Minnesota Health Care Commission

Report

February 1997

The Impact of Managed Care and Other Forms of Health Care for Persons with Chronic Conditions, Disability, or Terminal Illness

The mission of the Minnesota Health Care Commission is to help Minnesota communities, providers, group purchasers, employers, employees, and consumers improve the affordability, quality, and accessibility of health care.

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1995 Minn. Laws Chap. 234 Art. 2
Sec. 34

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Minnesota Health Care Commission

The Impact of Managed Care and Other Forms of Health Care for Persons with Chronic Conditions, Disability, or Terminal Illness

Title: *The Impact of Managed Care and Other Forms of Health Care For Persons with Chronic Conditions, Disability, or Terminal Illness*

Author: Minnesota Health Care Commission

Publisher: Minnesota Health Care Commission

Date and Place of Publication:
Minneapolis, Minnesota,
February 1997

As required by Minnesota Statute 3.197, the cost of this report is estimated to be $16,500. This cost is inclusive of : staff research and report production; meeting costs of the Commission's Service Purchasing and Delivery Work Group and the Minnesota Health Care Commission; and printing and mailing costs.

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Summary

Introduction

The 1995 MinnesotaCare law required the Minnesota Health Care Commission to:

- *study the impact of managed care and other methods of health care delivery on the quality of life and care provided to terminally ill patients;*
- *study the impact of managed care and other methods of health care delivery on the quality of life and care provided to persons with chronic illness or disability;*
- *hold hearings at various sites in Minnesota and take testimony from concerned citizens; and*
- *present a report to the Legislature and Governor.*

Although no additional funds were appropriated to the Commission specifically for this report, it was possible to integrate this study with, and draw upon, other concurrent studies and research conducted by the Commission during the time period 1995-1996. In addition, the following research strategies were also undertaken to the extent possible to address the study questions: literature reviews; informational interviews and contacts with other key agency staff and organizations; focus groups; three public hearings (in East Grand Forks, Mankato, and the Twin Cities area); reviews of administrative records; and a variety of discussions and other forums.

It should be noted that perhaps no single study, regardless of funding level, may be sufficient to address the increasingly complex, value-laden topic of care for persons with terminal illness and disability. The issues frequently considered in discussions of this topic reach from fundamental individual needs or concerns, to choices and tradeoffs with sweeping social, legal, and ethical implications. In addition, the data and information needed to adequately address the study objectives above are often currently very limited or not available. The health care system is currently undergoing rapid changes, and the number of persons with chronic illness and disability is projected to increase dramatically with a rapidly aging population. As a result, the issue of care for persons with chronic illness, disability, and terminal illness is perhaps one of the most important challenges facing the health care system. The need for additional research, discussion, awareness, and understanding of this topic cannot be overemphasized.

For these reasons, our report should be viewed as a starting point. Our study charge initially grew out of concerns over "managed care" forms of health care delivery and financing for persons with disability and terminal illness. At its most extreme, these concerns took the form of allegations that managed care was leading to rationing of needed care and euthanasia. Our study found no evidence to support such a claim. However, we did find that the current health care system -- regardless of whether fee-for-service, managed care, or some hybrid -- can and should be improved to better care for persons with chronic illness, disability, and terminal illness. This report describes both the potential and peril of the current system. It seeks to engage policy makers, advocates, constituency group leaders, and others in broader discussions of these issues.

> *[We] found no evidence to support ... [allegations of euthanasia]... we did find that the current health care system can and should be improved to better care for [the target populations]...*

The importance of this topic in public policy discussions

The issue of health care for persons with chronic illness, disability, and terminal illness has taken on greater urgency because of two major, interrelated changes which are having significant impact on society, as summarized below.

First -- The delivery and financing of health care has been undergoing rapid changes over the past two decades in response to health care cost escalation, deteriorating access to care, and concerns about preserving and enhancing health care quality. A significant manifestation of these changes has occurred with the growth of, and concerns about, "managed care" forms of health care.

Health maintenance organizations (HMOs) are one well known form of managed care. However, *managed care is not limited to HMOs but is being used in most health care delivery and health insurance in Minnesota. Managed care -- in all its various forms -- is perceived as offering both "potential and peril" for the target populations.*

Second -- *Demographic changes, especially in the aging of the "baby boomer" generation, signal a potential dramatic rise in the number of persons who will need care for chronic illness, disability, and terminal illness.*

Many children and young people also experience disability and chronic illness, and not everyone faces declining health with aging. However, the rate of chronic conditions and disability does increase significantly with age, and the aging of the population over the coming decades is likely to bring with it major increases in the disabled and chronically ill populations.

Scope of this study: Limitations and Methods

The essential definitions and data needed to carry out a rigorous impact evaluation as described in the study charge above are generally lacking.

For example:

- *There is considerable disagreement as to what constitutes quality of life, and how to measure it. This is especially important in examining issues of care at the end of life. Disagreement also exists as to what constitutes quality health care, and how it may be measured.*
- *The term "managed care" is extremely broad, and there is no single standard definition of managed care in use.* It has been estimated that over 80 percent of persons with traditional coverage for acute health care needs in Minnesota now are under some form of managed care, but the types and levels of managed care used vary significantly.
- Many of the most severely disabled receive health care through the state's Medical Assistance (MA) program. *Except for a limited time period in the mid-1980's, persons with disabilities on MA have received their care through a fee-for-service system, and have not been enrolled in MA's Prepaid Managed Care Program (PMAP). Therefore, experience with MA managed care for this group is limited and now nearly ten years old.*
- *Recent, objective, well-designed studies and data on health care quality and outcomes, especially for the more narrow focus of the target populations in Minnesota, are very limited.* To the extent they exist, the studies were typically *conducted a number of years ago.*
- *Rapid changes in the health care market, changing views about medicine's role in death and dying, and other ongoing social and legal developments make this evaluation topic a moving target.*

Where information relevant to this study exists, it is often anecdotal. Caution is needed when attempting "apples to apples" comparisons, in drawing inferences, or using the information available to generalize from one situation to another.

This study incorporates information from:

- *Analysis of "macro" level health indicators* (e.g., infant mortality, overall death rate, death rates due to particular illnesses or injuries, rates of particular diseases)

A number of information sources were utilized in the study. Because much of the information is anecdotal, or is from earlier studies that may not be relevant to Minnesota's current health care environment, it is difficult to draw inferences.

- *Literature searches*
- *Studies conducted of previous state PMAP demonstration projects in the late 1980's*
- *The experience of other states which have implemented prepaid managed care for disabled and chronically ill populations under Medicaid.*
- *Public hearings and forums*
- *The Commission's 1995-1996 study of the integration of acute and long term care*
- *Review of summary administrative and legal data*
- *Additional meetings, contacts, focus groups, and discussions*

Findings

- Much of the data cited in the literature and available from previous PMAP studies indicate either no difference between fee-for-service and managed care in terms of health outcomes, quality of care, and satisfaction, or some advantages of managed care. (It is difficult to know how representative the data are of Minnesota's target populations at this time.)
- To date, we have found no evidence of rationing of needed care, or euthanasia, of the target populations in response to health care cost containment pressures as sometimes has been alleged.

Concerns are often related to perceptions and apprehensions that must also be understood and addressed. In many instances these concerns exist equally in fee-for-service settings as in managed care settings.

- Concerns and important issues regarding care of the target populations have been raised. In many instances, these concerns exist equally in fee-for-service settings as in managed care settings.

- Regardless of the quality of the available evidence, negative perceptions and apprehensions about the future direction of health care delivery and financing have been raised. Because even relatively small changes in health care will have significant implications for those who rely on the system the most, the concerns and apprehensions of the target populations must be understood and better addressed.

- Many concerns reflect larger issues of meeting the needs of the target populations under the current narrow "medical model" of acute, episodic health care delivery and financing. Debates over how broadly medical care should be defined, or alternatively, what should be covered by third party reimbursement, are not new and have been occurring for over forty years. These debates are now taking on greater urgency in the wake of cost-control pressures, pending federal reductions in outlays for Medicare and Medicaid, changes in the economy, and the aging of the population.

- Levels and types of consumer protection and assistance vary throughout the system. However, since 1995, there have been efforts to ensure more consistent consumer protections across the state's regulated health insurance market. For example, all regulated health plans are required to develop and implement an appeals process, effective July 1, 1997. Still, this requirement does not apply to the self-insured market or public programs.

- There often seems to be a lack of knowledge of protections, services or help available to aid consumers and others in navigating the health care system.

- Because of the perceived conflict over length of life versus other definitions of quality of life, there is considerable disagreement regarding quality end-of-life care. Persons with terminal illness vary in their desire for life-sustaining treatment. However, studies indicate that many patients want limits on the use of life-sustaining treatment. Frequently these desires are not communicated, acknowledged or followed. As a result, death for many patients takes place in a hospital rather than other desired settings, and occurs with pain, fatigue, difficult breathing, or other symptoms that generally could be better managed. This is an issue throughout the system.

Preliminary Recommendations

There is little hard data specifically relating to Minnesota on the study topic. However, based on the research conducted, a number of preliminary recommendations have been developed.

- **Broader discussions and collaborations are needed to address the continuum of needs for the target populations.**

  The discussions and collaborations should be designed to:

  - meaningfully involve the target populations, their families and their care givers. Efforts now underway by the Department of Human Services to involve stakeholders in the planning of the demonstration projects for persons with disability should be replicated and expanded.
  - help achieve greater integration between acute and long term care (note: while the term "long term care" often refers to nursing home care, the term here refers to the broader spectrum of services for persons with chronic and ongoing illness or disability).
  - help foster private sector insurance alternatives which cover long term care needs, and which can help reduce dependence on public programs. The recently passed federal Health Insurance Portability and Accountability Act of 1996 (also known as the "Kassebaum-Kennedy bill"), for example, includes certain tax advantages for individuals or employers purchasing long term care coverage, which may help encourage the purchase of this type of insurance.

- **Improve the monitoring of health care and health outcomes for persons with chronic illness, disability and terminal illnesses.**

  - Tools are needed to monitor the outcomes of care for the target populations. The tools could be refinements of existing measures, such as the Health Plan Employer Data Information Set (HEDIS), which have been developed jointly by employers and health plans to measure quality and value among competing health plans. Alternatively, the tools could represent new developments. It will be important that all methods used be specifically designed for the target populations.

  - Authorize, fund, develop and implement a rigorous evaluation of the Department of Human Services planned pilot projects to enroll persons with disability in managed care. The evaluation should be initiated with the start of the project and should be sufficient to adequately assess the pilots and to provide information needed to continuously improve health care for the target populations.

- **Explore and implement methods to make the existing health care system more consumer responsive for the target populations.**

  - Identify, and help create greater awareness of, existing resources and remedies to aid the target populations in meeting their health care needs. This would include for example, assistance through state agencies, ombudsmen offices, federal protection such as the Americans with Disabilities Act, and others.

  - Develop and implement additional sources of information and assistance as needed.

- **Risk adjustment and other tools should continue to be developed and implemented to reduce financial incentives to deny care or coverage to those often most in need of financial protection and high levels of quality care.**

- **Lessons or models developed as a result of the above recommendations should be examined to help bring about a more integrated, consumer-responsive, high quality health care system for the general population as well.**

While the Health Care Commission's study charge did not specifically include recommendations, it will be important to consider the suggestions above, not only to improve health care for the target populations, but for all Minnesotans. The Commission is willing to continue to develop these recommendations in the future. Because of its broad representation, including private health plans, self-insured plans, public programs, consumers, employers, providers, and other key groups, the Commission is well positioned to continue this effort.

Discussion

The importance of this topic in public policy discussions

The importance of care for persons with chronic illness, disability, and terminal illness as a public policy issue reflects at least two major, interrelated changes which are having significant impact on society, as described below.

1. First, the delivery and financing of health care has been undergoing rapid changes over the past two decades in response to concerns about health care cost escalation, deteriorating access to care, and concerns about preserving and enhancing health care quality. A significant manifestation of these changes has occurred with the growth of, and concerns about, "managed care" forms of health care.

- Health maintenance organizations (HMOs) are one well known form of managed care. However, managed care is not limited to HMOs but is being used in most health care delivery and health insurance in Minnesota. Managed care has been viewed as offering both "potential and peril" for the target populations of this report.

2. Second, demographic changes, especially in the aging of the "baby boomer" generation, signal a potential dramatic rise in the number of persons who will need care for chronic illness, disability, and terminal illness. According to a report from the state demographer, Minnesota's population of persons over age 65 is projected to grow from 550,000 in 1990 to 900,000 by 2020, while the state's population of "old-old" over age 85 is projected to increase 72 percent over the same time period, from 70,000 in 1990, to 120,000 in 2020 (Minnesota State Demographer's Office, 1996).

I. A closer look at changes in the health care system

A recent Minnesota Health Care Commission report found that "Minnesota's health care market has been rapidly changing in response to a number of influences and trends, many of which began a number of years ago, but which are now more visible and influential" (Minnesota Health Care Commission, 1997). In particular, the study notes the importance of efforts to contain costs, which during the period 1980-1990 were rising an average of over 10 percent per year, resulting in a doubling of health care costs approximately every seven years. High levels of health care inflation directly affect state government, as Minnesota's Medicaid program is second only to K-12 education in total spending, and has become one of the fastest growing areas of public expenditures (Governor's Office, 1997).

One outcome of efforts to address escalating health care costs, as well as the deleterious effects of higher costs on access to care, and quality of care available, was the growth of a variety of forms of "managed care". As described in the Commission's report on the *Evolution of the Minnesota Health Care Market*, managed care is a broad term which refers to a variety of strategies or techniques to: prevent the need for serious, more complicated health care; coordinate care for efficiency and effectiveness; maintain overall quality; and reduce unnecessary services and reduce costs. Currently, few insurers in Minnesota use a pure indemnity plan, which simply pays for services obtained by the policyholder on a fee-for-service basis. Managed care techniques such as negotiated fees and volume discounts, provider networks, utilization review, and others are widely used, even by insurers which are not typically viewed as "managing" care (Minnesota Health Care Commission, 1997).

While Minnesota's first HMO was established in 1944, growth in HMO enrollment surged in the 1970's, led largely by employers seeking to contain costs while providing access to quality, comprehensive care for employees and their dependents. The state of Minnesota, acting as a buyer both for its employees, and for public programs such as Medical Assistance, has also increased its purchase of managed care over the last decade. Competitive pressures have led to other insurers and payers adopting managed care. The same pressures have led to increasing consolidation in the market, with a number of mergers and other changes. This has been reflected by the dominance in the state's insurance market of four large entities, development and growth of multi-hospital systems and other provider organizations, and development and growth of purchasing coalitions.

The paradox of managed care

As a result of these developments, it is estimated that over 80 percent of Minnesota's population with acute care health coverage is in some form of managed care. The situation has also resulted in a strange paradox. Enrollment in managed care is at an all time high and growing. A 1995 statewide survey found high levels of satisfaction with managed care overall, and higher levels of satisfaction in managed care than with fee-for-service plans. Rising health care costs have been held in check in recent years. Yet, despite these accomplishments, concerns and adverse publicity about the perceived threats or failures of managed care are widespread (Minnesota Health Care Commission, 1997).

The "potential and peril" of managed care

Managed care has been described as a source of both "potential and peril" (Miles et al., 1995). On the one hand, managed care offers the promise of better organizing, integrating, and delivering care that most effectively meets the needs of the patient while containing costs to keep care affordable and available. A criticism of traditional fee-for-service "unmanaged" care is that it occurs in a fragmented and piecemeal manner, with too many wasteful gaps or overlaps in care, and no overall accountability for outcomes. Moreover, fee-for-service operates in an unfettered manner; the more services provided, the greater the reimbursement to those who provide them. This creates a problematic set of incentives for overuse or overtreating, which can be equally harmful to patients as underserving. In theory, managed care is designed to address these problems through changes in organization and financial incentives that promote overall accountability for delivery of needed, effective services. Furthermore, the same incentives should promote prevention and early intervention to avoid more costly episodes of care.

Conversely, another view holds that managed care offers "peril." According to this view, managed care "...threatens patients and families with rationing of important emerging therapies, limited access to costly beneficial treatments, [and] impersonal bureaucracies." Concerns have been raised that under managed care, physicians " advocacy to patients' interest[s]" will be "tempered by financial conflicts of interest and 'loyalty' to the managed care organization" (Miles et al., 1995), or concerns about maintaining their practice and income if not part of a managed care plan.

A key concern arising in the context of this study is that the pressures to contain health care costs will lead to decisions to limit or withhold needed care, and that these pressures will be greatest where costs are greatest.

- A major study of persons with chronic illness published recently reported that "a disproportionately large majority of all direct health care services, including physician visits, prescription use, and costly hospitalizations are used by persons with chronic conditions. Their per capita costs are over three times higher than those of persons without chronic conditions" (American Medical Association Science News Press Release. 1996; Hoffman et al., 1996).

- Only a fraction of the chronically ill are severely enough affected by their condition to be disabled, and the needs and health care utilization of persons with disability may vary significantly. Nonetheless, a recent U.S. General Accounting Office report found in comparing disabled and nondisabled Medicaid beneficiaries that "disabled individuals have medical costs that are generally higher than those of the typical Medicaid beneficiary." The same report found that in "fiscal year 1994, disabled persons were about 15% of the Medicaid population and accounted for 39% of Medicaid expenditures, including long-term care" (United States General Accounting Office, 1996).

- A number of studies have found that end of life care is also very expensive, and that over 10 percent of health care resources are spent on those in the last year of life (Emanuel, 1997).

Despite physical and/or mental limitations associated with their health conditions, many persons with chronic illness, disability, and terminal illness can effectively advocate on their own behalf for the quality services they need, or have access to effective advocates. Still, concerns have been raised that many of these individuals may be incapable of effective self-advocacy, and may lack access to other advocates. In addition, the target populations may have fewer economic resources, and be more isolated in the community, making it harder to organize, seek legal aid, benefit from administrative or regulatory assistance, be influential politically, or otherwise protect their interests.

Evidence that either the potential or peril of managed care is being realized for the target populations is often nonexistent, difficult to generalize to Minnesota's current environment when it does exist, and too often is limited to press or other anecdotal accounts. However, regardless of the reality, the growth of managed care and other changes in the health care delivery system are leading to what many feel is a justifiable anxiety and negative perception about the future. Because perceptions shape reality, it is important that they be acknowledged and understood to the same degree that verified abuses or successes in the health care system be understood.

Concerns about the perceived threat of changes to the health care system are often felt to be especially justified among the target populations. Persons in good health can be expected to have relatively few contacts with the health care system, and even dramatic changes in the system may be experienced by healthy persons as only occasional, minor inconveniences. The target populations however, may have substantial needs to be met on a very frequent or ongoing basis. Even minor changes in the delivery system may have significant implications for persons with ongoing or major health needs, their families, and caregivers.

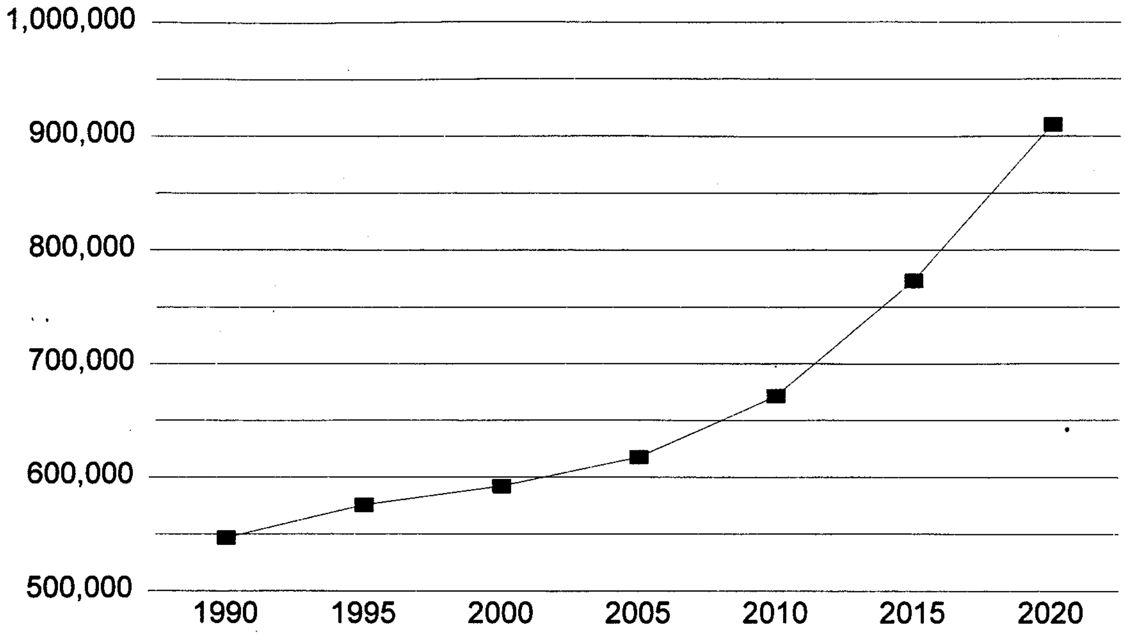
Similarly, other groups have also voiced concerns about growing or shifting burdens as the delivery system changes. County government for example, has pointed out that it currently funds 40 to 60 percent of mental health services for persons with severe and persistent mental illness. Counties also provide substantial funding for treatment of children with emotional illness and emotional disturbances, persons with chemical dependency, and individuals with developmental disabilities or related conditions (MCoy, 1996). Counties have raised questions about their role and responsibilities with wider implementation of managed care for persons on public programs. Businesses and individuals have also raised questions about whether health care changes will result in cost-shifts and new burdens.

While concerns about managed care are being raised nationwide, it has been pointed out that Minnesota's managed care environment is unique. Minnesota's employers spearheaded the movement toward managed care over 20 years ago, and have acquired a great deal of experience with managed care that employers in many other states do not have. They have been nationally recognized innovators as proactive, "prudent purchasers" of health care, organizing the market for quality, efficient care. Minnesota's HMOs are required to by state law to be non-profit, and therefore are not subject to the perceived conflicts of for-profit HMOs in other parts of the country. Finally, Minnesota's HMOs are required to be incorporated in Minnesota, which means that the HMO is accountable to the community and residents which it serves (MinnesotaCare State Agency Workgroup, 1996).

II. Concern about the "demographic wave"

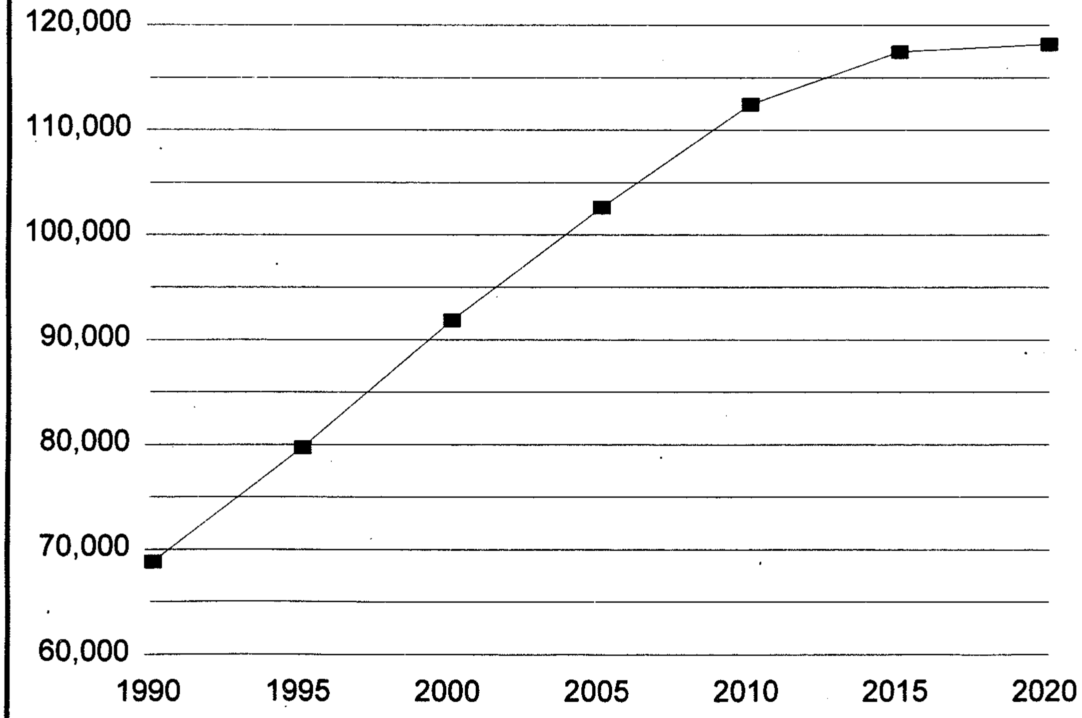
A second reason that this study topic is of particular interest is related to demographic projections regarding the aging of the population and the growth in the number of persons with chronic illness and disability. Perhaps the single most dramatic change to occur in the U.S. over the next 25-50 years will be the relatively silent one of the aging of the largest age group in American society, the "baby boomers" born in the two decades following World War II. This will result in an unprecedented increase in the population over age 65, and in the "old-old" population over age 85. In the US, the elderly population in 1990 was roughly one-eighth of the total population. By the year 2030, approximately one-fifth of the US population will be age 65 and over (Hoffman et al., 1996).

In Minnesota, the number of persons over age 65 is projected to increase from approximately 550,000 in 1990 to over 900,000 by the year 2020. The number of persons over 85 is projected to increase from approximately 70,000 to nearly 120,000 during the same period (Minnesota State Demographer's Office, 1997). (See charts below)



Projected growth, Minnesotans over 65
1990-2020

Source: Minnesota State Demographer, County Projections: 1990 to 2020



Projected growth, Minnesotans over 85
1990-2020

Source: Minnesota State Demographer, County Projections: 1990 to 2020.

In reporting on the public health implications of this trend, many researchers have noted that the number of persons with disability "increases significantly with age." Guralnik et. al. further report that disability in older persons "affects both their quality of life and the need for care, and has a major impact on their families and the entire health care system" (Guralnik et al., 1996).

While persons with chronic health conditions are often not considered disabled, chronic health conditions also have a significant impact on the entire health care system. It has recently been estimated that "over 45% of noninstitutionalized Americans have one or more chronic conditions and their direct health care costs account for three fourths of US health care expenditures." **The impact of chronic conditions nationally has been projected to increase from the 1990 total of about $425 billion in direct health care costs, to nearly $800 billion (in 1990 dollars) by 2030** (Hoffman et al., 1996).

Scope of this study

The essential definitions and data needed to carry out a rigorous impact evaluation as described in the study charge above are generally lacking. For example:

- There is considerable disagreement as to what constitutes quality of life, and how to measure it. Disagreement also exists as to what constitutes quality health care, and how it may be measured. These disagreements are perhaps most evident in deep ideological divides over end of life care. Efforts to achieve one objective -- preserving life -- may often come at great emotional, physical and financial costs. These efforts may be perceived to conflict with equally strong efforts to promote dignity, control pain, and to meet family and individual needs during the process of dying (Council of Scientific Affairs et al., 1996; Sprung, 1990; McCue, 1995; Lynn et al., 1997).

- The term "managed care" is extremely broad, and there is no single standard definition of managed care in use. It has been estimated that over 80 percent of persons with acute health care coverage in Minnesota now receive their care through some form of managed care, but the types and levels of managed care used vary significantly.

- Many of the most severely disabled receive health care through the state's Medical Assistance (MA, or Medicaid) program. Except for a limited time period in the mid-1980's however, persons with disabilities on MA have generally received their care through a fee-for-service system and have not been enrolled in MA's Prepaid Managed Care Program (PMAP). Consequently, experience with managed care for persons with disability on MA is limited, and is now nearly ten years old.

- With the exception of the PMAP studies above, objective, well-designed large studies and data on health care quality and quality outcomes, particularly for the more narrow focus of the target populations in Minnesota, are not available.

- Rapid changes in the health care market, changing views about medicine's role in death and dying, and new levels of discussion regarding a variety of related issues make this evaluation topic a moving target.

As a result, our study often relied upon anecdotes and information which were readily available. Much information is qualitative rather than quantitative, or was developed in other settings and in previous time periods that may not be relevant to Minnesota. It is difficult, and often inappropriate, to draw inferences from such information.

This study incorporates information from:

- *Analysis of "macro" level health indicators* (e.g., infant mortality, overall death rate, death rates due to particular illnesses or injuries, rates of particular diseases). (Are concerns about possible under treatment or under service of the study target populations reflected in macro-level indicators of overall health?)

- *Literature searches* (What does the literature on other large-scale, well-documented studies report with regard to the study objectives?).

- *Studies conducted of previous state PMAP demonstration projects in the late 1980's* (What was the experience of previous demonstration projects which enrolled persons with disability and chronic illness?).

- *The experience of other states which have implemented prepaid managed care for disabled and chronically ill populations under Medicaid.* (What has been the experience of other states with the target populations? What lessons might be learned?)

- *Public hearings and forums* (What can be learned from the testimony of those directly involved or affected? What do other groups and forums present on the topic?)

- *The Commission's 1995-1996 study of the integration of acute and long term care* (How is acute and long term care currently provided? What are the relationships between acute, episodic care and other forms of care for persons with chronic health conditions and disability?)
- *Review of summary administrative and legal data* (A number of health care complaints and grievance mechanisms are monitored and maintained by the state. What does the experience from these mechanisms potentially indicate about the study objectives?)
- *Additional meetings, contacts, focus groups, and discussions*, including meetings with advocates and with DHS staff planning five pilot demonstration projects to enroll persons with disability in managed care.

Findings

In spite of the limitations of this study, numerous findings and conclusions are important to consider.

- Data to accurately and adequately address the study objectives are very limited.
- Much of the data cited in the literature and available from previous PMAP studies indicate either no difference between fee-for-service and managed care in terms of health outcomes, quality of care, and satisfaction, or some advantages of managed care. (It is difficult to know how representative the data are of Minnesota's target populations at this time.)
- To date, we have found no evidence of rationing of needed care, or euthanasia, of the target populations in response to health care cost containment pressures as sometimes has been alleged.
- Concerns and important issues regarding care of the target populations have been raised. In many instances, these concerns exist equally in fee-for-service environments, as in managed care environments.
- Regardless of the quality of the available evidence, negative perceptions and apprehensions about the future direction of health care delivery and financing have been raised. Because even relatively small changes in health care will have significant implications for those who rely on the system the most, the concerns and apprehensions of the target populations must be understood and better addressed.

- Many concerns reflect larger issues of meeting the needs of the target populations under the current narrow "medical model" of acute, episodic health care delivery and financing. Debates over how broadly medical care should be defined, or alternatively, what should be covered by third party reimbursement, are not new and have been occurring for over 40 years. These debates are now taking on greater urgency in the wake of cost-control pressures, pending federal reductions in outlays for Medicare and Medicaid, changes in the economy, and the aging of the population.

- Levels and types of consumer protection and assistance varies throughout the system. However, since 1995, there have been efforts to ensure more consistent consumer protections across the state regulated health insurance market. For example, all regulated health plans are required to develop and implement an appeals process, effective July 1, 1997. This requirement does not apply to the self-insured market or public programs.

- There often seems to be a lack of knowledge of protections, services or help available to aid in navigating the health care system

- Because of the perceived conflict over length of life versus other definitions of quality of life, there is considerable disagreement regarding quality end-of-life care. Persons with terminal illness vary in their desire for life-sustaining treatment. However, studies indicate that many patients indicate that they want limits on the use of life-sustaining treatment. Frequently these desires are not communicated, acknowledged or followed. As a result, death for many patients takes place in a hospital rather than other desired settings, and occurs with pain, fatigue, difficult breathing, or other symptoms that generally could be better managed. These results occur in both managed care and fee-for-service settings.

- There is much that can and should be done to improve the health care system for persons with chronic illness, disability, and terminal illness.

Study methods leading to our findings

There was no single source of information for this study, so many sources were used. Some of the sources provided hard objective data, while other sources provided information which was anecdotal in nature.

- ***Macro level data on health status measures***

We found many macro level indicators of health in Minnesota (e.g., infant mortality, overall death rate, death rates due to particular illnesses or injuries, rates of particular diseases) to be among the best in the country (Data provided by Center for Health Statistics, 1996). The ReliaStar Corporation, which annually ranks states according to health status, announced in November 1996, that Minnesota was the healthiest state in the nation. The ranking was based on a combination of seventeen factors which measure disease, lifestyle, access to health care, occupational safety and disability, and mortality. Minnesota has been number one in the rankings for four of the last seven years, and number two in the other three years (Reliastar Financial press release, 1996). However, whether these rankings also reflect, or would persist in the absence of, good quality health care and outcomes for the target populations, could not be determined.

▸ *Literature reviews*

Literature on the outcomes of care under managed care and fee-for-service

An independent literature compilation and review of a number of large, well-documented scientific studies comparing outcomes of care for those in fee-for-service health care arrangements and managed care was recently completed by the University of Minnesota's Center for Biomedical Ethics (Center for Biomedical Ethics, 1996). Studies reviewed were graded according to such criteria as: whether the study was completed after 1985; whether managed care and non-managed care populations were adequately controlled and matched to avoid differences resulting from health status of the two populations; whether the study was published in a peer-review journal; whether the study was broad based; whether there might have been conflicts of interest in conducting the study.

The literature review reported that outcomes of managed care were generally equal to or better than fee-for-service (Center for Biomedical Ethics, 1996). However, it may be difficult to generalize from the studies reviewed from the literature to the current target populations of interest in Minnesota. Many of the studies were completed a number of years ago, were conducted in other parts of the country, used self-reported data, or have other methodological limitations that may make their application to this study more difficult. This literature review is provided as Appendix 6.

Literature on outcomes of care for terminally ill patients

Taken together, the literature, as well as ongoing medical, social, and legal debates, indicate often strongly conflicting views and attitudes regarding quality outcomes for persons with terminal illness. With the development of advanced medical technologies, especially such as ventilators in the late 1950s and 1960s, it became possible to save and prolong lives of persons who previously would have died in the absence of the technology (Tina

Stevens, 1995). These capabilities have led to what some have termed the "medicalization of dying" (McCue, 1995), which has emphasized intensive medical care and "extraordinary" measures to prolong life. This is often perceived to be reflected in where and how most people now die. Whereas the majority of deaths as recently as 50 years ago occurred in the home, it is now estimated that more than 80 percent of persons in the U.S. die in institutions, primarily hospitals and nursing homes (McCue, 1995).

This transformation toward more reliance on medical or institutional settings at end of life has also been perceived to offer "potential and peril" to dying patients and their families. Many individuals and families greatly value the possiblity of even slightly longer lives that may be possible through aggressive medical intervention. However, others may feel that if such interventions are associated with pain, suffering, loss of dignity or control, or undue financial burdens, they would prefer less aggressive end of life care.

The past 40 years have seen a plethora of legal decisions and campaigns to address the issue across a broad spectrum of ideological and ethical points of view. As a result, the literature often seems to suggest two parallel courses over the last few decades.

As early as 1957 for example, the International Congress of Anesthesiology, "concerned by ethical problems in the use of resuscitative measures, sought guidance from Pope Pius XII." The response from the Pope emphasized the need for authorization from the patient's family, and that the family was bound to use "ordinary rather than 'extraordinary' measures to prolong life" (Tina Stevens, 1995).

The intervening decades since the papal message have seen the growth of a movement toward legal and policy means to allow patients and their families more decision making power regarding dying. The period has seen significant discussion of advanced directives, living wills, do not resuscitate orders, hospice care, and other reactions to the "medicalization" of dying.

At the same time, concerns have also been raised that persons at or near death without medical intervention not be devalued, and that society not permit the type of "aberration" that allowed the rise of Nazi genocide during the Second World War (Sprung, 1990). Thus, the last 40 years has also seen "baby Doe" legislation to ensure life preserving treatment, and a variety of complex legal cases involving disputes over ending life support for persons in persistent comas (e.g., Nancy Cruzan, Karen Quinlan). Most recently, the debate has reached the U.S. Supreme Court, which recently heard arguments regarding the issue of physician assisted suicide.

Despite the controversy, the literature on outcomes for terminally patients often reflects modern science's limited involvement in coming to understand terminal illness and death. As reported in 1994 by the American Medical Association's Council on Scientific Affairs, "modern medicine has largely failed to note how a patient lives during the now prolonged course toward dying", and while "reliable, straightforward descriptions of the experience of dying persons and their families are needed" few of these studies have been undertaken (AMA Council of Scientific Affairs, 1994).

One major study of the dying process has very recently been published, and is an outgrowth of two earlier projects designed to "understand and improve decision making for seriously ill and elderly hospitalized patients" (Lynn et al., 1997). Researchers in the study interviewed family members of severely ill and elderly persons who died and also examined medical records of the patients. Interviews of over 3350 families of patients who died were completed in five different teaching hospitals which varied by location and size. Information regarding the patient's insurance coverage (i.e, whether fee-for-service or managed care) was not included in the published account of the study. The study raises serious questions about end-of-life care, and what should be perceived as "quality" care for the terminally ill.

The researchers found that in the last three days of life, 55 percent of patients were conscious, and that "among these patients, pain, dyspnea, and fatigue were prevalent. Four in 10 patients had severe pain most of the time. Severe fatigue affected almost 8 in 10 patients. More than 1 in 4 patients had moderate dysphoria. Sixty-three percent of patients had difficulty tolerating physical or emotional symptoms." They noted that pain was found even among patients who had diseases in which "severe pain might not have been expected" (Lynn et al., 1997).

The researchers also found that "overall, 11% of patients had a final resuscitation attempt. A ventilator was used in one fourth of patients, and a feeding tube was used in four tenths of patients. Most patients (59 percent) were reported to prefer a treatment plan that focused on comfort, but care was reported contrary to the preferred approach in 10% of the cases." They concluded: "Most elderly and seriously ill patients died in acute care hospitals. Pain and pain symptoms were common and troubling to patients. Family members believed that patients preferred comfort, but life-sustaining treatments were often used." The researchers suggest that their findings "indicate important opportunities to improve the care of dying patients" (Lynn et al., 1997).

Decision making for patients with terminal illness and at the end of life is complex. Many families and patients are willing to risk pain and other symptoms in order to extend life. Concerns have been raised that those patients who desire this level of care may be denied it because of cost-containing incentives in managed care.

Often of particular concern is coverage for costly interventions which are considered life saving by the patient or family, but which are not covered by insurers because they are considered "experimental" or investigational. In 1995, the Minnesota Legislature was embroiled in controversies over one such procedure, the coverage of autologous bone marrow treatments for breast cancer. The Legislature subsequently passed a mandate requiring insurers to cover the procedure. The net effect of the mandate in terms of costs and patient outcomes is not known at this time however, and there is still significant controversy in the medical community regarding the potential risks and benefits of the procedure. Some members of the Legislature who participated in the debate have suggested that a new process be established to help guide decision making regarding these procedures in the future.

The question of financial incentives in providing care for the terminally ill generally requires more study. A recently published report indicates that savings from alternatives such as hospice care and advance directives may be much less than typically forecast, potentially creating fewer direct financial incentives to use these alternatives (Emanuel, 1997). We found no reliable evidence to determine whether, or the extent to which, care which should be provided terminally ill patients was being withheld. As with issues of the definition of medically necessary care however, there are many questions regarding the level of care which can be expected under insurance arrangements, especially related to coverage for unproven experimental or investigative procedures.

A mirror image to the concern above regarding underservice of terminally ill patients is that of overtreatment, or ignoring patient wishes. Both Lynn, et. al. (cited above), and the AMA Council on Scientific Affairs, have noted how entrenched the "medicalization" of dying has become. Most patients fear that death will be painful, and want the pain controlled (Council of Scientific Affairs, 1994). However, as the study by Lynn and others demonstrates, death is often painful and troubling. According to the research team , this occurs at least in part because "inadequate professional training and dysfunctional aspects of delivery system organization are important barriers to effective pain control" (Lynn et al., 1997).

The AMA's Council on Scientific Affairs also has found similarly that:

> "Although guidelines and a curricula on pain management have been developed, oncologists and others report serious perceived shortcomings in management of cancer pain. Certainly, no one need be in serious pain, since physicians could always relieve pain with anesthesia or profound sedation. For some this is an unacceptable trade-off, but it is always available. ... the prescription of pain medications to the point of obtundation in the last days of life may more commonly reflect provider behavior than patient preferences or needs" (AMA Council of Scientific Affairs, 1994).

The difficulty of significantly changing the current course of dying is evidenced in the results of the 1995 *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT).* This large study centered around a program to clearly address patient end of life preferences and decision making regarding resuscitation, alleviation of pain, and other issues. The study evaluated the use of a "specially trained nurse" who " had multiple contacts with the patient, family, physician, and hospital staff to elicit preferences, improve understanding of outcomes, encourage attention to pain control, and facilitate advance care planning and patient-physician communication" (The SUPPORT Principal Investigators, 1995). Despite the significant additional communication between patients, families, and health care professionals, the intervention was termed "ineffectual" and did not result in more responsiveness on the part of the health care delivery system to patient preference (Lynn et al., 1997).

The literature on care for the terminally ill, together with social, legal, and medical developments over the last four decades, frequently reflect strongly conflicting views on quality outcomes for persons with terminal illness. The "medicalization" of dying is associated with both life sustaining potential, and perils of unnecessary pain, suffering, and costs. Managed care has been viewed as threatening those near the end of life with financially motivated rationing of needed care; conversely, because of its potential for more flexibly coordinating and integrating care, managed care is also seen as a potential vehicle for more patient centered care and control in dying (Miles et al., 1995).

- ***Studies of previous Prepaid Medical Assistance Program (PMAP) demonstration projects***

Persons with disability and the elderly were temporarily enrolled for a short period in the mid-1980's in PMAP demonstration projects conducted in Hennepin, Itasca, and Dakota counties. A number of different evaluations were subsequently conducted which also included data collection on the target populations of interest. The evaluations compared fee-for-service with the prepaid (managed care) settings on such variables as: functional status, services used, health status, and costs. Overall, the evaluations often showed no difference between the two groups on health or functional status, and some lower resource use in managed care (Minnesota Department of Human Services, 1996). A more detailed summary of the evaluation findings is provided as Appendix 2.

- ***Studies of other state Medicaid programs which have enrolled the target populations in managed care***

According to a recent report of the U.S. General Accounting Office, 17 states have enrolled persons with chronic illness and disability in managed care. With the exception of Arizona, which began enrolling these groups in 1982, the other programs are less than 3 years old. Six states require enrollment of all Medicaid eligible individuals, while the others are implementing much smaller voluntary or demonstration projects for a portion of disabled Medicaid eligibles.

The GAO report focused on efforts states were making to address two key issues: 1) building safeguards into the programs which protect the target populations through adequate planning and consensus building; and, 2) tailoring various aspects of the program (such as enrollment and monitoring) to meet the specific needs of disabled beneficiaries. The report also discussed state efforts to reduce financial incentives for health plans to not enroll, or to under serve, the target populations. A brief summary of the GAO report is provided as Appendix 3. The report did not provide any information on the outcomes of care or quality of life for those enrolled in the state's programs (United States General Accounting Office, 1996).

- ***Public hearings***

Three public hearings were conducted as part of the study, in East Grand Forks, Mankato, and Little Canada (for the Twin Cities metro area) in the Fall of 1996. Public testimony was gathered in conjunction with regularly scheduled meetings of the Regional Coordinating Board (RCB) in the regions for each respective hearing. The hearings were publicized through statewide notices and invitations to disability, chronic care, and terminal care organizations, announcements at the Minnesota Health Care Commission and RCB meetings, local media contacts, Commission and RCB mailings, postings and flyers, and through other meetings, discussions, and phone contacts.

Those who testified at the public hearings included persons with disability and chronic conditions, family members, advocates, care providers, representatives of local and state government, representatives of organizations, and others. A number of state legislators and county officials also attended, or participated in taking testimony. **We encourage readers to review Appendix 1 for a much fuller record of the testimony from these public hearings.**

The testimony helped illustrate and personalize a number of issues or concerns, but it remains unknown how representative the testimony is of the views or experience of the target populations more generally. In addition, the testimony often focused on perceptions or apprehensions rather than, or in addition to, actual experiences.

Perhaps not surprisingly, most testimony drew attention to actual or perceived problems, complaints, or concerns. Testimony describing positive experiences or perceptions was also offered in a few instances. As described in much greater detail in Appendix 1, some persons testified as to problems in obtaining particular services under their health coverage arrangement, particularly regarding durable medical equipment. A few cases of apparent poor customer service or poor quality of care were presented. Some persons indicated that it was difficult to find out about how coverage decisions were made, or how to influence the coverage decisions. Many persons with problems or grievances felt that they were dealt with insensitively or rudely. A number of individuals expressed concerns that under managed care, access to specialists may be limited, or that relationships with current providers would be disrupted, potentially resulting in difficult, time-consuming efforts by patients and families to obtain the level of knowledgeable, sensitive, skilled care that was desired. A striking observation is that there was frequent indication that persons testifying often lacked knowledge of possible consumer protections or assistance which might have been available.

Many of the experiences and concerns of those testifying did not seem to be limited to highly managed forms of care, but existed (or would likely have existed) also in less managed or fee-for-service environments. This seemed especially true of many issues regarding limits on services or products that were covered under an insurance arrangement.

Finally, it is often difficult to assess the factors possibly contributing to the type of testimony we received. Whether testimony of unfavorable experiences or perceptions represents "tip of the iceberg" cases or rare, isolated examples is not clear at this time. Other data, most notably a 1995 statewide survey of over 17,000 persons with health coverage, reported generally high levels of satisfaction with health coverage arrangements, and higher rates of satisfaction overall with managed care arrangements than with traditional fee-for-service arrangements (Minnesota Health Data Institute, 1995). Here too, however, the survey may not adequately depict the much smaller subset of persons with chronic illness, disability, or terminal illness.

Consolidation in the market has raised numerous concerns generally related to a distrust of large organizations. Because over two-thirds of private health care coverage in Minnesota is provided through employers, a sizable number of Minnesotans may be reacting to changes or limitations that their employers are putting into place with regard to their health care, irrespective of other changes in the health care delivery system.

Many employers for example, are offering their employees only one choice of health plan, thereby significantly restricting the choices and options available to employees and their families. Some employers are changing benefits plans and coverage. Employers are presumed to offer the benefits that a majority of employees desire, while balancing overall costs. Some individuals will invariably find that they need or would prefer broader coverage than is provided through their employer. At this time, over half of all state employers offer health coverage (Minnesota Department of Health, Health Economics Program, 1995). Discussions about broadening the scope of health coverage have also led to concerns that if employers are over-regulated, or are required to offer more extensive benefits, they may discontinue offering coverage.

Rapid change in the health care industry is leading to heightened anxieties and fear of the unknown. In particular, changes in established physician-patient relationships, customary sites of care, ability to obtain treatments or benefits provided previously -- whether actual, pending, or only perceived changes -- are creating significant apprehensions. As the state's recent survey of those in managed care suggests however, actual experience with managed care may be much more positive than earlier apprehensions warranted. While the public hearings conducted for this study provided needed insights and examples, much better information, and broader ranging dialogues on these issues, continue to be important to assessing changes in the health care market.

The Minnesota Health Care Commission serves as a forum for broader dialogue on the issues. It has invited groups such as Minnesotans Concerned for Life (MCCL), which originally raised allegations that managed care was leading to rationing and euthanasia, to discuss their concerns. The MCCL refused, citing their preference to take such issues to the Legislature directly. The Commission also invited Citizens Concerned for Choice in Health Care (CCHC), which has cited strong concerns regarding managed care and recent health care reforms. The CCHC also declined the invitation. The Commission intends to further network and provide forums over the next year to help address issues of consumer needs and protections in a rapidly changing health care market.

▸ *Administrative data*

A variety of state agencies and organizations exist to oversee health care delivery or to assist consumers. In addition, a variety of mechanisms have been established to record complaints and grievances.

The Minnesota Department of Health, for example, licenses and regulates HMOs and community integrated service networks (CISNs), collects data on complaints submitted to the Department, and takes action on those complaints. The Department of Commerce licenses and regulates commercial health insurance companies and Blue Cross and Blue Shield of Minnesota. The Department of Human Services maintains quality assurance and oversight responsibilities for care purchased on behalf of persons enrolled in public programs (Medicaid, General Assistance Medical Care, and MinnesotaCare). DHS also maintains an ombudsman's office to assist DHS enrollees in the Prepaid Medical Assistance Project (PMAP). Other health care related ombudsmen offices include Mental Health and Mental Retardation, and Older Minnesotans.

A copy of the categories of written complaints received and addressed by the Minnesota Department of Health in 1996 is attached as Appendix 4. The Department registered 573 written complaints for 1.1 million enrollees in 1996. The most frequent type of complaint was for referrals, followed by medical necessity, and quality of care. According to MDH staff who compiled the information, the rates and types of written complaints recorded in 1996 have remained relatively unchanged from previous years.

A list of appeals regarding benefits and coverage through the Prepaid Medical Assistance Program (PMAP) administered by The Department of Human Services, DHS, for 1995 and 1996 is also attached as part of Appendix 4. The DHS PMAP Office of the Ombudsman reported 77 appeals out of 160,000 PMAP enrollees in 1995, and a preliminary total through August, 1996 of 63 appeals out of 194,000 PMAP enrollees for 1996.

Of the 63,000 inquiries and complaints received by the Commerce Department in 1996, 1162 became investigative health insurance files. This resulted in over $617,000 being recovered for the policyholder. A list of categories of Commerce Department health-related recoveries is provided as part of Appendix 4.

Current methods of complaint tracking are designed to serve functions other than to address the specific objectives of this study. As a result, the administrative data we accessed did not aid greatly in evaluating the outcomes of care for the target populations. Much of the information is reported in summary form, and does not indicate whether the complaint involved someone from the target populations, nor the exact nature of the problem. In some cases, records of complaints or corresponding administrative actions are not yet maintained in a database for easy access, retrieval, or research. Typically some "trigger" event or established level of communication is needed before action is initiated or the complaint becomes part of a database. The Health Department list of complaints for example, records only written complaints, and does not include complaints received via telephone.

In addition to the complaint process above, the MDH Managed Care section conducts a quality assurance examination of all health maintenance organizations (HMOs) and community integrated service networks (CISNs) licensed by the state. The examination encompasses the plan's quality assurance program and activities, complaint and appeal systems, access and availability standards and practices, and utilization review practices. The health care delivery system of the plan is further evaluated through on-site clinic visits conducted at the time of the examination.

Finally, all health plan companies must annually file an "action plan" with either the Commissioners of Health or Commerce. In addition to other reporting requirements, the plan must include a detailed description of the health plan's "policies and procedures for enrolling and serving high risk and special needs populations", including persons with chronic illness and disabilities (Minnesota Statutes. 62Q.07). The action plans are available for review by the public, so they will have knowledge of the plan's policies regarding the target populations.

- ***The Health Care Commission's 1995-1996 study of integration of acute and long term care***

The data and perspectives we reviewed often did have a number of recurring themes, many of which were also explored in a previous Commission study to integrate acute and long term care. That study was undertaken because the current health care delivery and financing system has typically been organized around what many have described as a "medical model" to treat primarily acute, episodic needs. The current medical model may no longer be adequate as the major causes of illness, death, and disability shift from infectious disease to chronic conditions associated principally with aging.

Chronic conditions often require more long term, ongoing forms of care and support, including assistance with activities of daily living and many non-medical services. Despite the frequent misconception that long term care means nursing home care, most long term care is currently provided for informally, usually through family members.

Few long term care services are typically now covered under current private insurance arrangements. Instead, they are often funded directly by the users of the services themselves and their families, or through public programs, especially the federal-state Medicaid program, and other programs administered at the local level.

These long term, chronic care services have not been effectively integrated into overall health care delivery and financing. The Commission's 1995 study found that greater integration was needed, and outlined a number of guiding principles and goals to begin a process of integration.

Application of the medical model has often resulted in narrow definitions of "medical necessity", the standard for the provision of care in HMOs, and in other similar standards for other forms of care delivery, including fee-for-service. According to advocates for persons with disability, and as cited a recent study by the U.S. General Accounting Office, the narrow focus on acute, episodic care is often too limited to meet the needs of persons with disability (United States General Accounting Office, 1996).

Health coverage limits the services that will be covered to those which are medically necessary. For example, the definition of medically necessary which applies to Health Maintenance Organizations (HMOs) and Community Integrated Service Networks (CISNs) limits coverage to treatment that restores, maintains, or prevents deterioration of health. However, many persons with chronic or disabling conditions may be unable to restore or maintain their conditions, and are denied services as a result. Persons with congenital problems often are born without a particular function. In many instances, they must first acquire the function before being able to receive treatment which is covered by their health insurance policy. These *habilitative* services (as distinguished from *rehabilitative* services) are often at the center of the controversy, regardless of whether an individual maintains fee-for-service or managed care health coverage.

The AMA's Council on Scientific Affairs also found the current medical model to be too limited in providing end of life care. According to the Council, the health care system "is fragmented over time and across services, so that no one can promise the patient enduring, comprehensive care. Thus, no one bears an obligation to assess overall system performance or address its shortcomings". As a result,

> "many of the services that most commonly benefit dying persons are not regularly included in insurance benefits. Maintenance physical therapy, spiritual counseling, pain management, reassurance by home visits, and family emotional support are often not covered services. ...This unavailability of services results in many counterproductive components in

> the health care system. Intensive care unit services for persons known to be near death are available and are covered ... however, home visits for simple medical problems ... or for family support are often not available or reimbursed." (AMA Council of Scientific Affairs, 1994)

In much of the recent public testimony and conversations with representatives and advocates for the disability community it was often this problem -- that current health coverage and financing mechanisms are not well suited to the broader needs of the target populations of this study -- rather than any form of observable "rationing" of services under current standard benefit plans, that was perceived as a central issue.

Debates of how broadly medical care should be defined, or alternatively, what should be covered under third party reimbursement, are not new. While these debates have been occurring since the growth of modern health insurance following World War II, they now have greater urgency. Overall health care cost containment, pending federal reductions in outlays for Medicare and Medicaid, and an aging population will likely increase the strain on both the acute care and long term care systems. New models of efficiently financing and delivering long term care services in concert with more traditional medical services are needed.

- ***Review of planning by Department of Human Services of pilot projects to enroll persons with disability into managed care arrangements***

The Department of Human Services is planning for five pilot projects to enroll persons with disability who are currently in fee-for-service into managed care. The goal of the pilots is to "address aspects of the current system which affect the clinical outcomes as well as quality of life, for people with health care disabilities." The models will focus on "assuring access to quality health care and appropriate utilization of services while achieving cost efficiencies." The pilots are scheduled for implementation in mid-1998, and are described in more detail in Appendix 5.

Significantly, the planning process has incorporated significant input and feedback from key stakeholder groups and persons with disability generally. As issues of health care for this studies target populations are considered, it would be useful to further examine and possibly incorporate lessons from the DHS experience. The planning process has adopted the following guiding principles:

" Models explored in the project should meet the needs of individuals and should be based on the following guiding principles:

- Commitment to individual participation and choice

- Assurance of quality services and supports
- Development of cost containment strategies
- Commitment to a community based system of services and supports
- Involvement of stakeholders in planning, development, implementation and evaluation
- Integration and coordination of public and private funding sources and
- Recognition of the unique needs of children with disabilities."

The planning process also emphasizes the importance of building in sound evaluation of the pilots from the outset, to seek answers to questions such as " What is working, for which people, under what conditions?" A longitudinal study design will be used to track persons enrolled in the pilots over time, and to compare them with appropriately matched enrollees who continue to use fee-for-service on such variables as outcomes, cost, and satisfaction.

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Appendices:

1. Public testimony
2. Evaluations of Minnesota PMAP
3. U.S. GAO report summary
4. State agency health coverage complaint reporting
5. Description of Department of Human Services demonstration projects to enroll persons with disability into managed care
6. *Managed Care Outcomes* (Literature review by the University of Minnesota's Center for Biomedical Ethics)

Appendix 1:
Public Testimony

Appendix 1: Public testimony

Three public hearings were conducted as part of the study, in East Grand Forks, Mankato, and Little Canada (for the Twin Cities metro area) in the Fall of 1996. The public testimony was gathered in conjunction with regularly scheduled meetings of the Regional Coordinating Board (RCB) in the regions for each respective hearing. The hearings were publicized through: statewide notices and invitations to disability, chronic care, and terminal care organizations; announcements at Health Care Commission and RCB meetings; local media contacts; Health Care Commission and RCB mailings; postings and flyers; and through other meetings, discussions, and phone contacts.

Those who testified at the public hearings included persons with disability and chronic conditions, family members, advocates, care providers, representatives of local and state government, representatives of organizations, and others. A number of state legislators and county officials also attended, or participated in taking testimony.

Below is a brief overview of the testimony, organized according to key issue areas. Following this overview is a longer, more detailed summary of the testimony, including full copies of written testimony we received. It was beyond the scope of the study to attempt to further clarify the situations described in the testimony.

Overview of Testimony by Key Topic/Issue

- **Coverage/Medical Necessity/Utilization Review**

  - The definition of medically necessary is inadequate because rehabilitation to restore function for conditions related to illness or accident is covered, but habilitation services for someone born with a condition (e.g., cerebral palsy) are not covered. This is not an issue only of HMOs, but is a universal problem in Minnesota.

  - Don't know who decides medical necessity or how medical necessity is decided -- insurers need to consult with consumers, realize individual needs are unique, invest in some equipment and supplies now for future savings later.

  - Don't know when a mental health service is a covered service, and when it is a social service that is not covered.

  - Decisions about coverage are made by people that are not medical people, and who are only concerned about the bottom line. When some disabled people are denied services, it sometimes prevents them from even being able to get out and complain.

- Coverage of speech apraxia denied -- extensive appeals and communications ensued before services for apraxia were paid for

- Patient described problems obtaining durable medical equipment, medical supplies, rehabilitation, and home care. Denial of electric wheelchair led to shoulder injury and surgery. Payment for inpatient rehabilitation was limited, and home care was not covered.

- Doctor prescribed an electric scooter for patient with multiple sclerosis. Insurer denied coverage for the scooter. According to the patient, scooters would be covered only for persons bed ridden or limited to a chair, and then only for use at home. The denial of mobility aids is contrary to current public policy that calls for keeping people employed and off public entitlement programs. The insurer requires persons to be unemployed and eligible for Medicaid to obtain mobility aids.

- Family with 14 year old daughter with cerebral palsy, seizure disorder, learning disabilities, and dystonia. Experienced difficulties with coverage of wheelchairs and services such as PT, OT. Numerous referrals and appeals required. Getting one piece of equipment took 8 months, 6 prior authorizations, at least 7 letters from professionals, and she still can't use it.

- Patient experienced a complex, difficult appeals process to obtain services. Needed to access specialists to provide information and documentation necessary for the appeals.

- Discussed case of 17 year old in motorcycle accident, who sustained a spinal chord injury. Insurance covers acute and emergency care. Coverage, service authorizations, and reimbursement, etc. for nursing home and home health care, electric wheelchair, and other needs much more limited, difficult. It is important to employ experienced professionals with credentials as insurance company case managers, who ask about: patient options, patient choice, adjustment issues, and family dynamics for caregiving.

- **Quality**

  - Rude, insensitive treatment by health plan staff -- customer service representatives specifically.

  - Ankle injury misdiagnosed as a sprain, needed surgery that was delayed, surgery was unsuccessful. Has incurred significant expense for durable medical equipment that was not covered but which is needed because of the injury, and has gone far into debt.

  - Piece of equipment (a stander) from a durable equipment company arrived without parts which resulted in delays in getting the equipment.

  - Inadequate, insensitive response to mental illness in 14 year old; 14 year old subsequently ran away and has not returned.

- **Access to specialists and services**

  - Person with multiple sclerosis working for self-insured employer experienced a change in network providers when the employer changed plans. The change in plan also resulted in a reduction in benefits. The new network does not include doctor or hospital patient used for 10 years previously. As a result of the situation, the patient has paid more out of pocket for hospitalizations and has received the wrong dosage of medications.

  - Concerned about hospital where patient had received care being dropped from health plan. Concern about continuity of care and access to appropriate treatment.

  - Seeing someone in network requires bypassing closer providers who are not in network; travel is costly (both financially, and in terms of time, effort, etc.).

  - Son with Tourette's syndrome, seizure disorder, and mental retardation has a doctor that knows him well. Concerned that managed care will mean a different provider that does not know son, and a new system (of paperwork, prior authorization, appeals, etc) to be learned.

  - Patient with disability concerned about quality of care, continuity of care, and consumer choice. Concerned that in rural area, choices are already limited. Will I be able to continue seeing my specialists under managed care? Will I be able to have my personal care attendant covered? Afraid of change because I don't see how advantages will outweigh disadvantages.

- **Costs and financing**

  - The primary goal of managed care is to keep the patient population as healthy as possible, not to increase hospital admissions or promote unnecessary procedures. Appropriate management of care and early intervention bring cost containment.

  - Son has spastic quadriplegia and breathing problems. Has had ongoing breathing, mobility, and communication needs for 11 years. While needs have been constant, insurance coverage and social supports have fluctuated. Likened situation to "game" of "disability hot potato" -- tossed back and forth between publicly funded medical services, privately funded health care services, social services and educational services. Funding was designed to meet the needs of the service system, not the patient. The result was also cost-shifting.

- Contractual restrictions, gatekeeper financial incentives, and unsubstantiated practice targets too often inappropriately mold patient management. Medical and nonmedical caregivers risk being dropped from limited network participation if treatment averages or costs exceed thresholds. Standards of care developed for the acute care setting may not be appropriate for treating chronic illness.

- The current Medical Assistance prior authorization process for durable medical equipment is extremely restrictive. The state of Minnesota could save money by not limiting the purchase of wheelchairs to contract wheelchairs. A wheelchair that doesn't meet the needs of the patient is a waste of money. Potential savings could also be achieved if patients could purchase supplies from discount stores under a voucher system rather than being limited to medical supply companies.

- Reimbursement rates to providers are too low for durable medical equipment.

- Problem is cost -- I currently spend more than 10% of my income on insurance and deductibles

- By taking care of small things now, you can save money in the future. (Refusal of insurer to pay for $100 solution to irrigate catheter could lead to urinary tract infections and kidney troubles later).

Proposals/suggestions

- Looking to leaders to develop equitable definition of "medically necessary" services, including all long term care services. Individuals with extraordinary needs must have access to home and community based supports, which are no longer defined primarily as "medical", "social", educational", or "job related", but as components of a person-centered system that values self-determination, interdependence, and access to needed services.

- Move personal care assistant services out from medical model and into community, similar to the New Jersey Personal Assistance Services program.

- Adopt an independent living model of home care and personal care attendants with less medical intervention such as fewer nursing visits. The program was much like this in 1988. Consumers have the experience to train and manage their own PCAs. It is paramount that consumers have a choice of provider and PCA working with them.

- We need a totally different system for the disabled community : flexibility; choice; consumer involvement; accurate information. Need case manager to mediate/coordinate between HMO and family. Goals should be to maximize function and quality of life, not just restoration. Health care professionals and decision makers are needed who listen and involve consumers.

- Funding for personal care attendants should be directed toward wages and benefits for PCA's rather than administrative requirements imposed by acute care regulations and standards.

- Send out meeting notices for public testimony in braille and regular print

- Minnesota counties provide 40-60% of funding for mental health services for individuals with severe and persistent mental illness. It is important to integrate these local dollars in the delivery and financing of health care and to bring about effective service coordination across multiple funding sources.

- Patients and families in hospice care report positive experience, due to four tenets of the hospice model: 1) patient and family focused 2) holistic approach used 3) interdisciplinary team using variety of views and expertise and 4) ensures continuum of care for patients and families. Hospice care should be considered the blueprint for exemplary care.

▸ **Other**

- There are two kinds of inability to buy insurance: 1) if you don't have the money to buy insurance; 2) if coverage of needed services is not included in the health plan.

- Without equipment needed to travel and without personal care attendants, I would be unable to work.

- Medica's Center for Healthy Aging provides information, referral, and other services, to seniors. Medica is aware of the need to integrate medical and social services and to provide services beyond health care. HMOs are aware of the need for choice, and survival in the market depends on choice.

Summary of Testimony Presented at the Joint
RCB 5 and 6 and Minnesota Health Care Commission meeting, October 22, 1996

Below is a summary of testimony presented at the joint Regional Coordinating Boards 5 and 6 and Minnesota Health Care Commission meeting held in Mankato, October 22, 1996. This is not a verbatim transcript but a very detailed summary.

Persons Who Testified:

1. Tom Brick, Minnesota Council on Disability
2. Dr. Anthony Jaspers
3. Lynn Stern- Southwestern Council for Independent Living (Marshall)
4. John Walsh- signed up, but was not present to testify
5. Doug Miller, St. Clair, MN
6. Bob Brick - signed up, but was not present to testify
7. Lee Ann Erickson
8. Debra Neidfeld
9. Lorrie Dahl, Director of Hospice Services, Immanuel-Mayo Health Systems, Mankato
10. Kay Sonneckson, Speech Pathologist, Blue Earth
11. Walter Stoba, Licensed Clinical Social Worker, Mayo Medical Center, Rochester
12. Cathy Strom, Program Coordinator for Disabled Student Cultural Center, Uninversity of Minnesota, Representative to Student Health Advisory Committee and Senate Advisory Committee on Disability Issues, University of Minnesota
13. Dennis McCoy, Deputy County Administrator, Blue Earth County, Mankato

1. Tom Brick, Minnesota Council on Disability

Referenced recent article by Dr. Steven Miles that most deadly form of rationing in this country is the inability to buy insurance.

There are two kinds of inability to buy insurance:
1) if you don't have the money to buy insurance;
2) coverage of needed services is not included in the health plan.

The second type of inability to buy insurance is a concern. The HMO definition of medically necessary covers treatment of rehabilitation to restore function for conditions related to illness or accident. A person born with the condition however (e.g., cerebal palsy), who never had a particular function like walking, can be denied under the definition of medically necessary the physical therapy to develop the ability to walk. This is a common denial in health plans, and why a number of people end up on Medical Assistance or MA through the TEFRA program.

Not only rehabilitation but habilitation should be covered.

Not criticizing just HMOs; all indemnity insurers offering the state qualified plan do essentially the same thing. This is a universal problem in the state of Minnesota.

Other important items not covered by Minnesota health plans: there are limitations on maintenance therapy after 60-90 days (denied as custodial care); limits on durable medical equipment. Wheelchair coverage is fine for someone with a single use due to a broken leg, but is not sufficient for persons with lifelong need.

2. Dr. Anthony Jaspers:

Offering perspective of practicing physician on topic of managed care for chronically ill and disabled population.

Managed care is a philosophy of medical practice and economics that seeks to improve the health of patient populations, improve access to care, contain costs by using primary care providers as the focal point of an integrated system of care. The focus is on helping people healthy and out of expensive care settings like hospitals or emergency rooms.

Physicians do share in the financial risk of patient care, increasing their motivation to maintain and improve overall health status. This is an important point, particularly regarding the care of chronically ill patients. The chronically ill person uses proportionately more resources than a healthy person regardless of whether that person has managed care coverage or fee for service coverage. Persons with diabetes, high blood pressure, asthma, or arthritis are also at far greater risk for morbidity and mortality than the average person. Managed care systems seek to achieve optimal health status for these individuals. A lesser goal would diminish patient quality of life and have financial implications for the patient, the health care system, and society as patients require more expensive interventions for chronic conditions that have not been managed. For example, proper management of rheumatoid arthritis can eliminate or delay the need for a joint replacement. Chronically ill patients often require more office visits than the average patient but these encounters are necessary to avoid serious complications

The landmark Diabetes Complications and Control Trial proved that close monitoring of glucose levels and regular contact with a physician by insulin dependent diabetics could result in significantly reduced rates of retinopathy, a diabetic eye disease, strokes, and amputations. Use of managed care to improve health, reduce costs, is consistent with standards of appropriate medical care. More examples: November, 1995 study published in the journal of the AMA found that mortality rates for hypertensive patients were equivalent in managed care and fee for service. The same study compared mortality rates for diabetes and again found equivalent outcomes between care settings. An October 1995 study in the New England Journal of Medicine reported that HMO patients with lower back pain had lower utilization and outcomes equal to patients, orthopedists, and primary care doctors in fee for service settings.

Just last month a study published in the Journal of the AMA found that patients with rheumatoid arthritis in fee for service and managed care settings received equivalent quality and quantity of care over an eleven year period. Finally, this month the Journal of the AMA published a study showing that patients with hypertension, diabetes, recent heart attack, and heart failure showed no significant differences in health status between managed care and fee for service settings when followed over a four year period.

Conclusion: Important distinction managed care offers the chronically ill patients. Its primary goal is to keep the patient population as healthy as possible, not to increase hospital admissions or promote unnecessary procedures. Though much has been made of managed care's focus on cost containment, it's only through appropriate management of care and early intervention that cost containment can be achieved.

3. Lynn Stern- Southwestern Council for Independent Living (Marshall)

The majority of individuals served by the Southwestern Council for Independent Living in Marshall are recipients of the state Medicaid program as well as individuals who receive Medicare benefits. For individuals with disabilities who receive both of these benefits, it has proven to been a (____???) combination with respect to access and securing needed medical equipment.

Individuals are unable to find providers who are willing to meet their equipment needs because they are expected to do so at a loss to their business. Further, the caps that are placed on the amount authorized for basic equipment ignores the need of those who require more specialized equipment, such as communications equipment, or seating and positioning devices such as I have in my wheelchair here. This places a burden on that individual to battle for what's needed. In the meantime, the individual is either left to substandard equipment or in some cases has no equipment at all. Thus there is the risk to health and safety while untimely requests and appeals are required.

Many consumers are also finding it increasingly more difficult to meet basic health care needs because of the managed care approach. Managed care creates complications for individuals with disabilities who may require a greater level of covered services, who may need access to more specialized providers who are housed in different locations, such as a different clinic or different hospitals, or for those who may require more timely intervention than their nondisabled peers.

Consumers in rural areas are especially vulnerable to issues related to access. Oftentimes, seeking treatment or maintenance services from a professional requires that the individual has to travel to a more metropolitan area, something Medical Assistance prefers to keep to a minimum, obviously to reduce the transportation costs involved. Unfortunately, this cost containment does not recognize the issues related to appropriate physical access or access to specialty care as it relates to a diagnosed condition or illness. For example, let's say I need to see an orthopedic specialist, and my local hospital or clinic has a visiting specialist who comes, this would be deemed an appropriate referral. However, no consideration is given to whether that individual has a level of experience related to my specific disability, nor is there any consideration given to whether or not the exam room I may be using is appropriately accessible to me and physical access is an issue, particularly in rural areas.

As an individual, I purchase my own health care coverage privately, and generally I have to say that I have had positive outcomes with regard to meeting my health care needs and the services I have received. My primary problem however relates to the cost. I currently spend more than 10% of my annual income on insurance premiums and deductible expenses. And I know that this may not seem like much, yet there are many other expenses related to my personal health that have yet to be factored into this equation. For example, required equipment necessary for me to travel is not covered. I receive personal care services every day at no charge and those would result in about seven hours a day of personal care assistance which are currently provided by a family member. Without the equipment I need to travel and without the personal assistance I need to function, I would be unable to work. I have asked myself sometimes why I do work, because it doesn't always seem very cost effective. I understand the reluctance of the consumers I serve as to why they are concerned about becoming more independent and going to work because of the threat of the loss of benefits in order to do that.

I am relatively healthy now and I enjoy this luxury as it means that I do not have to deal with the rising concerns or complications that are changing our health care system is experiencing on a daily basis. I cannot however allow this luxury to lure me into a false sense of safety or security when it comes to health care costs or services.

We cannot allow our health care system to segregate, isolate, or negate persons with disabilities and their medical needs in an ongoing effort to contain costs. Rather it is only by recognizing and responding to the health care challenges of those with disabilities that we will enhance independence, promote attitudes toward self-reliance and work, and ultimately reduce costs for care. We all know the old adage "busy hands are happy hands" and that with purpose and meaning in life, people tend to remain happier and healthier.

4. John Walsh- signed up to testify but was not present

5. Doug Miller, of St. Clair, MN

Is a C6-C7 quadriplegic. Has used a wheelchair for past 16 years, has been employed full-time for the past seven years.

Covered by the Minnesota Comprehensive Health Association (MCHA). Glad that Minnesota has MCHA, as no other insurance company would provide coverage. MCHA premiums are reasonable. My problem is what MCHA will pay for, and how much they will pay.

Needs supplies on a daily basis for things like bowel and bladder care, and also need medical equipment. MCHA pays for most of these items, but the amount they pay is well below what I have to pay. The reason MCHA gives for this is: on any item they approve the amount that is the average for the geographic area that I live in, and pay 80% of that average price. Has never been able to find a vendor that sells products at a price close to what MCHA says is the average for the area.

Vendor used for past 16 years recently dropped being a participating provider from MCHA. The vendor said he could not make a profit on what MCHA paid. Don't know if this true; in my opinion. everyone from manufacturers to vendors to providers to insurance companies are making a killing financially. The ones biting the bullet and getting the shaft are consumers -- we have no choice.

Prices for health care and medical equipment are outrageous. Can't buy the supplies I need for what MCHA is willing to pay. Wants to know who is making decisions and how decisions are made about average price.

Mayo doctors and therapists recently recommended a new wheelchair. Also recommended an exercise bike to be pedaled with the arms. Recent research shows that wheelchair users are prone to shoulder problems, which affect the ability to stay independent. With shoulder problems, may not be able to make independent transfers from wheelchair, and may need personal care attendant, or electric wheelchair, which costs four times what a regular chair costs. Lack of exercise causes weight gain, which also affects shoulders.

MCHA approved the wheelchair, but would pay only half the costs, but denied the exercise bike as not medically necessary.

In closing, wants to stress: don't know who is deciding medically necessary or what it should cost, but whoever it is way off the mark in my case. Hopes insurance companies would be required to 1) consult with consumers regarding these products; 2) not categorize people, realize that each individual's medical needs are different; 3) realize that getting people like me the right equipment now will save them thousands of dollars later.

6. Bob Brick- signed up but was not present to testify

7. Lee Ann Erickson

Mom of 2 adult sons with Developmental Disabilities. Son Ted has Tourette syndrome, seizure disorder, and mental retardation. Ted is currently on MA, and system has worked well. Have had choices, and access to specialists for Tourettes and seizures.

When hear the term managed care, have fears and concerns regarding accessibility. Ted's doctor knows him well. Will we have to go through the process of establishing a trust process with someone else? Will Ted be able to access the specialist he needs? How long would this process take.

Details are currently handled between Ted, his doctors, and me. I expect managed care will add a few more people to do prior authorization and other things. How much time will be spent on phone calls and paper work? How timely will service delivery be? Will there be competent appeals process? Will copays be a part of the system? If so, Ted will have considerably less to spend on living independently. He may no longer have the same access to social activities and personal belongings.

When we consider long term care, I hope we see a system that includes choice, consumer satisfaction and involvement, and services that are accessible -- services that meet the needs of the consumer and not the financial needs of the managing entity, and that services will be delivered in a timely manner.

8. Debra Neidfeld

Mom of 8 year old boy, David, born prematurely and spent 5 of his first 14 months in the hospital. At age 5 son was diagnosed with autism. Feel like went through medical world and then experienced other issues where behavioral kinds of things became the problem.

In son's lifetime have been through two appeals. The initial appeal was at age 3 after PCA services were to be cut totally from four hours a day to nothing, based on a letter from a noted physician. Obtained a number of appointments to get information needed to address appeal -- obtained appointments with cardiologists, nephrologists, GI, and a surgeon circumventing that [noted] physician. Won the appeal, and were able to maintain PCA care at level requested. One month later received letter from referee asking: how they could not have addressed the [PCA care issue] as they had when such a noted physician made the recommendation? Had I not been able to access those other physicians at that point in time, clearly that physician was not open minded enough to make referrals for us. I managed to get the information needed on our own. I shudder to think what would have happened to David and our family without those supports.

Second appeal was August this year, again regarding a cut of PCA hours. Accessed a specialist, again got the information and provider documentation that was needed, and again won the appeal. The referee said that about 80% of appeals are being approved. Have to wonder, at what cost to the system and families, when the approval rate is that high? Don't we need to look at this -- it's clearly a cost containment effort. We have private insurance and access TEFRA. With an 80% approval rate, the system is not working right. It feels like this is an entirely a cost containment issue.

Chose to access an intensive behavioral modification program. The program is very time-consuming, very expensive. Payment is by us, and now through the school system. I have two letter recommending this treatment from physicians at the Mayo center, and yet I am not able to access it through TEFRA or insurance. I keep hearing the words the woodwork effect, the costs. This may be the best for my son long-term, and yet we are unable to look at that because of cost containment efforts.

I keep thinking that if there had been no way to access those specialists, and I am still struggling with the payment for the behavioral therapy, and we are managing and able to do it, but there has been a lot of stress to our family --- if there had been no way to access those specialists my fear is that managed care will take that away from us. My fear is: What would have happened? And not that you need to circumvent physicians, but at times that is necessary too. Managed care doesn't feel like much of a friend to my family or my son.

9. Lorrie Dahl, Director of Hospice Services, Immanuel-Mayo Health Systems, Mankato, also representing the statewide hospice organization.

(See copy of written testimony that was provided, attached)

10. Kay Sonneckson, speech pathologist, Blue Earth

Here as a consumer based on own medical situation. Here due to concerns regarding managed care agencies regarding benefits given to consumers.

In my most recent professional experience, my patient had no idea that the HMO he had been paying into would not cover his expenses once he was transferred into a long term health care facility after a debilitating accident that left him unable to walk, talk, or take care of any basic needs.

Initially he went through prior authorization; the HMO prior authorized services. When the billing came through they reviewed it and denied it, but Medical Assistance came through for him. The bottom line was that he had no voice in his coverage. HMO's made the decision, not the individual's physicians or therapists. Who makes the decisions, and what are they based upon? This is an arbitrary decision based upon an unknown to the consumer.

I as a consumer do not seem to understand where they make their decisions or what they are basing their decisions on when it comes to payment. Frequently, those making the decisions do not have a complete understanding of the medical and therapeutic procedures. Not only are restorative procedures, but also maintenance procedures, difficult for individuals to obtain. Without those services individuals physically and emotionally suffer, and many regress. This scenario costs us as taxpayers. I have observed individuals to be denied necessary therapeutic services which they have ultimately paid for. Grievance procedures are so difficult or overwhelming -- I am going through this now, and they are very overwhelming, and very frustrating -- it becomes easy just to give up when not receiving any support.

In summary, as a professional representing many independent service providers as well as a concerned person, I am attempting to relate to you a need for increased regulation over managed care organizations, which is not an easy issue to deal with. Hope we can allow patients to receive medically necessary treatments without the hassle, along with giving them easier grievance procedures when they have that right. It is extremely important for changes to occur so that all people receive the proper medical care.

[Clarifying question by Nan Schroeder, Health Commission: Are you going through internal grievance procedure of HMO or through Health Dept.?

KS: Through HMO

NS: Did you know that the Health Department has a grievance procedure you can access as well?

KS: No, and my patients do not know where to go.

NS: On the back of -- I don't want to speak for the Health Department because there is someone here from there -- but on the back of all HMO enrollee's cards there is a number for member services, as well as a number for the Health Department. You might want to call, or talk to (Norm Hanson from the Minnesota Department of Health was identified).

KS: That's good information. As a health professional I don't know how far I have to go with grievance procedures, because I do have to deal with HMOs.]

11. Walter Stoba: Licensed Clinical Social Worker, Mayo Medical Center
[see written notes also submitted by Mr. Stoba, attached]

12. Cathy Strom, Program Coordinator for Disabled Student Cultural Center, University of Minnesota, Representative to Student Health Advisory Committee, and Senate Advisory Committee on Disability Issues, University of Minnesota

Speaking to personal issues, but also relevant to issues a number of students have with current HMO.

Have multiple conditions, including a bleeding disorder, endometriosis, degenerative joint disease, a traumatic brain injury, and have been rear-ended at red lights three times since 1987. Have a lot of health issues and ongoing health care needs.

Here summarizing an injury at the University of MN in November, 1993 that still doesn't have resolution.

Changed to managed care in March, 1993. Had injured ankle in June. Injured ankle in November, and was told that it was a preexisting condition and a sprain. I saw an orthopedic doctor for about three minutes, was given a cam walker and a cane and told to come back December 20. A month later, the HMO rescheduled the appointment to December 27. I called a doctor outside the plan I had seen before, was seen immediately, sent to an orthopedic surgeon the same day, was told that I should not have been walking on the foot -- it should have been put into a cast immediately and that it was probably not a simple sprain.

Filed a complaint with the Department of Health. In March, my HMO let me see an orthopedic surgeon. It turned out it was not a sprain, I had torn the calcaneal cuboid joint. I could not have the surgery until June because they had only one foot specialist and the schedule was full. I had the surgery, but the doctor was no longer with my HMO, so I no longer had follow up care from him. For six weeks I tried to explain I had incredible pain, and was told to take Tylenol. Finally I changed all of my providers again, saw the new foot surgeon, was told that the surgery had failed. They had used a CAT scan to determine the injury, but just a plain x-ray to determine that the surgery was successful. I had six weeks of incredible pain, and had been sent to psychiatrist to deal with my issues. After changing all my providers again, I did have another surgery in 1995. About a year ago I was having problems and was told I needed psychiatric care and some orthotics. It turned out in May that I found out that the fusion done the year before had failed. I am tired of being denied appropriate health care because I have chronic health needs. I am tired of being asked to pay for Cam walkers that because they are durable medical goods cost $300 apiece. Using a cam walker means that the Dr. has ready access to the joint -- that costs $300, casts cost $100. Because it is a durable medical good they pay for one. If you're walking on them they last maybe 12 weeks. I have had five of them. I don't think I should have to pay $1200 for casting materials. This injury has caused my to put off finishing my Ph.D. I had enough savings to support my two children and finish my Ph.D. I am now $20,000 in debt, just in supplementary costs that went with this. I have now found out my HMO is refusing most of the medical costs they did approve.

I changed HMOs in September and requested my medical records be transferred August 9. When I went in to see the orthopedic surgeon on October 11 my records had not arrived yet, and the soonest I can meet with my surgeon is Nov. 8.

13. Dennis McCoy, Deputy Co. Administrator, Blue Earth County

Here speaking to county role for service delivery to individuals with disabilities.

Minnesota counties have extensive history of service delivery involvement for individuals with disabilities.

This results largely from the state's supervised, county administered, social service system in Minnesota. In this context, Minnesota counties have substantial funding and service delivery responsibilities to a range of individuals with disabilities. On a given day, counties will do very well with those responsibilities or very poorly. On balance, counties have done an excellent job over the decades in developing funding and delivering services identified as important to their constituents. I believe that introducing managed care principles in health and human services delivery to individuals with disabilities must be approached very carefully. Individuals with disabilities rely on many services which are not historically part of managed care programs. Disabled individuals need different service delivery approaches, which build upon existing infrastructure and expertise to avoid traumatic or dramatic disruption of their accomplishments at work, home, and in the community.

Minnesota counties provide anywhere from 40-60% of funding for mental health services for individuals with severe and persistent mental illness. Minnesota counties also provide substantial funding for treatment of children with emotional disturbances and severe emotional disturbances. They also provide substantial funding for individuals with chemical dependency, or individuals with developmental disabilities or related conditions.

The system will not operate as it does today without effective integration of these local dollars. The system will not operate effectively until there is a joint effort at the local level between consumers and other stakeholders to identify how the system might be best designed to meet the needs of individuals requiring these services. Counties view communities as something more than a primary health care issue. We believe effective service coordination across multiple funding sources is critical to ensuring an individual receives the services they need, when they need them, and in the quantity their condition warrants. It's not a simple view of the community or individuals or is it an opinion that is shared at all levels of government. The acquisition of health care is important to individuals with disabilities, but their acquisition of daily support systems, habilitative services, and other nonmedical services are critical to their ability to continue living and fulfilling their potential in communities of their choice. I am concerned that care shifting incentives currently exist and must be rectified in the future. As we make modifications to the health and human services delivery system, we must ensure service responsibility cannot be easily shifted from one sector to another. This results in service fragmentation at the user level, something we agree is inefficient and ineffective. Minnesota counties agree to cost containment, quality, and access must be assured. We also know that health and human service delivery systems in the rural part of the state are substantially different than in the metropolitan part of the state. We want to work with you, the Legislature, providers, and, most of all, the individuals who rely on these services, to ensure that a system is designed that benefits all Minnesota citizens.

HOSPICE: AN EXEMPLARY MODEL OF CARE

"All of the people that I had contact with were people that knew what our family was faced with and they showed so much care, love, and emotion."

One of the most comforting things for us were "the talks with the nurse, clergy, social worker, and volunteers."

"The Hospice Team understood what was going on and told us in a way we understood."

The most important aspect of Hospice care for us was "to know there was someone to call on when we needed help. The information about what to expect was one of the things that kept us from panicking."

These are some of the comments we receive from patients and families who experience Hospice care. What, we may ask, are the factors that ensure this positive experience? Above all, I am convinced that the **CARE** provided by the Hospice Team members, is the observable feature of Hospice. However, I believe that the **HOSPICE MODEL**, the basic foundation by which that care is provided, is the unobservable distinguishing factor and is characterized by four essential tenets.

First of all, Hospice care is patient and family focused. Care is initiated with a family conference involving the patient and as many family members as possible so that all understand the mutual goals of Hospice care. Care and support are provided for family members of all ages in all locations. Our patients and families participate in planning their care and are helped to assume as much independence in their own care as they are able to manage. Family members who assume responsibility as the Primary Caregiver, are helped to provide care in a way many thought they'd never be able to do. Decisions about care are made by our patients and families based on the question, "How will this improve my quality of life for the time I have left?"

Secondly, Hospice care is provided using a Holistic approach. We know that physical, social, emotional, and spiritual needs all impact a person's health in any of those respective dimensions. Therefore, Hospice attends to not only the physical aspect of a person's terminal illness, but also to that person's emotional and spiritual needs. Additionally, families are impacted in a way that none of us will ever realize until we are faced with a similar situation. For this reason, Hospice keenly acknowledges and ministers to the physical, emotional, and spiritual needs of family or significant others.

A Holistic approach requires a variety of expertise and viewpoints provided through an interdisciplinary team. No one individual can meet all the needs of a patient or family, and therefore at team comprised of a physician, nurses, home health aides, social worker, chaplain, and volunteers offer their clinical expertise, care and support. This team convenes weekly to hold care conferences, reviewing the plan of care for each patient and family from the physical, social, emotional, and spiritual dimensions. Team members develop a very close relationship with Hospice patients and families, and when a patient dies the team grieves too. With a vital purpose, this team provides much needed care and support to one another.

Finally, the Hospice model is designed to ensure a continuum of care, across all settings, for the patient and family. The majority of care in Hospice is provided in a person's home with a family member as the primary caregiver. However, when a person's symptoms cannot be managed at home, or when a primary caregiver is not able to provide the level of care that may be needed, hospitalization becomes necessary. This transition occurs smoothly will all admission and transportation arrangements being coordinated by the Hospice nursing staff. The plan of care and special needs are communicated to the hospital staff and overall care coordination is provided in the hospital by Hospice team members, thus creating a seamless system for the patient and family.

These four essential tenets of the Hospice Model are what sets Hospice apart from other approaches to providing care. As the leaders in our country struggle over health care reform, what it should look like, what is should feel like, I think it would be worth their while to consider the Hospice Model as the blueprint for exemplary care.

Walter Stobaugh - Licensed Independent Clinical Social Worker and Supervisor at Mayo Medical Center Rochester past 16 years.
past 11 years with people with disabilities -TBI, CVA, SCI, MS,
Acute hospital, Comprehensive Acute Rehabilitation, Brain Injury Out Patient Program - group and individual therapy.
Past chair of DHS TBI Advisory committee
DHS-Task force on Managed care for persons with disabilities.

Counseling for patients and families around adjustment to disability/illness.
Address financial concerns
Identify local resources
Assist patients and families in planning their discharge.

Acute Rehabilitation
John Jones -17 y/o single on July 1, 1996 motorcycle accident form suburb of St. Paul MN. sustained a C5 incomplete SCI and L femur & pubic Fx.
injured near Rochester and brought to SMH.

HMO authorized emergency and acute care. Mr. Jones stabilized in Halo and medically stable. Patient and family desired Acute rehabilitation at SMH.
UR call to HMO. NO, not covered. Family informed. They called HMO

HMO checked employer policy coverage. SMH was a provider. Pt and family chose SMH.

In assisting planning for discharge, pt needed a rental Electric and manual wheelchairs. I called Case manager, referred to customer service, list of preferred providers, only one in Rochester, branch office.. I had experience with this provider in the past. Rochester office unable to come up with adequate chair in timely manner. Hospitalization would need to be extended. Another local vendor had chair and worked with Preferred provider to subcontract the chair and dismiss the patient in a timely manner.

Frequent scenario. On any private/group/HMO insurance we need to call right away to the insurer to verify benefits for Home care/Skilled nursing facility coverage. Prior authorization ?needed Home Health care, Equipment preferred providers. I give to patient, so they can choose. Many patients do not know the specifics of these services as they only use them when hospitalized or traumatic events occur.

Skilled care for home care - RN, PT, OT, SP then possible HHA/PCA

Few willing to provide a transition aid and nursing from hospital to home.

Patients with High Quadriplegia SCI need manual and electric wheelchair - only pay for one.

Rarely pay for bathroom equipment - bath bench, toilet seat riser, bars in shower or commode (less expensive than a Fx hip).

Pushing for Subacute care when patient has acute rehabilitation goals.

Brain Injury - Cognitive Rehabilitation - OT, SP, Neuropsychology, PT
Comprehensive treatment program as out patient.
Classified by a major insurance provider as MENTAL HEALTH Treatment to case manage it.
This is not Mental Health treatment, it is cognitive Physical rehabilitation teaching compensation techniques to recover from TBI/CVA/Brain Attack.
Welcome case management, but based on Knowledge of rehabilitation services and patient need. Success of program 70% return to independent living and on to employment. Need for education on BI Rehab.

I am often contacted by HMO/Insurance Case managers (varying ability, background, knowledge, skills.) to assess discharge needs. Often this is a good sign that they are willing to plan and be a point of communication for the patients needs. I have spent many years of my career advocating for patients by educating these case managers on the rehabilitation process, functional needs, and goals to be accomplished by the patient and rehabilitation team. I have worked with insurance clerks, RN, QRC, Supervising insurance representatives, etc.

Chronically, many patients end up on Medical Assistance/Title XIX) when they are no longer able to pay premium with out the employers subsidy through the past employment. Some have income low enough to move to MN Care or expenses high enough to go on Minnesota Comprehensive.

Our medical center puts the needs of the patient first in an integrated practice to advocate, deliver what the patient needs no matter what. The needs of the patient come first. We strive for this daily.

Good case management will ask about
    Patient options
    Patient choice in providers and local service for equipment
    Patient adjustment issues
    Family dynamics, especially for care giving
They know the impact for future use of services and costs.

Employ experienced Professionals with credentials in their field of expertise.

Coordinating care in a partnership with providers and patients/families has a positive financial outcome and promotes care which is individualized.

Design benefits to support independent living with a disability in the community. Decrease cost shifting to public sector by covering in home services or less costly services not traditionally covered.
Allow flexibility in benefits by CM in a cost effective manner.

Summary of public testimony presented at the joint Regional Coordinating Board (RCB) 1-Minnesota Health Care Commission (MHCC) Meeting
November 13, 1996

A special joint RCB 1 - MHCC meeting was held in East Grand Forks, MN on November 13, 1996 to receive testimony for the Commission's study of health care for persons with chronic conditions, disability, and terminal illness. Three persons testified related to the Commission study, as summarized below. In addition to the testimony provided for the Commission study, the RCB provided a forum for broader discussion regarding managed care issues and perceptions, which followed. For information on the additional RCB discussion regarding managed care, please contact RCB staff at: 1-800-627-3529.

The information below is not a verbatim transcript, but has been prepared as a very detailed summary.

Dan Wilson, Northwestern Mental Health Center. [Addressed issue to Eric Anderson, Minnesota Department of Human Services, regarding implementation of managed care for MinnesotaCare]. We are sorting out some the issues, such as when a service is a covered service and when is it a social service. Adequate discussion of these issues has not occurred prior to setting up contracts. It would be helpful to have some more discussion of the boundaries. Cost-shifting is a major question related to that. If we reduce the access to services for the severely emotionally disabled children as well as *[muffled]* populations then we will be shifting back to some of the categorical [*muffled*].

[Eric Anderson, Department of Human Services, clarified that current managed care contracting in that region for the MinnesotaCare program does not include the severely emotionally disturbed or seriously persistently mentally ill people. He also clarified the scope of covered services for physically disabled persons as the same medically necessary services which have been covered under fee for servcie medical assistance. If services are social services and are not medically necessary services, they are not Medicaid covered services and not included in the contracts with the health plans. There is a learning curve to figure out where the health plans perceive their obligations to end and where the State perceives their obligations to end and where the county social service agencies begins. It is going to be a learning process for local community mental health centers to find that equilibrium.]

Audrey Richardson, RCB 1 chair, requested any additional comments.

Pat Baranski: One of my concerns relates to the previous question of determination of benefits or services that would be supplied. So often the disabled people end up being put in the hands of an agency or a board, or something that are not necessarily medical people. They look at the bottom line, and they will say they don't think that it is necessary, rather than consider the overall health and affect that it will have on the person. An examples is as simple as a type of enema used by many people on Medical Assistance. Medical Assistance will not pay for that particular kind of enema. If you use the kind that Medical Assistance says it will cover, it affects the ability of the person to take care of themselves. Again, that is being determined by somebody that says "we don't think that is medically necessary". Individuals are left at the mercy of somebody that could care less other than the bottom line, and that is the fear that individuals have. You know, its one thing to be in the place of being a stockholder and getting the benefits by cutting these costs, but it is totally different when you are that person and somebody says this is not medically necessary.

[In response to a question by Kent Peterson, Minnesota Department of Health, Mr. Freanski said the case he was referring to was fee-for-service, and elaborated:] I feel that it would be worse in the future [under managed care]. If somebody in St. Paul makes a decision that something is no longer medically necessary, the person in Northwest Minnesota may be captive in their house as a result, and they can't even get out to complain. Do you understand what I am saying? It's easy to be able to be here and complain and get in somebody's face and say " why are you doing this to me, I am stuck in this predicament" when you cut me off, but I can't even come down and complain.

Audrey Richardson asked for another question or presentation.

Mickey Kyler: I am Mickey Kyler, and I am from Crookston and I serve as an advocate for State Council on Disability, and I am here representing myself, as a consumer, and my family and my community.

I have had personal experience that *[muffled]* and I do pay for that out of my own pocket now because my life depends on it. I was talking to some people around the state of Minnesota yesterday and this morning about HMOs and what their feelings are about it, especially people in my predicament with PCA services. PCA services are being cut drastically by an HMO down in the Cities area where they experimenting with HMOs and PCA services right now.

I am concerned about the quality, continuity of care as well as the consumers choice not only for myself but for my family and community. These issues are very important to us, because being in a rural area we are already limited for our options for our health care. HMOs are a business that are out to make money. Insurance companies are designed to deal with acute care and they do well at that, however, we are asking them to provide health coverage for consumers who have chronic illness and disability that require costly maintenance. The HMOs may be able to provide this service for awhile but then they will be forced to change the definition of medically necessary for [cutting off ?] consumers from their maintenance services. The HMOs are already doing this in the Cities with their PCA services. It is cost effective for them and there are no incentives for the HMOs to maintain the same quality of covered services as the Minnesota

Health program for the chronically ill and disabled.

What will happen with health care if I am forced to go on an HMO? Will I receive doctors who are specialists that normally work with me? Will I get the equipment that is necessary for my daily living? Will I be able to continue living independently with PCA care or will my time be so diminished that I can't survive? These are questions that all of us in the disabled and chronic community have. Most of all, will I have a choice about the kind of care I receive or will I be treated as a second class citizen because I carry and require daily living in- care help. What will happen to those of us who have chronic illnesses or disabilities, and we who are considered uninsurable now, how will we save our State money and what price will the insurable citizens pay? It is hard for us to be supportive of this effort with so many questions unanswered.

We offer many nightmare stories about HMOs that considered medically necessary services unnecessary. We have worried about the limited choices for consumers who had to do without some service or equipment because their HMOs don't cover it or they are allowed to use only certain providers for their health care. We are afraid of this change because we can not see the advantages will outweigh the disadvantages. That is all. Thanks.

RCB 4 - MHCC Meeting
Public Testimony
December 4,1996

Susan Arnett - Individual
See attached written testimony.

Ken Moses - Metro Center for Independent Living
See attached written testimony.

Krista J. Westendorp - Parent
See attached written testimony.

Eric Eoloff - Allina Health System
No written testimony.

MaryJo George - MS Society
See attached written testimony for Curt Hadley, Iva Anderson, and Janice Johnson.

Priscilla Pope
No written testimony.

Anita Boucher- Courage Center
No written testimony -- provided handout, "Medical Assistance Managed Care for Persons with Disabilities: Core Principles for Service Delivery Systems"

Written testimony was submitted by the following:
Dr. Stephen Bolles
Morgan Grant
Cindy Johnson
Lynda Adams
George Failes

Good evening. I am Susan Arnett. I am here to recount a success story for my 10 1/2 year old son. Clay, and an abysmal disaster for our healthcare system. Clay was born with speech apraxia, a soft neurological disorder. In laymen's terms, Clay was not able to use speech articulators to form sounds needed in our spoken language. For some unknown cause, the nerves do not connect the messages to the appropriate area of the brain. Hence, the nerves do not act as message lines to the various articulators — mouth, lips, jaw, vocal cords, and cheeks. Unlike some speech disorders, each attempt at a sound takes on new forms and rarely was the same sound repeated for a given word. Clay's speech at age 6 was unintelligible. He was struggling in the classroom. Today, in spite of our HMO, Group Health, and our school district, Clay has overcome his speech apraxia, is 100% intelligible, and in the school district's talented and gifted program.

Speech apraxia is not a rare, 1-in-a-million disease. We have talked with dozens of families and shared our story to help them in their struggles. It is not a disorder that children will outgrow without specialized intervention.

At age four our school district tested him for speech and the following fall, 1990, began a traditional speech therapy program. In the summer of 1991, I called our HMO, Group Health, and inquired about summer supplemental speech therapy. I was rudely treated and told they didn't have anyone on staff that did speech therapy — try Courage Center. After two years in the school speech program, Clay was still 85% unintelligible and had made little if any progress. In the spring of 1992, during conferences, the school therapist gave us a copy of an article from a professional magazine. She thought he might have what the article talked about — speech apraxia.

At this point our nightmare with HMO bureaucracy and stonewalling began. Since we were in a health coverage program we assumed a neurological condition would be covered. We were dead wrong. Group Health only provided coverage for "treatment to correct the effects of illness, injury or a medical condition." Neurological disorders are medical conditions but not in the eyes of Group Health.

We linked up with a speech clinician at the University of Minnesota. Clay was immediately diagnosed with severe apraxia and intense therapy began — 3 sessions a week of 30 minutes each. This went on for many months before we relaxed and only had two sessions a week. Therapy lasted 2 1/2 grueling years. With some budget management we were able to pay for Clay's therapy while the battle raged over whose responsibility it was to cover the costs. Clay was lucky. Many families could not endure the costly therapy and precious developmental years would be wasted over rhetoric and fingerpointing.

Our first request for coverage letter went out to Group Health in April, 1992.

In May and July, 1992 the HMO denied all coverage.

In July, 1992. by a letter we were told all appeals had been exercised. We were not even aware we had been involved in an appeals process.

July, 1992 — A phone call with Group Health indicated that the medical director (who was not a learned speech disorder person) had decreed that apraxia was not a medical condition and would not be covered despite all of the literature to the contrary.

In July, 1992, we also learned of other Group Health patients that were receiving coverage for apraxia.

August, 1992 — We made an appeal to the State Health Department, asking for medical treatment coverage and exposing the discrimination practices of Group Health — playing God to determine who and who would not receive coverage for speech apraxia.

September, 1992 — HMO denied coverage of speech apraxia to the Health Department. At this point we got involved with the state organization of Speech Clinicians (MSHA) and the national organization (ASHA). They also wrote letters to the HMO and the Health Dept. stating the medical community (JCAHO) recognizes verbal apraxia therapy as a medical condition and services it as such.

November, 1992 — The Health Dept. denied coverage without ever investigating the other apraxia patients being covered by Group Health. In essence, if the HMO said no, then the answer was no.

December, 1992 — We wrote the Health Dept. requesting further clarification on their decision. They commented that they have denied coverage to speech apraxia requests before. The HMO doesn't have to provide coverage since it's not mandated by law.

December, 1992 — We called our legislator and began to investigate ways to solve this issue of coverage.

January , 1993 — By letter the HMO pointed the blame and responsibility onto the school district

March, 1993 — A speech clinician confronted the HMO that some patients are being covered for speech apraxia. This was happening when the HMO denied such actions in September, 1992 to the Health Dept.

May, 1993 — We met with HMO and were able to restart the appeals process.

July, 1993 — We were told that they (the HMO) technically didn't have to allow us an appeal meeting, since we had used up all our appeals in letters.

August, 1993 — Formal Letter of Appeal and hearing. Group Health denied and closed the books. All avenues of appeals and requests were exhausted, Through all this Group Health never informed us what are rights were nor was the request for coverage process ever explained.

The Health Department was a rubber stamp for the HMO and not once did they ever give us any indication of being pro-consumer.

Seventeen months had passed and we were frustrated, had definitely been discriminated against, and were no closer to a solution than when we started. The only shining star during this time was that our son could finally say his name after living with it for 6 1/2 years. And, his parents could at last understand his communication.

My husband estimates he spent over 360 hours with letters, appeals, repeated phone calls which Group Health didn't return, follow up calls and so on. The 360 hours was valuable lost work time that employers need to realize happens when HMOs shirk their responsibility and fight a coverage. My husband wasn't the only one spending valuable time. I, too, spent countless hours. I made contacts when my husband couldn't, relayed phone calls coming to the house, drove our son to and from the University three times a week during evening rush hour — sleet or snow.

School districts are not equipped with the speech clinicians that have had training in apraxia therapy. They don't have the funds, nor the staff to support intense, lengthy therapy sessions. They can handle the generic speech disorders, but not extreme cases due to medical problems. These cases belong in the healthcare providers arena. Verbal apraxia therapy should begin by the time the child is 2 years old. Most school districts don't even begin screening till the children are 3 or 4 years old. Schools typically work with a nine month calendar — screening being done in the spring and treatment begins in the fall. Valuable months of development time are lost. Lost developmental time creates emotional and mental traumas that result in frustrated and angry children due to the lack of ability to communicate with those around them. Clearly therapy administered through healthcare providers would offer timely solutions and many related problems, psychological, social, etcetera would not have a chance to start. In effect, reducing the real costs of healthcare. Working with speech apraxia does take more of a medical background and points to the need for speech apraxia to be a covered service.

Again, speech apraxia is not a rare, 1-in-a-million disease. There are hundreds of children in Minnesota with this need. ASHA has estimated that 2.6 million Americans suffer from speech or language disorders. Furthermore, articulation disorders, of which apraxia of speech represents one subgroup, account for nearly 60% of all speech and language disorders. It is not a disorder that children will outgrow without specialized intervention.

For these reasons, the financial infrastructure of our health care system must make room for coverage of these disorders. These are not simple developmental delays of a slow starting child who is expected to outgrow the limitation and function at age level within a few months or years. These are pervasive disorders of communication and learning development, based in motor deficit that will hinder these children and their ability to function in our society for the rest of their lives.

Therapy came late for Clay. By the time he entered school, he was a very frustrated child, and to this day still has trouble socializing because of the isolation he suffered due to the inability to communicate with peers. I had been a teacher and spent many hours working with him to get him through the first grade reading program, which was totally phonics. If we hadn't fought so hard to stay afloat I shudder to think where Clay would be today — an academic failure, friendless, and mad at the entire world. What problems would occur due to this I can only speculate. Our son, Clay was fortunate, we had the means to get him the therapy he needed. Today he is 100% intelligible in his communication, and in the talented and gifted program with an IQ in the 98th percentile.

In March of 1995, nearly three years after our fight with the entangled web of bureaucracy, deceit and denial began, we finally recouped our out of pocket expenses ($10,870.60) for the therapy sessions from our school district only after threatening law suit and going through arbitration and mediation. Car expenses, mileage, parking fees, lost work time were all absorbed by us or my husband's employer. The soft costs of time were in excess of $30,000.00. Over 1/2 half of that cost was related to the efforts to obtain coverage. If the therapy would have begun at the age of two years old the correction would have happened much quicker. In the long run costs for therapy would not have been $10,870.60, but perhaps 1/2 of that number.

In closing, speech apraxia children are not a lost cause. Most are average or above in intelligence. With the appropriate therapy they can be achievers and contributors to society. HMOs need to accept their responsibility and cover children with the speech apraxia disability. In the long run it would be much more cost effective to pay for speech therapy and not have years of medical care for emotional, physical and mental problems stemming from being unable to communicate.

Speech clarity is not an educational option, but a necessary part of life. Without the ability to communicate, children will be unfairly prevented from reaching their true potential.

Thank you.

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INTRODUCTION FOR
PROPOSED PERSONAL ASSISTANCE SERVICES PROGRAM
BASED ON THE INDEPENDENT LIVING MODEL

I'm Ken Moses, the Independent Living Coordinator at the Metropolitan Center for Independent Living in St. Paul and a member of the Minnesota Consortium for Citizens with Disabilities. We're strongly urging the State of Minnesota to move Personal Assistance services for people with disabilities out from under the medical model and into the community, in line with the national Independent Living Movement, and the Federal Community Attendant Services Act of 1995 and other federal legislation -- and we have a detailed program ready to be implemented.

The New Jersey Personal Assistance Services Program, which is the primary model for this proposal, is a current working program that's been in operation for about ten years, and is considered a model program nationally. It's funded through its own state budget appropriation rather than as part of any Health Care programs. I was the Chairman of the committee that did the 1994 revision of the New Jersey regulations as well as serving as a Personal Assistance worker under the program, and can report that Personal Assistance services provided in this way work more efficiently and at much less cost than any other alternatives in use today.

The most important point of consumer-driven Personal Assistance programs is the emphasis on Independent Living. Under this philosophy, the disabled person is not a protected patient with little or no control of his or her own life. Rather, these people become Consumers of services, just like the rest of us -- and ***they*** (not medical professionals or second parties) take full adult responsibility for their own lives and the services needed to manage them. They make decisions regarding everyday activities, as well as major life decisions, and must be willing and able to accept the responsibility and consequences of those decisions.

Many people with disabilities have for years managed their own personal care. That option should exist for those who choose it, regardless of funding source. Consumers who are capable of paying for part or all of their own services, or have other sources of private funding, could choose to manage their services through this Program.

Our intention is to provide the services necessary to allow Consumers with disabilities to function, as nearly as practicable, on a par with non-disabled people. Specifically, our goals are to assist self-directed adults with physical disabilities to:

(a) be employed in a paid occupation;
(b) receive training or education directly related to employment; or
(c) actively participate in community-based independent living.*

With support like this, people with disabilities can participate in family and community activities, and become employed in regular jobs -- in other words, they can become full citizens and taxpayers, in turn reducing the cost of state-subsidized services. (Our proposal includes a cost-share structure where the Consumer pays a share of the cost of services based on the Consumer's financial status.) A side benefit is that many more people with disabilities would be able to remain in their own homes and avoid institutionalization in nursing homes, which have repeatedly been shown to be the most expensive way -- and the most demeaning way -- to support these people.

Other cost savings come from the enormous reduction in paperwork achieved by eliminating most medical evaluations and medical record-keeping, which serves no purpose for the vast majority of Consumers who would be served by this program, since they are healthy and active people who happen to have a disability, and require services which are not medical in nature.

The Program is to be governed by a state-wide Consumer Advisory Council, with daily overall administration supervised by the Commissioner or Administrator of a designated State department. The elimination of a bureaucracy of government employees further reduces the overall cost and government intrusion of the program, and the use of a Consumer Council ensures that the program will be tightly monitored by people with a vested interest in its success. The actual Personal Assistance services are provided by regional Service Providers who may in turn subcontract with one or more Provider Agencies. These providers would handle payroll management, withholding of taxes, employee background checks, and so on, but a key provision is that the Consumers retain the authority to hire, direct, and fire their own Personal Assistants regardless of who the employer-of-record is. The Provider Agencies would train and certify their employees as Personal Care Assistants outside the nursing-license system, which is actually inappropriate for Personal Assistance services anyway.

The complete proposal is available from MCIL via E-mail or on disk or paper. I'll be glad to answer any questions you may have.

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*"Community-based independent living" is defined as meaning that a self-directed Consumer is actively participating in community-based activities aside from employment or education, including but not limited to homemaking, parenting, searching for employment, volunteer service, participation on governing boards, or serving on committees.

PROPOSED INDEPENDENT LIVING PERSONAL ASSISTANCE SERVICES PROGRAM

Submitted by Ken Moses, Chairman of the committee that did the revision of the regulations of the New Jersey program which is the main source for this proposed new program. The New Jersey Personal Assistance Services Program is a current working program that's been in operation for nearly ten years, and is considered a model program nationally. I'll be glad to answer any questions about wording, meaning, intentions, or history of any of the contents. I'm now the Independent Living Coordinator at the Metropolitan Center for Independent Living (MCIL), 1600 University Ave. W., Suite 16, St. Paul, MN 55104-3825; 612-603-2013 (voice), 612-603-2001 (tdd), 612-603-2006 (fax); 102225.1412@Compuserve.com (E-mail).

(Derived from New Jersey's Personal Assistance Services Program, PL1987 c350, amended 1992, and NJAC 10:123A; and the Federal Community Attendant Services Act of 1995 proposed by the American Disabled for Attendant Programs Today (ADAPT) organization; and MCIL's policy manuals; and Minnesota Rules 9505.0335, Personal Care Services)

INTRODUCTION ==

The most important point of consumer-driven Personal Assistance programs is the emphasis on Independent Living. Under this philosophy, the Consumer (not medical professionals or second parties) takes full adult responsibility for the Consumer's own life and the services needed to manage it. The Consumer makes decisions regarding everyday activities as well as major life decisions, and must be willing and able to accept the responsibility for those decisions.

There are current PCA consumers who have for many years managed their own personal care without the intrusion of a vendor organization. That option should still exist for those who choose it, regardless of funding source, but it is outside the scope of this proposed Program. However, consumers who are capable of paying for part or all of their own services, or have other sources of private funding, could still manage their services through this Program.

The Program, within the limits of funds appropriated or otherwise made available to it, shall assist self-directed adults with physical disabilities to:

(a) be employed in a paid occupation;
(b) receive training or education directly related to employment; or
(c) actively participate in community-based independent living.

The Program does not guarantee services to any individual, and is thus not intended to be a source of primary care-givers Rather, its function is to provide the services necessary to allow the Consumers to function in the community on a par (as nearly as practicable) with non-disabled people.

The Program is to be governed by a state-wide Consumer Advisory Council, with daily overall administration supervised by a designated State department and its Commissioner or Administrator.. The actual Personal Assistance services are to be provided by regional Service Providers who may in turn be subcontracting with one or more Provider Agencies. In an case, the Consumers have the authority to hire, direct, and fire their own Personal Assistants regardless of who th employer-of-record is.

CONSUMER BILL OF RIGHTS ==

Each Consumer, and, as appropriate, each Applicant, is:

(a) To be treated with courtesy, respect, and full recognition of the Consumer's dignity, individuality, and right control the Consumer's own household and lifestyle, including the identification and determination of the Consumer's ow needs, schedules, and the services necessary to meet these needs, and the consequences of both accepting and refusing t available choices;

(b) To be served by Personal Assistants who are properly trained and competent to perform their duties;

(c) To receive services in compliance with all State laws and regulations without discrimination based on race, religion, gender, sexual orientation, age, creed, or disability in the provision or quality of services, and to be informed of any limits or restrictions on services;

(d) To be free from mental and physical abuse, neglect, and exploitation;

(e) To be accorded privacy, while receiving services, in communications and in all daily activities;

(f) To be accorded respect for the Consumer's property rights;

(g) To have the Consumer's personal, financial, and medical records treated as confidential;

(h) To be free to fully exercise the Consumer's civil and due process rights without penalty or retaliation, and to be assisted by a Personal Assistant as appropriate and necessary;

(i) To receive in a timely manner all decisions regarding eligibility and amount and kind of services and the reasons therefore in writing and, if appropriate, via alternative means of communication, along with the administrative hearings and appeals procedures;

(j) To have access to a fair appeals process through which disputes can be resolved;

(k) To receive written information regarding Consumer standards and responsibilities and all costs of service in the Personal Assistance Services Program, including what to do if rights are violated; and to have them verbally explained as needed;

(l) To have as few Personal Assistants entering the Consumer's home as possible;

(m) To have the right to interview, screen, select, and supervise the Consumer's Personal Assistants; and

(n) To dismiss those Personal Assistants that do not respect Consumer rights.

DEFINITIONS

The words and terms defined in this section shall have these meanings unless the context indicates otherwise:

"Advisory Council" means the state-wide Advisory Council on Personal Assistance Services, created by state regulations for this Program.

"Applicant" means a person who applies for services under the Personal Assistance Services Program.

"Assessor" means a person with suitable background and qualifications (such as a master's of social work degree, or a bachelor's degree and three years of experience in rehabilitation services, or a registered nurse with a bachelor of science degree in nursing, or other suitable qualifications) who is employed by the Program or its Provider Agencies to conduct eligibility and service assessments.

"Available" (in regard to caregivers) means physically present, willing, able, and appropriate, as determined with full consideration of the Consumer's personal values.

"Commissioner" means the Administrator of the state agency designated to administer this Program.

"Community-based independent living" means that a self-directed Consumer is actively participating in community-based activities aside from employment or education, including but not limited to homemaking, parenting, searching for employment, volunteer service, participation on governing boards, or serving on committees.

"Consumer" or "eligible Consumer" means an individual who meets the eligibility standards of this Program, with or without an exception to a specific standard; an "active Consumer" is an eligible Consumer who is currently receivin Personal Assistance services from the Program.

"Education or training" in regard to a Consumer means being enrolled in courses or training programs directly relate to employment; in regard to a Personal Assistant, it means suitable instruction and certification in the skills of Persona Care and Personal Assistance services and in the philosophy of Independent Living. "Training" may include the attendanc and participation of a Consumer or Personal Assistant in an established Independent Living educational program, o equivalent, as defined by the Program's regulations.

"Employment" in regard to a Consumer means working in a paid occupation, including but not limited to full-tim employment; part-time employment; the practice of a profession; self-employment; farm work; home-based employment; c other gainful work; and includes work for which payment is in kind rather than cash.

"Informal caregiver" means an individual who is 18 years of age or older residing in the household for other than th purpose of sharing expenses.

"Personal Assistant" or "Personal Care Assistant" or "Personal Care Attendant" means a person who meets th qualifications with regard to training, equivalent work experience, or certification established in these rules or by the stat and who provides Personal Assistance services to a Consumer who is eligible for the Personal Assistance Services Program

"Personal Assistance services" means assistance with activities of daily living and related tasks performed by a Personal Assistant including (but not limited to):

(a) Personal Care services.
(b) light housekeeping activities such as laundry, shopping*, and meal preparation (heavy-duty housekeeping activities are specifically not included).
(c) light home maintenance activities such as picture-hanging and closet and wardrobe maintenance (heavy-duty home maintenance activities are specifically excluded).
(d) assistance with paperwork and communication, including telephone calls, meetings with other service people, etc.
(e) assistance with mobility, including driving or other forms of transportation, accompaniment on public or private transportation, etc., whether for medical services* or Consumer's personal needs.

"Personal Care" services include assistance in essential daily activities including (but not limited to):

(a) routine bowel* and bladder* assistance, including catheters.
(b) routine menstrual care and assistance.
(c) skin health maintenance*, including application of powders, lotions, ointments, and treatments such as heat and soaking.
(d) range-of-motion exercises*.
(e) respiratory assistance*, including use and maintenance* of devices such as inhalers and ventilators.
(f) transfers* to and from bed, wheelchair, car, etc.; and ambulation*.
(g) bathing*, grooming*, hair washing*, nail care, etc.
(h) turning* and positioning*.
(i) health-related tasks that can be delegated to and performed by a qualified Personal Care Assistant, including but no limited to management of medications (including insulin), furnishing medication that is self administered*, tub feeding, routine ventilator and catheter use.
(j) use and maintenance of prosthetic* and orthotic* devices.
(k) dressing* and undressing*.
(l) cooking, meal preparation*, and feeding*.

*(*from Sec. 54, Minnesota Statutes 1994, section 256B.0627, subdivision 4)*

"Physical disability" means a severe impairment of a permanent or long-term nature which so restricts a person's abilit to perform essential activities of daily living that the person needs assistance to maintain the person's independence an health.

"Residence" or "private residence" means a house or apartment, educational facility (e.g., dormitory or campu apartment), rooming or boarding house, or group home; but not a long-term care facility or an inpatient hospital;

"Provider Agency" means a regional Office for the Disabled, Independent Living Center, or other agency designated b the county or state government, subject to approval by the Commissioner, to administer the Personal Assistance Service Program within its service area. It may subcontract actual service provision to another agency or agencies which mu operate under the Program's rules. A Provider Agency shall have an advisory council or board of directors of which at lea 51% of the members are persons with disabilities.

"Program" means the Personal Assistance Services Program.

"Program administrator" means the professional employee (Commissioner) of the designated State agency charged wit the administration of the Personal Assistance Services Program and answerable to the Advisory Council.

"Relative" means a person who is 18 years of age or older and is related to the Consumer by blood or by law.

"Residence" or "private residence" means a house or apartment, educational facility (e.g., dormitory or campu apartment), rooming or boarding house, or group home; but not a long-term care facility or an inpatient hospital;

"Resident" means a person whose permanent domicile is in the State of Minnesota, or a student enrolled in a full-tin accredited program at an accredited school in the state.

"Responsible party" refers to the person with the legal authority to represent the Consumer and the capability providing the incidental support care necessary to assist an otherwise eligible Consumer to live independently. Normal this will be the Consumer, but if the Consumer is under 18 years of age or otherwise unable to accept legal responsibilit another person must be designated as the responsible party.

"Self-directing" or "Self-directed" describes a person who does not need or want a medically-based person organization to operate and oversee personal care services and can manage and supervise a Personal Assistant; is able make decisions regarding daily activities and to make major life decisions; and is willing and able to accept t responsibility for those actions.

"Service area" is the geographical area served by the Provid

"Statement of understanding" means a document which sets forth the terms and conditions of the Program and the responsibilities of the Consumer under these rules, and the Consumer's acceptance of the same.

"Temporary physical disability" means a severe disability caused by injury or illness (such as broken bones) which results in the Consumer meeting the definition of "physical disability," but from which the Consumer is expected to substantially recover within a predictable time and no longer meet the eligibility requirements of this Program.

"Values of the Applicant or Consumer" means the Applicant's or Consumer's choices in achieving and maintaining an independent life style.

"Written" or "in writing" shall be understood to include, if appropriate because of the Consumer's disability, "and via alternative means of communication," pursuant to the provisions of the Americans with Disabilities Act of 1990.

TARGET POPULATION

For the purposes of the Personal Assistance Services Program, the target population includes those persons who (as defined above):

(a) are residents of the State of Minnesota;
(b) are between the ages of 18 and 65 inclusive;
(c) have a severe physical disability;
(d) are self-directed; and
(e) are in need of Personal Assistance services.

ELIGIBILITY

Eligibility standards

For the purposes of the Personal Assistance Services Program, an eligible Applicant or Consumer shall meet these standards (with exceptions as noted below):

(a) Shall be between the ages of 18 and 65 inclusive;

(b) Shall have a severe physical disability, the nature of which shall not in itself be a criterion for determining eligibility;

(c) Shall be a resident of the State of Minnesota;

(d) Shall be in need of Personal Assistance services pursuant to a written Personal Assistance services plan, prepared by the Applicant or Consumer, and approved by the staff of the Provider Agency;

(e) Shall be one who is self-directed, as determined by an assessment conducted by an assessor;

(f) Shall not have a relative or other informal caregiver available to provide the services that the eligible Applicant or Consumer needs;

(g) Shall live, or plan to live upon becoming eligible, in a private residence;

(h) Shall have a licensed physician confirm in writing that the eligible Applicant or Consumer has a severe physical disability and requires no assistance in the coordination of therapeutic regimes, and that the Personal Assistance services will be appropriate to meet the eligible Applicant or Consumer's needs; and

(i) Shall be:

1. **employed in a paid occupation;**
2. **receiving training or education directly related to employment; or**
3. **actively participating in community-based independent living.**

Exceptions to eligibility standards

In applying for exceptions, Consumers must meet all other eligibility criteria established under the Program.

(a) Applicants under Age 18:
   1. Must be employed or attending an accredited educational or training program;
   2. Must obtain the consent of the Applicant's parent or guardian unless the Applicant is an emancipated minor; and
   3. Must designate a person over age 18 with the legal authority to act as a Responsible Party in all matters relating to this Program, unless the Applicant is an emancipated minor.
   4. At some time between the Consumer's 18th and 21st birthdays, the Consumer must submit a change notice to the serving Provider Agency to document the change in status to self-responsibility, signed by both the Consumer and the former Responsible Party.

(b) Consumers over Age 65:
   1. Must be employed or attending a post-secondary educational or training program, or actively involved in community-based independent living, for a minimum of five hours per week;
   2. Must provide documentation that they have applied for other equivalent services for which they may be eligible;
   3. Must be current recipients of Program services who are aging out of the Program; and
   4. The most recent assessment of the Consumer must document that the Consumer's situation remains essentially unchanged.

OPERATING STANDARDS

Individual Personal Assistance services plan

(a) The individual Personal Assistance services plan shall be designed by the Consumer to meet the Consumer's specifi needs for Personal Assistance services and negotiated and approved by the Consumer and Provider Agency.

(b) A Personal Assistance services plan shall include:
   1. A list of the Personal Assistance services to be provided; and
   2. An estimate of the time needed for and frequency of Personal Assistance services. If the disability is of a temporar nature, the plan must also include an estimate of the ending date of the services.

(c) Any special arrangements (including but not limited to issuance of keys to the Consumer's home or car, permission t use the Consumer's home or car or other personal property, reimbursement for use of the Personal Assistant's car, roommat arrangements for live-in Personal Assistants, etc.) may be included in or attached to the plan of services for reference an for use in the event of a dispute.

(d) The Consumer and the Provider Agency shall review the plan within 45 days after start-up of services (or earlier i requested by the Consumer) and revise the plan upon request of the Consumer or the Provider Agency.

(e) The Consumer may use no more than the number of hours in a given period authorized by the approved plan o services. Any adjustments to the Consumer's plan of services must be authorized by the Provider Agency on a case-by-cas basis.

(f) The Provider Agency shall perform a social reassessment and financial evaluation, and review and revise as needed th Consumer's Plan of Service and cost share responsibilities, at 12-month intervals commencing with the date of eligibilit Such reviews and revisions must be completed within 30 days of the anniversary of the original determination of eligibilit In the case of a temporary disability, the provided services will end on the estimated date unless an extension is requested b the Consumer, in which case the Consumer must make such a request at least five working days prior to the estimat termination date.

Service standards

(a) Personal Assistance services are defined above.

(b) Duplication of services

1. Personal Assistance services provided to eligible Consumers shall supplement and not duplicate services available through relatives, other informal caregivers, or other service programs for which they may also be eligible.
2. Personal Assistance services provided for the purpose of receiving training or education shall not replace or duplicate those services provided by an educational institution as mandated by Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794.
3. Personal Assistance services provided during employment shall not duplicate those services provided by an employer as mandated by the Americans with Disabilities Act of 1990, and may not replace ADA-mandated services unless that employer chooses to provide them and pay for them directly through this Program.
4. Personal Assistance services are suspended during a period of hospitalization and resumed automatically (with notice) when the Consumer is discharged to the Consumer's community residence.
5. Shared Personal Assistances services are those provided to two or more eligible Consumers at the same time by one Personal Assistant. Examples include the situation of eligible Consumers sharing a home or a Personal Assistant assisting several eligible Consumers at a meeting or other event.
   (a) Only one Consumer at a time may claim the hours of service provided by the one Personal Assistant. The Consumers may divide the hours up equally or unequally as they wish, but no two Consumers may claim the same time period on their time sheets. Attempts to do so ("double-billing") may be cause for suspension o termination of services.
   (b) Personal Assistance service hours may not be used for those not eligible for this Program, including but no limited to members of the Consumer's family or household; and any Consumer attempting to do so may b suspended or terminated from the Program. Exceptions would include situations like occasional dinner partie where the Consumer would normally perform the duties of host or where no extra work on the part of th Personal Assistant is required. The Consumer and Personal Assistant must agree beforehand that services ar to be provided under such circumstances.

(c) Program funds shall not be used for medically-oriented services, including the supervision by registered nurses. It is no the responsibility of the Personal Assistance Services Program to arrange for or provide skilled nursing, therapy, or relate medical care and treatment services which the eligible Consumer may need.

(d) Using a Personal Assistant as a personal driver is allowed as a Personal Assistance service:

1. If using the eligible Consumer's motor vehicle, the Consumer's insurance policy must show that the Persona Assistant is a fully-covered driver under that insurance policy.
2. Any person serving as a Personal Assistant under the Personal Assistance Services Program may not provide driving or transportation services in the Personal Assistant's own vehicle unless proof of proper liability insurance i presented by the Personal Assistant, and both Consumer and Personal Assistant agree in writing to th arrangement, and the Personal Assistant's driving record is acceptable to the Provider Agency.
3. All proofs of insurance and vehicle-related agreements must be submitted to the Provider Agency before a Persona Assistant may provide any driving services, and must be resubmitted whenever such insurance policies o agreements are renewed or modified.
4. Any costs incurred by the Personal Assistant in providing driving services (fuel, tolls, etc.) are to be paid directly t the Personal Assistant as agreed upon privately between the Consumer and the Personal Assistant.

(e) Relatives of Consumers may not serve as paid Personal Assistants to Consumers to whom they are related under th Program unless an exception is granted by a state Relative Hardship Waiver.

(f) Consumers may request that Personal Assistance services continue to be provided while they are away from home o vacation or business, subject to all other service standards and availability of Personal Assistants. The Consumer is to pa any incidental expenses (such as meals, transportation, or hotel rooms) incurred in employing a Personal Assistant aw from the Consumer's regular home, school, or work location.

(g) The eligible Consumer shall be responsible for recruiting Personal Assistants, or selecting and interviewing them fro the roster provided by the Provider Agency. Becoming eligible for the Program's services will not automatically guarant that a Personal Assistant will be immediately available.

Exceptions to service standards

If an exception to (hospitalization) above is granted, these additional standards apply:

(a) If Personal Assistance services are requested when other supports (informal caregivers or relatives) are not available, temporary modification of the Consumer's Service Plan will be made with the Provider Agency to reflect current need.

(b) Essential communications, advocacy (with the hospital staff), household, and home maintenance services may b continued on a limited basis only when other supports are not available.

(c) Direct personal care services may not be provided under any circumstances under the Program during a period o hospitalization.

(d) If the situation is an emergency, the request may be in verbal form and the response of the Director of the Provide Agency shall be immediate. The Consumer and Provider Agency must document the request as soon as possible.

Transfer of services to another service area

(a) Once determined to be eligible for Personal Assistance services under this Program, a Consumer retains that eligibilit when moving to another service area within the State, unless terminated from the Program as described below.

(b) If an eligible Consumer moves to another service area and wants to retain Personal Assistance services, the servic Provider Agency of origin will continue to pay for those services for a period of no more than six months if the destinatio Provider Agency cannot immediately fund services for the transferring Consumer.

(c) If there is a waiting list for Personal Assistance services in the destination service area, the Consumer will be placed o that waiting list immediately upon application or moving, and, after the six-month transition period, will be grante services in accordance with the priority rules above.

(d) The Consumer must notify, in writing and in advance, the Directors of the Provider Agencies of both the service area origin and the destination service area, in order to effect the transfer of services.

Suspension or termination of service

(a) Definitions

1. Suspension of service may be either voluntary or involuntary. Voluntary suspensions involve verifiable situations which an active Consumer requests, in writing, a temporary cessation of services of no more than 90 days. A other suspensions are considered to be involuntary.
2. Termination of service may be either voluntary or involuntary. Voluntary terminations involve verifiable situatio in which an active Consumer agrees to permanent cessation of services. All other terminations are considered to b involuntary.

(b) Consumers suspended or terminated from services shall receive written notice from the Provider Agency of suspensio (and confirmation of the duration of suspension) or termination prior to the effective date of the action.

(c) Involuntary suspensions or terminations shall be a result of non-compliance with Program regulations and procedur which include but are not limited to:

1. Failure to submit information necessary to determine or reaffirm social and financial program eligibility in a time fashion;
2. Failure to pay fees, or maintain and submit timesheets as required, or attend training programs as required;
3. Verifiable abuse or misuse of Personal Assistance services or Personal Assistants;
4. Continued non-acceptance and/or dismissal of Personal Assistants without proper justification;
5. A change in the Consumer's situation which results in an increase of risk to the Personal Assistant's health welfare, as determined by the Provider Agency; or
6. Failure to meet Program eligibility requirements or to obtain approval for an exception.

(d) All suspensions shall be limited to a duration of 60 days, at which point the Consumer may request an extension of days more. At the end of that period, the Provider office will determine whether the Consumer's services are to be resum or terminated.

(e) All decisions will be made on a case-by-case basis.

Confidentiality and disclosure of information

(a) All identifiable personal information regarding Applicants or Consumers under this Program obtained or maintained under this Program shall be confidential and shall not be released without the written consent of the Applicant or Consumer or their authorized agent except as noted in (b) and (c) below. In the case of Applicants or Consumers who have AIDS or are HIV-positive, release of any information shall also be subject to the provisions of <applicable Minnesota laws> This prohibition against unauthorized disclosure shall not be construed to prevent:

1. The release of statistical or summary data or information in which Applicants or Consumers cannot be identified: or
2. The release to the Attorney General or other legal representative of this State of information or files relating to the claim of any Applicant, Consumer or Consumer's authorized agent challenging the Program's statutory or regulatory authority or a determination made pursuant thereto: or
3. The release of information or files to the State Treasurer or duly authorized representatives for an audit, review of expenditures, or similar activity authorized by law.

(b) Disclosure of information without the consent of the Applicant, Consumer, or Consumer's authorized agent shall be limited to purposes directly connected with the Program pursuant to State law and regulations.

CONTRACTING AND FEES ==

Contracting for services

The Provider Agency may:

(a) Contract with other service providers, including but not limited to private individuals, for the provision of Personal Assistance services pursuant to this Program's regulations; or

(b) Employ individuals as Personal Assistants where appropriate and shall develop employment policies consistent with Minnesota regulations for individuals working as Personal Assistants.

Provider fees

(a) Fees for services under the Personal Assistance Services Program shall be based on an hourly rate (to be specified) to b paid to the contracting service provider or contracting individual Personal Assistant for each hour of Personal Assistanc service provided under this Program.

(b) The fees paid by the Provider Agency for its authorized assessments of eligible Consumers shall be <$204.36> for eac initial assessment; <$102.18> for annual re-assessments; and ($51.09) for each interim assessment. <rates in brackets ar current figures>

Consumer fees

(a) All references below to the Consumer's income or ability to pay shall be construed to include the Consumer's spous and/or minor children who reside in the same household as the Consumer or file a joint tax return with the Consumer. Th Consumer fee shall apply only to a Consumer whose combined annual gross income exceeds the State's applicable incom eligibility limit for social services established pursuant to the Social Services Block Grant Act (P.L. 97-35, 42 U.S.C. 139 et seq.) and set forth at (e) below.

(b) The Consumer fee for Personal Assistance services shall be based on the ability of the Consumer to pay for thes services.

(c) Failure of the Consumer to pay the appropriate Consumer fee within 60 days of the date of billing pursuant to t Consumer sliding fee scale at (e) below, without good cause, shall be grounds for suspension or termination from t Personal Assistance Services Program.

(d) The Consumer sliding fee scale schedule at (e) below shall be applied to eligible Consumers. The percentage colum indicated on the fee scale denotes the percentage of the total cost of the service to be paid by the Consumer, based on th family's gross income as indicated.

(e) Consumer sliding fee scale: <example>

Family size: 1 person single	2	3	4	5+	Fee share
0-15,162	0-19,927	0-24,493	0-29,158	0-33,923	0%
15,163-18,163	19,928-22,928	24,494-27,494	29,159-32,159	33,924-36,924	1%
18,164-21,164	22,929-25,929	27,495-30,495	32,160-35,160	36,925-39,925	2%
21,165-24,165	25,930-28,930	30,496-33,496	35,161-38,161	39,926-42,926	3%
24,166-27,166	28,931-31,931	33,497-36,497	38,162-41,162	42,927-45,927	4%
27,167-29,167	31,932-33,932	36,498-38,498	41,163-43,163	45,928-47,928	5%
29,168-31,168	33,933-35,933	38,499-40,499	43,164-45,164	47,929-49,929	6%
31,169-33,169	35,934-37,934	40,500-42,500	45,165-47,165	49,930-51,930	7%
33,170-35,170	37,935-39,935	42,501-44,501	47,166-49,166	51,931-53,931	8%
35,171-36,171	39,936-40,936	44,502-45,502	49,167-50,167	53,932-54,932	9%
36,172-37,172	40,937-41,937	45,503-46,503	50,168-51,168	54,933-55,933	10%
37,173-38,173	41,938-42,938	47,504-47,504	51,169-52,169	55,934-56,934	11%
38,174-39,174	42,939-43,939	47,505-48,505	52,170-53,170	56,935-57,935	12%
39,175-39,675	43,940-44,340	48,506-49,006	53,171-53,671	57,936-58,336	13%
39,676-40,176	44,341-44,841	49,007-49,507	53,672-54,172	58,337-58,837	14%
40,177-40,677	44,842-45,342	49,508-50,008	54,173-54,673	58,838-59,338	15%
40,678-41,178	45,343-45,843	50,009-50,509	54,674-55,174	59,339-59,839	16%
41,179-41,679	45,844-46,344	50,510-51,010	55,175-55,675	59,840-60,340	17%
41,680-42,180	46,345-46,845	51,011-51,511	55,676-56,176	60,341-60,841	18%
42,181-42,681	46,846-47,346	51,512-52,012	56,177-56,677	60,842-61,342	19%
42,682-43,182	47,347-47,847	52,013-52,513	56,678-57,178	61,343-61,843	20%
43,183-43,683	47,848-48,348	52,514-53,014	57,179-57,679	61,844-62,344	21%
43,684-44,184	48,349-48,849	53,015-53,515	57,680-58,180	62,345-62,845	22%
44,185-44,685	48,850-49,350	53,516-54,016	58,181-58,681	62,846-63,346	23%
44,686-45,186	49,351-49,851	54,017-54,517	58,682-59,182	63,347-63,847	24%
45,187-45,687	49,852-50,352	54,518-55,018	59,183-59,683	63,848-64,348	25%
45,688-46,188	50,353-50,853	55,019-55,519	59,684-60,184	64,349-64,849	26%
46,189-46,689	50,854-51,354	55,520-56,020	60,185-60,685	64,850-65,350	27%
46,690-47,190	51,355-51,855	56,021-56,521	60,686-61,186	65,351-65,851	28%
47,191-47,691	51,856-52,356	56,522-57,022	61,187-61,687	65,852-66,352	29%
47,692-48,192	52,357-52,857	57,023-57,523	61,688-62,188	66,353-66,853	30%
48,193-48,693	52,858-53,358	57,524-58,024	62,189-62,689	66,854-67,354	31%
48,694-49,194	53,359-53,859	58,025-58,525	62,690-63,190	67,355-67,855	32%
49,195-49,695	53,860-54,360	58,526-59,026	63,191-63,691	67,856-68,356	33%
49,696-50,196	54,361-54,861	59,027-59,527	63,692-64,192	68,357-68,857	34%
50,197-50,697	54,862-55,362	59,529-60,028	64,193-64,693	68,858-69,358	35%
50,698-51,198	55,363-55,863	60,029-60,529	64,694-65,194	69,359-69,859	36%
51,199-51,699	55,864-56,364	60,530-61,030	65,195-65,695	69,860-70,360	37%
51,700-52,200	56,365-56,865	61,031-61,531	65,696-66,196	70,361-70,861	38%
52,201-52,701	56,866-57,366	61,532-62,032	66,197-66,697	70,862-71,362	39%
52,702-53,202	57,367-57,867	62,033-62,533	66,698-67,198	71,363-71,863	40%
53,203-53,703	57,868-58,368	62,534-63,034	67,199-67,699	71,864-72,364	41%
53,704-54,204	58,369-58,869	63,035-63,535	67,700-68,200	72,365-72,865	42%
54,205-54,705	58,870-59,370	63,536-64,036	68,201-68,701	72,866-73,366	43%
54,706-55,206	59,371-59,871	64,037-64,537	68,702-69,202	73,367-73,867	44%
55,207-55,707	59,872-60,372	64,538-65,038	69,203-69,703	73,868-74,368	45%
55,708-56,208	60,373-60,873	65,039-65,539	69,704-70,204	74,369-74,869	46%
56,209-56,709	60,874-61,374	65,540-66,040	70,205-70,705	74,870-75,370	47%
56,710-57,210	61,375-61,875	66,041-66,541	70,706-71,206	75,371-75,871	48%
57,211-57,711	61,876-62,376	66,542-67,042	71,207-71,707	75,872-76,372	49%
57,712-58,212	62,377-62,877	67,043-67,543	71,708-72,208	76,373-76,873	50%
58,213-58,713	62,879-63,378	67,544-68,044	72,209-72,709	76,874-77,374	51%
58,714-59,214	63,379-63,879	68,045-68,545	72,710-73,210	77,375-77,875	52%
59,215-59,715	63,380-64,380	68,346-69,046	73,211-73,711	77,876-78,376	53%
59,716-60,216	64,381-64,881	69,047-69,547	73,712-74,212	78,377-78,877	54%
60,217-60,717	64,882-65,382	69,548-70,048	74,213-74,713	78,878-79,378	55%
60,718-61,218	65,383-65,883	70,048-70,549	74,714-75,214	79,379-79,879	56%
61,219-61,719	65,884-66,384	70,550-71,050	75,215-75,715	79,880-80,380	57%
61,720-62,220	66,385-66,885	71,051-71,551	75,716-76,216	80,381-80,881	58%
62,221-62,721	66,886-67,386	71,552-72,052	76,217-76,717	80,882-81,382	59%
62,722-63,222	67,387-67,887	72,053-72,553	76,718-77,218	81,383-81,883	60%
63,223-63,723	67,888-68,388	72,554-73,054	77,219-77,719	81,884-82,384	61%
63,724-64,224	68,389-68,889	73,055-73,555	77,720-78,220	82,385-82,885	62%
64,225-64,725	68,890-69,390	73,556-74,056	78,221-78,721	82,886-83,386	63%
64,726-65,226	69,391-69,891	74,057-74,557	78,722-79,222	83,387-83,887	64%

65,227-65,727	69,892-70,392	74,558-75,058	79,223-79,723	83,888-84,388	65%
65,728-66,228	70,393-70,893	75,059-75,559	79,724-80,224	84,389-84,889	66%
66,229-66,729	70,894-71,394	75,560-76,060	80,225-80,725	84,890-85,390	67%
66,730-67,230	71,395-71,895	76,061-76,561	80,726-81,226	85,391-85,891	68%
67,231-67,731	71,896-72,396	76,562-77,062	81,227-81,727	85,892-86,392	69%
67,732-68,232	72,397-72,897	77,063-77,563	81,728-82,228	86,393-86,893	70%
68,233-68,733	72,898-73,398	77,564-78,064	82,229-82,729	86,894-87,394	71%
68,734-69,234	73,399-73,899	78,065-78,565	82,730-83,230	87,395-87,895	72%
69,235-69,735	73,900-74,400	78,566-79,066	83,231-83,731	87,896-88,396	73%
69,736-70,236	74,401-74,901	79,067-79,567	83,732-84,232	88,397-88,897	74%
70,237-70,737	74,902-75,402	79,568-80,068	84,233-84,733	88,898-89,398	75%
70,738-71,238	75,403-75,903	80,069-80,569	84,734-85,234	89,399-89,899	76%
71,239-71,739	75,904-76,404	80,570-81,070	85,235-85,735	89,900-90,400	77%
71,740-72,240	76,405-76,905	81,071-81,571	85,736-86,236	90,401-90,901	78%
72,241-72,741	76,906-77,406	81,572-82,072	86,237-86,737	90,902-91,402	79%
72,742-73,242	77,407-77,907	82,073-82,573	86,738-87,238	91,403-91,903	80%
73,243-73,743	77,908-78,408	82,574-83,074	87,239-87,739	91,904-92,404	81%
73,744-74,244	78,409-78,909	83,075-83,575	87,740-88,240	92,405-92,905	82%
74,245-74,745	78,910-79,410	83,576-84,076	88,241-88,741	92,906-93,406	83%
74,746-75,246	79,411-79,911	84,077-84,577	88,742-89,242	93,407-93,907	84%
75,247-75,747	79,912-80,412	84,578-85,078	89,243-89,743	93,908-94,408	85%
75,748-76,248	80,413-80,913	85,079-85,579	89,744-90,244	94,409-94,909	86%
76,249-76,749	80,914-81,414	85,580-86,080	90,245-90,745	94,910-95,410	87%
76,750-77,250	81,415-81,915	86,081-86,581	90,746-91,246	95,411-95,911	88%
77,251-77,751	81,916-82,416	86,582-87,082	91,247-91,747	95,912-96,412	89%
77,752-78,252	82,417-82,917	87,083-87,583	91,748-92,248	96,413-96,913	90%
78,253-78,753	82,918-83,418	87,584-88,084	92,249-92,749	96,914-97,414	91%
78,754-79,254	83,419-83,919	88,085-88,585	92,750-93,250	97,415-97,915	92%
79,255-79,755	83,920-84,420	88,586-89,086	93,251-93,751	97,916-98,416	93%
79,756-80,256	84,421-84,921	89,087-89,587	93,752-94,252	98,417-98,917	94%
80,257-80,757	84,922-85,422	89,588-90,088	94,253-94,753	98,918-99,418	95%
80,758-81,258	85,423-85,923	90,089-90,589	94,754-95,254	99,419-99,919	96%
81,259-81,759	85,924-86,424	90,590-91,090	95,255-95,755	99,920-100,420	97%
81,760-82,260	86,425-86,925	91,091-91,591	95,756-96,256	100,421-100,921	98%
82,261-82,761	86,926-87,426	91,592-92,092	96,257-96,757	100,922-101,422	99%
82,762-83,262	87,427-87,927	92,093-92,593	96,758-97,258	101,423-101,923	100%

(f) Each Consumer shall provide verification of income for determination of applicable fees upon application to th Personal Assistance Services Program, and annually thereafter. Acceptable verification includes, but is not limited to, pa stubs, W-2 forms, or photostatic copies of the actual 1040 form filed with the Internal Revenue Service, business record pension statements, and/or correspondence from employers or agencies (for example, Social Security Administration, Sta employment agencies).

(g) If the costs of an eligible Consumer's Personal Assistance services are covered in whole or in part by another State Federal government program or insurance contract, the government program or insurance carrier shall be the primary pay and the Personal Assistance Services Program shall be the secondary payer.

(h) Both the Personal Assistants providing Personal Assistance services and the Consumer receiving those services sha sign timesheets periodically as requested by the service provider attesting to the hours of service rendered, and the Person Assistant shall then be paid by the Provider Agency or its subcontractor.

(i) All collected Consumer fees shall be retained by the Provider Agency for the purpose of providing Personal Assistanc services.

Standards for adjustments in Consumer fees

(a) Adjustments in Consumer fees shall be based on verifiable increased or decreased expenses which result from Consumer's disability which may include, but are not limited to, items such as:

1. Unreimbursed or unreimbursable medical expenses;
2. Transportation expenses;
3. Adaptations to home or vehicle; or
4. Unreimbursed or unreimbursable additional hours of Personal Assistance services over and above those ho authorized to the Consumer by this Program, if certified as necessary by the Provider Agency.

(b) Adjustments in Consumer fees may also be considered when these verifiable expenses are increased or decreased:

1. College tuition;
2. Alimony/child support; or

3,

3. Emergency home repair expenses.

(c) Adjustments in Consumer fee, when approved, shall be effective as of the first day of the calendar month succeeding the month in which the written request is received by the Provider Agency. The Consumer is responsible for paying the cost-share fee previously established until the effective date of such approval.

(d) A Consumer requesting adjustment in his or her consumer fee shall continue to pay the original percentage of the total cost of service assessed pursuant to Consumer Fees (a), (b), (c), and (d) above, pending the Consumer's submission of written justification under (a) and (b) and approval by the State Program Administrator of the Consumer's request for an adjustment.

(e) Adjustments in Consumer fees shall be re-evaluated annually or more frequently if necessary.

PERSONAL ASSISTANTS

Requirements for Personal Assistants

(a) All persons desiring to serve as Personal Assistants under the Personal Assistance Services Program, whether recruited by the Provider Agency or by the Consumer, shall be at least 16 years of age and shall meet at least one of these qualification requirements:

1. Completion of an approved training course authorized by the State Board of Nursing or Department of Health as a homemaker/home health aide, or a long-term facility nurse aide course authorized by the Department of Health;
2. Completion of a certified training program in a hospital, rehabilitation facility, or a long-term care facility as an aide or Personal Assistant;
3. Completion of a training course offered by this Program or its contracting agencies for Personal Assistants, and certification in personal care by a staff assessor; or
4. At least one year of experience in the provision of Personal Assistant services for adults, and certification in personal care by a staff assessor.

(b) Regardless of previous training or qualifications, all new Personal Assistants in this Program must be oriented in the Independent Living approaches and philosophy.

(c) Personal Assistants shall have a current liability policy which covers personal injury and property damage, prior to employment. This liability policy shall be paid for by the Personal Assistant if under an independent vendor contract with the county, or by the Provider Agency if the Personal Assistant is an agency employee.

(d) Personal Assistants may be recruited by eligible Consumers, or new Consumers may bring Personal Assistants with them from other programs, subject to the Personal Assistants' meeting this Program's requirements.

(e) Personal Assistants will be listed on a roster maintained by the Provider Agency and made available to eligible Consumers on request. Under the principles of Consumer self-direction, assignments of specific Personal Assistants to specific Consumers will not be made by the Provider Agency, but only through interviews by the eligible Consumers Consumers are free to recruit Personal Assistants who are not on the roster, but they must meet the qualification requirements above before they may begin working.

CONSUMER AND PERSONAL ASSISTANT TRAINING

Requirements

(a) Consumers: Those who have been determined eligible for the Program shall be required to complete a training course i Orientation & Philosophy of Independent Living. For Consumers who were accepted or transferred into predecessors of th Program prior to its establishment, the Orientation & Philosophy course is also required but may be waived on approval o an assessor of the Provider Agency who knows the Consumer's history.

(b) Personal Assistants: Within one year from the date of hiring, all Personal Assistants are required to complete tw courses: Orientation & Philosophy of Independent Living, and Basic Skills & Techniques for Personal Assistants.

Waivers to requirements

(a) Waivers for Orientation & Philosophy will not be granted for either Consumers or Personal Assistants. However, proof of having completed an equivalent Independent Living course offered by a similar Program will be accepted at the discretion of the Provider Agency.
(b) Waivers for Basic Skills & Techniques for Personal Assistants will be considered with documentation of prior training or education in the course contents, which must have been completed within 5 years of the request, or documentation of continued employment as a Personal Care Assistant since the training.
(c) Requests by Consumers for in-home training sessions will be considered on a case-by-case basis.

Penalties

(a) Consumers who refuse to accept Independent Living training within one year of beginning to use the Program's services will have their Personal Assistance Services Program services suspended until they have met the requirements.
(b) Personal Assistants who refuse to attend required courses (or obtain waivers) will be suspended from employment under the Personal Assistance Services Program.

Reimbursement for training

The Training Contractor will compensate Personal Assistants for all training sessions at a standardized statewid rate. If the training is provided by the Provider Agency or its subcontractor, the reimbursement will be at the same hourl rate as the Personal Assistance employment itself.

COMPLIANCE WITH LAWS

Requirements of Provider Agency

Under the direction of the designated State agency, each Provider Agency shall:
(a) Abide by all laws and regulations concerning employment of persons hired to administer or work in the Persona Assistance Services Program including, but not limited to, the <Rehabilitated Convicted Offenders Act,> Minnesota Rule Part 4668.0020 subpart 15, <abuse> Minnesota Statutes Sec. 626.557, and the Immigration Reform and Control Act c 1986 (P.L. 99-603);
(b) Conduct (or require of providers with whom they contract) a background check that satisfies them as to th appropriateness of each Personal Assistant;
(c) Establish a separate accounting regarding receipt and use of cost share monies collected to ensure that cost sha monies are used to expand or enhance Program services in that service area. These funds shall not supplant any existir allocation. This separate accounting and supporting documentation shall be made available to the designated State agenc and
(d) Establish a local Advisory Council (which may be the Provider Agency's Board of Directors) of which at least 51% the members are persons with disabilities; preference for membership shall be given to those who are also active Consume of this Program's services. This Advisory Council shall serve as a resource to the Provider Agency on matters pertaining the local administration of the Personal Assistance Services Program.
(e) Require that any subcontractors hired by the Provider Agency to provide Personal Assistance services abide by t regulations of the Program.

...

Duties of Provider Agency

(a) Ensure that the operation and performance of the Personal Assistance Services Program is in compliance with laws and rules governing the operation of the Program:
(b) Provide information and outreach for the Personal Assistance Services Program:
(c) Complete the necessary forms and research to determine eligibility of Applicants. and provide appropriate assistance to Applicants and Consumers in completing all necessary forms;
(d) Determine cost share amount when applicable:
(e) Maintain and update individual Consumer files:
(f) Designate a staff person to serve as primary contact person for Applicants. eligible Consumers. and Personal Assistants involved in the Program. and document such contacts;
(g) At the request of an active Consumer. arrange for Personal Assistance services or exceptions to these regulations: and upon request of the Consumer. provide individual help in arranging for back-up Personal Assistance services. The back-up plan shall be coordinated and mutually agreed upon by the Consumer and the Provider Agency as part of the Consumer's Plan of Services:
(h) Refer persons to other agencies. programs. and services for which they may be eligible:
(i) Maintain fiscal. statistical. and demographic records for the Program or provide data for others to do so:
(j) Prepare monthly reports for timely submission to the designated State agency;
(k) Serve as liaison to the designated State agency for the Program: and
(l) Oversee the local Program including verification of timesheets signed by eligible Consumers and Personal Assistants attesting to hours of services rendered.

Provider Agency disqualification

(a) Provider Agency (or its subcontractor) may be disqualified from participation in Personal Assistance Services Program funding for good cause including, but not limited to:
1. Failure or refusal to comply with Program laws. rules. or contract requirements: or
2. Refusal to furnish the designated State agency with required reports. or to make available for review such files and records as required.

(b) The designated State agency shall provide a 60-day written notice to the Provider Agency if it intends to pursue disqualification. The notice shall specify the designated State agency's reasons for such action. and shall specify corrective actions required. A copy of this notice shall also be sent to the state Advisory Council.
(c) The process of Provider Agency disqualification should not result in loss or interruption of services to those active Consumers currently receiving services.
(d) If the designated State agency seeks to disqualify a Provider Agency for failure to comply with these rules. such Provider Agency shall be afforded an opportunity to request an administrative hearing. pursuant to the state's Administrative Procedure Act and Rules.

STATE ADVISORY COUNCIL

(a) Membership
1. Membership shall consist of one member from each of the State's Provider Agencies administering this Program an appointed by the Commissioner. at least 75% of whom are Consumers of services under this Program:
2. Vacancies shall be filled in the same manner as provided for the original appointments;
3. Members shall serve without compensation. but shall be reimbursed for reasonable expenses incurred in th performance of their duties;
4. The Advisory Council shall select a chairperson and a vice-chairperson from among its members. and a secretar who need not be a member of the Council. to serve two-year terms: and
5. The state Department shall provide such stenographic. clerical. administrative. and professional assistance as th Advisory Council requires to carry out its work.

(b) Duties

1. Serve as a resource to the Commissioner on matters pertaining to this Personal Assistance Services Program, and the development, implementation, and evaluation of such services;
2. Advise the designated State agency on issues relevant to the development, implementation, and evaluation of the Personal Assistance Services Program;
3. Evaluate the effectiveness of the Personal Assistance Services Program in meeting its objectives, and share that evaluation with the Commissioner and Provider Agencies; and
4. Implement the above through utilization of stenographic and clerical staff, administrative assistants, and other such professional staff as provided by the designated State agency.

ADMINISTRATIVE PROCEDURES ==

Screening

(a) Upon Applicant inquiry to the Provider Agency regarding the Personal Assistance Services Program, Provider Agency staff shall elicit information necessary to conduct pre-application screening and shall complete the screening within five working days of the Applicant's inquiry.

(b) The Applicant shall be notified in writing within five working days after completion of the Provider Agency screening as to the results of the Applicant's inquiry regarding participation in the Personal Assistance Services Program.

1. If the Applicant is determined to be ineligible, the Applicant shall be informed in writing of this determination and the right to appeal.
2. If the Applicant appears eligible as a result of the screening, staff from the Provider Agency shall inform the Applicant in writing of this determination and enclose all documents necessary to process the application. The disposition letter shall also advise the Applicant that eligibility does not guarantee services under this Program and that the Program is not an entitlement program.

Assessment

(a) A member of the staff of the Provider Agency shall perform an assessment within 30 days upon notification from th Applicant to the Provider Agency of completion of the application package which includes:

1. An Application and Statement of Understanding;
2. An Income Declaration with proof of income;
3. A Physician's Certification, as required above; and
4. A Consumer Plan of Service.

(b) Within 30 days of notification from the Applicant of the completion of the application package, the Provider Agency assessor shall perform a social evaluation of the Applicant to determine if the Applicant meets the eligibility criteria.

(c) Within 30 days of notification from the Applicant of the completion of the application package, a member of the staff o the Provider Agency shall perform a financial evaluation to determine the ability of the Applicant or the Applicant's spou to pay for Personal Assistance services according to the sliding fee scale established in these Rules.

Disposition of application

(a) The Provider Agency shall notify the Applicant in writing within 15 days from the date of completion of the assessment regarding the finding of the social and financial evaluations, and the Applicant's right to appeal.

(b) If an Applicant is determined eligible, in addition to (a) above the notification shall include:

1. An approved plan of service listing the services to be provided, including an estimate of the time needed and frequency of Personal Assistance services.
2. An estimate of the total cost of the Consumer's Personal Assistance services;
3. If applicable, an estimate of the amount of money that the eligible Consumer or that Consumer's spouse is required to pay toward Personal Assistance services;
4. If funding is immediately available, a roster of Personal Assistants screened by the Provider Agency, from which the Consumer may interview and hire the Personal Assistant(s) needed to provide the approved services.

(c) In the event an Applicant is determined eligible for the Personal Assistance Services Program and funding prohibits the start-up of services within 30 days from the date of the Provider Agency's notification to the Applicant regarding the results of the social and financial evaluations, such Applicant shall be placed on a waiting list for services. An Applicant's position on a waiting list shall be determined by the Provider Agency.

(d) Prioritization for service delivery shall be determined by the Provider Agency using this order of priority:

1. Employment
2. Education or Vocational training
3. Community-based independent living
4. Absence of alternative services

Procedures for applying for exceptions and adjustments

In applying for exceptions. Consumers must meet all other eligibility criteria established under the Program.

(a) A Consumer requesting exceptions to established standards or adjustments in Consumer fees shall submit a writte request and justification to the Provider Agency.

(b) The Provider Agency shall review the request on a case-by-case basis.

(c) The Provider Agency shall make the determination whether to allow the exception or adjustment and respond to th request within 30 days of its submission; and shall notify the State Program Administrator and the Applicant or Consume of this determination.

(d) The State Program Administrator shall review each determination and approve or reject it, on a case-by-case basis an considering the Provider Agency's recommendations, and respond to the request within 30 days of the Provider Agency' notification of determination.

(e) In making the determinations and recommendations on exception and adjustment requests, both the Provider Agenc and the State Program Administrator shall:

1. Give consideration to the values of the Applicant or Consumer;
2. Require a showing of unusual or emergent circumstances before granting or making a positive recommendation;
3. Take into consideration the funding available;
4. Make the determination or recommendation based upon other services received by the client or Applicant throug other funding sources; and
5. Make the determination or recommendation based upon a review of the facts presented on a case-by-case basis.

(f) The granting of an exception shall be provisionally effective with the notification by the Provider Agency; it shall finally effective or rescinded with the notification by the State Program Administrator. If either 30 day period pass without a determination, the request shall become effective on the 31st day.

(g) If the request is for an exception to (hospitalization) above and the situation is an emergency, the request may be verbal form, and the response of the Director of the Provider Agency shall be immediate. The Consumer and Provi Agency must document the request as soon as possible.

Administrative hearings

(a) If services received or requested are to be denied, reduced, suspended, or terminated, the Provider Agency shall provide written notice to the Applicant or Consumer at least 30 days prior to such action, indicating the reason(s) for the action to be taken and citing the basis for the decision. In addition, all written notices of such adverse action shall contain this statement:

> An Applicant to or Consumer of the Personal Assistance Services Program, who is dissatisfied with any decision regarding an eligibility determination or other matters pertaining to participation in the Personal Assistance Services Program, may file a request for an administrative hearing before an Administrative Law Judge to contest that decision.
>
> A request for an administrative hearing must be made within thirty (30) days of the date of written notice of an adverse agency action.

(b) An Applicant or Consumer may request an administrative hearing before an Administrative Law Judge to contest a agency denial, reduction, suspension, or termination of services, denial of a request for an exception, or a failure to act upo a request for services within a reasonable time. A request for an administrative hearing will operate as a stay of any advers agency action pending the final administrative determination of the administrative hearing.

(c) Upon completion of the administrative determination, the Applicant or Consumer shall receive a copy of the writte decision within 30 days from the date the written request for an administrative hearing was received by the Administrativ Hearings Coordinator.

(d) Administrative hearings under this chapter shall be conducted pursuant to the applicable laws of the State o Minnesota.

Other considerations:

Medical-system involvement?
Banking of hours?
Grandfathered but incompetent consumers?
Vulnerable adult law?
Consumer protection?
Assumption-of-risk language?

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Testimony for the Minnesota Department of Health
Regional Coordinating Board 4
Public Hearing on Managed Care Issues
for People with Chronic Illness and Disabilities
December 4, 1996

Thank you for this opportunity to give policymakers some ideas on how managed care programs have worked for people who have extraordinary health care needs. My name is Krista Westendorp. My husband and I moved to the metro area ten years ago with our two daughters Jessica and Jill and our son, Aaron, who was born with a brainstem lesion resulting in spastic quadriplegia and breathing problems. I have also worked as a nurse in Children's Health Care Home Care and Hospice Program for the past ten years.

Elements of managed care were emerging when Aaron was born. In order for us to qualify for home nursing care for him when we were ready to take him home from the hospital we were put into a "case management" program, and each of our insurance plans since then has used case management. Our experience with case management has been largely a gatekeeping relationship, partly because we have always had our own access to medical research and best practice information. Until recently there have been no "usual and customary" precedents set for the care of children like Aaron(very few had survived before the advent of monitoring and respiratory technologies), especially their care at home. Each significant element of care or piece of equipment he needed has had to be run through a denial and appeal process, taking weeks or months to resolve, and requiring letters and calls of support from physicians and therapists. Aaron has lost much valuable developmental time waiting for crucial supports.

Aaron's extraordinary needs have not changed a lot since he was born 11 years ago--they are generally about breathing, mobility, and communication. The puzzling thing to me is that although his needs have remained fairly constant and predictable, insurance coverage and social supports to assist us in meeting these basic ongoing needs have been anything but stable. Early on we were introduced to the game of "disability hot potato". In this version of the game we are the potato and we get tossed from the realm of "publicly funded medical services" to "privately funded medical services" to "social services" to "educational services". The funding stream follows the service realms, not the potato. People keep telling me that the object of the game is to meet our needs, but it is clear to me that because of the overall design of the supports we are often first meeting the needs of these separate service systems. If funding streams followed individuals who had control over which services would best meet their needs, naturally more creative, efficient, and responsive systems would evolve, with many of the current resource-consuming regulatory systems becoming no longer necessary.

Another object of the game seems to be to shift costs from one realm to another. The way health maintenance organizations have accomplished this has been by each creating their own definition of "medically necessary services." I am looking to leaders in our health policy community to work with Minnesota's citizens to form an equitable definition of "medically necessary services", including all long term care services. A crucial component of this will be for us to recognize that individuals with extraordinary needs must have access to a continuum of sensible home and community based supports, which are no longer defined primarily as "medical", "social", "educational" or "job related", but more importantly, as components of a person-centered system that values self-determination, interdependence, and access to needed services.

Senator Sheila Kiscaden spoke at the Regional Coordinating Boards conference on November 22 , and stated that our problem-solving process so far has been a reactionary one that looks at individual stories rather than the whole, and follows a rule of rescue instead of creating a statewide and national consensus that recognizes finite resources. I think we would all welcome a system that is proactive instead of reactive, but I also believe that individual stories will always have the power to change the world. In listening to the experience of one of its members, a community has a fresh opportunity to rethink its priorities and realign systems created to serve all of its members. Thank you.

STATEMENT BY

CURT HADLEY

FOR THE JOINT MEETING OF REGIONAL COORDINATING BOARD FOUR AND THE MINNESOTA HEALTH CARE COMMISSION

DECEMBER 4, 1996

My name is Curt Hadley and I live in St. Cloud. I have been diagnosed with multiple sclerosis, a chronic neurological disease with varying symptoms such as numbness, extreme fatigue, and poor coordination. I was the Human Resources and Benefit Manager for Anderson Trucking Service, Inc. (ATS) headquartered in St. Cloud. I held that position from Jan. 1986 through Dec. 1995. I am now in training and development. In January of 1996, ATS changed insurance carriers with a corresponding change in network providers. The company is self-insured. This change resulted in both a financial burden and several other problems for me including limited access to specialists for my MS.

The problem with my new network of providers is the level of expertise in the area of MS. I normally go to specialty hospitals such as Fairview Riverside in Minneapolis which has a ward dedicated to the treatment and care of people with MS. Most neurologists from St. Cloud refer their patients to a specialist within the Twin City metro area once the patient requires more aggressive treatment .

When I received care at Fairview Riverside, my old plan was paying 90% of claims up to $10,000 and then 100% thereafter each calender year as long as I called into my insurance company to pre-certify myself before going to the hospital. The new plan did not include the doctor I was seeing for my MS, nor did it recognize the associated hospital as a facility in their network. The new plan made it very difficult to pre-certify myself to go to the hospital that specializes in care for people with MS and to see my neurologist that I been seeing for the past 10 years. My medical coverage was cut to 70% after a $500 deductible with no maximum conversion to 100%. I was hospitalized in April of 1996 and my insurance was paid under these guidelines with $3000 coming out my pocket. While the network does extend into the metro area, this hospital was not recognized as a network facility and I was penalized 30% since a network hospital was available to me within 20 miles of my residency.

Recently, because the network assigned to me lacks expertise about MS, I was prescribed the wrong dosage which was extremely scary for me and my family. I was hospitalized due to a car accident and was held overnight for observations. After receiving a shot of morphine for pain I was asked about my other MS medications. I answered the question the best I could and when I was asked the dosage for Klonopin, I stated that I thought the dosage was 10 mg, the same as Baclafin. At 11:30 that night I was given that dosage. The next day a neurologist was brought in to observe me because of concern of head injury because I was unable to stay awake. Later the hospital called my home and talked to my son about the dosage on the label of my MS medications. The dosage for Klonopin should have been .5 mg and not 10 mg. I had been given the equivalent of three weeks worth of Klonopin in just one dose. At a specialty hospital familiar with MS and associated medication, the dosage would have been noticed.

Since the change of networks, I have been forced to contend with more problems financially and physically because I don't have access to specialists who can properly treat my MS. I feel that changes need to be made so people like myself can have access to doctors and facilities that are only located in the metropolitan areas.

Obviously, the management of my care has not been the greatest. I had been denied an electric wheelchair which led to the need for rotator cuff surgery, nursing home care, PCA services, and at least $10,000 in lost wages. The insurance company has paid out more money on these costs than they would have paid for the electric wheelchair.

When I finally got out of the Caroline Center it was because of the Department of Rehabilitation Services (DRS) paid for someone to come to my my home and help me with transfers in and out of wheelchair. The funding ran out for that program and I am now forced to pay for home care out of pocket. As I was leaving the Caroline Center, the nursing home and the insurance company were suggesting I spend down my assets so I would qualify for Medical Assistance which would qualify me for assistance for my PCA care. So far, I have been able to manage the expense for a PCA because of the money that I inherited from my grandmother, however, when this money runs out I am unsure where I will go next.

More recently, I have been diagnosed with colon cancer and diabetes. One of my biggest expenses is the co-payment for doctor visits, supplies and prescription drugs. Because of numerous visits and prescriptions that I need, this is very expensive.

Now again, I am facing a new problem with MedCenters refusal to pay $100 for a solution that helps to irrigate my catheter. I cannot afford to pay this expense out of my pocket. However, because my catheter is not being properly irrigated, I am now having urinary tract infections which could lead to kidney troubles down the road. Once again, MedCenters refusal to pay a small expense will most likely lead to larger expenses for them and myself.

So obviously, I haven't had a very good experience with my managed care. There needs to be more foresight into the decisions made of what equipment and services that insurance should pay for. Decisions to turn people away until their medical condition becomes life-threatening is not a sound business practice. By taking care of the small things now, you can save money in the future. Furthermore, there should be an option for people like me to buy into Medical Assistance so that I can continue to work and not have to spend my whole life savings. Please help me and others with a chronic illness to receive the health care we are entitled to.

STATEMENT BY

IVA ANDERSON

FOR THE JOINT MEETING OF REGIONAL COORDINATING BOARD FOUR AND THE MINNESOTA HEALTH CARE COMMISSION

DECEMBER 4, 1996

My name is Iva Anderson and I live at 1050 Thorndale Ave. in New Brighton. I want to thank you for allowing me to testify. I would like to tell you about the problems I have had and am currently having with my managed care plan. Essentially, I have had problems getting coverage for durable medical equipment, medical supplies, rehabilitation, and home care.

My problems with my health plan (MedCenters) started in February of 1993 when my doctor prescribed an electric wheelchair. At that time I was a full-time employee at the Minneapolis Public Library. I was losing strength in my upper body due to multiple sclerosis and could no longer push myself very well in my manual wheelchair because of the pain.

The electric wheelchair was denied. We appealed the decision, and after numerous letters and phone calls from the doctors and occupational therapists about the medical need for this chair, MedCenters still denied the chair. After I started experiencing a lot of pain in my shoulders I went to my doctor. He again tried to appeal to MedCenters for the electric wheelchair and it was again denied.

I was in such terrible pain that I couldn't move and was taken to the hospital. I was eventually given an orthopedic referral and an MRI and they found I had two torn tendons in my rotator cuff. I underwent major surgery and was transferred to the

Ebenezer Caroline Center (now known as the City of Lakes Transitional Care) for rehabilitation.

Medcenter did pay for some of my rehabilitation but the nursing home informed me with just one day's notice that MedCenters was going to quit paying for my stay there. At this point I didn't feel I was ready to go home as I couldn't even transfer myself or push myself around. So I paid the expense for rehabilitation out of my own pocket. My bill for approximately 4 months was $18,600. It wasn't cheap at $150 a day. If I was able. I would have gladly gone home because I was still paying my mortgage. but MedCenters wouldn't cover home care and they still would not approve the wheelchair.

Ironically, MedCenters still denied me the wheelchair because I was able to leave the care center and go back to work. Evidently, they will only cover electric wheelchairs as long as I was homebound. This simply doesn't make sense. The electric wheelchair would help me to be more independent and employed. The only reason I was able to function at work was because my co-workers were kind enough to push me wherever I needed to go.

In addition to the $18,600 that I was charged at the care center, I also lost approximately $10,000 in wages and had to pay a $600 co-payment for prescriptions. I had to cash in my savings bonds that I had planned to use for my retirement.

MedCenter finally did agree to pay for the electric wheelchair after my story was published in Doug Grow's column of the *Minneapolis Star and Tribune*. When they did approve the chair, they only covered $2,000 of the over $10,000 total cost. The rest of the money came from the generosity of others.

Testimony for Regional Coordinating Board
December 4, 1996

My name is Janice Johnson and I have had Multiple Sclerosis for over ten years. I live at 6320 113th Place North in Champlin. I am employed full time as a manager by Northrup King Co

My employer switched to a managed care plan through Health Partners in January of 1996. I have three observations to share with you as a result of my experience.

First, even though my neurologist is on Health Partners list of approved specialists, the hospital where he practices and where I have gone for treatment has been dropped. I am very concerned about access to appropriate treatment and about the continuity of care.

Second, My doctor prescribed an electric scooter in July of this year (1996). I was losing strength in my legs and could no longer walk more than a short distance. The electric scooter was denied. I appealed and was informed that electric scooters were covered for persons who would otherwise be bed ridden or confined to a chair and then only for use in the home. I appealed to my employer to overrule this definition. I asked how this definition came about and was informed that it was a combination of corporate policy and Health Partners' recommendations. No action has been taken yet.

Third, denial of appropriate mobility aids for the partially disabled is not only contrary to the best interests of disabled individuals but is contrary to current public policy. Public policy calls for keeping people employed and off public assistance entitlement programs. The definitions used by Health Partners to determine who gets mobility aids, requires the successful applicant to be unemployed and eligible for Medicaid.

The net effect is to pressure an otherwise productive taxpayer out of the workplace and into dependence on tax supported entitlement programs. An end result that is bad, both ethically and economically.

Janice Johnson
December 4, 1996

Good afternoon. My name is Dr. Stephen Bolles. I am a doctor of chiropractic practicing in Minneapolis. Thank you for taking public testimony today.

It is appropriate to address certain deficiencies that have become apparent in health care reform. Issues such as access to health care providers are serious considerations before policymakers today.

If health care reform were a car, and cost considerations were the fuel in the gas tank, the car would be sputtering. The initial glee managed care plans experienced from cutting provider compensation and imposing arbitrary, unjustified and in some cases dangerous, treatment targets has given way to a grim awareness: there is little left there to cut. Turning in on itself, we are now seeing the early bloodletting from systems performing surgery on their own administrative superstructures. It will be interesting to see where the next wave of cuts will come from.

The relative freedom of these efforts have had some obvious and some less obvious consequences. One of the more hidden dangers is the fact that even educated consumers are not often clear about the significant pressure cost plays in their care.

Contractual restrictions, gatekeeper financial disincentives, and unsubstantiated practice targets imposed on patient care too often inappropriately mold patient management. Worse, medical and non-medical caregivers face the very real prospect of being dropped from limited network participation if treatment averages or costs exceed thresholds not supported by an ounce of clinical research or scientific data. Exacerbating these problems is the fact that these issues, arguably considerable as malpractice problems, are more often viewed as bookkeeping prerogatives. Providers, in fact, may be ambushed by plans. The Blue Select plan, for instance, imposes a 12-visit average on chiropractic participants for continued participation, although Blue Cross/Blue Shield may authorize additional care.

Chronic illnesses have emerged as the largest area requiring health care management for the US population. Our thinking and assumptions about what constitute reasonable thresholds of adequate care may need to be re-examined.

Parameters defining adequate care in an ambulatory setting oriented toward acute care problems may tolerate certain stresses that become intolerable if the needs of that same population shift to management of more chronic illnesses or problems. Plans that place a minimum number of primary contact providers in a given region arguably do not serve the public well under these conditions. A patient with a solitary acute need may not mind an occasional 30 or 40 minute drive overly much. That same person with a chronic musculoskeletal or physiological condition may be placed, not even at a disadvantage, but have their health detrimentally affected by the same degree of access.

Professional cultural limitations, persistent institutional prejudice and historic discomfort limiting referrals between medical and non-medical providers reduce access and place consumers at an additional disadvantage. And access is even a greater issue for those providers who are excluded from networks providing care for patients whose care is supported by the taxes paid by those same providers who are on the outside looking in.

Mandated benefits would not even be an issue if managed care systems were responsive to patient needs in the first place. Legislative imposition of these benefits is difficult to see as a problem. Consequently, the wisdom of making legislative responses to patient and constituent needs more difficult and unwieldy is hard to fathom. We should, I believe, instead be talking about the intransigence of health plans and the lack of an adequate check and balance system on their activities.

Thank you again for your time and attention.

Ms Nancy Cusick
Minnesota Health Care Commission
12 East Seventh Place
P.O. Box 64075
St Paul, MN 55164-0975

November 29, 1996

Dear Ms. Cusick:

I will not be able to attend the Dec. 4 hearing on managed care and other health care delivery systems. I wish to submit this written testimony.

The current Medical Assistance prior authorization process for durable medical equipment is extremely restrictive. In most cases contract equipment is the only equipment that is authorized. The individual need or needs for durable medical equipment is not something that can be met by a one size fits all approach. For example not all wheelchairs are the same. Much like shoes different styles and sizes are appropriate for different people. The State of Minnesota could save money by not limiting purchases of wheelchairs to contract wheelchairs. A wheelchair that doesn't meet the needs of the consumer is a waste of money. Consumers have been injured and lost independence due to the equipment or wheelchairs that do fit or meet their needs. Loss of independence due to ill purchased equipment can lead to cost shifting by increasing the need for additional personal care hours. I strongly believe that if the Department of Human Services studied how durable the durable equipment is that they are contracting for and the cost of maintaining that equipment over the expected life of the equipment, they would find that far more is being spent on contract than off-contract equipment. I have experienced first hand. The State of Minnesota has saved $200.00 or more a month in electric motor repairs for my power wheelchair since 1986. Prior to receiving off-contract electric motor replacements for my power wheelchair I was having motor repair on an average of every 4 to 6 weeks. At first the prior authorization for the off-contract motors was denied, I appealed and won. Not many consumers have the energy or the time to go through the appeals process.

Medical supplies is another area where potential savings could be achieved, if consumers had the ability to purchase supplies from a discount store instead of being limited to medical supply companies. Often the same products can found in the local discount store for half the price than at the medical supply companies. One remedy could be, consumers could purchase supplies by using a voucher.

Personal Care Assistant hours for many consumers come into question, historically when DHS is pressed by the state legislature or Governor to stop the increase or reduce expenditures in this program. No regard is given to the fact that previous DHS Personal Care Assistant hour assessments substantiated the consumers need for those hours. If a consumers health or condition did not improve than why would their hours need to be reduced. A huge amount of money has been wasted by DHS fighting to reduce PCA hours and consumers fighting to retain their PCA hours. Most often when PCA hours are reduced, consumers are in greater danger of placement in a long-term care facility, increased acute medical care or hospitalization.

Preadmission screens for the PCA program should be conducted in the county the consumer resides in and that screening to recognized throughout Minnesota without being re-screened. For whatever reason a consumer may decide to move out of the county they are living in, there is no reason to re-screen because preadmission screening are conducted by public health nurses.

I suggestion DHS look to other states and adopt what is working successfully in home care. Many states have an independent living model for home care or personal care assistant service programs with less medical intervention such as fewer nursing visits leading to lower costs. Prior to 1988, our personal care assistant program was very a cost effective independent living modeled program with greater consumer empowerment program. Over the years the Personal Care Assistant Program has become an extremely and medically modeled program which attributed to the sharp increased cost of the program. Although the PCA consumer's need for PCA service is to maintain independent living in their community it is in the nature of maintenance or assistance and not care. There is no need for the program to be medically modeled without any realized for the consumer or taxpayer.

For many PCA consumers, the consumer support grant program would be cheaper method of purchasing home assistant or PCA services. Consumers or their families would train, screen and manage their own PCAs. This would be much like the program was prior to 1988. Under the Consumer Support Grant program, consumers would receive 80% of the funding that is currently spent on their PCA services.

Health Maintenance Organizations have had a wealth of experience with preventive and accuse health care. They clearly have not had any or very limited experience home health care or personal care assistant services. It is incomprehensible that the State of Minnesota would consider giving the management of the personal care assistant program to a profit entity. Administration costs surely will be higher with a HMO. Without a substantial increase in funding for the personal care assistant program and potentially higher administration cost, services will have to be rationed or reduced. Again reduction or lost personal care assistant service hours could lead to higher occurrence of consumers needing accuse health care and/or being place in long-term institutional setting such as a nursing home.

Personal Care Assistant Providers are increasingly having difficulty staffing consumers with personal care assistants due to the low reimbursement rate per PCA service hour. Consequently Personal Care Assistant Providers are not able offer employees a hourly rate of pay making them competitive with nursing homes, fast food restaurants and other entry level jobs. High turnover rate of PCAs leads to lower quality of care as well as high training costs.

If the State of Minnesota wants to contain costs of programs like the Personal Care Assistant program, I suggest that streamlining of PCA training requirements and reduce regulations place could reduce costs. The Health Care Financing Administration stated that home care is over regulated. Reforming the personal care assistant program from medically model to an independent living model with less medical intervention will save money. Maximize dollars spent for personal care assistant to direct services not governmental bureaucracy.

Consumers have the expertise to manage and train their own PCAs, they do need help paying for it. Please remember that PCAs enter the consumers home and work with them in very personal way. The nature of home care is intrusive, so it paramount that consumers have a choice of provider and PCA working with them.

Thank you very much for time and consideration of my concerns.

Most Sincerely,

Morgan Grant
11[illegible]0 Hennepin Ave. #706
Minneapolis, MN 55403

cc Governor Arne Carlson
Senator Don Samualson
Senator Linda Berglin

Fax Tran mittal Memo

No. of Pages 4 Today's Date 12/6 [illegible]

To David Haugen From Cindy Johnson

Company Dept of Health Company —

Location Location Dept. Charge

Fax # 28 -3658 Telephone # 28_6358 Fax # 731 6330 Telephone # 731-6

Original Disposition ☐ Destroy ☐ Return ☐ Call for pickup

Comments // Draft is alittle rough but I promised to send you a copy. Thanks for the opportunity to testify at the hearing

Cindy

Testimony By Cindy Johnson - 2130 Ames Avenue St. Paul, MN 55119
at the Regional Coordinating Board Meeting on December 4, 1996

SUBJECT: Managed Care Issues

I am Cindy Johnson, a parent and an advocate. I am here today because I have already had many experiences coping with managed care particularly in trying the get my daughters many needs met within these systems. I have had all of the big three HMO companies and have had problems with all, some worse than others.

Just alittle background information, my daughter, Jenna is already 14 years old. She is a bright, social and beautiful teenager who faces challenges with cerebal palsy, a seizure disorder, learning disabilities and deteriorating dystonia. She needs one-on-one care during all awake hours and continous monitoring during the night. She relies on a wheelchair for mobility and a computer for written communication and most importantly she relies on me to get her needs met.

Our managed care experience began 4-1/2 years ago when I got married, I married a State employee and we automatically went on his insurance, which at the time was the largest HMO in the state. We went from fee for service to "managed care". Jenna had 17 speciality doctors who were mostly not in the network and she now needed to have referrals by a pediatrician who did not know her, what she needed. He was required to be a "gate keeper" for the HMO he served. This particular gate keeper doctor did not listen to what we needed and we fought battle after battle until open enrollment appeared seven months later. We jumped off that managed care ship and onto the next ship starting the first of the year. Before switching, we read every detail, called customer service and attended health care fairs at my husbands work, we literally spent hours researching before jumping ship. I might add that any of these plans would have worked fine for the rest of our family.

Jenna had to re-adjust again to a different "primary care doctor" who again didn't have a clue who she was or have any experience with her level of disability. This HMO, at first offered a more fee for service-type option IF you used their providers. We had to switch thankfully listed as providers. We had a good experience for a year and when open enrollment came up again, we went through the same long process of making sure by reading details, calling customer service and attending the health fair and were assured nothing would change. So, we stayed with HMO number 2, only to find out after it was too late to switch, that things had indeed changed. The HMO had made a "little" change that now all services had to be referred by our primary care doctor. After many battles, over a manual wheelchair and therapy services, we discoverd that our primary care clinic had signed on with a mediary organization that functioned between the clinic and the insurance company. This organization had its own restrictions and "ISN" that was different from what we were told at open enrollment time. Every time we needed a referral it had to go from primary care dr. to specialtity care dr back to primary care dr. to mediary organization for approval then finally to the insurance company for approval or disapproval. I spent one of the most frustrating years of my life fighting insurance parties, and Jenna often didn't get the services she needed until it was almost too late.

Following this third year of catastrophies, we again evaluated the options and selected a third HMO option at open enrollment time. Everything fit, we would keep our same primary care doctor (who by now knows her well), all the specialists and 'probably' the center where Jenna received PT, OT and theraputic swim sessions. We were told by customer service and at the health fair that although this center was not currently a provider, we could ask for an exception and it shouldn't be a problem. We did, we were denied and by this time it was too late to switch back, if we even wanted to. Jenna went without services for two months while we tried to convince the HMO to include the center into its network because other options did not meet her needs. A call to the Dept Of Health HMO Compliance div. helped us to maintain PT services until a decision was made. Eventually, after alot of stress and worry, the center was finally accepted into the network.

When open enrollment came the last year, we again did our research and decided to stay with the same HMO. After being burnt twice, we held our breath for awhile after the first of the year until we knew things really hadn't changed. Gee, its open enrollment time again ....and we are staying put (hopeful that the fine print won't change anything this year) and grateful that its working well now.

I wanted to give an example of a bad experience and one good experience we have had this past year.

THE STANDER FIASCO:

It all started last March.

Jenna outgrew her standing frame (used it 7 years). PT and I checked out all options.

Letter from PT to primary care dr. recommending specific stander

Referral to physiatrist. Appt with her. She writes letter to primary dr.

Primary Dr. makes referral for prior authorization and to DME Co.

DME follows up with authorization to insurance and also to MA

Insurance pays 80%, MA 20%. by the time authorization complete, equipment not longer mfgd. New type stander not available until June.

Distict Rep borrows us a stander for a month because I screamed very loudly.

New stander available late July. Price went up.

need to reauthorize new price - 4/6 weeks

Stander finally arrives in early September - without all parts - DME Co. and Rep forgot to order a back (It used to be standard).

DME has to re-prior authorize cost of back with insurance and MA. Orders back. Oops, forgot to order mobile unit - $700 more. Another letter from primary dr and PT necessary. Re-prior authorize with insurance and MA. We just received the back so she can use unit. We still have not received prior authorization for mobile attachment. It was medically necessary for Jenna to have this piece of equipment 8/21/96 when we returned from her surgery in Pittsburgh.

In summary - 1 piece of equipment, 8 months, 6 prior authorizations, at least 7 letters from professionals and she still can't use it.

I believe the most cost effective health care Jenna received was way back 5 years ago before we had managed care. If she needed a stander, her PT and Physiatrist and I would decide the best piece of equipment to meet her needs and place an order with the DME provider. That's it....within 30 days she would have had the right stander, at the SAME price without all the administrative expense and without six prior authorizations. She does not need 5 standers.....there seems to be this perception that if given a chance, consumers will order everyhing they can. We can barely fit one stander in our home.

THE SURGERY ORDEAL:

out of state- out of plan -not available here Medically necessary
She had no hope without surgery.......two weeks before surgery was scheduled, we thought, no way!
Five specialist wrote letters to recommend procedure
Asked for a supervisor customer service to help with process
Persistent - I called twice a day
Approval within two days - One of our doctors on review team?
I felt the person helping us cared, personally delivered information to decision maker, communicated and was respectful.
Changed my opinion that managed care always bad
Feels like HMO has evolved some over last five years

I think the paperwork, administrative expense and my anxiety costs are too high!

MY 12 MAJOR CONCERNS:

-Feels like HMO companies don't understand special needs
-HMO haven't listened very well
-HMO has not provided accurate information before open enrollment deadline to decide
-Appeal process take too long - cases heard by internal person
-Levels of administration and approval systems are cumbersome
-You have to be very persistent - time consuming
-Saving money seems to be too high a priority
-What I say is not as important as what the doctor says
-Doctors have incentive not to make referral
-I usually can not get to decisions makers to discuss case

-It's too hard with special needs to get what you need within regular system
-It's not fair to "dump" this child on a primary care doctor. he only get same rate and processes dozens of referrals, makes calls, writes letters and sometimes about procedures he isn't familiar with.

I am involved as a consumer can be in my daughter's care and at this point, the system makes it very difficult to meet our goals. I wish someone could show me where it saves $ and will avoid cuts. I keep hearing thru coordinating things $ can be saved, and we could avoid further cuts... my experience says it costs more to manage more. The goal is to SAVE $, and if by adding levels of authorization and red tape it ends up costing more, as I am absolutely sure it does in our case, we are throwing away precious health care dollars. We can't allow the things that have happened to us to be part of a new delivery system.

I am very worried, WE finally have our health care system worked out after five long years. I am worried about moving all people with disabilities into managed care. What about those of us who already are managed? How will it work to have two plans?

I don't even want to think about the long term care piece and how acute care and LT care can be combined effectively. What incentive is there to keep Jenna at home if the HMO doesn't share costs of institutional care?

At the very least, to make it work:

1) We need a totally different system for the disabled community
    - flexibilitiy
    - choice
    - consumer involvement
    - accurate information
2) Trained case manager to mediate/coordinate between HMO and family

3) Goals to maximize function and quality of life, not just restoration

4) Health care professionals and decision makers who listen and involve consumers

I think the challenge will be to incorporate "what we need" into the plan, and particularly, to have the flexibility to make changes when things don't work.....and most importantly, not just considering cost savings as the ultimate goal.

Thank you

ACB
American Council of the Blind
of Minnesota

P.O. Box 7341 • Minneapolis, Minnesota 55407

December 5, 1996

Ms. Nancy Cusick
Ninnesota Health Care Commission
121 East Seventh Place
P.O. Box 64975
St. Paul MN 55164-0975

Dear Ms. Cusick:

The invitation to present testimony on the impact of managed care on the disabled was delayed as it was transmittede via mail from the Minneapolis office to the above address. We are the Minnesota chapter of the national American Council of the Blind and therefore would appreciate receiving future announcements at the above address both in Braille and regular print. This will expedite response as the mail is picked up by either a Braille reader or myself who uses a close circuit television magnifier. We had hope to have a representative present, however, he was denied a metro mobility trip.

It is evident from the above how important communication and transportation in various forms are to the blind, not only in this specific meeting but also in all matters pertaining to health delivery systems!

I'm writing some of our concerns both on behalf of the ACB of Minnesota but also the Sensory Impaired Seniors Coalition, a group member of the Minnesota Senior Federation. There are many hearing impaired among the blind population as well as such chronic problems as diabetes, glaucoma and other visual deterioration related to the aging process. In reviewingHealth Care Choices, a publication of the Senior Federation, we are very much concern about the fragmented and lack of uniformity of hearing and visual care among the various HMO's used by individual subscribers. Many who are on SSI and use the Minnesota Comprehensive care, obtain durable medical equipments and medical care that do not seem available to those who, despite low income, do not qualify for medical assistance and therefore, must purchase plans that do not provide appropriate hearing or eye care needed to continue living independently. As far as can be ascertain, only two plans offer hearing aids on some kind of co-payment and there's little or no low

vision optics or care available. Such equipments are considered as non-qualified durable medical equipments and are often too expensive to purchase. Such equipment are available to medical assistance users or possibly Minnesota Comprehensive users. It appears that the system lacks a forthcoming uniform and appropriate eye and hearing health care to keep people living independently as long as possible. Finally, because there are so many documents in print, the blind nust wait until a reader is available to try to comprehend the documents. One would readily appreciate all our problems if every Braille reader would demand that the insurance providers had to send documents in Braille!

Sincerely,

George Failes, Vice President, ACB-M and Chair of Sensory Impaired Seniors Coalition

December 13, 1996

Nancy Cusick
Minnesota Health Care Commission
121 E. Seventh Place
P.O. Box 64975
St. Paul, MN 55164-0975

Dear Ms. Cusick;

Although I was not able to attend the RCB meeting last week, and was not able to get this to you prior to the meeting I decided to submit my comments anyway.

I have worked with individuals with physical disabilities who receive personal care services for many years, first as the policy coordinator for Medical Assistance personal care services for the Department of Human Services and, currently I work for a personal care provider organization. I have been following the progress of managed care for several years. I would like to address not only my concerns but also those that many consumers have expressed about managed care.

1. The consumers that I know and work with define disability as a functional need for assistance that will require the provision of independent living services for an undefined period of time but generally long term.
2. The consumers do not consider personal care services to be a medical service. They are health related independent living services that are necessary to maintain an optimal level of wellness and independence. These include assistance with activities of daily living (ADLS) such as bathing, grooming, dressing, eating, transfers, mobility, toileting, positioning, range of motion, respiratory services, monitoring, cuing, and supervision, plus assistance with homemaking, shopping, all types of communication, transportation, and social and recreational activities.
3. Personal care services are not acute care and do not require a medical model.
4. Personal care must be recognized as a specialty service for individuals with disabilities who have unique needs and require daily assistance with activities of daily living and other independent living services.

5. Service costs should be directed to wages and benefits for personal care assistants rather than the additional administrative costs associated with requirements imposed by acute care service regulations and standards.

6. Based on individual needs and preferences, consumers must be able to choose from various service models - independent providers, consumer directed provider organizations, shared service systems etc. Consumers must maintain the ability to change providers when their needs can be better met by that change (not limited to once a year for example).

7. Eligibility must be based on functional needs, not age, diagnosis, disability or income.

8. Services must be available wherever needed, 24 hours/day, 7 days per week.

9. As individually appropriate, consumers must maintain maximum ability for self-direction and self-reliance in order to individualize services that best meet their needs and to continue to receive services in the most cost-effective manner.

For purposes of these comments I am focusing on personal care services as currently defined by the Minnesota Department of Human Services as they are the services of most concern to the consumers.

The consumers believe that the provision of personal care services requires special consideration under Minnesota and national health care reform because personal care is a critical independent living service required by a special needs population, all of whom have a disability as defined above.

Individuals who need these services are trained to manage their medical, health care and independent living service needs. Because of their daily need for medical and assistive devices, personal care and other independent living services, the client, in directing their own care, must coordinate a variety of resources with specialized expertise to meet their needs.

The ways in which personal care services differ from traditional health and medical services include client direction and individualized services, client training of the Personal Care Attendant (PCA), choice of provider, daily long term service provision, and emphasis on activities of daily living and independence rather than medical procedures. Recent Federal legislation made changes to the Medicaid regulations and allows states to waive the requirement that personal care services be authorized by a physician and supervised by a registered nurse - a clear recognition of the difference between medical model and independent living model services.

Because independent living services for individuals with a disability require extended hours for personal care services the personal care providers must be recognized as a specialty service.

Personal care services are delivered by individuals who assist in tasks required to perform ADLs based on the functional need of each individual. These tasks are carried out on a daily basis to provide the support that the disabled individual needs to remain at home in the community. Traditional "health care" services are provided outside of this system in a medically directed model.

Consumers feel that being forced into a system that does not recognize, or is unable to accommodate individualized daily care needs can actually jeopardize their health. Documentation proves that associated medical costs increase without appropriate personal care services. For example, consumers are hospitalized more frequently due to skin breakdown, urinary tract infections, respiratory problems, depression etc.

In addition, by inserting personal care services into the traditional acute care medical model, requirements (training, paperwork and regulation) would be imposed that would increase the cost of providing the service. This cost increase has already been experienced by some Medicare Certified Home Health Agencies that provide personal care services even though personal care services are not a Medicare covered service. These standards far exceed the requirements for PCAs who provide services under the direction of the client with supervision from a registered nurse.

Minnesota's current managed care program is based on traditional acute care needs or medical model home health care during recovery or rehabilitation. Insurance companies and health plans have recognized those services and have provided coverage to the general public under these guidelines. Currently unrecognized by third party payers, and left for consumers, family or Medicaid to pay for, are the long term (maintenance) personal care services needed by individuals with disabilities.

Since 1977, the Minnesota Department of Human Services has worked with consumers and since 1988, with provider organizations, to develop standards for personal care services. While still in the process of definition and refinement, the Department has achieved a level of expertise not found in any other third par plan. Through the years the Department has become fa the consumers and their service needs. Because servi authorized through one central source there is potent consistency in the provision of service as well as ma the amount of services provided. Program compliance responsibility of the Department of Human Services, r Department of Health. This again indicates that it i perceived as a medical service.

Forcing personal care services into proposed health c through a complex management system which requires cc and sub-contracting will add administrative costs to system that already achieves three of the major goal care reform; control of eligibility, control and revi amount of service and cost control.

Thank for the opportunity to present these comments. will be useful in designing managed care for persons disabilities. If you have any questions or would li information please feel free to contact me at 645-72

Sincerely,

Lynda Adams

Lynda Adams
7805 E. River Road #112
Minneapolis, MN 55432-2429

Adopted - 9/23/96

MINNESOTA CONSORTIUM FOR CITIZENS WITH DISABILITIES (MN CCD)
c/o Arc Minnesota, Attn: Bob Brick, 3225 Lyndale Ave, So, Minneapolis, MN 55408, (612) 827-5641

MEDICAL ASSISTANCE MANAGED CARE FOR PERSONS WITH DISABILITIES CORE PRINCIPLES FOR SERVICE DELIVERY SYSTEMS

Quality of Care:

- Promotion of consumer-chosen, short and long term functional outcomes.
- Providers with specific expertise and experience in serving the target population.
- Comprehensive benefits without arbitrary limits or exclusions.
- Prevention and early intervention strategies used to prevent complications or secondary disabilities.
- Disability-specific health and self-care education for enrollees and their caregivers.
- Privacy-sensitive systems for collection, analysis and application of *relevant* data.

Care Coordination:

- A consumer-driven system of care management, designed to avoid fragmentation of services, prevent cost shifting, and promote coordination across acute, chronic and long term health care systems.
- A model that supports and empowers consumers, maximizing their independence.
- Care coordination that varies in intensity as needed and desired by the individual and family.
- Coordination of health care services with social, educational, vocational, and related services.
- A system that ensures continuity of care as networks are formed and as network providers change.

Access:

- Culturally competent service delivery in the most appropriate setting, to be determined with the individual.
- Fully accessible services and sites (physical accessibility, transportation, interpreters, etc.)
- 24-hour access to urgent care services, coordinated by experienced disability providers who have access to information about the individual enrollee's health condition.
- Access to specialists and to specialty services.

Meaningful consumer involvement:

- Early and continuous consumer involvement in systems design and implementation.
- Consumer participation in governance of managing entities, as well as local and state-level advisory committees which guide policies on publicly-financed health care for persons with disabilities.

Choice in individual health care decisions:

- Consumer choice among managing entities.
- Consumer choice among providers, including specialists and allied health providers.
- Meaningful consumer participation as members of the team in individual care planning.
- No single entity should have 24-hour control over all services delivered to an individual.

Dispute Resolution:

- Expedited process for approving exceptions to limits on services.
- Expedited complaint resolution process.
- Independent advocacy services.
- Independent appeals process.

Payment:

- Fiscal incentives/disincentives must not place the health, safety or independence of individuals at risk.
- A clear system for tracking how all funds are spent.
- Any money saved is set aside to meet the needs of people on waiting lists.

MN CCD is a broad-based coalition of organizations of persons with disabilities, providers, and advocates, dedicated to improving the lives of persons with disabilities. We address public policy issues that affect people with disabilities by collaborating with others, advocating, educating, influencing change, and creating awareness for understanding.

Written testimony was received from all persons who testified at the RCB Region 4-MHCC hearing with the exception of Eric Eoloff, Center for Healthy Aging, Medica, and Priscilla Pope. Because the tape recorder did not function properly at the meeting, no transcript of the testimony is available. Below are brief summaries of Mr. Eoloff and Ms. Pope's comments from staff notes.

Eric Eoloff, Center for Healthy Aging, Medica (no written comment provided)

Presented on Center for Healthy Aging. The Center, along with Medformation, provides information, referral, and other services to seniors. The Center is staffed by registered nurses and social workers. Medica is aware of the need to provide services beyond health care, and the need to integrate social and other services. HMOs are aware of the need for choices, and that survival in the market is dependent on offering choices.

Priscilla Pope (no written comments)

Attended meeting to speak to issues of managed mental health care of 16 year old daughter. The daughter was not comfortable with her male social worker, and requested a female counselor over a two month period. She never received a response, and there was no recognition or reaction to her depression. The family could not obtain her MMPI results. The daughter was later referred to another male provider. She then ran away, and has never returned home. Family felt overwhelmed by a hostile system. No regulators ever said the quality of care was abominable. The county and state should be concerned because the next step will be juvenile justice. Standards are needed for addressing mental health crises, along with quicker responses to crises.

Appendix 2:
Evaluations of Minnesota Prepaid Medical Assistance Program (PMAP)

Excerpted from: Minnesota Department of Human Services. Minnesota Health Care Reform Waiver: Minnesota Prepaid Medical Assistance Project Plus, No. 11-W-00039/5 Status Report, July 1996. (1996). St. Paul, MN: State of Minnesota, Department of Human Services.

Section Four-Evaluation

4.1 Federal Evaluation of Phase 1

The Health Care Financing Administration (HCFA) has contracted with the Urban Institute to evaluate Phase 1 of the MinnesotaCare Health Care Reform Waiver.

4.2 Historical Evaluation of the Prepaid Medical Assistance Program (PMAP)

Minnesota has taken a multifaceted approach to the evaluation of PMAP over the years: PMAP evaluation was designed to investigate from a variety of perspectives, the effectiveness of a prepaid, capitated Medicaid delivery system for a diverse group of Medicaid enrollees. What follows is an overall description of many of the approaches taken to evaluate the various aspects of PMAP.

4.21 State Evaluation Advisory Committee

In 1986 an evaluation advisory committee representing a diverse body of government, health and human service interest groups met to develop a comprehensive evaluation plan which integrated federal, state and county efforts. The advisory committee developed an elaborate set of questions dealing with prepayment issues. This was fashioned into a comprehensive evaluation plan reflective of existing time, resource and human constraints. This evaluation plan represented a thorough, wide-ranging and detailed inquiry into the impact of PMAP on the Medicaid populations in Minnesota's three initial demonstration counties. It was understood, however, that previously unidentified constraints might hinder the exploration of all the questions initially identified in the evaluation plan. The State assumed responsibility for carrying out the evaluation plan to the extent possible.

4.22 Federal Evaluation

HCFA was particularly concerned with prepayment results regarding AFDC and aged populations and contracted with the Research Triangle Institute (RTI) to conduct individualized and cross-project studies of the Medicaid managed care demonstration projects. RTI was charged with evaluating cost containment effects, utilization of services, quality of care, access to care, client satisfaction, and physician and institutional participation, using information gathered from encounter and client survey data, medical records, and case studies.

Although RTI's study was more extensive for other state sites, Minnesota's evaluation included a client satisfaction survey and case studies. Using a pre-test/post-test study design, RTI completed a survey of 300 AFDC and 300 aged PMAP enrollees in Hennepin County and an equal number of non-PMAP MA recipients in the control group. The survey included questions dealing with consumer satisfaction, utilization of services, health status and functional ability.

It was anticipated that RTI would analyze the encounter data received from the health plans. However, delays in receiving acceptable data prevented this analysis.

Lewin and Associates was under subcontract with RTI to complete case studies describing the project in Minnesota. The case study reports were based on key informant interviews and dealt with such issues as the marketing of health plans, consumer choice concerns, and implementation problems. Lewin and Associates interviewed state, county, legislative and provider personnel associated with the project. Lewin and Associates completed a total of four case study reports between 1984 and 1988.

The findings across all sites highlighted greater-than-anticipated start-up difficulties with the project, problems with enrollment and eligibility data, and unattractive reimbursement levels for providers as well as some difficulties related to access.

RTI reported that case management by health plans reduced utilization and that limitations on freedom of choice by enrollees did not adversely affected the quality of health care received. The integrative report was cautiously optimistic regarding the ability of prepaid programs to realize a modest savings in Medicaid costs without adversely affecting the quality of care, access to care or the satisfaction of participants in managed health care programs.

4.23 County Studies

Hennepin County studies.

Impact of PMAP on county-contracted and operated mental health and chemical dependency providers. In 1986 Hennepin County PMAP staff conducted a study to evaluate the cost of out-of-plan use of county-contracted and operated mental health and chemical dependency agencies. This was an important consideration to Hennepin County, as agencies that previously billed Medicaid were frequently being denied payment by prepaid health plans because the services were provided "out-of-plan" or without prior authorization by health plans.

The 25 agencies that participated in the study were asked to document when PMAP enrollees requested services, the types of services provided, and whether the agency requested prior approval from the health plan. The study concluded that the amount of financial loss to these agencies as a result of absorbing out-of-plan costs represented a small percent of their budgets, so they were willing to continue to provide uncompensated care to PMAP enrollees.

Hennepin County Crisis Intervention Center study. Conducted in 1987 and 1988, this study was administered by Hennepin County's Office of Planning and Development, the State Medicaid PMAP Office and the Community Services Management and Planning Department to determine whether enrollment in a prepaid health plan affected the use of the free Hennepin County Crisis Intervention Center by chronically mentally ill individuals. The study concluded that chronically mentally ill persons enrolled in health plans through the PMAP used the agency significantly less often than a comparison fee-for-service chronically mentally ill group.

Institutionalized elderly Medicaid recipients in Hennepin County. Hennepin County sponsored a 1988 study of the impact of a prepaid health care delivery system on the institutionalized aged. Data from 800 patient charts were examined to determine if the study group manifested adverse health outcomes after a year of receiving health care through prepaid health plans. Functional health status, number of physician visits, therapy visits, length and number of hospitalizations and changes in nursing home case mix classifications were measured.

Chart reviews of the two study groups revealed no significant differences in the health status of the two groups. While the study group showed a decrease in the amount of occupational and physical therapy received, all other ancillary services such as visits to a primary care physician and specialists remained the same.

University of Minnesota study of non-institutionalized elderly recipients. Using DHS data, a research team from the University of Minnesota School of Public Health studied the ability of health plans to provide care to a group of non-institutionalized aged Medicaid recipients. The team examined health and functional status, cost and use of medical services by the aged, comparing aged consumers on the fee-for-service system with aged consumers using health plan services. The study results demonstrated that there were no statistical differences between the two groups in any of the areas of health care measured by the study.

University of Minnesota study of the impact of capitation on chronically mentally ill. A research team from the University of Minnesota School of Public Health used DHS data to study the effect of using a capitated system of health care for the chronically mentally ill. The results of this 1987 to 1988 study indicated that there were no notable differences relating to mental health status, or physical and social functioning between the group receiving health care through the fee-for-service system and those receiving care through a managed care program provided by health plans.

Dakota County studies.

Client satisfaction survey. Dakota County contracted with the Program Evaluation Resource Center (PERC) to conduct an evaluation on access to and satisfaction with mental health and chemical dependency services. The PERC study indicated a decline in mental health service use between 1986 and 1988, a decline in chemical dependency services, somewhat longer waiting times and fewer appointments per month. Overall, there was satisfaction with outpatient mental health care.

Interviews with Dakota County nursing homes. The Dakota County Nursing Home Study was conducted to examine the reasons for a series of grievances filed during 1987 in Dakota County on behalf of aged participants in PMAP. The study revealed that nursing home staff were dissatisfied with additional administrative work involved, and were confused about some health plan policies and transportation issues.

Itasca County study.

Itasca County satisfaction survey. In 1989, the State and Itasca County conducted a survey that measured the reaction of Itasca County Medicaid enrollees to receiving their health care through a managed health care system. The 41% who responded indicated satisfaction with the level and quality of health care being provided. Enrollees indicated that the waiting times involved to receive that care had not changed because of its delivery through Itasca Medical Care. Enrollees were least satisfied with the health plan's vision services and the requirement to obtain a referral to a specialist through a primary care physician.

Itasca County conducted a second client satisfaction survey in 1990 with a response rate of 37%. The respondents to the GAMC survey seemed satisfied with instructions they had received on how to access health care and were comfortable with their primary care physicians.

Appendix 3:
US General Accounting Office Report summary

Brief summary of GAO report --

Medicaid Managed Care: Serving the Disabled Challenges State Programs.

In July 1996, The United State General Accounting Office issued the report, *Medicaid Managed Care: Serving the Disabled Challenges State Program.* The report notes the following:

- Increasingly, states are considering using managed care for Medicaid enrollees who are disabled.

- Few of the 6 million currently disabled Medicaid enrollees nationwide are now served through managed care.

- Efforts to enroll persons with disabilities into Medicaid managed care affect three stakeholder groups:

    1) disabled beneficiaries, who include a small number of very vulnerable individuals who may be less able than others to effectively advocate on their own behalf for access to needed services;

    2) the prepaid care plans, which are concerned about the amount of financial risk involved in treating people with extensive medical needs;

    3) and the states and federal government, which run Medicaid.

- 17 states have programs enrolling persons with disability into Medicaid managed care.

    - Six states require mandatory enrollment; of the six states, only Arizona's program is more than three years old (it was started in 1982).

    - Three states and the District of Columbia have small scale voluntary programs solely for disabled persons, none of which serves more than 3000 persons.

    - Seven other states and the District of Columbia allow disabled beneficiaries to enroll voluntarily in plans open to other Medicaid beneficiaries. In these states, less than 20% of the disabled population have chosen to enroll.

[See appendix 1, attached, with detail on 17 states]

- State's quality assurance activities can fall into two main categories:

1) Building safeguards into the programs through adequate planning and consensus building

    - Important to build in beneficiaries and advocates in program planning and design

    - Important to hold ongoing meetings to address issues as they arise

        -- has resulted in practice guidelines and technology assessments for persons with disabilities

2) Tailoring various aspects of the program (such as enrollment and monitoring) to meet the specific needs of disabled beneficiaries.

    - *addressing concerns about continuity of care*

        -- e.g., through flexibility in allowing specialists to serve as primary care providers
        -- e.g., allowing beneficiaries to enroll with providers outside their geographic areas
        -- e.g., continuity of care referral forms (plans receive notice of life sustaining ongoing treatment needs)
        -- e.g., requirements for plans to maintain existing plans of care or develop transition plans (Del. and Va.)

    - *helping in plan selection*

        -- e.g., through information, education

    - *providing access to a range of services*

        -- e.g., requirements for case management (in most states farthest along)
        -- e.g., requirements for "designated advocate"

    - *monitoring quality of services provided*

        -- e.g., Va will conduct survey of all disabled disenrollees
        -- e.g., use external professional review contractors for studies specifically designed to measure the quality of care for disabled enrollees (3 states developing RFPs)
        -- e.g., targeted quality of care studies (three states and DC)
        -- e.g., quality improvement goals (Mass is setting annual qa goals, requires plan to select additional goals; Medicaid staff review progress toward goals)

-- e.g., use of encounter data

☆ resolving concerns about medical necessity

-- 3 states use an appeal process (the medical director of Medicaid program has the authority to overturn decisions about medical necessity -- however, advocates say the process is time consuming, requires significant self-advocacy)

-- some states are redefining medical necessity, with guidance on or monitoring of, its application

[See also appendix 2, Table 5.1, Key Approaches for Including Disabled Beneficiaries in Medicaid Managed Care and Examples of State Initiatives]

▸ Three main approaches are available to address risk selection issues: risk adjustment; reinsurance; and risk corridor.

1) Risk adjustment:

- 2 states have implemented a form of risk adjustment, 1 is in the process of doing so.
- Risk adjustment is evolving (currently even the best predictors of health care costs explain less than half the variation in costs of providing care)
- Application to disabled is limited
- Administratively difficult

2) Reinsurance:

- Relieves some pressure on health plans faced with expensive cases, it does not remove the negative incentives [to not enroll or underserve].
- Plans may still benefit from enrolling the healthiest eligibles or from underserving the high cost cases that do enroll.
- In some areas, Medicaid managed care reinsurance may not be readily available in the private market and may not be available for small health plans. State Medicaid agencies become de facto insurance companies with the associated risks and resource requirements.

3) Risk corridors:

   - Now being used by 5 states.

   - Unlike reinsurance, risk corridors work in 2 directions, sharing both losses and profits with health plans below and above preestablished ratios.

   - As the only mechanism that specifically limits health plan profits, risk corridors have the greatest impact on incentives facing health plans to either reach for the lowest cost recipients in any given rate cell or to underserve the high-cost enrollees they cannot avoid.

     -- When $1 dollar saved from restricting service translates to $1 of profit, a health plan may be willing to risk losing enrollees who are dissatisfied with health plan service. With risk corridors, however, $1 saved may only translate to 30 or 40 cents in profit reducing the benefit side of the equation. Because health plans understand how risk corridor arrangements operate before entering into Medicaid prepaid care agreements, corridors also have the unique feature of being a retrospective adjustment with prospective risk.

Follow up needed (cited in GAO report:)

- Oregon, District of Columbia, and Virginia are seeking proposals from external professional review contractors for studies specifically designed to measure the quality of care for disabled enrollees. (P 44)

- Arizona, DC, Ohio, and Va will begin in 1996 to conduct additional quality of care studies focused specifically on care for disabled enrollees

- 1990 -- AZ random sample of DD to determine satisfaction and progress in fulfilling IEPs

- DC, Ohio, and Va are collecting encounter data and will begin evaluating care beginning in 1996 or 1997

- Wisconsin -- release of eval of its program in Dec 1996

GAO report summary - Appendix 1

states.[20] For the five mandatory programs with available data—Arizona, Oregon, Tennessee, Utah, and Virginia—participation ranged from 15.2 to 100 percent of all disabled Medicaid beneficiaries. Participation by eligible beneficiaries in the voluntary programs targeted exclusively to disabled individuals ranged from less than 1 percent to almost 11 percent, and participation in the remaining voluntary programs ranged from 3 to 20 percent.

Table 2.1: Enrollment of Disabled Beneficiaries in 17 State Medicaid Prepaid Managed Care Programs, February 1996

	Disabled Medicaid beneficiaries			
State	Total disabled eligibles	Total enrolled in prepaid program	Percentage enrolled in prepaid program	Yea enrollmen b disable bega
Mandatory programs				
Arizona	64,456	56,775	88.0[a]	198
Delaware	12,198	N/A	N/A	199
Oregon[b]	39,906	28,423	71.2	199
Tennessee	138,931	138,931	100.0	199
Utah[c]	17,155	8,158[d]	47.6	198
Virginia	91,082	13,817[d]	15.2	199
Voluntary programs targeted only to disabled individuals				
District of Columbia	3,200[e]	8	0.25[f]	199
Ohio	36,000[e,g]	294	0.82[h]	199
Wisconsin	22,041[e,i]	2,404	10.9	199
Voluntary programs for the general Medicaid population				
California	770,067	28,262[j]	3.7	197
Colorado	45,042	8,842	19.6	197
Florida	N/A	N/A	N/A	198
Maryland	83,350	10,496	12.6	197
Michigan	234,517	42,373	18.1	197
New Jersey	143,793	4,226	2.9	198
Pennsylvania	247,902	50,443	20.4	197
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population				
Massachusetts	164,366	7,935	4.8	199

(Table notes on next pag

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[20] These two states—Delaware and Florida—do not disaggregate SSI and related categories to distinguish among aged, blind, and disabled beneficiaries.

GAO report summary -
Appendix 1

mentally ill are not enrolled in prepaid plans, while nursing home residents are.

Table 2.3: Extent to Which 17 States Include Severely Disabled Beneficiaries in Medicaid Prepaid Care Programs, February 1996

State	Institutional populations included?[a]	Home and community-based services participants included?[b]
Mandatory programs		
Arizona	NF, ICF/MR, IMD	Yes
Delaware	No	No
Oregon	NF	Yes
Tennessee	NF, ICF/MR, IMD	Yes
Utah	No	Yes
Virginia	No	No
Voluntary programs targeted only to disabled individuals		
District of Columbia	NF, ICF/MR	No
Ohio	No	No
Wisconsin	No	No
Voluntary programs for the general Medicaid population		
California	No	No
Colorado	NF	Yes
Florida	No	No
Maryland	No	No
Michigan	No	No
New Jersey	No	No
Pennsylvania	No	Yes
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population		
Massachusetts	No	Yes

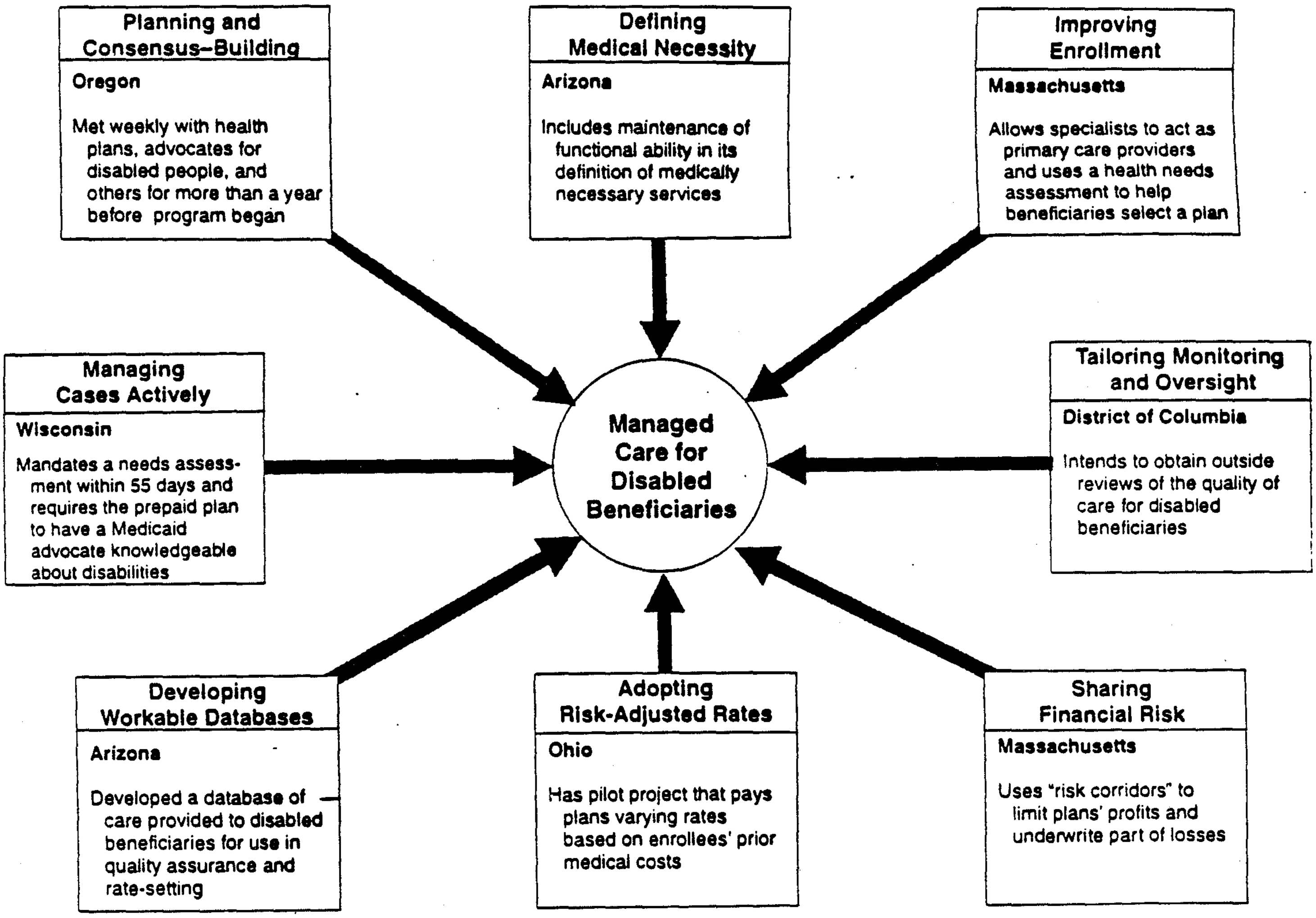
[a] Institutionalized beneficiaries include residents of nursing facilities (NF), intermediate care facilities for the mentally retarded (ICF/MR), and institutions for mental diseases (IMD).

[b] Home and community-based services programs provide a broad range of services to beneficiaries who, in the absence of such services, would require care in Medicaid-covered institutions. Beneficiaries these programs serve include disabled people who might need care in a nursing facility and those who are developmentally disabled or mentally retarded who might need care in an ICF/MR.

GAO report summary -
Appendix 2

develop effective prepaid programs. These key areas, and examples of state actions to address them, are illustrated in figure 5.1.

Figure 5.1: Key Approaches for Including Disabled Beneficiaries in Medicaid Managed Care and Examples of State Initiatives



Planning and Consensus–Building

Oregon

Met weekly with health plans, advocates for disabled people, and others for more than a year before program began

Defining Medical Necessity

Arizona

Includes maintenance of functional ability in its definition of medically necessary services

Improving Enrollment

Massachusetts

Allows specialists to act as primary care providers and uses a health needs assessment to help beneficiaries select a plan

Managing Cases Actively

Wisconsin

Mandates a needs assessment within 55 days and requires the prepaid plan to have a Medicaid advocate knowledgeable about disabilities

Tailoring Monitoring and Oversight

District of Columbia

Intends to obtain outside reviews of the quality of care for disabled beneficiaries

Developing Workable Databases

Arizona

Developed a database of care provided to disabled beneficiaries for use in quality assurance and rate-setting

Adopting Risk-Adjusted Rates

Ohio

Has pilot project that pays plans varying rates based on enrollees' prior medical costs

Sharing Financial Risk

Massachusetts

Uses "risk corridors" to limit plans' profits and underwrite part of losses

To date, few states have significant, long-term experience with programs that mandate enrollment by their disabled population. Even fairly

Appendix 4:

State agency health coverage complaint reporting

Minnesota Department of Health

- HMO and CISN closed non-medical complaints by category for calendar year 1995
- HMO and CISN closed medical complaints by category for calendar year 1995
- Complaint definitions

HMO and CISN Complaint Information

HMO and CISN Closed Non-Medical Complaintsby Category for Calendar Year 1995

Source: Department of Health, Managed Care Systems

Category	Blue Plus	CMGHP	First Plan	GHI	HP	Mayo	Medica	MHP	NWNL	UCare	HMO Not Specified	Total
Non-Medical												
Administration/Claims	1	0	0	3	7	0	14	0	2	0	1	28
COB/Subrogation	0	0	0	0	2	0	2	0	1	0	1	6
Dispute Resolution	2	0	0	0	0	0	0	0	0	0	0	2
Rate Increases	1	0	0	6	4	0	9	0	0	0	0	20
Copayments	1	0	0	8	9	0	37	0	2	0	2	59
Eligibility	1	0	0	11	10	0	27	0	1	0	0	50
Continuation/Conversion	0	1	0	6	4	0	6	0	0	0	0	17
Termination	0	1	0	0	4	0	9	0	0	1	0	15
Other	5	1	0	13	14	0	32	0	0	1	10	76
Total	**11**	**3**	**0**	**47**	**54**	**0**	**136**	**0**	**6**	**2**	**14**	**273**
Total Enrollment	**70,201**	**15,215**	**10,180**	**119,878**	**346,426**	**4,299**	**589,478**	**29,898**	**23,324**	**39,073**		**1,396,485**

** Taken from the *1995 HMO Operations Report*, Department of Health, Managed Care Systems

HMO and CISN Closed Medical Complaints by Category for Calendar Year 1995

Source:1995 HMO and CISN Annual Statements

Category	Blue Plus	CMGHP	First Plan	GHI	HP	Mayo	Medica	MHP	NWNL	UCare	HMO Not Specified	Total
Medical												
Quality of Care	3	0	6	23	10	0	19	2	0	0	0	63
Access to Care	1	1	1	11	12	0	23	1	1	2	1	54
Prior Authorization	5	1	0	11	30	0	51	1	1	3	2	105
Nursing Home/Long Term Care	1	0	0	1	0	0	6	0	0	0	0	8
Home Care	0	0	0	0	1	0	1	0	0	0	0	2
Mental Health/Chemical Dependency	2	0	0	1	0	0	14	0	0	0	0	17
Medical Necessity/Mandated Benefits	3	1	0	10	28	0	30	0	2	2	2	78
Emergency	2	0	0	2	12	0	14	0	1	0	0	31
Other	1	0	0	4	4	0	13	0	0	0	6	28
Total	**18**	**3**	**7**	**63**	**97**	**0**	**171**	**4**	**5**	**7**	**11**	**386**
Total Enrollment	**70,201**	**15,215**	**10,180**	**119,878**	**346,426**	**4,299**	**589,478**	**29,898**	**23,324**	**39,073**		**1,396,485**

** Taken from the *1995 HMO Operations Report*, Department of Health, Managed Care Systems

COMPLAINT DEFINITIONS

Non-Medical Administrative and Plan Management Issues

Administrative/Claims:
The timeliness of claims processing and overall administrative handling of policies and procedures.

COB/Subrogation:
Coordination of benefits is an antiduplication provision which prevents overpayment and designates the claims payment sequence for individuals covered by multiple contracts. Subrogation refers to the recoupment of benefits initially paid by the health plan and then paid under another insurance carrier.

Dispute Resolution:
The process by which an enrollee can appeal or grieve an adverse determination.

Rate Increase:
An increase in the monthly premium charge by the health plan.

Copayments:
The amount of payment for which the enrollee is responsible. A cost sharing feature.

Eligibility:
The predetermined factors which are used to determine whether to enroll an enrollee into the health plan.

Continuation/Conversion:
Programs of extended coverage eligibility following certain events, including death, divorce, termination of employment or retirement.

Termination:
The conclusion of eligibility for the enrollee or employer sponsored group.

** Taken from the *1995 HMO Operations Report*, Department of Health, Managed Care System

Medical Issues Related to the Delivery of Health Services

Quality of Care:

The quality of enrollee encounters and effect on health outcome.

Access to Care:

The ability of the enrollee to obtain necessary health care in a timely manner in a location reasonably convenient for the enrollee.

Prior Authorization:

The preadmission review of non-emergent care for appropriateness and medical necessity of a hospital admission or medical service.

Nursing Home/Long Term Care:

Any aspect of the delivery of health care services in a skilled nursing facility.

Home Care:

Any aspect of the delivery of health care services in the home setting.

Mental Health/Chemical Dependency:

Any aspect of the delivery of health care services to a mentally ill or chemically dependent person, by a mental health or chemical dependency professional.

Medical Necessity:

Health care services appropriate, in terms of type, frequency, level, setting, and duration, to the enrollee's diagnostic testing and preventive services.

Emergency:

Services rendered in an emergency room or urgent care center for an unexplained or sudden onset of an illness, injury or other medical condition.

** Taken from the *1995 HMO Operations Report*, Department of Health, Managed Care Systems

Minnesota Department of Commerce

- Closed health insurance files, and recovery
- Enf -- opened health insurance files

Closed Health Insurance Files, and Recovery

From: 1/1/96 **To:** 12/31/96 *Printed: 2/11/97*

Code	Type of Coverage	Recovery Amount
250	A & H) Policy	$731.01
251	A & H) Individual	$152,589.76
252	A & H) Group	$304,329.57
253	A & H) Dental	$3,780.40
254	A & H) Dread disease	$4,200.00
255	A & H) Credit disability	$9,064.92
256	A & H) Disability income	$110,510.78
257	A & H) Hospital Indemnity	$13,750.98
260	A & H) Medicare supplement	$6,412.09
265	A & H) Nursing home (long term)	$12,109.35
	Grand Total:	**$617,478.86**

Total Health Insurance Files Closed: **1124**

Enf - Opened Health Insurance Files

From: 1/1/96 To: 12/31/96 *Printed: 2/11/97*

Health

Coverage	Number of Files
A & H) Group	563
A & H) Individual	247
A & H) Disability income	83
A & H) Dental	82
A & H) Medicare supplement	77
A & H) Nursing home (long ter	42
A & H) Credit disability	29
A & H) Policy	25
A & H) Hospital Indemnity	7
A & H) Dread disease	5
A & H - Medicare Select	2
	1162

Minnnesota Department of Human Services

- 1995 PMAP appeals (by issue)

1995 PMAP APPEALS (BY ISSUE)

PROG	APPEAL TYPE	HP	CO	ISSUE	RECEIVED	OUTCOME
MA	ADMINISTRATIVE	56	27	06/94 Coverage/FFS?	6/07/95	DISMISSED
MA	SERVICE	53	27	2 Issues: Admin/Bill	1/23/95	H/P PREVAILED
AFDC	SERVICE	56	27	CD Outpt Treatment	5/11/95	RESOLVED B/HEARING
AFDC	ADMINISTRATIVE	50	27	Change Health Plans	1/18/95	H/P CH N/ALLOWED
AFDC	ADMINISTRATIVE	56	27	Change Health Plans	1/20/95	H/P CH /ALLOWED
AFDC	ADMINISTRATIVE	58	62	Change Health Plans	5/16/95	H/P CH N/ALLOWED
GAMC	ADMINISTRATIVE	87	62	Change Health Plans	8/16/95	DISMISSED
MA	ADMINISTRATIVE	53	27	Change Health Plans	2/10/95	H/P CH N/ALLOWED
MA	ADMINISTRATIVE	53	27	Change Health Plans	7/12/95	WITHDRAWN
MA	ADMINISTRATIVE	56	27	Change Health Plans	1/12/95	H/P CH /ALLOWED
AFDC	SERVICE	54	62	Chiropractic	6/20/95	H/P PREVAILED
AFDC	SERVICE	54	62	Chiropractic (1)	5/01/95	RESOLVED A/HEARING
AFDC	SERVICE	54	62	Chiropractic (2)	5/01/95	RESOLVED A/HEARING
MA	BILLING	56	62	Clinic Visit	11/21/95	RESOLVED B/HEARING
AFDC	BILLING	53	27	Clinic Visits	11/16/95	H/P PREVAILED
GAMC	SERVICE	87	62	DME: Bilat/Pal Brace	5/23/95	WITHDRAWN
AFDC	SERVICE	50	02	Dental Braces	6/22/95	WITHDRAWN
AFDC	SERVICE	50	27	Dental Braces	10/06/95	RESOLVED A/HEARING
MA	SERVICE	50	27	Dental Braces	1/31/95	H/P PREVAILED
AFDC	SERVICE	50	02	Dental Braces	9/08/95	WITHDRAWN
AFDC	SERVICE	58	62	Dental Braces	2/08/95	RESOLVED B/HEARING
GAMC	SERVICE	87	02	Dental Bridge	12/06/95	H/P PREVAILED
MA	SERVICE	50	27	Dental Bridge	11/06/95	H/P PREVAILED
AFDC	SERVICE	58	62	Dental Bridges	6/30/95	H/P PREVAILED
MA	SERVICE	50	27	Dental Dentures	4/01/95	H/P PREVAILED
AFDC	SERVICE	50	27	Dental Partial	6/29/95	RESOLVED B/HEARING
GAMC	SERVICE	88	27	Dental Partials	9/15/95	RECIP PREVAILED
AFDC	SERVICE	53	27	Dental Plate	2/22/95	RESOLVED B/HEARING
AFDC	SERVICE	56	27	Dental Porc Crown	8/28/95	H/P PREVAILED
GAMC	SERVICE	87	27	Dental Prior Auth	2/27/95	RESOLVED B/HEARING
AFDC	BILLING	50	27	Dental Sealant	8/28/95	RESOLVED B/HEARING
GAMC	SERVICE	88	27	Dental Upper Partial	3/07/95	RESOLVED B/HEARING
MA	BILLING	50	27	Dental: Non-Par (1)	2/14/95	RESOLVED B/HEARING
MA	BILLING	50	27	Dental: Non-Par (2)	2/14/95	RESOLVED B/HEARING
MA	BILLING	50	27	Dental: Non-Par (3)	2/14/95	RESOLVED B/HEARING
MA	SERVICE	53	27	Dental: Non-Par (4)	3/01/95	DISMISSED
AFDC	SERVICE	54	62	Dental: Orthodontia	9/27/95	RESOLVED B/HEARING
AFDC	BILLING	54	62	E/R: Non-Par	1/24/95	H/P PREVAILED
AFDC	BILLING	53	27	E/R: Non-Par	10/09/95	WITHDRAWN
AFDC	BILLING	54	62	E/R: Non-Par	3/13/95	RECIP PREVAILED
MA	BILLING	53	27	E/R: Non-Par	1/23/95	H/P PREVAILED
AFDC	BILLING	54	62	Emergency Room	10/12/95	DISMISSED
AFDC	BILLING	54	62	Emergency Room	6/15/95	RESOLVED B/HEARING
GAMC	BILLING	89	62	Emergency Room	7/19/95	RESOLVED B/HEARING
MA	BILLING	54	62	Emergency Room	9/15/95	RESOLVED B/HEARING
MA	BILLING	56	62	Family Planning	7/13/95	RESOLVED B/HEARING

PROG	APPEAL TYPE	HP	CO	ISSUE	RECEIVED	OUTCOME
AFDC	BILLING	54	62	Home Care Services	12/06/95	WITHDRAWN
AFDC	BILLING	56	27	Immunization: Non-Pa	4/03/95	RESOLVED B/HEARING
AFDC	SERVICE	50	27	Inpatient Stay	7/26/95	RESOLVED A/HEARING
GAMC	BILLING	81	62	Lab Bill	11/29/95	RESOLVED B/HEARING
MA	BILLING	54	62	Medical bill	11/20/95	RESOLVED B/HEARING
MA	BILLING	51	27	Mental Health	9/19/95	RESOLVED B/HEARING
AFDC	BILLING	50	27	Mental Health	10/09/95	WITHDRAWN
AFDC	SERVICE	54	10	Mental Health	5/08/95	RESOLVED B/HEARING
MA	BILLING	56	62	Mental Health	9/22/95	RESOLVED B/HEARING
AFDC	SERVICE	51	62	Methadone Treatment	12/01/95	RESOLVED B/HEARING
AFDC	SERVICE	51	62	Methadone Treatment	12/06/95	RESOLVED B/HEARING
GAMC	BILLING	81	62	Orthopedic	11/08/95	RESOLVED B/HEARING
AFDC	BILLING	43	27	Out of Service Area	11/09/95	RESOLVED B/HEARING
AFDC	SERVICE	43	27	PCA/DME	8/03/95	H/P PREVAILED
MA	SERVICE	54	62	Physical Therapy	3/23/95	DISMISSED
AFDC	BILLING	50	27	Physician	4/03/95	WITHDRAWN
GAMC	BILLING	88	27	Physician	8/15/95	H/P PREVAILED
MA	BILLING	50	27	Physician: Non-Par	7/19/95	RESOLVED B/HEARING
MA	BILLING	54	62	Physician: Non-Par	4/01/95	H/P PREVAILED
MA	BILLING	56	27	Physician: Non-Par	3/23/95	WITHDRAWN
MA	SERVICE	50	27	Speech/Occ Therapy	7/12/95	H/P PREVAILED
MA	BILLING	50	27	Supplies	7/06/95	RESOLVED B/HEARING
GAMC	SERVICE	87	27	Surgery	1/31/95	WITHDRAWN
GAMC	SERVICE	87	19	Surgery GendReassign	10/13/95	RESOLVED B/HEARING
AFDC	SERVICE	50	19	Surgery/Gastroplasty	6/13/95	H/P PREVAILED
AFDC	SERVICE	50	27	Surgery/Reconstructi	9/11/95	RESOLVED B/HEARING
AFDC	SERVICE	50	27	Surgery: StomachTuck	10/10/95	RESOLVED B/HEARING
AFDC	BILLING	54	62	Transportation	1/24/95	RESOLVED B/HEARING
GAMC	BILLING	89	62	Transportation	3/23/95	RESOLVED B/HEARING
GAMC	SERVICE	83	27	Vision	7/06/95	H/P PREVAILED
AFDC	SERVICE	56	62	Vision Eyeglasses	2/01/95	RESOLVED A/HEARING

SUMMARY OF PMAP APPEALS FOR CALENDAR YEAR 1995

PROGRAM	APPEAL TYPE	COUNTY	OUTCOMES
38 AFDC	8 ADMINIST	3 ANOKA	2 H/PLAN CHANGES ALLOWED
25 MA	32 BILLING	1 CARVER	3 H/PLAN CHANGES NOT ALLOWED
14 GAMC	37 SERVICE	2 DAKOTA	5 APPEALS DISMISSED
		42 HENNEPIN	10 APPEALS WITHDRAWN
		39 RAMSEY	33 RESOLVED BEFORE HEARING
			24 APPEALS HEARD:
			5 RESOLVED AFTER HEARING
			17 H/PLAN PREVAILS
			2 ENROLLEE PREVAILS

TOTAL OF 77 APPEALS
160,000 ENROLLEES

1996 PREPAID MN HEALTH CARE APPEALS

PROG	APPEAL TYPE	HP	CO	ISSUE	RECEIVED	OUTCOME
AFDC	SERVICE	53	27	CHEM/DEP: ASSESSMENT	2/08/96	RESOLVED B/HEARING
AFDC	SERVICE	56	62	CHEM/DEP: METHADONE	4/19/96	PENDING
AFDC	SERVICE	56	62	CHEM/DEP: METHADONE	5/13/96	DISMISSED
AFDC	SERVICE	56	62	CHEM/DEP: METHADONE	5/30/96	DISMISSED
AFDC	SERVICE	56	62	CHEM/DEP: METHADONE	6/05/96	PENDING
AFDC	SERVICE	56	62	CHEM/DEP: METHADONE	6/19/96	PENDING
AFDC	SERVICE	56	62	CHEM/DEP: METHADONE	7/03/96	PENDING
GAMC	SERVICE	87	27	CHEM/DEP: METHADONE	5/28/96	PENDING
GAMC	SERVICE	87	27	CHEM/DEP: METHADONE	6/10/96	WITHDRAWN
GAMC	SERVICE	87	27	CHEM/DEP: METHADONE	7/01/96	PENDING
MA	SERVICE	56	19	CHEM/DEP: METHADONE	6/11/96	CONTINUED
MA	SERVICE	56	62	CHEM/DEP: METHADONE	6/05/96	WITHDRAWN
AFDC	BILLING	53	27	CHIROPRACTIC	7/01/96	RESOLVED B/HEARING
GAMC	BILLING	85	69	CHIROPRACTIC	7/26/96	RESOLVED B/HEARING
AFDC	BILLING	50	02	CHIROPRACTIC CARE	2/02/96	DISMISSED
AFDC	SERVICE	56	62	CHIROPRACTIC CARE	1/05/96	WITHDRAWN
AFDC	BILLING	50	27	DENTAL BILLS	8/07/96	RESOLVED B/HEARING
MA	BILLING	56	27	DENTAL BILLS	7/01/96	RESOLVED B/HEARING
MA	BILLING	56	27	DENTAL SERVICES	7/16/96	PENDING
AFDC	BILLING	50	70	DENTAL SURGERY	6/11/96	RESOLVED B/HEARING
AFDC	BILLING	50	27	DENTAL UPPER PARTIAL	7/16/96	PENDING
MA	BILLING	50	27	DENTAL/PORC.RETAINER	7/10/96	H/P PREVAILED
MA	BILLING	50	27	DENTAL: COPAYS?	5/14/96	RESOLVED B/HEARING
AFDC	SERVICE	50	27	DENTAL: FLIPPER	2/14/96	RESOLVED B/HEARING
AFDC	BILLING	56	62	DENTAL: ORTHODONTIA	3/01/96	RESOLVED B/HEARING
AFDC	SERVICE	50	27	DENTAL: ORTHODONTIA	6/10/96	PENDING
AFDC	SERVICE	50	02	DENTAL: PARTIAL	1/12/96	DISMISSED
MA	SERVICE	50	27	DENTAL:UPPER PARTIAL	7/30/96	RESOLVED B/HEARING
AFDC	BILLING	53	02	E/R	6/12/96	PENDING
MA	BILLING	54	82	E/R	6/20/96	RESOLVED B/HEARING
GAMC	BILLING	83	19	E/R AND PHYSICIAN	7/15/96	RESOLVED B/HEARING
AFDC	BILLING	51	02	EMERGENCY ROOM	4/18/96	RESOLVED B/HEARING
AFDC	BILLING	54	71	EMERGENCY ROOM	4/05/96	RESOLVED B/HEARING
GAMC	BILLING	83	27	EMERGENCY ROOM	2/16/96	RESOLVED B/HEARING
GAMC	BILLING	87	19	EMERGENCY ROOM	7/31/96	PENDING
MA	BILLING	54	62	EMERGENCY ROOM & TRA	1/08/96	RESOLVED B/HEARING
GAMC	SERVICE	87	27	GENDER REASSIGNMENT	7/22/96	PENDING
MA	SERVICE	01	62	HUNTINGTON CLINIC	6/20/96	RESOLVED B/HEARING
MA	BILLING	54	82	INPATIENT	5/23/96	RESOLVED B/HEARING
MNCA	ADMINISTRATIVE	01	82	MAND/PARTICIPATION	8/05/96	WITHDRAWN
AFDC	ADMINISTRATIVE	51	10	MANDATORY PARTICIPAT	1/29/96	DISMISSED
MA	ADMINISTRATIVE	01	27	MANDATORY PARTICIPAT	5/28/96	PENDING
MA	ADMINISTRATIVE	60	31	MANDATORY PARTICIPAT	3/26/96	WITHDRAWN
MNCA	ADMINISTRATIVE	01	62	MANDATORY PARTICIPAT	5/21/96	AFFIRMED
MNCA	ADMINISTRATIVE	24	27	MANDATORY PARTICIPAT	7/10/96	DISMISSED
MNCA	ADMINISTRATIVE	01	27	MANDATORY PARTIPATIO	6/12/96	WITHDRAWN

PROG	APPEAL TYPE	HP	CO	ISSUE	RECEIVED	OUTCOME
GAMC	BILLING	81	62	MENTAL HEALTH	4/16/96	RESOLVED B/HEARING
AFDC	SERVICE	50	27	MENTAL HEALTH SERVIC	4/05/96	DISMISSED
MA	SERVICE	50	27	PCA DENIAL	8/13/96	PENDING
MA	SERVICE	56	82	PCA DENIAL	8/19/96	PENDING
MA	SERVICE	60	31	PCA REDUCTION	6/18/96	RECIP PREVAILED
MA	SERVICE	60	31	PCA: REDUCTION	4/26/96	RECIP PREVAILED
AFDC	SERVICE	56	82	PCA: TERMINATION	4/29/96	WITHDRAWN
GAMC	BILLING	90	31	PHYSICIAL BILL	2/14/96	RESOLVED B/HEARING
AFDC	BILLING	56	27	PHYSICIAN	4/22/96	RESOLVED B/HEARING
AFDC	BILLING	56	62	PHYSICIAN BILLS	3/01/96	RESOLVED B/HEARING
GAMC	BILLING	81	62	SPECIALIST	4/16/96	RESOLVED B/HEARING
AFDC	BILLING	43	27	SPECIALIST: ONCOLOGI	4/16/96	RESOLVED B/HEARING
AFDC	SERVICE	60	31	SPECIALIST: REFERRAL	2/14/96	H/P PREVAILED
AFDC	BILLING	50	27	SUPPLY: AIR PURIFIER	6/10/96	PENDING
GAMC	SERVICE	87	27	SURGERY: GENDER REAS	2/15/96	CONTINUED
MA	BILLING	54	62	VISION: EYE DROPS	7/31/96	PENDING
GAMC	SERVICE	87	62	VISION: EYE SURGERY	5/30/96	CONTINUED

SUMMARY OF PREPAID APPEALS (TO DATE) 1996

PROGRAM
28 AFDC
18 MA
13 GAMC
4 MNCRE

APPEAL TYPE
7 ADMINIST
28 BILLING
28 SERVICE

COUNTY
4 ANOKA
1 CARVER
3 DAKOTA
25 HENNEPIN
5 ITASCA
17 RAMSEY
1 ST LOUIS
1 SCOTT
1 SHERBURNE
5 WASHINGTON

OUTCOMES
7 DISMISSED
7 WITHDRAWN
24 RESOLVED BEFORE HEARING
25 HEARD:
    17 PENDING
    2 HEALTH PLAN PREVAILED
    2 ENROLLEE PREVAILED
    3 CONTINUED
    1 STATE AFFIRMED

TOTAL OF 63 APPEALS
194,000 ENROLLEES

Appendix 5:
Description of Department of Human Services planned demonstration projects to enroll persons with disability in managed care

The Minnesota Demonstration Project for People with Disabilities

Minnesota Department of Human Services

Background

At the direction of the state legislature, Minnesota has been moving toward statewide implementation of managed care in the Medical Assistance program over the last decade. The Prepaid Medical Assistance Program (PMAP) is being implemented on a county-by-county basis, and currently covers the majority of Medical Assistance recipients in the state. Certain excluded populations are exempt from enrolling in Medical Assistance however, including individuals with disabilities who are under age 65. These excluded disabled individuals which include persons with developmental, mental health and physical disabilities will soon be part of a demonstration project currently being planned in the state.

The 1995 Legislature authorized the Commissioner of Human Services to establish pilot demonstration projects to serve MA recipients, (Laws1995, Chapter 207, Article 8, section 42). The Demonstration Project for People with Disabilities (DPPD) is currently in a planning phase, with enrollment expected to begin mid-1998. Currently there are approximately 66,000 Minnesotans eligible for Medicaid because of a disability. This population is growing at a rate of ten percent per year. In 1993, expenditures for this population were close to 8 million dollars. If this growth rate continues, 90,000 people will be eligible for Medicaid because of a disability by 1999 with projected expenditures of over 12 million dollars. While people with disabilities comprise about 13 percent of the people who receive Medicaid-funded health care services, the cost of these services represent 37 percent of the total Medicaid expenditures. It is believed that significant cost savings can be realized with the development of effective and successful managed care models for persons with disabilities.

Currently this population is served under the fee-for-service system of Medicaid payment. Criticism of this system has been significant, focused primarily on the categorical inflexibility which affects access to appropriate services, fragmentation and lack of coordination between the acute and continuing care systems. In addition, there has been historic over utilization of certain types of services (such as inpatient psychiatric admissions) and cost-shifting between sectors of the service delivery system.

The Guiding Principles

Models explored in the project should meet the needs of individuals and should be based on the following guiding principles:

- Commitment to individual participation and choice
- Assurance of quality services and supports
- Development of cost containment strategies
- Commitment to a community-based system of services and supports
- Involvement of stakeholders in planning, development, implementation, and evaluation
- Integration and coordination of public and private funding sources and
- recognition of the unique needs of children with disabilities

Demonstration Project Sites

A number of planning initiatives are underway to explore the experience of managing care for people with disabilities. These include The Project for Persons with Developmental Disabilities, The Southern Mental Health Initiative, Children's Mental Health and Family Service Collaboratives, and others. The intent is to combine these initiatives into one comprehensive demonstration project which will encompass these projects and will include five project sites. Currently the five projected sites include two northern sites; Itasca and Northeast (including Carleton, Cook, Koochiching, Lake and St. Louis Counties), two southern sites; Olmsted and the Southern Minnesota Health Initiative (including Blue Earth, Freeborn, LeSueur, Nicollet and Rice), and one metro site.

Models will be developed which address aspects of the current system which affect the clinical outcomes as well as the quality of life, for people with disabilities. These models will focus on assuring access to quality health care and appropriate utilization of services while achieving cost efficiencies. This will be done by developing appropriate and comprehensive provider networks, and pairing this service delivery system with pre-established reimbursement arrangements. If managed care is to serve people with disabilities "better" than the current fee-for-service system, several things must take place; 1) models must reflect such comprehensive and appropriate provider networks, 2) models must include care management strategies which improve and ensure access to necessary services, 3) models must allocate resources according to "case mix" characteristics and individual need rather than on the basis of programmatic or categorical eligibility criteria, and 4) models must contain proper financial incentive to undermine cost-shifting. This project will test such assumptions indicating whether or not managed care models can achieve these goals for persons with disabilities.

Planning Assumptions

An integrated complement of natural, generic, and specialized services and supports designed to support individuals in community environments will be developed. Services will enhance or maintain the individual's health, adaptive ability, community presence, and opportunities for growth and development in all settings.

- Enrollment will be mandatory for persons with disabilities in the selected geographic areas
- Contracts will be awarded to MCOs
- Models must include a choice of delivery networks or providers for the consumer
- Consumer access and safeguards will be emphasized
- The MCO will assume financial risk through a prepaid, capitated arrangement
- All Medicaid covered services will be included in the capitation
- Individual choice and responsibility in planning services and supports will be maximized
- Individuals will be educated and assisted in planning and evaluation services and supports.

In addition to the local planning efforts by consumers, parents, providers, county and state staff which has been occurring for several years, DHS reconvened a Stakeholder Committee in 1996 to provide ongoing input into project design and policies. Committee members have volunteered to participate in work groups on consumer strategy, consumer safeguards, consumer education/enrollment and contracting specifications. The work of this committee will be integrated with the site-based planning which is the nucleus of project design.

Partner's meetings have also been held during the last year which have been designed to provide both information to stakeholders regarding issues which effect both acute and continuing care as well as a forum for dialogue. Stakeholders from around the state as well as nationally recognized authorities have participated in small and large group discussions promoting information exchange at the Partner's meetings. Partner's meetings will continue to be held approximately every 3 months.

Managing Entities

The managed care organizations (MCO's) in this project will include some combination of county and private service providers, who will manage the long term care for people with disabilities. Discussions are taking place about how the acute care health needs of individuals enrolled in the DPPD will be met. Negotiations are underway to determine the relationship of the MCO's with health plans who may accept responsibility for the acute care needs of individuals enrolled in the project.

Partners qualified to create an MCO are defined as entities who individually or in partnership with other entities can manage a comprehensive package of delivery and support networks and systems. Partners can bear financial risk for all or a portion of the service package and must serve a sufficient number of enrollees to ensure state and entity efficiency.

Target Population

The target population includes people eligible for Medicaid because of a disability, including SSI eligible individuals in targeted geographic areas, children with severe emotional disturbances and adults with mental illness who are served through the county mental health delivery system. The four disability groups to be served in the DPPD include physical, mental health and developmental disabilities and people who are chemically dependent. The demonstration project sites will phase in these groups of people, beginning with people with developmental disabilities, although the ultimate goal is to have all five project sites include all four disability groups.

The Evaluation System

An evaluation system is being designed to assess the DPPD for the purpose of performance measurement and quality assurance. This system will have two components. The first is the *implementation or process evaluation* which focuses on performance measurement to direct program development. This component is being designed to provide timely and responsive information which will shape the project models based upon the feedback form those using, providing and designing the system. The purpose of this component is quality assurance and program improvement through monitoring of individual client outcomes. It is intended to provide an on-going feedback loop of information from consumers of services to providers to administrators, so that adaptations and adjustments can be made to improve the system.

The second component is the *outcome evaluation* which focuses on goal attainment and outcome measurement. This is an assessment of how well the overall project outcomes (not individual client outcomes) were achieved for the purpose of drawing conclusion about what worked well and what did not. The product of this evaluation component is a "lessons learned" report to share with policy makers and other sites for the purpose of replication.

The fundamental question that both components of the evaluation system seek to answer is "*What is working, for which people, under what conditions?*" Answering this question provides direction for high quality service development, and the ability to make decisions about replication.

A longitudinal design will be used to track people enrolled in the demonstration project over time. A variety of measures will be monitored, including utilization of services, the effectiveness of and satisfaction with those services, cost, and the outcomes that people are able to achieve. This will take place in the fee-for-service system and the managed care system, so that comparisons can be made. The study methodology is a quasi-experimental design, including pre-test and post-test measures, as well as experimental and comparison groups. Comparison groups will consist of demographically matched populations in neighboring counties to the project sites.

The Robert Wood Johnson Planning and Implementation Grant

Minnesota has recently been awarded a $500,000 grant to design innovative managed care models to serve people with disabilities. This grant will support continued planning and development through a variety of activities. The DPPD will develop and test approaches to the delivery and financing of continuing and acute care, including supportive services, to persons with disabilities. Minnesota will seek to enhance planning activities, develop functional assessment tools and create evaluation systems which involve local and state stakeholders in the design. The DPPD will allow Minnesota to test the assumption that cost-savings can be realized while maintaining or improving care and consumer outcomes with the development of effective and successful managed care models for persons with disabilities.

The Robert Wood Johnson Self Determination Grant

Minnesota was selected as one of sixteen states to receive a $400,000 grant to fund the development of three sites which melds the values, vision, and goals of self determination. The Self Determination Project will demonstrate the how individuals with developmental disabilities can increase control over their lives. The project will seek to employ principals which serve to enhance and/or provide support mechanisms which:

1. incorporate person-centered planning;
2. individually controlled budgets;
3. consumer-controlled housing;
4. outcome-based quality assurance;
5. quality improvement assistance;
6. consumer education and support;
7. consumer and family choice of providers;
8. consumer and family choice of support staff; and
9. the type and amount of support.

State and Federal Authority

State legislative authority will be sought in the 1997 Legislative Session to obtain the ability to maximize flexibility in designing, implementing, evaluating and adjustment of the DPPD. If the requested authority is granted, it should be effective no later than July, 1997. However, DHS will continue planning efforts prior to this date, so that valuable time is not lost.

A waiver must be sought from the Health Care Finance Administration (HCFA) for approval of the DPPD, explaining how health care quality standards will be protected. The State Department of Human Services (DHS) submitted the initial federal waiver request for the demonstration project in late 1996. A final waiver request will need to be submitted in mid-1997, before Minnesota will be granted authority to capitate Medicaid payments to local communities.

Questions

Questions regarding the DPPD may be directed to Kathleen Schuler at the Department of Human Services at (612) 297-4668.

Appendix 6:
Managed Care Outcomes, Center for Biomedical Ethics, University of Minnesota

The Center for Biomedical Ethics
UNIVERSITY OF MINNESOTA

Managed Care Outcomes

December 1996

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RESEARCH ON MANAGED CARE OUTCOMES

"The plural of anecdotes is not data."

Study Selection

It is important to evaluate the quality of the studies evaluating the relative outcomes of managed care and traditionally insured care. This bibliography focuses on health outcomes, not on consumer or patient satisfaction which is a different and important topic. I gave each study a "Quality of Research" QOR score. Studies got:

- one point for including only data after 1985 in order to assure that the data reflected relatively recent experience with managed care,
- one point for controlling or matching the managed care and the non-managed care population because persons in managed care can be healthier or wealthier and this can alter the findings,
- one point for being published in a peer reviewed journal because peer-review is a process by which experts in a field critique a study carefully to find flaws and correct them before publication,
- one point for having more than one institution on the managed care and fee for service sides in order to assure that the study is more broadly typical of health care institutions
- one point for not having any author who was a member of an insurance or managed care corporation or who had an interest in the outcome of the study to minimize bias in interpreting or stating results.

There are five possible points. The first section of this report gives studies with Quality of Research Scores of 4 or 5. Literature reviews were not scored in this manner; they have different ways of assuring quality.

The major findings of each study was classified as to:
"Quantity of care" examining how care decreases or increases access to services,
"Quality of care" referring to how well the care conforms to predetermined standard of care,
"Outcome of care" which refers to whether the patients are better off after being treated.

NEGLIGENT INJURIES IN THE PRE-MANAGED CARE ERA

Injuries to Hospitalized Patients in the Fee-for-Service Era

33,200,000
Hospital Admits

Harvard Malpractice Study
New England Journal 1991;324:370.

332,000 Negligence Injuries[
60% underused diagnostic or preventive services.
40% during invasive procedures.

90,000
Deaths

Comments: Even before managed care and its incentive to do less, wrongly omitting diagnostic and preventive tests were the most common preceding cause of injury to patients. This study did not study overtreatment per se, but the injuries to patients that caused deaths were in the most hazardous and costly types of procedures—surgeries which many believe have been overincented by fee for service medicine.

PRENATAL CARE to CHILDHOOD

Carey TS et al. Prepaid versus traditional Medicaid plans: Lack of effect on pregnancy outcomes and prenatal care. Health services research. 1991;26:165-181. QOR5

Purpose: To study prenatal care and birth outcomes for comparable groups of women on Medicaid/AFDC in two captitated managed care and two fee-for-service plans in California and Missouri.

Quantity: Similar use of clinics.

Outcomes: Similar C-sections, pregnancy complications, birth weights, and low birth weight babies.

Conclusion: There was no difference in prenatal care or birth outcome.

Krieger JW et al. Medicaid prenatal care: A comparison of use and outcomes in fee-for-service and managed care. American Journal of Public Health 1992;82:185-190. QOR5

Purpose: A study of prenatal care use and birth outcomes in comparable groups of Medicaid patients in three managed care plans fee-for-service health care.

Quantity: Similar use of clinics.

Outcomes: Equal to modestly increased birth weights.

Conclusion: Medicaid recipients enrolled in managed care plans used prenatal care similarly to fee-for-service families and show equal, to modestly higher, birth weights.

Tussing AD Wojtowycz MA. Health maintenance organizations, independent practice associations, and cesarean section rates. Health Services Research 1994 Apr;29(1):75-93

A data set consisting of 104,595 obstetric deliveries in New York state in 1986 is analyzed.

Quantity: HMOs reduced probability of a Cesarean section 1.3%.

Valdez RB et al. Prepaid Group Practice Effects on the utilization of medical services and health outcomes for children: Results form a controlled trial. Pediatrics 1989;83:168

Purpose: To examine expenses and health care outcomes for children.

Quantity of care: No differences in costs.

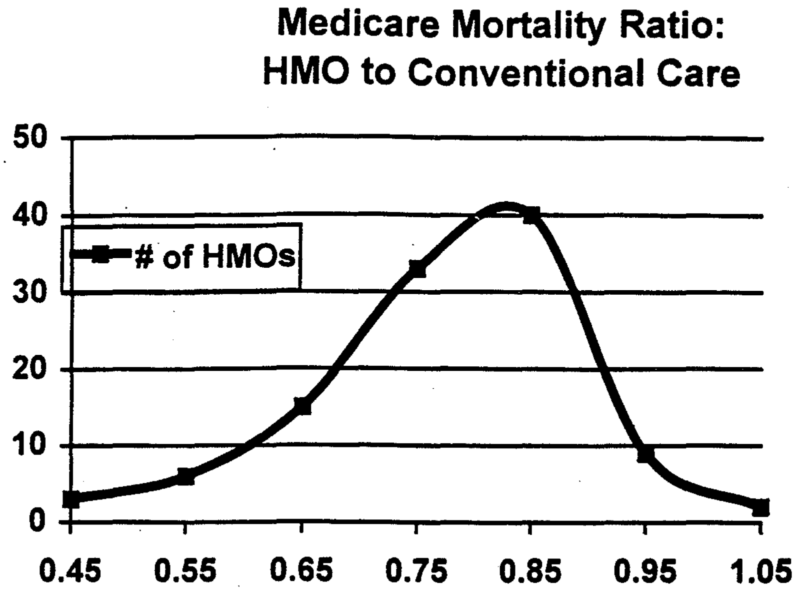
Quality of Care: No difference in roles, social, behavior, mental health or overall health or vaccinations, vision or hearing status.

OLDER PERSONS

Riley G, Lubitz J, Rabey E. Enrollee health status under Medicare risk contracts: An analysis of mortality rates. Health Services Research 1991;6:137-63. QOR5

Purpose: This huge scale study examined mortality rates for a million Medicare beneficiaries in 108 HMOs comparing their death rates with the death rates in local fee-for-service populations, adjusting for aged, sex, institutional status, population density, and Medicaid enrollment.

Outcomes: The mortality rate in HMOs was 80% that of fee-for-service, with a left skew to even lower ratios.
Conclusions: Beneficiaries enrolled in capitated risk contracts (managed care) have lower than average mortality rates.



Retchin SM et al. How the elderly fare in HMOs: Outcomes from the Medicare competition demonstrations. Health Sciences Research 1992;27:651-659. QOR5

Purpose: A prospective study of outcomes for 17 managed care plans in ten communities compared with 10 communities without HMOs that was controlled for baseline health.
Quantity and outcomes of care: There was no significance differences in medical visits according to various symptoms or rate change of health status with regard ability to perform personal care, to maintain their households, the number of restricted activity or bed days, self ratings of health, pre and post measures of abdominal pain, arthritis, bleeding, diarrhea, angina, shortness of breath, nonvoluntary weight loss, loss of eyesight, persistent cough, and fainting and access to and use of health care for all of these.

Lurie N Christianson J Finch M Moscovice I. The effects of capitation on health and functional status of the Medicaid elderly. A randomized trial. Annals of Internal Medicine 1994;120:506-11 QOR5

Purpose: To determine the effect on health and functional status outcomes of enrollment of noninstitutionalized elderly Medicaid recipients in prepaid plans compared with traditional fee-for-service Medicaid.
Outcome: There were no difference between prepaid and fee-for-service groups in deaths, fair or poor health, physical function, activities of daily living, visual acuity, or blood pressure or diabetic control. Prepaid patients had a trend toward better general health scores (P = 0.06) and well-being (P = 0.07) than fee for service patients. Prepaid patients were less likely to have a physician visit (-16.5%) or inpatient visit (-11.2%).

Ware JE et al. Difference in 4-year health outcomes for elderly and poor chronically ill patients treated in HMO and fee for service systems. JAMA 1996;276:1039.

Purpose: To compare physical and mental health outcomes for chronically ill adults in an HMO and fee for service system. 2235 persons, 1986-1990, age 19-97 with hypertension, diabetes, heart failure, depression in five cities.

Quality: The health of persons who were old and poor declined more rapidly in managed care. There was no trend in mental health outcomes.

Preston JA, Retchin SM. The management of geriatric hypertension in Health Maintenance Organizations. J American Geriatrics Association. 1991;39:683-690. QOR5

Purpose: To compare quality of medical care for non-adjusted populations of Medicare enrollees with high blood pressure in eight HMOs as opposed to those in 87 fee-for-service settings.

Quality of care: HMO patients with high blood pressure had better or equal quality of care for most criteria than in fee-for-service settings in recording medicine (94% vs 88%), recording smoking histories (75% vs 65%), checking standing and sitting blood pressures (9% vs 3%), checking retinas for damage 44% v 27%), checking the heart (91 v 80%), and getting chest X-rays (73 v 64%), obtain a urinalysis (78 v 65%), blood check of kidney function (76 v 67%, perform dietary counseling for obese persons (78 v 47%), perform dietary counseling on all person (36% v 27%). Fee-for-service enrollees had 43% more medication changes for mental changes.

Clement DG et al. Access and outcomes of elderly patients enrolled in managed care. JAMA 1994;271:1487-1482. QOR5

Purpose: Objective: to assess access and outcome for matched samples of 14000 elderly persons in HMOs and managed care for joint pain and chest pain.

Quantity of care: Managed care persons with joint pain were 20% more likely to receive a physician visit, equally likely to have x rays, and 40% as likely to see a specialist, 40% more likely to get a prescription, equally likely to get physical therapy, were 43% less likely to have follow up recommended, and 17% less likely to be seen for followup. Managed care patients with repetitive chest pain were 50% less likely to have visited a physicians (though no one reported difficulty in arranging an appointments). They were 35% less likely to see a specialist, equally likely to get an electrocardiogram or a chest x-ray, therapeutic , diagnostic interventions. They were 23% less likely have followup recommended

Outcome of care: There was no difference in the likelihood of eliminating joint pain (if not eliminated, it was less likely to be improved).

Both groups were equally likely to have chest pain eliminated.

Retchin SM, Preston J. Effects of cost containment on the care of elderly diabetics. Archives of Internal Medicine 1991;151:2224-2248. (QOR4, -1 for matching)

Purpose: To compare the care of elderly diabetics in eight HMOs to fee-for-service care.

Quality of care: HMO enrollees were more like to have retinal examinations (48% vs 30%), urinalysis for diabetic kidney failure (89 v 74%) and more likely to be referred to an ophthalmologist if they had difficult to control diabetes. (45 v 11%) Equal numbers were treated with insulin or oral drugs but HMO enrollees were more likely to have e medication changes. Flu shots were more likely to be given in fee-for-service than HMOs (62% v 19%).

Conclusion: HMO diabetics received better care.

Coffey E et al. Capitated Medicare and the process of care of elderly hypertensive and diabetics: results from a randomized trial. Am J Med 1995;98:531-6. QOR5

Purpose: to measure quality of care of diabetes and high blood pressure in elderly Medicaid recipients in managed care and fee-for-service plans.

Quantity of care: There was no difference in drug or non drug therapy, access to medications, costs, advice on preventive counseling. Use of home monitoring. A few more fee-for-service patients were using insulin after a year.

Conclusion: No detectable differences between fee-for-service and managed care groups in the degree to which they managed diabetics.

Carey TS, Weis K. Diagnostic testing and return visits for acute problems in prepaid case-managed Medicaid plans compared with fee for service. Arch Int Med 1990;150;2360-2372. QOR5.

Purpose: to assess the effects of managed care versus fee-for service care on the treatment of urinary tract infections, pelvic inflammatory disease, and vaginitis in comparable groups of women at sites in California and Missouri.

Quality of care: There was greater (improved) use of diagnostic testing for vaginitis and pelvic inflammatory disease in the managed care sites. There was trend for more followup visits in the managed care groups.

Tarlov AR Rogers WH. Primary care performance in fee-for-service and prepaid health care systems. Results from the Medical Outcomes Study. JAMA 1994 May 25;271(20):1579-86 QOR5

Purpose. To examine differences in the quality of primary care delivered in 1208 adult patients with chronic disease with fee for service insurance or a prepaid independent practice association (IPA), or a health maintenance organization (HMO) in locations in three cities. OUTCOMES MEASURES. Seven indicators of primary care quality--accessibility (financial and organizational), continuity, comprehensiveness, coordination, and accountability (interpersonal and technical) of care. Performance on each was evaluated in FFS, IPA, and HMO settings.

Quality of care: Financial access was highest in prepaid systems. Organizational access, continuity, and accountability were highest in the FFS system. Coordination was highest and comprehensiveness was lowest in HMOs.

HOSPITAL AND INTENSIVE CARE

Carlisle DM et al. HMO vs fee-for-service care of older persons with acute myocardial infarctions. Am J Public Health 1992;82:1626-1630. QOR5

Purpose: To compare three HMOs with a national sample of fee-for-service patients in groups that were matched for the level of severity of illness.

Quality of care: HMOs were much more likely to provide good care by criteria of patient monitoring, physician training nurse training and somewhat less likely to provide optimal technological care. The quality of technical therapeutic service was the same. Mortality was the same between the HMO and FFS patients at 30 days (23.2% vs 23.5%) and at 180 days (14.4 vs 34.5%)

Every NR Fihn SD Maynard C et al. Resource utilization in treatment of acute myocardial infarction: staff-model health maintenance organization versus fee-fot-service hospitals. The MITI Investigators. Myocardial Infarction Triage and Intervention. J Am Coll Cardiology 1995:401-6.

Purpose. To compare invasive procedures and length of stay for 998 patients admitted with heart attacks to two staff-model HMO hospitals and 7,036 patients at 13 fee-for-service hospitals between 1988 and 1992.

Quantity of care: Fee for service patients were 1.5 times more likely to get angiography and twice as likely to have surgery and had a hospital stay that was 1 day shorter apparently because of more on-site cardiac catheterization facilities in fee-for-service hospitals.

Every NE et al. Resource utilization in treatment of acute myocardial infarction: staff model health maintenance organization versus fee-for service hospitals. J Am Coll Cardio 1995;26:401-6. QOR5

Purpose: to compare the use of invasive procedures, length of stay, and mortality for comparable patients with heart attacks admitted to HMO and fee-for service hospitals.

Quantity of care: It proved impossible to compare due to the differences in the hospitals.

Outcomes: There was no difference in mortality.

Paone G Higgins RS Spencer T Silverman NA. Enrollment in the Health Alliance Plan HMO is not an independent risk factor for coronary artery bypass graft surgery. Circulation 1995 Nov 1;92(9 Suppl):II69-72 QOR3

Purpose: To determine the effect of managed care on coronary artery surgery for HMO and fee-for-service patients undergoing surgery between 1990 and 1994. Age, sex, medications, history of prior angioplasty myocardial infarction, extent of coronary disease, preexisting comorbid conditions, unstable clinical syndromes and left ventricular dysfunction were comparable for both groups.

Outcomes: In hospital mortality was the same, mean ICU stay (HMO, 2.6 days; FFS, 2.3 days), and total hospital stay HMO, 9.8 days; FFS, 8.6 days were similar. These data refute the notion that managed-care health insurance delays referral of patients with coronary artery disease or results in suboptimal outcome.

Rapoport J Gehlbach S Lemeshow S Teres D
Resource utilization among intensive care patients. Managed care vs traditional insurance.
Archives of Internal Medicine 1992 Nov;152(11):2207-12 QOR4

Patients in managed care plans (n = 159) and with traditional insurance (n = 389) were compared with respect to length of stay, hospital charges, charges for specific services, and use of mechanical ventilation.

Quantity of care: The managed care group had 30% to 40% shorter hospital and intensive care unit stays, lower charges, and less use of mechanical ventilation than the traditionally insured group for medical and emergency surgery subsamples. The differences were more pronounced in the patients with lowest severity of illness.

MENTAL HEALTH AND COMMUNITY BASED CARE

Rogers WH et al. Outcomes for adult outpatients with depression under prepaid or fee-for-service financing. Arch Gen Psych 1993;50:517-25. QOR5

Purpose: To compare two year changes in symptoms and function in patients receiving prepaid or fee-for-service mental health care from psychiatrists, psychologists, other therapists and physicians in three cities.

Quantity of care: Fee-for-service patients were equally likely to get psychotherapy, were 15% more likely to have the possibility of depression inquired into , were equally likely to get health, equally likely to get antidepressants and twice as likely to get antidepressants ultimately.

Outcomes: In prepaid business, 12% saw psychiatrist; in fee-for-service 24%. Psychiatrists treated sicker patients and the outcome in prepaid was an additional .8 disability. The outcomes of all other patients were the same.

Strum R et al. Mental health service utilization of outpatient mental health care among depressed patient in prepaid and fee-for-service plans among depressed patients in the Medical Outcomes Study. Health Services Research 1995;30:319-40. QOR5

Purpose: to compare mental health care use in managed populations over two years in prepaid and fee for service plans.

Quantity of care: There were 35-40% fewer visits in the managed system. This was worse for patients treated by psychiatrists.

Shern DL et al. Partial capitation versus fee for service in mental health care. Health Affairs 1995;14:208-19. QOR5.

Purpose to compare alternative Medicaid reimbursement studies over a multi year period for intensive case management of comparable groups of mentally ill persons.

Quantity of care: Managed care clients managed longitudinally had progressively fewer direct contacts with therapist as they got better and progressively more and individually programs of indirect contact through individually designed programs of community based services. In fee for service systems the direct contacts remained constant and indirect contacts declined.

Outcome of care: Greater improvement was seen in capitated care in scores describing unmet needs, hopelessness, and self mastery.

Conclusions: Capitation permits creativity and individualization of treatment plans for mentally ill clients which enables them to wean from provides to greater health and independence in communities using more flexibly arranged case management plans.

Schlenker RE et al. Patient-level cost of home health care under capitated and fee for service payment. Inquiry 1995;32:252-270.(QOR4, journal is copyright controlled by Blue Cross rather than an independent professional association).

Purpose: to examine whether comparable groups of Medicare patients receiving HMO and fee for service home care will receive comparable care and have comparable outcomes.

Quantity of care: HMO enrollees receive fewer home visits for skilled nursing care, home health care, physical therapy, occupational therapy, speech therapy, and medical social services, than fee-for service patients though they were serviced for a comparable amount of time.

Outcomes of care: HMO patients has less improvement in functional recovery.

Conclusion: HMO patients may be providing too little services to home service clients.

Wells KB, Katon W, Rogers B, Camp P. Use of minor tranquilizers and antidepressant medications by depressed outpatients: results from the medical outcomes study. Am J Psychiat 1994;151:694-700

Purpose: to compare use of minor tranquilizers and antidepressant medications by depressed outpatients across different treatment settings.

Quality of care: 23% of the depressed patients, had recently used an antidepressant medication and 30% had used a minor tranquilizer. The level of use was similar for different types of depression. Psychiatrists' patients were most likely to use medications. 39% of patients taking antidepressants used too low a low dose. Patients in prepaid health care plans were twice as likely as those in fee-for-service care to use minor tranquilizers, despite controversy over their efficacy.

Wells KB et al. The effects of a prepaid group practice on mental health outcomes. Health Services Research 1990;25:615-25. (Not available at this time)

Wells KB et al. Detection of depressive disorder for patients receiving prepaid or fee-for-service care. JAMA 1989;262:3298-3302. (Not available at this time)

Adams CE Kramer S Wilson M. Home health quality outcomes: Fee-for-service versus health maintenance organization enrollees. Journal of Nursing Administration 1995 Nov;25(11):39-45

Quality outcomes were compared between home health patients enrolled in the traditional Medicare fee-for-service (FFS) program versus a health maintenance organization (HMO) with a Medicare cost contract with the federal government. The quality outcome scores were similar between the two patient groups.

CANCER

Riley GF et al. Stage of cancer at diagnosis for Medicare HMO and fee-for-service enrollees. Am J Public Health 1994;84:1598-1604. QOR5.

Purpose: Twelve sites were examined stage at diagnosis for cancer.

Outcomes of care: HMO enrollees were diagnosed at earlier stages for female breast, cervix colon , melanomas and at later stage for stomach cancer. There was no difference for cancer of the prostate rectum, cheek, throat, bladder uterus, kidney, or ovary. These seems to confirm more aggressive screening programs or more attentive clinical care in managed care.

Vernon SW Hughes JI Heckel VM Jackson GL

Quality of care for colorectal cancer in a fee-for-service and health maintenance organization practice [published erratum appears in Cancer 1994 Dec 15;74(12):3249]. QOR4

There were no differences between FFS and HMO cases for duration of symptoms before diagnosis, training of physician who diagnosed the tumor, anatomic location of the tumor, type of primary treatment, Dukes' stage at final diagnosis, or survival. The findings from this study are consistent with those from studies reporting little or no difference in the process or outcome of care for patients with different types of medical insurance coverage.

Greenwald HP, Henke CJ. HMO membership, treatment, and mortality risk among prostatic cancer patients. American Journal of Public Health 1992;82:1099-1104. QOR5.

Purpose: To compare treatment and mortality between matched populations of fee-for-services and managed care (HMO) patients with prostate cancer who were followed for 80 months.

Quantity of care: HMO patient were less likely to receive surgery and more likely to receive radiation:

Outcome of care: HMO patients had a 38% lower mortality, and better quality of life during disease than fee-for-service patients. HMOs were particularly life saving for low income persons.

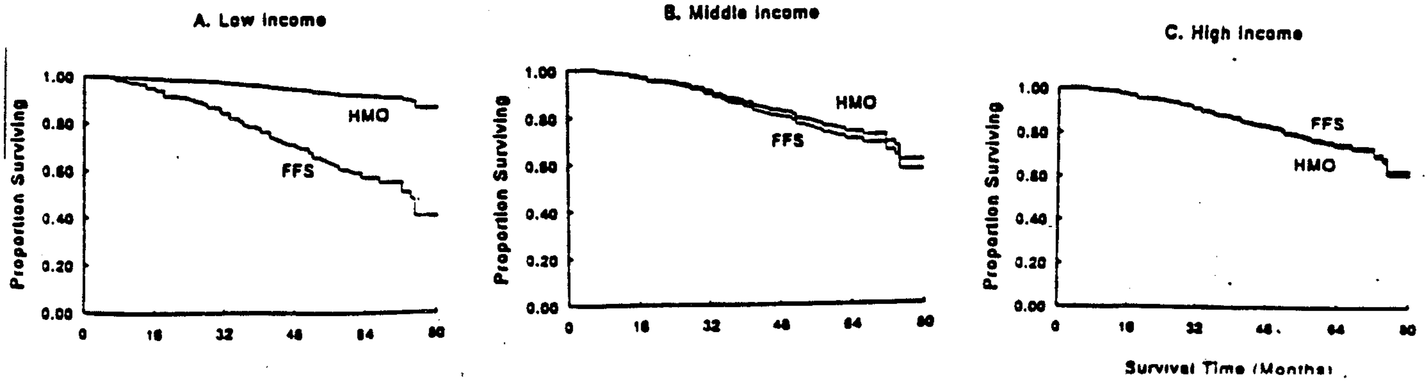


FIGURE 2—Survival by treatment setting by income category. HMO = health maintenance organization; FFS = fee-for-service.

REVIEWS OF MANY STUDIES

Miller RH, Left HS. Managed care plan performance since 1980: A literature analysis. JAMA 1994;271:1512-19.

Purpose: A comparison of studies addressing health care utilization, expenditures, premiums, use of preventive tests, examinations, procedures, quality of care, and enrollees satisfaction. The studies had to be after 1980, include good comparison groups that were adjusted for severity of illness, and had to use statistical tests to control for control for potentially misleading errors of simplistic conclusions.

Quantity of care and outcomes of care: There was 2-29 % less hospital used, no significance change in outpatient use, comparable physicians access, 22% fewer procedures, tests, and treatments that were expensive or had less costly alternatives for childbirth, heart disease, colon and colorectal cancer and stroke. Managed care enrollees consistently received more preventive care tests, procedures, and examinations for cancer and high blood pressure and breast, pelvic, rectal cancer; and physical examinations as well as smoking counseling. Managed care and fee-for-service provide roughly comparable quality of care according to process or outcomes measures for a wide variety of serious and less serious conditions.

Outcomes of care: The outcomes of managed care were comparable to traditional reimbursement.

Wells KB, Sturm R. Care for depression in a changing environment. Health Affairs 1995;14:78-89.

This is a thorough review. Prepaid psychiatry shows some evidence of poor quality of care in terms of detection, counseling, use of tranquilizers, continuity of antidepressants, provider continuity. Fee-for-service does not distinguish itself in terms of higher quality of outcomes despite much higher costs.

DEFINITIONS

Price Rationing: (fee for service)

If you can not pay $100,000 up front for a kidney transplant, this hospital and its surgical team will not take you as a patient. The patient does not enter the health care system. Absent a few circumstances (e.g., immediately life threatening emergencies or late stage labor that are covered by the federal anti-dumping act), the hospital has no further obligation to the patient. Options: bargaining, shopping other providers.

Premium-based Rationing: (insurance pricing)

If you can not pay $7000 for insurance for your family, then the insurance company is not obliged to issue a policy under any circumstances. This form of rationing access to health care is demonstrably injurious and is increasing as we economically polarize society and as employers decrease their contribution to employees' policies and decrease coverage for dependents. Overall, employer drop out from health care financing uninsures an additional 15-25,000 Minnesotans per year. Options: Medicaid requires indigency. MinnesotaCare has a limited eligibility. MNCHA is very costly.

Managed Care Rationing: (service or benefits controls)

A managed care plan can attempt to decrease access to or use of health care services, specialists, medications. Unlike price or premium rationing, the managed care plan remains accountable to this patient, offering the patient substantial leverage. Options: internal, legal, and public appeals.