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ABSTRACT

This collection of papers on managed care and long-term supports for people with developmental disabilities includes a range of reprinted articles and resource materials that provide different kinds of information and opinions on the impact of managed care. Articles include: "A Position Statement on Managed Care and Long-Term Supports in Developmental Disabilities" (Center on Human Policy at Syracuse University and others), summarizing some of the principles and values that should underlie managed care if and when it is implemented; "Keeping the Faith: System Change, Managed Care and Long-Term Supports for People with Developmental Disabilities" (National Association of State Directors of Developmental Disabilities Services, Inc.); "Overview and Implications of Medicaid Managed Care for People with Developmental Disabilities" and "Technical Elements, Demonstration Projects, and Fiscal Models in Medicaid Managed Care for People with Developmental Disabilities" (Theodore A. Kastner, Kevin K. Walsh, and Teri Criscione); and "Beware the Managed Health-Care Companies" (John Ashbaugh and Gary Smith), which provides a cautionary note on the managed care system. The final series of articles do not directly deal with long-term development disability services, but raise concerns from the broader disability rights community and include: "McManaging Your Health" (Billy Golfus and Wendy Brower); "Managed to Death" (Josie Byzek); and "Getting Up to Speed". Includes a list of resource organizations which can be contacted for additional and updated information on the status of managed care. (Most articles contain references.) (CR)

INFORMATION PACKAGE ON MANAGED CARE AND LONG-TERM SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280

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INFORMATION PACKAGE ON MANAGED CARE AND LONG-TERM SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Contents

Reprints: Selected Articles from Mouth, September 1996

McManaging Your Health

by Billy Golfus and Wendy Brower

Managed to Death

by Josie Byzek

Getting up to Speed

PREFACE

The topic of "managed care" in developmental disabilities reminds me a bit of the "World Wide Web" or "WWW." A couple of years ago, almost no one knew anything about the WWW. Today, everyone is talking about the WWW, and just about every major organization in developmental disabilities, and many individuals, have a WWW "home page." Similarly, "managed care" has become, almost overnight, a major issue dominating policy discussions in the field of developmental disabilities. Many states are moving toward the implementation of managed care approaches for developmental disability services. Reactions from leaders in the field to this development range from cautious optimism that this approach will result in a more effective and equitable service delivery system to extreme skepticism that managed care represents a mean-spirited cost cutting device to limit services to people with developmental disabilities and their families.

Managed care is still new. We have little experience with system wide managed care approaches. The jury is still out, so to speak. Time will tell how managed care affects people with developmental disabilities and their families.

Because of the uncertainties surrounding the long-term impact of managed care, we have included in this "information package" a range of reprinted articles and resource materials providing different kinds of information and representing different opinions. I will briefly review these and explain why we decided to include them as resources.

The "Position Statement on Managed Care and Long-Term Supports in Developmental Disabilities" was originally developed jointly by the Center on Human Policy (Steve Taylor), the Robert Wood Johnson National Project at the Institute on Disability at the University of New Hampshire (Jan Nisbet, Don Shumway, Richard LePore), and Responsive Systems Associates (John O'Brien). The final version was based on suggestions from Dennis Harkins of Wisconsin's Bureau of Developmental Disabilities Services, John Agosta and Mady Kimmich of the Human Services Research Institute, Patty Smith of the National Parent Network on Disabilities, Charlie Lakin and Bob Prouty of the University of Minnesota, Cathy Ficker-Terrill of the Ray Graham Association, Janna Starr of the United Cerebral Palsy Association, Stan Herr of the University of Maryland at Baltimore Clinical Law Office, and Gary Smith of the National Association of State Directors of Developmental Disabilities Services, Inc. (although these persons do not necessarily endorse the wording of the final version). This position statement is intended to summarize some of the principles and values that should underlie managed care **if** and **when** it is implemented.

The brief monograph on "Keeping the Faith" was published by the National Association of State Directors of Developmental Disability Services Inc. (NASDDDS). NASDDDS has been a leader in developing materials and position statements addressing the statewide implications of managed care and is a key national resource in this area.

The following two articles by Theodore A. Kastner, Kevin K. Walsh, and Teri Criscione, which are forthcoming in Mental Retardation, provide the most comprehensive overview of managed care and technical elements in the field of developmental disabilities written to date. These are essential reading for anyone concerned about managed care.

The next article by John Ashbaugh of the Human Services Research Institute and Gary Smith of NASDDDS is an important cautionary note that, in our opinion, must be taken seriously by anyone concerned with developmental disability services.

The final series of articles are reprinted from Mouth. Although these do not deal directly with long-term developmental disability services, they are thought-provoking and raise a series of concerns from the broader disability rights community.

At the conclusion of this package, we list some resource organizations which can be contacted for additional, and updated, information on the status of managed care. This list is not intended to be exhaustive, but is designed to point readers to some of the major organizations working in this area.

Julia Searl and Pam Walker assisted in the development of this information package. Bonnie Shoultz and Rachael Zubal provided guidance and assistance in producing it.

We wish to express our appreciation to Gary Smith, Theodore Kastner, Kevin Walsh, Teri Criscione, and John Ashbaugh for their permission to share their excellent materials with a broader audience. In addition, we wish to thank Stephen Stidinger of the American Association on Mental Retardation for permission to reprint the articles published or forthcoming in Mental Retardation and Tom Olin and Lucy Gwin of Mouth for their willingness to allow us to reprint the three articles published there.

Steven J. Taylor, Ph.D.
Director
Center on Human Policy

REPRINT: A POSITION STATEMENT ON MANAGED CARE AND LONG-TERM SUPPORTS IN DEVELOPMENTAL DISABILITIES

A POSITION STATEMENT ON MANAGED CARE AND LONG-TERM SUPPORTS IN DEVELOPMENTAL DISABILITIES

In the past decade, the field of developmental disabilities has witnessed the emergence of innovative and responsive approaches to supporting people in the community. Family support, supported living, person-directed support services, supported work, and home ownership have become realities for an increasing number of people and their families. Yet public policies and funding mechanisms have often limited the development of these effective forms of assistance. Major sources of funding for developmental disability services have discouraged the development of flexible services and have only recently been used by some states to fund more responsive supports. New health care policies--most notably, the concept of "managed care"--will present new challenges and opportunities.

Managed care refers to administrative controls over the use and costs of services. Managed care approaches are increasingly used to coordinate the delivery of health-related services and short-term medical care. In medicine and health care policy, opinions about managed care remain divided. Some observers believe that managed care holds promise for resolving quality and access problems and controlling the spiraling costs of medical and related services. Others have expressed concerns that managed care shifts decision-making from the local level to remote and impersonal organizations, creates significant access problems for persons with complex and significant needs, and contains inadequate consumer safeguards.

Since many states are moving rapidly to enroll people with developmental disabilities in managed care plans for long-term services and since this approach is largely untested in this area, it is **imperative** to define the principles and values that must underlie managed care in developmental disabilities.

WHEREAS:

Families of children with developmental disabilities should receive the services necessary to maintain their sons and daughters at home.

Families of children with developmental disabilities should have maximum choice over the nature and types of home and community-based services provided to them.

People with developmental disabilities should be able to exercise the same degree of choice about where and with whom to live as nondisabled persons in American society.

Adults with developmental disabilities--with the support of guardians, in exceptional circumstances--should be able to select the agencies or individuals from whom they will receive support.

Adults with developmental disabilities should receive supports and services based on their individual preferences and choices.

People with developmental disabilities should have the same opportunities as other American citizens to have homes of their own, meaningful work, and fulfilling personal life styles.

AND WHEREAS:

People with developmental disabilities, family members, and advocates must be centrally involved in decision-making and planning regarding the administration of services.

Decisions regarding services and support for specific adults and children with developmental disabilities, or their families, should be made as close as possible to the people being served and, specifically, in the communities in which they live.

Unmet needs for services for people with developmental disabilities and their families exist in virtually every state and community.

Neither public bureaucracies nor large private corporations have demonstrated widespread success in administering local services responsive to individual needs.

Operators of congregate settings have not produced evidence to demonstrate their cost-effectiveness or superiority in the quality and responsiveness of their services over supported living and individualized home ownership approaches.

People with developmental disabilities and their families are not commodities, and organizations must not be permitted to realize unreasonable benefits from addressing their needs.

The effectiveness of managed care or health care organizations in administering long-term supports and services for people with developmental disabilities and their families has not been demonstrated.

THEREFORE, WE, as representatives of associations or as individuals, endorse the following principles if and when managed care is implemented:

Managed care must not be used to limit the supports and services people with developmental disabilities need to live successfully in the community.

Managed care should discourage placement in congregate facilities and encourage services that support people with developmental disabilities to live in their own homes and to participate in the everyday life of their communities as citizens, workers, and students.

Managed care must be administered in a manner that permits decisions regarding allowable services to be made in local communities and by people knowledgeable about and chosen by the specific individuals to be served.

Among the options available through managed care must be subsidies and individual financing options that enable people with developmental disabilities or their families to purchase services from either certified agencies, generic service providers, or private individuals.

Funding for services under managed care must be sufficient to support people with the most intensive needs to live in the community.

Cost savings realized through the more efficient administration of services must be committed, first, to addressing unmet needs for long-term support of people with developmental disabilities and their families.

Managed care organizations must be evaluated by the interest in and commitment to the communities they serve and their sensitivity to the racial and cultural heritage of members of those communities, as well as by the accessibility, quality, responsiveness, and cost-effectiveness of their services.

People with developmental disabilities, their family members, and advocates must be involved in all planning and decision-making regarding the implementation of managed care.

Proponents of managed care must demonstrate the benefits of this approach in terms of accessibility, quality, and responsiveness of services and the achievement of cost-containment goals.

--July 1996

Developed by the Center on Human Policy at Syracuse University, Putting People First, a national project funded by the Robert Wood Johnson Foundation and the Institute on Disability at the University of New Hampshire, and Responsive Systems Associates, 1996. Please feel free to reproduce this statement.
This statement is available in Braille, large type, audio cassette, or computer disk upon request.

REPRINT: KEEPING THE FAITH: SYSTEM CHANGE, MANAGED CARE, AND LONG-TERM SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

KEEPING FAITH

SYSTEM CHANGE, MANAGED CARE, AND LONG-TERM SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

A Working Document

December 1996

National Association of State
Directors of Developmental
Disabilities Services, Inc.

About this document

Over the past two years, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) has devoted a considerable amount of time and resources to assessing the pros and cons of using managed care techniques to reconfigure the delivery of services and supports to people with developmental disabilities. Among the results of this work to date are:

- the preparation and distribution of the nation's first comprehensive position statement on managed care and long-term supports for individuals with developmental disabilities;
- the publication of a groundbreaking guidebook on managed care and developmental disabilities services,* which has been widely acclaimed and frequently cited as the seminal work on the subject;
- the co-sponsorship of six national and statewide training seminars on managed long-term supports,* as well as participating in literally scores of similar workshops and meetings sponsored by other organizations; and
- the provision of technical assistance to more than a dozen states that are in various stages of exploring the prospects of restructuring their MR/DD service systems along manged care lines.

Based on these experiences and the realities of the current public policymaking environment, we are convinced that:

(a) over the next few years many states will be forced to restructure the financing and delivery of long-term supports to persons with developmental disabilities in order to avoid a steady deterioration in the quality and accessibility of services; and

(b) the intelligent, value-based adaptation of managed care techniques can play an important role in enabling public developmental disabilities systems to respond effectively to this challenge.

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* This work was undertaken in collaboration with the Human Services Research Institute, Inc. of Cambridge, Massachusetts.

We recognize that managed care is fraught with uncertainty and peril. However, we also are convinced that, unless public developmental disabilties service systems become more cost-effective and accountable for valued outcomes, they will be less and less able to fulfill their mission and be increasingly subject to privatization. In the absense of a forthright response to these issues, we are profoundly concerned that existing service systems will be absorbed into managed care arrangements that serve interests other than those of the individuals and families who are the intended beneficiaries. If managed care comes to public MR/DD service systems, all key stakeholders should be involved in designing the state's basic approach in order to assure that the best interests of people with disabilities and their families remain paramount.

This white paper summarizes NASDDDS' views regarding the basic challenges which public MR/DD service systems face today; it explains why we believe that such systems will have to be realigned and outlines the principles and policies that should guide this realignment process. The paper is labelled a working document because it should not be viewed as the final word on the subject. Instead, our aim is to stimulate discussion and debate within the community of individuals who are committed to the values we share. These values are reflected in the Association's mission statement and guiding principles, which specify in part that NASDDDS will "...assist member states to build a person-centered system of services..." in which "...people with developmental disabilities have a right to:

(a) be treated with dignity and respect;

(b) be independent and make individual choices;

(c) participate in family and community life;

(d) have opportunities to maximize their full potential; and

(e) receive outcome-based services and supports."

CURRENT POLICYMAKING ENVIRONMENT

Nationwide, hundreds of thousands of indiviuduals with developmental disabilities and their families rely on long-term services and supports provided through publicly-funded developmental disabilities service systems. The central mission of these systems is to enable individuals with developmental disabilities to live and work in their communities, achieve self sufficiency, and excercise their full citizenship rights.

Over the past two decades, states have made major strides in improving the quality and cost-effectiveness of publicly-funded developmental disabilities services. The number of individuals residing in costly, segregated public institutions has been cut in half and scores of such facilities have been closed. States have aggressively expanded their home- and community-based waiver programs while de-emphasizing the development of expensive intermediate care facilities for persons with mental retardation and related conditions (ICFs/MR). States also have initiated and rapidly expanded family support and supported living and employment programs that more effectively meet the needs of their customers and make better use of scarce public dollars. More attention has been focused on improving the quality and accessibility of publicly-funded services as well.

A great deal has been accomplished, but much more remains to be done. Trapped between rising consumer expectations and tighter budget constraints, public MR/DD service systems today face enormous challenges, including:

- **Limitations on federal Medicaid payments to the states.** Currently, federal-state Medicaid dollars underwrite 70 percent of the operating costs of public developmental disabilities systems. But with both President Clinton and Republican and Democratic Congressional leaders supporting a balanced federal budget, legislative steps to contain the growth in federal Medicaid outlays are inevitable. Reduced access to federal Medicaid dollars will have serious consequences for developmental disabilities services as well as the public system's capacity to respond to the legitimate needs of people with developmental disabilities and their families.

- **State Medicaid cost containment initiatives.** States are intensifying their efforts to contain Medicaid spending, particularly through the application of managed care approaches across a wider spectrum of Medicaid recipients and services. Accounting for 35 percent of all Medicaid spending, long-term care services -- including Medicaid-funded ICF/MR and home and community-based services for people with developmental disabilities -- are not likely to be exempt from these cost containment initiatives.

- **Shifting federal and state budget priorities.** Federal domestic assistance is being cut in order to reduce the federal deficit. Furthermore, human services programs are being assigned lower priority in some states due to other pressing budgetary priorities.

- **Waiting lists.** Despite the steady growth in funding for developmental disabilities services over the past decade, most states today have long waiting lists for services. In some states, these waiting lists have climbed so high that individuals have little prospect of receiving services except in dire emergencies.

- **Growing demand.** Service demand will continue to grow for the foreseeable future due to a host of complex demographic factors, including the increased longevity of individuals with severe disabilities and the higher expectations of families that have had access to early intervention and special education services during their children's formative years.

Public developmental disabilities systems face a turbulent, challenging and unsettled future. At stake is their ability to respond to the critical needs of individuals and families in a timely, reliable, and effective manner.

The widening gap between available resources and consumer demand is confronting state and local officials with thorny policy choices. Should the gap be closed by narrowing eligibility for services? Should the range of services and supports be cut back? Should access to certain services be narrowed? Should systems operate on a triage basis?

These choices have enormous implications for the future role and mission of public developmental disabilities systems.

There is a distinct possibility that public developmental disabilities systems will be swept up in broader statewide managed care initiatives. If so, the result could be narrower access to specialized developmental disabilities services and the substitution of generic assistance that is not well suited to the purpose. There are legitimate fears that under managed care, essential values -- individual and family choice, community integration, and person-centered service delivery -- would be subordinated to economic interests.

The application of managed care concepts and approaches must be based on solid public policy principles, goals, and objectives. Managed care can work in the best interests of individuals and families only when it is employed as an instrument to secure improved efficiency, measured against performance and outcome standards that embrace essential policy goals and values.

THE SYSTEMS CHANGE AGENDA

If public systems are to keep faith with their fundamental mission of furnishing effective supports to people with developmental disabilities and their families, **all system stakeholders must confront today's harsh realities and agree on systematic changes** that will place such systems in a better position to carry out their mission. The consequences of failing to act are very high.

A central element in this system change agenda must be productivity improvements -- i.e., optimizing services and outcomes within the constraints of a global budget. The resolute pursuit of this objective is absolutely necessary if public systems are to withstand pressures to define away the problem by narrowing eligibility or constraining access to essential services. Faced with the prospect of capped funding and rising demand, **public systems must adopt "what's needed, no more, no less" as a practical operating philosophy.**

Current public systems are burdened with both state- and federally-imposed rules, regulations, and funding methods that create enormous barriers to the cost-efficient delivery of services and supports to individuals with disabilities and their families. Funding streams are categorical and fragmented. Slot management approaches often result in a "one size fits all" system which furnishes people with what is available not what is most cost-effective or what they really want.

Fee-for-service payment systems penalize service providers for using dollars more efficiently and create other barriers to flexibility and agility in delivering person-centered supports. The regulation of service systems remains grounded in process and paper. **New approaches to rewarding exemplary performance and achieving valued outcomes must be developed.**

As a result of federal policies and other factors, many public developmental disabilities systems are over-invested in costly service models. The financial burden of maintaining such models has foreshortened the capacity of service systems to respond to the needs of youth transitioning from school to adulthood or to step in promptly to meet the needs of individuals when their families no longer are able to provide supports. **States need to accelerate the shift away from costly service models by emphasizing publicly-funded supports that are blended with other natural and community supports.**

System change is threatening. It is marked by turbulence and uncertainty. However, it is abundantly clear that, **unless productivity is improved, public developmental disabilities systems will be less and less able to carry out their mission.** Waiting lists will become longer and longer. It will become increasingly difficult to provide high quality services and supports. **Maintaining the status quo will have particulary disastrous consequences for people who need supports but are locked out of the service system.**

System change must be anchored in and constantly referenced to the essential mission of public systems: supporting people with disabilities to live everyday lives in their communities. System change must be continuously informed by person- and family-centered values.

A MANAGED CARE APPROACH TO RESTRUCTURING SERVICE SYSTEMS

The intelligent, informed, value-based adaptation of managed care approaches can serve as a platform for reconfiguring and, thereby, improving the productivity of public developmental disabiities systems and strengthening the emphasis on valued outcomes. Managed care approaches -- intermediaries responsible and accountable for systewide performance, capitation and risk assumption, managed utilization of costly services, cost savings incentives, and performance indicators -- provide promising tools for system improvement.

Managed care techniques can help public developmental disabilities systems to replace fragmented, categorical funding with single-stream approaches that deploy dollars more flexibly to meet the unique needs of each individual. System incentives can be created to foster improved productivity. Managed care offers new opportunities to reconfigure systems along customer-driven and directed lines. Process regulations can be replaced by objective measures of the service system's performance in achieving desired public policy outcomes.

Still, there is scant experience in applying managed care strategies to the delivery of long-term services and supports. Important differences exist between the delivery of long-term supports and health care services, where there is more experience with managed care approaches. Health care touches one aspect of an individuals life; long-term supports, in contrast,

18

affect many different facets of an individual's life. Moreover, experiences with managed health and mental health care raise important cautions concerning the interplay between economic incentives and maintaining the integrity of service delivery.

In public developmental disabilities systems, the **introduction of managed care must be approached cautiously** and with full recognition that new and distinctive managerial strategies will be required to successfully adapt managed care technology to the needs of people with life-long disabilities and their families. **It is enormously important that system stakeholders play a central role during all stages of defining how such techniques are to be applied** if the end result is to be a service system that advances shared beliefs and leads to valued outcomes.

INSTITUTING A MANAGED CARE SYSTEM

Any attempt to accomplish systemic change through a managed care approach must be framed by public policies that clearly articulate the central goals of the public system while ensuring that the interests of people with developmental disabilities and the public at large are protected. A suggested policy framework for the introduction of managed care to MR/DD service systems is outlined below.

Managed Care Framework

- *The central mission of the public system should be to enable individuals with developmental disabilities to live everyday lives, achieve self-sufficiency, exercise self-determination, and become integral, valued members of their communities;*
- *Individuals, families, and service providers should maximize the use of natural supports and other community assets in meeting the needs of each person;*
- *Individuals and families should have access to necessary and effective services and supports consistent with the limitations imposed by available resources;*
- *The responsibilities of the public system in responding to individuals in crisis should be clearly delineated;*
- *Family supports should be emphasized, both as a means of making more effective use of scarce resources and as a firm foundation for building circles of community support for individuals with disabilities;*
- *Individuals and families should be given the option of directing the delivery of services and supports within reasonable policy parameters;*
- *The service system should be managed on the basis of performance and outcomes;*

Managed Care Framework (Cont'd)

- *Consumer rights should be clearly articulated and consistently applied;*
- *Protections of individual health and safety should be vigorously enforced without compromising individual control and self-determination;*
- *Consumers and families -- as well as other stakeholders -- must be granted ample opportunity to participate in system redesign, procurement decisions, oversight, and evaluation;*
- *Cost savings which are achieved through system restructuring should be earmarked for waiting list reduction and/or quality improvement initiatives; and*
- *The system should be fully accountable to consumers, public officials, and taxpayers, including continuous legislative oversight of the design, implementation, operation, and outcomes of the new system.*

A well-articulated policy framework is absolutely vital to ensuring that managed care concepts are instituted in a manner that serves the best interest of individuals with disabilities, their families, and the general public.

MANAGED CARE DESIGN PRINCIPLES

The introduction of managed care approaches to the delivery of publicly-funded services and supports for people with developmental disabilities must be framed by the public policy principles outlined above and be the end-product of a design process that is grounded in the following guidelines and principles:

- All state and federal funding for long-term services and supports to people with developmental disabilities should be consolidated in order to promote integrated service delivery and global system management;
- Such funding should be carved out (rather than folded into a broader managed care system) and administered under a separate plan that is crafted specifically to meet the long-term support needs of individuals with developmental disabilities and their families. This plan should include formal mechanisms for coordinating the delivery of developmental disabilities services with those managed by other public systems that affect the well-being of such individuals, including health care and mental health services;
- The developmental disabilities service authority (DDSA) in each state, in partnership and collaboration with individuals, families, and other stakeholders, should play a central role in designing, implementing, and operating the system. DDSAs, in tandem with other responsible

state agencies, must be held accountable for plan perfomance. The DDSA also must be equipped with the authority and the resources to manage the system, including the enforcement of contractual requirements, evaluation of system performance and outcomes, protection of consumer rights, and the assurance/improvement of service quality;

- The managed care plan must clearly define: (a) eligibility; (b) the services and supports to be furnished to eligible individuals; (c) the obligations of managed care entities in ensuring the timely, effective delivery of benefits defined in the plan; (d) standards for the procurement of managed care entities; (e) consumer rights (including prompt resolution of consumer grievances); (f) service provider credentialing standards; (g) the methods to be used in collecting and employing performance and outcome data; and (h) risk sharing arrangements;

- The plan should seek to provide all eligible individuals with access to needed and desired supports. To the extent that resources are inadequate to support the delivery of necessary services to all enrollees, the plan also should specify the strategies for achieving universal access to supports within legitimate time frames, including methods of redeploying the savings resulting from productivity improvements;

- Service decisions should be based on person- and family-centered assessments and planning processes anchored in the fundamental public policy aims that frame the system;

- The plan must provide for consumer-directed options that enable individuals and families to self-managed supports. These options may include vouchers, individual budgets, cash and counseling approaches, and other recognized and accepted models of support that will enable individuals and families to excercise self-determination, encourage the development of consumer collaboratives that make it possible for individuals and families to work together as a "purchasing block", and expand the network of supports beyond traditional service providers. The use of these options must be subject to appropriate safeguards. Accountability for the use of public funds must be retained;

- The plan should be based on decentralized decision-making and community-based management in order to foster effective interaction with natural and other community supports;

- Individuals and families must have *bona fide* choices among service agencies, including non-traditional vendors. Managed care organization procurement policies should foster comprehensive provider networks/panels;

- Capitation methods must be risk-adjusted to ensure that funding is adequate and, consequently eligible individuals, regardless of the severity of their disability, are able to access needed services and supports;

- Risk bearing arrangements should be phased-in gradually. Provisions should be made for the use of stop-loss, reinsurance, and other risk sharing arrangements in order to reduce potential conflicts of interests in meeting the needs of individuals who require intensive services and supports;

- Plans must contain adequate provisions for rapid-response crisis services, including clearly fixing responsibility within the system for the provision of such services;

- Individuals and families must have access to grievance and appeal mechanisms designed to fairly and rapidly address disputes arising from decisions made by the managed care entity and the individual/family;

- The plan must contain appropriate and adequate safeguards to ensure access to a broad range of services and supports, includng "grandfathering" participation by existing providers during initial implementation and having appeal mechanisms for use when providers are adversely affected by the contracting decisions of managed care entities;

- Managed care initiatives should be implemented on a multi-year basis, employing, whenever feasible, pilot projects and interim milestones to assess the soundness of the approaches being undertaken; and

- Procedures should be included for updating the managed care plan as well as the contracts implementing the plan in order to accommodate lessons learned and make necessary adjustments in provider payments.

Careful system design, based on the preceding guidelines and principles, is absolutely essential to ensuring that a coherent, well-articulated and accountable managed care system operates in the best interests of individuals, families and the general public.

MANAGED CARE ORGANIZATIONS

The selection of entities to serve as managed care organizations is enormously important. These entities play a pivotal role in any managed system. Public policies governing the procurement of such entities must ensure that managed care organizations meet minimum standards and demonstrate essential capabilities. People with disabilities and their families should play a substantive role in the selection process. These standards include:

Policies Governing MCO Procurement

- *A mission-based, person- and family-centered organizational philosophy;*
- *Demonstrated experience in managing the delivery of services and supports for people with developmental disabilities;*
- *The delineation of, and a central role for, people with developmental disabilities and their families in organizational governance, quality improvement, and evaluation;*

Policies Governing MCO Procurement (Cont'd)

- *A commitment to promoting innovative support strategies, including consumer-directed alternatives;*
- *A solid track record in working constructively with service provider agencies to achieve improved performance and responsiveness;*
- *Clear organizational capabilities to fulfill the requirements spelled out in the procurement specifications that are based on the managed care plan;*
- *Demonstrated capabilities in establishing effective and productive linkages with other community resources and organizations;*
- *Financial solvency;*
- *A well-articulated quality assurance and quality improvement plan;*
- *Willingness to contract on a performance basis, including the use of incentives and penalties based on negotiated benchmarks that address access to services, timely response to consumer needs, consumer satisfaction, and desired outcomes; and*
- *An effective management information system, plus appropriate equipment and technological capabilities.*

In selecting managed care entities state policies should give preference to non-profit organizations and/or existing, statutorily recognized local administering agencies.

In addition, states should encourage the development of multiple, locally-based managed care organizations in order to foster effective ties to local communities.

CONCLUSION

Public developmental disabilities service systems must confront the enormous challenges posed by modifications in federal and state policies which are likely to impose strict limits on the dollars available to meet current and future service demand. These systems must embrace productivity improvement as a central goal while keeping faith with their core mission and values.

Managed care approaches can be valuable tools in unifying existing service systems and allowing them to deliver "what's needed, no more, no less" effectively and efficiently. Service systems must be designed to advance the essential public policy aim of enabling people with developmental disabilities to live full, productive, self-determined, everyday lives in their communities. Individuals with disabilities, their families and other stakeholders must participate in the redesign process and have meaningful roles in the ongoing management of the system. The central aim should be to create a system grounded in person-centered support principles, including consumer-managed, consumer-directed service alternatives, that offer real opportunities to link natural and other community resources with public supports to best meet the needs of the target population.

These outcomes will be achieved only if the redesign process itself is informed by critical principles that ensure the coherent adaptation of managed care approaches to long-term supports for people with developmental disabilities. It is essential that the organizations chosen to carry out this redesign be carefully selected so that all stakeholders can be confident that the resulting service system will operate in the best interests of individuals and families.

REPRINT: OVERVIEW AND IMPLICATIONS OF MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

OVERVIEW AND IMPLICATIONS OF MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Theodore A. Kastner, M.D.
Associate Professor of Clinical Pediatrics
Columbia University -- College of Physicians and Surgeons
Director, Center for Human Development
Department of Pediatrics
Morristown Memorial Hospital

Kevin K. Walsh, Ph.D.
Director of Research
Center for Human Development
Department of Pediatrics
Morristown Memorial Hospital

Teri Criscione, M.P.A.
Administrative Director
Center for Human Development
Department of Pediatrics
Morristown Memorial Hospital

CONTACT:
**Kevin K. Walsh, Ph.D.
Center for Human Development, #60
Morristown Memorial Hospital
100 Madison Ave.
Morristown NJ 07962-1956
(201) 971-4095 (Center)**

(609) 794-5795 (KKW)

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OVERVIEW AND IMPLICATIONS OF MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

ABSTRACT

The inclusion of people with developmental disabilities in managed care as part of general efforts by states to enroll all Medicaid recipients in such plans is reviewed. Managed care is defined and the processes by which managed care organizations deliver services are explained. Escalating costs and utilization are discussed as the primary reason for the shift to managed care. The use of Medicaid Section 1115 waivers by states to include Medicaid recipients is explored. The relationship between acute health care and long-term care, and the utilization patterns in each, are briefly described. Finally, elements of managed care that are particularly important to people with developmental disabilities, such as care coordination, maintenance of quality, and individual and family support are discussed.

OVERVIEW AND IMPLICATIONS OF MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

During the last 30 years the landscape of services for people with mental retardation and other developmental disabilities has been substantially rearranged. Many people with developmental disabilities have found themselves more involved in their communities with increased control over their lives. However, health care is one area in which they have not been as easily and fully integrated into general community structures (Crocker, 1991; Hayden & DePaepe, 1991). Although there has been some success in providing health care in community settings (Minihan & Dean, 1990; Criscione, Kastner, O'Brien, & Nathanson, 1994), several challenges remain (Kastner, Walsh, & Criscione, 1994). Foremost among the challenges is including people with developmental disabilities, most of whom are Medicaid recipients, in the reshaping of the American health care system brought about by the recent expansion of managed care (General Accounting Office 1996a; 1996b).

The Medicaid program began in 1965 as Title XIX of the Social Security Act and has grown into the single most important program for people with developmental disabilities -- providing beneficiaries with both acute and long-term care (Braddock & Hemp, 1996). As Braddock and Hemp point out, Medicaid is a federal-state partnership that allows states flexibility in designing coverage and benefits. especially in certain waiver programs. For a more complete treatment of the genesis and development of the Medicaid program and how it has been used for people with developmental and other disabilities, readers are referred to excellent sources already in the literature (see Braddock & Hemp, 1996 and General Accounting Office. 1996a, 1996b).

The Growth in Medicaid Services and Managed Care

Although some form of managed care has been an element of many health care plans since the 1970s and 1980s, the debate over health care reform early in the Clinton administration rapidly accelerated the expansion of managed care. In the American workplace, managed care organizations such as HMOs have successfully contained health care costs while maintaining health for employed individuals (Shortell, Gillies. &

Anderson, 1994). By 1994, many employer plans had slowed increases in health care insurance costs and actually achieved modest decreases. In contrast, Medicaid expenditures in the early 1990s soared. Following steady increases of about 10 percent annually during the 1980s, total Medicaid spending increased by 31 percent in a single year (FY 1990-91). In the next fiscal year, it increased by 27 percent (Tudor, 1995). Although growth has slowed somewhat since then, among people with disabilities the absolute levels of Medicaid utilization and expenditures are striking. Braddock and Hemp (1996) reported that in 1975 over 11 percent of Medicaid recipients were disabled; 2.3 percent of recipients had developmental disabilities, just over half a million individuals. By 1992, this number had grown to over 1.3 million individuals with developmental disabilities who were receiving Medicaid benefits in all 50 states (Braddock, 1996; Braddock & Hemp, 1996). Similarly, state and federal Medicaid spending in 1980 totaled about $25 billion. By 1990 this figure had risen to about $72 billion and by 1995 Medicaid spending totaled $159 billion (General Accounting Office, 1996a). On an individual basis Medicaid payments for people with disabilities rose from $1,200 per user in 1975 to $7,956 in 1993 (General Accounting Office, 1996a; Health Care Financing Administration, 1995). Confronted with such rapidly escalating health care costs, nearly all states are considering the implementation of mandatory managed care programs for Medicaid recipients. This widespread shift by states to include Medicaid recipients in managed care systems may have profound effects on the lives of people with developmental disabilities.

Actually the shift of Medicaid recipients to managed care has already begun. In 1990 there were slightly more than 1.5 million Medicaid enrollees in managed health care programs nationwide. By the end of 1994 this number exceeded 8 million (Armstead, Elstein, & Gorman, 1995); in the following fiscal year -- June 1994 to June 1995 -- Medicaid managed care enrollment grew from just over 8 million to 11.6 million, representing more than 32 percent of all Medicaid recipients. Although a considerable number of Medicaid recipients are already enrolled in some form of managed care, this is not yet generally true of people with disabilities. However, since people with disabilities now comprise 15 percent of all Medicaid recipients, but account for about 37 percent of all Medicaid expenditures, there is a strong incentive to enroll them in managed care (General Accounting Office, 1996a, 1996b).

In addition to planning for shifting acute care into managed care some states are considering using managed care programs to administer long-term care services, although some authors have identified possible problems in this area (Smith & Ashbaugh, 1995; Ashbaugh & Smith, 1996). The impact such policy changes will have on quality and cost of acute health care for people with developmental disabilities remains speculative (Birenbaum, 1995; Kastner, et al., 1994). In this article we provide a background and introduction to managed care and consider the rationale for extending it to the Medicaid population with a focus on people with developmental disabilities. While Medicaid funds are used to provide both acute health care services and long-term care to recipients, in this paper our focus is acute health care. We touch on long-term care only to show its impact on overall spending and to point out implications for system development. In a companion article (Kastner, Walsh, & Criscione, 1997), we consider long-term care more fully while reviewing models of managed care and specialized managed care demonstration projects highlighting clinical and fiscal outcomes.

What is Managed Care?

In traditional fee-for-service plans, health care resources flow from a payer (usually an employer, insurer, or government agency) to health care providers (either public or private hospitals, physicians, and other health services) in exchange for services provided to the beneficiary. Consumers typically have access to the health care providers and facilities of their choice. Because access to services, especially in employer-paid plans, is not controlled, this form of health care reimbursement creates provider incentives for increased utilization. Coupled with expensive advancing technology, such increased utilization exacerbated rising costs. To contain costs employers turned to managed care.

Managed care is a system of health care resource allocation that emphasizes *management* of costs by controlling access through primary care providers ("gatekeepers"), and employing utilization review and other costs controls. Types of services, intensity of services, and specific service providers are determined, by contract, before enrollment of the person. Fees are set and the total cost of services per patient, called *capitation*, is determined beforehand. Although managed care does not necessitate capitation, such *prepaid* plans are an increasingly popular form of managed care. Actually managed care is moving beyond simple cost controls and utilization review as ideas such as *integrated service networks* and *organized delivery systems* appear (Shortell, et al., 1994). We will discuss these advancements in the companion article (Kastner, Walsh, & Criscione, 1997).

Prepaid managed health care is often delivered primarily by health maintenance organizations (HMOs) and by groups of affiliated providers known as independent practice organizations (IPAs) or preferred provider organizations (PPOs) which contract with payers on a prospective basis to provide specific services to a covered population. The increasing use of prepaid managed health care has been associated with a slowing in the rise of health care costs. As we noted, health care costs for employers actually decreased by 1 percent in 1994 as employees found themselves with fewer options for fee-for-service care. In 1995, HMO enrollment by employed individuals surpassed traditional health plan coverage for the first time (Bureau of Labor Statistics, 1995). However, health care costs continue to grow for individuals insured through public programs such as Medicaid and Medicare using traditional fee-for-service reimbursement plans. State governments are confronted with the choice of decreasing the number of individuals eligible for services, decreasing benefits, offsetting program costs through higher premiums, increasing taxes, or by generating special revenues through excise taxes on cigarettes or alcohol -- so-called sin taxes. These options have generally met with stiff opposition.

Managing resources more effectively is another way of improving resource allocation and creating new service options for all people, including those with developmental disabilities (Kastner, 1992; Medicaid Working Group, 1993). Given the public acceptance of managed care, and recognizing that prepaid health care delivery can control costs, states have begun to explore the expanded use of prepaid, managed health care to serve people who are poor, elderly, or disabled (e.g., Brown, Gurnick-Clement, Hill, Retchin, & Bergeron, 1993). While most states plan to limit the use of prepayment to acute health care services, some states are considering using managed care programs to administer long-term care services for people with developmental disabilities. These efforts rely on Medicaid Waivers as a means of containing health care costs and expanding coverage (Riley, 1995; Rotwein, et al., 1995).

Medicaid Waivers

States have always had the option, under Medicaid law without a waiver, to contract for managed care for Medicaid beneficiaries as long as enrollment was voluntary and that disenrollment was permitted at any time. As states move to *mandated* enrollment in managed care, waivers are required -- that is, the freedom of beneficiaries to choose health care providers is *waived*. Section 1915 Program Waivers and Section 1115 Demonstration Waivers are the two types of waivers designed to allow states to develop innovative solutions to health care problems. Section 1915(b) waivers, a type used extensively by states to enroll nondisabled Medicaid recipients in managed care, are more restrictive than Section 1115 waivers. Section 1115 waivers are broader in scope because they waive federal regulations concerning the types and enrollment mix in prepaid plans. This has paved the way for mandating the inclusion of Medicaid recipients with disabilities in managed care (Rotwein, et al., 1995).

At the time of this writing, 17 states have implemented managed care programs, with mandatory programs for people with disabilities in six states (Arizona, Delaware, Oregon, Tennessee, Utah, and Virginia). Some states, such as Oregon, Hawaii, Rhode Island, Kentucky, and Florida have approved 1115 waivers that mandate managed care and expand enrollment, but not necessarily to people with disabilities. Still other states have fully voluntary programs or perhaps specific voluntary programs for people with disabilities (General Accounting Office, 1996a). Regardless, nearly all states are in the process of developing and submitting 1115 Waivers or are considering doing so in the future (Riley, 1995). All of the approved waivers propose to achieve savings by using managed health care programs to serve current Medicaid recipients and to limit the cost of new enrollees. In addition, all of the currently approved waivers expand Medicaid eligibility. For example, all states, with the exception of Rhode Island, expand coverage to low-income families who were previously ineligible for Medicaid. Other states (e.g., (Tennessee, and Oregon) mandate the inclusion of the aged, blind, and disabled in managed care programs (Perkins & Melden, 1994).

Holahan, Coughlin, Ku, Lipson, and Rajan (1995) estimated the impact of hypothetical expansions of 1115 Waivers assuming that all states adopt the same expansion policies. They found that though Medicaid expansion would cover many previously uninsured people, such expansions would be quite costly, and require substantial savings in either state Medicaid programs themselves or in other state programs. These authors review the approach to funding this expansion in each state, noting expectations for increased efficiency and cost savings, cuts in other health care programs, and premium contributions or copayments as sources of funding for Medicaid expansion, as well as diversion of disproportionate-share hospital payments. Disproportionate share hospital funds are those payments hospitals receive from some states to offset losses incurred in providing care to people with disabilities. Thus, although 1115 waiver programs may increase access of people with developmental disabilities to health care providers, there are clearly potential drawbacks in terms of limits or unavailability of certain needed services.

Problems that must be surmounted if states are to effectively use Medicaid 1115 Waivers include the following: (1) Medicaid reimbursement rates are already low and may not be able to be reduced further in capitated arrangements; (2) hospital disproportionate share funding differs substantially from state to state; (3) states have a limited ability to raise new funds including those related to premium contributions and copayments; and (4) states may have limited ability to make cuts in other health care programs. Additional barriers exist in regard to economic and implementation issues, provider disinterest, and congressional opposition. In spite of these, however, Holahan et. al. (1995) conclude that the absence of federal health care reform provides an incentive for increased state participation in new demonstration and research projects through the waiver.

Additionally, there may be more challenges in the inclusion of people with *developmental* disabilities. For example, specific subgroups of people with developmental disabilities (e.g., people with profound mental retardation or people with quadriplegia) may be at increased risk as the allowable levels of certain types of services (e.g., inpatient hospitalization) are reduced. Additionally, access to mental health and behavioral services, including crisis services may be limited (Bouras, Kon, & Drummond, 1993; Davidson, et al., 1995). These and similar problems as well as several aspects of the quality of care may be at risk until adequate system components and quality improvement systems are included in managed care organizations serving people with developmental disabilities (General Accounting Office, 1996b).

Financing of Services for People with Developmental Disabilities

To chart a reasonable course for the future, it is important to understand the current organization and financing of the developmental disabilities system. Federal Medicaid funds administered by the Health Care Financing Administration (HCFA) have supported both long-term residential services as well as acute health care services for people with developmental disabilities. Additionally, support for developmental disabilities services include other state and federal funding streams that originate from many sources, as shown in Table 1.

Insert Table 1 Here

Note that funding for long-term care services is inextricably entwined with funding for acute health care services. Fiscal analyses of health care and/or long-term care services are frequently unable to identify and account for all costs because of the mixing of these funding streams (e.g., Fujiura, Roccoforte, & Braddock, 1994; Fujiura & Braddock, 1992). When the costs of residential, habilitative, and health care services are totaled, the costs of care in institutional and community settings are often found to be approximately equal (D. Braddock, personal communication, 1993; Knobbe, Carey, Rhodes, & Horner, 1995). However, such comparisons are quite complex in both the nature of the individuals compared and the estimation of the costs. For example, a recent study by Campbell and Heal (1995) reported that "cost bore a U-shaped relation to agency size, with intermediate-sized agencies being the least costly and large or small agencies being more costly" (p17).

Long-term Care Services

Total public spending for mental retardation and developmental disabilities services in the US, including long-term care. increased from $3.457 billion in 1977 to $17.228 billion in 1992 (Braddock, Hemp, Bachelder. & Fujiura. 1995). Adjusted for inflation. the 1988-1992 growth rate of 28 percent slightly exceeded the 1984-1988 growth rate of 25 percent. Most of this growth was due to expansion of services in the community through the Home and Community-Based Services (HCBS) waiver program. Although the number of large state facilities and the number of individuals living in them continues to decline, the number of small facilities, and individuals living in them continues to increase (Prouty & Lakin, 1994). While the costs of the Intermediate Care Facility for the Mentally Retarded (ICF/MR) program that typically supported institutional services grew only 5 percent between 1988 and 1992, the costs of the HCBS waiver program grew from $248 million in 1988 to over $4 billion in 1995. These figures show that the HCBS waiver has become the primary financing vehicle for residential services in most states, making this wavier program one of the fastest growing Medicaid expenditures.

A number of states developed demonstration projects under the Medicaid Community Supported Living Arrangements (CSLA) program authorized by Congress in 1990 (Burwell, Bachman, & Lakin, 1995). This program sought to reduce the costs of services and, nationally, figures from the demonstration projects suggest that this goal was achieved. Burwell. et al. (1995) report that annual per recipient expenditures in the CSLA programs averaged $9,142 compared to $23.343 in HCBS waiver settings and $66,720 for ICF/MR level care. However, since the authority of the demonstration projects in the eight demonstration states ended in 1995, this program has terminated. People who were served in this program typically continue to receive supports under HCBS waivers -- many of which were modified based on experience with the CSLA program. This may be a viable model in the future should residential services come under the auspices of some form of managed care.

At present. long-term care for people with developmental disabilities remains very costly. For example. as of June, 1994 there were 77,692 individuals living in state operated facilities nationwide, of which most (just over 67,000) were in larger facilities (Mangan, Prouty, Polister, & Lakin, 1995). In 1994, the average per diem cost for state

MR/DD facilities was $257 in facilities with between 1 and 15 residents and $225 in facilities with 16 or more residents. Long-term care has become almost totally supported by combined state and federal Medicaid payments. As Gettings (1994) points out, in fiscal year 1993 "...the states, collectively, spent more than $15 billion on such services...of this total, over $13 billion, or more than 85 percent of the total. was obtained through Federal-State Medicaid payments." (p. 105) In terms of relative cost. people eligible for the ICF/MR program represent less than 1 percent of the Medicaid-eligible population. However, services provided to them account for more than 9 percent of all federal Medicaid costs (Braddock et. al., 1995). In a period of intense interest in cost containment, this discrepancy has come under scrutiny, with the possibility that long-term care may eventually become capitated as part of a larger *managed social service* solution. (cf., Ashbaugh & Smith, 1996; Kastner, 1992).

Acute Health Care Services

As a group, people with mental retardation or other developmental disabilities have increased requirements for health care services (Beange, McElduff, & Baker, 1995; Rubin, 1987). However, little specific information is known about the overall utilization and costs of health care services for this group. Minihan and Dean (1990) detailed the outpatient health care utilization of more than 300 people with mental retardation in community settings and reported adequate access to primary care but a lack of specialty services. Other studies have focused on health care financing and utilization (Birenbaum, Guyot & Cohen, 1990) or inpatient utilization (Criscione. Kastner, Walsh, & Nathanson, 1993; Criscione. Walsh, & Kastner, 1995).

Birenbaum, et al., (1990) found that young adults with severe and profound mental retardation and children with autism experienced higher rates of outpatient utilization than did nondisabled comparison individuals. Higher costs were associated with increased utilization; about $1,000 for children with autism and $1,700 for young adults with severe/profound mental retardation compared to just over $400 for a typical US child. Inpatient hospitalization was above average as well. About 10 percent of children with autism and 25 percent of young adults with severe/profound mental retardation were hospitalized during a year. compared to only 3 percent of all children. Furthermore, higher average lengths of stay were found in this study. Similarly Criscione and her colleagues in a series of studies of inpatient utilization in New Jersey reported higher lengths of stay and increased costs in groups without care coordination (Criscione, et al. 1993; Criscione, et al., 1995). Recent work by this group (Walsh, Kastner, & Criscione, 1997) has also documented significant growth trends in inpatient utilization for people with developmental disabilities over a ten-year period as well.

Kronick and his colleagues (Kronick, Zhou, Dreyfus, Connors, Tobias, & Master, 1994) studied the cost and utilization of health care services for persons eligible for SSI in Ohio, Wisconsin, and Florida. The study population included all of the SSI recipients under age 65 in Ohio; all SSI recipients 15 years of age or older in Milwaukee County; and about one-third of the children receiving SSI in Florida. Thus the Florida sample in this group differs substantially from the Ohio and Wisconsin samples. People with mental retardation constituted between 2.4 and 2.9 percent of all people eligible for SSI in these states. The average costs of health care for people with mental retardation, in 1989 dollars ranged from $6,650 in Ohio, to $7,129 in Wisconsin, to $18,371 in Florida. Major service categories included in the analyses were acute inpatient hospitalization, outpatient hospital care, physician services/clinic, home health care, personal care attendant services, rehabilitation therapy, durable medical equipment, outpatient mental health services, pharmaceuticals, transportation, laboratory/radiology, dental services, transitional long-term care, and other miscellaneous services including Medicare crossover payments. Medicare crossover costs are those paid by Medicaid after costs covered by Medicare have been paid for individuals with dual eligibility (Medicaid and Medicare). These residual costs "crossover" to the Medicaid system. The single largest cost item in all three states was acute hospitalization (ranging from 32 percent in Wisconsin to 48 percent in Florida). As such it will likely become one of the major targets for cost containment in a managed health care system. The next most expensive service category was pharmaceuticals (ranging from 7 percent in Florida to 15 percent in Ohio). This analysis is remarkable for the variability found between states in service consumption. For example, while mental health services consume 9.3 percent of all resources in Ohio, this expense accounts for only 5.5 percent of health care expenditures in Wisconsin. Even more striking is the variability within groups. For example, in Ohio the average cost for the health care of a person with mental retardation was $6,650, yet the standard deviation was $15,207 showing that the expenditures are quite heterogeneous with some beneficiaries requiring far more than the average and some requiring far less.

In summary, people with mental retardation and related developmental disabilities appear to account for substantial portions of Medicaid spending as part of a larger group of all people with disabilities. This conclusion is supported by data from the Congressional Quarterly (1995) which identifies per capita spending on Medicaid services by state and type of beneficiary. People with mental retardation and developmental disabilities are not specifically identified, however, the average per capita cost for a person with a disability was $7,215 in 1993 ranging from $3,368 in Alabama to over $15,000 in Connecticut. These figures include long-term care costs. Compared to the US average for adults between 21 and 64 of $1,717, people with disabilities account for more than 4 times the amount of Medicaid dollars. These imbalances in spending between people with developmental disabilities and the general population, arising in both long-term care services and acute health care services, will likely be seen as amenable to *managed* solutions.

Elements Important to People with Developmental Disabilities

As states turn toward managed care, it is important to identify system components that will enhance outcomes for people with developmental disabilities.

Disability Specific Interventions. As people with disabilities move into managed care, certain disease categories may either be targets for utilization reduction or may be provided at inadequate levels if utilization rates are only based on the general population. For example, Walsh, et al. (1997) found that hospital admissions for mental health or neurological disorders resulted in the longest hospital stays and the highest hospital charges of all conditions for which people with developmental disabilities were hospitalized. Recent research suggests that when care coordination or other community-based supports such as those for psychiatric and behavioral crises are available, these negative financial outcomes are reduced (Davidson, et al., 1994; Criscione, et al., 1995).

It is imperative that provisions be made for services that are used more frequently by people with developmental disabilities.

Another example of the success of disability-specific planning has been reported using what are known as "model waivers" historically smaller waivers than the HCBS program. Some of these, known as Katie Beckett Waivers. allow states to transfer funds from hospital and institutional care to home care for up to 200 blind, disabled or technology-dependent children who require long-term institutional care. In a study of the cost-effectiveness of the Maryland Medicaid Model Waiver Program, the annual health care costs of 10 children (6 who were ventilator-dependent and 4 who were oxygen-dependent with a tracheostomy) were examined over the first year of enrollment (Fields. Rosenblatt, Pollack, & Kaufman, 1991). Overall, the mean annual home health care costs were $109,836 for ventilator-dependent children, which represented an annual savings of approximately $79,000 per child. For children with a tracheostomy who were oxygen dependent, the mean annual home health care costs were $63,650, with an annual savings of approximately $83,000 per child. When extrapolated to the full number of 50 eligible children allowed by the waiver application, the authors estimate that this program could save approximately $4,000,000 per year in health care costs. In some states these "model" waivers have grown much larger than 200 individuals and have demonstrated the strength of blending together conventional health care services and other community supports.

Care Coordination. Although, care coordination has been shown to be efficacious in the general population (e.g., Winstead-Fry, Bormolini, & Keech, 1995), it may be especially important for people with developmental disabilities in managed care systems. Care coordination refers to coordinating or providing linkage among the various services required to meet individual needs. Care coordinators have usually been included in social/health maintenance organizations (S/HMOs) in which they arrange for the provision of all primary, acute, and long-term care services through the organization. Research has indicated that care coordination can reduce utilization for people with developmental disabilities. For example, Criscione and her colleagues (Criscione. et al., 1993; Criscione, et al., 1995) reported that measures of inpatient utilization -- average length of stay, readmission rates, hospital charges, and hospital charges adjusted for case mix -- were reduced for patients who had received care coordination compared to patients admitted to the hospital by community-based physicians without the benefit of care coordinators.

As managed care incorporates more people with developmental disabilities, care coordination will also benefit patients by providing *clinical integration*, that is "...the extent to which patient care services are coordinated across the various personnel, functions, activities, and operating units of a system" (Shortell, et al., 1994, p. 52). In light of the values of inclusion in the field of developmental disabilities, the notion of integration as discussed by Shortell and his colleagues and by Stone (1993) is especially pertinent as health care for people with developmental disabilities moves toward managed care. One area, for example, noted by Stone is the integration of formal and informal services -- a task that is central to care coordination. Finally, the notion of care coordination as promoting inclusion is reinforced by the revised definition of primary care recently adopted by the Institute of Medicine which includes "...the provision of *integrated, accessible* services" (emphasis in original) as a key element (Donaldson, Yordy, & Vanselow, 1994).

Quality. Concerns about quality are especially important to people with developmental disabilities with the emergence of managed care. Fortunately, new models of quality management, developed from advances in process engineering and employing social science measurement techniques, make present-day objective, scientific approaches to quality improvement possible (Friedman, 1995). New quality elements include a number of ideas not previously part of the health care arena, such as health care report cards and benchmarking, patient satisfaction assessment, quality indicators, practice guidelines, and, in the public sector, federal and state oversight (Jencks, 1995). It is critical that quality initiatives already underway such as the standardization of information according to the Health Plan Employer Data and Information Set (HEDIS) as developed by the National Committee for Quality Assurance (NCQA) be employed and tailored, as needed, to address the needs of people with disabilities (Gold & Felt, 1995). Of particular importance to people with developmental disabilities, managed care organizations must have adequate internal quality assurance components that include consumers with disabilities, and use them to develop indicator measures specific to people with developmental disabilities when needed. Quality assurance and quality improvement activities must employ information from several sources, including management information, utilization data, clinical outcome indicators, functional health status measures, satisfaction surveys, complaint data, disenrollment statistics, and input from the community advisory committees.

Using such information, managed care organizations need to continuously address quality through annual work plans that include regular quality review as well as focused studies, that is, data collection and analysis on specific clinical indicators, some of which are directly pertinent to people with developmental disabilities. Additionally, management reports should regularly address recommendations for corrective action, with such corrective action constituting the "follow up" items for future quality assurance cycles. Finally, state review and federal oversight processes need to be mapped into the quality processes of managed care organizations. In this way, quality assurance will be sensitive to people with disabilities, while at the same time continuously assessing the quality of clinical and health care service elements.

Individual and Family Support. In their study of health care services for children and young adults with developmental disabilities. Birenbaum. et al. (1990) noted the following: (1) there was little emphasis on preventive care or habilitative services; (2) approximately 15 percent of parents experienced refusals or limitations in health insurance: and (3) about 10 percent of all families of children with mental retardation spent 15 percent of their income on health care for their children. In addition. the stress on families as caretakers is reflected in the extraordinary amount of time required for providing care. In one study of children with severe quadriplegia, the average time spent by family members providing basic care was 24.9 hours per week. Feeding activities accounted for 14.8 hours per week, or about 60 percent of basic care time (Barabas. Matthews & Zumoff, 1992).

Experiences such as these have prompted Birenbaum and Cohen (1993) to recommend the following: (1) personal care and family support should be included in health care services: (2) family-centered care should be promoted: (3) appropriate programs and care should be provided for young adults no longer in school; (4) financing and organizing of family supports and subsidies should be administratively simple; (5) Medicaid should be expanded to increase the use of home and community-based services; and (6) financial support should be provided to families. As more people with developmental disabilities have remained in or been returned to families, awareness of changes needed in service systems has grown (Herman & Hazel, 1991; Krauss, Simeonsson, & Ramey, 1989). In addition, families and family care settings now include people with developmental disabilities who also have challenging medical, behavioral, or psychiatric needs (Blacher, 1984; Hayden, Lakin, Hill, Bruininks, & Chen, 1992).

Outcome studies specifically addressing monetary supports for families are limited. One study examined the impact of the Michigan cash voucher program for over 3,000 families of children with severe disabilities (Herman, 1994). Under this program, each family received a monthly check of $256.74. Of 1,283 families responding to a 1988 survey most reported satisfaction with the subsidy program. Families reported that they used cash subsidies to purchase professional services (76.2%), respite services (67.2%) and parent support services (68.7%). Parents' rating for the services in greatest need included sitters, life planning, speech and physical therapy, and more assistance in teaching their children skills.

Providing health care services through managed care has the potential to address some of these needs and to enhance preventive care while minimizing out of pocket costs and coordinating services. At present, managed care systems are not likely to affect the availability of other service categories -- such as education, habilitation or training, and additional support services. However, since some of these services are closely related to the future need for long-term care, using managed care as a means of providing both acute health care and long-term care may create incentives for provision of such habilitative and support services. Specifically, if managed care providers are responsible for the costs of long-term care, they may find it more cost-effective to invest in family support services.

Interdisciplinary Assessment. Interdisciplinary assessment has long been a hallmark of service planning and delivery for people with developmental disabilities. Its importance is reflected in the individual planning structures in early intervention (the

Individual Family Service Plan), education (the Individual Education Plan), and residential/habilitative settings (the Individual Habilitation Plan). While there is anecdotal evidence that interdisciplinary assessment lends itself to better coordination of care and improved patient outcomes, there is increasing dissatisfaction with team functions relative to federal and state regulation (Holburn, 1990; 1992) . Perhaps for different reasons, some health professionals and disabilities advocates prefer to see the elimination of interdisciplinary models of care. Regardless, the cost effectiveness of interdisciplinary assessment in developmental disabilities has never been adequately assessed.

A recent article on comprehensive geriatric assessments for elderly people living in the community offers some insight into the potential role of interdisciplinary assessment and treatment in managed care systems. Stuck et. al. (1995) examined the cost-effectiveness of annual home-based assessments conducted by nurse practitioners working in collaboration with gerontologists. When compared to controls, elderly people who received the assessment had a significantly lower need for assistance in performing basic activities of daily living or admission to a nursing home during a three-year period. This was accompanied by an increased use of primary care physicians. These authors estimated the cost of the intervention to be about $6,000 for each year of disability-free life gained. Thus, there may be a role for annual assessment as a means of containing costs and improving care. Its effectiveness suggests that the current interdisciplinary model of services may be streamlined to create a more cost-effective alternative to the current interdisciplinary team processes used in the ICF/MR program.

Discussion

The findings and experiences reviewed here show that the costs of care for Medicaid recipients needs to be controlled and that managed care is the method being adopted by states to accomplish it. The success of managed care in providing adequate health care services for people with developmental disabilities may well rest on how carefully it is planned and whether it includes elements important to this group. To fully serve people with developmental disabilities managed care must address coordination of care and, possibly, individual and family supports since the need for such supports is driven, in part, by a perceived lack of health care services. Managed care may improve the ability of families to care for disabled children by improving access and coordination of health care services. Additionally, respite and other support services may reduce the need for long-term care.

Although there may be some clear advantages to managed care for people with developmental disabilities there are some clear disadvantages as well, foremost among them are access and quality issues. Table 2 identifies several advantages and disadvantages of managed health care for people with developmental disabilities. However, the nature of managed care is rapidly changing and will undoubtedly change further as states implement Section 1115 waiver programs. As these programs are developed there are clear opportunities to include elements that are important to people with developmental disabilities. To take advantage of these opportunities it is important that people with disabilities and their advocates identify areas critical to the quality of care they will receive. For example, questions remain about the nature and extent of care coordination and integration of care as well as some of the other elements identified in this paper that will be included in managed care contracts. Integration and quality assessment issues may be especially important since people with disabilities often experience associated functional deficits or other complications that cut across life areas. People with developmental disabilities and their advocates will want to know whether and how interdisciplinary processes will be incorporated into managed care systems.

Insert Table 2 Here

Similar issues exist in the areas of quality assurance, quality improvement and consumer satisfaction. It is important that the developmental disabilities community clearly articulate a consensus vision of quality in health and long-term care and that it adequately communicate this to state Medicaid divisions and managed care organizations. For example. HCFA has promulgated guidelines for quality assurance under its Quality Assurance Reform Initiative (QARI) that are more extensive than those typically found in commercial employer-paid HMOs. QARI guidelines require HMOs, for example, to include consumers in the quality assurance processes and assure consumers a voice on quality assurance oversight committees. However such guidelines, while sensitive to issues of consumer empowerment, are generally silent in regard to disability, especially developmental disabilities. Similarly, national accrediting bodies, such as NCQA, need to become cognizant of the needs of people with disabilities and include specific indicator measures in the HEDIS set.

Given its prominence and significant accomplishments, coupled with the level of private and public interest, managed care is rapidly becoming the predominant form of health care delivery in America. This inevitability suggests that people with developmental disabilities and their advocates must work to maximize the effectiveness of managed care in meeting their needs. Implementation of managed care must be compatible with professional standards and values and must be responsive to individual needs. While managed care programs offer the benefits of reduced out-of-pocket costs and protections from the financial consequences of catastrophic illness, these benefits will be of little use if access to needed services, both specialty medical and related support services, is severely restricted. Consumers, service providers, professionals, and advocates need to become familiar with managed care in general as well as with the specifics of local plans. In addition, consumer advocacy can shape the availability of services within specific managed care plans. Finally, creation of a non-discriminatory, cohesive, appropriate, and efficient health care system should lead to improvements in available managed care options as well as higher quality health care services for people with developmental disabilities.

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Table 1
Funding Sources for Mental Retardation and Developmental Disabilities Services

Community Services	Institutional Services
State Funds	*State Funds*[a]
General state funds	General state funds
Local/county overmatch	Local/county overmatch
SSI state supplemental	Other state funds
Other state funds	
Federal Funds	*Federal Funds*
ICF/MR	ICF/MR[a]
HCBS Waiver	Title XX/SSBG[b]
Model 50/200 Waiver	Other federal funds[b]
SSI and ADC funds (from Waiver participants)	
Other Title XIX programs	
Title XX/SSBG programs	
Other federal funds	

[a] Public and private facilities
[b] Public facilities only

(Adapted from Braddock, Hemp, Bachelder, & Fujiura, 1995)

Table 2

Potential Advantages and Disadvantages of Managed Health Care for People with Developmental Disabilities

Advantages	Disadvantages
- Identified primary care provider	- Limited choice of primary care provider
- Identified care coordinator	- Limited choice of care coordinator
- Incentives for preventive health care	- Providers unfamiliar with consumer's disabilities
- Care Coordination	- Utilization control mechanism reduce specialty access
- Reduced paperwork	- Incentive to exclude consumers with higher-than-average costs
- Reduced out-of-pocket expenses	- Limited choice / access to specialists familiar with disabilities
- "One stop" access to care at many staff model HMOs (e.g., lab, pharmacy, and other ancillary services on-site)	
- Protection against catastrophic illness	

REPRINT: TECHNICAL ELEMENTS, DEMONSTRATION PROJECTS, AND FISCAL MODELS IN MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

TECHNICAL ELEMENTS, DEMONSTRATION PROJECTS, AND FISCAL MODELS IN MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Theodore A. Kastner, M.D.

Associate Professor of Clinical Pediatrics
Columbia University -- College of Physicians and Surgeons
Director, Center for Human Development
Department of Pediatrics
Morristown Memorial Hospital

Kevin K. Walsh, Ph.D.

Director of Research
Center for Human Development
Department of Pediatrics
Morristown Memorial Hospital

Teri Criscione, M.P.A.

Administrative Director
Center for Human Development
Department of Pediatrics
Morristown Memorial Hospital

CONTACT:

**Kevin K. Walsh. Ph.D.
Center for Human Development. #60
Morristown Memorial Hospital
100 Madison Ave.
Morristown. NJ 07962-1956
(201) 971-4095 (Center)**

(609) 794-5795 (KKW)

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TECHNICAL ELEMENTS, DEMONSTRATION PROJECTS, AND FISCAL MODELS IN MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

ABSTRACT

A general model of the structure and functioning of managed care is presented describings elements critical to service delivery for people with developmental disabilities. A number of technical elements of managed care systems are presented and reviewed in relation to the inclusion of people with disabilities. The elements described include: provider networks, fiscal elements, risk estimation, case-mix, management information systems, practice parameters and quality improvement. Several managed care demonstration projects are reviewed and finally, a multi-year hypothetical budget model including long-term care is presented as a framework for considering how managed care affects specific service structures. Implications for people with developmental disabilities are discussed.

TECHNICAL ELEMENTS, DEMONSTRATION PROJECTS, AND FISCAL MODELS IN MEDICAID MANAGED CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

As states shift Medicaid recipients, including people with mental retardation and other developmental disabilities, into prepaid managed care health plans it is imperative that consumers and other members of the developmental disability community understand how managed care works. In the past Mediciad provided acute health care through fee-for-service arrangements in which doctors, hospitals, and other health care providers were reimbursed for the type and number of services rendered. Following the reduction in health care expenditures achieved in the private sector through managed care (Shortell, Gillies, & Anderson, 1994), states are beginning to turn to managed care to provide for Medicaid beneficiaries (General Accounting Office, 1996; Kastner, Walsh, & Criscione, Part I, 1997).

Conceptually, managed care involves an organization assuming management control over three critical elements in the health care system (see Figure 1). First, managed care organizations (MCOs), paid either by employers or government agencies (payers), manage *access* to health care services by developing panels of credentialed providers, some of whom are primary care providers acting as "gatekeepers" for service access. Second, *financial incentives* are rearranged, typically through some form of contracted *prepayment*, that links revenue to careful service use. Thus at the end of the specified period (typically annually), the part of the premium payment that is unspeant represents profit. Third, actual *utilization* of health care services is further controlled through processes known as *utilization review* in which pre-approval is required for many services in relation to standard treatment protocols, called *clinical practice guidelines*. The intended results are that needless utilization of health care services is removed from the system, costs are reduced, and, because of prepayment, incentives are created that encourage providers to focus on promoting health rather than on treating illness. In traditional fee-for-service reimbursement systems, providers increase revenue by providing *more* services: in managed care systems, increases in revenue are related to providing *fewer* services. Quality management elements are also included to ensure that fewer or poorer quality services do not result from the desire to create additional profit.

Insert Figure 1 About Here

Unlike in fee-for-service systems, the possibility of revenue loss exists at all levels of managed care systems, including the payer level, the managed care organization, and the providers. Financial loss is characterized as *risk* and when risk is spread across the various entities in managed care systems it is referred to as *risk sharing*. In traditional fee-for-service systems insurers bore all the risk, passing excess costs back to the payer, typically an employer or government agency. Providers were generally protected from risk and were permitted to provide whatever level of services they deemed necessary. With prepayment, managed care systems divide financial risk among various elements of the system with the idea that risk will provide incentives for cost containment. Although conceptually simple, in actual practice managed care systems can be exceedingly complex, taking on many forms and producing a dizzying number of acronyms (Kongsvedt, 1993). The fundamental questions about managed care for people with developmental disabilities are: (1) whether the incentive systems in managed care will enhance access to services or preclude access to needed specialized services through rationing, (2) whether people with disabilities will really receive quality services, and (3) whether the shift to managed care for acute health care services will be followed by the inclusion of long-term care services.

Although many people with mental retardation and related disabilities have health care needs similar to the general population, as a group people with developmental disabilities generally require more health care services (Beange, McElduff, & Baker, 1995; Birenbaum, Guyot, & Cohen, 1990; Walsh, Kastner, & Criscione, 1997), and, in many cases, specialized services (Chicoine, McGuire, Hebein, & Gilly, 1994; Minihan & Dean, 1990). Since the thrust of managed care is to restrict access and to control utilization, managed care could be disadvantageous for people with developmental disabilities. On the other hand, managed care could improve access to health care services for many who have experienced severe access problems under fee-for-service systems in the past, particularly those individuals covered by Medicaid.

Managed care is already maturing beyond its early configurations as concerns about access, quality and comprehensiveness highlight the "value" in health care. One principle gaining prominence is that of *integration* as large managed care organizations develop into organized systems or integrated delivery networks. *Integration* here refers to coordinating care across providers, functions, activities, and operating units of a health care system (Shortell, et al., 1994).

According to Mezey and Lawrence (1995) there are at least four areas in which service integration could enhance efficiency: (1) acute and long-term care services; (2) administration and funding of home and community-based care; (3) formal and informal services; and (4) the integration of categorically distinct (mentally disabled, physically disabled, elderly, developmentally disabled) long-term care programs to become long-term care programs for diverse populations. Additionally, several states are reorganizing health and other social supports such that "wrap around" supports and lead case management or care coordination may emanate from different agencies. Accordingly, a variety of demonstration projects have been funded with the goals of containing cost, expanding the numbers of eligible individuals served, or reconfiguring the existing service system (Stone, 1993). These include fee-for-service health care demonstration projects, managed care demonstration projects with or without capitation, and projects addressing long-term care such as social health maintenance organizations.

Later in this paper we examine models of managed care taking as our starting point the description of a number of existing demonstration projects that focus on people with disabilities. However, first we examine critical structural components of managed care as they relate to people with developmental disabilities. Our purpose is to present some options on how the concept of managed care can be put into practice with this population, and, in general, to provide an overview of how managed care models might actually *work*.

Technical Elements of Managed Care

Provider networks. The success of managed care for people with developmental disabilities will, first and foremost, depend upon the nature of partnerships between managed care organizations and existing developmental disabilities health care providers -- including hospitals, primary health care providers, psychiatrists, neurologists, dentists, other medical specialists, and allied health professionals. These providers must begin to affiliate to create networks of providers which can then form partnerships with HMOs, other managed care organizations or state agencies. Network development should focus on highly qualified, accessible providers currently serving this population to allow people with developmental disabilities to maintain continuity of care with the health care providers of their choice. Since managed care will significantly increase competition, providers who are inefficient or lack quality will not be utilized. This vertical approach to integration will enhance efficiency by encouraging providers to be attentive to cost-effectiveness and quality. Thus developmental disabilities providers capable of bringing efficient alternatives to the marketplace will find their services in demand.

Traditional providers of long-term care may also benefit from forming networks. Since Medicaid dollars are the predominant means of funding community-based services, managed care provides an opportunity for funding for non-profit organizations which typically have not had relationships directly with health care payers. Indeed, if long-term care services are included in the shift to managed care, non-profit community residential providers must work in partnership with managed care organizations if they are to maintain funding. Such an approach seems foreign to many in the field based on a presumed *medicalization* of non-medical aspects of life (Ashbaugh & Smith, 1996; Krauss, 1993; Smith & Ashbaugh, 1995). However, it may be that as managed care brings with it an emphasis on health and wellness rather than illness, building community-based networks for support can be seen as an appropriate managed care activity. For example, the Robert Wood Johnson Foundation, one of America's pre-eminent *health* care granting foundations, has funded projects such as the Monadnock Self-Determination Project in New Hampshire (Shumway & Nerney, 1995), a project "...designed to help people with developmental disabilities who need long-term support determine the services they require to live successful and productive lives in the community" (p. 3).

Fiscal Analyses. Although analysis of fiscal data is a process, the outcome of the analysis -- the capitation rate -- derives from estimated levels of service and related costs, and forms a fundamental structural element in managed care. Extensive capitation rate-setting analyses have been conducted in the general population, but have only just begun in developmental disabilities. Unlike the general population, however, the monthly cost of providing health care to the Medicaid population is known. A preliminary analysis of health expenditures in the SSI population conducted by the Medicaid Working Group suggests that costs of care are increased for people with developmental disabilities (Kronick, et al., 1994). In addition, the distribution of costs among inpatient, outpatient, home care, pharmaceutical and other items differs substantially when people with developmental disabilities are compared to other disability groups and the general Medicaid population. Similarly, capitation rates will vary depending upon the covered benefits, eligibility, provider experience, and patient experience.

As analyses of utilization data in unmanaged populations of people with developmental disabilities progress, results should be compared to the cost and utilization experience for patients receiving managed health care services in various demonstration projects. Such analyses need to address the following: (1) the current levels of health care expenditures per recipient per month, (2) analyses of expenditures by type of service, (3) the level of expenditures, the number of users, and expenditure per user, for each service type, (4) the relationship between recipient characteristics and expenditures; (5) identification of the major providers of care, and (6) recommendations on reimbursement systems and benefit packages.

Risk Estimation. Predictions of both health care utilization and associated *risk* become more accurate as the size of the population "pool" increases, which has prompted the evolution of rather large managed care organizations. Capitation rates must be *risk-adjusted* based on the expected utilization and *case-mix* (see below) of particular groups (Epstein & Cumella, 1988; Newhouse, 1994). Since utilization has been found to be highly variable in people with developmental disabilities (Kronick, et al., 1994; Criscione, Walsh, & Kastner, 1995), it is important to understand its impact on risk and how this may affect specialized networks or larger managed care organizations. For example, as one analysis noted: "Many states believe that if the capitation rate is set at 90 or 95 percent of average Medicaid expenditure, that will reduce their expenditures on Medicaid services. However, this will only be true if the prepaid plans enroll "average" patients" (Leibowitz & Buchanan, 1990, p. 79). If utilization of the enrollees is above average, as is likely with people with disabilities, the plans may not be financially viable in the long run, even if money is saved in the short run.

The higher variance in utilization in people with disabilities can be overcome by increasing the size of the population (Wrightson, 1990). Therefore, if managed care organizations are interested in serving people with developmental disabilities, they may need to enroll as many individuals as possible. While many managed care organizations may initially compete to provide services to people with developmental disabilities, we believe that eventually, competition will be limited. In small states with fewer than 20,000 people with developmental disabilities, no managed care provider may express interest in the population. This may require the creation of regional consortia for the purposes of distributing risk. However, this concept may be difficult to implement.

Case-mix prediction. Accurate prediction of health care costs requires an ability to anticipate the types of patients who will be served (the *case-mix*) and the utilization and unit cost of services to be provided. In plans serving a variety of disabled populations, but not adjusting capitation rates for risk. fiscal stability depends upon the maintenance of the anticipated case-mix. If the case-mix changes, for example the program attracts many more enrollees requiring mental health services than other types of enrollees, adjustments would be critical to assure that service allocations are adequate. To be viable, specialized disability networks will need to be accurate in predicting the percentage of enrollees with each disability and their relative costs to the program.

At the same time, the availability of generic and specialty services in competition with each other tend to create case-mix problems. For example, patients with medical problems may elect enrollment in specialized systems that offer specific services which meet their needs. Conversely, healthy patients may enroll in generic MCOs because they have no current pressing health care problems. The net result of such self-referral by patients with more complex health care needs may drive up the costs of care in specialized settings. At the same time, the improved case-mix in the generic providers may provide "windfall" profits.

Capitation adjustment schemes, especially in Medicaid populaitons, are still under development (Kronick, Dreyfus, Lee, & Zhou, 1996; Wolf & Gorman, 1996). Given the heterogeneity of the developmentally disabled population with respect to health care needs. case-mix adjustment schemes will be increasingly important. Perhaps patricularly important to people with developmental disabilities is the potential to develop capitation based on *quality adjustments* (e.g., Hanchak, Schlackman, & Harmon-Weiss, 1996). In this arrangement providers can earn additional compensation based on the *quality* and cost-effectiveness of the care they provide to their patients.

Specification of benefit packages and prospective budgeting. Designing a benefit package and system of care requires collaboration and negotiation between different state agencies responsible for serving people with developmental disabilities. Defining a benefit package may prove to be difficult if health care and long-term care are to be funded under separate systems because these two services are currently blended. For example in ICF/MR settings, if health care services are separated from residential services, the long-term providers may be forced to negotiate with managed care providers for health care services currently provided within the ICF/MR program.

Further, accountability for services and supports typically associated with residential services will need to be assigned. Given the focus on cost-containment in managed care, it is likely that services such as behavioral services, rehabilitation therapies, and nursing support will be rationed. The result may be that managed care will provide a limited or capped service level of care (e.g., a limit of 20 annual contacts with a rehabilitation therapist or mental health professional) with the remainder of these services paid for on a fee-for-service basis by the long-term care system. In this scenario, there would be significant potential for cost shifting from the acute health care system to the long-term care system. However, approaches which preserve separate health care and long-term care systems may prove equally as difficult. Also, the impact of health care rationing on certification and continued reimbursement of long-term care providers is unknown.

Regardless, following the definition of an adequate benefit package, fiscal data analysis will allow managed care organizations to develop *pro forma* budgets to identify time frames for achieving financial and utilization outcomes. Note that if acute health care and long term care funding are pooled into a single stream and are no longer tied to categorical eligibility, a wide range of service options become possible. This will likely take the form of increased primary health care and expanded home and community-based options, such as individual and family supports and respite. Increased use of these options, however, will likely be offset by decreases in utilization of specialist and hospital care.

Management information systems. While most health care management information systems are concerned with utilization, cost, and reimbursement processes, health information systems can also serve to improve population health in the following ways by: (1) identifying the levels, trends, and distributions of health in the population served; (2) providing a basis for understanding the determinants of these different aspects of health; and (3) providing a basis for resource allocation that is effective in improving health (Wolfson, 1994). New management information systems, especially in MCOs serving people with developmental disabilities, should incorporate overall measures of population health as part of a family of health status and administrative outcomes. The system should link extended elements of networks and merge administrative and self-report data systems. Finally, such systems should be standardized, utilizing a template to gather health information from the system. In this way, not only will the reimbursement aspects of the system be served but so too will access and quality issues important to people with developmental disabilities.

Finally, a comprehensive and fully integrated management information system will serve people with disabilities by making it possible for the MCO to track specific enrollees, refine risk adjustment measures, define and measure appropriate outcomes relevant to people with disabilities, and generate values scales upon which aggregate health indices can be created.

Development of practice parameters and utilization review. Practice guidelines refer to codified approaches to medical care that are used in both diagnostic and therapeutic contexts. Such guidelines are useful for guiding provider behavior on a prospective basis, but they are also used retrospectively to assess quality (Kongsvedt, 1993). Most managed care organizations use practice guidelines to assure compliance and enhance practitioner skills, but also as a basis for managing utilization. However, some clinical practice guidelines currently in use are not appropriate for people with developmental disabilities because of significant differences in morbidity. The success of a managed care program serving people with developmental disabilities will depend upon the development of practice guidelines which address the specialized clinical areas associated with this group.

Encouraging providers to use the practice guidelines is at the heart of utilization review, a set of processes designed to bring the uncontrolled practices of fee-for-service systems under management control based on approved clinical practice guidelines and benefit package limitations. This necessarily involves changing human behavior. Thus general behavior change strategies such as fiscal incentives, rewards, sanctions, step-wise change, conflict resolution, and, iin some cases, disciplinary action, will be useful. Additionally, earlier appropriate management, for example in the form of care coordination, often obviates the need for negative practices in utilization review, since care coordination is associated with reduced utilization (e.g., Criscione, et al., 1995). Furthermore, recent research on developmental disabilities (Walsh, et al., 1997) suggests that large-scale utilization control mechanisms, such as the Medicare DRG system, may prove to be ineffective for people with developmental disabilities. Regardless, given the specialized needs of people with developmental disabilities, it is clear that care coordination, clinical practice guidelines, quality assurance and utilization review need to be closely linked in systems serving people with developmental disabilities.

Quality assurance and improvement. The measurement of quality in health care has been heavily influenced by management activities in private industry. Current standards are built upon Deming's principles addressing issues related to management commitment, statistical process control, and continuous improvement (Friedman, 1995). The Health Care Financing Administration has recently embarked on a program of measuring health care quality using an accepted definition of quality, explicit domains of measurement, and formal validation procedures characterized by face validity, construct validity, reliability, clinical validation, and tests of usefulness. Indicators of quality focus on process and outcome measures keyed to the range of service types, medical conditions, and payment systems (Jencks, 1995; Armstead, Elstein, & Gorman, 1995). Based on principles in total quality management this approach is extents traditional quality assurance activities into health care quality improvment systems (Gagel, 1995).

Quality assurance and quality improvement initiatives in the field of developmental disabilities have not attained this level of sophistication. There are no universally agreed upon definitions of health care quality, nor are there standardized processes or outcomes of care. It is likely that a quality assurance program for health care services for people with developmental disabilities will closely resemble those already in use in health care field, which focus on costs, utilization, outcomes and consumer satisfaction. Adaptation of general health care quality systems will require the development of state-of-the-art developmental disability practice guidelines, health care outcome indicator measures, adapted health status measures, and interpretable consumer satisfaction measures. Many of these quality development activities will need to be pursued in collaboration with HCFA and national accrediting entities such as the National Committee on Quality Assurance (NCQA).

Practitioner skill development and credentialing. Lack of experienced and skilled providers often proves to be the weak link in the system of health care for people with developmental disabilities. Investments must be made to improve and maintain provider skills. Although MCOs routinely review the *credentialing* of providers (i.e., obtaining and reviewing provider documentation such as their license, certifications, malpractice history, etc.), there will, nonetheless, be educational needs, especially in systems serving people with developmental disabilities. Birenbaum (1995) identifies a number of concerns about managed care settings two of which are directly relevant. First, he points out that widespread managed care will reduce the proportional number of practicing specialists, thus increasing competition for their services. Second, the reduced availability of specialists will place increased demand on the breadth of knowledge of the primary care providers.

The need for educational interventions are more important as the size of provider networks increases and the volume of patients seen by individual providers decreases. For example, providers with a case load of several hundred patients with disabilities are likely to have higher skill levels with disabilities than providers with only a handful of patients. This perspective has implications for the design and configuration of the provider network. For a network of many providers, which offers patients a greater range of choices, centers of excellence may be needed to provide consultation and education. New technologies for consultation and distance learning such as targeted continuing medical education newsletters, e-mail, and internet access will also be required.

Managed Care Demonstration Projects for People with Disabilities

To see how some of the elements described above actually function, we review a number of projects for people with disabilities already moving toward managed care. These demonstration projects are based upon three premises: (1) that health care coordination can contain costs and improve outcomes for people with developmental disabilities, (2) that managed care, with an emphasis on health care coordination, can be adapted to this population and serve as a vehicle for expanded use, and (3) that when individuals and families are provided greater fiscal control, they will appropriately "ration" services. These propositions are based upon early experiences with community-based demonstration projects and social health maintenance organizations (S/HMOs). Although evidence exists to support the first two points, the third has not been fully validated. In addition, the lack of external control in monetary family support models suggests that this policy direction could ultimately add to costs. Alternatives to cash-based models, such as voucher systems, may provide more control relative to inflationary trends in family supports and furthermore may provide data upon which to assess the efficiency of such programs.

The demonstration projects we describe illustrate the various ways management and coordination can be imparted into service systems. We point out the strengths and weaknesses of each, describe the particular disability group targeted, and review any available outcome studies. Some of these programs are more formally *managed care* programs than others, and one is an approved HMO; but all illustrate important lessons about controlling health care costs while maintaining access to quality services.

Social Health Maintenance Organizations (S HMOs)

These organizations are often associated with services for aging adults, going beyond HMOs by offering certain social services normally provided by state or local agencies in addition to typical managed health care services (Leutz, Greenberg, Abrahams, et al., 1985). Early projects had an insufficient number of healthy enrollees resulting in higher than expected operating costs, and although now beginning to operate balanced budgets, they have not achieved the goal of truly integrated health care delivery. Despite these problems a new generation of integrated demonstration projects for older adults is underway (Stone, 1993; Richardson, 1995). Similarly, there are a number of managed care demonstration projects for people with mental retardation and developmental disabilities which use a capitated model of financing. Most fall somewhere between HMOs and S/HMOs in the range of services provided.

Community Medical Alliance. The Community Medical Alliance (CMA) is a S/HMO in Boston serving people with severe disabilities (including spinal cord injury, cerebral palsy, muscular dystrophy, Huntington's disease) and AIDS (Master, Dreyfus, Connors, Tobias, Zhou, Kronick, 1995). The program grew out of Boston's Community Medical Group, a fee-for-service demonstration project. At the time of this writing its network included 13 primary care teams, comprised of physicians and nurse practitioners, and 8 hospitals. To support its primary care teams CMA contracts for the following services: acute general hospitalization, medical specialty services, home health care services, private duty nursing services, home infusion therapy services, day health services, adult foster care services, care and protection beds, mental health and substance abuse services, institutional hospice, skilled nursing facility and chronic disease hospital services, nutrition services, and medical equipment and supplies.

CMA is paid on a capitated basis. The initial monthly capitation rates were set at 95 percent of the estimated fee-for-service utilization: $1,998 per month for individuals with severe physical disabilities and $3,756 for those with AIDS. In 1993, CMA found actual medical costs to be much lower than this rate, around $1,300 per patient per month in the physical disability program and $2.950 in the AIDS program (Master, et al., 1995). While these savings are impressive, it should be noted that the initial capitation rates were only estimates. In addition, the small numbers of patients in the program suggest that one patient with a need for extraordinary care, such as bone-marrow transplantation or other experimental procedures, could have a significant negative financial impact on the program.

One of the unique aspects of CMA was the creation of a profit sharing agreement using a risk "corridor." A risk corridor is a limit placed on both profits and losses that an MCO negotiates with the payer, in this case the state Medicaid agency. Under this arrangement, CMA shares in the profits or losses up to a variance of five percent. Fiscal outcomes, profits or losses, above or below this amount either accrue to or are the responsibility of the state Medicaid agency. Follow-up studies of CMA suggest that rates of inpatient hospitalization , such as admission rates and length of stay, have substantially decreased. Furthermore, there appears to be a redistribution of resources from the hospital to the home and from specialty care to primary care. Finally, quality assurance monitoring has demonstrated a decreased rate of decubiti and associated hospitalizations, a particularly difficult and potentially dangerous problem for those served by CMA..

Two Unique Models

The I-Care Program. The Independent Care, or I-Care, Program represents a specialized or "boutique" model of managed care for people with specific disabilities. This program is a product of a partnership between the state Medicaid agency, the Milwaukee Center for Independence, and an HMO which is piloting a capitated managed care program for people with a variety of disabilities including substance abuse, mental retardation, and mental illness. Providers were recruited through the University of Wisconsin (Milwaukee). In this program, the state and its partners have also implemented a risk corridor profit sharing arrangement and provided stop-loss insurance. insurance that covers the costs of extreme cases. The project has a target of 3,000 enrollees.

Health Services for Children with Special Needs, Inc. Recently, the federal Health Care Financing Administration (HCFA) granted approval for the establishment of Health Services for Children With Special Needs, Inc. (HSCSN), an HMO in the District of Columbia for children who are eligible for Supplemental Security Income (SSI) (Corro, 1995). HSCSN began operation in December, 1995 and anticipates serving 3,200 children in the District providing all acute and long-term care services. The benefit package incorporates a unique care management program which includes a full interdisciplinary team process. This care coordination component serves to integrate all health services. long-term care, and other social services provided by the HMO. Individual care plans are reviewed and updated every six months or following a relocation. Not surprisingly, care coordination represents one of the major costs of this HMO.

Unlike other programs, HSCSN provides for both the acute and long-term care needs of its enrolled children. Fiscal analyses of pediatric SSI recipients in the District of Columbia (Corro. 1995) confirmed the belief that a disproportionate amount of resources are consumed by a minority of recipients. In a study of 2,600 children, expenditures totaled $29.8 million. However, 4.9 percent of children consumed 65.7 percent of the resources because 125 and 150 children are currently residing in out-of-home placements.

HSCSN is paid $1000 per month on a prospective basis and, in turn, reimburses primary care providers associated with the HMO on a fee-for-service basis at 85 percent of prevailing rates during the first two years of operation. Beginning in the third year HSCSN will begin paying its providers on a capitated basis, essentially sharing the risk with providers at that point. Given that HSCSN is a voluntary program, its overall success will depend in part upon its ability to convince families to relocate their children home from institutions and create savings which can be used to fund new community-based services. Accordingly, HSCSN has developed annual targets for the reduction of long-term care utilization as part of its business plan.

Care Coordination In A Fee-For-Service System

Morristown Developmental Disabilities Center. The longest running community-based health care program for people with developmental disabilities is the Developmental Disabilities Center (DDC) located at Morristown Memorial Hospital in Morristown New Jersey. During the past 14 years. the DDC has provided primary care. specialty services, and inpatient care to more than 2.200 patients. Research from the DDC (Criscione. Kastner, Walsh, & Nathanson, 1993; Criscione, Kastner, O'Brien, & Nathanson, 1994; Criscione, et al., 1995; Kastner, 1991; Walsh, et al., 1997; Ziring, 1987; Ziring, et al. 1988) has demonstrated that specialized care settings with large patient volumes stimulate expertise resulting in decreased inpatient costs through improvements in efficiency and effectiveness. The DDC has nurtured the concept of "critical mass" to achieve efficiency (Walsh. 1992), implying that similar gains in effectiveness and efficiency may not be possible in generic systems of care.

Research from this program found that care coordination resulted in hospital lengths of stay. readmission rates, and hospital charges similar to the general population. when corrected for diagnosis-related group (Criscione, et al., 1993; Criscione, et al.. 1995). For example, in the general population the average length of stay in New Jersey hospitals was 7.6 days compared with 7.1 days nationally (American Hospital Association, 1993), but for people who received care coordination by the DDC, the average length of stay was found to be 6.9 days. In contrast, the average length of stay for each admission of an adult with developmental disabilities who did not receive care coordination was 11.7 days in 1983, dropping to 10.1 days in 1991. At least some of the extended hospital stays were due, no doubt, to inadequate discharge planning resulting in prolonged hospital stays. Therefore, if care coordination services are targeted to such sub-groups, they may produce substantial gains relative to the investment.

The need and potential effects of care coordination services are not trivial. With neither care coordination nor managed care, health care utilization trends for people with developmental disabilities are often quite the opposite of the general population. For example, the most recent study in the DDC series documents that the nationwide implementation of a prospective payment system for inpatient care (diagnosis related groups, or DRGs) was not associated with a reduction in inpatient utilization and costs for people with developmental disabilities (Walsh, et al., 1997). On the contrary, total annual hospital days for adults with developmental disabilities in New Jersey increased 58 percent between 1983 and 1991. This increase was primarily a result of more frequent admissions rather than an increase in average length of stay. By contrast, for the general population of New Jersey during the same period, number of hospital days showed a 6 percent decrease under the prepaid DRG system.

In summary, the Morristown DDC and the Boston CMA models suggest that health care resources can be reallocated from acute hospitalization and specialty care to home-based services and primary care settings. Furthermore, these and the other models reviewed point to the importance of some form of care coordination in managed care for people with developmental disabilities. However, there is no conclusive evidence from either S/HMOs or the other demonstration projects that managed care can consistently reduce long-term care costs for people with developmental disabilities. Since the HSCSN program in Washington, DC will provide for both acute and long-term care needs, it may shed light on this question in the future.

A Hypothetical Managed Care Budget Model

As we have noted, despite potential dangers such as funding restrictions and issues of quality and consumer choice (e.g., Birenbaum, 1995; Smith & Ashbaugh, 1995), managed care could create incentives for improved access and cost-effectiveness across the continuum of acute and long-term care services for people with developmental disabilities. To promote interest and understanding, we present a hypothetical fiscal model of managed care incorporating long-term care services. Hypothetical four-year estimated budgets are presented highlighting the potential effects of managed care on resource allocation. Presented in terms of percent of total budget, the budget model reflects preliminary estimates intended only to illustrate the type of changes in service configuration likely to occur under managed care. It is partially based upon published actuarial data and outcome studies. but does not represent formal actual costs of any existing managed care system. The model includes four separate budget categories: (1) health care services, (2) habilitative care, and (3) long-term care. and (4) other, primarily administration and family support/respite services. Current health care services are taken to represent about 10% of total costs in this model. Health care services, without the long-term care components, in this budget represent acute care services likely, in most states, to be taken into managed care rather quickly. Considering these services alone, at 100 percent rather than 10 percent of overall premium, would serve as a budget model for the movement of acute care services into managed care.

Health Care Component

The health care services includes a care coordination component intended to improve the quality of care while reducing unnecessary utilization. The health care services part of the estimated budget shown in Table 1 compares estimated current resource allocation for health care services with resource allocation occurring over time in a managed care model. The current resource allocation estimates have been derived, on a percentage basis. from the cost distributions described in Kronick et. al. (1994) for three states -- Ohio, Wisconsin. and Florida. Changes over time in the *pro forma* budget are derived from our analysis of experience with generic managed care programs and demonstration projects for people with developmental disabilities. However. since capitation rates will vary by states and, in some cases, be altered by applications of risk adjustments. the actual capitated dollar amount is less important than the percentage of overall budget. Therefore, actual amounts are not shown in the hypothetical budgets presented here. Rather. figures in budget categories are presented as percentage of overall budget.

Insert Table 1 About Here

New costs for services in a managed system arise from costs associated with the following services: enriched primary services, increases in dental care, respite and family support services, care coordination, and interdisciplinary assessment. Additionally a portion of funds will be withheld by states to provide savings for the Medicaid system and, due to the MCO, there will be substantial increases in administrative overhead costs. Estimates for some of these items were derived from the literature. For example, Criscione et al. (1993), estimated the costs of care coordination in the DDC program at $668 in 1989 dollars; we used an approximate figure of only $500 member per year which is well below Criscione et al.'s average expenditure. To some extent such case management costs can be made up through higher levels of primary care reimbursement. Administrative costs in the acute health services portion of our managed care model increase 400 percent in the period, about 12 percent more than similar fee-for-service systems. Increased administrative costs are due to the following elements of managed care: (1) the management information system; (2) a quality assurance - quality improvement program; (3) the development, maintenance and dissemination of clinical practice guidelines; and (4) utilization review and clinical consultation activities.

In managed care such new costs are offset by estimated savings in other areas. For example, Criscione, et al., (1995) suggest that inpatient health care costs can be reduced by approximately 25 percent or just over 30 percent when adjusted for case-mix.. Since the DDC model is a fee-for-service model, thus we have used 31 percent for the reduction of inpatient costs. In addition, implications from experience and the general utilization literature suggest that ancillary rehabilitation therapies, mental health services and behavioral services will receive less funding under managed care. Mental health services provided through managed care will likely focus on psychopharmacological interventions instead of intensive behavioral or psychological treatments. Finally, funding for specialists, home health, durable medical equipment, drugs, Medicare crossover and hospital disproportionate share allowances are all cut in the managed care model. Medicare crossover payments are those not covered by the Medicare system for dually eligible (Medicaid and Medicare) individuals that "crossover" to the Medicaid system. Although many categories show reductions, recall that in managed care reductions in funding are not necessarily related to reductions in levels of service. Efficiencies should be created by managed care programs. Additionally, they provide leverage in the marketplace to obtain discounts for services from providers. As Table 1 shows. we estimate that three years may be required for a managed care organization to reach utilization targets and break-even.

Finally, note that disproportionate share costs (state funds provided to offset losses from serving people with disabilities) were estimated to be only 1 percent of costs under this model. Disproportionate share costs actually range up to 10 percent in some states. In states with higher disproportionate share costs, the overall budgets will be larger. In addition. the phasing out of disproportionate share reimbursement over a number of years may be useful in offsetting the initial increases in administrative costs of managed care.

Including Long-Term Care in the Model

Despite concerns about this type of model (e.g., Smith & Ashbaugh, 1995), managed care can be used to provide health care and long-term care services to people with developmental disabilities currently receiving these services. Basic combined health care and long-term care costs as well as the costs of ancillary habilitation services of between $90,000 and $110,000 have been reported for people with intense needs (Knobbe, Carey, Rhodes. & Horner, 1995), while other groups of people with developmental disabilities have been found to cost less (Fujiura, Roccoforte. & Braddock, 1994). Finally, nationwide studies (Mangan, Prouty, Polister, & Lakin. 1995) have revealed U.S. weighted average per resident per day long-term care costs of $257 in facilities with fewer than 16 individuals, and $225 in facilities with more than 16 individuals.

When long-term care components are included, health care expenditures are initially considered as 10 percent of premium. Studies of service utilization costs in long-term care settings, other than the studies cited, are infrequent and there may be substantial variance among states. To complete our hypothetical budget process, we were able to create approximate estimates of costs for various component habilitative services using data from the New Jersey Division of Developmental Disabilities and other states in regard to the costs of habilitative and long-term care services. Costs for specific habilitative care including rehabilitation services and behavioral services are based upon staffing ratios commonly observed in ICF/MRs. We recognize that there may be further efficiencies that could be extracted from the ICF/MR model. However, without reliable estimates we have elected to use the typical configuration of this program as a basis. We have added the long-term components of the model onto the budget for health care showing these cost categories separately implying separation of these distinct service elements (Zawadski & Eng, 1988).

New and expanded long-term care services include supported living, independent living, family homes, sponsor homes, and family support. In most cases, costs associated with these are substantial due to the shift away from institutional placements. For example, support for individuals living in supported living arrangements or their family's homes is increased by 83 percent and 94 percent respectively in the budget model. There is an increase in funding for supported employment of 100 percent. These new services are funded through cuts in existing services and reductions in their administrative costs. There are modest decreases in nearly all professional services as these are increasingly addressed by the acute health care system.. For example, administrative costs can be substantially reduced as the management information system is funded in the managed health care system. The result is that substantially more funding can be directed to long-term care options, particularly in the home. This should result in an increase in the number of individuals served and a proportionate decrease in the substantial number of individuals on waiting lists waiting lists for services. For example, Prouty & Lakin, (1995) reported estimates of approximately 56,000 people with mental retardation or developmental disabilities on waiting lists for residential services in 1993.

We anticipate that the health care coordination/long-term care model may be associated with higher levels of inpatient utilization than the managed health care model. In existing ICF/MR systems, for example, hospital stays for postoperative care are likely shortened when individuals return to the facility and complete recuperation in a center's infirmary prior to returning to a regular residential setting. Therefore, as policy makers close institutions and increase the number of people with developmental disabilities living in the community, there may be pressure that tends to increase inpatient utilization, requiring very careful management in order to meet budget requirements.

Obstacles to implementation

A major obstacle to the acute health care component of the model is the administrative overhead cost. Currently, state Medicaid systems operate with an overhead cost of approximately 3 percent in comparison to managed care organizations which have overhead costs of between six and 16 percent. Managed care organizations create profit in efficiency savings in the various service. When these profit margins are included, the overhead costs of managed care organizations range from 22 to 26 percent. Therefore, at current rates, if states considered a capitated financing system for health care services, a shortfall of approximately two to 22 percent would occur. To cover this deficit the managed care company must achieve reductions in the costs of care, reductions in overhead costs of managed care organizations or a combination of both.

A second potential problem if managed care is only brought to the acute health care component will be the absence of linkage with long-term care systems. If the managed care organization is confronted by cost overruns in acute health care, it may attempt to shift costs from the acute care system to the long-term care system. Under this scenario, the sickest patients would be moved to the jurisdiction of the long-term care provider, thereby improving the case-mix and profitability of the managed care provider in the health care sector.

A third area of concern with the managed health care model is the need for agreement between the health care system and the long-term care system over programmatic responsibility for ancillary habilitative services including behavioral services, rehabilitation therapy, and interdisciplinary assessment. If these are shifted to the long-term care system before the it is under managed care to escape the cost containment emphasis of managed care in the acute system, it may lead to increased long-term care costs in the long run. If left in the acute health care system, people with developmental disabilities may face caps on service levels or perhaps confront problems with quality. It may be that in spite of these concerns, leaving long-term care outsode of managed care may be more attractive to developmental disabilities advocates, policy makers, and habilitative care providers such as community non-profit organizations preferring to continue contracting directly with state developmental disabilities agencies. Under this scenario, habilitative and long-term care could be funded under a block grant arrangement between the federal government and state developmental disabilities agencies.

On the other hand, there are attractive element to the managed coordinated acute health care/long-term care model. First, greater degrees of system integration increase overall efficiency (Mezey & Lawrence, 1995). The resulting savings in administrative costs can be redirected to new services. Second, duplication of health care and other professional services is reduced through improved care coordination. Third, cost shifting from the acute to the long-term care system is eliminated. Finally, the elimination of categorical eligibility increases the opportunity for the creation of new service options in home and community-based settings. This feature may be particularly attractive to advocates and consumers who desire more choices.

The major drawback with the coordinated health care/long-term care model is the inability to predict whether consumers will leave long-term care settings in favor of new community care settings. If community care options are not attractive and consumers choose to stay in high-cost institutional settings, the additional costs of the new home and community-based care options will result in cost overruns. This is exactly the challenge faced by the Health Services for Children With Special Needs, Inc. We look forward to their experience as an indicator of the potential success of this model.

Limitations of This Analysis

With Medicaid costs continuing to increase by at least 10 percent each year and waiting lists for long-term care services of just over 18 percent of people in need of services, there is a need for structural changes in the developmental disabilities service system. Nearly everyone is dissatisfied with some aspect of the model presented here. Regardless, there is substantial disagreement within the developmental disabilities community as to a direction for reform. Given this situation, it is possible that the marketplace will be the dominant source of services for people with developmental disabilities. On the other hand, market forces may not predominate if policymakers step in and construct alternatives. As in any activity undertaken by health futurists, we assume that current market behavior is the best predictor of future behavior. If this is true, managed care is likely to encompass both acute and long-term care services for people with disabilities in the near future. If the developmental disabilities community does not respond to the same market forces as the general population, then there may be different arrangements. Regardless, we assume that our financial analyses provide some preliminary insight into the challenges posed by managed care. Finally, of course, significant changes in the amount of funding available for people with developmental disabilities, for example, may decrease the relevance of these analyses.

Conclusions

Current public policy favors the implementation of managed health care for people with developmental disabilities. Managed health care demonstration projects have shown some promising results, although experience is limited, especially in the area of long-term care. Experience to date suggests that it may be possible to direct inpatient hospital and medical specialty resources toward improved care coordination, access to primary care, and enhanced administrative support. Such outcomes would be beneficial to people with developmental disabilities. many of whom have limited acces to primary care, and often little or no health care coordination at present. While there is less information available regarding the use of managed care in providing long-term care, the potential to improve efficiency, eliminate categorical eligibility, and create new home and community-based options may stimulate further exploration of these models. It is reasonable to explore how managed care models can be created that serve both health care and long-term care needs without losing sensitivity for consumers with developmental disabilities. There are, to be sure, barriers to reform in the developmental disabilities system -- including weak market forces, internal resistance. the costs of retooling, and legal and regulatory restraints. The future of managed care for people with developmental disabilities will be determined by states' abilities to implement common governance and policies and to promote the development of systems that reflect certain unique needs of individuals with developmental disabilities. Toward that end, examining the possibilities of managed care may require changes in the culture and values of developmental disabilities providers. a dedication to improving care management processes, and a desire to increases the effectiveness of supporting systems. When these values are linked with effective management practices -- total quality management, efficient administration and information systems. and sound fiscal management -- the field of developmental disabilities will be be in a position to meet the challenges posed by managed care. Regardless, an understanding of managed care and how it affects both acute health care and long-term care systems, and the people they serve, is something that few in the field should be without.

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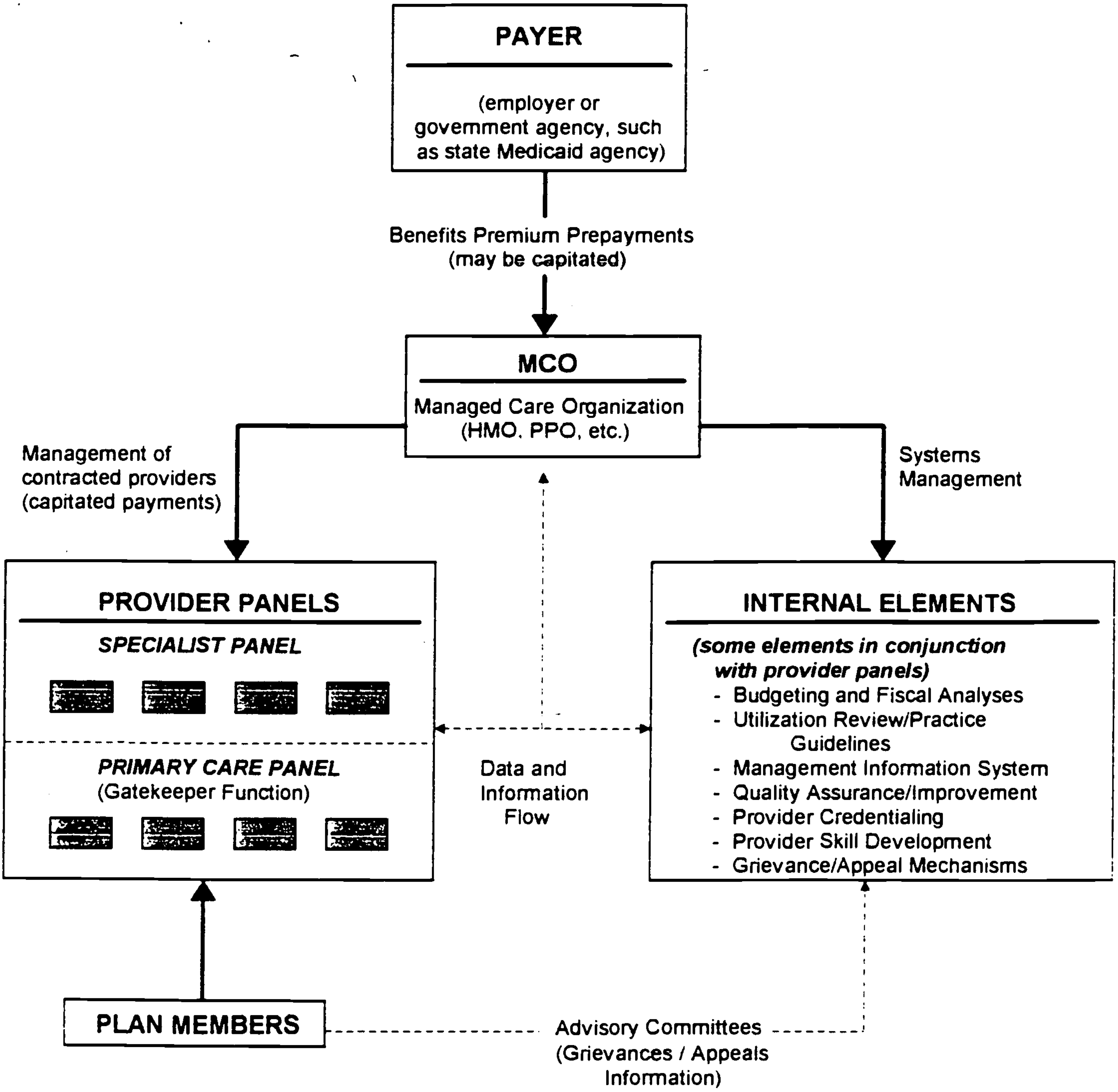

Figure 1. A generalized structural model of a managed health care care system.

Table 1
A Hypothetical Budget for a Health Care Coordinated/Long-Term Care Model

	Year of Operation				
	Current Experience	End of Year 1	End of Year 2	End of Year 3	Entire Period
	Percent of Expenditure	Percent of Expenditure	Percent of Expenditure	Percent of Expenditure	Percent Change
SERVICE CATEGORIES					
Health Care	**10.00**	**11.18**	**10.48**	**9.95**	**-.005**
Acute Inpatient Hospitalization	4.00	3.50	3.00	2.75	-31
Specialty Care	.80	.70	.65	.60	-25
Primary Care	.75	.90	1.00	1.00	33
Home Health Care	.30	.30	.25	.20	-33
Rehabilitation Therapies	.30	.30	.25	.20	-33
Durable Medical Equipment	.35	.33	.30	.30	-14
Mental Health Services	.60	.50	.45	.40	-33
Drugs	1.10	1.00	.95	.90	-18
Transportation	.10	.10	.10	.10	0
Laboratory / X-Ray	.50	.45	.43	.40	-20
Dental Services	.05	.08	.10	.10	100
Respite / Family Support Services	0	.03	.05	.05	--
Medicare Crossover	.30	.20	.10	0	-100
Administration	.30	1.50	1.50	1.50	400
Care Coordination	0	.50	.60	.70	--
Medicaid Savings	0	.25	.25	.25	--
Interdisciplinary Assessment	0	.05	.05	.05	--
Disproportionate Share Payments	.10	.05	0	0	-100
Onter	.45	.45	.45	.45	0
Residential/Habilitative Services	**43.80**	**41.20**	**38.35**	**36.56**	**-17**
Behavioral Services	4.50	4.00	3.50	3.00	-33
Rehabilitation Services	3.00	2.50	2.25	2.00	-33
Durable Medical Equipment	.40	.35	.30	.25	-38
Nursing Services	4.00	3.50	2.50	2.00	-50
Nutritional / Feeding Services	.40	.35	.30	.30	-33
Day Programs	28.00	27.00	26.00	25.00	-11

Supported Employment	1.50	2.00	2.5	3.00	100
Interdisciplinary Assessment	2.00	1.50	1.00	1.00	-50
Long-Term Care	**36.20**	**43.00**	**45.50**	**48.00**	**33**
ICF/MR Group Home	15.00	13.00	10.00	10.00	-33
Supported Living	6.00	9.00	11.00	11.00	83
Independent Living	4.00	5.00	6.00	7.00	75
Family Home	7.20	11.00	13.00	14.00	94
Sponsor Home	4.00	5.00	5.50	6.00	50
Other	**10.00**	**8.00**	**6.50**	**5.50**	**-45**
Administration	10.00	6.00	4.00	3.00	-70
Family Supoprt / Respite	0	2.00	2.50	2.50	--
TOTALS	**100.00**	**103.38**	**100.83**	**100**	**--**

Costs expressed as a percentage of current year premium

REPRINT: BEWARE THE MANAGED HEALTH-CARE COMPANIES

PERSPECTIVES

Beware the Managed Health-Care Companies

John Ashbaugh and Gary Smith

Managed-care mechanisms were first devised nearly 2 decades ago in the attempt to contain runaway costs in acute medical care. Indeed, managed care has slowed the growth in health-care expenditures. It is, therefore, attractive to policy makers and budget makers who are trying to contain the costs of long-term care for people with lifelong disabilities.

Organizations within and outside of the long-term care industry are considering how they might survive and even prosper in the managed-care world. Service agencies supporting people with developmental disabilities are taking a hard look at the costs of the various services they offer in order to better price and better package their offerings in the more demanding, cost-conscious managed-care environment. Some are forming comprehensive service and support networks in order to qualify as local managed-care organizations. Others are establishing statewide managed-care organizations in the event that state policy makers opt to contract for the services of statewide managed-care organization(s) to administer the developmental disabilities system.

Managed-care corporations from the health-care industry are entering the field. Their representatives are talking to state and county officials about how they might bring their managed health-care experience to bear in long-term care. This is cause for concern. On average, health-care expenditures for people with disabilities amount to a small fraction (about 5%) of their expenditures for long-term care. Individuals representing managed health-care corporations know little about the long-term needs of people with disabilities. There are important differences in how managed care can and should be approached in health care and in long-term care. In this article we have highlighted these differences, differences that warn against embracing managed health-care models and the managed health-care companies that hope to introduce them into the long-term care arena.

Consumer Choice

In the medical community, physicians and medical specialists reign. By virtue of their specialized knowledge, medical professionals are qualified to decide appropriate treatment and care. Under managed care their decisions may be influenced by fiscal incentives, second-guessed, and constrained through practice guidelines and utilization management procedures. Still, care decisions are largely theirs and not frequently made by the consumers. Indeed, the most common managed-care mechanisms in the medical field are those designed to limit consumer choice (e.g., patient triaging, gatekeeping, and primary care case-management mechanisms).

In the developmental disabilities community, the specialized knowledge of professionals is valued so far as it goes. Clinicians are not sanctioned in the same fashion as physicians to control care. As service planning has evolved into whole life planning, the plans are increasingly being formulated by consumers and their families, with invited input from professionals, friends, and others concerned. The movement is away from narrow plans and practice approaches where consumers are led by professionals through a continuum of services. The key choices for most persons with developmental disabilities are about "getting a life," not about a kidney stone, sore throat, or heart murmur. These choices are too important to be made by a distant outsider who is hardly known by the family and consumer. They are too expansive to be made by a physician.

A number of states are crafting managed-care arrangements designed to promote consumer choice. Consumer-driven mechanisms, unknown in the world of managed-care health care, promise to be centerpieces in the managed-care of persons with life-long disabilities. Family support, consumer-managed personal assistance programs, and supportive living programs provide ample evidence that consumers and families can get considerable mileage out of very limited funds.

Consumer managed-care refers to arrangements whereby each individual with disabilities and his or her family or guardian have the authority within predefined limits to decide how to expend funds in support of the person with disabilities. This approach operates under two basic assumptions: (a) consumers working on limited budgets will spend more prudently in order to get the most value for their money and will increase their use of natural supports in lieu of public supports, and (b) consumer choice will spawn a competitive market economy where those providers, new and old, representing the most value to all consumers will survive.

In health care, care management is largely in the hands of trained clinicians. In long-term care, care management is largely controlled by the consumers. Would managed health-care companies be inclined to give over this authority?

Management and Financial Capacity

In health care, the managed-care organization plays a pivotal role in the implementation of managed care by administering the delivery system on behalf of the payor in order to deliver essential health-care services at a cost the payor can afford. It further serves as the conduit through which all funds are channeled. The managed-care organization develops the supplier network, imposes rules on its operation, and serves as its fiscal intermediary. As a rule, the managed-care organization must keep system expenditures within a cap, and it assumes most or all of the risk for cost overruns; therefore, the organization has a strong economic interest in being a tough negotiator with suppliers, ferreting out overutilization, and improving system productivity.

As managed-care organizations in the health-care industry, large managed health-care companies have a number of strengths:

- *Sophisticated Management Systems*: Larger managed-care organizations boast of highly automated financial management systems that allow the real-time tracking and monitoring of expenditures against budget, the funding of service and support costs, and efficacious claims processing. Their administrators have developed elaborate performance-monitoring systems using batteries of performance indicators and assorted and tested utilization management mechanisms.
- *Negotiating Power:* They have the purchasing power to negotiate price advantageous arrangements with affiliated providers and suppliers.
- *Investment Capital.* As large, private, for-profit corporations, they have the capital needed to invest in cost- effective management and service technology and to assume full responsibility for any costs of care that exceed revenues.

However, these attributes, critical to success in managing health care, count for little and even stand as liabilities in the developmental disabilities long-term care field.

Sophisticated Management Systems

Consumers with developmental disabilities seeking health care are continually in and out of service. They present a wide range of ills that demand widely varying treatments, most of which take minutes to complete. Liability considerations demand tight record-keeping. The cost accounting, client tracking, payment, and performance-monitoring systems required to manage care in this dynamic environment are far more sophisticated, burdensome, and costly than those needed to manage less dynamic and complex long-term care systems. At least one state spent millions of dollars futilely attempting to make these overly complex, "med techie" systems work in managing long-term care for persons with developmental disabilities. Even now there are functional and affordable systems on the market.

Similarly, the utilization management systems in which the managed health-care companies take some pride promise little value in long-term care. Although such systems certainly make sense for managing the use of therapeutic services, there are few if any long-term care services where they would generate savings. In reality, where are the cost savings from the 6-month ICF/MR utilization reviews? Even worse, as managed-care mainstays, these systems would represent a return to the centralized, rule-bound (regulated) systems of governance that turn front-line workers into passive actors and that needlessly override consumer and family choice.

Negotiating Power

Compared to the world of medicine, there is relatively little room for savings to the state through price negotiation. Except for Intermediate Care Facilities for the Mentally Retarded (ICF/MR) rates, protected through law and regulation, rates are already low in most developmental disabilities long-term care systems. Although some providers might withstand rate cuts, others would have all they can do to survive. Rate negotiations must be sensitive to differences in local requirements and contributions, programs, and clients. In most states, reasonable rate reductions cannot be achieved simply through the imposition of leaner, across-the-board rates. As for the ICFs/MR, it is a safe bet that their rates will rapidly approach those of the non-ICF/MR providers once the special ICF/MR entitlement ends—with or without centralized rate negotiation.

Investment Capital

The added resources that a large for-profit corporation might invest in long-term care arrangements for people with developmental disabilities seems attractive until one realizes that the need for investment capital is quite limited. Investment capital is needed to fuel development in growth industries. With the imminent capping of Medicaid, the principal growth sector in the developmental disabilities long-term care industry will be in the area of non-facility-based supports—most of which will demand little in the way of capital to expand.

Nor is there much to be gained in developmental disabilities long-term care through the application of expensive technology. On the service side, the high-cost, breakthrough technologies that continue to advance medical practice and the cost of treatment are not the same driving forces in long-term care. On the administrative side, as noted earlier, the management-system requirements relating to long-term care are far less challenging and expensive than in the medical arena.

In fact, it is quite possible that large, private, for-profit managed-care organizations would drain more resources from a long-term care system than they would add. The for-profit, big-corporate identity could impede the ability to attract community support. Donors and volunteers will be understandably reluctant to give their time in the interest of improving a profit-maker's bottom line. A for-profit mission would also hinder efforts to enlist the active support of front-line workers in cost-containment attempts. In the developmental disabilities field, like any service field, the morale of direct-service workers is critically important. Cost containment is not a mission that motivates service workers or endears a service agency to the persons it is ostensibly there to serve. Cost-containment efforts engineered by a for-profit enterprise would be certain to undercut the morale of front-line workers as they continue to toil, most at less than competitive scale.

Investment capital to many entitlement-weary policy makers and budget makers is perceived as a must for a managed-care organization to assume the risk for long-term care expenditures over and above the cap set by the payor (state or county). If managed health-care companies are able to accept full responsibility for treating whatever illnesses befall their "covered lives," why not make them liable for the cost of long-term care for those in need as well? This cannot be done because the demand for publicly sponsored long-term services and supports among people with developmental disabilities, let alone the millions of others who become disabled when they are adults, far exceeds the resources available to provide them. Even now, residential services in most states are available only to those persons in near-crisis situations. Several years ago, Hayden (1992) estimated that there were roughly 200,000 persons with mental retardation on formal waiting lists for residential, day, and vocational services. This figure does not include the many more individuals who do not bother applying, given the remote chance of success. The notion that managed health-care organizations would be willing and able to offer anything approaching full coverage of long-term services and supports for people with developmental disabilities is unrealistic. States and counties, the end payers, cannot afford it.

The risk associated with the unmet demand can and should be kept to a negligible level by keeping the managed-care organization's obligation reasonably close to the number currently served. Provisions can be included to convert cost savings into waiting list reductions. This fixed obligation will be no less effective than an open-ended obligation in addressing unmet demand and will avoid the need for investor capital to cover what might otherwise be perceived to be a large potential risk. In truth, the risk is negligible (as later discussed) given the enormous discretion involved in assessing the "need" for long-term care supports.

The sophisticated management systems developed by the managed health-care companies are impractical for purposes of managing long-term care operations. The power to ratchet-down rates is nothing more than most payers (states and counties) have had all along. As long as the state or county does not needlessly introduce the appearance of risk through an open-enrollment plan, there is little need to pay a premium that would ostensibly cover it.

Profit

The greater the risk that managed-care organizations are expected to assume for expenditures above the cap, the more control they must be given over who gets served and what services they get. It is reasonably comfortable to hand over such control to a managed-care organization responsible for medical treatment because recognized medical necessity criteria establish when the managed-care organization has an obligation to provide treatment, and practice guidelines can be devised to indicate what treatment is appropriate. It is a far less comfortable proposition to hand over such control to a managed-care organization administering long-term supports to people with developmental disabilities. Decisions about whom to serve and what supports to provide persons with developmental disabilities are highly discretionary, loosely tied to subjective notions of life quality rather than clear-cut necessity criteria. Need depends as much if not more on the availability of natural supports as it does on clinical and functional criteria. Bottom line, managed long-term care is about the rationing of limited public supports.

It is a risky proposition to have profit-making enterprises such as the managed health-care companies rationing scarce resources in the long-term care arena where clear cut rules and guidelines cannot be established to protect the interests of the unserved and underserved. It is not unlike handing a kid in the proverbial candy store the jelly beans and instructing him to distribute them to any children that need them more than he does. It pits profit against need, with the managed-care organization, the profit-maker, the final arbiter.

This is an untenable situation. The profit allowed a long-term managed-care organization serving people with developmental disabilities should fit the industry (i.e., it should be minimal). Aside from the entitled and protected ICF/MR sector, developmental disabilities long-term care has not been and should not be an industry funded at the level where profit can be the primary motivator of the agencies involved. It is an empty argument that profit is needed to cover financial risk in long-term care. There *is* no financial risk. The risk in such care lies more with the consumers than the managed-care organization, given the considerable discretion inherent in the provision of long-term care services and supports, nor are sizable profits necessary to engender cost-effective behavior. In a competitive or quasi-competitive environment, nonprofit organizations will perform every bit as cost effectively as for-profit organizations.

In summary, managed-care organizations have the potential to improve developmental disabilities systems in important ways that are not now possible given the current power of the interests vested in state developmental disabilities systems. Most state administrators do not have the political support needed to reshape long-term care delivery systems, systems that are effectively controlled by supply-side interests. Managed-care organizations can lead providers and consumers to substitute less cost-effective service arrangements for more cost-effective service arrangements.

The concerns we have raised in this paper pertain to the ability of large, for-profit, managed health-care companies to accomplish the necessary restructuring to effectively deal with individuals who have developmental disabilities. One fear is that they will install the professionally dominated utilization-management models of cost containment with which they are most familiar and comfortable, models that will result in less cost-effective care than would ensue from allowing consumers and families to manage their own care within a cap.

Another concern is that these organizations will negotiate unreasonably low rates with providers, which would result in care that is of marginal quality. Still another problem is that they will institute management systems that are more complex, burdensome, and expensive than are needed to administer long-term care systems.

The most serious concern is that the managed-care organization's profit drive will do more harm than good for consumers, families, and taxpayers. A central part of a managed-care organization's function in the care field is the allocation of limited resources. The fear is that a for-profit managed-care organization will be more likely to allocate fewer rather than more resources because of the profit motive, as has been the pattern observed in health care (Families USA, 1995). Not only does the profit motive stand to decrease the availability of public resources, it could well undermine community support leading to fewer contributions from donors and volunteers. Any profits from managing the long-term care of people with developmental disabilities should be minimal. Granted, this will discourage large managed health-care organizations from entering the field. Is that a problem for you?

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Authors: **JOHN ASHBAUGH, MBA,** Senior Vice President, Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140. **GARY SMITH,** Director of Special Projects, National Association of State Directors of Developmental Disabilities Services, 6893. S. Miller, Littleton, CO 80123

REPRINTS: SELECTED ARTICLES FROM MOUTH, SEPTEMBER 1996

McMANAGING YOUR HEALTH

by Billy Golfus and Wendy Brower illustrated by Frank Billey

Starting with Billy: Managed Care is the current jargon for bottom line health care. I don't mean to sound like a Karl Marxist but it's all about money.

And there are people who'd rather have a dollar in their pocket than to have you alive.

Again I have to point to Professor John McKnight of Northwestern University who teaches that the word *care* gets attached to everything. This ain't about health care, it ain't about managed care; it's about those gonifs lining their pockets.

The care question I have is, why don't disabled people care enough to stop this? We and older people are going to suffer the most.

We are in deep, deep shit. Nobody's going to come along and fix this if you don't.

They're handing you the stone bar of soap, telling everyone to hand up your clothes and REMEMBER YOUR NUMBER. They're leading you to the gas chamber.

But what I don't get is that everyone is going quietly.

You are not going to get adequate health care under this managed care deal just by acting polite and having a bright smile. It doesn't matter if they like you. Shitcan that one. You've got to be vocal and LOUD and don't stop yelling until we get something reasonable for health care in this country.

We're not just talking a trip to the doctor with no lollipop; we're talking life and death for some people, with plenty of pain and discomfort for the rest of us. The suits are trying to save money, and we're the first notch in their belts. You best get off your duff and learn what's going on about this managed care mishugas, and get involved.

> Care can't be produced. Care can't be managed. It is not a system. It is one person caring for another, from the heart.
>
> *—John McKnight*

My pal, Wendy Brower, is an activist who's got an actual item disability herself. She's helped promote "When Billy Broke His Head," worked at the University of MN in Disability Services, has got a history of political troublemaking, and knows her disability onions.

Writing an article together seems a little like cooking and eating an egg together, but hey, people share the weirdest things.

Wendy is a lot more policy-conference-professional than yours truly, so consequently she sees sides of the issues that I can't stomach. It takes an adult to sit at a professional conference like Wendy did last fall at the U of Minnesota.

Wendy Brower:

I'm sitting next to a 'policy analyst' from one of our state's largest counties. 'How will you provide health care to people with disabilities and the elderly if Congress passes block grants?' I ask.

She quickly responds, 'We'll just put everyone in managed care.'

Hmmm. Seems like a pretty simple response to a pretty complicated issue. Isn't health care for people with disabilities, people living in poverty and the elderly already managed?

Providing Medicaid/ Medicare to elders and disabled people costs billions of dollars, so the politicians and bureaucrats are figuring out new ways to cut costs. They've decided that *managed care* is the way to go.

Congress has gotten the message from voters that the federal budget must be balanced. Remember those government shutdowns when Clinton and the Congress didn't agree on what to cut for FY96?

The fight between Newt's Republicans and Clinton's Democrats is still going on. Regardless of who wins, the budget cutters in Washington DC are going to send less money to the states.

The losers, as usual, will be the disabled, the poor, the elderly.

Here's how it works. If you're disabled or poor, or both, most likely you get your health care and other social 'services' paid for through Medicare/Medicaid. Even if you live in an institution or nursing home or ICFMR [that's Intermediate Care Facility for the Mentally Retarded — whooo!] the tab is picked up by the government.

About half of the money comes from the federal budget, the other half comes from your state's budget.

That means it all comes from taxpayers — the VOTERS.

The Washington spin doctors say that the health care cuts will actually be good because local politicians will have more flexibility and CONTROL.

So it's at the local level where you've got to watch them closely.

Even with a lot less money, the politicians and bureaucrats still talk, talk, talk about things like quality assurance and about protecting the most vulnerable. But in reality they have to either raise taxes — a big no-no for politicians — or reduce services.

What do you think they're going to do?

The first thing the governors will do is tighten the definition of disability. That will make groups of people ineligible for services. Invisible disabilities will be the first ones dropped.

Each state will have the

power to decide who gets health care and who doesn't.

[Editor's note: In the name of economy, Congress and our President have already made a law to drop people invisibly disabled by drugs and alcohol from Social Security, Medicaid, Medicare and HUD housing.]

States will also be able to decide what is a 'medical necessity.' It's my guess that this is where bureaucrats will do their real chopping.

Where do social services fit in? Psychotherapy? Emotional or marriage counseling?

The professionals *care* jargon is about things like: adverse selection, capitation, benefit exception, case-mix adjustment, gatekeepers, stop-loss, and utilization management.

Just last week at a conference about managed care, one hundred people in the room (mostly government folks) talked about the importance of involving disabled people in these meetings.

Then I heard one professional skeptic say, in that old familiar way, 'I know what's best for them. I'll decide.'

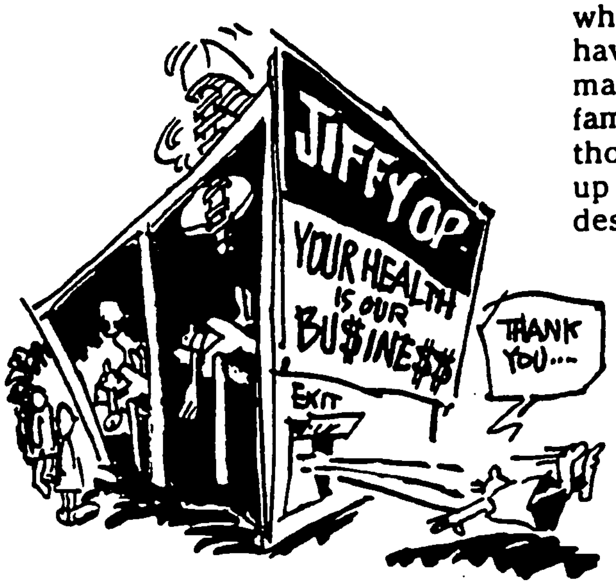
A disabled friend of mine who heads an independent living center told me, 'I don't mind managed care as long as I'm the one doing the managing.'

> The first thing the government will do is tighten the definition of disability... Invisible disabilities will be the first ones dropped.
>
> — *Wendy Brower*

Billy Golfus:

Remember the power to make the definitions — that's always the real power. In fact, that's going to be one of the first ways they limit services. They'll just redefine who is, or isn't, disabled.

They've already saved costs on psychological and emotional troubles. They limit psychotherapy sessions to half a dozen or something else unrealistic.



See, everybody knows what a broken leg is, but psychological and emotional things are different. If you limit the visits to six or eight, it keeps the cost way down. Doesn't help the person (unless you're St. Francis of Assissi) but it does keep the cost down.

Remember: That's what managed care is all about.

Another major problem lurks behind these large organizations' handling (refusal to handle, actually) of psychological troubles/disabilities. The organizations have standing orders for the therapists to report certain things. Which means that people cannot deal with their problems in a safe environment.

That's the gig.

But ethics are not a part of our modern business-run health care. And I suppose it never appears to the posse mentality that the people they are so eager to punish are looking for help.

People looking to change whatever behavior, or having trouble in their marriages or with their families or their jobs, are those most likely to show up in psychotherapy. They deserve some protection.

This is a serious breach of ethics favoring the posse and the dollar over people. It's another instance where business and "care" are incompatible.

HMOs are a bet that you won't get sick —

you know, *too* sick. Because as long as you don't get too sick, they'll make money. See how the word "care" is confusing here? See how they care about your health? It's not billed as brother's keeper kind of stuff, it's primarily a business. So there are other considerations that come before your health and comfort.

Since I know they don't really care about you — or me either — what motivates them health caring pros is money, and the opinion of their colleagues. Remember: the helping professionals are just sheep with attaché cases.

Speaking of the professionals, you'd be shocked to know how much the CEOs of these managed care companies make for cutting your services. [See chart page 32.] Half a million a year is close to the mark for most of them. We can't really know exactly because they can conceal those salaries in stock options and cooked books.

Silent Cal said, "The business of America is business." That's why they do this managed care stuff in the first damn place. Making money at the expense of others is the American way.

When people don't need the health "care," the HMOs make money, and when people do need it, they don't. So it's obvious what kind of a population they want. They sniff out a population that doesn't need service. They limit the elderly, the disabled, and pre-existing conditions so the HMOs can make a buck. They're like insurance companies. Insurance companies have lots of exclusions, and limited coverage, and lots and lots of dodging. Have a loss and see if I lie. The business of America is business, remember?

> HMOs are a bet that you won't get sick — you know, *too* sick. Because as long as you don't get too sick, they'll make money. See how the word "care" is confusing here?
>
> — *Billy Golfus*

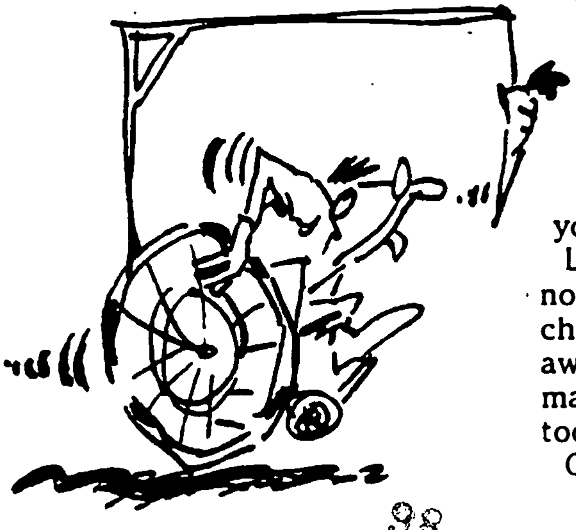
The elderly and people with disabilities don't form the needed alliance. Part of that is nobody wants to *be* us. We're the "there but for the grace of God" folks. Elderly folks say, "I feel pretty good. As long as my health holds up..."

[Editor's note: in June, the American Association of Retired Persons, AARP, stopped fighting managed care and formed its own HMO corporation.]

And, of course, African-Americans don't want to identify with us because "their problems are different." (I still can't get over Rosa Parks turning down Wade Blank when he asked her to support disabled people's right to ride the bus.) It would be nice if we had allies, but we don't.

So, as that great philosopher James Brown said, *Please, please* get out there and get informed.

If you don't, that stone bar of soap may not be as farfetched as it seems. Disabled people were among the first the Nazi genocide was aimed at.



Over half of the states here in the US of A in the Thirties had laws to sterilize people with disabilities —*in this country*.

See why I'm pushing you to get involved.

Look, if you keep making noise, something will change. Water will wear away rock. Don't ignore managed care, or it will be too late for all of us.

Go team GO!!!

Managed to Death

It's a new medical term: *Futile Care.* Translation: if you're too expensive, you die.

by Josie Byzek

The managed care industry is a giant vampire that sinks its fangs into our wallets and sucks our lives away.

That's a hard statement. It may even shock you. You may not want to believe it. But it's true.

Let me tell you how I know.

I come up to the Mouth House every other month to write. This time, my assignment was to report on a woman who was killed by her health insurance.

The facts didn't add up, so we killed the story. This was Tuesday afternoon. Tuesday evening, we hit the Internet asking for managed care anecdotes. 24 hours later we had more horror on hand than we could stomach.

One man lost both his parents to managed care. Another guy escaped from an institution in Medicare managed care and can't get anything he needs — a wheelchair, a feeding tray, anything.

One guy's HMO doctor suggested he have his toes cut off to save money on orthopedic shoes. (Note: this is not Medicaid managed care. He's insured by his employer.)

It goes on. I wrote about some of them here. I couldn't write about them all.

Today is Friday, and the stories are still coming. I write a little, then I go kill monkeys on a computer game. That's how hard these stories are to tell.

I'd like for you to meet Ruth MacInnes. She was managed to death in 1990. California's investigation of her death wasn't closed until 1995.

In some California HMOs, to get health care you have to sign arbitration clauses. That means you can't sue and you wait years while California investigates.

On condition that you accept the hard fact that what happened to Ruth can happen to you, her daughter Patricia is sharing her mother's true story with you.

In fact, Patricia kept calling to tell me more, and more. On the third call I had to say, "This is too much. We can't get it all in here."

Ruth MacInnes joined Pacificare, a Medicare HMO that Wall Street is calling a winner. For a while under Pacificare's care, everything was peachy keen. Then Ruth got sick, showing symptoms of heart disease. The doctors denied it until the very last stages. Every time she saw the HMO clinic doctors, they acted like she was one of those *hysterical women.*

Ruth told her doctors about her blackouts, her memory loss and her confusion. The doctors did nothing: Not one single test. For two and a half years, nothing.

Ruth got dizzy. She looked ashen. The doctors said it was an inner ear infection. She got a blood test and some pills.

Then Ruth's arm got this funny tingling sensation and she woke up gasping for air.

Her daughter, Patricia, called the doctor — Dr. Genius, let's say — to ask about Ruth's symptoms. The doctor became angry, and dismissed the situation. Patricia drove her mother to a hospital.

In the hospital, Ruth never saw a cardiologist. Dr. Genius put her on a high dose of a heart medicine, Isordil. Isordil must be monitored.

Doctor Genius then okayed a long car trip to New Mexico. No problem.

Ruth's heart disease was an assassin, stalking her. Dr. Genius said, "Don't worry."

No cardiologist would see her until weeks after the car trip. By then her records were lost. Then doctors shuffled her around.

Meanwhile, her assassin was closing in. Ruth's fingers turned blue. All Doctor Genius said was, "Come on down to the clinic."

Ruth was friends with an emergency room nurse, who took her blood pressure. It was so low that it didn't register.

The nurse realized Ruth was in cardiogenic shock. So they called Doctor Genius, who said to drive Ruth into the clinic and DON'T CALL 911.

This time, Ruth's daughter, Patricia, balked. She called 911. According to Patricia, "The paramedics were incredulous about the condition she was in." But Ruth finally did get to see a cardiologist. He was dismissive, too, and never notified Ruth's primary doctor.

Patricia had to call Doctor Genius the next morning. Doctor Genius thought hard: Maybe it's kidney problems. Hours later, a nephrologist showed up at the hospital, and immediately said Ruth had severe heart disease. At last! An accurate diagnosis!

"Most tragically," wrote Patricia about what followed next, "my mother was written off prematurely by HMO doctors.

"When she became semi-comatose, doctors urged tube feeding not be continued, per a living will directive." This was a directivedrawn up by those very same doctors.

Ruth lay in a hospital bed for six weeks without food. That's how long it took for Patricia to get the euthanasia order reversed.

When Ruth got food again, she regained consciousness and lived for another seven and a half months.

California investigated Ruth's death from 1991 to 1995. Although the Department of Corporations admitted that Pacificare provided unacceptable medical care for three years, no action will be taken against that company.

Ruth MacInnes's death remains unavenged.

My own grandmother has had congestive heart disease since 1989. They caught it when she showed symptoms similar to Ruth's.

She's had catherizations, a quadruple by-pass, stress tests, lasers shot into her arteries, carefully monitored medications, lengthy stays in hospital ICUs attached to wires and tubes. And she's still alive — thank God. My grandmother's doctor answers to *her*, not to a managed care company.

Now managed care has developed a hard-hearted new weapon in its lethal arsenal. It's called Futile Care.

Futile Care.

That's when your doctor decides that since you're not going to get better, you ought to die quick and cheap.

The following excerpt is taken from a program for two back-to-back ethics conferences which took place this June in E. Lansing, Michigan:

> There is legitimate concern in our society that disabled individuals are [claiming] various forms of discrimination, including discrimination by health professionals.
>
> Few would doubt that Down Syndrome infants who are denied life-saving surgery are morally, inappropriately discriminated against.
>
> *But, we are less confident that the state of Oregon can be justifiably accused of discrimination against the disabled in its rationing/ priority setting programs.*
>
> [italics mine]

Well, excuse me, but if I'm denied life-saving treatment because I'm expensive, I'm dead.

I don't care if I cost more than the six million dollar man. I don't want to die. Saying I should die because I cost too much is pretty damned discriminatory.

It gets better:

> ......we can articulate a concept of health care for the disabled [as allowing access to] needed health resources *without granting unlimited access to health resources to which others have a stronger just claim.* [italics mine]

So, if others have a stronger claim than I do, they get to live instead of me?

I wonder who gets to pick who has the "strongest" claim.

My favorite workshop heading listed in the brochure features some of the best double-speak I've ever read:

Futilitarianism. Exoticare. Coerced Altruism: The ADA meets its limits. by Dr. E. Havi Morreim. Quality of life and end of life care of the incompetent disabled person: The challenge of *non-discriminatory discrimination.* [Italics mine]

Now, there's a challenge.

Futile Care is a form of health care rationing that is based on a category of patients — the dying," according Wesley Smith, legal counsel for the International Anti-Euthanasia Task Force. "Doctors and HMOs can refuse care if care is 'futile' - not worth the money."

Smith gave me a chilling example of Futile Care that almost took the life of a Colorado woman. Her name is Elizabeth Coralu and she has cancer.

Elizabeth signed a living will. When she got sick, her HMO automatically slapped her into a hospice. According to her brother, Dr. Tarao Coralu, she developed nasty skin breakdowns, and was drugged into oblivion. He took her from the hospice and got her to a hospital where she received real care.

Today the HMO is fighting to send her back to that hospice. They say she's going to die anyway. And she signed a contract — her living will *aka* advance medical directive — saying that if she got sick, she wouldn't fight her death.

They say that now, because she's sick, she's not competent to change her mind. So nothing she says counts.

Also, they're trying to get her brother legally removed from her life. Why? Because helping his sister stay alive is also a breach of her contract.

Futile Care. That's what an HMO planned for Baby Ryan from Washington state. Ryan's a preemie.

When he was ten days old, and apparently ill with a kidney condition, HMO doctors decided he was a candidate for a kidney transplant. Then they decided instead that it was, as they told his dad, "time for him to die." No more dialysis; no life-saving measures.

Frantic, Ryan's father begged the courts for an injunction forcing the hospital to keep his son alive. Then he had his son transferred to another hospital.

That hospital was able to wean Ryan off dialysis. Although he'll probably always have a disability, he doesn't need a transplant now.

Sometimes Futile Care is administered to a person who would live if they had real treatment, but real treatment is just too expensive. Like with Carley Christie, a little girl with a rare form of kidney disease called Wilm's Tumor.

Wilm's Tumor is treatable, but only by an inter-disciplinary team which can coordinate a large number of specialists during the surgery.

Her HMO physician wouldn't refer her to the right specialists because of the cost. This gatekeeper said Carley didn't need all of those specialists anyway. In fact, a surgeon-friend of this doctor's could do the job just as well.

Because of the way managed care reimburses doctors, the doctor would have had to pay out of pocket for the surgery.

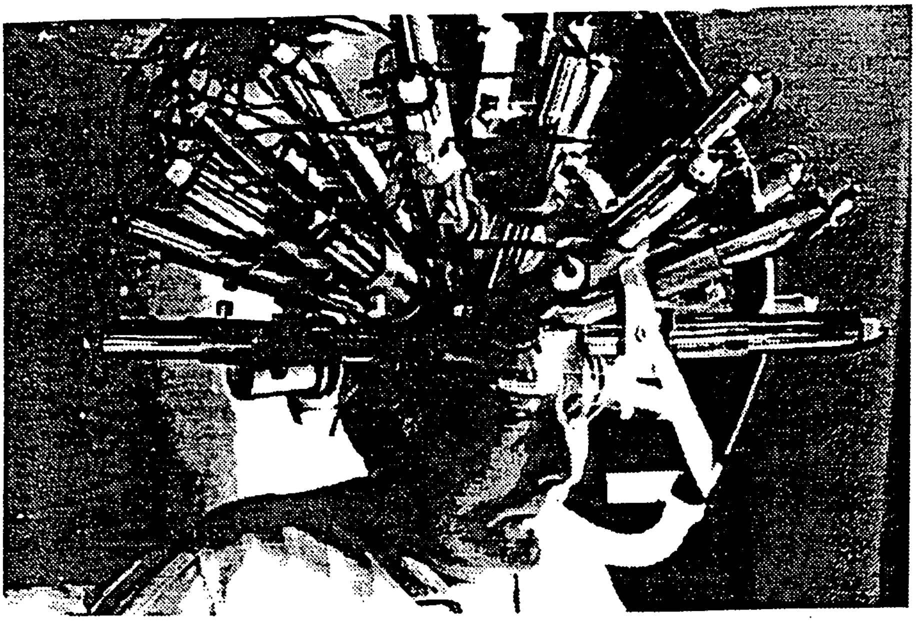
The final blow came when the managed care company — Take Care of California — said they didn't care who would did the surgery, they wouldn't pay Carley's hospital bill.

Like just about everyone who gets health insurance in California, Carley Christie's family had signed onto a fine-print binding arbitration clause when they joined Take Care of California. So they were locked out of the courts, and had to rely on arbitration.

For once, the good guys won and Take Care of California had to *Take Care* of Carley's medical bills. Not even the State of California, well-known for corruption on all levels of its health services system, could let this one slide. They slapped Take Care with a half a million dollar fine.

Take Care is appealing the decision. Go figure.

Managed care is big business. Go take a look at page 31, you'll see what their top execs make. Make special note of Leonard Abramson, CEO of U.S.



Healthcare Corporation. Besides his annual multi-million-dollar paycheck, Abramson landed a *one billion dollar bonus* for helping merge his company with Aetna Insurance, a giant in the insurance industry.

But in June HMO stocks started to slide. While not long ago these stocks were booming, Wall Street backed away big-time when, in June, leading HMOs announced dividends far lower than analysts had projected.

This means trouble for me and you. On July 12 of this year the Associated Press reported that HMOs might have to cut expenses too deeply if they want to please Wall Street investors.

I wonder whose expenses will be cut: mine or yours?

One managed care company, Minneapolis-based United Healthcare, says that its costs have risen 3 to 4 percent so far this year.

It's the doctors' fault, according to United. Doctors are spending far too much money treating patients and prescribing drugs.

Sometimes managed care is bizarre as well as sinister. Via the Internet, I hooked up with Scott Graham of Nebraska.

Scott's doctor suggested that instead of the HMO having to buy $500 orthopedic shoes to fit his brace, he might just want to have a few toes removed. One-time cost, you know.

Scott pays $200 out of his own pocket every month for his health care. Another $600 per month is paid by his employer. That's $9600 a year whether Scott gets sick or not. Scott has been wearing the same pair of $500 shoes for four years. He needs a new pair.

His HMO won't pay for them. A cheapie amputation, though... well, that's different.

There is some light on the horizon. California, the original nursery for this monster called Managed Care, is trying to stuff the monster back in its cage. A voter referendum is on the ballot in November.

California voters may pass the Patient Protection Act.

If so, Californians can have second opinions when they're stymied by managed care. They'll have access to their own medical records. No more mandatory arbitration clauses to keep managed care's secrets out of the news. When a managed care company ignores a patient's symptoms, that person can sue.

For more information on Proposition 216, call Jamie Court, Patient Protection Act, at (310) 392-0522.

California is only one state out of fifty. Will your survival depend on your geography?

Meanwhile, Congress has held hearings on the gag orders imposed by managed care on the doctors it enlists. Doctors under gag orders can't tell you that you really ought to see a specialist the plan won't pay for, can't speak publicly about managed care's ills; can't "disparage" the plan or compare it to its competitors. In other words, if your doctor signed on with managed care, he can't level with you. Scary thought.

Scarier: Assisted suicide and Futile Care thrive under managed care nationwide. Think about it: The community may be cheaper than institutions, but death is cheaper than life. And lots of us are pretty damned expensive alive.

I know we have 'way too many battles to fight already.

I know that when we lose a battle, some of us die.

But, guys, managed care is just too big to ignore.

In just two days' time I found more managed care horror stories than I could stomach.

And that's just the tip of the iceberg.

Long ago, we were told to remember the Titanic's meeting with the tip of an iceberg.

Get involved *now*. ▬

Getting Up To Speed

It's not going to be easy, but it damned sure better be *quick*.

"We could run some tests. But that would cost money, wouldn't it?"

33 States to the Rescue

Always a good source on health care issues, Families USA has published *HMO Consumers at Risk: States to the Rescue* just in time for the mad rush into managed care.

33 states have passed (or rejected) consumer protection legislation recently. Here's an up-to-date (to June 1996) source on all of it. Learn what protects you in your own state and how you can help make those protections stronger.

Some focus on disability issues. But as you'll see, our health care is still up in the air. No state has found health coverage answers for people with chronic conditions, but some are trying one thing or another.

The book is 60 large format pages of invaluable information. Send $15 to Families USA, 1334 G St. NW, 3rd flr., Washington DC 20005. E-mail: info@familiesusa.org.

Quality Watch

Getting shafted by your HMO? Call Quality Watchline at **1-800-720-8090**. This line is run by the Consumer Coalition for Quality Health Care, a network of health advocacy organizations.

They're not after your money. They will connect you with other advocates in your state for managed care reform. And please *talk to them*. They want to know about your real life experiences with managed care. These are horror stories they can use (without using your name) to talk sense to state and federal legislators.

The Coalition wants to draw attention to abuses of managed care so we can get legislative support for reform.

And yes, they *want* to hear about issues in managed care for people with disabilities. The Coalition is endorsed by Public Citizen and literally thousands of other genuine advocates who represent 35 million Americans.

Bill of Rights

The Managed Care Consumers' Bill of Rights: a health policy guide for consumer advocates is a treasure. Packed with information and how-to's, it's 84 pages long in large format and costs $5.

Well researched and very clear, this book sets out real health care policy which states can adopt. Want to take a look at sample legislation? Sources for it are listed here.

Plus there's a long resource list that's almost as good as Mouth's Rolodex. You could call up Blue Cross or the American Hospital Association and ask 'em what's happening.

Bill of Rights explains managed care terms and conditions, including what is known as *adverse action*. (All the ways that managed care can kill you.)

To order send $5 to PPEF (Public Policy Education Fund), 94 Central Ave., Albany, NY 12206. Or call to order at 418-465-4600.

Kids' Medicaid

Medicaid Managed Care: An Advocate's Guide for Protecting Children is a resource manual from the National Association of Child Advocates. (They know zero about what they call our *special needs*.) Technical info, resources, plus ways to make Medicaid agencies accountable. Order it for $40 from NACA, 1522 K St NW, suite 600, Washington DC 20005.

ADA vs. HMOs

Cigna is the insurance mega-conglomerate which says, in its commercials, that Cigna is "in the business of caring." Cigna was insuror of the now-infamous New Medico chain of brain injury fraud centers. Yeah, that's *caring*.

Cigna, targeted by ADAPT at last May's action, is in the managed care business too. And now a woman with a disability, Michelle Weiss, has filed a federal class action suit against Cigna Healthcare, Cigna's HMO.

Weiss's attorney believes, among other things, *that managed care will deprive Weiss and others of the equal access guaranteed by the ADA.*

Attorney D. Brian Hufford is the person to contact for more on this. 212-921-4110.

AMA Survey

The American Medical Association has surveyed public and physician opinion on U.S. health care. 77% of Americans say they would pay more for health care if they could pick their own doctors.

52% of physicians say they are losing their power to furnish the best care for their patients due to interference by government and by insurance/managed care companies.

One third of the 1,000 physicians surveyed say that unequal access to medical care is the main problem facing U.S. health care today.

49 States McManage Medicaid

One out of seven Americans has a Medicaid card.

And one third of Medicaid recipients in 1995 were enrolled — willingly or not — in managed care. By 1998, 85% of Medicaid health benefits will be delivered by managed care companies.

Alan Bergman of the Governmental Activities Office of United Cerebral Palsy Association in Washington, DC, says that more changes to Medicaid have come about in the last 18 months than at any time in Medicaid history. "But there is an air of complacency among people with disabilities," he adds.

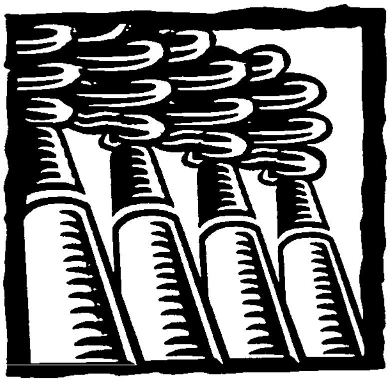
Bergman advises that we become familiar with state legislators who serve on state Insurance Committees. Bergman urges us to include ourselves when states hammer out contracts they will award to managed care companies.

That's where the rubber meets the road: word for word in the contracts. So far, most state contracts don't say much about what is called "long-term care" — the kind of care you may well need for a chronic condition and almost any disability.

"The risks in managed care are phenomenally high," Bergman says. "It's all about who's in charge."

He tells us of one state, Oregon, where disability and consumer advocates "spent 18 months at the table, slugging it out with state policymakers" — with excellent results.

Managed care *can* go right. Bergman says, if all of us get on the ball right now.



Your health or their industry?

Managed Care companies decide how much health care you deserve. Meantime, their CEOs are paid well to make sure you aren't healthier than you need to be.

Listed below are a few such CEOs whose for-profit corporations are listed on the stock exchange.

Managed Care: Who's Getting Healthy?

Company	CEO / 1994 Pay & Perks
United Healthcare	W. W. McGuire / $ 6.1 million
U.S. Healthcare	Leonard Abramson / $ 2.9 million
Humana	D. A. Jones / $ 1.9 million
Magellan/Green Springs	Mac Crawford / $1.4 million
Value Health	Robert Patricelli / $1.2 million
Healthtrust	R. C. McWhorter / $1.1 million

BRIEF LIST OF RESOURCE ORGANIZATIONS

Center for Managed Long Term Supports for People with Disabilities

Human Services Research Institute
525 Glen Creek Road, NW, #230
Salem, OR 97304
(503) 362-5682
Email: hsri@hsri.org
URL:
http://www.hsri.org/manage/CMLTSPD.html

The National Association of State Directors of Developmental Disabilities Services (NADDDS)
113 Oronoco Street
Alexandria, VA 22314
(703) 683-4202
fax (503) 362-7729

This ongoing project involves the provision of training and technical assistance to agencies interested in developing, adapting and using managed care strategies in the delivery of long term supports to people with disabilities. It is a collaborative enterprise of the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services. The Center was created in 1995 recognizing the inherent value, risks and inevitability of managed care approaches. It is founded on a common commitment to further managed care approaches that advance the inclusion, self-sufficiency and self-determination of people with developmental disabilities.

Center for Vulnerable Populations

The National Academy for State Health Policy
50 Monument Square, Suite 502
Portland, ME 04101
(207) 874-6524

The Institute for Health Policy
Brandeis University
P.O. Box 9110
Waltham, MA 02254
(617) 736-3900

Co-directed by the National Academy for State Health Policy and the Institute for Health Policy at Brandeis University, the Center for Vulnerable Populations supports research, policy analysis, and best practice studies regarding vulnerable populations and disseminates its work to state health policymakers. The Center is funded by a grant from the Henry J. Kaiser Family Foundation.

Families USA

1334 G Street, NW, Third Floor

Washington, DC 20005
(202) 628-3030
(202) 347-2417
Email: info@familiesusa.org
URL: http://epn.org/families.html

Families USA is a nonprofit organization that runs many different projects on health care, including one on managed care. Their Managed Care Consumer Protection Project provides information, technical assistance and training to other organizations who provide health care to a variety of consumers. The organizations in the community learn to monitor managed care plans and assist consumers with identified problems. Families USA also serves as a clearinghouse for public policy on a variety of health care issues, including managed care. While their focus as an organization is not specifically on people with developmental disabilities, their training and information can be applied in this area, due in part to the agency's goal of working with a specific community or group and the concerns they voice.

Institute for Health and Disability
Box 721, 420 Delaware Street, S.E.
Minneapolis, MN 55455
V/TTY: (612) 624-3939
fax (612-626-2134
E-Mail: instihd@tc.umn.edu
URL: http://www.peds.umn.edu/Centers

The Institute for Health and Disability is a network of programs for children and youth and their families designed to improve the health and functioning of children and youth within the context of their families and communities. These projects share a focus on young people from birth to 24 years of age, and share the fundamental belief that the needs of children with chronic illness or disability share many of the same needs regardless of their medical or health condition.

The Institute for Health and Disability includes the Center for Children with Chronic Illness and Disability, a rehabilitation, research and training Center dedicated to the study and promotion of the psychological and social well-being of children with chronic health conditions and their families, and the National Center for Youth with Disabilities, an information, policy and resource center for youth, plus a host of other projects and programs in the areas of research, training and information dissemination.

MCARE: National Clearinghouse on Managed Care and Long-Term Services and Supports for Adults with Developmental Disabilities and Their Families

Institute on Disability, University of New Hampshire
7 Leavitt Lane, Suite 101
University of New Hampshire
Durham, NH 03824-3512
(603) 862-0034
Email: MCARE@unh.edu
URL: http://www.mcare.unh.edu/

The Institute on Disability at the University of New Hampshire has established a National Clearinghouse on Managed Care and Long Term Services And Supports. The MCARE clearing house will target national, state, and local policy-makers as well as advocates for people with developmental disabilities and their families, working to assure that the values incorporated into many of our systems, such as self-determination and community inclusion implemented with flexibility and innovation, are embedded in managed care arrangements.

MCARE will work to insure that policy-makers, advocates, families, consumers, researchers, and others have the most up-to-date information available. Information on waivers, managed care arrangements, quality outcomes, and contract specifications will be compiled and made available using the Internet and more traditional forms of print and telecommunications. Additionally, on-line conversations and conferencing will be organized to assist people in their analysis of current trends and emerging issues.

National Association of Child Advocates

1522 K Street, N.W.
Suite 600
Washington, DC 20005
(202) 289-0777

The National Association of Child Advocates (NACA) is an organization that is devoted to the creation and sustenance of state- and community-based child advocacy organizations. With 51 member organizations in 40 states and seven cities and communities, NACA serves as the hub of information exchange among existing and emerging multi-issue child advocacy organizations at the state and local levels.

Most of NACA's member organizations are providing critical leadership on children's health issues in their states and localities. Some are leading broad-based coalitions addressing the many serious issues arising from the rapid transformation in health care delivery systems that is occurring across the country, including the increasing reliance on managed care. Others are engaged in active partnerships with pediatricians, school nurses, and other health care providers concerned about the health and well-being of children. Still others are leading the fight for expansions in health insurance for children through targeted children's health insurance initiatives or statewide comprehensive health care reform. NACA is also the author of Medicaid Managed Care: An Advocate's Guide for Protecting Children.

NOTICE

REPRODUCTION BASIS