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What Are the Effects of Managed Care on Adult Guardianship Agencies and Clients?

A Focus Group Report

by
Erica F. Wood
Commission on Legal Problems of the Elderly
American Bar Association

For the
Public Policy Institute
American Association of Retired Persons

The Public Policy Institute, formed in 1985, is part of the Research Group of the American Association of Retired Persons. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

The views expressed herein are for information, debate, and discussion, and do not necessarily represent formal policies of the Association.

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Foreword

As new options are offered to Medicare beneficiaries and as the number of Medicare beneficiaries enrolled in risk-based plans (such as managed care plans) grows, more individuals who are considered "vulnerable" (e.g., those who are frail, chronically ill, very old) will begin receiving care from these organizations.

In general, the research literature is inconclusive as to how older beneficiaries fare in managed care settings.[1] Still less is known about the experiences of particular subsets of the beneficiary population who are likely to make the heaviest demands on the health care system, in terms of expenditures and use of services. AARP is particularly interested in the experiences of the sickest and frailest members of society in managed care plans because of the importance of ensuring appropriate access to care and high quality services to vulnerable groups of individuals.

The September 1997 meeting of the National Guardianship Association presented a unique opportunity to investigate managed care from the perspective of those who are legal guardians of incapacitated individuals —the most "vulnerable vulnerable." In convening these focus groups, we hoped to learn from those with first-hand knowledge about the experiences of guardians and their clients in dealing with managed care plans. Although this research only affects a small audience, we hope that the knowledge gleaned from this work will contribute to the development of a research agenda that will inform our understanding of how incapacitated persons fare in managed care.

Many of the issues identified by the focus group participants are frequently reported by (or on behalf of) those who are high users of managed health care generally and may not be unique to the guardian/client relationship. However, it appears there may also be circumstances around the relationship that are unique and that require special arrangements and improved communication between guardians and health plans. Clearly, the agencies and health plans must better understand their mutual responsibilities.

On the basis of these focus groups, the author of this report, Erica Wood of the American Bar Association's Commission on Legal Problems of the Elderly, recommends several steps to modify managed care plan practices to improve service to this small but growing subset of the Medicare beneficiary population. While the Association has not taken policy positions on these particular recommendations, it supports public policy research to determine the impact of managed care systems on older persons, those with chronic conditions, persons with disabilities, and/or persons with low incomes.

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[1] See, for example, Miller, Luft. "Does Managed Care Lead to Better or Worse Quality of Care?", *Health Affairs*. September/October 1997.

Executive Summary

Background. Guardianship is a legal tool for the protection of vulnerable persons who lack capacity to make decisions about their financial and/or personal affairs. In guardianship proceedings, a court generally makes a finding of incapacity and appoints a surrogate to manage the affairs and/or to make personal and health care decisions for the incapacitated person. A guardian acts as a "fiduciary," meaning the guardian owes the individual a special duty of care and accountability. While guardians often are family members, friends, or trusted advisors, sometimes at-risk individuals -- especially indigent persons -- have no one willing and able to serve. Over the past 20 years, public and private guardianship agencies have developed at the local, regional and state levels to serve this susceptible "unbefriended" population.

Since many guardianship clients are especially frequent users of medical services and often need specialized treatment, they may be particularly affected by the tidal wave of managed health care. Driven by cost containment, managed care represents a paradigm shift in the practice of medicine -- a shift that brings both great risks and great opportunities for consumers.

Purpose. The purpose of this study was to identify issues for further research concerning the effect of managed care on adult guardianship clients and to inform the development of educational materials to facilitate the relationship between guardianship agencies and managed care plans.

Methodology. To explore the effect of managed care on adult guardianship clients and guardianship agencies, the American Bar Association Commission on Legal Problems of the Elderly conducted two focus groups on managed care at the 1997 National Guardianship Association conference. The 22 participants represented public, private not-for-profit and private for-profit agencies in 13 states, caring for several thousand clients. The majority of these clients were elderly, although a number were younger persons with developmental disabilities, mental illness or mental retardation. Many of the clients were indigent. Many were in nursing homes, assisted living facilities, and mental institutions, although some were living at home. Most had multiple physical and mental health conditions and chronic illnesses, and were generally a needy and fragile group. They were covered by Medicare, Medicaid or other health insurance, with the largest number generally in Medicaid.

Findings. Focus group participants described a number of specific actions they routinely take on behalf of clients in managed care, including seeking information from managed care staff, negotiating and advocating on matters concerning client care, selecting managed care coverage for clients, enrolling and disenrolling clients, seeking access to physicians, pursuing grievances and appeals, and accompanying clients on medical appointments.

Agency participants named important benefits of managed care for their clients, especially preventive services and coordination of care. Yet many voiced serious concerns including: physicians' and gatekeepers' lack of knowledge about the clients' disabilities and special needs; difficulty in getting geriatric assessments and access to specialized services;

reluctance of health plans to place or keep patients in the hospital, as well as possible premature discharge; plan responses to end of life treatment issues; the need for transportation to medical providers; and the need for provider visits to frail clients in long-term care.

Agency participants contended that the complexity and cost containment approach of managed care plus the rapid changes in the marketplace have made their jobs harder and consumed inordinate amounts of staff time advocating for clients. Participants indicated that not all managed care plans understood and responded to the agency's function as a fiduciary and surrogate decision-maker. They also outlined difficulties caused by lack of plan procedures for enrolling people who have a guardian, and for sending notices to the guardian.

Conclusions and Recommendations. While the focus groups give a "snapshot" of selected guardianship agency experience with managed health care, more study clearly is required on: (1) how managed care affects vulnerable groups in general; and (2) how managed care affects guardianship agencies and clients specifically. As guardianship populations and managed care populations both continue to grow, several of the focus groups' most salient themes may bear particular examination and suggest areas for future research. These include:

- Care coordination -- the role of care coordinators or "special needs coordinators" in managed care plans, as well as the education of primary care physicians and "gatekeepers" on aging, disability and cognitive impairment;

- Access to services -- the need for geriatric assessments, access to specialists and needed acute care, and availability of plan providers to visit clients in long-term care facilities;

- Enrollment -- mechanisms for enrolling individuals with questionable or diminished capacity; and

- Agency-plan partnerships -- the need for managed care plans to recognize and respond to the agencies' surrogate decision-making role, and fully involve the agencies in decisions about client health care.

What Is the Effect of Managed Care on Adult Guardianship Agencies and Clients? A Focus Group Report

I. Background

A. Introduction

Guardianship is "a crucial last line of protection for the ailing elderly"[2] and persons with mental disabilities. A legal tool for the protection of vulnerable populations, guardianship is a judicially created relationship in which a court gives one person (the guardian) the power and the duty to make personal and/or property decisions for another (the incapacitated person). The appointment of a guardian occurs when a judge decides an individual lacks capacity to make decisions on his/her own behalf. The guardian steps into the shoes of the incapacitated person to make decisions and see that they are carried out. Every day guardians make critical decisions about the medical treatment, care, placement, finances and lifestyle of incapacitated persons that judges have placed under their protection. A guardian acts as a "fiduciary," meaning the guardian owes the individual a special duty of care and accountability. While the number of adults under guardianship in the United States is unknown, one often quoted source[3] placed it at about 400,000 ten years ago; indications are it is larger today.

Guardians are often family members or friends. If the funds of the incapacitated person are sufficient, the court may appoint attorneys or other trusted advisors to serve. But many -- especially indigent persons -- have no family, friends, attorneys or others available as guardians. Over the past 20 years, public and private guardianship agencies have developed to fill this void. They serve the at-risk "unbefriended" population that may otherwise slip through the cracks of social programs, languish unattended or be subject to abuse and exploitation. These agencies are a last resort -- "a catchall for those who have no one else."[4] A number of states have developed public guardianship programs through a specially created office, a government social services agency or by contract with private providers.[5] A "public guardian" has been defined as:

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[2] Bayles, F. & McCartney, S., "Guardians of the Elderly: An Ailing System," Associated Press Special Report, p. 1 (Sept. 1987).

[3] Ibid., p. 5.

[4] Ibid., p. 14.

[5] Siemon, D., Hurme, S. & Sabatino, C., "Public Guardianship: Where Is It and What Does It Need?" Clearinghouse Review, National Clearinghouse for Legal Services, Inc., Vol. 27, No. 6, pp. 588-599 (Oct. 1993). See also Schmidt, W., et al, Public Guardianship and the Elderly, Ballinger Publishing Company, Cambridge MA (1981); and Schmidt, W., Guardianship: the Court of Last Resort for the Elderly and Disabled, Carolina Academic Press, Durham, NC (1995).

> "A nonprivate individual or agency (including an employee of the state or county, a governmental office, quasi-governmental program, or volunteer program that receives some state or county government funding and/or oversight) lawfully invested with the power and duty to take care of people and manage their property and rights because they are considered incapable of managing their own affairs by reason of some peculiarity of status."[6]

In some states these government-funded programs serve hundreds of incapacitated persons throughout the state. At the same time, a burgeoning number of private for-profit and not-for-profit agencies have sprung up to meet the growing needs as well.[7]

Guardianship agencies may be statewide, regional or local. They may be staff-based, volunteer-based, or use a combination of models. Some serve specific populations (older persons, those with developmental disabilities or mental retardation), while others have a broader clientele. The agencies may receive public or private funding -- sometimes including fees from the estates of those able to pay -- or may depend on a combination of these resources. All of the agencies exist to serve those who otherwise would be in society's "no man's land." They routinely make decisions about where their clients will live, how their money will be spent, and what health care they will get -- sometimes including tough judgment calls on life support systems and end of life treatment. With the greying of the population, the aging of the baby boomers, the survival of more persons with disabilities, and changes in the social services system and in medical technology**,** the need for adult guardianship is bound to increase.

Today, adult guardianship agencies are facing a new challenge: responding to the tidal wave of managed health care. Managed care recently has become a dominant force in the private sector,[8] and increasingly, an important force in the public sector as well. The proportion of Medicare beneficiaries enrolled in managed care plans has more than doubled in the past decade, and Medicaid beneficiaries now are enrolled in some form of managed care in almost every state.[9] Moreover, Medicare+Choice, enacted in 1997 by Congress in the Balanced Budget Act,[10] authorizes a wider range of managed care choices. Driven by cost containment, managed care represents a paradigm shift in the practice of medicine -- a shift that brings both great risks and great opportunities for consumers. Since many guardianship clients are especially frequent users of medical services and often need specialized treatment, they may be particularly affected by the managed care trend.

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[6] Seimon et. al., "Public Guardianship,"p. 588.

[7] The Center for Social Gerontology currently is compiling information on guardianship service providers throughout the nation in its National Study to Assess and Improve the Quality of Guardianship Service Providers. The Center is located at 2307 Shelby Avenue, Ann Arbor, MI 48103.

[8] The proportion of employees in medium and large firms enrolled in managed care has increased from 29% in 1988 to 81% in 1997, according to KPMG Peat Marwick, 1997, cited in Kaiser Family Foundation, "Malpractice Liability and Managed Care Plans", in "Market Facts: The Changing Health Care Marketplace Project"(November 1997).

[9] Kaiser Family Foundation, "Medicare at a Glance" & "Managed Care," The Kaiser Medicare Policy Project (April 1997); and Kaiser Family Foundation, "The Medicaid Program at a Glance," The Kaiser Commission on the Future of Medicaid (November 1997). Also see Health Care Financing Administration, http://www.hcfa.gov.

[10] Public Law 105-33. Sec. 4001 of the Balanced Budget Act adds a new Part C to the Medicare program by establishing sections 1851 through 1859 of the Social Security Act as "Medicare+Choice."

B. Methodology

To explore the effect of managed care on adult guardianship clients and guardianship agencies, the American Bar Association Commission on Legal Problems of the Elderly conducted two focus groups on managed care at the September 1997 National Guardianship Association (NGA) Conference. The focus groups were used to identify issues for further research and to inform the development of educational materials. The NGA meeting provided an ideal forum, drawing both public and private guardianship agency representatives from many states.

In July, the ABA Commission and AARP sent a recruitment letter (Appendix A) to all NGA members, inviting them to express interest in participation in a focus group on managed care by returning a form with their name, agency, address and telephone number. The Commission received close to 70 replies, and listed these in a state-by-state table indicating whether the agency was public, private not-for-profit, or private for-profit. In cases where this was not clear or not previously known, staff checked by telephone. Staff then selected 26 invitees (13 for each of two focus groups), dividing them evenly by the three categories, and seeking representation from different states. Staff sent invitation letters, and made follow-up telephone calls to ascertain attendance. After a number of substitutions due to invitees' schedules, a final list emerged, although four invitees from the second group ultimately did not participate.

The focus groups were facilitated by trained AARP staff. ABA Commission staff observed the sessions, took notes and made audiotapes. Discussion centered around 12 questions with additional prompts for added insights (Appendix B). Invitees were asked to fill out a background questionnaire in advance, giving information about their agency and clients. Of the 22 focus group participants, 17 filled out the questionnaire. These responses served as the basis for the overview below on the focus group participants and the guardianship clients (see annotated questionnaire at Appendix C).

C. Focus Group Participants

One focus group had 13 participants, and the other group had nine. The total of 22 included representatives of five public guardianship agencies, eight private not-for-profit agencies and seven private for-profit agencies (as well as one individual from a state agency on aging and one from a university) in 13 different states. Agency size ranged from 16 clients in a local program to 723 clients in a statewide program. The focus group participants generally were the agency program directors or coordinators, the public fiduciaries, presidents, or partners. Their responsibility ranged from coordinating local programs (in the case of statewide systems) to supervising guardianship case managers, to serving dozens of clients individually.

In most cases, the participants' experience with managed care was substantial. Almost all had clients in managed care, with the number ranging from three to 366 managed care clients. The majority of those who volunteered and were selected for the focus groups were from states with a high penetration of managed care. In three cases, participants had a substantial clientele in managed care, but had not calculated the exact number or percent. In two cases, they attended the focus group because they anticipated imminent large scale enrollment of Medicaid

beneficiaries in managed care in their state or in their caseload, and in one case because the agency was being solicited by plans to enroll their clients. Most of the participants dealt with several managed care plans for their clients. Two dealt with 20 or more plans, two with seven plans, and the remainder generally dealt with between two and six plans.

D. Guardianship Clients

Together, the focus group participants stood in a fiduciary capacity to several thousand clients. The majority of these clients were older persons, although a number of participants served populations with developmental disabilities, as well as younger clients with mental illness and mental retardation of all ages from 18 up. The average age reported ranged from 51 to 86.

The agencies served large numbers of indigent persons, but their clientele represented a wide range with respect to income and assets. The average income reported by month ranged from $484 to $3,000 per month; and the average income reported by year ranged from $6,000 to $18,000 per year. The public agencies and private not-for-profit agencies served particularly indigent populations. One statewide program reported serving a clientele that was "82% indigent." Of the private for-profit agencies, most served a clientele of modest means, although one agency reported serving a wealthier clientele in addition to those of modest means, with incomes up to $17,000 per month.

Client assets generally were minimal or non-existent, but ranged from zero to $5,000,000. Of those participants who reported client assets, four said the assets were $2,000 or less, and five said $100,000 or less. One noted that private pay client assets were $200,000, while indigent client assets were zero. On the high end, three for-profit agencies reported serving clients with respective assets of approximately $175,000; $500,000; and $100,000 - $5,000,000.

The agencies had managed care clients in nursing homes, assisted living facilities, mental institutions, and in the community living at home, with the largest numbers in nursing homes and assisted living (see annotated questionnaire, Appendix C). They had managed care clients on Medicare, Medicaid, and covered by other health insurance, with the largest numbers generally on Medicaid (Appendix C). They reported that many of their clients were dually eligible for Medicare and Medicaid, with the number ranging from 7 to 253 such clients.

Most clients had multiple physical and mental health conditions, and several agencies described their clients as "100% at-risk and vulnerable," "medically fragile," "with serious health problems requiring multiple specialty areas," "with longstanding mental illness," and "with high medical needs." Cognitive impairments included dementia (especially Alzheimer’s Disease), mental illness, mental retardation, depression, and brain injury. One participant noted that 30-35% of the agency clients were "dually diagnosed with developmental disabilities and mental illness, requiring ongoing psychiatric care." The agencies named a list of specific medical treatments required by clients, including: psychiatric care, cancer treatment, gastrostomies, tracheostomies, colostomies, medication for diabetes, medication for hypertension, edema boots, oxygen and cataract surgery, as well as podiatry, physical therapy, occupational therapy, and speech therapy.

Thus, the client population represented by the participating guardians was a needy and fragile group with high medical requirements. Many had multiple medical conditions calling for highly specialized care, equipment and therapy. The central question put to the focus group participants was: how does such a client fare in a managed care environment? Beyond this, what is the role of the guardianship agency in supporting such a client in a managed care environment?

II. Findings: Agency Perspectives on Managed Care

A. What Actions Do You Take for Your Clients Concerning Managed Care?

Focus group participants described a number of specific actions they routinely take on behalf of clients in managed care. They discussed initial decisions about selecting managed care coverage for their clients as well as their role in the enrollment process, disenrollment, agency-plan contacts, grievances and appeal, and overall advocacy. They also described their actions in accompanying clients on medical appointments, and in reporting to the court on activities relating to the managed care coverage of their clients.

In general, guardianship agencies appear to spend a great deal of time on the phone seeking information from managed care staff or negotiating matters concerning client cases. Many participants expressed frustration with plan personnel's lack of understanding of their clients' disabilities and exceptional needs. They also reported they often are unable to get the information they need on plan policies and procedures. Comments included:

> "I think the number one concern is about the gatekeeper. More time is spent by myself and my staff trying to explain to them a crisis situation."
>
> Sometimes plan personnel "can't tell you who the participating physicians are. [Lists] are not updated" often enough.
>
> "I've called the same plan several times requesting the same thing, and have to do several different procedures to get the same result more than once."
>
> "They don't have time to train their staff. . . so you can go around a long time to find somebody that will commit to something."
>
> "[Plan staff] that review the record and make decisions are not health care professionals" and may not fully understand "what we are talking about."

1. Decisions About Selecting Managed Care Coverage. In each group session, participants cited a number of factors bearing on the choice of health insurance coverage for their clients. Some pointed out that many clients already are enrolled in plans when the guardianship appointment is made -- "most of the people that come to us usually already are on insurance." Others observed that they sometimes have no choice for their Medicaid clients who may be assigned to specific plans.

When a choice is offered, the agencies seek to match client needs and income with specific managed care programs -- "We're choosing in part based on the client's particular set of problems and the match with a managed care company." For example, one participant explained that most of her clients have developmental disabilities (DD), but the majority of plans do not provide any specialized services for the DD population -- "In this case we need to choose based on where the few physicians that specialize in DD are." Other considerations mentioned were who the client's primary care physician has been and whether that doctor is in a particular plan, whether there are any coinsurance requirements, whether the agency has had good experiences with a plan for other clients, the availability of providers that will visit mental health/long-term care facilities, and the availability of transportation.

2. Enrollment. The concept of guardian as surrogate decision-maker can complicate the enrollment procedure. One participant remarked that "There's nothing, no mechanism in the whole enrollment process to let [the plans] know who is enrolling people." There may be several consequences to this. First, plan personnel may not recognize that guardianship agencies have authority to enroll incapacitated persons. One agency staff person described being told, "You can't enroll anybody. They're going to have to enroll themselves." Second, once a client is enrolled, the agency may not receive information or notices, since these may be sent to the incapacitated person at his/her own address. Third, incapacitated people may enroll without the knowledge of the guardianship agency -- and may enroll in multiple plans, causing administrative entanglements that must be sorted out. One client, for example, had enrolled in several plans, and the agency director described how she contacted the plans to explain that the client was under guardianship and could not make decisions. Other agencies, however, "have not experienced this at all."

3. Disenrollment. Guardianship agencies also may spend time on disenrollments. Some agencies reported disenrolling clients if they foresee a problem or feel the match with individual needs is not appropriate -- "We might try to disenroll them [the clients] before they have any problems . . . and get them into something else." If problems occur, the agency may disenroll the client right away, and plans usually are amenable to this. "They're usually glad. These are not cheap clients." Yet other plans, participants reported, seek to deter disenrollments and “try to keep you." Finally it was noted that clients who have enrolled in multiple plans may cause agencies -- and plans -- to devote scarce resources to disenrollments.

4. Access to Physicians. Guardianship agency staff may have difficulty in reaching the client’s physician to discuss treatment options. The physicians have full caseloads, and may not be readily available by phone. “The doctors are overworked with patients. You have to wait all day for a return call from the doctor, and then they call when you’re on the phone,” a participant lamented. Another agreed that “physicians don’t have the time to talk to you because they’re seeing so many patients.” One remarked that she has to go through nurse practitioners to reach doctors, and she is concerned that the nurses may not accurately convey patient needs. (Participants did not, however, specifically compare this to physician access in a fee-for-service system, in which physicians also may be very busy, although one observed that in managed care there is “an adversarial relationship with physicians . . . that creates a high tension level”, among agency staff.)

5. Grievances and Appeals. While some agencies reported no experience with grievances and appeals, one participant stated she files one or two grievances each week. Several expressed frustration at delays in the grievance and appeal process. "By the time [the plans] respond to you, its too late," one observed. Another explained, "You might start, and three months later you're still waiting to hear." One participant felt such delays made complaining pointless, but others stated it was important to voice concerns. "There comes a point when you really have to let them know" if the agency is dissatisfied with client care.

6. Advocacy. Almost all of the participants emphasized that their agencies spend increased amounts of time advocating for clients in managed care--beyond, what they contend, would be necessary with traditional insurance coverage. They stressed the fact that their clients are vulnerable and unable to fend for themselves, and the guardianship agencies, as fiduciaries, must devote time and energy on a day-to-day basis to get needed medical care:

> "We spend a lot of time advocating for them. And without this, they don't get good care."
>
> "You have to advocate, advocate, advocate, since there's no family involved."
>
> "The work to be an advocate for someone with even partial capacity is a very high workload."
>
> "We've got so many people that are so incapacitated and can't advocate. It requires a lot more assertiveness [than in the fee-for-service system]."

7. Medical Appointments. Participants varied on the necessity of accompanying clients on appointments with medical providers. Some did not feel this practice was necessary regularly. Others go with clients when they expect a problem. "The case manager for our agency may go, or if it's a really big problem, I will go myself." Several said they go now (for their managed care clients), but did so less in a fee-for-service environment. "We used to not have to go on every one, and that's why there's an impact. Somebody has to go every time."

8. Report to Court. Agencies also varied in whether and to what extent they specifically include all of these managed care activities in their annual guardianship report to the court. Several stated they do not include it. Others do, "as a backup to how many hours we've spent."

B. How Has Enrollment in Managed Care Plans Affected Your Clients?

Agency participants named a number of important benefits of managed care for their clients, especially in coordination of care. Yet many voiced serious concerns, especially in five major areas. While the impact of managed care appeared mixed, the negatives seemed to predominate in the focus group.

1. Overall Benefits; Coordination of Care. Most of the participants acknowledged that their clients received more preventive services in managed care -- for example, well visits,

flu shots and mammograms. One remarked that "most of my clients have not been to a doctor for five to ten years for prevention. They're not used to going for wellness." She welcomed this as a positive change. Some participants noted their clients received more dental and eye care in managed care plans, although others recognized this was still a critical unmet need. Some described specific treatments for elderly and other frail clients that have been exactly what was needed: "We had a 97-year-old woman who just had eye cataract surgery, and it's the most wonderful thing." Another advantage cited was that managed care standards of practice have excluded "some of the truly lousy physicians."

One particular benefit of managed care is the potential for care coordination and planning. Participants noted that some plans have designated special care coordinators for older persons and persons with disabilities, or those with special needs. This seems to work well, particularly when the plan's care coordinator and the guardianship agency's case manager work together on individual cases.

> "One of the HMOs assigned one care coordinator to special populations, persons with developmental disabilities and so on....Once I hooked up with him, he's been really helpful."
>
> "We have exceptional-needs coordinators in plans in my state, and every client that is particularly tough is assigned to an exceptional-needs coordinator...and we're in pretty routine communication with them."
>
> "We have one person that we really communicate with, a case manager."
>
> "The HMO care coordinators are finally becoming experts. [The agency's case manager] and the HMO care coordinator should be working together but they're not. Sometimes they're working against each other."

Other plans, however, lacked a care coordinator position. "They need to designate one person to deal with and communicate with," one participant suggested. Another maintained that "because you don't have a specific person assigned for the HMO to your client, no one's in charge to know what the primary diagnosis is, so we have to be more persistent."

2. Concerns About Managed Care. There was a perception among many of the participants that managed care plans often lacked sufficient focus on the exceptional needs of agency clientele -- that, in general, "frail elderly are not well served in managed care," particularly in Medicaid managed care, where attention is more likely to be devoted to families with children. One agency director felt some plans have the attitude that "if there is a public fiduciary, somehow these folks are not as important, if they're old." She cited the example of plan reluctance to address depression in older persons. Another participant reflected that "there are a number of elderly who would do much better with psychotropic medication, but primary care physicians don't want to address this." Guardianship clients may need multiple prescription drugs, and while HMOs may cover more medications than fee-for-service, "there are different formularies for different plans, and the physicians don't even understand" what is covered by which plan. Two participants commented that, despite managed care's preventive approach and

potential for care coordination, plan physicians seemed to lack the time or knowledge of aging/disability to track specific client needs and to recommend timely solutions:

> "I find that usually what happens is they [plan providers] tend to let things go, and so [the clients] are in the worst condition by the time they provide services...and it costs more for the HMO to treat them, since they do not treat right away."
>
> "We had a client on a ventilator, and we had recommended to get her off the ventilator, and the HMO said no, but we spent time to get them to work with us, she got off the ventilator, and she's doing fine. Seems doctors are more creative in fee-for-service."

Focus group members raised specific concerns about managed care in the following areas:

a. Assessments. A theme that surfaced repeatedly throughout both focus groups was the need for geriatric assessments. The participants observed that effective assessments are critical to court determinations of incapacity, to design of a treatment plan, and to decisions about hospital discharge and long-term care placement.

Two participants were troubled by plans' lack of responsiveness for evaluations needed in the judicial process. One reported, "before we go to guardianship, the court wants a geriatric evaluation, and in the managed care that's offered [here] for seniors, they don't understand what a geriatric evaluation is. It might be four lines on a page." Another added, "lt might take 90 days and you're trying to coordinate with a court system with a 30-day turn-around."

Several agency representatives noted difficulties in getting evaluations after the determination of incapacity, to best identify treatments and services. "If your client has dementia, getting evaluations is difficult," one stated. According to another, "you can't get assessments. There are clients that you know are fixable and you can't get assessments. [The plans] say there's no turning the person's cognition around. They won't use a more sophisticated meds expert. They'll use a general practice person." This may be particularly problematic if the person has been without medical care for long periods. Another issue cited was the practice of discharging people from the hospital without an assessment and treatment plan. One participant recounted her anxiety about plan enrollees who were discharged from hospitals without a clear diagnosis, and placed in nursing homes, where there were no assessment resources.

b. Access to Specialized Services. Two agencies noted that they serve large populations of people with developmental disabilities, and that many of these individuals are now growing older, and some have mental illness. Finding plan providers who can respond to these complex needs is challenging. One participant explained, "Some of my biggest worries are about people who have really specialized needs, somebody that's elderly and developmentally disabled and mentally ill. There's no way they'll ever get their medication needs met because the very few people that specialize in whatever anomalies they have may not be in the health plan. The problem is increasing as people with developmental disabilities are living longer and becoming elderly." Another added, "We serve people with developmental disabilities with a high level of medical needs...A big problem is access to specialists. Our folks use neurologists

and orthopedists and a range of specialists. (The managed care plan may have) a good primary care physician, but the specialists are not on the plan's list."

Three agency representatives underscored the need for behavioral health specialists and psychologists. They said there are very few geriatric psychologists available through the managed care plans. A number of older persons are depressed, and need psychological counseling. One guardianship agency reported that it contracts out privately for this, and pays independently, without insurance coverage.

One comment concerned lack of adequate home health services. After a hospital stay, "the follow-up home health visits are limited, so where you might be able in the past to have two to three weeks of home health, plans will authorize two visits. Or they won't authorize, but they'll do physical therapy maybe in one visit to teach the caregiver what to do, where in the past they would have a number of visits to get them on the road." She added that the caregiver may be frail, old and under duress as well.

c. Lack of Sufficient Hospitalization; Premature Discharge. Most of the respondents (15 comments) remarked about the reluctance of managed care plans to place or keep patients in the hospital, possible premature discharge, and the resulting "bouncing ball" syndrome in which clients are discharged, returned to acute care, and discharged and returned again.

Several participants experienced cases in which they believed clients needed hospital care, but it was not authorized by the managed care plans in which their clients were enrolled. One agency director remarked that "There are a number of clients who need to be stabilized, but managed care behavioral health won't hospitalize them unless they're in imminent danger." Another described an alarming occurrence in an abuse situation. "One of the most scary experiences is with abuse, taking people out of their home. You've got a court order, you're going in with the locksmith, the police, the ambulance, and then managed care won't put them someplace. You can't get a placement. They've got scabies, they've got bedsores, they've got you name it, and [plans] say that's not acute care material."

Other participants described cases in which clients were discharged from the hospital too soon, discharged without a care plan, or discharged without the consent of the guardian:

> "My experience is that hospitalizations are much shorter. There's a willingness to discharge people who are at risk as far as we can see, and yet we're told they're OK to go."
>
> "They don't have a safe discharge plan."
>
> "There's no sense of any plan. The plan is to get them out as quickly as possible."
>
> "You say 'We don't have a treatment plan' and they say 'We've got to get him out of the hospital bed.' Why? They still need medical care."
>
> "People have been discharged without my knowledge."

"What managed care plans want is [for the court to appoint] guardians so they [the patients] won't spend any extra hospital days, and I say, if you've got a guardian, this isn't going to help you do that."

On the other hand, one participant had a different view of the discharge issue. "I don't know that I've experienced any premature discharge," she reported.

Several agency staff were troubled by transfers from a hospital to another hospital, to long-term care or to community settings. Such practices, as well as repeated hospital re-entries were believed to cause their clients significant transfer trauma and discontinuity in medical care.

One noted that "a problem has been that if an elderly person is hospitalized and then goes to a nursing home, their regular doctor doesn't follow them. They're assigned a different doctor who has no history of working with them, and we have to re-educate that doctor."

Another reported that lack of mental health and other specialized services causes repeated hospitalizations which do not help the clients. Because of the lack of these services, "we're often faced with repeated hospitalizations, which still don't get to the problem of the mental illness."

A third participant was frustrated at cost containment efforts that result in the denial of needed acute care. "They don't really mind shipping them out [of hospitals] and then bringing them back in 48 hours in worse shape because they figure they've saved money for two days of hospital care.

d. End of Life Treatment. While the focus group questions did not specifically include end of life treatment and decision-making, five participants spontaneously addressed the issue. They were alarmed by plan reactions to client values, and by tendencies among plan personnel to pressure for discontinuance of treatment.

"We've had doctors asking us [for authority] to write DNR ["Do Not Resuscitate"] orders when they know the client would not have wanted that."

"They want DNRs up front."

"We have physicians that request our guardians [for authority] to do a DNR order...It's not just ageism, but if they're mentally retarded, [plan personnel] say 'What quality of life do they have?'"

"They [plan personnel] can't understand why it's a priority to advocate for someone who wants to be kept alive, if at all possible."

One participant described a plan's approach to advance directives as too coercive. "I put 'undecided' [on a form asking about the client's desires on withholding nutrition and hydration] and they said that was not acceptable. Before they know what's going on, they want an answer."

e. Need for Transportation; Need for Provider Visits. Nine comments emphasized the need for transportation, particularly in rural areas, and the need for provider visits to frail clients in long-term care settings. While some plans provide transportation, geography and plan boundaries often remain a problem for the focus group participants' clients. According to agency staff in a rural region, "Geography is a factor. Usually there's only one game in town, only one hospital in a county. In some cases, people are 60 miles from routine medical care." It may be up to the guardianship agency to transport clients. "How," asked one, "can I afford to take clients to this and that HMO?"

Thus, guardianship agencies welcomed plan inclusion of transportation services, and this was sometimes a factor in selecting plans for clients. One participant described a managed care system in her area that "will provide transportation. We try to get people into the system so they can have access to that." However, even if transportation is provided, it may be difficult for older people in rural areas to use. "Transportation is provided," recounted one agency representative, "but we're in a rural area and you've got commutes of 40 miles....A van picks up as many people as it can en route to services, so you have an elderly person on that van from 7:30 a.m. until they get back at 6:00 at night. They get to different facilities and have to wait for everybody else to get picked up or dropped off."

Clients who reside in long-term care facilities may not be able to use transportation, or to leave the facility. Several comments highlighted the reluctance or inability of providers to make visits to these facilities. "Providers don't like to come to nursing homes," according to one participant. Another observed that clients in long-term care often cannot benefit from many of the services the plan offers, since they cannot get to them. "Plans usually don't send podiatrists to convalescent homes. The companies do not provide for people that are in facilities that cannot be transported to their doctors, and so what good is it for the senior that can't get out of a convalescent bed...to have podiatry care, annual eye visits or annual audio visits" if they cannot get there. In other cases, plans do send doctors to make facility visits, but the client must then use this doctor rather than the one they have used previously. "Clients in a nursing home have got to use the doctor that comes out for the plan...even if they've been with [another doctor] for 20 years." Participants did not discuss why the agencies continued the managed care enrollment for these clients.

C. How Has Client Enrollment in Managed Care Plans Affected Your Agency?

In addition to the effects of managed care on their vulnerable client populations, focus group participants described direct effects on the operation of their agencies as fiduciaries. They discussed changes in day-to-day staff activities, as well as plan recognition of and response to the guardianship role.

1. Day-to-day Agency Staff Activities. The great majority of participants (18 comments) contended that the complexity; rapid changes in the marketplace, including mergers and acquisitions; and the cost containment approach of managed care have made their jobs harder and consumed inordinate amounts of their already limited staff time. This is especially true when they must deal with multiple plans with differing procedures and coverage

requirements, all of which are subject to change. Interfacing with managed care plans was described as "draining," "a whole lot more paperwork," "a black hole," "a whole other level of bureaucracy," and "a huge workload" requiring "a lot more assertiveness."

One participant estimated that with the advent of managed care, his agency now spends "30% more time" advocating for client health care, and another claimed it consumed "100% more time....because what used to happen was I would get a call and be informed, generally speaking [about patient care]. Now I need to go and call....Everything is something I now initiate." An agency director reported that "we use much more staff time, and much more sophisticated staff time. I can't send case aides with people. I have to send guardians [for] negotiations. They're actively negotiating on the part of the client in every appointment." A second director explained, "We now have a managed care coordinator. It was a position we never needed before, because guardians can't keep up with the day-to-day changes, which plans are open, which plans are or are not offering which services. It just requires a knowledge base and time that they just can't keep up with." A third director summed all of this up as "an enormous unfunded mandate on the service system."

2. Plan Recognition of Guardianship. In the 15 comments participants made on the health plans' recognition and response to the concept of guardianship, the key was whether the plans understood and respected the agency's function as a fiduciary and a surrogate decision-maker. In some cases they did. When a plan learns of the guardianship, according to one agency, "the doctors open their records up. They'll call me." Another agreed: "I think we get good cooperation as far as making decisions." A majority, however, indicated a need for more recognition of the guardianship role, and more direct involvement of their agencies in clients' health care.

> "The plans need to recognize we're partners in this, and that we need to look out for the people we've been court ordered to care for, and that we aren't going to go away. And we've had some success when they finally realize we aren't going to go away."

> "It occurred to me how little I am now involved in any treatment processes with managed care. It seems to sort of go on, and I may be informed of the outcome, but not of the processes at all, other than to consent."

Five participants were troubled that plans or plan providers failed adequately to consult with the guardianship agencies about medical treatment; in some cases, participants reported, plans had made decisions or provided treatment without the agency's knowledge or consent.

> "People would be discharged without my knowledge. A plan or a non-plan will have been done. And essentially I will be told I need to consent to have some treatment and that's it."

> "Many times I've been asked to sign without any explanation of the implications of what I'm signing."

> "I had a physician make a choice for one of my clients just last Thursday, without my even being contacted."

"We've had health plans go ahead and make medical decisions and never called us in the process. Just leave us out and never called us in doing basic procedures or surgery on our clients without telling us at all."

"I'm not informed until things have been done, and being informed after is very frightening because I have an obligation to take care of people."

To make plans "partners" in the health care of clients, several participants agreed that educating managed care personnel about guardianship and surrogate decision-making would help. "Lots of education is needed." One obstacle, though, is the high turnover of plan staff and providers. "Our guardianship association has brought people in to talk [with the plans about guardianship]," explained one agency director, "and what we've found is because of mergers and people leaving, turnover, the process needs to be done again."

III. Conclusions and Recommendations

The focus groups give a snapshot of fewer than two dozen of the nation's hundreds of adult guardianship agencies "on the front line" in securing health care for a frail and incapacitated clientele -- in this case, several thousand vulnerable and often chronically ill individuals. Agency staff are overworked and anxious, and may sometimes have funding constraints as well.[11] It is difficult to sort out how much of the frustration they expressed is due to managed care and how much to the challenging nature of their role as a "last resort" for society's neediest. Moreover, the snapshot is taken at a still tumultuous time in the transformation of the health care delivery system. The managed care industry is in flux, with mergers and acquisitions, experimentation with new capitated delivery forms, and a backdrop of massive state and federal governmental changes as well. Additionally, "the fee-for-service sector is also changing rapidly, and differences between HMOs and fee-for-service are narrowing."[12] Advocates for vulnerable enrollees are riding these tidal waves of change.

The question of how managed care affects this fragile population and these fiduciary agencies cannot, of course, be answered by two focus groups. Indeed, perhaps the most evident outcome of the focus groups is that, given the comments of the participants, far more -- and more rigorous -- research is needed on how managed care affects the guardian's role specifically, and more generally, how vulnerable populations fare in managed care. This echoes observations of several experts. "Little is known about health outcomes in managed care for the elderly," according to a 1994 article in the American Medical Association's journal.[13] Similarly, a 1996

[11] For a recent detailed examination of guardianship agency clientele, and the extent and kinds of services provided, see Schmidt, W., et. al., *Evaluation of the Virginia Guardian of Last Resort and Guardianship Alternatives Project*, available through the Virginia Guardianship Association, Richmond VA (First Year Evaluation, March 1997; Second Year Evaluation, July 1997). This report describes the demanding nature of the job and the diverse needs of the clients. Annual reports of state public guardianship agencies also are useful.

[12] Meyer, J., Silow-Carrol, S. & Regenstein, M., "Managed Care and Medicare," New Directions for Policy, American Association of Retired Persons Public Policy Institute, #9614, p. 22 (August 1996).

[13] Miller, R. & Luft, H., "Managed Care Plan Performance Since 1980: A Literature Analysis," Journal of the American Medical Association, Vol. 271, No. 20 (1994).

article in the journal of the American Society on Aging[14] notes "a paucity of research, combined with a surfeit of anecdotes, resulting in a lot of rhetoric on the various sides of many issues" concerning managed care and older enrollees. A 1996 AARP publication maintains that "more research is needed before conclusive statements can be made about how effectively managed care plans can serve Medicare beneficiaries."[15] Finally, a 1997 study recommends greater focus on the specific problems of Medicare/Medicaid dual eligibles.[16]

As guardianship populations and managed care populations both continue to grow, several of the focus groups' most salient themes may bear particular examination. Further research would provide a more in-depth understanding of the relationship between guardians and the health plans in which their clients are enrolled. In addition, the following recommendations could help to improve access to care for vulnerable populations, including the clients of the agencies that participated in these focus groups.

A. Care Coordination

Managed care plans are designed to coordinate the delivery of services. That is inherent in their purpose and structure. Care coordination could be especially beneficial for frail older enrollees with diverse needs, cognitive impairments and difficult medical histories. Focus group comments indicated that when this works, it is a boon to guardianship clients and, in turn, helps the agencies. "Special needs coordinators" for exceptional populations seem particularly helpful. But comments also revealed that all too often plan coordination is lacking, and that the brunt of actual care coordination, as well as advocacy for special client needs, falls on the fiduciary agencies. Moreover, several agencies noted that "gatekeeper" primary physicians who should, in theory, be coordinating a plan of care may not be trained in treating older persons, especially those with disabilities, and may lack the necessary time and experience. As a result, "there may also be an incorrect diagnosis, leading to delayed or incorrect treatment or a misdirected referral."[17]

Focus group participants highlighted the importance of designating a special needs coordinator, or at least a health plan contact responsible for communication with the guardianship agency about client needs. Also critical is education of both the coordinator and the primary care physician on aging, disability, and cognitive impairment.

B. Access to Services

Experts have speculated that capitated systems may be problematic for older persons and other high-risk populations. "A capitated fee system, by its very nature, creates incentives that can be unfriendly to individuals who require substantial resources from the health care system."[18]

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[14] Fox, P. & Fama, T., "Managed Care and the Elderly: Performance and Potential," Generations, American Society on Aging, Vol. XX, No. 2, p. 32 (Summer 1996).

[15] Meyer et. al., "Managed Care and Medicare," p. iii.

[16] Feder, J., Medicare/Medicaid Dual Eligibles: Fiscal and Social Responsibility for Vulnerable Populations, for The Kaiser Commission on the Future of Medicaid (May 1997).

[17] Meyer et. al., "Managed Care and Medicare," p. 9.

[18] Ibid.

A major study published in 1996 found that for chronically ill elderly Medicare patients, declines in physical health were more common in HMOs than in fee-for-service, and patients who were elderly and poor were more than twice as likely to experience such declines in health in an HMO than in fee-for-service.[19]

While the focus group agencies did not specifically point to declines in their clients' health care status since enrollment in managed care, they repeatedly commented on lack of assessments (especially geriatric assessments), difficulty in accessing specialists, and insufficient length of hospital stays. The cumulative effect of these factors could be deleterious to the health of the frail guardianship population. Indeed, at least one study has indicated "some evidence that restricting access to specialists sometimes has adverse effects on patients, posing particular risks for people in poor health."[20] Solutions for guardianship clients might include:

- Plan provision of complete assessments for each guardianship client, upon requirement for court hearing, upon enrollment, upon hospital discharge (if not already done), and reviewed/updated on a regular basis thereafter. This could lead to the development of an effective care plan, and is congruent with recommendations concerning elderly enrollees by health policy experts:

  > "Health plans should be required to conduct a comprehensive health assessment of new patients upon enrollment, followed by specific provisions for improved access to primary and specialty care on a routine basis. With every new enrollee who has a serious health problem (or at the point when one develops), the managed care organization needs to determine the appropriate types, amounts, and range of services that would most effectively and efficiently treat the enrollee."[21]

- Allowing enrollees the option of designating appropriate geriatric or other specialists as primary care physicians for guardianship clients;

- Addition of geriatric or other specialists in chronic illness, long-term care, developmental disabilities, and mental illness to plan provider networks;

- Plan allowance of out-of-network specialists or services required for guardianship clients;[22] and

- Availability of plan providers to visit long-term care facilities regularly.

C. Enrollment

Focus group participants raised the quandary of enrollment of incapacitated persons in

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[19] Ware, J.E., et al., "Differences in 4-Year Health Outcomes for Elderly and Poor, Chronically Ill Patients Treated in HMO and Fee-for-Service Systems," *Journal of the American Medical Association*, 276, pp. 1039 - 1047 (1996).

[20] Congressional Budget Office, *The Effects of Managed Care and Managed Competition*, Washington DC (1995).

[21] Meyer et. al., p. 11.

[22] Also recommended by Meyer et. al., pp. 10-11.

managed care. How, they asked, should the plans best be made aware of the guardianship at the time of enrollment, so that court-appointed surrogates can receive notices, voice concerns, and prevent enrollment in multiple plans by an unknowing client? In marketing, plans are prohibited from discriminating on the basis of disability, and cannot inquire about cognitive impairments; at the same time, plans should not enroll people who lack the capacity to contract. What mechanism, then, will plans use to ensure enrollees have capacity to sign an enrollment agreement. What mechanisms are needed to recognize the authority of surrogates to make health care decisions?[23] This question is under discussion by the Alzheimer's Association, the ABA Commission on Legal Problems of the Elderly, and others, especially as the Health Care Financing Administration (HCFA) prepares to implement the new Medicare+Choice program under the Balanced Budget Act.[24] From the guardianship agency perspective, it is a question that deserves the attention of policymakers if managed care is to work for frail and disabled beneficiaries.

D. Agency-Plan Partnership

A refrain throughout both focus groups was the need for managed care plans to recognize and respond appropriately to the agencies' surrogate decision-making role. "Managed care plans should," as one participant phrased it, "listen to what guardians with a fiduciary responsibility have to say." Plan personnel and providers, the agencies contended, should understand: what is involved in judicial guardianship proceedings, what it means for an agency to assume a fiduciary responsibility, and what kinds of diverse care requirements a typical guardianship client might have. When plan personnel , including providers, lack this understanding, guardianship agencies too often find themselves at odds with plans.

The focus group participants raised the desirability of the plans and the guardianship agencies ultimately working together in the health care of the clients. That would mean establishing a protocol of contact, collaborating on care plans and cooperating when a health care crisis occurs. It also would mean working together in respect of client values in end of life treatment. In managed care, "conflicts will inevitably arise in managing the deaths of those who cannot speak for themselves."[25] "Managing" the deaths of clients is part of the job of the guardianship agency under state law, and plans must look to the agency for guidance. Plan-agency cooperation might be enhanced by:

- Education of plan personnel and providers about incapacity and guardianship, and re-education in response to personnel and health plan turnover;

- Designation of plan special needs coordinators;

- Development of working relationships between plan coordinators -- as well as plan

[23] For Medicare beneficiaries, federal law does not specify who has authority to enroll an incapacitated enrollee in a managed care plan. HCFA's policy is that the authority of persons other than the beneficiary to enroll or disenroll is dependant on state law. HCFA Operational Policy Letter #7 (OPL95.007[Revised][Revised]).

[24] Karp, N. & Wood, E., "Incapacity and Medicare Managed Care: Enrollee Health Care Decision-Making," A Paper for the Alzheimer's Association, by the ABA Commission on Legal Problems of the Elderly (April 1998).

[25] Sulmasy, D., "Managed Care and Managed Death, Arch Internal Medicine, 155, pp. 133-136 (1995).

gatekeeper primary care physicians -- and guardianship agency case managers;

- Linkage at state and local levels of policymakers in managed care/health care delivery with the guardianship/protective services network;

- Increased funding for guardianship agencies; and

- Education/training for guardianship agency staff about managed care, and exploration of a "managed care coordinator" position to interface with plans and track changes in plan policies and procedures.

Taken together, all of these steps may affect health care for the nation's most frail and vulnerable adult population, and would make guardianship agencies such as those in the focus groups truly "partners" with the managed care plans. That, concluded one of the focus group agency directors, is something to aim for -- "to be recognized as a partner in this, in someone's health care."

Appendix A
Recruitment Letter

June 25, 1997

Re: Managed Care Focus Group

Dear NGA Member:

Managed care is exploding on the health care scene, with an estimated 58 million Americans enrolled in HMOs and another 81 million in other types of plans. The number of Medicare beneficiaries enrolled in managed care has more than doubled since 1991, and enrollment is growing by about 100,000 per month. At the same time, state are experimenting with a variety of Medicaid managed care systems. All of this represents a virtual paradigm shift in the practice of medicine.

How will this wave of managed care affect guardianship agencies and wards? While there is growing attention these days to the rights of managed care enrollees, there is very little attention to the rights and needs of enrollees with diminished or fluctuating capacity.

To learn more about the nexus of managed care and guardianship, we are planning a focus group on managed care at the September National Guardianship Association meeting in New Orleans. We are writing to determine:

- whether you have had experience with managed care for your clients; and

- whether you are interested in participating in a focus group on managed care at the NGA meeting.

If your answer to both questions is YES, please let us know so that we may include you in our plans. Either e-mail Sally Hurme at sally.hurme@aarp.noli.com or mail/fax the attached form to Sally at AARP.

After the focus group, we will compile the results in a report which will be useful to a broad range of policymakers as managed care continues to evolve. We are excited about this project, and expect to learn a lot from you.

Sincerely,

Sally Hurme
Legal Advocacy Group
AARP

Erica Wood
Commission on Legal Problems of the Elderly
American Bar Association

Appendix B
Moderator's Guide

Focus Group on Managed Care
At the National Guardianship Association
September 22, 1997

Introduction:
Good morning/evening, my name is Katharyn and I'll be moderating the focus group today. Thank you for agreeing to participate in discussing your professional experiences with managed care for your clients. As you are probably aware, this focus group is being conducted by the AARP Public Policy Institute, with the assistance of the American Bar Association Commission on Legal Problems of the Elderly.

The specific purpose of this focus group is to gain information on the effects of managed care on surrogate decision-making agencies and their client populations. Your comments will help us to identify issues for further research and for educational materials. We will be preparing a report from the focus group, and you will receive a copy of it.

Before we begin the discussion today, I'd like to mention a few things:

- First, you may have noticed the tape recorder and the two people sitting _____. They are there to take notes and handle the tape changes, so that we can quickly and accurately prepare the report.
- Second, I'd like to stress that everything you say is confidential: no names will be attached to any comments at any time. No names will appear in the report.
- Third, there are no right or wrong answers to these issues. We are interested in your experiences and your opinions. If you disagree or have had different experiences from someone else, please speak up. And, when you are talking, please try to speak one at a time and in about as loud a voice as I am using now.
- Finally, because we have a lot of questions to cover today, I may need to interrupt you to move on to another topic. If this happens, please don't be offended. I want to make sure that we are able to finish the discussion on time.

Questions:

1. I'd like now to go around the table and have you each tell us
   your name,
   how long you have been involved with guardianships, and
   the kind of agency you work for and some of its key characteristics
   Let's start with the person on my left.

2. When you purchase health insurance for your clients, how do you go about doing so?
   Probes: What are key considerations for you? Do they include selection of primary care provider?
   What about the client's history or the client's specific health care needs?
   How actively do clients participate in the decision?
   What about cost savings? Geography?

How about the enrollment of other clients?

3. As a fiduciary for your clients, in general, what have been your experiences with managed care?
   Probes: Do you accompany your client on visits to doctors or other health care providers?

4. Have you found any differences in care for your clients in managed care versus those in fee-for-service? If so, could you please tell us about the differences?
   Probes: How about care coordination?
   What about access to health care specialists?
   How accessible are the facilities? What about transportation to and from?
   Do your clients receive more or less or about the same level of attention?
   How much choice do your clients have?
   What about the quality of care they receive?
   How do the cost savings compare?
   What about access to preventive health care services?
5. What actions have you taken on behalf of your clients in managed care? [FOR ACTIONS MENTIONED, ASK: What were your experiences like?
   Probes: What about enrollment? Disenrollment?
   How about health care decision-making?
   What about filing grievances and appeals?

6. In what ways has your role as a fiduciary been recognized or been challenged by health plans? What happened?

7. How does having clients in managed care affect the day-to-day operation of your agency?
   Probes: Is there less paperwork? More?
   Are you having to do more care coordination? Less?
   Do you include managed care actions in your reports to courts?

8. What have been your experiences in communicating with managed care plans on behalf of your clients?
   Probes: Whom have you dealt with?
   Are you able to reach someone when you call?
   Within the plan itself, how easy or difficult was it to make contacts?
   How sufficient or adequate was the information you received about plan policies and procedures?
   How timely was the plan's response to you?
   How easy or difficult was it for you to maneuver through the plan?
   Is your main plan contact with the provider?

9. Turning now specifically to clients residing in long-term care facilities, what have been your experiences with managed care for them?
   Probes: Do the plan providers visit long-term care facilities?
   Is transportation to plan providers supplied?
   Do you think that long-term care clients are getting the acute care they

need? What lead you to form that opinion?

10. Have you ever been approached by managed care plans to enroll your clients? If so, what was your response?
Probes: Did they offer group incentives? What kinds?

11. Generally, what would make it easier for guardianship agencies to serve clients in managed care?
Probes: What about training for guardianship agencies about managed care? How about better linkages between guardianship agencies and managed care entities?

12. Those are all the questions I have. Do you have anything else to add?

Closing:
Thanks again for taking the time to participate today. We really appreciate it! We also would welcome any additional information you would like to send. Such information could be sent to: Sally Hurme, AARP Legal Advocacy Network. Her card is in the copy of the Counseling Older Clients book that she and Erica are handing out as you leave. Again, thanks.

Appendix C
Annotated Background Questionnaire

Background Information
Managed Care Focus Group Participants
at the National Guardianship Association
September 1997

1. We are interested in knowing how many of your guardian clients are enrolled in the various forms of managed care plans. By "managed care plans" we mean any system of health care delivery that includes limited providers, negotiated provider reimbursement, and utilization review, such as HMO, PPO, point of service, Champus, etc. Please fill out the following table to indicate the number of guardianship clients your agency/business presently services who are enrolled in managed health care plans, their place of residence, and the total number of clients you are presently serving.

	Clients in Medicare/ managed care	Clients in Medicaid/ managed care	Clients in other types of managed care	Clients NOT enrolled in managed care	TOTAL clients now serving
Clients in nursing homes	*R*=0-25*	*R=0-210*	*R=0-74*	*R=0-80*	*R=4-290*
Clients in assisted living	*R=0-11*	*R=0-137*	*R=0-24*	*R=0-27*	*R=3-235*
Clients in community	*R=0-36*	*R=0-65*	*R=0-100*	*R=1-142*	*R=1-132*
Clients in mental facility	*R=0-19*	*R=0-8*	*R=0-31*	*R=0-13*	*R=0-51*

** R=range*

2. Number of agency clients who are dually eligible for Medicare and Medicaid: *Range=7-253*

3. Average age of clients your agency presently serves: *Range=51-86*
Average income of clients: *Range=$484 - $3,000 per month (with one up to $17,000 per month); $6,000 - $18,000 per year*
Average assets of clients: *Range=0 - $500,000 (with one up to $5 million); half of the responses $2,000 or under*

4. Number of clients for which you are individually responsible: *Answers ranged from 0 to 723, but some interpreted this to be number of agency clients.*

5. Briefly describe health care status and needs of your agency's guardianship clients: *Dementia, brain injury, Alzheimer's Disease, cancer, physical deformities, health care needs which require different levels of treatment, mental problems, depression, frail elderly with primary diagnosis of dementia or clients with a long-standing mental illness, elderly with skilled nursing needs, health status varies greatly but majority live in health care facility/board and care, at-risk and vulnerable, medically fragile, dually diagnosed with developmental disabilities and mental illness, high medical needs, seizures, gastrostomies, tracheostomies, diabetes, hypertension, assistance with activities of daily living, physical therapy, occupational therapy, speech therapy, edema boots, oxygen, g-tube feeding, colostomy, cataract surgery, health care needs which need to be monitored and for which they are receiving medication and treatments, mentally retarded, both mentally retarded and mentally ill, health problems which require multiple providers and multiple specialty areas, most problems are chronic high risk for abuse/exploitation, podiatry care, eye care*.