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# Medicaid Managed Care and Working-Age Beneficiaries with Disabilities and Chronic Illnesses

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*Even after a decade of study, there are still many questions about how working-age adults with disabilities or chronic illnesses are faring in Medicaid managed care. This article draws from recent research to examine two critical issues: the need for better outcome measures specific to this population and the importance of evaluations that accurately estimate program effects, despite continued policy change, considerable differences among States, and extreme population diversity. The authors outline a research agenda that will help policymakers develop a more precise sense of how managed care practices affect different subgroups of working-age adults with disabilities and chronic illnesses and how practices could be altered to improve Medicaid's ability to meet their needs.*

## INTRODUCTION

One of the greatest challenges facing the Medicaid Program is to deliver care effectively to working-age beneficiaries who have a disability or chronic illness.<sup>1</sup> There were 7 to 8 million such individuals in 2000 (Allen and Croke, 2000; Hoffman, Klees,

<sup>1</sup>For our purposes we consider this population to include persons with disabilities (defined broadly as persons whose conditions limit daily activities) and chronic illnesses (defined broadly as persons with conditions that require ongoing medical treatment).

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and Curtis, 2001). Not only do they face substantial limitations in their ability to engage fully in American life, they require organizationally complex care to maintain their health and functioning. This care is delivered by multiple providers in numerous settings, including clinics, hospitals, offices, and individuals' homes. Delayed or inappropriate care can exacerbate their conditions and, in the extreme, limit their ability to live independently. As a group, these individuals have extraordinarily diverse service needs and use substantial amounts of care. Although they include just slightly more than 60 percent of working-age Medicaid beneficiaries, they account for over 95 percent of Medicaid expenditures for this population (Allen and Croke, 2000).

Several investigators have outlined elements of a basic approach to caring for individuals with disabilities or chronic illnesses (Hill and Wooldridge, 2000; Wagner et al., 2001). Ensuring that all working-age Medicaid beneficiaries are in service systems that include these basic elements is challenging under fee-for-service (FFS) or managed care arrangements. Different financing arrangements may shift the nature of these challenges, but in either case, the issues are complex. For example, in the 1980s there was a concern that FFS incentives were leading to uncoordinated care, duplication of services, and higher than necessary costs (Starr, 1982). In the early 1990s, many State Medicaid Programs adopted managed care as a means for controlling costs, improving service coordination, and enhancing quality of care.

Changes were made so rapidly in many States that there was little time to conduct comprehensive studies to show whether managed care practices had better or worse outcomes (or made no difference) compared with FFS systems. From the beginning of the move to Medicaid managed care, however, experts expressed concern that managed care would decrease access to needed specialty services and threaten health outcomes, especially for people with disabilities and chronic illnesses (Sutton and DeJong, 1998). Now more than 70 percent of States use managed care plans to serve adult Medicaid beneficiaries who receive Supplemental Security Income (Kaye, 2001). Yet, even after a decade of experimentation and study, we still know little about how well working-age beneficiaries with disabilities or chronic illnesses are faring in Medicaid managed care plans.

In response to this situation, the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services funded a project to review the recent literature on Medicaid managed care and propose a research agenda that would help to guide future program and policy development (Ireys, Thornton, and Dodge, 2002). Managed care as an overall approach to financing health services is evolving at both conceptual and operational levels, but many managed care practices (e.g., standard satisfaction surveys; tracking of high users) are likely to remain in use. Are they likely to be effective? In this article, we aim to present key findings from our review as a means for developing a research agenda that will ultimately yield information useful to State Medicaid agencies in their ongoing efforts to improve care for beneficiaries with disabilities and chronic illnesses.

First, we focus on basic elements that should be present in a system of care suitable for people with chronic illnesses and

disabilities and describe critical population characteristics that make it difficult to implement these elements statewide. Our list of elements is derived from reports by investigators and consumer representatives who have examined this issue. We then summarize findings from studies that pertain to (1) State Medicaid Programs; (2) managed care organizations that accept Medicaid risk contracts; and (3) providers who deliver care. We also consider two critical research issues. One is the need for widely accepted and accurate outcome measures that are specific to people with disabilities or chronic illnesses. The other is the challenge of designing and implementing evaluations that can produce accurate, relevant results in the face of constantly changing programs and extensive variation among States. On the basis of our review, we outline a research agenda that will help policymakers develop a more precise sense of how managed care practices affect different subgroups of people with disabilities and chronic illnesses and how those practices could be altered to improve Medicaid managed care's ability to meet their needs.

Analysis of the methods and data used in the studies that we reviewed may be found in Ireys, Thornton, and Dodge (2002). In addition, because we focused on the working-aged Medicaid population, we did not review reports on children with disabilities and chronic illnesses (Curtis et al., 1999) or on Medicare beneficiaries enrolled in managed care (Pope et al., 2000).

## **BASIC ELEMENTS IN A SYSTEM OF CARE**

Several groups have attempted to define the necessary elements in an effective care system for people with disabilities or chronic illness (Anderson and Knickman, 2001; National Chronic Care Consortium, 1995; Smith and Ashbaugh, 1995; Wagner

et al., 2001). These elements would be necessary in either a FFS or managed care system. Consumer advocates and others emphasize the importance of a consumer choice and empowerment through a person-centered approach, integration across a full and flexible array of services within and outside a network in order to match services with beneficiaries' needs, and the use of interdisciplinary care teams (Batavia, 1999; Shalala, 2000). According to some reports, a well-performing system should enable people with disabilities and chronic illnesses to help shape and carry out their own care. Clinical staff should help them to understand the dynamic status of their conditions and impairments, providing education and support to assist them in following their treatment regimens (Wagner, 2000).

In addition to the importance of consumer decisionmaking, existing reports and program reviews underscore that the following basic elements are critical to caring effectively for people with disabilities and chronic illnesses, including working age-Medicaid beneficiaries:

*Identification.*—Care systems should contain systematic efforts to identify and assess people with disabilities or chronic illness before they experience serious adverse events. Medicaid managed care plans need information management systems that foster identification of beneficiaries with disabilities and chronic illnesses, and primary care providers should receive training and support to help them identify people with these conditions or at high risk for developing them.

*Prevention and early intervention.*—Systems should deliver care to prevent the deterioration of an individual's chronic condition and to the extent possible the onset of secondary conditions. Systems should provide early intervention strategies to

help individuals with disability or chronic illness to build physiologic reserves and to seek timely care.

*Interdisciplinary and comprehensive care.*—Care should be delivered by clinical teams that have experience and expertise in serving this population. The system should cover a full continuum of primary, acute, and long-term care services, including medical care, special care units, specialized diagnostic centers, rehabilitation, adult day care, skilled nursing home care, other home care services, respite care, hospice, preventive care, care consultation, caregiver support, drugs, medical equipment, assistive technologies, mental health and counseling services, and transportation.

*Accessible urgent care.*—People with disabilities or chronic illnesses, and their family members or caregivers, should be able to obtain a response to urgent care needs from a knowledgeable clinician or clinical team who are accessible 24 hours a day.

*Service integration and management.*—There should be systematic efforts to coordinate and integrate the various medical-care services with each other and with social and support services and long-term custodial care. The management structures and information systems should support integration efforts.

The challenge for Medicaid managed care plans and the State Medicaid agencies lies in ensuring that all working-age beneficiaries with disabilities or chronic illness have access to these key elements. What makes that challenge so substantial, however, are three characteristics that distinguish this population.

First, people with disabilities and chronic illnesses have both chronic and acute care needs. The importance of ongoing care to address chronic illness and conditions

means that these individuals require a different mix of services than do other members of Medicaid or commercial health plans (Vladeck, 2001). Chronic care requires more attention to long-term relationships between providers and patients, with more of a focus on maintaining functioning and preventing further conditions than on curing an acute condition. It is also more likely to require organizationally complex care delivered by multiple providers.

Second, the diversity of underlying conditions and care needs along with the diversity in their consequences complicates systemwide delivery of comprehensive care. In addition, many individuals have multiple conditions, including both physical and mental health conditions that co-occur and interact in complex ways (Anderson and Knickman, 2001). Furthermore, there are diverse attitudes. People make different choices about managing chronic symptoms, such as pain, and about what constitutes a comfortable level of functioning and independence (Benjamin, 2001). They also can differ in the level of rapport they expect to have with the caregivers with whom they have ongoing interactions. Finally, they differ in their health literacy and ability to obtain and understand information about plan and treatment options.

The third critical population characteristic involves intensity of need. Total Medicaid expenditures for people with disabilities and chronic illnesses are higher than for people who do not have these conditions. For example, in 1995, State Medicaid Programs spent from 1.5 to 3 times more for all services to blind and disabled beneficiaries than for beneficiaries in general (Liska et al., 1997). In a study of the Supplemental Security Income (SSI) population in Washington State, 19 percent had annual expenses greater than \$10,000, compared with 2 percent of the population

enrolled in the State's public employee health insurance plan (Madden, Skillman, and Mackay, 1999).

More effective health systems for this population will require Medicaid agencies and managed care plans to develop special provisions and procedures (or separate stand-alone programs) that account for and are concordant with these characteristics. The current literature, however, provides only a weak foundation of knowledge to support this goal. For example, a recent review of treatment of chronic illness in managed care plans mentioned very few studies that included working-age Medicaid beneficiaries (Christianson et al., 2001). If future research efforts can build a more solid and comprehensive base of information on service implications of population characteristics, State agencies and managed care plans will be in a stronger position to implement effective programs.

## **STATE MEDICAID PROGRAMS**

State Medicaid Programs have used several strategies for improving managed care's performance in relation to beneficiaries with disabilities and chronic conditions. They have established managed care contracts that specify enrollment policies, benefit packages, payment rates, reporting requirements, and quality assurance methods (Regenstein, Schroer, and Meyer, 2000). They also have worked directly with consumers, through ombudsman programs, hot lines, and other outreach and education efforts (Mittler and Gold, 1999; Regenstein, Schroer, and Meyer, 2000).

Research into effective State practices is complicated by the diversity among State Medicaid Programs and their managed care initiatives. States differ widely in what services their Medicaid Program actually pays for because they can elect to provide different sets of optional services and to

include or exclude provisions for medically needy populations. The multiple provisions for selecting coverage benefits and implementing waiver programs have made State programs enormously complex (Gold and Mittler, 2000). This complexity contributes to difficulty in conducting generalizable studies of the impact of Medicaid managed care on this population.

The current literature, however, offers a number of suggestions regarding “best practices” with respect to these decisions, but few definitive conclusions on whether particular choices in program design lead to particular population outcomes. Moreover, several studies have underscored the value of substantial consumer involvement in program design, especially in relation to enrollment practices and strategies for monitoring quality of care (Shalala, 2000). Evidence also is increasing on the potential benefits of consumer-directed services, such as personal assistance services (Benjamin, 2001). Integrating and extending these approaches is likely to be an important activity for State Medicaid Programs during the next several years (U.S. General Accounting Office, 1999).

There is also a growing sense that mandatory enrollment carries the risk of high consumer dissatisfaction and that this risk can be lessened with a carefully phased transition process and appropriate enrollment methods (Regenstein, Schroer, and Meyer, 2000). Voluntary enrollment, in contrast, may lead in some situations to substantial underenrollment of people with more severe or costly conditions if these people believe that enrollment in managed care is not in their best interests. In any event, managed care plans that enroll a disproportionate number of people with special health care needs are at high risk for financial losses. If capitation rates are not adjusted to account for the specific care

needs of an enrolled population, then plans may avoid enrolling this population, encourage disenrollment of high-cost individuals, or leave the Medicaid market altogether. Despite recent research on methods of risk adjustment (Kronick et al., 2000; Hwang et al., 2001; Weiner et al., 1998), the application of this research to Medicaid populations has lagged. Most States have yet to implement adequate health-based risk adjustment methods for their managed care programs (Holahan, Rangarajan, and Schirmer, 1999; Kaye, 2001).

Aside from special efforts regarding enrollment information, few State agencies have developed strategies to inform beneficiaries in this population about the performance of managed care plans. Very little is known regarding effective educational methods for people who have sensory impairments, limitations in intellectual functioning, or other cognitive impairments. State Medicaid agencies have used a variety of methods to assess quality of care, including the use of structural and operational standards, performance measures, practice guidelines, and review of grievance and appeals processes, but only a few States have applied disability-related indicators of quality (Landon, Tobias, and Epstein, 1998; Regenstein, Schroer, and Meyer, 2000). Development of performance measures suitable for this population has quickened somewhat in the last several years. For example, some Medicaid agencies now have begun to report standard survey data for SSI populations (Independent Care, Inc., 2001; New Jersey Department of Human Services, 2000). It is not clear how many States will report these data in the next several years. Furthermore, low survey response rates (typically less than 50 percent) raise questions about the validity of these reports.

The extent to which Medicaid Programs use this information to enhance program operations is not known.

## MANAGED CARE ORGANIZATIONS

More effective managed care systems for people with disabilities or chronic illnesses depend on efficient methods for identifying individuals in this population, assessing their needs, and developing individualized health care strategies. It is not possible to deliver any targeted services or care plans without first being able to identify the population who needs those services. Furthermore, these services can be expensive, so budgetary concerns mean that managed care plans must have ways of targeting services to the people who need them most. Despite a wide range of options (e.g., using provider information, member surveys, or analysis of administrative and claims data), most plans have no systematic means for determining whether a new member has a chronic health condition or whether an existing member has developed one (Kaiser Commission on Medicaid and the Uninsured, 1999). Research on Medicare managed care plans suggests that analysis of claims data is more effective than repeated surveys at identifying existing members with chronic illness or disabilities (Coleman et al., 1998). However, it appears likely that multiple approaches, including screening by primary care physicians, will be needed to ensure complete identification of this population.

As experience with care coordination for high-risk populations in managed care settings has grown, so too has the recognition that this concept involves more than financial monitoring of high-cost enrollees in an attempt to minimize future expenditures (Chen et al., 2000; Rosenbach and Young, 2000). Ideally, the medical, social, and sup-

portive services needed by individuals in this population should not only be coordinated, but also integrated into a coherent system of care that consumers can understand and negotiate without serious problems. Numerous approaches to care coordination for working-age adults with chronic illnesses or disabilities have been described by Wagner, Austin, and Von Korff (1996), but few empirical studies have assessed their outcomes or cost effectiveness.

Comprehensive research on disease management programs has only just begun (Wagner, 2000; Christianson et al., 2001). As a result, many questions remain unanswered, including: What approaches to disease management work effectively for this population, in which there are high rates of comorbidity and complex challenges around medication adherence? How should these programs be paid for?

The health of individuals with disabilities and chronic illnesses will be influenced by whether they have access to an appropriate range of primary and specialty care providers. Information from case studies, focus groups, and personal accounts suggests that the initial implementation of managed care interrupts relationships with specialty providers (Aizer and Gold, 1999; Batavia, 1999). Few empirical studies, however, have addressed issues of assuring provider continuity during transitions from FFS systems or from one managed care plan to another.

Originally, many companies that operated Medicaid managed care plans had little experience in providing care to low-income, vulnerable populations with chronic conditions. As the market has shifted, more "Medicaid-only" plans have emerged, especially in urban areas. These plans are typically sponsored by hospitals and community health centers, have a history of serving vulnerable populations, are

committed philosophically to strengthening their communities overall, and have established partnerships with local health departments. How length of experience with this population influences program development is an important, but as yet unanswered, question.

## PROVIDER PERSPECTIVES

Although health outcomes for this population will be influenced substantially by decisions made at the policy and program levels (that is, by State Medicaid agencies and managed care plans themselves), provider characteristics also will play important roles. Effective treatment of chronic conditions is often based on clinical experience with individual variation in disease expression. Consequently, people with chronic health conditions typically value relationships with familiar and knowledgeable providers. People with chronic conditions expect to have long relationships with physicians and other health professionals who are important in providing care (Batavia, 1999; DeJong, 1997).

Primary care providers, however, vary in the degree to which they are interested in or knowledgeable about chronic health conditions, and therefore will vary in the nature of the clinical decisions they will be comfortable in making. Some primary care providers will be more likely to refer patients to specialists, depending on their degree of experience in treating certain chronic conditions. Many families of people with chronic health conditions identify the specialist as the physician who knows the patient the best, not the primary care provider (Perry and Ireys, 2001).

Providers also differ widely in their skill and inclination to coordinate medical or related services. Spending time on activities needed to coordinate multiple services that patients use frequently over long peri-

ods of time is inherently difficult for busy and often highly-stressed health professionals. Long-established behavior patterns shaped by a provider's training, insufficient financial incentives, and lack of evidence regarding the effectiveness of care coordination all contribute to substantial variation in whether Medicaid beneficiaries with disabilities or chronic illnesses have access to care coordination (Wagner, 2000). We could find no studies that explicitly focused on the question of whether enhancing provider capacity to coordinate care (however that might be operationalized) influences health outcomes for people with disabilities or chronic illnesses.

Innovative models of team care and physician practices have been developed (Wagner et al., 2001), but little research has examined the implications of variation in the behavior of physicians and other providers in relation to outcomes for Medicaid beneficiaries with disabilities or chronic illnesses. In addition, little is known about (1) the relationships between physicians and managed care organizations, or how these relationships affect care for vulnerable populations (Gold, 1999) and (2) how to change physician behavior, especially if the change involves vulnerable populations and risky interventions (Soumerai et al., 1998).

Although there have been numerous surveys of physician attitudes toward managed care, little work has focused on how physicians actually change what they do with and for people with chronic health conditions after they enroll in managed care plans. Many physicians and other health care providers fail to understand the subtle complexities of capitation payments and financial incentives (Anderson and Bilenker, 1998; Gold, 1999). Furthermore, payments to physicians are becoming more complex. Practices may contract with numerous managed care plans, each with

somewhat different incentives and rules (Collins et al., 1997). Some plans are beginning to adjust payments to providers based on quality measures. The impact of this practice on people with chronic illnesses and disabilities has not been studied.

Overall, we found a striking discrepancy between the importance of health professionals to working-age Medicaid beneficiaries with chronic conditions and what is known empirically about how to encourage providers to adopt new behaviors (for example, including consumers in decision-making) that might lead to improved outcomes. Although the provider-managed care organization relationship is gaining more attention overall, few studies have examined this issue in relation to patients with disabilities and chronic illnesses.

## **CRITICAL RESEARCH ISSUES**

### **Outcome Measurement**

Research into managed care performance requires concrete, agreed-upon measures of outcomes for people with disabilities or chronic conditions. For the purposes of this article, we define outcomes as population-specific indices of health outcomes, service utilization rates and expenditures for general and specialty care, out-of-pocket costs, and consumer satisfaction. Measures of these outcomes are widely used in general studies of health care and health care services, but existing measures are not always suitable for Medicaid beneficiaries with disabilities or chronic illnesses.

Overall, few studies have used health outcomes to compare differences between FFS and managed care systems. In their evaluation of the effect of the Community Medical Alliance on people with acquired immunodeficiency syndrome, Masters et al. (1996) used two health-related out-

comes: (1) rates of decubitus ulcers among the severely physically disabled and (2) the hospitalization rates for pneumocystic pneumonia. Their study compared rates within the same population before and after the program changed from FFS to capitated prepayment. Hospitalization rates for both pneumocystic pneumonia and decubitus ulcers decreased after the implementation of capitated prepayment (Master et al., 1996; Meyers et al., 1997). It is important to note that sample sizes used were quite small. For example, only 45 patients were assessed for decubitus ulcers.

Excluding case studies, we found no other investigation that used health outcomes in assessing the impact of managed care on a population of people with chronic health conditions. In part, this may result from problems in using standard measures of health outcomes for people who have serious ongoing chronic conditions. General population measures are often insufficiently sensitive to the dimensions of health (for example, pain, unpredictability of symptoms, functioning) that are salient to people with disabilities or chronic illnesses. Other measures of functional outcomes include items related to limitations in daily activities. These approaches, however, may reflect stable characteristics of a person's health condition, and therefore, would be unaffected by a managed care intervention. Finding population-specific health and functional status measures that are sensitive to changes in the health care delivery system presents a major research challenge.

Costs have been a key outcome for studying this population, but they capture only part of overall system performance. Short-term cost increases cannot be easily interpreted as a favorable or unfavorable change. Integrating this population into Medicaid managed care plans may lead to



increased expenditures, at least in the short term, because previously unmet needs are identified. For example, the State of Washington terminated Medicaid managed care contracts for people with disabilities when the extent of unmet need became clear following case management interventions (Madden, Skillman, and Mackay, 1999; Verdier, Somers, and Harr, 1998).

Overall, the limited literature is mixed on the question of whether working-age people with disabilities and chronic illnesses have different cost and utilization outcomes depending on whether they are in FFS or managed care systems (Fama and Bernstein, 1997; Nelson et al., 1998). Much of the work in this area has focused on commercial populations and so provides an inadequate basis for judging the cost experience of Medicaid beneficiaries with disabilities or chronic illnesses. A recent report on Medicaid beneficiaries with disabilities in Oklahoma suggests that overall costs were less for most participants in the year following their entry into managed care compared with the previous year in the traditional FFS system (Shaller Anderson, Inc., 2002). However, the sample selection methods in this study raise serious questions about the generalizability of the results.

Several aspects of satisfaction have been used to assess system performance, including satisfaction with access to care and general satisfaction with quality of care. Overall, managed care systems may have reduced some of the sources of dissatisfaction, but increased others. A number of studies indicate that people with disabilities and chronic illnesses who are enrolled in Medicaid managed care are dissatisfied with their care and report problems with access to specialists, specialty care, and medical equipment (Druss et al., 2000; Hawkinson and Frates, 2000; Regenstein,

Schroer, and Meyer, 2000). In contrast, several studies have revealed high satisfaction and few problems with access to services for enrollees with disabilities or chronic illnesses (Hill and Wooldridge, 2000; Leichter, 1999; Master, 1998). Some States have begun to report data from SSI populations who have completed the Consumer Assessment of Health Plans Survey<sup>®</sup>, but low response rates (less than 50 percent) raise questions about the validity of the results. While it appears possible to obtain high response rates by using methods designed to accommodate the special needs of many people with chronic illness or disabilities, few studies have used these methods. Moreover, it is unclear how States or managed care plans have used results from these surveys to reduce sources of dissatisfaction.

### **Research Design Challenges**

Many methodological challenges prevent easy assessment of the impact of managed care on the population of working-age people with special health care needs. For example:

*Continuous system change.*—The managed care market has changed the landscape of American health care dramatically in a short period of time, and it continues to evolve rapidly (Brown, 2001). This rapid rate of change creates major challenges for conducting methodologically strong studies or program evaluations that can document the impact of managed care on this population. Results of a complex or lengthy study may be ready only after policy changes have made the results irrelevant.

*Lack of clear, agreed-upon standards or counterfactuals.*—Analysis of the impact of managed care must be measured against a specific standard. Is this standard based on FFS models or is it derived from a set of principles or attributes that define an ideal

managed care system? Within the research community there is a lack of consensus over which type of comparison is appropriate (Hill and Wooldridge, 2000; Kastner et al., 1997; Sofaer et al., 1998; Master et al., 1996; Von Korff et al., 1997).

*Diversity in study populations.*—The inherent heterogeneity of this population and the wide practice variation among State programs (such as mandatory versus voluntary enrollment) mean that any one study is likely to have some biases in its sample and limited generalizability of its results. As a result, no single evaluation of the impact of managed care will be sufficient to answer major policy questions. For example, States vary in their enrolled populations, so that conclusions from one State may not apply to another State; furthermore, difficulties in assessing selection into managed care overall or into specific managed care organizations contribute to difficulties in estimating both the effect of risk selection and study generalizability. Also, both program development and research have been hampered by the lack of a broadly accepted definition of this population, and a corresponding operational, cost-effective strategy for identifying individuals who meet the definitional parameters (Bethell et al., 2002). The diversity in the population overall has hindered the development of a consensus on how to define subgroups on which policies and programs could be targeted. Should subgroups be defined in terms of diagnosis, functional status, service need, availability of family support, or some combination of these factors?

*Large sample size requirements.*—Large variability within this population means that large samples are needed to assure valid and generalizable findings. Special stand-alone programs typically focus on a small subgroup of this population and, hence, face major challenges in developing

evaluation designs that yield robust results. Special programs that are integrated into general managed care plans may encounter selection biases that contribute to methodologic problems in their evaluation.

## **COMPONENTS OF A NATIONAL RESEARCH AGENDA**

Our literature review points to wide gaps in many areas between what we know and what we need to know to improve managed care practices for working-age Medicaid beneficiaries with disabilities and chronic illnesses. Filling these gaps efficiently will require sustained and coordinated efforts from consumer organizations, Federal agencies, foundations, States, managed care plans, and legislators. A national research agenda must aim to develop evidence based on rigorous research that is sufficiently compelling to point all stakeholder groups toward a more effective system of care. Coordination is especially needed to establish studies that build strategically on each other and to maximize links between the development of better outcome measures and their application by State agencies and health plans to the process of monitoring and improving managed care service systems.

Although needs, capabilities, and attitudes vary among the general Medicaid population, the greater complexity of conditions and service systems for those working-age beneficiaries with disabilities and chronic illnesses magnifies the importance of this issue. In particular, this group is more likely to have multiple conditions and to require care provided in different sites (clinics, hospitals, and home) and from different providers. Delivering organizationally complex care to people with varying needs, capabilities, and attitudes represents a significant challenge for Medicaid managed care, and for research on its

effects. Because of the diverse characteristics of this population and their requirements for an equally diverse service system, important policy questions pertaining to this challenge will not be answered by a single approach or study. Improving the Medicaid service system for this population demands a research effort that is conceptually and operationally broad.

As a step toward developing a new research agenda, we identify six areas of concentration. Based on our review of the literature, we believe that progress in these areas will contribute substantially to enhancing managed care systems for working-age Medicaid beneficiaries who have disabilities and chronic illnesses.

*Defining needs more clearly for purposes of program planning.*—The heterogeneity of needs, capacities, and attitudes within the large population of Medicaid beneficiaries with disabilities and chronic illnesses suggests that a range of managed care practices and products will be needed to promote positive health outcomes. The same approach to service integration, financing, or developing provider networks is not likely to be effective for all of the different subgroups of individuals within this population. How should the relevant subgroups be identified? How should diagnosis, level of functional impairment, number of comorbidities, and presence of family supports be combined to identify key subgroups to whom different types of programs could be offered? An overarching goal of research efforts in this area will be to improve an understanding of how beneficiary characteristics are linked to the structure and process of health care delivery.

*Establishing system goals.*—One of the most difficult challenges in this area will be to develop a consensus on specific goals for Medicaid Programs in relation to working-age beneficiaries with disabilities and chronic illnesses. There is little argument

that the health care system should treat people with acute illnesses effectively and efficiently to restore their health. But the goals for treating disabilities and chronic illnesses are less clear. Do these goals include helping people with disabilities or chronic illness to promote or maintain their functioning to the extent that they can live independently or become competitively employed? Health and social outcomes become blurred, leading to uncertainty about what the specific goals of health interventions should be for this population. Agreement on specific goals is essential, however, before State Programs can identify the changes and methods required to implement a statewide system that is based (perhaps only partially) on a managed care approach. Such an agreement will also be necessary to establish a coherent national research agenda. A comprehensive set of goals would address the specific steps that Medicaid managed care systems should take in order to address effectively the needs of the various subgroups of people with disabilities and chronic illnesses as well as an operational definition of what it means to say that a managed care plan is adequate for this population. Our current knowledge base provides partial insights into these issues, but more comprehensive approaches will emerge only from a process that brings the key stakeholders together in an effort to establish priorities and define jointly the important questions and methods to guide a national research agenda. Stakeholder groups include consumers, Federal and State Medicaid administrators, directors of managed care plans, providers, legislators and their staff, and the leadership of foundations and Federal agencies that support research in this area.

*Improved understanding of how to change systems.*—Given a consensus on important goals, some changes in current practices

and procedures will be required. The critical issue then becomes how to change the care system with its many different providers, consumers, and organizations, each with their own sets of incentives and constraints. How can such complex systems be changed in a way that will efficiently enhance the overall service system for this population? What studies will be needed to enhance an understanding of how to implement changes and disseminate best practices in respect to consumer involvement, care coordination, screening methods, and provider networks? What can consumers, providers, managed care organizations, and Medicaid agencies each do to remove obstacles to improvements in delivering chronic and acute care services to this population? Answers to these questions will shed light on how good ideas can be translated into effective programs.

*Developing financing systems that promote service delivery improvements.*—Most managed care plans and providers want to provide efficient care to people with disabilities and chronic illnesses. But shortfalls between resources required for this care and available payments can grow quickly. How can policymakers create incentives that will reward both managed care plans and providers for superior performance in caring for this population? Better methods of risk adjustment are only one part of the answer. New models are needed that integrate both financing and service delivery in the context of consumer-driven, community-based systems of care. In addition, stable financing is required to maintain a basic level of services for beneficiaries with disabilities and chronic illnesses. If the financial pie is dramatically insufficient, even the best risk adjustment method will do little to improve the service system.

*Understanding how outcomes are influenced by multiple factors.*—What factors really matter in determining health out-

comes of people with disabilities and chronic illnesses? Although large-sample, longitudinal, multi-State and multi-method research projects are expensive, these studies will provide information not otherwise available on what factors shape the performance and impact of managed care service systems.

Finally, transcending all of these areas is an urgent need for adequate data. Many critical questions will be answered only with better encounter data for working-age adults in Medicaid managed care plans and with databases that shed light on patterns of cost and service use overtime and across multiple service providers. These databases can only be constructed by linking information about beneficiary needs, capacities, and attitudes with information on processes and outcomes of service delivery. In addition, for those who are dually eligible, Medicare and Medicaid data will need to be combined in order to develop a comprehensive understanding of their patterns of service use and cost. Building these data sets will require better encounter data from managed care plans, broad population surveys, and multiple measures of outcome—as well as the resources to integrate these diverse sources of information. With strong databases, a coordinated research effort will provide stakeholder groups with the information needed to work together toward the common goal of improving systems of care for working-age Medicaid beneficiaries.

## CONCLUSIONS

During the last decade, most State Medicaid Programs moved well beyond their traditional role of paying claims. They became active managers of resources and health plans in an effort to establish efficient systems of care for vulnerable populations (Brown, 2001). Many changes were

driven by political or financial expediency, rather than by decisions based on high-quality research studies. In most States, there were few opportunities to conduct studies on whether managed care practices had better or worse outcomes (or made no difference) compared with FFS systems. Furthermore, many of the points that we make in relation to beneficiaries with disabilities and chronic illnesses also pertain to the Medicaid population in general. Whether managed care practices have improved outcomes relative to FFS systems is an open question for many subgroups of Medicaid beneficiaries.

Beneficiaries with disabilities and chronic illnesses have been referred to as the “canaries in the coal mine” (Jacobi, 1999). Major changes in the Medicaid environment are likely to affect them quickly and dramatically because of their vulnerability and high rates of service use. Comprehensive system reform efforts, no matter how incrementally they are implemented, must eventually address the needs of this population because a very large portion of any State’s Medicaid budget will be allocated to pay for the services they require. Although their operational forms are likely to evolve, Medicaid managed care practices and plans are here to stay in most States. A return to a single FFS system is unlikely.

Based on our reading of the recent literature, we identified several methodological challenges and areas of focus for additional research in this area. In spite of a decade’s worth of enrollment of persons with disabilities and chronic illnesses into Medicaid managed care, we still have little evidence about its impact on the quality of patient care. Research studies can provide State Medicaid staff with useful information, but only if they anticipate the sizable methodological challenges and strive for

rigorous evaluation in critical areas such as patient outcomes. As States cope with sharp budget constraints, they will need, even more urgently than now, practical and methodologically sound information with which to guide the further development of managed care for persons with disabilities and chronic illnesses.

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