medical Outcomes Study,¹⁵⁻¹⁷ this project involved a variety of HMO control subjects.

It is worthwhile examining the factors that did and did not explain the severely mentally ill subjects' retention within the HMO. There was no support for the contention that HMO members were "disenrolled" due to severe mental illness.⁹ Of course, as expected in a "prevalence" study, subjects with very brief periods of enrollment were unlikely to be included in the sample. Consequently, length of HMO eligibility prior to the study was a good predictor of enrollment duration during follow-up. Indeed, when length of enrollment before the study period was included in the Cox proportional hazards analysis, the severely mentally ill subjects had retention times longer than the membership controls but equivalent to that of the diabetic subjects and the pharmacy controls.

We were also unable to find evidence that this HMO

"routinely excluded any coverage of chronic mental illness."¹⁰ Indeed, the severely mentally ill subjects in cohort 1 were provided amounts of service that generated costs to the HMO several times that of the membership controls. This cost difference was accounted for chiefly by mental health care. Based on the HMO's cost data, it appears that 36% of the severely mentally ill subjects in cohort 1 exceeded the state-mandated outpatient mental health benefit of \$2000 per 24 months. Psychiatric inpatient costs were generally less than the state-mandated \$8500 per 24 months, but 9% of severely mentally ill cohort 1 subjects did exceed the benefit limit. Looking at combined inpatient and outpatient mental health costs showed that 12% of severely mentally ill cohort 1 subjects exceeded the \$10500 per 24 months limit. Of course, one could challenge the accuracy of the cost data. However, it should be noted that some of the costs (e.g., general hospital inpatient psychiatric services) represent payments from the HMO to its vendors. In any event, it seems clear that coverage was provided to HMO members who were severely mentally ill. Furthermore, HMO costs were not related to enrollment duration.

An important issue is the HMO's policies toward serving persons with severe mental illness. As with many HMOs, this organization's mental health services were theoretically limited to treatment of conditions that, in the judgment of the attending physician, were subject to significant improvement through relatively short-term therapy.⁴¹ In practice, as demonstrated by these results, mental health services were provided to persons with chronic conditions. Since this approach to persons with severe mental illness may not be found in other HMOs, these results may have limited generalizability.⁴²⁻⁴⁴

Indeed, the distinctions among HMOs⁴⁴ may explain the apparent discrepancy between the retention data from this project and the implication from the Medical Outcomes Study¹⁵ that severely mentally ill subjects would have a shorter enrollment than healthier members. It should be noted that the Medical Outcomes Study was conducted in several prepaid settings (including a traditional staff model HMO), with the poorest outcomes for depressed psychiatric patients observed in independent practice associations.¹⁷ Differences between the independent practice association approach to severe mental illness and that provided by traditional HMOs could be responsible for the disparate outcomes observed in the 2 studies. As Judith L. Feldman, MD, remarked: "When you've seen one HMO you've seen one HMO" (oral communication, 1988).

The integrated service delivery system provided by traditional HMOs may be of particular value for severely mentally ill members who have physical as well as mental health problems, as suggested by our data. It is interesting to note that the costs of general medical-surgical care for severely mentally ill subjects were similar to those of the pharmacy controls even though the Chronic Disease Score suggested that the former had more physical illness than

the latter. An integrated system might be more efficient than a mental health "carve-out" for people with both physical and severe mental health problems. On the other hand, while the data from cohort 2 suggest that this HMO is continuing to serve severely mentally ill members, the now fiercely competitive health care environment⁴⁵ makes one wonder if any HMO will be able to provide the level of mental health service described here.

It should be pointed out that the HMO was by no means the sole provider of mental health care to these individuals. Nearly half of the severely mentally ill subjects in cohort 1 also used community mental health services. Furthermore, the use of community mental health care was associated with longer duration of HMO enrollment. While this observational study cannot determine causality, it is conceivable that the subjects who maintained their HMO membership were also to optimize use of both private and public services. One might imagine that the HMO's expertise in areas such as psychopharmacology, emergency psychiatric services, and inpatient psychiatric care could complement the public mental health sector's capabilities in fields such as rehabilitation and vocational training. Unfortunately, shrinkage of public sector mental health funds combined with private sector competition may leave persons with severe mental illness struggling to find appropriate care.⁴⁶ Nonetheless, there may be considerable value in studying ways HMOs and community mental health agencies can work together to offer an efficiently integrated package of services that will benefit people with severe mental illness.⁶

NOTES

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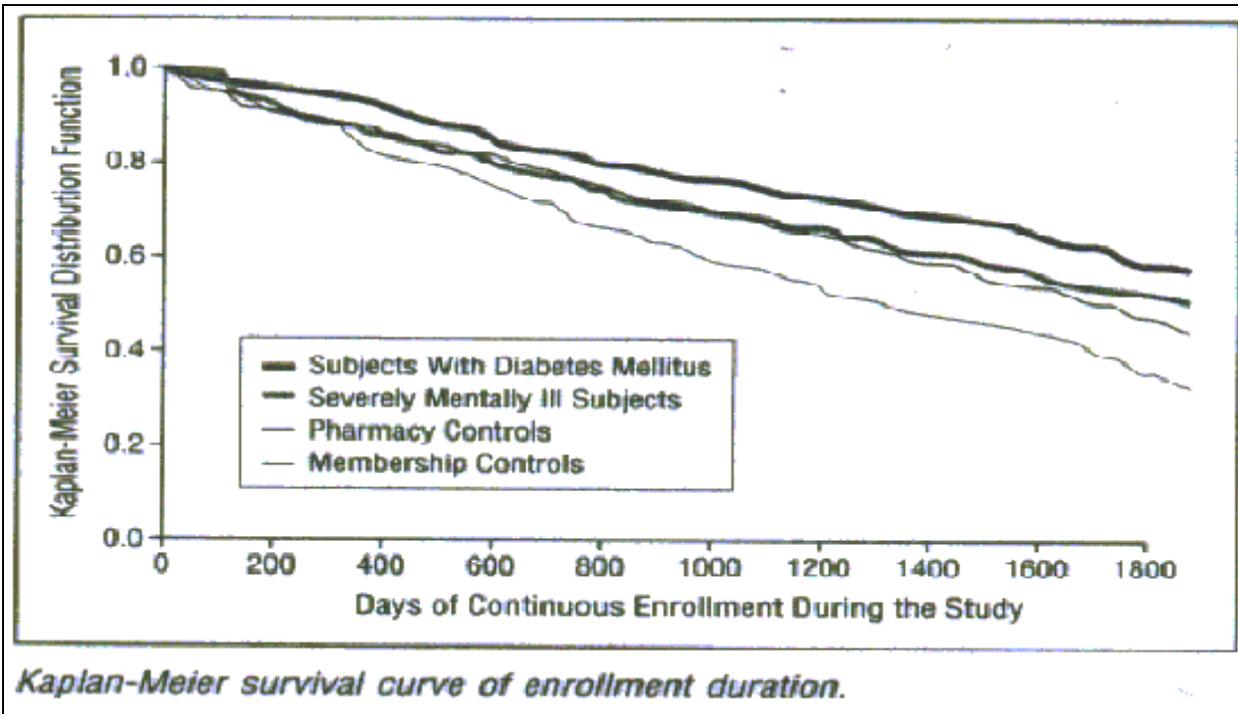
TABLE 1. SERVICE UTILIZATION* Number (Percent)			
Service	Severely Mentally Ill Subjects (n=250)	Pharmacy Controls (n=250)	Membership Controls (n=250)
Inpatient Admissions			
- Medical-surgical	11 (27)	15 (48)	5.9 (18)
- Psychiatry	31 (66)	0	0.096 (1.5)
- State hospital	6.1 (32)	0.88 (11)	0.068 (1.1)
Outpatient Visits			
- General medical	770 (1010)	770 (1130)	610 (920)
- Mental health	460 (560)	8.7 (46)	18 (140)
- Substance abuse	27 (110)	7.3 (64)	4.9 (32)
Used Community Mental Health Program	101 (40)	12 (5)	12 (5)
* Services per 1000 member-months of health maintenance organization enrollment. All data are presented as mean (SD) unless otherwise indicated. Data were collected from 1986 through 1990.			

TABLE 2. COSTS OF CARE, 1987 THROUGH 1990 Number (Percent)			
Service	Mean (SD) Cost Per Member Per Month, 1990 \$		
	Severely Mentally Ill Subjects (n=225)	Pharmacy Controls (n=223)	Membership Controls (n=218)
Inpatient			
- Medical-surgical	59 (182)	77 (531)	35 (147)
- Psychiatry	118 (317)	0	0.4 (6)
- Substance abuse	2 (12)	0.1 (1)	0
Outpatient			
- General medical	59 (69)	55 (83)	43 (67)
- Mental health	94 (138)	4 (24)	3 (19)
- Substance abuse	7 (32)	2 (16)	1 (8)
Pharmaceutical			
- General medical	14 (25)	9 (19)	6 (11)
- Psychiatric	28 (39)	0.4 (2)	1 (5)
- Substance abuse	0.0004 (0.005)	0.03 (0.4)	0
Total	380 (473)	149 (592)	90 (194)

TABLE 3. SUBJECTS WITH NONZERO COSTS* Number (Percent)			
Service	Severely Mentally Ill Subjects (n=225)	Pharmacy Controls (n=223)	Membership Controls (n=218)
Inpatient			
- Medical-surgical	76 (34)	49 (22)	34 (16)
- Psychiatry	88 (39)	0	1 (1)
- Substance abuse	4 (2)	2 (1)	0
Outpatient			
- General medical	212 (94)	208 (93)	183 (84)
- Mental health	192 (85)	13 (6)	17 (8)
- Substance abuse	36 (16)	7 (3)	8 (4)
Pharmaceutical			
- General medical	205 (91)	198 (89)	159 (73)
- Psychiatric	205 (91)	44 (20)	35 (16)
- Substance abuse	1 (1)	1 (1)	0
Total	220 (98)	212 (95)	189 (87)

TABLE 4. DURATION OF ENROLLMENT IN DAYS*		
	Cohort 1 (1986-1990)	Cohort 2 (1990-1995)
Subjects with diabetes mellitus	1424 (39)	1437 (40)
Severely mentally ill subjects	1263 (45)	1298 (48)
Pharmacy controls	1236 (45)	---
Membership controls	1023 (47)	---

* Data from Kaplan-Meier survival distribution function. Data are given as mean (SE); ellipses indicate not applicable.



MANAGING THE CARE OF SCHIZOPHRENIA: LESSONS FROM A 4-YEAR MASSACHUSETTS MEDICAID STUDY

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Background: In 1992, Massachusetts launched a statewide managed care plan for all Medicaid beneficiaries.

Methods: This retrospective, multiyear, cross-sectional study used administrative data from the Massachusetts Division of Medical Assistance and Department of Mental Health, consisting of claims for 16400 disabled adult patients insured by Medicaid in Massachusetts between July 1, 1990, and Jun 30, 1994. The main outcome measures include annual rates of hospitalization, emergency department utilization, and follow-up care 30 days after discharge; length of inpatient stay; and per-person inpatient and outpatient expenditures.

Results: Between 1991 and 1994, the likelihood of an inpatient admission decreased from 29% to 24% and was accompanied by a slight reduction in length of stay (median number of bed-days per admission dropped by 3.3 days). There was a slight decrease in the number of patients who sought care in general hospital emergency department utilization. However, there was a small increase in the fraction of patients readmitted within 30 days of discharge. Medicaid and Department of Mental Health expenditures for mental health per treated beneficiary decreased slightly, from \$11060 to \$10640, during the 4-year study period.

Conclusions: Although per-person expenditures dropped and most patient patterns of care remained the same, longer-term study is recommended to assess whether the trends can be maintained.

The treatment of schizophrenia remains a major clinical challenge to health care providers.¹ The behavioral problems and thought disorders that are characteristic of schizophrenia make management complex and expensive. For example, in the United States, even though slightly more than 1% of adults have the disorder, treatment expenditures account for more than 2.5% of all health care expenditures.^{2,3} It is not unusual for those with schizophrenia to have disabilities that lead to loss of employment and private health insurance. When this occurs, government becomes the primary health care insurer. Almost two-thirds of all the expenditures for schizophrenia treatment come from federal, state, and local government sources.²

With so much government money at stake, it is not surprising that reforms are rapidly changing the provision of government services to the mentally ill. All but 6 states are pursuing managed care for Medicaid beneficiaries, including those with severe mental illness, such as schizophrenia. In some states, Medicaid managed care plans tap into existing health maintenance organization networks.⁴ In other states, Medicaid contracts with mental health managed behavioral care companies to provide administrative functions and direct beneficiaries to a local provider network.

There are 2 fundamental issues in the evaluation of managed care for the severely mentally ill. First, can managed care succeed in providing quality care to

psychiatrically disabled patients, especially those diagnosed as having schizophrenia?^{5,6} These individuals are at high risk for catastrophic psychiatric and medical care but seldom are able to navigate effectively within the health care system and often lack advocates on their behalf. Even though providers surveyed in Massachusetts have reported that quality has not been compromised,⁹ both critics and advocates would like to have more evidence before accepting this conclusion.

The second issue is whether managed care actually reduces costs of shifts costs onto families, other state agencies, or medical care providers. When there are strong financial incentives to reduce acute hospital admissions, managed care plans will be financially motivated to divert beneficiaries to the long-term care system run by the state mental health agency. Individuals with schizophrenia are likely to be eligible for both Medicaid benefits and a state-funded long-term care system of community and hospital-based services. Shifting costs to the state mental health agency may result in greater profits for managed care plans but may not improve continuity of care; moreover, the societal costs may be higher. To date, there are no studies of how the reduction in mental health expenditures for acute care might shift costs to long-term care.

Evaluations of managed care plans are in an early stage of development, and little descriptive information is available to provide benchmarks against which to compare

different approaches to cost containment.¹⁰ Earlier reports^{9,11} of the Massachusetts plan studied only the first year after implementation. In addition, these studies were limited to claims for mental health treatment.

We developed a database on adult Medicaid beneficiaries with schizophrenia to examine access to care, use of services, and treatment costs associated with schizophrenia before and after the introduction of managed care. Because care for our disabled population is not limited to services reimbursed by Medicaid alone, the data are drawn from 2 state agencies: the Division of Medical Assistance (Medicaid) and the Department of Mental Health (DMH). Data cover 2 years of the plan after implementation and include nonpsychiatric medical care, pharmacy, transportation, and dental care. These additional data are important to include because they account for roughly 40% of the total expenditures. We also examined incident patients, those not treated for schizophrenia before managed care was introduced.

PATIENTS AND METHODS

The Massachusetts Managed Mental Health Program

In 1992, Massachusetts received a 1915b waiver from the Health Care Financing Administration. Under this plan, all beneficiaries were asked either to enroll in a local health maintenance organization or to select a Medicaid-approved primary care clinician. Virtually all psychiatrically disabled beneficiaries chose a primary care clinician. Medicaid contracted with a single proprietary vendor, Mental Health Management of America, a division of First Mental Health, Boston, MA, to manage the provision of mental health benefits. The vendor had 4 specific cost-containment strategies: (1) negotiation of reimbursement rates with a network of providers who would be paid on a fee-for-service basis, (2) implementation of an aggressive utilization management plan, (3) development of community-based alternatives to hospitalization, and (4) collaboration with the DMH to fund emergency service teams to screen patients for appropriateness of inpatient admission, with a view toward diverting many of them to alternative treatment sites.

Under the terms of the contract with Medicaid, the vendor was required to make available to recipients all the mental health and substance abuse benefits: acute inpatient treatment, crisis stabilization, outpatient evaluation and treatment, psychiatric day treatment, residential detoxification, and methadone treatment. The vendor was directed to add diversionary services, including acute residential treatment programs, family stabilization teams, and partial hospitalization programs. The contract further specified that the vendor would be responsible for the centralized functions of utilization review, claims processing, systems support, and provider relations, and for decentralized regionally based case management and

network management. The contract with the vendor excluded payment for long-term nursing home care, mental health services provided by the DMH, and any medical treatment or outpatient pharmacy. In addition, it did not include members of health maintenance organizations and those who had Medicaid as a second payer. Disabled beneficiaries were covered at a higher rate than other beneficiaries, and providers were reimbursed by the vendor on a fee-for-service basis.

Data Sources

We used administrative data obtained from Medicaid and the DMH. Together, these files provided information regarding patient sociodemographic status, reimbursed inpatient and outpatient care, discharge diagnoses, and timing of services.

Definition of Cross-Sectional Cohorts

We created 4 separate cohorts, 1 for each fiscal year of the study, that together described treatment spanning the period from July 1, 1990 (the start of fiscal year 1991) through June 30, 1994 (the end of fiscal year 1994). The members of each cohort consisted of all adult Massachusetts Medicaid beneficiaries, aged 18 to 64 years, who were disabled and treated, either as inpatients or outpatients, for schizophrenia (*International Classification of Diseases, Ninth Revision, Clinical Modification*, primary diagnostic code of 295) at least once during the fiscal year. The cross-sectional cohorts were created by assigning patients with a schizophrenia claim to the fiscal year in which the claim was submitted; for this reason, it was possible for patients to appear in more than 1 cohort.

With the use of the patient's unique Medicaid identification number, patient-level files for each fiscal year were constructed by identifying paid claims for all psychiatric and substance abuse care (claims with a primary diagnostic code of 290-315), medical care (claims with any primary diagnostic code excluding V codes and 290-315 or any claim with a mental health *Current Procedure Terminology* procedure code), and other services, such as pharmacy, transportation, and dental care. Finally, to ensure that we had a complete record of service use for each patient, we merged state hospital admissions from the DMH inpatient files with the administrative Medicaid information by means of unique patient identification numbers.

Sociodemographic and Comorbidity Data

We used Medicaid membership files to identify the date of birth, sex, race, and residence ZIP code for each patient in our study cohort. To measure the degree of substance abuse in our sample, we assumed that if a patient was ever diagnosed as a substance abuser (primary or secondary diagnostic *International*

Classification of Diseases, Ninth Revision, Clinical Modification code of 291, 292, 303.00, 303.90, 304, or 305) in a given year, then the patient had a drug or other alcohol abuse problem in the given year.

Admission Type

During the study, the DMH had contracted with a few general hospitals for inpatient beds to replace some of the beds in state hospitals closed as part of a larger deinstitutionalization plan. Thus, DMH-funded admissions occurred in both state and general hospitals. To differentiate between beds funded by Medicaid and those funded by the DMH, we classified each mental health inpatient admission as either a DMH admission or a Medicaid admission. The admission policy for Medicaid recipients to a DMH bed required that beds be available to forensic patients and to patients with behavioral management requirements that could not be met in general hospital psychiatric units or in freestanding psychiatric facilities otherwise reimbursed by Medicaid.

Evaluation of Access to Care

We defined access to care in each year as the number of Medicaid beneficiaries with a primary diagnosis of schizophrenia who had at least 1 Medicaid-paid claim. We also examined the number of incident patients in each year. We classified a patient as incident if there was no mental health claim with a primary diagnosis of schizophrenia for the patient in the previous year(s). Because we did not have Medicaid data before 1991, we were unable to identify new patients in 1991 and consequently may also have overestimated the number of incident patients in the remaining years.

Mental Health Inpatient Utilization

We defined mental health inpatient utilization as hospital admissions with primary mental health discharge diagnoses corresponding to schizophrenia, or any other psychiatric and substance abuse disorder. Because we hypothesized that hospital admissions would drop as a result of the screening and diversion programs of the managed care plan, we examined the distribution of mental health inpatient admissions in each year. We also estimated the likelihood of having any mental health inpatient admission by the percentage of patients who had at least 1 such admission in a given year. Finally, for those patients who had at least 1 mental health inpatient admission in a given year, we examined the number of bed-days per admission.

Continuity of Care

To describe follow-up care after discharge, we first defined inpatient transfers as admissions to another hospital within 24 hours after a discharge and then linked information from the transfers to form a complete inpatient

episode of care for each patient in our cohorts. We then categorized each discharge into 1 of 4 mutually exclusive categories: discharges for which there was no outpatient or inpatient contact within 30 days, discharges for which there was outpatient contact within 30 days, discharges resulting in rehospitalization within 30 days, and discharges for which both an outpatient contact and a rehospitalization within 30 days resulted. Outpatient contact included a visit to any hospital outpatient department or to a clinic; a visit to a physician office; or the provision of any 1 of a set of mental health services, such as psychological testing, case management, or day treatment.

Because we believed that, ideally, continuous patient care should be rendered from 1 provider, we also calculated the number of unique hospitals to which patients with more than 1 hospitalization were admitted. Finally, we estimated the distribution in each year of general hospital emergency department visits. We did not calculate the distribution for state hospitals because they do not have emergency departments.

Assessment of Expenditures

We derived costs for Medicaid services from the paid claims that indicated the amount reimbursed. Although we could not determine whether paid claims overestimated or underestimated the true cost of treatment, these costs represented public expenditures through this entitlement program. Because the DMH operates on a fixed budget and records only use of services, we estimated costs for inpatient care by means of the per diem for state hospitals calculated by the DMH. These estimated per diem costs are based on accounting costs, calculated by dividing total annual inpatient expenditures, including capital costs, by the number of actual patient bed-days in each facility annually. Hospital-specific per diem costs were used to estimate the episode costs for each person admitted to a DMH facility by multiplying the calculated per diem by the number of days in the episode.

Inpatient mental health expenditures (psychiatric or substance abuse care) were dichotomized into Medicaid and DMH admissions to examine the extent of cost shifting between these 2 government agencies. All inpatient expenses are clustered together so that room and board, ancillaries, and physician fees are included.

Outpatient mental health expenditures included hospital outpatient department or clinic services, physician services, and other mental health services provided in free-standing mental health agencies.

Non-mental health expenditures were composed of medical care, pharmacy, transportation, and dental care. Claims for the last 3 categories did not report diagnoses, and consequently we were unable to distinguish mental health--related from non-mental health--related

expenditures.

We aggregated the inpatient and outpatient mental health expenditures and then added all categories for total expenditures. Within each category of expenditures we report the number and percentage of persons with any expenditures, the average expenditure per person with any expenditure, and the total expenditure. For inpatient care we also report expenditure per admission.

Statistical Analyses

We computed simple univariate summary statistics by year. For continuous-valued variables, we calculated sample means and SDs; we also constructed box plots¹² to display the center and spread of the distributions of the observations. Inpatient utilization was stratified by admission type (DMH or Medicaid). All expenditure figures are reported in 1994 dollars by adjusting expenditures in 1991, 1992, and 1993 for inflation by means of the gross domestic product deflator.¹³

RESULTS

Description of the Cross-Sectional Cohorts

Between July 1, 1990, and June 30, 1994, we observed 16400 disabled adults who contributed a total of 32135 annual observations. Despite changes in the number of treated beneficiaries during the 4-year period, we found that the sociodemographic characteristics remained virtually unchanged (**Table 1**): approximately half the beneficiaries were female and the majority were white, with a mean age of 41 years. Eleven percent were ethnic or racial minorities. Comorbid substance abuse increased as a proportion of the total study population. This increase might be a coding artifact resulting from changes in diagnostic practice or an increased awareness of substance abuse. Reimbursement of the treatment of substance abuse received much attention from providers because of the emphasis placed by the managed care vendor on outpatient rather than inpatient detoxification. It is also possible, given increases in the level of alcohol and other drug dependence in the general population, that there is increasing substance abuse among many of these patients, and the increase is being documented by providers.

Access to Care

The number of Medicaid beneficiaries with schizophrenia being treated increased from 6614 in 1991 to 7541 in 1994 (Table 1). However, in 1993, the year managed care was introduced in Massachusetts, the number of treated beneficiaries increased by more than 3000 from the previous year. This 1993 increase occurred despite a decrease in the number of providers. The increase might be an epidemiological phenomenon, but the

stable demographic characteristics suggest that is not the source of the increase. More likely, the increase can be attributed to the advocacy work of the mental health provider community and family members who wanted to ensure that those who met the eligibility criteria were actually enrolled in Medicaid. In fact, the incident patients in 1993 were more likely to be older, white, female, and substance abusers than new patients in the remaining years (Table 1). The most striking demographic change for new schizophrenia patients was the higher percentage, in all years, of substance abusers.

Mental Health Inpatient Utilization

The percentage of patients who had at least 1 inpatient admission dropped by 4 percentage points during the study period, from 29.8% in 1991 to 25.4% in 1994 (**Table 2**). The decrease in the likelihood of a mental health admission during the study period was larger for DMH admissions than for Medicaid admissions (Table 2). Even though the probability of an admission decreased, the total number of DMH admissions remained almost the same in all 4 years. Medicaid admissions dropped 65% in 1993 but returned to the pre-managed care level by 1994. For those admitted, the median number of bed-days per admission decreased by about 3.3 days; there was a drop of 2.5 days for Medicaid admissions and of 3 days for DMH admissions (**Figure 1**).

Continuity of Care

We found little evidence of change in continuity of care. Rapid readmissions were up slightly, from 22.1% in 1991 to 24.2% in 1994 (**Table 3**), but there was essentially no change in the absence of outpatient follow-up contact, with the proportion of discharges without any follow-up contact remaining at 29%. (We were unable to identify in these data follow-up that may have occurred through DMH-funded community support services.) For patients with multiple admissions, there was an increase in the percentage who were admitted to more than 1 hospital (Table 3) but no increase in the percentage of patients who used emergency departments.

Mental Health Expenditures

Inpatient

Medicaid inpatient expenditures dropped dramatically in 1993, in the first year of managed care, but rose the following year (**Table 4**). The savings in Medicaid inpatient expenditures were largely offset, however, by increased expenditures on DMH hospital admissions. The annual Medicaid per-inpatient costs dropped below pre-managed care levels, while DMH per-inpatient costs were higher after implementation of the managed care program.

Outpatient

Both total expenditures and pre-treated beneficiary expenditures rose from their pre-managed care levels. The large increase in the number of beneficiaries in 1993 led to a dip in per-treated outpatient expenditures, but by 1994 this effect had disappeared. Given the large reductions in inpatient treatment, it was expected that outpatient treatment would expand, although these increases suggest only a modest cost shifting from inpatient to out-patient treatment.

Non-Mental Health Expenditures

Total expenditures of inpatient and outpatient medical and surgical care rose with the influx of new beneficiaries in 1993 (and then dropped as the number declined in 1994), but the per-person treated costs were about the same across all 4 study years. These data do not provide evidence that mental health treatment was shifted to the non-mental health sector. Other non-mental health expenditures include transportation and dental costs, which remained essentially the same during the study period. Pharmacy costs doubled both in total expenditures and per person treated.

Total Expenditures

The total Medicaid and DMH expenditures for mental health per treated beneficiary fell slightly from \$11090 to \$10600 during the 4-year study period. When all other Medicaid reimbursed care is added to mental health care, there is a slight increase in the total per-person expenditures (Table 4). The total dollar expenditures fluctuated with the number of treated beneficiaries across the study years, but it was decreasing, not increasing, at the end of the study period. The total Medicaid and DMH dollar expenditure for mental health care after managed care reversed the upward trend and stabilized at about \$80 million in 1993 and 1994 (Figure 2).

COMMENT

Using a unique database of patient-level mental health treatments constructed from 2 sources, Medicaid and the DMH, we found that managed care was associated with some gains in continuity of care but a slight increase in rapid readmissions. Furthermore, there were reductions in mental health expenditures at the per-person level, primarily because fewer inpatient bed-days were reimbursed by Medicaid. The use of DMH inpatient beds for these beneficiaries remained about the same. Total mental health expenditures during the 4-year study period were contained, despite a growth in the number of treated beneficiaries.

There are several general conclusions from this study. First, because our measures of access and continuity of care are based on administrative data, they are limited in their scope and sensitivity. Furthermore, we

have no way of knowing whether the pre-managed care levels were appropriate. Finally, for those with chronic illnesses, examination of short-term results is not an adequate indicator of the value of managed care. Information regarding the appropriateness of processes of care, such as the adequacy of discharge planning, or knowledge regarding patient well-being is crucial in judging the adequacy of quality. Because there is no clear evidence about the effectiveness of managed care plans to provide services needed by the most seriously mentally ill, we believe that continued research is essential to document the benefits or risks to clients.

Second, although we established that there were cost savings under managed care, we cannot be certain of the actual magnitude of the savings. Our assessment before and after managed care allows only 2 types of comparisons. The first type simply focuses on levels and directions of trends observed before and after implementation. The second approach compares observed postintervention levels with the levels that would have been expected in the absence of the intervention.¹⁴ From the perspective of the first approach, the vendor appears to have achieved a net reduction in expenditures and service use. The reduction in Medicaid inpatient expenditures was a function of 3 factors: the negotiated rates with the network hospitals, the reduced number of admissions, and the reduction in the total number of bed-days.

Third, the introduction of this managed care plan resulted in an unanticipated increase in the number of beneficiaries treated for schizophrenia. In this study we observed an increase in additional patients in 1993 who had a profound effect on the system, at least in the first year. The increase in treated patients in 1993, which shrank in 1994, tells us less about access to care and more about diagnostic variability in mental health. Rather than roughly 3000 members losing their coverage, as it appears, we found that they remained enrolled and were being treated for other mental illnesses. The marked increase in the number of beneficiaries in 1993 is real, regardless of diagnostic category. However, it creates a denominator problem: comparing percentages across years may be misleading, and per-person mean costs may be lower because individuals who need less intensive treatment are added to the membership. For example, the proportion of treated beneficiaries who had 1 or more admissions to a DMH inpatient bed during a year appears to drop from 15% to 10%, but the actual number of admissions did not change. This suggests that many of the new patients were among those less seriously ill. Trends such as these have been exhibited in a range of evaluations in a number of divergent fields.^{15,16} Their ubiquitous character suggests the need for caution on the part of administrators and providers who would attempt to learn in the first few months after implementation what the ultimate effects of managed care will be on savings or service use.

Our final conclusion relates to cost shifting. We did find some evidence of cost shifting in this study. For example, one striking finding is the doubling of pharmacy costs. The increases in pharmacy costs observed might raise concern that psychosocial treatments are too often replaced by pharmacological interventions, but what seems more likely is that pharmaceutical costs have risen, especially for patients who are taking newer antipsychotic medications. Additionally, the growth in medical expenditures might signal cost shifting to that sector, and the fact that per-person medical care costs increase slightly might signal such a shift. The growth in medical expenditures are important because they compose about a third of all the health care dollars spent by Medicaid and the DMH on treatment for those with schizophrenia.

This report must be considered carefully in the light of its limitations. The mental health environment in Massachusetts at the time of this study was in transition. Reforms that are a response to fiscal and social problems are rarely unidimensional. In Massachusetts, prepaid managed care was only 1 aspect of a more global effort to privatize the Massachusetts mental health service system in the early 1990s. This effort entailed the closing of 3 state hospitals and the expansion of community-based services provided by vendors under contract to the DMH. The current study design does not rule out secular trends.

Although this study raises many questions, it also provides preliminary findings about the relationship of managed care with service use and with expenditures for seriously mental ill adults with schizophrenia. Future studies of managed care will need to continue to explore the trade-off between quality of care and costs, cost shifting between government agencies, and the difference between short-term and long-term effects.

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TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF CROSS-SECTIONAL COHORTS*							
	All Patients, No. (%)				Incident Patients, No. (%)		
	FY 1991 (N=6614)‡	FY 1992 (N=7295)‡	FY 1993† (N=10685)‡	FY 1994† (N=7541)‡	FY 1992 (N=2528)§	FY 1993 (N=5484)§	FY 1994 (N=1774)§
Age, y							
- 18-21	172 (2.6)	184 (2.5)	331 (3.1)	179 (2.4)	118 (4.7)	246 (4.5)	104 (5.9)
- 22-39	3234 (48.9)	3503 (48.0)	4843 (45.3)	3538 (46.9)	1302 (51.5)	2480 (45.2)	934 (52.6)
- 40-64	3208 (48.5)	3608 (49.5)	5511 (51.6)	3824 (50.7)	1108 (43.8)	2758 (50.3)	736 (41.5)
- Mean±SD	41±12	41±12	41±12	41±11	39±12	40±12	38±11
Female	3182 (48.1)	3486 (47.8)	5808 (54.4)	3470 (46.0)	1201 (47.5)	3291 (60.0)	764 (43.1)
Race							
- African American	618 (9.3)	699 (9.6)	891 (8.3)	772 (10.2)	260 (10.3)	430 (7.8)	187 (10.5)
- American Indian	3 (0.0)	3 (0.0)	9 (0.1)	4 (0.1)	1 (0.0)	5 (0.1)	0 (0.0)
- Asian American	19 (0.3)	25 (0.3)	28 (0.3)	22 (0.3)	14 (0.6)	15 (0.3)	12 (0.7)
- Hispanic	86 (1.3)	125 (1.7)	188 (1.8)	102 (1.4)	76 (3.0)	126 (2.3)	38 (2.1)
- White	5865 (88.7)	6413 (87.9)	9537 (89.3)	6464 (85.7)	2164 (85.6)	4891 (89.2)	1377 (77.6)
- Unknown	23 (0.3)	30 (0.4)	32 (0.3)	177 (2.3)	13 (0.5)	17 (0.3)	160 (9.0)
Substance Abuse	636 (9.6)	775 (10.6)	3108 (29.1)	1023 (13.6)	355 (14.0)	1875 (34.2)	324 (18.3)
<p>* Patients are disabled Massachusetts Medicaid beneficiaries treated for schizophrenia. FY indicates Fiscal Year. † Managed care plan years. ‡ Number of treated beneficiaries § Number of new treated beneficiaries.</p>							

TABLE 2. MENTAL HEALTH INPATIENT UTILIZATION* FOR DISABLED PATIENTS WITH SCHIZOPHRENIA				
	FY 1991	FY 1992	FY 1993†	FY 1994†
No. of treated beneficiaries	6614	7295	10685	7541
Total No. of admissions	3937	4624	2486	3870
Distribution of hospital admissions, No. (%)‡				
- 0	4690 (70.9)	5120 (70.2)	9146 (85.6)	5623 (74.6)
- 1	991 (15.0)	1120 (15.4)	1001 (9.4)	1085 (14.4)
- 2	459 (6.9)	471 (6.5)	318 (3.0)	388 (5.1)
- 3	198 (3.0)	252 (3.5)	114 (1.1)	202 (2.7)
- 4	125 (1.9)	148 (2.0)	58 (0.5)	108 (1.4)
- ≥5	151 (2.3)	184 (2.5)	48 (0.4)	135 (1.8)
≥1 inpatient admission, No. (%)‡				
- All admissions	1924 (29.1)	2175 (29.8)	1539 (14.4)	1918 (25.4)
- DMH admissions	1082 (16.4)	1098 (15.1)	1038 (9.7)	915 (12.1)
- Medicaid admissions	1170 (17.1)	1466 (20.1)	608 (5.7)	1232 (16.3)
<p>* Hospital admissions for treatment of mental illnesses or substance abuse. † Managed care plan years. ‡ Percentage was calculated with number of treated beneficiaries used as the denominator. FY indicates fiscal year; DMH, Department of Mental Health.</p>				

TABLE 3. CONTINUITY OF CARE FOR DISABLED PATIENTS WITH SCHIZOPHRENIA*				
	No. (%)			
	FY 1991	FY 1992	FY 1993†	FY 1994†
Follow-up care within 30 d of a discharge				
- None	1077 (29.2)	1199 (27.3)	932 (38.0)	1117 (29.7)
- Outpatient contact	1797 (48.7)	2178 (49.7)	1159 (47.2)	1729 (46.0)
- Rehospitalization	142 (3.8)	127 (2.9)	124 (5.1)	215 (5.7)
- Rehospitalization and outpatient contact	677 (18.3)	880 (20.1)	238 (9.7)	696 (18.5)
- Total No. of Discharges	3693 (100.0)	4384 (100.0)	2453 (100.0)	3757 (100.0)
Distribution of unique hospitals‡				
- 1 hospital	361 (38.7)	342 (32.4)	227 (42.2)	298 (35.8)
- 2 hospitals	364 (39.0)	431 (40.9)	213 (39.6)	381 (45.7)
- 3 hospitals	145 (15.5)	171 (16.2)	64 (11.9)	113 (13.6)
- 4 hospitals	42 (4.5)	71 (6.7)	24 (4.5)	29 (3.5)
- ≥5 hospitals	21 (2.3)	40 (3.8)	10 (1.9)	12 (1.4)
- Total No. of Patients With ≥ 2 Hospitalizations	933 (100.0)	1055 (100.0)	538 (100.0)	833 (100.0)
Emergency department visits				
- 0	5626 (85.1)	6219 (85.3)	9894 (92.6)	6653 (88.2)
- 1	545 (8.2)	577 (7.9)	562 (5.3)	435 (5.8)
- 2	192 (2.9)	221 (3.0)	140 (1.3)	210 (2.8)
- 3	92 (1.4)	97 (1.3)	44 (0.4)	82 (1.1)
- 4	44 (0.7)	69 (0.9)	22 (0.2)	43 (0.6)
- ≥5	115 (1.7)	112 (1.5)	23 (0.2)	118 (1.6)
- Total	6614 (100.0)	7295 (100.0)	10585 (100.0)	7541 (100.0)
<p>* FY indicates fiscal year. † Managed care plan years. ‡ Distribution of patients with 2 or more hospitalizations categorized by the number of unique hospitals to which they were admitted during the fiscal year. In FY 1991, 38.7% of the 933 patients who had at least 2 hospitalizations went to a single hospital, 39.0% were admitted to 2 distinct hospitals, 15.5% were admitted to 3 distinct hospitals, 4.5% were admitted to 4 distinct hospitals, and the remainder (2.3%) were admitted to 5 or more distinct hospitals.</p>				

TABLE 4. ANNUAL EXPENDITURES FOR DISABLED PATIENTS WITH SCHIZOPHRENIA*				
	FY 1991	FY 1992	FY 1993†	FY 1994‡
Mental Health Expenditures‡				
Medicaid mental health inpatient admissions				
- No. of inpatients	1170	1466	608	1232
- Average annual expenditure per inpatient, \$	16916	17722	10205	13673
- Total annual expenditure, x\$1000	19791	25980	6205	16845
DMH mental health inpatient admissions				
- No. of DMH inpatients	1082	1098	1038	915
- Average annual expenditure per DMH inpatient, \$	40323	44773	57898	54997
- Total annual expenditure, x\$1000	43629	49161	60098	50322
Outpatient mental health care				
- No. who are outpatients	6517	7191	10695	7541
- Average annual expenditure per recipient, \$	1525	1574	1246	1752
- Total annual expenditure, x\$1000	9938	11319	13108	12774
Non-Mental Health Expenditures				
Inpatient or outpatient non-mental health care				
- No. who received non-mental health care	5736	6386	9541	6325
- Average annual expenditure per recipient, \$	6478	7389	6928	7672
- Total annual expenditure, x\$1000	37157	47054	66102	48527
Pharmacy				
- No. who use pharmacy	6239	6964	10142	6980
- Average annual expenditure per recipient, \$	897	1087	1331	1634
- Total annual expenditure, x\$1000	5598	7573	13503	11407
Transportation or dental care				
- No. who use transportation or dental care	3896	4115	6521	4225
- Average annual expenditure per recipient, \$	425	450	441	441
- Total annual expenditure, x\$1000	1654	1852	2875	1865
Total Expenditures				
No. of patients	6614	7295	10685	7541
Average annual expenditure per patient, \$	17806	19594	15151	18796
Total annual expenditure, x\$1000	117767	142940	161891	141740
<p>* FY indicates fiscal year; DMH, Department of Mental Health. † Managed care plan years. ‡ All expenditures have been converted to 1994 dollars by means of the gross domestic product deflator. The cumulative inflation rates from 1991 until 1994 were 7.1%, 4.1%, and 2.1% respectively.</p>				

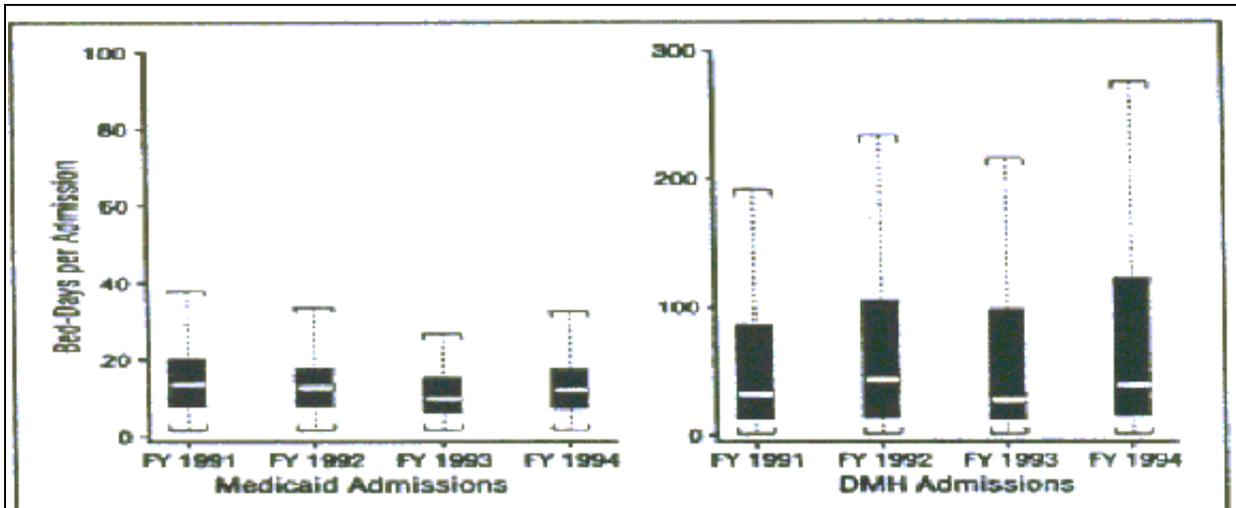


Figure 1. Distribution of bed-days per admission among adult (aged 18-64 years) Massachusetts Medicaid beneficiaries treated for schizophrenia from July 1, 1990, through June 30, 1994. The horizontal line in the interior of the box is located at the median of the data, the height of each box is the interquartile distance, and the dotted lines extend a distance of 1.5 times the interquartile distance. FY indicates fiscal year; DMH, Department of Mental Health.

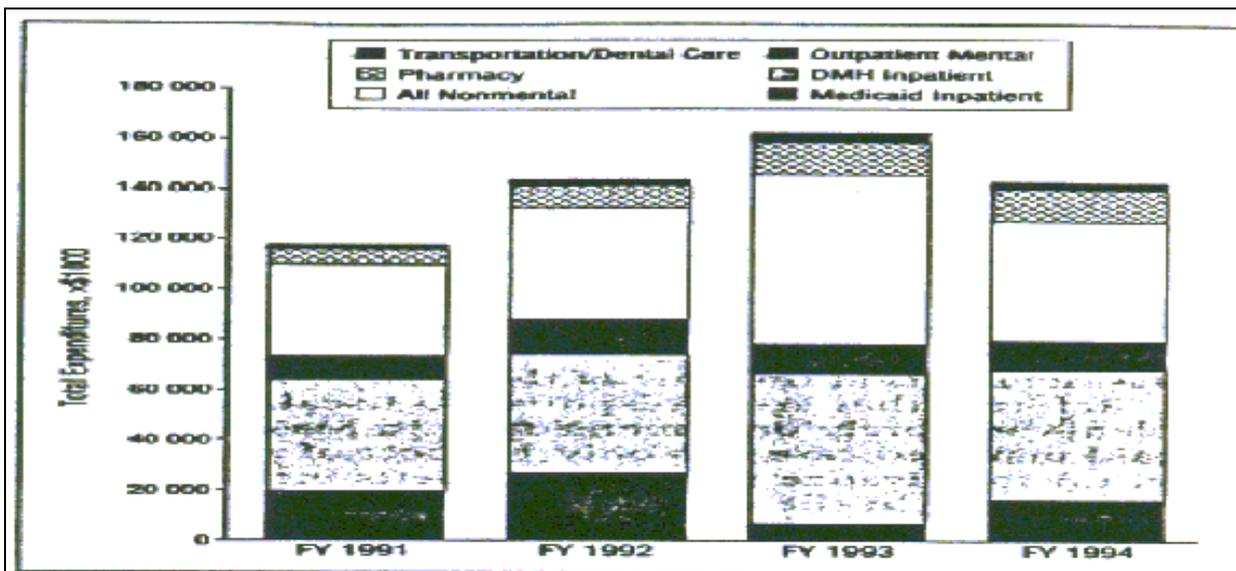


Figure 2. Total expenditures for disabled schizophrenic patients by type of care among adult (aged 18-64 years) Massachusetts Medicaid beneficiaries treated for schizophrenia from July 1, 1990, through June 30, 1994. All expenditures have been converted to 1994 dollars by means of the gross domestic product deflator and are reported in thousands of dollars. Totals are reported in Table 4. FY indicates fiscal year; DMH, Department of Mental Health.

IMPACT OF MANAGED CARE ON ADULTS WITH AIDS OR PHYSICAL DISABILITIES

REACTOR BIOGRAPHIES

Gerbon DeJong, Ph.D.

Gerben DeJong is the Director of the National Rehabilitation Hospital Research Center (NRH-RC) and the Director of the Research and Training Center in Medical Rehabilitation and Health Policy (RTC-MR&HP) in Washington, DC. He also serves as a Professor in the Department of Family Medicine at Georgetown University's School of Medicine. Prior to coming to NRH in 1985, Dr. DeJong was a Senior Research Associate and Associate Professor in the Department of Rehabilitation Medicine at Tufts University School of Medicine in Boston, MA. Dr. DeJong's academic training is in economics and public policy studies. His main research interests are in disability and health outcomes, health care utilization, disability policy, long-term care policy, national health care policy, and biomedical ethics. He is the author or co-author of more than 140 papers on health, income maintenance, and disability issues. He is perhaps best known for his seminal work on disability and health policy and the independent living movement. His works have appeared in a variety of health, science, business, and public policy journals. His works have appeared in more than seven different languages. In 1985, he received the Licht Award for Excellence in Scientific Writing from the American Congress of Rehabilitation Medicine. He is a frequently invited speaker both in the United States and abroad. In 1984, he was a Fulbright Scholar in the Netherlands serving with the research staff of the Social Security Council.

Dr. DeJong is an ardent student of health care reform and the managed care revolution. He is especially interested in managed care's probable impact on medical rehabilitation, on people with disabilities, and on other vulnerable populations. During the Clinton transition, Dr. DeJong served on the Transition Team's working group on long-term care policy. During the health care reform debate in the 103rd Congress, he spoke throughout the country on health care reform. He continues to testify before Congress on health care and disability income issues. In 1993, Dr. DeJong presented the honorary Coulter Lecture to the American Congress of Rehabilitation Medicine on the topic of "Health Care Reform and Disability." In 1994, he gave the keynote address to the National Brain Injury Association's annual meetings on the future of health care reform and brain injury. In 1995, Dr. DeJong presented the honorary John W. Goldschmidt Lecture at NRH on "Empowering the Consumer and Enabling the Provider in an Era of Managed Care."

Tony Dreyfus

Tony Dreyfus joined the Medicaid Working Group in 1993 to work on rate setting, casemix adjustment and Medicare waiver issues. The Group was organized with funds from Pew and Robert Wood Johnson to assist in the creation of managed care programs for Medicaid recipients with significant disability or chronic illness in Wisconsin, Ohio, Missouri and New York.

Mr. Dreyfus has been working in the past year with Richard Kronick, also of the Medicaid Working Group, on the development of a diagnosis-based risk adjustment system for people with disabilities. Mr. Dreyfus works part-time with the Community Medical Alliance, a managed care program for Medicaid recipients with late-stage AIDS or severe physical disability.

*Co-authored articles include "Making Risk Adjustment Work for Everyone" (*Inquiry*), "The Community Medical Alliance: an Integrated System of Care in Greater Boston for People with Severe Disability or*

AIDS" (*Managed Care Quarterly*), and "Diagnostic Risk Adjustment for Medicaid: the Disability Payment System" (*Health Care Financing Review*).

Mr. Dreyfus earned his master's degree in planning at MIT and has worked in economic analysis, teacher training and curriculum development, elder homecare, and in a group home for men with mental retardation.

Lex Frieden

Lex Frieden is Senior Vice President at The Institute for Rehabilitation and Research (TIRR) in Houston, TX. TIRR is a comprehensive medical rehabilitation center which provides clinical, educational, and research programs pertaining to spinal cord and brain injuries and other disabling conditions. He is also Professor of Physical Medicine and Rehabilitation at Baylor College of Medicine.

From 1984-1988, Mr. Frieden served as Executive Director of the National Council on the Handicapped (now the National Council on Disability), an independent Federal agency located in Washington, DC. In this capacity, he was instrumental in conceiving and drafting the recently enacted Americans with Disabilities Act (ADA).

A graduate of Tulsa University, Mr. Frieden has been honored as a Distinguished Alumnus. He also holds a master's degree in social psychology from the University of Houston. He has done additional graduate work in rehabilitation psychology at the University of Houston with support from an SRS doctoral fellowship, and he has been awarded a World Rehabilitation Fund Fellowship to study programs for disabled people in Europe. Currently, he is Deputy Vice President for North America of Rehabilitation International.

Mr. Frieden, a quadriplegic due to a spinal cord injury, has been involved in the organization of several groups of disabled individuals including the American Coalition of Citizens with Disabilities, the Coalition of Texans with Disabilities, and the Houston Coalition for Barrier Free Living.

Working in the independent living movement by severely disabled people since the early 1970s, Mr. Frieden has published several books and papers on independent living. He served as a consultant panel member for the United States House of Representatives' Committee on Science and Technology from 1976-1978, and he prepared the background paper on "Community and Residential Based Housing" for the White House Conference on Handicapped Individuals in 1977. From 1989-1990, he represented the United States on a disability and employment panel at the Organization for Economic Cooperation and Development in Paris, France.

He has received two Presidential Citations for his work in the field of disability, and he was honored by the U.S. Jaycees in 1983 as one of America's Ten Outstanding Young Men.

ACCESS, USE AND SATISFACTION OF THE UNDER 65 MEDICARE- DISABLED IN HMOs AND FEE-FOR-SERVICE

Leonard Gruenberg, Ph.D.

Leonard Gruenberg is the President and founder of DataChron Health Systems, Inc. Dr. Gruenberg received his doctoral degree in theoretical physics from Columbia University, and has worked for more than 20 years as a Researcher and Consultant in the field of applied health services research. His primary research focus has been associated with financing of health services for elderly and disabled populations. He has developed payment models for managed care programs for elderly and disabled populations that are being used by the Health Care Financing Administration in demonstration programs including the SHMO, PACE, and CNO projects.

Prior to establishing DataChron, Dr. Gruenberg headed up research on Medicare's TEFRA payment formula (i.e., the AAPCC) at the Brandeis University Institute for Health Policy, served as Director of Research for Elderplan (the SHMO in Brooklyn, NY), conducted evaluation and operations research at the Hebrew Rehabilitation Center for the Aged in Boston, and directed long-term care research at the Massachusetts Department of Public Health.

COMMON VARIABLES FOR HMO 1 AND MCBS

- Demographics
 - S Age, gender, race/ethnicity, educational level, marital status
- Health Status
 - S Self-reported health
 - S Diagnoses: high blood pressure, heart problems, cancer, diabetes, rheumatoid arthritis, other arthritis
 - S Impact of health on social activities
- Functional Activity
 - S Bending, kneeling, or stooping, lifting or carrying groceries, walking several blocks
 - S Bathing and dressing
- Satisfaction
 - S Overall satisfaction
 - S Satisfaction with information given
- Usual Source of Care
 - S Have regular doctor
 - S Doctor is interested in overall health
- Preventive Care
 - S Mammogram, pap smear, hysterectomy, flu shot, pneumonia vaccine shot, smoking behavior

RESEARCH QUESTION

Did those in poor health and those with functional limitations report lower levels of satisfaction?...more problems with access?

MEASURES OF POOR HEALTH, FUNCTIONAL LIMITATIONS

- Poor Health
 - S Self-reported health status
 - S Report having serious or chronic condition
 - S Impact of health on social activities

- Functional Limitations
 - S ADL: limited a lot in bathing and dressing
 - S Limited a lot in walking one block

TABLE 1. ENROLLMENT BY MEDICARE CATEGORY: U.S. AND HMO: 1991-1995						
Year	U.S. Medicare Disabled Population*		HMO 1		HMO 2	
	Disabled	Aged	Disabled	Aged	Disabled	Aged
1991	3,385 9.7%	31,485 90.3%	1,090 2.4%	45,112 97.6%	0 -	0 -
1992	3,579 10.1%	32,019 89.9%	1,410 3.0%	45,161 97.0%	71 0.4%	18,362 99.6%
1993	3,863 10.6%	32,477 89.4%	1,567 3.4%	45,069 96.6%	186 0.9%	20,423 99.1%
1994	4,151 11.2%	32,799 88.8%	1,763 3.8%	44,773 96.2%	339 1.4%	23,963 98.6%
1995	4,500 12.0%	33,100 88.0%	1,918 4.1%	45,054 95.9%	667 2.5%	26,256 97.5%

*U.S. data are given in 1,000s.

TABLE 2. ENROLLMENT BY AGE AND GENDER									
Age	U.S. Medicare Disabled			HMO 1			HMO 2		
	Female	Male	Total	Female	Male	Total	Female	Male	Total
<20 years	0.18	0.07	0.12	0.00	0.52	0.28	1.28	1.97	1.69
20-34 years	12.95	14.27	13.76	5.67	6.70	6.23	7.26	7.02	7.12
35-44 years	18.75	22.90	21.29	9.51	12.24	10.99	22.65	19.38	20.68
45-54 years	29.25	23.82	25.92	27.30	20.36	23.53	20.51	18.82	19.49
55-59 years	15.02	17.04	16.26	22.85	18.17	20.31	40.17	45.51	43.39
60-64 years	23.85	21.90	22.66	34.66	42.01	38.66	8.12	7.30	7.63
Total	100.0 (1,451)	100.0 (2,294)	100.0 (3,745)	100.0 (652)	100.0 (776)	100.0 (1,428)	100.0 (234)	100.0 (356)	100.0 (590)

*U.S. Medicare population data is given in 1,000s.

TABLE 3. TOTAL ENROLLMENT OF THE DISABLED POPULATION: 1991-1995								
Year	HMO 1				HMO 2			
	Enrolled at Start of Year	New Enrollees During Year	Disenrollees During Year		Enrolled at Start of Year	New Enrollees During Year	Disenrollees During Year	
			Voluntary	Death			Voluntary	Death
1991	1,090	453	98	35	0	272	1	0
1992	1,410	330	116	57	271	382	10	3
1993	1,567	383	108	79	640	354	18	8
1994	1,763	385	158	72	968	629	20	24
1995	1,918	591	199	89	1,553	258	85	31

TABLE 4. DISENROLLMENT RATE BY MEDICARE CATEGORY: 1991-1995				
Year	HMO 1		HMO 2	
	Disabled	Aged	Disabled	Aged
1991	7.84%	5.29%	0.74%	-
1992	7.79%	4.59%	2.20%	-
1993	6.49%	4.86%	2.24%	-
1994	8.58%	4.62%	1.59%	-
1995	9.61%	4.69%	5.23%	-

* Not includes disenrollments due to death

TABLE 5. UTILIZATION RATES: A COMPARISON OF THE U.S. AND HMO 1					
	U.S. Medicare		HMO 1		State FFS
	Disabled	Aged	Disabled	Aged	Total
1992					
- Inp.adm*	364	311	486	284	241
- Inp.days*	3,134	2,587	2,932	1,520	1,360
- SNF adm*	11	28	16	23	23
- SNF days*	311	767	501	503	542
1994					
- Inp.adm*	370	337	451	259	305
- Inp.days*	2,774	2,291	2,638	1,396	1,573
- SNF adm*	13	43	25	29	40
- SNF days*	353	1,169	523	596	867
per 1,000					

TABLE 6. UTILIZATION RATES BY MEDICARE CATEGORY FOR HMO 1 (1994)		
Health Service	HMO 1	
	Disabled	Aged
Hospital admissions*	451	259
Hospital days*	2,638	1,396
Day surgeries*	267	164
SNF admissions*	25	29
SNF days*	523	596
ER visits*	862	531
Physician visits	23.8	11.3
Prescriptions	31.3	18.3

* per 1,000

TABLE 7. REPEATED HOSPITALIZATIONS: 1991-1994				
# of Hospital Episodes	HMO 1		MCBS	
	Disabled	Aged	Disabled	Aged
Percent of Persons by Number of Hospital Episodes				
0 episodes	53.8%	62.6%	63.0%	58.2%
1 episode	18.2%	17.3%	15.9%	20.5%
2 episodes	10.0%	10.5%	7.7%	9.6%
3 episodes	5.7%	4.8%	3.5%	5.0%
4+ episodes	12.3%	4.9%	10.0%	6.8%
#Obs	942	2,293	3,054,920	24,201,805
Number of Hospital Days/1,000 per year				
0 episodes	0	0	0	0
1 episode	1,169	1,103	1,600	1,525
2 episodes	2,595	2,345	3,475	3,875
3 episodes	3,650	3,682	5,850	5,600
4+ episodes	9,333	7,527	12,650	10,775
#Obs	942	2,293	3,054,920	24,201,805

TABLE 8. DISTRIBUTION OF HOSPITAL DAYS BY NUMBER OF EPISODES				
# of Hospital Episodes	MCBS		HMO 1	
	Disabled	Aged	Disabled	Aged
1 episode	12.7%	18.5%	11.6%	19.5%
2 episodes	13.4%	22.0%	14.2%	25.1%
3 episodes	10.4%	16.5%	11.4%	17.9%
4+ episodes	63.5%	43.0%	62.8%	37.6%

TABLE 9. SERVICES UTILIZATION IN HMO 1 BY NUMBER OF EPISODES: 1991-1994					
# Episodes	0	1	2	3	4
Aged					
- SNF days*	0	485	877	924	2,022
- Day surgeries*	103	130	177	216	275
- ER visits*	208	408	831	1,167	1,719
- Physician visits	7.5	9.7	13.0	16.7	22.5
- Prescriptions	12.5	16.8	23.7	28.1	34.7
Disabled					
- SNF days*	0	149	202	236	1,489
- Day surgeries*	92	164	277	434	474
- ER visits*	323	797	738	1,648	2,032
- Physician visits	10.9	16.5	25.7	30.7	51.4
- Prescriptions	18.2	28.5	39.2	44.5	50.8
* per 1,000 persons					

TABLE 10. DISTRIBUTION OF SERVICES IN HMO 1 BY NUMBER OF EPISODES: 1991-1994					
# Episodes	0	1	2	3	4
Aged					
- Inpatient days	0.0%	19.5%	25.1%	17.9%	37.6%
- SNF days	0.0%	26.3%	28.8%	13.8%	31.0%
- Day surgeries	50.0%	17.4%	14.3%	7.9%	10.4%
- ER visits	30.5%	16.5%	20.4%	13.0%	19.7%
- Physician visits	48.8%	17.5%	14.1%	8.2%	11.4%
- Prescriptions	48.1%	17.9%	15.3%	8.2%	10.5%
Disabled					
- Inpatient days	0.0%	11.6%	14.1%	11.4%	62.8%
- SNF days	0.0%	11.1%	8.3%	5.5%	75.1%
- Day surgeries	26.1%	15.6%	14.5%	13.1%	30.7%
- ER visits	23.6%	19.6%	10.0%	12.8%	34.0%
- Physician visits	30.0%	15.4%	13.1%	9.0%	32.5%
- Prescriptions	35.4%	18.7%	14.1%	9.2%	22.6%

TABLE 11. A COMPARISON OF THOSE AGE 65-69 WHO WERE DISABLED AND THOSE AGE 65-69 WHO WERE NOT DISABLED: HEALTH SERVICE UTILIZATION		
1995 Utilization Rates	Disabled 65-69	Aged 65-69
Hospital admission*	432	150
Hospital days*	2,096	645
Day surgeries*	227	114
SNF admissions*	46	6
SNF days*	999	74
ER visits*	703	365
Physician visits	16.6	9.1
Prescriptions	29.8	16.2
* per 1,000 persons		

TABLE 12. A COMPARISON OF PAYMENTS MADE BY AGE IN HMO 1 HEALTH PLAN		
HMO 1 AAPCC Rates		
HMO 1	60-64	65-69
Part A		
- Male	\$182.29	\$156.90
- Female	\$227.86	\$132.76
Part B		
- Male	\$116.28	\$101.17
- Female	\$146.88	\$88.52

TABLE 13. COMPARING HMO 1 QUESTIONNAIRES TO MCBS	
Health and Functional Status	
In general, compared to other people (your/sp's) age would you say your health is excellent, very good, good, fair, or poor?	In general, would you say your health is excellent, very good, good, fair, poor?
How much of the time during the past month has (your/sp's) health limited (your/sp's) social activities, like visiting friends or close relatives?... none of the time, some, most, all	During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups? not at all, slightly, moderately, quite a bit, extremely
How much difficulty, if any, (do you/sp) have stooping, crouching or kneeling? Would you say: no difficulty at all, a little difficulty, a lot of difficulty, not able to do it	Does your health now limit you in any of these activities? If so, how much?--bending, kneeling or stooping--yes limited a little, yes limited a lot, no not limited at all
How much difficulty, if any, (do you/sp) have lifting or carrying objects as heavy as ten pounds, like a sack of potatoes? Would you say: no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, not able to do it	Does your health now limit you in any of these activities? If so, how much?--lifting or carrying groceries--yes limited a little, yes limited a lot, no not limited at all
What about walking a quarter of mile, that is, about 2 or 3 blocks? no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, not able to do it	Does your health now limit you in any of these activities? If so, how much?--walking several blocks--yes limited a little, yes limited a lot, no not limited at all

TABLE 13. COMPARING HMO 1 QUESTIONNAIRES TO MCBS	
Because of a health or physical problem do you/sp have any difficulty...(yes, no, doesn't do) Is this because of a health or physical problem? Do you/does sp receive help from another person? Does someone usually stay nearby just in case you need/sp needs help... Do you/does sp use special equipment or aids to help you/him/her with...? Who helps?--bathing or showering, dressing	Does your health limit you in bathing or dressing yourself? yes limited a little, yes limited a lot, no not limited at all
Preventive Care	
Have you/has sp a mammogram or breast x-ray since a year ago? (yes, no, refused, DK)	When was last time you had a mammogram? (never, within last 12 months, within last two years, within last three years, within last five years, more than five years ago)
Have you/sp had a pap smear since a year ago? (yes, no, refused, DK)	When was last time you had a pap smear? (never, within last 12 months, within last two years, within last three years, within last five years, more than five years ago)
Have you/sp ever had a hysterectomy? (yes, no, refused, DK)	Have you had a hysterectomy (surgical removal of uterus)?...yes, no
Did you/sp have a flu shot for last winter (between September and December)? (yes, no, refused, DK)	Did you get a flu shot during the last 12 months? yes, no
Have you/has sp ever had a shot for pneumonia? (yes, no, refused, DK)	Have you ever had a pneumonia vaccine shot (pneumococcal vaccine, pneumovax)? yes, no
Have you/has sp ever smoked cigarettes, cigars, or pipe tobacco? (yes, no, refused, DK) Do you/does sp smoke now? (yes, no, refused, DK)	Do you currently smoke cigarettes? yes, no never smoked
Diagnosis	
"Has a doctor ever told you..."	"Has a doctor ever told you..."
Hypertension or high blood pressure	Hypertension or high blood pressure
Myocardial infraction or a heart attack	Heart problems
Angina pectoris or coronary heart disease	Heart problems
Other heart conditions such as congestive heart failure, problems with the valves in the heart, or problems with the rhythm of your heart	Heart problems
Skin cancer	Cancer
Any other kind of cancer, malignancy or tumor	Cancer
Diabetes, high blood sugar, or sugar in your urine	Diabetes diagnosed before age 40. Diabetes diagnosed at age 40 or later.
Rheumatoid arthritis	Rheumatoid arthritis
Arthritis other than rheumatoid	Arthritis
Satisfaction and Access to Care	

TABLE 13. COMPARING HMO 1 QUESTIONNAIRES TO MCBS	
Is there a particular doctor you/sp usually see(s)?	Do you have a HMO 1 doctor you consider to be your regular doctor?
Now I am going to read some statements people have made about their medical care... For each statement please tell me whether you strongly agree, agree, disagree, or strongly disagree--The doctor(s) often seem to be in a hurry. Doctor does not explain your medical problems to you	In general how satisfied with each of the following items related to quality of care at HMO 1? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied--Amount of time doctors spend with you. Amount of explanation or information provided.
The overall quality of the medical care (you have/sp has) received in the last year? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.	Overall, how satisfied are you with HMO 1? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.
The information given to (you/you or sp) about what was wrong with (you/sp)? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.	Amount of explanation or information the doctors give you? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.
The concern of doctors for your overall health rather than just an isolated symptom or disease? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.	Personal interest and attention the doctors give you? Very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.

TABLE 14. AGE AND GENDER COMPOSITION OF SURVEY RESPONDENTS, %						
Age	HMO 1			MCBS		
	Male	Female	Total	Male	Female	Total
Less than 20 years	0.3	0.3	0.3	0.1	0.0	0.1
20-34 years	7.4	5.3	6.5	8.4	7.6	8.1
35-44 years	12.7	12.9	12.8	19.8	18.8	19.5
45-54 years	18.2	24.7	21.1	24.2	23.7	24.0
55-59 years	19.6	20.2	19.9	17.0	18.6	17.6
60-64 years	41.9	36.5	39.5	30.4	31.3	30.7

TABLE 15. RACE AND ETHNIC COMPOSITION, %				
	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
White	97.3	95.1	92.3	79.9
Black/African American	0.8	2.3	6.1	14.6
Other	1.9	2.6	1.6	5.5

TABLE 16. EDUCATIONAL LEVEL, %				
	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Age 65 and over	Under age 65
Grades 0-8	7.8	7.9	24.9	25.7
Grades 9-11	12.0	12.5	16.3	21.0
High school graduate	35.2	31.8	32.6	35.4
Some college	24.4	30.4	13.3	11.8
College graduate	8.3	8.5	7.2	3.8
Post-college work	12.4	9.0	5.8	2.4

TABLE 17. MARITAL STATUS, %				
	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
Currently married	69.1	58.0	57.4	53.2
Widowed	22.3	6.9	33.9	8.2
Divorced/separated	6.6	19.8	5.0	18.3
Never married	2.0	15.3	3.6	20.3

TABLE 18. OVERALL HEALTH STATUS OF SURVEY RESPONDENTS, %				
Rating of Health	HMO 1		MCBS*	
	Aged 65 and over (n=1,429)	Under age 65 (n=838)	Aged 65 and over (n=22,757*)	Under age 65 (n=1,558*)
Excellent	5.5	3.2	17.8	4.2
Very good	26.2	9.6	25.4	8.4
Good	43.4	31.4	30.6	18.1
Fair	20.3	36.5	18.6	30.9
Poor	4.6	19.3	7.6	38.5

* in 1,000s

TABLE 19. DIAGNOSES, %				
Diagnosis	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
High blood pressure	45.8	47.5	47.9	41.8
Heart problems	32.5	33.7	33.9	36.0
Cancer	21.2	16.4	17.2	13.0
Diabetes	14.7	27.9	13.8	15.8
Rheumatoid arthritis	17.3	22.1	9.4	17.2
Arthritis other than rheumatoid	51.5	44.1	45.3	40.6

TABLE 20. FUNCTIONAL DIFFICULTY: PERCENT REPORTING SOME DEGREE OF DIFFICULTY				
Functional Activity	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
Bending, kneeling, stooping	62.0	78.7	67.9	80.5
Lifting or carrying groceries	38.5	72.5	37.8	63.9
Walking several blocks	41.4	70.7	43.3	70.3
Bathing and dressing	14.4	35.5	8.8	24.5

TABLE 21. IMPACT OF HEALTH ON SOCIAL ACTIVITIES: PERCENT REPORTING SOME DEGREE OF IMPACT				
	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
Health has limited social activities	39.8	66.8	32.8	71.7

TABLE 22. OVERALL SATISFACTION, %				
Level of Satisfaction	HMO 1		MCBS*	
	Aged 65 and over (n=1,465)	Under age 65 (n=843)	Aged 65 and over (n=22,786*)	Under age 65 (n=1,558*)
Very satisfied	32.0	38.4	38.2	27.3
Satisfied	55.6	47.3	49.2	53.1
Neutral	10.5	9.1	3.8	8.4
Dissatisfied	1.5	3.7	1.1	3.2
Very dissatisfied	0.4	1.4	7.7	8.0

* in 1,000s

TABLE 23. LEVELS OF SATISFACTION FOR ASPECTS OF CARE, %						
Aspect of Care	Aged 65 and Over			Under Age 65		
	Very satisfied/ satisfied	Neutral	Dissatisfied/ very dissatisfied	Very satisfied/ satisfied	Neutral	Dissatisfied/ very dissatisfied
HMO 1						
- Amount of explanation or information provided	79.3	14.0	6.6	80.8	11.8	7.5
- Time spent with doctor	80.8	14.1	5.1	78.6	13.0	8.4
- Doctor's interest in overall health	88.4	10.1	1.5	83.9	11.4	4.8
MCBS						
- Amount of explanation or information provided	85.1	N/A	13.7	82.4	N/A	16.1
- Time spent with doctor	83.0	N/A	16.5	77.0	N/A	21.7
- Doctor's interest in overall health	85.5	N/A	6.6	80.4	N/A	9.4

TABLE 24. PREVENTIVE CARE, %*				
Preventive Practice	HMO 1		MCBS	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
Mammogram*	57.9	59.8	37.5	33.5
Pap smear*	39.7	49.8	32.5	41.3
Hysterectomy	51.1	44.9	40.5	44.5
Flu shot*	80.6	71.2	43.4	25.1
Pneumonia vaccine shot*	64.7	46.2	22.1	18.2

* Percent who answered "yes" to experiencing preventive care item within the past year.

TABLE 25. SMOKING BEHAVIOR, %				
	HMO 1		MCBS*	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
Currently smoke	8.6	23.1	26.1	57.5
Ever smoked	52.4	57.6	57.3	70.0

TABLE 26. REGULAR PHYSICIAN, %				
	HMO 1		MCBS*	
	Aged 65 and over	Under age 65	Aged 65 and over	Under age 65
Have Primary Care Physician	91.2	91.1	81.5	69.9

TABLE 27. SIGNIFICANT CORRELATIONS		
Measures of Satisfaction/Access	Significant Variables	Sign
Overall satisfaction		
Overall quality of service	Asthma Depression	+ +
Quality of care provided by doctors	Asthma Arthritis	+ +
Quality of care provided by physician assistants		
Quality of care provided by nurses	Arthritis	+
Time spent with doctors	Asthma Diabetes at age 40 or later	+ -
Overall access to care	Bathing and dressing Arthritis	+ +
Getting night and weekend care	Asthma	+
Getting emergency care	Bathing and dressing Bronchitis	+ +
Have regular doctor	Age Gender Arthritis	- + -

HOW THE OREGON HEALTH PLAN SERVES PEOPLE WITH DISABILITIES: SYSTEM DESIGN ISSUES AND FIRST-YEAR IMPACTS

Margo L. Rosenbach, Ph.D.

Margo Rosenbach is Executive Vice President of Health Economics Research, Inc., Waltham, MA. She is the Principal Investigator of the HCFA-funded Evaluation of the Oregon Medicaid Reform Demonstration, which assesses the impact of Oregon's Section 1115 Medicaid waiver on quality, access, utilization, satisfaction, and program costs. The Oregon Health Plan (OHP) involves expansion of Medicaid eligibility, increased enrollment in managed care, and implementation of a priority list to determine Medicaid benefits. The Disability Component of the evaluation focuses on the impact of OHP on people with disabilities. Dr. Rosenbach is also the Principal Investigator on several other Medicaid demonstration evaluations, and has a special interest in access to care among vulnerable populations. Dr. Rosenbach received her Ph.D. in Health Policy from the Heller Graduate School, Brandeis University.

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OBJECTIVES OF THE OREGON HEALTH PLAN

- Expand Medicaid eligibility to those below the Federal Poverty Level, without regard to categorical criteria.
- Set reimbursement levels sufficient to cover costs, to eliminate cost shifting.
- Make an overt commitment to managed care, where feasible.
- Develop a prioritized list of health services that would be used to establish the scope of benefits, based on the availability of State funds.

PHASED IMPLEMENTATION

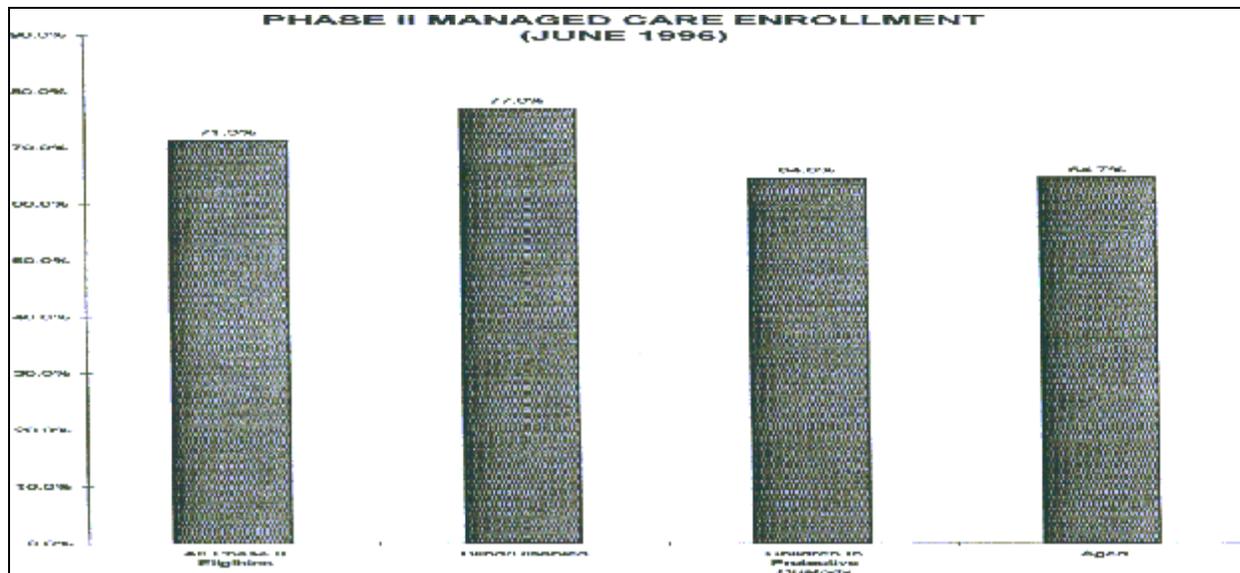
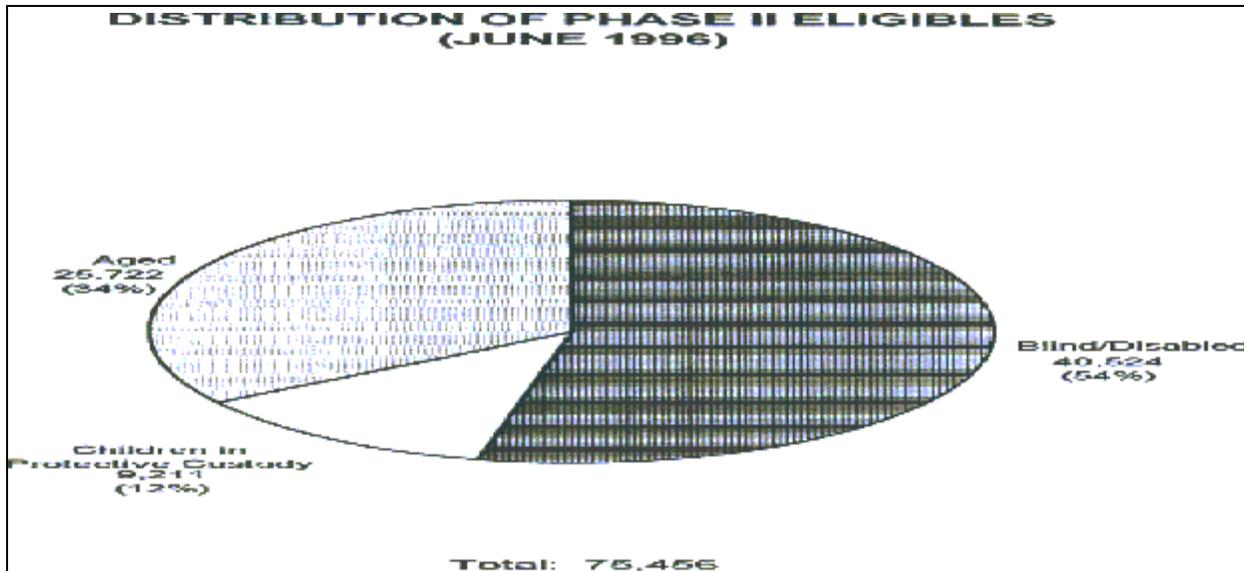
- Phase I implemented February 1, 1994 (AFDC, General Assistance, poverty-level pregnant women and children, and Medicaid expansion).
- Phase II implemented January 1, 1995 (disabled, children in foster care, and elderly).

SYSTEM DESIGN ISSUES

- Choice Counseling
- Continuity of Care Referral Form
- The Ombudsman
- The Exceptional Needs Care Coordinator
- The OHP Benefit Package
- Coordination of Acute Care and Long-Term Care

FIRST-YEAR IMPACTS

- Provider Issues
- Consumer Issues
- Access to Care
- Mental Health Services



COMPARISON OF PHYSICIAN AND HOSPITAL USE AMONG PEOPLE WITH CHRONIC ILLNESS IN HMO AND FFS PLANS

Teresa Fama

Teresa Fama is the Deputy Director of the Robert Wood Johnson Foundation National Program Office, "Chronic Care Initiatives in HMOS." Through this program, Ms. Fama is engaged in fostering and evaluating innovations in the management of people with chronic conditions who are enrolled in HMOS. Prior to her involvement with the Robert Wood Johnson Foundation, Ms. Fama was an analyst at the Prospective Payment Assessment Commission (ProPAC), where she worked on Medicare post-acute care financing issues. Prior to ProPAC, Ms. Fama was a Senior Associate at Lewin-VHI, Inc., a health care consulting firm. Ms. Fama has a Master of Science degree from the University of Rochester in Rochester, NY.

RESEARCH QUESTION

Do chronically ill HMO and FFS enrollees use the same level of physician and hospital services?

DATA SOURCE

1992 National Health Interview Survey

METHODS

Descriptive and multivariate analyses

PRIOR WORK (*HEALTH AFFAIRS*, SPRING 1995)

- Refuted the notion that chronic illness is more prevalent among people covered by indemnity plans than by HMOS
- Could not examine Medicare and Medicaid

CURRENT WORK

Examined two subgroups:

- People with at least one of 15 chronic conditions
- People who reported their health as fair or poor

DESCRIPTIVE FINDINGS: MD VISITS

- HMO enrollees with chronic conditions more likely than FFS enrollees to visit a physician
- For users, no difference in number of visits

DESCRIPTIVE FINDINGS: HOSPITAL STAYS

- HMO enrollees with 8+ bed days less likely than FFS enrollees to be hospitalized
- For users, no difference in average length of stay

REGRESSION RESULTS

- HMO enrollees with chronic conditions more likely than FFS enrollees to visit a physician
- For users, no difference in number of visits
- No difference in likelihood of a hospital stay or, for users, in the average LOS
- No difference found for subgroup who perceived their health as fair/poor

LIMITATIONS

- Self-reported data
- Non-elderly only, with private insurance
- Can examine utilization only, with some inference about access to care
- Can't conclude anything about patterns of care or outcomes

POLICY IMPLICATIONS

- Data indicate that chronically ill have better access to physician care in HMOS than in FFS
- HMOS appear not to be skimping on care for chronically ill population
- Question remains: To What Extent are HMOS "Shadow Practicing" the FFS System?

Variables	Percent with 1+ Visits			Mean Number of Visits		
	Indemnity	HMO	Total	Indemnity	HMO	Total
Has Chronic Condition	85.8%	89.3%*	86.8%	7.6	8.4	7.8
Perceives Health as Fair/Poor	89.0	88.7	88.9	12.2	13.8	12.6
Has Limit in Major Activity	91.5	93.4	92.0	12.2	13.9	12.8
8 or more Bed Days	96.9	98.0	97.2	12.4	13.8	12.9
All Persons	77.3	81.4*	78.6	4.6	4.9	4.7
N (in thousands) =	83,993	38,263	122,256	64,927	31,146	96,073

* Percentage is significantly different at p<.05, compared with indemnity plan.
SOURCE: National Center for Health Statistics, 1992 National Health Interview Survey.

TABLE 2. HOSPITAL STAYS IN THE PRIOR 12 MONTHS						
Variables	Percent with 1+ Visits			Mean Number of Visits		
	Indemnity	HMO	Total	Indemnity	HMO	Total
Has Chronic Condition	9.7%	8.2%	9.3%	7.6	6.9	7.4
Perceives Health as Fair/Poor	20.0	16.1	18.9	8.6	8.6	8.6
Has Limit in Major Activity	19.1	14.5	17.7	8.8	10.2	9.1
8 or more Bed Days	32.7	26.5*	30.7	8.7	8.6	8.7
All Persons	4.8	4.1*	4.6	5.8	5.7	5.8
N (in thousands) =	83,993	38,263	122,256	4,031	1,561	5,592
* Percentage is significantly different at p<.05, compared with indemnity plan.						
SOURCE: National Center for Health Statistics, 1992 National Health Interview Survey.						

A MANAGED CARE PROGRAM FOR WORKING-AGE PERSONS WITH PHYSICAL DISABILITIES: A FEASIBILITY STUDY

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EXECUTIVE SUMMARY

This report presents the findings of a study funded by The Robert Wood Johnson Foundation (RWJF) and conducted by the Research Program of the National Rehabilitation Hospital (NRH) to determine the feasibility of developing a managed health care program for working-aged persons with physical disabilities in the Washington, DC, metropolitan area. Members of the physically disabled population tend to be highly vulnerable to such conditions as decubitus ulcers, scoliosis, acute urinary tract infections, and lower respiratory tract infections. They have substantially higher rates of hospitalization than persons who are not disabled. The proposed program is intended to provide access to affordable comprehensive health care services for physically disabled persons aged 18-65. Its objective is to prevent the escalation of minor health concerns to major problems that require hospitalization or other forms of institutionalization.

The feasibility study was conducted by a Research Team consisting of specialists in rehabilitation and health services research, and was reviewed by an Oversight Committee consisting of representatives from local government, the insurance industry, disability organizations, and the provider community. The study had four parts, which are as follows:

1. Analysis of the appropriate conceptual model on which to base the proposed program, and determination of the program's general parameters;
2. Identification and survey of members of the target population to determine whether they would benefit from, and be interested in, the program;
3. Assessment of the prospects for offering the program to members of the target population through public and private sector payors of health care; and
4. Analysis of the financial feasibility of the program through projections of likely cost savings to payors as a result of the program.

Based on these analyses, the researchers conclude that the proposed program is feasible, and recommend that it be developed and implemented. A summary of the results of each analysis and the overall conclusions of the study are provided below.

Analysis of Managed Care Models

As initially conceived, the proposed program was to

be based on the health maintenance organization (HMO) model of managed care. Under the HMO model, the provider is placed "at risk" financially for providing all covered services needed by its enrolled population during the period of enrollment. The program was to be offered through the disabled individual's underlying health insurance, such as Medicaid, Medicare, Blue Cross/Blue Shield, or other private health insurance plan. The insurer would pay the program a capitation payment to provide a comprehensive set of health care services, as needed, to one of its beneficiaries during the enrollment period.

However, this initial conceptualization changed as a result of the findings of the feasibility study. The HMO model was abandoned due to:

- insufficient cost and utilization data, based on the actual claims experience of the target population, for the accurate calculation of capitation rates;
- concerns about financial viability of a program based on the HMO model (due to the high risks of the target population and lack of adequate claims data on which to base capitation rates);
- the relatively small number of persons likely to be enrolled in the program as compared to the number of enrollees typically required for a viable HMO;
- the unlikelihood that the program would be able to secure affordable reinsurance; and
- concerns by the disabled community over the strong cost-containment incentives of capitation financing and problems in replicating a program for disabled persons based on the HMO model.

Under the revised conceptualization of the program, it would be based on the preferred provider arrangement (PPA) model of managed care. Under the PPA model, the disabled person's insurer would negotiate preferred provider rates with the program for each type of service offered to its disabled beneficiaries, and the program would provide such services as needed. As compared to the HMO model, the PPA model is (a) less financially risky for providers because they do not bear the responsibility of providing the comprehensive care of their enrollees for a single capitation payment; (b) somewhat less dependent on accurate cost data, large enrollment, and reimbursement; (c) less likely to result in conflicts of interest between providers and patients, due to its somewhat weaker incentives for cost containment; and (d) more readily replicable in other areas of the country, including small urban areas.

The Proposed Program

The program would provide a comprehensive set of inpatient and outpatient services to its enrolled population. These would include outpatient primary care services, inpatient hospital services, medical specialty services, home visits by nurse practitioners, and emergency attendant care. It would address the health care needs of persons aged 18-65 who reside in the Washington, DC, Standard Metropolitan Area (SMA) and who have any of the following diagnosed disabilities:

- amputation
- cerebral palsy
- cystic fibrosis
- head injury
- multiple sclerosis
- muscular dystrophy
- post-polio
- spina bifida
- spinal cord injury
- stroke.

The program would be offered through a variety of public and private sector insurance programs to their beneficiaries who qualify under the program as members of the target population. Enrollment in the program would be entirely voluntary on the part of the beneficiary, though disabled persons who choose to enroll in the program would "lock themselves in" for the annual enrollment period. The program, as currently envisioned, would have a small administrative and clinical staff, and would be based in an outpatient facility. It would also contract on a preferred provider basis with hospitals and practitioners in the Washington, DC, area to provide services to the enrolled population.

The Market Analysis and Survey

A market survey was needed to identify physically disabled persons of working age in the Washington, DC, metropolitan area, and to assess their unmet health care needs and their desire for the proposed program. The market area for the survey was defined as the Washington, DC, SMA. To identify members of the target population, an initial screening survey was developed by the researchers and distributed to members of 18 disability organizations in the market area. To be included in the study group, a respondent to the screening survey had to be:

- 18 to 65 years of age;
- a resident of the market area; and
- a person who has at least one of the ten diagnosed disabilities included in the target population for the program.

The main survey questionnaire was sent to 993 persons who indicated through the screening survey that they are

members of the target population. There were 607 usable responses to the main survey questionnaire (a response rate of 61 percent).

The information objectives of the survey were to develop a demographic profile of the members of the target population; to describe their health and functional status; to evaluate their use of inpatient and outpatient health care services; to determine their level of satisfaction with their current health care services; to examine the extent to which they are covered by health insurance from the public and/or private sectors; and to ascertain their preferences for a managed health care approach to meeting their health care needs. The survey results most pertinent to determining the feasibility of the proposed program are summarized below.

Demographic Profile

Overall, the study group is predominantly white (85 percent), male (56 percent), well-educated, and not currently employed (59 percent). Only 12 percent of the respondents did not complete high school. Some 37 percent have either a college or graduate degree. Only 41 percent of the study group are working full- or part-time. Some 16 percent are unemployed and seeking work. About a third of the members of the study group have an annual household income of less than \$10,000. Almost a quarter of the study group have an annual household income of more than \$50,000. Slightly over half of the members of the study group receive Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI) or both.

Health and Functional Status

About three-quarters of the study group rate their own health as either "good" or "excellent." Some 55 percent of the study group use either a manual or a power wheelchair. About two-thirds of the study group take care of their own personal needs; the remaining third obtain help on a regular basis from another person. Some 12 percent of the entire study group use a paid attendant to meet their personal care needs. Overall, the group consists of a relatively large number of persons with substantial functional limitations.

Health Care Utilization

About a quarter (26 percent) of the study group were hospitalized at least once during the 12 months prior to receiving the survey. Some 37 percent of all respondents hospitalized in the previous 12 months were hospitalized two or more times during that period. Because some had multiple admissions, the entire study group averaged 45 hospitalizations per 100 respondents during the previous 12 months. Of those hospitalized, half were hospitalized for a week or less; half were hospitalized for a week or more. Some 16 percent were hospitalized for more than

two weeks. The average length of stay for the most recent hospitalization was 13 days.

Those who were hospitalized in the previous 12 months were asked how many of their hospitalizations could have been averted if they had received early treatment by a doctor or other health care provider knowledgeable about their disability. Of those who responded to this question, 23 percent indicated that at least one hospitalization could have been averted. Some 28 percent of the study group had difficulty in the past year finding a physician who was knowledgeable about the particular health care needs related to their disabilities.

Health Insurance Coverage

About 96 percent of survey respondents have some form of health insurance coverage: 27 percent have only public sector coverage; 43 percent have only private sector coverage; and 26 percent have a combination of both public and private sector coverage. Some 17 percent of respondents receive health benefits under Medicaid; 20 percent of respondents receive benefits under Medicare; and an additional eight percent receive both Medicare and Medicaid. Of those who have some form of private coverage, most have traditional private health insurance (77 percent). A minority of those with private coverage use a private HMO (13 percent).

Preference for a Managed Care Program

Members of the study group were asked to rank their preferences for three specified types of health care plans. About half (52 percent) of the survey respondents indicated that their first choice would be a managed care plan in which choice of provider is limited to a group of practitioners who are knowledgeable of their disability-related problems, but in which patients would have considerable control over the coordination of their own care. This plan is rated third by only four percent of the respondents. Preference for this type of plan is strong across all disabilities except among respondents with cerebral palsy.

Some 29 percent of the study group indicated that their first choice would be a plan in which choice of provider is limited to practitioners specifically knowledgeable of disability-related problems, but in which the plan is responsible for coordinating the patient's care. Almost half (49 percent) indicated that this type of plan would be their third choice. Some 31 percent of the group indicated that they prefer a traditional health plan in which choice of provider is not limited and the patients are responsible for coordinating their care.

The Payor Analysis

Under the proposed program, health care payors such as Medicaid, Medicare, Blue Cross/Blue Shield, other

commercial insurers, and self-insured corporations would pay the program negotiated rates per service for providing health care services to their disabled beneficiaries. For this reason, third-party payor involvement is essential to the success of the program. A central component of the feasibility study was to determine whether the various public and private sector payors in the Washington, DC, area would be interested in offering the program to their beneficiaries with disabilities. Throughout the study, members of the Research Team met with public and private sector payors.

The researchers determined that Medicaid participation in the proposed program would be essential to its feasibility, because it is believed that physically disabled Medicaid recipients comprise the single largest pool of potential enrollees for the program. The District of Columbia Office of Health Care Financing (DCOHCF), which administers the District's Medicaid program, indicated that it would be willing to participate in the program if it can obtain "waivers" necessary for federal Medicaid funding of the program from the U.S. Health Care Financing Administration (HCFA). It is expected that HCFA will approve the Medicaid waiver request prepared by the Research Team on behalf of DCOHCF, and the program will be able to receive funding under DC Medicaid. Once approved, similar waiver requests will be prepared for the program on behalf of Maryland and Virginia.

Medicare participation in the proposed program would also contribute importantly to the program's feasibility. Funding of the program by Medicare is somewhat less likely than is funding by Medicaid, though it is still very feasible. Medicare waivers for a research or demonstration project would be needed for Medicare participation in the program, but approval of such waiver requests by HCFA is more discretionary than approval of Medicaid waiver requests. Once the program has been applied to Medicaid recipients, the Research Team will be able to estimate program costs adequately to apply for a Medicare waiver. There is a reasonable probability that Medicare funding could be secured by the third year of the program.

The prospects for funding of the program by private sector payors such as Blue Cross/Blue Shield and other commercial insurers are least optimistic. Impediments to private sector participation include (a) difficulties for insurers in identifying disabled persons among their beneficiaries and in determining their costs; (b) high costs of negotiating for and operating a separate program for a relatively small number of disabled beneficiaries; and (c) difficulties in addressing the administrative complexities of paying for services under the program. Despite these impediments, private sector insurers have expressed interest in meeting the needs of their disabled beneficiaries, and it is likely that some private payors will cover services provided by the program.

The likelihood of obtaining reinsurance for the program at a premium that would permit the program to operate in a financially viable manner is small. It is expected that this will not preclude the program's feasibility, because the risk of extraordinary losses is substantially reduced due to the adoption of the preferred provider model for the program.

The Financial Analysis

The Research Team had initially proposed to RWJF to develop a series of income statements and cost projections for the proposed program, based on varying assumptions on program utilization and per capita rates. However, due to the lack of available cost data based on actual claims experience, and the modification of the proposed program from a capitation-financed program to a preferred provider program, such projections are too speculative at this time. Instead, the Research Team developed a set of projections as to likely cost savings by Medicaid as a result of the managed care program.

It is anticipated that annual cost savings to the Medicaid program would range between \$25,000 (if only 250 Medicaid recipients enroll in the program) to \$125,000 (if 500 recipients enroll). Projecting that 300 Medicaid recipients would enroll in the program by its third year, the Research Team believes that Medicaid is most likely to save \$55,000 a year as a result of the managed care program. Cost savings are likely to be similar for Medicare and private sector insurers that offer the program, and to increase over time as hospital costs increase more rapidly than program costs.

In addition to reducing health care costs, the program would enhance access to high-quality care for persons with disabilities. It is through such enhanced access to managed care that the program is expected to reduce the number of avoidable hospitalizations and emergency room visits by disabled persons, and to increase the cost-effectiveness with which they receive health care services. The high rate of hospitalizations of disabled persons and their poor access to informed comprehensive care have resulted in substantial disruptions to their lives, including financial hardship and interference with their social and work responsibilities. The researchers believe that the program's expected ability to reduce such disruptions for disabled persons is as important as the modest cost savings expected for payors.

Conclusions/Recommendations

Based on the results of this study, the researchers recommend that the proposed program should be developed and implemented. There appears to be a strong interest in, and desire for, a managed care program among the target population of persons with physical disabilities in the Washington, DC, metropolitan area. A majority (70 to 80 percent) of the members of the study group prefer some

type of managed health care program over a traditional health care program. These respondents, and other members of the target population they represent, are likely to consider enrolling in the proposed program if it is offered to them.

Almost all persons (96 percent) surveyed have some form of health insurance that could potentially offer the program to their beneficiaries with disabilities. There appears to be considerable interest among the payor community in the program, and a substantial likelihood that the program would be financially viable. The DC Medicaid Program is very likely to be willing and able to offer the program to its recipients. Similarly, there is reason to believe that the Virginia and Maryland Medicaid programs will be willing to participate. Medicare and the private sector insurers may also participate once the program has been implemented.

This study further confirms the findings of other studies that have found a high rate of hospitalizations among the disabled population. It is noteworthy that 23 percent of the respondents who had been hospitalized at least once in the previous 12 months indicated that they believe at least one hospitalization could have been averted if they had access to early preventive care. These results suggest that the proposed program, which would provide prevention and early detection of disability-related health problems, would help to reduce unnecessary hospitalizations and thereby reduce the health care costs of the disabled population. However, even if such cost savings do not result, the program is still very likely to enhance access to care and quality of services for disabled persons without increasing costs.

The specific form that the program should take must be decided during a technical design and development stage of this project. Results from the market analysis suggest that the target population includes many sophisticated health care consumers who would prefer to retain substantial control over their own health care within a managed care system, as well as a significant number of persons who would prefer that health care professionals maintain primary control. One implication of this finding is that the program should consider offering enrollees two options, one in which the staff would coordinate their care and another in which enrollees would coordinate their own care. In either case, care would be provided by a limited number of practitioners specifically knowledgeable of the health care needs of working-age persons with physical disabilities.

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A VISION FOR THE FUTURE: INTERVIEW WITH GERBEN DEJONG, PH.D.

Jane Mattson Prince, Ph.D., and Janet Haas, M.D.

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Q: *You obviously have a very strong interest in disability and health policy issues. Could you summarize your many research projects in disability and health policy by telling us about the major themes they encompass?*

A: Our health services research portfolio falls into two main categories of research issues. The **first category** of issues pertains to medical rehabilitation as a distinct provider group in the American health care system with its own financing, service delivery, and outcome issues. The **second category** of issues pertains to people with disabilities as a distinct consumer group within the larger health care system with its own health care needs, access issues, and outcome concerns. In the second category, we are concerned with the full spectrum of health care services, not only medical rehabilitation services, that people with disabilities may need.

Our research addresses the full spectrum of health service issues--health care need, capacity, access, service delivery, utilization, costs, outcomes, consumer satisfaction, and health care financing. In addition to our investigator-initiated and contract research projects, we are also home to the Research and Training Center (RTC) on Medical Rehabilitation Services and Health Policy funded by NIDRR [National Institute on Disability Research and Rehabilitation]. We also conduct, with Georgetown University, a health policy research fellowship program for people with disabilities.

Q: *In your description of your research, you touched on an area that is of enormous interest to brain injury professionals. Brain injury programs have proliferated in the past 16 years but recently, many have recently closed and while others have consolidated or merged. This change in the industry may have reflected the tremendous changes in reimbursement precipitated by managed care. Managed care has had a significant impact on who has care and for how long they have it. Do you think that, by the Year 2000, managed care will be the dominate way in which we deliver and pay for health care?*

A: Yes, very definitely. Approximately, 70% of all people who participate in employer-sponsored health plans are now enrolled managed-care plans. Even Medicare and Medicaid, the first and third largest payers of brain injury rehabilitation services, respectively, are converting rapidly

to managed care. I predict that, by 2000, over 50% of the Medicare and 85% of Medicaid will be managed care. Other payers of brain injury rehabilitation such as commercial insurers, workers' compensation, and CHAMPUS have also introduced managed care options that will become more prevalent in the years to come.

Those who look to Medicare as the remaining bastion of fee-for-service medicine should think again. Medicare and Medicaid remain the fastest growing portions of the federal budget. Politicians are perfectly content to let the "market forces" of managed care bring down the costs of these two programs and make the hard decisions for them. The politics of the federal deficit and the economics of health care converge on managed care. In other words, managed care is the harmonic convergence of deficit politics and health economics. It is unstoppable. We have to figure out how we can make managed care work for the people we serve.

Q: *How is managed care being implemented in the public sector especially in Medicare and Medicaid? Do individual state Medicaid programs contract with private managed health care plans such as health maintenance organizations (HMOs)? Will each state offer more than one managed care plan to its Medicaid participants?*

A: In many markets, Medicare beneficiaries can choose whether they want to enroll in a managed care plan. In a highly managed care market such as the Los Angeles, about 40% of all seniors already participate in a managed care plan. In the parlance of the Medicare program, these plans are commonly referred to as "at-risk Medicare contracts." The Medicare program sets the premium at 95% of what Medicare theoretically would have spent for the same population adjusting for age and county of residence.

Until recently, Medicare was introducing managed care more quickly than state Medicaid programs. Currently, state Medicaid programs are converting to managed care more rapidly than the Medicare program. Medicare beneficiaries can usually choose between a managed care and a fee-for-service plan. In most states that have converted, Medicaid recipients can only choose between two or more managed-care plans.

State Medicaid programs typically invite proposals

from managed health care plans in response to RFPs [requests for proposals]. States typically like to see two, three or more HMO's in each market in order to spur competition. The managed-care industry is already bidding vigorously on Medicaid contracts. One has only to read the reports of Wall Street analysts to appreciate how managed care plans are poised to move aggressively into the Medicaid market.

Q: *Some of the larger HMO's have significant experience working with catastrophic injuries. Companies such as Kaiser Permanente, US Healthcare, and others may have had good results in managing these cases. Do you think that this track record will help them compete successfully for Medicaid contracts?*

A: I cannot attest to the track records of Kaiser and US Healthcare with respect to catastrophic injuries. Yes, having a good track record is important in helping secure contracts. I doubt, however, that a health plan's track record with catastrophic injuries is being examined all that closely at this time. Managed-care plans scrambling to get into the emerging Medicaid markets are ill-equipped to address large populations of people who have disabling health conditions. Up until recently, managed care's largest market consisted of people who participated in employer-sponsored plans. Moreover, the first Medicaid participants to be enrolled managed care have been AFDC [Aid to Families with Dependent Children] recipients, not SSI [Supplemental Security Income] recipients [who are also Medicaid eligible]. Employer-sponsored enrollees and AFDC recipients are, on average, much healthier and less impaired than the disabled populations served under the SSI program or the SSDI [Social Security Disability Insurance] program [who are Medicare eligible]. Many managed care plans are at the bottom of a learning curve as they move into those portions of the Medicare and Medicaid markets comprised of people with disabilities. I believe that, at least in the short term, many people with disabilities such as those with significant brain injuries will not be well served.

In many states, the transition of managed care has been chaotic. In the District of Columbia, for example, there have been problems with people who have not been enrolled properly with family members being assigned to primary-care gatekeepers located at the opposite ends of town. Again, remember, that Medicaid only pays about 11% or 12% for inpatient brain injury rehabilitation. This percentage is bound to increase as problems in the private health insurance market continue to get passed on to the public sector.

Q: *You describe a fair amount of chaos for health care services and payment for individuals who sustain brain injuries over the next decade.*

A: I don't know that it will last for ten years, but there certainly will be chaos in the short term. I believe that, over the long term, things will be better organized than in the past for reasons I hope I will have a chance to elaborate later in this interview.

Q: *How will health plans and health services be organized in the future? How will that affect access to services for people with brain injuries?*

A: We don't need a crystal ball. The future is already here. Our center conducted a study of how medical rehabilitation is faring in the three most highly managed-care markets in the country, namely San Diego, Minneapolis-St. Paul, and Worcester, Massachusetts. Our study uncovered a number of trends worth noting. One important trend is how managed care is forcing consolidation of providers into three or four major provider networks within each market. In the Minneapolis-St. Paul market, most providers have been organized into three main "integrated service networks" or ISNs for short. For people with brain injury, their access to services will depend on how their health plan is tied to one of these networks and whether the network includes the full range of health services that people with brain injuries need-- from initial acute care and rehabilitation to ongoing health care services following rehabilitation. For providers of brain injury services, their referrals will depend on whether they are a member of an ISN. If not, they are at risk of being frozen out of the market since one purpose of the ISN is to keep patients within the network.

There are even larger forces at work here and some historical perspective can be useful in ascertaining their probable impact on people with brain injuries. Until recently, our health care system was a provider-driven system that competed not on price and quality as in other markets, but largely on prestige. Prestige competition meant that providers competed on the basis of their latest technology, their academic affiliations, the size of their research grants, the credentials and size of their medical staffs, their level of specialization, and the bed-size of their institutions. Prestige competition encouraged capacity building such as the development of brain injury rehabilitation services during the 1980s. Prestige competition helped to make American health care the most sophisticated and technologically advanced in the world, but it has also led to tremendous excess capacity that made American health care frightfully expensive. With the advent of managed care and capitation payment, our health care system has become a payer-driven system where price (i.e., costs) has replaced prestige as the defining element in the competition. People with brain injuries are disadvantaged in a system that competes mainly on price because people with brain injuries may require considerable services of indefinite duration.

In the shift from a provider- to a payer-driven health care system, one element has remained, namely, risk competition where health plans and risk-bearing entities seek to avert having to enroll or serve high-risk groups with potentially high health care costs such as those with brain injury. Unbridled risk-based competition means that certain groups will be underserved, excluded, or simply priced out of the market.

Although the incentives of a payer-driven system do not bode well for people with brain injury, I believe that we are on the verge of yet another major shift in American health care, namely the shift from the current payer-driven system that competes on price and risk to a consumer-driven system that competes on price and quality as in most other markets.

Effective quality competition as both the health-plan and health-provider levels requires a number of preconditions. Most important is the availability of quality-related information that consumers, employers, and governments can use to evaluate health-plan and provider performance in determining whether to contract with, or enroll in, a health plan and its corresponding provider network. By quality-related information, I mean data about outcomes, consumer satisfaction, and health-plan disenrollment rates, adjusted, of course, for the case mix or severity mix of the people participating in a particular health plan.

Quality competition is where I see the interests of both providers and consumers converge. In the absence of sound quality information, providers of brain injury services must compete mainly on price and will find themselves ratcheted down by payers over time. Quality competition, in addition to price competition, will help to create a more level playing field for providers. Moreover, quality information is sorely needed by consumers and their representatives who need to make informed choices about where best to obtain services. Effective quality competition is essential to the survival of the nation's brain injury rehabilitation capacity.

Q: *Since consumers and providers have a mutual interest, what can they do in the short term to foster effective quality competition?*

A: First, the rehabilitation industry has to organize itself to develop an agreed-upon set of quality indicators. Fortunately, the industry has already made some significant advances in outcome measurement and has the basic building blocks to develop industry-wide quality indicators that can be used to evaluate the performance of both providers and health plans. I would strongly recommend the involvement of the industry's consumer constituencies to obtain both their insight and their political support for implementation.

An important technical challenge, I believe, is to develop risk adjusters or severity adjusters by which quality indicators can be adjusted for the case mix of people served in various programs and health plans. Only then can we make effective comparisons across providers and health plans.

Second, consumers and providers need to pressure their respective state governments to make sure that, as their Medicaid programs convert to managed care, there be a choice of plans in each state and that there be quality indicators across a whole spectrum of health services, including brain injury services, by which consumers can make informed choices about health plans. Not every consumer needs to be a sophisticated shopper of health plans but a well-informed minority can alter a health plan's market share and can be the opinion leaders that cause others to follow suit.

Third, consumers and providers need to pressure the federal government to insist that there be comparable quality indicators in both the Medicare and Medicaid programs across state lines. Some degree of standardization will be needed in order to ease the burden on health plans and providers who operate across state lines. Standardization will also facilitate comparisons of comparable health plans and providers in different states.

Fourth, brain injury providers and consumers need to pressure quality standard-setting organizations such as NCQA [National Committee on Quality Assurance] which accredits managed-care plans on behalf of large-group purchasers in both the private and public sectors. National accrediting bodies such as NCQA need to include rehabilitation indicators in their standard repertoire of quality measures.

There is much more that can and should be done. The point is that the brain injury community, both consumers and providers, should insist on a level-playing field on which providers can compete and consumers can choose.

Q: *Even if we create a more level-playing field, will there not be serious discontinuities in health care coverage for people with newly-acquired brain injuries? In the past, many individuals has unlimited coverage under their automobile no-fault insurance; today fewer individuals have substantial auto no-fault coverage. There are individuals who come into the system with worker's compensation, but many cases come with only limited commercial health insurance. As they deplete their benefit, how can they access Medicaid or Medicare? Will managed care provide a vehicle by which there be greater continuity of coverage from one health plan to another?*

A: The majority of individuals will have some health care

coverage. Of those who have no coverage at the time of their injuries, many will eventually become Medicaid eligible because of low income or because they have exhausted their financial resources that would otherwise render them ineligible for Medicaid. Regardless, of the source or type of health care coverage, managed care will be the dominant arrangement.

Having a health plan is only half the battle. The other half is whether the health plan will pay for rehabilitation services. Many health plans nominally include rehabilitation benefits in one form or another. The problem in managed care arrangements is obtaining access to the benefit vis-a-vis a physician gatekeeper or case manager. Moreover, there is a real issue as to whether a person will be able to obtain services in a setting most appropriate to his or her needs. Here is where individual and family advocacy becomes so important. The issue then, is a three-fold: First, does the person have a health plan? Second, does the health plan really cover the range of rehabilitation services needed? And, third, will the case manager authorize the services? In other words, having health insurance means little unless the health plan is prepared to pay for the services needed.

I believe that significant discontinuities between private-sector and public-sector coverage will remain for the foreseeable future. This is especially the case now, as mentioned earlier, for individuals who become eligible for Medicaid following a means test that requires an individual to deplete their resources. In other words, they must first impoverish themselves. There is also a continuity problem for working-age people who apply for Medicare. Applicants face a 24-month waiting period after first becoming eligible for disability income benefits under the Social Security Disability Insurance program for which there is already a 5-month waiting period--29 months in all, not to mention the several months it initially takes to apply for DI benefits.

Within, the Medicaid program, however, there are many changes underway at the state level that will help diminish, but not necessarily eliminate, some of the current discontinuities. State Medicaid programs are becoming less categorically oriented. In the past, you had to be an AFDC [Aid to Families with Dependent Children] recipient or an SSI [Social Security Income] recipient, or be "categorically related" to such recipients except for income, in order to qualify for Medicaid benefits. Today, many states have applied for, and received, federal "waivers" that enable them to provide Medicaid coverage for a broader segment of the population. Some of the discontinuities or disruptions will not be as severe or as long lasting as they once were. During the health care reform debate in the 103rd Congress there was some discussion of making the Medicaid program also function as a "wrap-around" program for private sector health plans. The problem in implementing the concept was that it would encourage private plans to shift their costs to the public sector and such a plan would

require a policing or gate-keeping function between private and public health plans.

Managed care by itself will not solve the discontinuities from one health plan to another, from the private sector to the public sector. The health care reform debate and the managed care revolution has spurred us as a nation to think more creatively about how these discontinuities can be addressed. These changes have forced us to "think outside the box" and cast away self-limiting assumptions. To illustrate, the six New England states are now banding together to apply for a federal waiver that would enable each state to pool both Medicare and Medicaid funds and coordinate benefits, perhaps under a managed care umbrella, for those who receive both Medicare and Medicaid benefits by virtue of their dual eligibility for both DI and SSI benefits. Such an arrangement may help to dissolve some of the discontinuities between acute and long-term care.

Q: *In some of your writings you underscore another important discontinuity, namely, the discontinuity in meeting the ongoing health care needs of people with disabilities once the rehabilitation phase of their care is completed. Many people with disabilities in managed care plans believe that most primary care physician gatekeepers do not fully understand their constellation of ongoing health care needs and find that they are blocked from obtaining the services they need from specialists. What can providers and consumers do to alter this state of affairs? Should they demand that a specific kind of gatekeeper be used for people with significant impairments?*

A: Medical rehabilitation providers have been slow in addressing this important issue. Many rehabilitation providers thought it was enough simply to refer the patient back to his or her primary care provider if he or she had one. For years, people with disabilities have been telling the rehabilitation community that their needs were not being met by primary care providers who did not understand their needs were not being met by primary care providers who did not understand their needs and who often had offices and examine tables that were not fully accessible. In many instances, former rehabilitation consumers rely on their rehabilitation physician when they doubt the medical advice and care they receive from traditional primary care providers. This problem dates back before the days of managed care but the problem has come to a head in managed care because most managed care physician gatekeepers are primary care physicians who have little training or knowledge about the health care needs of people with significant disabilities.

I do not want to mislead you. Organized rehabilitation medicine has not been totally asleep on the issue of primary care. Several meetings and conferences have

addressed this issue. One noteworthy meeting was the April 1995 conference cosponsored by the Rehabilitation Institute of Michigan and the NRH Research Center on the role of organized rehabilitation medicine in primary care.

Quite candidly, most primary care physicians would prefer not having too many people with disabilities in their practice. We learned this several years ago, when we attempted to develop a network of primary care physicians as part of Robert Wood Johnson Foundation project on disability and managed care. People with catastrophic injuries are viewed as a losing financial proposition for most primary care providers. People with disabilities require much longer-than-average office visits and they consume more downstream health services which count against the primary care gatekeeper's utilization score card that is carefully monitored by the managed care plan.

Thus, in a capitated managed-care environment, payers have few incentives to attract, and providers such as primary care providers have few incentives to serve, people with disabilities. Once people with disabilities are in a health plan, it is to the advantage of the plan to more effectively manage their ongoing health care. This state of affairs provides an opening for rehabilitation providers to negotiate capitated carve-outs with managed care plans in keeping with the kinds of services people with disabilities need and actually want.

Rehabilitation providers often understand the ongoing health care needs of people they serve far better than most primary care providers. Rehabilitation providers need to think about how they can become an upstream primary care provider in a managed care environment for people with disabilities. Dr. Bruce Gans of the Rehabilitation Institute of Michigan framed it well he suggested that rehabilitation providers need to ask themselves the following question: "Are we in the business of rehabilitation or are we in the business of health care for people with disabilities?" The answer to the latter opens up many new possibilities.

The concept of carve-outs for selected groups of people with disabilities is not a new. Community Medical Associates (CMA) in Boston, for example, has a successful capitated health plan with Massachusetts Medicaid for a group of working-age people who require personal assistance services. This is akin to the "disease-management" programs that are emerging across the land. These are programs in which providers carve out populations within health plans in order to better meet the health care needs of the plan's subscribers and thus also avert the downstream expenditures that would otherwise compromise the bottom of line of managed-care organizations.

Q: *Capitation involves shared risks in which rehabilitation providers assume more risk.*

Providers will realize adequate profits if they assess accurately the resources that will be used over time to reach a specified outcome. Are you saying that if providers are willing to become risk-taking or risk-bearing entities that they will be prone to render more efficient care that will become the standard of future care?

A: The answer is yes--if certain conditions are met--but the reasons differ somewhat depending on the phase of care one is speaking about, whether it be the rehabilitation phase or the post-rehabilitation phase of care.

For a provider to be a risk-bearing entity **during the rehabilitation phase**, it must have reasonably accurate information about the probable costs associated in attaining a particular outcome for a patient with a particular clinical and psycho-social profile. This requires the provider to invest heavily in information systems that can provide the cost and outcome information needed to price its services with reasonable confidence. It also means that each provider has to accumulate enough experience over time to develop the confidence intervals needed to measure its risk exposure. As competition intensifies, each provider will have to determine how it can achieve the predetermined objectives in the most efficient manner. Over time and through experience, new standards of care will emerge as providers are incentivized to achieve quality outcomes at a price.

At the risk of some digression, I believe that efficient markets driven by price and quality concerns, also have significant implications for the role of research and the development of practice guidelines in establishing standards of care. In short, if markets work efficiently, what then should be the role of research and the development of practice guidelines? I believe their roles will change. Practice guidelines are anchored in "scientific evidence" and supplemented with consensus expert clinical opinion. The gold standard for scientific evidence is the randomized clinical trial (RCT). RCTs have a number of inherent limitations. RCTs usually investigate a limited number of interventions or combination of interventions. The ability to generalize study findings is sometimes severely limited by the criteria used to select the study sample. RCTs are an enormously expensive and inefficient way to arrive at a scientific basis for clinical practice.

I believe that, if markets are structured appropriately with the right incentives, providers are smart. Very smart. One only has to observe how providers are able to game any payment system to their advantage. Establish fair rules based on costs and outcomes, and providers will figure it out. In other words, an efficient market system based on sound rules and sound information, is tantamount to thousands of scientific experiments as each provider seeks to maximize outcomes and minimize costs. Yes, RCTs will still be needed to answer certain questions, but I believe that sound price-and-quality competition will bring

us more quickly to a better standard of rehabilitative care than will a thousand RCTs. RCTs and much of clinical research is needed because we do not have efficient markets to ferret out inefficient and nonbeneficial care. This is where health services research comes in. Health services research can help clarify whether markets are sufficiently efficient and can evaluate how provider and patient inputs relate to predetermined outcomes.

In the area of brain injury rehabilitation, Paradigm Health Corporation, though not a provider, is an example of an entity that uses clinical and outcome data to negotiate prices and to determine its risk exposure. Paradigm is an organization that serves as a broker between payers and rehabilitation providers. Because it has accumulated a substantial data base, it has the historical data with which to determine the probable costs and outcomes that should be expected in providing rehabilitation services to a patient with a particular clinical profile.

Another variant on the Paradigm model is a market concept developed by Robert Magnuson, MD who suggests that health plans purchase rehabilitation services through a bidding process that would work like this: when a subscriber incurs a major disabling impairment, the health plan would issue an RFP [request for proposal] by fax or e-mail to qualified rehabilitation providers. The RFP would describe the clinical and psycho-social profile of the patient and outline the desired therapeutic objectives and outcomes. Each eligible provider would be asked to fax back, within 24-48 hours a proposal and a fixed price. The rehabilitation provider may also want to send a nurse or, in the case of brain injury, a neuropsychologist to examine the patient and medical record more closely before sending in its bid. To make informed bids, the rehabilitation provider would have to draw heavily on previous outcome and cost data. This approach would be particularly attractive in health markets where integrated service systems do not include rehabilitation providers and where payers, such as auto insurers and workers' compensation do not have corresponding service networks in the area in which the patient lives.

For a provider to be a risk-bearing entity for ongoing health care services **during the post-rehabilitation phase**, it also must have information about the probable costs associated in providing health services during a given enrollment period. If the enrollee's health plan is incentivized to retain subscribers from one enrollment period to another--by grading health plan quality in part on disenrollment rates, then the health plan and health provider will also be incentivized to avert longer-term downstream costs by providing the necessary up-front preventive services. The Community Medical Alliance of Boston, I mentioned earlier, determined that clinical depression and pressure sores were two sentinel conditions, that if managed proactively, would save them considerable costs both in the short-term (current enrollment period) and in the long-term (beyond the current enrollment period). These

kinds of experiences will eventually help to establish new standards of care for ongoing health care needs of people with disabilities during the post-rehabilitation phase of care.

In establishing capitation rates, providers can examine the claims history files of their target population. Some of these data are proprietary but there are a number of public-use files, stripped of personal identifiers, at the federal and state levels for Medicare and Medicaid respectively. Providers willing to go at risk can use these data as benchmarks by which to capitate their services and offer payers a price that beat these benchmarks.

Q: *Let's go back to the rehabilitation phase of care. You have spoken about the need for a system that competes on price and quality where quality is defined in large part by health and functional outcomes. What is the role of outcome studies today and what do you see as the role of outcome studies in the future?*

A: Good question. The best way to answer this question is to go back to my thesis that the American health care system of the past was a provider-driven one that competed on prestige and risk; that the system of the present is a payer-driven one that competes on price and risk; and that the system of the future will be a consumer-driven one that will compete on price and quality. The role of outcome studies is different in each of these three systems.

In the provider-driven system of the past that competed on prestige, the role of outcomes research was to help establish the academic and scientific legitimacy of a field, a specialty, a profession, or a particular intervention. The ultimate and intended audiences were not payers or consumers but mainly one's professional peers, particularly those in related disciplines. Outcomes research was, and to some extent, remains, an important weapon in prestige competition. Medical rehabilitation's desire to obtain a foothold in the National Institutes of Health is one example of how a profession or discipline has sought legitimacy among its professional peers. I do not mean to be cynical at all but simply wish to illustrate how prestige competition was fundamental to the business of research.

In the payer-driven system of the present that competes on price, the role of outcomes research is cost minimization, i.e., to help establish the minimum that payers should be required to pay or cover in their benefit packages. In other words, health plans seek to cover and pay only those services for which there is a proven benefit or outcome. Payers are confronted with many claims about efficacy but are seeking more explicit evidence for these claims.

Outcome research in a payer-driven system is also promoted by providers who see outcome studies as a

defense against the unrelenting drive to cost minimization.

In the consumer-driven system of the future

will compete on quality as well as price, the role of outcomes research is to help consumers and large-group purchasers to make informed choices about health plans and health providers based on risk-adjusted comparisons of outcomes and other quality indicators. In the consumer-driven system of the future, outcomes research will become much more institutionalized; it will become part of the infrastructure of our entire health care system. It will become an integral part of how we do business. We will still be doing ad-hoc studies in response to specific information needs, but outcomes research will become much more ubiquitous. Because health-plan and provider outcomes will be so important competitively, there will also be powerful incentives to game the outcomes research process. I envision an auditing subindustry to emerge that will audit the integrity of outcomes research data analogous to the way in which public accounting firms audit financial statements.

Q: You mention that, in today's payer-driven system, health plans want to cover and pay only those services for which there is adequate evidence of benefit or outcome. Could you explain or illustrate what you mean by this?

A: Health plans are constantly bombarded with coverage and payment demands for services that sometimes appear to be of marginal benefit. In a payer-driven system where cost-minimization or price is central to the competitive process, health plans do not know how to triage many of the demands for coverage or claims for payments.

To illustrate, the NRH Research Center faced this issue recently when it completed a year-long study on the effectiveness of medical rehabilitation services for CHAMPUS [Civilian Health and Medical Program of the Uniform Services]. One purpose of the review was to determine which medical rehabilitation services might be added or deleted from the CHAMPUS benefit package. CHAMPUS requested that the NRH Research Center, under a subcontract to another firm, review the medical rehabilitation literature for each of 13 major impairment groups represented in medical rehabilitation including traumatic brain injury. To facilitate this process we commissioned a panel of rehabilitation physicians, each of whom prepared a paper that reviewed the best available literature in their respective impairment area of expertise. Project methodologists rated the scientific rigor of this literature and an allied health panel evaluated whether each paper was sufficiently responsive to allied health issues.

We learned that there was more literature than we had anticipated but very little of this literature attained the level of scientific rigor eventually sought by CHAMPUS. Nathan Cope, MD prepared an outstanding review of the

brain injury literature and your readers will want to know that this literature is among the stronger literatures in medical rehabilitation.

We also learned that the literature is not organized to answer the questions that CHAMPUS, and other payers ask on a daily basis. CHAMPUS, it turned out, wanted to know how each individual rehabilitation service contributed to outcomes. For example, CHAMPUS wanted to know how many hours or visits of PT or OT should be covered and what would be an appropriate length of stay in a rehabilitation center for a person with a particular impairment. The medical rehabilitation literature is not organized at the therapy level and the allied health literature is quite weak. Moreover, in daily practice, the configuration of individual therapies are customized to the needs of each individual patient in keeping with the nature of the impairment, medical history, functional status, psychosocial profile, lifestyle needs, and other individual and family circumstances. Such individualization makes generalization about units of therapy very difficult.

A significant portion of the medical rehabilitation outcomes literature is organized around systems of care as exemplified by the model systems such as the brain injury model systems program. Dr. Cope said it best when he, in his paper, argued that TBI rehabilitation cannot always be reduced to a single 'silver bullet' and that TBI rehabilitation is "multifactorial with many poorly defined elements delivered with variable intensity and expertise over differing time spans." He argued that in addressing questions about the overall efficacy of TBI rehabilitation, it often become necessary "to consider the TBI rehabilitation process to essentially comprise a 'black box' consisting of various permutations of all these treatments." Health plans such as CHAMPUS want to know what is in the black box and how much of the black box they should pay for.

Q: Are payers asking the wrong question?

A: In some ways they are. Payers are mainly concerned about outcomes in helping them determine whether a service should be included in their benefit package. In everyday practice, however, their quest for cost minimization causes payers to focus mainly on inputs and the cost of those inputs. They are input, not outcome conscious. They are looking at the wrong side of the input/output equation. I believe that too many health plans are still encumbered by the baggage of the fee-for-service, provider-driven system that focuses on a separate payment for each input. In today's managed-care, payer-driven system, this focus has led to tremendous micromanagement by health plans of health care providers including rehabilitation providers.

I believe we should let providers worry about inputs and let payers worry about outcomes. I believe that in the consumer-driven system of the future, when there is

effective quality competition, payers will pay for outcomes and will let providers worry how to configure the Dr. Cope's black box to maximize outcomes. This gets back to my earlier comment that, if markets are structured appropriately with the right incentives, providers will figure out how best to provide their services both effectively and efficiently.

Q: *The team concept has been important in both brain injury rehabilitation and medical rehabilitation generally. How has managed care affected the team concept and what do you see as the future for the rehabilitation team?*

A: The concept of the rehabilitation team has been sacrosanct in medical rehabilitation. It embodies several important patient-care and professional values and gives expression to the notion of "interdisciplinary rehabilitation." Theoretically, it is the team's task to define the contents of Dr. Cope's black box.

With managed care, the team concept has been under attack because it is seen as a very expensive way to organize services in the face of declining reimbursement in a managed care environment. Moreover, managed care's review of each therapy or service to be rendered, has sometimes induced competition within teams as to whose skills are most needed and which personnel will be given the dollars to provide services. In short, the very collaborative nature of the team is in many ways threatened. Many providers have significantly altered their approach to teams or have abandoned the team concept altogether.

I believe that predictions about the team's demise is premature. In the current payer-driven, managed-care environment, it may be disappearing but I believe it will make a comeback, albeit not necessarily in its previous form. In a more consumer-driven system where price and quality are paramount, I believe that providers will need to assemble teams to help determine the best configuration of services the individual patient may need in order to attain a predetermined set of outcomes. Each patient, not each professional service area, will be a cost center and it will be up to the team to figure out how to maximize the outcomes in keeping with the funds available. In the future, teams may even be incentivized accordingly. If they are, you will also see some blurring of the boundaries between professional disciplines in medical rehabilitation as team members put aside professional prerogatives in pursuit of patient goals.

Q: *You have indicated that we are moving toward a more consumer-driven health care system that will compete on price and quality including health and functional outcomes. What evidence do we have currently that would*

suggest that such a system will emerge?

A: The linchpin of a well-functioning market is a consumer who can make **informed** choices about price and quality. Up until recently, consumers had little information upon which to make informed choices about health plans (presuming they has a choice) or health providers. Basic data about the performance of health plans and providers have generally not been available to the public. By contrast, anyone contemplating the purchase of an automobile, for example, can always turn to *Consumer Reports* to obtain data about a model's past performance. I realize that some people do not like to see health care reduced to a commodity but, if we want a market-based health care system, then we do need to think about health care as a commodity--as well as any other attribute we may want to give it.

Many of us have seen consumer satisfaction surveys of health plans but they really do not tell us much. Many of these surveys are self-anointed seals of approval. The differences between health plans are marginal and most satisfaction surveys typically do not report the experiences of those who had significant health care needs and significant encounters with the health care system during the previous year.

More encouraging, I believe is the health care report card movement that is gaining momentum across the country. Health care report cards rate health plans and health providers based on health outcomes as well as consumer satisfaction surveys.

At the forefront of the health care report card movement has been the fast-growing National Committee on Quality Assurance (NCQA) in Washington, DC and more recently, the Foundation for Accountability in Portland, Oregon. NCQA is the accrediting body for managed care plans much the same way that JCAHO is the accrediting body for health providers such as hospitals. In early 1997, NCQA will be releasing its third version of HEDIS (Health Plan Employer Data and Information Set) which provides for a standard set of quality indicators for health plans. If you want to find information on any of the 200 health plans that NCQA has rated, you can locate it on the Internet at <http://www.ncqa.org>. Many large employers demand that health plans be accredited by NCQA before they make the health plan available to its employees.

Another important development is the publication of *Health Pages*, a consumer health magazine similar to *Consumer Reports*, which rates health plans and health providers in several large markets around the nation--Atlanta, Boston, Columbus-Cincinnati, Pittsburgh, St. Louis, Phoenix, Denver, South Florida, Los Angeles, and more to come.

One can identify many other examples of a stronger consumer-based, outcomes-oriented focus in health care:

Consider the Cleveland Health Quality Choice Program which provides severity-adjusted outcomes and patient satisfaction data for 29 Cleveland-area hospitals. Consider the North Central Texas HEDIS Coalition which has developed a report card on seven HMOs on HEDIS performance measures and member satisfaction data from independent surveys. Consider how NCQA and *Health Pages* have combined forces in Denver to develop an HMO report card that compares the HEDIS performance results of several Denver-area health plans such as Cigna, FHP International, Kaiser, MetraHealth, Pru and Sloan Lake. Consider the Pittsburgh Business Group on Health which has spearheaded a similar cross-HMO comparison involving HealthAmerica HMO, Keystone Health Plan West, and US Healthcare.

This is only a sampling. The leading edge in the development of a more consumer-driven health care system is the large employer who is demanding that health plans, particularly managed care plans, provide standardized outcome and consumer satisfaction data. Large employers believe that they have the health care cost spiral under some degree of control and are now turning their attention to quality issues and want to know what value they are getting for their money. Small employers are still concerned mainly about price. Large employers have clout with managed care companies and have market power akin to a purchasing cooperative or a health alliance. Consider for example, the National HMO Purchasing Coalition which includes 10 employers such as Sears. All HMOs must meet the Coalition's quality specifications if the plan is to be offered to Sears' employees.

In many ways the information needs of large purchasers are similar to those of individual consumers and the information being sought by large employers are being made digestible to ordinary consumers as in the Denver market where NCQA, by working with *Health Pages*, is making its findings available to the average consumer.

I believe that we are entering a new era of health care accountability and that rehabilitation providers better figure out quickly how their performance data can be made digestible to the consuming public as well as to their traditional referral sources. I have many thoughts on this and only wish that we had more time to explore what should be the industry's response to this growing movement.

Q: *You seem quite convinced that will eventually evolve into a more consumer-driven system. What do you see as the main threat to the emergence of such as system?*

A: If there is a threat, I believe it may come from potentially excessive consolidation in many health care

markets. A consumer-driven system presumes that there will be a choice of health plans and provider networks. I do not want to dwell on this but a day does not go by when one does not hear of another merger or acquisition in health care. The urge to merge is also very great in rehabilitation. Some degree of consolidation is both necessary and inevitable as excess capacity is wrung out of the system. Earlier in this interview, I indicated that an advanced managed-care market like Minneapolis-St. Paul has already consolidated into three main provider networks and some observers are now asking whether consolidation in the Twin Cities has gone too far. Excessive consolidation is a potential threat to both competition and choice.

Q: *What is the role of government in developing a more consumer-driven system? Will markets self-correct?*

A: The consumer-driven system of the future will not get there by itself but I do believe that there is sufficient momentum in the system to get us there.

Government has a very vital role. Government, particularly at the federal and state levels, has an important role in making sure that the conditions for a sustainable consumer-driven, risk-neutral, market-based health-care system are in place. There is no such thing as a free lunch and there is no such thing as a free market. Markets are like sports. There have to be rules, boundary lines, referees, and the power to sanction those who violate the rules in order assure fair play and a level-playing field. The problem with health care, compared to most other kinds of market, is that it more susceptible to manipulation because players will try to win by competing on risk rather than price and quality.

One important role of government is to reduce risk competition and to promote price-and-quality competition. This means that government may have to sponsor research in developing risk adjusters that can adjust prices and outcomes on the basis of case-mix; sponsor carve-outs for certain "high-risk" populations; and establish guidelines as to how health plans market their services in order to minimize risk selection. One of the most important steps for government, in the short run, is to make sure that Medicare and Medicaid, as they convert to managed care, take on the characteristics of a more consumer-driven, risk-neutral system and that they do not fall prey to the risk competition that has plagued American health care.

Finally, government also has an important role in monitoring consolidation in the health care system and to prevent excessive consolidation that undermines effective consumer-based competition. At present, I very much doubt that government has adequate resources in the Department of Justice's Anti-trust Division or in the Federal Trade Commission to monitor the current flurry of mergers

and acquisitions, not only in health care, but also in other industries such as the telecommunications and the banking and financial services industries.

Q: *Let's shift the discussion around another issue important to people with brain injuries. What about long-term supports for people with brain injury? It seems that we still a long way from having a continuum of services available to an individual with a brain injury over many year's of individual's remaining life?*

A: This is a frustrating question especially for observers such as myself who believe that there has to be a good answer lurking somewhere. The integration of acute and long-term services has probably been the most vexing issue in American health and social policy. There have been many interesting proposals, demonstration projects, and population-specific programs. The list is long. None, however, seem to form the basis for a more unified social policy response that can take into account the diversity of individual needs and financial circumstances and can create the societal consensus that will sustain such a social policy politically. Our society's willingness to develop a sound long-term services policy is limited by the perception of many people that their individual or family risk for needing long-term services, apart from nursing home care in old age, is fairly minimal and distant. Most people, especially younger people, see such needs as remote and prefer not having to deal with it. As a result they do not plan for it privately nor do they support it politically.

My first inclination is to think about how sound market-based solutions can be forged but I frequently run into one or more limitations that undermine market solutions. I believe that we can bring more market-based solutions to some government-sponsored programs that will serve the interests of both consumers and public accountability. As many of your readers know, I have been a proponent of

publicly consumer-directed long-term services but I believe that current approaches have not dealt adequately with limitations on both the demand and supply sides of the market that require some level of government sponsorship to rectify. I believe that long-term services will always require some combination of public and private sponsorship in order to create effective markets and to make the costs palatable to the general public and affordable to the individual or family.

Q: *Overall though, you paint a fairly bright view for the future, do you not?*

A: I am optimist. There is much doom and gloom among both consumers and providers about managed care. Much of it is understandable but we do need to look to the future. While we are mired in the travails of the current system, I see a new system emerging one that will be in the interests of both consumers and providers. But, as I said before, the new system, while inevitable, will not come by itself. If the new system is to be responsive to the needs of TBI consumers and providers, the TBI community needs to organize itself and become a player in the emerging consumer-driven health care system of the future. The TBI community needs to make sure that the quality indicators that drive the new system address those issues that speak to the needs of TBI consumers. It will take the goodwill of many people and will require the participation of government to help create the level-playing field about which I spoke.

The shift from a payer-driven system that competes on a price and risk to the consumer-driven one that competes on price and quality is an exciting one. Quality competition is where the interests of both consumers and providers converge.

PERSPECTIVE AND ANALYSIS--MARKET FORCES: MEDICAL REHABILITATION UNDERGOING MAJOR SHAKEUP IN ADVANCED MANAGED CARE MARKETS

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The fast-growing \$27 billion medical rehabilitation industry is undergoing its greatest transformation since the traditional inpatient model of medical rehabilitation came of age in the 1980s. Nowhere is this transformation more evident than in the most advanced managed care markets such as San Diego, Minneapolis-St. Paul, and Worcester, Mass. These markets presage the changes that are beginning to hit medical rehabilitation in other markets as managed care makes its march through the American health care economy.

For many years, medical rehabilitation occupied a largely unnoticed niche in American health care, providing restorative services to people who acquire a disabling impairment because of a congenital condition, a traumatic injury, an acute illness, or a chronic health condition that limited their ability to function independently. Through an array of therapeutic services, such as physical, occupational, and speech therapies, and through the use of prosthetics, orthotics, and other assistive technologies, medical rehabilitation services enabled people with impairments to manage their own daily needs and, whenever possible, return to an active and productive lifestyle.

Since the mid-1980s, organized medical rehabilitation has become a major player in the post-acute continuum of health care services. The number of inpatient programs more than doubled in the ten-year period since then. From 1985 to 1994, the number of free-standing rehabilitation hospitals increased 175 percent from 68 to 187 hospitals, and the number of rehabilitation units based in acute-care hospitals increased by 118 percent from 386 units to 804 units. With this growth, medical rehabilitation physicians, known as physiatrists, enjoyed increasing compensation and new-found recognition among their physician peers.

With the dramatic growth of managed care, however, the Golden Age of hospital-based medical rehabilitation has come to an abrupt end. This change of fortune is particularly evident in the more advanced managed care markets often considered harbingers of things to come. To find out what has been happening to medical rehabilitation providers in these markets, the National Rehabilitation Hospital (NRH) Research Center, as part of a grant from the National Institute on Disability and Rehabilitation Research, conducted dozens of interviews with leading payers, providers, and health care experts in the San Diego, Minneapolis-St. Paul, and Worcester areas.

Researchers supplemented these interviews with data from local newspapers, the trade literature, published market data, and other third-party information sources.

MARKETS CONSOLIDATE, PROVIDERS SCRAMBLE

In all three markets, according to the Group Health Association of America, well over 50 percent of the total population is now enrolled in health maintenance organizations (see table). Managed care has also penetrated the senior population through the use of at-risk Medicare contracts. Seniors are an important market segment for inpatient rehabilitation providers. Nationally, these providers depend on Medicare for 70 percent of their revenues.

In two of the markets, San Diego and Minneapolis-St. Paul, high levels of managed care penetration have precipitated the consolidation of health care providers into three or four competing integrated provider networks and have forced rehabilitation providers to realign themselves accordingly.

In the San Diego market, the dominant provider networks now include **Sharp Health Care, Scripps Health**, and the University of California San Diego or **UCSD Healthcare Network**. Both Sharp and Scripps include medical rehabilitation providers who, as network members, are in a strong position to capture medical rehabilitation patients.

Large unaffiliated for-profit rehabilitation providers such as the San Diego Rehabilitation Institute (SDRI) and Continental Hospital, part of the national Continental Medical Systems chain, are scrambling to retain market share by diversifying their rehabilitation capacity to include lower-cost settings, such as subacute beds and outpatient care, to make themselves price competitive with the major networks. Both SDRI and Continental are for-profit providers that entered the San Diego market in the late 1980s and early 1990s mainly as inpatient rehabilitation providers.

In Minnesota--dubbed the land of 10,000 mergers--the consolidation movement includes mergers between provider networks and health plans, effectively blurring the line between providers and payers. The Minneapolis-St. Paul market has consolidated into three payer-provider

networks: **Blue Cross and Blue Shield of Minneapolis, Allina Health System Inc., and HealthPartners** which, combined, control 78 percent of the market.

The Allina system includes Sister Kenny Institute, a long-standing and well-recognized name in the nation's rehabilitation industry. Sister Kenny appears well positioned mainly on the strength of Allina's market position. By contrast, North Memorial Hospital has sought to maintain its independence but finds itself effectively frozen out of many rehabilitation admissions. Once patients participate in one of the larger systems, they usually stay in those systems.

In a much smaller market, Worcester's leading health plan has been the **Fallon Community Health Plan**, a group-model HMO that has also been caring for Medicare beneficiaries since 1980. Although able to contain costs, Fallon experienced very little price competition until Boston area-based Pilgrim Health Plan (now, **Harvard Pilgrim Health Care**) entered the central Massachusetts market in 1994 and New Hampshire-based **Healthsource Inc.** entered in 1995 by acquiring **Central Massachusetts Health Care** of Worcester.

Fairlawn Hospital remains Worcester's only major inpatient rehabilitation provider, but it has seen a decline in census as HMOs have looked to subacute rehabilitation providers. Fairlawn has responded by making strategic alliances through shared ownership. Fairlawn is now one-third owned by Fallon and one-third owned by **Advantage Health**, a large publicly traded rehabilitation chain.

PROVIDERS INTEGRATE VERTICALLY

Thus, one common denominator across the three markets has been the desire of rehabilitation providers to integrate vertically with larger health systems for fear of losing patient referrals from acute-care hospitals if they remain outside large systems. Several rehabilitation providers have remained independent either from conscious choice or from lack of foresight. One informant in the later category said: "We thought we were God's gift because we were the premier hospital for many diagnoses." Most providers have come to realize that fierce independence often comes at a price--survival.

Vertical integration is also occurring *within* rehabilitation as providers assemble a broader array of rehabilitation settings that will enable them to move patients more quickly to lower-cost settings at the earliest possible moment. In addition to the traditional inpatient program, the "rehabilitation continuum of care" increasingly includes a subacute program, an outpatient program, and a home-based rehabilitation program. Informants often spoke about a "seamless" continuum of care in which physicians and therapists follow the patient as he or she moves into less-

structured settings.

HOSPITAL-BASED REHABILITATION DECLINES

The economic driver in establishing a wider array of rehabilitation settings is simply costs, particularly the cost of traditional inpatient rehabilitation, which can quickly reach \$1,000 per day and more. In many instances, managed care payers bypass inpatient rehabilitation altogether and insist that patients traditionally seen in inpatient programs obtain their rehabilitation in subacute units instead. Inpatient rehabilitation's "bread-and-butter" patients, such as older patients with a stroke or hip fracture--which previously made up more than 50 percent of traditional inpatient programs--are now going to subacute settings instead. In the three highly managed care markets, inpatient programs are being reserved for a handful of impairment groups such as persons with severe traumatic brain injury, spinal cord injury, and younger persons with stroke.

Inpatient utilization has declined dramatically in the three advanced managed care markets. Occupancy rates are off by 40 percent or more in some facilities. An average length of stay of 30 days or 35 days only five years ago is now down to 19 day or 20 days, but appears to be leveling off because, as one respondent indicates, "results were falling off as well." In the face of declining lengths of stay, some observers have begun to question whether inpatient rehabilitation, as traditionally organized and practiced, may be a vanishing breed.

SUBACUTE REHABILITATION BOOMING

As the utilization of inpatient rehabilitation has declined, subacute rehabilitation has become the new growth industry in highly managed care markets. Respondents in the three markets report that "there is a huge, huge explosion of subacute providers." "Subacute is booming everywhere." One informant in the Worcester area reports that "there are five brand-new subacute facilities within a 15-minute drive."

The growth of subacute rehabilitation appears to spring from three sources of sponsorship. First are the traditional inpatient providers who have diversified by offering a subacute alternative. Second are existing skilled nursing facilities (SNFs) that have added a rehabilitation component in response to what is seen as a new market opportunity. And third are the fast-growing national for-profit chains, such as Manor Care, NovaCare, and TheraTx, that have anticipated the demand for subacute rehabilitation in more highly managed care markets.

Subacute providers typically price their services at about \$300 to \$500 per day, half the inpatient rate. People usually remain in subacute care longer than they do in

traditional inpatient rehabilitation, however.

INPATIENT PROVIDERS RESPOND BY SLASHING COSTS

Traditional inpatient providers insist that predictions of their demise are premature and have responded by slashing their costs in order to become more price competitive. The Sharp system in San Diego, for example, reduced its administrative overhead by eliminating 100 positions through layoffs and attrition and by removing entire levels of management. "On a system basis," said one respondent, "there's been a radical reorganization, and we are doing everything we can to reduce our costs...It's moving very, very quickly."

At Sharp, managers are now responsible for multiple entities throughout the system. There is no longer a therapy director at every site within the system, but one director for the entire system. One respondent characterized the approach as being "system-oriented rather than entity-based." At Fairlawn Hospital in Worcester, the staffing mix has changed. Fairlawn has eliminated LPNs entirely from its mix of RNs, LPNs, and nurse aides. Many providers have resorted to using more therapy extenders and fewer higher-salaried professional therapists.

THERAPY TEAMS REORGANIZED

The need to slash costs has prompted inpatient providers to reevaluate one of rehabilitation's most cherished institutions, the "interdisciplinary team approach" to rehabilitation in which each discipline or department develops a treatment plan that is reevaluated and renegotiated in weekly team meetings. One facility in the Minneapolis-St. Paul market has adopted what it calls a "transdisciplinary team approach," in which the team comes together initially to identify "the barriers to discharge" and to designate the steps that each therapy will take to remove the barriers identified.

Other providers have turned to one of health care's latest rages, critical pathways, as a way of making treatment plans more predictable and as a way of representing the expectations for each patient to managed care payers. Providers are attempting to break down the boundaries and turf issues between the professional therapies that often add to the cost of doing business.

NICHE MARKETING

Rehabilitation providers have learned that reengineering, cost-cutting, and downsizing are not enough. These internal adjustments cannot substitute for the market savvy that is needed in a rapidly changing market. As managed care markets mature and become

crowded with new entrants, rehabilitation providers are learning to create niches and to emphasize their uniqueness in contract negotiations.

According to one marketing director, rehabilitation providers will, in the future, offer a menu of niche services. "They have a short window of opportunity to become specialists in wound care, HIV, etc. If they can franchise it, they can ride that market segment for a while. They have to make themselves have value." "They need to stop thinking of the rehabilitation hospital as the \$35 million centerpiece of their business."

Another rehabilitation market strategy has been to form alliances and joint ventures with somewhat similar competitors in order to shore up market share and to develop a unique continuum of services that will be attractive to payers. Such market strategies also allow competitors to eliminate duplication and achieve economies of scale. As one respondent indicated: "Why do you have to have cardiac rehabilitation services at four or five locations in the community when you could funnel all of that into one and be more efficient and have better outcomes too?" The respondent did not address the potential restraint-of-trade and anti-trust issues implicit in horizontal integration strategies.

FULL CAPITATION YET TO COME TO REHABILITATION

With managed care, the fee-for-service and cost-based methods of rehabilitation payment are vanishing rapidly, but full case-rate capitation has yet to come to rehabilitation in any significant way. Most acute and subacute rehabilitation providers in the three markets studied are being paid on a fixed per-diem basis, where length of stay is negotiated depending on patient status and progress.

One rehabilitation hospital reports being paid a declining per-diem amount the longer the patient remains in the hospital. For a given type of patient, for example, the hospital receives twice as much payment for Days 1 through 7 than for Days 31 through 35. "In effect," said one respondent, "it's risk sharing because once you go beyond the 21st day, you're getting a reimbursement rate that's well below your cost. It's not a DRG, but it's certainly a front-loaded system to get your patients out quickly..."

Capitation arrangements, where they do exist, typically do not extend yet to the individual rehabilitation facility. An entire provider network may be capitated for a health plan member's hospitalization, but that hospitalization may include all types of inpatient care--acute care, rehabilitation care, psychiatric care. Interest in full case-rate capitation for rehabilitation specifically remains limited to niche programs with considerable experience serving well-defined populations; for instance, people with spinal cord injury.

PAYERS LACK SOPHISTICATION ABOUT OUTCOMES

Informants in the three markets report that functional outcomes are not, for the most part, being considered by payers. Quality is more or less assumed. In contract negotiations, informants say, managed care payers give price much greater consideration. One informant said, "Frankly, in this market place, nobody asks, nobody cares [about outcomes]. While this is a huge market in terms of HMO penetration, the level of sophistication still is not where it should be."

Informants complain that payers are only looking at price; they do not consider functional outcomes gained per dollar. Hospital-based providers in particular would like to see payers give more consideration to outcomes and functional gains per dollar spent in order to create a more level playing field between them and their subacute competitors.

Some providers report that payers are beginning to ask the right questions, especially for people with catastrophic injuries. They are asking, "Do you have outcomes for your brain-injured patients? Do you have critical pathways for your brain- and spinal-injured patients?"

IMPLICATIONS FOR PROVIDERS IN OTHER MARKETS

Most rehabilitation providers are already experiencing, to some degree, many of the trends in leading managed care markets. Providers in other markets would do well to consider the experiences of their counterparts represented in the three-market study.

A central finding is that traditional hospital-based rehabilitation should no longer be considered the focal point of a rehabilitation service delivery system. Diversification attempts that merely remake the rehabilitation hospital as the hub of a larger multifacility program will fall short of the changes required by the new marketplace. The need for rehabilitation hospitals will continue, but is therapeutic mission will be more focused and targeted.

Traditional rehabilitation providers will thrive to the extent to which they form strategic alliances that will guarantee them a supply of patients. To be nonaligned, a rehabilitation hospital will have to be a fairly specialized center of excellence with a national or broad regional market base. Very few rehabilitation programs qualify. Whether national or local in focus, rehabilitation programs of all kinds require a therapeutic focus or identity that separates them from their competitors.

Despite the doom and gloom that grips parts of the rehabilitation hospital industry, demographic demands will require that health systems include a substantial

rehabilitation component in order to accommodate a rapidly growing disabled population, especially in the older age groups. Rehabilitation will remain a growth industry. The point of market saturation has yet to be determined.

The greatest change demanded by the managed care revolution is the change in mind set. In the former fee-for-service, cost-based reimbursement systems, more was better: the more service rendered, the more revenue produced. In the emerging fixed-fee or fixed-cost environment, less is better: the less service provided, the more net income produced. Managed care has reversed the financial incentives governing provider behavior in the past.

IMPLICATIONS FOR MANAGED CARE PAYERS

The question remains whether quality and outcomes are being sacrificed when financial incentives are reversed. In the drive for lower costs and prices, purchasers may be overlooking the product they are purchasing. Managed care payers would do well to demand quality and outcome data upon which they can make comparisons across provider networks. Rehabilitation providers are far more sophisticated in outcome measurement than purchasers assume. Standardized and reliable, cross-provider, functional outcome data are already available, and managed care payers would do well in making these data one of the bases upon which they make their purchase and payment decisions.

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TABLE 1. HMO PENETRATION			
Market	1991	1994	Increase
San Diego	36.0%	53.8%	+49.4%
Minneapolis/St. Paul	46.0%	55.1%	+19.8%
Worcester	51.0%	58.8%	+15.3%

SURVIVING MANAGED CARE AND PREPARING FOR THE NEXT REVOLUTION IN AMERICAN HEALTH CARE

Gerben DeJong, Ph.D.

February 24, 1996

INTRODUCTION (Rehab 2000=heads up)

A. Purpose of presentation

1. Outline what is happening in the larger health care system;
2. Tease out some of the implications for people with disabilities, the allied health professions, and the medical rehabilitation industry; and
3. Identify some of the steps that both consumers and providers can/must take to reposition themselves in a manner that will
 - a. Make health care and rehabilitation more responsive to the consumer,
 - b. Address the economic concerns of providers, and
 - c. Respond to the financial constraints of the payer community and the public at large..

B. Thesis

- # As we move toward managed health care, there is much doom and gloom, but there are also enormous opportunities for both the consumer and the provider alike.
- # As we move toward managed care, health care providers across the board are scrambling to reposition themselves in a drastically altered marketplace. **In the short term**, providers need to do what they have to do to survive.
- # **In the long-run**, provider interests are best served by working with the consumer community. In a health care system that, historically, has been provider-driven, providers have not looked to the consumer as vital to their economic interests.
- # Moreover, consumers, especially those with disabilities and chronic health conditions, have interests that are not particularly well-served by the financial incentives inherent in managed care.
- # I believe we are entering a special period in which the interests of consumers and the interests of providers are beginning to converge on several key points. If we fail to seize this moment, I believe we will lose an historic opportunity to unlock the promises of a truly market-based health care economy.

C. Note:

- # Where I am coming from. Originally trained as an economist. A strong believer in a market-based health care system. Also believe that managed care is a necessary corrective to the excesses of the past. The problem with managed care today is that it is being hoisted on a health care system that violates all the precepts of a competitive market system. As such, managed care is likely to intensify the risk-based competition that is so detrimental to the well-being of people with disabilities and chronic health conditions.

D. Objectives

1. Outline the extent to which managed care is rapidly becoming the dominant method of health care financing
 - a. Geographically
 - b. By payer
 - (1) Private sector
 - (2) Public sector
 - (a) Medicare
 - (b) Medicaid
2. Outline how managed care is reshaping health care system and the rehabilitation industry
 - a. Health care in general
 - b. Medical rehabilitation
 - c. The buzz words of the 1990s
 - d. Mergers, acquisitions, alliances
3. Discuss the emergence of the consumer/ demand side of the market and identify some of the steps needed to strengthen it
4. Identify some additional steps that need to be taken in order to secure a consumer-driven, risk-neutral, market-based system
5. Provide a brief summary of action steps
6. Close by noting how collaboration between consumers and providers is essential to achieving a health care system that we can live with

I. THE GROWTH OF MANAGED CARE

- A. Geographically
1. Highest penetration in West and Northern states (Minnesota and eastward); penetration varies greatly within states. See outdated map in Appendix.
- B. By payer
1. Private sector (**Slide 5**)
 - a. 1993--26% of private health insurance market=managed care
 - b. 1994--38%
 - c. 1995--50%?
 - 65% of employees in mid to large firms were enrolled in managed care in 1995 up from 29% in 1988.
 - d. 2000--85-95%
 2. Public sector (Medicare and Medicaid)
 - a. Growth in Medicare and Medicaid programs
 - Medicare
 - Medicaid
 - b. Threat to federal and state budgets
 - (1) Federal budget (see pie chart in Appendix)
 - (a) Medicare, Medicaid, and interest on the federal debt are the 3 big drivers of the current deficit
 - (b) This is why the Clinton Administration made health care reform its #1 priority

Without bringing health care under control, one cannot bring the federal budget and deficit under control—unless one is willing to make deep/ painful cuts in other parts of the budget. That is what is happening now.
 - (c) The arithmetic of the federal budget and the growth of the Medicare and Medicaid programs make these programs an obvious and inevitable target.
 - c. Managed care provides politicians a great deal of political cover.
 - (1) By cutting costs and services through managed care, politicians can let “market forces” make the hard decisions for them.
 - (2) No politician is willing to go out front to propose specific program cuts in health care for fearing of stirring up one constituency or another.
 - (3) Clinton’s health care reform program looked to managed care to make some of the hard decisions.
 - (4) The Republicans are doing the same. Not willing to face the wrath of the voters, particularly older voters, when it comes to cutting the Medicare program.
 - (5) Bottom line: Managed care, regardless of its

excesses or shortcomings, will have the support of the political process as well as the momentum of the economic market place.

The politics of the federal deficit and the economics of health care converge on managed care. Managed care= harmonic convergence of deficit politics and health economics.

- d. Managed care penetration in Medicare and Medicaid
 - (1) Medicare
 - (a) End of 1994, 9% of Medicare beneficiaries enrolled in managed care +32% increase in 1995 +45% increase in 1996 (projected)
 - (b) By 2000, 25-85% of Medicare will be managed care (estimates)¹
 - (c) Managed care penetration within selected markets
 - (2) Medicaid
 - (a) States are moving rapidly to convert their Medicaid programs from traditional FFS to managed care programs (Lewin-VHI, 1995)
 - (b) All but 8 states have Medicaid managed care programs of some type
 - (c) One-third are now in FFS primary care case management (PCCM)
 - (d) By 1998, 85% of Medicaid participants (exclusive of those in nursing homes) will be in some form of managed care.
 - (e) §1115 and §1915 waivers. TennCare, Michigan, Rhode Island, New York
 - (f) TennCare
 - Currently 7 HMOs and 5 PPOs
 - 400,000 Medicaid subscribers and 800,000 new eligibles

II HOW MANAGED CARE IS RESHAPING HEALTH CARE AND ITS CONSEQUENCES FOR ALLIED HEALTH AND THE REHABILITATION INDUSTRY

- ◆ Bear with me here. Trying to make a point which will become more obvious later.

A. Health care in general

1. Economic drivers

- a. Economics of MC is forcing individual health care providers to become part of a network of providers that can provide the full continuum of care. The drive toward “vertical integration” and “integrated service networks” (ISNs).
 - Minneapolis-St. Paul market
 - 90% MC penetration
 - 3 main networks

- b. To remain price competitive, provider networks must keep their costs down (and their risks low).
 - c. Cost- and profit-sharing mechanisms are encouraging individual providers to eliminate unnecessary services; reduce hospitalizations in particular.
 - d. The primary care physician (PCP) gate-keeper has become a central figure in determining who gets access to what and how much.
 - e. The PCP shares much of the financial risk. His/her compensation/bonus will depend in large part upon the savings achieved by the network of which he/she is a part.
2. Shifting the competition
- a. Shifting away from prestige competition
 - Historically, providers competed on the basis of the latest technology, their academic affiliations, the credentials and size of their medical staffs, their level of specialization, and the bed-size of their institutions.
 - This prestige competition has helped to make American health care the most sophisticated and technologically advanced in the world, but it has also led to tremendous excess capacity that has made American health care frightfully expensive.
 - b. Shifting to price competition
 - (1) In the new health care system, price has replaced prestige as the defining element in competition
 - (2) "... the hospital industry still has a long way to go before excess capacity, costs and waste are fully wrung out of the system."
 - c. Risk competition still remains
 - (1) Marketing to groups that are, on average, younger and healthier
 - (2) Tweaking benefit plans to attract lower-risk populations
 - (3) Discouraging high users from joining or continuing with their plans once large claims are made
 - (4) Passing on high-cost users to other health plans
 - As a result of risk-based competition, certain groups will be underserved, excluded, or simply priced out of the market.
 - (5) Especially true in individual and small-group health markets. (Scism, 1994)²
3. Shifting ownership status: Not-for-profit → for-profit
- a. Physician groups
 - Physician groups tend to be undercapitalized; take too much money out of the group; forced to go to Wall Street to acquire capital needed to:
 - (1) Finance network expansion
 - (2) Finance new capital equipment needed to keep services in-house and to reduce the need to refer patients to hospital-based facilities
- b. Hospitals
 - (1) Debt financing (used by not-for-profits) becomes part of the hospital cost structure that must be recovered by billing and revenues.
 - (2) Debt financing cannot as compete well with equity financing.
 - (3) Hospitals need major infusions of capital in order to retool or upgrade their facilities and to acquire nonhospital partners.
 - (4) Hospitals are prone to look to Wall Street for the financing they need.
 - (5) Once publicly traded, facilities are subject to buy-outs and mergers and all the other things that can happen on Wall Street.
- B. Impact on health care providers in general
- # The "bleeding edge" of managed care
1. Hospitals
- a. Some cutting costs by 25% or more in order to retain market share
 - b. Elimination of excess capacity
 - Example: hospital beds in Minneapolis-St. Paul market

1981	9,188		
1984	7,436		
1992	5,348	-42%	
2. Physicians
- a. Reduced need/demand for specialty medical care
 - (1) Year 2000 surplus of 115,000 specialists (CGME)
 - (2) Year 2000 surplus of 165,000 specialists (Weiner, 1994). See table in Appendix.
 - (3) Lewin-VHI study on demand for PM&R physicians
 - b. MCOs deselecting physicians on short (30-90 days) notice.
 - (1) "Termination-without-cause" clauses.
 - (2) For-cause reasons being expanded.
 - c. Physician income
 - (1) Income decline
 - (2) Modeling income decline
 - (3) Shifting from fixed pay to variable pay
 - d. Formation of for-profit, publicly traded national physician corporations
 - e. Physicians selling practices to hospitals to avoid overhead, personnel, and paperwork costs
- ◆ California health systems and networks
- # Even largest medical groups and networks appear to have little market leverage with respect to price.
 - # Even the best, most highly acclaimed, systems

- are having difficulty
- C. Impact on medical rehabilitation in particular
1. Providers being forced to reduce costs in order to remain a recognized provider within a health plan (including the referral of patients)
 2. LOS is shortening dramatically in inpatient medical rehabilitation facilities
 3. Therapy teams reorganized. The interdisciplinary team model under attack.
 4. Growth of nonhospital alternatives (see table in Appendix).
 - a. Outpatient programs incl. day treatment
 - b. Subacute, SNF-based rehabilitation
 - c. Home-based rehab
 5. Vertical integration: Medical rehabilitation being forced to become part of larger health care networks with a continuum of rehabilitation settings.
 6. Horizontal integration: Medical rehabilitation providers joining forces with like providers in order to acquire market share and strengthen position for managed care contracts
 7. More for-profit providers
- # See article from *Managed Care Reporter* in Appendix: "Medical Rehabilitation Undergoing Major Shakeup in Advanced Managed Care Markets."
- D. Buzz words
1. Capitation, contact capitation
 2. Incentive compensation
 3. Pod-level risk pools
 4. Market share
 5. Vertical integration
 6. Horizontal integration
 7. Integrated service networks
 8. Partnering, joint ventures
 9. Mergers/acquisitions/consolidations
 10. Reengineering, downsizing, restructuring
- E. Impact on consumers
1. Consumers feel they have lost choice and access
 2. Employers offering fewer or no choices of health plans
 3. Health plans limiting the choice of providers
 - ◆ Both consumers and providers are concerned that managed care may undermine traditional bioethical principles such as those that relate to (a) patient autonomy and (b) the physician's fiduciary responsibility to the patient (Biblo, 1995; Council on Ethical and Judicial Affairs, 1995).
- F. Mergers, acquisitions, alliances
1. Acute hospital industry (Skolnick and Prime, 1994)

Columbia-HCA Healthcare Corp (COL) (see drawing in Appendix)

 - a. Grown from 20 hospitals to 340 hospitals & 100+ freestanding surgery centers in just 4 years; \$22 billion in annual revenues.
 - b. In late April, completed its \$3.3 billion takeover of HealthTrust, a 116-hospital system and is moving its headquarters from Louisville to Nashville (Hilzenrath, 1995)
 - c. Seeks to operate as many as 500 hospitals in a few years.
 - d. Going international. Joint venture with (a) Britain's largest independent health care provider, General Healthcare Group PLC and (b) a health unit of the French conglomerate Groupe Generale des Eaux (Tomsho, 1995). Columbia/HCA has "an appetite that is seemingly insatiable."
 - e. Columbia/HCA's cardinal rule of acquisitions: "Never pay for an empty bed unless you are buying the facility to close it." Why buy a facility you intend to close: eliminate competition; "it pays only for the ability to fill up beds in existing facilities by closing the hospitals that it buys."
 2. Home care industry
 - a. Size
 - (1) \$22-billion industry, 1995
 - (2) \$40-billion industry, 2000
 - b. Names
 - (1) Coram (CRH)
 - (2) RoTech Medical (ROTC)
 - (3) Lincare Holdings (LNCR)
 - (4) American HomePatient (AHOM)
 - c. Mergers and acquisitions in home health services
 - From 1992-94 there were \$3.7 billion of mergers and acquisitions in the home care industry.
 - In summer 1995, Manor Care, a leading nursing home chain, headquartered in Silver Spring, MD, purchases a controlling interest

- in Home Health Inc. for \$42 million.
 - The recent Homedco/Abbey merger makes it the largest home care company with revenue of more than \$1.1 billion.
3. Medical rehabilitation industry
- a. **Horizon/CMS**, formerly Horizon Healthcare
- (1) In February 1994, Horizon Healthcare buys Greenery Rehabilitation Group (20 facilities and 2,800 beds)
 - (2) In August 1994, Horizon Healthcare acquires 13 peopleCare Heritage nursing facilities with 2,200 beds in the Dallas area
 - (3) In 1995, Horizon Healthcare buys Hillhaven (nation's second largest nursing home chain, (\$1.5 billion in annual revenue)
 - (4) In March 1995, Horizon Healthcare acquires Total Rehabilitation, Inc. and Rehabilitation Network, Inc. in Michigan for \$6.5 million of Horizon common stock
 - (5) In June 1995, Horizon Healthcare acquires buying Continental Medical Systems for \$502 million
 - (6) Later Horizon/CMS (new name) purchased Pacific Rehabilitation & Sports Medicine, Inc. for \$62 million
- b. **HealthSouth** = the Columbia/HCA of the rehabilitation industry
- (1) Started in 1984; went public in 1986 with 7 facilities and \$12 million in annual revenues
 - (2) In September 1994, HealthSouth buys 30 NME hospitals for \$300 million cash
 - (3) In spring 1995, HealthSouth buys Nova Care hospitals
 - (4) In December 1995, HealthSouth buys AdvantageHealth for \$325 million³
 - (5) In 1995 HealthSouth acquired 130 independent rehabilitation centers
 - (6) As of the end of 1995, HealthSouth operates 850 outpatient and rehab facilities in 44 states with projected revenues of \$2.5 billion in 1996.
 - (7) It now controls about 40% of the nation's rehabilitation hospitals, twice the share of its nearest competitor, Horizon/CMS.
- c. Growth of subacute providers such as **Nova Care** and **Therax**
4. Reading (tongue in cheek)
- If you really want to know what is going on in health care, don't read the *New England Journal of Medicine* or any of the medical literature, read the *Wall Street Journal*.
 - Perhaps time for the *Archives of PM&R* and the *Journal of Head Trauma Rehabilitation* to develop investment reports that includes
 - (1) Annual and quarterly sales
 - (2) Quarterly earnings
 - (3) Earnings per share
- (4) High and low stock prices over the last 12 months
- (5) Etc
5. Consider following statement from a stock analyst report (name of company has been changed):
- "In our opinion our opinion, the ABC Rehabilitation Inc. has maintained impressive rates of internal growth. It is noteworthy for its efficient operations, high margins, excellent receivables management and tremendous cash flow, which have in turned enabled it to make acquisitions without leveraging its balance sheet. While ABC has not actively pursued partnerships to broaden its services horizontally or vertically to reposition itself for managed care, its well-run operations could make it attractive to an acquirer ... We recommend ABC as a buy."
- a. What's missing from this statement?
 - b. There is no sense of the product, the people who produce it, the people who use it, and its future viability. No sense of the quality of the product.
 - c. There is no sense of the consumer, the drivers of the demand for the services
 - d. There is no sense of the producer of the services, i.e., the professionals in terms of their training, commitment, philosophy, competence, productivity. Human capital not considered.
 - e. It assumes that the driver is quarterly earnings, potential for being a take-over target.
 - f. The statement above seems almost vacuous.
 - (1) Yes, efficient operations, decent margins, good receivables management, and excellent cash flow are essential to the well-being of any organization but they cannot replace the fundamentals related to consumer demand, quality of services, and price.
 - (2) Nor does it give you a clear picture of the market fundamentals, i.e., the need/demand for the product nor the supply within a given market area.
 - (3) You cannot get an adequate read of an organization and its services merely by looking at the brochures and videos produced by the marketing department nor by merely reading the financial statements produced by the accounting department. In capital markets, these departments are in the business of perception management – they want to create an image of an organization as dynamic and fiscally healthy. They do not necessarily give you a true picture of what is actually happening.
- # Restructuring of the health care system = the privatization of health care reform
- # Today's shake-out is akin to:

- The shake-out in the banking and financial services industry during the late 1980s and into the 1990s on the heels of the S&L crisis
 - The restructuring of the communications industry starting with the break up of AT&T a decade ago and continuing with the convergence of computer, cable, and telephone technologies in the 1990s
- III. **EMERGENCE OF THE CONSUMER/DEMAND SIDE OF THE MARKET AND THE STEPS NEEDED TO STRENGTHEN IT**
- A. Historically, consumer side has been weak but the role of the consumer is becoming stronger (as we will see later)
- B. An informed consumer is essential to a well-functioning market-based system.
1. Perfect knowledge = key assumption in the economic theory of perfect competition.
 2. A market without informed consumers is not a "free market" in the real sense of the term.
 3. We cannot have market-based solutions to the problems of our health care system without an informed consumer.
 - The champions of market-based solutions are being disingenuous when they do not at the same time champion the consumer and his/her right to make informed decisions about health plans and health providers.
 - What the champions of market forces really mean is the forces of capital markets, i.e., Wall Street. In my humble opinion, Wall Street is often ill-informed about the fundamentals of health economics. Too much of what happens in health stocks is fueled by the perceptions created by high-flying hospital company CEOs, by marketeers, and by the expectations created by stock analysts' reports. Stock prices often move on the most flimsy information.
- C. Consumer choice is important at two different stages/levels
1. When choosing a health plan
 - a. The more important choice
 - b. Consumers have most clout when choosing a health plan
 2. When choosing a provider
 - a. Presumes that there is a choice of provider within a health plan or health network
 - b. Consumer choice also constrained by gate-keeper referral
- D. Consumer knowledge being strengthened
1. Consumer satisfaction
 - a. Ratings of individual health plans
 - b. Ratings of individual providers
 2. Health outcomes ("report cards")
 - a. For health plans
 - b. For health providers
 - c. Examples:
 - (1) Washington, DC area's **Consumer Checklist**.
 - (2) National Committee for Quality Insurance (NCQA) HEDIS 2.5 (Health Plan Employer Data and Information Set). HEDIS 3.0 to be released in early 1997. Information on 200 NCQA-rated health plans available on the Internet at <http://www.ncqa.org>
 - (3) **Health Pages** which currently rates health plans and health providers in 5 markets (Atlanta, Boston, Columbus-Cincinnati, Pittsburgh, St Louis) and was scheduled to start in 4 other markets starting this fall (Phoenix, Denver, S Florida, Los Angeles)
 - (4) Cleveland Health Quality Choice Program – outcomes and pt. satisfaction among 29 Cleveland area hospitals. Includes severity adjustments.
 - (5) North Central Texas HEDIS Coalition developed a report card on 7 HMOs on HEDIS performance measures and member satisfaction data from independent surveys.
 - (6) Denver – NCQA and *Health Pages* released an HMO report card comparing HEDIS performance of Denver-based Cigna, FHP International, Kaiser, MetraHealth, Pru and Sloan Lake.
 - (7) Pittsburgh Business Group on Health spearheaded a similar cross-HMO comparison involving HealthAmerica HMO, Keystone Health Plan West, and US Healthcare.
- E. Leading role of the large employer
1. Demanding that health plans, particularly managed care plans, provide standardized outcome and consumer satisfaction data
 - Large businesses more likely to demand this information than small businesses. Smaller employers are mainly concerned about price.
 2. Have market power akin to purchasing cooperative or health alliance
 - National HMO Purchasing Coalition involving 10 employers, e.g., Sears. All HMOs must meet Sears' quality specs

3. Information interests of large purchasers and small consumers are, in many ways, similar
4. Jackson Hole II, June 1995:
 - "Monitoring quality = the next battlefield."

IV. IMPLICATIONS FOR REHABILITATION AND ALLIED HEALTH PROVIDERS

- A. The price imperative (short-term)
- B. The quality imperative (long-term)
 1. Providers will be bargained down by payers if the competition remains largely on the basis of costs and price.
 2. It is in the provider's interest to see that the competition shifts from one largely based on price to one that is based on *price and quality* (i.e., consumer satisfaction and outcomes)
 - Price and quality competition is in the interest of both the consumer and the provider. Here is where the interests of consumers and providers converge.
- C. The challenge for rehabilitation: How consumers choose a health plan
 - One of the great challenges facing medical rehabilitation in a consumer-driven health care system is how to reach out to, and communicate with, the consumer who is making a health plan choice.
 - Most consumers, especially younger ones, never envision a need for medical rehabilitation services and many will not even know what these services are. The need for medical rehabilitation services is often considered by the average consumer to be a remote possibility and, as such, will not be carefully scrutinized by the consumer when making a health plan decision.
 - Thus, consumers are not likely to make much of an investment in learning about rehabilitation and the quality of various providers within plans when making a health-plan choice.
- D. Four actions

This state of affairs will require four actions on the part of the medical rehabilitation industry:

 1. The industry will need to develop, in collaboration with a more neutral entity (e.g., NCQA), as well as the business community and the consumer community, a single standardized rehabilitation score (with possible

subscores) by which health plans will be rated based on the capabilities and performance of the plan's entire network of rehabilitation providers. Such a score would be largely outcome based (and risk adjusted). Such a score would also create enormous peer pressure to exclude subpar providers and encourage collaboration in helping to improve the plan's overall rehabilitation score.

2. The industry will have to convince various health system governing boards, large employers, and health insurance purchasing cooperatives that a rehabilitation rating system is needed to help consumers make their annual side-by-side comparison of competing health plans. Without such a rating, consumers will overlook the rehabilitation component of a health plan and health plans may not be adequately motivated to include the best possible network of rehabilitation providers.
3. The industry will have to adopt the single-score concept (with possible subscores) as the basis for rating individual providers. Such ratings would guide consumers, physician gate-keepers, and health plan case managers in selecting a within-plan or out-of-plan provider when a rehabilitation need arises.
4. The medical rehabilitation industry will have to undertake an education strategy to inform consumers, physician gate-keepers, and case managers what rehabilitation scores or ratings mean for the choices they need to make when choosing a plan or selecting a provider.^{4,5}
- E. Another way to frame the challenge: The spark-plug and sound-system analogy
 1. Will consumers choose a health plan based on the quality score of a rehabilitation provider network associated with the plan?
 - a. Consumers probably will not choose a health plan based solely on who is the rehabilitation provider
 - b. Consumers do not buy an automobile based on the brand or quality of the spark plug in the automobile; they might choose an automobile based on the brand-name sound system in the automobile (Pioneer, Bose).
 - c. Consumers do choose a health plan based on quality and reputations of key providers.

Examples:

 - (1) The primary care physician or gate-keeper (e.g., a pediatrician)
 - (2) The OB-GYN
 - (3) A specialist with whom the consumer has had a long-standing relationship (e.g., a neurologist)
 - (4) Other providers (e.g., oncologists) if the consumer perceives that he/she is a risk of

- acquiring a particular health condition (e.g., oncology practice).
- d. Rehabilitation providers will have to convince would-be consumers that they are the moral equivalent of a Bose sound system; that they are at risk of acquiring a condition that will require rehabilitation (stroke = "brain attack")
2. The situation is different for those who already have an impairment that has required, or may, in the future, require rehabilitation
 - a. These consumers already understand their risk
 - b. The rehabilitation provider's franchise with the consumer would be even stronger if it saw itself not only as a provider of rehabilitation services but also as the gate keeper or PCP that will meet the ongoing needs of the disabled population.
- F. Rehabilitation providers as PCP/gate keeper for people with disabilities
1. Rehab needs to position itself at the front end of the health care "food chain," not at the back end; need to become an "up-stream" provider instead of a "down-stream" provider.
 2. Rehabilitation providers understand the ongoing health care needs of the disabled population better than most primary care physicians. Rehab physicians understand how various up-front interventions can avert the "down-stream" (specialist and hospital) costs that person with disability is otherwise likely to incur.
 3. Many primary care physicians consider people with disabilities as a "drag" on their practice – can't turn patients around fast enough.
 4. In many instances, rehab providers already serve as the *de facto* primary care provider.
 5. In the near term, there are remarkable opportunities to cut win-win-win deals with managed care organizations:
 - a. The consumer
 - Needs a reliable source of primary care currently not available
 - Needs an informed gate-keeper who understands his/her particular constellation of health care needs
 - b. The provider
 - (1) Needs to capture a population such that he/she is not left at the vulnerable end of the "food chain"
 - (2) Capitating a high-cost population can be financially profitable
CMA in Boston capitated at approx. \$27,000 per enrollee per year
Rehab providers need to negotiate capitated
- carve-outs with health plans (including Medicare & Medicaid).
In California, a 14-physician oncology group practice negotiated a carve-out with a MCO and found that their income increased 40% at a time when national average income for oncologists decreased.
Rehab providers may, in the short term, want to team up with PCPs in order to shore up their network's primary care capabilities.
- c. The payer
 - Wants some certainty about costs managing a higher-cost population
6. **Are rehabilitation providers in the business of rehabilitation or in the business of health care for people with disabilities?**
 7. Significant implications for training of rehab physicians and allied rehab professionals
- V. **OTHER STEPS THAT NEED TO BE TAKEN** (longer term)
- A. Develop risk adjusters
 1. Essential to developing a more risk-neutral health care system
 2. Need to risk adjust outcomes
 - a. Outcomes adjusted on basis of risk, severity of impairment, severity of illness, functional limitation upon admission
 - b. Without risk adjustment for outcomes, one program cannot be compared fairly with another
 3. Need to risk adjust health plans
 - Health plans will continue to discriminate against high-end users of health care such as people with disabilities and chronic health conditions without some form of risk adjustment
 4. Difficulty
 - S Development of an appropriate risk adjustment methodology for health plans and providers is probably the single greatest analytic challenge for the remainder of the 1990s
 - S Need to start with simple risk adjusters and learn how to refine them over time.
 - B. Develop a standard benefits package
 1. Essential to minimizing risk competition
 2. Essential in helping consumers make informed choices among health plans when making side-by-side comparisons
 - Addresses the "homogeneous product"

assumption in the theory of perfect competition

- C. Get people to understand the important role of government
- # Even for those who would like to see a reduced role for government in the provision of health care, need to understand the importance of government in creating a more level-playing field in health care.
- Government essential to the development of rules that will result in a more consumer-driven, risk-neutral, market-based system
- D. Initiate antitrust action, where necessary, to preserve effective competition in local and regional markets
1. The present trend of mergers, acquisitions, and consolidations reflects market-share competition. Everybody wants to be part of a larger system so they will not lose out in obtaining managed care contracts.
 2. Some within-market consolidation is needed to help achieve some economies of scale that will make health care cheaper.
 3. Excessive within-market consolidation represents the single greatest threat to the development of genuinely competitive consumer-driven market.
 4. Health care reform would have helped put the brakes on excessive consolidation.
 5. We still have a window of opportunity to structure Medicare and Medicaid managed care to insure effective competition. In the absence of comprehensive reform, we can do a lot to make sure that Medicare and Medicaid managed care adheres to principles of market competition.
 - This is another area in which consumers and providers can collaborate for the remainder of the 1990s.

VI. **SUMMARY CHECKLIST: STEPS THAT NEED TO BE TAKEN**

- A. Near-term (next 2 years)
Rehabilitation providers (individually or collectively)
1. Reposition. Redefine your business. Get into the business of providing health care for people with disabilities and chronic health conditions, not just the rehabilitation business.
 2. Research what health plans are currently spending annually on the health care needs of disabled populations that rehabilitation providers are qualified to

manage.

3. Consult with consumers to determine what they need/want, what they seek in a health plan, and how they want to have their care managed.
4. Reorient. Become the PCP/gate-keeper for selected groups of people with disabilities. Retrain.
5. Work with other provider groups to develop a provider network than can deliver a continuum of care for people with disabilities (including primary care, outpatient care, acute inpatient, inpatient rehabilitation, subacute rehabilitation).
6. Negotiate capitated carve-outs with MCOs. Offer MCOs the possibility of risk-sharing in managing the health care needs of a high-user population. Offer going full-risk after 3 years.
7. Convince large employers, health purchasing cooperatives, and others representing the consumer side of the market that a rehabilitation rating system is needed to help consumers make their annual side-by-side comparison of health plans

Providers and consumers

8. Begin working together to develop a composite quality/outcome score and subscores that will be meaningful to consumers and referral choices when choosing a health plan or a rehabilitation provider. Seek government funding for the development of such composite scores.
9. Read the *Wall Street Journal*, not *JAMA* or *NEJM* to know what is really happening in health care.

Consumers

10. As Medicare moves toward managed care, insist that Medicare subscribers have a choice of at least 3 viable health plans in each market areas.
11. As state Medicaid programs move toward managed care, insist that Medicaid participants have a choice of at least 3 viable health plans in each market area.
12. Petition to initiate antitrust action if Steps 10 and 11 are not implemented and if there is excessive concentration in local markets.

B. Longer term (2-5 years)

Providers

1. Work to make rehabilitation the sound system, not the spark plug, of health plans.

2. Expand the current MREF education strategy to inform consumers, physician gate-keepers, and case managers what rehabilitation scores or ratings mean for the choices they need to make when choosing a health plan or selecting a provider.
3. Provide full disclosure of outcome data across all rehabilitation providers; eliminate selective self-serving disclosure; abolish secrecy.

Consumers

4. Join forces with large employers in getting health plans to adopt disability ratings and rehabilitation scores.
5. Insist that each health plan include a report card in its marketing material that includes a disability service and rehabilitation score as certified by an independent organization.
6. Demand full outcome disclosure (risk adjusted to the extent possible) from rehabilitation providers.
7. Make quality/outcome scores and subscores available on the Internet in a manner that will enable consumers and referrals sources to probe more deeply when attempting to make informed choices.
8. Keep a watchful eye for excessive within-market concentration and anticompetitive practices that limit consumer choice and raise prices artificially.

Providers and consumers

9. Update methods for quality/outcome scores and subscores.
10. Work with NCQA, health plans, and other organizations in developing risk adjusters that will minimize risk competition and can be used to risk adjust quality and outcome measures.

Remember: An informed consumer is the single most important element in truly consumer-driven health care system

VII. IN CLOSING

- A. Strong believer in market-based approaches
 1. More creative, more dynamic, and ultimately more responsive
 2. However, we need to make sure that the conditions for a market-based health care system are effectively in place. We mentioned a few of them:
 - a. Standard benefit package

- b. Consumer knowledge
 - c. Competition on price and quality/outcomes, not price, risk, and market share
3. Organized consumer groups are essential in making sure that we develop a genuinely competitive market system.
 - B. Also believe in the principles of managed care provided managed care is organized on a level-playing field
 - C. Moving from a provider-driven → payer-driven → consumer driven health care system
 1. Differences between these systems are outlined in table in Appendix.
 2. In a payer-driven system, both the consumer and provider are disadvantaged; a consumer-driven system is the provider's best hope for a more level playing field
 3. A consumer-driven system will **empower the consumer** to make choices and **enable the provider** to compete on a level playing field.
 4. I believe that the movement toward a consumer-driven system is inexorable and unstoppable. There are threats to the development of such a system. However, effective collaboration between consumers and providers is our best hope for achieving the outcomes we all want.

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NOTES

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1. By covering increasing out-of-pocket costs for prescription drugs, managed care companies are luring Medicare subscribers into Medicare managed care plans. This was the same enticement that the Clinton health care reform plan had: It tried to secure the endorsement of the retirement-age population by including Medicare coverage for prescription drugs.
2. A *Wall Street Journal* article (Scism, 1994) on the Golden Rule Insurance Company illustrates this problem well:

Screening insurance applicants carefully, Golden rule tries to sell policies only to the healthy or to those whose existing medical problems can be exempted from coverage. And when cherry picking fails and the company gets stuck with someone with a big medical problem that isn't exempt from coverage, it still does well ... because its hardball legal tactics often carry the day.
3. Just before being acquired by HealthSouth, AdvantageHealth purchased the 202-bed Harmarville Rehabilitation Center in Pittsburgh and its 7 affiliated outpatient centers.
4. A rating system such as the one outlined here will require collaboration between organizations such as the Uniform Data System for Medical Rehabilitation (UDS_{MR}) and the Commission on Accreditation of Rehabilitation Facilities (CARF). UDS_{MR} for example, might well become the principal provider of standardized performance data and CARF will likely become the principal evaluator of provider capabilities. I believe that, in a consumer-driven health care system, the role of CARF, for example, will shift from its conventional accreditation function to also becoming producer of standardized data on which provider capabilities will be evaluated and translated for consumer consumption.
5. The consumer-driven medical rehabilitation assessment system envisioned here will also come to replace the physician-based assessment used by organizations such as the *US News and World Report* in conducting its annual survey of the 10 best rehabilitation hospitals. Such surveys are based largely on physician-peer perceptions that are shaped less by the provider's quality of patient care and more by the provider's academic and research prowess and by the provider's marketing and public relations capabilities.

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APPENDIX

PROJECTED SURPLUS BY SPECIALTY ¹			
Specialty	Projected Supply in Year 2000 ²	Projected Demand in Year 2000	Percentage Range of Surplus
Neurosurgery	4,285	1,449-2,736	57-196%
Plastic Surgery	5,204	1,882-2,311	125-177%
Cardiology	14,999	7,002-9,792	53-114%
Anesthesiology	28,161	14,426-16,143	74-95%
Ophthalmology	17,141	9,014-10,946	57-90%
Neurology	8,265	4,542-5,400	53-82%
Radiology	26,324	15,706-18,496	42-68%
General Surgery	33,058	20,313-21,815	52-64%
Gastroenterology	7,346	4,752-4,967	48-55%
Orthopedics	19,896	13,103-16,537	20-52%
<p>1. Governance Committee analysis.</p> <p>2. Data represent 83% of all known active, nonfederal physicians in the U.S. and exclude residents and fellows.</p> <p>Source: Weiner, Jonathan P., "Forecasting the Effects of Health Reform on US Physician Workforce Requirement," <i>JAMA</i>, July 20, 1994. ©The Advisory Board Company 1995</p>			

How Markets Evolve				
Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
<p>Unstructured</p> <ul style="list-style-type: none"> • Little managed care • Little hospital consolidation • Few insurers active as providers • Few physician groups • Overuse of hospital care fuels oversupply of beds 	<p>Loose framework</p> <ul style="list-style-type: none"> • Most managed care is discounted fee-for-service; by late Stage 2, some capitation • Hospital consolidation begins • Insurers begin to acquire or partner with providers • Physicians organize in groups; primary care doctors move toward large groups • Oversupply of beds supports deep price discounts 	<p>Consolidation</p> <ul style="list-style-type: none"> • Heavy managed care penetration, including government programs • Managed care dominates payment scene • Some capitation, especially of primary care MDs • Hospital mergers accelerate • Primary care doctors accelerate movement to groups; specialty doctors begin to form groups • Plans begin dropping doctors, hospitals: shift in physician supply begins • Managed care consolidation; providers, insurers begin to align • Overcapacity begins to shrink • Providers develop continuums of care 	<p>Managed competition</p> <ul style="list-style-type: none"> • Employer coalitions buy health care • Managed care payment dominates • Little fee-for-service • A few large health care "players" dominate • Providers, insurers strongly align • Doctors not in groups pushed out • More pressure to eliminate beds • Shift in physician supply • Use of specialists and their fees driven down dramatically • Networks develop full continuums of care, especially subacute • Providers, insurers organize to serve "covered lives" • More than 50 percent HMO penetration 	<p>Endgame</p> <ul style="list-style-type: none"> • Networks with market share form true partnerships with insurers • Providers focus on their unique strengths • Integrated systems manage patient populations
<p>Markets</p> <ul style="list-style-type: none"> • Nassau, Long Island, N.Y. • Omaha, Neb. • Syracuse, N.Y. • Little Rock, Ark. • Birmingham, Ala. • Research Triangle, N.C. • New ark, N.J. • Shreveport, La. 	<p>Markets</p> <ul style="list-style-type: none"> • Louisville, Ky. • Miami • Dallas/Fort Wroth • Cincinnati • Tampa/St. Petersburg, Fla. • Atlanta • Orlando, Fla. • Cleveland • St. Louis • New York City • New Orleans • Indianapolis • Nashville, Tenn. • Philadelphia 	<p>Markets</p> <ul style="list-style-type: none"> • Orange, Calif. • Milwaukee • Portland, Ore. • San Francisco/Oakland • Detroit • Sacramento, Calif. • Denver • Boston • Salt Lake City • Phoenix • Seattle • Washington, D.C. • Houston • Chicago 	<p>Markets</p> <ul style="list-style-type: none"> • San Diego • Minneapolis/St. Paul • Los Angeles • Worcester, Mass. 	<p>Markets</p> <ul style="list-style-type: none"> • No markets--yet

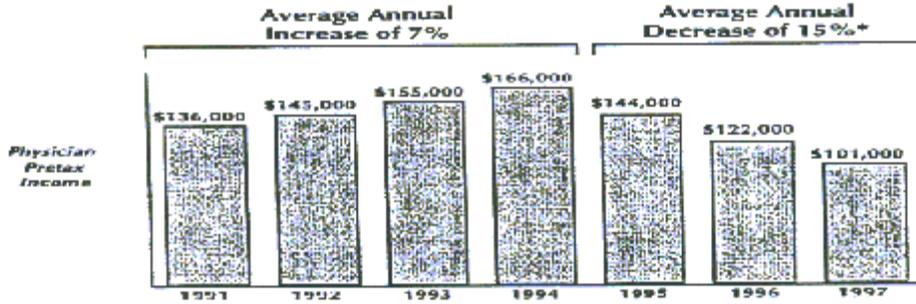
SOURCE: *Hospitals & Health Networks*, 1995; APM Inc. and University Hospital Consortium, 1995
Editor's note: This chart presents a view from APM Inc. and the University Hospital Consortium of stages of health care markets evolving as a result of reform and identifies markets in the various stages.

Yearly Estimates of the Number of Rehabilitation Facilities, SNFs, and Long-Term Care Hospitals in the U.S.: 1985-1994							
Type of Facility	1985	1987	1989	1991	1993	1994 ⁶	Percent Change 1985-1994
Rehabilitation Hospitals ¹	68	88	125	152	180	187	+175
Rehabilitation Units ²	386	539	642	672	783	804	+118
Long-term Care Hospitals ³	86	87	89	91	109	113	+31
Skilled Nursing Facilities (SNFs) ⁴	6,725	7,379	8,688	10,061	11,309	11,436	+70
Comprehensive Outpatient Rehabilitation Facilities (CORFs) ⁵	86	141	184	201	229	237	+176
1. Number of hospitals excluded from coverage under the Medicare PPS. 2. Number of units excluded from coverage under the Medicare PPS. 3. Number of long-term care hospitals excluded from coverage under the Medicare PPS. 4. Number of SNFs participating in Medicare Health Insurance Program. 5. Number of CORFs participating in Medicare Health Insurance Program. 6. As of August 1994. SOURCE: Wolk and Blair (1994).							

Comparing Provider-, Payer-, and Consumer-driven Health Care Systems			
Dimension	Provider-driven (supply side)	Payer-driven (intermediary)	Consumer-driven (demand side)
Key value	Provider autonomy	Cost minimization	Consumer sovereignty
Basis of competition	Prestige & risk	Price & risk	Price & quality
Economic goals	Revenue maximization	Market share/profit maximization	Cost-effectiveness (efficiency)
Pricing	"Usual & customary"	Discounting	Value-based
Method of payment	Fee-for-service	Case-mix (eg, DRGs, FRGs), RBRVS capitation	Risk-adjusted capitation, carve-outs
Quality	Accreditation Credentialing	Perception of quality, CQI, TQM	Outcomes, consumer satisfaction
Access	Provider-controlled	Payer-controlled	Consumer choice
Capacity	Excess capacity	Reduced capacity	Balanced capacity
Utilization	Overutilization	Underservice	Balanced
Utilization review	Retrospective	Prospective	Not needed
Costs	Not important	Very important	Relative to outcome
Outcomes	Elimination of pathology, "satisficing"	Reduced utilization, reduced costs	Health status, functional status, quality of life, consumer satisfaction
Outcome disclosure	Confidential/secret	Selective disclosure	Full disclosure
Providers as price takers	No	Yes	Yes
Homogeneous product	No	No	Yes, standard benefit package
Knowledge & expertise	Rests with provider	Second-guessed by payer	Made accessible to consumer
Rating	Experience rating	Experience rating	Community rating
Risk adjustment	No	Some case-mix adjustment	Yes
Governance	Provider dominated	Payer dominated	Consumer dominated
SOURCE: DeJong & Sutton (1995)			

Modeling the Income Decline for California Physicians

Effect on Personal Income over Time

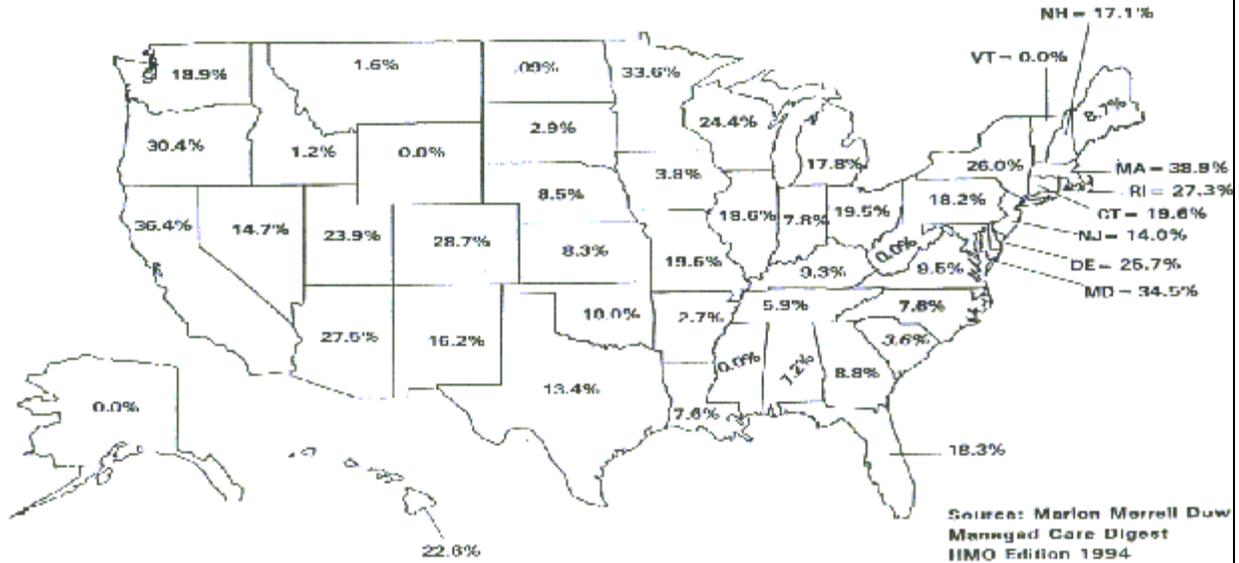


*Annual decrease is modeled on the following assumptions:
 + Physician revenues are 90% capitated, 10% fee for service; this mix remains constant over time
 + Overhead is 50% of group revenues
 + Revenue from capitated contracts decreases by 5% annually
 + Practice overhead increases by 4% annually

Source: Governance Committee Interviews and analysis; 1994 Total Compensation Survey, HayGroup, Walnut Creek, Calif.

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HMO Penetration

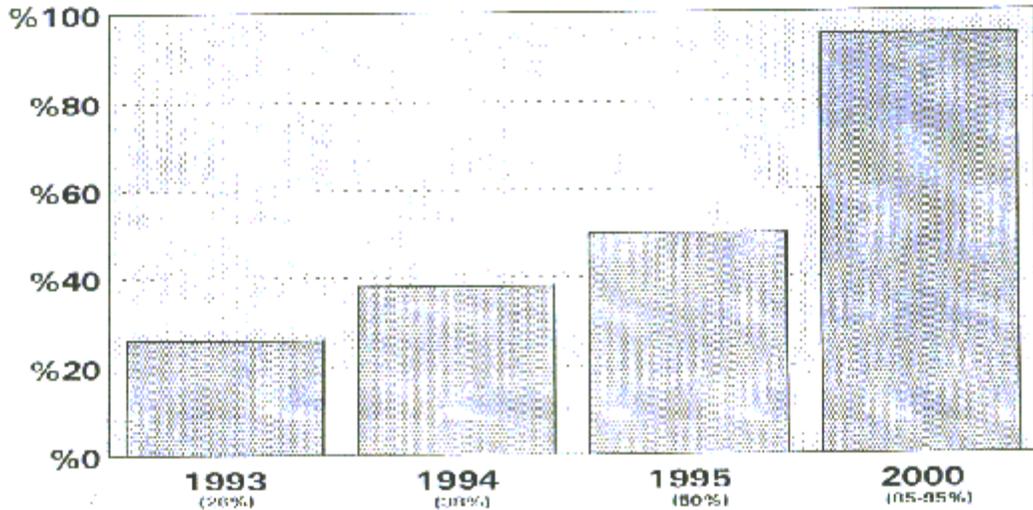


Source: Marlon Merrell Duw Managed Care Digest HMO Edition 1994

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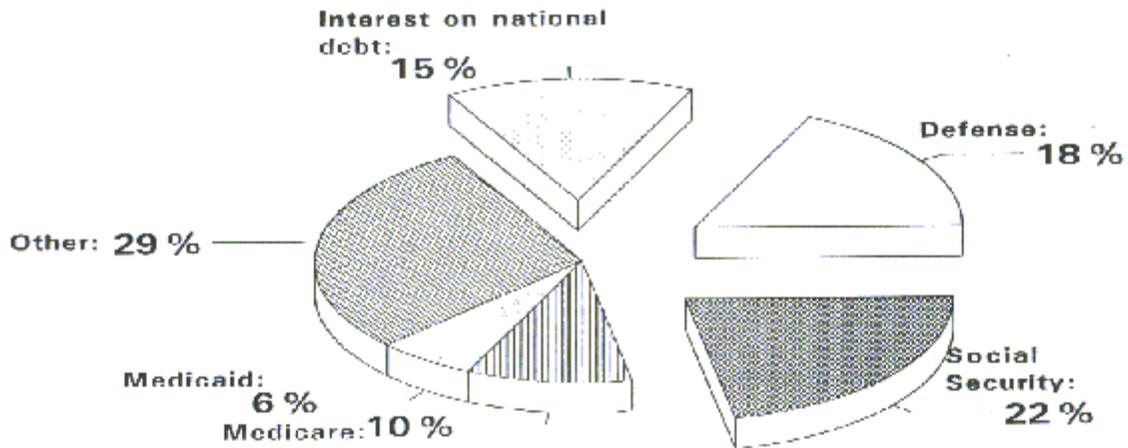
The Growth of Managed Care

Private Health Insurance Market



NRH Research Center

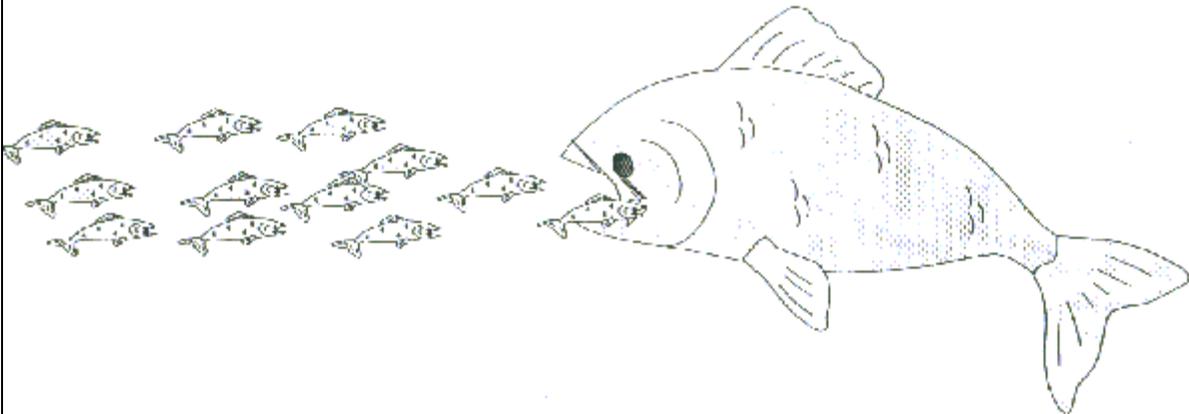
Federal Government Spending



Source: *The Washington Post*
 Sunday, May 28, 1995

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