



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

MANAGED CARE AND PEOPLE WITH DISABILITIES: RESEARCH PROJECT DESCRIPTIONS

February 1996

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 Office of Disability, Aging and Long-Term Care Policy. 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 Andreas Frank.

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Andreas Frank

U.S. Department of Health and Human Services

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OVERVIEW

Expanding managed care coverage to individuals with disabilities is a relatively new phenomenon. While managed care poses great opportunities for people with disabilities in the way of more emphasis on preventative services, continuity of care and lower out of pocket payments resulting from the elimination of co-payments and deductibles, it poses risks as well. The economic incentives embedded in managed care may also result in more limited access to basic services, particularly the specialty care required by people with special health care needs, and it may result in unaffordable premiums as insurers attempt to compensate for expected higher costs of enrolling disabled persons. In addition, few managed care providers have the expertise necessary to treat people with significant disability.

In an era marked by rapidly growing health care expenditures, the public and private sectors are increasingly looking toward managed health care systems to control health care costs and improve access to a coordinated continuum of services. The reason for this interest is clear, people with disabilities constitute a disproportionate share of the overall health care expenditures, and until payers can contain the costs and more effectively manage the care of people with disabilities, savings in overall health care expenditures will be difficult to realize. Yet designing managed care systems for the disabled has proven to be extremely difficult to achieve, mostly because there is a great deal of variation between the needs of people with disabilities, and unclearly defined clinical practice standards of care. Designing cost-effective, outcomes-oriented, and consumer-sensitive managed care systems for people with disabilities continues to be extremely challenging for both the private and public health care sectors.

Unfortunately, at present the U.S. Department of Health and Human Services and the private sector has little information on the experience of disabled populations in the traditional health care system and virtually none on what happens to these populations when they are enrolled in managed care plans. The absence of accurate and reliable data in this area makes it increasingly difficult to determine if managed care has a significant potential to improve quality health care services while containing costs, or if managed care will limit access to specialty providers and services important for people with disabilities.

In an effort to better understand the impact of managed care on disabled populations, staff from the Office of the Assistant Secretary for Planning and Evaluation's (ASPE) Office of Disability, Aging and Long-Tenn Care Policy (DALTCP) and the Office of Health Policy (HP), in collaboration with HCFA, have developed a series of research and evaluation efforts focused on managed care and people with disabilities. This research plan includes a variety of projects to promote knowledge on the experiences of disabled populations in managed care in public health care systems such as Medicaid and Medicare, as well as in employer-based and self-insured plans. Research projects include:

- Conducting statewide Medicaid managed care demonstration evaluations collaboratively with staff from HCFA's Office of State Health Demonstrations so that they include an analysis of impacts on persons with disabilities who receive Supplemental Security Income (SSI) benefits.
- Documenting the experiences and effects of managed care for disabled populations who are privately insured through large employer insurance plans.
- Funding grant awards which use disability-relevant data to examine effects of enrolling people with disabilities into managed care systems.
- Identifying public and private managed care sites that serve children with disabilities and conducting descriptive analyses and site visits in order to identify barriers to integrating acute and long-term care services for children with disabilities.
- Examining the health and long-term care expenditure patterns of children with disabilities using Medicaid tape-to-tape data in four states as well as private employer data.
- Identifying innovative public and private managed care plans serving working aged adults with disabilities (ages 18-65) and conducting site visits in an effort to develop a guidebook to aid states in developing more accountable and efficient managed care systems serving people with disabilities. This project includes a focus on both public (Medicare, Medicaid) and private managed care systems.
- Convening a national conference on managed care for people with disabilities to synthesize and share research results, disseminate best practices information, and stimulate thinking on the future potential for managed care plans which serve disabled populations. This conference will include research from both public and private health delivery systems which serve people with disabilities.
- Identifying public and private managed care sites that have developed interdisciplinary education and training programs for professionals caring for persons with disabilities.
- Identifying and describing particular settings where professionals and students in the health care and human service professions receive interdisciplinary instruction and practicum experience in the provision of health care to people with disabilities across a continuum of care.
- Conducting a three-year Disability Supplement to the Health Interview Survey to provide detailed information on the prevalence and characteristics of children, working-age adults, and elderly Americans with disabilities; what type of health care plans they belong to, their perceived health status, their use of non-medical

services, including frequency of use, who pays for these services, and out-of-pocket costs.

These proposed research projects will contribute information on issues of access, quality, cost, and outcomes for disabled populations within managed care systems to assist decision-makers, administrators, and providers in developing thoughtful and appropriate policies. Moreover, improvements in our knowledge base regarding the experiences of disabled populations enrolled in managed care may facilitate more prudent and informed decisions on the part of purchasers and consumers. Furthermore, by providing reliable condition-specific utilization and cost data on people with disabilities, it may be possible to promote more efficient rate-setting, reinsurance and risk adjustment strategies for various disabled populations. The following materials provide a more detailed description of the ongoing project.

ISSUE PAPER AND EXPERT MEETING ON MANAGED CARE FOR PERSONS WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Andreas Frank

PURPOSE: This issue paper highlights policy-relevant research on managed care plans serving people with disabilities in an attempt to outline research areas in DALTCP's 1995 research agenda on managed care. This paper was intended to stimulate discussion and feedback from experts which participated in DALTCP's meeting on managed care and people with disabilities. The paper provides a brief overview of existing research, summarizes policy issues of importance to the Department, and suggests research priorities for the future. Issues addressed in the paper include functional and demographic characteristics of people with disabilities in managed care systems; impact issues including consumer satisfaction, quality of care, accessibility, range of services, targeting issues; financing and reimbursement issues and quality assurance and monitoring issues.

RESULTS: This paper was presented at the second research agenda meeting, in December, 1995. Experts in the field discussed the research presented in the paper, and recommended areas of potential research and data collection. A summary of the meeting, and the experts' recommendations are available.

CONTACT PERSON: Andreas Frank, ASPE (202-690-6443)

COMPLETION DATE: January, 1995

LINK: <http://aspe.hhs.gov/daltcp/reports/resagmc.htm>

NATIONAL CONFERENCE ON MANAGED CARE FOR PEOPLE WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Mimi Bernardin, MedStat Group

PURPOSE: The goal of the national conference is to bring together researchers, policy makers, providers, and consumer representatives to examine the available empirical evidence regarding the impact on people with disabilities of Medicare and Medicaid managed care plans as well as managed care in the private sector. The conference would be organized along four broad themes:

- The service needs of people with disabilities and how well these needs are met in the current health care system.
- How people with significant disabilities actually fare vis-a-vis cost, quality, and access in different types of managed care arrangements (e.g. HMO's, PPO's, point of service plans, plans which integrate acute and long term care services) and how their experience in managed care compares with what would otherwise occur in the fee for service system.
- The strengths and weaknesses of methods available to providers for incorporating people with disabilities into managed care plans.
- Methodologies for measuring the outcomes of managed care for disabled populations.

PROGRESS TO DATE: A steering committee comprised of key governmental individuals will meet in February, 1996 to formalize the agenda, the invited guest speakers, the commissioned papers, and the date of the conference. A report of their meeting will be available in late February, 1996; a report of the conference will be available in Fall, 1996.

CONTACT PERSON: Andreas Frank, (202-690-6443)

COMPLETION DATE: Fall, 1996

LINK: <http://aspe.hhs.gov/daltcp/reports/96cfpkes.htm>

RESEARCH INVENTORY ON MANAGED CARE AND PEOPLE WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Mimi Bernardin, MedStat Group

PURPOSE: The purpose of the research inventory is to bring together all research activities related to managed care and people with disabilities. This inventory examines research projects focused on: utilization and costs, outcomes data, quality assurance activities, implementation analyses, risk selection/risk adjustment, case management practices, and others. Each research project's methodology is explained, the date of expected completion is listed, the sponsoring organization is listed, and principal investigator is listed.

CONTACT: Andreas Frank, ASPE (202-690-6443)

DATE OF COMPLETION: The preliminary draft of the inventory will be available in February, 1996. Revisions and updates of the inventory will be conducted periodically.

LINK: <http://aspe.hhs.gov/daltcp/reports/inventory.htm>

INNOVATIVE MANAGED CARE PLANS SERVING PEOPLE WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Sally Bachman, MedStat

PURPOSE: In spite of the rising level of interest by public and private payers in expanding managed care enrollment to include people with disabilities, there are few systematic data available about plans that successfully serve individuals with complex health care needs. The purpose of this project is to gather qualitative data about public and private managed care plans that provide efficient yet clinically appropriate care to working age adults with disabilities. Data will be gathered through site visits to approximately six plans and telephone interviews with another ten plans. Research questions will focus on consumer participation, provider training and recruitment, quality of care, risk adjustment and risk sharing arrangements, service delivery models, disease specific practice guidelines, and outcome measurement.

PROGRESS TO DATE: All site visits will be completed by February, 1996. To date, over 15 plans have been contacted. Sites to be visited include: Health Alliance, Intermountain Health Care, Group Health of Puget Sound, Community Medical Alliance, Arizona's Physician IPA, and others. Sites on which information has been collected on include: Fallon Community Health Plan, FHP, Harvard Community Health Plan, Kaiser Permanente - Colorado, MCARE, Pacificare, United HealthCare Corporation, and others. A written report will be available in April, 1996 and will be presented at the National Conference planned in September, 1996.

CONTACT: Andreas Frank, ASPE (202-690-6443)

REPORT AVAILABLE: April, 1996

IMPACT OF MANAGED CARE ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS

PRINCIPAL INVESTIGATOR: Sally Bachman, MedStat

PURPOSE: The purpose of this proposed research is to assess how different organizational and financial characteristics of managed care affect the health care utilization, service benefit package, management of referrals, and per capita expenditures for children with special health care needs. This study intends to address the impact of various organizational characteristics, financial incentives, and payment methods within managed care arrangements on the provision of health care services. In addition, this study intends to study the impact of managed care plans' organizational and financial characteristics on families' out-of-pocket expenses, and per capita expenditures.

PROGRESS TO DATE: All site visits will be completed by February, 1996. A written report will be available in April, 1996 and will be presented at the National Conference planned in September, 1996.

CONTACT: Gavin Kennedy, Ruth Katz, ASPE (202-690-6443)

REPORT AVAILABLE: Fall, 1996

LINK: <http://aspe.hhs.gov/daltcp/reports/startes.htm>

IMPACT OF MANAGED CARE ON CHILDREN WITH DISABILITIES IN FLORIDA

PRINCIPAL INVESTIGATOR: Elizabeth Shenkman, Ph.D., University of Florida --
Institute for Child Health Policy

PURPOSE: The purpose of this grant is to assess how different organizational and financial characteristics of managed care organizations (as measured by physician and other provider payment methods, financial incentives, risk sharing, benefit package design, and management of referrals) affect health care use, the child's functional status, families out-of-pocket expenses, and per capita expenditures for children with special health care needs. A total sample of 750 children will be included.

PROGRESS TO DATE: Data are currently being analyzed. Project began in September, 1995.

CONTACT: Andreas Frank (202-690-6443)

REPORT AVAILABLE: A final report will be available in Fall, 1996.

LINK: <http://aspe.hhs.gov/daltcp/reports/famooopes.htm>

IMPACT OF MANAGED CARE ON MEDICARE DISABLED BENEFICIARIES UNDER THE AGE OF 65

PRINCIPAL INVESTIGATOR: Leonard Gruenberg, Ph.D., DataChron, Inc.

PURPOSE: The overall purpose of this project is to learn more about utilization patterns, health status, access to care and patient satisfaction for the disabled beneficiaries who are younger than age 65 in both the fee for service and managed care systems. The project is a collaborative effort of DataChron Health Systems, Inc., the Center for Health Research at Kaiser Permanente, and the Fallon Clinic.

Data regarding utilization patterns of 2,300 under 65 disabled Medicare members of two TEFRA (risk) HMOs will be analyzed and compared with similar data regarding 2,000 disabled fee-for service Medicare recipients who participated in the Medicare Current Beneficiary Survey (MCBS).

This project will provide descriptive and comparison information about utilization, costs, patient characteristics, satisfaction and access in both TEFRA plans and fee-for-service arrangements for this population. In addition, this project will include an examination of the HMO case-mix issues and of HMO costs for these populations.

PROGRESS TO DATE: Data is currently in the process of being analyzed. The project began in September, 1995.

CONTACT: Andreas Frank, ASPE (202-690-6443)

REPORT AVAILABLE: A final report will be available in FALL, 1996.

DISABILITY SUPPLEMENT TO EXISTING HCFA EVALUATION OF THE OREGON 1115 DEMONSTRATION

PRINCIPAL INVESTIGATOR: Margo Rosenbach, Ph.D., Health Economics Research, Inc.

PURPOSE: The HCFA Evaluation examines the impact changes in the financing and delivery of health care services in the State of Oregon, through 1115 waiver demonstration authority. The disability supplement to the existing HCFA evaluation of the Oregon evaluation attempts to add a disability focus to the statewide evaluation. This supplement will focus on the experiences of disabled children and disabled adults (physically disabled, mentally retarded, developmentally disabled) enrolled in the Oregon Health Demonstration. The disability supplement will examine cost and utilization data, and link these data to functional data collected by state agencies. In addition, the supplement will conduct a survey of consumers and providers to examine issues of satisfaction, access, quality, health status, and functioning.

CONTACT: Andreas Frank, John Drabek (202-690-6443)

COMPLETION DATE: Fall, 2000

REPORTS AVAILABLE: Annual Progress Reports Available.

TRAINING FOR PROFESSIONALS CARING FOR PEOPLE WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Christopher DeGraw, Center for Health Policy Research, Georgetown University

PURPOSE: Effective health care for persons with disabilities often requires the services of both health care and human service professionals. The purpose of this project is to identify and describe particular settings where professionals and students in the health care and human service professions receive interdisciplinary instruction and practicum experience in the provision of health care to people with disabilities across a continuum of care. The project will include a literature review, site visit reports, and a final report on interdisciplinary training in relation to care for people with disabilities. The project is being conducted with the guidance of a Technical Advisory Group by the George Washington University Health Policy Center.

CONTACT PERSON: Kathleen Bond, ASPE (202-690-6443)

LINK: <http://aspe.hhs.gov/daltcp/reports/intdises.htm>

DISABILITY SUPPLEMENT TO THE NHIS SURVEY

PURPOSE: DALTCP has a longstanding commitment to improving basic data on disability, aging and long-term care. Typically, ASPE works with other DHHS agencies to augment planned or existing surveys; in particular ASPE's staff expertise and funding are used to (a) fill gaps in planned data collection activities, (b) make sure that surveys contain policy relevant questions (c) make sure that samples are of sufficient size to represent small but policy-significant populations (e.g. mentally retarded and developmentally disabled persons) and (d) help set priorities for data analysis.

One of the most significant activities currently underway is the **Disability Survey** conducted from 1994 through 1996. Among multiple agencies, DALTCP staff worked to coordinate plan, develop, coordinate, and identify sources of support for the Disability Survey. For the first time ever, the resulting analyses will provide detailed information on the prevalence and characteristics of children, working-age adults, and elderly Americans with disabilities; how they live, work, and go to school; health care utilization, income, assets, participation in Federal programs, health insurance; and non- medical services, including frequency of use, who pays for these services, and out-of-pocket costs.

CONTACT: Michele Adler, ASPE (202-690-6443)

HEALTH AND LONG-TERM CARE EXPENDITURE PATTERNS OF CHILDREN WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Bill Crown, SysteMetrics

PURPOSE: Because childhood disability is relatively rare, most surveys and data sets have relatively little information on the number of children with disabilities, their service use and expenditures. This project examines two very large claims data sets which are likely to contain a significant number of children with disabilities. The first of these comes from the Medicaid Tape-to Tape Project, and contains claims and enrollment data for every child covered by Medicaid in 1992 in selected States. The second comes from the MEDSTAT Market Scan data, and contains claims information from numerous employer-based private health insurance plans throughout the U.S.

Using diagnosis codes and other criteria, an attempt will be made to identify all children in the data set with severe disabilities. Data on the amounts and types of services that they use will be tabulated. Every child who receives Medicaid services will be included in the study, not just those who receive Medicaid coverage through SSI. This project builds upon a previous ASPE study which focused on children who were either high cost or who received Medicaid through SSI.

CONTACT: John Drabek, ASPE (202-690-6443)

LINK: <http://aspe.hhs.gov/daltcp/reports/children.htm>

COMPARATIVE OUTCOMES AND PROCESSES OF PREPAID MANAGED CARE FOR HIGH-RISK POPULATIONS

PRINCIPAL INVESTIGATOR: Richard Kronick, University of California at San Diego

PURPOSE: The purpose of this study is to learn more about the effects of managed care on persons with disabilities. Specifically, this study will add new information in five areas: 1) In what ways, if any, do providers reorganize the delivery of care to persons with disabilities under managed care? 2) When given a choice between capitated HMOs and providers paid under fee-for-service reimbursement, what subsets of people with disabilities are attracted to HMOs? 3) What are the effects of managed care on health care utilization and on health expenditures for persons with disabilities? 4) What are the effects of managed care on health outcomes and patient satisfaction? 5) What conditions, health care consumption patterns, or other indicators are particularly good markers of severe disability in working age adults and children? How can this information be used to construct reimbursement systems that encourage health plans to serve severely impaired subsets of persons with disabilities?

The study will conduct this research in four widely different settings: 1) The Community Medical Alliance, a health plan in Massachusetts that was created to develop specialized delivery systems for a small number of Medicaid eligibles with end-stage AIDS and with severe physical disabilities, 2) Detroit and surrounding areas in Michigan, where over 30,000 SSI recipients are receiving care in full at-risk HMOs and another 90,000 SSI recipients are receiving care in a primary care case management model, 3) Health plans in Columbus and in Cleveland that are centered around academic health centers, and 4) a health plan in central Missouri that is attempting to develop delivery systems that serve the needs of persons with disabilities in a rural setting.

CONTACT PERSON: Andreas Frank, ASPE (202-690-6443)

COMPLETION DATE: Fall, 1996. Progress Reports will be available sooner.

LINK: <http://aspe.hhs.gov/daltcp/reports/diarskad.htm>

PRIVATE PAYORS SERVING DISABLED INDIVIDUALS AND RESEARCH SYNTHESIS ON MANAGED CARE FOR PERSONS WITH DISABILITIES

PRINCIPAL INVESTIGATOR: Brian Burwell, MedStat Group

PURPOSE: In spite of the rising level of interest by public and private payers in expanding managed care enrollment to include people with disabilities, there are few data available about the experience of people with disabilities in either public or private managed care plans. The proposed research project will focus on two areas: 1) an evaluation of employer-based managed care plans for people with disabilities and 2) a synthesis of policy relevant research results produced by other investigators about the impact of managed care on people with disabilities.

The employer-based study will address policy issues in five major areas. The first issue that will be addressed is how to develop a methodology to identify people with disabilities in databases constructed from private insurance claims. Second, cost and utilization analyses will be conducted to determine the health care utilization patterns, and care coordination of people with disabilities in private health care plans. Third, cost data will be analyzed to examine the impact managed care has on total health care costs and various components of these costs for people with disabilities. Fourth, risk-adjustment methodologies of private payers will be examined in an attempt to learn more about how employers set rates with managed care plans, and how plans respond to various risk adjustment methodologies. Finally, the employer-based study will examine policy issues related to the functional status of people with disabilities serves in managed care plans (i.e. what functional data do employers collect? how do employers use this data to set rates? what types of outcome data do employers collect about persons with disabilities?, etc.)

In addition to the employer-based study, this project will attempt to synthesize ASPE-wide research related to managed care and people with disabilities with other privately and publically sponsored research related to managed care and people with disabilities. This synthesis will address some of the following questions: How does participation in managed care plans for people with disabilities vary by payment source, disability group or geographic area? Are the healthcare needs of people with disabilities being met through managed care arrangements? What are financing arrangements that are most likely to lead to both consumer satisfaction and appropriate care management in managed care plans?

CONTACT PERSON: Andreas Frank, John Drabek (202-690-6443)

LINK: <http://aspe.hhs.gov/daltcp/reports/privpay.htm>