



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

RESEARCH AGENDA:

MANAGED CARE

January 1995

Office of the Assistant Secretary for Planning and Evaluation

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The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared by HHS's ASPE/DALTCP, in conjunction with a contract between DALTCP and Lisboa Associates. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Nancy Eustis.

RESEARCH AGENDA: Managed Care

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This package includes the Background Paper which was distributed at the Office of Disability, Aging and Long-Term Care Policy's "Expert" meeting and the Summary Paper of the meeting's discussion. The opinions and views expressed in this package are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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FOCUS GROUP ON MANAGED CARE SYSTEMS FOR PEOPLE WITH DISABILITIES "DEVELOPING A RESEARCH AGENDA"

December 5, 1994

I. INTRODUCTION

This paper provides background information for a meeting on managed care and people with disabilities. The meeting will be hosted by the Office of the Assistant Secretary for Planning and Evaluation's Office of Disability, Aging, and Long-Term Care Policy in Washington, D.C. on December 5, 1994.

The purpose of the meeting is to:

- Review the implications of the movement toward managed health care for people with physical and mental disabilities; and
- Flesh out a program of research and demonstration which improves our understanding of the impact of managed care on people with disabilities and how it can become more responsive to their needs.

In particular, we ask you to help us: (1) assess the benefits and risks that managed care may pose to people with disabilities; (2) identify key policy concerns that the Federal Government and States must consider in designing managed care initiatives for people with disabilities; (3) highlight relevant research that has been done or is currently underway; and (4) suggest policy relevant projects and studies which ASPE might pursue.

II. CONCEPTUAL AND POLICY FRAMEWORK

A. Defining Managed Care For Individuals with Disabilities

In this paper we use the term "managed care" very broadly to refer to health care systems that integrate either the financing, the delivery or both of primary care, acute care and, much less frequently, long-term supports. The goal of managed care is to control health care costs and improve access to and continuity and coordination across a continuum of services. Managed care plans can range from prepayment models with full capitation to fee for service plans where a primary care case manager authorizes all covered services provided by others. Managed care can also refer to a network of providers who coordinate their efforts on behalf of an individual client without consolidating decision-making or risk in a single entity.

For the purposes of this paper, "individuals with disabilities" includes individuals of all ages with ongoing conditions or chronic illnesses that result in a need for extra medical services or assistance with daily living tasks. It is important to note that most experience to date in managed care for individuals with disabilities has been focused on elderly individuals (e.g., Social Health Maintenance Organizations (SHMO) Program of All Inclusive Care for the Elderly (PACE), TEFRA HMOs). In this paper, we will generalize this experience to the disabled population to the extent possible, but readers should be aware that the comparison will not be absolute due to the different characteristics and needs of younger people (including children) with disabilities and the elderly disabled. An additional challenge for readers of this paper and participants in the expert meeting will be to look at the extent to which the SHMO and PACE models are replicable across the age spectrum.

B. The Policy Context: Health Care Reform

Our interest in the implications of managed care for people with disabilities arises from our participation in the health care reform debate and the aftermath of that debate. Clearly, the Administration's health care proposal put a tremendous emphasis on managed care as a vehicle for controlling health care costs and moving toward universal health care coverage. The great promise of managed care is that it will allow people to receive a more appropriate range of services at less cost to themselves and to public programs.

We have talked with many people from the disability community over the past two years in conjunction with our work around health care reform. We heard little about the promise of managed care and much about their fears and concerns. Here are the kinds of questions they asked us.

- Why won't the private insurance market continue to select out people with significant disabilities, further perpetuating a two tiered system...one for healthy people and one for people with chronic conditions and disabilities?
- How will managed care plans achieve cost savings? Will they limit the access of people with disabilities to essential health services like preventive care, rehabilitation services and comprehensive drug coverage?
- How will long-term needs for rehabilitation, personal assistance services and assistive devices be treated?
- Will the amount of services be limited by arbitrary cost caps?
- Will utilization controls deter people with disabilities from seeking specialty care? Will doctors with specialized experience in caring for people with disabilities even be allowed to participate in managed care plans?
- Will the gatekeepers for managed care plans have enough experience to understand the special needs of people with mental or physical disabilities?

In today's climate, where universal health care reform seems less likely, State reform initiatives also appear to be directed toward the creation of managed care systems. In this case the goal is to achieve savings in public programs, particularly Medicaid, and reinvest at least some of the savings in covering previously uninsured lower income groups.

Within the last few years we have witnessed a dramatic growth in the number of States requesting Medicaid waivers which allow them to mandate the enrollment of Medicaid recipients in managed care arrangements. Currently, statewide reform efforts using the 1115 waiver authority have been approved in six States and over ten new waiver proposals or amendments have been submitted to HCFA.

There is significant variation in the extent to which statewide reform efforts seek to include people with disabilities in their managed care arrangements and the extent to which both acute care and long-term care needs are addressed. Washington State's plan to provide health and long-term care services to all it's citizens is the most comprehensive State proposal at this point. The State of Oregon, which already has an approved waiver to create a managed care system for the AFDC population, now has a proposal into HCFA to cover aged, blind, and disabled SSI recipients. Rhode Island, Tennessee and Florida also are considering mandating the participation of various populations with disabilities in their statewide reform efforts.

Regardless of the movement around comprehensive statewide health care reform initiatives, the proportion of Medicaid recipients in managed care has steadily increased. At least 16 States enroll the SSI disabled population in Medicaid managed care plans. Many of these recipients participate in 1915(b) (freedom of choice) waiver

programs. A recent study conducted by Brandeis University estimated that about 12% of SSI disabled Medicaid recipients are now in managed care arrangements.

The greatest momentum around managed care is in the private sector. Some private sector plans extend managed care principles by creating arrangements for populations with special needs (e.g., the management of subacute care by hospitals and SNFs; the development of contracts between providers of rehabilitation services and employer based health plans; new forms of home health care to manage high risk and special populations).

Of particular interest to our goals is the work carried out around the integration of acute and long-term care. The first generation efforts to tackle the challenge of integrating these services have been targeted on the elderly and carried out by the Social Health Maintenance Organizations, On Lok and Pace and the TEFRA HMOs'. The Robert Wood Johnson Foundation and the Chronic Care Consortium are also taking leadership roles in developing new, integrated service delivery models. RWJ is paying particular attention to the application of managed care principles to the under 65 population with disabilities including children.

In short, the movement toward managed care in the public and private sector is an important and continuing trend that is likely to have a significant impact on people with disabilities. This will occur whether or not national health care reform is achieved any time in the near future.

The remainder of this paper highlights what we believe to be critical policy areas and related research issues around managed care and disability. The paper focuses on the following topics:

- *FUNCTIONAL AND DEMOGRAPHIC CHARACTERISTICS OF PERSONS WITH DISABILITIES IN MANAGED CARE* including the extent to which people with disabilities participate in managed care; the demographic, functional and health status characteristics of enrollees; and patterns of disenrollment.
- *THE IMPACT OF MANAGED CARE* including how participation affects access to needed services; quality; affordability and costs; and individual outcomes such as consumer satisfaction, health status and functioning. Also comparisons of the impact of the traditional fee for service system and managed care on disabled participants.
- *TARGETING* including whether managed health care plans can be successfully organized and marketed to a broad population which includes both healthy persons and persons with special needs or are more effective when targeted to people who are already disabled; e.g., On Lok and Pace.
- *FINANCING AND REIMBURSEMENT* including identifying the financing barriers to successful managed care systems and new approaches to overcoming these

barriers including funds pooling and risk management and risk adjustment methodologies.

- *SERVICE COVERAGE AND ORGANIZATION OF THE DELIVERY SYSTEM* including the extent to which and how specialized services such as long-term rehabilitation, assistive technology, transportation etc. are included in managed care arrangements; the effectiveness of various approaches to integrating acute and long-term care services; and the feasibility of operating generic delivery systems for people of all ages and conditions with disabilities.
- *QUALITY ASSURANCE* including the development of new methods for measuring quality such as consumer satisfaction measures and the development of quality indicators for monitoring the impact of managed care on people with disabilities.

III. ISSUE AREAS

A. Functional and Demographic Characteristics of Persons with Disabilities in Managed Care

1. Policy Issues

Many people with disabilities believe that managed care is a threat to the delivery of high quality health services for people with special needs. To make managed care more responsive requires a better understanding of how today's system works. We place a very high priority on collecting basic descriptive information about the experience of managed care plans in serving people with disabilities, particularly persons with significant functional impairments and how this experience compares with that of traditional fee for service plans.

2. Research Completed or Underway

Virtually no information is available on the extent of participation of younger persons with disabilities in managed care plans. Fama and Fox recently analyzed the National Health Interview Survey to determine if the chronically ill under age 65 are under represented in managed care plans. The study concluded that people with disabilities (broadly measured) are not disproportionately represented in indemnity plans suggesting that neither HMOs nor indemnity plans benefit from favorable selection and that HMOs have been no more successful at risk selection than indemnity plans (Fama, 1994).

The Medicaid program which has lagged behind the private sector in developing managed care arrangements, has seen a steady increase in the enrollment of Medicaid recipients over the last decade. A recent survey of eight States conducted by the Institute for Health Care Policy at Brandeis University shows widely different participation patterns for disabled Medicaid recipients. For example, in California only 3.2 % of SSI recipients were enrolled in managed care plans, while in Colorado about 40% were enrolled and in Kansas over 50% of SSI disabled recipients were in managed care. Arizona, with the largest statewide effort to capitate both acute and long-term services for Medicaid recipients, enrolled 11,699 elderly and physically disabled persons and 6,437 persons with mental retardation or other developmental disabilities in fully capitated plans as of January 1994.

Harriette Fox, et al., conducted a survey in 1993 of all State Medicaid agencies to determine their policies for enrolling and serving special needs children in HMOs. This survey found that one-third of the States require Medicaid recipients to enroll in an HMO or other managed care plan and that most of these provide some type of protection for at least some special needs children. These include

exemptions from enrollment, arrangements for providing out of plan care, and exclusion of services from HMO contracts. However, Fox concluded that in most cases, the special protections that States provide to special needs children do not affect all chronically ill and disabled children and may not be effective in ensuring that these children receive adequate care.

The Medicare Risk Program (implemented under the Tax Equity and Fiscal Responsibility Act or TEFRA) allows HMOs to assume responsibility for providing all Medicare covered services under a capitated payment. TEFRA HMOs have increasingly captured a greater percentage of the older population with about 2.9 million elderly persons enrolled in 233 different plans. While there is little detailed information on the experience of older persons with significant disabilities in these plans, results from an evaluation conducted by Mathematica (Hill and Brown, 1992) show that Medicare beneficiaries with chronic health problems are less likely to enroll in HMOs. For example, enrollees had fewer functional disabilities and other indicators of chronic health problems than non-enrollees; they also were less likely to be over 80 and less likely to be Medicare-entitled because of disability rather than age. Further, they were less likely to exhibit serious health problems such as cancer, heart disease or stroke.

3. *Directions for Future Research*

What is the rate of participation in private managed care plans by people with disabilities? in Medicaid managed care arrangements? in TEFRA HMOs? Are people with disabilities disproportionately represented in the traditional fee for service system in comparison to the general population?

What is the nature and severity of the disabilities of participants? How do managed care providers identify particularly high risk persons who may require intensive and high cost services?

What services are available in managed care plans which address the needs of people with disabilities? What service use patterns typify managed care participants with differing levels of disability and need?

What marketing, enrollment strategies, and eligibility assessments are used to enroll people with disabilities in the managed care plans?

Are there new ways existing data can be analyzed to describe the participation of people with disabilities in managed care?

How can we use information from the Federal Health Benefits Program, consumer satisfaction surveys carried out in the private sector, national survey data, private insurance data bases (MEDSTAT) and other specialized data bases to better understand the number and characteristics of people with disabilities in managed care?

What original data collection is most important to carry out to describe the participation of people with disabilities in managed care and how can we efficiently go about collecting it?

B. The Impact of Managed Care

1. Policy Issues

Some aspects of managed care have the potential to be more advantageous than traditional fee for service arrangements for people with disabilities. Managed care plans can ensure providers more discretion than the traditional fee for service system in allocating resources. Theoretically, the ability to access a more comprehensive range of services and providers can enhance continuity of care, coordination, and appropriateness of services provided.

Such discretion can even allow a shift away from institutional settings to community-based services, which are widely preferred by most people with disabilities. In a carefully case managed system new benefits may be added without uncontrollable increases in costs. If case managers are skilled at understanding the service needs of people with disabilities, more appropriate as well as less costly care may result; e.g., decreased use of hospitals and increased emphasis on preventive services and the timely provision of community based, "low tech," long-term care services.

In addition, under managed care arrangements, people with disabilities can potentially limit their exposure to high copayments and deductibles. To the extent that managed care systems avoid extensive use of copayments, enrollees are shielded from a financial threat that is particularly difficult for people with chronic conditions who use a lot of care.

However, as we discussed at the beginning of this paper, many aspects of managed care are potentially disadvantageous to people with disabilities. The major concern is that more emphasis on cost savings will translate into greater risk or less care or inappropriate care for the most vulnerable people.

2. Research Completed or Underway

Most of the research on managed care outcomes for people with disabilities has been targeted on the elderly. The Mathematica evaluation of TEFRA HMOs examined the impact of managed care on enrollees with functional impairments. Results indicated that HMOs increased the probability that enrollees in poor health and those with functional impairments were admitted to the hospital and reduced the number of hospital days and home health visits. Quality of care results suggest that these reductions are more likely the result of eliminating

unnecessary services or substituting other types of care than of restricting access (Brown, 1993, HCFA Review).

A study conducted by Clement et al. in 1990 of over 12,000 Medicare beneficiaries reporting joint pain or chest pain in the previous 12 month period found that HMO enrollees were less likely to report seeing a specialist for care, to report that follow-up had been recommended or to report that progress of their symptoms had been monitored.

Shaughnessy et al. (1994) examined longitudinal primary data on health status and service use for a random sample of 1,632 Medicare beneficiaries who received care from 38-certified home health agencies. They compared the cost and quality of home health care across three financial arrangements: HMO-owned agencies, HMO contractual agreements, and FFS systems. Several findings on utilization, cost and outcomes raise important questions about the impact of managed care on elderly recipients. HMO patients averaged fewer visits than FFS patients during the 60-day period following admission; similarly, patients receiving care from HMO-owned agencies had fewer visits than those receiving care from agencies with contractual agreements. While the FFS patients were less ADL and IADL impaired than their HMO counterparts, service use and patient-level costs of Medicare home health care were considerably lower for HMO than for FFS beneficiaries, even after adjusting for the less intense case mix of HMO patients. Further analysis indicated that FFS patients exhibited significantly superior case mix-adjusted outcomes for 14 of 55 measures. This finding held in comparisons between FFS patients and HMO-owned and HMO-contracted agencies respectively. The superiority of outcomes for FFS patients, who typically received more total home health visits and by discipline, suggests that HMO patients may be underserved in this area. At the same time, the absence of observed differences in outcomes for selected types of patients (e.g., those requiring wound care) suggests that HMOs (with lower service intensity) may be more efficient than the FFS sector for certain procedures. The observation that beneficiaries receiving care from HMO-owned agencies are characterized by the lowest cost and most inferior case mix-adjusted outcomes among the three financial arrangements highlights the importance of distinguishing between HMO arrangements and the need for further investigation into a range of managed care practices.

There is also some very limited information on the impact of managed care on disabled children. In a survey of 22 administrators of Medicaid managed care plans serving children with disabilities, McManus and Fox found that access to pediatric specialists, occupational, physical, speech and language therapy was limited; the full range of EPSDT services is not generally provided; and communication between HMO's and special education providers was relatively rare. It is not clear from this study or others how children receiving Medicaid services outside managed care plans or similar children receiving services through private health plans fare in comparison to participants in managed care.

A study conducted by Horowitz and Stein, Yale School of Medicine in 1989 compared benefits offered to children in a small sample of Connecticut HMOs to traditional indemnity plans. The study found that HMOs offered more preventive care; however, both types of plans restricted the services most needed by children with disabilities and chronic conditions; e.g., prescription drugs, durable medical equipment, mental health services.

The National Institute on Disability and Rehabilitation Research (NIDRR) within the Department of Education is focusing its 1995 research agenda on analyzing the effects various gatekeeper arrangements have on access, the degree of consumer choice in managed care plans and the efficacy of existing managed care models serving the disabled. However, results of these studies are not available.

There is limited information on the experience of working age adults with disabilities in managed care arrangements. Allan Meyers and Robert Masters at Boston University School of Public Health conducted a review of seventeen managed care plans serving high risk populations. Evidence presented suggests that insofar as the managed care plans affect costs medical care utilization patterns, or quality, the effects have been limited to subsets of high-risk populations. For example, disabled adults (n=205) participating in an Independent Living primary managed care plan experienced fewer hospital days per person than did those in the comparison group (Meyers, 1989). Another controlled comparison found that chronically ill Medicaid eligible elderly (n=978) had lower Medicaid expenditures and fewer hospital admissions than did those in the comparison group (Meyers and Masters, 1989). Fourteen of the seventeen studies in the review were limited in focus to the elderly and only three studies examined prepaid managed care plans.

The Section 1115 waiver demonstration authority requires that HHS conduct a comprehensive evaluation of the 1115 waivers. Evaluations are currently being planned for five States (Hawaii, Tennessee, Kentucky, and Rhode Island, and Ohio). HCFA has expressed interest in working collaboratively with ASPE and other federal agencies to develop an add-on to their evaluation efforts specifically designed to examine the impact of managed care on people with disabilities.

3. *Directions for Future Research*

What is the baseline of health and long-term care services and benefits provided to people with disabilities and will managed care systems make things better or worse?

What is the impact of managed care on people with special needs? How do people with disabilities rate their satisfaction with coverage, availability of

specialty care, choices of providers, enrollment process, grievance process, ease of obtaining appointments, travel time to provider, and staffing decisions?

How does managed care compare to fee for service plans with respect to morbidity and mortality outcomes for different sub-populations of people with disabilities? maintenance or improvement in functioning? disenrollment rates and consumer satisfaction?

How does managed care affect service use patterns? Is there any evidence that managed care plans prescribe more or less preventive services; access to specialists; is there any evidence they reduce unnecessary hospitalizations; e.g., hospital emergency rooms visits; etc.

Are individuals with disabilities in fee for service plans more or less able to obtain rehabilitation services such as occupational, physical, speech and language therapy? Is there any more (or any less) access to long-term rehabilitation services?

Are particular sub-populations; e.g., children with functional impairments and chronic conditions; working age adults with significant physical disabilities; people with cognitive or mental impairments; better or worse off under managed care arrangements than they would be in the fee for service system? How do service use patterns differ for these populations in comparison to what their experience would have been in a typical indemnity plan?

Are there important cost differences between providing services to people with disabilities under a managed care plan versus a fee for service plan? How do various cost control strategies effect access to care, quality of care, and affordability of care for disabled populations and how do they compare with cost containment strategies in the traditional fee for service system?

How can ASPE, OMC, ORD, OSERS, the Medicaid Bureau, the Veteran's Administration, and other public and private agencies coordinate their research efforts to examine how people with disabilities are faring under managed care arrangements?

C. Targeting Issues

1. Policy Issues

A critical design decision in the development of managed care systems serving people with disabilities is whether to enroll a population which includes healthy and disabled individuals or to enroll an already disabled population. Another important decision is whether enrollment will be mandatory or voluntary for the target population. Identifying the target population is critical because decisions

regarding capitation rate, reimbursement method, scope of benefits, and risk arrangement (full capitation, partial capitation) are made subsequent to selection and identification of risk pools.

Plans have varied in the approaches they have taken. Several new plans now in the development stage are attempting to carve out whole categories of the disabled population; e.g., the District of Columbia's proposal to serve all SSI-eligible children with disabilities under a new managed care system; Rhode Island's CHOICES program which will include all persons with mental retardation and other developmental disabilities under managed care; and, Utah's provision of all Medicaid mental health services through a managed care system. A small number of States are beginning to integrate people with disabilities into their 1115 plans for the general population (Washington and Oregon).

Even within plans that carve out a particular population with disabilities, there is considerable concern regarding the level of severity which can be accommodated. Some approaches are based on the assumptions that the only way to address the financial concerns of a capitated system is to have a mix of participants who have different health care trajectories. For example, the Community Medical Alliance in Boston enrolls a mix of already disabled individuals such as individuals with cerebral palsy who have a relatively flat clinical course, individuals with AIDS who have a progressive course requiring more services later, as well as individuals with spinal cord injury who require more front-loading of services (Meyers, 1994).

Unfortunately, there is little data available from traditional managed care providers in the private sector which would permit us to examine the trade-offs between inclusive models which serve all types of people versus specialized plans. From the viewpoint of the prospective consumer, considerable skepticism has been expressed about equal access to care in a "separate but equal" health care system--many people with disabilities and their representatives fear that care in a "disabled only" system will be severely constrained and of inferior quality.

Another important targeting choice is whether to operate a specific program for a subpopulation of the disabled community; e.g., a separate system for people with mental illness, or people with mental retardation, or the frail elderly etc. or a generic program which includes all people with disabilities.

Generic systems of care have been slow to develop because systems of care coordination, and centralized clinical expertise cannot be readily developed for all groups of people with disabilities. There is concern that a generic service delivery system for all ages of people with disabilities could not adequately address the highly specialized needs of individuals with mental health problems, mental retardation, frail elders, adults with physical disabilities, and children with disabilities.

2. *Research Completed or Underway*

Information about the trade-offs of targeting managed care to a general population versus carving out specialized populations is still in its infancy. HCFA has funded two models of managed care specifically designed to provide a continuum of acute and long-term care services to elderly persons. The Social Health Maintenance Organization (SHMOs) were designed to finance and deliver a comprehensive package of acute, ancillary, short term nursing home and community long-term care services targeted at a representative group of elderly Medicare persons.

In contrast, the PACE program, designed to integrate acute and long-term care services, was initially designed to only enroll elderly Medicaid recipients who are already disabled and at risk of nursing home placement. Limitations on the design of the evaluation of these demonstrations seriously limit the generalizability of findings.

3. *Questions for Future Research*

What are the advantages and disadvantages of designing and implementing specialized managed care systems for people with disabilities versus implementing models which include disabled persons along with the general population?

How does the experience of people with disabilities enrolled in-managed care arrangements along with the general population differ from those who participate in carve outs or specialized plans? Do they have access to more or less services? are they more or less costly? Do they have the same or different outcomes?

How do open managed care plans manage risk for potentially high cost populations in comparison with specialized plans?

What is the experience of managed care systems which attempt to include all people with disabilities in a single organization versus those that serve particular subpopulations? What are the advantages and disadvantages of generic versus specialized plans regarding participation, appropriateness of service coverage and costs?

D. Service Coverage and Organization

1. Policy Issues

In this section of the paper, we highlight some of the design and training issues States and providers face in organizing and operating managed care delivery systems which include people with disabilities.

Coverage of specialized services. From the perspective of the consumer, the success of managed care systems in serving individuals with disabilities hinges heavily on the breadth and flexibility of benefits. From the perspective of the provider, the benefits offered may effect financial risk. An area of particular concern is access to ongoing rehabilitation services (occupational, physical, and speech-language therapies). The debate around health care reform generated serious concerns among disability groups about the definition of these services used in the basic benefit package, the imposition of annual or lifetime caps to limit their use, the role of gatekeepers and primary care case managers in accessing these services and most importantly who should pay for them and how they should be paid for. These same questions pose a significant challenge in current public and private insurance plans; anecdotal evidence suggests that private managed care plans are increasingly limiting coverage for rehabilitation therapies.

Most rehabilitation services offered in private plans are provided for a specific period after an acute medical event such as a car accident or stroke. Yet a variety of long-term rehabilitation services may be necessary to prevent secondary conditions as well as to maintain conditioning and functioning in the years and months following rehabilitation after an acute event. During the health care reform debate, some people with disabilities clearly articulated a belief that if more of these services were covered by managed care plans, there would be an increase in independence and a decrease in rehospitalization rates. It would be desirable to investigate these hypotheses.

Provider reluctance to cover long-term rehabilitation services is based on a lack of information about costs in combination with limited knowledge about what services of what intensity and duration are likely to improve outcomes. This lack of information makes it difficult for providers to accept financial risk.

Integration of health services and long-term supports. A second key design issue in organizing managed care systems for people with disabilities is the extent to which and how long-term care services should be integrated with acute care. People with significant disabilities may need access to both acute care services and long-term supports such as personal assistance services...sometimes for the remainder of their lives. In some cases, these supports are successfully provided by family members and other informal caregivers. However, most families are not able to manage the burden of providing intensive services; e.g., 24 hour supports

for their adult family members for an extended period. Access to personal assistance services may be the prerequisite for a working age person with a disability to hold a job, be self supporting, raise a family and otherwise participate in community life.

Managed care models that offer and coordinate transitional and long-term care services, in addition to acute care are sometimes referred to as integrated service delivery models. They have the potential to cover or to coordinate a wide range of health and supportive services. To the extent they can control access to acute and long-term care services, they also have the potential to limit the cost shifting that now goes on between hospitals, nursing homes and community based services. To the extent that full control of a comprehensive array of services permits the substitution of lower cost more appropriate services for higher cost care, savings to the entire health care system may accrue.

Most experts agree that there is extremely limited experience to guide the development of successful models of integrated care. Models developed to date range from vertical integration efforts which attempt to consolidate all services under a capitated arrangement within a single delivery system to network arrangements where providers attempt to coordinate services on behalf of an individual across a wide range of settings.

There are a significant number of administrative, financial, and clinical barriers to creating integrated system of care for people with disabilities. These barriers include: lack of financial incentives, difficulty in establishing capitation rates, reorganizing medical structures traditionally bifurcated around acute medical and long-term care service lines, developing new clinical pathways, an inability to predict potential expenditures and risks associated with integrating care, and resistance from State bureaucracies to pooled funding streams.

Developing a Manned Care Workforce. A third design issue in organizing and delivering managed care systems for people with disabilities--and one that has received very little attention--is the development of a workforce that is trained in how to address the full range of care needs of the consumer (and family) and how to coordinate efforts to achieve this goal. Graduate medical education, nursing, social work, pharmacy and therapy programs have not tended to focus on the interdisciplinary needs of people with disabilities, and few models of service delivery have adopted such an approach. The field of geriatrics provides a framework that may be useful in designing educational curricula and practice guidelines for serving the "under age 65" as well as the elderly population in that it is devoted to the care, treatment, and rehabilitation of older persons, as well as health promotion and disease prevention (Butler, 1992). Geriatrics requires comprehensive assessment and service delivery, encompassing social and behavioral as well as medical aspects of care, and emphasizing a team approach to caring for patients.

2. *Research Completed or Underway*

Coverage of Specialized Services. Little is known about the experience of managed care plans in covering and paying for specialized services like rehabilitation or including physicians who specialize in treating people with disabilities in their provider network.

The National Institute of Health within the Public Health Service is currently interested in developing a research agenda around medical rehabilitation outcomes research. NIDRR is examining reimbursement models for inpatient rehabilitation care.

The Health Services Research and Development Service within the Department of Veterans Affairs is conducting two studies related to long-term rehabilitation services. The first focuses on the effect patient-selected outcome measures have on the percentage of patients who are successful in achieving their rehabilitation treatment goals. The second focuses on whether the provision of ongoing primary care services for inpatients discharged from the hospital can reduce rehospitalization rates.

Carl Granger and others at American Academy of Physical Medicine and Rehabilitation and American Congress of Rehabilitation Medicine have created a set of Functional Independence Measures (FIM) to develop a patient classification system to determine categories of need for rehabilitation services. This classification system is the first prospective payment system of its kind that uses data from the Uniform Data System along with clinical judgement to classify people in need of medical rehabilitation services. Such systems have the potential to highlight who needs long-term rehabilitation services, and to justify the payment of such services for groups of individuals with disabilities.

Margaret Stineman at the University of Pennsylvania Medical Center has developed and refined patient classification systems and case mix measures that can be used in calculating hospital reimbursement rates for elderly people with physical disabilities. These systems could potentially be used in prospectively estimating the resources needed to care for people within managed care structure.

The National Chronic Care Consortium has assembled a task force led by Cathy Michaels of Carondelet Health Care in Tucson to develop a risk identification instrument that will help providers to identify and manage patients who are at high risk of using extensive and costly services. This instrument will identify risks for specific conditions and interventions, and will include tools to assist providers in identifying risk.

Integration of Care. Most of the research in this area has targeted the frail elderly. HCFA has sponsored two pioneering initiatives over the past ten years to

develop managed care arrangements which integrate acute, chronic and long-term care for the elderly (described earlier in this paper)--the SHMOs and PACE.

The success of the SHMOs in achieving an optimum integration of acute and long-term care services has been questioned by several studies (Newcomer, 1990; Harrington 1993; Manton 1994). While SHMOs clearly succeeded in offering long-term care services to their members, these studies conclude that they failed to achieve a well-coordinated system of care with acute and chronic medical services. Harrington identified the following types of limitations: lack of communication between physicians and SHMO case managers; lack of understanding by physicians of the long-term care benefits provided by SHMOs; few practitioners trained in geriatrics; insufficient attention to identifying and treating medically at-risk members.

The PACE organization and management model appears to reinforce a high degree of coordination between acute and long-term care services. A multidisciplinary team consisting of a nurse, social worker, physician, and others is responsible for assessing each participant's needs; developing plans of care including in-home, day health and medical services; and on-going monitoring. Considerable staff time is devoted to staff interaction. The impact of this type of model on participant outcomes has yet to be determined. It is clear that the PACE sites have experienced considerable turnover of physician staff. According to an analysis of PACE operations (Kane, 1992) the demands for practice in a very different model have made recruitment and retention of physicians in PACE sites difficult.

The Mental Health Services Program for Youth (MHSPY) is a special initiative sponsored by the Robert Wood Johnson Foundation to develop seven integrated systems of care for children with severe mental, emotional, and behavioral disturbances. Using prepaid capitation ranging from \$1,600 to \$3,600 per member month, these systems provided a flexible array of health, mental health, education, juvenile justice and social services. Results from the final evaluation of this initiative are not available.

Community Medical Alliance (CMA) in Boston developed an integrated, fully capitated system of medical, health, and social services for some of the most costly and medically complex subpopulations of Medicaid's SSI population including persons with AIDS, adults with severe disabilities, and individuals with spinal cord injuries. Initial evaluations suggest cost savings and quality care (Masters, 1994).

The National Chronic Care consortium has assembled a task force led by Alice Kethley of the Benjamin Rose Institute in Cleveland to develop a tool to measure the degree of integration that exists in managed care systems serving persons with chronic care needs. This tool is intended to be used for evaluation purposes

as well as for a "report card" to inform consumers and advocates. A final product is scheduled to be completed by April 1995.

The Maternal and Child Health Bureau within the Public Health Service is conducting numerous State research and demonstration projects aimed at developing new knowledge and approaches to integrated health care systems for children with disabilities. A few of these projects focus specifically on managed care arrangements, the majority focus on coordinating integration efforts between existing providers, hospitals, and specialty care centers.

The Robert Wood Johnson Foundation is funding a series of initiatives to develop integrated care for people with chronic conditions (one of these is a replication of the PACE model targeted on children with disabilities, in South Carolina).

Developing a Managed Care Workforce. A 1987 NIA-sponsored Consensus Conference on geriatric assessment indicates that under certain conditions this technology can lead to improved diagnosis and treatment outcomes. NIA sponsored a randomized, controlled prospective study, scheduled for completion in January 1995, comparing geriatric assessment and treatment planning with usual community medical diagnosis for 442 subjects. Preliminary analysis indicates that geriatric assessment units were significantly more likely to identify and treat cognitive impairment, depression, and incontinence than were community physicians. Identification of these prevalent problems may lead to treatment that can reduce morbidity and improve the quality of life of older adults and their families. According to data from caregiver interviews, family caregivers were significantly less likely to experience increase in burden over time than caregivers of patients seen by community physicians (McDowell et al., 1994).

The On Lok model (and the PACE replications) is perhaps the best example of a managed care arrangement that employs this philosophy. The team, consisting of nurse, social worker, physician, and others, is responsible for assessing each participant's care needs; developing individualized plans of care; delivering and/or arranging delivery of services; and ongoing monitoring of quality, costs, and treatment results. Effort is made to enlist the paraprofessional as well as the professional staff in the discussions of consumer status and change (Kane et al., 1992).

There is currently a shortage of geriatricians and psychiatrists in the United States as well as a dearth of training programs that have an interdisciplinary focus. Reuben (1992) has emphasized the need to make careers in geriatrics more attractive, including eliminating financial disincentives and dispelling the myths of ageism. These concerns are applicable as well to the development of a well-trained and knowledgeable workforce that will be able to meet the diverse needs of younger populations.

3. *Future Directions for Research*

Service Coverage and Long-Term Rehabilitation

Which specialized services; e.g., personal assistant, rehabilitation, mental health, dental care, home and community services, transportation etc. do managed care plans need to provide to effectively serve people with disabilities?

What role do gatekeepers and case managers play in coordinating the range of services needed by people with disabilities?

How do HMOs and other managed care plans arrange for access to specialized care? To what extent do they refer people with disabilities to specialists outside the plan?

How many people with what characteristics now receive long-term rehabilitation and other specialized services and from what payment sources? How does payment source effect quality and cost?

Which managed care models; e.g., staff and group HMOs, PPOs, open-panel HMOs) provides greatest accessibility to specialty providers? Why?

To what extent do managed care plans favor more familiar (and potentially more costly) medical services over home health care and rehabilitation services with which they are less familiar?

Can we predict who will need specialized services, what types of services they will need and for how long?

How can specialized services including long-term rehabilitation services be incorporated into capitation models without jeopardizing the plans financial viability?

Which are the most cost effective settings for providing rehabilitation services? How does this vary based on consumer characteristics?

How can the benefits of long-term rehabilitation be determined?

Integration of Care

Can/should both acute and long-term supportive services needed by people with significant disabilities be integrated into a single, consolidated managed care arrangement or only medical and health related services? If all services should not be integrated, how should the acute and long-term care support systems be linked and coordinated?

What models of integration are most promising and how does this vary depending on the nature of the population of people with disabilities to be served? What barriers to integration must be removed for it to be successful?

What differences are there in outcomes and consumer satisfaction when services are integrated vertically versus through networking strategies?

What are the risks and advantages of building integration efforts off of existing administrative structures such as Medicaid, aging networks, Title V, versus creating new authorities?

What barriers exist in the development of specialized integrated care systems for children with disabilities, working age adults with physical disabilities, the dually eligible, the MR/DD population and how can they be addressed?

Developing a Managed Care Workforce

What is the supply of service providers who understand the needs of individuals with disabilities or who provide specialized services, such as rehabilitation or assessment? Is the supply adequate to meet demand? How large is the pool of physicians and ancillary personnel who are trained in or experienced in providing health services to special needs populations? How did they get involved in specialized care? What steps are necessary to increase the pool of providers who are able and willing to treat people with special needs?

E. Financing and Reimbursement

1. Policy Issues

Financial incentives which would encourage providers to include people with significant disabilities in managed care are largely lacking in today's system. The result is that managed care plans attempt to select in "good risks" while avoiding bad ones. Providers who do encourage the enrollment of disabled individuals in plans that are fully capitated face a number of risks. First, there is little empirical basis for predicting the added costs (if any) of serving a population with disabilities. Under capitation arrangements where the provider is at risk if costs exceed the capitation payment, this is a large hurdle. To complicate matters further there are huge variations in the service use patterns of even people with similar levels of disability. To the extent that a provider does try to cover more high risk populations in private plans, premium rates must be adjusted or the plan could end up losing money. Two problems then face the provider. First, there is little guidance from past experience about how to set rates in such a way as to reflect potential costs. Second, if higher premium rates are charged, more healthy participants are likely to opt for lower cost plans, leaving the plan financially vulnerable.

Two types of financial incentives have been developed to try to address the special problems of incorporating high risk populations into managed care arrangements: Risk Sharing and Risk Adjustment.

Another critical issue related to financing of managed care for individuals with disabilities is the question of "who pays?". There are multiple segregated sources of financing for health care for people with disabilities--some specialized, others generic health care payers. How can these diverse financing streams be combined to deliver appropriate managed care systems? An example of a combined system is the approach currently being tried in five counties in Minnesota, which combines Medicare and Medicaid to provide managed health and long-term care services to the elderly.

Risk Sharing. The first major question in need of resolution relates to how risk can be shared between payers and providers, especially in the context of integrated funding streams. We need to find ways to spread the risk by specifying who pays for what and outlining whether and how States can offer reinsurance plans.

The second major risk sharing question concerns risk sharing between plans and providers. One way to protect providers against the risks associated with fully capitated plans is to permit them to develop separate contracts with certain providers outside the plan who are willing to share the risk. For example, under TEFRA risk contracts, HMOs may develop separate contracts for separate services and providers even though the care may be for the same person and addressing the same conditions. While separate contracts may limit some of the risk of the managed care plan by shifting it to other providers it may also result in more fragmented care and potentially conflicting care and cost management goals.

Many States have developed partially capitated programs to encourage managed care plan providers to serve high risk populations. There are two type of partially capitated programs, either acute care programs in which outpatient services are capitated or specialty carve-out programs, where specialty set vices are capitated. Partially capitated programs, in theory, should provide incentives to integrate services around a particular set of services such as acute care or long-term care. Partial capitated programs may include reinsurance or stop loss provisions to insure that providers are protected from losses above a certain amount.

In addition, the Federal Government has allowed States to carve out coverage entirely of those high cost subpopulations for whom risk sharing arrangements are difficult to create due to tremendous variability of costs within a particular group (e.g., mentally ill, children with disabilities, MR/DD, dually diagnosed, severely physically disabled). A substantial portion of individuals in these groups

require a range of health related service much broader than those generally classified under acute care such as ongoing maintenance therapies, personal assistance services, durable medical equipment, and assistive devices.

Risk Adjustment. Risk adjustment is the process of modeling and calculating the expected expenses of one class of person or persons in a plan relative to others. Risk adjustment methodologies attempt to ensure that plans with high risk enrollees are not inappropriately penalized and those with low risk enrollees are not inappropriately rewarded.

Progress in risk adjustment for people with disabilities has a long way to go. We lack the kinds of actuarial information we need to predict service use and cost. It is made more difficult because of the tremendous variation in the characteristics, service needs and utilization patterns of persons with disabilities.

Research suggests that the predictive validity of risk adjusters traditionally used such as age, sex, Medicaid status, nursing home status, and geographic adjusters explains only a small proportion of the variation across individuals (MPR, 1993). Because of this fact, alternative risk adjusters have been proposed which include clinical information, prior utilization data, self-reported information, functional status measures, and mortality adjustment measures. High collection costs, unreliable information, and issues with patient confidentiality often prevent such information from being gathered.

Researchers agree that even with substantial improvements in the collection of risk factor information and modeling techniques for people with disabilities, risk adjustment methodologies will only account for a small degree of variability (Luft, 1994). In the absence of the "perfect risk adjustment model" many managed care organizations serving the disabled and non-disabled have relied on prior utilization and cost data to estimate service expenditures. However, such data often fail to capture physical and cognitive measures of functional capacity which are essential to estimating potential care costs in certain populations. Until or unless risk adjustment methods emerge which protect providers from financial loss due to serving high risk populations, risk selection practices designed to weed out risk will prevail.

Many States have experimented with insurance market reforms to provide incentives for plans to serve people with disabilities while simultaneously protecting the plan from high risk. Creating subsidized condition-specific high risk pools, mandatory and voluntary reinsurance pools, community rating, and purchasing cooperatives are examples of attempts to control for risk despite the lack of adequate risk selection criteria.

It may be possible to manage risk by structuring plan operational characteristics; e.g., should people be randomly assigned to plans or be allowed to sign up for

the plans of their choice? Some experts suggest that random enrollment should equally distribute risk among programs.

2. *Research Completed or Underway*

A National Chronic Care Consortium task force led by Michele Lepore of Henry Ford Continuing Care Corporation in Detroit is attempting to develop a risk contracting model to assist in the development of acute and long-term care managed care systems serving persons with chronic illness. The model intends to address management issues, gatekeeping arrangements, and risk management contracting.

An important component of the Medicaid Working Group is Medicaid risk adjustment. The Community Medical Alliance in Boston, serving individuals with spinal cord injury and AIDS, is experimenting with new severity of impairment measures, and functional status measures to improve their ability to accurately predict future service use and cost. While these models are specific to particular disabilities such as spinal cord injury and AIDS, learning the methods by which we can develop similar clinically descriptive analog can potentially benefit other managed care plans serving people with disabilities.

Randy Ellis at Boston University is currently developing expanded diagnostic cost groups for disabled individuals in managed care systems. Using a sample of 680,000 Medicare beneficiaries, he is attempting to develop a classification system for inpatient and outpatient medical expenditures. While individuals with disabilities such as HIV/AIDS, Diabetes, SCI, TBI, Renal Dialysis are included; others such as children with disabilities are missing from this study.

James Fowles and others of Johns Hopkins University recently conducted a side-by-side comparison of claims-based and survey-based risk assessment methods for approximately 6,000 adult and elderly HMO enrollees in Minnesota. Such studies would be extremely useful in managed care plans serving subpopulations of the disabled community.

3. *Research Questions*

What are the advantages and disadvantages of various risk sharing arrangements? How do different risk sharing mechanisms affect the willingness/capacity of the managed care provider to insure access to a broader range of services including rehabilitation and specialized services? to coordinate services across settings?

How do different risk sharing arrangements affect the participation of people with disabilities in managed care? their service use patterns and their costs? their satisfaction with the plan?

What new risk adjustment strategies, or insurance market reforms, are being developed to offset the incentives of managed care providers to select out potentially high risk persons? Are some approaches more promising than those used to date? why?

Are current risk adjustment methods sufficiently sensitive to compensate for variation due to disabling conditions, or severity of impairment?

To what extent can insurance reforms such as subsidized high risk pools, community rating and purchasing cooperatives designed to promote cross-subsidization of high and low risk groups promote the development of managed care serving the disabled? What barriers will not be overcome by insurance reform alone?

When is reinsurance an appropriate strategy; what potential does it service for different managed care arrangements serving people with disabilities?

F. PAS Financing and Service Delivery System Infrastructure

1. Policy Issues

The principal policy issue which faces both the proponents and critics of managed care is the extent to which its emphasis on cost controls reduces the quality of care provided. For high risk populations this is an especially serious threat.

The regulation of managed care plans is uneven. With the passage of the Federal HMO Act in 1973, managed care plans are responsible for a set of quality standards through the process of Qualification or Certification in order to contract with the Federal Government to enroll people covered by Medicaid and Medicare. However, State bureaucracies responsible for such oversight and regulatory decisions (i.e., Department of Insurance and Department of Health) may overlap and duplicate one another, as well as leave unaddressed gaps. Fragmented regulatory procedures have the potential to place people with disabilities at risk. For example, managed care systems which integrate a continuum of acute and supportive services are currently outside the purview of most State regulatory authorities.

Accreditation is the main process by which States attempt to regulate quality. Similar to State Certification processes, State vary in their degree of regulation and oversight over the process for determining the qualification of provider networks serving people with disabilities. In some States accreditation reviews are required to be conducted and the results are made available within the States, in other States accreditation is a condition for licensure.

2. *Research Conducted or Underway*

How should quality of care be measured for people with disabilities? (i.e., enrollee satisfaction, actual versus expected mortality rates, medication compliance, rates of preventable rehospitalization, etc)? How can these indicators be applied?

How can new indicators be developed to address the issues of consumer empowerment and quality of life?

What methods of regulation, oversight and monitoring are most effective for people with disabilities?

To what extent can expansion on HEDIS standards to include standards of care for people with disabilities assist in State regulatory efforts?

What are the training needs of providers in managed care systems-serving people with disabilities? What do people with disabilities identify as the critical skills needed by providers?

How do private managed care systems provide continuing education and training to providers? Can public managed care systems similarly use such efforts?

What special training is provided to primary and specialty providers who serve a disproportionate share of people with disabilities?

In what types of managed care arrangements is accreditation as a condition of licensure overburdensome, and in what conditions is it most appropriate to improve quality for people with disabilities?

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**FOCUS GROUP ON MANAGED CARE SYSTEMS FOR
PEOPLE WITH DISABILITIES:
Summary of Discussion and Written Comments
From Expert Meeting**

December 5, 1994

I. ACKNOWLEDGEMENTS

We wish to thank the thoughtful and enthusiastic participation of the experts who gave generously of their time and talents. They have played a key role in representing the views of researchers, advocates, and service providers to ASPE in the development of its research agenda on managed health care systems serving people with disabilities.

We wish to especially thank the many experts who assisted in the preparation of the issue paper used for the meeting.

II. INTRODUCTION

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) sponsored a expert meeting on research related to managed care and people with disabilities. The meeting was hosted by the Office of Disability, Aging and Long-Term Care Policy (DALTCP) at the Quality Hotel Capital Hill in Washington, D.C. on December 5, 1994. This day long meeting was part of an ongoing series of three expert meetings on disability topic areas that DALTCP is considering for inclusion in its research agenda. National experts who are academicians, researchers and service providers versed in the topic area were brought together with representatives of related federal agencies. Their charge was to review the implications of the movement toward managed health care for people with physical and mental disabilities; and flesh out a program of research and demonstration which improves our understanding of the impact of managed care on people with disabilities and how it can become more responsive to their needs. In particular, we asked their help to: (1) assess the benefits and risks that managed care may pose to people with disabilities, (2) identify key policy concerns that the Federal Government and States must consider in designing managed care initiatives for people with disabilities; (3) highlight relevant research that has been done or is currently underway; and (4) suggest policy relevant projects and studies which ASPE might pursue.

Welcome

Mary Harahan, Director of DALTCP's Division of Long-Term Care Policy, welcomed the participants and provided a policy context for their deliberations on developing a research agency on managed care for people with disabilities. She explained that DALTCP's interest in managed care arises from our participation in the health care reform debate and the aftermath of that debate. She explained that in, that debate we talked with many people from the disability community who told us much about their fears and concerns of people with disabilities entering the managed care arrangements. Key concerns included selection bias, access to specialty care, access to a broad range of rehabilitation services, appropriately trained providers and a broad range of preventive services. Additionally, she highlighted the urgency of our research agenda in light of the dramatic growth of States requesting Medicaid waivers which allow them to mandate the enrollment of Medicaid recipients in managed care arrangements as well as the growth of managed care within the private sector.

Ruth Katz, a program analyst within DALTCP, then framed what we believe to be critical policy areas and related research issues around managed care and disability. These policy areas include (1) functional and demographic characteristics, (2) the impact of managed care on people with disabilities, (3) targeting, (4) financing and reimbursement issues and (5) quality issues.

III. RECOMMENDATIONS ON KEY RESEARCH ISSUES

A. Functional and Demographic Characteristics

Experts believed, in general, that there was a lack of data and information on innovative State managed care arrangements serving people with disabilities. Suggested studies were recommended to include a distinction between administrative type, cost sharing arrangement, clinic service indicators, benefit packages, varying medical courses, functional impact, population served (physical and emotional characteristics) and programs targetting specific disabled populations. In addition, some panelist recommended clearer distinction between administrative arrangements, finance mechanisms, clinical models and provider relationships that target specific disabled populations.

B. Impact of Managed Care

Repeatedly, many experts suggested that ASPE focus its research efforts on outcome measures that will allow a better understanding of how the disabled are faring in managed care arrangements. However there was disagreement over the type of outcomes to use, and whether or not those outcomes truly reflect quality, or access. For example, does increased access to a specialty provider necessarily represent an improvement in care? Do fewer home health visits represent favorable selection, improvement in pre-discharge care, a limited benefit package and/or an impact of cost containment strategies.

Is improvement of managed care based more on better case management or a reduction in the utilization of unnecessary technology?

In addition, many panelists recommended the need for better indicators of outcomes. Long-term care researchers have had little agreement in the past over appropriate outcomes. Some basic outcome measures were recommended for future research studies such as: physical functioning, social functioning, consumer satisfaction, cognitive functioning, affect, morbidity, mortality, etc. Some panelists suggested that future research move toward condition specific outcome measures (such as pressure sores and PCP for PWAs) rather than trying to develop clinical performance measures or outcome measures accross heterogenous medical conditions.

Other recommendations on the impact of managed care on disabled populations included: (i) studies examining the consequences of incentives to underservice, and how such incentives can potentially take different forms with different populations (e.g., SHMO enrollees versus children with a disability), and (ii) effectiveness studies to

examine stratified groups of people who can profit from knowledgeable primary care case management and/or those who can profit from different type of rehabilitation therapies (including PAS, maintenance therapies, etc).

C. Targetting

The discussion of mandatory enrollment (as is prescribed with 1915 waivers) was discussed throughout the meeting. While most panelists expressed that there is no reason not to impose mandated choices of managed care plans if researchers are confident that the choices are safe and effective, they agreed that they do not currently know that those choices are safe or effective.

Panelists discussed how often pricing always increases for plans targetting disabled populations, and how little research there was on pricing and costs biased on specialized systems of care. Such research, that would examine cost-related subgroups with clinically and prognostically related characteristics, could potentially make it attractive for insurers and providers to enter sub-specialty markets. Other researcher posited that while their is a tendency for insurers to price disabled subgroups separately, they still are reluctant due to lack of accurate cost or utilization information.

Panelists recommended a series of preliminary research steps necessary prior to cost, outcome, or utilization review studies. It was suggested that a task force of providers and researchers be assembled to develop a useful and meaningful taxonomy or topology of people with disabilities so that specialized tracking systems can be developed. Specific questions to be answered were: what are the services provided to disabled? who are the meaningful subgroups? how can researchers tie these subgroups to utilization and cost data? how do we define outcomes? What are the clinically meaningful outcomes for subgroups of people with disabilities? How can researchers track these outcomes and encourage managed care plans to its own collect baseline data on people with disabilities? Natural partners for such research were suggested, including: IBM, Federal Employees Health Benefit Plan, Kaiser, California Employee Retirement System (CALPERS) (the 30 HMOs in California), etc.

D. Financing and Reimbursement

Panelists recommended further research to better predict the costs of clinically related groups of disabled populations. Many agreed that research on reimbursement categories, based on Carl Granger's functional independence measure work, was an important step in this direction as should be continued. However, some researchers pointed out that this will be extremely difficult within subgroups of disabled individuals with great variability in severity and utilization of services. Some researchers pointed out that variation in costs and utilization is not due to patient characteristics alone, but also to provider characteristics and payor/plan structure.

A few researchers suggested that it would be extremely useful to unbundle (at even a descriptive level) the variables that are contributing to total costs such as co-morbidities within a subgroup of people with disabilities--examining how many of those co-morbidities are retractable and treatable.

Panelists suggested payment-oriented research that would examine how providers are currently being reimbursed to provide primary care and specialty services to people with disabilities.

E. Service Coverage and Organization of the Delivery System

Many researchers pointed throughout the meeting at the dramatic rise in primary care case management (PCCM) because of the lack of State infrastructure that currently exists to support the development of managed care arrangements. Some panelists recommended research to promote the development of a provider infrastructure, and to better understand why some doctors are more inclined to work with disabled populations. Along this line, panelists suggested contacting doctors at Evercare, who have developed contracts with specialists who train primary care practitioners in ways of feeling more comfortable in caring for people with disabilities.

Along similar research lines, panelists questioned the technology that providers use to assess if they are conducting the appropriate intervention at the correct time. Such technology could include practice guidelines for providers caring for disabled specific subgroups, performance review, disability specific instrument development, best practices guidelines, prior approval mechanisms, specialty training, annual or semi-annual registration, or interagency mechanism of tunnelling information back to physicians. The emphasis here is on testing technology within managed care plans for providers, not financing mechanism or cost containment strategies.

Other researchers suggested research on various gatekeeper arrangements in relation to rehabilitation within different settings (acute, subacute, home).

Panelists suggested further research to develop performance measures specific to caring for people with disabilities. HEDIS chronic care measures were recommended as a good start, but many of their limitations were pointed out.

Some panelists recommended studies comparing outcomes, access, benefits, cost and utilization between staff and group model HMOs serving people with disabilities. Peter Fox and the Robert Wood Johnson Foundation will potentially study patients with three clinical conditions and tracking what happens to them over time.

Other panelists suggested research examining advances in technology such as prosthetics, orthotics, indwelling robotics, communication devices, cognitive and sensory aides and retrofitting. Specific questions such as who is going to pay for them,

how much will their costs vary, to what degree does customization effect success are important research questions that have yet to be answered.

Panelists also recommended studies on the amount of in-service training that occurs in different managed care arrangements for people with disabilities, including the education for unpaid providers. HERSA within SAMPSA is currently conducting public sector provider education.

F. Quality Assurance

Panelists varied in their recommendations for quality assurances. Some believed the best strategy included: (i) the need for improved instruments and methods to understand in a clinically meaningful way how to better serve a disabled population, (ii) identification of delivery systems that facilitate or provide efficacious treatments for disabled populations, (iii) redefine what we mean by quality--developing medical guidelines and population pathways, and (iv) rationalize what are quality assurance mechanisms mean. Other panelists believed that quality assurance instruments, such as report cards, were meant for the low risk populations, not for high risk populations. They recommended quality assurance research that focused on both generalized measures (as outlined in the paper) as well as condition specific measures (e.g., the extent to which children stay in school, employment attainment for MR/DD, access to and utilization of other ancillary services, etc.).

Panelists agree that the development of baseline measures of quality for people with disabilities is extremely important to create; however, the panelist could not decide precisely what measures would be reflective and accurate accross differently disabled individuals.

Some panelists recommended qualitative studies on what physicians understand chronic illness to be, and subsequently how they define quality in their practice, technical competencies would be useful to examine in such a study.