

TAB 2:

INTRODUCTION

INTRODUCTION

Welcome to the conference and Harbournowne! We are glad that you arrived safely, and look forward to working closely with you over the next few days.

The conference, *Beyond the Water's Edge: Charting the Course of Managed Care for People with Disabilities*, is intended to draw together and present empirical research findings on the experience of people with significant disabilities in managed health care, particularly how managed care plans affect access to care, service use, quality and cost.

This conference will be successful if it achieves three related goals:

- Educating a large group of academic researchers, government policy experts, state officials, health plan and consumer representatives regarding available research evidence on the effects of managed health care on the lives of people with disabilities.
- Identifying gaps in the knowledge base that need to be filled if managed care organizations are to learn how to effectively serve disabled populations.
- Stimulating new research to support more efficient and effective strategies for the financing, organization and delivery of health and long-term care services to people with significant disabilities.

This notebook contains an overview paper for the entire conference, followed by track papers highlighting what we consider to be some of the interesting questions and issues to guide the group in break out sessions. In addition, we have included presentation materials from authors, separated by track and session.

Many of the data in this notebook are new, and as such, have not been published yet. New data contained in this notebook should not be distributed unless the author personally agrees. The materials are compiled merely for purposes of discussion and debate. It is hoped that much of the new data will be included in the thematic issue of *Health Affairs*, on managed care and people with disabilities, that will be an eventual product of the research and evaluation data presented at this conference.

Whereas we have tried to make sure that all information is correct at the time of printing, we understand that there will be additional changes that will need to be made. Please forward corrections to us at our fax number 202-401-7733 so that future copies will be correct.

We hope you enjoy your two days in Harbournowne. If there is anything we can do to make your stay more comfortable, please do not hesitate to let us know.

CONFERENCE OVERVIEW-- MANAGED CARE AND PEOPLE WITH DISABILITIES: DEMOGRAPHICS, TRENDS AND POLICY ISSUES

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DRAFT: Citations will be included in the final version of this paper

I. INTRODUCTION AND BACKGROUND

This paper sets the stage for a national conference on managed care and disability sponsored by the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services. The conference is intended to draw together and present empirical research findings on the experience of people with significant disabilities in managed health care, particularly how managed care plans affect access to care, service use, quality and cost.

The conference will be successful if it achieves three goals:

- Educating academic researchers, government policy experts, state officials, health plan and consumer representatives regarding available research on the effects of managed health care on the lives of people with disabilities.
- Identifying gaps in the knowledge base that need to be filled if managed care organizations are to learn how to effectively serve disabled populations.
- Stimulating new research to support more efficient and effective strategies for the financing, organization and delivery of health and long-term care services to people with significant disabilities.

II. PEOPLE WITH DISABILITIES: WHO ARE THEY?

Defining disability for purposes of managed care is complex. The number, age composition, and other characteristics of people with disabilities vary greatly depending on how disability is defined. In addition, while many people have chronic illnesses as a result of a particular health condition, only a subset will experience disability as a result.

First, let's look at alternative ways to define disability. According to the recently released 1994 Disability Supplement from the National Health Interview Survey (NHIS), there are as few as 11.6 million people of all ages with disabilities (if only long-term care needs are used) and as many as 59.4 million (if all measures are used). (See Table 1.)

Of the literally hundreds of ways to define disability, four major disability definitions are examined here. All disabilities result from a physical, mental, or emotional health condition. These four major definitions all refer to disabilities which are expected to last at least a year. It is possible for many overlaps to occur among the definitions. In fact, a sizable number of people are disabled according to all four definitions. The four major disability definitions are:

- Functional: Either (1) limitations in or inability to perform a variety of physical activities (i.e. walking, lifting, reaching); (2) serious sensory impairments (i.e. inability to read newsprint even with

glasses or contact lenses); (3) serious symptoms of mental illness (i.e. frequent depression or anxiety; frequent confusion, disorientation, or difficulty remembering) which has seriously interfered with life for the last year; (4) long-term care needs (i.e. needing the help of another person or special equipment in order to perform basic activities and instrumental activities of daily living); (5) use of selected assistive devices (i.e. wheelchairs, scooter, walkers); (6) developmental delays for children identified by a physician (i.e. physical, learning); and/or (6) for children under 5, inability to perform age-appropriate functions (i.e. sitting up, recognizing walking).

The functional definition of disability is the most widely accepted and the most useful for many policy and research purposes. According to the functional definition, there are 47.6 million Americans with functional disabilities: 6.1 million children, 25.7 million working-age adults, and 15.8 million elderly. 11.6 million of these individuals have disabilities severe enough to require long-term care. Those who need long-term care include 400 thousand children, 5.3 million adults aged 18-64 and 5.9 million elderly persons.

- Work Disability: Refers to limitations in or the inability to work as a result of a physical, mental or emotional health condition. About 16.9 million working-age adults (18-64) reported a work disability.
- Perceived Disability: As stated in the ADA, includes those individuals who either reported that they considered themselves to have a disability or that others considered them to have a disability. Slightly over 19 million Americans (2 million children, 11.1 million adults aged 18-64, and 6 million elderly) are perceived by themselves or others as having a disability. The definition of perceived disability is useful for civil rights purposes. It is interesting to note that this figure is considerably lower than the number with functional or work disabilities.
- Disability Program Recipients: Includes persons covered by SSI, SSDI, Special Education or Early Intervention Services, and/or disability pensions. Altogether, 13.8 million people, including 4.7 million children and 9.1 million adults aged 18-64, received benefits from disability programs. Since these programs are not targeted on the elderly, those aged 65 or over were not included in these counts.

If all four definitions are used to define disability, the number of disabled persons in the U.S. increases from 47.6 million people to almost 60 million, of whom 9 million are children, 34.2 million are working-age adults, and 16.2 million are elderly.

The likelihood that a chronic health condition will result in disability varies greatly. In general, the more common a chronic condition, the lower the risk of a disability.

The most common chronic health conditions relate to mental health, mental retardation, cognitive impairment and learning disability.

- Mental Illness: According to the Disability Supplement, of the 23.5 million Americans reporting a mental illness, 5.1 million or 22 percent have long-term care needs, 9.9 million or 42 percent do not need long-term care, but have other functional disabilities, and 8.4 million or 36 percent have no functional disabilities at all.
- Mental Retardation and Other Developmental Disabilities: Of the 6.6 million people reporting mental retardation or a developmental disability, 2.7 million or 41 percent need long-term care, 3 million or 45 percent have a functional disability (but do not need long-term care), and 900 thousand or 14 percent have no functional disabilities.

- Cognitive Impairments: Of the 5.1 million adults who report either Alzheimer's disease, other related dementias, or who report serious problems with confusion, orientation, or memory, 2.2 million or 43 percent need long-term care, 2.4 million or 47 percent have functional disabilities but do not need long-term care, and 500 thousand or 10 percent have no functional disabilities.
- Learning disabilities: Of the 4.5 million people under age 65 who report a learning disability, 900 thousand or 20 percent need long-term care, 2.1 million or 47 percent have a functional disability (not including long-term care), and 1.5 million or 33 percent have no functional disabilities.

NOTE: All numbers in this Section are ASPE/DALTCP estimates from the 1994 Disability Supplement of the National Health Interview Survey.

TABLE 1: PREVALENCE OF DISABILITY USING ALTERNATIVE DEFINITIONS: 1994				
	Total	Age 0-17	Age 18-64	Age 65+
US Population	259,626,000	70,023,700	158,577,400	31,024,900
DEFINITION 1--FUNCTIONAL DISABILITY	47,601,405	6,099,411	25,675,901	15,826,093
-- With Long-Term Care Needs	11,583,000	392,990	5,332,610	5,857,400
-- Without Long-Term Care Needs	36,018,405	5,706,421	20,343,291	9,968,693
DEFINITION 2--WORK DISABILITY	16,949,000	N/A	16,949,000	N/A
DEFINITION 3--PERCEIVED DISABILITY	19,093,000	1,974,400	11,111,500	6,007,100
DEFINITION 4--DISABILITY PROGRAM RECIPIENT	13,775,000	4,691,700	9,083,300	N/A
DEFINITION 1-(Functional) OR 2-(Work) OR 3-(Perceived Disability) OR 4-(Disability Program Recipient)	59,436,000	9,018,700	34,235,400	16,181,900
<p>NOTES ON DISABILITY:</p> <ol style="list-style-type: none"> 1. Functional disability includes those persons who reported that at least one of the following activities was expected at last 12 months or more. These activities include: (1) limitations in or inability to perform a variety of physical activities (i.e. walking, lifting, reaching); (2) serious sensory impairments (i.e. inability to read newsprint even with glasses or contact lenses); (3) serious symptoms of mental illness (i.e. frequent depression or anxiety; frequent confusion, disorientation, or difficulty remembering) which has seriously interfered with life for the last year; (4) long-term care needs (i.e. needing the help of another person or special equipment in order to perform basic activities and instrumental activities of daily living); (5) use of selected assistive devices (i.e. wheelchairs, scooter, walkers); and/or (6) children's serious broadly defined developmental delays (i.e. physical, learning) mentioned by a physician and (for those under 5) specific delays in development and functioning. 2. Work Disability refers to limitations in or the inability to work as a result of a physical, mental or emotional health condition. 3. Perceived Disability, as stated in the ADA, includes those individuals who either reported that they considered themselves to have a disability or that others considered them to have a disability. 4. Disability Program Receipt includes persons covered by SSI, SSDI, Special Education or Early Intervention Services, and/or disability pensions. 				
<p>SOURCE: ASPE/DALTCP Tabulations from 1994 Disability Phase I Supplement to the National Health Interview Survey, by Michele Adler and Bob Clark in 11/96 for forthcoming publications.</p>				

III. TRENDS IN THE USE OF MANAGED CARE

The concept of managing health care is not novel--primary care physicians, often seen as the central figure in a well functioning, primary care focused health care system--have long been charged with managing or coordinating the full range of health care needs for their patients. And managed care, in its more recent connotations of risk-bearing entities, still has roots back to the early part of this century. What seems heightened is the focus on the use of managed care to control health care utilization and costs, in contrast to other long standing goals of access and quality. Employers cite cost containment as a principal goal. And most State Medicaid activities focused on managed care have similarly been driven by concerns of costs, accompanied to varying degrees by efforts to link cost containment to an expansion of access. The Medicare program has suffered criticism, whether well founded or not, for not more aggressively encouraging beneficiaries' enrollment in health maintenance organizations.

Although most current discussions of managed care focus on health maintenance organizations and other risk-bearing arrangements, managed care runs a spectrum from a physician or other professional serving as a case manager to risk-bearing entities. A variety of arrangements, such as preferred provider organizations and point of service options, as well as activities, such as prior authorization and utilization review, fall in between. The availability of various provider arrangements differs by insurance status--private, Medicaid or Medicare.

Private Sector

The variety of survey estimates available makes it difficult to firmly fix the number of privately insured individuals enrolled in managed care. For example, a 1994 Foster Higgins survey, which includes only employers with 10 or more employees, reported that 42 percent of employees were enrolled in fee-for-service indemnity plans, 27 percent were in preferred provider organizations, 13 percent were in point of service plans, and 17 percent were in health maintenance organizations. Recently, the trend has been toward a continuing decline in fee-for-service enrollment as fewer employers offer that option, and a move from HMO to POS options within managed care.

Surveys consistently show that managed care penetration varies significantly by firm size. For example, in contrast to the Foster Higgins survey, in 1993, firms with fewer than 25 employees had 78 percent of employees in the fee-for-service system, HMOs covered 8.2 percent, with 3.6 percent in point of service plans. The remaining 8.9 percent of employees in small firms were enrolled in preferred provider organizations. Although a significant number of privately insured people remain in the fee-for-service system, little exists that is not managed in some form. A 1991 HIAA study estimated that at that time, only 5 percent of private insurance was not managed through utilization review or similar activities.

Public Sector--Medicaid

Use of managed care in the Medicaid program has grown rapidly in recent years. In 1983, 3 percent of Medicaid beneficiaries were enrolled in managed care. This is in contrast to 1995, when 11.6 million beneficiaries--almost one-third of beneficiaries--were enrolled in managed care. Growth has been particularly rapid in recent years.

Within the Medicaid program, managed care models include primary care case management, as well as prepaid models with full-risk plans, including both HMOs and health insuring organizations (HIOs), and limited risk prepaid health plans. HMOs have been used in the Medicaid program since 1983, while enrollment in primary care case management models began in 1986. By 1995, 63 percent of plans were full risk plans, 25 percent were partial risk plans, and 12 percent were primary care case management.

Although full and partial risk plans are the predominate provider type, a significant number of beneficiaries are receiving care in primary care case management systems. In 1995, 46 percent of enrollees were in full risk plans, 23 percent were in partial risk plans, and 31 percent were in primary care case management.

Enrollment of beneficiaries who are disabled into managed care systems has dramatically increased. As reported by GAO in a recent study, 17 States had enrolled beneficiaries with disabilities in State-wide or pilot prepaid managed care programs on either a voluntary or mandatory basis. (Note that the report excludes enrollment in the PACE project as well as the Minnesota Senior Health Options project, targeted for implementation in January 1997). Enrollment in these States ranged from less than 1 percent to 100 percent of beneficiaries with disabilities. Across the 15 States with available enrollment data, just over 400,000 beneficiaries with disabilities, or roughly 19 percent of eligible enrollees in those States, were enrolled in prepaid managed care.

Most States exclude their beneficiaries who are most vulnerable--those receiving institutional or home and community-based care under 1915(c) waivers--from participating in prepaid managed care. Of the 17 States, 12 States excluded beneficiaries receiving institutional care, both nursing facilities and intermediate care facilities for the mentally retarded. Ten States excluded beneficiaries receiving 1915(c) waiver services.

Virtually all States have excluded the provision of long-term care services within the capitation rate in their State-wide programs. With the notable exception of the District of Columbia's voluntary program serving children and youth with disabilities, most State efforts to integrate acute and long-term care through capitation models have been small scale demonstration projects.

Public Sector--Medicare

By the close of 1995, over 10 percent of Medicare beneficiaries were enrolled in HMOS; most of that enrollment, 8.8 percent, was in risk-based HMOS while 1.9 percent was in cost based plans. The Congressional Budget Office has estimated that 17 percent of Medicare beneficiaries will be enrolled in HMOs by the year 2002.

Enrollment of beneficiaries with disabilities in Medicare managed care is relatively sparse. According to tabulations from the 1993 Medicare Current Beneficiary Survey (MCBS), approximately 100,000 beneficiaries who are under age 65 and are disabled were enrolled in Medicare HMOs, 3.3 percent of this population. Analyses using the 1994 MCBS (the most recent year available) indicated that beneficiaries who are under age 65 and disabled, report functional limitations, fair or poor health status, or report five or more medical conditions are significantly less likely to be enrolled in an HMO. For example, while 33.9 percent of Medicare FFS beneficiaries report one or more ADL, 23.7 beneficiaries enrolled in HMOs report that number of functional limitations. And while 8.2 percent of Medicare beneficiaries in the FFS sector report their health status as poor, only 4.5 percent of HMO enrollees report their health status as poor.

IV. POLICY ISSUES

People with disabilities frequently face significant barriers in obtaining needed health care services. Many lack health insurance. Those who are insured rely heavily on public funding, through Medicare and Medicaid. Within the insured population, many are underinsured due to conditions on coverage such as pre-existing condition limitations. Further, many consumers with disabilities find that the services they need most, such as personal assistance or durable medical equipment, are not covered. Medical necessity criteria create additional barriers. Finally, because people with disabilities are disproportionately poor, out of pocket costs create an impediment to receiving care.

It is in the context of the current health care system for people with disabilities that policy makers are asking--what are the advantages and disadvantages of managed care solutions for serving people with disabilities? Can managed care address any of the significant health care barriers now faced by this population? What specific features of managed care systems appear most effective and how can they be put into practice? How can managed care systems effectively address and prevent problems of access and quality, in a cost conscious manner?

Managed health care arrangements potentially hold great promise for people with disabilities given the emphasis on preventative health care services, care coordination/management, flexibility in service delivery, continuity of care across settings and the ability to reduce or eliminate co-payments and deductibles. At the same time, the economic incentives inherent in managed care, in combination with a lack of knowledge and experience on the part of policymakers, plans and providers regarding how to make managed care work for disabled populations, could be potentially harmful.

The challenges and opportunities facing managed care systems as they expand to cover new, more vulnerable populations such as the SSI disabled and frail or chronically ill elderly Medicare beneficiaries are complex. For example:

- Disabled populations are significantly heterogeneous; definitions of disability are varied and represent vastly different perspectives and policy and service implications;
- The attitudes of disabled people, providers and policy makers about the meaning of disability can be significantly different; many disabled people emphasize what they can do rather than focusing on limitations: public policy tends to focus on identifying limitations as the criterion for receiving assistance;
- Disabled consumers frequently demand control over their own lives and the desire to exercise the maximum degree of choice possible; managed care systems, almost by definition put limits around personal choice;
- People with disabilities frequently need life long assistance from social and supportive services in addition to primary and acute care services; these services are rarely included in a managed care plan's benefits.
- People with disabilities frequently receive health and supportive services from multiple payment sources and programs; managed care models have to address the coordination of services across programs as well as within a single program or insurance plan. This requires the coordinated purchasing of services by payers as well as integrated service delivery by managed care plans.
- Payers, insurers and providers face great uncertainty in trying to calculate the costs and benefits of providing the services deemed most important by the disability community; for example, there is very little conclusive information on the efficacy of home health services, physical therapy, occupational therapy and other rehabilitation benefits, particularly what quantity of such services is necessary to maximize outcomes.

This section of the paper identifies the key policy questions which need to be addressed in defining how managed health care arrangements should relate to disabled populations. The underlying question is: can managed care work for people with disabilities? If the answer is yes, what are the special considerations in structuring financing, service delivery, quality assurance, and information systems so that people with disabilities have the best experience possible and costs are controlled? Through this paper and the

conference for which it was prepared, ASPE seeks to apply research findings to the formulation of the answers.

As we contemplate these policy questions, it is important to do so from several perspectives--most notably, that of the consumer, policymaker, individual provider, managed care organization and of course, ultimately, the taxpayer. All have a stake in identifying issues and answering questions, but the issues of concern and the favored approach will vary considerably depending on point of view and the consequences. For example, how to define and manage the benefit package can be looked at from several perspectives. Payers may want to know how to insure that payments made to plans offer incentives to neither underserve or over serve their customers. Consumers may want a wide range of choices and easily accessible services with minimal prior authorization so that if out of plan services are the preferred ones, they are attainable. The managed care organization may be concerned about offering the highest quality services to a particular group of people with chronic disease and or disability without risking adverse selection if too many such people discover how good they are.

If managed health care arrangements are to succeed in serving people with disabilities, it will be critical that all relevant stakeholders have the information and tools they need to answer these questions and others like it. The remainder of this paper discusses key disability related policy issues.

The overarching issue is whether or not managed care arrangements can be made to work for people with disabilities and still reduce spending over the fee for service system. Conversely, should a strong fee for service system be maintained for people with special health care needs? If so, can the fee for service system be improved to meet the needs of people with disabilities and contain or reduce spending--without creating two separate systems, one for people with special needs and one for everyone else?

People with disabilities report that they frequently experience difficulty accessing high quality, individualized health care services. These complaints have arisen mostly from people in fee for service systems, because until recently, people with disabilities have not had much experience with managed care. As managed care gains more hold, consumers fear that problems they currently experience in the fee for service system will grow worse, and fragile, hard-gotten relationships with trusted providers will be disturbed--all in the name of cost savings.

The disability community has been vocal in its criticism of managed care, fearing that access and quality of care problems will be exacerbated. Nevertheless, the movement of states to mandate the participation of SSI populations in Medicaid managed care and the accelerating participation in Medicare risk contracting guarantees that many more disabled persons will become managed care enrollees. A key role for the policy research and evaluation communities is to assess how well managed care plans are able to serve vulnerable populations in comparison with more traditional fee for service arrangements and how the potential benefits of managed care can be maximized. Managed care, broadly defined, has the potential to be a positive force in shaping services for people with disabilities by increasing the range of treatment options, enhancing coordination and continuity of care, conserving scarce resources and using outcome data to improve treatment.

A second key question is how to make the financial incentives inherent in managed care compatible with the needs of people with disabilities. In other words, how can a viable managed care market be created in which plans truly compete for market share on the basis of price and quality, not on questionable enrollment strategies?

Financial incentives which would encourage health plans and providers to include people with significant disabilities in managed care are largely lacking in today's system. Health plans which seek to develop high

quality programs for populations with special health care needs risk attracting a concentration of high cost persons. Unless a specialized payment source also accompanies their enrollment, plans will experience large financial losses causing them to raise premiums, ultimately driving out healthier, lower cost people. If plans are to be encouraged to effectively serve disabled populations, financial incentives must be created to reward this behavior. Risk adjustment strategies have been proposed as one solution to this dilemma and are being tested for both Medicare and Medicaid enrollees. The question is whether risk adjusters can be crafted to encourage plans to enroll people with disabilities and serve them well and also discourage plans from drawing down higher rates and large profits while avoiding disabled people with higher costs. The jury is out on this key question. It is clear that much more empirical work is needed before plans and payers are comfortable with setting premium rates to account for the potential costs of serving people with significant disabilities.

Should people with disabilities be incorporated into mainstream health plans or should plans specialize in serving vulnerable populations?

One approach to limiting risk to health plans for serving disabled populations is to develop specialized “carve outs” for high cost populations for whom risk sharing arrangements are difficult to create (e.g., persons with chronic mental illness, children with severe disabilities, the MR/DD population, HIV/AIDS). States have typically developed carve outs for a discrete set of specialty services; primary and acute care services usually remain with the state’s mainstream plans and providers.

For many years, some states have carved out their behavioral managed health services to limit expensive and often unnecessary inpatient care and substitute early intervention and a much more comprehensive network of services in the community. The motivation was to both manage speciality services more effectively and to protect and insure a funding stream for the community providers of these services. More recently, several state programs are attempting to carve out new categories of the disabled population and place them in specialized managed care plans; e.g., the District of Columbia’s Health Care Services for Children with Special Needs, an example of a major carve out of a special population, which integrates acute and long-term care services under a single provider with a capitated rate for Medicaid eligible children with disabilities; Rhode Island’s CHOICES program, which will provide services to people with mental retardation and other developmental disabilities; and the Wisconsin ICARE program, a specialized care plan for people with severe disabilities.

There is not a lot of empirical information available to judge the efficacy of carve outs versus mainstream approaches to serving people with disabilities in managed care. From the viewpoint of the consumer, considerable skepticism has been expressed about equal access to care in a “separate but equal” health care system--many people with disabilities fear that care in a “disabled only” system will be severely constrained and of inferior quality. Issues related to potential violations of the Americans with Disabilities Act have been raised. It is also not clear that carve outs are successful strategies for maintaining adequate levels of funding to speciality services. The more visible and highly regarded the speciality program, the more it may attract very sick and high cost people, requiring more and more services and requiring upward adjustments in payment rates. This phenomenon may be difficult to defend to state legislators seeking Medicaid cost savings. Also proponents of main streaming believe it is easier to demonstrate the efficacy of specialized services in a more integrated plan where the expectation is that by providing them the need for acute services will be reduced.

Should the financing and delivery of acute services and long-term care be integrated to assure continuity of care, and if so, to what extent?

Many people with disabilities have acute and long-term care needs...particularly needs for home care, personal assistance services and rehabilitation services. In general managed care coverage does not

include long-term care benefits which are largely funded through Medicaid (although increasingly, with respect to home health, through Medicare as well) and through out of pocket payments. Further, private health care insurance typically excludes long-term care coverage.

Among the potential benefits of integrating acute and long-term care services are: provision of a comprehensive service package that recognizes the dynamic interaction of the acute and chronic needs of people with disabilities; reduced fragmentation of services and more consistent, cost effective care across time, place and profession; and, potential for costs savings by substitution of less expensive home and community based services for hospital and nursing home care.

Models that integrate acute and long-term care typically have one or more of the following characteristics, although experience has shown that none of these alone or in combination ensures that a system is integrated:

- a combination of acute and long-term care financing and service delivery for an elderly or disabled population or subpopulation;
- an organized continuum of services and providers;
- incentives for cost containment such as: prepayment, full or partial capitation, case management fees, utilization review;
- a case management function designed to assure continuity of care over time and across separate service delivery systems; and
- specialized training for providers so they are aware of the full array of services and providers and know how to help consumers access them.

Achieving effective integration of acute and long-term care has proven enormously difficult both with respect to financing and service delivery. A particularly nettlesome problem is how to effectively finance and serve the dually eligible population...that is persons who are eligible for both Medicare and Medicaid within an integrated care model. Considerable attention needs to be paid to identifying and evaluating approaches to integrating services across funding streams as well as the feasibility of integrated funding.

Much of the research on the integration of acute and long-term care has been conducted through several federal demonstration projects (SHMO, PACE, Evercare etc.). A variety of other demonstrations are under development or in the early phases of implementation. Although all intend to provide integrated acute and long-term care services, the models are designed for different subsets of people with disabilities, and test a variety of benefit packages, case management models, payment approaches, and financing streams. Questions have been raised about the effectiveness of the current models in achieving service delivery coordination between primary care providers and community based providers. Evaluation results will be critical in an effort to develop effective, responsive models of managed care for people with disabilities.

How can the values of consumer choice and empowerment be reconciled with managed care service organization and delivery?

A fundamental value within the disability community is the concept of consumer choice. People with disabilities and their advocates articulate a need for self-determination. This is especially notable in the personal assistance services (PAS) arena for people with physical disabilities. Rather than rely on formal, agency-directed services, some consumers (particularly younger ones) are seeking flexible policies that allow them to hire, train, and--if necessary--fire the individuals who help with their daily living tasks. This is

in direct contrast to the traditional personal care service mode, under which an agency employs, trains and assigns individual providers to a person.

As consumers with disabilities and their representatives contemplate moving into managed care, respecting choice and empowerment is a frequently raised theme. Should participation by people with disabilities in managed care always be voluntary? Many states are mandating the participation of welfare recipients and, increasingly, SSI recipients into managed care. What information do people with disabilities need to have to make informed choices with respect to plans and benefits? Should consumers be able to move at will in and out of a particular plan?

Can plans manage care, assure quality and control costs if enrollees are able to switch plans with almost no advance notice? This issue becomes more complex for plans serving individuals who are eligible for both Medicaid and Medicare, since Medicare allows consumers extensive flexibility to move among managed care and fee for service plans.

Another question relates to choice of providers. Generally, consumers enrolled in fee for service arrangements have more say than those in managed care about who will provide their primary and specialty services. For a person with a disability, for whom it may be very difficult to find a knowledgeable provider, choice issues are critical. For example, we have learned anecdotally that there is only a handful of gynecologists who know how to provide prenatal and childbirth services to women with paraplegia. To ensure healthy outcomes for both mother and child, it may be necessary for plans to have special arrangements to enable women with paraplegia to see these providers. Alternatively, plans may need to provide more training to expand the pool of qualified, available providers.

Most disabled consumers and their families strongly believe that they should be able to choose between fee for service and managed health care, as well as have a wide range of choices between managed care plans, if this is what they opt for. They also seek broad choices in individual providers.

Achieving consumer choice with respect to service benefits is somewhat more complex. How can concepts of choice and self determination be appropriately applied to acute and primary care...regardless of whether the consumer has a disability and whether the health care is a fee for service or managed care plan. Clearly, certain protocols must be followed in the practice of medicine and certain professional and technical skills are required. An individual does not typically self diagnose an infection and choose an antibiotic. On the other hand, under some circumstances, it may be perfectly reasonable for a person who needs to increase range of motion to decide not to visit a physical therapy center twice a week and choose instead to have the help of a family member for daily exercises, with monthly consults with a physical therapist.

Consumers, managed care organizations, policy makers and other stakeholders will need to agree on the boundaries of choice in the provision of acute and primary care. Consensus may be difficult between professionals and consumers and between consumer groups where younger disabled persons may be far better equipped to manage their health care than most frail older people.

There are several related issues in the arena of choice of providers. First, many physicians and other practitioners are unprepared to serve people with disabilities--even when the disability is unrelated to the reason for seeing the doctor. In order for consumers to have meaningful choice, there must be more than one or two providers from whom to choose. In addition, plans must be responsible for educating consumers and giving them information about quality and access, in order for consumers to make viable choices.

Finally, it is important to examine and reconcile how choice principles will apply to integrated care models. For instance, if a consumer is receiving cash to hire and direct his or her own personal care provider, how

will that provider and the consumer interact with the case coordinator from the managed care organization where the consumer receives primary and acute care services?

How should accountability be institutionalized in a managed system of care?

Our ability to specify health care outcomes for people with disabilities is in a much less advanced stage than it is for non-disabled populations. Measures of effectiveness for impaired and disabled populations are almost universally lacking from today's efforts to develop quality assurance systems and performance measures. Combining quality assurance activities designed in a demonstration context, such as the quality assurance system under development for PACE, with efforts to include measures that monitor care for those with disabilities in ongoing programs, such as the addition of functional measures to Medicare HEDIS, are critical as we strive to more effectively assess the quality of care provided by managed care systems.

Further, the ability to compare how people with disabilities fare in the fee for service system relative to various managed care settings, is important but methodologically complex. The work of the Foundation for Accountability (Facct) is particularly important in this respect.

A most important key to accountability is likely to be the existence of educated and informed consumers and their families who have access to the information they need to select among plans and providers and the ability to leave plans with unacceptable levels of quality. Maximizing choice is probably the best option for achieving accountability and quality in the long run.

How can plan and provider capacity be developed to address the health and long-term care needs of people with disabilities?

Critical design questions must be addressed before managed care systems are fully prepared to serve people with disabilities and chronic conditions. Two key operational questions concern the design of benefit packages to ensure that specialized services are available and the development of a managed care workforce.

From the consumer's perspective, the success of managed care systems in serving those with disabilities hinges heavily on the breadth and flexibility of benefits and access to them. From the perspective of the provider, the benefits offered may seriously affect financial risk. Areas of particular concern include access to ongoing rehabilitation services (physical, occupational, and speech-language therapies), assistive technologies, and mental health supports. Adaptive equipment coverage is another key area of concern--surrounded by many questions from consumers: can a managed care plan accommodate my growing child as his or her equipment needs change? How can I be sure that my wheelchair or crutches will be customized to me, and not provided "off the shelf?" Another important consideration in designing service packages is whether and how special transportation needs will be addressed. Not surprisingly, although consumers are generally satisfied with the Oregon Health Plan, which includes the SSI disabled population in mainstream Medicaid managed care plans, these are some of the main concerns they cite with the plan. Others wonder whether it is even reasonable to expect the managed care plan to provide these and other services when these services are not covered under the fee for service program.

In addition to identifying and defining the services to be covered, managed care organizations aiming to serve people with disabilities must also address the issues of annual or lifetime caps to limit use of these services, the role of gatekeepers and primary care case managers in accessing these services, and, maybe most important, who should pay for them and how they should be paid for. In the example of rehabilitation services, current private and public plans are struggling with these very questions. Anecdotal evidence suggests that private managed care (and some fee for service) plans are increasingly limiting coverage for

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

A related problem for plans as they make the necessary changes in order to serve a range of individuals with disabilities and chronic conditions is the challenge of developing a workforce that is prepared to address the full range of care needs of the consumer (and family) and coordinating hiring and training efforts to achieve this goal. Graduate programs in medicine, nursing, and therapy programs, among others, have tended not to focus on interdisciplinary work, or the interactive and interdependent role of health care provider and person with a disability, and in-service training programs often overlook the need. A recently reported study indicates that most medical schools have not even kept pace with the shift to managed care for the general population. As a result of the lack of preparation, individual professionals serving people with disabilities create their own networks of providers with whom they work, with varying degrees of success. But much work needs to be done to develop models of training and service delivery that embrace the values of communication and teamwork in serving people with disabilities who have multiple and complex needs. The field of geriatrics provides a framework that may be useful in designing educational and practice guidelines in this regard.

V. CONCLUSION

It is the hope of the sponsors of this conference that research presented over the three day meeting will lead to discussion and additional inquiry that advances our knowledge of managed care and its applications and implications for people with disabilities. Further, conference participants are encouraged to debate these policy issues thoroughly and identify additional concerns.